Research Topics

Addressing epistemic injustice in mental health

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Addressing epistemic injustice in mental health

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Editorial: Addressing epistemic injustice in mental health

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Editorial on the Research Topic
Addressing epistemic injustice in mental health

The relationship between knowledge and power is well established and in mental health the limitations of psychiatric knowledge well- rehearsed. In this context, disability and survivor movements have long been concerned with inequalities in knowledge production, and with action to address these and support empowerment.[1] Epistemic injustice was conceptualised by Fricker as a form of social injustice, which occurs when people's authority 'as a knower' is ignored, dismissed, or marginalized.[2] The idea is attracting increasing interest in the mental health field because of the recognition of the asymmetries of power between people using mental health services and mental health professionals. People experiencing mental distress are particularly vulnerable to forms of epistemic injustice arising from deeply embedded social stigma, negative stereotyping, and assumed irrationality, amplified by other forms of systemic inequalities, notably race, gender sexuality, disability, and age.

The goal of this Research Topic is to examine how epistemic injustices in the mental health field occur and how epistemic justice can be advanced. It is essentially concerned with the question of whose knowledge counts and how can we ensure that lived experience is foundational to our knowledge about mental health. The fifteen papers in this Research Topic are wide-ranging and cover both theoretical and practical aspects of Fricker's differentiated, but overlapping, aspects of epistemic injustice: i.e. testimonial injustice (the down grading and dismissal of individual testimony) and hermeneutical injustice (the absence or disadvantaging of collective interpretations and meaning of lived experience).

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[1] Beresford, P., 2003. *It's our lives: A short theory of knowledge, distance and experience*. London: OSP for Citizen Press. Available at: It's Our Lives: A short theory of knowledge, distance and experience - Shaping Our Lives.

[2] Fricker, M., 2007. *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

The first two articles by Russo and Levin, provide a critical examination of the concept of epistemic injustice and problematize its uncritical incorporation into the fields of psychiatry and mental health. Together they provide an invaluable reference point for the subsequent contributions. Russo raises concerns about the intellectualization of the idea of epistemic injustice and how it's co-option by the psy-complex can exacerbate the marginalisation of lived experience, by not critically examining its foundations. She highlights how Mad Studies has the potential to address this by advancing first person knowledge, independent of the psy-complex; concluding with the hope that it further fosters hermeneutical justice. Foucault famously argued that knowledge is never neutral and reflects the operation of social power, providing a theoretical basis for the idea of epistemic injustice.[3] In her perspective, Levin uses Critical Race Theory to consider alternative approaches to Foucauldian ideas about knowledge and power that challenge the presumed "superiority of "white, Western and modern ways of knowing the world". In a similar vein to Russo, Levin argues for lived experience and the diversification of "knowledge about knowledge".

Hultman and Hultman, a young disabled woman and her mother, use critical personal narratives to explore their lived experience of epistemic injustices in the Swedish mental health system. Their account brings to life the injustices described by the previous authors. Notably, the professionals' willingness to tell the young woman what was wrong with her or to disbelieve her account of suicidal feelings. They describe a stark paradox that while the daughter's disability was focused on, there was failure to provide support for her basic needs associated with this. Similarly, Bergen et al. focus on communication practices for people seeking emergency care for self-harm and suicidal ideation and self-harm in emergency departments in England. Using conversation analysis of video recordings of biopsychosocial assessments, their findings show how practitioners undermined service users' lived experience through a variety of means including implying inconsistency and implausibility. They highlight how this can leave service users feeling more distressed and discouraged from help-seeking whilst acceptance and validation of experience leads to more positive outcomes. How potential service users are viewed in policy also shapes the service response and the support they may access. This is illustrated by Levin et al.'s policy analysis of discourses guiding provision for girls identified as being in distress and needing support from Israeli public social services. Their research shows how policies can play a critical role in "maintaining, shaping or correcting epistemic injustices." They describe how the policy descriptions of girls in distress renders them as passive and voiceless and ignores the social context of their lives – conceptualizing this as existential epistemic injustice.

The legitimation of lived experience is, therefore, a critical axis for understanding and promoting epistemic injustice. This is the focus for Grim et al.'s study, which identifies practical barriers and facilitators to legitimation. They identify the need for shifting culture to integrate service user knowledge and propose a model to increase equality and the meaningful and sustainable co production of knowledge. This requires shifts in the current paradigm involving organisational and financial commitment. Nouf and Ineland contribute significantly to this academic discourse through a meta-analysis incorporating 544 narratives of lived experiences within mental health services in the Nordic countries. Their innovative contribution introduces the concept of "epistemic citizenship," synthesizing the policy concept of 'active citizenship' with the theoretical construct of 'epistemic injustice.' Their findings shed light on the structural impediments that impede the establishment of arenas wherein service users are accorded the status of equal epistemic citizens.

The contributions from Hultman and Hultman, Grim et al., and Nouf and Ireland underline the central role that research methods play in knowledge construction through the delineation of the research question and the methods used. Okoroji et al. describe the experience of two third-sector organisations, in England, to explicitly address how power symmetries can be addressed in research. They highlight the problems of 'elite capture', such that participatory research can lack representativeness, and 'epistemic exploitation', such that "lived experience becomes a perpetual testimony with little influence". The authors, therefore, advocate for a pragmatic approach that focuses on achievable change.

With the aim of informing the current Mental Health Act reform in England, Mooney et al. present a participatory model of research practice, using photovoice. Their contribution illustrates transformative research practices capable of acknowledging and valorizing lived experiences while concurrently addressing structural disparities, through accentuating the expertise of participants from racialized communities with experience of compulsory detention. As Crenshaw[4] has powerfully argued systems of oppressions intersect to shape experience and amplify discrimination. Two further papers consider the intersection of race and mental health and propose action to address associated forms of epistemic injustice. Smith et al. detail the Patient and Carer Race Equality Framework, (PCREF). This framework aims to identify and redress racial disparities pervasive in mental health care in England and Wales. The authors underscore the guiding principles and priorities of the PCREF, elucidