frontiers | Research Topics

Qualitative research applied to public health: New topics and insight

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Qualitative research applied to public health: New topics and insight

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Table of contents

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Editorial: Qualitative research applied to public health: new topics and insight

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Editorial on the Research Topic
Qualitative research applied to public health: new topics and insight

The concept of public health refers to the science and art of preventing diseases and promoting, protecting, and improving health (1). The essential functions of public health include monitoring the health of the population, keeping watch on risk factors, guaranteeing access to healthcare services, and promoting research, among others. Although there have been many advances over the years in vaccine development, emergency response, the promotion of sexual and reproductive health, and access to medicine, a single solution has yet to be found which meets the needs of the population in different health systems (2). Classical epidemiology studies the phenomena of health and disease in the community, considering the population as a group of individuals without considering the many individual and social factors. Qualitative methodology contributes to the study of the determinants of health and disease, healthcare planning, the detection of needs, and the evaluation of interventions from the experiences of individuals and societies (3). In the face of a unitary, measurable, and external reality to the cognoscente, there is a reality which each person creates within the framework of their culture, tradition, and history. Therefore, the implementation of a dual research perspective in public health must involve quantitative approaches that address the generality of the study problem, but also qualitative ones, which include multiple layers of diversity and the range of lived experiences (4, 5). As reflected in our Research Topic, the experiences of patients, professionals, and families are key to understanding public health problems.

Research does not occur isolated from the interests and powers of the academic, scientific, personal, or theoretical field (6). Together with the technical interest in knowing the reality in order to transform it (Zang et al.), practical interest points to the intersubjective understanding of the health-disease process, and emancipatory interest points to actively taking charge of this process. In line with studying the experiences of patients, Wang et al. found specific action plans, medical feedback, and periodic records as facilitators of adherence to lifestyle prescriptions among patients with non-alcoholic fatty liver disease. Bailey-Davis et al. found that obese patients undergoing treatment in primary care expect personalized treatment options and referrals to effective community programmes. Campaña et al., suggests that being a woman with a low educational background coming from the public health system outside of the capital could contribute to barriers for effective healthcare for lung cancer in Chile. Gabay, proposes that positive experiences in the relationship between the patient and nurse instill hope for being discharged in intensive care units. Experiences of young generations on the social problems of parental care are addressed by Peng et al., emphasizing that governments should guarantee that adult children receive help to balance their work, life, and parental care responsibilities. Chen et al. found that major epidemics accelerate and promote major social changes, technological development, political, and economic measures. Experiences of members of public health associations in tracking and treating COVID-19 cases in migrants and refugees are studied by Dawson-Hahn et al.. Qualitative research also studies the experiences of evaluating public health intervention programmes, such as the case of Thoumi et al. when addressing health inequalities in Latinx communities in North Carolina; or the perspective of professionals on the barriers, facilitators, and elements for improving the +AGIL Barcelona programme (Canet-Vélez and Solis-Navarro). Teaching-learning experiences are also addressed by qualitative research in the different stages. In undergraduate studies, Zhu et al. suggests that a synthesis of knowledge and practice is needed to improve the professional skills of undergraduate nursing students. In postgraduate studies, Sánchez-Muñoz et al. found that the residency period is important in the training and acquisition of skills as a Family and Community Nursing Specialist Nurse in Spain, and improvements are needed to guarantee quality training and more visibility. Myroniuk et al. recommends involving health sciences students in public health programmes aimed at the community. Experiences of public healthcare professionals have also been studied in our Research Topic. Canet-Vélez et al. suggests that legal regulation has provided a security framework for nurse prescribing. However, strategies are needed for its comprehensive development, public acceptance and to give visibility to nurse prescribing at an international level. Along with practical interest, emancipatory interest is key in qualitative research. Researchers analyze public health problems through self-reflection, seeking social transformation, and participant involvement for change. This positioning generates empowerment, leading patients to participate in decision-making and take charge of their own health. Along these lines, Röger-Offergeld et al. studied how the participation of women as co-researchers leads to their social empowerment beyond the results of the research itself. Melhem et al. found that health literacy and empowering survivors of colorectal cancer promotes a more positive experience when interacting with healthcare systems.

Gadamer and Habermas criticize the excessively objectified and decontextualized nature of positivism and instrumental reason in 20th century philosophy, recognizing the role of the subject in the creation and acquisition of knowledge and understanding (7). Qualitative research is increasingly common in contemporary health sciences, helping to incorporate the perspectives of the participants (patients, family, professionals, managers, etc.) in the design and development of the research, treating them as equals. Qualitative public health researchers could strengthen dialogue with conventional research paradigms by fostering an understanding of interdependencies (8). Investigating social determinants and health inequities requires epidemiologists and public health researchers to expand theories, research methodologies, and involve all participants (9, 10). The perspective of those who use public health services differs from the professional, clinical or academic perspective (11). Qualitative research enables an understanding of how people interpret and respond to public health policies, thus weighing the sources of academic and experiential knowledge (12). The main strength of qualitative research is the in-depth and rich descriptions of data that is studied (13). For this reason, it is used in global public health when the problems cannot be analyzed from traditional quantitative approaches, when "silenced voices" are not heard, or when sociocultural contexts are key in decision making and problem solving (14). This contribution, which complements epidemiological research, is key for all knowledge disciplines that develop research on global public health and on all communities in particular.

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Nurse-patient interactions in intensive care, transitions along the continuum of hope, and post-discharge management of chronic illness—A mixed methods narrative inquiry

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KEYWORDS

Bricolage, hope, intensive care, longitudinal, narrative, nurse-patient interactions, qualitative, selection mechanisms

Introduction

In 2035, estimates are that 50% of the population will be 65 and older with a life expectancy of 100 years and an expansion of chronic illness (1, 2). When chronic illness becomes acute, patients are re-admitted to the hospital and suffer from psychological trauma (3, 4). Acute illness breaks the continuity of life, shaking the certainty in one's world. Acute illness distinguishes between life prior to the illness and life since the illness. In acute illness one re-examines life's sequence from the safe past to the shaky present through the vague, unknown perspective, into the unsettled future. Chronic illness can result in depression, anxiety, low determination to fight the disease, poor self-management of illness, and low quality of life (5, 6). Patient-nurse interactions can lead to self-management of chronic illness, but chronically ill patients report low satisfaction with experiences of nursing care (7, 8). Studies have called to promote interventions to improve nurse-patient interactions (9, 10).

Hope is one of the core psychological resources for effective coping with traumatizing illness and may facilitate self-management of illness (11).

Psychodynamic features of the theory of hope, calls to revisit hope and test nurse-patient communication that instills hope in patients facilitating self-management of chronic illness post-discharge. What place does hope occupy upon the deterioration of one's health? Hope is a psychological phenomenon, a multidimensional, dynamic attribute of individuals, encompassing possibility, active involvement, and confidence in a future outcome (12). The phenomenon of hope encompasses both conscious and unconscious aspects (13). The conscious aspect of hope is manifested in one's ability to set goals and attain them (12). The unconscious aspect of hope is manifested in one's relentless pursuit to cope with distress while deepening one's commitment to a better future. Vitality and happiness are positive emotional outcomes of hope that emerge upon one's progress toward achieving one's pursuit. These positive emotional outcomes of hope are intermixed with negative emotional outcomes such as frustration and hopelessness, when one encounters impediments on the way to achieving goals (12).

Once a physical illness develops, hope may facilitate one's coping with pain, disability, and other illness-related stressors (12). Hope motivates patients to prevent health

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deterioration (14). Meta-analyses on hope in chronically ill adults suggest that hope sustains life (14). While hopeful patients focused on improving clinical outcomes and recuperating, patients who lacked hope were anxious and focused on self-pity, compromising healing (15). A high level of hope when facing discouraging circumstances may stem from the belief that no situation is completely devoid of hope (16).

Levi (16) outlined a continuum of hope, with distinct profiles of hope reflecting unconscious processes of pessimistic hope, reclaimed hope, and mature hope (16). Levi defines three profiles of hope (13, 16).

1. *Pessimistic hope* has a future orientation, encompassing a desire to move forward, but it is accompanied by anxiety, sadness, and fear, making it difficult to connect to the essence of hope and its outcomes. Pessimistic hope is manifested in suspicion and skepticism toward nurses and their ability to help, requiring the nurse to contain these feelings, accept them, and be continuously present. Pessimistic hope makes it possible to deal with crises by avoiding interpersonal relationships and protecting the patient from emotional overwhelming. The inner feeling is that of the false self (17). Pessimistic hope, however, is still hope, which enables an inner mental process that may lead to receiving assistance and expressing one's true self (17). Protective regression in pessimistic hope inhibits the potential for growth that underlies the essence of hope.
2. *Reclaimed hope* is inspired by others. The nurse may "bear" the hope during the patient's hospital stay and give the patient hope. Reclaimed hope is an alternative route that allows enhancement of hope by the nurse, who is external to the self (16). The patient may unconsciously entrust his or her hope to the nurse (13, 16). The nurse may sense the hope entrusted through countertransference processes. When the relationship becomes established, the hope can be retracted from the nurse to the patient.
3. *Mature hope* is a solid personal resource. Those with mature hope contain it independently to deal with general life events and crises. In mature hope the true self of the suffering patient, which is hidden in the depths of the soul, is revealed. Hope expresses tenacity, courage, bravery, and realism, creating a potential for transformation and growth. Hope, even if it is unconscious at the beginning, when the patient becomes aware of difficulties and feels frustration on the way to achieving goals, will promote a deep inner commitment to realizing goals (13). Winnicott (17) claimed that every person is born with the capacity for hope. Patients, therefore, may expect the nurse to contain their feelings and help them reconnect with the hope concealed within them (13). Mature hope requires consistent coping when facing a grim reality. Finally, hopelessness, the lowest extremity of the hope continuum, is found in depressed patients (13). Hope is a personal resource rather than a product of external circumstances, which makes it possible to view illness as the context within which hope is explored (16). Thus, hope is not attributed to the medical condition but rather to the interpretation of the patient's narrative that directs the patient's future course. What profiles of hope do patients have in coping with acute chronic illness during lengthy hospitalizations?

While qualitative studies can broaden our knowledge of factors underlying hope in hospitalized patients, most of the existent research on hope in illness is quantitative, focusing on outcomes of low and high hope in patients (18, 19). Studies on patient experiences in acute care and on nurse-patient interactions that facilitate mature hope are scarce (20, 21). Also, although individuals are the authority regarding their own experience in a health crisis, patient reports have been disregarded (4). Since patients with lengthy hospitalizations in the ICU stressed the need for nurses to recognize their crisis and support them in times of despair (22, 23), the nurse-patient interaction may be a source of hope and may yield satisfaction with care.

Hope is, to some extent, relevant for all therapeutic relationships, which makes it possible to borrow theoretical frameworks across fields (13). Borrowing the continuum of hope from psychoanalysis, the current study explores nurse-patient dyadic interactions and transitions among hope profiles during lengthy hospital stays. This qualitative study seeks to identify interactions that inspire hope during lengthy hospital stays at the ICU from the patient's perspective and to elucidate communication that may facilitate mature hope. Since narratives convey subjective interpretation of events, allowing us to understand how encounters of patients with nurses, shape patients' experiences, this study seeks to gain insights regarding patients' experiences with data that are typically unavailable from other sources (24).

This narrative study seeks to begin closing this gap in the state-of-the-art and to identify pathways by which nurses facilitate transitions among profiles of hope and satisfaction in acute care. The explorative study responds to previous calls to elucidate communication that inspires hope in patients and enhances satisfaction during hospitalizations (20). The three research questions are (a). What profiles of hope are evident in nurse-patient dyads? (b). How does the interaction with nurses facilitate transitions from hopelessness to pessimistic hope to reclaimed hope to mature hope in patients? (c) Do transitions along the continuum of hope shape patient satisfaction with nursing care post- discharge? Insights from this narrative study may allow nurses to intervene to facilitate hope in clinical practice and enhance patient satisfaction.

Methods

Ethics

Following IRB approval (#0076), participants who had been hospitalized several times in the last year were recruited to participate in the study. The author informed them that they could stop the interview at any time. Participants signed an informed consent form regarding their participation and publication. Identifying details of participants, nurses, and hospitals were omitted and names were replaced by pseudonyms (25).

Participants

Ten secular Israelis aged 66–81 participated in this study post-discharge from a 1-month acute care hospitalizations in tertiary medical centers (1,200–3,200 beds) due to life endangering cancer, heart disease, neurological disorders, or motor vehicle accidents.

Procedure

Snowball sampling was used. Two interviews were conducted with each participant at the participant's home, extending across Israel. The first interview was conducted within the first 2 days post-discharge and the second a month later, to capture the period of negative outcomes and assess satisfaction with care (26). Each interview lasted about 2 h. Participants stressed that despite their immense physical discomfort, they wished to promote change in interactions of nurses with patients at the ICU by sharing their experience. Interviews were audiotaped, transcribed verbatim, and translated from Hebrew to English. To generate a deep, unstructured narrative, as typical in narrative interviews, one question was asked (27): "How did you arrive at the hospital and what did you experience there?" The author listened attentively, making no attempt to comment, ask, or judge what they said and attempting to send a non-verbal message of comfort as participants shared their narrative. The twenty narrative interviews provided adequate information power, as information saturation was evident from in patient experiences of interactions with nurses during their hospitalizations (28).

Mixed methods data analysis

"Qualitative narrative studies are interpretive post-positivist inquiries, eliciting the perspectives of participants which are becoming the preferred strategy of qualitative researchers, including in nursing, to understand experiences (27). Each set of interviews was analyzed separately. Data analysis was guided by the data-driven method of selection mechanisms for narratives, applied in health regarding specific events rather than life stories (22, 29). The analysis entailed the following three steps at the participant's level, and a fourth step at the group level. In the first *step*, each transcribed interview was read as a whole unit and initial themes were identified for each participant (27). In the second *step*, each narrative was analyzed using six selection mechanisms that described what participants unconsciously chose to tell and what they chose not to tell regarding their interactions with nurses (22).

The following selection mechanisms were identified: inclusion, which refers to facts and experiences reported by the participants (e.g., everything that happened during the hospital stay); clarification, which refers to events that participants highlighted (e.g., lack of updates or no interpersonal communication with nurses); omission, which refers to events that participants viewed as irrelevant for the desired endpoint (the dynamics with one's family); silencing, which refers to events that participants perceived as conflicting with the desired outcome (e.g., sharing the experiences of other patients); flattening, which refers to the minimization of events that participants perceived as unimportant (heightened distress and fear); and attribution of appropriate meaning, which refers to the meaning that participants attributed to events that are compatible with the goal, although these may not necessarily be congruent with their original meaning (nurses' perceived attitude). In the *third step*, the endpoint of each interview regarding interactions, hope profile, and satisfaction was identified, as it emerged from the analysis. The endpoint themes involved hope and interactions with nurses during the hospitalization. In the interviews conducted at 1-month post-discharge it was important to explore whether there was a transition in participants' profile of hope and to assess the satisfaction with nursing care reported by patients. In the *fourth step*, at the group level, the Bricolage method was applied to identify common elements among experiences of participants regarding interactions with nurses, profiles of hope, satisfaction and self-management of illness (30). The Bricolage method enhances the depth of the analysis, creating new insights (30)."

Research quality criteria

The author maintained qualitative research standards, ensuring quality, rigor, and trustworthiness (27). Also, the author outlined the aims of the study and the research questions; documented data collection methods; rendered the data analysis transparent; outlined the proper sampling method to answer the research questions in a way that enables conceptual generalizability; linked the conceptual discussion of the findings to an existing theory on hope that explains the relevance of the findings to the population of nurses; included and discussed negative experiences of participants; applied the findings to the practice of nursing; and finally, evaluated the theoretical contribution of the findings (31).

Findings

Findings from the first interview are presented in three layers. First, the profiles of hope that were identified, guided by Levi's continuum of hope theory (13, 16). Second, wellbeing in interactions and transitions among profiles of hope were analyzed. Third, common elements among subgroups were analyzed, regarding interactions with nurses, transitions among hope profiles, and satisfaction with nursing care, applying the Bricolage method.

Findings from the second interview are presented by the profile of hope and patient responsibility to manage the illness at 1-month post-discharge.

Phase 1: Interviews upon discharge

Profiles of hope

Hopelessness

Lack of communication for long periods of time was perceived by participants as a lack of caring and deepened their sense of hopelessness:

> "I was in a wheelchair. I had never been this ill, it was very scary. I did not know what had gone wrong and what to expect. My worst fear was my next fall. What would I be doing when it happened again? I just sat there for ages. No one approached me, my head exploded with thoughts about what would happen" (Adi, 78); "When I was re-admitted again with excruciating pain, the nurse recognized me but did not ask or say a thing. They didn't care about me and pushed me away

> like a rag: 'Go have a stomach, liver, and kidney ultrasound at your local clinic and then come back.' I was hypoglycemic with heart fibrillation. Five clinicians gathered around my bed. They did not talk to me. No one answered my questions. At night I had another heart attack due to an infection. I had open heart surgery" [long silence, sitting hunched over on the couch] (Yoel, 81).

Pessimistic hope

Participants described negative emotions due to interactions with nurses:

> "The nurse came by to see me but didn't notice me at all. She hardly spoke to me. I had excess fluid in my head that pressured my brain and caused a cognitive regression, loss of memory, and walking disorder. I was scared to death when I was told of the planned procedure [silence]. For them it was technical, for me… I felt intense cold throughout my body" (Koby, 74); "They did not fight for me. They were very technocratic. Basically, they did their job and that's it. They don't really care about me. If my fifth hospitalization this year taught me anything, it's that the hospital is a huge factory, and I am only a kettle that needs fixing. No one talked to me. Not a nurse, not a social worker or a psychologist" [silent] (Ella, 66).

Reclaimed hope

When participants were processing the crisis and felt in good hands this may have allowed them to rely on the nurses to take their hope and hold on to it, in their uncertain situation:

> "I kept falling, my legs would not hold me. The nurse said, 'the doctor read your CAT scan and there are definitely deficiencies, but the doctor will hold a consultation and let you know about surgery.' I felt in good hands. Despite my objection to surgery, I decided that if I needed surgery to come out of this, then surgery it is" (Moshe, 72).

Martin attributed his hope for recover to the encouraging communication with the hopeful nurse:

> "One day the nurse announced: 'Today we are standing'. She sensed my fear and said, 'Don't worry, I will hold you if you fall. I checked your leg strength – you should be able to stand up'. She was tiny. I was afraid of falling, but she held me. Eventually I succeeded. It felt amazing" (Martin, 68).

Mature hope

> "It was very late at night. The nurse said 'You are in the Intensive Care Unit (ICU) but we hope it will not spread. It is very unpleasant, but we hope you will overcome this'. I felt very close to him. He kept talking and instilled so much hope in me. After a few days, I felt that I would be okay" (Shaul, 69).

Interaction with nurses and transitions from hopelessness to pessimistic hope to reclaimed hope to mature hope

From hopelessness to pessimistic hope

When nurses shared their hope and expressed their professional view regarding rehabilitation, they facilitated the development of hope in participants.

Nurit had no desire to have surgery and shared how the nurse's fresh perspective had helped her accept her new grim reality and agree to have yet another surgery:

> "I had no resources to deal with the news. I was on my way to surgery for the fifth time this year. It was too much, too much. I didn't want any hospital, any physician, any nurse or surgery. When I shared my inability to accept my new medical reality the nurse had an interesting expression. She was quiet for a few minutes. Then she looked at me and said: 'It is challenging, yes. There is nothing simple about this. But do you know how many people would change places with you? How many would want to detect their cancer early on, remove it, and move on with life?'" (Nurit, 79).

The nurse held on to hope for Nurit, who was shocked by the grim news that the cancer had spread. In time, Nurit developed independent mature hope:

> "My body is traumatized, due to the surgery. Recognizing my limitations is part of the healing process. I am functioning on a lower level, less capable, have no strength or energy. I'm at the bottom of the climbing wall of my life. I need to climb up again and again. I need a lot of physical and mental strength to deal with such a transition. But who wants to stay down there? No one! I sure don't. I'm lucky that I can continue and play the 'music' of rehabilitation" (Nurit, 79).

From pessimistic hope to reclaimed to mature hope

When nurses allowed participants to share their emotional experiences, this facilitated a positive change in their emotions and attitudes.

Eli transitioned from reclaimed hope to mature hope through the communicative behavior of the nurse, which made a huge difference for him:

> "'You are not dying on me', she said. 'You will live'. She hugged me. At that moment, I had no doubt that I would remain alive [tears]. Patients whose nurse kept their spirits up persevered, patients who had an easy condition but were depressed died because their disease spread. I think the biggest difference among doctors and nurses is their message to the patient. I think that 50% of the treatment is one's hope that they will live. It encouraged my determination to heal [quiet]. I owe her my life" (Eli, 68).

Koby added his similar experience, stressing the impact of the interaction with the nurse on processing his trauma while she held on to hope for him:

> "I was so sad. Then I felt afraid. Friends and colleagues slowly drift away from you when you are that sick. The nurse would stay with me to talk about my fear of missing the weddings of our children and not knowing my grandkids. I was devastated. She would come with coffee and chocolate, and I would share what I could not share with anyone in the world. She made a huge difference for me. I was lucky" (Koby, 68).

Bricolage

Two common themes distinguished between the subgroups. One group of participants lacked hope both throughout their hospital stay and a month post-discharge, expressing anxiety and dissatisfaction with care. Ella, Adi, Roni, and Yoel remained devoid of hope. Yoel felt that he had been better off before the surgery, as the last operation had left him disabled:

> "I was there so many times this year. They already know me by name. The experience was horrific. Hallelujah! I am home. I hope I stay home. I came out of there in a wheelchair, nothing will be the same. I will not be readmitted" (Yoel, 81) [Yoel refused to be readmitted and died 8 months post discharge].

The second group transitioned from hopelessness to pessimistic hope to reclaimed hope and to mature hope, expressing gratitude toward the nurses and satisfaction with the nursing care. Martin, Moshe, Shaul, Nurit, and Michelle had, in their view, exceptional experiences and transitioned across profiles of hope.

Common themes in the transition from pessimistic to reclaimed hope and to mature hope Four participants (Eli, Michelle, Martin, Moshe) experienced interactions that instilled in them hope and directed them to seek information, reappraise their resources, and believe in their rehabilitation. They were encouraged to ask the nurse questions to improve their functional limitations. Participants treated by a nurse who reflected hope transitioned to mature hope. Thus, Martin shared his transition from reclaimed to mature hope:

> "You start off from the worst place, you don't know anything, you don't feel your legs, you cannot stand. Suddenly, you wake up one morning with no motor senses. You just slowly assimilate that you have no control. We can only do the best we can. That's it. If anything happens, you cope with it. I understand that I have no choice but to manage myself" (Martin, 68).

Phase II: Interviews at 1-month post-discharge

Hope and responsibility for post-discharge for illness management

Participants who lacked hope upon discharge remained devoid of hope 1-month post- discharge. They expressed a fear of hospitals, disappointment with the nurses, and dissatisfaction with care. Ella elaborated on her experience and how instead of empowering her, the interaction made her feel diminutive. Participants were traumatized by insensitive communication by nurses. Ella, Yoel, Adi, and Koby, who felt a lack of hope upon discharge and a month post-discharge, accepted their functional impairment, did not feel responsible for rehabilitation and illness management and did not look forward to the future. Ella shared her point of view:

> "It's not enough to know medicine if you don't understand the human soul. Nurses are technicians, they have forgotten to communicate and to be healers. They don't know how to listen; they no longer hear anything. I am disabled but if they would at least communicate with me it could have been different. I am left with the sickness, and death is approaching" (Ella, 66).

Koby felt a lack of hope and was determined to refuse surgeries in the future:

> "They were condescending and did not care about me. I decided that whatever happens to me, I would not go through any more surgeries. I can hardly walk since the operation. I am not active. People should stay away from hospitals" (Koby, 74).

Participants who described hope upon discharge felt hope, gratitude, and satisfaction with the nursing care. Martin described his determination to walk again:

> "I told myself, 'No matter how long it takes, you will walk again!' Every time some negative thought surfaces like 'you will never walk again' – I shove it away. It's tough but I am encouraged. Every day I force myself to take more steps than the day before, regardless of the pain or how long it takes" (Martin, 68).

Eli, who expressed mature hope upon discharge, displayed hope and commitment for rehabilitation a month later:

> "I am slowly recovering and getting back to a blessed routine. It's complex, but I have no complaints, I am lucky and so thankful. Every day I feel privileged to be alive" (Eli, 68).

Michelle expressed continued mature hope at 1-month post-discharge and gratitude after four readmissions in a single year:

> "In this whole journey all we have is this moment, the here-and-now. When I reflect on the hospitalization, I remember the exceptional dedication of my nurses during the four times I was hospitalized this year. All of them were so sensitive in their communication with me. I remember the entangled, intertwined roads of my journey. A ton of hours filled with my worries and their listening, encouragement, and support. Their beneficial presence undoubtedly encouraged me to return four times to the operating table for complex surgery. Our presence is a gift. We really only have the current moment" (Michelle, 74).

To sum, participants whose nurses interacted with them by holding eye-level conversations, containing their negative feelings, discussing the potential for improvement, and holding on to hope for them, allowed the participants to process

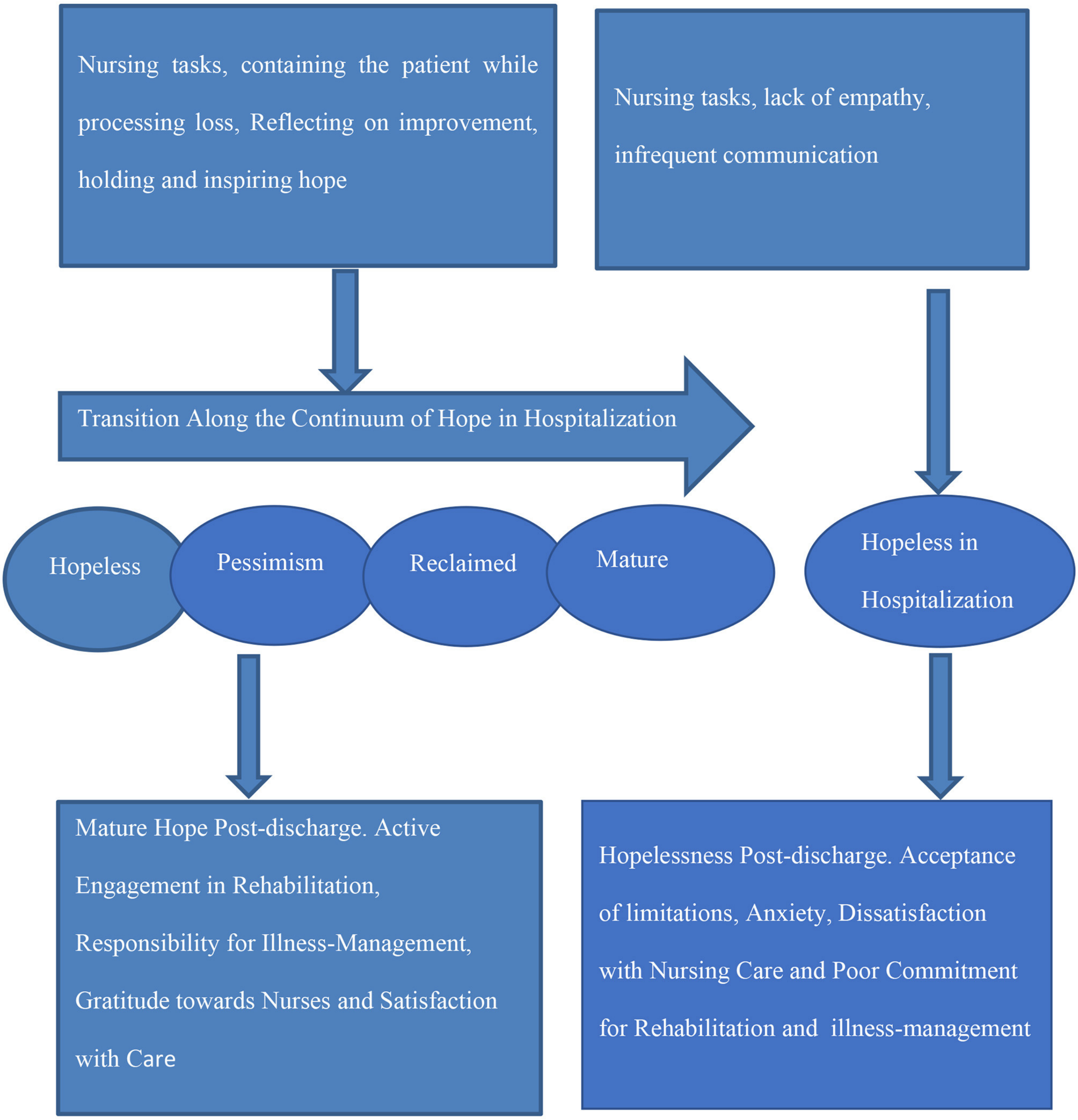

FIGURE 1
Work of hope in nurse-patient interactions in hospitalized patients and post-discharge satisfaction with nursing care.

their negative emotions and reclaim their hope. While the participants processed their emotions, the nurses held on to hope in their stead. Nurses facilitated the development of mature hope in participants, who reported that the nurses had instilled hope in them and expressed satisfaction with the care. Participants who felt no hope upon discharge, lacked hope and were dissatisfied with care at 1-month post-discharge as well. These participants were determined to resist future readmission to the hospital. Figure 1 presents the research findings.

Discussion

This study voices the narratives of in-patients begins to close the gap in the state of the art regarding how nurse-patient interactions may facilitate psychodynamic hope in lengthy hospitalizations and post-discharge illness management. Borrowing the hope continuum from psychoanalysis, this study explored patient interactions with nurses, patient transitions across profiles of hope during lengthy hospitalizations in intensive care, and patient self-management of illness. This mixed-methods qualitative study has several contributions. Theoretically, the study extends the knowledge on psychodynamic hope in nurse-patient interactions in hospitalizations and links it to patient self-management of illness. Insights from this study broaden our understanding of the mechanisms of psychodynamic hope and reaffirm that hope is essential for patients and that nurses are in a unique position to improve patient satisfaction in lengthy hospitalizations by building nurse–patient relationships that instill hope.

Methodologically, this study is based on the patient perspective. This study analyzed narratives by the selection mechanisms method at the individual level to reveal hidden layers in nurse-patient interactions and using the Bricolage method at the group level, it demonstrated that qualitative narrative research can produce insights even shortly after a health crisis. Practice recommendations of this study elucidate interactions that facilitate movement from hopelessness to hope during hospitalization, and self-management of illness post-discharge.

Profiles of hope among patients in intensive care

Findings highlight the nurse-patient interaction as a source of hope and of satisfaction with care. Patients in intensive care may experience a painful separation from hope, which then becomes conspicuous by its absence as the patient feels pain, fear, overwhelming symptoms, and a weakening of the self (22). The patient needs to experience acceptance and no judgementalism which may facilitate psychological safety and self-reflection (22). When patients are frustrated, they need nurses to contain their frustration, anger, despair, and hopelessness, until they are able to generate hope within themselves (13, 16). Hope may not necessarily originate from the patient who is experiencing loss and trauma, may be inspired by nurses, who may serve as a bridge to hope. The interaction with the nurse may allow patients to reclaim their hope from the nurse who functions as a source for hope and develop mature hope (13).

Interactions with nurses and the process of transitioning along profiles of hope

Fostering hope in situations of loss requires reconciling the patient's despair with the nurse's attitude of potential change, enabling patients to contain the despair while developing hope Despair is shared with the nurse, who "sees" the patient through empathic attunement and through interpretation and sense making, thereby meeting the patient's need for containment (18). The patient may encounter self-alienation and aloneness due to processing the loss, but at the same time may contact and share the distress with the nurse (22). In these moments the nurse may "hold on to" the patient's hope, and when the patient is ready, pass it back to the patient with realistic anticipation and mature hope (16). When the patient accepts vulnerability and copes with the hospitalization as a challenge that can be overcome, there is a potential for mature hope (13). Hope and hopelessness are important determinants of emotional wellbeing, increasing comfort and life satisfaction (32). Findings support studies on the powerfulness of hope (14, 15). The Nurse-patient interaction may help the patient move through the process from regression to dependence, enabling a connection with the nurse and satisfaction with care (33, 34).

Hope during the hospitalization and post-discharge

Without transitioning along the continuum of hope, participants felt no hope both throughout their hospitalization and a month post-discharge. Where there was no hope, there was no post-discharge self-management of illness among participants. Since in the dyadic relationship, nurses may also experience an overwhelming sense of their own helplessness, inability to "do something" to revive the treatment, inability to maintain hope, and perhaps identifying with patients' sense of hopelessness, it is complex process of bringing together the nurse, who is willing to help unconditionally, and the patient who is not completely certain of her or his needs (22). To set in hopes for patients, it's essential for nurses to distinguish between patients' gratification for the relationship with the nurse and patients' underlying frustration with limitations in functionality. Careful reassurance of the nurse-patient relationship and sensitivity of the nurse may facilitate independent hope in patients even when they are facing a grim reality making hope a phenomenon that is inextricably intertwined with the dynamics of the relationship in the here-and-now of hospitalizations.

Compatible with a recent study, hope should be fostered by providing information to help patients develop an understanding of the motional difficulties and encourage their active role in their self-care (32). In contrast to previous studies, however, even hopeful patients need a space of self-alienation from friends and relatives when they were hospitalized as they are unable to share their feelings with others (12, 22). Exploring the importance of the nurse-patient interaction, the findings are compatible with a study which found that nurse–patient interactions are a source of hope in nursing homes (33). Nurse-patient interactions that inspire hope, may empower nurses through granting greater meaningfulness to building relationships with patients (35).

Implications for practice

To increase patient satisfaction with nursing care throughout the hospitalization and post-discharge, nurse-patient interactions should instill hope in patients who face loss and hopelessness in lengthy hospital experiences. Relationships entail an active presence of nurses as providing comfort and hope, which translate into higher involvement with patients in their care. The findings call upon nurses to first acknowledge patients' feelings regarding their crisis and to be aware of the importance of embracing patients' despair and interacting in a way that leads patients to mobilize courage and develop hope. Nurses may facilitate the development of hope by being sensitive toward the unique psychological needs of patients, and by assessing patients' ego strength and fragility (18).

The nurse may honor the patient's despair through empathy on one hand and hold the conviction that the patient can and should progress on the other. Training may target (a) the art of containing the emotional needs of patients while working in a chaotic work environment of intensive care; (b) shifting from providing clinical care to integrating clinical nursing care with building positive relationships with patients so they can lean on nurses until they develop hope independently; (c) since patients may perceive the nurse with both hope and suspicion, it is imperative that training also targets skills of attentiveness, empathy, and reflection. It is extremely important to incorporate work with hope in nursing care. A vision of hope as a source for better recovery and patient satisfaction should be incorporated into all treatment models.

Conclusions

Hope in hospitalizations is psychodynamic and essential for patients. Nurses are in a unique position to improve patient satisfaction in lengthy hospitalizations by building nurse–patient relationships that instill hope affecting post-discharge self-management of illness.

Limitations and directions for future research

The findings link nurse-patient interactions in acute care to hope and satisfaction with care. While the role of the patient-nurse interaction is critical, one must bear in mind that narratives and the interpretation of events are affected by the personality, construction of reality, life experience, culture, and emotional and cognitive state of each participant. These limitations call for further research which may explore both hope and satisfaction with nursing care among hospitalized patients in a quantitative study with a large sample. Future studies may also explore the experiences of nurses in the context of instilling hope through interactions with hospitalized patients.

Author contributions

The author confirms being the sole contributor of this work and has approved it for publication.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Factors influencing adherence to lifestyle prescriptions among patients with nonalcoholic fatty liver disease: A qualitative study using the health action process approach framework

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Background and objective: Lifestyle modifications aimed at weight loss have been introduced as a cornerstone of nonalcoholic fatty liver disease (NAFLD) management. However, very few patients follow the doctor's prescription to change their lifestyle to achieve weight loss in the real world. The purpose of this study was to use the Health Action Process Approach (HAPA) model to examine the factors that affect adherence to lifestyle prescriptions among patients with NAFLD.

Methods: Semi-structured interviews were conducted with patients with NAFLD. Reflexive thematic analysis and framework analysis were used to determine naturally identified themes and allocate them to theoretically driven domains.

Results: Thirty adult patients with NAFLD were interviewed, and the identified themes were mapped directly onto the constructs of the HAPA model. This study revealed that key barriers to adhering to lifestyle prescriptions are related to the coping strategy and outcome expectation constructs of the HAPA model. For physical activity, conditional limits, lack of time, symptoms such as fatigue and poor physical fitness, and fear of sports injury are the primary barriers. Barriers to diet are mainly diet environment, mental stress, and food cravings. Key facilitators for adherence to lifestyle prescriptions include developing simple and specific action plans, coping strategies to flexibly deal with obstacles and difficulties, receiving regular feedback from doctors to improve self-efficacy, and using regular tests and behavior recording to enhance action control.

Conclusions: Future lifestyle intervention programs should pay particular attention to the planning, self-efficacy, and action control-related constructors of the HAPA model to promote the adherence of patients with NAFLD to lifestyle prescriptions.

KEYWORDS

nonalcoholic fatty liver disease (NAFLD), Health Action Process Approach (HAPA), lifestyle, exercise, diet, physical activity

1. Introduction

Nonalcoholic fatty liver disease (NAFLD) is the leading cause of chronic liver disease worldwide, affecting 25% of the global population. NAFLD is associated with cardiometabolic disorders: obesity, insulin resistance, type 2 diabetes mellitus, high blood pressure, and atherogenic dyslipidemia, all of which increase the risk of a heart attack or stroke (1). Due to the close relationship between NAFLD and metabolic syndrome, some scholars have recently proposed renaming NAFLD as metabolic-associated fatty liver disease (MAFLD) (2). The prevalence of NAFLD has increased to alarming levels, placing an enormous burden on affected individuals and healthcare systems (3).

Lifestyle modifications aimed at weight loss have been introduced as a cornerstone of NAFLD management. However, it is difficult for patients with NAFLD to change their lifestyle to achieve weight loss in the real world. A study showed that only 30% of patients with NAFLD lose more than 5% of their body weight within 13 months (4). NAFLD clinical guidelines reported that lifestyle intervention programs should be recommended, when possible, and tailored to patients' preferences to ensure long-term adherence (1, 3, 5, 6). Currently, there is limited research on the factors affecting adherence to lifestyle prescriptions among patients with NAFLD. To the best of our knowledge, there is only one study that has explored the preferences and unmet needs of individuals with nonalcoholic steatohepatitis (NASH) (7). The study pointed out that patients needed assistance in managing their lifestyles, but it was "not" examined this aspect in depth.

The behavior change model is a theoretical psychological method of describing the factors that affect in all kind of behavior, which can guide the development of behavior intervention (8). One such model is the Health Action Process Approach (HAPA) (9). The HAPA model postulates that behavior change is a dynamic and continuous process comprising two distinctive phases. The first phase is the motivational phase, which plays an important role in increasing risk perception (e.g., the risk of NAFLD disease becoming serious) and action self-efficacy (e.g., how to stay confident in the ability to sufficiently perform regular exercise and a healthy diet plan), and managing outcome expectations (e.g., expected pros and cons of the outcomes of participating in changing an unhealthy lifestyle); this strengthens the formation of intentions for behavior change (e.g., "I intend to do physical activities at least 5 days per week with 30 min each time").

Once individuals have established an intention, they enter the second phase, the volitional phase (10). In this phase, individuals may benefit from a series of volitional self-regulation strategies for behavior initiation and maintenance. This includes action plans (e.g., when, where, and how to enact regular exercise), coping strategies (e.g., how to maintain a limited energy intake level when confronted with obstacles), maintenance self-efficacy (e.g., how to stay confident about the ability to eat sufficient portions of fruits and vegetables when obstacles occur), recovery self-efficacy (e.g., how to stay confident about the ability to restart exercise behavior after disengagement), and action control (e.g., how to constantly self-monitor themselves to prevent relapse). In addition, promoting an individual's perceived social support is equally important for maintaining behavior and preventing relapse (11).

The HAPA model has been widely used in various areas of behavior change, including interventions for diet (12), physical activity (13), and meditation adherence (14). Some studies have shown a strong correlation between the HAPA model and improved diet and exercise adherence in individuals with chronic diseases (15), suggesting that the HAPA model is appropriate for developing adherence to lifestyle prescriptions. To the best of our knowledge, to date, only one qualitative study has explored the application of the HAPA model to pharmacist-assisted medication adherence among unreachable patients (16). How to use HAPA model to guide patients with chronic diseases to adhere to a healthy lifestyle is still worth studying.

Hence, this study aimed to investigate the factors influencing adherence to lifestyle prescriptions aimed at weight loss within the framework of HAPA so as to provide ideas for lifestyle intervention for patients with NAFLD and other chronic diseases.

2. Methods

2.1. Study design

This is a qualitative, descriptive study. Conducting individual interviews using thematic analysis was the most suitable approach to understanding the preferences and needs of the patients with NAFLD to adhere to lifestyle prescriptions in a real-world setting. Researcher reflexivity is known to influence the results, as researchers' beliefs, experiences, and context can shape the interpretation of the findings.

The study was conducted from July 2022 to September 2022. The study was conducted in accordance with the ethical guidelines of the 1975 Declaration of Helsinki and was approved by the Ethical Committee of Beijing Youan Hospital (approval number: 2018–095). All patients provided written informed consent to have their information used (anonymously) for research purposes.

2.2. Participants

Patients with NAFLD were recruited from the outpatient clinic of Beijing Youan Hospital. The inclusion criteria were as follows: (1) aged above 18 years and (2) diagnosed with fatty liver by B-type or liver biopsy. The exclusion criteria were as follows: (1) having hepatitis B or C virus and (2) having a diagnosis of liver cirrhosis or hepatocellular carcinoma. We employed a purposive sampling strategy with maximal variation to identify shared patterns in the data (17). We aimed to recruit a sample of patients based on their age, gender, and length of time since diagnosis. It was estimated that 30 interviews would be needed to reach thematic saturation (as determined by an investigator consensus, as is the gold standard in qualitative studies) (18).

2.3. NAFLD definition and classification

The presence of fatty liver disease of all patients involved was assessed using a B-type ultrasound. The presence of fatty liver disease of some patients were also confirmed using liver biopsy. Liver fat content and the presence of fibrosis were measured with the Fibroscan 502 touch device (Echosens, Paris, France). Regarding the value of the controlled attenuated parameter (CAP), liver steatosis was classified into three grades: mild liver steatosis: 238–258 db/m, moderate liver steatosis: 259–292 db/m, and severe liver steatosis: >292 db/m. The degree of liver steatosis corresponded to the degree of fatty liver.

2.4. Procedures

The hepatologist referred the eligible patients to a research assistant in the adjacent room, who then explained the purpose of the study to them. Those who were interested were provided with a detailed explanation of the study and the interview process. Only those who were willing to participate were provided with consent forms and then proceeded with the interview. Thirty patients were referred to the research assistant, and all of them agreed to be interviewed.

The eligible participants participated in a semi-structured individual face-to-face interview for approximately 10–40 min each. The interviews were conducted by a member of the research team with expertise in qualitative research. The HAPA framework was used to develop the interview schedule. The interview questions (see Appendix Interview Guide) were based on the participants' understanding of the role of a healthy lifestyle and its effects on NAFLD, the outcomes of inactivity and an unhealthy diet, the need for a lifestyle intervention plan, the difficulties and obstacles in implementation, the need for coping strategies, ways to improve the ability of action control and self-efficacy, and so on. The interviews were transcribed verbatim and modified to remove any identifying information. The transcripts were then uploaded to NVivo11 (QSR International, Melbourne, Australia) qualitative analysis software.

2.5. Analysis

Both reflexive thematic analysis and framework analysis were used to determine naturally identified themes and then allocate them to pre-selected theoretically driven domains to assist in the identification of the factors affecting adherence to lifestyle prescriptions; we followed Braun and Clarkes' (19) instructions for conducting a reflexive thematic analysis. First, two researchers, L.W. and H.Z., became familiar with the interview material after multiple readings of the transcripts (Step 1, Familiarization). This included note-taking to help facilitate proper comprehension of the data. Second, subsequently, L.W. and H.Z. independently coded each interview (Step 2, Generating codes). An inductive thematic analysis was conducted to identify new "candidate" themes by combining similar codes to create major categories using a thematic map (Step 3: Constructing themes). These themes were then deductively mapped against the HAPA (9). These themes were then reviewed and checked against the data set, and "candidate" theme names were provided, clearly reflecting the meaning of each (Steps 4 and 5, Revising and defining themes). Finally, the results were written down, which allowed the continuous testing of the themes (and refinement if needed as a final stage of analysis) to determine how well they answered the research question. The quotes were anonymized and presented to illustrate the core meaning of the themes (Step 6, Producing the report).

2.6. Reflexivity

L.W. conducted qualitative interviews with the participants. L.W. is a female research fellow with experience in qualitative research in lifestyle management. This may have influenced the questions that the interviewer delved further into, for example, when the participants spoke about the need for a lifestyle plan. The researchers involved in the analysis (L.W. and H.Z.) are accredited exercise physiologists and dietitians, indicating that they brought a wealth of knowledge to the process of data interpretation. While this may have affected the interpretation of the results, the themes were deductively mapped to the pre-established domains. The remaining authors were not involved in the qualitative interviews or data analysis; however, they were allowed to review themes and suggest different interpretations of the data.

3. Results

3.1. Participant characteristics

Table 1 displays the characteristics of the 30 participants. The age of participants ranged from 22 to 63 years, with a mean age of 40.2 years (SD = 11.8). Half of the participants were women, and 30.0% of them were unmarried. Additionally, 80.0% of the participants had an undergraduate level of education or above. All the patients involved had severe fatty liver disease.

3.2. HAPA

The thematic analysis of the interviews produced multiple themes for each domain (Table 2). The framework was updated based on the thematic data (Figure 1).

3.3. Risk perception

Regarding the risk of fatty liver disease, most of the patients were aware that fatty liver disease would progress into cirrhosis and hepatocellular carcinoma, but the majority of the patients were not aware that fatty liver disease would cause other diseases, such as cardiovascular and cerebrovascular diseases. While discussing the impact of an unhealthy lifestyle, most patients reported that the most immediate impact is gastrointestinal discomfort resulting from unhealthy eating habits, which can, in turn, affect the quality of sleep and other aspects of daily life. In addition, regarding long-term effects, most patients stated that an unhealthy lifestyle would aggravate the fatty liver disease and increase the risk of other chronic diseases such as high blood sugar and high uric acid, and so on. The patients with a shorter history of the disease reported higher levels of risk awareness and more frequent unhealthy

TABLE 1 Participants' characteristics.

Variables		*n* (%)
Age	<30	5 (16.7)
	30–39	9 (30.0)
	40–49	8 (26.7)
	≥50	8 (26.7)
Gender	Male	15 (50.0)
	Female	15 (50.0)
Marital status	Married	21 (70.0)
	Unmarried	9 (30.0)
Education level	≤Senior high school level	6 (20.0)
	Undergraduate level	18 (60.0)
	Postgraduate level	6 (20.0)
Weight status	Normal weight	4 (13.3)
	Overweight	14 (46.7)
	Obese	12 (40.0)
Current work status	Working full-time	18 (60.0)
	No work	5 (16.7)
	Student	2 (6.7)
	Retired	5 (16.7)
Monthly income (RMB)	<3,000	9 (30.0)
	3,000–9,000	8 (26.7)
	>9,000	13 (43.3)
Duration of NAFLD	<1 year	3 (10.0)
	1–4 years	10 (33.3)
	5–9 years	9 (30.0)
	≥10 years	8 (26.7)
Commodities	Diabetes	7 (23.3)
	Hypertension	4 (13.3)
	Hyperuricemia	7 (23.3)
	Dyslipidemia	22 (73.3)

TABLE 2 Interview themes.

Domain	Theme
Risk perception	Serious progression of condition leading to NASH or HCC
	Serious progression of condition leading to other diseases
Outcome expectancies	Fat loss
	Changes in objective data
	Resolution of signs and symptoms
	Physical condition becomes better
	Sports injury
Goals	Reversal of NAFLD
	Improve health
Action plans	Simple
	Convenient
	Specific
	Systematic
	Timetable
Coping strategies	Plans for different conditions
	Make it part of the routine
	Start with a low exercise level and gradually increase it
	Take the first step to start exercising
	Tips for social and dinner parties
	Prepare some food in advance
	Eat some low calorie food instead
	Allow eating what you like once in a while
	Enjoy something else instead food
Action control	Self-supervision of behavior
	Monitor simple indicators at home
	Controlled by external forces
	Regular feedback from the doctor
	Regular follow up at the hospital
Self-efficacy	Encouragement and support from doctors
	Encouragement and support from family members/friends
	Mutual supervision and successful experience among patients

Themes from interview analysis grouped by domain.

lifestyle behaviors compared to those with a longer history of the disease.

> "Fatty liver will cause cirrhosis. Fatty liver will cause abnormal liver function, which may make me more prone to cancer. I'm worried about that." P2

3.4. Outcome expectancies

Outcome expectancies are divided into positive outcome expectations and negative outcome expectations. While discussing the positive outcomes of a healthy lifestyle, most patients expressed the great importance of treating fatty liver through lifestyle changes. The majority of the patients had experienced the benefits of a healthy lifestyle, such as improved sleep, physical relaxation, greater flexibility, and mental wellbeing. To treat fatty liver disease, the patients expressed their hope to improve clinical indicators and symptoms, such as fatigue, and reduce body fat. In addition, the majority of patients had experienced a relapse of fatty liver disease. They expressed a wish for this disease's symptoms to be resolved. Regarding the possible negative outcomes of a healthy lifestyle, the patients expressed concerns about potential sports injuries resulting from engaging in regular exercise. These concerns served as a barrier to patients' willingness to exercise regularly. Regular exercise as a treatment for fatty liver is associated with a negative outcome expectancy, which is sports injury. Most patients who were overweight or obese were worried about knee joint injuries, which hindered their ability to adhere to regular exercise for a long time.

> "I went out for a walk before and felt relaxed. I slept soundly at night." P1
>
> "There is repeated experience of fatty liver disease. If I pay attention to the lifestyle, the fatty liver disease will improve; if I don't pay attention to the lifestyle, the fatty liver disease will get worse." P17

3.5. Goals

The majority of patients stated they did not have a clear goal for fatty liver treatment. They anticipated that the fatty liver would resolve itself and not become worse. The patients were aware that they needed to exercise more and eat less as part of their lifestyle management goals; however, they did not establish specific goals. Moreover, although most patients had experienced weight loss, they had not set clear goals for their weight management.

> "I know I need to eat less and exercise more. I don't know how." P10

3.6. Action plans

3.6.1. Physical activity

Most patients knew that they needed to engage in more physical activity, but they had not made or provided a detailed plan. They expected simple, convenient, specific, and systematic timetable-based plans. Some patients reported that creating a detailed plan would make implementing and adhering to lifestyle prescriptions easier.

3.6.2. Diet

The patients acknowledged the need to reduce their food quantity, eat more vegetables, and reduce their intake of staple foods and oil, among other things, but they did not know how to arrange their diet to fit their needs: What to eat, how much to eat, or what type of food they need to eat. A recipe or dietary standard may be helpful. Some patients mentioned finding it difficult to estimate the weight of their food and expressed a desire for a more understandable method of measurement.

Most patients reported receiving exercise and diet advice from other liver doctors or healthcare professionals, but the advice they received was general and lacked specificity. Moreover, when the patients looked up relevant knowledge, they found it difficult to differentiate between right and wrong information. The patients with NAFLD expressed a desire for professional lifestyle management to help them manage their condition more effectively.

> "I didn't make a plan. I went to exercise if I wanted to, and I didn't go if I didn't want to." P18
>
> "Just to know how should I eat every day, I want to get a nutrition plan that will meet my nutritional needs without having excess energy." P23

3.7. Coping strategies

All the patients did not know how to overcome the difficulties and obstacles hindering their adherence to lifestyle prescriptions. While discussing factors that might affect patients' adherence to lifestyle prescriptions, patients reported that the difficulties and obstacles encountered in regular exercise mainly existed in the following areas: (1) conditional limitations, such as adverse weather (rain, cold, and hot), poor air quality, and quarantine at home due to the COVID-19 pandemic; (2) lack of time owing to work commitments, a heavy academic burden, or busy housework, among other things; (3) disease symptoms such as fatigue; and (4) physical fitness, as patients were prone to experiencing fatigue. Notably, women were more frequently hindered from regular exercise than men due to housework. Most patients with NAFLD reported that they had not used coping strategies before and that it was easy for them to give up when encountering these difficulties and obstacles. Having an alternative plan in mind for these situations could help them stick to their exercise routine.

The difficulties and obstacles when attempting to adhere to a diet plan mainly exist in the following aspects: (1) diet environments, such as social and dinner parties or regular meals with few choices; and (2) psychological factors, such as mental stress, hunger cravings, craving for delicious food, and so on. Patients stated that a diet plan that predicts these conditions can help them develop healthy eating habits.

> "For example, like last year, I kept running for a while, but it was too cold in winter, and I didn't want to go out for exercise." P4
>
> "I usually have a lot of learning tasks, which may limit my exercising time. I think maybe I can set an alarm clock and improve my learning efficiency so that I can free up time to exercise." P3

3.8. Action control

The patients stated that the following strategies might help them maintain a healthy lifestyle: (1) self-supervision of behavior through the use of activity trackers or taking photographs of their food; (2) monitoring simple indicators at home, such as weight or waist circumference; (3) seeking external support from others, such as doctors, family members, and others; (4) receiving regular feedback from their doctors to assess whether what they did was right or wrong; and (5) attending regular follow-up at the hospital to monitor changes in their clinical indicators.

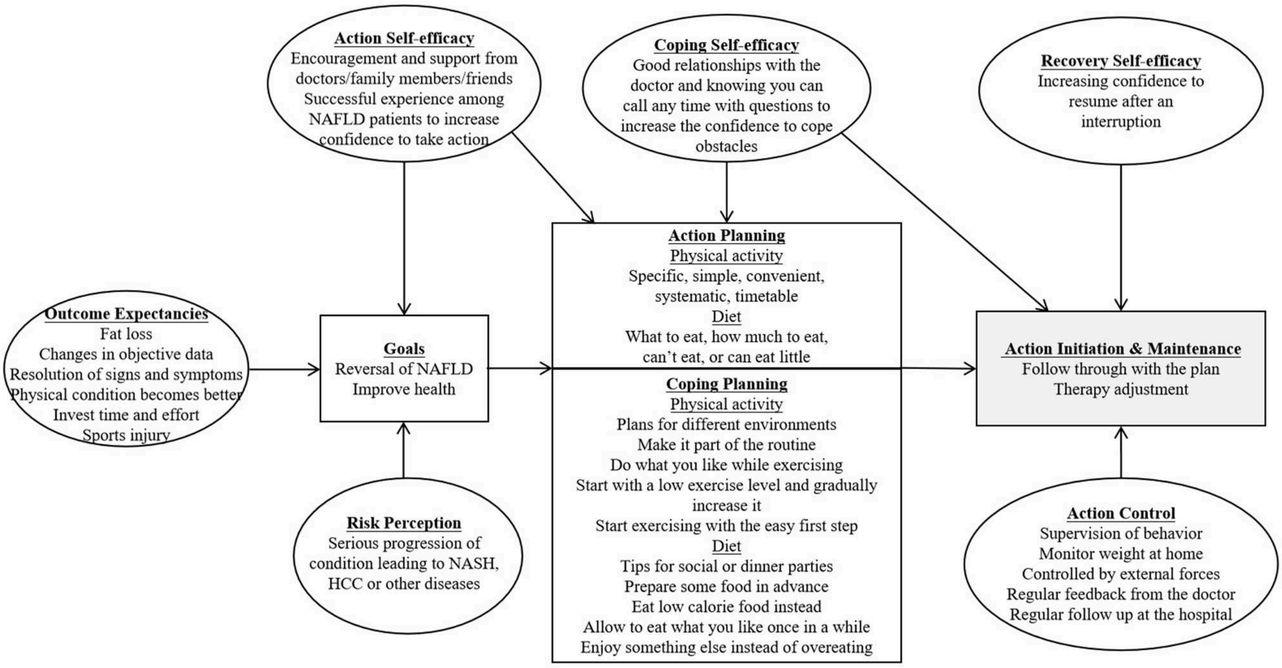

FIGURE 1
HAPA Framework. The HAPA component of this figure was adapted from Schwarzer (9).

> "There was a time when I socialized a lot. I gained weight. Well, I can make changes later in time." P4

3.9. Self-efficacy

Self-efficacy is a factor that affects patients' adherence to lifestyle prescriptions. The patients mentioned that the following aspects could improve their self-efficacy and enhance their confidence in modifying their lifestyle: (1) receiving encouragement and support from doctors (being able to contact their doctor whenever they have a problem and receiving their feedback on the effectiveness of their implementation); (2) receiving encouragement and support from family members and friends (verbal encouragement or support through actions); (3) sharing mutual supervision and successful experience with other patients.

> "I sometimes go swimming with my friends. We can swim in competitions, which makes it easier for me to keep going. But if my friends don't go, I will also be lazy." P2

4. Discussion

The present study used the HAPA model to identify the factors affecting adherence to lifestyle prescriptions among patients with NAFLD. The main findings of this study were those patients with NAFLD are aware that they can manage their condition by changing their lifestyle, but they are uncertain about what specific actions to take or how to implement them effectively. Patients need to have a strong sense of self-efficacy to manage their condition effectively; they need to have achievable action plans and coping strategies, as well as support networks and methods of action control to facilitate their transition to a healthy lifestyle. This study highlights the significance of action plans, coping strategies, action control, and the self-efficacy construct. These findings have important implications for the design of lifestyle prescriptions that can help patients manage their conditions successfully.

The study was performed in the outpatient clinic of a hepatology hospital. All the patients involved suffered from severe liver disease. Most patients with NAFLD visited the hospital for treatment because of fatty liver disease. At ordinary times, most patients in our clinic had severe fatty liver disease. They received advice on mainly exercise and diet from liver doctors or other healthcare professionals. In addition, 80.0% of the participants had an undergraduate level of education or higher. While the patients' education level in this study was higher than that reported in previous studies involving patients with NAFLD (7, 20, 21), it was similar to the findings that higher education levels are usually associated with greater risk awareness and a greater emphasis on disease treatment (22, 23).

In terms of adhering to regular exercise, having coping strategies is necessary for patients to overcome any obstacles they may encounter while implementing exercise prescriptions. Conditional limitations, a lack of time, and fatigue were reported as barriers to regular exercise in other similar studies (20, 24, 25). Our study also found poor physical fitness as a barrier for patients with NAFLD. Moreover, female patients were more likely to be hindered in their ability to exercise regularly due to household responsibilities. Currently, the research on effective intervention strategies for addressing these barriers is very limited. Some patients with NAFLD also mentioned fatigue or laziness as barriers to following a healthy lifestyle (24). When faced with this situation, taking the first step toward exercising may be helpful, such as putting on sneakers and going outdoors. A few patients mentioned struggling with poor physical fitness and ability; this reason was supported by some studies showing that patients with NAFLD have a lower physical function and performance status (26). Additionally, patients with NAFLD experience perceived exertion more frequently when exercising at similar intensities to those with chronic hepatitis C (27). However, most of them can accept starting with a low level of exercise and gradually increasing it to overcome this barrier (28).

To enhance patients' adherence to regular exercise, this study suggests that action plans should be simple, convenient, specific, and systematic, as well as include timetables. This finding is unsurprising, given that patients desire plans that can be implemented without requiring much thought; these findings are consistent with a similar study conducted on patients with diabetes (28). Although clinical guidelines recommend patients with NAFLD should take aerobic exercise ≥3 days/week (≥150 min/week moderate intensity), resistance exercise ≥2 days/week, and reduce sedentary behavior (29), these reference estimates can support exercise plans, but the planning should be tailored to individual patient's needs, preferences, and access to resources. ACSM's guideline (30) suggests that exercise plans should include frequency, intensity, time, type, volume, and progression. In addition, the content of the plan should be simple, convenient, and easy to carry out, and the format should be a schedule with exact timing.

In terms of diet, the most significant barriers identified were environment and psychological factors, which must be considered when devising coping strategies. The most commonly reported barriers to a healthy diet among the participants in our study were related to the social environment, such as dinner parties or regular meals with limited food options. This finding is similar to that of an Indian study (25), which found that festivals, weddings, family or friend visits, and being provided with meals at the workplace were significant barriers. To address these challenges, recommendations could include reducing participation in social gatherings, eating at home more often, or making conscious food choices when attending dinner parties.

Regarding action plans for a healthy diet, a recipe that includes what to eat and how much to eat would be helpful for patients. Taking pictures or making videos can help patients better understand diet plans. Clinical guidelines recommend appropriate dietary patterns and composition, and dietary habits should be altered primarily based on energy restriction to a daily rate of 500 to 1,000 kcal. Moreover, it has been reported that the amount of weight loss should be the same regardless of the type of diet followed (29). On this basis, clinical practice should be easier to understand and implement.

Self-efficacy has been demonstrated as an important factor for behavior change (31), and our study is not an exception. Our finding further emphasizes that regular motivational support from health workers such as specialists/dietitians/exercise physiologists in patients' lifestyle behavior management is highly beneficial for patients to continue with a healthier lifestyle (7, 32). Patients with NAFLD often lack the motivation to change their behaviors (33). In such cases, patients can contact their doctors when they have questions and receive feedback when they implement the plan, which would be suggested to enhance their confidence.

Action control is a behavioral influence factor that deserves more attention. Action control is similar to self-supervision. Participants demonstrated that their action control was poor and needed to be strengthened. Monitoring of diet and physical activity progress by a healthcare professional was reported to be beneficial. In terms of regular exercise, patients suggested that a pedometer would be a useful tool to allow them to check and monitor their progress (20). In addition, patients can get regular supervision and feedback from doctors. They can also regularly supervise their exercise and diet behavior and monitor weight by themselves. Regular follow-ups by hospitals would help patients maintain a healthy lifestyle.

There are several limitations to note for this study. First, the demographics of the patients involved were fairly homogeneous. All of our patients had severe fatty liver disease, and the average level of formal education was higher than that of the general population. These characteristics could have impacted the reported outcome expectations and risk perceptions, as other studies have highlighted a misunderstanding of fatty liver disease and neglect of treatment. The sociodemographic characteristics of our participants may have also impacted the need for lifestyle prescriptions. Second, the factors we identified from discussions with patients were verified in our study. Therefore, more experiments are needed to examine these factors in the future. Third, the findings do not indicate what made participants behave in one way or another. In the future, researchers should consider studying the path of behavior formation by combining quantitative studies.

Several strengths of this study are also worth considering. One strength of our study was that it is one of the few qualitative studies that focused on acquiring patients' perspectives regarding lifestyle prescriptions. The insights gained from our research add to the existing literature, informing future, larger-scale quantitative studies on the facilitators and barriers of interest. The other strength of our study was that it highlights the importance of action plans and coping strategies, which have not been mentioned in previous studies on this topic.

5. Conclusions

The present study used a novel method by adopting the HAPA model to explore strategies for promoting adherence to lifestyle prescriptions among patients with NAFLD. In addition, learning from patients' perspectives is essential to accommodate their feedback for future lifestyle interventions for managing NAFLD. Although the barriers and facilitators identified included all constructs of the HAPA model, action plans, coping strategies, action control, and self-efficacy were the most prominent. Developing a patient-appropriate lifestyle action plan, developing coping strategies to overcome obstacles and deal with difficulties, and receiving feedback from physicians on lifestyle implementation are key facilitators for patients with

NAFLD to adhere to an appropriate lifestyle prescription. The present study contributes to a growing body of literature that explores techniques for incorporating the patient's viewpoint into early lifestyle interventions and stakeholder discussions regarding NAFLD management. In the future, we should consider conducting intervention research on these strategies to examine their effects.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding authors.

Ethics statement

This study was approved by the Ethics Committee of Beijing Youan Hospital (Ethics Number: 2018-095). The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

Conceptualization and funding acquisition: LW, JZ, and HR. Methodology and formal analysis: LW and HZ. Validation: JZ and YL. Investigation: JZ, YL, and XW. Writing—original draft preparation: LW. Writing—review and editing: JZ and HR. Supervision: WY. Project administration: HZ, JZ, and HR. All authors have read and agreed to the published version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1131827/full#supplementary-material

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Cancer literacy among Jordanian colorectal cancer survivors and informal carers: Qualitative explorations

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Introduction: Cancer patients face a variety of challenges in understanding their diagnosis and treatment options. Making informed decisions requires health literacy. There is scant research on how colorectal cancer (CRC) survivors and their caregivers engage with healthcare systems and obtain cancer-related knowledge to maintain proper health literacy, which is crucial for enhancing their outcomes.

Materials and methods: In-depth semi-structured interviews (IDIs) with CRC survivors ($n = 15$) and online focus groups (FG) with informal caregivers (ICs) were held in Amman between Jan-June 2020. In-depth interviews were conducted using semi-structured interview protocol that addressed the healthcare experience of CRC cancer survivors. FGs evaluated ICs' perspectives of e-health for cancer care support. IDIs and FGs were done in the local Jordanian Arabic dialect, which was then translated into English. Transcribed audio-recordings were thematically coded and framework analysis was used.

Results: The findings are organized around a central concept of "exploring the level of literacy and its impact." From the overarching theme, three themes and subthemes emerged, including: (1) The current state of counseling and information provision, (2) The impact of lack of information, awareness, and literacy and (3) The health system's influence on literacy.

Conclusions: Poor cancer literacy hinders patients throughout their cancer journey. Empowering cancer patients is crucial for a more timely and positive patient experience. Increased cancer literacy together with the creation of health-literate organizations and systems have the potential to improve patients' treatment throughout the continuum of care.

KEYWORDS

cancer, health literacy, experience, patient engagement, informal carers, qualitative, health promotion (HP), Arab

Introduction

Colorectal cancer (CRC) is the third most prevalent cancer in males, the second in women, and the second major cause of cancer death worldwide (1). CRC incidence and death are declining in western nations. In Asia, Eastern Europe, and South America, CRC incidence and death have risen rapidly. The Arab population is not an exception; although having lower rates of CRC than western nations, the illness has been growing in Arab nations over the last decade (2). CRC is Jordan's second most frequent occurring malignancy and the most common among men. It is the second most prevalent cancer in women, following breast cancer (3). Across the care trajectory, CRC survivors have high and persistent cancer related information and education needs. These needs are may be due to lack of high-quality educational resources and poor information distribution modalities that meet patients' informational needs and expectations throughout the cancer trajectory (4). These requirements include information on diet, medications, dietary supplements, lifestyle changes, physical activity, sexual function, self-management of symptoms and side effects of treatment, available support groups, ability to return to work, health insurance issues, financial concerns, and life and travel insurance. In addition, studies revealed that CRC patients'/survivors' need information on the disease, its cause, therapy, surgery, stoma issues, prognosis, body image, post-surgical expectations, survival, family cancer risk, and long-term effects and follow-up of a CRC diagnosis (4, 5). In addition, they outlined that CRC survivors need to be aware of the risks associated with metastasis, recurrence, recurrence therapy, prevention, and risk reduction (4, 5).

CRC carers also have special needs throughout the cancer journey. CRC carers may develop depression, anxiety, and psychological distress similar to patients due to the stress of providing care. Such health issues may significantly impact patients' and carers' quality of life and health outcomes. Thus, CRC survivors should be supported by providing them appropriate assistance and information and education in relation to the patients they care for, their prognosis and care needs (6). To meet patients' information needs, modern healthcare models promote patient decision-making and participation. Within that context, Health literacy (HL), as a concept, becomes critical (7).

HL is a thriving area of research and practice that examines people's capacities to manage the challenging requirements of health across their lifetime (8, 9). HL is a multifaceted and heterogeneous phenomenon. The term is used to describe a person's level of proficiency in the acquisition, processing, and application of knowledge essential to making informed decisions about one's health and in promoting the health of oneself and one's community. The term "health literacy responsiveness or organizational health literacy (OHL)" refers to how well services, organizations, and systems accommodate individuals with varying levels of HL by providing them with relevant and easily accessible health information and resources (8, 10). Navigating the health care system requires navigation HL (HL-NAV), which entails choosing the right physician, communicating effectively, keeping tabs on results and findings, and starting treatment as soon as feasible. This calls for an acceptable level of HL that enables patients to navigate information according to their needs (11, 12). HL-NAV is, thus, a subset of HL. The goal of HL-NAV is to manage information so that patients can easily navigate the health-care system and "find the right care at the right time in the right place" (13). Additionally, the digitalization of healthcare systems brought digital health literacy "DHL" as a new dimension of HL. "eHealth literacy" evolved into "digital health literacy" and is now used interchangeably (14, 15). In 2006, Norman and Skinner (14) defined eHealth literacy as the ability to search, receive, comprehend, and evaluate health information online to solve health issues (14). HL underpins DHL, which involves managing Internet sourced information and disease self-management using digitally available resources (14, 15). Norman and Skinner (14) in 2006 defined DHL as a meta-competency with six sub-competences: analytical skills (literacy, numeracy, media, and information literacy) and context-specific abilities (HL, computer literacy, and scientific literacy). With the introduction of DHL, HL's curative content is expanded to include prevention-oriented material (16).

Currently, HL is interpreted using a range of definitions and conceptual frameworks. The European Health Literacy Consortium's work forms the basis for the World Health Organization's (WHO) HL model (8), which consists of 12 subdivisions relating to health promotion, prevention, and treatment. In this context, HL represents an "asset" that integrates concepts of sustainability and empowerment. According to the Edwards model (17), HL is an "asset" that develops over time as a dynamic process driven by personal, emotional, and enabling variables, and active participation in patient-provider communications and decision making (9, 17). Contrarily, according to the HL "risk" perspective, low HL is associated with a number of adverse consequences; including but not limited to: increased likelihood of illness, hospitalization, emergency room visits, failure to use preventative services, inability to comprehend health information and prescription errors, and poor health outcomes in the elderly (9). Importantly, HL is modifiable, and enhancing HL is widely seen as a means of enhancing health outcomes. Considerable evidence indicates that even in industrialized nations, HL skills are inadequate (18). The results of the first European comparative study on HL in populations conducted in eight countries, found that nearly half of respondents (47.6%) had unsatisfactory HL (19). United States (US) and Canadian studies had comparable outcomes. According to the US Department of Health and Human Services (20), 90% of participants in "the Healthy People 2030 initiative" report having difficulties using easily accessible health information in a range of contexts. Nearly two-thirds of Canadian adults and 90% of seniors lack the ability to independently access, grasp, and act on health information and services as well as make sensible health decisions (21). According to the Institute of Health Equity in the United Kingdom, 42% of English people between 16 and 65 have trouble understanding and using basic health information; this rises to 61% when numeracy is necessary (22). Many health information producers lack the skills and equipment to offer content and activities that cater to the requirements of low-literate individuals (22). Patients with cancer can face a significant informational burden related to their diagnosis and treatment (9, 23). Cancer literacy poses a unique set of obstacles compared to HL for other chronic conditions as patients are required to learn a new language of medical jargon, provide their consent for procedures, and they must know where to go and when to seek timely support (23). Since early screening, diagnosis, or treatment may have an impact on survival rates, thus a variety of time-sensitive decisions must be made by both the patient and practitioners (23). Early identification of cancer greatly improves patients' chances of survival. Treatments for cancer can be complicated, requiring interdisciplinary teams, diagnostics, medicines, and the ability to monitor and control side effects. Early diagnosis may be possible with histopathological and genetic testing, although understanding the results amidst medical jargon might be challenging (8, 9, 22). Accordingly, there may be serious clinical ramifications due to the actions (or lack thereof) of patients and healthcare providers. Further, new communication technologies and the increasing complexity of health systems have made it feasible for people to get health information instantly and continually, and "e-health literacy" is posing a challenge for patients, informal caregivers, local and international health governing bodies (8). Patients with low HL are more prone to have a fatalistic attitude toward cancer and its prevention (24), and they also have greater unmet information needs (4, 11, 15). Low HL has also been linked to avoiding medical visits and uncertainty regarding screening (10, 24, 25), which may contribute to screening avoidance. In addition, those with low HL are less likely to know about cancer screening tests including mammograms, colonoscopy, and prostate-specific antigen, and they are also less likely to accurately identify the type and specifics of cancer that is being checked for (25). In fact, the complexity and sophistication of cancer therapy can be daunting, even for patients with a sufficient level of HL. Similarly, adequate HL that spans the continuum of care from diagnosis to survivorship or end-of-life decisions are required to facilitate constructive dialogue about cancer-related issues with caregivers, family, and relatives. Despite advancements in cancer prevention and improvements in cancer survival in the general population, low cancer related HL may lessen the ability for risk management with patients being less able to manage their risks, therefore having unfavorable effects along the cancer care trajectory (11, 23). HL is therefore required for patient empowerment and can minimize health services utilization and medical expenses. Patient empowerment, the process through which individuals obtain a greater understanding of and control over their own health, is an essential component of implementing HL efforts throughout their life. The WHO has identified HL as a key social determinant of health, and the promotion of HL as a key objective of the public health sector (26). Previous qualitative research that addressed cancer related HL included patients with prostate cancer, breast cancer, and hematological malignancies (9). Nonetheless, there is a scarcity of qualitative evidence about the literacy of CRC patients, particularly in the Arabic-speaking world.

In Jordan or any of its neighboring Arab nations, there are a paucity of research examining CRC survivors' and their caregivers' experiences of healthcare and cancer-related information. Therefore, doing a study on Arabic culture in the Middle East is of significant use to bridge the existing knowledge gap. In order to improve the present healthcare system, qualitative approaches would provide valuable insights to better understand CRC patients and their ICs interactions with the healthcare system in connection to the many facets of HL. This is partly because, despite the rise of digital health information, patients still need to understand and process information to use it correctly (15). The outcomes of this study may inform the creation of evidence-based e-health interventions and educational opportunities customized to varied levels of HL to improve HL in CRC patients and their ICs.

Materials and methods

Ethical considerations

This study is part of a larger project to develop e-health interventions for Jordanian CRC survivors' cancer supportive care and educational needs. The study was approved by Kingston University's ethical guidelines for scientific research (approval number/1416) and Jordan University Hospital's (JUH) Internal Review Board (IRB), protocol ID (10/2019/8990). CRC survivors signed consent forms and were informed of the study's purpose before the interviews. Before the online FGs, ICs consented verbally.

Study design and setting

This qualitative study uses the phenomenological premise of producing a textual account of what participants experience and a structural description of how they experienced it in terms of circumstances, situation, and context to investigate how survivors and ICs acquire information during healthcare encounters. Individual interviews with CRC survivors were conducted to better understand their lived experiences and show the complexity of patients' interactions with healthcare systems before, during, and after treatment. We chose one-on-one interviews with cancer patients due to the sensitive and private nature of their experiences (27). Focus groups (FGs) with ICs examined caregiving challenges and experiences. The format used enabled them to exchange ideas and generated meaningful discussions (28, 29). The FGs were carried out as a follow-up to a previous study, which showed that DHL was the only independent predictor of eHealth app use and information receptivity among CRC survivors (15). In addition, previous work identified that CRC survivors' age as an independent factor in determining their use of online information (4). Thus, in this study, we examined this phenomenon qualitatively using ICs as digital mediators. The FGs were divided into two sections; in one, ICs shared their caring experiences and in the second they brainstorm about eHealth/digital interventions and digital solution requirements, the latter section will be the subject of a separate publication.

Data collection

Participants and recruitment

CRC survivors' interviews

Individual interviews were conducted with a convenient sample of ambulatory CRC survivors who had curative surgery. Demographic and clinical data were gathered from patients' electronic medical records. Participants were identified by two oncologists, and a member of the medical team contacted them. The primary investigator (SJM) contacted potential participants 1 week after the medical team to answer questions and provide study details. Interested patients received participant information sheets (PIS) *via* email or WhatsApp. Participants who met all eligibility requirements (CRC survivors eligibility shown in Table 1), were scheduled for an interview following the receipt of their consent forms *via* email or WhatsApp. Figure 1 shows the recruitment procedure.

The first author (SJM), a qualitative female researcher (PharmD), conducted in-person interviews at JUH, a large semi-government tertiary hospital in Amman, Jordan. The semi-structured interview guide was based on an a priori framework and a literature review of CRC survivors' experiences, with an emphasis on cancer-related literacy (1–3, 30–33). An open-ended biographical framework and probing questions were used to better capture patients' complex interactions with healthcare services throughout their journey. Among the questions were: "how was your cancer diagnosed and treated?," "tell me about the whole process and give examples" and "give me your perspectives on the whole process." The interviews covered diagnostic routes from the patient's perspective of symptoms appraisal and help-seeking, patient-provider communications, challenges during treatment and follow-up, physical and psychosocial challenges, support and coping strategies, information acquisition, comprehension and processing, the counseling process, accessing resources and health services, and online resources. Before beginning the formal research, a pilot interview with a cancer survivor was undertaken, audiotaped and transcribed verbatim to test questions clarity, flow, and format.

TABLE 1 Eligibility criteria for CRC survivors' interviews and ICs' focus groups.

CRC survivors' semi-structured interviews	Informal carers (ICs) focus groups
Eligibility criteria*	
To be an adult ≥ 18 years.	To be an adult ≥ 18 years.
Diagnosed with CRC and have finished curative therapy (i.e., are in follow-up or surveillance stage, preferably between 6 and 2 years after treatment completion).	To be a proficient Arabic speaker.
Clinically well and capable of participation as determined by the medical provider(s).	To be a current informal carer of a CRC patient.
Proficient Arabic speakers and able to give informed consent	To be digitally literate

*All criteria must be met for successful enrolment.

The patient interview guide is included in Supplementary material 1.

ICs' focus groups (FGs, $n = 3$)

Convenient sampling was used to recruit ICs. A member of the medical staff selected 21 ICs and contacted them to inform them of the objectives of the study. The first author (SJM) contacted the 15 carers who agreed to participate and asked if they had any additional questions before sending them the PIS and the written consent form *via* WhatsApp or email. Table 1 provides the FGs' eligibility requirements for ICs. Skype FGs with ICs were done in small groups (3–4). The FGs' guide was flexible, and probing questions were asked to delve deeper into some topics. The FGs' topic guide can be found in Supplementary material 2.

The first author (SJM) conducted all CRC survivors' interviews and ICs FGs in Jordanian Arabic, recorded them on audiotape, transcribed them verbatim in Arabic, and then translated them into English. Two Arabic-English bilingual colleagues, (RK) and (SNG), reviewed the translated transcripts for linguistic validation. (RK) and (SNG) are senior female university academics with extensive qualitative healthcare research experience. Transcripts were not returned to participants for feedback. Neither the interviews nor the FGs were witnessed by any third parties. Password-protected, de-anonymized participant data was only accessible to study team members.

Data analysis

For the analysis, the framework methodology was applied, which included a qualitative thematic analysis with five interconnected phases for a systematic auditing process (34).

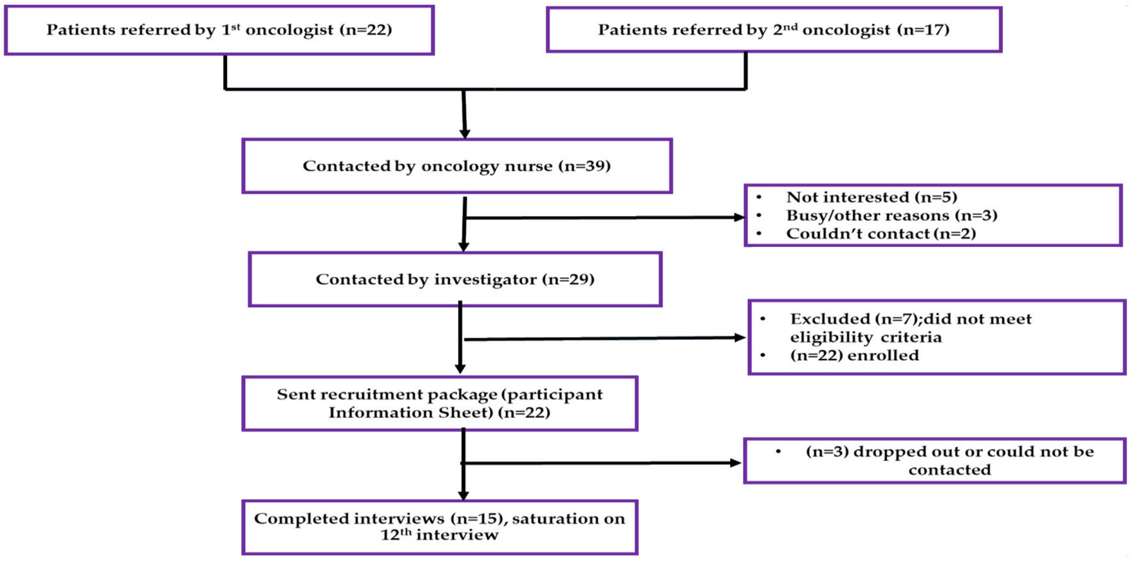

FIGURE 1
Study flow diagram.

Analysis consisted of familiarization, framework identification, indexing, charting, mapping, and interpretation (34, 35). Deductive-inductive hybrid analysis was used to analyze the transcripts. Inductive coding uses open (unrestricted) coding and theme refinement to derive themes from data, while deductive coding uses pre-selected themes and codes based on previous literature and preconceived ideas about the research subject (34, 35). A small sample of interview transcripts were read and reread to search for data patterns. A coding approach was developed to identify themes and correlations between qualitative data extracts, revealing a pattern in how CRC survivors and their ICs interact with healthcare systems across the cancer continuum. This was done by evaluating the different lenses and dimensions of HL and how it may affect survivors' literacy, as well as any other key considerations related to the study objectives. Due to the heterogeneity of HL's conceptualizations and definitions, the analysis used a priori concepts and definitions, but new themes were also constructed inductively where data could not be accommodated by the framework, in order to avoid forcing data into predetermined categories (35). The "HL Pathway Model and HL Skills Framework" was used as a foundation for a priori analytical framework to analyse data on HL skills and develop strategies to improve HL in cancer survivors (17, 36–38). Previous model by Edwards et al. (17) defines HL development as a lengthy process influenced by personal, emotional, and enabling factors that culminates in dialogues and collaborative decision making. HL is regarded as an "asset" for cancer patients' decision-making since they must make challenging decisions (17). Pre-diagnostic findings were analyzed using the theoretical framework of the Pathways to treatment model to reach similar conclusions to other early cancer detection studies (36, 37). This model examines the characteristics of patients, providers, the system, and illnesses in four stages: (symptom) evaluation, help-seeking, diagnostics, and pre-treatment. Even though it acknowledges that patients may consult with different healthcare providers at different times, the process is typically depicted as following a linear path that ends with a diagnosis from healthcare providers (HCPs). Inductive open (unrestricted) coding was used to address culture, participant experiences, health care system contextual components, and unexpected features of participant experiences or how they ascribe meanings to events (34). Deductive themes refined inductive codes. The analysis was done iteratively, for instance, the authors' review and revision of the existing themes resulted in the emergence of a number of new themes (34). All authors verified the final themes and subthemes to ensure data analytic bias, validity of interpretations, and consistency of findings.

Quality appraisal and rigor

The Consolidated Criteria for Reporting Qualitative (COREQ) Research reporting list was used for methodological rigor (Supplementary material 3) (39). Recording and transcribing interviews, using a flexible interview guide to examine participants' perspectives, and holding regular research meetings to discuss results ensured data credibility and transferability (40, 41). Data integrity was ensured by transparent data collection, management, and analysis (42). Direct quotations, sample and context descriptions (43), and connections to prior research serve transferability (43–45).

Results

Participant characteristics

CRC survivors' individual interviews

Between January 15 and February 28, 2020, interviews with 15 participants were conducted. The median age was 57 and the average was 55.4 (range 33–72). The average interview lasted 72 min (range 55–112). All participants were married. Data saturation was used to determine how many interviews were required for reliable results. After no new themes emerged, three more interviews were done to ensure thematic saturation (43). Most participants ($n = 9$) were medium-term survivors, and the median time after surgery was 11 months (range: 6–22). The majority were diagnosed at stage 3. Participants' characteristics are provided in Table 2.

Informal carers' focus groups

Between 12/6/2020 and 28/6/2020, three FGs with a total of 10 ICs were held online [FG number (hour: minutes)]: FG1 (2:47), FG 2 (3:02), FG 3 (2:51). Table 3 shows participants' characteristics. The concept of theoretical saturation of themes was used when the third FG did not generate new ideas. Hence further research such as analyzing data from a fourth focus group session was not pursued, and the data obtained was deemed sufficient to meet the study objectives (46). According to Guest et al. (47), theoretical saturation can be guided by the assumption that conducting 2–3 FGs with a semi–structured guide in a relatively homogeneous population will likely capture at least 80% of the themes on a topic, including the most popular ones, with three to six FGs identifying 90% of themes. In this case, the third FG outlined the reach of saturation.

Themes

The Thematic analysis revolved around a central concept of "exploring literacy and its impact" and three overarching themes: *(1) Current state of information provision and counseling, (2) Impact of lack of information, awareness and literacy, and (3) Healthcare system structure and its impact on literacy.* Themes, subthemes, and framework analysis findings are depicted in Figure 2. Additional comprehensive list of quotes that support the finding is found in Supplementary material 4.

Theme 1. Current state of information provision and counseling

Subthemes (1A—1D) depict the multifaceted and contextual interactions with the health care system that influence literacy development, information acquisition, and processing.

TABLE 2 Characteristics of participants of semi-structured interviews ($n = 15$).

Variable(s)	CRC survivors ($N = 15$)
	N (%)
Age (years)[a]	58 (33–72)
Male(s)	9 (60)
Female (s)	6 (40)
Education	
Primary (5–8 years)	0 (0)
Secondary (9–12 years)	2 (13.3)
High school/collage/diploma (12+ years)	6 (40)
University (14+)	7 (46.6)
Employment	
Employed	6 (40)
Unemployed (capable/uncapable)	7 (46.7)
Retired	2 (13.3)
Cancer type	
Colon	12 (80)
Rectal	3 (20)
Cancer stage	
Stage I	0 (0)
Stage II	5 (33)
Stage III	8 (54)
Stage IV	2 (13)
Treatment modality	
Chemotherapy, surgery	9 (60)
Chemoradiation, surgery	4 (26.6)
Chemotherapy, surgery, palliative chemotherapy	1 (6.7)
Surgery	1 (6.7)
Stoma	
None	5 (33)
Temporary, reversed	8 (54)
Permanent	1 (6.7)
Unknown	1 (6.7)
Route of diagnosis	
Self-led	3 (20)
Multiple point of contact	5 (33.3)
Incidental	2 (13.3)
Emergency admission	5 (33.3)
Time since diagnosis (years)[a]	2 (1–5)
Time since surgery (months)[a]	11 (6–22)
Comorbidities	
Yes	6 (40)
No	9 (60)

[a] Median (min, max).

TABLE 3 Characteristics of participants of focus groups ($n = 3$).

Variable(s)	Informal carers ($N = 10$)
	N (%)
Age (years)[a]	36 (26–62)
Male(s)	4 (40)
Female (s)	6 (60)
Education	
Primary (5–8 years)	0 (0)
Secondary (9–12 years)	0 (0)
High school/collage (12+ years)	1 (10)
University (14+years)	3 (30)
Masters/Ph.D. (18+ years)	6 (60)
Occupation	
Medical professional	5 (50)
Engineering, design, tourism	3 (30)
Academia	1 (10)
Housewife	1 (10)
Patients' cancer type	
Colon	8 (80)
Rectal	2 (20)
Relationship of carer-patient	
Son/daughter	7 (70)
Stepmother	1 (10)
Spouse	1 (10)
Sibling	1 (10)
Time since patients' diagnosis until time of study (caregiving experience) (years)	
2–3 years	5 (50)
4–5 years	4 (40)
5+ years	1 (10)

[a] Median (min, max).

1A. Quality and format of information

Underuse of patient-directed materials, information presented verbally, and inconsistent written materials across departments/facilities, led to inadequate cancer-related HL. Patient counseling was only delivered verbally during doctor-patient interactions, and patient handouts differed widely among departments and institutions where patients were treated. Patients at various hospitals and stages complained about inconsistent patient-directed materials. In addition, booklets and written counseling plans were not matched to respondents' requirements or stage of therapy. Respondents said that while they are provided in-depth information regarding their condition, it is written in language that they cannot comprehend, with the

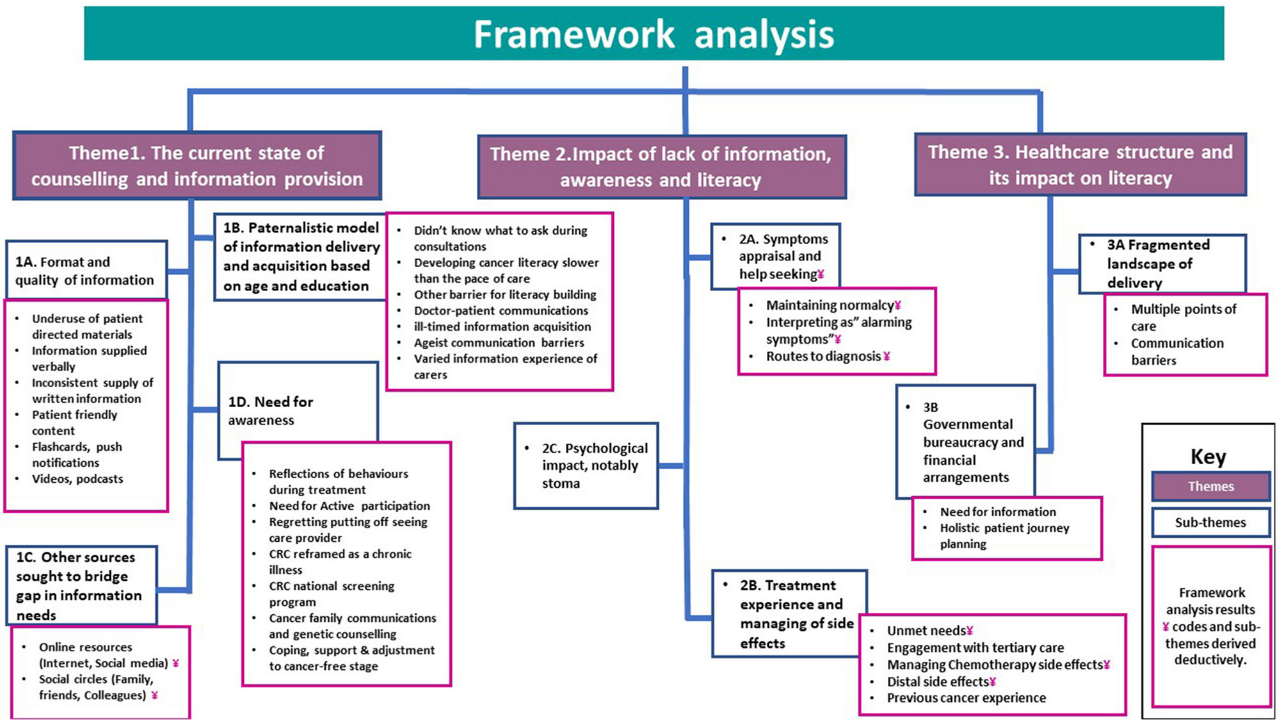

FIGURE 2
Theme(s), subthemes, and framework analysis findings.

latter acting as another barrier to successful counseling and HL development.

> *"At the other hospital where I received chemotherapy, no patient counseling or explanation of my medications or side effects is provided; you simply get the pills and nothing more." (CRC Survivor male, 58 years)*

The sub-quality of information extended to dietary education and guidance.

> *"I received nutritional plans from the center, like I should avoid legumes, but there is no specific plant, or food, they said you should try and see which types of foods work best, but I had many problems, like bursting, filling quickly, bad smell." (CRC survivor male, 63 years)*

Even after becoming cancer free, one respondent reflected on the dire state of resources and information. The interviewee underlined the need for trustworthy, patient-directed resources to assist them cope, support, and transition to cancer-free stage since they didn't know where to turn for credible information regarding CRC.

> *"Finding what I need might be difficult. Since beating cancer, I've realized how much I still need to learn, but I don't know where to seek for resources." (CRC survivor male, 58 years)*

1B. Paternalistic model of information delivery and acquisition based on age and education

Mistimed or withheld information, lack of confidence in asking questions or understanding what to ask during consultations, ageist communication, and information provision that is dependent on the receiver's education level were all examples of paternalistic information flow and communication between healthcare practitioners, patients, and their ICs, as well as between ICs and patients. All these approaches lead to poor HL or HL that grows at a slower rate than care delivery. These communication approaches can undermine patient empowerment and participation in treatment decisions. Some patients indicated they didn't know what to ask during diagnosis consultations, but having all of their medical data and regular follow-ups let them feel more confident about information sufficiency. Others stated that their doctors pay great attention to them, but that it is up to the patients to ask the correct questions in order to receive the best answers, which is tough and leaves patients with a shallow understanding of the disease and many unknowns.

> *"All of my queries were answered by the physicians and nurses, who were very kind and helpful. But I'm not always sure what questions to ask to get a deeper understanding...... " (CRC survivor male, 58 years)*
>
> *"I honestly don't know, since they do investigations and tell me they are doing this and that. I didn't choose which therapy to do. I just go to my doctor, and he tells me what to do. After four cycles, I'm not sure why the doctor recommended a colonoscopy." (CRC survivor male, 72-years)*

The treating physicians' knowledge, reputation, and faith influenced patients' paternalistic decision-making styles. Though finding the right specialist was difficult, patients feel safe in their care. One cancer survivor said he let the doctor make all treatment decisions due to his urgency and lack of cancer knowledge. After treatment, he realized his lack of plan engagement hampered his post-treatment management. Participants who did not actively participate in decision-making and placed too much reliance on their doctors acknowledged regretting these behaviors, but they also confessed that they had attempted to educate themselves but failed mostly due to lack of resources. *"I didn't have much to do with my treatments, and I mostly relied on the treating surgeon. After all, it's all about having a good surgery, and you don't send a boy to do a man's job." (CRC survivor male, 72 years, high school)*

> *"The consultant is a well-known surgeon who has done many similar surgeries, so I knew I could trust him. He was in charge of everything, along with the medical teams. Now it's up to me to take care of myself, which is why I started learning about my symptoms. I didn't find many helpful things on the internet, like diet plans for people with colorectal cancer based on their stage and procedure." (CRC survivor male, 58 years)*

Some patients thought herbal, traditional, or alternative medicine could help them heal, but they were concerned their doctors would patronize them because they solely believed in conventional therapy.

> *"Doctors are somewhat patronizing, and sometimes they just push conventional medicine, but I think I can find more ways to help me heal and boost my immune system. Cancer therapies have a lot of toxicities that hurt your body, so I'm tired of the side effects, and if I tell my doctor that I'm taking soursop, turmeric, or I'm cleaning my colon, he or she will look at me like I'm crazy." (CRC survivor female, 61 years)*

In addition to the healthcare team's paternalistic approach to patient information, some ICs used ageist approaches to seek age-biased professional decision-making about patient diagnoses and treatments. Caregivers felt that divulging the diagnosis would cause emotional distress or lower the spirits of the patients they care for, especially elderly, disabled, or advanced disease patients. Some patients were informed unwittingly or late in their treatment. ICs also stressed the importance of presenting information in a way that never caused anxiety and was patient-friendly, personalized, and easy to understand because patients' emotional and cognitive capacities may hinder their ability to learn during therapy.

> *"We were worried about the emotional and mental reactions, so we talked to the doctor and the whole staff to not tell him [his 71-year-old dad] anything. However, a doctor who wasn't on staff got into his room and told him everything, and my dad thought she was mistaken for another patient because she didn't know about our agreement to keep it a secret. We needed a psychiatrist to inform him professionally. Our biggest concern was that telling him would kill his positive attitude. Seniors fear everything." (IC male, 26 years)*

Depending on their education, ICs received different types of information, which led to a variety of experiences. Caregivers with a medical background reported being well-informed about the patients they were caring for and that doctors included them completely in decision-making. Additionally, their education enabled them to find reliable information. Despite being an engineer, one carer said his education didn't help him find relevant CRC information.

> *"I am an engineer, and I had no idea what cancer was or what was going on with my father." I kept searching and reading until I discovered that the colon is 1.50 cm long, which I had never known before." (IC male, 26 years)*
>
> *"The consultant involved me in every aspect of my dad's treatment, even the protocols, because I'm a doctor. I also used medical resources to learn about his case and prognosis. It's different when you explain these things to carers, who are usually more engaged if motivated or have higher education." (IC female, 27 years)*

1C. Other sources of information sought to bridge gap in information needs

Participants preferred patient-friendly videos, animation, push notifications, and podcasts. One patient was interested in reading extensively about the illness. Alternative information sources and patient experiences are listed below to fill the information gap.

Online resources

Several patients who used the Internet to fill their knowledge gaps during treatment said they learned more about cancer by reading online cancer-related material. Several informants said they had trouble finding useful, relevant information to improve their literacy. Some survivors gave generic or non-specific answers when asked about their search strategies. Few patients' search strategies aligned with their treatment plans, so their searches were successful. *"I specifically researched the "FOLFOX'" chemotherapy regimen online. Although my experience was terrible, the doctors never addressed these issues, so I researched how to prepare for chemotherapy. I mostly use the internet for diet and lifestyle research." (CRC survivor male, 68 years)*

Patients' ability to access complex and in-depth information online about some problems, such as LARS (Lower anterior resection syndrome), was limited due to lack of information and inadequate education catered to their HL by their clinicians.

> *"I won't be able to get the finest information if I don't know what exactly is wrong with me and what physicians label it in their terminology because they frequently withhold information regarding anticipated symptoms until they manifest." (CRC survivor male, 67 years)*

Lack of understanding of colonoscopy findings and the desire for more information prompted the use of social media to bridge information gaps; however, the downsides included misinformation, language barriers, and emotional and psychological ramifications for some patients.

> *"In the Facebook group (ask doctor), people share treatment reports and ask doctors to explain colonoscopy results. I tried to learn more because I didn't understand my case after initial consultations.... I was shocked when the admin said anything cancer-related should be discussed privately between the patient and his provider... I knew "it's cancer" before meeting the oncologist." (CRC survivor male, 68 years)*

Patients' social circles

Patients relied on family and friends as mediators with medical expertise or digital abilities to help them improve their literacy by deciphering medical records, communicating with health specialists, and seeking information.

> *"When I'm with my stepmother at her appointments, she feels more at ease. Sometimes she's too shy to tell her doctor what she's going through with her rectal cancer, so I talk to their doctors about these symptoms." (IC female, 41 years)*

Lifelong ostomates valued peer support in the form of practical and psychological advice. *"Because it was new [ostomy bag], I was upset, but a co-worker with a similar issue helped me keep going. He had a permanent colostomy before me. He gave me practical advice on how to live after the colostomy and informed me of his subsequent actions." (CRC survivor male, 58 years)*

1D. Need for awareness

CRC was reframed as a chronic illness, and participants recognize the need for a national screening program and cancer family communications and genetic counseling information. Some patients stressed the importance of a CRC awareness and screening program, *"Neither of my parents work in medicine, so they don't know about colonoscopies. Both my parents never had colonoscopies. I told them because they're over 50."* (IC female, 27 years). Whereas, others regretted delaying medical treatment due to ignorance and lack of HL. *"I didn't even ask why my blood level is six or what it means. This could be because I don't fully understand what it means."* (*CRC survivor female, 33 years)*

Younger survivors with children described how they sought information to help them explain the importance of cancer to their children. "*Googled "how to tell my kids I have cancer... the internet helped, but not enough. Cancer is hard to say. Fearful. Cancer frightens. When I got home, my kids saw my scars and colostomy bag. That day, their innocence was taken from them. They grew up when life suddenly became real. I don't want them to wake up one day and say, 'I wish I hadn't done that,' so I think it's inevitable. 'Mom, you got cancer? Returning?' I struggle to balance my patient concerns with my motherly duties." (CRC survivor female, 36 years).*

ICs, in particular, stressed the importance of cancer family communications and the need for resources on how to communicate cancer-related topics to patients in a way that preserves their spirits and provides psychological support. They also reported that it was challenging to explain genetic counseling and educate family members. *"I'll never forget the doctor's words to me after the surgery: 'It may happen to you and your siblings and sisters."' Therefore, it is hereditary, and we need to monitor.... my brothers had phobias.... they wished to know when they should be required to observe, conduct exams, and so on. When must screenings be conducted if there is a program that informs people, particularly those who have a family history." (IC male, 35 years)*

Theme 2: Impact of lack of information, awareness and literacy

Literacy, awareness, and information availability had an influence on CRC patients' symptom assessment and medical help seeking. In addition, it impacted CRC patients' treatment experiences and quality of life including self-efficacy in managing treatment side effects and the psychological impact of treatment, particularly stoma.

2A. Symptoms appraisal and medical help seeking

Patients sought medical care in diverse ways due to the lack of standardization of health-care pathways. Symptoms appraisal and help seeking in the pre-diagnostic phase outlined diagnostic routes used and symptoms evaluation and interpretation whereby participants pondered on physical changes that they later identified as symptoms. The timing, consistency, and frequency of bowel movements were examined and compared to normal or anticipated patterns. Initially, symptoms were normalized and understood as innocuous attributions. Patients with chronic stomach pains ascribed their symptoms to H-pylori, whereas those with occasional constipation or regular diarrhea believed they had irritable bowel syndrome. A change was more likely to be recognized as abnormal if it was large, emerged quickly, became recurring or was accompanied by additional changes, lasted longer than expected, made routine daily activities difficult, or raised concern among family members. "*My father lost 10 to 11 kilos in 2 weeks while doing the same activities and eating the same diet; nothing had changed except for the rapid loss of weight, and once we received the blood test results, we knew that his Hb is 7.5 or 7.8, we freaked out.... It would be impossible for us to tell if my father has cancer without any symptoms of weight loss." (IC male, 26 years)*

Participants who thought their bleeding was due to hemorrhoids were likewise unlikely to contemplate CRC, but those who observed that it persisted were more likely to consider cancer or seek medical attention. *"Because there was bleeding from the anus, I initially assumed I had hemorrhoids for like 2 months but after that when I used to go to the restroom, I would notice that the blood had darkened. When I use toilet paper, I notice that there is a bulk and some hardness in the anal area. So, I went to the hospital ER." (CRC survivor male, 58 years)*

Despite significant changes in bowel habits and despite the advice of his family, one patient managed to maintain some feeling of normalcy while adjusting to a severe and debilitating condition. This is due to the fact that he assumed that as he had a clear medical history, his digestive function was gradually declining with age. *"I used to go to the toilet to poop every 3–4 weeks recently, but before that I remember I used to go more often, I thought it was normal, I was oblivious about that ...... My daughter insisted I be checked out since I had restroom problems. I was obstinate and didn't want* *to listen to anyone's advice.... In my mind, it seemed sense that as we grow older, our bodily functions would slow down....." (CRC survivor male, 72 years)*

For other patients, preserving normalcy included self-medication with laxatives or antidiarrheals for symptomatic relief utilizing herbal or traditional remedies. However, in cases where the physical effect of symptoms became intolerable or threatened regular daily activities, patients were more likely to seek medical attention. *"I experienced constipation for 10 days, tried senna, and lactulose from the pharmacy, but too full and unable to defecate. I visited the ER because I couldn't sleep or sit and had stomach pain." (CRC survivor male, 58 years)*

Fainting, dizziness, bloating, and fatigue are examples of non-specific changes that made some patients being oblivious of the implications of their symptoms. Most of the time, vomiting or anemia were not thought to be signs of CRC. Hence, participants took vitamins and minerals to alleviate these negative effects. The rationalization of pre-existing assumptions, such as they don't have a cancer family history, broadened and validated their feeling of normalcy. Participants, particularly those younger in age, rationalize their symptoms by asserting that they had considered cancer or CRC as a disease that affects the elderly. Additionally, younger patients said they were too busy with careers and families to seek medical attention when they first experienced vague symptoms, so they never considered CRC a diagnosis. *"It seemed exceedingly unlikely that I would be given a cancer diagnosis at my age, even if I was completely oblivious of what are the symptoms." (CRC female, 36 years)*

While some participants found it helpful to talk to family and friends, this was not always the case, and other participants disregarded their relatives' suggestion to see a doctor. However, one survivor said that her loved ones discouraged her from seeking medical attention in favor of more natural, holistic approaches. *"Friends and relatives assured me that my constipation was typical and that I shouldn't worry about it, suggesting various natural remedies and herbs." (CRC survivor female, 61 years)*

One participant, as an exception, was able to spot the changes in bowel movement right away since she had previously experienced regular bowel movements and who, on the advice of her family decided to seek care in the private sector. *"I rarely get constipated because I eat a healthy Mediterranean diet and go to the bathroom in the morning or after coffee. After a month, a drugstore laxative didn't work, so I was scared... My husband called a doctor cousin after I told him. I was moved to this tertiary hospital after a private colonoscopy a week earlier." (CRC survivor female, 59 years)*

Five out of 15 patients were diagnosed at the emergency department (ER) as were patients with a non-specific or non-classical presentation, or those with rectal bleeding. "*I was at a wedding when I frequently felt like vomiting. They called an ambulance to take me to the emergency room, where I had a CT scan and lab work." (CRC survivor male, 72 years). Three* out of fifteen were self-directed to the private sector based on family consultation or advice. After developing a symptom, some respondents sought care from multiple physicians, switching back and forth until their symptoms deteriorated. Because of the delay in diagnosis, several patients needed to be admitted as emergencies when their diseases deteriorated after having been treated for another diagnosis. One interviewee described how general practitioners misinterpreted her symptoms and treated her until her condition deteriorated. *"I couldn't eat or drink because I felt sick and lightheaded. Constipation prevented me from pooping seven times in 2 months. The private hospital doctor near my home didn't examine me thoroughly because he thought my problem was minor. However, I was prescribed medication for symptoms relief. When my condition deteriorated, my spouse took me to this hospital, where I was finally diagnosed." (CRC survivor female, 53 years)*

2B. Treatment experience and managing side effects

CRC survivors and ICs cited numerous unmet needs associated with coping with adverse effects of chemotherapy or post-operative care activities. The latter was mainly in relation to ostomies, for example difficulties in locating adequate ostomy supplies, affording the expenses of stoma supplies in addition to dealing with other stoma-related issues such as leakage, poor odor, herniation, prolapse and psychological-practical ostomy life style adjustments. *"Because of the colostomy, I can't sit in a chair for long periods of time without experiencing pain on the surgical side. I had to wear dishdashi (long dress) at first since I was unable to wear trousers or my own clothing. In the end, I figured out how to dress regularly again, including using a belt to secure it.... I can't even wear my socks without the help of my wife. The transition to my unfamiliar setting was taxing on my body and mind, and it took me nearly 1 year and a half to adjust." (CRC survivor male, 58 years)*

The social stigma attached to discussing bowel abnormalities and ostomies were also raised by interviewees. Because they perceived their stoma as a short-term fix, they lacked self-management skills. Several ostomates had a low quality of life as a result of their stoma. Conversely, those who viewed it as a permanent component were better able to mentally adjust. Several responders said they weren't given nutritional guidance or time to prepare for treatment or colostomy management. "*When the doctor said the stoma is "temporary," I didn't worry about having it for a short time and didn't pay much attention to what does it mean to have a stoma!*" (*CRC survivor male, 53 years)*

Despite their low quality of life, frequent hospitalizations, and ER visits, participants believed they should accept chemotherapy's side effects because of their preconceived notions about their inevitability. Because alopecia is a common side effect of chemotherapy, some patients reported only questioning their doctors about it. However, some informants experienced distal side effects that were difficult to manage and differed from their expectations. *"They gave me chemotherapy, and they said it won't cause any hair loss, this is what I was concerned about, but now I have numbness in my feet that is getting worse.... "(CRC survivor male, 56 years)*

Several respondents said they had a dreadful experience with side effects and that they had unexpected side effects that their physicians hadn't warned them about. Some patients felt misinformed because their assumptions about treatments and potential adverse effects did not match what their doctors had told them. As a result, they had frequent emergency hospitalizations. *"It has been a hell of a ride... The five rounds of chemotherapy were a* *nightmare and absolutely destroyed me, in contrast to what they had told me...... I had terrible diarrhea and had lost a lot of weight, so I stayed there for 3 or 4 days. I used to weigh 75 kg, but when I was admitted, I only weighed 59 Kg, so I was treated as if I weighed 59 kgs until my immunity came back to normal, which was zero." (CRC survivor male, 58 years)*

On the other hand, patients or caregivers with prior cancer caregiving experience reported more resilience, developing knowledge and skills and acceptance of the condition, despite the challenging experience they had, which enabled them to better cope with the disease. *"Historically, both my aunt and uncle (on my dad's side) and my aunt (on my mom's side) died from cancer. My mom had two types of cancer, while my dad had it three times and is colon-free (nearly total colectomy). We're familiar with 'cancer.' We all get regular check-ups but prepare for the worst." (IC female, 38 years)*

2C. Psychological impact, notably stoma-related

Psychological barriers to professional care (guilt, embarrassment) and post-surgery weight loss among ostomates make life with an ostomy less than desirable and keeping ostomates at home and away from social engagements. As mentioned above, patients and ICs felt the pre- and post-operative food instructions were inadequate, resulting in poor self-management. Some patients lost a lot of weight because they couldn't change their diet or choose foods that wouldn't overfill or leak the ostomy bag. Others felt ashamed and struggled with stomas. *"I was ashamed because no matter what I ate, it would fill up and burst. I lost my appetite and couldn't eat a variety of meals after having a colostomy, so I dropped from 85 to 60 kilograms." (CRC survivor male, 53 years)*

Theme 3: Healthcare structure and its influence on literacy

The fragmented healthcare system, government bureaucracy, and financial arrangements affect cancer patients' ability to learn about and discuss their condition. Most Jordanian cancer patients receive treatment at various government-funded sites. Fragmentation and the need to acquire financial arrangements and government cancer insurance information before sectoral transfer for treatment fulfillment made government formalities time-consuming and burdensome. This calls for a holistic journey strategy and process simplification to reduce red tape. *"Sometimes I don't even know which care provider is taking care of me ...... When they moved me from one facility to another, I also had to fill out government paperwork and applications." (CRC survivor male, 58 years)*

Without interoperable electronic health records and synchronous and asynchronous patient notes, specialists from different health systems are less likely to communicate electronically (such as tumor boards). Thus, fragmentation may decrease care quality and increase inequality. *"My doctor, a medical oncologist at another facility, doesn't see me regularly. So, I go every 6 months. My doctor won't tell me when to see him or her. The hospital doesn't care if the patient shows up... Never..." (CRC survivor male, 58 years)*. Some cancer patients had to be readmitted to hospitals for treatment multiple times because of poor self-management, communication hurdles, and the fragmented nature of cancer care. *"I didn't know who to call when I had side effects from chemotherapy because I got it at a different place not this hospital. So, my family had to pick me up again to the ER." (CRC survivor male, 58 years)*

Discussion

Using qualitative approaches, this study moves beyond the limiting definition of HL toward a broader conceptualization that accounts for the complex nature of HL phenomena through an in-depth analysis of the experiences of CRC survivors and ICs during their interactions with the health care system along the care trajectory from pre-diagnosis to survivorship. The study highlighted contextual, individual, sociocultural, and healthcare system determinants affecting HL of survivors and carers and information acquisition, provision and interpretation. In addition, it highlights the impact of HL on symptoms interpretation and seeking medical care and resources used to bridge this gap, while outlining changes that are needed to improve health outcomes.

Internal/external healthcare system context and HL status

Due to methodological inadequacies and varied HL conceptualizations, Humphrys et al. (48), could not fully analyse HL's impact on early cancer diagnosis. However, low HL is linked to poor quality of life after cancer diagnosis, treatment decision-making difficulties, and low cancer screening rates.

According to the findings, the environment and organization of the healthcare system had an impact on how cancer survivors with CRCs and their carers were developing their cancer literacy. Many CRC survivors in Jordan seek emergency or tertiary treatment due to a lack of awareness of CRC symptoms, delayed help-seeking, and unstructured health care and referral pathways. The experiences of those patients who received a cancer diagnosis through an emergency pathway indicate that the majority of them had recurrent evaluation and help-seeking (49). These findings concur with Abu-Helalah et al. (50), who showed that the most common causes of delayed presentation among Jordanian CRC patients were misdiagnosis by physicians or pharmacists (38.4%), a lack of understanding that the patient's symptoms were suggestive of cancer (58.5%), and a lack of motivation to see a doctor (3.0%). The findings demonstrated a knowledge gap about CRC screening and symptoms, emphasizing the need for Jordanians to adopt improved health care strategies and CRC promotion efforts. Lack of patient-centered training programs on the importance of CRC screening as well as insufficient CRC publicity may be to blame (51, 52). These results support earlier quantitative studies that called for a countrywide deployment of a CRC screening program, suggesting that as a first step, this CRC screening program should be adopted at primary care clinics and community hospitals at a national level. This qualitative sample, although is supportive of this argument, this goes beyond the scope of this research. The complexity of health care systems, especially in cancer, raises difficulties for patients and users to navigate them during the pre-diagnostic period (13, 53). HL-NAV is needed for healthcare system navigation and communication. To navigate the health care system and find the best solution for their health issues, patients must be able to choose an appropriate access point, explore many institutions, and identify an appropriate entry point (54, 55). HL-NAV is relational and depends on patients' HL-NAV and the health care system's complexity and demands, particularly the quality and types of information and communication available (56). This study highlighted low HL-NAV among CRC patients driven by a bureaucratic and fragmented healthcare system and lack of effective information and resources. Low HL-NAV among patients results in confusion, useless and unpleasant searches, ambiguity, and treatment gaps as seen in the results (57). In the digital era, developing digital solutions to help patients and carers navigate the healthcare system is vital to overcome the fragmented landscape of care delivery, governmental care centrality, and financial arrangements that prevented some survivors and ICs from getting care. Future CRC diagnosis will increasingly incorporate digital technology. Smartphone symptom-checking apps are available in several countries (58). These apps collect gastrointestinal symptoms to track pre-existing disorders. These programs can instantly update the patient's electronic health records (EHR). Thus, detecting delays and investing in digital solutions to get patients to the correct specialist at the right time can improve CRC diagnosis. Although CRC was reframed as a chronic illness, which emphasizes the need to focus on survivorship care, recent research by Melhem et al. (4), demonstrated that CRC survivors have persistent unmet information needs during this stage. Therefore, CRC survivors and ICs sought alternate sources of information to bridge their informational gaps and improve HL *via* the internet and social media, but their benefits were offset by lack of DHL skills, inadequate search strategy, and suboptimal online information quality (15). Furthermore, survivors sought emotional and informational support from family, friends, and colleagues. Due to a lack of HL and standardized information, several patients showed low stoma self-efficacy and stoma-related psychological impacts, such as feelings of shame or humiliation. Pate et al. (59) reported that pre-surgery education and standardized, health-literate written materials improved stoma self-efficacy. Therefore, by strengthening self-efficacy, patients may be better able to manage their ostomy and care for themselves after leaving the hospital, thus avoiding issues and improving outcomes.

A growing body of research reveals that HL is contingent on the individual's abilities and skills as well as the requirements and constraints of the healthcare system (9, 36, 60). Despite rising expectations, cancer survivors struggle to manage their disease and care (61).

Cancer literacy was influenced by organizational literacy contextual factors, including access and verbal/written communication which were substandard and inconsistent in addition to the format and quality of information provided that were suboptimal and not tailored to CRC survivors' HL skills and information requirements. The information was in jargon and not formulated in patient friendly formats which were deemed more favorable such as videos, podcasts, animations of push notifications to match patients and IC HL skills. Varied experiences in engagement in information provision and decision making and involvement in treatment calls for the customization of patient/carers information delivery that is adaptable to the HL level. This will ensure health equity in information and care delivery without exacerbating inequalities among CRC survivors and ICs.

OHL is a new concept that emerged to satisfy the requirements of the majority of patients with poor HL (60). It refers to a healthcare delivery system that uses strategies to assist people in participating in their treatment, navigating the healthcare system, understanding medical information, and taking charge of their health (60, 62, 63). The crucial function that OHL plays in improving patients' self-management support and communication have been underappreciated (64, 65). Consequently, healthcare reforms necessitate the development of responsive health care delivery systems and health-literate organizations that incorporate HL into their strategies (60). To the same extent, there is a need to give solutions to alleviate shortages and obstacles of HL by helping patients better comprehend health information, simplifying health care, and receiving more comprehensive support (66). Improvements in HL are necessary before patients may be empowered, which would transfer authority and responsibility from healthcare providers to patients and boost patient engagement. This transition may increase the quality of care through improved treatment decision-making and the utilization of self-management opportunities, resulting in better health outcomes (67, 68). Enhancing HL by fostering open lines of communication and collaboration between healthcare providers, patients, and family members can expedite the delivery of high-quality care that is both personalized and cost-effective. In order to facilitate the shift to health-literate organizations (60), it is necessary to design patient-centered literacy programs that target and focus on patients with lower levels of literacy.

The notion of OHL emphasizes the challenges each patient encounters over the course of treatment and it can only be understood in the organizational context of care since patients' capacity to absorb health information and navigate the care-seeking process is tied to healthcare system needs and the challenges they experience (60). There are several approaches for organizations and services to promote HL. Design elements that make navigation easier for patients and their caregivers can be used in health clinics and hospitals. The signage at hospitals might be written in simple language so that individuals of all literacy levels could read it. Through simple-to-use internet platforms, new technological advancements can make it easier to acquire healthcare services.

CRC patients and carers' health care interactions and HL

The ability to make informed decisions is constrained by a lack of relevant knowledge, the complexities of benefits and drawbacks of therapies, and uncertainty pertaining to the care process (66). However, the urgency in decision making prompted inactive involvement of some CRC survivors while delegating decisions to their oncologists. CRC patients do have preferences regarding different treatment options and outcomes, however, these preferences are not homogenous and seem to depend on personal factors like age and gender. Despite the existence of these preferences, the majority of patients prefer a passive role in the decision-making process, which in part may be explained by the severity of the disease (69). Interaction with the healthcare system was influenced by ageism and medical paternalism which may impede the development of cancer related HL. Physicians' decision-making processes involving information, communication, and treatment have been found to vary depending on the patient's age. Many cultures, especially those of Asia (70, 71), Southern Europe (71, 72), and Latin America, are reluctant to inform elderly patients of a cancer diagnosis or prognosis, which echoes the findings presented. One study indicated that physicians spent less time with older patients and paid less attention to their needs and choices compared to younger patients (71). Cancer patients in Jordan and culturally equivalent nations favor paternalism, if not authoritarianism, when it comes to medical decisions. Patients relinquish their autonomy because 'the doctor knows best' (73). Lack of confidence, ambiguity about which option to take, competing ambitions, or anticipating self-blame for disappointing results lead to this mindset (74). Paternalism remains the most preferred source for information provision among CRC survivors despite Jordanian physicians' endorsement of patient autonomy, engagement in treatment options and self-management (15). This runs counter to the assumption that paternalism should be avoided. However, this notion should be tailored to cultural perspectives and attitudes that cannot be changed overnight (15, 74). Treatment-survivorship expectations gaps were mentioned by some CRC survivors due to their passivity and late engagement in their care which undermined their ability to develop HL skills and knowledge to effectively self-manage post-treatment. Several studies on CRC survivors highlighted the dissatisfaction in HCP communication styles and lack of knowledge, time or empathy (31, 33). Other survivors' related factors for miscommunication include embarrassment to ask providers for support, for fear of appearing ungrateful, bothering the HCP or making a big deal out of symptoms that may be normal (6), a finding echoed in this study.

The relationship between HL and empowerment is inconclusive. The WHO recognizes HL as a social determinant of health and improved HL as a key goal of public health. Increased HL is identified as a necessary prerequisite for achieving patient empowerment, which can reduce the utilization of health services and healthcare costs (19). On the other hand, a review by Schulz and Nakamoto (75) highlighted that despite the effects of HL and patient empowerment being intricately intertwined, the two concepts are independent and distinct. HL does not always imply empowerment and *vice versa*. Mismatches between the two can have negative consequences. High HL without a corresponding high degree of patient empowerment may create unnecessary patient dependence on health professionals. However, both are important patient-related variables to consider during screening and health promotion campaigns for the general population (75, 76).

Strengths and limitations of the study

To the best of our knowledge, this is the first exploratory study to focus on CRC survivors and ICs healthcare experiences and its relationship to the multidimensionality of HL. The research conducted in Jordan; a country representative of Arab Middle Eastern culture also illuminated the importance of understanding the sociocultural factors impact on HL in the context of oncology. The study's strength rests in its in-depth interview methodology and open-ended format. Participants were able to bring up themes and subjects that were important and significant to them, which may not have come up in structured interviews or research that used quantitative methods. Although HL in its restrictive skill based and functional view can be measured using standardized assessment tools, the qualitative methodology allowed the understanding of survivors and ICs health experiences and their relationship to the broader sense of HL as crucial element for patient engagement. It also allowed the linkage of these aspects to the multiple dimensions of HL (Nav-HL, OHL, and DHL). The findings of the study maybe be used to design an e-health teaching program for patients with poor literacy and guide healthcare services reforms for this population. Additionally, our results highlight the need of changing the Jordanian health care system into a literate system.

Convenience sampling from one large semi-government-run tertiary hospital reduces the generalizability and may be a limitation of the study. However, individuals were treated in a variety of settings in multiple facilities, since their therapies were carried out in a number of hospitals in private and public sectors, thus their aggregate experiences may be holistic and provide insight into a population with limited research.

Implications for practice and future research directions

Low Cancer HL is a barrier to efficient and timely diagnosis and care delivery across the cancer continuum. Empowering cancer patients is essential for better outcomes. The need for adopting healthcare policies to transform healthcare organizations into "literate organizations" that provide health practitioners with education, information, and tools, need to be addressed by healthcare policy maker to enhance cancer literacy. In order to guarantee that the patients receive timely and adequate care, public health policy should also consider the establishment of national screening program and awareness through online educational programs. These programs must be designed to raise patients' comprehension of their diseases and treatment alternatives, which should result in patients who are more knowledgeable and empowered.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

This study was authorized by Kingston University's ethical guidelines for scientific research (approval number/1416) and the Internal Review Board (IRB) at Jordan University Hospital (JUH), protocol ID (10/2019/8990). The patients/participants provided their written informed consent to participate in this study.

Author contributions

SJM and RK conceived, designed, and planned the study, did proofreading and editing, and conducted data analysis and interpretation. SJM did data gathering and translation and wrote the substantial amount of the article. RK being a senior author supervised the implementation of the Project. SN-G contributed to linguistic validation of transcripts, codes, and themes mapping. All authors has been approved and revised the papers.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1116882/full#supplementary-material

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Experience, facilitators, and barriers to the implementation of a multicomponent programme in older people living in the community, +AGIL Barcelona: A qualitative study

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Introduction: The +AGIL Barcelona programme is a multicomponent care intervention for frail older adults (FOAs) living in the community. To improve the programme, it is essential to investigate the experience of all participants. Our objective was to explore the perspective of FOA and professionals about the barriers, facilitators, and improvement elements of the development of the +AGIL Barcelona programme. Qualitative descriptive approach. Were included FOA and professionals who participated in the +AGIL Barcelona programme.

Methods: Three focus groups and four interviews were conducted. These were analyzed following the qualitative method of content analysis. The criteria of scientific rigor of credibility, dependence, and transferability were ensured throughout the study.

Results: Three themes and seven sub-themes were developed: facilitators (positive experience and perceived benefits), barriers (self-perceived health status, digital divide, and continuity of the programme at home), and improvements elements (programme continuity and adaptation of technology). All the participants felt satisfied, highlighting aspects such as interpersonal relationships and social contact, face-to-face sessions guided by a physiotherapist, and the functional improvement achieved. Some of the difficulties were the self-perception of frailty, the need for technological support, and continuing the exercise programme at home.

Conclusion: The FOA who participated in the +AGIL Barcelona programme perceived direct benefits for their health and physical condition due to

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the development of self-confidence by being able to perform physical exercise despite their baseline condition, and the professionals experienced an improvement in the quality of care due to work in a multidisciplinary team.

KEYWORDS

frailty, community-integrated care, exercise implementation programme frailty, exercise implementation programme, exercise

Introduction

Aging population is a global reality that requires adapting and integrating different levels and models of care to provide appropriate healthcare to this group's needs and specific characteristics (1). In addition, the coordination and integration of frailty programmes for the older adult population are challenges that aging entails in our society.

The concept of frailty has evolved since Linda Fried described the physical frailty phenotype (2). Frailty is currently defined as a state of vulnerability, potentially reversible, to internal and/or external stressors (3). This state entails adverse health effects such as functional impairment, hospitalization, disability, institutionalization, increased morbidity and mortality, and increased health expenditure (4). In Europe, in 2019, the prevalence of physical frailty was 15% in people over 65 living in the community (5).

There is consensus and robust evidence on managing frailty with strategies based on geriatric assessment and multifactorial interventions where multicomponent physical exercise, nutrition, management of polypharmacy, and health education are the central axis of the programmes (6, 7). Older people believe in the potential of physical activity to improve their physical and mental states. However, it is essential to consider that lack of social support, previous sedentary habits, difficulties in accessing programmes, and apathy are significant barriers to the participation and adherence of older people in exercise programmes (8, 9).

Current research on the experience of frail older adults (FOAs) and professionals in implementing physical exercise programmes is almost non-existent (10). However, a study indicates that the accessibility to the environment where the exercise is carried out is closely related to the security perceived by the frail older person (10). Furthermore, it should be considered that frailty is accompanied by reduced physical strength, slow mobility, vision problems, and fatigue, which are perceived as a risk for the individual (10). Thus, to successfully implement these programmes, shared decision-making between the professional and the older adult is essential to balance risks and benefits. In particular, finding an intrinsic motivation allows for identifying objectives that frail adults can achieve in their practice of physical exercise (11–14).

The +AGIL Barcelona programme is a multicomponent care intervention for FOA living in the community, building on a comprehensive care model that involves primary, geriatric, and community care. Its results show clinically and statistically significant improvement in physical function and gait speed in patients with different degrees of initial frailty (15). In the last years, given the restrictions imposed by COVID-19 and to improve its scalability, the digital component of the programme was incremented (16). The use of digital technologies could be a motivation for FOA to perform physical exercise. Even so, it has been observed that, regardless of age, educational level, or opinion regarding technology, frailty is a condition that leads to less use of digital technology (17). Furthermore, the successful use of digital tools in health promotion programmes for older adults highly depends on the motivation and support they receive when using these tools (18).

For this reason, the main objective of this study was to explore the perspective of FOA and professionals about the barriers, facilitators, and improvement elements of the development of the +AGIL Barcelona programme, including its digital component.

Methods

Design

The research design was a qualitative descriptive whose objective was to describe the phenomenon and its characteristics through the participants (19).

Context and participants

This qualitative study was part of the +AGIL Barcelona, "A community programme of integrated care for FOA" (15). The programme is carried out due to the collaboration between a specialized geriatric team (GT) and a primary healthcare team (PHC). The PHC consists of a primary care doctor and a nurse who identify potential participants, refer them to the GT, and do subsequent follow-ups. The GT includes a geriatrician (who assesses the participants and proposes them a tailored multifactorial intervention) and a physiotherapist (who once a week performs an exercise session). Both teams provided advice and health education in the primary healthcare center (PHCC) and facilitated continuity with available resources in the community.

The GT performs a comprehensive geriatric assessment and a frailty status evaluation. Based on the results, a multifactorial intervention is planned and proposed. It includes pharmacological treatment adequacy, counseling, health education, detection and management of cognitive impairment or loneliness, and a physical exercise programme, supervised by the physiotherapist in 10 one-hour group sessions per week, with individualized dosing for

TABLE 1 Research questions.

Area	Research questions for frail older adults	Research questions for the health and social professionals
Overall programme (facilitators and barriers)	1. How have you experienced the programme in general? How did you feel during the sessions?	1. What overall assessment do you make of implementing the intervention?
	2. Once all the sessions were finished, what has been your experience? What aspects would you highlight?	2. What aspects would you highlight?
	3. What positive things would you highlight about the physical exercise programme? What has motivated you or would encourage you to continue doing the sessions?	3. What components were perceived as facilitators during the intervention and what elements could be included to favor or support the intervention?
	4. What barriers (problems, trouble) occurred during the implementation the +AGIL Barcelona programme?	4. What barriers occurred during the implementation of the +AGIL Barcelona programme?
Use of technologies	5. In the use of "technology," how has your experience been? What did you think?	5. What barriers did you perceive in the participants? What was the main barrier perceived by you in the participants?
	6. If you could choose, what would be your preferences related to the devices (Apps) and the type of sessions (face-to-face, online, and group)?	6. How could the digital divide be minimized in order to improve implementation?
	7. What would help or motivate you to use them more? (Technological aids)	7. Would some aspects will enhance the use of digital resources?
Improvement	8. We would like you to help us improve this programme. What changes could be made? How do you think it would be better for you?	8. From the different moments of implementation, what aspects of improvement could be incorporated? (design/planning, intervention, and evaluation)
	9. Would you incorporate anything that we haven't thought of? Would you remove any?	

each participant in terms of type, intensity, and progression of multicomponent exercises. In addition, the exercise component is complemented by strategies to increase the participant's empowerment, adherence, and continuity of exercise in the community and by the Vivifrail app, a publicly available digital application providing an exercise programme tailored to an initial auto-evaluation of physical function (15).

Our study was recruited using convenience criteria such as feasibility, access, interest, and time until data saturation was reached (20). The sample consisted of 22 participants: 11 end users and 11 professionals from the health and social sector. The inclusion criteria were as follows: (1) users with willingness and cognitive ability to express their experience that they are doing at least half of the programme at the time of the interview or have recently completed the programme and (2) health and social professionals (general practitioner, nurse, physiotherapist, civic center manager, healthcare manager, and geriatrician) involved with the +AGIL Barcelona programme. There were no exclusion criteria.

All participants were invited personally or by email and informed about the objective and content of the present study, the data collection methods, and the need to sign the informed consent for data collection.

Data collection

Information was collected using focus groups and individual interviews to ensure the triangulation and saturation of information from October to December 2021. Three focus groups (two FOA and one professional) and four interviews (one FOA and three professionals) were conducted. Focus groups were implemented, keeping groups separate between FOAs and professionals to maximize the comfort of all participants to express their experiences and opinions. The script protocol for the interviews and focus group was evaluated by two experts in methodology and two in the subject of study. Table 1 presents an outline of the areas explored and the questions used.

Three researchers (MSR, OC, and LSN) conducted the focus groups and individual interviews in pairs, with one researcher moderating and another assisting and taking field notes. All of them were audio and/or video recorded.

The interviews lasted between 30 and 45 min, and the focus groups were between 45 and 90 min. The privacy of the participants was ensured through pseudonymisation. The FOA focus groups were held in spaces provided by the primary healthcare center, ensuring their confidentiality. The focus groups were face-to-face and were complemented by an interview. As for the professionals, due to the COVID-19 safety measures, the focus groups and the interviews were carried out online. Transcripts were distributed to all the participants, and they accepted the transcript's contents.

In addition, all participants' basic sociodemographic data (age and gender) were collected. The professionals were asked about their basic training and years of experience. For the characterization of the FOAS, data were extracted from the baseline comprehensive geriatric assessment. These data were as follows: functional ability measured with the Barthel and Lawton–Brody index; physical performance measured with short physical performances battery (SPPB); frailty status measured with the Rockwood clinical frailty scale (CFS); cognitive state measured with Mini-Cog test; polypharmacy understood as the chronic use of at least five drugs or more and falls in the last year.

Data analysis

Content analysis was used, developing the phases of preparation of the transcripts, analysis with the coding of units of meaning, and grouping into categories and thematic axes (21). This process was carried out with the support of ATLAS-ti program version 9.

The analysis of focus group discussions and individual interviews was carried out independently by two researchers (OC and JR). Once finished, the codes, categories, and themes were unified and agreed upon.

The criteria of scientific rigor proposed by Graneheim and Lundman (21) and Graneheim et al. (22) of credibility, dependence, and transferability were ensured throughout the study. The checklist of COREQ qualitative designs was used to execute and evaluate the study (23).

Ethical considerations

This study was approved by the Clinical Research Ethics Committee of the Institut Universitari d'Investigació en Atención Primaria, Jordi Gol. Informed consent was requested from the participants. Confidentiality and anonymity in data processing were guaranteed.

Results

The main characteristics of the participants are presented in Table 2. The mean age of FOA was 83 years, the majority were female population (91%) and 70% had over 3 points in the Mini-Cog test. A total of 78% of participants were vulnerable to being moderately fragile, 45% had falls in the last year, and 82% had polypharmacy. The professionals were also mostly women (82%), with a high experience of 15 years (SD = 4). The most prevalent profession was a doctor: two general practitioners (GPs) and two geriatricians, followed by three physiotherapists.

The results have been structured into three themes: Facilitators, barriers, and elements of improvement for the continuity of the programme and seven sub-themes shared by users and professionals: positive experience, perceived benefits (at the physical-emotional level and improvement in interdisciplinary work and patient care), self-perceived health status, digital divide, continuity of the programme at home, programme continuity, and adaptation of technology (Figure 1).

TABLE 2 Description of participants.

Frail older adults characteristics	*N* = 11
Age, years (mean ± SD)	83 ± 5
Sex	
Female (*n*)	10
Male (*n*)	1
Living alone	4
Functional ability (median ± IQR)	
Barthel index	95 (73.8–98.8)
Lawton-Brody	7.5 (1.8–8)
Physical performance (mean ± SD)	
SPPB score	6.4 ± 3.1
Clinical frail scale (*n*)	
Very fit	0
Well	0
Managing well	2
Vulnerable	4
Mildly frail	2
Moderately frail	3
Severely frail	0
Cognitive impairment	
Mini-Cog score < 3	3
Polypharmacy, person (*n*)	9
Falls in last, year (*n*)	5
Professionals characteristics	*N* = 11
Age, years (mean ± SD)	43 ± 5
Sex	
Female (*n*)	9
Male (*n*)	2
Professions (*n*)	
Civic center manager	1
General practitioner	2
Geriatrician	2
Healthcare manager	2
Nurse	1
Physiotherapist	3
Professional experience, years (mean ± SD)	15 ± 4

IQR, interquartile range; SD, standard deviation; SPPB, short physical performance battery. Polypharmacy was defined as the use of more than five drugs.

Theme facilitators: Programme experience and benefits obtained by the FOA and professionals

The experience was perceived as very positive for both the FOAs and the professionals. FOAs expressed feeling good throughout their participation in the programme. It was feasible, given that the instructions for performing the exercises were clear, and adapted to each user and the different levels of difficulty or impediment.

> *"Next day I feel better than previous. Not only today, no, no, the day after. I" 'm really happy about it. FOA1.*
>
> *"The majority of them, also feel a functional improvement, and they liked it!" PROF4.*

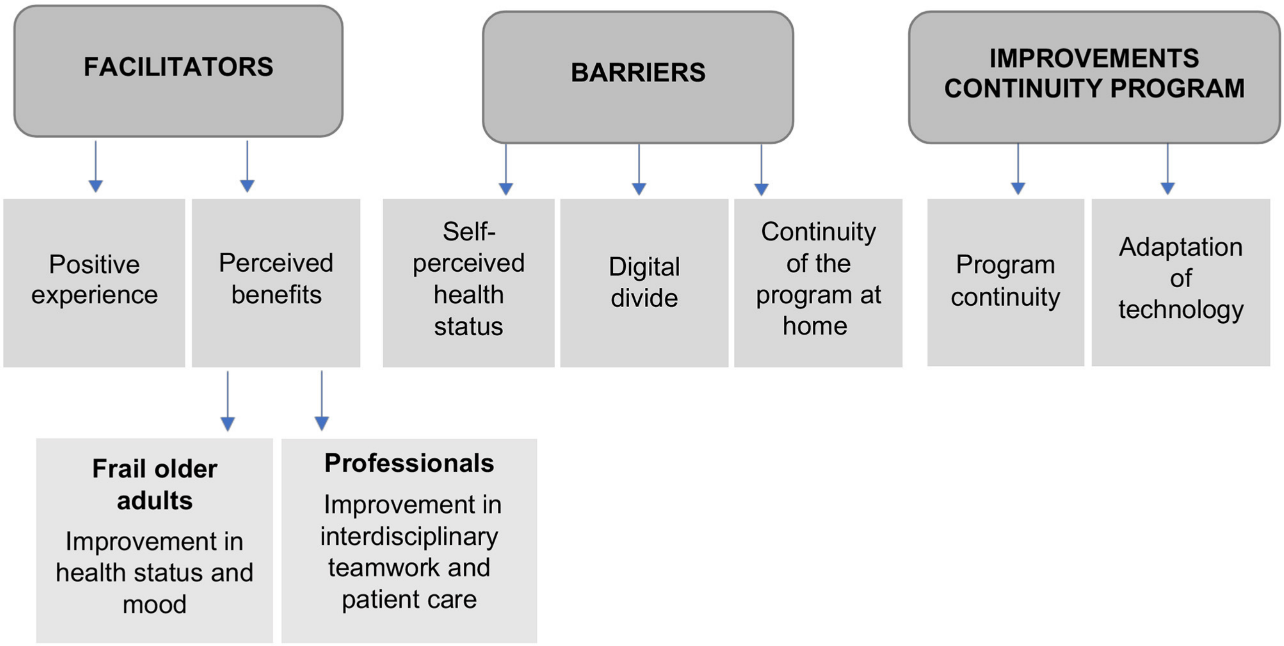

FIGURE 1
Themes and sub-themes.

> *"…in general it was very nice, very positive* (related to the +AGIL Barcelona programme) *(…) because people feel very happy." PROF11.*

In addition, the interpersonal relationships created during the programme were valued very positively. It was an incentive for FOAs, a positive obligation, and a motivation to socialize. A close relationship between FOAs and professionals favored this.

> *"…socialization, the fact of sitting with more people, the fact of leaving the house, (...) is much higher than being able to do things at home." PROF3.*
>
> *"Here you participate, you meet one, another one, it is the fact you go out home, to come here and come back, it is very different." FOA2.*

Thus, both agreed to highlight the perceived benefits on health and quality of life. The FOAs mostly agreed on the perceived benefits of physical exercises, such as improving mood and feeling more agile. They also reported improving their ability to move, balance, and posture, which offered them more security when walking, an essential aspect for those with a history of falls.

> *"We previously detected and delayed disability and improved older people's quality of life. Therefore, for me it is the key to this type of implementation." PROF7.*
>
> *"…it gave me more security for everything, to walk, to move." FOA1.*

Professionals valued the multidisciplinary approach and teamwork. The programme's success consisted of the team's communication and integration. There was no professional intrusiveness in the teams but they shared criteria from different perspectives, emphasizing the satisfaction of all parties. The comprehensive geriatric assessment was very useful and practical. It provided a comprehensive and holistic vision and allowed the complexity of care to be incorporated into the FOA throughout the intervention, especially in adapting the intervention to each FOA. In general, the professionals perceived that the interconnection between services (primary care and geriatric care) and an expert multidisciplinary health team was essential and beneficial.

> *"…here those of us who are here know about exercise, we know about pathology, we know about aging, we connect very well and we create a multidisciplinary team for the whole that we generate together." PROF9;*
>
> *"…it is very necessary this connection between services, because sometimes we thought "no, that thing is not mine because I'm more in the social part," at the end we all end up having an impact ways[sic] and therefore it is very necessary to have this connection." PROF11.*

For the FOAs, the presence of the physiotherapist was one of the most motivating elements. Thus, they appreciated his individual attention, the pleasant atmosphere, the varied exercises, explanations, and patience.

> *"I met he* [physiotherapist], *who did not knew[sic] him and I liked him very much, really. I liked him very much and then we started doing what we had to do. And I liked him. I liked the way he talked to us, it seemed like no, that he wasn't looking at you, but he was watching you." FOA10.*

> *"Very nice, treats you well, explains things to you, makes jokes." FOA7.*

Theme barriers: Digital divide, the health status of users, and monitoring of the programme at home

The incorporation of digital technology to perform physical exercise online due to COVID-19 was developed with difficulties. FOAs showed low use of online digital technologies, combined with a low predisposition and a strong opposition to the use of technologies due to the lack of skills with devices and apps.

> *"It is more pleasant to stay with a group of people than with mobile phones." FOA5.*
>
> *"I say more than 70% are patients that don't have the technologic skills that we have." PROF5.*

The closest or most helpful device for them was the mobile phone; some used WhatsApp for video calls, which did have positive aspects as a complement, support, and possible motivation for the programme. However, some FOAs indicated that they would be more positively disposed toward technology if it could be made more accessible to use and if they could have technology support at home to guide them. Finally, FOAs identified their personal devices as very basic, with few applications; consequently, it did not allow them to use a high range of possibilities.

> *"…I have a mobile only to call my sons when I needed or when they need me." FOA2.*
>
> *"Yes, with WhatsApp it was easy for me." FOA9.*
>
> *"I said no mobiles and tablets, I said no, I couldn't use it and I will get the device and don't use it. However, I learned how to use it step by step." FOA8.*

The professionals indicated that the FOA presented difficulties in managing the technology. In general, the use is complex for them; they do not know its usefulness, have low learning capacity, are unaware of their digital divide, and prefer face-to-face to socialize, especially after COVID-19.

> *"I say more than 70% are patients that don't have the technologic skills we have." PROF5.*
>
> *"…some of them didn't know or did not answer the call." PROF10.*
>
> *"Then the majority said yes initially* (at the video call exercise)*; however, when they were in group they said "I prefer to come here, to be in touch, to talk with colleagues, to go to the place we meet," all this has limited the digitization process." PROF6.*

The self-perceived health status and expectations were barriers perceived by both professionals and FOAs. In particular, the health status because they recognized their physical limitations or comorbidities. They highlighted aspects such as osteoarticular pain, fatigue, fear of falling, and self-perceived frailty.

> *"I come here also for health. During last years I got three, four or five surgeries and I did not have energy." FOA6.*
>
> *"What I have the most is vertigo, then I have the chair next to me to lean on for a moment." FOA1.*

In addition, isolation due to COVID-19 has increased the lack of mobility and created more difficulties in moving.

> *"…many people benefit from the intervention and also there are people that sometimes surprise us, because they used a trolley walk or they had a very reduced mobility and after, they have improved and of course, these people have lost a lot with the COVID." PROF4.*

Frail older adults also report problems reconciling personal and family activities with attendance at the programme.

> *"…he said "I could not come because my husband or my wife, I have to prepare the meal at that time and in the afternoon I have to accompany him and I won't be able to go, not because I don't want to." PROF11.*

The professionals identified barriers related to the expectations and lack of awareness of the FOAs, who tend to confuse the programme with physical therapy sessions, or sometimes their initial attitude could be reticent because they had signed up due to the prescription of the primary health professional who referred them or his family.

> *"Sometimes when I think there is a lack of communication with the referral team, (…), that patients come a little confused, that they don't know why they come" PROF6.*

Concerning the continuity of the programme at home, carrying out instructions at home was perceived as a barrier by FOAs and professionals due to its low adherence. The FOAs expressed laziness and lack of motivation to exercise alone at home, and once their exercise programme ended, the practice of physical exercise decreased. Therefore, some FOAs tried to maintain the continuity of physical activity in community services.

> *"…at home there is no obligation. At home is your house and you do what you want." FOA1.*
>
> *"…he gave me the exercise shit to do it at home, I do it… sometimes. From time to time, when I'm not lazy. Now, yes here* (in the center)*, yes, I do." FOA3.*

Theme improve elements: Continuity of the program and technological adaptation

The continuity of the programme was a prominent topic for both the FOAs and the professionals. Both proposed to increase the number of weeks of the programme or exercise sessions and/or their duration. In addition, they offered long-term follow-up and the option to repeat the programme in future to avoid losing the benefits gained.

> *"I thought it is a very good programme, in general. It must be established in every primary care center and more sessions would be better." PROF10.*
>
> *"Perhaps a good thing should be to have more than ten sessions, (. . .) and more time." FOA1.*

The FOAs proposed adding equipment for the exercises and maintaining the social and face-to-face activity. However, the majority stated that the programme was perfect for them. They would not change anything about the activities or exercises, or in their planning, and they valued the figure of the physiotherapist.

> *"It was not the type of exercises you say "ups, I can't do it." No, no, very well." FOA10.*
>
> *". . . the way he explains you understand. And if someone didn't understand, he has a lot of patience to explain to him what he had to do. Because there were quite a few of us and other people. . . Like me, it's a bit hard for us to talk." FOA11.*

For the professionals, it was essential to incorporate new community spaces to carry out the sessions and to continue with the personalized and proactive treatment given to the FOAs.

> *"But the most important is not only it continuous, is that have to expand and escalate to the rest of the community." PROF4.*
>
> *"Yes, the visit goes a long way, because really having the time we have to assess a patient as it is done, I think the patient appreciates it a lot. . . ." PROF5.*

It was also proposed to shorten the initial assessment, encourage feedback between professionals and FOAs, and improve coordination between teams by relocating functions.

> *". . . that improvements have already been implemented with respect to synthesizing the assessment a bit." PROF2.*
>
> *"In this way, I think that giving regular feedback about the results, as with everything, can help to get confidence in the programme and consolidate it." PROF10.*

There was a discrepancy between FOA and professionals regarding the importance of resolving the use of technology in the programme. On the one hand, FOAs do not feel this need and dismiss it as a resource, considering that they cannot acquire the necessary technological skills. On the other hand, the professionals valued the usefulness that the use of technologies could represent to give continuity to the programme, proposing a new figure in the team that teaches and is an active help in solving problems with digital applications.

> *"But I'm very clumsy with the mobile. I have it for 1 year. . . ." FOA1.*
>
> *"It favors adherence* (use technologies), *it is clear that sustainability must be sought, and that is why we thought that technology could be one of them. And in this sense (. . .), learning will be required and, therefore, well, if we were not born technological, someone must teach us." PROF11.*
>
> *"Many of the people that are on the presential sessions can't do this using a screen." PROF9.*

Discussion

The +AGIL Barcelona programme findings were facilitators (positive experience and perceived benefits), barriers (self-perceived health status, digital divide, and continuity of the programme at home has a positive experience), and improvements in the continuity of the programme (programme continuity and adaptation of technology). In addition, all the participants felt satisfied, highlighting aspects such as interpersonal relationships and social contact, face-to-face sessions guided by a physiotherapist, and the functional improvement achieved. Some difficulties were in response to the self-perception of frailty, the need for technological support, and continuing the exercise programme at home.

The +AGIL Barcelona programme was a very positive experience for everyone involved, with different perceptions of the benefits. The participants perceived direct benefits to their health and wellbeing, and the professionals experienced an improvement in the quality of care provided to their users. Both views complement each other and go in the direction of the objectives set by the programme: person-centered design, with a multifactorial strategy, close to the person and built-in integrated care model, involving primary care, geriatrics, and community resources (24).

Person-centered care is an essential aspect of care for older people and is a guiding principle of this programme "Person-centered care" means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their healthcare, supporting their realistic health and life goals (25). Even so, the healthcare reality makes it difficult to implement programmes based on the preferences of the FOAs (25), and, in this sense, it should be noted that +AGIL Barcelona is perceived as a beneficial intervention adapted to the preferences and needs of the FOAs with good healthcare and interprofessional integration. The source of motivation for the participants was the improvement in their health and fitness, changes they had noticed when they performed the exercises. There is evidence to support this result (26). Other aspects that contributed to the positive experience of the programme were as follows: (1) the positive experience that included participation in the face-to-face sessions, (2) sharing the experience with peers, (3) functional and emotional improvement, and (4) social contact. These factors, especially those related to the social aspect of the activity, have been reported previously (27, 28).

The individualized exercise plan was a strong facilitator due to various factors such as attendance, social interaction, individualized prescription adjusted to each participant, and close supervision with a specialized physiotherapist were key points for FOAs to feel capable of performing physical exercise amongst their peers. Previous studies report that the programme's characteristics (individualization, scientific correction, and limited duration) are fundamental to achieving higher levels of adherence to exercise programmes in older adults. These characteristics are similar to the facilitators found in our programme (28, 29).

On the other hand, it has also been reported that reinforcement with peer stimulation, fun during the activity, social aspects driven by performing group activities amongst peers, and the supervision of health professionals are key points to motivate older people to exercise (27, 29, 30). The presence of an expert and multidisciplinary team of geriatricians and physiotherapists integrated into the primary healthcare team is a facilitator of the FOAs care process, resulting in benefits for all those involved. Previous studies highlight the importance of multidisciplinary team intervention to reinforce the FOA's participation and compliance concerning physical activity and healthy habits (29).

In the review by Franco et al. (9), it is stated that the barriers to the participation of older adults in physical activity programmes are as follows: lack of social support, previous sedentary habits, conflicting priorities, accessibility problems, and apathy. Another important barrier is the belief that age-related decline is inevitable and impossible to reverse without the ability to perform the physical activity due to self-perceived frailty. In accordance with this review, in our study, barriers related to self-perception of frailty, comorbidities, pain, conflicting priorities, and fear of falling due to climatic factors (rain) were reported as barriers. However, no lack of social support, apathy, or accessibility problems was reported.

These barriers were addressed (resolved) by developing an individualized programme based on the comprehensive geriatric assessment in an environment close to the FOAs, such as its primary healthcare and community center. The FOAs indicated that their self-perceived health and frailty status were barriers. However, they also indicated that conducting group sessions with people in the same condition, guided by the physiotherapist with exercises adapted to their abilities, was essential for their self-confidence and acceptance that they could perform physical exercise despite their baseline condition.

Finally, an important point to highlight is the use of technology by the participants; they often discard it before trying to use it, or it is challenging for them to use and discard it. This fact has conditioned their assessment of the programme's continuity and technological adaptation. Similar opinions have been reported in other studies (31). There is a recent report on the most common topic barriers to adopting mobile applications for health-related interventions amongst older adults: being unaware of the existence of mobile health applications, lack of technological skills, lack of perceived ability and time, absence of professional involvement, and violation of trust and privacy, many of which were mentioned by the FOAs in this study (32). This topic is a difficult barrier to overcome. There is no single solution path; however, the proposals indicated by FOA and professionals align with what is reported in the literature, e.g., simplifying the technology to the user (33, 34) and receiving education and support for its use (35).

Strength and limitations

One of the programme's strengths is the high participation of both older adults and professionals. In particular, it highlights the presence of professionals who care for FOA from different areas of the health and social system, thus making their perspective known throughout the care continuum. The main limitation of the current study is that participation in the focus groups was voluntary, which could have resulted in selection bias. This was represented by only one FOA participant agreeing to hold an individual interview, although a broad invitation was made. A possible explanation could be attributed to the difficulty of social interaction generated by the pandemic. On the other hand, this study was carried out in a post-pandemic situation. Therefore, the transferability of the results may be limited.

Conclusion

The +AGIL Barcelona programme had a positive impact on all the participants. Direct benefits for their health and physical and emotional wellbeing were perceived. The development of interpersonal relationships and social contact managed to develop self-confidence and acceptance to perform physical exercise despite the baseline condition and their self-perception of frailty. There was an improvement in the quality of care due to multidisciplinary teamwork. Some barriers were overcome by a complex person-centered intervention that included a first comprehensive geriatric assessment and guided group sessions of adapted exercises by an expert physiotherapist. The +AGIL Barcelona programme is a complex intervention that requires multiple stages for its implementation and sustainability. This study provides key information to adapt and consolidate community-integrated care programmes.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by Clinical Research Ethics Committee of the Institut Universitari d'Investigació en Atención Primaria, Jordi Gol. The patients/participants provided their written informed consent to participate in this study.

Author contributions

Conceptualisation: OC-V, MS-R, LMP, and MI. Methodology: OC-V, MS-R, and JR. Validation: OC-V, MS-R, LMP, JR, JV, and MI. Formal analysis: OC-V, LS-N, MS-R, LMP, JR, JV, and MI. Investigation, writing—original draft, and writing—review and editing: OC-V, LS-N, MS-R, LMP, JR, LS-B, RT-C, FD-G, JV, and MI. Supervision and project administration: MS-R, LMP, and MI. Funding acquisition: MS-R, LMP, JV, and MI. All authors contributed to the article and approved the submitted version.

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Conflict of interest

LMP has received honoraria for teaching activities by Nestlé, unrelated with the topic of the present work. MI have also received honoraria by Nestlé for presenting at scientific meetings and serving as members of expert advisory boards, unrelated to the present work.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Reflections on major epidemics in history reported by online English news media and literature: interaction between epidemics and social conditions

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1. Introduction

In the long course of history, human beings have been afflicted by various epidemics, infectious diseases and plagues. Pestis, smallpox, cholera, influenza, Ebola and so on existed or still exist in human society and have a huge impact on the development of society and the historical progress. The COVID-19 pandemic since 2020 has made the entire world different from the past in many aspects, including people's psychology, lifestyles, learning and teaching styles, etc. Meanwhile, social conditions also exert their effects on the spread of an epidemic, as well as on prevention and control. To control any potential follow-up pandemic and prevent the public from again experiencing a severe and widespread infection, it is important to study the interaction between epidemics and social conditions.

In this study, text-based data on historic major epidemics were mainly collected from online English news media reports and literature published from 2003 to 2023. Text-based artifacts refer to already existing documents, archives, or reports (1). They are commonly used as sources of evidence in qualitative data collection concerning policy studies and text studies (2). The content analysis method was employed to analyze the interaction between epidemics and social conditions, which includes the impact of major epidemics on human society and the impact of social conditions on major epidemics. This analysis may raise the public awareness of epidemic prevention and control. Additionally, public health workers and government agencies might be inspired by the understanding of the interaction between epidemic spread and social conditions, thereby acting to improve their response capacity in a future public health emergency.

2. The impact of major epidemics on human society

2.1. The impact of major epidemics on population and social psychology

The most immediate social impact of major epidemics is a massive reduction in population. Different diseases affect population size differently according to social periods.

The Justinian Plague of 541–542 AD claimed nearly 100 million lives; The Black Death killed 50 million people between 1,346 and 1,350; The Spanish Influenza Pandemic of 1918–1919 claimed about 50 million lives around the globe (3); The COVID-19 pandemic caused more than 6 million people to deaths between 2020 and 2022, and the number is still increasing (4). The reason for the high fatality rate of epidemics is that they are highly contagious diseases and spread rapidly in a short period of time. In modern times, when overall medical care is better, fewer deaths have occurred than in the aforementioned plagues, but major epidemics have still dealt a large blow to human life. That is why the outbreak of a major epidemic causes social panic to some extent, and the degree of panic is related to social conditions at the time. During the reign of the Black Death, Europe was a society that was religious at its core, lacking basic medical care or an understanding of the disease's origin. Such social conditions led to widespread panic. Some Christian people regarded the Black Death as punishment from heaven because they believed they lived a life of sin (5), while others accused the Jews of poisoning wells, and hence thousands of Jews were killed as a result of this belief. Thus it can be seen that people are prone to act impulsively under the panic induced by epidemics, compounding the social crisis. At the beginning of COVID-19, episodes of so-called "panic buying" appeared in Canada due to fears about the rapid spread and potential deadliness of the novel coronavirus. However, excessive stockpiling of food and other supplies during the new coronavirus outbreak could actually be self-defeating, while accelerating the spread of the disease (6).

2.2. The impact of major epidemics on social life

The impact of major epidemics, especially the COVID-19 pandemic, are embodied in all walks of life. From the perspective of food, clothing, housing and transportation, the continuing epidemic has accelerated the process of establishing an e-world. As social distancing becomes the new normal of life, consumers are shifting from physical stores to online platforms for clothing, food, daily necessities, and healthcare, mainly through the use of various apps. At the same time, the rapid development of digital technology has created a variety of new business models. Accordingly, some countries have issued relevant policies to develop online medical services, propel telecommuting, accelerate the digital transformation of traditional enterprises, and build virtual industrial parks to promote the development of a shared economy (7). In terms of entertainment, the continuing COVID-19 pandemic has led to the suspension of offline tourism and the closure of many public entertainment venues such as cinemas. Therefore, cloud viewing, virtual tourism and virtual e-sports have become means of entertainment and relaxation for people (8, 9), trends in line with the current practice of maintaining social distance. Thus it can be seen that the degree of Internet use is increasing and social contact becomes gradually more virtual under the influence of the epidemic.

2.3. The impact of major epidemics on government agencies

In periods of epidemics, the most significant change in government agencies is the adjustment in working mechanisms and foci. During the COVID-19 pandemic, government agencies have piloted flexible working arrangements while advocating for employees working from home. This not only ensures the normal operation of government agencies but also provides convenient conditions for epidemic prevention and control, as well as travel by staff to promote consumption. This working mechanism may be a future trend due to a more highly developed Internet. In response to the pandemic, governments' foci have changed dramatically. Looking back at major outbreaks in history, such as cholera, SARS, MERS and now COVID-19, government agencies have concentrated on fighting the epidemic while simultaneously resuming work and production. In the fight against the COVID-19 epidemic, the focus of Chinese government agencies has mainly centered on initiating emergency public event responses, controlling population flow, avoiding mass gatherings and mobilizing medical resources (10). In terms of resumption of work and production, government agencies have carried out effective interventions, one of the typical characteristics of which is an increase in financial expenditures by government agencies (11).

By contrast, institutional dismantling or budget cuts have occurred in some countries or regions. Take Brazil for example: the central government dismantled the Brazilian Ministry of Agrarian Development and subsequently the National Secretariat for Food and Nutritional Security. The decentralization of the Brazilian National System for Food and Nutritional Security further led to budget cuts and administrative changes for key projects (12). As another example, Hong Kong was confronted with difficulties in formulating a budget for 2023 due to supply-chain disruptions, high inflation, tightened monetary policies, rising interest rates, and a contraction of the local economy partly caused by repercussions from the COVID-19 pandemic (13).

2.4. The impact of major epidemics on humanism

Major epidemics have a significant impact on the process of humanistic development. First of all, such an impact is reflected in education. Due to changes resulting from the COVID-19 pandemic, teachers and students have greater autonomy and choice. The traditional offline teaching mode has been transformed into an online teaching approach, and students have more autonomy in choosing their favorite courses and teaching methods rather than being constrained by having to attend on-campus courses. For instance, in the online mode, "nutritional knowledge" contrasted with "lack-of-nutrition knowledge" provides an example of a revolution in changing teaching and learning trends, impelled by students' options in the education field (14). In addition, the epidemic will completely change the traditional educational evaluation system. Students can directly give feedback to teachers and schools, and the hierarchy between teachers and students will be diluted (15). There are social media apps that allow students to report directly to teachers on how well they are doing, and schools ask students for feedback. This educational revolution endows teachers and students with rights, new freedoms and equality, thereby promoting humanistic development by affording them more flexibility.

The impact of the pandemic on humanistic progress has also increased in the speed of globalization. For a certain period of time, epidemics hindered people's communication in space and affected economic development. For instance, international businesses such as transport, oil and gas, extractive industries, and health care in the most affected countries of Sierra Leone, Liberia and Guinea were affected to varying degrees by Ebola. However, not only will this set of circumstances not end globalization, it will call for a new era of globalization with more humanistic caring while highlighting the global significance of the concept of a community with a shared future for mankind. Given the impact of the COVID-19 pandemic, countries around the globe have been providing mutual aid, maintaining reciprocal exchange, and sharing knowledge and research results, all of which undoubtedly play a positive role in awakening humanistic spirit and promoting global collaboration (16, 17).

3. The impact of social conditions on major epidemics

3.1. The impact of road traffic networks on epidemic spread

Influenza A (H1N1) reached several cities in mainland China in 2009 by means of imported cases (18) and spread as people traveled within China, primarily *via* airways, highways, and railways (19). As to the COVID-19 epidemic, rapid transportation has indeed increased the speed and scale of the spread of the epidemic. Dock workers along sea routes once became extremely high-risk groups. Since there are in the transportation, storage and sale of cold chain products, imported cases are still the top priority in China's epidemic prevention efforts. Concerning land transportation, the rapid development of express industry has brought greater convenience to people's lives. However, once the products sold online are infected, the related articles would be quickly sent to different places *via* express delivery. There is no denying that complex transport networks increase the risk of infection, despite the fact that a high flow of people are the root cause. This can be seen both in domestic news about traffic restrictions in severely affected areas and in foreign journals regarding transport policies introduced during the pandemic. That is why travel was restricted in nations and across nations (20).

3.2. The impact of socio-economic factors on epidemic spread

According to the report on SARS in 2003, the negative impact of SARS on the economy of China and Asia was clear. Tourism bore the brunt, followed by trade and investment (21). Epidemics have an impact on the economy, while the level of economic development also affects the spread of epidemics. Countries and regions with better economic environments have sufficient financial support and therefore are more likely to control the spread of epidemics to a certain extent. Take Canada for example: it invested a considerable amount of capital in vaccine production and led world in its vaccinated population. In slightly more than 2 months, after posting a record of more than 9,000 COVID-19 cases in a single day, Canada's daily case count shrank by 90% (22). Meanwhile, it should be noted that higher numbers of infection are recorded for groups that have higher population density, groups that have a higher proportion of youth, and groups that have lower income. Northeast Calgary set a clear example for this. According to the 2015 census, median household income in Ward 5 and Ward 10 was much less than the city-wide median; a comparably high percentage of households there have five or more people per home and both wards skew younger than the citywide average; infected residents there are working-class Calgarians and they work on the front lines (23). Therefore, socio-economic conditions were likely contributors to increased coronavirus rates in this city.

3.3. The role of modern technology in epidemic prevention and control

Artificial intelligence (AI) has already been employed to screen people to assess the risk of infection. For example, China deployed AI-powered temperature screening in public places during the COVID-19 pandemic. Temperature screening helps to detect symptoms and isolate suspected infections. Besides, thermal cameras have been adopted in COVID-19 case detection to quickly and accurately provide thermal imaging for body temperature. In addition, an AI-powered smartphone app was developed to track the geographical spread of the coronavirus, which aims to predict the population and communities who are the most vulnerable. This app also enables healthcare providers to disseminate information in real time while notifying individuals of potential infection hotspots in real time to avoid travel to those areas (24).

Big data plays an important role in tracing the source of infection and determining the movement trends of infected people. Such data can control close contacts in a short time and reduce the further spread of epidemics. Big data played a significant role during the COVID-19 outbreak. On June 11, 2020, a new case was reported in Xicheng District, Beijing. Since the infected person used a mobile phone to make a payment, the expert team employed big data analysis to quickly locate the source of the infection. This information was shared with other relevant departments, thus preventing the spread of the epidemic. This undoubtedly reflects the important role of the application of big data in determining the source of infection and controlling close contacts in a brief amount of time (25).

Big data can provide real-time monitoring of epidemic outbreaks, making epidemic prevention and control more efficient and convenient (26). As early as the Chikungunya outbreak in Europe in 2017, big data was used to assess the risk of virus transmission, virus import, and close dispersal of epidemic sources (27). Compared to previous outbreaks, the use of big data in the current surveillance of COVID-19 is unprecedented, with its open data set containing daily numbers of new infections by country (and even, in some cases, by city) (28). Dynamic data management and real-time information sharing have been fully realized. In addition, data query, statistics, and summaries are implemented according to different permissions.

During the COVID-19 epidemic, telemedicine has served as the first line of defense, employed by doctors to slow the spread of the coronavirus. Online consultations, telemonitoring, sensors and chatbots, etc., have reduced the time required for diagnosis and treatment. This advancement allows for rapid follow-up while allotting medical resources to various locations, thereby preventing the risk of contagion *via* professionals by avoiding direct physical contact and reducing the risk of exposure to respiratory droplets. An additional benefit of this advancement is an acceleration in the time required to train health professionals. Therefore, telemedicine based on the use of the Internet and associated technologies provides increased convenience and ready accessibility to information and communication related to health (29).

4. Conclusion

Based on online English news media and literature, this study investigated and analyzed major epidemics in history to explore the interaction between epidemics and social conditions from multiple perspectives. The findings show that major epidemics exert both positive and negative effects on society. On one hand, major epidemics had impact on population size, resulting in social panic, and meanwhile might lead to budget and institutional dismantlement of government agencies. On the other hand, major epidemics accelerated the progress of establishing an e-world in social life and education, promoted globalization with increased humanistic care and collaboration, and forced government agencies to change working mechanisms and foci on preparation for future pandemics. The findings also show that social conditions play a significant role regarding epidemics. Advanced road traffic networks increase the spread and scale of epidemics. Therefore, restrictions on population circulation represent a critical measure in epidemic prevention and control. Meanwhile, decreasing population density and improving economic conditions are also necessities. Additionally, modern technology such as AI, big data and telemedicine play an essential role in epidemic prevention and control. Hence, promoting the development of modern technology in an ongoing manner is the key to dealing with major epidemics in the future. Of course, all government agencies should perform their respective duties, and people should actively respond to minimize damage. A series of political and medical measures can be enacted to ease social and economic pressures. Rapid response, timely formulation of corresponding measures, and the establishment of specialized institutions for thorough elimination and prevention of disease following an outbreak can effectively alleviate or even end an epidemic. In future studies, it will be important to summarize the similarities and identify the differences among various epidemics. Only by learning lessons from history and developing a series of plans to face future emergencies can epidemics be controlled in a timely manner at the beginning of a given outbreak.

Author contributions

XC conceived the idea, revised the initial manuscript in Chinese, and prepared the first draft in English. XW, YZ, YS, ZX, and SZ sourced the study data from online English news media and literature and analyzed the data and prepared the initial manuscript in Chinese. LL conceived the idea, revised the first draft in English, and provided extra materials for inclusion in the paper. XC and LL contributed to the final manuscript. All authors agree to be accountable for the content of the work.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Experiences in the training of specialist family and community nurses: a qualitative study

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Introduction: The specialist Family and Community Nurse Practitioner (FCNP) is a professional who, after a period of training, is qualified to be part of multidisciplinary teams in primary care. The aim of this study was to describe and understand the experiences of nurses during their training process in the specialty of Family and Community Nursing in Spain.

Methods: A descriptive qualitative study was carried out. Participants were recruited by means of convenience sampling from January to April 2022. Sixteen specialist nurses in Family and Community Nursing from different autonomous communities in Spain participated in the study. Twelve individual interviews and one focus group were conducted. Data were analyzed following a thematic analysis method in ATLAS.ti 9.

Results: The results showed two themes and six subthemes: (1) Residency period, more than a training: (a) Training during the residency period; (b) Specializing through a constant struggle; (c) Moderate optimism about the future of the specialty; and (2) A journey from illusion to disappointment: (a) Beginning of the residency: feeling special; (b) During the residency: between satisfaction and misunderstanding; (c) At the end of the residency: power and frustration.

Conclusions: The residency period is important in the training and acquisition of competencies for the Family and Community Nurse Practitioner. Improvements are needed to ensure quality training during residency and to help give visibility to the specialty.

KEYWORDS

primary care, family and community nurse, specialist nurse, training, experiences, qualitative study

1. Introduction

The World Health Organization (WHO) describes the Family and Community Nurse Practitioner (FCNP) as the professional who, through a comprehensive and holistic vision, takes on the mission of accompanying people from birth to death to develop their health potential, promoting the different family, work, and social environments to facilitate this development (1, 2). These professionals are prominent components of multidisciplinary primary care teams alongside other health professionals (3).

Internationally, several common competencies and/or standards have been developed to define the role and articulate the value of FCNPs in primary care practice (4–6). Although there is ambiguity in the title or appointment of this professional, the training process in the acquisition of competencies generally varies from 2 to 4 years depending on the regulations established in each country (7). In Spain, after the 4-year nursing degree, the specialist nurse is trained after passing an entrance exam to the specialty, in accordance with Article 20.2 of the Law on the Management of Health Professions (2003). There are several specialties regulated in Royal Decree 450/2005 of 22 April 2005: Occupational Nursing, Geriatrics, Pediatrics, Obstetrics and Gynecology (midwifery), Mental Health and FCNP (8). The training for the FCNP specialty is as Resident Internal Nurse (RIN) together with Family and Community doctors in Multiprofessional Teaching Units accredited by the Ministry of Education (8).

In the Order SAS/1729/2010, of 17 June, which approves and publishes the training programme for the specialty of Family and Community Nursing, resident nurses will be tutored by a tutor during the 2 years of training. At least 4 months each year must be spent in the same health center as their tutor and the rest of the time they may rotate through other specific services or devices decided by the teaching committee of the multidisciplinary units. In this training they are instructed to work within interdisciplinary primary care teams and other hospital and community facilities (9). Their competencies are linked to the provision of advanced care in clinical family and community care to individuals throughout their life cycle and families; public and community health; epidemiological surveillance; teaching; management of care and services in family and community settings; and research in the area of nursing (6, 10).

The WHO in one of its reports highlighted the importance of investing in the training of nurses, emphasizing the contribution made by the nursing profession and confirming that investing in it is a benefit to society rather than a cost (11). Similarly, there is evidence linking the specialist nurse to increased quality of care (12). The integration of FCNP specialists has been associated with increased quality of care at the family and community level, in addition to a reduction in healthcare costs, as they are able to deliver person-centered care incorporating research and evidence-based practice (13, 14). They are thus considered a valuable resource in healthcare systems as they have the knowledge, competencies, and skills for health promotion and prevention, acute and chronic disease management, in addition to supporting the work of the entire primary care team (15, 16).

Despite the competencies assumed by FCNPs, studies that have analyzed the experiences of these nurses in the training they receive are practically scarce in Spain and internationally (17). Analyzing their experiences could help health system organizations to guide their training and take advantage of this valuable resource with a consequent improvement in the quality of care (5). For this reason, the aim of this study was to describe and understand the experiences of nurses during their training process in the specialty of Family and Community Nursing in Spain.

2. Materials and methods

2.1. Design

A descriptive qualitative study was conducted (18). This design allows us to describe the felt reality of the participants from a closer perspective. It is therefore possible for us to learn about the experiences regarding the training of the specialty of FCNPs from the perspective of specialist nurses in Spain. The quality standards of the COREQ guide (19) were followed (Supplementary File 1).

2.2. Participants

The study was carried out between January 2022 and April 2022. Participants were recruited by convenience sampling through social networks due to the ease and availability of access to participants. To this end, a total of 233 nurses specializing in FCNP from all over Spain were invited by means of a letter via email. The inclusion criteria were: (1) to be a specialist nurse in family and community nursing; and (2) to have completed the training period in the last 5 years. The exclusion criteria were: (1) failure to reply to the study invitation e-mail; (2) failure to sign the informed consent form; and (3) not speaking Spanish. 191 specialist nurses did not respond to the invitation. 42 participants replied to the email, of whom 26 did not give their consent to participate in the study. In the end, a total of 16 FCNPs from different autonomous communities in Spain with a mean age of 29.88 years (SD = 6.2) were included in the study. The most important characteristics of the participants can be consulted in Table 1.

2.3. Data collection

Data collection was made through 12 individual semi-structured interviews and a focus group of 4 nurses. Data saturation was reached with 12 participants and confirmed with the remaining participants (20). The questions were developed based on the literature review on specialty training. The interviews and the focus-group discussion were conducted by two study investigators using the Zoom platform due to the COVID 19 pandemic and the geographic location of interviewees. One of the researchers conducted the interviews, and the other took notes in a field notebook. The individual interviews lasted an average of 45 mins. The duration of the focus group was 60 mins. The development of both was recorded with the consent of the participants and later transcribed by the researchers. All the participants accepted to answer questions once the interviews had been transcribed. Table 2 shows the protocol and script of the interviews.

2.4. Data analysis

The transcripts and field notes were entered into the computer software. Data analysis was performed by two researchers, following a thematic analysis method that contained a series of

TABLE 1 Socio-demographic characteristics of participants.

Participants	Source of data	Age	Gender	Marital status	Autonomous community of qualification	Year of completion of specialty	Time working in primary care (including residency period)
1	Focus group	32	Female	Single	Madrid	2020	3 years and 9 months
2	Focus group	35	Female	Single	Madrid	2020	3 years and 9 months
3	Focus group	51	Female	Single	Madrid	2020	3 years and 9 months
4	Focus group	27	Female	Single	Madrid	2020	3 years and 9 months
5	Interview	27	Female	Single	Madrid	2021	2 years and 9 months
6	Interview	25	Female	Single	Madrid	2021	3 years
7	Interview	26	Female	Single	Castilla-La Mancha	2020	3 years and 8 months
8	Interview	28	Female	Single	Madrid	2019	6 years
9	Interview	26	Female	Single	Castilla-La Mancha	2021	4 years
10	Interview	31	Female	Single	Madrid	2018	5 years
11	Interview	27	Female	Single	Madrid	2020	2 years and 7 months
12	Interview	28	Female	Single	Madrid	2018	3 years
13	Interview	31	Female	Single	Madrid	2019	4 years
14	Interview	27	Female	Single	Cataluña	2021	4 years
15	Interview	28	Female	Single	Madrid	2018	5 years and 6 months
16	Interview	29	Female	Single	Madrid	2019	5 years and 6 months

TABLE 2 Interview protocol.

Phase	Development	Content/Sample question
Beginning of the interview	Reasons	As Family and Community Nurse Practitioners, we would like to hear about your experiences of the training you have received in your specialty.
	Ethical issues	Participation is completely voluntary, and withdrawal from the study is at your discretion. The sessions will be recorded and subsequently transcribed. Your identity will be protected, and your name and personal data will not be disclosed.
	Introductory question	Describe your experience as a nurse in Family and Community Nursing in recent years?
Development of the interview	Conversation guide	Describe your specialty training during your residency years? What do you think about it? Do you think that more training is needed during the residency period for Family and Community Nurse Practitioners? What is your opinion? Do you think you have acquired the necessary competencies, and why? How prepared do you think you were when you finished your residency? What training would you add or eliminate? Why?
	Final question	Would you like to say anything else that you think is interesting and we have not referred to?
Closing the interview	Acknowledgments	Thank you very much for your participation and for dedicating your time to this research. Your input is very important for the study and will be very helpful.
	Proposal	We would like to remind you that you can contact us if you feel you have anything else of interest to add at a later date. After finishing the transcription process of the interviews we will show them to you, and once the study is finished we will show you the results.

phases (21): (1) Familiarization with the data: the transcripts were read by the researchers to understand everything the participants said. (2) Systematic data coding: the most significant quotes were selected and assigned codes using the "*in-vivo* coding," "open coding," and "apply codes" functions in ATLAS. ti. 9. (3) Generation of initial themes from the coded data: initial themes were generated by grouping codes that shared patterns of meaning and had a meaningful relationship around a central idea. (4) Theme development and review: all generated themes and the quotations on which they were developed were double-checked for consistency with the codes they included. (5) Detail, designate, and delimit themes: the researchers reviewed the final themes, refined them, and created the final names for the themes. (6) Report writing in preparing this research report: the most demonstrative citations were selected. Finally, the researchers clarified the report by filtering out the essential fragments and relating them to the literature review and the aims of the study.

TABLE 3 Themes, subthemes, and units of meaning.

Theme 1. The residency period, more than a training.	1.1. Training during the FCNP residency period.	Complete training, different training, extra training, tough process, lack of quality training, lack of quality trainers.
	1.2. Specialization through constant struggle.	On-call, mentoring, versatile girls, lack of knowledge of the specialty, struggle with the medical teaching unit, hospital, and on-call tutors, family at the health center.
	1.3. Moderate optimism about the future of the specialty.	Pessimistic future, improvements in the future, changes in nursing management, exceptional pathway, specific exchange, specific competitive examinations.
Theme 2. A journey from illusion to disappointment.	2.1. Beginning of the residency: feeling special.	Feeling happy, emotions, motivation, feeling overwhelmed, feeling special.
	2.2. During the residency: between satisfaction and incomprehension.	Feeling happy, comfort, anxiety, satisfaction, overloaded, feeling located, dependence, feeling lost.
	2.3. At the end of the residency: power and frustration.	Lack of comprehension, feeling powerful, frustration, hope, commitment, undervalued, loneliness, feeling prepared, disappointment, feeling independent, worth.

2.5. Rigor

The quality criteria of Lincoln and Guba (22) were followed in this descriptive qualitative study. Credibility: the process by which the data were collected was described in detail. In addition, the analytical process was carefully checked by two independent reviewers. Transferability: the method, participants, setting, and context of the study were thoroughly described. Dependability: the study methodology was described in detail. Reliability: two investigators who were not involved in data collection verified the data analysis. Confirmability: the analysis of the interviews was sent by email to the participants to validate the results and confirm their responses.

3. Results

Two main themes and six subthemes were obtained from the data analysis, and these allowed us to describe the experiences of FCNPs during specialty training (Table 3).

3.1. The residency period, more than a training

This topic described the training that the FCNPs received during the training period. They considered the residency an excellent training opportunity although they described it as a tough process in which they had to constantly struggle to be trained as specialists. Despite this, they reported not feeling recognized as specialists, but they were optimistic and expected positive changes for the specialty in the future.

3.1.1. Training during the FCNP residency period

The participants perceived that the training during the residency period was useful, positive, and wellplanned, and could not be achieved with any other type of training. However, several of the participants reported that the research-based training was deficient and considered that more importance should be given to evidence-based nursing and research training for nurses in the training plan for the FCNP specialty.

> *"With a degree you can't even get the same training, not even with a Master's degree, not by a long shot"* (P5).
>
> *"I consider that in general I have acquired the necessary competencies with the exception of training in research"* (P11).

They also suggested that the interdisciplinary courses could be updated or modified. They considered it interesting to add more practical courses related to Family and Community Nursing skills. They detailed courses such as management of chronic diseases, basic notions of nutrition, electrocardiograms, wound management, bandages, or more specific situations in consultation or at home, and even communication skills with adolescents with mental illnesses. Likewise, they gave great importance to updating training in education, prevention and health promotion, and insisted that the community nursing part was somewhat deficient and that they themselves should seek complementary training.

> *"I would also give more weight to the community part, which I think is given little weight. This seems to be the catchphrase, but it is the complete specialty"* (P15).

They also insisted on the lack of quality in certain courses or rotations, giving three reasons for this: the perceived lack of motivation and training of some trainers; the organization of the teaching units, which are much more medical than nursing, and the differences in training between teaching units and autonomous communities.

> *"In quantity of training I would not add anything, but rather in quality…"* (P9).

The FCNPs referred that a fundamental pillar on which their training depended were their tutors at the health center and the trainers they met in the different rotations and courses. It was they who transmitted their knowledge and new updates to them daily during the training. And they specified that if the trainer was well qualified and motivated, they transmitted exceptional knowledge to them. On the contrary, if the trainer was unmotivated or was not an expert in the subject, the opposite was true. As a result, they perceived that their training greatly depended on the preparation and motivation of their trainers.

> *"My experience in Madrid was very good because my center was accredited with specialist tutors"* (P10).
>
> *"Many times the training depended on what the tutor did, and we know that there is also a lot of variability"* (P8).

3.1.2. Specializing through constant struggle

Similarly, they described the specialty period as a tough process. They attributed this to the low salary they received and the large workload during the residency period: care work, training, emergency room shifts, and different rotations.

> *"The specialty seems tough to me because we work long hours… and all for a very low salary"* (P13).

Most of them focused on the difficulty of the emergency room shifts and the lack of supervision that exists in this rotation. They said that they should be supervised, but, during this rotation, most of the participants found supervision non-existent. In addition, they perceived that training in the emergency department was limited to mere nursing techniques and did not feel that it added value to their specialty. However, they insisted that the assignment of a formal tutor specializing in emergency medicine would allow them to learn not only the techniques but also to consolidate concepts. And they described that when this was not the case, the emergency rotation was poorly focused training in which they simply felt they were cheap labor.

> *"What I wanted to emphasize is that the shifts basically do not provide any knowledge because they are poorly focused… we go to an emergency department where it is very difficult to find a specialist tutor in emergency medicine"* (P1).

They also detailed the lack of knowledge of their role especially in hospital rotations, where they generally found themselves more neglected. One of the things that surprised them the most was the lack of knowledge of the competencies of the FCNPs among their colleagues, many of them nurses, resident interns, and attending physicians. They pointed out that on some occasions even the rotation tutors themselves did not know what the role of the FCNP residents was. All this lack of knowledge made learning difficult.

> *"It is totally unknown to people. And not only by the people in the street but also professionals… "* (P10).
>
> *"… and I was surprised when they asked me what the EIR* [Resident Intern Nurse] *was"* (P12).

On the other hand, they said that this does not usually happen in their reference Health Centers, where coworkers had much greater knowledge of the role of the FCNP resident, indicating that this helped their training. In addition, they said that the tutors for this rotation were usually more involved and encouraged their training in fields such as health education, community interventions or research, helping and giving them information about participation in courses and congresses.

> *"My tutor at the Health Center was a woman standard bearer for nursing and was very supportive, and she was very attentive to my residency"* (P14).

3.1.3. Moderate optimism about the future of the specialty

Participants were moderately optimistic about the recognition of their specialty. Hopeful participants mentioned evolutionary nursing and believed that specialties would be the basis for the future of nursing. But they equally perceived that at present this was complicated.

> *"I hope (that the EFyC* [Family and Community Nurse] *will be recognized) with all my heart"* (P13).
>
> *"I think we are going to get better, but it's a very slow process"* (P6).

They mentioned that successive generations of new residents have already perceived positive changes in the training provided by the Teaching Units. And they compared the current situation of nursing specialties to what previously happened with physicians.

> *"There are some (rotations) that they have removed because they did not contribute anything to us and others that they have added"* (P5).
>
> *"I believe that our situation will improve as it did with the physicians"* (P9).

But for this to happen and to be able to achieve the advancement of the specialty, the FCNPs said that it is the nursing colleagues themselves who must make the initial advances, raising awareness and emphasizing the role of the specialist nurse to the nursing area, in addition to making changes in the management and leadership of nursing, salary recognition, and the creation of exchanges and specific competitive examinations for specialist nurses.

> *"Recognizing specialties, putting into effect the specific exchanges, encouraging people to apply for the EIR, clarifying competencies, supporting training, and improving it every day by adapting it to the new health trends"* (P7).

And they believed that, if this happens, by increasing the number of FCNPs they will cease to be a minority, which would also favor the development of the specialty.

> *"There are more of us and we are really starting to be recognized"* (P16).

3.2. A journey from excitement to disappointment

This theme described the feelings expressed by the nurses specializing in FCNP from the beginning of their residency to its completion in order to enter the world of work. The participants related the desire to specialize with commitment to their vocation. They also insisted that although they considered nursing to be a vocational profession, they were not heroines but rather people with their own lives and personal relationships that should be respected.

3.2.1. Beginning of the residency: feeling special

At the beginning of the residency, most of the participants felt overwhelmed by a new experience which for many of them it was not only a change of work but also a personal one. Participants reported that they had to move from home and loved ones in order to specialize. Nevertheless, they felt excited and very motivated. In addition, they were very proud of having passed such a complicated test as the EIR exam and were thus able to opt for a place to train as a specialist, which was not achieved by all applicants in the test.

> *"It was a lot of things together... So I had a first month of adaptation that was somewhat overwhelming"* (P15).

They found themselves motivated and referred to their desire to learn, to do research, to absorb all that they would discover during the training, to grow as an FCNP. They even thought that their opinion could be important to modify certain things and improve the training, such as adding or eliminating certain courses and rotations through different services related to the specialty and external rotations.

> *"I felt motivated and happy as I had achieved my goal"* (P8).

3.2.2. During residency: between satisfaction and incomprehension

At this stage the participants described sensations ranging from happiness and satisfaction to incomprehension, passing through a mixture of feelings between comfort and being overwhelmed. They perceived that in many situations they felt overwhelmed and overburdened, and even experienced anxiety at certain points. The excessive hours of the workday, courses, and the end-of-residency research project were situations that pushed some of the participants to the limit.

> *"The last few days I wanted to quit. I was super saturated"* (P6).

On the other hand, most of them agreed that certain rotations, especially in hospital rotations whose emergency departments were at the top of the ranking, they felt out of place and lost. Even the participants in this study themselves did not know what their role really was at the beginning of their training.

> *"When I started residency at the beginning, I didn't really know what my competencies were as a resident"* (P5).
>
> *"It is not that I was uncomfortable in the hospital, but they frequently failed to understand what our role was"* (P16).

On the contrary, they expressed the comfort they felt when they were in the health centers where their tutors were located. They normally considered the coworkers, the rest of the residents, and the tutor to be as a real family.

> *"At the health center you are more like family"* (P16).

They also explained that on many occasions they had felt dependent on the tutors and/or the Teaching Unit. They came to feel undervalued. They felt that how they should act or work was imposed without considering their opinion even if they did not agree. They felt they had to justify all their actions in order to be taken into account in decision-making, which was not enough on several occasions. But in spite of this, they gradually felt more comfortable in their situation as the residency period went on, and in general they felt happy and satisfied with their learning progress both professionally and personally.

> *"You have to insist all the time... and in any discussion, as a resident, I've always had to challenge what's been said"* (P5).
>
> *"I was satisfied with the decision I made to start it [the training]"* (P13).

3.2.3. At the end of the residency: power and frustration

This subtheme describes the feelings of the participants once the training period was over and they had obtained the title of specialist in FCNP. They agreed that they felt empowered and independent, with the full capacity to be able to solve their patients' problems and with the security of knowing most of their competencies in primary care. They were proud of themselves for having achieved their goal and felt prepared to work in their job as specialists but also felt hurt as they did not feel that the administration recognized them as specialists or helped them to develop all their skills.

> *"I think we have a very powerful relationship with people and a lot of power to make changes in society"* (P8).
>
> *"It is very sad and painful that a profession as important and valuable as ours is not recognized"* (P13).

Before starting their specialty, they felt committed to the population, and after the course in FCNP this feeling remained. However, they reported feeling somewhat limited in their work as specialists. Because of this, they often described feeling frustrated, wasted, and stagnant because, although most of them managed to work in Primary Care, they were not able to develop all their competencies as specialist nurses but rather covered back-up positions and were not able to exploit their full potential.

> *"I have managed to work in Primary Care, which was what I wanted, but there are certain barriers that prevent us from doing our job 100%"* (P16).

Despite all these mixed feelings, most of the participants were hopeful that in the future their specialty will advance, they will be able to develop all their specialist competencies and they will be truly recognized. However, they felt that it was worthwhile to specialize not only for the increase in knowledge, but also for their personal growth, and they felt very good about what they had done.

> *"I would definitely do it again… it has allowed me to acquire a lot of knowledge and have a fluency behind the desk that I would not have obtained otherwise, and well… also for personal growth"* (P4).

4. Discussion

The aim of this study was to describe and understand the experiences of nurses during their training process in the specialty of FCN in Spain.This study is not a nationwide representative study, and it is restricted only FCNPs who have been trained in the communities of Castilla.The participants described that this training period was harder than usual and they had to constantly overcome obstacles, and, on the other hand, it was like a journey where they went from illusion to disappointment with the profession. The training was a unique learning opportunity in which they became nurses qualified to perform their work (12). This fact can be observed in several studies, where primary care nurses are trained in multiple competencies and feel prepared to perform their duties (6, 10). Thus, the study by Guo et al. described how community nurses who had not received specific training felt less prepared and more stressed in their care work (23).

They also thought that, although the training plan of the FCNP residency provided them with excellent training in FCNP skills, they considered that a series of changes in rotations and courses that would provide them with more knowledge in topics related to the specialty should be made. One of the problems commented by the participants was the absence of content related to research. However, in contrast, Hernández-Crespo et al. pointed out the low number of hours of training in Public and Community Health topics taught in the teaching units compared to clinical and research topics (24). This could be due to the fact that each training unit teaches different contents, so it would be necessary to unify the concepts to be taught. Miranda Neto considers that training plans during residency should be well defined and are an opportunity to train specialist nurses in the competencies needed to provide advanced care in primary care (25). In this sense, it is necessary to train specialist nurses with new teaching methodologies such as clinical simulation and provide them with greater empowerment and self-efficacy in the work they must perform (26). During FCNP training, the methodologies applied were classroom teaching and clinical practice.

On the other hand, the FCNPs felt motivated and satisfied with the training although they were also overloaded by the heavy workload they had to put up with in primary care, which caused them some discomfort (27). This overload of patients could be solved by shiring new FCNP. The participants were committed to their work but insisted that their lives were frequently not respected and the administration took advantage of their participation without even acknowledging it (28). These facts cannot be compared with other studies as no research has been found describing the feelings or sensations experienced by the specialist nurses during their training in primary care.

These nurses are moderately optimistic about their future. They feel that the specialty is not recognized neither by the population in general nor by their peers (16, 17). They relate this situation to the lack of knowledge that the specialty suffers due to the lack of clarity of its role (3, 6). Various authors have highlighted the absence of a consensus on the definition and the use of different standardized terms around the designation of FCNPs at the international level (3, 7). Further progress on this topic could strengthen the development of standardized definitions and make their role visible to society and healthcare administrations (29). A best way to promote FCNP socially is by solving patients' problems. However it is also necessary to demonstrate the FCNP's functions and this social usefulness to the politicians who fund and regulate the services, and to the managers who run them. Lack of appreciation and feeling undervalued led our participants to demotivation, which could have an impact on the quality of care provided (30). Benefits in quality of care and efficiency of community nurse specialists compared to other groups have also been shown. The implementation of quality nursing care leads to efficient nursing care with a reduction in the number of hospital stays and in the consumption of resources (31, 32).

The participants in this study felt that in the not-so-distant future the nursing profession and its specialties will advance as has happened with the medical profession (9). However, for this to happen, the nursing colleagues themselves must also evolve and advance in the recognition of the specialty (2). Vanhook et al. consider that the key to the favorable evolution of the FCNP lies in changes in undergraduate training, specialized training, and in administration (33). For this, it is necessary that jobs are defined, and specific work grants are created for recruitment (2).

4.1. Limitations

This study has several limitations: Firstly, it was carried out with FCNPs who have been trained only in the communities of Castilla—La Mancha, Girona, and Madrid due to the offering of the FCNP specialty in these communities. Even so, it was important for us to know the situation of specialist nurses in the Spanish context. Secondly, the participants are all women, and this may have influenced the results. However, rather than being a limitation, it is also a reality since the nursing profession is primarily a female profession. Finally, the different data collection techniques were carried out in online format, and therefore non-verbal language could not be clearly seen. On the other hand, scientific rigor has given credibility to the study.

4.2. Future lines of research

Future research could describe the experiences of FCNPs once they have completed their training when they enter the world of work. In addition, it would be necessary to know the perceptions of other health professionals with respect to this group, and/or the perceptions of the patients themselves, in order to seek recognition of this training by coworkers, patients, and even political leaders.

5. Conclusions

The participants stated that specialization in FCNP was a unique training opportunity in which they became highly skilled specialist nurses in the performance of care. During the training they faced several obstacles. They were happy and proud to become FCNP nurse specialists although after completing the training they were frustrated due to the lack of recognition of their work, related to the lack of knowledge of nursing specialties. The results of this study demonstrate that it is necessary to continue working on unifying and improving the training received by FCNPs at the national and international levels. It is important to include in the training programs for residents curricular content that is adapted to the specialty. Education systems should therefore strengthen training to ensure that FCNP specialists acquire the necessary competencies to perform the healthcare work for which they have been trained. In addition, it is a priority to give greater visibility to FCNP by health organizations and for it to acquire greater recognition.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by Department of Nursing, Physiotherapy and Medicine, University of Almería. The patients/participants provided their written informed consent to participate in this study.

Author contributions

FS-M and MR-F: conceptualization and study design. FS-M, MR-F, IF-M, and MV-M: data collection, data analysis, and manuscript writing. JG-M, IS-G, and SN-N: interpretation and study supervision. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1154084/full#supplementary-material

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First year nursing students' reflections about developing their verbal nursing skills during their nursing education in China: a qualitative study

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Objective: The aim of the study is to explore the expectations of a group of first-year nursing students in China about developing their verbal and social interactional skills during their nursing education.

Background: Nursing students' communication skills were not fully developed in China. Students have many challenges to face regarding developing their nursing skills, especially interaction skills, when they start their education.

Design: A qualitative design was used in this research.

Method: Twelve second-semester undergraduate nursing students were interviewed on the basis of purposive sampling, and qualitative content analysis was employed.

Results: The main theme was 'facilitating a caring nurse–patient relationship' and 'using a knowledge base for performing nursing care'. The first theme comprises two sub-themes, 'caring approach' and 'helping and involving the patient in care', with three and two categories, respectively. The second theme comprises the two sub-themes, 'knowledge needed to be able to understand the patient' and 'health and treatment information', with three and two categories, respectively.

Conclusion: A synthesis of both knowledge and practice is needed to improve the nursing students' interaction and professional skills during their nursing education.

KEYWORDS

verbal nursing skills, nurse–patient interaction, nursing education, content analysis, qualitative study

1. Introduction

With the view of the human as a biopsychosocial and spiritual being, nursing practice is increasingly emphasizing values and human dignity. As caring being the core of nursing, the ability to provide patient-centered and value-based care is an essential quality for nurses (1). And cultivating nurses with humanistic care attributes has also become an important goal of nursing education. A review (2) summarized that humanistic care is a multifaceted process during which the nurses provide a healing environment for the patient to ensure the patient's human dignity and prioritize it. The nurse who excelled in clinical literacy tries to help the patients move toward positive attitude and independence. And this process could be realized through establishing constructive and dynamic interaction.

Therefore, developing interactional skills in nursing is considered to be a key element for a caring relationship between nurses and patients (3, 4), and the development of these skills during their nursing education is essential for nursing students for their encounters with their future patients (5). It is often stated as being difficult to learn just by reading textbooks, but instead requires a variety of different types of practical training (6, 7). Bach and Grant (3) maintain that adequate and effective interactions for establishing a caring relationship are considered as the first steps towards the nursing profession in nursing education. However, the students' abilities in this particular area are poorly developed in the Chinese nursing education system (8, 9).

People learn things in relation to their experiences (10). Attention has to be paid to the students' thoughts and feelings, and to supporting the student's knowledge construction in order to create a supportive learning context. The capability of the Chinese nursing education to incorporate the students' expectations for developing their interaction skills may affect the degree to which the education is accepted and the effectiveness of the students' learning (11). A lack of understanding of the students' experiences can lead to a mismatch of information between faculty and students, and a failure to achieve the results expected by faculty. This may lead to a psychological fallout and a change of major during the students' nursing education.

2. Background

Nurses are expected to be able to manage several difficult situations, including giving medical treatment and interacting with patients. It has been shown in several studies in European and Asian countries that nurses' interactional skills are perceived as important for giving successful treatment (12–15). Aspects that patients perceive as important for the quality of care include being listened to and respected and meeting nurses who show a caring and understanding attitude (16–18). From an existentialist point of view, the importance of nurse–patient interaction and a good caring relationship reflects people's pursuit of human value and dignity.

A good interactional skill is helpful for learning in the clinic and needs to be trained during nursing education. Nursing students who possess this skill find themselves more confident and perform better in their learning and caring for the patients when they are in the clinic (19). However, many students in China face a major challenge in establishing a good, caring relationship, due to an inherent self-centered and inconsiderate nature based on excessive parental affection as the only child in their family. Providing them with training that focuses on how to interact with other people with empathy based on mutuality is a necessary element in the nursing education (20).

Many requisites are required for the establishment and maintenance of the nurse–patient relationship according to nursing theories. Firstly, the view of human beings is intertwined with interactions in a caring process, in which the two sides exchange their expectations and beliefs on the basis of mutual trust (21). The nurse–patient relationship is also founded on the nurse's concern for the patient's well-being, enabling the patient to alleviate suffering, recreate balance and find meaning in life in a state of illness (1). Moreover, it is important that the nurse balance her professional power over the patient in this asymmetric relationship (22) and make the relationship develop from a superficial to a deeper level (1, 23).

Nursing educators in China have started to focus on the development of students' interactional, emotional, ethical and other humanistic care abilities, but more effort still need to be invested. Nursing teachers in China pay less attention to nurse–patient communication than to the basic theory, knowledge and skills of nursing due to the influence of the traditional medical teaching mode (19, 24). Studies showed that humanities courses accounted for less than 9% of the total teaching hours in nursing colleges in China, and the curriculum differed between schools and lacked a systematic and scientific basis (24–26). Educational methods are mainly traditional didactic and experimental imitation, with some schools adding narrative teaching, role-playing and case discussions in recent years, but generally lacking integration with social practice and attention to the needs of students' individual development (25–27).

Nursing students, therefore, are facing significant limitations in developing a humanistic approach (19). Chen and Wang (8) identified a number of problems in the communication between nursing students and patients: weak communication awareness, a lack of communication skills, an inability to integrate theory with practice, the majority of students having difficulties adapting to the caring environment and a lack of self-confidence in communication with the patients.

Approaches such as clinical learning, reflection and health care experiences have been found to influence students' ability to interact with patients and contribute to harmonious and trusting relationships. For example, clinical practice can help students understand how their theoretical knowledge can be used in their future daily work as nurses; a reflective approach during the clinical studies increases students' flexibility to interact with patients (6, 7). Furthermore, the graduate study experiences, previous hospital experience and nursing experience may lead to greater compassion among the nursing students towards the suffering of the patients and strengthen their self-confidence as a healthcare provider (21, 28).

Differences were found in the first-year nursing students' perceptions of their verbal and social interaction skills across cultures and educational systems in our previous study (21). We carried out the present study from a phenomenological perspective in order to gain a greater understanding of this phenomenon among Chinese first-year students and present another picture of its meaning. We hope to contribute valuable knowledge through the lived experiences of students in this qualitative study in comparison to the result from our previous quantitative study.

2.1. Aim

The aim of the study is to explore the expectations of a group of first-year nursing students in China about developing their verbal and social interactional skills during their nursing education.

3. Materials and methods

3.1. Design

For any student's expectation of her/his interactional skills, regardless of individual differences, there are essential structures that make it up. It is known that qualitative approach are feasible for settings in which the experience of individuals is of concern and can provide evidence for developing applicable knowledge and affecting policy making (29). This study used a qualitative, descriptive methodology, based on an inductive content analysis of interviews, to find a common structure of the experiences of the first-year nursing students at a medical university in southeast of P.R. China. To reach the objectivity and be faithful to what it is, we strived for descriptive identification of the phenomenon understudy, eliminating the researcher's personal inclinations and predispositions. Thirty-two items of Tong qualitative research report were observed (COREQ) (30).

3.2. Ethical considerations

The performance of this study was guided by the Standards and Operational Guidance for Ethics Review of Health-related Research with Human Participants (31) and approved by the institutional review board of the Wenzhou Medical University (No. 2022-019). Ethical approval was not required in China at the time the study was conducted, so it was obtained after the data collection was completed. Written informed consents were signed by the participants prior to the data collection. They were informed about the aim and design of this study, and all of them consented to participate in the study on a voluntary basis. They were also informed that they had the right to withdraw at any time without clarifying the reasons and that their withdrawal would not have any negative impact on them. Confidentiality was assured; no names or places are mentioned in the results.

3.3. Setting and sample

Twelve Chinese undergraduate nursing students were selected in a process of purposive sampling. The participants' demographic information is shown in Table 1. They were numbered A1–A12. Their average age was 20.42 ± 0.64. Since the total number of male nursing students ($n = 52$) in semester two was much lower than the number of female students ($n = 285$), we chose less male participants than the female participants. And most of them were from urban areas and had no experience related with nursing. Four of them (A7, A9, A10, and A12) had some experience interacting with nurses as outpatients or as relatives of patients. They were in the second semester of their four-year nursing education and had completed the courses of nursing psychology and introduction to nursing in their first semester prior to the interview. They had learned some nursing theory and knowledge about interpersonal relationships, and they had been to the hospital for an internship, where they practicing their knowledge from the two aforementioned courses on two occasions. Furthermore, they had also studied the humanities a little after being admitted to the university.

TABLE 1 Basic information of participants (n=12).

Variable	Group	Frequency (participant)
Age	19	1 (A10)
	20	5 (A4, A5-A7, and A11)
	21	6 (A1-3, A5, A9, and A12)
Gender	Female	9 (A1-A3,A5-A6, and A9–A12)
	Male	3 (A4, A7, and A8)
Origin	Rural	5 (A5–A7, A9–A10)
	Urban	7 (A1–A4, A8, and A11–A12)
Experience related with nursing	Yes	4 (A7, A9–A10, and A12)
	No	8 (A1–A6, A8, and A11)

3.4. Data collection

All the 12 face-to-face interviews, without any dropout, were conducted by the first author who had known the participants well since they entered university. No changes were made to the interview guide after the first interview and its data were included in the analysis. The data was collected from March 12th to June 6th 2018 until no new information was discovered. Prior to each interview, the researcher made an appointment to confirm the interviewee's choice of location and an uninterrupted, untimed interview. All the students talked Mandarin fluently. Each interview lasted from 30 to 72 min. A semi-structured interview guide was used, focusing on the student's perception of verbal and social interaction with patients and the nurse–patient relationship. Examples of the questions: *Can you tell me about your thoughts about caring for patients? Can you give me an example or examples of these; How do you think relationships with patients are created? Can you give me an example or examples of these; What do you think it is like to talk to the patients about their feelings and thoughts? Can you give me an example or examples of these; Do you think it is difficult for you to do it?* Probing questions, such as '*Can you tell me more about that?*' and '*Can you explain more?*', were asked to gain in-depth data. Every interview was audio-recorded.

3.5. Data analysis

The audio-recorded interviews were transcribed verbatim and analyzed by performing a qualitative content analysis (32, 33). The text was read several times to gain a sense of the whole and become familiar with it. Meaningful units with relevance to the study were identified, condensed and labeled with codes (32). The analysis was performed by each author for comparison. The process continued, and various categorizations were tested several times. Different interpretations of the text were discussed among the researchers until consensus was reached. We also questioned and reflected on our preunderstandings during the analysis process, where the latent meaning of the text was also in focus. After member checking with two interviewees, an overarching theme with two sub-themes was

TABLE 2 Examples of content analysis process.

Meaning units	Condensed meaning units	Codes	Categories
I feel that if I communicate with a patient now, because I have not learnt that much, I can only let the patient know that I am genuinely taking care of him and sincerely want him to be healthy. I can only do my best to make him trust me. (A12)	To let the patient know that the nurse sincerely wants him to be healthy and to gain his trust	Be sincere	Trustful relationship
By mastering communication skills, you can subtly integrate the assessment into the daily conversation with the patient, and you can complete the work easily and effectively. (A2)	Integrate the assessment into the daily conversation	Be flexible in communication	Communication method

TABLE 3 Presentation of theme, sub-themes, categories and sub-categories.

Themes	Sub-themes	Categories
Facilitating a caring nurse–patient relationship	Caring approach	Friendly and understanding approach
		Show interest
		Trustful relationship
	Helping and involving the patient in care	Helping the patient
		Inviting the patient
Using a knowledge base for performing nursing care	Knowledge needed to be able to understand the patient	Observe the patient
		Learn about the patient
		Communication method
	Health and treatment information	Inform the patient
		Teaching

confirmed based on the subcategories, categories and the text as a whole. Examples of the analysis process is presented in Table 2.

4. Results

Two main themes, 4 sub-themes and 10 categories were identified from the analysis (Table 3). The nursing students described what they believe is essential for developing verbal and social interaction skills during their nursing education to become skilled nurses.

4.1. Facilitating a caring nurse–patient relationship

This theme can be described as actions to facilitate a caring nurse–patient relationship by developing a caring approach combined with helping and involving the patient in her/his care. The caring approach can be understood as the skills that nurses need for their development as nurses, which includes showing the patients that you are prepared to interact with them by having a friendly and understanding approach and by showing interest in who the patient is or in her/his problems. The students describe the caring approach as being patient with the patient, expressing oneself as forthrightly as possible, sometimes using humor and being easy-going while trying to think from the patient's position or perspective. They describe showing interest as listening attentively with an encouraging attitude while accompanying the patient and trying to have as good eye contact as possible in a suitable way. They also describe that it is important to try to develop a trusting relationship with the patients, which could be done by paying respect to the patient and being sincere.

> *'…when I meet a new patient, I must first let her/him know that I can empathise with her/his illness and I can understand him/her. If I cannot do that, I will find something we have in common. When we have this, then we can build a relationship through empathy'.* (A12)
>
> *'…you have to show as much kindness and friendliness as you can'.* (A10)

Helping and involving patient in her/his care is important for developing students' skills in helping the patient and inviting the patient to take part in their care. The help could be in the form of trying to relieve physical discomfort, assisting the patient with solving economic problems, and building social relationships. The students indicate several aspects that they see as necessary to be able to stimulate the patients to take an active part in their care. The students state that, as a nurse, you have to take responsibility for initiating communication with the patient. Furthermore, they state that patients' involvement in their care could be promoted by involving the patients in their disease management by communicating the patient's condition, treatment plan and treatment progress in detail.

> *'When you go to check their physical condition, talk about their recent situation and how they feel. The patient will then feel that someone cares and that there is emotional resonance'.* (A3)
>
> *'Nurses are supposed to tell the patients how to take the medicine and how many bottles of saline to have in an intravenous drip. Just let them know these things. Tell them in the morning, and then they can schedule the day'.* (A1)

4.2. Using a knowledge base for performing nursing care

This theme can be described as the knowledge that nurses need to be able to understand the patient and provide information about health and treatment. It is more closely connected to the knowledge base that nurses need to have to be able to provide care. The nursing students discussed the importance of developing skills to obtain the knowledge needed for understanding the patient by communicating with and observing the patient in different ways. This could be done by focusing on the patient's behavior and incorporating assessments into their daily conversations with the patients. They also talk about the need to improve their skills in learning about the patients' physiology, psychological needs, living habits, social background and social contacts.

> *'By mastering communication skills, you can subtly integrate the assessment into the daily conversation with the patient, and you can complete the work easily and effectively'.* (A2)
>
> *'Talking about his daily life, beating around the bush to care about his physical condition, and then learning about his psychological condition by watching how he behaves in the conversation. At first, ask him a question, and then, as he speaks, observe his behaviour, for example, his words, eyes and movements'.* (A6)

They also express that they need to develop their skills in using different communication methods and learn about the patient by asking her/him, asking the family members and the doctor. Developing their skills in using open-ended and fixed questions and using questionnaires to support their communication are examples of these methods. The students describe that communication is essential for the patients' recovery and should be gradual, frequent and in an easy-to-understand language. They also maintain that it is important to try to grasp the right time to communicate. Furthermore, they also describe it as being flexible in communication, communicating in accordance with the patient's characteristics and condition.

> *'When talking with the patient about feelings and thoughts in the process of treatment, I will learn about his daily life first and then ask him about his intuitive feelings about the treatment gradually. Next, I would ask him about his thoughts on whether it is valid or not according to his intuitive feelings. Then, I would ask him about his thoughts on treatment and improve the treatment plan based on these, as well as some test results'.* (A5)

Furthermore, they must develop communication skills to teach and inform patients about different health and treatment issues. They spoke of education being delivered in sections, that they can use a case methodology and that they have to be flexible in their communication. Understanding the patient's characteristics and condition is the most important and basic communication premise. Therefore, they must communicate drug effects and provide information about how medical administration is carried out, as well as the importance of exercise.

> *'Some aspects, such as exercise, diet and sleep, should not be discussed all at once, so I do not think I am going to mention them all at once. Maybe I will talk about the recent diet with him when he comes to ask me in the morning and then tell him about the methods of exercising when he takes an injection'.* (A10)

5. Discussion

To work as a nurse means, to a great extent, to interact with patients in various ways with the main aim to support patients' health and well-being. However, studies have found that the new nurses lack the knowledge to understand the existential qualities that are both common and unique to different conditions and different patients (9, 23). It is therefore critical for the educational institutions to develop the communicating ability of the nurses and nursing students to help them provide quality care in the future.

The nursing students in our study confirm that both the facilitation of the caring relationship and the application of knowledge are required in their future work. It could be understood that they knew the importance of intertwining caring interactional skills with knowledge and are eager to learn how to facilitate caring relationships and the related knowledge of caring. Several studies, including our previous research, reported that the Chinese nursing students had a lower level of caring competence than seen among their foreign counterparts (34, 35). Essentially, this is a problem related to how the transfer of medical knowledge and humanistic care knowledge are balanced during nursing education. For a long period, China's nursing education system has focused on the treatment of disease more than the development of humanistic competence (2). However, the theoretical underpinnings of nursing is holism and humanism. Nurse educators are required to make the students understand deeply that well-being is not merely the absence of disease, but a harmonious state on the basis of the interconnection among mind, body, spirit, and environmental and social conditions. And the nurse's communication and deep engagement with a patient is the way in which the patient's well-being could be provided.

The students regarded consideration, friendliness and understanding as equally important as showing interest in and building a trusting relationship with the patients. They knew that to give special attention to, cherish and appreciate the patients would allow love and caring to come together in a new form of deep transpersonal caring. It could be seen that they mainly gained this understanding from some of their life experiences, while a deep understanding of related knowledge or nursing theory on how to facilitate a caring relationship might be more important for them. The nursing humanistic theories are abstract and difficult for novice nursing students to understand, and applying these theories into practice is even harder (36). China has recently begun to promote ideological and political educations that emphasize morality and ethics, humanity and love (37). In this context, it is necessary to infuse the essence of caring theory into educational curricula and clinical practice models to develop a sense of intentional caring in students throughout their education (38).

The students described that helping a patient was not only about actively addressing her/his illness but also included many psychological and social problems and allowing the patient to take charge of her/his own treatment and arrangements. This somehow reflects their understanding that the human being is a whole person and that well-being encompasses existential dimensions of freedom and vulnerability (23). Nursing students thus need to learn how to provide value-based care before they encounter the patient's lifeworld, to be able to promote patients' physical, spiritual and existential well-being (21). The instructors are supposed to provide as much contextual information about the patient as possible in the classroom setting and challenge the students to provide care strategies in relation to the patient's lifeworld.

Being able to gain knowledge about understanding the patients through verbal interaction and behavior observation and learning the communication methods and techniques are considered to be important aspects for the development of their caring capability, according to the students. Nurse educators have to make the students understand during their nursing education that the perception of every patient is unique as they have different values, culture, race, beliefs, past experiences and expectations (39). Each patient acts based on her/his perception of illness, well-being and other situations. Since the patient's perception could be found through talking and observing behavior, a nurse is expected to ask the patient about the feelings and observe her/him in order to understand her/him better (40). A nurse should create a supportive environment for this process (41). This is the only way the nurse can understand the patients from the inside out and provide them with the help they need. The students admitted that though they remembered what they had learned about communication in the class, they currently lacked the ability to have more profound conversations with the patients, which could be achieved through 'reflection in action' and developing the knowledge that goes beyond the theoretical studies (8).

The students stated that the level of mastery of communication skills and professional knowledge in their interactions with the patients was what may affect the quality of care they provide to patients. Patients are the masters of their own health and they have the right to be informed about the knowledge of their disease and their own health conditions so that they can make decisions for themselves. The nurse works as a health educator, resource provider and counselor to work together with the patient to achieve her/his well-being (38). It is important that the meaning of well-being is not taken for granted, whether the nurse emphasizes the patient's initiative or vulnerability (23). The students noted that more practice should be provided on the basis of their theoretical lessons so that they could develop interactive skills adapted to different contexts in real-situations. The use of scenario simulation and interactive panel discussions, the artificial intelligence-based virtual counseling application, and the intensive training of the tutoring system have proved helpful in improving students' oral communication, psychological response and conflict resolution ability (42–44).

There are some limitations to this study. One is that the interviewer had been the interviewees' teacher for 1 year, which may have made some of the interviewees a little nervous. A result could be that they might not express their ideas freely and fully during the interviews. The interviewer tried to have a convivial and relaxing conversation prior to reaching the relevant topic of this study to help them be relaxed. The other limitation is that the students had gained some knowledge about nursing psychology and communication after they entered university, so their original ideas about the nurse–patient interaction may have been affected. There is also a risk that some of the students could answer the questions in accordance with the textbooks they have read.

6. Conclusion

A concept that systematically reflects humanistic caring is lacked among the Chinese student compared to their foreign counterparts. They are eager to possess the qualities and abilities in the establishment of a good nurse–patient relationship, while gaining professional knowledge in their education. A harmonious caring relationship is supposed to be established through a considerate, understanding and friendly approach in helping the patients. They need to learn and understand the deeper mechanisms that enable this relationship and to apply them in the future.

7. Implications for nursing education

Nurse educators in China are suggested to systematically set the curriculum in accordance with caring theory and infuse its essence into the clinical practice models. Intentionally use a variety of teaching methods to challenge students' ability to acquire background knowledge about patients and to provide nursing strategies that are relevant to patients' lifeworld. Moreover, personalized teaching methods to cultivate the nursing students' communication skills and professional abilities are also needed from a lifeworld perspective.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Institutional Review Board of Wenzhou Medical

University. The patients/participants provided their written informed consent to participate in this study.

Author contributions

XZ, HX, and MR conceived the study. XZ collected data. XZ, HX, and MR conducted data analysis. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Experiences of Spanish nurses in the rollout of nurse prescribing: a qualitative study

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Introduction: Nurse prescribing has legal recognition in Spain, after a long regulatory process, with confusing, changing legislation that does not fully coincide with the reality of nurses' practice. There is currently no research available on how nurses have experienced the rollout of nurse prescribing. The objective of this study is to describe the experiences of nurses in the rollout of nurse prescribing in the province of Barcelona, Spain.

Method: A descriptive qualitative study with intentional sampling was carried out between March 2021 and July 2022. The data were collected through semi-structured individual interviews and discussion groups. The participants were 24 nurses working in the province of Barcelona who were accredited in nurse prescribing or involved in the rollout of nurse prescribing. The data were analyzed using thematic analysis, following Braun and Clark. The COREQ checklist was used to report findings.

Results: We describe nurses' responses on the following themes: internal and external barriers; strategies to support nurse prescribing in the initial rollout and proposals for improvement; and factors linked to nurses' satisfaction.

Discussion: The regulatory process has provided a safety framework for nurse prescribing. Strategies are needed for its comprehensive development and its acceptance among the public. The findings give visibility to nurse prescribing internationally.

KEYWORDS
nurse prescriber, electronic prescription, nurses, strategies, community care, qualitative

1. Introduction

Nurse prescribing is currently legal in countries such as the United States, the United Kingdom, Sweden, South Africa, Australia, Canada, New Zealand, Brazil, France, Ireland, Argentina, Norway, Finland, and the Netherlands (1, 2). The application differs across countries, although there are three basic models: independent prescription, supplementary prescription, and prescription based on indications for patient groups (2, 3). In almost all of these countries, nurses are required to receive specialized training before prescribing drugs autonomously (1). In Spain, nurse prescribing for medications and health products has been legal since 2018 (4, 5), after a regulatory process that lasted more than 10 years. As of April 2021, a thousand nurses already had digital cards that allow them to prescribe medications and health products electronically (6).

The concept of nurse prescribing has evolved over the years according to the standards set by national and international bodies. The concept of nurse prescribing arises as a result of this professional growth, as an autonomous, advanced, and specialized practice that is part of the nursing process itself and the nursing care plan (7). Nurse prescribing is defined as the ability to select and indicate techniques, medications, and health products for the benefit and to meet the health needs of the people subject to care during professional nursing practice, under criteria of good clinical practice and clinical judgement (8).

Nurse prescribing has evolved in response to local factors such as the lack of healthcare professionals, the changing needs of patients, and the management of chronic diseases (9). In the last two decades, numerous countries have given nurses the legal authority to prescribe, although legal, practical, organizational, and educational conditions vary considerably from country to country (9, 10).

In studies in Qatar and Australia, researchers found that the development of nurse prescribing contributes to the clinical growth of those who have become prescribers (11, 12). Similarly, in studies conducted in England, researchers have shown that the development of nurse prescribing has allowed nurses to prescribe with confidence (13), improved teamwork (14), and led nurses to be perceived as experts and supportive leaders (15). A study carried out in Ireland found that recently graduated nurse prescribers have high job satisfaction linked to greater autonomy and responsibility (16), and one study in England highlights the importance of nurse prescribers' ability to practice autonomously (17).

The study by Ruiz et al. has shown that the practice of nurse prescribing is associated with better care for people who require healthcare, more effective use of time and resources, and improved cooperation among health professionals (18). Other studies show Irish community nurses' satisfaction with their prescribing role (19) as well as the satisfaction of patients, who positively evaluate their effort in prescribing medications (20). The effects of nurse prescribing on medication and patient outcomes seem positive, although more studies with more rigorous methodological designs are required to draw definitive conclusions (2). Along the same lines, Fox's review (9) emphasizes that the introduction of nurse prescribing must be planned, and the outcomes should be reported, thus supporting its adoption in clinical practice to obtain positive results in the health of the population.

On the other hand, the World Health Organization (21) reaffirms that with limited resources and a tense economic climate, policymakers and health departments must maximize the current potential of healthcare professionals by allowing staff to work within their full scope of practice, optimizing patient and system outcomes. This includes blurring professional boundaries and developing the roles of nursing, pharmacy, and related healthcare professionals to collaboratively meet prescription needs.

At the European level, Irish nurses established nurse prescribing around 2010, and their experience and publications of scientific evidence on the evolution of the prescribing process have made them points of reference in this area. Irish nurses have increased the scope of nursing practice by ensuring safe and effective nurse prescribing (20). As of 2019, 13 countries in Europe have national laws on nurse prescribing. They vary considerably in the medications that nurses can officially prescribe, for what health problems, and under what type of prescription (22).

In the case of Spain, the following nurse prescribing models are used: (a) independent and autonomous nursing prescription (drugs and health products not subject to medical prescription) and (b) collaborative nurse prescribing to an independent prescriber, where sometimes the nurse performs a standardized collaborative prescription and can adjust the dose under established protocols (23). Spanish nurses have extensive training in pharmacology (24), as well as extensive knowledge of health products used by people with chronic health problems, and within their competencies are health promotion and education (18).

A study carried out in Andalusia between 2009 and 2015, showed that the incorporation of nurse prescribing into the public health system meant a significant reduction in healthcare expenditure on health products aimed at the management and monitoring of chronically ill patients, and therefore, an improvement in efficiency (18). Another study carried out in the field of primary care in Catalonia in 2019 showed that nearly 20% of appointments with nurses required at least one prescription and, of these, 72% were prescription drugs and the rest were health products, basically dressings (25). Other studies have shown that nurse prescribing allows the patient to solve health problems with a single professional visit and that, at the same time, contributes to the professional satisfaction, self-esteem, and autonomy of nurses, making it possible to streamline flows and procedures and benefits the multidisciplinary team (26).

In Catalonia, there is consensus on the benefits of nurse prescribing in that it empowers nurses, facilitates the leadership of nurses in care processes, fosters person-centered care, and contributes to the continuity of care (7). To our knowledge, no research describes the process of the rollout of nurse prescribing in Spain from the point of view of the nurses involved, and there is insufficient information on the experiences of prescribing nurses themselves in the international literature. Our qualitative approach uses nurses' opinions and lived experiences, as well as their expertise and knowledge of the context, to understand nurse prescribing from nurses' perspectives.

The main objective of this study is to describe the experiences of nurses regarding the rollout and implementation of nursing prescriptions within Catalonia's electronic prescription system. This objective is divided into three parts: (1) to describe the challenges in the rollout of nurse prescribing; (2) to describe strategies for boosting nurse prescribing; and (3) to describe participants' satisfaction with their role as prescribers.

2. Materials and methods

2.1. Design

This is a qualitative study with semi-structured individual interviews and discussion groups. We used the consolidated criteria for reporting qualitative research (COREQ) (27).

TABLE 1 Guide for discussion groups and individual interviews.

1. How has nurse prescribing evolved in Barcelona?
2. What specific challenges and general challenges have occurred during the rollout of nurse prescribing?
3. What elements can facilitate the process of the electronic prescription led by the prescribing nurse?
4. What barriers must be overcome for nurse prescribing to be consolidated as a health resource?
5. What strategies have been necessary, from the beginning, to make the journey to the present day?
6. What strategies would you propose to support the rollout of nurse prescribing?
7. What should the nursing community do to improve nurse prescribing in the future?
8. What has been your experience as a nurse prescriber?
9. What does being a nurse prescriber mean for your professional career?
10. To what elements or factors would you link your satisfaction?

2.2. Setting and participants

The study population was active nurses in the province of Barcelona from two different profiles: (1) accredited nurses who worked in primary care centers, urgent primary care services, and nursing homes in the city or broader province of Barcelona that have pioneered nurse prescribing; (2) nurses involved in the regulation and rollout of nurse prescribing in Catalonia between 2009 and 2019. We used intentional sampling to seek maximum variation in profiles. We excluded nurses who worked in specialized mental healthcare or pediatric centers.

To recruit the sample, we drew on public nurse prescribing data. The Col.legi Oficial d'Infermeres i Infermers de Barcelona (COIB), the province's professional nursing organization, drew up a list of candidates who were accredited in nurse prescribing, currently working, and wrote prescriptions. To select the sample, we sought a balance between homogeneity, which fosters discussion based on shared experience, and heterogeneity, which favors variety. We contacted potential participants by email to inform them of the purpose of the study and verify that they met the inclusion criteria. As for nurses with the profile of experts in the regulatory process for nurse prescribing, they were known figures in the field and therefore we contacted them directly by phone.

2.3. Data collection

The two discussion groups were held at the COIB facilities, lasting 60–90 min, and were led by two members of the research group (JM and OC). Individual interviews and discussion groups were audio-recorded, respecting all ethical requirements. The five individual interviews were conducted at the workplaces of each of the nurses interviewed. These interviews lasted 30–50 min and were carried out by a researcher of the project (JM). Table 1 presents the guide used for both discussion groups and individual interviews.

2.4. Ethical considerations

This project was approved by the research ethics committee of the Blanquerna Faculty of Health Sciences, Ramon Llull University *CER-FCSB_10_6_2021*. Participants' confidentiality has been protected according to the European General Data Protection Regulation (RGPD), Regulation (EU) 2016/679, and Organic Law 3/2018 of 5 December on the Protection of Personal Data and Guarantee of Digital Rights. All participants provided written, revocable consent on a paper informed-consent document, before participating in the study. Participants were assigned an alphanumeric code to preserve their confidentiality, and their identities are known only to the principal investigator. Data (recordings, field notes, and transcriptions) are stored in an encrypted external hard drive that is held by the principal investigator.

2.5. Data analysis and rigor criteria

The interviews were transcribed verbatim, and a thematic analysis was carried out with the support of the Atlas-ti.9 software. To identify the data, we followed Braun and Clarke's (2014) six phases: data familiarization, initial code generation, theme search, coding, development of themes and subthemes, and writing a final report. Two researchers (OC and RC) independently analyzed the transcripts, carrying out audits. To resolve any discrepancies, the analysis was repeated by a third researcher (PG). Information saturation was reached in the data provided by the participants (28). Credibility was ensured by triangulation of data across participants and cross-verification of the discussion groups, individual interviews, and field notes. To facilitate transferability, we recorded detailed descriptions of participants' demographic information and the data collection methods. To ensure confirmability, we used the audit technique and wrote field notes and memoranda to connect the data and the findings.

3. Results

We invited 28 nurses (24 women and four men) to participate in the study. Those who agreed to participate were 24 women: 19 accredited nurse prescribers who participated in the two discussion groups and five nursing experts who had been key figures in the regulation and rollout of nurse prescribing. Because we wanted to draw out the unique expertise of these five participants, we chose to conduct individual interviews with them instead of a discussion group (Table 2).

The nurses who participated in the discussion groups had an average age of 41.1 years and professional experience of 17.5 years (between 5 and 31 years), and 58% had completed nurse prescribing training. Of this group, 63% had a master's degree and 17 of the 19 nurses worked in primary care centers. The expert nurses who participated in the individual interviews had an average age of 55 years, 24 years in professional practice (between 10 and 35 years), and all held administrative, management, and training positions.

The results are described below according to the three study objectives.

TABLE 2 Sociodemographic characteristics of participants.

Group discussions							
Participant ID Code	Gender	Age	Nurse prescribing training	Highest level of studies achieved	Workplace	Worked as a nurse (Years)	Worked as a legal NP (Months)
P1	F	29	–	M	PHC	7	7
P2	F	43	yes	M	PHC	16	3
P3	F	42	yes	M	PHC	22	6
P4	F	32	–	M	PHC	11	10
P5	F	40	yes	M	PHC	20	4
P6	F	39	yes	BN	PHEC	18	3
P7	F	53	yes	SFCN	PHEC	29	3
P8	F	52	–	BN	PHC	27	12
P9	F	31	–	BN	PHC	5	12
P10	F	53	–	DS	PHC	31	6
P11	F	43	yes	BN	PHC	25	5
P12	F	37	yes	M	NH	13	12
P13	F	45	yes	M	NH	28	12
P14	F	44	yes	SFCN	PHC	20	6
P15	F	31	–	M	PHC	7	1
P16	F	43	yes	M	PHC	27	4
P17	F	30	yes	M	PHC	8	6
P18	F	35	–	SFCN	PHC	11	5
P19	F	30	–	BN	PHC	7	6

Individual interviews					
Participant ID Code	Gender	Age	Years in management	Highest level of studies achieved	Professional role function
P20	F	58	30	PhD	Ma, NT, SFCN
P21	F	70	35	BN	Ma, NT
P22	F	51	10	PhD	Ma, NT
P23	F	54	25	DS	Ma, NT, SFCN
P24	F	45	20	SFCN	Ma, NT, SFCN

BN, bachelor of nursing; DS, doctoral student; F, female; M, master's; Ma, manager; NP, nurse prescriber; NT, nursing trainer; PhD, Doctor; PHC, primary health center; PHEC, primary health emergency center; SFCN, specialist in family and community care nursing.

3.1. Challenges of the rollout of nurse prescribing (Objective 1)

Table 3 contains the themes and subthemes that we detected in our analysis for objective 1. It describes both internal and external barriers.

3.1.1. Barriers to the rollout of nurse prescribing

We detected two types of barriers in the regulation of nurse prescribing: internal barriers created from within the nursing community and external barriers.

3.1.1.1. Barriers internal to the nursing community

Participants reported that nursing care is in constant change to respond to the needs of the population. This is stressful and often divides a very plural group, who do not always believe in the value of nurse prescribing.

> *"The great barrier is that we still don't fully believe in the importance of nurse prescribing."* **P24**
>
> *"We never stop evolving and it's non-stop... super stressful. Because of this we end up being a divided group, because of so many changes. And in the end, nurse prescribing is just one more thing."* **P6**

TABLE 3 Themes and subthemes related to the challenges of nurse prescribing.

Objective 1	Themes		Subthemes
Challenges in the rollout of nurse prescribing	Barriers to development	Internal	- Constant changes and innovation in nursing care - Unequal professional self-recognition - Lack of training in pharmacology
		External	- Very restrictive catalog, and a physician has to sign off on prescriptions by nurses - Nurse prescribing was not regulated outside the treatment plan - Complex administrative procedure - Lack of confidence in nursing skills

TABLE 4 Themes and subthemes related to strategies for boosting nurse prescribing.

Objective 2	Themes	Subthemes
Strategies for boosting nurse prescribing	Actions taken during the initial rollout	- Leadership and active participation of nurses - Explaining nurses' preparation for prescribing - Demonstrating the scientific evidence surrounding the benefits of nurse prescribing from other countries
	Areas for improvement	- Increase the catalog of drugs, supplies, and treatments that nurses can prescribe - Normalize nurse prescribing among the public - Promote nurse prescribing within the nursing community itself, with respect to other consolidated roles - Provide recognition and external support for the responsibility inherent in nurse prescribing - Provide continuous training in pharmacology - Change the "medication plan" to a "treatment plan"

TABLE 5 Themes and subthemes on the satisfaction derived from nurse prescribing.

Objective 3	Theme	Subthemes
Participants' satisfaction with their role as prescribers	Positive aspects	- Feeling empowered - Being recognized for their role and competencies - Benefits for patients and the general public - Aspects related to colleagues on the team - Milestone achieved by the nursing community

Some nurses do not see nurse prescribing as indispensable or do not see themselves as prescribers for reasons such as a lack of training in pharmacology or a lack of conviction in their capacity to develop these skills.

> *"I think we're still very divided between nurses not seeing themselves as prescribers, not feeling like prescribers. And nurses who do. Sometimes we have to look at ourselves, inside the profession, where we have strengths, where we have weaknesses, and here I think it's a weakness: where we don't all stick together"* **P7**
>
> *"I believe that from the school of nursing or from the health center, they need to make a move and truly train people who have more difficulty prescribing."* **P6**

3.1.1.2. Barriers external to the nursing community

Having a legal framework to prescribe gave recognition to nurse prescribing as a function that is integrated into the patient record that is shared among professionals. Achieving a regulatory framework was the first challenge, and it required effort and perseverance. Still, the participants described the catalog of medicines and devices that nurses can prescribe as very restrictive and incomplete. In addition, in some areas or situations, such as in emergencies, home care, or care for chronic patients, the nurse's word is not final (a physician must sign off on the prescription).

> *"In primary and community care, they are super in favor of nursing broadening its catalog of pharmacological prescription, because they rely on the training and preparation of nurses. In the hospital environment, there's a certain fixation with the idea that nurses can't prescribe"* **P6**
>
> *"We in the emergency room, in addition to the fact that we have acute demand, there are very clear protocols, which is like if you diagnose a streptococcal infection, you follow the protocol, you have a case history and you have to prescribe an antibiotic. But you have to go to the doctor to sign it for you."* **P5**

It would be an advance if the prescription was regulated and collaborative into the treatment plan of the patient. Nurse prescribing is not limited to medications and devices; it also applies to diet, physical activity, and social issues, aspects that are inherent to nursing.

> *"Therefore, here we need a lot of progress toward collaborative prescribing based on protocols and clinical practice guidelines."* **P20**
>
> *"Nurse prescribing is the nursing activity that points out the best treatment regimen, but it doesn't necessarily have to include a drug."* **P21**

The administrative process for obtaining the card that makes it possible for nurses to prescribe is complex and lengthy. Currently, not all nurses have done so yet. Nurses must take the initiative to request the card and then the health center must certify their length of employment.

> *"We have a lot of problems with people who didn't start the process at the time... and that today still don't have the card for prescribing, and that generates a lot of frustration."* **P4**
>
> *"The whole bureaucratic procedure has been a bit complicated... through the company how to request it. They should make it really easy, so these nurses could call a single phone number and find out how to get the card and make it really easy."* **P24**

The participants detected a lack of confidence in their skills and responsibilities among some health professionals and part of the population, reflecting misinformation about nurse prescribing.

> *"To this day, the vast majority of the population does not know that nurses can prescribe and neither do nurses themselves understand very well what they can prescribe."* **P24**
>
> *"I believe that when we are aware of the responsibility that the nurse has when we go to work on the treatment plan jointly, the added value of nurse prescribing [. . .] will be appreciated"* **P23**

3.2. Strategies for boosting nurse prescribing (Objective 2)

In this section, we describe past and present actions taken to boost nurse prescribing and also the participants' ideas for how to improve in future (Table 4).

3.2.1. Actions taken during the initial rollout

Participants pointed out the leadership and active participation of the COIB at the beginning of the regulatory process for nurse prescribing, and later its perseverance in ensuring that nurse prescribing would be integrated into the electronic prescription system. They also recall the support of the Catalan Ministry of Health at important times, such as the approval of Royal Decree 180/2019.

> *"At the time, remember who was the Minister [of Health], which is the one who signed so that [nurse prescribing] could be developed here in Catalonia... Then the Col.legi [COIB], [worked on] [...] professional development along with key elements for working on this topic"* **P24**

It was necessary to demonstrate the nurses' competence in prescribing. The curricula of the nursing degree had to be reviewed to document nurses' training in clinical pharmacology, which had always been present in the curriculum. It was also demonstrated that nurse prescribing was extensive in other countries, and there was scientific evidence about its benefits in different specialties.

> *"Having a nursing degree already accredited you sufficiently for the training received... in addition, novice nurses are accredited through an extra course in prescription"* **P21**
>
> *"... Nursing must ensure its competence. Our role in prescribing is endorsed in publications with results showing good practices and benefits. . . . We just need to be allowed to perform [prescriptions] and not be questioned."* **P5**

3.2.2. Areas for improvement

Participants stressed the limits of the current prescribing catalog for nurses.

> *"The catalog is not real in terms of the activities that we carry out. It's necessary to expand the products and drugs. If they don't increase, nurse prescribing might not [cover] the things that are necessary for the patient, although it includes a series of products that are obviously important in our daily work, but insufficient."* **P23**
>
> *"We need the Col.legi [COIB] to work to expand this catalog."* **P19**

Participants reported that it was essential to normalize nurse prescribing among the public as well as empower nurses to prescribe. This would mean carrying out the complete care process, from the detection of needs to the action to solve the detected problem. This would contribute to a more effective service covering patients' needs, thanks to the development of nursing competencies.

> *"We will only finish consolidating nurse prescribing when citizens normalize it, so that they see it as good for them, the results in terms of people's health."* **P21**
>
> *"As a nurse, I have prescribed medications; I have changed doses. And in an ICU [intensive care unit] also you might incorporate medications, you modify some and you remove others. So the issue is to normalize this."* **P15**

It would be positive to carry out actions in the media to make nurse prescribing known to the public, as well as to provide scientific evidence about its usefulness and benefits.

> *"If nurses are really so important, we'll give them the credit they deserve, and in this case, because if prescribing is very important, well you have to inform the public."* **P24**

Participants described having to defend themselves as prescribers, which generates insecurity and burnout.

> *"It's a cultural issue. We're still a female profession, with all that it brings. We have to justify what we do, why we do it. Also because we're constantly changing."* **P2**

> *"We have gone to pharmacy sessions and they say to us, 'But why are you here?'. Well, because we also prescribe. In nurse prescribing everyone has to stay in line. If the doctor says 'I'll take this [medication] away [from the patient]', nurses can comment from an autonomous point of view or a collaborative one."* **P4**
>
> *"There's been a change in the hospital, it [nurse prescribing] has been valued more, but the doctors have their speciality and we're more general. The doctor has a well-defined place, and we have to justify ours. This wears us down a lot, explaining why nurse prescribing needs to exist."* **P4**

Disciplinary inequalities must be resolved. For example, participants wondered why resident nurses in a specialty cannot prescribe when medical residents can.

> *"But specialist nurses in the second year cannot prescribed, but medical residents can.... This has been reported to management."* **P8**
>
> *"Promote the culture of prescribing so that really when undergraduate nursing students come to do their practicum, they have to internalize the issue of nurse prescribing, just like when doctors finish they have it [internalized]."* **P3**

Nurses' predisposition toward prescribing would improve if the responsibility it implies were recognized and supported. Not all nurses want to prescribe, but this should not be an individual choice. In other types of nursing activities, optionality would be unthinkable. For this reason, it is necessary to focus on the causes of this reluctance, be it the will, the knowledge, or the attitudes of nurses.

> *"Many think, they feel that this increase in responsibility is not supported by anything, that it's not recognized."* **P8**
>
> *"Many think, they feel that this increase in responsibility is not supported by anything, that it's not recognized"* **P8**
>
> *"But that's it, I believe that the issue of compulsory education is precisely one of the problems we have, because if you always have the possibility of not doing it, you can think, 'Tomorrow someone else will come and they'll do it'. Can you prescribe or not? If not, get training."* **P13**
>
> *"We are trained, we have training, and those who don't [having training] need to get trained. Because the problem of a lot of nurses sincerely is assuming that responsibility. 'Do I want to assume that responsibility or not?"'* **P6**

Achieving a change from a "medication plan" to "treatment plan" would be an improvement. This modification would involve incorporating pharmacological treatment into a more global and integrative perspective, which would contribute to the quality of care.

> *"To look for points where the two groups [nurses and physicians] can come together and complement each other. [...]"* **P11**

3.3. Participants' satisfaction with their role as prescribers (Objective 3)

This third objective was to explore participants' satisfaction with nurse prescribing and the impact of being a nurse prescriber on their professional careers (Table 5).

3.3.1. Sources of satisfaction

Participants reported positive experiences with nurse prescribing and linked this satisfaction to several factors. Participants perceived nurse prescribing as a process by which nurses increase their decision-making and leadership capacity. This led participants to feel more empowered in their workplace, as their roles and competencies are recognized, and they become reference points both for patients and colleagues on their team. Nurses who have pioneered nurse prescribing have become role models for nurses who are gradually taking on this role.

> *"Satisfaction [for me] is the recognition for the work that I, that nurses, have been carrying out for a long time. And the benefit it brings to the population of not having to wait for a prescription to be validated [by a physician]."* **P4**

This is recognition of a profession that has opted to expand its functions in a regulated way. After a long wait, the fact that the nurse's signature is finally present on electronic prescriptions just like other professionals is seen as a milestone for nursing.

> *"I'm celebrating because it was something that we were waiting for.... It has been possible to make this card a reality, when it seemed it would never happen."* **P24**
>
> *"I thought the moment would never arrive when I could end my visit with a person by prescribing care that is included in the medication plan. For me it has been comforting."* **P20**

4. Discussion

4.1. Summary of evidence

Our analysis sheds light on nurses' initial experiences of the rollout of nurse prescribing, which can serve as a reference to other countries that are undertaking this process. The prescription of medications by nurses is increasing worldwide, but research in Europe is limited (22). No review of the rollout of nurse prescribing exists (9), and there is no previous data on nurses in our context, especially from a qualitative perspective.

The results of the study also point to the limited visibility of nurses in clinical practice, possibly due to a lack of indicators, as highlighted by Nascimento (29). Another finding relates to the complex phenomenon of professional responsibility in the practice of nursing (30) and the empowerment of nurses through specific competencies such as nurse prescribing. True empowerment involves a nurse controlling her practice (31), and at this early stage of the rollout of nurse prescribing in Barcelona, this has not yet occurred.

The participants reported that the regulation of nurse prescribing in Barcelona has provided a legal framework as well as the recognition of their authority and autonomy. Nurse prescribing is extensive in other countries and has clear benefits, as seen in studies that show a higher demand for incontinence prescriptions directed by nurses (32).

Our participants' satisfaction with nurse prescribing is high, coinciding with patient satisfaction found in a study by Duarte (33). Nurses achieve higher levels of patient satisfaction, compared to primary care physicians (34, 35).

At the same time, we learned that not all nurses want to prescribe. Perceptions of competence, role, and risk influence the decision to prescribe (36), but this tendency would likely change if the responsibility assumed by nurse prescribers were recognized and supported by health managers, professional teams, patients, and the general public (37). Nuttall's (3) study reveals that some primary care nurses did not see nurse prescribing as part of their role, but overall nurse prescribing was seen as an essential component of nursing, especially for specialist nurses. Numerous barriers remain for the full implementation of nurse prescribing, and overcoming them requires a more coordinated approach (38). Other studies show that the lack of recognition of nurse prescribing is coupled with the lack of knowledge on the part of the population about the rigorousness of the nursing field (39). Ignorance of the regulations and conditions governing the prescription of medications is identified as a universal problem, which is why it is important to inform colleagues and multidisciplinary teams (19). Nurses seek the competency of prescribing, for their professional development and the efficiency of the public health system (40, 41), in line with health managers, who are interested in authorizing and expanding this competency, considering how it benefits patient safety and the health system itself (18).

Fox's review (9) offers practical recommendations for the implementation and adoption of non-medical prescriptions by the different agents involved. Implementation requires significant organizational support and careful planning to maintain interdisciplinary relationships and clarify roles and responsibilities. Also, to allow optimal uptake of nurse prescribing, it is necessary to earn the trust and support of patients, clinicians, and health administrators. The legalization of nurse prescribing also implies changes in power and inter-professional relationships, requiring adjustments to enable the effective implementation of nurse prescribing (3).

Participants identified the need for continuous training in clinical pharmacology, at the same time deprescribing must also be considered, from the non-medicalised perspective of the population. For this reason, the analysis of the types of nurse prescribers, prescription restrictions, and the necessary supervision models is key (42). There is an ongoing need to help nurses increase their knowledge and skills to support their prescribing role (43).

Hindi et al. (44) show that there are still barriers to the implementation of independent nurse prescribing in primary care teams. They argue that for nurse prescribing to be efficacious, there must be appropriate training for nurse prescribers, effective integration with the rest of the primary care team, and acceptance by patients. Graham-Clarke et al. (45) show that nurse prescribing seems to be easier to adopt when it is part of the person's overall care. When new roles need to be established, nurse prescribing takes longer to be universally adopted.

Nurse prescribers can improve people-centered care (3). It makes it possible to provide holistic health promotion (46), and nurses prescribe for a wide range of patients in a manner comparable to that of physicians (2).

We need more studies about the effects of nurse prescribing, and for it to thrive, it must be recognized, understood, and included in organizational processes. At the same time, we must address the challenges that nurse prescribers encounter during their daily practice. Moreover, on the other hand, university schools of nursing need to promote nurse prescribing.

4.2. Limitations of this study

Qualitative studies with small samples are useful for identifying questions that deserve further research, but they have a limited capacity for generalization. The sample size was adequate for our purposes because data saturation was reached on the topic of the participants' experiences surrounding nurse prescribing. However, these results cannot necessarily be extrapolated to other healthcare systems, so care must be taken in drawing comparisons internationally. Nonetheless, they may be relevant in other countries where nurse prescribing is in the regulatory phase or its initial rollout. In addition, this was a short-term study, while prolonged engagement with participants can provide a valuable way to identify present and future challenges. By including only the nurses who had the most experience with nurse prescribing, we may have missed the reasons why nurses at other centers are not prescribing as much. Future studies should consider a broader range of accredited nurse prescribers to give us a fuller picture. Finally, in retrospect, the wording of our question about satisfaction with nurse prescribing could have conditioned the responses. However, the impact on the overall data was minimal because this was the last question we asked. Moreover, when asked this question, several nurses told us about challenges and barriers (rather than satisfaction), suggesting that the question did not prevent negative opinions from surfacing.

4.3. Implications for clinical practice

This study may be useful for health administrators and policymakers. The findings of this study are relevant for clinical practice internationally, as they provide suggestions for how to facilitate the rollout of nurse prescribing, increasing the efficiency of public services, especially given the current shortage of health professionals worldwide. Health centers can call on nurse prescribers as they redistribute care activities to make the best use of available resources. Nurse prescribing could be crucial in improving the efficiency and quality of treatment plans. Also, understanding nurses' experiences can help professional associations and schools of nursing tailor their training in nurse prescribing and support nurse prescribers.

5. Conclusion

The regulatory process for nurse prescribing has lasted a long time but has provided a legal and safety framework. We detected barriers to nurse prescribing both inside and outside the nursing community that must be overcome in order for nurse prescribing to be consolidated within clinical practice. At the same time, we identified present and future strategies to facilitate the development of nurse prescribing, which will affect the nurses themselves, the population cared for, and the management of public health services.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Research Ethics Committee of the Blanquerna Faculty of Health Sciences, Ramon Llull University CER-FCSB_10_6_2021. The patients/participants provided their written informed consent to participate in this study.

Author contributions

PG-E, GJ-S, and OC-V contributed to funding acquisition and design of the study. JM-R and OC-V performed the data collection. OC-V and RC performed the analysis and interpretation of data. OC-V and RC wrote the first draft of the manuscript. PG-E, EM, GJ-S, and JM-R involved in drafting the manuscript or revising it critically for important intellectual content. All authors read and approved the final version of the manuscript.

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Conflict of interest

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How Midwestern College students protected their families in the first year of COVID-19

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Introduction: College students routinely visit their families due to geographic proximity and their financial dependence. Consequently, the potential of transmitting COVID-19 from campus to their families' homes is consequential. Family members are key sources of support for one another in nearly all matters but there is little research uncovering the mechanisms by which families have protected each other in the pandemic.

Methods: Through an exploratory qualitative study, we examined the perspectives of a diverse, randomly sampled, group of students from a Midwestern University (pseudonym), in a college town, to identify COVID-19 prevention practices with their family members. We interviewed 33 students between the end of December 2020 and mid-April 2021 and conducted a thematic analysis through an iterative process.

Results: Students navigated major differences in opinions and undertook significant actions in attempts to protect their family members from COVID-19 exposure. Students' actions were rooted in the greater good of public health; prosocial behavior was on display.

Discussion: Larger public health initiatives could target the broader population by involving students as messengers.

KEYWORDS
college students, COVID-19, family, infectious diseases, public health, qualitative methods

Introduction

In the early stages of the COVID-19 pandemic, the international media showed American students partying on beaches and on campuses during Spring Break. Despite their awareness of, and exposure to, scientific expertise, students were not innate models of pandemic public health best practices (1–3). However, news outlets failed to capture college students' on-and off-campus prosocial behavior—where they limited their own social activities and engaged in public health best practices to minimize COVID-19 transmission, for the benefit of society and their families (4). Because of students' routine family visits, due to their geographic proximity to parents and their dependence on family members for financial and emotional support during their college years (5–7), the potential of transmitting COVID-19 from campus to their families' homes is consequential. Nuance in college students' COVID-19 risk mitigation strategies remains relatively unknown, as students likely faced numerous trade-offs in sustaining relationships and being mindful of public health.

Family members are key sources of support for one another in nearly all matters (8–11), including health decisions such as routine vaccinations (12–14), accessing antiretroviral treatment for HIV/AIDS (15, 16), and screening for degenerative diseases such as cancer (17, 18). Family members' roles and support in the COVID-19 pandemic—while potentially like the circumstances surrounding other health issues—remains comparatively less known since it is a novel disease with little extant research in this area (19). Initially, healthcare workers faced an ethical dilemma of contemplating refusing to work to protect their family members from contracting COVID-19 (20). Family members also faced a moral dilemma to not visit or care for relatives in nursing home and older adult care facilities (21–23). Notably, fostering positive relationships with older family members has helped college students cope with pandemic-related stresses (24). But beyond this, there is little research uncovering the mechanisms by which families have protected each other in the pandemic.

We examined the perspectives of a diverse group of students from a Midwestern University (MWU—a pseudonym), in a small town, to identify COVID-19 prevention practices with their family members. Our semi-structured interview data were collected at a crucial juncture between the end of December 2020 and mid-April 2021, with a widely available vaccine on the horizon and a year's worth of students' experiences managing the COVID-19 pandemic with their families. During the time of our study, this Midwestern town, in conjunction with MWU, enacted standard COVID-19 restrictions, such as wearing masks in public spaces and social distancing, based on scientific guidance from national and local public health leaders and stakeholders. The state, however, never mandated wearing masks, social distancing, or other commonsense protocols to prevent COVID-19 transmission; after this study ended, the state took extraordinary legal efforts to prevent local level jurisdictions to mandate any COVID-19 prevention mechanisms. Students like those at MWU are important in quelling the spread of COVID-19 due to their transience between their college town and "home" residences (25). No students interviewed considered this small town their home because their parents—who they tended to visit during holidays or special events and live with outside of the academic calendar year—lived in other parts of the state or beyond. These "home" residences were usually at least an hour away—as is common in small American "college towns." Given students' exposure to strict campus COVID-19 protocols and constant COVID-19 prevention messaging from university leaders, we ask here: did students engage in best prevention practices away from campus with their family members? Students navigated major differences in opinions and undertook significant actions in attempts to protect their family members from COVID-19 exposure, with varying degrees of success. The objective of our study is to provide the scientific community much needed, in-depth, insight into the conversations about COVID-19 prevention and the extent to which strong relationships were tested during a time of great uncertainty.

Materials and methods

Study design

Our exploratory qualitative study data come from Midwestern University (MWU) students who initially took part in the *MWU Study of Seropositivity and Risk for SARS-CoV-2 and COVID-19* (ethics approved under University of Missouri, IRB protocol 2028427). We interviewed 33 participants, drawn from 1,155 students who took part in a survey, agreed to be part of follow-up studies, and provided an email address to be contacted at regarding follow-up studies (the total number of survey participants, which also included faculty and staff was 2,894). Student participants were not selected based on any particular degree program. Through a "nested" sampling design (26) stemming from the representative MWU student data—an advantage over conventional convenience or snowball samples—we randomly selected students (including both undergraduate and graduate) to interview from three different groups to ensure diversity of the sample: (1) an initial 10 students regardless of individual characteristics (sampled from $N = 1{,}155$); (2) 13 non-White students (sampled from $N = 117$); and (3) 10 LGBTQ+ students (based on self-identification; sampled from $N = 151$). Gender, ethnicity, and sexuality are relevant to the American student context and key to this stratified random sample.

Our sampling strategy aimed to maximize the heterogeneity of our sample to reflect the experiences of the diverse student body and achieve saturation among the ideas of different demographic groups. Also, based on our prior experience curating qualitative samples, we believed that the number of participants in each group would give us a high probability of reaching saturation in COVID-19 experiences and perspectives (27)—which ended up being the case with our data. Of the 33 students interviewed, 20 identified as female (60.6%), 12 as male (36.4%), and 1 as non-binary (3.0%). Along racial lines, 17 participants identified as non-White (51.5%), while 16 identified as White only (48.5%). Further, 23 participants identified as heterosexual (69.7%), with the other 10 participants identified with another sexuality (30.3%).

Analytic techniques

We conducted individual semi-structured interviews, using a script, over Zoom with the 33 students which lasted between 35 min and 1 h; three of the authors conducted all interviews. The interviews were recorded and transcribed. Students were asked broad questions about the COVID-19 pandemic, including how it had generally changed their lives, whether they knew anyone who was infected with COVID-19, their worries about their futures and family members, what they do to protect themselves from becoming infected, the lessons they learned about themselves in the pandemic, and what colleges need to know to better understand student needs, among others. Using qualitative methods, we conducted a thematic analysis (28–31) through an iterative process with the aim of assessing how students navigated the COVID-19 pandemic and managed relationships with family members. All authors read the transcripts and independently generated a list of initial general themes in the data around COVID-19 experiences and prevention. Next, the team met to compare and discuss their lists. In this process we expanded, consolidated, and redefined our initial ideas, and then created a more-targeted master list of themes that we defined in a codebook for further exploration in the data—including the family-oriented themes described in the results section. We engaged in multiple test coding and debriefing sessions to resolve discrepancies to ensure trustworthiness of coding between authors (32). Authors then coded the transcripts via the codebook using Atlas.ti.

We presented our results with a participant pseudonym, gender identity (M, F, NB), White/non-White racial/ethnic indicator (W, NW), and month of interview. However, in this paper, we did not break down our themes along these characteristics. While our analyses did not uncover meaningful differences across these categories, participant characteristics provided context and conveyed similarities experienced by all students despite gender and racial differences of our respondents.

Results

This paper focuses on two primary themes that emerged from the data during our co-analyzed qualitative thematic analysis method: (1) Differing Perspectives and (2) Protective Actions. Within these major themes, we also identified several prominent sub-themes through this method—found below. To contextualize our findings, the MWU student body was certainly at risk of transmitting COVID-19 during the time of this study—the end of December 2020 to mid-April 2021—because of limited existing or enforceable COVID-19 prevention policies (outside of clinical settings) due to state-level politics; COVID-19 prevention efforts were consequently limited on the MWU campus. Most students in our sample were employed at least part-time, mainly in service sector positions too (such as at restaurants, department stores, or grocery stores), with only a few having worked in a hospital setting at any point since the onset of the pandemic. Nearly all students lived away from their parents and grandparents during the academic year—when this study took place. Generally, the results indicate that students undertook best practices to prevent COVID-19 transmission but doing so took an emotional toll on them.

Differing perspectives

The sheer difficulties of maintaining family life amid the global pandemic led to contention over views of how to sustain relationships. Some students expressed concern over how their family members were taking less COVID-19 precautions as them—due to political, regional, or otherwise inexplicable reasons. Other students described their family members going above and beyond best preventative practices which raised students' anxieties about the pandemic.

Politics

The constantly changing, polarizing, American political debates about the severity of COVID-19, mask mandates, and social distancing contributed to intra-family differences in protective practices. Family members who participants identified as politically conservative—which was substantial in the conservative-leaning state that our research was based in—were most at odds with students:

> It is a point of contention between my stepdad and I. My stepdad is very conservative and is on the like, 'we don't need to wear masks,' kind of a train. I don't know how my mom deals with it … but I think he's starting to come around (Ana, Female, NW, Feb2021).

While Ana was slightly optimistic about her father, other students, like Jasmine and Rebecca, were not and depicted serious arguments with their parents. Political-based divisions within families, over COVID-19 prevention, were not trivial; irreconcilable differences in opinion between students and parents led to painful conversations:

> My parents live ten hours away … in Texas. And Texas, especially right now, is not the best place for the pandemic, and throughout this whole thing has been a fiasco. I feel like our relationship has been kind of strained a little bit. I went home a few weeks ago for my brother's senior night and ended up yelling at them for 45 minutes about not following COVID practices properly. And so, that coupled with last summer, when everything was happening with Black Lives Matter as well as the pandemic—a lot of tension there … just because they have a 'difference of opinion,' as they put it, on a lot of the science, which is kind of annoying (Jasmine, F, W, Apr2021).

On a few occasions, these intra-family divisions spilled out in public spaces. In Rebecca's case, she could no longer hold back her true feelings about her dad's COVID-19 choices:

> I worry about my dad, who's a paramedic, who's constantly exposed to it. Doesn't always take proper precautions when he's not working, which I find very interesting … I'm from [a small town], which is like 20 miles west of here … A lot of people that think all this is a hoax. And my dad does lean conservative … He went to Walmart without a mask, and I was trying so hard to not yell at him, but I yelled at him. I was like, 'What are you doing? I'd rather you not die. Thank you' (Rebecca, F, W, Jan2021).

Cognitive dissonance

Not all family members' and students' discordant views were based on politics; these other differences were inexplicable, which perplexed and frustrated students. Lauryn (F, NW, Jan2021) could not reconcile her mom's educational attainment and belief in misinformation as she described, "A lot of it I hear from my mom, and she is a scientist, but she is also on WeChat a lot … a lot of misinformation gets spread around. We are like 'mom you are a researcher; you should know this!'" This cognitive dissonance was surprising to Lauryn because of the perception that scientific training and COVID-19 best practices adherence were congruent with one another. Grace (F, W, Jan2021) witnessed this cognitive dissonance in her sister, who also attended MWU. They were both exposed to the same campus and community COVID-19 prevention messaging, but Grace's sister generally disregarded safety measures for no apparent reason:

> You know, she was seeing small groups of people, but those people were seeing other people, so the circle got larger … I stopped hanging out with her just because I wanted to be safe and Thanksgiving break was coming up. I had a conversation with her. I was like, 'You know, you're going home to mom and dad. They're at risk, you know?' She was like, 'Oh, I'm being fine. You know, whatever.' And then she comes home for Thanksgiving, and she tests positive for COVID …

It remains unclear whether the intra-family feuds arising from not following public health guidelines persisted, but respondents' passionate descriptions of these exchanges suggest fundamental differences that continue to divide Americans as the pandemic progresses.

Misunderstood messaging

There were enough instances of frustrated students whose parents were perceived to go too far above and beyond best public health practices, to warrant a theme. However, these differences were not based in politics but disagreements over how best to prevent COVID-19 transmission.

When at home with his mom, Alex (M, NW, Mar2021) described her as "going crazy and we'd disinfect all her groceries before coming in and stuff. But like, once I came back to MWU, I did not do all that." Grace (F, W, Jan2021) also described her dad—who has some health issues—as "crazy" because "he does not leave the house … Whenever we are around him, he's like, 'Stay away from me.'"

In another example, Alexis (F, W, Jan2021) understood her family's source of reasoning for being so cautious in the pandemic, but implied she was not as strict as them:

> My family like I said—my dad being a doctor—since the beginning of the pandemic we have taken it really seriously. I think my mom was wanting to wear a mask before it was the thing to do. People would look at her weird in the store because no one thought that was what you were supposed to do at the beginning of the pandemic, but we did that early because of my dad's knowledge. My family has always taken it seriously. My dad's parents have only done curbside getting food or groceries. They have really sheltered in.

Theo's (M, NW, Feb2021) mom went as far to put an end to his pursuit of employment by saying "no, you cannot get a job. You're going to get COVID and you are going to bring it here or you are going to give it to all of us."

Students who were in these situations may have been annoyed at their family members, but these exchanges conveyed that students' and their families' influences on one another were complicated and multi-directional.

Protective actions

Students discussed their prosocial behavior and attitudes, i.e., the desire to protect others, taking two primary forms: limiting visits or conducting visits at a distance or virtually. Even though many had relatives who worked in health care or other high-exposure jobs, students perceived their potential exposure at college as high and did not want to be the one to bring COVID-19 "home." To ensure that their loved ones—and themselves—stayed safe and healthy, they only reconsidered these behaviors once a vaccine was available.

Limiting exposure

Nearly all our respondents took proactive steps to reduce the risk transmitting COVID-19 to their families by limiting how many times they physically visited throughout the year. Jeff (M, W, Mar2021) took a hardline stance and would not even see his grandparents when visiting home. He made this decision out of an abundance of caution "because me being a college student, I'm exposed way more. Me at work, I could be exposed and not know it." He saw his risk and potential for exposure as greater than that of his grandmother. This delay in seeing loved ones so as not to infect them sometimes came with a heavy price. Grace also did not visit her grandparents, as she explains, "Oh, I was saying both my grandmas, I have not seen them in a year. One of my grandmas actually passed away and that was difficult because I had not seen her in a long time." (Grace, F, W, Jan2021).

Even nearby siblings were avoided by some due to common exposure risks. Lucas (M, NW, Mar2021) justified his distance from his family by saying, "I just do not know where they have been. They do not know exactly where I've been. We've been at school with all these other university students. So, neither one of us can say without a doubt that we are completely clean."

Social distancing and virtual visits were not necessarily easier, as students implied some sadness and concern with this approach. Jordyn's (F, W, Mar2021) somber tone when describing Christmas was emblematic of the feelings of many students. She explained, "we sat outside with masks and exchanged gifts with my grandparents. That was all we did. I have not really seen them in a while."

Over the semester in which the interviews were conducted, the COVID-19 vaccine became increasingly available to older and immunocompromised individuals and then to the general public. Over this period, we identified a change in optimism regarding visits with older family members and potential future visits. Madison (F, W, Apr2021) summed this feeling when she stated:

> So, my family was really worried about my sister getting it, because she has viral-induced asthma that's pretty bad. But she was able to get the vaccine. She got a referral from the doctor to go get it. That was a big thing. My grandparents, obviously, but they both had the vaccine. You know, so, they're a little bit less worried now, but definitely before they got the vaccine, they were all very concerned about getting it and passing it to other people.

Madison and others felt that their choices opened a bit more and their guard relaxed when those they worried about had access to vaccines, and thus had more protection if they were to get COVID-19.

Still, taking significant actions to protect family members at times came at a cost to relationships—some more outwardly evident than other, particularly when the person did not understand the motivation for staying separate. Rebecca (F, W, Jan2021) noted that the pandemic "has put a strain on some of my relationships, particularly with one of my family members who was very upset that she could not see us for Christmas. It is like, 'I know that you have not been taking this seriously, and I love you, and I'm happy to schedule a Zoom call with you, but I'm not going to see you in person.'" As we show in the next section, differing levels of "taking [COVID-19] seriously" impacted the ways that students felt about relationships with their families.

Twinges of conscience

MWU student participants made it clear that they embraced protecting their immediate and extended family members from COVID-19, especially those in ill health. Underscoring all these were students' worries, fears, and guilt of potentially transmitting COVID-19 to relatives given the high risk of exposure that students faced on campus. Given the news in the early days of the pandemic that older persons were especially at risk, students were particularly concerned about infecting their grandparents. Madison (F, W, Apr 2021) described her worries about getting COVID-19, not just because of her own health, but because of concern for her grandparents, "I was worried about others getting it … My grandpa has heart issues … my grandma broke her hip over the winter." Similarly, Sebastian (M, NW, Mar2021) was concerned for his grandparents and parents—who live together—because in mid-March 2021 "none of them ha[d] gotten the vaccine yet," so he worried about the consequences of them getting sick.

For others like Isla (F, NW, Feb2021), the stakes were, arguably, even higher:

> My dad has one kidney, asthma, and he works in the healthcare field. My mom also works in the healthcare field. My stepdad has a horrible heart. My sister has an autoimmune disease. We have a lot of things going on in the family. During the summer I was very worried about giving COVID to my family. During the first semester I wanted to go back home, and it was difficult for my parents to tell me no that they couldn't have me home until winter break … it is hard to not go home when I want to and hard to be so cautious.

While Isla thought it was important to protect her at risk family members, it was challenging for her that being cautious meant not being able to see them.

Students prioritized their family members' health concerns over their own. Shawn (NB, NW, Apr2021) indicated where his concerns lay when saying "I'm not even that concerned with my health. I'm just concerned with passing it to my mom, dad, and my niece. Because even though they have taken precautions too, I interact with them the most when I go back home."

Students' actions were often spurred explicitly by the imagined guilt that would be felt if they infected their families. This duty and potential guilt were enough to keep students away from family members, even those who live alone and wanted the social connection of visiting family; Courteney (F, W, Jan 2021) asked, "What if I have it and I do not know, and I end up giving it to her, and things like that?"

Alexis (F, W, Jan2021) shared how stories her father told her made her worry about being the one to infect her family members. She said,

> My dad is a doctor … he saw some patients die because their children brought COVID to them and so I was kind of worried about that—seeing my grandparents and being the one that would bring COVID to them. You know? That has been my biggest concern over time.

Ashley (F, W, Apr2021) conveyed an even heavier form of guilt, due to the size of the town her mom resides in she "would be worried about getting COVID, going home, passing it to my hometown, because we are not a very big town. Like, if my mom got it, the rest of our community would, too." This sense of being bringing COVID-19 home weighed heavily on students during the 2020–2021 academic year, making them make different choices than they would have otherwise.

Discussion

At the time of data collection, our study was (and continues to be) novel because it emphasized the role of students within their extended families in navigating the COVID-19 pandemic. Most studies of college students' health have focused on depression, stress, and limited physical wellness routines amid massive career uncertainty (33–39). Although such studies are undoubtedly important, the exposure to evidence-based policies and discussions of COVID-19 at institutions of higher education gave students a unique perspective on the pandemic; this infection prevention information was transmitted to extended family members during a time of disinformation and health vulnerability. Thus, the key role of college students within their extended families ought to be better understood. Therefore, our work is an important contribution to this field.

Our findings suggest that the students who participated in our research understood the gravity of the pandemic, even in its early stages. For the most part, students were engaged in a myriad of COVID-19 risk mitigation strategies that they thought about and acted upon in relation to their families. Some students seriously worried about family members not taking the virus seriously enough, and for some this even led to strained relationships. Sometimes when comparing their own strategies with their families they saw their families as over-zealous, but few thought risk mitigation was unnecessary. To manage their own worries about family members, students took practiced social distancing and limited in-person visits, especially with respect to their grandparents. Students' actions were not only self-serving but also rooted in the greater good of public health; prosocial behavior was on display.

Our research supports and builds on the limited existing research on how families protected each other from COVID-19 infection early in the pandemic. Overall, it was not surprising that students genuinely cared for their family members' well-being and took actions to prevent COVID-19 transmission. However, the extent to which students pleaded and negotiated with parents to improve their prevention methods—rather than simply estranging themselves from their parents—implies that "blood" is indeed "thicker than water;" supportive family ties in times of health crises have rarely been as stringently tested in prior work with less contentious (though no less serious) prevention/treatment discussions around vaccinations and diseases (12–14, 17, 18). With their grandparents, though, students faced the moral dilemma that family members were documented to have faced early on in the pandemic—balancing the benefits of visiting and interacting with potentially frail individuals to show support and boost morale, or keeping away and not risking transmitting COVID-19 to the older family members (21–23). The student participants took strong precautions in avoiding contact with their grandparents but implied regret and sadness, as found elsewhere (24), in doing so because these self-imposed restrictions came at the expense of maintaining or building upon such important relationships. The detailed recollection of COVID-19 conversations provided by participants offers in-depth, previously unidentified, insight into the ways in which families grappled with the major, life-altering, shock of a global pandemic.

Based on our analyses, it appears that the parents, not grandparents, of students, mostly from Generation X—those born after the Baby Boomers but before Millennials—were the primary source of COVID-19 contention. The parents of young adults are a sizeable and possibly key demographic whose attitudes and behaviors could be changed regarding public health best practices; we found no discussions of contentious discussions where students' strongly encouraged grandparents to engage in best prevention practices, compared to parents, implying that grandparents espoused similar views on pandemic health risks as students did. We can only speculate about the mechanisms leading to these results, but the oldest generations of Americans experienced major public health crises, including the polio epidemic, which could have influenced their behaviors. These findings push the existing literature which found that Millennials and those in Generation Z were more receptive to COVID-19 information (and misinformation) online, even if

Generation X and older were more receptive to COVID-19 vaccination in general population studies (40–42). When considering MWU's location in the Midwest, in a state with little political appetite to impose stringent public health policies, college students could be a practical means for spreading information and adopting practices that could mitigate the spread of COVID-19 and other viruses. Systemic, multi-institution research is needed to see if these results are robust. Larger public health initiatives could then target the broader population by involving students as messengers.

Our study has important limitations. First, it is unknown whether this prosocial behavior reflects all students' perspectives at MWU even though we acquired a diverse sample of students from a larger, stratified randomly sampled student population. Of course, variation across universities within and between states is unknown too. Second, there is likely selection bias among those who participated in this qualitative study—by indicating their interest in doing so from the prior *MWU Study of Seropositivity and Risk for SARS-CoV-2 and COVID-19* survey—compared to those who opted-out or never participated in the prior study to begin with. Participation could be a proxy for willingness to acknowledge and discuss the realities of the COVID-19 pandemic—leading to a sample of the most proactive individuals and masking broader differences across demographic characteristics. Third, we cannot identify if social desirability influenced participants' responses. Participants may have altered their responses regarding COVID-19 preventative actions to present themselves as engaging in best practices and doing the most they could to protect family members, with the purpose of presenting oneself to the interviewer as someone practicing socially acceptable pandemic behavior. Nonetheless, these data offer an important vantage point into the range of students' mindsets in the throngs of the pandemic—students were generally responsible public health stewards, not liabilities who focused on partying above all else, as was depicted early on.

Students in our study generally engaged in best COVID-19 preventative practices and our detailed data convey the important role that students played in their extended families' health decisions during the pandemic. We hope, in the interests of public health, that our students' perspectives on preventing COVID-19 infections are, in fact, widespread and representative. This would bode well for future American public health initiatives around subsequent COVID-19 variants, influenza season, and future pandemics given the prevalence of young Americans who attend college and their dual relationship with the towns they temporarily reside in and their permanent homes where their families live.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the TM (tyler.myroniuk@health.missouri.edu).

Ethics statement

The studies involving human participants were reviewed and approved by the University of Missouri Institutional Review Board Protocol #2028427. The patients/participants provided their written informed consent to participate in this study.

Author contributions

TM, MT, and ID: conceptualization, data curation, formal analysis, investigation, methodology, software, writing—original draft, writing—review and editing. ES: conceptualization, data curation, formal analysis, investigation, methodology, software, writing—original draft, writing—review and editing and funding acquisition. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Adverse childhood experiences, unhealthy lifestyle, and nonsuicidal self-injury: findings from six universities in Shaanxi province, China

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Background: Nonsuicidal self-injury (NSSI) is a serious public health problem. The role of adverse childhood experiences (ACEs) and lifestyle on the risk for NSSI is still underexplored, especially among college students. We aimed to investigate the association of ACEs with the risk of NSSI, and effect modifications by lifestyle among college students.

Methods: A total of 18,723 college students from six universities were recruited through a multistage, random cluster sampling method in Shaanxi province, China. The Adverse Childhood Experiences International Questionnaire was used to assess ACEs for each participant, and the Chinese version of the Ottawa Self-injury Inventory was used to assess the presence or absence of NSSI behaviors. Information about lifestyle was collected by a self-designed questionnaire. The associations of NSSI with ACEs and lifestyle were analyzed using logistic regression models. Furthermore, we constructed a combination score of multiple lifestyles and evaluated whether lifestyle modified the effect of ACEs on the risk of NSSI.

Results: The prevalence of NSSI for the past 1 month, 6 months, and 12 months was 3.8, 5.3, and 6.5%, respectively. 82.6% of participants have reported experiencing at least one type of ACEs, and participants with higher levels of ACEs (≥4) were more likely to have higher odds of developing NSSI during the past 1 month (OR, 4.10; 95%CI, 3.38–4.97), 6 months (OR, 4.76; 95%CI, 4.03–5.62), and 12 months (OR, 5.62; 95%CI, 4.83–6.55), as compared with participants with low levels of ACEs (0–1). There were additive interactions between ACEs and lifestyle. Compared with participants with low levels of ACEs and healthy lifestyle, participants with high levels of ACEs and unhealthy lifestyle had the highest odds of NSSI during the past 1 month (OR, 5.56; 95%CI, 3.80–8.31), 6 months (OR, 6.62; 95%CI, 4.73–9.42), and 12 months (OR, 7.62; 95%CI, 5.59–10.52).

Conclusion: These results suggest that ACEs play an important role in the occurrence of NSSI among college students, especially in those with unhealthy lifestyle. Our findings may help develop targeted intervention strategies for the prevention of NSSI.

KEYWORDS

nonsuicidal self-injury, adverse childhood experiences, lifestyle, epidemiology, college students

1. Introduction

Suicide is a serious global public health issue. Globally, more than 700 thousands people die by suicide every year (1), accounting for approximately 1.3% of all deaths. According to previous reports, suicide has been considered to be the second leading cause of death among young individuals aged 15–29 years worldwide (2). Moreover, reports suggest that the incidence of completed suicide among this younger age group in China has been on the rise (3). Given that individuals within this age bracket was still have a long life-cycle, further action, strengthening and acceleration of ongoing efforts in suicide prevention are crucially needed, especially in the special era of accelerate pace of life, and rapid social-economic development in China (4).

Nonsuicidal self-injury (NSSI) is defined as the deliberate direct destruction or alteration of body tissue without a conscious suicidal intent, which was regarded as a gateway of suicide behavior (5, 6). Repeated NSSI will habituate individuals to not fear physical pain, lowering psychological resistance to engage in lethal self-harm, thereby increasing the likelihood of suicide attempts. Therefore, NSSI may consequently amplify an individual's suicide risk according to the Three-Step Theory. Thus, exploring potential NSSI-related intervenable determinants is essential to reduce the prevalence of NSSI and, ultimately, to reduce suicidal behavior.

Multiple factors were identified as potential causes of NSSI, which involved genetic, biological, psychological, physiological, and other factors (7). Notably, previous clinical observations and cohort studies have emphasized the critical role of early-life adversity in the development and progression of poor mental health conditions, and the adverse childhood experiences (ACEs) were identified as a significant predictor of NSSI (7–9) and also considered to be a "toxic stress." However, most studies of the relationship between ACEs and NSSI were mainly on the basis of inpatients or adolescents, and the investigation on this issue needs to be strengthened among college students who are facing the development challenge of transitioning to adulthood (10). College students are vulnerable to external stressors during this period (10) due to peer pressure, academic pressure, and social anxiety, especially those with their own vulnerabilities and childhood adversities. In addition, many health-related behaviors (e.g., smoking, alcohol drinking, unhealthy diet, etc.) originate during adolescence and frequently lead to impaired adult health conditions (11, 12). Recent studies have provided convincing evidence that unhealthy lifestyle behaviors may contribute to both psychosocial and physical disorders (13, 14), and such lifestyles may influence each other in a clustered fashion instead of acting independently on one's health (12). But the extent to which the occurrence of NSSI can be influenced by modifiable lifestyle factors is unknown, regarding multiple behaviors as a lifestyle risk index may provide new insight into the related issue. Moreover, although people with multiple unhealthy lifestyles may be more sensitive to the adverse effects of various forms of toxic exposures (15), it is still unclear whether unhealthy lifestyle is an exacerbating factor on the association between the "toxic stress" -ACEs- and NSSI. Given that unhealthy lifestyle and ACEs were generally related to immune dysregulation (16, 17), the cumulative level of inflammation of the two drivers may have a more profound impact on the adverse health conditions. Therefore, this study hypothesizes that unhealthy lifestyle might be an exacerbating factor on the association of ACEs with NSSI.

Therefore, we conducted this study to address the associations of NSSI with ACEs and lifestyle risk index (a combination of modifiable, health-related behaviors) among college students, and to further explore the joint effect of the lifestyle and ACEs on the risk of NSSI.

2. Methods

2.1. Study design and participants

Through a multistage, random cluster sampling method, participants were recruited from universities from October to November 2022. Specifically, we randomly selected a total of 6 universities from 57 universities in Shaanxi province, China. Then, we selected approximately 2–4 classes from all the colleges and grades in each sampled university, resulting in a total of 20,165 undergraduates in 559 selected classes were invited to participate in the baseline survey and planned to follow up every semester. Before conducting surveys, each selected class has two class cadres who have received standardized training to guide other classmates to fill out the structured questionnaire using a Quick Response code (QR Code). We also set a calculation question and a choice question in the structured questionnaire for quality control. Finally, a total of 19,622 students submitted their online questionnaires. For the present study, we excluded students who failed to fill the questionnaire completely, completed in a short time (<500 s, determined by a pretest and the 1th percentile calculation), and have invalid questionnaire assessed by logic questions, leaving a total of 18,723 students included for the final analyses. All participants gave their electronic informed consent prior to participate in the study. The study was approved by the Ethics Committee of The Second Affiliated Hospital of Xi'an Jiaotong University (Approval number: 2022–248) and conducted in accordance with the principles of the Declaration of Helsinki.

2.2. Measures

2.2.1. Demographic variables

Socio-demographic characteristics including birthdate, gender, grade, registered permanent residence, sibship, parental educational attainment, lifestyle (e.g., smoking, drinking, diet, etc.), height, and weight were collected by a self-designed general information questionnaire.

2.2.2. Adverse childhood experiences

The Adverse Childhood Experiences International Questionnaire (ACE-IQ) developed by the WHO was used to assess ACEs in participants. Briefly, a total of 13 domains of adverse experiences during the first 18 years of their life were asked. There 13 domains include physical abuse, emotional abuse, sexual abuse, family substance use, family incarceration, family mental illness, domestic violence, parental death or separation, emotional neglect, physical neglect, bullying, community violence, and collective violence. Ho et al. translated the ACE-IQ and applied it to the Chinese population, suggesting a good reliability and validity (18). Overall, the Cronbach's alpha coefficient of the ACE-IQ was measured as 0.69 in the present study. In this study, a response of "ever" for each domain was coded one score, then we summed the total score of the 13 domains. The summary score of 13 domains ranged from 0 to 13, with a higher score denoting more childhood adversities. According to previous studies on the cut-off values of ACEs and the distribution of ACEs in the present study (19, 20), we then classified participants into the following three groups based the ACEs score: low levels of ACEs (0–1), intermediate levels of ACEs (2–3), and high levels of ACEs (≥4).

2.2.3. Nonsuicidal self-injury

The Chinese version of the Ottawa Self-injury Inventory was used to assess the presence or absence of NSSI behaviors. This scale was widely used to evaluate the participants' frequency of 10 items of NSSI (i.e., hitting, head banging, stabbing, pinching, scratching, biting, burning, and cutting) during the past 1 month, 6 months, and 12 months without suicidal intent. If a participant gives an affirmative answer to whether they exhibited one or more abovementioned self-injury behaviors over the past 1 month, 6 months, or 12 months, he/she was regarded as having NSSI behaviors within a specific period of time (21). Zhang et al. has shown a good reliability and validity in Chinese population (22). Overall, the Cronbach's alpha coefficient of the Chinese version of the Ottawa Self-injury Inventory was measured as 0.90 in the present study.

2.2.4. Lifestyle

Lifestyle behaviors were collected through a standardized questionnaire. As described in previous studies (23, 24), unhealthy lifestyle factors included current smoking, current alcohol drinking, insufficient physical activity, abnormal weight (obesity or underweight), and unhealthy diet. Current smokers were defined as participants who smoked one or more cigarettes during the past 30 days. Current alcohol drinkers were defined as those who had drunk alcohol at least one glass of wine during the past 30 days. Physical activity was measured by the International Physical Activity Questionnaire Short Form (IPAQ-SF), and physical activity categories include low, moderate, and high based on the standard cut off levels of calculated metabolic equivalents (METs) (25). Those who score 'high' on the IPAQ-SF mean that they meet any of the following criteria: (a) ≥3 days of vigorous intensity activity and ≥ 1,500 MET minutes per week; (b) ≥7 days of any combination of walking, moderate or vigorous intensity activities and ≥ 3,000 MET minutes per week. Those who score 'moderate' on the IPAQ-SF mean that they meet any of the following criteria: (a) ≥3 days of vigorous intensity activity for at least 20 min per day; (b) ≥5 days of moderate intensity activity and/or walking of at least 30 min per day; (c) ≥5 days of any combination of walking, moderate or vigorous intensity activities and ≥ 600 MET minutes per week. Those with 'low' levels of physical activity was participants who did not meet any of the criteria for either 'moderate' or 'high' levels of physical activity. In this study, the low category of physical activity was considered as unhealthy. Body mass index (BMI) was calculated by dividing body weight by the square of height, while underweight and obesity were defined as BMI less than 18.5 kg/m^2, and higher than 28 kg/m^2, respectively. In consistent with previous studies, unhealthy diet was defined as participants who ate red meat every day or vegetables/fruits less than daily (24). Each unhealthy lifestyle was assigned one score, and the summed score of the five behaviors was the lifestyle risk index, which also refers to the term of unhealthy lifestyle score, ranging from 0 to 5 (Supplementary Table S1) (26). According to previous studies on the cut-off values of unhealthy lifestyle score and the distribution of unhealthy lifestyle score in the present study (27, 28), participants were classified into three categories according to their unhealthy lifestyle score (favorable lifestyle, ≤1; intermediate lifestyle, 2; unhealthy lifestyle, ≥3).

2.2.5. Others

We additionally assessed the depressive symptoms using the self-rating depression scale (SDS). The SDS includes 20 items which are scored between 1 (never or very infrequency) and 4 (most or all of the time) and reflects their recent feelings for nearly 1 week. We then converted the summed score of the SDS for each participant to a standard score by multiplying it by 1.25, and the presence of depressive symptoms was defined as a standard score higher than 50 (29). The Pittsburgh Sleep Quality Index (PSQI) including 18 items was used to evaluate the sleep quality of the last month, which yields seven domains including sleep latency, duration of sleep, habitual sleep efficiency, sleeps disturbances, use of sleep medications, daytime dysfunction, and overall sleep quality. The total score of the abovementioned seven domains yields a global PSQI score ranging from 0 to 21, with a higher score (≥8) defined as sleep disorder or poor sleep quality (30, 31). Because previous studies have reported a significant relationship between social support and improved mental health conditions, the Adolescent Social Support Scale (ASSS) including 16 items was used to ascertained social support, with higher scores indicated a higher level of social support. The Cronbach's alpha coefficients of the SDS, PSQI, and ASSS were measured as 0.88, 0.85, and 0.98, respectively.

2.3. Statistical analysis

All data were implemented in R 4.0.2 software.[1] Continuous and categorical variables were presented as mean ± standard deviation (SD) and counts (percentages), respectively. Descriptive statistics were calculated for demographic variables and compared using chi-squared test for category variables while t-test for continuous variables. Logistic regression models were used to estimate the associations of NSSI with ACEs and lifestyle and to calculate the odds ratios (ORs) and 95% confidence intervals (CIs). We first ran an analysis for the association between total ACEs score and NSSI, with adjustment for gender, grade, race, registered permanent residence, sibship, parental education, lifestyle, sleep quality, depression symptoms, and social support. Then, the ACEs categories were incorporated into models to explore potential nonlinear relationship between ACEs and NSSI. Similarly, we also estimated the relationship between lifestyle and NSSI with logistic regression model. We additionally examined the effects of the combination of ACEs and lifestyle on the risk of NSSI (9 categories with low levels of ACES and healthy lifestyle as reference). The additive interaction was evaluated by using two indexes: the relative excess risk due to the interaction (RERI) and the attributable proportion due the interaction (AP) (32). The formulas of RERI and AP calculation were set as follows: $RERI = RERI_{11} - RERI_{10} - RERI_{01} + 1$; $AP = RERI/RR_{11}$. The 95% CIs for the RERI and AP were computed by simulating 5,000 bootstrap samples from the dataset used for

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[1] https://www.r-project.org/

estimation (33). If the CIs of the RERI and AP include 0 suggest no significant additive interaction. The main R packages used in this study included 'epiR', 'sjPlot', 'ggplot2', and 'forestplot'.

3. Results

Table 1 lists the baseline characteristics of the study population. A total of 18,723 (males, 34.9%) university students were included in this study. Most participants were Han nationality (97.0%), more than half were rural residents (54.0%), and 29.5% were from single child family. The prevalence of NSSI for the past 1 month, 6 months, and 12 months was 3.8, 5.3, and 6.5%, respectively. Of the 18,723 participants, 82.6% reported experiencing at least one type of ACEs and 9.8% reported experiencing at least four types of ACEs.

Students experienced various types of ACEs had higher prevalence of NSSI during the past 1 month, 6 months, or 12 months (Figure 1 and Supplementary Table S2). As depicted in Table 2, we summed the cumulated ACEs score as an exposure variable and analyzed their association with NSSI. After adjustment for gender, grade, race, registered permanent residence, sibship, parental education, healthy lifestyle, sleep quality, depression symptoms, and social support, each unit increases in ACEs score was significantly associated with the higher odds of NSSI during the past 1 month (OR, 1.23; 95%CI, 1.19–1.27), 6 months (OR, 1.26; 95%CI,1.23–1.30), and 12 months (OR, 1.30; 95%CI, 1.26–1.33). We then classified participants into three groups according to the ACEs score, to explore potential nonlinearity correlations; and results showed that participants with higher levels of ACEs (≥4) were more likely to have higher odds of developing NSSI during the past 1 month (OR, 4.10; 95%CI, 3.38–4.97), 6 months (OR, 4.76; 95%CI, 4.03–5.62), and 12 months (OR, 5.62; 95%CI, 4.83–6.55), as compared with participants with low levels of ACEs (0–1).

According to Supplementary Table S3 and Table 3, logistic regression revealed that there were significant relationships between lifestyle categories and NSSI. Specifically, compare with participants with a healthy lifestyle, those with an unhealthy lifestyle had significant increased prevalence of NSSI during the past 1 month (OR, 1.34; 95%CI, 1.05–1.73), 6 months (OR, 1.50; 95%CI, 1.21–1.87), and 12 months (OR, 1.38; 95%CI, 1.14–1.68). In addition, we observed a joint effect of unhealthy lifestyle and ACEs on the odds of NSSI that behaved in a dose–response manner; that overall odds of NSSI increased as both ACEs score and unhealthy lifestyle score increased (Figure 2). More specifically, in the multivariable-adjusted model, compared participants with low levels of ACEs and healthy lifestyle, participants with high levels of ACEs and unhealthy lifestyle had the highest odds of NSSI during the past 1 month (OR, 5.56; 95%CI, 3.80–8.31), 6 months (OR, 6.62; 95%CI, 4.73–9.42), and 12 months (OR, 7.62; 95%CI, 5.59–10.52). Additionally, we also observed positive additive interactions of ACEs with unhealthy lifestyle on the prevalence of NSSI (Figures 2 and Supplementary Figure S1). For instance, for intermediate ACEs with an unhealthy lifestyle, the RERI was 1.25 (95% CI, 0.04–2.45) for NSSI during the past 12 months, which suggested that there would be a 1.25 relative excess risk because of the additive interaction, accounting for 28% (3–53%) of the odds of NSSI in participants exposed to both intermediate ACEs and unhealthy lifestyle. Because the unbalanced sex ratio in the present study, we additionally performed a weighted model and results did not change substantially (Supplementary Table S4).

4. Discussion

In the present large-scaled school-based survey, we showed evidence that ACEs and unhealthy lifestyle significantly increased the odds of engaging in NSSI among college students. Furthermore, when examining the joint effects of lifestyle and ACEs, we found that the greatest relative increase in odds of NSSI was observed among those with high levels of ACEs and unhealthy lifestyle. The present study also provides quantitative data about the effect of the additive interaction between lifestyle and ACEs on NSSI.

There is considerable variation in the NSSI prevalence rates across different countries. A review of the prevalence of NSSI in youth per each low- and middle-income country identified in the reports shows 12-month prevalence rates ranging from 15.5 to 31.3% (34). In China, previous studies have indicated a relatively high prevalence or incidence of NSSI among youths. But most of these studies were conducted among middle-school students, while studies on the prevalence of NSSI among college students were still scarce, although this group are facing the development challenge of transitioning to adulthood and are vulnerable to external stressors during this period. In the present study consisted of six universities in Shaanxi province, China, we found that the prevalence of NSSI among college students was 3.8, 5.3, and 6.5% during the past 1 month, 6 months, and 12 months, respectively, which were comparable to the 5.5% previous reported in adults (35). However, it is lower than the prevalence reported in medical students in China. For example, Wan et al. conducted a study among 4,063 medical students in Anhui province, China, and showed a 13.4% prevalence of NSSI during the past 12 months (36). Wu et al. also presented a 9.6% prevalence of NSSI during the past 12 months in medical college students in China (37). The difference in the prevalence of NSSI reported by different studies may be related to study population, assessment tools, and locations. The present study population was sampled from students of different majors in six universities, which may overcome the limitation of the representation of selected population in previous studies conducted only in single university or only among participants of a specific major. Because the related study is still limited so far, further studies are needed in a nationally representative population.

There are increasing interests in studying the association between childhood adversities and NSSI. As shown by previous studies, childhood adversities destroy an individual's ability to appropriately regulate or manage negative emotional states, resulting in increased risk of emotional problems and extreme distress for individuals (38), and as a result, individuals may be more likely to engage in self-harm behaviors, such as NSSI. Although the association between ACEs and NSSI have been extensively studied among adolescents, investigations on this issue among college students are still limited. To the best of our knowledge, only two studies were conducted to reveal the relationship between ACEs and NSSI among college students. Siobhan O'Neill et al. conducted a small sample sized study in UK (N = 739), and their results indicated a significant relationship between high levels of ACEs and NSSI (39). Chen et al. showed that individuals with high levels of ACEs had significantly higher prevalence of NSSI among Chinese college students (N = 1,036) (40). The present study found significant accumulated effects of the number of ACEs on the odds of NSSI in the past 1 month, 6 months, and 12 months, extending the limited available evidence on the association between childhood adversities and NSSI.

TABLE 1 The baseline characteristics of the study population (N=18,723).

Characteristics	Past 1-month NSSI		*p*	Past 6-month NSSI		*p*	Past 12-month NSSI		*p*
	Never	Ever		Never	Ever		Never	Ever	
Gender, *n* (%)			0.509			0.239			0.018
male	6,290 (96.3)	241 (3.7)		6,203 (95)	328 (5)		6,143 (94.1)	388 (5.9)	
female	11,717 (96.1)	475 (3.9)		11,529 (94.6)	663 (5.4)		11,357 (93.2)	835 (6.8)	
Grade, *n* (%)			0.0017			0.25			0.03
1st	5,287 (97)	166 (3)		5,179 (95)	274 (5)		5,057 (92.7)	396 (7.3)	
2nd	4,267 (95.5)	201 (4.5)		4,214 (94.3)	254 (5.7)		4,175 (93.4)	293 (6.6)	
3rd	4,221 (96)	178 (4)		4,153 (94.4)	246 (5.6)		4,120 (93.7)	279 (6.3)	
4th+	4,232 (96.1)	171 (3.9)		4,186 (95.1)	217 (4.9)		4,148 (94.2)	255 (5.8)	
Race, n (%)			0.451			0.23			0.265
Han	17,479 (96.2)	691 (3.8)		17,215 (94.7)	955 (5.3)		16,990 (93.5)	1,180 (6.5)	
others	528 (95.5)	25 (4.5)		517 (93.5)	36 (6.5)		510 (92.2)	43 (7.8)	
Registered permanent residence, n (%)			<0.001			<0.001			<0.001
Rural	9,774 (96.6)	343 (3.4)		9,636 (95.2)	481 (4.8)		9,536 (94.3)	581 (5.7)	
Urban	8,233 (95.7)	373 (4.3)		8,096 (94.1)	510 (5.9)		7,964 (92.5)	642 (7.5)	
Sibship, *n* (%)			0.036			0.288			0.21
Being single child	5,292 (95.7)	237 (4.3)		5,221 (94.4)	308 (5.6)		5,148 (93.1)	381 (6.9)	
Having sibling(s)	12,715 (96.4)	479 (3.6)		12,511 (94.8)	683 (5.2)		12,352 (93.6)	842 (6.4)	
Maternal educational attainment, *n* (%)			0.274			0.5			0.144
Middle school or under	11,597 (96.3)	443 (3.7)		11,417 (94.8)	623 (5.2)		11,282 (93.7)	758 (6.3)	
High school	3,630 (96.1)	148 (3.9)		3,576 (94.7)	202 (5.3)		3,524 (93.3)	254 (6.7)	
College or above	2,780 (95.7)	125 (4.3)		2,739 (94.3)	166 (5.7)		2,694 (92.7)	211 (7.3)	
Paternal educational attainment, *n* (%)			0.257			0.398			0.446
Middle school or under	9,858 (96.3)	374 (3.7)		9,707 (94.9)	525 (5.1)		9,583 (93.7)	649 (6.3)	
High school	3,954 (95.8)	175 (4.2)		3,894 (94.3)	235 (5.7)		3,856 (93.4)	273 (6.6)	
College or above	4,195 (96.2)	167 (3.8)		4,131 (94.7)	231 (5.3)		4,061 (93.1)	301 (6.9)	
Sleep disorder, *n* (%)			<0.001			<0.001			<0.001
No	15,283 (97.6)	375 (2.4)		15,100 (96.4)	558 (3.6)		14,953 (95.5)	705 (4.5)	
Yes	2,724 (88.9)	341 (11.1)		2,632 (85.9)	433 (14.1)		2,547 (83.1)	518 (16.9)	
Depressive symptoms, n (%)			<0.001			<0.001			<0.001
No	16,900 (96.7)	574 (3.3)		16,658 (95.3)	816 (4.7)		16,453 (94.2)	1,021 (5.8)	
Yes	1,107 (88.6)	142 (11.4)		1,074 (86)	175 (14)		1,047 (83.8)	202 (16.2)	
Social support score, mean(SD)	67.4 (15)	59.4 (15.6)	<0.001	67.5 (15)	59.6 (15.2)	<0.001	67.6 (15)	60 (14.9)	<0.001
Healthy lifestyle, *n* (%)			<0.001			<0.001			<0.001
Healthy	3,169 (97.3)	87 (2.7)		3,141 (96.5)	115 (3.5)		3,102 (95.3)	154 (4.7)	
Intermediate	8,385 (96.8)	275 (3.2)		8,267 (95.5)	393 (4.5)		8,168 (94.3)	492 (5.7)	
Unhealthy	6,384 (94.8)	349 (5.2)		6,256 (92.9)	477 (7.1)		6,162 (91.5)	571 (8.5)	
ACEs, median (IQR)	1 (1–2)	2 (1–4)	<0.001	1 (1–2)	2 (1–4)	<0.001	1 (1–2)	2 (1–4)	<0.001
0–1	13,206 (97.9)	281 (2.1)		13,118 (97.3)	369 (2.7)		13,044 (96.7)	443 (3.3)	
2–3	3,045 (94.3)	183 (5.7)		2,950 (91.4)	278 (8.6)		2,889 (89.5)	339 (10.5)	
≥4	1756 (87.5)	252 (12.5)		1,664 (82.9)	344 (17.1)		1,567 (78)	441 (22)	

NSSI-1 m, NSSI during the past 1 month; NSSI-6 m, NSSI during the past 6 months; NSSI-12 m, NSSI during the past 12 months; SD, standard deviation; IQR, inter-quartile range; ACEs, adverse childhood experiences.

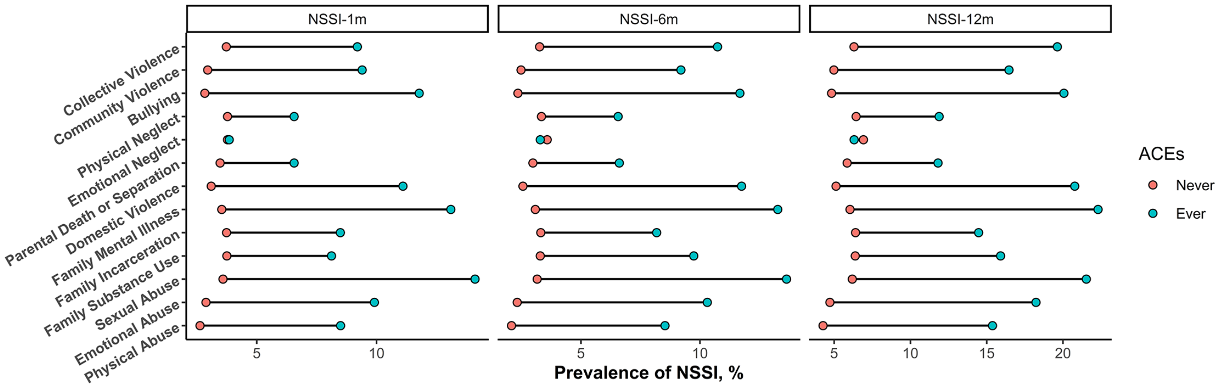


FIGURE 1
The prevalence of NSSI across different ACEs. Note: NSSI, Nonsuicidal self-injury; ACEs, adverse childhood experiences;

TABLE 2 Associations between ACEs and NSSI.

ACEs	OR (95%CI)		
	NSSI-1m	NSSI-6m	NSSI-12m
Each unit increases	1.23 (1.19–1.27)	1.26 (1.23–1.30)	1.30 (1.26–1.33)
Low levels (0–1)	Reference	Reference	Reference
Intermediate levels (2–3)	2.23 (1.83–2.72)	2.75 (2.33–3.24)	2.89 (2.49–3.37)
High levels (≥4)	4.10 (3.38–4.97)	4.76 (4.03–5.62)	5.62 (4.83–6.55)

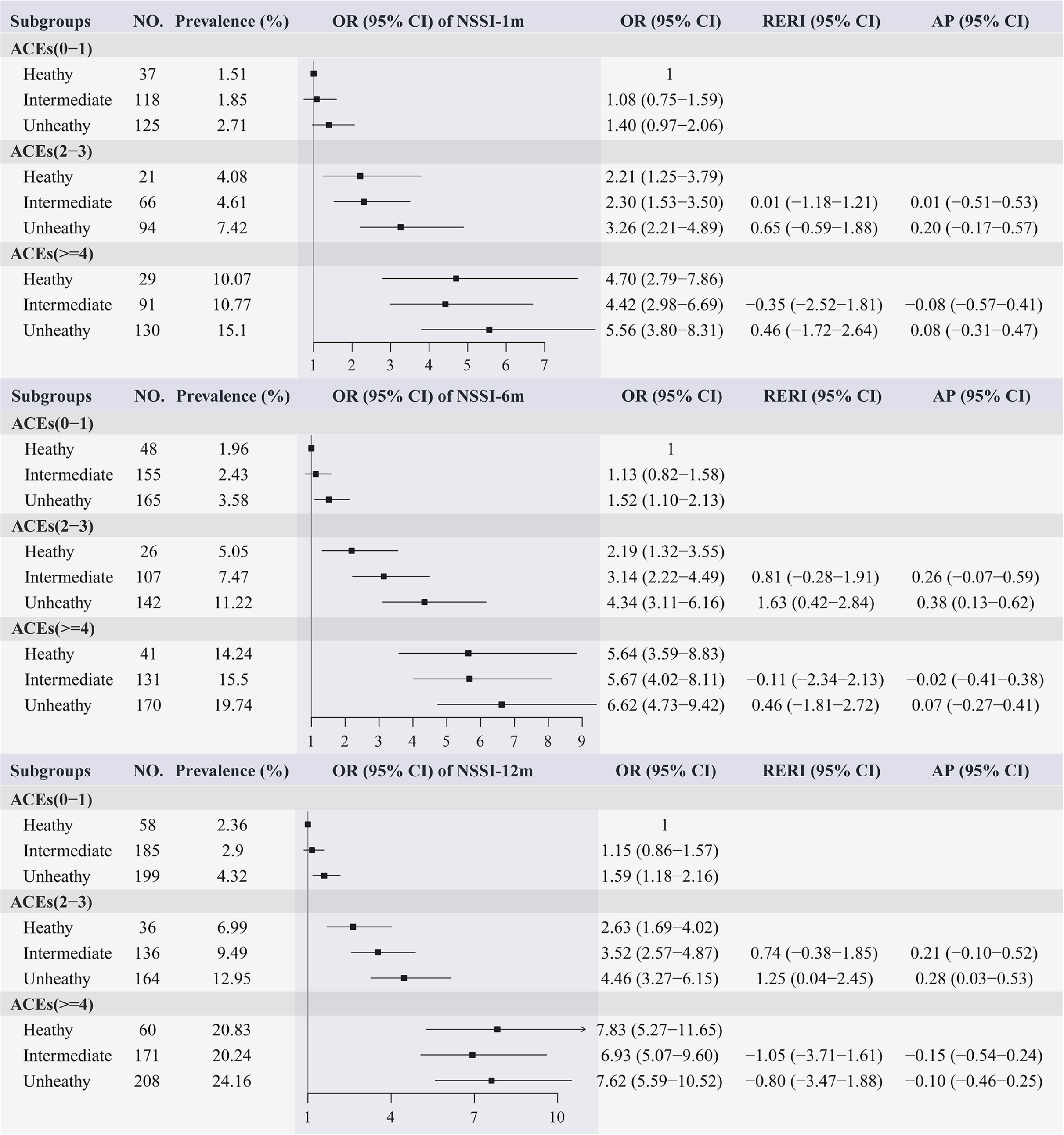
NSSI, Nonsuicidal self-injury; ACEs, adverse childhood experiences; OR, odds ratio; CI, confidence interval; All models adjusted for gender, grade, race, registered permanent residence, sibship, parental education, lifestyle, sleep quality, depression symptoms, and social support.

TABLE 3 Associations between unhealthy lifestyle score and NSSI.

Lifestyle	OR (95%CI)		
	NSSI-1m	NSSI-6m	NSSI-12m
Healthy	Reference	Reference	Reference
Intermediate	1.01 (0.79–1.31)	1.15 (0.92–1.43)	1.10 (0.91–1.33)
Unhealthy	1.34 (1.05–1.73)	1.50 (1.21–1.87)	1.38 (1.14–1.68)

NSSI, Nonsuicidal self-injury; OR, odds ratio; CI, confidence interval; All models adjusted for gender, grade, race, registered permanent residence, sibship, parents' education, ACEs, sleep quality, depression symptoms, and social support.

The causes of NSSI behavior in college students are complicated. As mentioned in a recent review (7), problem behaviors (e.g., smoking and drinking) may play important roles in the development of NSSI. Although most of problem behaviors are modifiable and related to lifestyle, no clear modifiable factors have been identified for the link between ACEs and NSSI to date. Recent studies have showed the maintenance or interventions of healthy lifestyle may be related to decreased risks of long-term physical and mental health conditions (41). A more recent study has provided convincing evidence that unhealthy lifestyle trajectory is associated with more than two-fold elevated odds for multiple domains of psychopathological outcomes over 5 years (42). However, studies on the modification effects of lifestyle on the association between ACEs and NSSI are still scarce. One of the reasons may be that most studies lacked statistical power to perform interaction tests or lacked information on potential lifestyles. For the present large-scaled population-based study, we collected detailed information on lifestyles that helps to explore possible interactions. We observed a joint effect of unhealthy lifestyle and ACEs on the odds of NSSI that behaved in a dose–response manner, and the additive interactions of intermediate levels of ACEs with unhealthy lifestyle on the prevalence of NSSI were statistically significant, which implies that individuals adopting an unhealthy lifestyle in daily life may amplify the adverse effect of ACEs on NSSI. To the best of our knowledge, our study is the first to examine the interactions between ACEs and lifestyle on the prevalence of NSSI among college students. The biologic mechanisms underlying the interaction effects of lifestyle on the relationship between ACEs and NSSI remain unclear. We speculate that college students who have been exposed childhood adversities may be particularly sensitive to negative social components of unhealthy lifestyle. Additionally, a recent study has reported a link between increased inflammatory levels and the development of NSSI (43). Given that unhealthy lifestyle and childhood adversities were generally related to immune dysregulation (16, 17), we speculate that the accumulated immune



Subgroups	NO.	Prevalence (%)	OR (95% CI) of NSSI-1m	OR (95% CI)	RERI (95% CI)	AP (95% CI)
ACEs(0−1)						
Heathy	37	1.51		1		
Intermediate	118	1.85		1.08 (0.75−1.59)		
Unheathy	125	2.71		1.40 (0.97−2.06)		
ACEs(2−3)						
Heathy	21	4.08		2.21 (1.25−3.79)		
Intermediate	66	4.61		2.30 (1.53−3.50)	0.01 (−1.18−1.21)	0.01 (−0.51−0.53)
Unheathy	94	7.42		3.26 (2.21−4.89)	0.65 (−0.59−1.88)	0.20 (−0.17−0.57)
ACEs(>=4)						
Heathy	29	10.07		4.70 (2.79−7.86)		
Intermediate	91	10.77		4.42 (2.98−6.69)	−0.35 (−2.52−1.81)	−0.08 (−0.57−0.41)
Unheathy	130	15.1		5.56 (3.80−8.31)	0.46 (−1.72−2.64)	0.08 (−0.31−0.47)

Subgroups	NO.	Prevalence (%)	OR (95% CI) of NSSI-6m	OR (95% CI)	RERI (95% CI)	AP (95% CI)
ACEs(0−1)						
Heathy	48	1.96		1		
Intermediate	155	2.43		1.13 (0.82−1.58)		
Unheathy	165	3.58		1.52 (1.10−2.13)		
ACEs(2−3)						
Heathy	26	5.05		2.19 (1.32−3.55)		
Intermediate	107	7.47		3.14 (2.22−4.49)	0.81 (−0.28−1.91)	0.26 (−0.07−0.59)
Unheathy	142	11.22		4.34 (3.11−6.16)	1.63 (0.42−2.84)	0.38 (0.13−0.62)
ACEs(>=4)						
Heathy	41	14.24		5.64 (3.59−8.83)		
Intermediate	131	15.5		5.67 (4.02−8.11)	−0.11 (−2.34−2.13)	−0.02 (−0.41−0.38)
Unheathy	170	19.74		6.62 (4.73−9.42)	0.46 (−1.81−2.72)	0.07 (−0.27−0.41)

Subgroups	NO.	Prevalence (%)	OR (95% CI) of NSSI-12m	OR (95% CI)	RERI (95% CI)	AP (95% CI)
ACEs(0−1)						
Heathy	58	2.36		1		
Intermediate	185	2.9		1.15 (0.86−1.57)		
Unheathy	199	4.32		1.59 (1.18−2.16)		
ACEs(2−3)						
Heathy	36	6.99		2.63 (1.69−4.02)		
Intermediate	136	9.49		3.52 (2.57−4.87)	0.74 (−0.38−1.85)	0.21 (−0.10−0.52)
Unheathy	164	12.95		4.46 (3.27−6.15)	1.25 (0.04−2.45)	0.28 (0.03−0.53)
ACEs(>=4)						
Heathy	60	20.83		7.83 (5.27−11.65)		
Intermediate	171	20.24		6.93 (5.07−9.60)	−1.05 (−3.71−1.61)	−0.15 (−0.54−0.24)
Unheathy	208	24.16		7.62 (5.59−10.52)	−0.80 (−3.47−1.88)	−0.10 (−0.46−0.25)

FIGURE 2
Joint effect of ACEs and lifestyle on the prevalence of NSSI. NSSI, Nonsuicidal self-injury; ACEs, adverse childhood experiences; OR, odds ratio; CI, confidence interval; RERI, relative excess risk due to the interaction; AP, attributable proportion due the interaction; All models adjusted for gender, grade, race, registered permanent residence, sibship, parents' education, sleep quality, depression symptoms, and social support.

dysregulation caused by the combination of ACEs and unhealthy lifestyle may be another plausible mechanism behind the observed interactions. However, more detailed specific mechanisms are needed to be further clarified in future studies.

Findings from the present study have important practical implications. Since these lifestyles are modifiable and adopting a healthy lifestyle is beneficial to individuals' physical health and mental well-being, from an individual's perspective, college students may benefit from healthy lifestyle to combat the hazards of childhood adversities, so as to reduce the risk of NSSI. Our findings may also be helpful to formulate targeted intervention strategies to reduce the adverse effect of ACEs on NSSI. For instance, if lifestyle-specific interventions (e.g., stop smoking, promote healthy diet, or increase physical activity) were conducted in college students, researchers are needed to further consider the adverse effects of childhood adversities and the potential interactions between childhood adversities and lifestyle. Notably, as revealed by a recent randomized controlled trial in Netherland, participants with a history of childhood adversity modified the effect of a lifestyle intervention on women's body composition (41), which might indirectly confirm the present findings. However, given the cross-sectional study design of the present study and the focus of the abovementioned mentioned study on physiological health, further cohort studies or trials in the field of neuropsychology are needed to illustrate the modification effect of lifestyle.

Some limitations of this study should be noted. First, although most available individual/parental demographic and lifestyle variables were incorporated into the model for adjustment, some residual or unmeasured confounding parameters could have affected the results. For instance, the confounding effect of the timing of childhood adversities may vary depending on sensitive period (44). Second, a self-report retrospective online questionnaire was used to access the prevalence of NSSI, which may result in recall bias. Third, the causal inference was still limited by cross-sectional study design for the present study. Last, the unbalanced sex ratio may limit the extrapolation of this study.

5. Conclusion

In conclusion, this study provides evidence suggesting that ACEs and lifestyle play an important role in the occurrence of NSSI among college students. Such findings may help develop targeted intervention strategies for the prevention of NSSI.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding authors.

Ethics statement

This study was approved by the Ethics Committee of The Second Affiliated Hospital of Xi'an Jiaotong University (Approval number: 2022-248). All participants gave written informed consent before enrolment in the study, which was conducted in accordance with the principles of the Declaration of Helsinki.

Author contributions

LZ contributed to the conception or design of the paper and drafted the manuscript. LZ, WW, YC, AA, XW, XY, YL, MW, and LM contributed to the acquisition, analysis, or interpretation of data for the work. LZ, MW, and LM provided a critical review of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1199882/full#supplementary-material

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Empowerment through participation in community-based participatory research—effects of a physical activity promotion project among socially disadvantaged women

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Introduction: Community-based participatory research (CBPR) approaches are associated with a range of positive impacts on empowerment. However, only a few studies have investigated the influence of different modes of target group participation on empowerment. The present study examined the empowerment processes and outcomes of women in difficult life situations through their participation as co-researchers in the form of Photovoice in "Stark durch Bewegung" (English: "Strong through Movement"), a CBPR project for physical activity (PA) promotion. The extent to which women's participation as co-researchers leads to empowerment was compared with other forms of participation.

Methods: The Photovoice approach consisted of three components: (1) photo task, (2) focus group interviews, and (3) exhibition of photos. It was then extended through participant observation. A total of 18 women took part in Photovoice. They took photos, were involved in four focus groups, helped in the analysis of data, and supported their exhibition. Two additional short focus group interviews in which four more women participated were conducted at the end of the project. The interview guideline was based on the SHOWeD questions proposed within the framework of Photovoice and enriched with various other questions (e.g., self-efficacy, social contacts, and community involvement). The data were analyzed based on a grounded theory approach.

Results: "Stark durch Bewegung" contributed to women's empowerment in several ways. By participating in the project's PA programs, the women reported numerous empowerment effects, such as improved self-efficacy, perceived competencies like swimming and language skills, and social networks. By participating as co-researchers, they perceived empowering processes on organizational and community levels that are comparable with other forms of participation (e.g., participation in a cooperative planning group) but also differ from them at relevant points (e.g., encouraging them to reflect on their own PA behaviors). The willingness to get involved in Photovoice was estimated to be significantly higher than in other possible forms of participation.

Conclusion: Our findings support the notion that health promotion interventions with marginalized groups can contribute to their empowerment on multiple levels when participants become equal partners in the CBPR project. Involving women as co-researchers has advantages over other forms of participation in terms of their empowerment.

KEYWORDS

photovoice, focus group interviews, grounded theory, co-researchers, multiple empowerment levels

1. Introduction

The existence of social inequalities remains a central challenge in the field of prevention and health promotion. Health-related inequalities negatively affecting socially disadvantaged groups can be observed in all OECD and EU countries (1). Social disparities also exist in participation in PA and PA promotion, which is an important area of prevention and health promotion (2–4). This is especially true for women of low socioeconomic status (SES) and their leisure-time PAs (5, 6). Given the increased incidence of non-communicable diseases (e.g., cardiovascular disease, type II diabetes mellitus) in this target group (1), women with low SES could particularly benefit from the health-promoting effects of PA. Unfavorable conditions such as living in a deprived neighborhood, multiple burdens as a single parent, unemployment, and poverty often lead to relatively poor health and physical inactivity (7).

Tailored PA programs should address factors that encourage and help women with low SES to become physically active, including the high costs of PA programs, lack of childcare, and being too far from home (8). In the past, public health interventions were often conceptualized as top-down concepts mainly driven by professionals, and thus they often missed the needs of target groups. In recent years, however, participatory approaches to co-creation have become a central component of public health interventions and health promotion research (9, 10). Community-based participatory research (CBPR) approaches aspire to equally involve the target group, stakeholders, and researchers to combine "knowledge and action for social change to improve community health and eliminate health disparities" (11). They are based on several principles, such as participation and empowerment of participants, acquiring health literacy, building on strengths and resources within the community, genuine partnership, co-learning, capacity building among all partners, applying findings to benefit all partners, dissemination of results, and long-term partnership commitments (12, 13). CBPR focuses on and addresses the factors identified that hinder women from the target group from engaging in PA.

In CBPR, the extent of participation, as a key element in these concepts, is further described with different continuum models (14, 15). For example, Balazs and Morello-Frosch's (15) continuum ranges from community members being research subjects to becoming research partners. In all models, a true partnership among target group members, stakeholders, and researchers is a crucial element and ideally relates to all phases of the research process. In this context, *co-creation* is an umbrella term to describe stakeholder engagement in different research and program process phases. It includes various modes of participation, such as co-planning, co-implementation, and co-research (9). Achieving a balance between research and action toward health equity is the gold standard (15). However, some authors question whether community participation in CBPR is necessarily a means to empower communities (16). Significant differences in stakeholder engagement in CBPR projects, ranging from full participation to no participation, were identified (17). Participatory research demands a great willingness and readiness from the participants to expose themselves to their own opinions, experiences, and personal views of the situation and to share power with the participants (18).

Photovoice is a CBPR method in which people are invited to participate as co-researchers and document their lives, take responsibility for how they want to present themselves, and describe their situation and living environment with accessible and easy-to-handle means (e.g., mobile phone). The theoretical framework of *Photovoice* derives from the principles of documentary photography, feminist theory, and the empowerment approach according to Paolo Freire (19, 20). The photos taken by members of the target group and brought into the research process challenge the researchers to look at the world through the same lens as the photographer (21). Furthermore, the method allows people to engage in dialogue with other stakeholders (e.g., policymakers) and advocates for change in their communities. It compensates for the existing language difficulties of target groups and supports a participatory empowerment process (22–24). The main difference between *Photovoice* and other photo-based research approaches, also known as *photo-elicitation* or *photo-interviewing* (25), lies in (a) who takes the photos, (b) the intention to use the photos to initiate actual change, and (c) the active participation of the interviewees in possibly all phases of the research process. Since its introduction through Wang and Burris (23), *Photovoice* has been used in health promotion to explore the views of different vulnerable groups. These include, for example, children and youth (24), people with disabilities (26), homeless people (27), residents of nursing homes (28), and women in specific life situations such as low-income, single-parent, immigrant backgrounds, and so forth (29, 30). In promoting PA, *Photovoice* was mainly used with children and adolescents, people with disabilities, and older people to investigate their attitudes, opinions, and factors that may hinder or promote their PA. Regarding socially disadvantaged middle-aged women, few *Photovoice* studies on PA and PA promotion (31, 32) concerning barriers, beliefs, and resources exist so far. Despite careful and in-depth analysis of literature databases, we could not find any studies in German-speaking countries.

One fundamental principle of CBPR is to promote processes by which participants gain more control over their lives (13, 33). Health promotion programs that focus on participation are associated with several positive elements of *empowerment* (34, 35). Different uses and meanings of empowerment can be found in the literature (36, 37). However, the view of Rappaport (1984), who defines empowerment as "a process: the mechanism by which people, organizations, and communities gain mastery over their lives" [(38) cited after (39), p. 43], is the one that is often shared in public health literature (39, 40). Different authors propose multiple levels of empowerment: individual, organizational, and community. From a theoretical perspective, it is also critical that a distinction is made between empowerment processes ("empowering") and outcomes ("empowered") so that the mechanisms through which empowerment supports and creates health are understood (39, 41, 42). At the same time, the latter differentiation leads to various understandings of the concept of empowerment (37). Zimmerman's empowerment approach considers processes and outcomes on all three levels and is commonly used. In the following, we refer to these considerations and to "empowerment outcomes on the individual" level and "empowering processes on the organizational and community levels" (39). Our approach has been used in previous studies examining the empowerment of socially disadvantaged women through their participation in PA promotion (43, 44).

According to Zimmerman (39, 45), "empowerment outcomes at an individual level" may be classified into three components: intrapersonal, interpersonal, and behavioral. Intrapersonal refers to people's self-image, expressed through ideas such as self-efficacy, perceived competence, and their motivation to be in control of their lives. Interpersonal relates to the understanding and feelings people have toward their community and related sociopolitical issues as well as to how people use analytic skills to influence their environment. Behavioral empowerment outcomes indicate the actual level of people's involvement in formal (organizational) and informal (community) activities (e.g., informal groups and/or networks). At an "organizational level, empowering processes" offer opportunities for people to participate in organizational decision-making. By contrast, at a "community level," activities that can lead to empowering processes include getting improved access to community resources, open government structures, and tolerance for diversity. However, given that empowerment by its very nature embraces the need to listen to the voice of the people, Zimmerman (39) highlights that the exact meaning of empowerment and the processes for bringing it about can only truly be understood in the context of its use. Nonetheless, the three components outlined are useful in classifying the types of activities that might be relevant.

A recent review showed that health promotion interventions positively impact the empowerment of different target groups (35). At the same time, it was concluded that most studies examine the effects at the level of individual empowerment while studies at the organizational and community empowerment levels are less common. Studies investigating the outcomes of different levels or modes of participation in CBPR projects are rare (17). Using the example of CBPR interventions to promote PA (1), it can be shown that perceived empowerment outcomes and processes depend on the mode of the participants' participation (43, 44). Women who participated in the planning (co-planning) and implementation (co-implementation) of the project reported broader and multiple empowerment effects compared to those only involved in PA courses. However, program outcomes related to the participation of the target group as co-researchers have not yet been considered and compared.

The following primary research questions were addressed based on the abovementioned theoretical underpinnings.

- What empowerment processes and outcomes were perceived by women in difficult life situations through their participation in a CBPR project for PA promotion?
- Which empowerment processes and outcomes may be attributed to the participation of the women as co-researchers?

2. Materials and methods

2.1. CBPR project "Stark durch Bewegung"

"Stark durch Bewegung" (English: "Strong through Movement") was a community-based participatory research project to promote PA among women in deprived and difficult life situations[1] in a suburb of the city of Augsburg, Germany, which had high migration rates (67.7%). The community of health insurance companies in Bavaria funded the project from April 2019 to September 2022. The project used a participatory approach to involve the women actively in planning, implementing, and evaluating tailored PA programs and PA promotion activities. Other stakeholders involved in the project were Augsburg's city council members, city council staff, and representatives of various community associations like sports clubs. At the beginning of the project, a project office (a position with coordination tasks) was set up in the Health Department of Augsburg. The office was responsible for coordinating the project activities and was financed by the health insurance companies. To monitor and evaluate the project, a position for a research assistant was also implemented at the university.

A significant challenge in participatory work with vulnerable groups is their equal engagement in the *co-creation process*, not least because of language issues and problems of power imbalances (9). Power must be shared to empower marginalized groups (46, 47). For this reason, a cooperative planning approach was chosen for *project planning* to involve women as *co-planners*. This approach ensures the effective involvement of all relevant stakeholder groups (target group, researchers, and other stakeholders), for example, by including a qualified moderator accepted by all participants and agreed-upon communication rules based on respect and equality. Furthermore, the ideas, priorities, and measures are formulated jointly throughout the planning process, with the moderator ensuring that everyone's wishes are heard and equally included (47). Therefore, 6 target group women and 10 other stakeholders (city council members, city council staff, representatives of various community associations like sports clubs, exercise instructors, and staff members of the University of Augsburg) participated in the cooperative planning group, together with the researchers responsible for the project ($n = 3$). The cooperative planning group was led by a moderator, a staff member (research assistant) of the University of Augsburg, especially to assure equal engagement in the discussions of the participating target group. To support equality, the number and length of the individual participants' speeches were likewise recorded and reported back to the moderator after each session. These details were considered in the next meeting to ensure the most equal involvement of all participating groups. Planning followed a standardized protocol (with the main issues of setting a planning goal,

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[1] According to the BIG project, a project for the promotion of PA among women in difficult life situations, these women were defined as those who are unemployed, have low income or receive social welfare, have low educational attainment, have a migration background, or are single mothers (37).

reviewing the ideas of the participants, prioritizing ideas, and developing actions) in seven planning group meetings.[2] These meetings served to discuss the actions that need to be taken to improve the opportunities of women in difficult life situations to participate in PA.

Cooperative planning took place from October 2019 until June 2020, which was interrupted by the first COVID-19 lockdown in Germany. Commonly developed PA courses should have started in September 2020, but due to the second lockdown, the beginning of the programs was postponed to spring/summer 2021. Finally, the courses started online in May 2021 with 10 participants and then face-to-face in July 2021 with 41 participants in the first block of the programs (one block lasted 12 weeks). Owing to the long break, almost all women already recruited for the programs in September 2020 had dropped out and new participants had to be found. There were 75 and 111 women who participated in the second and third blocks, respectively (Table 1). Based on the wishes of the target group in the planning phase, four kinds of PA programs were realized in July 2021 after the Corona break: Moving in the Water, Walking to Running, Pilates & Dancing, and Self-defense/Fit-Bo. There was a high demand for the programs, especially for the water courses. Except for the course "Walking to Running," which took place outdoors, each course was limited to a maximum of 15 participants by the insurance companies, following their prevention guidelines.

The following framework conditions highlighted as important by the women in the cooperative planning process were also implemented: availability of childcare, close to home, no cost, and PA programs for women only (safe space).

During project implementation, the city officials rejected the intended employment of the target group women on a mini-job basis to support the project office manager (co-implementation) in the Health Department of the city of Augsburg. Nevertheless, the women were still able to participate on a more informal basis, if they desired, in this phase: they helped with participant recruitment, assisted exercise instructors with participant lists and Corona testing, were involved as PA instructors, and helped to organize meetings besides training (breakfast together), among other activities. For most of these activities, they received monetary compensation.

Women used a *Photovoice* approach to serve as co-researchers (co-evaluation) in the project evaluation (22, 48). The *Photovoice* approach was based on a standardized process. Participating women took the photos (Step 1), interpreted the photos together in focus group discussions and a separate evaluation session (Step 2), and shared the themes identified with policymakers and other stakeholders by organizing and holding an exhibition together with the researcher (Step 3) (22, 49).

We used the *Photovoice* approach and participant observation to collect data based on the above considerations.

2.2. Data collection

A three-component strategy was applied to implement *Photovoice* for data collection, which was extended by participant observation (fourth component).

TABLE 1 All physical activity programs within the project period with numbers of participants.

Sports courses	Block 1 July 21–August 21	Block 2 October 21–February 22	Block 3 March 22–July 22
Water 1	7	12	13
Water 2	–	13	16
Water 3	–	–	18
Pilates 1	13	23	20
Pilates 1	–	–	18
Walking	9	12	10
Fit Bo	12	15	16
Sum	**41**	**75**	**111**

(1) The *first component* was to give participating women a photo assignment ("Take photos of your everyday life around the theme of PA and sports") to enable them to collect data relevant to them. The researcher invited all women joining the PA courses in person and via WhatsApp to participate. The *Photovoice* participants were asked to use a smartphone camera to capture about 8–10 photos within one week. They could send them to the researchers via WhatsApp or Wetransfer.com. All the women chose WhatsApp since it is their daily communication tool.

(2) During subsequent focus group discussions (*second component*), the target group members had the opportunity to collectively interpret their photos, examine their personal views compared with other participants, and discuss them in critical dialogue. Using the photos as stimuli, the focus group discussions were also based on an interview guideline to enable a similar process across the four different focus groups. The guideline consisted of three sections: (a) opening phase, (b) questions about the photos, and (c) expanding questions. In the *opening phase*, the participants were welcomed, and the procedure and general conditions (e.g., recording, anonymity) of the focus group discussion were explained. The *questions about the photos* were based on the SHOWeD guide developed by Wang and Burris (49) and adapted to our context. The opening question was formulated openly to initiate a free conversation without raising expectations. The first question was: How was the photo task for you? Moreover, this phase was based on the following questions: What do you see here? What is really happening here? How does this photo relate to your lives? What is essential for you in this photo? What meaning does the picture have for you? The expanding questions were focused on the following areas: purpose and special features of the PA courses, changes in PA behavior, general changes (e.g., nutrition, self-efficacy, social contacts), cooperation with partners (exercise instructors, city of Augsburg, University of Augsburg), wishes, and suggestions for improvement. With the women's consent, each interview was audiotaped and wholly transcribed. Data analysis was based on a grounded theory approach, and all group interviews were conducted by sequence analysis (see data analysis section below). After a first evaluation by the researchers, the women who participated in the group discussion were asked to join a separate evaluation meeting to discuss, improve, and expand the preliminary results. They all showed up, and another

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[2] Session 1: Getting to know each other and Brainstorming, Session 2: Prioritization, Sessions 3–6: Action planning, Session 7: Adoption of a catalog of measures.

seven women joined the group to share their views and opinions on the project.

(3) At an exhibition, selected photos and interview quotes from the group discussions and a video produced especially for the occasion were presented as a *third component*. All women participating in the group interview were asked if they would like to show their photos and interview quotes at the exhibition. To ask them, the researcher joined all PA courses for two weeks to reach all participants, all of whom ($n = 18$) agreed. For the video, again, all women in the project (75) were asked by the researchers during the PA courses and via WhatsApp, in German, Turkish, Persian, and Hebraic languages, if they wanted to be a part of it. Fifteen of the women agreed to participate. The video showed 1–4-min sequences from the participating women telling who they are and what the project means to them. The video recordings were taken shortly after the PA courses, so no extra effort was required from the women. The exhibition aimed to sensitize relevant decision-makers in Augsburg to the women's situation and share the project's benefits with them and the public. Additionally, it should show that the project not only opens an avenue to improve mental and physical health but can also create cultural openness and social integration, promote democracy, start an empowerment process, and open an opportunity for dialogue. All women participating in the PA courses were invited by the researchers at the courses and via WhatsApp to contribute actively to the design and implementation of the exhibition. A total of 10 women followed the invitation, 8 of whom had already participated in the *Photovoice* study. The exhibition took place in a special showroom in the city center of Augsburg and lasted 12 days (July 12–23, 2022). At the opening ceremony of the exhibition, all women participating in the project, the exercise instructors, stakeholder groups, politicians from various parties in Augsburg, the Equal Opportunities Officer, interested citizens, and the local press were invited. About 60 people attended the event. After the exhibition, 11 women (7 participating in the *Photovoice* and 4 contributing to the exhibition) were interviewed in short focus group interviews. The researchers asked them, "How was the exhibition for you?" They were likewise given the chance to describe their thoughts about the exhibition and the project in general. The exhibition was meant to create publicity and support a sustainable implementation within the city council structures beyond the end of the project.

(4) Besides the group discussions, participant observation took place from October 2022 to July 2023 as a *fourth component*. To enable proper documentation, the researcher joined all courses at least twice a month, from course block 1 to course block 3. During the PA courses, these observations and conversations were logged by minutes, notes, and memos.

2.3. Sample

To reach the women for the **photo task** and **subsequent focus group interviews**, the researcher actively joined all PA courses within the first eight weeks to get to know the women and build trust. Owing to COVID-19 and an announced third lockdown in Germany, the researchers decided to use this mode of data collection at an early stage of the project in December 2021 and January 2022. Therefore, the women were recruited from block 2 of the programs (Table 2). For the photo task and subsequent focus group interviews, all women participating in the four PA courses in block 2 were asked. For each group discussion, 3–5 women attended, and the duration was between 40 and 70 min. Out of 75 women, 18 agreed to participate (Table 2), 17 of whom had an immigration background. Only 1 woman did not show up. Instead, 3 additional women came to the group discussions without informing the researcher beforehand; they said they were interested in the group discussion and wanted to take the opportunity to speak German and talk to other women from different countries. Given the long Corona break, almost all women who initially participated as co-planners in the planning phase had left the project. Since a co-implementation employing a target group of women to support the project office in the city of Augsburg could not be realized, the 18 women involved in *Photovoice* were primarily engaged in the project as co-researchers.

TABLE 2 Number of focus group interviews and participants in block 2 of the PA courses.

Group interview	Swimming	Walking/ running	Pilates/ Dancing	Fit Bo/ Yoga
Number of participating women	5	5	3 (+2 listening women)	3
Nationality	5 from Turkey	2 from Turkey, 3 from Afghanistan	5 from Turkey	1 from Germany, 1 from Iran, 1 from Afghanistan

After the exhibition, 11 women (7 participating in *Photovoice* and 4 contributing to the exhibition) were interviewed in the form of **two short focus group interviews**. For the additional **participant observation**, the researcher actively joined all PA courses at least twice a month.

2.4. Data analysis

Reflexive grounded theory was conducted to analyze the data from all interviews (50). The characteristics of this theory are a circular-iterative approach and hermeneutic interpretation work. Reflective grounded theory emphasizes the importance of the researcher and the research interaction for knowledge formation.

In each phase of the research process, there was a constant interaction and analysis with the topic of empowerment, the research setting, the target group, and the two researchers themselves. After a first evaluation of the researcher (see first step below), all interviewed women were involved in the form of a group interpretation session with the researcher. They added details missing in the interviews, corrected the researcher's interpretation when wrong, and reflected on their empowerment. Language barriers were challenging as two women could not read or write and most of them could not speak German very well. Again, because we had women with different mother languages, we decided not to have a translator. During further data analysis of the researcher (see second step below), the participating women were involved on a regular basis. The researchers wrote independent memos to focus on and elaborate the thoughts and reflexive attitude. The results were compared several times. All phases were accompanied by literature research to compare and reflect the findings.

For the **data analysis, open, axial**, and **selective coding** were conducted (50): In the **first step** for all group interviews, the starting sequences were **openly coded** line-by-line to analyze and compare as many small units as possible since no categories should exist at the beginning of the process. These first findings were written down in memos, discussed, and adapted. This step added conceptual codes and notes to a manageable number of categories. At this point, it was decided which phenomenon would be observed based on its frequent occurrence, namely, empowerment. The primary type of empowerment provided the key to understanding the fundamental problems and theoretically integrated the (partial) concept found and developed. The **second step** was **axial and selective coding**. The findings were systematically ordered, related to one another, and categorized by comparing them with similar and different cases to extend, validate, and consolidate the modeling. Categories were found, invented, constructed, and elaborated only during analysis. The two researchers worked partly independently of each other, and their results were repeatedly compared. This step was carried out until a theoretical saturation degree was reached. The aim was to formulate a theoretical model of limited range, which is presented in Section 3. An overview of the resulting category system is shown in Table 3.

The following Results section concentrates on the interview quotes of the women. The presentation of the photo data would go beyond the publication's scope and will be done elsewhere.

3. Results

The women reported different effects on all three empowerment levels defined in the introduction, namely, individual, organizational, and community.

3.1. Individual level

On an individual level, the interviewees/co-researchers mentioned various aspects of perceived empowerment which cover intrapersonal, interpersonal, and behavioral aspects. *Intrapersonal aspects* refer to how people think about themselves, *interpersonal aspects* relate to people's understanding of their environment and community, and *behavioral aspects* concern people's involvement in the community.

3.1.1. Intrapersonal component

3.1.1.1. Self-efficacy

All women reported changes in **self-efficacy** through participating in the project. Self-efficacy refers to **confidence in one's ability to perform a particular behavior successfully or achieve a desired goal**.

Regarding PA **behavior, almost all women reported "being more confident in being physically active regularly", and—very importantly—they attribute their increased activity level to their initiative**.

> I move more. Otherwise, I would be at home. I would just sit in front of the TV and not do much. I'm the type who doesn't go out alone. I have to force myself. This project is excellent for me; I only have Monday and Tuesday off. Wednesday, I run. I am happy about that. In our country, they say, "I pull myself with the rope on this day." Wednesday is running, Thursday is swimming, and today is Pilates (Pilates, Woman A).

Only a few women were regularly physically active before joining the project. For example, one swim class participant was already jogging alone every day. She taught herself to run longer distances and, over the course of the project, developed the "confidence to take on the role of a PA instructor" in the program (Walking to Running) and coach the other women.

> I quit smoking five years ago. Then I started to do sports because I had gained too much weight; I had to start. It was such a short distance in the beginning, of course. First, 1 kilometer then back again. But now I can do it every day. I feel bad for not doing it (Swimming, Woman B).

Accessing adequate PA courses was an essential precondition for the women to participate regularly; the courses needed to be appropriate to their lives and settings. During the planning phase of the project, the women emphasized the importance of the courses being close to home and that women-only courses provided a safe space. In the interviews, they expressed excitement about getting such programs and thus achieving their goals. This was especially true for the participating Muslim women because, so far, there were no programs for women only and free of charge in the city of Augsburg.

> But with us, there are limits. For example, we are not allowed to mingle with strangers. Women are okay, but not the men. But since we didn't have the opportunity for a long time, we are really happy that now there is the opportunity, and we want to continue. For us, it's the first time we are getting something like this (Walking to Running, Woman B).

For non-Muslim women, these above conditions were essential aspects of their participation as well.

> That's why I don't need the gym, with all the musclemen sometimes in there or gawping at you. So I like it more that I can train by myself or with friends (FitBo, Woman A).

Some women said that the perceived effects of regular PA **positively impact their daily lives**. They experienced their otherwise rather meaningless everyday life—as they describe it themselves—with new meaning and structure. This was especially true for women whose children had just left home. Women with young children also reported effects such as enjoying the company of other women and doing something for themselves and not the children, housework, etc.

> It is so with me; I now always have programs, weekly programs, but now they are even more programmed in my life, the days and weeks. That's quite great. I have to; this day I go to sports and so

> on. That's neat, and sports are even more a part of my life (Walking to Running, Woman B).

The focus group discussions revealed differences among the women regarding their **belief in understanding the photo task**. Some women seemed and believed to have understood the photo task and were the first to speak in the group interviews. They were confident about the starting question of the interview, their photos, and how they got along with the task. These women wanted to share their pictures and experiences. This group mainly comprised women with good German language skills and sporting backgrounds.

> With photos? Yes, I took pictures when I was running and in the kitchen. And then I (photographed) my prayer rug. Because I pray

TABLE 3 Overview of the category system.

Main category	Individual level	
Subcategory	**Intrapersonal level**	
Domains	Self-efficacy	• Confidence to be physically active regularly
		• Getting access to adequate physical activity offers
		• Positive impact on their daily lives
		• Confidence to take the role of the exercise instructor
		• Belief in understanding the photo task
		• Confidence in talking to responsible persons in the city
		• Confidence in being heard by city officials
	Domain-specific perceived control	• Facing their fear of water
		• Facing daily pain issues
		• Overcoming their fatigue/depression
	Perceived competences	• Letting go of the poolside
		• Learning how to swim
		• Improving swimming techniques
		• Enhancing nutrition skills
		• Improving language skills
Subcategory	**Interpersonal level**	
Domains	Critical awareness	• Awareness of the importance of the support of the group and the exercise instructors
		• Awareness of the importance of support from the husband and/or children
	Understanding causal agents	• Understanding causal agents in the community
Subcategory	**Behavioral level**	
Domains	Social Contacts and networks	• New social contacts and networks
Main category	Organizational level	
Domains	Assisting others	• Assisting instructors
		• Assisting project coordinators & researchers
	Taking on independent tasks	• Role of a exercise instructor
		• Role of a co-researcher
	Participation in decision-making	• Involved in the development of program contents throughout the program
	Initiating decision -making processes on their own	• Initiating swimming courses
		• Expressing their needs and wishes to city officials as a primary stimulus for project sustainability
Main category	Community level	
Domains	Access to communal resources	• Access to communal spaces like public indoor swimming pools, public gyms, and exhibition room
	Sense of community	• Cultural openness
		• Women stood up for other women
	Open government structures	• Speaking • At different events in the community (exhibition, project closing ceremony, etc.)

> three times a day, I said to myself, "I'll photograph it" (Walking to Running, Woman A).
>
> I was jogging, so I took the first one (Walking to Running, Woman B).

Others seemed quite unsure or needed help understanding the photo task.

> That is, (doing) it (photos) yourself is wrong, that is so. In the beginning, I also did not understand (the photo task). But (photograph) everyday life, you wrote afterwards (Walking to Running, Woman B).
>
> I didn't understand at first, either. Then I understood (Walking to Running, Woman E).

The latter women took pictures of them doing housework, cooking, of home-cooked food, their children and grandchildren, and meeting with friends. Hence, they were initially unsure whether to show their photos to the others, as the photo task involved photographing one's everyday life around PA and sport. Throughout the interviews, they reflected on their everyday life through PA, sports, and potential barriers to participation based on the photos together with the other women. As the interviews progressed, the women received confirmation of their pictures from the group and became confident. They even agreed to show the photos at the exhibition.

> It was also an opening of the personality in such a way that we showed ourselves personally, familiarly, the way we live, or what we do, not only in writing but also through pictures. These are already personal things, what you want to show or what not to. One wanted to help the other women so they could participate. There was such a desire from the women, but there was also a demand. You show that, and then you somehow open doors and gates (Interview after Exhibition, Woman B).

During the presentation of their photos at the exhibition and their participation in the opening ceremony together with political decision-makers and other city stakeholders, a few women were strengthened because they could **talk to persons of authority in the town** and **were heard by them**.

> No, it was already good; it was a shaking up that we could say that we were also here. We are invisible in the city because we are not loud, but we are there. Society is like that; you can't just look away. You can´t ignore the refugees or the Ukrainians, or, I don't know, foreigners; they are just there in the city. You can only do something together. Side by side, it would only work for a short time. There would be big problems. And you can only be noncommittal in such groups, get to know each other, and accept and respect the others (Interview after Exhibition, Woman A).
>
> That we are taken notice of by the city, that we are also there (Swimming, Woman C).

3.1.1.2. Domain-specific perceived control

The women also reported domain-specific control effects related to perceived pain (e.g., back pain), overcoming fatigue and anxiety from water, and in general. Perceived control is defined as the belief in one's ability to control situations or events (45).

Several Turkish women talked about their **fear of water**, often triggered by negative experiences with water/swimming in the past, as most of them did not know how to swim. This aspect seemed very stressful for all women concerned, and it seemed important for them to overcome this fear. They face it, but not alone, without anyone watching, but in the presence of the group and the exercise instructor.

> Then I didn't go swimming for a year. I didn't go to the sea anymore either. Then my daughter forced me; you have to overcome your fear somehow. Why don't you go to the sea again? And so slowly, I did it again, but I always get this panic when I'm in deep water. I could swim, but I don't know where this panic comes from. It has always accompanied me (Swimming, Woman D).

One of the interviewees said she called all her family members, friends, and the researcher to tell them that she had overcome her fear of the water and could swim now. After overcoming their fears, some women even switched roles and helped other women with fears in the swimming courses. They were proud of themselves, gained self-esteem, and showed this openly to others. This outcome was especially true for Turkish women, who usually go to the beach on vacation in Turkey during the summer.

Another critical issue for the women was **daily pain**, such as back pain, intervertebral disc problems, and Achilles problems. Participating in regular PA, especially swimming, helped them manage and relieve their pain. They even reported that their pain returned when they did not participate in the PA programs of the project for a week or two.

> I also noticed my vertebrae and my neck; swimming helps a lot. I also noticed that. And when I'm in the water and feel my legs, I feel good, have no pain. Or if I stand, then I'm even fitter. But when I stopped, I noticed that I saw a pulling again (Interview after Exhibition Woman A).

Furthermore, many of the interviewed women stated that they were able to **overcome their fatigue and depression through regular PA**. They explained that they felt tired in their daily lives and experienced how PA helps them overcome this fatigue. They perceived that it enabled them to be positive and feel more energetic daily. The following quote shows the psychological importance of the project for many women. They regain control of their lives, at least for a few hours a week.

> I have less stress. I think, "Ah, Monday is swimming. Good, a little exercise is good." And Friday, I will wait until Friday. Friday is also good; I do Pilates. I refrain from thinking about so much wrong; always think good. It's good for my brain, it's good for everything and the body. And I have less back pain. Less pain in my legs too. Sport is always good. Stay healthy (Pilates, Woman C).

3.1.1.3. Perceived competencies

The women perceived that they acquired different competencies through participation in the project. Some addressed that they learned **to let go of the poolside** while others **learned how to swim** or **improved their swimming techniques** by participating in the project's swimming courses. One said she thought she knew how to swim already but found out at the beginning of the swimming courses that her technique was not good. Another woman said that learning the techniques and getting them explained in detail helped her by teaching her children how to swim, which she had not been able to do before.

> Also, in the pool, I'm just on the edge of the pool, [Name of the exercise instructor] knows. She said, "Now let go." But this fear is so big. *Interviewer*: But now you let go. *C*: Thank God, but it took a long time. For years (Swimming, Woman C).

Concerning the other PA offers of the project (e.g., Pilates and Walking to Running), the women indicated that they **felt fitter**. Specific motor competencies acquired were not articulated in their context. For them, walking means going for a walk together, talking with others in the fresh air on the riverbank about their daily lives, challenges, and questions about jobs, the German system, or educational topics.

> Well, I also think that the condition is strengthened a bit if you train regularly. So, of course, the essential requirement is there, but if you then train regularly, then it tends to stay and doesn't fall off again, and then you have to build it up again ultimately. I have already noticed that (FitBo, Woman B).

The women likewise reported the acquisition of competencies related to **healthy eating**. Although it was not an explicit topic for the semi-structured group interview, they talked about their definition of healthy food, what they try to do to stay and eat healthy, and where they buy healthy products. Almost all women took a picture of their home-prepared meals, even though the photo task was to take pictures of everyday lives in terms of PA and sports. Some did not understand the photo task. This could be taken as a sign that nutrition is essential to them. For this reason, they frequently asked the exercise instructors about healthy food and how to lose weight.

> I make so much dough stuff, börek, and stuff. Now I have fewer sweets in my kitchen. I try hard because I'm 50 years old, and my kids must learn about correct nutrition (Walking to Running, Woman B).

Most of the women with a migration background wanted and were able to improve their **language skills**. They have experienced that language skills are crucial to participation in foreign societies and to opening new opportunities. The reasons some had not previously learned German fluently were as follows: language courses were too expensive, they did not know where they could get the information, they did not have time, they were not sure that they would stay in Germany, and they would have had to learn. In their daily lives in their communities, they mostly speak their mother tongue and, therefore, German is not needed. However, as the children got older, they suddenly saw the need as they had to stay in Germany and look for a job or task. Participation in the PA programs of the project and *Photovoice* was therefore also seen as an opportunity to speak German and improve their language skills.

> We talk about what we have done and how we learn many new words. Because we also still need the language, articles, and words. Then we learn something from each other and culturally, and we ask, "Where are you from?" (Walking to Running, Woman B).

3.1.2. Interpersonal component

Over the course of the project, the women developed an understanding of the social support needed to participate regularly in PA (**critical awareness**).

In this context, most of the women stated that they could not motivate themselves to exercise independently: they needed **the social support of the group or exercise instructors** to attend courses weekly. During the project, they developed the confidence to exercise regularly. Still, the settings (e.g., women-only courses, safe space), the other women, the researchers, and the exercise instructors helped them stay in the programs. Self-directed WhatsApp groups and regular prompts also supported this participation in training. At the same time, a group dynamic and a sense of togetherness were created in the group. Different rules for participation, such as regular attendance and punctuality, were negotiated together.

> And when I have time, I only do it in the morning; it's no fun alone. I always need someone to be there. I'm that kind of person. I always have to have someone to join in, and that's very rare. There are so many girlfriends who are really lazy. But, when I say I made börek, everyone is there. But when I say let's do sports, no one is there (Swimming, Woman D).

Support from their husband or children was also seen as essential for regular PA participation. The older generation (parents and parents-in-law) seemed more critical of women's activities, especially sports. However, that also differs depending on the cultural background (e.g., Muslim).

> C: My husband and my children always say, "Mom go, go do sports."
>
> A: Yes, yes, they support. "Swim and go for a walk!" Do everything. Many Turkish women are, unfortunately, under their in-laws and mothers-in-law. And you're not allowed to do that, yes.
>
> C: Today I can't come, today it's very boring. I have to stay at home and sleep a little. And my son says to me, "Mom, please go do sports, please go. Go. It's good; sport is better. Go." Then my sister-in-law comes, and we go together (Pilates, Women A and C).

The women also developed an **understanding of causal agents in the community** and local authorities. They became aware that they had to talk about the project and publicly state their wishes and ideas to be heard. That implies that they were not seen or recognized by the city council and other city citizens, or they did not feel they were seen and heard.

> The exhibition was very nice; it was great, it was something we did. That we talk about the project and what we have done. And our voices were also heard, so lovely. And there are things like that; many women don't have opportunities. But now there is the project, more options, and many women motivate each other (…) and such a voluntary project, that's great (Interview after Exhibition, Woman G).

3.1.3. Behavioral component

Another important aspect of empowerment is networks and the quality of networks. Within the PA programs, the women could connect with exercise instructors and especially women with different migration backgrounds. Most of them have had networks within the same migration background before. Owing to their participation as co-planners and co-researchers, they could also **gain additional social contacts and networks** by connecting with exercise instructors, university members, politicians, and other involved parties and organizations.

> Then I said, then I'll join the project. You get to know the people, you get to know the cultures, and so on. Different cultures. We are Turks, and they are Afghans, how they live, and so on; they already have a culture of their own. And we've been living in Germany for a long time; we've been in Germany – I think I came here when I was six, six years old. I went to school here and so on, we grew up here. So we like living here. So in the meantime – I like Turkey too, but Germany too. […] We live in two cultures (Walking to Running, Woman A).

3.2. Organizational level

During the project, the women had several organizational participation opportunities: (1) assisting others, (2) taking on independent tasks, and (3) participating in or (4) initiating decision-making processes independently.

3.2.1. Assisting others

Some women **assisted the exercise instructors in the implementation of the PA programs**. As participants in the respective programs, they conducted Corona testing for the other participants during the COVID-19 restrictions. They also kept the attendance lists, encouraged all participants of the programs weekly via WhatsApp to come to training regularly, and helped organize sports equipment for the sports courses for all women, among other tasks.

Furthermore, the women **supported the city project office's coordinator in recruiting participants for the PA programs**. They used their private networks to develop or expand their networks.

> So I like it. Yes, I also have all my friends and circle; I also told them. There is such a project, I said to everyone. For example, my girlfriends, a few girlfriends participate (Pilates, Woman A).

However, the women sometimes disagreed with the approach of the project officials (e.g., concerning the handling and recruitment of participants). They would have **liked to have had more of a say** and advocated, for example, for a stricter approach to absenteeism, as the programs were restricted to 15 participants, and some of them (especially swimming programs) had quite long waiting lists.

> He is also nice. But [name of the project coordinator in the city of Augsburg], please cross out if someone is away three times. Many women are waiting on the list. Can you give them (the place)? Many ask me: "Swimming, is there still swimming?" Turkish women, I have learned that Turkish women love water (Pilates, Woman A).

Unfortunately, contrary to the women's wishes, no additional project office position, filled by a woman from the target group as a mini job, was created in the city's Health Department.

The women likewise **supported the researchers in the implementation of the photo exhibition**. They painted the wall of the exhibition room, decorated the shop windows, designed, and decorated the feedback corner, put the pictures on the walls, and some brought food and Turkish tea for the opening ceremony. Furthermore, they made videos about the exhibition and posted these on Instagram and Facebook. Others helped during the opening hours as supervision and guide, helped clean the exhibition rooms, or wrote quotes of the interviews on the walls.

3.2.2. Taking on independent tasks

After being participants in some programs of the project, two women took on additional **roles as exercise instructors** in the course "Walking to Running" and one in the course "Pilates." The researcher asked all women face-to-face if they were interested in doing PA courses by themselves. Those women who were interested met with the researcher and an employee from the Bavarian State Sports Association (BLSV, Bayerischer Landessportverband e.V.), responsible for the program "Integration through Sports," in an extra meeting. There the women were informed about insurance issues, the possibility of acquiring an exercise instructor license by the BSLV, and how to do training and especially encouraged to do so. Twelve women came to the meeting, five were more interested, and so far, three women are teaching PA courses. In addition, 12 women attended a two-hour training course carried out by the city council, which trained them on how to teach, design, and create exercise courses.

> And on Sundays, I run with the women. I also talked to [name] yesterday that I should keep doing this (Interview after Exhibition, Woman A).

As part of the *Photovoice* study, the women were asked to document their daily lives in terms of PA and sports. By taking and discussing photos, they **took on the role of co-researchers**. In the focus group discussions, they interpreted their pictures together and explored different topics without being asked about them by the interviewer. As some showed photos of PA and others of doing housework, cooking, of their children and grandchildren, and meeting with friends, they reflected independently on these issues. They discussed them as possible barriers to their participation in PA in the group.

3.2.3. Participating in decision-making processes

At the beginning of the project, several women participated in decision-making processes during **project planning group sessions** (see Methods section). The four different kinds of PA courses realized in project implementation (Moving in the Water, Walking to Running, Pilates, and Self-defense/FitBo courses) were based on the women's wishes. The following framework conditions highlighted as significant by the women in the cooperative planning process were also implemented: childcare availability, close to home, without costs, and only for females (safe space).

As the project progressed, the women were also **involved in decisions about program content**. For example, as they indicated that "Fit-Bo" was too strenuous, it was replaced with yoga and dancing in consultation with them. The participating Muslim women wanted swimming lessons and expressed pleasure at receiving them through the project. Therefore, in the last block of the PA courses, there were three swimming courses initiated by the women and the researchers.

3.2.4. Initiating decision-making processes on their own

One participant **created a list of possible women interested (150) in swimming lessons** (like an unofficial petition). She showed this list to the researcher. These efforts provided the basis for implementing swimming lessons for women as part of the project. This woman gained insights into different bureaucratic processes and structures associated with implementing PA programs.

> When you sign up for it, it has to be binding, and I don't know how you can force people to go ahead or continue. I have now given [name] the list of women; he said there are many women. And if you do all the work and effort, you can see all this bureaucratic stuff, phoning, begging, pleading, and calling everybody, and then they don't come. Either it's too easy for them. They don't know how much dedication is behind it and how much time and energy (Interview after Exhibition, Woman A).

In the interviews, the women expressed how important the project was for them and wanted it to continue. They used the exhibition with photos and quotes **to describe their needs and wishes to the city officials and ensure the project's sustainability**. They activated their networks to get as many women as possible to participate and to give their wishes as much emphasis as possible.

> That the project always goes on, with swimming, sports, and running. That we always have programs in which we can participate. Many want to do that, but some can't express themselves (Walking to Running, Woman A).

The women were excited but, at the same time, proud to be able to present themselves and their circumstances.

> No, it was already good; it was a shaking up that we could say that we were also here. We are invisible in the city because we are not loud, but we are there. Society is like that; you can't just look away. You can't ignore the refugees or the Ukrainians, or, I don't know, foreigners; they are just there in the city. You can only do something together. Side by side, it would only work for a short time. There would be big problems. And you can only be noncommittal in such groups, get to know each other, and accept and respect the others (Interview after Exhibition, Woman A).

In addition, some face-to-face conversations between stakeholders and women occurred during the exhibition, and the women felt heard and recognized.

> The exhibition was excellent for me. Because there was such an exchange, where you saw people from different courses, I say. Because there were people from the university, from the chair, and then politicians and women who were disadvantaged and the target group, there was an exchange. So I was a project participant, a student, and I saw politicians. For example, I saw women from the same environment as me; yes, I saw very different people and talked to them. And there was an intercultural exchange. I liked that very much. *Interviewer*: And did you also talk to politicians and everyone? *G:* Yes, I talked to the artist in charge of the exhibition. I talked to them; I've forgotten the name now, but the head of the department (of the university), I talked to him. With the swim class instructor, [Name], with her I spoke, also with someone from the city, so really with everyone (Interview after Exhibition, Woman C).

3.3. Community level

3.3.1. Access to communal resources

As most of the participating women are Muslim, their religious background does not allow them to go swimming together with men (or at least they have to wear full-body swimsuits, which are not allowed in every swimming pool of the city of Augsburg, or the women are verbally attacked because of this and get mean looks). The headscarf was likewise perceived as an inhibiting factor for participation in regular PA by the women themselves. The same applies to some of them regarding gender-mixed sports groups or opportunities. When they participated in PA programs with the headscarf, they felt different but did not dare to take it off. At the same time, they felt they did not belong and therefore stopped participating again. Sports facilities for women only, such as women's fitness centers or other women-only sports groups, were often too far away or too expensive. Furthermore, they had no access to public indoor swimming pools in Augsburg and could not go swimming, as women-only swimming hours were unavailable. However, they were aware that other cities have such offerings.

> I wanted to go to the gym once, but it was mixed. And because I wear a headscarf and have to undress if it's too warm, and because it's diverse, I didn't dare, to be honest. So I said, "No" (Walking to Running, Woman A).

> Well, it bothers me. Where I was with and without a headscarf, I noticed how people looked at me and treated me. So the person without the headscarf always has priority. I saw that, unfortunately. They also treat you differently; you can feel that. You can think that, you notice that. If you didn't have a headscarf before and how you were treated there and with a headscarf, you see that, the fact that people react very differently. I don't know, with me (Walking to Running, Woman A).

During the project, the women **gained access to women-only indoor pool hours and women-only PA programs** in their neighborhood in the city of Augsburg, organized by the city council, the university, and the insurance companies. They were also given access to a suitable space in the city to exhibit their photos. These concessions not only allowed them to engage in regular PA but also to have a sense of belonging and being heard.

3.3.2. Sense of community

They also got to know other women in quite similar situations through the project. They reciprocally enhanced their understanding of their situation, experienced **cultural openness, and developed an understanding of and with other women** in comparable life situations.

> This project is quite good; now we know each other. This generation may open the doors, but our children come together later. Whether the headscarf or other people's hair is different or dressed differently, this is the opposite side; we get to know them (Walking to Running, Woman B).

In each group interview, at least one woman **stood up for the other women** who could have spoken German better or were introverted.

> You know, with many women, it's also the language. They don't dare. Because they don't know German so well, they can't defend themselves (…). Because if someone comes and says something that they don't understand or can't protect themselves from, they get sad. Then they will not go there anymore. (Pilates, Woman A).
>
> Many Turkish women think they are responsible for the kitchen, husband, cooking [Woman C: cleaning], or cleaning. "No, I can't come; I don't have time for that" (Pilates, Woman A).

3.3.3. Open government structures

The participating women **became politically active** by agreeing to present their photos and interview quotes at the exhibition. Some of them also decided to participate in an additional video shown at the photo exhibition. The video featured short (1–4 min) sequences of participating women talking about who they are and what the project means to them. Two women also took on the role of **speaking at specific project events (opening ceremony of the exhibition, closing ceremony of the project) in front of various stakeholders, such as local policymakers and other relevant authorities** in the city of Augsburg, to inform them about the project and its significance. Here the researchers again asked all women participating in the PA courses to do so.

> B: I was excited [researcher's name] because I had nothing prepared.
>
> A: But you spoke like a waterfall.
>
> B: Oh, what, there I have so much grammar.
>
> A: I asked her if she had studied it before. She said, "No."
>
> B: I didn't know either; what must I talk about? Later I said, "Oh, [own name], you talked wrong and didn't say that. But at least we are there. Whether there is something wrong or right." (…) There I had much joy when I participated. That's quite good; no one heard and understood us (before). (Interview after Exhibition, Women A and B).

However, the inclusion of women in the project presentation at various city council committee meetings was rejected several times by those responsible.

4. Discussion

4.1. Aim of the study

This paper aimed to explore the perspectives of women in difficult life situations on their participation in CBPR projects in terms of empowerment. Following the co-creation approach to health promotion (9), the women were included as co-researchers in the current CBPR project. A *Photovoice* approach was used for this purpose, including focus group discussions with the women and an exhibition of their photos, interview quotes, and short interviews. The study adds value to existing literature on the perceived empowerment effects of women in difficult life situations concerning different modes of participation (43, 44).

4.2. Principal findings and comparison with other studies

The principal findings are that the women in the present context perceived effects and processes on all three empowerment levels (i.e., individual, organizational, and community) through their participation in the CBPR project.

As a result of their *participation in the project's PA programs*, women reported empowerment effects on the individual level: They perceived more self-efficacy regarding regular PA, more control over certain important areas of their life like pain issues, overcoming fatigue, or fear of water, and gained different competencies. The latter point was in terms of PA participation and concerning further relevant areas, such as improving nutritional and German language skills. They also developed an understanding of supportive factors that are significant for them to engage in regular PA: support of family members and friends, as well as the support of a group and the exercise instructor. Furthermore, they made additional social contacts with women, especially from other cultures, due to their participation in the project's programs. The group acted as a motivator for regular PA participation. This is like findings from other studies on the empowerment effects of women's participation in PA programs (43, 44, 51).

Through participation as co-researcher, the women perceived a set of more generic competencies that impacted their everyday life and enabled them—in terms of the WHO (1997)—to take control of the determinants of their own and other people's health.

The photo assignment, for example, encouraged the women to reflect together on their daily lives concerning PA and sports. As some women had photos of sports and PA and others had pictures of their household, food, children, and grandchildren, differences in assessing the importance of specific domains became apparent. Finally, in focus groups, the photos served as stimuli to discuss their role as women in the context of the family and other areas of life as well as related possible barriers to their participation in sports and PA. As described by Freire (20), who proposes that photos enable people to reflect on themselves and their world and achieve critical consciousness about their situation, the images serve as a mirror for the participating women (49). Similar effects on raising awareness of the barriers to PA participation through discussing photos in the context of *Photovoice* have been described in previous studies (52). Through the mutual exchange, the women encouraged one another concerning their photos. Finally, they all agreed to show their photos at the exhibition to share their views and lives with policymakers, the media, family, friends, and other interested citizens.

Participating in the focus group discussions, as well as in conversations and as speakers at the exhibition, helped the women improve their German language skills further. This was not only a goal strived for by the women themselves with their participation in the current CBPR project, rather, they regarded language competence as an essential prerequisite for acquiring health literacy (53). In the focus groups, the women learned to better understand different cultural backgrounds and individual desires and needs related to PA. This also contributed to a better sense of community and can be seen as an advantage of group discussions versus individual interviews (54).

By exhibiting their photos, quotes, and a video, the women expressed their wishes and needs to relevant city leaders and citizens. With this, the women learned to be capable of influencing and even initiating far-reaching decisions and were valued for their opinion. Some women even gained the confidence to speak and represent the concerns of their peer group in conversations with and in front of city officials and leaders. As reported elsewhere, they felt heard and valued for their beliefs and ideas (55). Thus, they perceived some form of openness of the local government, even though the inclusion of women in the presentation of the project in various committee meetings of the city and their participation as co-project office managers in the city council were rejected several times by those responsible. It appears that the latter changes require patience and time and maybe longer project durations (37). Compared to the experiences from other CBPR projects, the lack of openness of the local government concerning the women's participation seems quite striking and possibly indicates a lack of readiness for the topic in the present municipality (43, 55, 56). Despite these circumstances, the fact that the project is sustainable is more than remarkable. From our point of view as participant observers, this is due to the exhibition of the photos and the attention the women attracted to their wishes and needs, especially among opposition politicians and the local media. Local newspapers and local social media were specially invited by the researchers (for several reasons). However, the dissemination of the results of *Photovoice* and how exhibitions may influence societal, organizational, and individual changes has yet to be studied and discussed in the literature (49).

Compared to the involvement of the women as co-planners and co-implementers (43), quite similar empowerment processes at the organizational and community levels were achieved by their participation as co-researchers through *Photovoice*. By participating as project office managers in a CPBR project for PA promotion (co-implementation), a few women reported developing skills related to office work (43, 44). In addition, the establishment of permanent groups like cooperative planning groups or health promotion labs possibly allows for more intensive and long-term collaboration among target group participants and other stakeholders (43, 54). While the empowerment effects just mentioned could not be shown in the current project, several other benefits of *Photovoice* in terms of empowering target groups in the context of CBPR became apparent. As discussed above, photos could at least partially counteract language problems and enable the inclusion of women who hardly spoke German (22). Additionally, the focus group consisted only of participants from the target group. As there was a relationship of trust between the group participants, they could express themselves much more freely (57). In contrast, a lack of willingness on the part of target groups to participate in mixed stakeholder groups has been described several times in the literature. This is attributed to the fact that, partly due to language problems, they feel uncomfortable in groups with policymakers and are unwilling to speak up (58). The willingness to get involved in informal groups (e.g., at women's regular breakfasts) is estimated to be significantly higher (44). The basic structure of *Photovoice* allows for a more informal nature of participation. In the present project, the women could and had to decide at any time if they wanted to participate, drop out, or begin. There were no regulations regarding this point. That again is an essential tool to gain empowerment and be responsible for oneself. Quite a few women made their own decision in this regard as well. This may be why the women's commitment to join and support the project was relatively high.

4.3. Strengths and limitations

Our data demonstrate that the women perceived *comprehensive empowerment effects* in terms of self-efficacy and skill development and even gained *empowering processes* in the form of social and community involvement and power through their participation in a CBPR project for PA promotion. In addition, it was shown that the participation of women in difficult life situations in a CBPR program in the form of *Photovoice* could achieve comparable effects on their empowerment as other forms of participation, such as cooperative planning. *Photovoice* can be carried out in different ways. Usually, there is the same focus group of 5–15 persons who meet several times to take pictures, give their photo headings, discuss the photos, and so on. In this project, the women could, at any stage, drop in or out and begin with the co-researching process. It was mostly the same women, but new women also participated in the exhibition preparation.

As reported in other publications, the *concept of empowerment is quite uncertain and fuzzy* (59). Subcategories differentiated by Zimmermann (39) often overlap and, in some cases, can hardly be distinguished. Empowerment is a process that takes time and develops in small steps, and the individual levels are mutually dependent. The willingness to open oneself to different issues, possible change, and modification in life is necessary to gain and learn new skills. Furthermore, skills and readiness are interdependent.

The *role of the researchers* in the present context must also be highlighted: The researchers were very open, flexible, and actively participated in the PA courses throughout the whole CBPR project, resulting in a high level of trust from the participants and an intensive exchange of ideas and needs throughout the whole research project. The times and locations of the focus group discussions were also tailored to the wishes and needs of the women. They mostly took place directly after the PA courses to make it easy for the women to participate. Given the use of WhatsApp groups for all courses, the women often called the researcher quietly when there were problems, new participants, and other concerns. Without this platform, the intensive participation of women in the project would not have been possible. This is critical in going native but is also an essential prerequisite for the participatory, and thus empowering, processes (49). Regarding the participation of the women in the research process, it should be noted that they were involved in data collection, analysis, and dissemination but not in the formulation of the research question. Possibly greater empowerment would have been achieved through an even broader participation of the women (57).

The *group discussions occurred in German* because the women were of different origins (Persian, Turkish, German, and Hebrew). Therefore, most did not use their mother tongue and could not express themselves easily. However, through the photos, these women also had their say, even if some admitted that they did not understand the photo task. As explained above, all the photos were discussed, interpreted, and contextualized in the group. In some interviews, the women helped one another and translated for those who could not speak German well, even though they had lived in Germany for more than 15 years. It should likewise be recognized that the researcher conducting the interviews is a German woman aged 40, and thus power relations could not be excluded.

Since at least one of the two researchers who performed the data analysis had *experience with the research question from previous projects, data analysis in the form of grounded theory* was chosen to be applied to the research object as openly as possible and to focus on how the women perceived their reality. The results and impressions from the analysis of the interviews together with the women were considered several times throughout the process of data analysis. In addition, as already requested by others (35), triangulation of the data and, therefore, different perspectives was carried out by combining interviews with participant observation data.

As the *Photovoice* group interviews took place after a one-year Corona break, *only some of the women involved in cooperative planning participated in Photovoice* because many had dropped out of the project due to changes in their life circumstances (new job, older children, etc.). Therefore, we did not have data on how the women felt about participating in cooperative planning.

4.4. Implications for further research and practice

Our findings support the notion that health promotion interventions with marginalized groups can contribute to their empowerment on multiple levels when participants become equal partners in the CBPR project. Including women as research partners in data collection and analysis leads to further empowerment outcomes and has advantages over other ways of participation. However, the inclusion of target groups in all phases of the research project possibly causes a summation and interdependence of effects, an outcome that should be reviewed. For example, to counteract the language problems of participants about understanding the photo assignment, intensive training in *Photovoice* is urgently required beforehand. Family support is essential for women's participation in PA and sports, so future projects should consider including family members in CBPR. The present study underlines that participation in PA alone already produces empowerment effects at the individual level. This result once again underscores the importance of PA interventions for health promotion.

Data availability statement

The raw data supporting the conclusions of this article is available upon reasonable request from the corresponding authors.

Ethics statement

The studies involving human participants were reviewed and approved by Ethik Kommission der Universität Augsburg. The patients/participants provided their written informed consent to participate in this study.

Author contributions

UR-O and HB-B initiated the study. UR-O designed the study, analyzed the data, and drafted the manuscript. EK conducted Photovoice, analyzed the data, and contributed to the draft of the manuscript. HB-B contributed to the study conception and critically revised the manuscript. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted without any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Qualitative inquiry with persons with obesity about weight management in primary care and referrals

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Introduction: Referrals to evidence-based weight management in the community-commercial sector are aligned with clinical recommendations but underutilized.

Methods: This qualitative study explored patients' perceptions and expectations about obesity treatment in primary care and referral to community-commercial sector programs. Individual semi-structured interviews were conducted with a sample of US persons with obesity via telephone. Audiotape transcripts, interviewer notes, and independent review of data by two investigators allowed for data and investigator triangulation. Transcripts were analyzed using thematic analysis.

Results: Data saturation was reached with 30 participants who had a mean age of 41.6 years (SD 9.4), 37% male, 20% Black/African American and 17% Hispanic, 57% college educated, and 50% were employed full-time. Three primary themes emerged: (1) frustration with weight management in primary care; (2) patients expect providers to be better informed of and offer treatment options; and (3) opportunities and challenges with referrals to community-commercial programs.

Discussion: Patients expect that providers offer personalized treatment options and referrals to effective community-commercial programs are an acceptable option. If patient-level data are shared between clinical and community entities to facilitate referrals, then privacy and security issues need attention. Future research is needed to determine feasibility of implementing clinical to community-commercial referrals for obesity treatment in the United States.

KEYWORDS

referral and consultation, obesity, obesity management, qualitative research, delivery of health care

1. Introduction

Persons with obesity (PwO) face personal, social, clinical, and health-system level challenges that converge in complex ways and function as barriers to effective treatment. To understand and manage these barriers, sequential steps in the treatment pathway have been outlined (1). The treatment pathway is assumed to begin by identifying oneself as overweight and followed by a desire to lose weight, weight loss attempt(s), seeking healthcare for obesity, and seeking care from a provider. A nationally representative cross-sectional study in the United States found that 92.7% of PwO perceive themselves as overweight, nearly all desire weight loss, and 6 in 10 have attempted weight loss (1). Few PwO (1 in 5) seek advice from a healthcare professional and among those that do, only 1 in 3 seek care from a provider (1). On average, PwO make 7 serious attempts at weight loss before seeking advice from a healthcare professional (2). Discordance between objective and perceived weight, desired and attempted weight loss, and weight-related stigma contributed to reluctance to seek help from healthcare professionals (1).

Once the topic of weight management is raised, providers are recommended to offer or refer PwO to intensive behavioral interventions but there has been little investigation of how PwO perceive the options and their involvement in deciding a course of action (3). Since effective weight management interventions include at least 12 sessions in the first year to address nutrition, physical activity, and behavioral skills (e.g., self-monitoring, problem solving, relapse prevention) (3) few providers are likely to have sufficient time or training in lifestyle medicine (4, 5) to offer them. Making referrals may be more feasible and will likely provide better outcomes (6). The opportunity to make a referral exists for providers within health systems but provider uptake may be poor, few patients may receive referrals and fewer may complete the referral. One in 5 providers in a large health system were responsible for over half of 17% of PwO receiving referrals to weight management (7). Among PwO who received a referral to a program within the health system, e.g., nutrition services, diabetes education, and bariatric surgical programs, 29% completed the referral (7). Improvements in providers making referrals and patients completing referrals are needed and, potentially, enhancing the variety of treatment programs will advance these improvements.

Commercial programs (WW, Jenny Craig, etc.) have been identified by nearly half of PwO and providers as effective weight management strategies (2). Regarding efficacy, PwO who received a referral to a commercial program lost double the amount of weight at 1 year compared to those who received provider advice (8). Notably, the rate of referral acceptance was 3 to 4 times higher (8) than that observed in US healthcare (7). While differences in out-of-pocket patient costs for clinical treatment (9) or commercial programs may influence referral acceptance, PwO did not identify finances as a leading barrier to initiating a weight management program (2). Importantly, participant household income was not detailed and many identified affordability of healthy food as a barrier to weight management (2). Despite acknowledgment that commercial programs are effective, it is unclear how these programs are perceived by PwO in the context of clinical care and the influence that provider, health system, or coverage would have on enrollment and participation.

Given the gaps identified, the purpose of this qualitative study was to explore the perceptions and expectations of PwO about discussing weight with providers, advice, and referrals. In the context of increased rates of obesity in the US and low implementation of clinical recommendations, a better understanding from the patient perspective about weight discussions, clinical advice, and referrals may advance public health goals to reduce obesity[1] (2, 7, 10).

2. Methods

2.1. Participants

This study was conducted with US adults (≥18 years). A survey research company (Qualtrics) surveyed an existing panel of adults (convenience sample) to identify interest and eligibility based on a calculated body mass index (BMI) ≥30 kg/m^2 (self-reported height and weight) and were English-speaking. Respondents were telephoned to achieve a purposive sample of approximately 25–30 PwO from urban, suburban, and rural communities, in total. Participant demographic data (age, race/ethnicity, sex, education, marital and employment status, weight perception) were collected by the interviewer. The study was approved by the Geisinger Institutional Review Board [2019-0292] and data were collected in winter 2019–2020.

2.2. Moderator's guide

The moderator's interview guide was developed by the study team and reviewed and enhanced by a patient advisory committee on obesity at [masked institution] (Supplementary Appendix A). The format included a moderator's introduction, opening question, specific topics, and probes. The guide included questions about experiences and perceptions of adult weight loss, experiences discussing weight with providers, the nature of advice, and referrals for obesity treatment. Participant opinions about the potential value and challenges of receiving a referral from clinical to commercial weight management programs were explored.

2.3. Procedures

Qualtrics scheduled participant-researcher calls and an appointment reminder was emailed. Interviews opened by confirming the participant's availability, receipt of study information and answering questions. All participants provided verbal informed consent. A semi-structured interview strategy was used to encourage conversation. Each interview was conducted by telephone, audio-recorded, and transcribed verbatim. All interviews were conducted by a trained qualitative interviewer (LBD). For their participation, interviewees received $50. Two research team members (LBD and AMP) read and discussed the transcripts as they were produced and reached consensus about the point of data saturation. The audiotape transcripts, the interviewer notes, and the independent review of two investigators allowed for data and investigator triangulation, respectively, which adds to the credibility and dependability of the interpretive findings (11).

2.4. Analysis

Data transcripts were the main unit of analysis, and each was read several times to obtain a sense of the whole and promote reliability in the results and interpretation. Transcripts were analyzed using thematic analysis, a process that involves six phases including familiarization with the data, generation of initial codes, searching for

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[1] https://health.gov/healthypeople

themes, reviewing themes, naming themes, and producing a final report (12). Researchers (LBD, AMP) used an open-coding approach to compare initial impressions (e.g., initial codes) from the data. After consensus was reached on initial codes, LBD applied an open-coding strategy to code all transcripts. Atlas.ti was used to manage the data. The coding output was evaluated, and discrepancies were discussed and resolved. Researchers derived the themes from the data using an inductive, constant comparative strategy through discussion of coded data to reach consensus on emergent themes.

3. Results

A total of 30 PwO participated out of 85 who were screened as eligible for participation. Participants did not dropout or refuse, *per se*, as data saturation was reached and there was not a need to continue to schedule interviews. Participants from rural/urban/suburban areas were equally distributed (Table 1). The mean age of participants was 41.6 years (SD 9.4), over a third were male, 20% Black/African American and 17% Hispanic, most had college degrees, and were working full-time. Most females were married whereas most males were single. Most participants perceived their weight as being overweight or very overweight although they used various terms to self-describe their weight status. Self-reported BMI was not made available to researchers after eligibility screening. Interviews lasted 21 min on average (range 16–28).

Three primary themes and several subthemes emerged from the inductive analysis (Table 2). Primary themes are: (1) frustration with weight management in primary care; (2) patients expect providers to be better informed of and offer treatment options; and (3) opportunities and challenges with referrals to community-commercial programs. Subthemes that emerged are identified and presented with primary themes below.

3.1. Frustration with weight management in primary care

Participants were asked about their experiences with weight management discussions in primary care, who initiated the conversation, and the treatment received. Three subthemes emerged within the primary theme: (a) when the focus is health, discussion is comfortable regardless of who initiates the topic; (b) frustration with vague advice from providers; and (c) frustration with managing obesity on your own.

When the focus is health, discussion is comfortable regardless of who initiates the topic. Participants reported concerns about the impact of excess weight on physical, biological, and mental health. Weight-related comorbidities were reported including mobility limitations, back and knee pain, arthritis, prediabetes, type 2 diabetes, hypercholesterolemia, high blood pressure, breast cancer, sleep apnea, polycystic ovary syndrome, and depression. Prevention of comorbidities was a concern, and several indicated having a positive family history of obesity-related chronic disease. Participants reported being aware of health risks associated with excess weight given their life experience with obesity, a history of discussions with providers, and self-directed research.

TABLE 1 Characteristics of persons with obesity interviewed.

		Males	Females	Total
		($N = 11$)	($N = 19$)	($N = 30$)
Age (Mean, SD)		43.2 (5.9)	40.6 (11.2)	41.6 (9.4)
Education (*n*, %)				
	High School/ GED	1 (9)	3 (16)	4 (13)
	Some College/ Technical	2 (18)	7 (37)	9 (30)
	College	7 (64)	7 (37)	14 (47)
	Post-Graduate	1 (9)	2 (11)	3 (10)
Marital Status				
	Married/ Living with Partner	5 (45)	10 (53)	15 (50)
	Separated	0 (0)	4 (21)	4 (13)
	Single	6 (55)	5 (26)	11 (37)
Employment Status				
	Full-time	9 (82)	6 (31)	15 (50)
	Part-time	0 (0)	3 (16)	3 (10)
	Unemployed	2 (18)	10 (53)	12 (40)
Weight Perception				
Very Overweight		2 (18)	5 (26)	7 (23)
	Overweight	8 (73)	14 (74)	22 (73)
	About Right	1 (9)	0 (0)	1 (3)
Race/Ethnicity				
	Black, African American	1 (9)	5 (26)	6 (20)
	Asian, Pacific Islander	1 (9)	0 (0)	1 (3)
	White, Caucasian	6 (54)	11 (58)	17 (57)
	Hispanic	3 (27)		5 (17)
	Other	0 (0)	1 (5)	1 (3)
Community Type				
	Rural	1 (9)	9 (47)	10 (33)
	Suburban	5 (45)	5 (26)	10 (33)
	Urban	5 (45)	5 (26)	10 (33)

> "When I started the discussion, I told him about the research I've been doing online, and that changed the whole conversation into a very helpful conversation instead of an uncomfortable one." -Female, age 36 years, post-graduate, full-time, married, overweight

In the context of health concerns, PwO initiated discussions about their weight or were open to the topic being raised by providers. Participants were ambivalent regarding concern of who raised the

TABLE 2 Themes and subthemes from qualitative interviews with persons with obesity about weight discussions in primary care and referrals for treatment.

Themes	Subthemes
Frustration with weight management in primary care	
	When the focus is health, discussion is comfortable regardless of who initiates the topic
	Frustration with vague advice from providers
	Frustration with managing obesity on their own
Patients expect providers to be better informed of and offer treatment options	
	Expect information about how obesity interacts with other chronic disease management
	Expect treatment choices for a personalized approach
	Value provider support in decision-making
	Details needed to inform decision-making
	Expectations for maintenance and relapse
Opportunities and challenges with referrals to community-commercial programs	
	Referral arrangements
	Follow-up, accountability, and care coordination expectations
	Data privacy, security risks, and ethical challenges

topic. Regardless of who initiated the discussion, provider attributes that contributed to comfortable conversations included empathy and a non-judgmental attitude.

> "If the doctor doesn't seem like they are attacking me with their comments about my weight and that they're more trying to really look out for my health, that's a lot more helpful to me, because I've had it go both ways and when it seems like a doctor genuinely cares about my health that's what really matters to me." -Female, age 30 years, some college, unemployed, living with partner, overweight

An established, respectful, and trusting relationship with the provider contributed to PwO comfort.

> "I have a really good relationship with my primary care doctor, so she does a really good job, with just kind of letting me know what I need in a sort of up-front kind of manner. No sugar coating. I mean, I feel comfortable after having that discussion with her." -Male, age 39 years, post-graduate, full-time, single, overweight

Conversely, PwO were uncomfortable when they felt labeled or judged by their weight status.

> "Well, definitely nobody wants to be told they're fat. Basically, my family doctor would just be, like, you are overweight. You need to lose weight, and it just was like kind of rude about it." -Female, age 40 years, some college, unemployed, divorced, somewhat overweight

Frustration with vague advice from providers. Participants were frustrated by the content of conversations about weight as the advice was non-specific and behavioral recommendations were "always like a suggestion, it's not like I am prescribing this to you."

> "Not specific. It was more of a conversation about moderation and then being physically active at least 30 min a day, but no set plan per se." -Male, age 42 years, college, full-time, married, overweight

Participants reported that providers made false assumptions about their motivation, specifically that they were lazy or would not make a serious effort, and that this was a barrier to receiving useful advice.

> "It just makes me feel like it's just the same old thing, diet and exercise. You worry they assume you're just lazy and you're not so much, but with the physical pain it's hard to exercise and so it just seems like circles kind of, the same old thing, same old thing. It's like I can't do a whole lot physically because I'm hurting. I need to get the weight off." -Female, age 44 years, some college, unemployed, divorced, obese

Receipt of written materials about healthy eating, provider assistance in identifying gym memberships covered by insurance, and any follow-up appointment for weight management was uncommon. Some PwO reported receiving a referral from their primary care provider for weight management. Among those referred to a bariatric specialist, half had undergone a surgical procedure. Few PwO had been referred to a registered dietitian/nutritionist and others indicated a lack of awareness that a provider could make a referral to a bariatric specialist or dietitian. No participant had received an anti-obesity medication prescription, and few reported using over-the-counter supplements.

Frustration with managing obesity on their own. Participants reported feelings of being lost, confused, and frustrated with weight management care.

> "…when you go to the doctor and weight loss is brought up, you almost feel as if they sent you out the door lost and confused and walking in circles with very minimal point in the right direction, so something like handing you a pamphlet, a booklet, a printout, anything with information…would be beneficial to a lot of people." -Female, age 36 years, some college, part-time, living with partner, overweight

Participants described the efforts to manage their weight as being self-directed and independent of their provider. PwO reported being left on their own to find an effective approach, yet they would welcome provider involvement.

> "Unfortunately, I don't always think of my doctor when it comes to weight loss. I don't feel like they don't always look for that. I feel like people are kind of left on their own sometimes to figure that

> out. So, it would be nice if it was woven into a medical visit." -Female, age 45 years, post-graduate, part-time, married, overweight

The experiences associated with frustration were related to primary care.

> "You know, it just makes you wonder just why it took my orthopedic doctor to do this and he's not really even into that kind of, it should have been my primary care that did it [made referral to bariatric program] a long time ago." -Female, age 44 years, some college, unemployed, divorced, obese

In contrast, PwO who discussed their weight with a specialist (obstetrics/gynecology, orthopedics, endocrinology, bariatrics) described the advice as useful.

> "She has given me pamphlets and some suggestive eating, diet things. Like for breakfast, different things that are good for diabetes and weight management, *Choose My Plate*, …things you can follow every day that will lead up to eating healthier and losing weight, getting control of my weight … no requirements of coming back to discuss it with her." -Female, age 57 years, college, unemployed, single, obese

3.2. Patients expect providers to be better informed of and offer treatment options

In this second primary theme, five subthemes emerged and include: (a) expect information about how obesity interacts with other chronic disease management; (b) expect treatment choices for a personalized approach; (c) value provider support in decision-making; (d) details needed to inform decision-making; and (e) expectations for maintenance and relapse.

Expect information about how obesity interacts with other chronic disease management. Participants expect more information from providers about how their physical, biological, and mental health conditions interact with obesity. Participants voiced concern about the complexity of their conditions and their expectation to learn more about how obesity management could affect their cardiometabolic conditions, cancer remission, pain, and mental/emotional well-being.

> "I would expect them to talk about what benefit that's going to have on me managing my past conditions and preventing any future conditions, maybe alleviating any pain that I have like back pain or leg pain and things. I would also expect, because of the history of breast cancer, them to talk about that, like what effects that would have on any recurrences or things like that." -Female, age 36 years, some college, unemployed, single, overweight

Conversely, some PwO were concerned about the side effects of their prescribed medications for comorbidities on weight management.

> "I have bipolar disorder, anxiety disorder, and PTSD and so some of the medicines that I take do increase a little bit of my weight." -Male, aged 47 years, some college, unemployed, single, heavy

Participants expect that providers will provide pathophysiological insight about obesity that helps them to better understand their situation and the benefits of weight management.

Expect treatment choices for a personalized approach. Participants expect providers to present treatment choices that are personalized. Specific personal factors that they expect to be considered are comorbidities, age, and sex.

> "I would expect them to deliver it to me as personalized as can be. I wouldn't feel comfortable with just a common program that has worked for some people that are not in the same situation as me, so I would appreciate it if it was kind of personalized and understood that this may help for my situation." -Male, age 33 years, college education, full-time, married, overweight

Additionally, PwO expect details about program effectiveness (weight outcomes, sustainability of weight loss) related to these factors.

> "I would like to know the success rate of people that are similar to me." -Female, age 57 years, GED, disabled, separated, overweight

Some expect the provider to understand their prior history of weight management attempts, successes, and challenges to inform treatment choices.

> "I would want more specifics, remember they went to school for that, they're more informed than I am." -Male, age 54 years, college, full-time, married, overweight

Balanced with a strong interest in a personalized approach, PwO expect the provider to make treatment recommendation(s), and they maintain an expectation of making a choice.

> "Multiple options, that way the choice would be mine to make." -Female, age 49 years, some college, retired, married, overweight

Value provider support in decision-making. Despite the general frustration with provider advice about weight management, PwO respect provider input and highly value their support in making a treatment decision. Participants anticipated that a provider's recommendation would help them feel comfortable in making a decision.

> "I think if my doctor were to say, listen, I'm aware of what your struggles are and I'm also a believer in this program, I think this could work. This is a good match. That would make me feel more comfortable, and also allow me the opportunity to discuss my experience with the doctor." -Female, age 45 years, post-graduate, part-time, married, overweight
>
> "It makes me feel that they trust and feel that the company is good and what they have to offer could benefit me. I value my doctor's opinion." -Female, age 44 years, some college, unemployed, divorced, obese

If the treatment choice was a referral to a program, the provider's recommendation could help the PwO focus their research on trusted and effective programs.

> "There's a chance I may or may not follow through with it. If [the doctor] recommended it, I'm more apt to follow through and stick with it, because chances are he's just looking out for my benefit." -Male, age 40 years, GED, unemployed, single, very overweight
>
> "It feels more genuine, it just feels like if I'm having a health care professional give me this information, it just feels more real and respectable then just something that I just happen to come across while browsing online." -Female, age 34 years, some college, full-time, married, overweight

Many PwO anticipated taking additional steps to learn about programs that were provider-recommended before making a treatment decision.

> "Their recommendation added to research online would lead me to find out what would be best for me. At first, I would probably try their advice." -Male, age 43 years, college, full-time, single, overweight
>
> "I would prefer for her to make a recommendation because I really trust my primary care doctor, so I would want her to make a recommendation and then I would do my research on my own." -Male, age 39 years, post-graduate, full-time, single, overweight

Details needed to inform decision-making. Participants are concerned about treatment costs and insurance coverage. Regardless of whether PwO felt they had the resources to pay out-of-pocket for treatment, this issue was top of mind.

> "I would expect probably a little bit of a run down on, there are so many out there right now, whether you're cutting carbs or you're cutting fat or calories. I'd probably want to know what style that was to see if it was even something that would interest me in my likes of food. The success rate would be nice. I know it's not always easy to have those statistics, but that would be nice; and maybe even some pamphlets just like little information about what this program has to offer. Maybe whether it's an exercise regimen or daily meal plan or you know whether they have a protein drink line. Things like that. Yeah, that would be helpful from the doctor." -Female, age 30 years, some college, unemployed, living with partner, overweight

Participants appreciate the nuances of insurance coverage and plans and do not expect their providers to be able to fully represent costs other than a general range.

> "Well, being a penny pincher, if [provider] had presented [weight management program] to me in a way where I felt like I had to do it, then I would have done it, of course. With programs and all these other things medical-related and insurance, I'm pretty skeptical and also pretty dissatisfied with the way insurance works … The trouble is asking how much classes were, and he didn't know. He told me to ask somebody else, and somebody else told me to ask somebody else, and it was just a circle of cycles … Everybody has different insurance and maybe it's hard for them to communicate it, or a company to communicate it, but I would think they could still communicate a range at least or something" -Male, age 42 years, post-graduate, full-time, married, slightly overweight

Treatment details such as nutrition modifications, physical activities, program format (virtual, in-person, hybrid; group, individual), schedule (synchronous/asynchronous, frequency, session length, program duration), safety, location, effectiveness, and weight loss sustainability are among the details that participants need to inform treatment decisions.

> "…if I could find something that I could go like once, maybe twice a month to an actual physical location and do the rest of it online, that would be a major convenience." -Male, age 40 years, GED, unemployed, single, very overweight
>
> "That it's healthy. It's safe. That it is a good alternative to trying to do it on your own. It's the best thing for my case specifically." -Female, age 40 years, some college, unemployed, divorced, somewhat overweight

"Are the results only while the program is taking place or are they lasting?" -Male, age 42 years, college, full-time, married, overweight.

Details could be communicated verbally, with written materials, or by directing PwO to a website, perhaps noted on a coupon or voucher.

> "…I wouldn't expect the doctor to provide me with all the details because it is not their specialty, but maybe just a brief summary of what it's all about … at least give me some sort of collateral like a pamphlet that would describe the options." -Male, age 33 years, college education, full-time, married, overweight

Expectations for maintenance and relapse. Participants acknowledged the chronic nature of obesity and expect care to continue after weight loss is achieved.

> "I would hope it would be open forever. The weight loss and the weight maintenance thing to me is an ongoing battle. It is not like some curable disease that once you are done with it, you don't have to worry about it." -Male, age 43 years, college, full-time, single, overweight

However, PwO had two perspectives regarding whether weight management should be a covered benefit after an initial successful weight loss (interviewer suggested 5%–10% but many participants identified 20% as successful weight loss). Some PwO expect weight management and maintenance to be a continuously covered benefit whereas others expected this to be limited to an initial attempt.

> "Well, yeah, I was thinking well that would be my fault, but I guess that's what I paid for. I guess if I broke my leg and then 2–5 years later, I broke my leg again, I would still expect them to pay for it." -Female, age 36 years, some college, unemployed, single, overweight

Those that held the latter opinion anticipated self-blame for weight regain and would not expect a payor to cover subsequent attempts.

> "I would think it wouldn't be [covered] if it was after 2 years, but I mean it is always a possibility, and it would be my own carelessness, so they helped me once, they may not help me again type of thing." -Female, age 30 years, some college, unemployed, living with partner, overweight

3.3. Opportunities and challenges with referrals to community-commercial programs

Participants conceptualized the possibility of their provider offering a referral for weight management to programs including WW (formerly Weight Watchers, $n = 29$), gyms ($n = 21$), NutriSystem ($n = 16$), Jenny Craig ($n = 8$), Curves ($n = 6$), and Noom ($n = 1$). Three subthemes emerged related to the potential value and challenges of receiving a referral from a provider to a commercial weight management program, primarily focused on WW, including: (a) referral arrangements; (b) follow-up, accountability, and care coordination expectations; and (c) data privacy, security risks, and ethical challenges.

Referral arrangements. All but one participant was enthusiastic about the potential to receive a referral from their provider to a commercial weight management program. The participant that did not endorse a referral noted a preference to navigate programs independently. Many indicated that receiving a paper coupon or digital code would be acceptable.

> "…it feels like [a referral from a primary care provider] would be a good motivator to check those things out and then start with a coupon, a code, for a discount of some kind, that makes it even more motivating so, yes, I would be interested." -Female, age 34 years, some college, full-time, married, overweight

In this workflow, a PwO could research the program after discussion with the provider, navigate cost and coverage with their insurance company or the program directly, and decide to sign-up with a code or coupon. Several PwO described the coupon or code as a valued incentive or a "push" to act.

> "Well, doing it on your own is kind of an elective choice. Doctor giving you recommendations on fixing the issue probably makes it more really … an issue … [a referral from a primary care provider] might give some people more comfort. Honestly, like okay, let's do this. Well, it's like more confidence, maybe it would be the push that they needed to get started on a healthier lifestyle, healthier path." -Female, age 23 years, less than high school, unemployed, married, overweight

Some PwO indicated a preference to pick up a coupon in a waiting room rather than direct receipt from a provider. Other PwO indicated a preference for the provider's office to manage a referral to a commercial weight management program in a manner like the existing workflow for specialist referrals.

> "It feels like they put [traditional referral within health system] back on me. I would have preferred that they had taken the reigns and set something up, but my recollection is they just suggested a couple of things and it was on me to determine that these other people were in network or wherever, and all that." -Male, age 42 years, post-graduate, full-time, married, slightly overweight

Follow-up, accountability, and care coordination expectations. Participants anticipate that a referral implies a partnership in pursuing weight management. As such, PwO see themselves as accountable to the provider in that they agree to the referral, will start the program, and will participate in the weight loss attempt.

> "Overall, I think it would help being held accountable through a program, and I'm more of a person that everyone has to be on a system, planned out. If I have a schedule to follow, actually I will hold myself more accountable. Also, if I am seeing doctors, I just feel like it would definitely help me, push me to where I need to be. Then ultimately help with my overall health." -Female, age 40 years, some college, unemployed, divorced, somewhat overweight

In turn, providers are expected to follow-up with the PwO to evaluate progress, suggest changes in treatment, and make modifications to their care plan.

> "Hopefully, the doctor would want to check in with me, and say, alright, what did you do? Were you doing in-person interviews, were you doing it online? I think I would want to know that I have that communication available to me." -Female, age 45 years, post-graduate, part-time, married, overweight
>
> "Maybe add a medication, change something, change the doses, take a medication or two off my list." -Male, age 40 years, GED, unemployed, single, very overweight

Participants envision that the partnership model includes the commercial weight management program and that the program could share the participant's progress with the referring provider to facilitate care coordination.

> "Yes, because I would consider it a partnership if he made that suggestion and I'm following that program, then I would expect him to have vested interest in how I'm doing." -Female, age 34 years, college, full-time, married, overweight
>
> "If they're sharing the information, I would expect him to evaluate my progress or no progress, whichever case it is. If they are sharing everything. Whatever it is they tell you, I would expect them to follow up on that and talk to me about it. If anyone of them sees any sort of progress I would expect someone to contact me with the information. If they are doing something for my benefit, I believe the more information they have or they share, it's going to be in my best interest instead of hiding anything between them." -Male, age 54 years, college, full-time, married, overweight

Participants anticipate that providers, or their designee, would call, email, or text them about changes to medication when weight loss is achieved. Some PwO anticipate that the provider would routinely address progress, maintenance, and relapse during care visits.

> "Oh, I think that would be fantastic because that's saying that it's not just a one and done, but he really believes in the change that needs to take place in my own life … if you are following up in 3 months, 6 months, whatever, there is an accountability that is there, and it's also a piece that allows him to better assist and serve my needs." -Male, age 42 years, college, full-time, married, overweight
>
> "That would actually show that they care a lot and they are not just there for the paycheck, just shipping you off to somebody else." -Female, age 23 years, less than high school, unemployed, married, overweight

Data privacy, security risks, and ethical challenges. The concept of data sharing directly between the provider's office and a commercial program, regardless of whether this was for arranging a referral or coordinating care, raised concerns about data security and privacy for some PwO. Clearly written disclosures and limited data sets (weight, height, obesity comorbidities but not social security number) were mentioned as strategies to address these concerns.

> "It would be good to have a disclosure or something that limits [commercial weight management program] as to what they can have specifically." -Female, age 65 years, college, full-time, married, a little overweight
>
> "As far as my weight and height, I don't care, but if it has my social security on it, that would concern me. But just basic information about my height, weight, age, I don't think that would be a problem for me." -Female, age 45 years, post-graduate, part-time, married, overweight

Participants perceive that their health data are protected and secure in the health sector but have the potential to be ""hacked" or "sold" in the commercial sector.

> "I think the doctor's office probably has extensive protection on their computers … I don't know how well [commercial weight management program] would." -Female, age 44 years, some college, unemployed, divorced, obese
>
> "I am worried about my information getting sold to everybody and their brother" -Male, age 40 years, GED, unemployed, single, very overweight

Other PwO were ambivalent noting that much information is publicly available and shared in social media. Participants raised concern about provider and program integrity if a financial relationship was suspected in that the provider receives payment for program referrals. Participants speculated that such a relationship could lead to biased program referrals that may not be in the patient's best interest.

> "I would prefer a choice, that way I wouldn't think that there was some type of kickback or referral system in place." -Male, age 50 years, college, full-time, overweight

4. Discussion

These findings give voice to PwO regarding how providers can engage them in discussions about weight management, their expectations for advice about treatment choices, how to involve them in decision making, and the potential to refer PwO to commercial weight management programs. Our findings suggest that PwO are not seeking treatment from healthcare providers because the quality of care they have received has been poor and leaves them frustrated. PwO may also experience weight-related social stigma from providers and therefore delay in seeking treatment (13). This stigma further isolates patients and reinforces self-management. PwO therefore feel they lack guidance for their weight loss approaches due to a lack of information regarding impactful lifestyle changes, medications, and surgical options that may help them. Treatment care gaps identified in nationally representative cross-sectional studies reemerged in this qualitative inquiry (1, 2). Consistent themes were the identification of having obesity, a desire to lose weight, multiple attempts to lose weight, limited advice-seeking from a healthcare provider, and obesity self-management independent of medical oversight.

Consistent with expert recommendations on patient-centered care (14), PwO expect productive and meaningful patient-provider discussions about weight management, advice, and arrangement of referrals for obesity. While providers deprioritize addressing obesity, patients would highly value provider input. PwO are willing to have discussions on obesity if providers approach the topic professionally and with effective advice. Interactions with providers are hoped to be compassionate and informative about their condition. PwO have a strong desire to be involved and informed about their obesity and how it interacts with their comorbidities. PwO also want providers to be competent enough with obesity management to give varied options or to offer a personalized plan. Our findings are consistent with an Australian qualitative study investigating patient expectations related to chronic disease management that found patients expected health outcomes to result from patient-provider interactions, available treatment options, and their own actions (15). Although obesity is considered a medical disease, it is not often treated as one, leaving patients to address it themselves.

Robust interest in referrals for obesity treatment in the community-commercial sector, outside the traditional US healthcare system, is a unique finding that is perhaps explained by PwO self-management due to limited care and referrals. An Australian study observed that patients distinguished between individual provider agency and the healthcare system in treating chronic disease, whereas our findings suggest that PwO expect providers in the US to be competent and to offer referrals to evidence-based programs (15). PwO offered critique about providers, but less about the healthcare system, *per se*, and instead offered insight to potential system solutions. As stated, PwO experienced vague advice, non-routine follow-up, and few referrals. Regarding competency, providers receive minimal training and education in obesity management (4, 5). Despite the USPSTF standard of care for obesity being the provision of behavioral lifestyle advice and follow-up care in the office or making referrals, few providers do this and do it well (3, 4). Regarding non-routine follow-up, cross-sectional research found that only 24% of PwO had a scheduled follow-up to initial weight-related conversations (2). In addition, structural barriers, like time constraints on appointments, can manifest in the clinical decision to deprioritize time-intensive behavioral lifestyle counseling.

Referrals may be a promising solution given the conceptual, structural, and cultural barriers, specifically weight stigma, that interfere with providers' communication of behavioral treatment strategies (16–18). PwO endorsed the idea of receiving direct referrals from their provider to effective obesity treatment programs in the community-commercial sector, a strategy with demonstrated feasibility and effectiveness in United Kingdom but not yet available in the US (7, 8). Advice given in a clinical appointment could then be implemented by programs in the community-commercial sector, especially if data regarding the PwO's care plan could be shared between these two entities. Privacy and security concerns would need to be addressed as well as the communication flow, primarily to ensure that the PwO has consented to receive the referral. This solution could dually address the provider's dwindling time with the PwO and shortfalls in provider competency, ensuring that personalized care with focused time for behavioral counseling in weight management could be delivered by trained and competent professionals. Patient education about how to choose an effective obesity treatment program may be warranted and paired with clinical communication to support shared decision making and referrals that will result in participation.

Treatment and maintenance costs were pervasive concerns, as they are with other chronic diseases, but PwO prioritize the need for system changes to better treat obesity. Presently, there are opportunities to meet their needs. The USPSTF concluded with moderate certainty that offering or referring PwO to intensive, multicomponent behavioral interventions would have a moderate net benefit (B recommendation) (3). Under the Affordable Care Act, most employer-sponsored insurance plans are required to cover, without cost-sharing, evidence-based USPSTF recommended preventive services that have a rating of A or B (19). Coverage for preventive services without cost-sharing applies only to Medicaid expansion and others enrolled in Alternative Benefit Plans (19). Coverage under Medicare Part B is more limited but provider-delivered weight-management is covered for PwO (19). Conservatively, if 35% of US adults have obesity (3) and more than 20 million adults are covered by private or Medicaid expansion (19), then 7 million PwO may be able to access weight management interventions, if available. The community-commercial sector could play a critical role in increasing the availability of interventions and promote referrals from the healthcare sector.

The strength of this study is insights from PwO regarding their experiences in clinical care, expectations, and opportunities for enhanced treatment outside of the traditional healthcare system. The study included a US sample with voices in rural, urban, and suburban areas that self-identified as having overweight or obesity. Qualitative methodologies offer insight into experiences and perceptions, but the findings do not represent, nor are they generalizable to, a broader and larger cross-section of the US population. Additionally, qualitative data interpretation is subject to bias, though triangulation strategies were employed to minimize bias.

Obesity is known to be a chronic medical condition yet is not routinely addressed by providers. PwO identified perceived roadblocks to care that are mainly based on non-specific advice, limited information about treatment options and follow-up care, and few referrals. Effective community-commercial programs as a referral option is an acceptable concept to address this care gap and may advance progress in achieving public health goals but research is needed to determine feasibility in the US healthcare system.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The study was approved by the Geisinger Institutional Review Board [2019-0292]. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

LB-D, AP, CR, CS, and GF contributed to the study conception and design. Material preparation, data collection, and analysis were performed by LB-D, AP, and DH. The first draft of the manuscript was written by LB-D. LB-D, AP, DH, MC, CR, KM, CS, and GF commented on the previous versions of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

LB-D and CS received a research grant from WW International, Inc. AP was employed by WW International, Inc. during the design phase. CR was employed by WW International, Inc. during the conduct of the study. GF and MC are employed by and are shareholders of WW International, Inc.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1190443/full#supplementary-material

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"*Healthcare should be the same for everyone*": perceived inequities in therapeutic trajectories of adult patients with lung cancer in Chile, a qualitative study

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Background: Globally, it has been reported that different social determinants of health affect health outcomes in lung cancer (LC). Research on the therapeutic trajectories of patients (TTP) is a novel field for identifying barriers and facilitators in health. The objective of this study was to reveal perceived differences in TTP with LC in Chile according to selected social determinants of health (SDH) and the experiences of patients, health professionals, and civil society leaders.

Methods: This is a qualitative paradigm, one case-study design. Online semi-structured interviews were conducted with patients with LC, health professionals, and civil society leaders. The strategies for the recruitment process included social networks, civil society organizations, health professionals, and the snowball technique. A thematic analysis was carried out.

Results: Selected SDH impact LC's TTP in Chile, particularly concerning health system access, health services, information, and patient navigation experiences. The analysis of the experiences of the participants allowed us to identify barriers related to the selected SDH in three stages of the TTP: initiation, examinations, and diagnosis and treatment. Individuals with limited education, those residing outside the capital, women, and those in the public health system encountered more barriers throughout their TTP.

Discussion: Study findings suggest that being a woman with low education, from the public health system, and not from the capital might represent one of the most powerful intersections for experiencing barriers to effective healthcare in LC in Chile. It is necessary to monitor the TTP from an SDH perspective to guarantee the rights of access, opportunity, quality, and financial protection.

KEYWORDS

therapeutic trajectory, lung cancer, social determinants of health, inequity, voice of patients

Introduction

Worldwide, lung cancer (LC) is the second most diagnosed (11.4%) and the first in mortality, responsible for 1.8 million deaths according to the World Health Organization and Global Cancer Observatory (GLOBOCAN) (1, 2). LC mortality has a heterogeneous distribution in the population according to the social determinants of health (SDH) model. Some SDH that have been identified that can influence health trajectories and outcomes are being a woman (3, 4) having a low socioeconomic and educational level (5), type of health insurance (6), and place of residence (7).

In Chile, LC is fifth in incidence (7.3%) and first in mortality (12.4%) (8), and is recognized as a significant public health problem globally. Since 2019, LC has been incorporated into the law on explicit health guarantees in Chile (AUGE/GES). This law establishes the maximum waiting time for receiving care in the suspicion, diagnosis, and treatment stages. Furthermore, it guarantees access to high-quality services for all citizens regardless of age, sex, socioeconomic status, or health insurance (9). Regarding health insurance, Chile has a segmented system divided into public and private. Public insurance is the National Health Fund (FONASA), with 75% of the population covered, including those lacking resources and low education (9). The private system has Social Security Institutions (ISAPRES) as insurance (9). The service provider network is not integrated and generates barriers for patients across many health conditions and health needs, including cancer (10).

Research on SDH in LC in Chile is scarce; however, different mortality patterns are identified, for example, a rise in the crude mortality rate in women (11, 12), and an increase in mortality rate as the years of schooling decrease, even after adjusting by age and sex (13). A previous research reported that the general mortality from cancer in people with a low educational level doubles that of people with a university level (14). Regarding the place of residence, differences have been identified in the risk of dying from cancer according to the region of the country; in LC, the highest risk of dying is in the country's northern regions (12). This difference may be related to barriers to effective care (15).

A novel research approach to therapeutic trajectories of patients (TTP) contributes to a deeper understanding of patient experiences and identifies barriers and facilitators to accessing effective care (15). TTP has been defined as the complex and dynamic path a person—and their significant ones—follow in search of solutions to their health problems, including clinical assistance, treatment, and rehabilitation (16). This concept incorporates the multiplicity of needs and experiences that a person interacts with the health system (17) and the processes carried out by the health system to provide quality care (18); furthermore, TTP addresses the different stages of the disease process (beginning, diagnosis, treatment, and following), shedding special light on the voices of patients, significant ones, and other relevant actors like healthcare teams (18, 19).

There is relevant international literature on TTP, indicating that cancer is extensively studied in this research area (17), specifically through the patient navigation model (20). This model defines patient navigation (PN) as the support and guidance offered to individuals with abnormal screening tests or a new cancer diagnosis to access the cancer care system and overcome barriers (21). PN is currently used as a strategy to optimize healthcare for subgroups of cancer patients that face more barriers and, therefore, less access to healthcare (20, 22, 23). Studies on the impact of PN programs in cancer have reported a significant reduction in time to diagnosis and treatment initiation (24) and a reduction in inequities in access to healthcare (25). For this study, PN and TTP are used as synonyms.

Previous research in Chile on the SDH of LC has revealed significant differences in cancer incidence and mortality (3–7). However, how the TTP of LC patients might be influenced by different SDH models is heavily understudied. This article aims to reveal perceived differences in TTP of adult LC patients in Chile according to selected SDH: gender, educational level, region of residence, and type of health, according to the experience of patients, health professionals, and civil society leaders. These results complement a previous study by the researchers (26). Considering the impact of PN programs to decrease inequities in cancer, delving into the influence of the SDH on the TTP of cancer patients in Chile is essential to seek mechanisms that might explain these differences and to propose novel solutions for health system improvement in Chile and other countries.

Methods

Study design

We conducted a qualitative study with an exploratory approach (27) that allowed us to understand a less-known phenomenon, such as the TTP and SDH in LC in Chile, to begin our knowledge of the object of study. The study followed a case-study design, which enables an in-depth exploration of the phenomena in their naturally occurring context, involving the study of a bounded system (or case) within a contemporary setting through detailed, in-depth data collection (28). A case study was defined as the experience of the TTP of adults with LC in Chile with a focus on the influence of selected SDH in these trajectories. The study design followed the COREQ criteria (Supplementary Table 3).

Participants

The number of participants was defined based on theoretical and feasibility criteria (27). At the beginning of the study, theoretical sampling establishes the profile of the study participants (29). The sampling units were threesome: (i) LC patients, (ii) health professionals who treat LC patients, and (iii) civil society leaders linked to LC. Given the focus on the complexity of the phenomena studied, qualitative research works with a few cases to deepen the meaning of the object of study, understanding reality through methods and techniques that produce narrative data (27). The number of participants was 18 patients, 8 health professionals (public and private health), and 1 civil society leader (total $n = 27$). The inclusion criteria for each group of participants are in Table 1. The exclusion criteria for all participants were a physical or mental condition limiting the person's ability to participate voluntarily in the study. The participants' decision-making capacity was assessed using the MacArthur criteria (30) during the informed consent process, ensuring their comprehension of the research project's information and implications. This encompassed awareness of potential effects, reasoning ability in decision-making, comparing alternatives and evaluating consequences, and freedom to express their choice in participating. Saturation of the information was assessed in the following dimensions: general TTP (beginning, diagnosis, and treatment), barriers, facilitators, needs, quality of care, and overall experience. After interim data analysis was conducted, information saturation was observed for all main dimensions of interest, and hence, we did not add participants to the sample size.

All participants were characterized demographically (Table 2). To address the absence of a civil society leader dedicated exclusively to LC in Chile, we interviewed a civil society leader from Argentina.

Recruitment and data collection

The recruitment process was carried out between October 2021 and March 2022. Strategies for recruiting patients included social networks, civil society organizations, health professionals, and the snowball technique (31). Interested participants provided contact information (telephone or email). Later, they were contacted by the study coordinator. In the case of agreeing to participate, the coordinator schedules the virtual, semi-structured interview. For health professionals and civil society leaders, recruitment was based on a mapping of relevant actors conducted by the research team. They were contacted via email and telephone, following a similar process as other participants. Virtual semi-structured interviews (Zoom, WhatsApp, and Meet) were conducted due to the COVID-19 pandemic, allowing access to patients in different regions using a pre-defined script based on the study's objectives (27). Sociodemographic data (age, sex, health insurance, region, and education) were collected at the beginning.

The semi-structured interview script included the following dimensions: (i) general therapeutic trajectory; (ii) barriers to healthcare; (iii) healthcare facilitators; (iv) health needs throughout the therapeutic trajectory; (v) quality of care; and (vi) overall evaluation of the experience. Table 3 presents the areas explored and the questions used for each group of participants. Interviews were facilitated by two trained staff, audio-recorded, and securely stored on a personal computer. During the interviews, patients could request to be accompanied by a family member.

Data analysis

Based on audio records, a verbatim transcription of all the anonymized interviews into Microsoft Word was made. Two members of the research team confirmed the transcripts of the interviews. Each interview was assigned a unique code to ensure participant information and confidentiality. Deductive thematic analysis was carried out manually using an interview matrix, a qualitative method that allows for identifying thematic patterns from the data collected (27). Information was organized based on categories according to pre-defined dimensions identified in the literature on therapeutic trajectories in cancer. In each category, codes were identified that were accompanied by participant quotes. This analysis delves into each TTP dimension from the SDH lens based on the following additional dimensions: educational level, gender, region of residence, and type of health insurance. Each TTP dimension was described in depth based on codes that specifically described each stage of the navigation process for adult LC patients (Table 2). For publication purposes, the research team translated the textual citations from Spanish to English and ensured accurate interpretation.

Rigor

The study applied the following rigorous criteria: triangulation of responses from participants (patients, health professionals, and civil society leaders) and reflexivity notes were considered (28, 32). Triangulation contrasted and compared participant groups' findings to obtain a more precise and comprehensive understanding of the studied phenomenon. Reflexivity entailed recording researchers' reflections, emotions, observations, and methodological decisions during interviews, enabling critical self-evaluation and regular research approach reviews with the investigation team.

Results

The selected SDH had an influence mainly on access to the health system, access to health services, access to information, and navigation in the health system. The results identify three specific moments where the SDH was influencing the TTP: (i) beginning, (ii) examinations, and (iii) diagnosis and treatment. Additionally, the results revealed that gender consistently influences the entire therapeutic trajectory. Results are summarized in Table 4.

SDH influence at the beginning

Participants perceive that an incomplete educational level acts as a barrier that impacts the time people decide to make an initial consultation for symptoms or signs, such as cough, tiredness, and fatigue. Unfortunately, these symptoms are known by patients and are associated with colds or other causes, and they do not provide immediate warning signs to patients, delaying the first cancer consultation. Patients with complete education show a better understanding of their health status and knowledge of medical benefits. Moreover, empowerment is observed in the medical-patient relationship, which allows them to express their requirements and be considered in medical decisions.

> *"Probably access is much easier for a patient in the private area, usually due to socioeconomic issues, it is a patient who has a higher level of schooling and education and that also*

TABLE 1 Inclusion criteria for patients, health professionals, and civil society representatives.

Patients	Health professionals	Civil society leader
Inclusion criteria		
(i) Over 18 years of age. (ii) Being treated for lung cancer in the healthcare public or private system in Chile. (iii) Having Internet access or telephone to participate in the interview.	(i) Working in the Chilean public or private health system. (ii) Being a specialist in any health profession in lung cancer. (iii) Having Internet access to participate in the interview.	(i) Over 18 years of age. (ii) Participating with an active role in civil society organizations related to lung cancer. (iii) Having Internet access to participate in the interview.

> *favors earlier diagnoses and in people with low resources and low educational level there is not much awareness that it is necessary to consult" (EU1M-PUBLIC/PRIVATE)*

The type of health insurance also generates differences at the beginning of TTP. Patients with private insurance who consult for respiratory symptoms can access a physician much sooner, who then requests tests to assess their health status, including imaging tests. This evaluation allows for early suspicions of LC and subsequent diagnosis.

> *"In August 2012, I had a very, very strong cold with a lot of decay, unusual for the colds I always had, and I went to a doctor here in the region and [SIC] sent me to do many tests, like a complete check-up, and among those tests, there was a chest scan...there it appeared, when the test was done, a nodule in the right lung" (P11M-PRIVATE)*

Contrastingly, the request for imaging tests for patients with public insurance with similar symptoms is not as frequent. Therefore, some patients with public insurance make their first consultation in the private system due to delays and mistrust of the public health system. After this first consultation, these patients receive a medical order to have an imaging exam (CT, MRI, or RX); however, they cannot afford to pay out-of-pocket for them and therefore return to the public system. If patients undertake their first consultation in primary care, they can access only a general physician without experience with LC and receive a diagnosis of other diseases.

> *"I decided not [SIC] go directly to a, to..., to the Cesfam* (primary healthcare) *that are so tedious because they attend you and they never give you the result of anything, they make you wait in excess" (P13H-PUBLIC)*
>
> *"Primary Health Care physicians don't know that lung cancer exists, they do not diagnosis." (M1H-PUBLIC)*

When suspicion of LC is established, people with public insurance experience new barriers related to the bureaucracy of the public system. Administrative and management barriers at the primary level of care are due to ignorance of how to navigate the system, long waiting lists, and a lack of equipment, to mention the most frequent ones. Sometimes, patients with public insurance are referred by primary healthcare physicians to perform specific exams in health institutions with a higher level of complexity or in the private system due to their unavailability in the public network. This situation produces worry and confusion because the system is not integrated, and patients must learn and understand how to access the new health institutions. Patient organizations contribute to addressing these situations.

> *"Occasionally I get confused in so many places… It's like having a horrible confusion, because if from one hospital they send you to another, from another… now they send me to the private clinic, they send me from one place to another, the truth is that I don't understand" (P13H-PUBLIC)*
>
> *"The biggest problem, I would say, is that in general, the health professional doesn't know who to refer to, because the patient must be referred to more than one specialist" (M2H PUBLIC)*
>
> *"Support to, to be able to resolve some critical issues that in the system appears, The patient in particular, due to his condition, is very difficult for him to overcome" (Soc. Leader)*

SDH influence in testing exams

Despite the fact that all interviewed patients with incomplete secondary education reported having public insurance, only some developed the entire TTP in the public system, largely due to delayed access to testing for the diagnosis of cancer. In order to afford private care, significant out-of-pocket spending was required, yet they chose it due to a lack of trust and long waiting lists in the public system. The mixed navigation of a proportion of patients with public health insurance becomes, at some point, a barrier of its own because the public and private systems are not sufficiently interconnected.

> *"The scanners, the magnetic resonance scanning, all those exams, the most difficult thing was to get the hours for that day... we didn't have the conditions to pay privately" (P7M-PUBLIC)*
>
> *"FONASA Patients arrive with their notification from a private practice that a doctor who requested a scan and found a suspicious nodule in neoplasia and they arrive, they are Fonasa patients and have to be treated here. A way to bring them was created because it was a mess" (M3H-PUBLIC/PRIVATE)*

Patients who fully navigate their TTP in the public system can also be referred to the private system when the waiting time for examinations or diagnosis is longer than the legal guarantee. In these cases, having a complete education is perceived as a facilitator because it allows the person to have more abilities to access and understand available information like what is guaranteed by law and how to demand its fulfillment.

TABLE 2 Socio-demographic characteristics of PARTICIPANTS.

Identification code	Health system	Gender	Age	Education	Region of residence
Patients					
P1F_PUBLIC	Public	Female	69	Incomplete	Metropolitan
P2F_PUBLIC	Public	Female	59	Incomplete	Metropolitan
P3F_PUBLIC	Public	Female	63	Complete	Metropolitan
P4M_PUBLIC	Public	Male	71	Complete	Other region (northern)
P5M_PUBLIC	Public	Male	77	Complete	Metropolitan
P6M_PUBLIC	Public	Male	65	Complete	Metropolitan
P7F_PUBLIC	Public	Female	76	Incomplete	Metropolitan
P8M_PUBLIC	Public	Male	63	Complete	Metropolitan
P9F_PUBLIC	Public	Female	56	Incomplete	Metropolitan
P10F_PUBLIC	Public	Female	80	Incomplete	Metropolitan
P11F_PRIVATE	Private	Female	64	Complete	Other region (southern)
P12M_PUBLIC	Public	Male	76	Complete	Other region (southern)
P13M_PUBLIC	Public	Male	67	Incomplete	Metropolitan
P14F_PUBLIC	Public	Female	66	Incomplete	Other region (northern)
P15M_PUBLIC	Public	Male	60	Complete	Other region (northern)
P16M_PUBLIC	Private	Male	73	Complete	Other region (southern)
P17M_PUBLIC	Public	Male	64	Incomplete	Other region (northern)
P18M_PUBLIC	Public	Male	76	Incomplete	Metropolitan
Health professionals					
Identification code	Health system work	Gender	Age	Medical specialty	Region of work
M1H_PUBLIC	Public	Male	63	Oncologist	Metropolitan and northern
M2H_PUBLIC	Public	Male	37	Oncologist	Metropolitan
M3H_PUBLIC/PRIVATE	Public/Private	Male	49	Thorax surgeon	Other region (southern)
M4H_PUBLIC	Public	Male	35	Oncologist	Metropolitan
M5H_PRIVATE	Private	Male	54	Hematooncologist	Metropolitan
M6H_PUBLIC	Public	Female	-	Oncologist	Other region (northern)
EU1_PUBLIC	Public	Female	31	Nurse	Metropolitan
EU2_PUBLIC/PRIVATE	Public/Private	Female	38	Nurse	Metropolitan
Civil society leader					
Identification code	Work	Gender	Age	Specialty	Country
Soc. Leader	Patient foundation	Male	52	Economist and public policy	Argentina

For patient participants, complete education is 13 or more years of schooling, and incomplete education is <13 years.

> *"The deadline expired. It was a month for them to give me attention and it was not like that, and I asked the second provider and I was referred, well, I also asked for a place that was... that was more advanced and they sent me to Santiago" (P15H-PUBLIC)*

People with public or private insurance who do not reside in the Metropolitan region describe barriers related to the quality of the exams carried out in regions and lower access to testing hours. In addition, the patient and family must cover the expense of travel, accommodations, and food to get to the metropolitan region or another region nearby where they can take their examinations. In this case, the centralization of health institutions and specialists is a critical barrier for patients who live in other regions despite having health insurance.

> *"The first thing that even the doctors tell you…go to Santiago, and one arrives in Santiago with the regional exams, they don't take them into account and they take them again…so it's all a waste of money for people" (P11M-PRIVATE)*

TABLE 3 Dimensions, codes, and questions of interview and analysis.

Participants	Dimension	Code	Questions
Patients	General experience	General health status	How is your current state of health?
	Therapeutic trajectory	General experience	How would you describe your therapeutic trajectory?
		First symptoms and access	What were the first symptoms? How did you detect them? Why did you decide to consult?
		Diagnosis process	How was the diagnostic process? Can you mention all the details that you remember?
		Treatment process	How was the treatment process? Can you mention all the details that you remember? How do you feel that the treatment has affected your life in general?
	Barriers and facilitators	Barriers	What barriers did you face to achieve the entire process of diagnosis, treatment and recovery, if applicable, for this disease? At what point in your therapeutic trajectory did you face those barriers?
		Facilitators	What facilitators did you face to achieve the entire process of diagnosis, treatment and recovery, if applicable, for this disease? At what point in your therapeutic trajectory did you face those facilitators?
Health professionals	Therapeutic trajectory	General information	How would you describe the therapeutic trajectory in the health system?
		Times in therapeutic trajectory	Do you identify differences in the time of diagnosis or treatment between health institutions (i.e., public, private, or region)?
	Barriers and facilitators	Barriers	What are the barriers to the therapeutic trajectory of the patient? At what stage of the therapeutic trajectory do these barriers appear? What barriers are from the health system, and what barriers are from the user or his family?
		Facilitator	What are the facilitators in the therapeutic trajectory of the patient? At what stage of the therapeutic trajectory appear these facilitators? What facilitators are from the health system, and what barriers are from the user or his family?
Civil society leader	Therapeutic trajectory	General information	How would you describe the experience of living with lung cancer? How would you describe the therapeutic trajectory of patients with lung cancer? Please consider the activities the patients had to carry out in the health system for diagnosis, treatment, and recovery.
		Diagnosis process	How is the diagnostic process?
		Treatment process	How is the treatment process?
	Barriers and facilitators	Barriers	What barriers do patients with lung cancer have to face to achieve the entire process of diagnosis, treatment and recovery, if applicable, for this disease? At what moment of the therapeutic trajectory do those barriers appear?
		Facilitator	What facilitators do patients with lung cancer have to face to achieve the entire process of diagnosis, treatment, and recovery, if applicable, for this disease? At what moment of the therapeutic trajectory do those facilitators appear?

SDH influence on diagnosis and treatment

Diagnosis and staging of LC are mainly obtained using scanners or biopsies. Differences in opportunities for these tests are perceived among participants based on education and health insurance. In addition, differences are recognized in how people express cancer information. People with an incomplete education provide information according to size, and people with a complete education provide information about size and stage. These differences may be related to how health professionals communicate with people with an incomplete education, which is unclear and possibly generates false expectations.

> *"They did a scan and mmm..., and they saw it was a tiny tumor" (P9M-PUBLIC).*
> *"I know that I am in stage four, terminal" (P3M-PUBLIC)*

During treatment, it is also possible to identify perceived differences in TTP with LC related to education, health insurance, and region of residence. Patients with public insurance with incomplete education perceived having complex treatments, such as chemotherapy, radiotherapy, surgeries, and immunotherapy. This is perceived to be associated with more severe stages of the condition at diagnosis for patients with these characteristics. The same perception is reported by healthcare teams. Patients with complete education and public health insurance were perceived to have fewer treatments, for example, surgeries or chemotherapy. Experiences of access to treatment of patients with public insurance are varied, with patients who access the treatment and others who are still waiting. In the case of patients who are not from metropolitan region, as in the other stages of the TTP, the barriers are associated with access due to the lack of infrastructure of local health institutions.

> *"For a long time with immunotherapy, then the immunotherapy stopped giving results, back to chemo and then they diagnosed the brain metastasis started with radiotherapy, ten sessions and also combined with chemo, that is, it was quite a bomb"[SIC] (P10M-PUBLIC)*

TABLE 4 Barriers and facilitators in lung cancer patient's trajectory from a SDH perspective.

SDH involved	Therapeutic trajectory stage	Barriers	Facilitators
Education level	Beginning	Delay in initial consultation.	Knowledge about health status. Empowerment in medical-patient relationship. Knowledge about health guarantees.
	Diagnosis	Access to scanners or biopsies. Unclear information about characteristics of diagnosis.	
	Treatment	Access to treatment.	
Health Insurance	Beginning	Physician without experience in lung cancer. Unavailable exam in the public network. High costs for imaging exam. Bureaucracy. Difficult navigation in the health system for administrative and management process. Not integrated public health network. Not integrated public and private health network.	Earlier access to a physician. Access to a requests tests to asses health status.
	Diagnosis	Access to tests. Unclear information about characteristics of diagnosis. Physician-patient relation.	
	Treatment	Access to treatment	
Place of residence	Beginning	Quality of the exams. Access to testing hours. Centralization of health institutions and specialists.	
	Diagnosis	Travel to get a diagnosis.	Regional center public institutions.
	Treatment	Access to treatment. Lack of infrastructure of local health institutions.	Regional center public institutions.
Gender	Beginning-Diagnosis-Treatment	Female. Loneliness. Changes of living roles.	Male. Company. Motivation.

> *"In private centers what they find is stage 1, that is, there are small nodules...the patient with early stage lung cancer is potentially curable" (M1H-PUBLIC)*

Gender as a cross-cutting SDH during TTP of LC patients

Gender is perceived to influence the TTP and LC profoundly. Male patients are generally accompanied by a woman throughout the whole TTP, either the wife, the daughter, or the granddaughter. In the case of female patients, the beginnings of TTP are lonely, and the motivation to recover is associated with their caregiving role. In addition, having to leave these roles due to the progress of the disease generates discomfort and anger.

> *"Look, at us, my husband was diagnosed, he was diagnosed because I took him to the doctor, because he had a lot of cough" (P13H-PUBLIC)*
>
> *"I didn't tell my children, I went to the hospital by myself, that's how it was" (P2M-PUBLIC)*

Discussion

This study explored through qualitative research the perceived influence of SDH during the TTP with LC in Chile, according to patients, healthcare teams, and leaders of LC organizations. The qualitative approach to the study problem has been recognized as relevant for addressing health inequalities (33, 34). Qualitative studies have focused on investigating the causes of delays in LC diagnosis.

Our study allows us to identify that people with incomplete educational levels (under 13 years), residents of regions outside the metropolitan area, women, and those belonging to the public health system face more barriers and fewer facilitators during their TTP. Herb et al. (35) identified that barriers during TTP can impact timely access to healthcare and health outcomes. In the case of Chile, the differences identified in our study related to SDH can influence the time to access and health outcomes, but more studies are necessary.

Other studies identified delays in the patient's decision to seek the initial consultation related to the type of symptoms, knowledge, fear, and cultural patterns (34, 36). Our study recognizes education level and the healthcare system as the leading social determinants impacting the decision to consult and being associated with less empowerment of patients in their relationship with the healthcare system and providers. These results are similar to those obtained by Sayani et al. (37), and Saab et al. (38), making it possible to recognize patterns of inequities in LC at a local and global level. In this context, primary healthcare is relevant to address this inequity; unfortunately, our study results identified important barriers in primary healthcare related to TTP, including professionals lacking experience or knowledge in suspecting LC, delays in test management and results, and administrative processes that complicate patient navigation.

Although the results of our study reveal that educational level and the health system generate the most significant number of barriers, place of residence and gender have been less studied and also generated barriers during TTP. Our study suggests that living outside of the Metropolitan region of the country is also a negative SDH for the TTP of LC patients, despite the patient's health insurance. This situation might be secondary to a lack of sanitary infrastructure for diagnosis and treatment. This reality deepens socioeconomic health inequities in the country due to long waiting lists, late diagnosis, and personal/family travel costs and accommodation to other regions to accelerate the time to diagnosis and treatment (39, 40).

Interestingly, gender was perceived as a deep, structural, and cross-cutting SDH of the TTP with LC in Chile. Barriers related to conventional gender stereotypes such as housekeeping and caregiving (41, 42) were constantly described throughout the TTP. The therapeutic trajectories of male patients were generally perceived to be accompanied by a female family member. On the contrary, the therapeutic trajectories of female patients were vastly described as lonely. Loneliness can influence individuals' motivations and relationships with the health system during the entire navigation (42). From an intersectional lens (43, 44), being a woman with low educational attainment in the public health system and not a resident of the metropolitan region might represent one of the most powerful intersections for experiencing barriers to effective healthcare in LC in Chile.

To overcome unequal therapeutic trajectories in LC, Chile must invest and implement specific strategies to involve patients in their healthcare (45) and in a patient-centered care model (46) to secure effective trajectories for these patients, including subgroups that are left behind based on evidence-informed SDH (47–49).

This is the first study in Chile to describe the influence of selected SDH in the TTP of LC from different actors and using a qualitative perspective. Hence, the study highlights the voice and experience of patients as well as health professionals and civil society leaders. The qualitative approach allowed us to explore emerging specific aspects related to the existing inequities based on a SDH lens.

This study has both strengths and limitations. Limitations are as follows: (i) limited representation of multiple and diverse existing subgroups in the country (ethnicities, regions of residence, etc.) and (ii) the difficulty of accessing patients with more severe stages of LC, which made it impossible to analyze the following stage. Despite the limitations, we believe this study contributes with a unique and unprecedented vision around the perceived influences of several SDH on the TTP of LC patients. Future studies could consider expanding sampling strategies to other population groups, adding other SDH such as age, type of occupation, and marital status, as well as mixed methods to integrate qualitative with quantitative data for a better understanding of this phenomenon.

Study findings suggest that selected SDH might play an essential, interactive, and changing role throughout the TTP in LC in Chile. To guarantee the rights of access, opportunity, quality, and financial protection, it is necessary to monitor the TTP from a SDH perspective.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by the Ethics Committee of the Faculty of Medicine of Universidad del Desarrollo. The participants provided their written online informed consent to participate in this study.

Author contributions

CC, BC, and AO: conceptualization and study design. CC and FV: data collection and data analysis. CC and BC: manuscript writing. AO and FV: review and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1228304/full#supplementary-material

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Cross-cultural metathemes of Chinese and Japanese university students' perspective on parental care

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Introduction: Due to declining birthrates and aging populations, parental care is going to place a greater burden on younger generations in the future, especially in East Asia where it is more common for children to provide care regardless of whether there is a national long-term care insurance program. Therefore, it has become important to understand the younger generation's views on parental care.

Methods: An explorative, metathematic qualitative study design was used. Data collection relied on semi-structured interviews, of which 19 Chinese and 19 Japanese university students were conducted from December 2021 to July 2022 using a snowball sampling method. Metatheme analysis was then used to identify broad cross-cultural metathemes and inter-relationships on parental care.

Results: Three parental care metathemes were identified for the perspectives of parental care: distrust of leaving parental care to others, responsibility to care for their parents, and importance of parent-child interactions about parental care.

Conclusion: To improve social support for care, both countries must improve long-term care service delivery and healthcare systems and ensure that there is a trusting relationship between healthcare professionals and the public. Governments should also ensure that adult children receive assistance to balance their work, life, and parental care responsibilities. The findings provide several practical suggestions for improving healthcare systems in China and Japan through the younger generations' views.

KEYWORDS

parental care, health policy, cross-cultural study, China, Japan

1. Introduction

Japan has an aging population and a declining birthrate. Currently, Japan has the highest global percentage of people over 65 years old (28.4%), which is expected to rise to 38.3% by 2055 (1). Japan's total fertility rate has also fallen from 2.14 in 1970 to only 1.42 in 2018 and has continued to decline (2). Meanwhile, China has a rapidly aging society and a declining birthrate, the latter of which is falling faster than in Japan. In 2022, over 13.7% of China's population was over 65, which is expected to rise to 30.1% by 2050 (3). China's 1979 one-child policy has led to the 4-2-1 family, that is, single-child couples must care for four older adults and their child (4). As China's birth rate is now at a historic low (5), the government has introduced a three-child policy to encourage families to have more children; however, many young parents find that the cost of having children is too high and tend to only have one or two children. Consequently, parental care for this generation will be a serious social problem in the coming decades (6).

A strong sense of filial piety continues to exist in Asian countries (7). In Japan, a highly developed country, traditional norms of filial piety coexist with new independence norms. Because of Japan's significant demographic changes, that is, a rapidly aging population and declining birth rates, many children are expected to have difficulty caring for their parents, meaning that the public service need will continue to increase (8). In China, traditional Chinese norms of filial piety mean that to ensure continued happiness, children must respect their parents, live with them, and care for them, all of which involve sacrifice (9). However, due to rapid socioeconomic development, modernization, and globalization, Chinese perceptions and values regarding filial piety are changing and more social resources and cultural support for older adults are now being provided (10, 11).

Japan's long-term care insurance system, which was established in 2000, was implemented under the slogan "from care by the family to care by society," (12); and China's "Guidelines for promoting the development of national undertakings for the older adults and improving the long-term care service system during the 14th Five-Year Plan period (2021–2025)," which was submitted by the State Council of China in 2021, advocates both family and societal support for the older adults by strengthening community care service capacity and establishing a long-term care insurance system similar to the system in Japan (13).

The centering of the parent-child relationship in Japanese society means that children have obligations and responsibilities to their parents, which means the Japanese need to take care of their parents (14). Also, in China, because of the previous lack of a functioning long-term care system, young Chinese have been the main caregivers for older adults, and, even today, 90% of older adults are still dependent on familial care (15).

Therefore, this study examined the views of Japanese and Chinese university students to identify the commonalities and differences in family care and social culture values, the results from which could guide future healthcare system needs. These days, university students are less influenced by parental and secular influences and more by their peers. Therefore, it was expected that they may have different perspectives regarding parental care to their parents and would be more likely to be more hesitant in following traditional parental care norms (16).

Previous studies have found that parental care perspectives have changed rapidly over the past few decades, which has raised concerns about the future of parental care by the generation born under the one-child policy (17). For example, Bifarin et al. found that the single-child Chinese student perspective of parental care in the UK was related to family obligations and filial piety expectations, which emphasized the importance of cross-border and cross-cultural exchanges (18). Although filial piety remains rooted in the Chinese psyche, further studies are needed to compare China with other Confucian-influenced Asian countries undergoing social, demographic, and economic changes (19). On the other hand, despite demographic changes, socio-economic development, and Long-Term Care reforms in Japan influencing traditional caregiving values, parental care is an important but unresolved issue (20). Tanaka et al. found that caregiving sons experience psychological distress, leading to high rates of abuse of their parents (21). Studies highlight the importance of adult children, particularly the oldest son, as caregivers for their parents in Japan (22). Conversely, the declining trend of bequests for altruism in Japan resulted in the increasing use of care services (23), and parental caregiving behavior of Japanese adult children is also heavily influenced by both the strength of altruism and the strategic bequest motive (24). However, there are relatively few historical studies that focus on the comparison of the younger generation's perspectives between different countries. Therefore, this study integrated the parental care perspectives of adult Japanese and Chinese university students to reveal the steps necessary to allow similar societies to examine their care practices.

Declining birthrates, aging populations, and conflicts between traditional norms and public parental care policies have become major social issues in China and Japan. Therefore, this study sought to identify the parental care perspectives of Chinese and Japanese university students to guide the development of possible healthcare programs that could provide better future parental care.

2. Methods

2.1. Design and participants

This exploratory study adopted a metatheme approach using semi-structured interviews. Metatheme is a qualitative method for cross-cultural research, which provide an analytically significant pattern to describe those patterns in rich, contextually appropriate ways within cross-cultural data sets (25).

Participants were recruited from University A in Japan and university B in China. Inclusion criteria comprised enrolled Japanese and Chinese adult university students. The potential subjects were approached from the referral of the teachers in University A and B, who only introduced the purpose of the study and were blind to the study procedure for diminishing possible conflicts of interest. A snowball sampling method was used, whereby eligible participants were asked to link the researchers to other potential participants. Students who expressed an interest to participate received an information sheet. Students had at least 2 weeks to consider the participant after receiving the information sheet and being informed that their participation was entirely voluntary.

Twenty-one Japanese potential participants and 19 Chinese potential participants expressed interest. Two Japanese students declined for time constraints. As a result, 19 adult Japanese university students at University A in Japan and 19 adult Chinese university students from University B in China were recruited, which exceeded the minimum number needed for metathematic qualitative research saturation (26). The number of participants in each school year was also balanced to ensure accurate data representation. The participants were divided into four Japanese focus groups and two Chinese focus groups according to the participant's willingness and schedules.

2.2. Data collection

Data were collected from December 2021 to July 2022. Before the interviews, the study participants were informed that their participation was entirely voluntary again. Two interviewers then conducted 80-min focus group interviews (FGI) that followed the consolidated criteria for reporting qualitative research (COREQ) guidelines (27). The interviews were digitally recorded. During the FGIs, two researchers participated in Japanese focus groups and three researchers participated in Chinese focus groups as observers. The observers record the data and non-verbal communication such as facial expressions and raising hands to maintain a heightened level of perspective (28). To identify and compare their perspectives, it isn't allowed researchers' beliefs and assumptions to shape the process of data collection (29). Interviewers and observers were fully trained in interview methods before the FGIs (30). During the FGIs, interviewers and observers paid attention to participants' wellbeing, if anyone shows or expressed signs of discomfort, the FGI would be paused immediately.

The FGIs, which were conducted at the participants' respective universities, focused on several main questions, namely, how do you feel about taking care of your parents? What is important to you when caring for your parents? Finally, what are your perceptions and opinions regarding the use of care services to care for your parents vs. taking care of them yourself?

2.3. Analysis

All FGIs were recorded with the written informed consent of the participants, from which transcriptions were made. Metatheme analysis was then used to identify the broad cross-cultural metathemes and inter-relationships (25).

The data analysis was conducted as follows. First, each transcript was repeatedly read to ensure familiarization and gain an overall sense of the data. The materials were then categorized and separated into fundamental units for each country that were relevant to the study goals. After the thematic analysis was completed, a list of themes for each country was developed and the metathemes were identified. To ensure that the culturally situated meanings of the site-specific themes were not lost, all themes were translated into Japanese by researchers who could speak both Chinese and Japanese. After further comparison of the similarities and differences, sub-metathemes were then developed for the related or comparable codes, the classifications for which were developed by comparing and grouping the subcategories. After that, the metathemes were compared and distilled into a smaller set of metathemes. After multiple review rounds, further convergent metathemes and sub-metathemes were developed.

To ensure analytical rigor, Lincoln and Guba's four-dimensional criteria were used: (1) credibility, that is, checking the study participants who cooperated; (2) transferability, that is, describing in detail the phenomena obtained from the analysis; (3) dependability, that is, specifying the entire data collection and results acquisition process in a report; and, (4) confirmability, that is, conducting continuing discussions between the co-researchers and the research team to decide on the final themes with the assistance of two public health and qualitative research experts (31).

2.4. Ethics

Approval from the Ethics Committee of the epidemiology research department at our university was obtained. All procedures were conducted in line with the Helsinki Declaration. An information sheet explaining the study's goals, procedures, and ethical considerations was given to each participant, which also explained that they could discontinue or withdraw from the study at any time, that the interview would be recorded and their anonymity would be preserved, and that the study may be published in journals or presented at conferences. Participant agreement was obtained by signature. On the day of the FGIs, the researchers repeated this information before the interview and received verbal agreement again from the participants.

3. Results

3.1. Participant characteristics

Interview data were obtained from 19 Japanese university students and 19 Chinese university students. The participants were divided into four Japanese groups and two Chinese groups. The mean age of the Japanese students was 20.94 (SD = 3.05), and the mean age of the Chinese students was 20.84 (SD = 1.68). Table 1 gives the basic participant attributes.

3.2. Parental care

Three metathemes were identified for parental care: distrust of leaving parental care to others, responsibility to care for parents, and the importance of parent-child interactions about parental care.

3.2.1. Distrust of leaving parental care to others

This metatheme comprised four sub-metathemes (Table 2).

Because both the Chinese and Japanese participants had poor impressions of nursing homes, they had a distrust of leaving parental care to nursing homes.

> The atmosphere in the nursing home is not particularly good, and I don't think my parents would be properly cared for if they lived there. If children are forced to leave their parents in a nursing home, the parents will feel as if they have been abandoned by their children. (C-2)
>
> I have seen the daily news about nursing homes, about the abuse and neglect by caregivers. After I heard about such a tough situation, I could hardly believe that my mother would be properly cared for in a facility. (J-9)

Participants from both China and Japan had doubts about the competency and professionalism of nursing home caregivers to take care of their parents.

> I doubt the expertise of the caregiver. I want to care for my parents by myself as much as possible, as being cared

TABLE 1 Participant characteristics.

JPN No.	Gender	Grade	Age	Birth order	CN No.	Gender	Grade	Age	Birth order
J-1	Female	4	23	First-born child	C-1	Female	1	19	Only child
J-2	Male	4	22	First-born child	C-2	Female	1	18	First-born child
J-3	Female	3	21	First-born child	C-3	Female	2	20	Only child
J-4	Female	4	22	Not first-born child	C-4	Female	2	20	Only child
J-5	Male	4	23	Not first-born child	C-5	Female	4	22	Only child
J-6	Female	4	21	First-born child	C-6	Male	4	23	Only child
J-7	Female	3	20	First-born child	C-7	Male	3	21	Only child
J-8	Female	3	20	First-born child	C-8	Female	2	20	First-born child
J-9	Female	3	21	Not first-born child	C-9	Female	3	20	Only child
J-10	Female	3	21	Not first-born child	C-10	Female	3	21	Not first-born child
J-11	Female	3	20	First-born child	C-11	Male	3	23	First-born child
J-12	Female	2	19	Not first-born child	C-12	Female	2	20	Only child
J-13	Female	1	19	First-born child	C-13	Female	1	19	Not first-born child
J-14	Female	2	19	First-born child	C-14	Female	4	22	First-born child
J-15	Male	1	19	Only child	C-15	Male	4	24	Only child
J-16	Male	1	19	Not first-born child	C-16	Male	3	22	Only child
J-17	Male	1	18	First-born child	C-17	Male	2	20	Not first-born child
J-18	Male	1	32	First-born child	C-18	Female	4	23	Not first-born child
J-19	Male	1	19	Only child	C-19	Male	1	19	First-born child

JPN, Japan; CN, China.
Japan: Group 1: J-1 J-6: Group 2: J-7 J-9: Group 3: J-10 J-14: Group 4: J-15 J-19.
China: Group 1:C-1 C-9;Group 2:C-10 C-19.

> for by a caregiver who lacks expertise may cause irreversible aftereffects. And they cannot grasp the psychological needs of my parents. (C-4)
>
> I don't know if the education level of the caregivers is getting better, but as long as it's left to those people, I'd be somehow worried......So, I think I'm a little distrustful that they will be able to properly care for my parents. (J-10)

Both the Chinese and Japanese participants distrusted the attitudes of the caregivers. The Chinese participants felt that the caregivers were not part of the family, and thought that caregivers might have negative thoughts, which would lead to distrust. The Japanese participants were doubtful and distrustful because they wondered whether the caregivers were motivated to be caregivers as this work was not an elite job.

> As caregivers are not family members, I do not feel secure that they could provide fully comprehensive care for my parents... I want to care for my parents by myself because if I leave them in a nursing home, I am afraid they might be abused, and that the caregivers would not be as caring as I would like them to be. (C-7)
>
> The caregivers entrusted to do the job should be highly motivated, but the fact is, those people have various problems (pay, stress) . . . For situations like this, I am not sure whether they would be motivated to care for my parents. So, I guess I'm a little distrustful at this stage. (J-10)

the Chinese or Japanese participants trusted the caregivers because there were few caregivers and they had a lot of work to do. As there were not enough caregivers for all the people who needed care, they felt anxious about the caregivers' abilities to care for their parents.

> Because a large number of older adults need to be cared for by a single caregiver, if my parents were left in the care of a facility, no one could ensure that they would be properly cared for. If the number of caregivers was increased, it would be feasible for me to leave my parents in a nursing home. (C-14)
>
> The number of caregivers is not enough for the people who will need care in the future. I am worried that my parents would not be cared for properly in this situation. (J-6)

In addition, this metatheme reflected the participants' distrust of leaving parental care to others. Even though caregivers and nursing homes exist, the Chinese and Japanese participants expressed their distrust of them, highlighting that there were several barriers to caregivers and nursing homes gaining their trust.

TABLE 2 Metatheme 1: distrust of leaving parental care to others.

Sub-metathemes	Themes	
	China	Japan
Poor impression of nursing homes	I would not leave my parents in a nursing home because I have many bad impressions of nursing homes	I have seen many incidents of abuse and violence in the news, and I'm distrustful of whether my parents could stay in a nursing home
	I am not comfortable with the atmosphere in a nursing home, so I would not leave my parents in their charge	
Doubts about the competency and professionalism of caregivers	If you leave a patient with a caregiver, I have doubts about their professionalism	I do not know if the caregivers' education level is improving, so I am not sure if they would be able to properly care for my parents
	I do not trust the professionalism of caregivers	
Distrust about the attitudes of caregivers	I do not trust the caregivers because they are not my family	I do not know if the caregiver is motivated, and I distrust them to care for my parents
	Caregivers are not wholehearted	
	When a caregiver cares for a parent, it is not full-service	
Fewer care workers are available on caring for their parents	I can rely on others to care for my parents only if the number of caregivers increases	The number of caregivers is less than the number of people who need care; therefore, I am concerned about whether they could properly care for my parents
	Not enough caregivers to properly care for my parents	Feel unable to properly care for their parents due to a lack of manpower and too much work to do

TABLE 3 Metatheme 2: responsibility to care for parents as their child.

Sub-metathemes	Themes	
	China	Japan
Responsibility to care for their parents	Following the principles of filial piety, all parental care is the responsibility of the child	When I became an older brother, I was taught that I had to be a good older brother
	The "firstborn concept" is an old belief and needs to be discarded	Gender equality in social participation is widespread, but the impression remains that care should be done by women
	All children should be responsible for parental care for fairness	I still have the impression that my sister would do all the work for me
Repayment for bringing up child	I have a responsibility and an obligation to care for my parents to repay their upbringing	I will take care of my parents because they raised me so far
	Responsibility to care for my parents recoups their cost of raising me	
Influence from surroundings	I want to care of my parents by myself because it is my filial duty	I hate to start bad rumors about me if I sent my parents to a nursing home
	Influenced by idioms like "growing up children, old people's security," I think it is my responsibility to care for my parents	If my parents enter a group home, people might think I am not fulfilling my role as a child, so I will take care of my parents
	I want to care for my parents myself because it is important for me to keep my filial piety.	
Balance between work and care	Family is more important than work	If it's hard to take time off from my job when I need to take care of my parents, I cannot quit and let others take care of my parents when they need care
	If I have no choice, I'll quit my job and care for my parents	

3.2.2. Responsibility to care for their parents

This metatheme comprised four sub-metathemes (Table 3).

Both the Chinese and Japanese participants believed that children should take responsibility for parental care. The Japanese participants believed that the eldest child should be more responsible and stressed that although gender equality is widely recognized in Japanese society, the impression remained that females should do the care. They also felt that it was socially recognized that more women than men should quit their jobs to care for their parents and that women must take responsibility. However, all Chinese participants believed that regardless of gender or birth order, all children should be equally responsible for parental care.

> I think it is the responsibility of every child to fulfill his or her filial duty… I think children have a responsibility and duty to

TABLE 4 Metatheme 3: importance of parent-child interactions about parental care.

Sub-metathemes	Themes	
	China	Japan
Consideration for parents' feelings about their own care	I want to take care of my parents by myself because I think my parents are not comfortable leaving them to others.	I don't want my life to be determined like this anymore, so although it is painful, at least I will get a home helper.
	I want to care for my parents myself because they may feel abandoned if I leave them to others	I'll follow my parents' advice, but if I care for them all the time, I'll tell them to move into a nursing home
Discussions with parents about their own care	If there is a conflict with parents, I will respect and compromise with their opinions	My parent's opinion is important to me, but I want to continue working and I want them to be in a nursing home when they need care
	It is important to respect parents' opinions and be as satisfied as possible	In fact, when I'm in that situation, I'd like to interact with my parents and try to convince them

> look after the parents who raised them, but this should not be the sole responsibility of one person. (C-3)
>
> When I became an older brother, I was told that I had to do things well, or something like that....After all, I am the older brother, so I think on my own involuntarily that I have to do everything right, that I have to support the family, and that I have to take care of my parents.... (J-2)
>
> Even in terms of work, when it comes to the choice of quitting a job and caring for the family, I cannot really imagine the man quitting, but I think someone would say that I (a woman) should quit my job and care for the family. (J-10)

The participants from both China and Japan stated that they wanted to care for their parents to repay them for raising them.

> My parents raised me and put in so much effort and went through so much suffering, so I think as a child I need to reward them. (C-8)
>
> I owe my parents a favor for raising me, and I don't think forcing them into a nursing home would be a good filial duty. Of course, I think parents want their children to take care of them as a way of repaying the favor they have done for us, too. (J-17)

The participants from both China and Japan stated that they were influenced by their surroundings to care for their parents. The Chinese participants explained that they were stressed by traditional norms and the Japanese participants emphasized the influence on their reputation and others' expectations of their role as a child.

> From the perspective of traditional norms, it is unfilial to leave my parents in a nursing home, so if I leave my parents to others, my parents would be very resistant, so I want to take care of them by myself. (C-18)
>
> If I decide to leave my parents at a nursing home,...rumors or some bad impressions (like the impressions imposed by society) would be spread by the people around me, which would make me feel uncomfortable. (J-19)

The Chinese participants stated that family was more important than work. If they could not balance parental care and their work, they would quit their jobs. The Japanese participants stated that if they were unable to balance caring for their parents with their work, they would keep their jobs and leave care to others.

> I am related to my parents by blood, so if there is a conflict (between work and caring for my parents), I think I would have to compromise and devote myself to caring for my parents. (C-16)
>
> I think my parents' opinion is important, I will try my best to take care of them, but when I cannot afford it or they need to be taken care of by others because of some of my personal issues, I would try my best to persuade them to move to a nursing home. (J-10)

In addition, this metatheme showed the responsibility of parental care for both Chinese and Japanese participants due to the repayment of parents' upbringing and influences from their surroundings. However, when comparing jobs and parental care, Chinese participants tended to take care of their parents, while Japanese would like to keep their job. On the other hand, Chinese participants emphasized equal responsibility for all children, and Japanese participants tended to believe women and first-born children should take up the responsibility.

3.2.3. Importance of parent-child interactions about parental care

This metatheme comprised two sub-metathemes (Table 4).

Both Chinese and Japanese participants stated that their parents' feelings were important. The Chinese participants stated that if they left the parental care to others, both their parents and themselves would feel resistance and loneliness, so they preferred to care for their parents by themselves as much as possible. The Japanese participants stated that although the parents' feelings were important, they also had their own lives and careers; therefore, even though it would be heartbreaking, they'd leave their parents to others.

> I would like to care for my parents myself as much as possible because if I care for my parents myself, it would provide psychological comfort, and if they were cared for by a caregiver, I believe my parents would feel alone. (C-2)
>
> No matter how much the parents hope for their children's care, absolutely their children still have their own lives. Although it

> is a little bit painful, at least, I think I would get a home helper or other services. (J-14)

Both the Chinese and Japanese participants emphasized the importance of seeking their parents' opinions about their care. If there was a conflict with the parents, the Chinese participants stated that they would compromise and the Japanese participants stated that they would seek to convince their parents.

> I would respect my parent's opinions if my thoughts on care diverged from theirs. Anyway, parents' feelings are the priority in care, and I want to satisfy their wishes as much as possible as a child. If we cannot work it out, I think I would do what they want. (C-13)
>
> I want to respect my parents' feelings and opinions, of course, but I don't want to force myself to cater to them, so I'd persuade them until they agreed with my opinions. (J-8)

In addition, this metatheme highlighted the importance of interactions between generations. Both Chinese and Japanese participants emphasized communication with parents, however, Chinese participants were more parent-centered, which means they would follow them as far as possible; whereas Japanese participants were more self-centered to convince their parents to agree with their ideas.

In summary, there were both similarities and differences in perspectives on parental care between Chinese and Japanese participants (Figure 1). Both Chinese and Japanese participants shared a similar perspective of distrust toward leaving parental care to others and taking care of their parents for repayment for upbringing and surroundings' influence. However, there were also some differences between Chinese and Japanese participants. Japanese participants tended to insist on their own ideas and convince their parents in continue their work and communicate with their parents, while Chinese participants tended to follow their parents' opinions. Furthermore, Japanese participants emphasized the importance of the first-born child and believed that women should take on more responsibility for parental care due to cultural background. In contrast, Chinese participants considered gender and birth order inequalities to be outdated and emphasized equality for all children.

4. Discussion

To provide some guidance on the future needs of the healthcare society, Chinese and Japanese university students were asked to give their perspectives on parental care in focus groups, from which three metathemes were identified: distrust of leaving parental care to others, responsibility to care for parents, and importance of parent-child interactions about parental care.

4.1. Similarities and differences on perspective of parental care

Both the Chinese and Japanese student groups had a mistrust of nursing homes because of news about the mistreatment of older adults. A Japanese Ministry of Health, Labor and Welfare (MHLW) publication, the "Act on the prevention of abuse on older adults and support for caregivers of older adults," reported that in 2020, 2,097 abuse cases on older adults had been referred and 595 judgments had been made (32). Because of the public distrust in nursing homes, a system is being developed in Japan to prevent abuse on older adults in nursing care facilities, which is hoped will ease resistance to the system and improve how the public views nursing homes (33). In China, attitudes toward nursing homes have shifted from it being a stigma to recognizing that nursing homes can provide high-cost professional care; nonetheless, some negative attitudes remain (34). It has also been reported that Chinese nursing homes are of low quality and have a low capacity to accommodate the older adults in China (35). For these reasons, putting parents in a nursing home is seen as unfilial, and many parents resist moving there.

The results from this study indicated that increasing the number and professionalism of nursing home caregivers were required, which agreed with a previous study that found nursing home caregivers in China are often poorly educated older adults who lack expertise (36). Although great efforts have been made to improve care services in nursing homes and require that healthcare workers have formal occupational training, there is a shortage of healthcare workers in China (37). As a result, the lack of care skills and the poor quality of medical care have received widespread attention (38). Even though the Chinese government has published "basic specifications of service quality in senior care organization," careworker in nursing homes was found underqualified for care work than other Western countries (35). Careworker job vacancies by prefecture in Japan are on average 3.97 times higher than the number of care workers employed in nursing homes (39). The MHLW estimated that 2.43 million care workers would be needed by 2025; however, the expected number is estimated at only 2.11 million, a potential shortage of 320,000 (40), which could lead to increased careworker workloads, which in turn could reduce the quality and safety of care.

In East Asian cultures, the firstborn is expected to live with their parents after marriage, and the firstborn and their partner are expected to take care of their parents (41). This study found that this was still the belief of most Japanese university students; however, the Chinese students felt that the responsibilities lay with all children regardless of their birth order. As Chinese caregivers are suffering from emotional and financial stress, sharing the care responsibilities would be easier (42). Nonetheless, although female work opportunities have increased in Japan and the expectations of care by the family have weakened, females were seen as being more likely to be the primary caregivers (43). However, the responsibilities are more equal in China because of its socialist system and legislation specifying (44). Further, because females have gained greater access to higher education in China, they are less likely to abandon their careers to take care of their aging parents and more likely to insist upon shared sibling responsibility (43).

Filial piety emphasizes dependence, obligation, and reciprocity in intergenerational relationships, all of which should strengthen intergenerational bonds (45). This study found that the Chinese

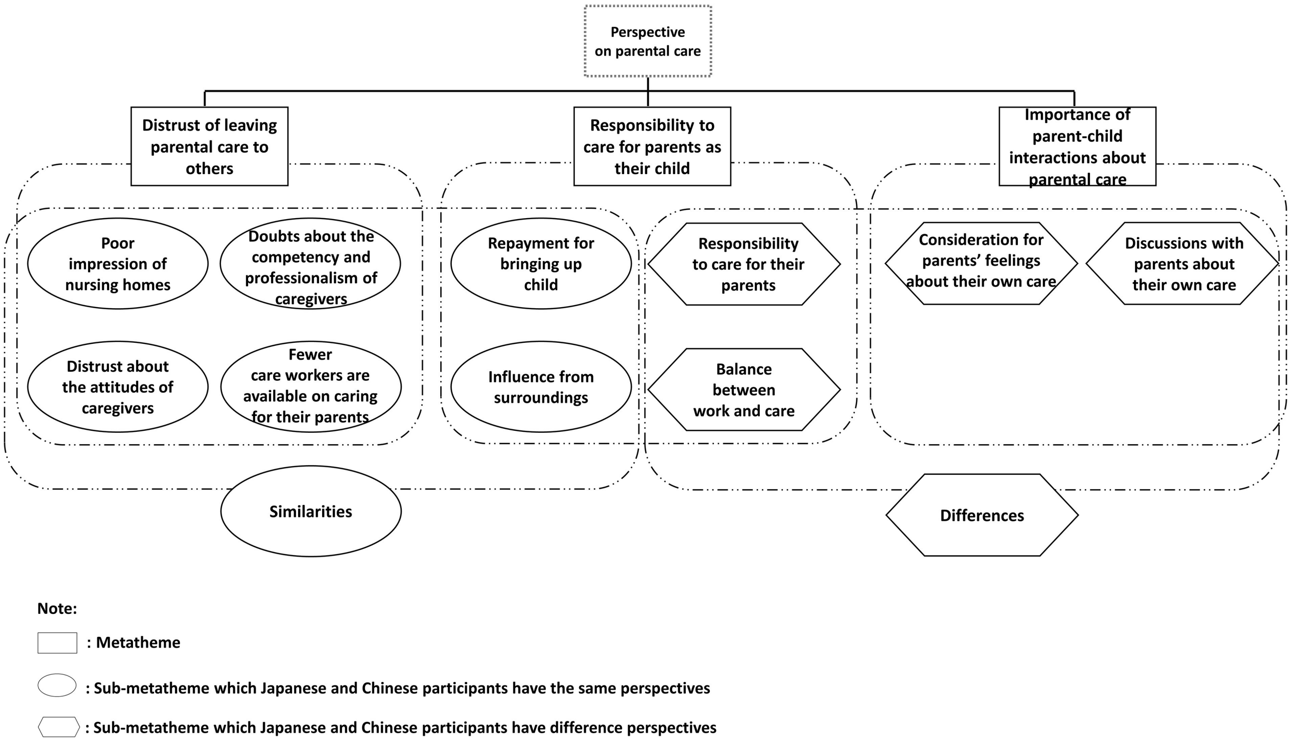

FIGURE 1
Perspectives on parental care between Chinese and Japanese university students.

participants were more likely to leave their jobs if they were unable to balance work and parental care, whereas the Japanese participants were more likely to place their parents in a nursing home. China has strengthened the social obligations of children to care for their aging parents (46); and in many Chinese families, older people continue to have strong bonds with their children and are involved in their daily lives, such as taking care of grandchildren and providing financial support, while they can also receive necessary care from their children as an exchange (47). Since the promulgation of Japan's long-term care insurance system, the family role has shifted from the direct provision of care to an organizational and administrative role and emotional support when using the available resources, which had led to a lower tendency for children to quit their jobs to take up parental care (48).

The Japanese and Chinese university student groups both stated that parent-child interactions were essential to strengthen parent-child connections and parental health. In China, Confucian filial piety was the guiding principle, which required children to ensure the emotional and physical wellbeing of their aging parents (49). Confucian culture means that older Chinese and their children have close emotional ties and high mutual emotional dependence (50). If their parents were resistant to entering a nursing home, both groups claimed that they would respect their parent's wishes (51). In Japan, however, because of the healthcare insurance scheme and economic growth, older parents tend to be more independent and less in need of their children's support; therefore, the participants said that they would seek to persuade their parents to enter a nursing home rather than compromise (52).

4.2. Practical implications

Based on the study's findings, several practical suggestions are given for improving healthcare systems in China and Japan. First, studies in Japan and the US found that the quality of long-caregiver services at nursing homes was poor (32, 53). Therefore, care service delivery and healthcare systems must be improved to build trust between healthcare professionals and the public. Second, because of cultural contexts such as filial piety, aging policies can have profound implications for both older adults and their children. Therefore, services and interventions must be developed to ensure the wellbeing and livelihoods of both the children and the parents. Third, caregiver gender equality, especially in Japan needs to be promoted (54). Fourth, similar to Japan, China needs formal policies such as nursing care leave in place to provide a better work and life balance for Chinese caregivers, and supports to mitigate the dissonance between their parental caregiver roles and their own lives.

4.3. Limitations

This study had some limitations. First, because only university students were included in the study, it was difficult to extrapolate the results to all people in the younger generations. Further, as none of the participants had yet experienced the difficulties of balancing parental care and work obligations, the findings were related to the potential worries they may have in the future. Therefore, more studies are required to determine the reactions to these problems in the coming decades. While it was found that the university students were willing to help with parental care, more quantitative research is needed because of the small sample size and the qualitative research frame. Future research should explore the perspectives of all younger generations on parental care. It could also be useful to examine the attitudes of other generations to explore generational differences. On the other hand, exploring the socio-cultural reasons influencing parental care perspectives, or comparing the differences in institutional systems for older adults across different nations is important. Such research can assist policymakers in alleviating potential concerns.

4.4. Conclusions

This study examined the attitudes of Chinese and Japanese university students toward parental care. The findings suggested that both countries needed to improve their care service delivery and healthcare systems and build trust between healthcare professionals and the public. Support will also be needed to assist children to balance their care responsibilities with their work and family life. Culturally, it was found that healthcare policies had significant social implications for older adults and their children; therefore, future service delivery policies need to consider the wellbeing of both the children and the parents.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Ethics Committee of Epidemiology Research at Hiroshima University (E-2633-2). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

XP played a central role in the research, planning the research, collecting data, analyzing and interpreting it, and writing the manuscript. HN carried out research planning, analysis, and interpretation and contributed significantly to the writing of the manuscript. YI interviewed the participants and analyzed and reviewed the manuscript. HC contributed to the analysis, interpretation, and writing of the manuscript and critically reviewed the manuscript. FS contributed to the analysis and interpretation and writing of the manuscript. MY contributed to the writing of the manuscript and critically reviewed the manuscript. RL contributed to the writing and the editing of the manuscript. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Enhancing nursing education to bolster nurse governance: insights from nurse managers

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Aim: In South Korea, the level of nursing governance is moving toward shared governance. This study sought to explore nursing education contents in undergraduate nursing programs necessary to improve the governance of nurses from the perspectives of nurse managers.

Methods: The study employs thematic analysis following the guidelines outlined in the Consolidated Criteria for Reporting Qualitative Research utilizing a qualitative research design. Our investigation involves general or tertiary hospital nurse managers intending to gain valuable insights and perspectives.

Results: Interview data from 14 nurse managers were analyzed. A total of one main and four sub-themes were derived from the qualitative data analysis. Analysis revealed the main theme, “occupational socialization.” The four sub-themes were education on “nurse–patient and nurse-colleague communicative interaction,” “humanity,” “career development,” and “nurses as politicians.”

Conclusion: The findings are valuable in suggesting critically needed educational content in undergraduate nursing programs to improve nursing governance. Future research should investigate the effects of the abovementioned themes on nursing governance among clinical nurses or nursing students for several years of follow-up data collection.

KEYWORDS

education, governance, communication, humanity, career, politics

1. Introduction

Governance is a multidimensional concept that encompasses the structures and processes through which participants within an organization guide, manage, and oversee the goal-oriented endeavors of other members. (1). Hess (1) developed a measurement of governance that assessed six subdomains: control over nursing personnel, participation in committees, access to information, conflicts and goal settings, influence over resources, and control over nursing practice. Governance is categorized as traditional, shared, or self-governance depending on how much nurses have authority, access, opportunities, and participation in these subdomains. The critical concept of shared governance is shared decision-making related to the six subdomains between the nurses and nurse leaders (2). Shared governance promotes positive outcomes for patients and nurses, such as job satisfaction, turnover intention, and empowerment (3, 4).

However, a study on nurses working in tertiary general and general hospitals (5) in South Korea reported that they recognized the governance level as traditional. Another study on nurse managers (6) found that they recognized the level of nursing governance as shared governance, but at the initial level, which means that most of the authority and opportunity for decision-making lie with nurse managers. In traditional governance, nurses do not have authority, access, opportunities, or participation in the six subdomains, which may cause lower job satisfaction and turnover. According to a report by the Hospital Nurses Association (7), the nurse turnover rate is 14.5%, and the annual turnover rate for nurses with less than 1 year of experience was 34.1% in 2021. New nurses' high turnover and low satisfaction rates affect healthcare organizations and nursing education institutions. The nursing education institutions provide nursing education and yield newly graduated nurses annually; efforts to improve nursing governance should be shared and supported.

Various studies in other countries regarding governance in nursing focused on the effect of shared governance of clinical nurses on nurse-side outcome variables such as satisfaction, nurse-sensitive indicators, and nurse engagement (8, 9), an integrative review of governance-strengthening strategies (10), governance of nursing students (11), and governance of nursing faculties (2, 12). However, in South Korea, except for studies on the current status of Korean nurses' governance and its correlation with related variables in clinical settings (5, 6, 13, 14), nursing education research on the current state of governance or investigation of educational demand from clinical practice to improve governance in nursing has not been conducted. Therefore, research that can provide primary data to prepare educational content related to nursing governance is required.

Nurse managers are at the management level in healthcare organizations. They utilize the hospital's policies, objectives, and plans for specific situations, reflect them in nursing practice, and direct, coordinate, and evaluate the clinical nursing activities performed by the nursing staff in the wards (15). Based on their critical roles in healthcare organizations, they can be equipped with an understanding of governance in nursing. A study on nurse managers' perception of governance in nursing highlighted that nurses lack the perception of given authority (6). Korean nurses may have a relatively limited understanding of professional governance compared to nurse managers. Thus, this study explored nursing education content in undergraduate nursing programs necessary to improve the governance of nurses from the perspectives of nurse managers.

2. Methods

2.1. Design

A qualitative study design was chosen to explore how nurse managers perceive the necessary education in undergraduate nursing programs to improve nursing governance. The study's reporting adhered to the Consolidated Criteria for Reporting Qualitative Research checklist or guideline.

2.2. Sampling strategy

The participants were nurse managers working in general and tertiary hospitals in the Seoul and Gyeonggi-do regions who voluntarily consented to participate. The inclusion criteria were at least 1 year of working experience as a nurse manager in a general or tertiary hospital. The author asked nurse executives in target hospitals to advertise this study to nurse managers; those interested provided their contact details voluntarily. The purpose and process of this study were explained to the participants. Participants were recruited until data saturation. The number of participants fulfills the required sample size for collecting qualitative data (16).

2.3. Data collection

Data were collected from May to June 2020 through individual interviews conducted by the author via telephone, given the COVID-19 restrictions. The author had experience conducting qualitative research on governance and other nursing-related topics. The interview time and date were set according to the participants' preferences and convenience. The interview questions derived from the literatures (1, 5, 6, 10, 11) were: "What kind of education is necessary for undergraduate nursing programs to enhance control over nursing personnel, participation in committees, access to information, conflicts and goal settings, influence over resources, and control over nursing practice?" "Why do you think the kind of education should be needed?" "Could you tell me any episodes regarding nursing governance?" All interviews were audio-recorded, pseudonymized, and transcribed verbatim by the author. Recordings were deleted after data analysis was completed. Each interview lasted 35 min on average. The author wrote notes in the field immediately after each interview. Data analysis was performed concurrently with data collection.

2.4. Data analysis

Qualitative data were analyzed via thematic analysis. The thematic analysis method outlined by Braun and Clarke (17) was utilized, encompassing the subsequent steps: gaining familiarity with the data, formulating initial codes, identifying themes, reviewing the themes, defining and labeling the themes, and writing the report. The author read through the data initially to gain familiarity and to assign codes. The field notes were useful to recall the air of each interview. A total of 18 codes were developed and checked for duplication or multiple codes expressing the same concept. The codes were organized into sub-themes and themes that the researchers felt represented the participants' responses. These final themes and sub-themes are illustrated in Figure 1. In the final stage of analysis, quotes that the researchers felt were accurate examples highlighting the themes were selected from the data. For the general characteristics of the participants, descriptive statistics using Microsoft 365 Excel were calculated.

2.5. Rigor and trustworthiness

The transcribed data were repeatedly reviewed to improve validity, transparency, and quality until no new concepts were generated. Since the author conducted the data analysis, the finalized and main themes were emailed to the participants to ensure their responses were adequately reflected.

2.6. Ethical consideration

Ethical approval was obtained from the author's institutional review board before data collection. Informed consent was obtained from all participants. All data and quotes were pseudonymized. This study adheres to the Declaration of Helsinki in all methodological aspects.

3. Results

A total of 14 participants were interviewed regarding nursing educational content to improve governance in nursing. All participants identified as women shared common characteristics: they were all over 38 years of age with the mean (SD) value of 44.79 (4.41) and they held a minimum of a master's degree as their highest level of education. Their average career years as a nurse manager were 7–8 years with the mean (SD) value of 7.46 (5.95). Data analysis revealed one main theme and four sub-themes. An overview of the themes is illustrated in Figure 1.

3.1. Occupational socialization

The main theme, "occupational socialization," appeared in the analysis of education needed in undergraduate programs to improve nursing governance. The sub-themes of communication with patients and colleagues, humanity, career development, and political participation were derived to describe the main theme.

3.1.1. Nurse–patient and nurse-colleague communicative interactions

Education on communication with patients and colleagues was considered necessary to enhance nursing governance. Such communication meant education on technical communication such as etiquette and Situation-Background-Assessment-Recommendation (SBAR), which should be performed in relationships with colleagues in a healthcare organization. Particularly, such communication skills are useful when presenting their opinions in committees. Moreover, to enhance the professionalism of nursing services based on patients' needs, the necessity of experiencing communication with various people was suggested.

> Communication is very important, and interpersonal relationships are in consecutive order; however, nowadays, nurses do not communicate. They were also unaware of courtesy (etiquette) in communication with physicians, nurses, and senior nurses. Courtesy is required during communication in a healthcare organization (Participant 10).
>
> We provided nurses with SBAR training. (···) We explained to new nurses how to communicate and perform SBAR when notifying doctors from the first orientation training, but they still do not… proficiently. These skills are necessary when nurses speak in committees or conferences (Participant 8).
>
> I had many opportunities in nursing school to communicate with friends majoring in other subjects. I think talking and listening to as many people as possible is important. It helps nurses when dealing with patients' needs in a hospital. It helps nurses understand what the patient wants quickl (Participant 9).

FIGURE 1
Education necessary to improve nursing governance.

3.1.2. Humanity

Nursing is a patient-centered care service. Participants stated that attention to the human aspect of nursing is needed to improve nursing governance. Additionally, as such attention is linked to reflection and nursing ethics, the need for education to cultivate humanistic knowledge was mentioned.

> When caring for patients, we need to understand humans. Even though I am a nurse providing nursing services to psychiatric patients, there are times when I wonder if I have an interest in patients or understand human beings when I cannot understand a patient's behavior (Participant 11).
>
> Nurses can be unskilled in functional tasks, but we focus on whether the nurse paid attention to patients with humanistic interest. Nurses who are interested in themselves tend to pay significant attention to patients. Nurses should be able to reflect on themselves and look inside their minds, but they do not know how to do that (Participant 12).

3.1.3. Career development

Participants suggested that education on career development as a nurse is necessary. As such, they mentioned education about clinical careers and human resources in healthcare organizations. Through education, nurses could have improved insights into healthcare staff management. Also, they could be convinced of their potential and strive to develop their career.

> I think that I have to learn about human resources (HR). I can develop through such education. If more intensive training on the development and HR part is provided, I would better understand the management of healthcare personnel and ensure that I am a nurse who can grow as an excellent nurse (Participant 8).
>
> We need an education that can teach nurses in advance about activities that can help them develop nursing careers in the wards so that they feel like they can work as a nurse for a long time (Participant 5).

3.1.4. Nurses as politicians

Participants emphasized the need for education on political participation. They reflected that they were not interested in such education. However, while considering ways to improve nurses' governance, they reflected on nurses who had not given this much consideration to politics and urged them to increase their knowledge and interest. As nurses' involvement in enacting the Nursing Act is needed, nurses' participation in decision-making is needed to improve nursing governance.

> Last year, I attended lectures on politics while preparing for the enactment of the Nursing Act. Ultimately, it is about political involvement, like governance is about participation. But we nurses did not give this much consideration. I think many nurses are unaware of the department focused on nursing politics newly established under the Ministry of Health and Welfare (Participant 7).
>
> [To enact the Nursing Act, nurses] have to put pressure on and negotiate with politicians such as members of the National Assembly. There is a need to increase the number of nurse activists and nurse politicians. Currently, there are few nurse politicians to represent the voices of nurses. Thus, nursing students need to become interested in politics in nursing school through education (Participant 13).

4. Discussion

This study aimed to identify undergraduate nursing programs' educational content to improve nurses' governance in South Korea. Nurse managers suggested the necessity of education for occupational socialization, highlighting the need for education on nurse–patient and nurse-colleague communicative interactions, humanity, career development, and political involvement.

The main theme identified in this study was "occupational socialization." Occupational socialization embraces the entire process of novices in an organization by adjusting themselves to the organization through learning its professional codes and values, culture, performing an expected job, and obtaining the skills necessary (18). A related theory in the field of physical education is the occupational socialization theory. Its framework comprises a time-oriented continuum: acculturation, professional socialization, and organizational socialization (19). The educations on communication, humanity, career development, and political involvement, which were this study's sub-themes, align with the suggested framework. Particularly, education on career development and political involvement can be viewed as related to professional and organizational socialization.

The first specific form of education required in nursing governance is nurse–patient and nurse-colleague communicative interactions. Guttman et al. (20) outlined that communication is one of the strategies to improve patient safety, but it remains an adaptive challenge to overcome in the healthcare sector. Appropriate communication can enhance nurses' work lives by increasing their satisfaction with professional communication and reducing Thas among colleagues (21). Moreland and Apker (22) also identified that communicative responses reduce conflict and stress among nurses and highlighted that communication training should begin in undergraduate nursing program to provide experiential learning techniques to create a culture of respect. Professional communication is likely related to participation in committees, a subdomain of governance. When nurses are involved in committees to make decisions on policies and nursing practice, they should present their opinions professionally. In South Korea, a study analyzing 48 out of 73 undergraduate nursing curriculums in 2009 revealed that 81.2% recognized the importance of communication and already had communication as a major course (23). This important communication education is covered in a single course with 2 credits in the first or second year of the four-year curriculum, and the lack of communication experience has been highlighted (23, 24). Thus, expanding or increasing credits for communication course(s) in undergraduate nursing programs in South Korea should be considered.

Additionally, our findings revealed the need for communication education, particularly regarding courtesy during communication with colleagues. It implies the need for organizational communication experience with colleagues as a member of the healthcare organization. Organizational communication involves complex interpersonal relationships (25). Thus, many communication experiences with various occupations in healthcare organizations is encouraged for undergraduate nursing programs.

Humanity is the second aspect of education needed for nursing governance. In particular, the participants indicated that nurses need to have an attitude to try to know and understand patients from a humanistic perspective. Patients are an important component of the metaparadigm of nursing (26, 27). Additionally, the concept of person-centered care has been introduced, and the American Association of Colleges of Nursing (28) defines it as holistic, personalized care delivered with respect and compassion, which guides nursing practice regardless of specialty and emphasizes the importance of liberal arts, such as humanities, for professional nursing education. Byma and Lycette (29) found that nursing students recognized the benefits of humanities-based activities, such as emotional development, communication, and new insights into best nursing practices. The current study derived a similar finding that interest in and understanding patients (human beings) are linked to reflection as a nurse. In other words, reflection on the nursing service spent on patient care is expected to positively impact the improvement of the control over practice areas in nursing governance. A total of 8 credits (4 courses) of the total graduation credits (130–140 credits) in nursing undergraduate courses in South Korea are awarded for humanity education (30). Nevertheless, the fact that such education was mentioned as necessary to improve nursing governance suggests the need to examine the effectiveness of such courses in the current nursing undergraduate curriculum.

Education on career development is the third type needed for nursing governance. Participants mentioned the need for education on HR, which is conducive to careers and can provide growth potential for nurses in health organizations. Moreover, it could affect nurses' understanding of the management of healthcare personnel. Notably, considering the results of a study (31) targeting Generation Y nurses born in the 1980s, they no longer want to be leaders and want to work as general nurses; this highlights the fact that education on career development is necessary. In South Korea, the concept of the career ladder system and its example cases have been introduced into the undergraduate nursing curriculum. However, this does not seem sufficient. Kalbfleisch and Burwell (32) suggested career-specific education for nursing practitioners in Canada. Thus, the nursing career-specific development process in tertiary and general healthcare organizations nationwide should be analyzed to develop educational content. The content finalized with experts can be utilized in undergraduate nursing programs and healthcare organizations; thereby, nursing students are likely to have an improved understanding of career development and control over personnel in nursing governance.

Political involvement was the fourth type of education required for professional governance in nursing. Nurses' political participation is essential for developing effective health programs and global health promotion (33). A recent study reported that students of nursing majors' political interest and participation are higher than those of other majors, but their political efficacy is low (34). Political efficacy refers to the subjective emotional judgment of how much a political actor can change the political environment with their efforts (35). It can be interpreted as confidence in politics. Even after becoming a nurse, owing to excessive stress and shift work related to the life and safety of the patient, the knowledge and confidence related to political participation are low compared to other medical-related occupations (36). Thus, nurses do not participate in healthcare policy decisions (37). Korean nurses have tried enacting the Nursing Act to specify the scope of their work according to the law. However, the fact that the enactment of the Nursing Act has still not been established implies the need to improve the political capacity of Korean nurses.

Regarding political involvement education, considering the subdomains of governance, namely control over personnel, control over practice, influence over resources, access to information, participation in committee structure, goal setting, and conflict resolution (1), governance is the authority given to nurses. With the concept of making good use of authority, governance in nursing can be viewed as a political activity in hospitals in a broad sense. Just as citizens exercise citizenship, nurses in hospitals should exercise the authority and opportunities given to them to raise their voices and participate in decision-making related to nursing practices (38). For this purpose, politics as educational content is needed in undergraduate nursing programs so that they can understand the definition of politics and the legislative process (39) in advance.

Since only a few studies about nursing governance from nurse managers' perspectives have been conducted, this study's findings are considered important but limited in scope. The data were collected from the participants whose institutions were general or tertiary hospitals, therefore this study's findings may not be generalizable to nurse managers' perceptions in primary healthcare institutions. Additionally, the data were analyzed by a single author. Thus, the author ensured that the results of this study contained the participants' intention through the feedback process with them.

Lastly, the interviews were conducted individually. Focus group interviews with nurse managers could provide rich data regarding nursing governance, although data saturation was achieved in this study.

5. Conclusion

This study aimed to identify nursing education methods for improving nurses' governance by targeting head nurses. This study found that necessary education was mainly related to organizational socialization. Specifically, education on nurse–patient and nurse-colleague communicative interactions, humanity, career development, and nurses as politicians were identified. First, regarding communication and etiquette between colleagues and patients, it is necessary to provide an educational environment in which nursing students can experience communication with various occupational groups engaged in medical institutions. Second, for the education on humanity, which includes an understanding of patients and is connected to reflection as a nurse and nursing ethics, it is necessary to check the effectiveness of such courses currently organized in nursing educational institutions. It may positively impact the improvement of the control over practice area through reflection on patient nursing work. Third, education on career development suggests the need for career-specific education to ensure the growth potential of a nurse within the organization. Thus, the control over personnel in nursing governance is expected to be enhanced. Fourth, education on political involvement is required for nurses' political participation. Governance can be viewed similarly as political activities within medical institutions. Therefore, it is necessary to prepare educational programs on "Nursing and Politics" in nursing educational institutions. Through education on communication, humanity, career development, and politics, the occupational socialization of nurses should occur gradually, thereby improving nursing governance. This study is meaningful in that it suggests vital educational content and the direction of education in undergraduate nursing programs to improve the governance of nurses in a situation where Korean nurses are confronting challenges moving toward shared governance in nursing (5). Further studies should examine the effects of these four themes on nursing governance in South Korea using surveys.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Woosuk University Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SC: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Visualization, Writing – original draft.

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Conflict of interest

The author declares that the research was conducted without any commercial or financial relationships that could be construed as a potential conflict of interest.

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Perspectives of public health organizations partnering with refugee, immigrant, and migrant communities for comprehensive COVID-19 case investigation and contact tracing

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Objectives: To understand public health organizations' experiences providing comprehensive COVID-19 case investigation and contact tracing, and related promising practices with refugee, immigrant and migrant communities.

Methods: We interviewed public health professionals (September 2020 to February 2021) from local and state health departments using a geographically stratified, purposive sampling approach. A multidisciplinary team at the National Resource Center for Refugees, Immigrants and Migrants (NRC-RIM) conducted a thematic analysis of the data.

Results: Six themes were identified: understanding community and public health context, cultivating relationships, ensuring linguistic and cultural concordance, communicating intentionally, evolving response, and implementing equity. The interconnection of themes and promising practices is explored.

Conclusion: As public health continues to learn from and build upon COVID-19 response experiences, the thematic findings and potential promising practices identified in this project may foster proactive, community-engaged solutions for public health, and other organizations working and partnering with refugee, immigrant, and migrant communities. Implementing these findings with COVID-19 into current and future public health crisis responses may improve public health, collaborations with refugee, immigrant, and migrant communities, and staff wellbeing.

KEYWORDS

case investigation and contact tracing, refugees, immigrants, migrants, qualitative

1. Introduction

Globally about one in seven people have experienced migration (1). The COVID-19 pandemic has had a disproportionate impact for refugee, immigrant, and migrant (RIM) communities in high-income countries outside the United States and in regional studies within the United States. People in RIM communities may have had limited access to testing (2, 3), higher risk of exposure (4, 5), higher risk of infection (3, 4, 6) and hospitalization (7), and limited access to vaccination (8, 9).

Early in the COVID-19 pandemic, the United States Centers for Disease Control and Prevention identified universal case investigation and contact tracing (CICT) as a core public health measure to interrupt transmission (10). In the context of other infectious diseases, CICT has been challenging when programs have limited capacity to interview people who speak non-dominant languages and do not have dominant-language proficiency (11). Ensuring staffing capacity in languages other than the dominant language, and recognizing community assets are both key to successful CICT with RIM communities (12). Sufficient public health capacity, staff training, community engagement, and education about the role of CICT are needed for CICT to be an effective tool for COVID-19 mitigation (13, 14).

Though there is an expansion of literature describing multiple aspects of the COVID-19 pandemic response in RIM communities, understanding the perspective of public health organizations about barriers and facilitators of effective and community-centered CICT and examples of promising practices are needed. The National Resource Center for Refugees, Immigrants, and Migrants (NRC-RIM) (15) sought to understand the perspective of public health, health (16), and community organizations (17) on CICT through a series of qualitative interviews. This manuscript describes the perspectives of professionals working within public health organizations on facilitators and barriers to CICT, and links them to promising practices of comprehensive CICT with RIM communities.

2. Methods

We conducted qualitative interviews with two goals: (1) to understand the perspective of public health organizations engaged in comprehensive CICT and (2) to identify promising practices implemented by public health partners working with RIM communities during the COVID-19 response. We define comprehensive CICT as the continuum of engagement with public health organizations to support people who were infected with or exposed to COVID-19, including culturally responsive strategies such as health education and communication, testing, case investigation, contact tracing, quarantine and isolation, health monitoring, and resource provision.

2.1. Interviewees

We interviewed public health professionals from local and state health departments across the United States using a geographically stratified, purposive sample approach across the Health and Human Services regions. Eligible interviewees were involved in some component of the COVID-19 CICT continuum. We asked interviewees to describe their professional perspective working within a public health organization including reflecting on programmatic and organizational approaches to CICT. We refer to dominant and non-dominant language in the introduction since differences in language between public health organizations and members of our communities is universal. We will, however, be focusing on English specifically in this manuscript since the interviews were conducted within the United States and focused on the United States public health response to COVID-19 at local and state health departments. Interviewees were identified through a network of public health practitioners and health care providers, the North American Refugee Health Service Providers listserv, and the Association of Refugee Health Coordinators listservs. The perspectives of professionals within health systems and community experts/organizations are reported elsewhere (16, 17).

2.2. Data collection and data analysis

Interviews were conducted from September 2020 to February 2021. We developed a semi-structured interview guide (Supplementary Table 1) with input from public health professionals and extant CICT literature. Demographics were collected via REDcap (18, 19) for each interviewee. Interviews were conducted in English, audio recorded, transcribed by a professional transcription service and analyzed in Dedoose version 9.0.107 (20).

Organizational level descriptive statistics were computed. A multidisciplinary team followed the phases of thematic analysis outlined by Braun and Clarke (21). Three team members participated in identifying patterns in the data. The first five transcripts were independently coded by two coders, discussed and reconciled as needed, guiding the iterative codebook development. Subsequently, one transcript was selected for review by two team members independently, followed up by a group discussion. The remaining 16 interview transcripts were coded by one team member (one team member coded 5 and the other team member coded 11). The codes were reviewed and patterns in the data were discussed during weekly team meetings. Upon completion of coding, themes were identified from observed data patterning, iterative thematic mapping, summaries and revisions, discussions and naming. Members of the broader team were intermittently involved in reflexive discussions about analytic team memos and thematic interpretations (21, 22).

We identified promising practice examples within the interviews by team consensus and they were shared on the NRC-RIM website for rapid dissemination as the team learned about them (15). The majority of the promising practices on the NRC-RIM website were identified from this set of interviews with public health organizations, with interviews with health systems (16) and community organizations (17), from review of the media or shared by partner organizations. After the thematic analysis, two team members identified promising practices from the NRC-RIM website to link to the themes in this analysis in order to provide concrete examples of promising practices. First, promising practices that were from the interviews in this data set were selected. Then if a promising practice was not available from this data set that aligned with the theme then through consensus three team members identified another example from the NRC-RIM website.

3. Results

3.1. Interviewee characteristics

We conducted 21, 45–60-min interviews with a total of 33 public health professionals, some interviews included more than one person (Table 1). Interviewees' roles included: State Refugee Health Coordinators and Program Leads, Public Health Nurses, Epidemiologists, Program Leads for CICT, Medical Directors of Public Health Clinics, and City/County Health Officers.

3.2. Themes and promising practices

Six themes were identified. Interview excerpts representing each of the six themes from this analysis are displayed in Table 2. In addition to the data examples supporting each theme, Table 2 links promising practices identified by interviewees from this data set and NRC-RIM website with the thematic analysis to provide concrete examples of these themes in action.

TABLE 1 Characteristics of participating organizations (*N* = 21) engaged in comprehensive COVID-19 case investigation and contact tracing with refugee, immigrant, and migrant communities from the United States HHS Regions from September 2020 to February 2021.

	Public health organizations (*N* = 21)
Total number of interviewees*	33
Location, by HHS region	
1 or 2	2
3 or 4	7
5 or 6	4
7 or 8	3
9 or 10	5
Organizational level**	
Local (City/County)	8
State	13
Regional	0
Organizational type	
Public health	21
Immigrant-specific organization***	11
Populations served****	
Refugees	9
Migrant workers	8
Other immigrants	9
Interview completed after first COVID vaccine EUA*****	6

*Many organizations requested group interviews with two or more staff members.
**Organization level was categorized as local (e.g., city or county) even if part of a state-wide, regional, or national group when the operational unit that participated in the interview was focused on a local area. For example, an interview focusing on an FQHC's city-wide programming would be categorized as "local" even if the FQHC was part of a state-wide FQHC network.
***We categorized organizations as "refugee, immigrant, migrant-specific" if the organization as a whole or the operational unit within the organization that participated in the interview (e.g., a state refugee health program within a Department of Public Health) focuses specifically on RIM communities.
****Many organizations work with more than one population.
*****December 11, 2020.

3.3. Understanding community and public health context

Interviewees described that public health organizations at the local and state level utilized their knowledge of community and public health system assets, needs, and challenges, leveraging existing resources to support a comprehensive CICT response to COVID-19.

3.3.1. Community context

Early in the COVID-19 pandemic, state and local public health organizations had a range of understanding around community needs, existing strengths, and resources, including whether or not their public health teams were reflective of RIM communities within their broader community. Interviewees acknowledged the myriad challenges RIM communities faced specific to participating in comprehensive aspects of CICT including: access to and/or fear of testing, the consequences of testing positive when living in high density housing, financial hardships, inability to access information due to language, literacy or technological barriers, and fear of sharing contact information related to potential immigration concerns. Interviewees also frequently identified specific RIM community strengths and resources including community-based organizations (CBOs), multilingual and multicultural media, places of worship, and employers who were developing messaging and/or programs for their employees.

3.3.2. Public health context

Interviewees highlighted the importance of specific public health teams and team members with pre-COVID-19 work experience that provided them a strong understanding of RIM communities in their geographic area, and engagement with partnerships that informed their understanding of community context (e.g., public health nurses assigned to visit community health centers semi-annually for technical assistance). Interviewees also recognized system-level tensions as vital pivot points to support the evolving response and movement toward promising CICT practices (e.g., hiring RIM community members to address CICT staffing-related challenges, or adapting quarantine and isolation resources for a state context when existing resources were culturally, and locality specific). The combination of understanding the community and public health context provided a foundation for adaptation, innovation, and growth for comprehensive CICT for COVID-19 inclusive of RIM communities.

3.4. Cultivating relationships

Effective CICT is facilitated by cultivating existing and new relationships that are grounded in trust between public health and RIM communities at the individual, community, and organizational levels. Trusting relationships fostered by individual public health professionals with RIM communities sometimes supported CICT efforts when public health organizations did not have established relationships:

TABLE 2 Select comprehensive CICT promising practice examples and supporting data excerpts by primary theme* (interview data from across the United States HHS Regions from September 2020 to February 2021).

Promising practices	Supporting thematic analysis excerpts
	Theme: understanding community & public health context
Working toward equitable language access	*The other group I work with is on communication, so we have been analyzing monthly surveys for the Municipality of* [city name] *since the beginning of the pandemic, and one of the things that was a critical component of those surveys was a focus group effort that was specifically targeting immigrants, refugees, and non-majority populations, and trying to find out, here in the Municipality of* [city name], *what were some of the barriers to services or challenges or issues that they were experiencing secondary to COVID.*
Bringing COVID-19 resources to agricultural workers	*There were also some settings where we knew upfront just based on outbreaks within workers who were here temporarily and primarily spoke Spanish on the east side within agriculture settings. So in those cases it was a little bit more of a known quantity that we did need to have some good language capacity available.*
	Theme: cultivating relationships
Partnering with community health boards to build community capacity	*We're very lucky to have ethnic community health boards in Washington…there's a coalition of the health boards as well, and I think folks have seen this as a really helpful way for the community to give voice to the things that they are seeing as health needs within their community and too, hopefully, for public health agencies to be able to contribute to that effort.*
Partnering with employers	*In terms of getting hard-to-reach people,* [Company name] *was instrumental with that. Within that company they also had a coordinator…she worked specifically with the employees who were refugees I believe, and so she also helped, coordinate with IRC to make sure that we, had what we needed and, if we needed help with any investigations, she would kind of help…*
Partnerships with state refugee health coordinators	*It's really important to have the connection with the local health departments and make sure that they feel like their needs are being met and that their concerns are being addressed…on the whole COVID response team…we have a liaison to local health departments. There's one individual person that heads that up and there's a group of people, so they work hard at trying to listen to what the locals have to say and what their concerns are. Otherwise, we know that it would not be successful, and it is, ultimately, their jurisdiction.*
	Theme: ensuring cultural and linguistic concordance
Collection of data about language	*…Having language data even reported on the front end of receiving the case is so important in order to make that match between a case investigator and a patient. I think that traditionally public health reporting systems do not always receive that information just through the ways that the channels have systematically been built and the data that's populated, and even the way that clinicians collect that information on the front end, all those pieces have to go right, and as you are doing a rapid response, that's one of the areas that I really recognized in the course of this that we need to strengthen…*
Staffing agencies to increase language capacity for CICT	*People really do appreciate getting a phone call from somebody who speaks their language…So that was one thing that was very nice about bringing on a staffing agency is that we were able to get…a broad spectrum of different languages that were spoken throughout.*
	Theme: intentional communication
Utilizing WhatsApp to reach RIM community members before CICT calls	*I used those apps quite a bit so—and one of them is-is the WhatsApp app and then basically I would text and say, "This is to help the department and I need to, um, speak – I need somebody to call me back and whatnot." So it is kind of like I think that it was just—oh, it is a real person versus I am just not gonna, um, answer any random calls…*
Cultural Navigators as liaisons between community and public health	*One of the CBO's* [community based organizations] *that we were working with for this pilot project for cultural navigation…They had rotating on call system where people could call in. There would always be somebody who could answer or call right back to understand if somebody had a question about COVID…Supported by trusted community members.*
Outreach to RIM communities prior to CICT engagement	*I think in addition to the case and contact investigation, part of it too was just the general messaging to communities about "If you get COVID, this is how things will go. Please do pick up the phone. This is why they are asking questions. No, they are not going to ask about your immigration status, or report something back to ICE* [Immigration and Customs Enforcement]*." Those parallel messages, setting expectations were really, really key.*

(Continued)

TABLE 2 (Continued)

Promising practices	Supporting thematic analysis excerpts
	Theme: implementing equity
Embedding equity	*So, again, with COVID and how it's impacted is, they have developed more—basically, more events where they are giving out food, and then again, over the phone assistance for people who are affected by COVID to kinda give them a priority in regards to assistance financially, because we do have, like, Action Committee,* [name redacted], *where they help with gas, electricity and water. There's another—there's a lawyer firm that actually helps with evictions that we are aware of, that we share their contact information. That way, if someone is in fear of eviction because their home keeps going back into quarantine and positives keep coming…*
COVID-19 community coordinators	*…The [City] based resource coordinators worked with the district resource coordinators and once we found out someone is positive, they cannot go to work, they have got bills they have got to pay, the ball would start to roll and so the contact tracing was now different because the way the state had it structured was you did everything on the phone with ours, we actually went knocking door to door.*
	Theme: evolving responses
Designated CICT trainer and training developer	*…We did not really have a training structure built…I train folks how to conduct interviews, how to conduct interviews, contract tracer calls to people that have tested positive for the virus, or the contacts of those people that have tested positive for the virus…I do a lot of the training development material…A lot of those issue that are very context-needed, that they* [case investigators] *need to know the context of where these people work, how do they work, how do they make a living…And as a bilingual [person] you need to be very sensitive to those things, and very cognizant that they exist. These challenges are very real for them.*
Supporting mental health for RIM communities	*Before we end the call* [case investigation interview], *of course, we offer assistance and referrals and then assistance in any questions or concerns they may have and fears as well as offer information for mental health.*

*The theme under which the promising practice is located/positioned was selected as a primary theme, however, many promising practices and excerpts span multiple themes.

> *…I used to direct the migrant farmworker program. So I have a close relationship with that program. I've become the direct link between the farm worker program and the health department…[when] we have an outbreak those cases all come through me…*

In some locations, public health teams already focusing on RIM communities were able to quickly build upon those community relationships, and those with strong established community-public health relationships could be further leveraged in the context of COVID-19:

> *That group is a fantastic community-based organization and a known trusted partner, and so when now COVID-19 is the new thing coming in, it was relatively easy to contract with them to provide information to say, "Hey, can you please ramp this up?"*

Interviewees frequently reflected on the importance of organizations fostering trust to facilitate CICT, identifying trust as fundamental to cultivating relationships. They acknowledged the importance of repairing broken trust, bolstering existing trust, and intentionally building trust to facilitate CICT. To foster trust in the CICT process some public health organizations engaged community leaders in case investigation; yet, this was not seen as a way to facilitate trust in every context. One interviewee reported feedback from a community partner indicating,

> *folks don't feel comfortable serving in that role [CICT]. They want to maintain their positions of trust in the community and feel like it moves them a little bit into that government role too much if they actually are the ones collecting sensitive information.*

The importance of building sustainable relationships between public health and RIM communities *before* they are needed in a fast-moving environment—like a pandemic response or another emergency—was highlighted across the interviews and well stated by an interviewee:

> *It's hard to build a relationship in an emergency … what are the ways that we could support and also structure so that the next time, or even going into the fall now, how can we better support both community and the folks that are doing public health work?*

Importantly, the aforementioned examples illustrate how modifying existing or building new relationships facilitates trust and requires an ongoing focus on communication and understanding community contexts and preferences.

3.5. Ensuring linguistic and cultural concordance

Ensuring linguistically and culturally concordant communication, services and support is essential to successful CICT with RIM communities. Interviewees explained that few systems had processes in place to identify languages spoken and/or preferred by COVID-19 positive community members they were attempting to engage in CICT. This gap in knowledge about language for CICT was due to multiple barriers such as language not being collected at the time of testing, or because language information did not have a field in their CICT software. These barriers frequently led to a best-guess approach to spoken language based on name or country of origin, if known. *"[I]t's an imperfect system but it's kind of the best that we can work with at this time."*

Interviewees described operational adjustments during the early phases of the pandemic that allowed multilingual staff members to temporarily shift into roles where they were using their language skills to conduct interviews, or train others on how to use telephonic, video and in-person interpreter services. Eventually organizations shifted to hiring practices that intentionally sought individuals with community-matched language skills and cultural backgrounds, or contracting with staffing organizations with multilingual staff. Interviewees also highlighted the nuance between people who speak a language as their heritage (primary) language compared to non-heritage speakers, observing a stronger sense of community trust with people who were heritage speakers. Herein lay the importance of both linguistic concordance—speaking the same language as the person you are interviewing—and cultural concordance—understanding cultural relevance, preferences, variations in language, and a shared framework of expectations.

The interviewees also recognized the need to ensure health education materials were available in the language and form of media that is preferable and accessible to the audience (e.g., oral PSAs or videos might be preferable to written material). Interviewees highlighted the importance of understanding and reflecting on the breadth of languages spoken within their jurisdiction (a point of intersection with the *Understanding Community and Public Health Context theme*), and the importance of prioritizing the development and dissemination of linguistically and culturally relevant materials, especially given the gap could lead to inequity in information access for smaller and less common linguistic communities. *"The weekly briefs from the mayor, they are always in English, so how do they get translated down to other languages … that real-time feedback from your mayor or leader during an emergency, that's really tough."*

3.6. Communicating intentionally

Intentional communication between public health organizations and RIM communities facilitated sharing and receiving information and promoted engagement in the CICT process. Interviewees described that public health organizations were messengers about CICT both at the individual level during CICT interactions, and at the community level disseminating information about COVID-19 and CICT. CICT interactions for COVID-19 needed to involve building trust with the person being investigated while simultaneously offering CICT process guidance, collecting information, providing COVID-19-specific resources, addressing concerns, and giving accurate messages with an emphasis on promoting community and individual health. As one interviewee described, *"That care coordination piece in addition to* [the] *public health piece about 'Here's the things you have to do', those two things in tandem are pretty important."*

Individually, interviewees described providing public health guidance in a systematic and factual manner as part of the CICT process, *"sure, we use scripts. But we are not salespeople … We're not trying to sell something. We're not trying to get them to do something. We're trying to provide public health guidance."* One trust-building communication strategy shared by an interviewee was intentionally framing the request for information that accompanies the initial CICT phone call as information that has the potential to benefit that individual, their family and the health of the community. Several interviewees described that after years of being advised not to share their personal information, RIM community members being contacted by public health practitioners asking for personal information over the phone was understandably not well received. Consequently, the need to effectively message the function and significance of CICT at the community level, via trusted community sources, was critical to successful CICT.

Additionally, iterative communication was needed within and between CBOs, employers, and public health to ensure everyone had up to date information; however, interviewees highlighted the challenges of making time for these "check-ins" during the pandemic and the "bureaucracy" that made getting the message out from public health slower than planned. As with many of the system-level tensions that became apparent or exacerbated during COVID-19, these became pivot points for public health as the response evolved. For example one interviewee described an appreciation for and recognition of the places where communities might be able to spread and receive messages more quickly than traditional public health messaging such as faith-based organizations: "*The* [redacted] *Community Center is not faith-based but does work with a lot of the different churches and has built a lot of relationships and rapport over time. Their director actually recorded a message about COVID-19 and health education … So the church leaders played it on Sunday during their Zoom services across – to disseminate information from this single place and trusted source."* Other interviewees also emphasized the value of public health getting messages out via social media in partnership with "*community level influencers and CBOs and then also being receptive to the feedback, creating that dialogue and being receptive to the feedback*."

3.7. Evolving response

The approach to CICT evolved over the COVID-19 response and required ongoing adjustment of public health roles, processes, and infrastructure to address organizational and community needs. Public health professionals experienced tension between stressed resources and the ability to innovate at the pace and in the ways that they wanted to for effective and comprehensive CICT. Organizations were unable to provide CICT for every person, and in many scenarios needed to prioritize case investigation, leaving contact notification to individual cases. Many interviewees described the urgent needs and emerging challenges RIM community members shared as the response evolved (e.g., feeling unsafe in their home, or having concerns of job loss while in quarantine and isolation). These challenges led to the development of approaches to support people through the CICT process such as explaining quarantine and isolation in detailed and culturally relevant ways, while also identifying financial or food resources, housing, or other supportive services.

To meet staffing needs, public health professionals utilized their knowledge of existing resources to identify other roles within their system (i.e., navigators or people who conduct CICT for tuberculosis), partner with other organizations (i.e., students at universities), and/or hire from contract agencies and recruited people from retirement. Ideally, public health organizations would have preferred to hire more staff from RIM communities; however, they described challenges finding time to navigate recruitment and hiring policy and procedure challenges, especially early in the pandemic. Public health organizations needed to adapt when engaging with workers in seasonal industries such as farms, food packing, and fishing, for example how to provide housing if an outbreak happened in communal housing. The ongoing evolution of the response also meant public health employees frequently shifted roles. Interviewees spoke about the energy and time their organizations required to continuously shift resources and staff, which contributed to staff stress and burnout, as described by one interviewee, *"…the public health folks are exhausted. Everybody's exhausted. It's been a year, and people are tired, and now we are trying to get vaccine out as fast as possible."* Similarly, another interviewee states *"It's the most intense professionally and personally [I have worked in] my life … we need to learn to adjust to this new reality, and that does not just include the health department … all of healthcare and all of society for that matter."*

3.8. Implementing equity

Public health systems varied in their emphasis on equity in implementing comprehensive CICT and supportive processes. Notably, this theme was not directly asked about in the interview guide, however, all of the interviews describe awareness of equity or inequity, and varying levels of equity in action. Within some public health organizations, interviewees identified specific people and teams who were focused on health and/or language equity that were trying to improve and enhance communication with immigrant communities. Interviewees also identified structural factors within the broader public health COVID-19 response that were contributing to inequities in data collection, testing and vaccine distribution, and characteristics of leadership and team structures. Collecting language at the time of testing was highlighted as a key area where health departments should improve their data collection. One interviewee explained

> *"… we realized that we were not capturing the data that we really needed, all the way down to the languages, to really be able to make strong recommendations to the developers of the software, to the developers of the contracted labs that we were using. So we began to take a deeper dive with that and then the governor started making executive orders to say to the labs, 'you're now required to collect race, ethnicity and language."*

Interviewees provided several examples of missed opportunities for language collection at the time of testing potentially contributing to their inability to identify individuals and communities who were being disproportionately impacted by COVID-19 infection, but underrepresented in the data because it was not being collected. Additionally, access to testing was limited for some communities because it was only done at drive up sites, making it inaccessible to anyone without a car.

Interviewees identified key areas where they sought support both outside and within their organizations to ensure equitable support for immigrant communities. In settings where employers provided housing such as for seasonal work, public health organizations played active roles in identifying sites for quarantine and isolation, and supporting on site testing and vaccination. Interviewees described that many people were facing challenges with meeting basic needs due to loss of wages, jobs or missing work due to illness. One interviewee emphasized, *"Assuring that the distribution of those social supports and financial resources was equitable, I think, is a really big challenge, and one of the challenges for folks accessing that support was language on the phone when they called for help."* A few public health professionals noted that teams that met weekly to debrief, reflect, and learn from one another were well positioned to identify equity concerns and raise them to leadership. Interviewees highlighted that training about discrimination, bias and cultural humility was important to be effective in comprehensive CICT and all public health activities.

Some interviewees also described the need to engage in advocacy within their organization to ensure funding could be allocated to CBOs. In many cases CBOs focused on communities disproportionately impacted by COVID-19 were doing the bulk of the public health work without a commensurate amount of funding. To address this barrier, some public health organizations sought creative ways to support partnerships, including one example of funding a health equity center led by a CBO and an academic medical center:

> *…our state was able to allocate funding specifically to provide COVID-19 education to communities that were disproportionately impacted by COVID-19 and so they did that relatively early on and pushed money to community-based organizations all around the state to do that direct outreach and support within their communities.*

The continuum of equity awareness and implementation varied across public health, indicating a need for an ongoing, multilevel support for teams and systems to expand equity efforts.

4. Discussion

Professionals working at public health organizations identified six themes that facilitate CICT for COVID-19 with refugee, immigrant and migrant communities: understanding community and public health contexts, cultivating relationships, ensuring linguistic and cultural concordance, communicating effectively and intentionally, acknowledging the evolving response, and implementing approaches with equity. There were many barriers discussed to CICT with RIM communities in the results, however, we chose to focus more on facilitators and promising practices in the discussion in order to elevate the positive deviants and lessons for future responses.

These themes and identified promising practices (Table 2) learned and re-learned by public health organizations during COVID-19 for CICT with RIM communities can be translated to other areas of public health practice that involve CICT or benefit from lessons learned herein: sexually transmitted infections, monkeypox, tuberculosis, vaccine preventable infections, foodborne illness, non-communicable diseases, lead exposure and injury prevention, and more. We paired the themes from this analysis with action items and resources to operationalize comprehensive CICT with refugee, immigrant and migrant communities (Table 3). The action items are derived from the public health professional interview data in our analysis and intended to facilitate comprehensive CICT. The action steps are organized with additional resources identified by our team to provide practical steps for readers.

In order to describe visually how the six themes may inform future CICT or other public health responses we interpreted the relationship between the six themes in Figure 1. Understanding community and public health contexts stands on its own as a square (representing a foundation) as a facilitator of CICT. The three themes of: (1) cultivating relationships, (2) ensuring cultural and linguistic concordance, and (3) communicating effectively and intentionally, each stand alone in their circles but also share key common features and often operate together therefore they overlap with one another. The understanding community and public health context square and the three intersecting circles are connected through a bidirectional arrow of implementing equity. We believe that the interaction between these four themes are critical to organizations being able to develop and implement programming to address disparities and move toward a goal of equity in health care outcomes Collectively all five of these themes are operating within the sixth theme of the evolving response to the COVID-19 pandemic, therefore, the evolving response is represented as a circle around all themes. Acknowledgement of the way these themes may operate together can inform community-centered CICT and other public health response activities.

The World Health Organization (WHO) released an *Operational Guide for Engaging Communities in Contact Tracing* of "best practice principles for community engagement and how they can be operationalized as part of any community-centered contact tracing strategy" (23). It includes 11 key principles: (1) understanding community context, (2) build trust, (3) ensure and maintain community buy-in, (4) work through community based solutions, (5) generate a community workforce, (6) commit to honest and inclusive two-way communication, (7) listen, analyze, and respond to feedback, (8) consider the use of contact tracing technology, (9) do not criminalize actions, (10) discourage and address, and (11) coordinate with all response actors. These WHO key principles closely align with the themes we identified with public health professionals in the US working with refugee, immigrant and migrant communities, during COVID-19 in 2020–2021, particularly key principles 1–7.

The WHO guidance describes the important role of people who are migrating or have experienced migration as key to include in developing community-centered CICT (23). The WHO guidance included limited reference to community-centered approaches in non-dominant languages (23). Therefore the findings of our thematic analysis about the importance of linguistic and cultural concordance, and concrete promising practice examples, provide an additional area for emphasis to support all communities in CICT. Teams that are more reflective of the communities they partner with noted that their cultural and linguistic concordance helped people of similar identities be more comfortable engaging in CICT (12, 16). Public health organizations that collected data about language at the time of COVID-19 testing matched linguistically concordant staff members with the case or contact, emphasizing the importance of routine language collection for public health surveillance (24). Often sustained partnerships between public health and CBOs led by refugee, immigrant and migrant communities played key roles in linguistic and cultural support. For example, a longstanding, 17-year community-engaged research partnership in southeast Minnesota quickly adopted a crisis and emergency risk communication framework in 2020 to address COVID-19 and reached 39,000 people in seven languages over a 6 month period with community-led COVID-19 messaging (25).

As the COVID-19 pandemic unfolded, public health professionals and organizations needed time and space to be creative and innovative, and policies that supported this innovation. Frequently, however, the resources and policies needed to support innovation were not available. As public health continues to learn from COVID-19, a sustained investment in public health system strengthening as an element of pandemic preparedness that includes refugees, immigrant and migrants will foster proactive solutions beneficial both for the public health crisis at-hand and for staff well-being. Public health system strengthening for pandemic preparedness and surge capacity planning could include: (1) enhancing epidemiologic surveillance including routine collection of language, race, ethnicity, and nativity data to inform public health interventions and predict workforce needs (24); (2) identifying funding mechanisms, resources and relationships that can be leveraged quickly in an emergency for surge capacity such as the ability to pay CBOs working in partnership with public health organizations; and (3) developing strategies to both retain and also to quickly onboard public health staff with linguistic and cultural expertise to ensure that language equity is a core component of any evolving response; and (4) funding program evaluation and research focused on CICT and other public health interventions with RIM communities. In sum, creating and sustaining mechanisms for linguistically-and culturally-informed community-engagement should be integrated into public health system strengthening and preparation for the next pandemic.

4.1. Limitations

The interviewees in this analysis were from professionals working within public health organizations, therefore the identified perspectives are from this vantage point and may be different than recommendations from community based organizations or health systems. These perspectives were described elsewhere (16, 17). The interviewees who participated had the bandwidth to participate in an interview during the early part of the COVID-19 response, and may not represent the perspectives of significantly burdened systems. Additionally, though findings and dissemination materials from this project might not be generalizable beyond the scope of this project, they might be transferable in some contexts/populations, with consideration of the project limitations.

5. Conclusion and public health implications

The thematic findings and promising practices identified in this project support proactive, community-engaged solutions for public health and other organizations working and partnering with refugee, immigrant, and migrant communities. Implementing these findings with COVID-19 into current and future public health responses could improve public health, language equity, collaborations with refugee, immigrant and migrant communities, and staff wellbeing. Lessons learned from comprehensive CICT with RIM communities and sustained investment in public health system strengthening may facilitate equitable implementation (26) through community-engaged responses across all public health programming.

TABLE 3 Action steps and resource, organized by theme,* for operationalizing comprehensive COVID-19 case investigation and contact tracing with refugee, immigrant, and migrant communities (data from multiple United States HHS regions; September 2020–February 2021).

Understanding community and public health context: use a layered approach to understanding community and public health system context to inform understanding and interventions.	
Action steps	*Evaluate public health and community context while considering current and historic relationships and partnerships.* ● *Community context:* build on existing resources and understanding of RIM communities in your area through a rapid community assessment. ○ RIM communities' countries of origin. ○ Languages spoken. ○ Geographical location/housing. ○ Established partnerships with community organizations. ○ Health providers. ○ Schools. ○ Employment/industry. ● *Public health system context:* evaluate the existing resources within the public health organization to support RIM communities. ○ Identify specific teams within the organization focused on RIM communities. ○ Evaluate staff demographics and alignment with RIM communities. ○ Incorporate multilingual and RIM communities within emergency response structure. ○ Access to scale up language services. ○ Enhance data collection of language on surveys, testing, when services are accessed. ○ Review policies to ensure that newly developed and existing materials are translated and culturally reviewed. ○ Consider approaches to funding community organizations and scaling up language services through staffing, contracting, or partnering. ○ Conduct, update, and review annually a rapid community assessment.
Resources	● NRC-RIM guiding principles. ● How to conduct a rapid community assessment and the addendum: considerations for conducting community assessment with refugee, immigrant, and migrant communities. ● Community mapping ● NACCHO Health Equity and Social Justice Initiative and Resources ● Designing and implementing equitable and inclusive Survey or NACCHO Public Health Quality Improvement Resources
Cultivating relationships: facilitate CICT by building on existing relationships and cultivating new relationships between public health and RIM communities.	

(Continued)

TABLE 3 (Continued)

Understanding community and public health context: use a layered approach to understanding community and public health system context to inform understanding and interventions.	
Action Steps	*Prioritize trust-building* ● Understand the community's current and historically contextualized story/experience of trust and/or distrust with systems. ● Engage in trust-building activities at the: ○ Individual /staff level ■ Personal awareness of bias. ■ Cultural responsiveness training. ■ Awareness of SDOHS impacting local immigrant communities. ○ Public health organization level ■ Policies and practices that build trust within communities. ■ Supportive staff training. ■ Hiring practices that include immigrant community representation.
	Consider characteristics of building new and strengthening existing relationships, and consider creating an inventory, which may include the following areas: ● Temporality (i.e., location on the continuum of new, existing, long-term relationships). ● Level (e.g., individual, program or organizational level) and consider if policies are in place to support relationships at these levels ● Category of relationship (e.g., informal or formal, community and/or organizational entities such as immigrant centered non-profit organizations, faith organizations, and employers). ● Trajectory (e.g., mutually agreed upon goals and MOUs such as a set type of work to be done under contract, short-term/circumstance-dependent staffing support, or a sustainable/long-term partnership with multi-faceted goals).
Resources	● Case investigation and contact tracing: build trust with targeted strategies. ● Partnerships: NRC-RIM guides, checklists and promising practices. ● Community engagement toolkit (with guides, checklists, and promising practices). ● Building partnerships across communities and systems. ● Benefits of community advisory boards. ● Community health workers. ● Partnering with FQHCs serving RIM communities.

(Continued)

TABLE 3 (Continued)

Understanding community and public health context: use a layered approach to understanding community and public health system context to inform understanding and interventions.	
Communicating intentionally: engaging in intentional communication with immigrant communities facilitates sharing and receiving information and promoting engagement in CICT.	
Action Steps	*Assess existing communication structures and processes, facilitators and barriers* ● Inventory existing: ○ Communication channels. ○ Messages. ○ Trusted messengers. ○ Technological facilitators (e.g., WhatsApp thread). ● Identify communication challenges in the inventory at the community and public health organization level.
	Review methods and approaches to bi-directional flow of information both listening and sharing ● *Listening:* Consider ways the organization is listening and learning information from the community, including: ○ Surveys. ○ Focus groups or listening sessions. ○ Community conversations. ○ Written or voice feedback. ○ Other community-informed listening strategies. ● *Sharing:* Consider these components of impactful messaging from the organization to the community. ○ Audience (e.g., individual, family, specific community, and community organization). ○ Approach (e.g., authentic/genuine, personalized, empathetic, and declarative). ○ Message clarity (e.g., general or COVID-19 specific health education). ○ Messenger (e.g., trusted messengers such as community or faith leaders, culturally and linguistically concordant staff). ○ Channel/method (e.g., in-person, phone call, text message, WhatsApp, translated written materials, social-media, video messaging, radio, print media, technology supported CICT/quarantine. and isolation/health monitoring tools and systems).
	Communicate intentionally, intra and inter-organizationally ● Intra-organizational communication strategies such as data sharing, clearly defined and communicated CICT processes, training development and implementation, and intraorganizational communication tech support. ● Inter-organizational communication strategies including seeking out/inviting, listening to and elevating/acting on stakeholders' experiences/knowledge and suggested strategies, making sure to include community partners and public health staff/teams.
Resources	● Effective communication guides, checklists, and promising practices. ● Outreach to RIM communities ahead of CICT efforts. ● Translation process and translated materials library. ● Build your own CICT campaign. ● Working toward equitable language access.
	Ensuring linguistic & cultural concordance: ensure linguistically and culturally concordant communication, services and support for RIM communities.

(Continued)

TABLE 3 (Continued)

Understanding community and public health context: use a layered approach to understanding community and public health system context to inform understanding and interventions.	
Action Steps	*Assess existing communication structures and processes, facilitators and barriers specific to linguistic and cultural concordance* ● Identify what is working well to ensure linguistic and culturally concordant communication. ● Identify language and culturally concordant/discordant messaging-related challenges ○ Lack of data and/or data sharing indicating preferred language. ○ Lack of access to language services when engaging in CICT (e.g., multilingual/ multicultural staff unavailable, language line services unavailable/limited access, and PH unaware of how to work with interpreters/need for training).
	Operationalize linguistic and cultural concordance as a best practice ● Language preference data collection and sharing practices, and identifying the processes needed when the data is not available. ● Leverage, hire or contract with multilingual/multicultural staff whenever possible. ● Provide opportunities for ongoing formal/informal training and learning exchanges around culturally concordant messaging.
	Consider approaches to linguistic and cultural concordance within your community and public health context ● Assess availability of language services (i.e., not always available for less common languages). ● Review policies, procedures, and institutional resources to translate and culturally validate new or existing messaging.
	Explore staffing variations, with a focus on consistency and sustainability ● Temporary public health internal re-deployment of language-proficient staff roles to meet RIM community CICT needs. ● Interpretation line availability. ● Contract staffing (e.g., companies, CBOs). ● Partner supported (e.g., CBOs, academic partners, and volunteers). ● Hiring new staff, ideally from local communities.
	Evaluate multilingual methods/channels ● Call-in-lines (through CBOs, health systems, public health). ● Text messaging. ● Communication systems (e.g., Sara Alert). ● Audio and video PSAs. ● Social media posts.
Resources	● Cultural navigators and/or Staffing agencies to increase language capacity. ● Multilingual coffee hour peer support group for CICT teams. ● Tips for working with interpreters during CICT. ● Working toward equitable language access. ● Sara Alert to automate symptom monitoring. ● Language access and content validation. ● Working with Interpreters during CICT.
Evolving responses: track and reflect on how emergency response CICT practices evolve over time to address community and system-level needs, challenges, new information, and changing public health guidance, as a way to enhance current and future responses and outcomes.	

(Continued)

TABLE 3 (Continued)

Understanding community and public health context: use a layered approach to understanding community and public health system context to inform understanding and interventions.	
Action Steps	*Monitor response evolution over time* ● Recognize *early* stage response needs. ● Consider approaches that facilitate adapting to frequent changes in guidance. ● Prioritize additional staffing and training based on the response needs over time.
	Responding to a new public health need requires ongoing inventory of challenges, and approaches for adaptation and innovation ● Ensure data sharing with attention to confidentiality ● Address funding barriers (i.e., resources and support services for cases and contacts in the context of CICT). ● Consider legal and economic/employment related issues for cases and contacts. ● Address the absence of necessary policies, procedures, or financial mechanisms to allow for rapid movement of funds and approaches. ● Navigate high staffing needs while recognizing staffing burnout.
Resources	● Continuing education: learning through training and NRC-RIM webinars. ● Social support services for RIM communities: a checklist for health departments. ● Supporting mental health in RIM communities during COVID-19 and beyond. ● Psychological first aid for CICT staff.
Implementing equity: creating processes that acknowledge and implement equity from within the public health system.	
Action Steps	*Need to develop and implement processes to re-evaluate activities with an equity lens.* ● Evaluate programs, processes and policies with a formal tool, such as the health equity impact assessment tool. ● Proactively promote programs and activities developed with an equity lens. ○ Ex. Pre-COVID activities such as a local public health consortium developing broad strategies to serve at-risk populations. ○ Ex. Intentional development of collaborative approaches in partnership with communities (i.e., vaccine rollout).
Resources	● Creating health equity zones. ● Embedding equity throughout the COVID-19 response. ● COVID-19 vaccine collaborative. ● Conduct a health equity impact assessment. ● Equity is fundamental to implementation science.

*This table presents data-informed action steps organized by primary theme, accompanied by resources selected by the NRC-RIM team that may aid in operationalizing comprehensive CICT for RIM communities. Many of the action items and additional resources provided are applicable to current and future comprehensive approaches to CICT, and other public health strategies/practices, expanding beyond COVID.

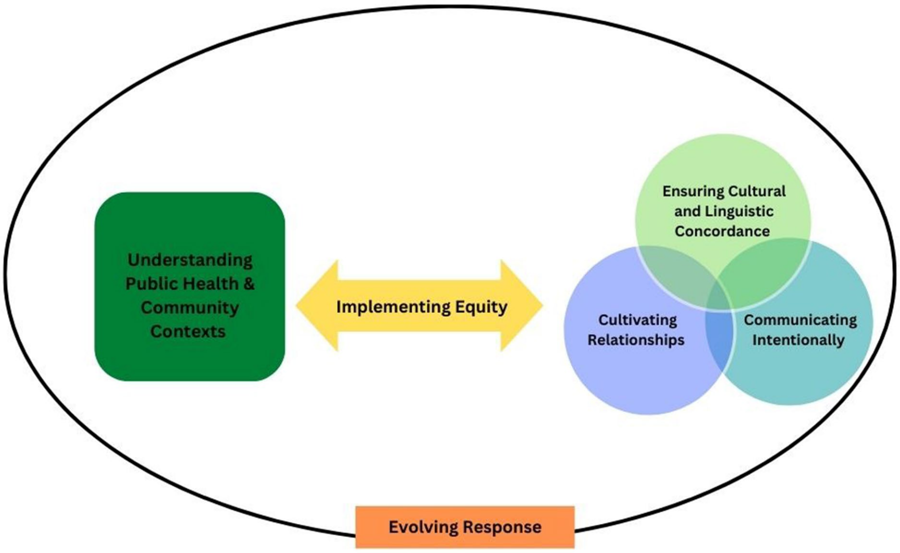

FIGURE 1
Comprehensive COVID-19 CICT promising practice facilitators: A thematic map of public health professional perspectives from the U.S. HHS Regions from September 2020 to February 2021. Understanding community and public health contacts stands on its own as a square (representing a foundation) as a facilitator of CICT. The three themes of: (1) cultivating relationships, (2) ensuring cultural and linguistic concordance; and (3) communicating effectively and intentionally each stand alone in their circles but also share key common features and often operate together. The un he understanding community and public health context square and the three intersecting circles are connected through a bidirectional arrow of Implementing equity. We believe that the interaction between these four themes are critical to organizations being able to develop and implement programming addressing disparities toward a goal of equity. Collectively, all five of these themes are operating within the six theme of the evolving response to the COVID-10 pandemic, therefore, the evolving response is represented as a circle around all themes.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

ED-H conceived and supervised the study and led the writing. WF led the analysis and co-wrote the manuscript. SK, SA, DA, YG, SH, and CT assisted with the study and analyses. FM assisted with the analyses and the writing. SE developed the figure and contributed to the writing. MK assisted with the study, interpretation, and writing. KaY supervised the study, and contributed to the writing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1218306/full#supplementary-material

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Promoting Latinx health equity through community-engaged policy and practice reforms in North Carolina

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Introduction: The Latinx Advocacy Team & Interdisciplinary Network for COVID-19 (LATIN-19) is a unique multi-sector coalition formed early in the COVID-19 pandemic to address the multi-level health inequities faced by Latinx communities in North Carolina.

Methods: We utilized the National Institute on Minority Health and Health Disparities (NIMHD) Research Framework to conduct a directed content analysis of 58 LATIN-19 meeting minutes from April 2020 through October 2021. Application of the NIMHD Research Framework facilitated a comprehensive assessment of complex and multidimensional barriers and interventions contributing to Latinx health while centering on community voices and perspectives.

Results: Community interventions focused on reducing language barriers and increasing community-level access to social supports while policy interventions focused on increasing services to slow the spread of COVID-19.

Discussion: Our study adds to the literature by identifying community-based strategies to ensure the power of communities is accounted for in policy reforms that affect Latinx health outcomes across the U.S. Multisector coalitions, such as LATIN-19, can enable the improved understanding of underlying barriers and embed community priorities into policy solutions to address health inequities.

KEYWORDS

health equity, Latino/Hispanic people, COVID-19, community-engaged research, community-academic partnership

Introduction

Growing evidence during the COVID-19 pandemic reinforced the association between disparate health outcomes and structural racism among historically marginalized populations (1–4). Populations who identify as Hispanic, Latino, or Latinx (herein Latinx) experienced disproportionate risk of COVID-19 disease burden, hospitalizations, and mortality compared to non-Hispanic, White populations (3, 5, 6). In addition, Latinx communities experienced significant declines in life expectancy (7). In North Carolina, Latinx communities represented over half of early COVID-19 cases despite comprising 10 percent of the state's total population (8).

Health inequities heightened during the pandemic reflect long-standing systemic exclusion from resources and opportunities to promote health (9–13). Systemic exclusion occurs when communities experience continuous and compounded legal, regulatory, and political injustices that hinder a population's ability to achieve health and wellbeing. For example, Latinx community members disproportionately lack health insurance coverage and live in neighborhoods with limited or unreliable access to a pharmacy, public transportation, or broadband Internet (4, 9, 13, 14). In addition, acculturative and socioeconomic stressors that stem from discriminatory immigratory practices, lack of stable employment, and racism contribute to declines in physical and mental wellbeing among Latinx populations (15). In North Carolina, Latinx essential workers are disproportionately represented in meat packing and food processing industries, which have limited workplace protections or paid sick leave. During the pandemic, these factors contributed to greater risk of exposure and inability to take time off when workers were sick. In addition, anti-immigrant sentiment, unpredictable immigration policy, and experiences related to family separation prevented Latinx individuals from seeking COVID-19 testing, vaccination, and treatment, or other public health benefits (16–19). For example, initial delivery of COVID-19 testing required government-issued identification or social security numbers, making resources inaccessible to Latinx community members without legal status (20).

Responding to local pandemic-related health inequities, Latina clinicians in Durham, North Carolina created the Latinx Advocacy Team and Interdisciplinary Network for COVID-19 (LATIN-19), a coalition of community, academic, healthcare, and policy stakeholders, that has met weekly since March 2020 and continues implementing its mission today (20, 21). Specifically, LATIN-19 was formed to address the multi-level health inequities faced by Latinx communities in North Carolina during the COVID-19 pandemic (22). These health inequities spanned disparities in COVID-19 mortality, morbidity, and risk of exposure, as well as inequitable access to COVID-19 testing, vaccination, therapeutics and other resources. Through weekly virtual meetings conducted by bilingual and bicultural coalition leaders, LATIN-19 has lifted community voices and created a bi-directional platform to increase community-engaged strategies in policy solutions (21, 22).

Community-academic coalitions, or partnerships among community-based participants including individuals or organizations with academic institutions, serve crucial roles to bring together community members, policymakers, and researchers across sectors to advance health equity in policy responses (23). Preliminary analysis suggests that community and policy interventions informed by LATIN-19 contributed to reducing the COVID-19 vaccine equity gap among Latinx populations in the state (21). North Carolina's COVID-19 vaccination strategies prioritized health equity through community partnerships, data, communication, and payment models, which mitigated the vaccination equity gap during the rollout of the vaccine (24, 25). By October 2021, Latinx populations in North Carolina were the ethnic group most likely to have been vaccinated with at least one dose (8). Despite the state's progress in improving health equity during its COVID-19 vaccination campaign, disparities in rates of COVID-19 therapeutic provision and booster vaccinations emerged in 2022. Latinx children were less likely to be vaccinated and Latinx community members were less likely to receive a booster or monoclonal antibodies (8). These continued disparities due to social and political determinants of health underscore the need for ongoing, long-term efforts to overcome established systemic barriers.

In this study, we examine barriers to COVID-19 testing and vaccination as identified by LATIN-19 meeting participants, assess the alignment of community and policy interventions to observed barriers, and recommend policy strategies to overcome identified challenges. We apply the National Institute on Minority Health and Health Disparities (NIMHD) Research Framework, an accepted tool for organizing complex factors associated with minority health and mapping gaps and opportunities that can inform systems-wide recommendations (26). The NIMHD Framework is an ecological model that captures different levels of influences on health disparities (individual, interpersonal, community, and societal) according to domains of influence (biological, behavioral, built and sociocultural environment, and health care system) and across the life course. Our study adds to the literature by identifying community-based strategies to ensure the power of communities is accounted for in policy reforms that address underlying structural inequities that affect the health of Latinx communities across the U.S.

Materials and methods

Data sources and assessment tool

We adopted the NIMHD Research Framework to systematically analyze 58 LATIN-19 meeting minutes from April 2020 through October 2021. These hour-long weekly meetings anchored LATIN-19′s response by providing a regular safe space for community members to voice concerns during the pandemic and for leaders from diverse sectors (e.g., medical, public health, social) to use these voices to inform change (22). Meetings were open to all participants, which included people with lived experiences. LATIN-19 meeting minutes also offered a longitudinal archive of robust, community-engaged discussions that occurred at different stages of the pandemic (e.g., masking guidance, testing access, vaccination rollout, back to school, etc.) allowing for in-depth consideration of evolving needs. Meeting minutes included input from LATIN-19 participants representing their own lived experiences or in their professional capacity in academic institutions, health care systems, public health departments, public school systems, CBOs, government, and faith communities.

Meeting minutes were taken initially by a trained and supervised medical student volunteer and later by a trained and supervised program coordinator. Meeting minutes were reviewed for accuracy by the meeting host. Therefore, all notes were taken by two individuals, lending relative consistency in style and selection

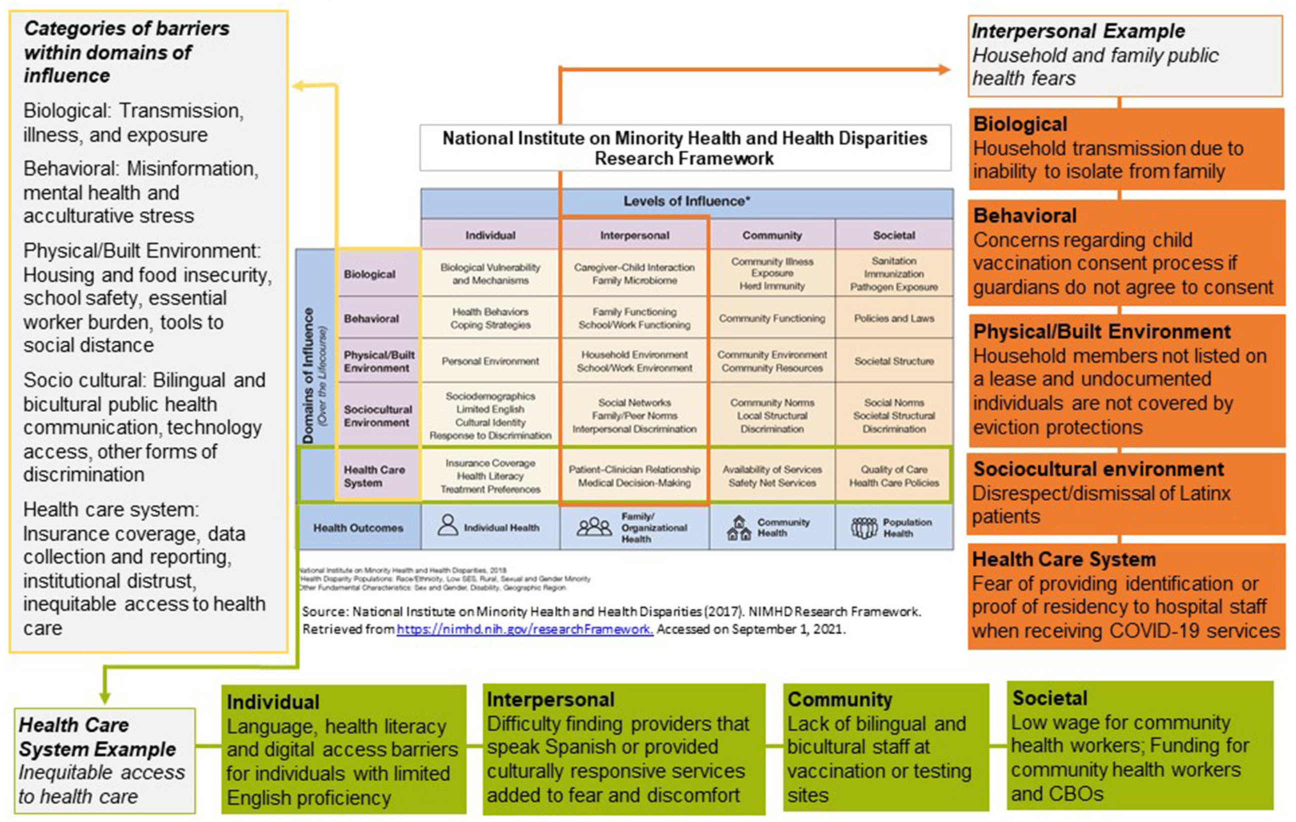


FIGURE 1
Illustrative examples of barriers identified in LATIN-19 meeting minutes using of the NIMHD research framework, April 2020–October 2021.

of important ideas or discussions to include in the notes. Notes were stored in Box, a secure online service provided by the university. Meeting minutes offer a useful alternative in community settings with limited resources to record, transcribe, and translate weekly community-based meetings. We also utilized Press Releases released by the North Carolina Department of Health and Human Services (NCDHHS) as a data source.

Study design and analysis

We conducted a directed content analysis by applying the NIMHD Framework's levels and domains of influence as our codebook (27). Using this framework-based deductive approach, nine team members coded data based on the NIMHD domains of influence in the first round of coding and the NIMHD levels of influence in the second round of coding (28). For each round, two coders independently coded each meeting minute and a third coder reviewed coding of all meeting minutes. Coding was performed in Microsoft Excel, instead of other commonly used Qualitative Data Analysis (QDA) tools, due to the number of coders, number of meeting minutes to review, and difficulties associated with blind coding across reviewers with typical QDA tools (29). The coding team met weekly to discuss coding discrepancies and build consensus on the application of the codebook to the meeting minutes.

Community interventions were defined as interventions led by community-based organizations (CBOs), whereas policy interventions were specific public health or health policy measures implemented by NCDHHS. Interventions that directly addressed an observed barrier identified in the LATIN-19 meeting minutes were considered an aligned intervention. Two team members reviewed Press Releases released by the NCDHHS between April 2020 and October 2021 to identify additional policy interventions that addressed community-identified barriers. Research was approved by the Institutional Review Board.

Results

Our analysis highlighted several long-standing systemic barriers in health care access, social and political determinants of health, and discrimination that re-emerged and persisted during the COVID-19 pandemic. We also identified key community and policy interventions that addressed these barriers. Below, we discuss these barriers according to the NIMHD levels of influence: individual, interpersonal, community, and societal. The same barrier could manifest across different levels of influence, which are not mutually exclusive. Figure 1 illustrates how we applied the NIMHD Research Framework. The figure also demonstrates how barriers were further categorized within domains of influence: biological, behavioral, physical and built

TABLE 1 COVID-19 barriers identified in LATIN-19 meeting minutes by levels and domains of influence (NIMHD Research Framework), April 2020–October 2021.

		Categories of barriers within domains of influence	NIMHD research framework levels of influence			
			Individual	Interpersonal	Community	Society
NIMHD research framework domains of influence	**Biological**		**Biological vulnerability and mechanisms**	**Caregiver-child interactions and family microbiome**	**Community illness, exposure, herd immunity**	**Sanitation, immunization, pathogen exposure**
		Transmission, illness, and exposure	Masking fatigue and inconsistent use of masking	Household transmission due to inability to isolate from household members	High hospitalization rates in Latinx community early in pandemic; concerns about spread at local schools	Increased exposure risk due to working essential jobs and needing to continue to work for a steady income
	Behavioral		**Health behaviors, coping strategies**	**Family functioning, school/work functioning**	**Community functioning**	**Policies and laws**
		Misinformation	Vaccine deliberation due to misinformation about individual immunity following infection and safety of vaccines for children and pregnant women	Concerns regarding child vaccination consent process if guardians do not agree to consent	Vaccine deliberation due to misinformation about side effects from the vaccine and speed of development and approval process	Limited public health communication in accessible formats (e.g., at health literacy level, digital and paper, multilingual)
		Mental health and acculturative stress	Concerns about self-isolation, hospitalization, and separation from family in the event of a COVID-19 positive case (re-traumatizing event for many families)	Fear that accessing COVID-19 services would affect household immigration status Fear of family separation due to restrictive hospital visitor policies	Fear of seeking medical care due to Public Charge	Fear of deportation resulting from contact tracing and data collection
	Physical and built environment		**Personal environment**	**Household environment, school/work environment**	**Community environment, community resources**	**Societal structure**
		Housing insecurity	Housing instability as a contributor to negative health outcomes	Household members not listed on a lease and undocumented individuals are not covered by eviction protections	Difficulty finding appropriate housing to quarantine	Exclusion from state-provided housing programs due to immigration status
		Food insecurity	None observed	Concerns about household and childhood food insecurity	Lack of asset mapping of food resources	None observed
		School safety	None observed	Inability to maintain COVID-19 precautions in schools (e.g., limited facilities for outdoor eating, staff shortages, insufficient PPE supplies, space/staff for social distancing)	Child/nurse ratios at schools too high for testing	Not all Durham Public Schools had funding to implement universal masking

(Continued)

TABLE 1 (Continued)

			NIMHD research framework levels of influence			
		Categories of barriers within domains of influence	Individual	Interpersonal	Community	Society
		Essential worker burden	Financial and employment-related burden due to essential jobs and confusion regarding employment protections for essential workers	Unable to miss work due to financial instability or work from home	Higher levels of uninsurance rates among essential workers	Lack of paid sick leave and PPE (e.g., masks)
		Tools to social distance	None observed	Difficult to social distance at home, at work, or in employer-provided housing (for farmworkers)	Inaccessible quarantine protocols to people with limited English proficiency	Inaccessible resources to be able to quarantine and isolate
NIMHD research Framework Domains of Influence	**Sociocultural environment**		**Sociodemographics, limited english, cultural identity, response to discrimination**	**Social networks, family/peer norms, interpersonal discrimination**	**Community norms, local structural discrimination**	**Social norms, societal structural discrimination**
		Bilingual and bicultural public health communication	Scarce multilingual and accessible information to meet health literacy level for people with limited English proficiency	None observed	Culturally inaccurate and incorrectly translated resources especially if translated by machine-learning applications	NCCARE360 and MyChart initially not in languages other than English Community health worker (CHW) training only offered in English
		Technology access	Confusion regarding vaccine eligibility among individuals without digital access	Difficulty accessing telehealth resources due to lack of WiFi among Latinx farmers	None observed	Digital literacy and digital divide preventing access to telehealth services or online resources
		Other forms of discrimination	Limited transportation options to access events	Disrespect or dismissal of Latinx patients	Lack of resources and limited knowledge about what would happen to asylum seekers complicated seeking testing services Lack of support provided to patients with limited English proficiency after hospital discharge on weekends	Difficulty applying to long-term acute care hospitals (LTACHs) for people lacking legal status or mixed-status households Trauma and systemic exclusion from health systems Fear of being monitored or tracked due to immigration status
NIMHD research framework domains of influence	**Health care system**		**Insurance coverage, health literacy, treatment preferences**	**Patient-clinician relationship, medical decision making**	**Availability of services, safety net services**	**Quality of care, health care policies**
		Insurance coverage	Reluctance to seek treatment due to unknown costs	None observed	High copays for COVID-19 testing and medical care	Medicaid churn due to fears of public charge and family separation, recertification requirements, and NC Medicaid change to Medicaid managed care

(Continued)

TABLE 1 (Continued)

			NIMHD research framework levels of influence			
		Categories of barriers within domains of influence	Individual	Interpersonal	Community	Society
		Data collection and reporting	None observed	Fear of providing identification or proof of residency to hospital staff when accessing COVID-19 medical services	Lack of race/ethnicity data created concern that reported cases were inaccurate	Delayed contact tracing and testing result dissemination Lack of data transparency regarding use of data (e.g., concerns about data sharing with U.S. Immigration and Customs Enforcement)
		Institutional distrust	Requirement of proof of identification initially required at many testing sites	Distrust in the medical system	Community members asked to participate in clinical trials, yet do not have equitable access to health care	Historical and contemporary distrust of health care system and data tracking
		Inequitable access to health care	Language, health literacy, and digital access barriers for individuals with limited English proficiency	Difficulty finding providers that spoke Spanish or provided culturally responsive services added to fear and discomfort	Lack of bilingual and bicultural staff at vaccination or testing sites	Low wage for CHWs Limited funding for CHWs and community-based organizations (CBOs)
Health outcomes			**Individual health**	**Family/organizational health**	**Community health**	**Population health**
			Disproportionately high COVID-19 exposure, cases, and mortality racial and ethnic disparities in testing and vaccination rates			

Source: Authors' analysis.

environment, sociocultural environment, and health care system. Table 1 summarizes barriers by level and domain of influence.

Participation represented in meeting minutes

Average LATIN-19 meeting participation during the study period was 76 participants per meeting (range 40–100). Initial average participation was 40 people in May 2020 and quickly increased to 85 people by July 2020. With the exception of October 2020, August 2021, and October 2021, all other months in the study period exhibited a monthly average participation rate above 70 people, an indicator of consistent and active participation. A peak monthly average occurred in February 2021–April 2021 (80–95 monthly averages), which was the time period of initial COVID-19 vaccinations. Broadly, LATIN-19 meetings included discussions of barriers Latinx community members experienced in North Carolina, as well as solutions identified by participants. LATIN-19 does not collect descriptive data on individual participants.

Individual barriers: lack of transportation and technology, limited language concordance, employment uncertainty, and financial consequences

Transportation and out-of-pocket cost barriers made accessing COVID-19 testing and vaccinations challenging. Individuals were unsure if transportation to testing sites would be covered, were worried about the cost of receiving testing or vaccinations without health insurance, and did not trust that vaccinations were completely free given confusing messaging. Furthermore, individuals feared unknown financial consequences due to limited paid time off and lack of clarity regarding who qualified as an essential worker. Confusion repeatedly peaked following intermittent changes to quarantine, mask, and social distancing requirements. Stress related to self-isolation, hospitalization, and separation from family due to quarantine protocols impacted mental health. In addition, individuals reported difficulties finding updated COVID-19 guidelines or information without a smartphone or Internet access. Another concern was the lack of high-quality, linguistically accessible, and culturally relevant COVID-19 information available for people whose preferred language was not English.

Interpersonal barriers: inability to quarantine at-home, miss work, and social distance at work or school

Precarious food, housing, and economic realities made mitigating COVID-19 transmission in households difficult as working-age individuals were unable to miss work or work from home. Further, as multi-generational and multi-family households are common in many Latinx communities, some families reported household transmission due to lack of space and inability to quarantine within their home. Cultural norms to care for older adult family members at home also placed households at higher risk of transmission. As schools transitioned back to in-person classes, most local public schools did not have facilities for outdoor eating, and faced staffing shortages, which reduced the ability to enforce recommended COVID-19 precautions. Concerns about potential eviction compounded household stress related to employment and transmission, especially if household members lacked legal status or were not listed on the lease. Federal eviction protections did not apply to these household members further worsening housing insecurity.

Community barriers: vaccine deliberation, concerns about public charge, limited bilingual or bicultural information and providers

Historical and contemporary mistrust of health systems and government institutions coupled with limited availability of information in Spanish contributed to vaccine deliberation, or considering information before making a decision, at the community level (30). Modifications to North Carolina Medicaid coverage during the pandemic, including the transition to Medicaid managed care in July 2021 and changes in medical billing codes, increased concerns about disruptions in Medicaid coverage and out-of-pocket costs for COVID-19 testing, vaccination, and hospital treatment. Importantly, changes to the Public Charge Inadmissibility Rule, which refers to receipt of public benefits that can negatively impact eligibility for lawful permanent residence, caused fear and concern regarding whether use of Medicaid benefits or COVID-19 treatment would impact immigration status. Ubiquitous language barriers further compounded existing mental health and acculturative stressors. Few sources of bilingual information existed for community members. Even when available, these resources were not accessible to community members with limited access to technology or limited health literacy; thus, community members increasingly relied on informal and often erroneous sources of information. Other barriers spanned social determinants of health, including food insecurity, and forms of discrimination. For example, families were referred to social service organizations that often lacked culturally trained staff or had limited availability of Spanish-speaking providers.

Societal barriers: data collection and reporting, fears of data use due to deportation risk, inaccessible services for underinsured or uninsured populations

Initially, data for COVID-19 testing was not publicly available by race and ethnicity, which hindered the development of interventions to overcome specific barriers that Latinx community members experience. Lack of clarity regarding data privacy and data sharing among state and federal agencies resulted in delayed or avoided treatment. Community members expressed fear of deportation due to the possibility of U.S. Immigration and Customs Enforcement using personal identification or proof of residency information collected at testing and vaccination sites in immigration status cases. These fears contributed to ongoing stressors related to immigration status and surveillance, resulting in reinforced trauma and reduced access to COVID-19 resources. Lastly, lack of insurance and long wait times (2–3 months) to receive Medicaid coverage led to inaccessible COVID-19-related services and increased stress from unknown out-of-pocket costs.

Alignment of community and policy interventions to observed community-identified barriers

Most observed barriers were addressed through at least one type of intervention (e.g., community or policy). Some categories within domains of influence, such as transmission, illness, and exposure; tools to social distance; bilingual and bicultural health communication; and equitable access to health care, were addressed by both community and policy interventions. However, some observed barriers lacked either a policy or community intervention, or both. For example, the following categories within domains of influence included at least one level of influence lacking an intervention: mental health and acculturative stress, essential worker burden, technology access, discrimination, insurance coverage, data collection and reporting, and institutional distrust. Specifically, neither community nor policy interventions addressed any of the observed barriers related to essential worker burden, such as financial burden, inability to miss work, and lack of paid sick leave. Several discrimination barriers also remained unaddressed by either community or policy interventions, such as disrespect of Latinx patients, lack of support for patients whose preferred language was not English after hospital discharge, trauma, and systemic exclusion from health systems.

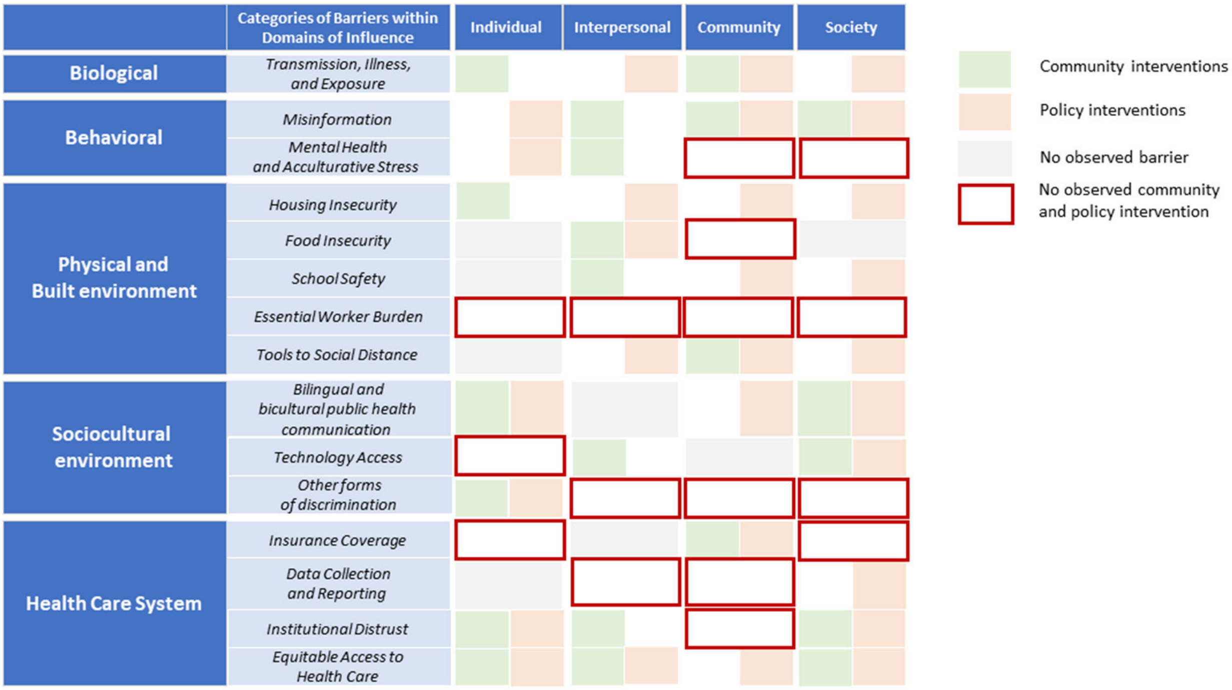
Community interventions leveraged expertise through iterative and bi-directional decision-making processes. These solutions focused on connecting Latinx community members to the right COVID-19 information, resources, and support systems while overcoming systemic barriers. Policy interventions focused primarily on amending and expanding existing health care infrastructure to improve access to services. These solutions leveraged policy change to better integrate social and health services and remove restrictions to access to existing public health services. In several instances, policy and community interventions jointly addressed the same observed barriers. For example, both community and policy interventions were developed to address challenges related to COVID-19 vaccine misinformation. Community-based organizations increased Spanish-speaking staff at community outreach events and developed bilingual websites on COVID-19 resources, whereas NCDHHS developed Spanish community health worker trainings and Spanish information campaigns. Figure 2 illustrates community and policy interventions organized by the barriers they address (see Supplementary material for a detailed summary of solutions).

Discussion

Our findings advance the literature on community-engaged strategies to promote health equity among Latinx populations experiencing systemic exclusion from health care, public health, and social services. As prior research shows, interventions to improve health equity require coordination and partnerships across sectors, authentic community engagement, and removal of policies that lead to inequitable health outcomes (21, 31). Here, we analyzed discussions from LATIN-19, a community-academic coalition that has regularly convened community members, researchers, public health leaders, and policymakers to engage in meaningful communication and mutual goal-setting since March 2020. Our application of the NIMHD Research Framework facilitated a comprehensive assessment of complex and multidimensional factors contributing to health disparities in Latinx health while centering on community voices and perspectives. To our knowledge, we are the first research team to use this framework as a tool to assess community-identified pandemic-related barriers and policy implications among Latinx communities (32, 33). We found that barriers clustered at the community and society levels, and community and policy interventions piloted during the COVID-19 pandemic focused on increasing access to social supports and developing and disseminating information in Spanish.

Importantly, most barriers identified in our study are not new or unique to the pandemic, underscoring that extensive documentation of systemic inequities is insufficient to lead to policy action. For example, access to linguistically appropriate resources has been a longstanding challenge, and worsened with the rapidly changing recommendations and guidelines during the pandemic (9–11). Similarly, pre-existing gaps in access to mental health care for Latinx populations widened during the pandemic (34, 35). Meanwhile, pandemic-related stressors disproportionately impacted the mental health of historically marginalized populations. For example, new modalities of family separation emerged during the pandemic. Families with household members without legal status were fearful of seeking medical care due to lack of communication once a family member was admitted to a hospital, restrictive visitation policies, and language barriers. Additional concerns surrounded logistics of obtaining remains of loved ones for transportation back to the country of origin. LATIN-19 participants noted that health systems often lack bilingual and culturally sensitive staff. Policy changes that resulted in more frequent communication to families when loved ones were hospitalized helped assuage fears of a "desaparecido," or disappeared individual, which is a common familial trauma among many Latin Americans across the region.

A near-term policy implication to reduce discrimination and institutional distrust is to expand the bilingual and bicultural workforce by including community health workers and CBOs as partners in public health or health care transformation efforts that uphold cultural humility. Additional policies outside of the health care domain, such as those removing requirements for presenting government identification or proof of residency when seeking COVID-19 testing or vaccinations, directly addressed community fears of tracking, separation, deportation, and discrimination. Such



	Categories of Barriers within Domains of Influence	Individual	Interpersonal	Community	Society
Biological	*Transmission, Illness, and Exposure*	🟩	🟧	🟩🟧	🟧
Behavioral	*Misinformation*	🟧	🟩	🟩🟧	🟩🟧
	Mental Health and Acculturative Stress	🟧	🟩	🟥	🟥
Physical and Built environment	*Housing Insecurity*	🟩	🟧	🟧	🟧
	Food Insecurity	⬜	🟩🟧	🟥	⬜
	School Safety	⬜	🟩	🟧	🟧
	Essential Worker Burden	🟥	🟥	🟥	🟥
	Tools to Social Distance	⬜	🟧	🟩🟧	🟧
Sociocultural environment	*Bilingual and bicultural public health communication*	🟩🟧	⬜	🟧	🟩🟧
	Technology Access	🟥	🟩	⬜	🟩🟧
	Other forms of discrimination	🟩🟧	🟥	🟥	🟥
Health Care System	*Insurance Coverage*	🟥	⬜	🟩🟧	🟥
	Data Collection and Reporting	⬜	🟥	🟥	🟧
	Institutional Distrust	🟩🟧	🟩	🟥	🟩🟧
	Equitable Access to Health Care	🟩🟧	🟩🟧	🟧	🟩🟧

🟩 Community interventions
🟧 Policy interventions
⬜ No observed barrier
🟥 No observed community and policy intervention

FIGURE 2
COVID-19 community and policy interventions by levels and domains of influence (NIMHD research framework), April 2020–October 2021. Policy interventions that did not directly address observed barriers noted in the LATIN-19 meeting minutes were not included in this analysis. Source: Authors' analysis.

measures were disseminated by trusted community organizations and led to improved vaccination coverage and, if implemented earlier, could have potentially prevented hospitalizations and deaths from COVID-19. These solutions were developed when community members and policy makers engaged in longitudinal, bi-directional information sharing during the pandemic. In response to the end of the Public Health Emergency, such solutions can be adapted to continue to remove systemic access barriers, address social determinants of health, and support community-based care delivery models as a fundamental prevention strategy for public health.

Second, alignment of policy and community interventions to address different components of the same barriers in tandem can lead to more comprehensive change. Community interventions tended to focus on reducing language barriers and increasing community-level access to social supports while policy interventions focused on creating the infrastructure to increase services to slow the spread of COVID-19. Community-based organizations and community health workers led efforts to distribute food, increase transportation, and increase access to community-based COVID-19 testing and vaccinations. In addition, community interventions advanced bilingual messaging to clarify that all individuals, regardless of immigration status, could access COVID-19 testing and vaccination. Simultaneously, policy interventions included increasing funding for CBOs to conduct COVID-19 testing and vaccinations, as well as advancing state-wide programs (e.g., North Carolina Integrated Care for Kids and NCCARE360) to increase access to social supports.

Our findings highlight the critical role that community-based partners play in building trust, expanding access to services, and communicating culturally relevant information. Community-academic coalitions, such as LATIN-19, can also promote policy or programmatic changes, such as advocating for the implementation of MyChart, an electronic medical record system, in Spanish to make it easier for patients to track and view health information. Formalizing such coalitions as key partners to policymakers can ensure that interventions, regardless of type, do not have unintended consequences or inflict harm on community members. Policy implications include closing funding gaps based on periodic analysis of locally available community-level data to facilitate community-engaged research. These data can inform real-time priority setting and resource allocation to interventions that are aligned to community priorities and lead to more sustainable and responsive reforms. Funding could support transcription and translation of community discussions into quantifiable data, training of community health workers to increase data collection capacity, and community advisory boards to inform which health system or public health performance measures are aligned to community priorities.

Third, addressing systemic barriers rooted in structural racism requires multifaceted, culturally congruent solutions across multiple levels and domains of influence. While many observed barriers included common health policy or social determinant of health domains (e.g., insurance coverage, food, employment, health literacy, access to services, medical distrust), other barriers included fears related to immigration status, discrimination, and acculturative stress. Longer-term policy implications include addressing the social and structural determinants of health that lead to health disparities in Latinx communities, such as lower access to employment and health benefits. This will require policy action, such as expanding insurance coverage, but also extending to policies that reduce acculturative stress. For example, community-based outreach is needed to reverse the chilling effect of misinformation related to Public Charge, which has deterred families from seeking medical services or enrolling in public benefits for which family members may be eligible (e.g., Medicaid, SNAP, or WIC). Continued monitoring and sharing of health data by race and ethnicity and by public benefit program would help identify gaps that require community-based partnerships. Further, the pandemic has stressed how health systems and policy makers need to financially support community partners that elevate community priorities to the level of large health systems, private sector leaders, and health departments. Policies that redirect financial resources to community partners could be achieved by sharing savings from alternative payment models that incorporate incentives for equitable outcomes.

Although not the focus of our study, future efforts could explore which types of interventions are most effective in addressing community priorities to improve public health. In our study, we considered interventions aligned if they addressed an observed barrier; however, we were not able to determine if a barrier was best addressed through a policy intervention, a community intervention, or both. Efficiencies could occur from policy and community interventions addressing the same domain of influence but different levels of influence. For example, a CBO is likely to have the local knowledge and cultural humility to address individual- or household-level concerns related to mental health and acculturative stress, but a policy measure to address these areas could include expansion of behavioral telehealth services. Efficiencies could also occur by a policy intervention collaborating with community-based partners to address a single barrier. For example, increasing culturally informed information could include contracting CBOs to create bilingual handouts for public health guidance.

Strong multisector coalitions, such as LATIN-19, can help bridge silos across academic institutions, CBOs, and policymakers, and lead to more effective collaboration across stakeholders. LATIN-19 continues to meet today to address well-established and persistent health inequities including improving health literacy, increasing participation of Latinx individuals in clinical trials, bolstering capacity for community health workers to engage in clinical research and care navigation, and increasing insurance enrollment among Latinx populations. Key lessons learned from LATIN-19 experience include actively and intentionally centering community perspectives in the design, implementation, and assessment of policy or community interventions; addressing operational silos that stem from different and multiple sectors (e.g., health, social, education, as well as profit or non-profit status) by encouraging continuous and ongoing discussion to solve problems and create solutions; and developing multi-sectoral interventions to adequately respond to underlying systemic barriers that lead to poor health outcomes.

This study has limitations. Meeting minutes did not include direct quotes from meeting participants. The presentation topics of the invited guest speakers may have also influenced the ensuing community-based discussions. Furthermore, meeting minutes excluded the perspectives of community members that could not attend weekly LATIN-19 meetings. Lastly, our analysis did not include an impact or effectiveness assessment of the interventions identified in the meeting minutes. Therefore, we are unable to draw causal inferences between identifying a specific issue by LATIN-19 and implementation of a policy or community solution or intervention.

Conclusions

Multisector community-academic coalitions, such as LATIN-19, enable the improved understanding of underlying barriers, community priorities, and solutions to address inequities. Policies that center historically marginalized voices and build on the power of community-academic coalitions can results in structural changes that promote health equity during public health crises. Further, sustainable and comprehensive policy and community interventions are needed to continue addressing systemic barriers and pandemic-related stressors that have negatively affected Latinx communities. Lessons from North Carolina can inform the national health policy discourse on how to embed community-engaged approaches in health policies to reduce marginalization and systemic exclusion that result in inequitable health outcomes.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

AT: conceptualization, methodology, formal analysis, funding acquisition, writing–original draft, and supervision. GP: conceptualization, methodology, formal analysis, funding acquisition, validation, and writing–original draft. FM: methodology, formal analysis, validation, data curation, project administration, and writing–original draft. EH, CP, and KK: formal analysis, writing–review and editing, and visualization. NC, AL, KR, and AO: formal analysis and writing–review and editing. IA and RC: conceptualization and writing–review and editing. RG-G: conceptualization, methodology, and writing–review and editing. VM-B: conceptualization, writing–review and editing, resources, and funding acquisition. All authors contributed to the article and approved the submitted version.

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Conflict of interest

VM-B was contracted by the North Carolina Department of Health and Human Services to serve as a Latinx Advisor during 2021. VM-B is Co-Founder of LATIN-19. RG-G, GP, and AT were Executive Board Members of LATIN-19. Executive Board Members do not receive any direct financial remuneration for their involvement in LATIN-19.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1227853/full#supplementary-material

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Knowledge, perceptions, and practices around zoonotic diseases among actors in the livestock trade in the Lake Victoria crescent ecosystem in East Africa

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Background: Zoonotic diseases such as anthrax, rabies, brucellosis, and Rift Valley fever pose a direct threat to health and undercut livelihoods in the communities in which they occur. A combination of anthropogenic and animal activities like migration and interaction with wildlife and their respective parasites and vectors drives the emergence and re-emergence of zoonotic diseases. Consequently, One Health interdisciplinary approaches that incorporate social scientists can provide key insights into complex local perceptions. The approach calls for collaboration between the human and animal health sectors, including the sharing of disease surveillance data necessary to alleviate disease impacts. Livestock traders interact closely with livestock, which puts them at elevated risk of infection and creates conditions by which they may spread zoonotic disease. It is thus essential to examine practices among actors involved in the livestock trade to understand the most appropriate ways to mitigate these risks.

Methods: A qualitative study was conducted among the actors in the livestock trade in Busia County on their knowledge and perceptions of zoonotic diseases and practices that may contribute to the spread, control, and prevention of zoonotic disease transmission. A thematic analysis framework was used to categorize and synthesize data from in-depth interviews (IDIs), key informant interviews (KIIs), and structured observations.

Results: Whereas participants could list livestock diseases, they could not identify which ones were zoonoses, demonstrating insufficient knowledge of zoonosis. They identify sick animals by checking for dropped ears, excess mucus production, diarrhea, bloody urinal discharge, and general animal activity levels. To prevent the spread of these diseases, they wash their animals, isolate sick animals from the rest of the stock, and vaccinate their animals. They seek help from animal health professionals for sick animals as part of curative practices. This shows that they perceive the diseases as serious and that they need to be attended to by professionals. The results also show that they perceive animals from outside the region to be more vulnerable to diseases compared to those from within. The actors in the livestock trade engage in practices like skinning dead animals before burying them; to them, this is a normal practice.

Some also consume dead carcasses. These increase the risk of zoonotic disease transmission.

Conclusion: The actors involved in the livestock trade are critical in the prevention and elimination of zoonotic diseases; hence, they need to be involved when developing intervention programs and policies for animal health extension services. Training them as a continuum of animal health workers blends lay and professional knowledge, which, alongside their intense contact with large numbers of animals, becomes a critical disease surveillance tool. Increasing awareness of zoonoses by using multi-disciplinary teams with social scientists is urgently needed so that practices like skinning dead animals before disposing of them and consumption of dead carcasses can be minimized.

KEYWORDS

zoonotic diseases, knowledge, perceptions, practices, livestock trade

Introduction

Any infectious disease potentially transmissible from animals, both wild and domestic, to humans is defined as a zoonotic disease (1). The diseases that infect humans from animals are caused by bacterial, viral, parasitic, or fungal pathogens and spread to humans through bites, scratches, vectors, or ingestion. Zoonotic diseases are categorized according to their route of transmission, namely vector-borne like Rift Valley fever or food-borne such as *Campylobacter*, *Salmonella*, *E. coli*, and *Listeria*; pathogen types such as microparasites, viruses, bacteria, protozoa, worms, ticks, or fleas; or degree of person-to-person transmissibility such as coronaviruses (CoV) and Ebola virus (2–5).

Humans live in close relationships with domesticated animals. These animals may have pathogens that are transmissible to humans and can be harmful to health (6). Zoonotic diseases pose problems for global health; they account for an estimated 60% of known infectious diseases and 75% of emerging infectious diseases that are reported globally (7). Endemic zoonotic diseases are prevalent in developing regions worldwide, particularly in areas where humans and animals reside in close proximity. Endemic zoonotic diseases persistently impose a significant disease burden, particularly across tropical regions. They affect human health and wellbeing directly as common causes of human disease and indirectly through impacts on livelihoods and food security because of livestock production losses. Despite these multiple impacts, endemic zoonoses are still rarely recognized and are poorly understood (8). These diseases pose health burdens in addition to having negative social and economic effects on communities. The infected individual becomes unproductive, and close relatives spend money providing care and treatment. Time and money spent searching for a cure may put a severe drain on family resources (9). Zoonotic infections in people and animals occur in the context of a wide range of co-endemic pathogens in a rural community in western Kenya (10). The varying public health burden and socio-economic impact of zoonotic diseases across time and geographical settings make prioritizing their prevention and control important (11). The emergence of zoonoses, both recent and historical, can be considered a logical consequence of both pathogen and human ecology and pathogen evolution as microbes exploit new niches and adapt to new hosts (1). Access to these new niches is mediated by human action in most cases, including changes in land use, extraction of natural resources, animal production systems, modern transportation, antimicrobial drug use, and global trade (1).

The emergence of infectious diseases is a result of a variety of interconnected factors. These factors encompass population growth, alterations in dietary, farming, and trade methods, as well as changes in land use, such as rapid urbanization, deforestation, and encroachment on wildlife habitats. Furthermore, ancient zoonotic diseases are resurgent, such as rabies, anthrax, brucellosis, bovine tuberculosis, zoonotic trypanosomiasis, and conditions associated with tapeworm infections (12). This resurgence is attributed to a combination of similar factors, including the transmission of pathogens from wildlife to domestic animal populations (12). The appearance and re-appearance of many diseases, including zoonotic diseases, have been driven by the changing and increasing interconnection among humans and animals and the intensification of human activities surrounding and encroaching into natural habitats, enabling pathogens in wildlife reservoirs to spill over to livestock and humans over time. Cultural changes as a result of the rise in population, economic developments, technical developments, and intensification of farming have created more intense interaction between humans and livestock (13). The increased risk of disease emergence and the possibility of pervasiveness have been linked to increased regional trade and travel, an increase in human and livestock populations, and changing subsistence systems reflected in agricultural practices that have led to agricultural intensification and significant environmental changes in recent times (14). This warrants the need for continuous surveillance and disease monitoring and an understanding of the cultural epidemiology of zoonotic diseases.

People's cultures, norms, knowledge, attitudes, and practices (KAP) can contribute to the spread, control, and elimination of various diseases, including zoonotic diseases (15), and also influence their health-seeking behavior. The KAP studies are popular as they help in assessing health-related beliefs and behaviors and how far community knowledge corresponds to biomedical concepts in the context of specific diseases and illnesses (16). Several KAP studies take a qualitative approach; however, qualitative KAP studies are also increasingly being carried out to get more in-depth perspectives on knowledge, attitudes, perceptions, and practices on health issues. Perceptions may be influenced by knowledge, cultural and religious practices, and lived experiences, and they in turn may predict action or behavior.

Social determinants of health are defined by the World Health Organization as conditions or circumstances in which people are born, grow, live, work, and age. These conditions are shaped by political, social, and economic forces (17). Apart from culture and norms, knowledge, perceptions, and attitudes—indicators of social inequality, including education and income—also play critical roles in determining access to healthcare as well as influencing how healthcare services are utilized (18). Kenya faces major health challenges that are influenced by various social and economic determinants such as access to safe water and adequate sanitation, nutrition, safe housing, occupational hazards, road safety, security, and income (19). Social determinants of health are shaped by public policies. The structure and quality of healthcare are considerably influenced by public policies made by governments (17). Social relationships impact adherence to medical treatment plans, seeking medical assistance, using healthcare services, and ultimately affecting health outcomes. Within healthcare organizations, social capital holds significance as it contributes to the effective provision of well-coordinated, high-quality care. These form very important concepts of social epidemiology (20, 21). Studies have shown that knowledge of reservoirs of zoonoses and how they are transmitted to humans has enabled early detection, reporting, and control (22). Knowledge or awareness about diseases varies across individuals and communities. Evidence shows that people's perceptions about disease risks such as transmission and health consequences influence their attitudes and health-seeking actions and behaviors toward the diseases concerned (23). The One Health approach recognizes the interconnectedness of global health issues and, as such, promotes the importance of and need for international, interdisciplinary, and cross-sectoral communication and collaboration at local, national, and international levels (24). For One Health interventions to work, it is best to work closely with the local people and relevant disciplinary players to understand their local conditions and context (25). An interdisciplinary One Health approach that incorporates social scientists can provide insights into the complex local perceptions influenced by knowledge, religious beliefs, and lived experiences and how interventions can be designed or improved while acknowledging and addressing critical issues around awareness, perception, and underlying practices (26). The potential for enhancing public health outcomes through early detection of zoonotic disease events before they spread widely among humans lies in the collaboration between the human and animal health sectors. This collaboration encompasses the exchange of disease surveillance data, fostering a joint effort through the One Health approach to safeguard the wellbeing of humans, animals, and the environment (27).

The livestock trade system is a complicated chain with producers, traders, and numerous other market participants who are all referred to here as "actors in the livestock trade." Animals travel from homes through different markets and trade routes to the last consumer or terminal market (28). Numerous informal chains with independent livestock and meat traders play a critical role in the livestock trade (29).

The flow diagram (Figure 1) shows how various actors in the livestock trade are connected.

The actors in the livestock trade include the livestock keepers, who rear the livestock and make the decision to sell them. There are traders whose business is to buy and sell livestock. Brokers engage in connecting potential sellers to buyers and vice versa. There are also animal trekkers whose role is to walk the livestock from their homes to the markets or across markets. The livestock movement is an important driver of infectious disease transmission and spread (23). In Kenya, livestock movements are motivated by a need for animals to access resources (pasture and watering) to ensure their survival and when they are sold or being sold, as this study has revealed. Livestock often travel several kilometers each day to reach communal resource areas or markets where extensive mixing of herds and contacts between animals occur, with considerable implications for pathogen transmission and subsequent disease spread (30). There is evidence of cross-border trading of livestock in Busia, and given that the borders are highly porous to animal movement, this may contribute to zoonotic disease spread (31). The East African Community (EAC) partner states share a similar disease profile (32); their borders are also highly porous to informal animal and human movement, which is common in countries where animal production is not intensive (31). With the ease of livestock movement across borders, zoonotic diseases can spread across the countries, and therefore the Lake Victoria Crescent ecosystem, which has a dense human population, cross-border trade, and intensifying farming, was chosen for this study. Understanding livestock movement and having livestock movement data can facilitate disease control and surveillance (33). Lake Victoria Crescent forms the right environment for strategic zoonotic disease control programs through public health awareness campaigns among local and foreign livestock traders. The area is occupied by non-pastoralist communities, which depart from the usual focus on pastoralism when considering livestock movement. It forms a critical area in relation to livestock and zoonotic diseases. The study sought

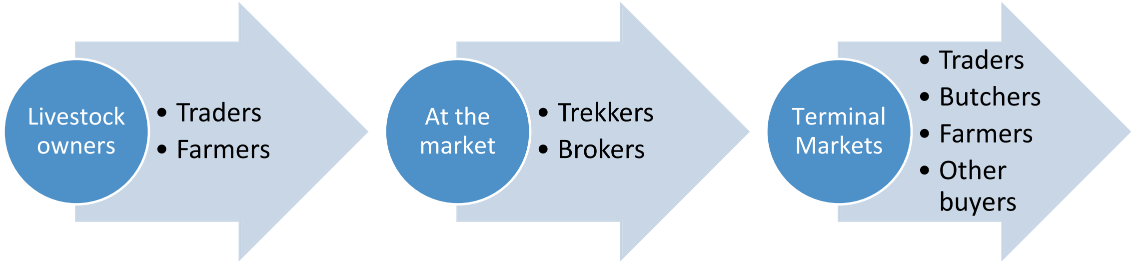

FIGURE 1
Different actors in the livestock trade.

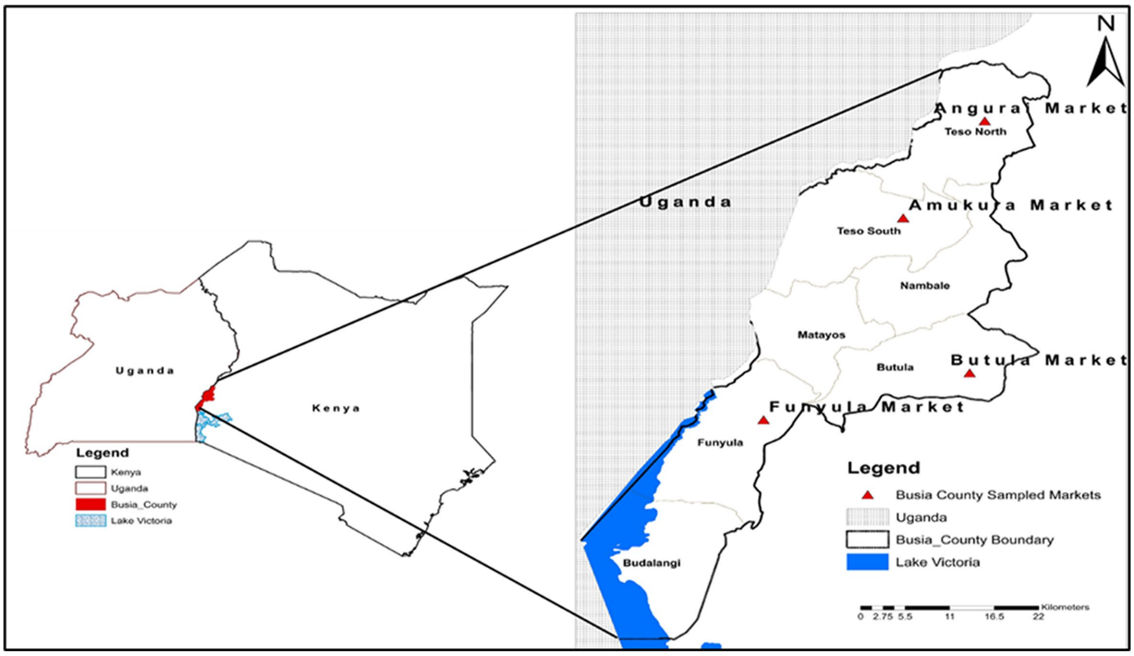

FIGURE 2
Map of the livestock markets in Busia County in the Western Kenya region.

to bring out knowledge and practices on zoonotic diseases in non-pastoral areas and, more so, among actors in the livestock trade in the Lake Victoria Crescent ecosystem.

Methods

Study area

The study was conducted in livestock markets in Busia County, Western Kenya, between November 2019 and March 2020. The markets were Amukura and Angurai, situated to the north; Butula, which was central; and Funyula, which is slightly to the south (Figure 2). Busia County is located in the western part of Kenya and broadly represents the Lake Victoria Crescent Ecosystem (10), where several zoonotic infections such as Brucellosis, Q-fever, bovine tuberculosis, human African trypanosomiasis (HAT), Rift Valley fever (RVF), and cysticercosis/taeniasis are co-endemic (10, 27). It borders Uganda with two border crossing points at Busia and Malaba towns. It is one of the four counties comprising the Western Kenya region and is situated at the extreme western border of the country.

Research design

This exploratory study used in-depth interviews, key informant interviews, and unstructured observation to understand the knowledge and perceptions of zoonotic diseases and practices of the actors involved in the livestock trade. The study began with in-depth interviews (IDI) with livestock traders and trekkers on their knowledge, perceptions, and practices in relation to zoonotic diseases. Knowledge, attitudes, and practices (KAP) studies are commonly used to identify knowledge gaps and behavioral patterns among sociodemographic subgroups for the effective implementation of public health interventions (34). They provide useful information, are cost-effective, and are simpler to design and execute with limited time and budget as compared to a more in-depth ethnographic study (35). KAP surveys can identify knowledge gaps, cultural beliefs, or behavioral patterns that may facilitate understanding and action. They can identify information that is commonly known and perceptions or attitudes that are commonly held. They can help identify factors influencing behavior that are not known to most people, reasons for their attitudes or perceptions, and how and why people practice certain behaviors. One drawback associated with these types of research is the tendency to overlook other forms of knowledge, given the predominant emphasis on biomedical knowledge. Additionally, assessing attitudes remains a challenging task within such studies. Questions regarding practices often fail to encompass real-world behaviors or account for influential contextual elements, potentially impacting their credibility. Nevertheless, KAP studies can prove highly valuable when it comes to appraising communal understanding and gaging shifts in knowledge after interventions such as awareness-building through media initiatives and educational workshops (36).

The in-depth interviews were followed by key informant interviews (KII) with the market chairperson, chairperson of the traders, chairperson of the trekkers, officers in charge of animal health at the market, and the market masters, who are county officials in the market. The in-depth interviews teased out the actors' knowledge and practices on zoonotic diseases; the key informant interviews then followed this. The key informant interviews aimed to provide more insight into the actors' knowledge of the diseases, their perceptions of the diseases at the community level, and some of the practices that may contribute to spreading or controlling zoonotic diseases. All the interviews were audio-recorded with consent from the study participants. The audio data were transcribed once the qualitative data from the in-depth interviews and key informant interviews were obtained. Where the interviews were not conducted in English, the audio data were translated and transcribed. The transcription was done verbatim. Transcription involves converting recorded audio, typically spoken language, into a written format to analyze a specific occurrence. The process of transcription is known to be time-consuming and often monotonous, requiring several hours to complete. Responding to the demand for enhanced transparency and reproducibility in scientific methods, the creation of accurate, comprehensive, and systematically constructed transcripts in both the source and target languages plays a crucial role (37, 38). Thematic framework analysis, a method for systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a dataset (39, 40) was used to systematically categorize and synthesize the qualitative data the interviews generated. All transcripts were read and reread for salient themes of how they identify sick animals, the common diseases that affect their livestock, and diseases that originate from animals to humans to respond to the assessment of knowledge and what action they take when they suspect an animal is sick, what preventive measures they take to avoid the spread of disease, and how they dispose of dead animals under their care to assess their practices. Under knowledge, the study looked for the respondents' knowledge of the symptoms of zoonotic diseases, the causes, the mode of transmission, and the availability of treatment options. Under attitudes, the study analyzed how the respondents perceive and evaluate zoonotic diseases. Under the theme of the practice, the study analyzed the respondents' conscious behaviors and actions toward sick animals. These actions could be informed by lay or acquired knowledge.

Sample and sampling procedure

Purposive sampling was employed to identify 30 actors (both male and female) among the livestock traders (41). The traders and trekkers were identified with the help of their market chairpersons, who functioned as gatekeepers. The chairpersons held authority over the market and managed various matters. They oversee all market affairs, including dispute resolution. Positioned as an outsider, engaging with them was vital to fostering trust and explaining the purpose of my study to the prospective participants, ensuring they understood that it was academic research and not associated with any monetary incentives. Informants, who included animal health officers, market officials, and county government officials, were purposefully sampled for key informant interviews.

Data collection methods

In-depth interviews (42) were conducted with 30 informants; the interviews lasted between 25 and 30 min. The interviews were conducted in the markets, away from crowds, to enable the informants to continue their operation without much interference. They were audio-recorded with consent from the study participants. Hamilton Majiwa, who is one of the authors and a native of western Kenya, conducted the interviews in Kiswahili. It was important to conduct the interviews in the markets to be able to observe the operations in the market in real time and to put into context the information given. In some instances, we experienced challenges from noise and curious onlookers. Curious onlookers were explained that only the responses of the selected respondents were needed at that time; they understood and walked away. Others expressed interest in participating, and we recruited them as participants in the study. This method allowed the respondents to express themselves in their own ways without restriction, as would happen with questionnaires (43). The interviews were audio-recorded with permission from the informants. Key informant interviews were also conducted with nine key informants. The interviews were also audio-recorded with permission from the informants. Unstructured observations (44, 45) were made in all the markets sampled by Hamilton Majiwa, who is one of the authors. The observations lasted between 30 and 45 min. Observation notes were taken, and these helped in understanding the activities in the market, like when the traders arrive, what other activities go on in and around the market, and how the actors in the livestock trade interact and conduct their operations within the market.

Ethical statement

Participants gave informed written consent before participating in the study. The study was approved by the International Livestock Research Institute Institutional Research Ethics Committee in Kenya (ILRI-IREC2017-08), which is registered and accredited by the National Commission for Science, Technology, and Innovation in Kenya, and approved by the Federalwide Assurance for the Protection of Human Subjects in the United States. A research permit was obtained from the National Commission for Science, Technology, and Innovation (NACOSTI) under License No. NACOSTI/P/19/2547.

Results

This study comprised 30 informants with distinct roles interviewed using in-depth interviews, key informant interviews, and observations. The informants consisted of 15 traders and 15 trekkers. Table 1 shows the profiles of the study participants.

Profile of the respondents

The study found that of the 30 informants, only 5 had completed secondary education. Most of the traders were over 30 years old, with the oldest being 60 years old, while the trekkers' ages ranged between 18 and 50 years old. In contrast to the trekkers, who were all male, among the traders, there were three females. All 15 trekkers and 14 traders identified themselves as Christians, while only one trader identified themselves as Muslim. Religion formed an important demographic characteristic because of certain food behaviors and practices that are influenced by religion.

Similar to a previous study (46), in this study, age, education level, religion, and sex did not seem to influence actors' knowledge and awareness toward zoonotic diseases, as the responses given did not differ much depending on these variables. However, religious affiliation affected practices as some informants reported that they do not eat animals that have not been slaughtered because this goes

TABLE 1 Demographic profile of the informants.

Characteristic	Frequency (n = 30)
Sex	
Male	29
Female	1
Age in years	
18–29	11
30–39	9
40 and above	10
Education level (Kenyan education system)	
With primary education	13
With secondary education	12
Above secondary education	5
Religion	
Christianity	29
Islam	1
Ethnicity	
Teso	11
Samia	13
Luo	6
Years in the livestock trade	
1–5	6
6–10	12
11 and above	12

against their religious beliefs. Similarly, those who were of the Muslim faith reported that they do not interact with or deal with pigs in any way. Ethnicity played a crucial role in livestock trading relationships. The study observed the presence of several ethnic-based clusters in the sampled markets. Traders from the same area or ethnic community tended to congregate in specific sections of the markets. This made it easier to identify traders and animals from different regions, such as Nandi County, which is a county located in the north Rift Valley in Kenya, or even those from neighboring Uganda. The ethnic composition of the informants was diverse, including individuals from the Teso, Samia, and Luo ethnic groups.

Religion, as one of the social demographics in this study, has a significant relationship to the practices that the actors engage in. Religious beliefs could potentially influence perceptions, actions, and subsequent One Health outcomes. Religion and religious rituals have been associated with infections and infectious diseases such as RVF, Ebola, and COVID-19 (47). Religion emerged as a key factor influencing the practices of the actors involved in the study. It played a role in shaping the informants' behaviors and perspectives toward livestock trading and zoonotic diseases. Muslim informants do not trade in pigs or pork-related products.

The study found that many traders are introduced to the trade through an apprenticeship by their relatives or friends. As a channel for achieving social inclusion, an apprenticeship offers opportunities and avenues to develop skills and proficiency in a trade (48). Apprenticeship, the process of developing from novice to proficient under the guidance of a skilled expert, varies across cultures and among different skilled communities; in many instances, it offers an ideal point of entry, and this was evident from the responses from the study participants like the one below.

> *"Before you start this job, you must have someone who is helping you because you cannot know what size of cow is sold for what price. You must have someone to guide you on the prices."* (IDI)

Starting the practice for trekkers seems to require low capital investment in terms of financial capital but more in terms of social capital; they need to be trusted, dependable, and popular to get business from the traders, as reflected in these excerpts:

> *"You need to be known to the traders and the buyers and to be trusted because someone cannot give you their animal if they don't trust you and know where you come from."* (IDI)
>
> *"For you to start as a trekker, you don't need capital; you just need to be known and trusted and also have an identity card."* (IDI)

The findings show that formal training was not a key component in terms of being a trader or a trekker. A key informant at Butula Market indicated,

> *"There is no training that one undergoes; they just come and start the business."* (KII)

The findings also indicate that information on how to identify sick animals used to be communicated to the traders, but that no longer happens. A key informant at Amukura Market responded to a question on whether the traders and trekkers undergo any training.

> *"We used to call them in the market and give them some basic education on how to identify sick animals, but we don't do that anymore. Now we just walk and inspect animals and remove the sick ones from the market."* (KII)
>
> *"I do not know if they undergo any training, but what I know is that anybody can just come and join the trade provided he or she has capital."* (KII)

In terms of learning the trade, apprenticeship on approximation and negotiation for prices, selection of good animals, and identification of sick animals were mentioned as very crucial by all the informants because they are what traders need to succeed in the business of livestock trade.

> *"Before you start this job, you must have someone who is helping you because you cannot know what size of cow is sold for what price. You must have someone to guide you on the prices."* (IDI)
>
> *"There is no formal training; however, people who have experience in the business must teach you how to negotiate prices. The experienced traders also teach you how to select a good animal that will give you good returns."* (IDI)

Knowledge

The study sought to bring out the actors' knowledge of zoonotic diseases. Therefore, the questions explored if the informants knew about zoonotic diseases and if they could name some of the zoonotic diseases, their modes of transmission, and some of the symptoms of zoonotic diseases. By asking the participants how they acquired knowledge of livestock diseases, it was established that vernacular radio stations, seminars, and workshops, through which information on livestock diseases is disseminated, have contributed to their knowledge of livestock diseases. The radio stations air programs that teach about livestock diseases. Seminars and workshops organized by the Busia County government Department of Veterinary Services and other non-governmental organizations working in the region also teach them about livestock diseases.

Knowledge of zoonotic diseases

The findings show that some informants know that diseases can come from animals and infect humans. We note that both the livestock traders and trekkers have some knowledge of zoonotic diseases, as demonstrated by the fact that most respondents know that there are livestock diseases; however, not all of them know that diseases that affect humans can originate from animals. The traders showed more knowledge of zoonotic diseases compared to the trekkers. Many of the informants named specific diseases such as foot and mouth disease (FMD), brucellosis, lumpy skin disease (LSD), and anthrax. This could be because they are the most common diseases in the area, as was corroborated by the key informant as shown below.

> *"The most common diseases in this area are Lumpy skin disease, foot and mouth, black water and anthrax although we have not had an outbreak recently in this market."* (KII)

The actors in the livestock trade know the clinical signs of livestock diseases in general. They have ways of identifying sick animals in general, and these do not necessarily indicate a zoonotic disease infection. The actors in the livestock trade identify sick animals by checking if they have: dropping ears, a lot of mucus in the nose, diarrhea, blood-stained urine, and low activity levels. This knowledge is shared by both traders and trekkers.

The results revealed knowledge of the transmission of zoonotic diseases through the consumption of meat and milk from infected animals; this was the most common among the respondents.

> *"I know diseases that can come from animals to humans, such diseases can infect you if you eat meat from infected animals."* (IDI)

From the study, the level of knowledge varies among the different actors; some can name some of the diseases and the modes of transmission and even identify the clinical signs, while others do not know of any diseases that can be transmitted from animals to humans.

Perception of zoonotic diseases

Perception toward zoonotic diseases can be influenced by various factors, such as cultural beliefs, religion, personal experiences, and access to information. These perceptions may evolve as new outbreaks occur, scientific understanding advances, and public health measures are implemented. The study sought to assess the perceptions of the different actors in the livestock trade toward zoonotic diseases. Actors in the livestock trade with a positive perception toward zoonotic diseases can contribute significantly to disease prevention and control. These individuals prioritize the health and welfare of both animals and humans. They understand the potential risks associated with zoonotic diseases and take proactive measures to minimize their transmission. On the other hand, negative perceptions among actors in the livestock trade can exacerbate the spread of zoonotic diseases. Actors with negative perceptions and careless or complacent attitudes may overlook the potential risks associated with zoonotic diseases, leading to inadequate disease control measures. This negligence could result from a lack of awareness. Some of the responses received from the informants are below.

> *"I have seen diseases in cows, mostly cows from Uganda. We have cows from Uganda, but when sold here in Kenya, they die easily from diseases."* (IDI)
>
> *"The animals from Uganda are the ones with diseases, their meat is reddish, tasteless, and very light, The Kenyan Government should put measures in place to first screen animals from Uganda for diseases at the border before they are allowed in Kenya. This will help in the control of diseases."* (IDI)

The study revealed that the actors perceive that most of the livestock diseases and zoonotic diseases originate from outside Busia County, and most are brought in by animals from Uganda. They also perceive the animals from Uganda to be more vulnerable to diseases as compared to the ones from Kenya. The animals from Uganda are therefore sold to butchers for meat and not to farmers for breeding. This could be a considerable risk if indeed the animals have diseases because it will expose consumers to the risk of infection.

On the issue of where they would get help from in case of a zoonotic disease infection, most informants responded that they would seek help from a hospital. The study also found out that most informants believe in conventional medicine and that there are healthcare facilities in many parts of the study area that are easily accessible to the residents of the study sites. Below are some of the responses received from the informants.

> *"In case of a suspected zoonotic disease infection, I will get help from the hospital, we have hospitals close by. We have Bumala and Murumba hospitals."* (IDI)
>
> *"If I get infected, I will get help from a hospital. The nearest hospital is about two kilometers from my home in Malakisi."* (IDI)

The study found that most of the actors will get help from a hospital in case of an infection or suspected infection with a zoonotic disease. They will call a veterinary doctor to help their animals. This was the response from many of the actors interviewed. This shows that they perceive zoonotic diseases as serious infections that need professional attention.

Practices of actors in the livestock trade

The actors have the practice of moving animals from one market to another, and some of the animals are moved into Kenyan markets from Uganda and vice versa. Results from the IDIs in the various markets indicate that up to five different markets are visited by the traders in a week and up to 20 in a month, trekking the animals from one market to the next. This can contribute to the spreading of diseases if an infected animal is moved from one market to another.

> *"I buy animals from different markets even from markets like Bukedia in Uganda. I go to different markets like Angurai, Myanga, Bungoma, Amukura, and even Nambale. The animals are trekked to different markets."* (IDI)
>
> *"I go to Amukura, Nambala, Kemodo, Myanga and we have a new one called Segero in Teso south. I go to the market every day of the week apart from Sunday."* (IDI)

There are those markets that the traders prefer going to more than others because of better prices and demand for the livestock.

There are also practices such as culling sick animals for consumption and the consumption of dead animals that have been shown to influence the transmission of zoonotic diseases (49). This kind of practice presents a risk of exposure to pathogens as well as the spread of pathogens to many other members of the community, contributing to the possibility of zoonotic disease infection in people. The study was informed of some practices that the actors engage in that are embedded in their cultural and religious beliefs. They engage in these practices because they believe that there is influence from a higher power that they cannot challenge or question. Most of these practices revolve around the way they would dispose of a dead animal. A question was asked about what the actors would do if an animal under their care died.

> *"In our tradition, most people don't like throwing meat away because you will throw away your luck, so even if you don't want to eat it, you call people who want and give it out."* (IDI)
>
> *"Some people say that if you bury a cow you have thrown away your luck and therefore a dead cow should be eaten, but some of us who are born again believe that luck comes from God when a cow dies, we bury it so that we can be safe from other diseases."* (IDI)

The study identified circumstances where some actors will eat meat from an animal that has died from an unknown cause because they believe that throwing away meat will bring bad luck to them. The study also shows a widespread practice among the actors to skin their animals when they die before burying them. This practice was mentioned by most of the respondents in different markets, and the reason for doing this was reported to relate to cultural beliefs among the informants from Teso, Samia, and Luo communities. They believe that if one does not do this, they will never be successful in the business, as burying an animal with the skin is akin to burying all one's wealth and luck. These practices seemed to cut across the three main ethnic groupings in the region.

Some practices were reported to be used by the actors in the livestock trade to control the spread of zoonotic diseases. The study findings indicate that there are practices that the actors in the livestock trade have adopted that help in the prevention of the spread of livestock diseases and, to an extent, the spread of zoonotic diseases. This involves activities such as the isolation of sick animals and separating animals that have come from one market and are bound to another market. Furthermore, the market chairpersons have also instituted rules that animals exhibiting any signs of sickness are not allowed in the ring where the animals are traded. In some markets, there are isolation crèches/structures for animals diagnosed at the market gates. The ones that find their way in are removed, and the owners are told to get help and only return them when they are well. This practice is enforced by the market chairperson and his team, "youths." The traders are also vigilant and will report any animal that appears sick in the livestock ring.

> *"I isolate sick animals, and then I call a veterinary doctor to come and help by treating it. I also ensure that dead animals are buried."* (IDI)
>
> *"If I am moving many animals and one of them falls sick, isolate it and tie it in a nearby homestead. I then inform the owner of the animal, who will then take action by calling a doctor. Then, I continue with the rest of the animals to my destination."* (IDI)

The practice of isolating sick animals was reiterated and confirmed by key informants.

> *"When we identify a sick animal in the market, we remove it from the market and advise the owner to get treatment for it and only bring it to the market when it is healed."* (KII)

The actors in the livestock trade seek help from animal health professionals when they identify that their animal is sick. They also identified the uptake of animal vaccination to prevent infection and the spread of diseases. These practices show that they know disease transmission and prevention. The study found that vaccination exercises are done when there is an outbreak, and these are normally government initiatives to prevent the further spread of the disease. There is also the issuance of movement permits by the veterinary office for animals that are being moved from one county to another.

> *"We issue movement permits to control diseases. Animals from an area with notifiable diseases will not be issued with movement permits."* (KII)

Discussion

As with other similar studies on knowledge of zoonotic diseases, the study revealed that the actors in the livestock trade in Busia do not have detailed knowledge of specific zoonotic diseases or details of disease control. Studies in Sub-Saharan Africa have pointed to limited knowledge among various actors on zoonotic diseases (23, 50). Many of the informants interviewed in this study know about livestock diseases but not much about diseases that can be transmitted from animals to humans and vice versa. Some informants mentioned brucellosis as a disease that can be transmitted from animals to human beings, which shows that some informants know brucellosis as a zoonotic disease. This is consistent with a study by Seyoum et al. (51) on knowledge, attitude, and practice among small-scale dairy farmers on milk-borne zoonotic diseases. Many study participants know about the potential health risks of drinking raw milk and link this practice to brucellosis. Anthrax, foot and mouth disease, and lumpy skin diseases were the diseases that most of the informants mentioned as the most common, and this was also affirmed by the key informants, although there was no recent outbreak of cases reported in the area at the time of the study. The fact that most of the actors mentioned these diseases could be attributed to the fact that whenever there is an outbreak, livestock markets are closed and quarantine of livestock is enforced.

The study found that the actors take zoonotic diseases seriously, even though a majority do not know about the existence of infections that can come from animals to humans. It is consistent with a study by Abdi et al. (50) that found a positive attitude toward zoonotic diseases; a high percentage of respondents had a positive attitude toward the prevention and control of RVF, a zoonotic disease. The positive perception is shown by the fact that they have preventive measures that they take, such as washing animals to remove ticks, taking animals for vaccinations, and visiting hospitals in cases of suspected zoonotic disease infection. The study also revealed that some actors believe that meat should be cooked appropriately to prevent zoonotic disease infections and that milk should not be consumed raw. The actors in the livestock trade take several measures to prevent the spread of zoonotic diseases and the occurrence of livestock diseases. The study also revealed that many actors seek help from hospitals in cases of zoonotic disease infection and from a veterinary doctor in cases where their animal is sick. This shows that they perceive the infections as serious. Recognizing the potential seriousness of diseases that can be transmitted between animals and humans, these actors in the livestock trade understand the importance of prompt medical intervention. By turning to a hospital, they aim to receive the necessary expertise to accurately diagnose, effectively treat, and prevent the further spread of such illnesses. By prioritizing their health and the wellbeing of their animals, actors demonstrate a proactive approach to managing zoonotic diseases to safeguard both themselves and their animal companions.

The actors' reliance on hospitals and veterinary doctors reflects a broader understanding of the interconnectedness between human and animal health. Their actions underscore the importance of the One Health collaborative efforts among medical professionals and veterinarians to effectively address zoonotic diseases and mitigate their impact. However, the study also revealed some negative perceptions among some actors in the livestock trade who believe that the animals that originate from outside Busia County and especially from Uganda are the ones that have diseases and are even calling for the restriction of such animals. This is consistent with a study by (52) that found negative attitudes toward zoonotic diseases in bush meat hunters and traders in Nsukka, southeast Nigeria.

The traders also perceive the animals from Uganda to be more vulnerable to diseases as compared to the ones from Kenya. The animals from Uganda are therefore sold to butchers for meat and not to farmers for breeding. This could be a considerable risk if the animals indeed have diseases because it will expose consumers to the risk of infection. The livestock traders do this to get a market for their animals and make a profit.

The study revealed that the actors have ways of identifying sick animals. These are not necessarily animals suffering from zoonotic infections, but just ways of knowing if an animal is sick. This is consistent with the findings of Onono et al. (53). These ways of identifying sick animals were noted as familiar to both trekkers and traders, and they included dropped ears, excess mucus production, diarrhea, bloody urinal discharge, and general animal activity levels. This knowledge of identifying sick animals was found to be passed from one person to another and is not acquired through formal training.

One of the drivers of One Health is the association between humans and animals, and this association is influenced by religious beliefs in different communities. Studies have shown the importance of religious beliefs and practices in the perception of human health (54). Religious beliefs could potentially influence perceptions, actions, and subsequent One Health outcomes. Studies have also shown that practices such as herding, residing with livestock, slaughtering, skinning, and consuming meat and milk from ill or dead livestock play a vital role in transmitting zoonotic diseases like Rift Valley fever (RVF) to humans (55, 56). Cultural practices like traditional African burials during the Ebola outbreak in the Democratic Republic of Congo and Sierra Leone and the reliance on traditional healers for treatment of malaria in Côte d'Ivoire have been shown to play a significant role in disease outbreaks (57, 58). Different ethnic groups and those from different religious backgrounds have varied beliefs and practices, as shown in the findings where the Samia and Teso do not believe in throwing away meat or burying dead animals without skinning them. Muslims do not come into contact with pigs in any way. This study found that some actors believe that when an animal dies, it must be skinned before it is disposed of. They also believe that meat cannot be thrown away, and therefore, when an animal dies, the meat will be eaten or given to people who want to eat it. Such practices as skinning dead animals before burying them and eating meat from dead animals are based on the culturally embedded beliefs of the Teso, Samia, and Luo, who believe that if they do not adhere to them, bad luck will follow them, and they will not prosper in the business of livestock trade or rearing livestock. Such practices significantly expose them to the risk of infection. This is consistent with a study (59) that found that pastoralists engage in practices embedded in their culture that expose them to the risk of zoonotic disease infections.

Results from the study also showed that the actors have practices such as separating sick animals from the rest, not allowing sick animals in the market, and vaccinating their animals, which can prevent the animals from spreading diseases (60–62). Unlike other studies that have shown that pastoralists self-medicate their animals for different reasons, like having high confidence in their abilities and low confidence in the skills of animal health service providers, limited access to animal health service providers, and high cost (63–65) this study found that the livestock traders engage the help of those that they perceive to be animal health experts whenever they identify that their animal is sick.

There are globally relevant zoonoses that everyone worries about and locally relevant ones that are important, such as anthrax, trypanosomiasis/HAT, rabies, brucellosis, and RVF (11). These diseases can spread rapidly in a particular region (epidemics) or spread widely in many countries worldwide (pandemics), leading to massive losses of life and livelihoods and having a significant economic impact. Understanding a community's knowledge and practices on zoonotic diseases is particularly important because it provides critical information to help design appropriate control and intervention measures for a zoonotic disease outbreak.

Conclusion and recommendation

The study revealed a lack of knowledge on zoonoses among several of the traders and trekkers in the livestock trade that participated in the study. They were not aware of any diseases that are transmissible between animals and humans. Even though few of them know about zoonotic diseases, some of the actors' practices show that they are aware of livestock diseases, and they take measures against them. As shown in other studies, low awareness and poor knowledge of zoonoses in pastoral and agro-pastoral communities are likely to increase the risk of contracting zoonoses (46). The findings indicate that skinning dead animals and eating carcasses from dead animals are common. It is also evident from the study that the actors (both traders and trekkers) move their livestock from one market to another and from one county to another, that is, Busia, Bungoma, and Kakamega, and some of them source animals from Uganda. This practice of the movement of livestock can contribute to the spread of zoonotic diseases from one region to another and across international borders. There is some control to ensure animals do not move from regions with notifiable diseases like foot and mouth disease or anthrax. This is in the form of the issuance of movement permits; however, the study noted that this was not effective as movement permits are only issued in some markets. The study found that of the markets under study, only one market had movement permits being issued, and it was only for animals that had been sold. There was no one checking if the animals coming to the market were from regions free of diseases. Even though several actors in the livestock trade interviewed do not know zoonotic diseases, they have in place practices that can help control these diseases, such as vaccination of animals, washing animals, separating animals for sale and those being kept at home, and ensuring that sick animals do not enter the market. These practices are likely to reduce the risk of animals getting infected and, in turn, infecting them with zoonotic diseases.

From the study findings, it is evident that cultural issues are important considerations in the control of infectious diseases, and therefore the study recommends incorporating cultural epidemiology and the One Health approach in the development of disease prevention, management, and control programs or interventions. Workers in the livestock sector need to be included in the development of interventions and policies for the control of zoonotic diseases so that their traditional beliefs and practices guided by experts in animal and human health are taken into consideration, without which some of the interventions may not work. The practice of skinning dead animals before disposing of them can be done more safely by having designated people do it since it is a firmly rooted cultural practice among the study participants. The study finds that the locals have a high propensity for information from vernacular radio stations, seminars, and workshops; therefore, it recommends the use of these for awareness creation on zoonotic diseases. It also recommends the use of cross-border intervention programs such as education and sensitization of the actors in the livestock trade in this Lake Victoria Crescent ecosystem and East Africa to help strengthen disease surveillance and control. In addition, the study also recommends the following:

1. Awareness creation of zoonotic diseases among the actors in the livestock trade.
2. Awareness creation and culture change programs targeting eliminating the practice of eating meat from sick animals or those that died of disease. This can be done by social scientists working together with public health officers and veterinary officers in the area.
3. The study also recommends further research: (1) exploring KAP on zoonotic diseases at household levels because animal production is at household levels and (2) exploring the community prioritization of zoonotic diseases and exploring KAP on specific zoonoses such as RVF, brucellosis, and anthrax as the study respondents mentioned them.

The findings of this study can be applied in similar settings, especially the cross-border points on control of zoonotic diseases.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by a research permit obtained from the National Commission for Science, Technology, and Innovation (NACOSTI) under License No. NACOSTI/P/19/2547. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. The study was approved by the International Livestock Research Institute Institutional Research Ethics Committee in Kenya (ILRI-IREC2017-08), which is registered and accredited by the National Commission for Science, Technology, and Innovation in Kenya, and approved by the Federal wide Assurance for the Protection of Human Subjects in the USA.

Author contributions

HM carried out the study; he developed the protocol and tools for the study and carried out the fieldwork, data collection analysis, and writing. SB is the supervisor, together with DO. They both assisted in reviewing the study and helping to improve it. They helped with reviewing the manuscript. EF won the grant for the study, and he also contributed to the review of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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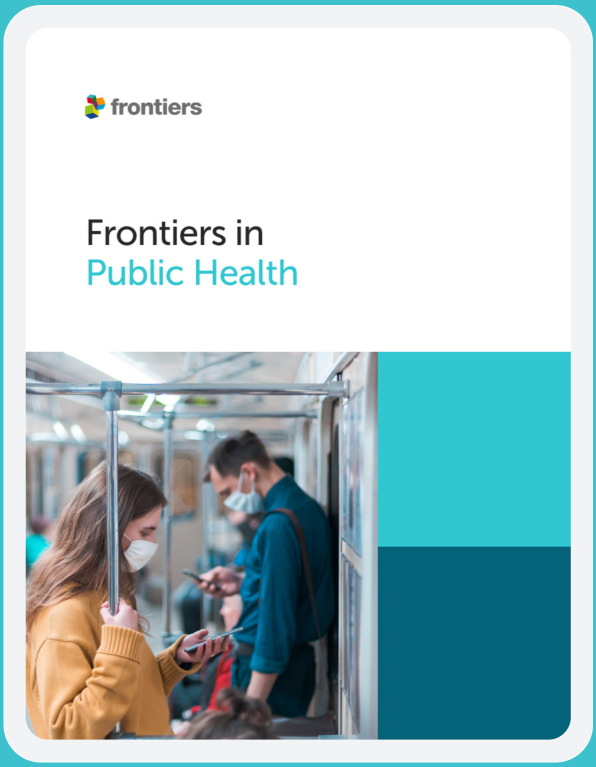

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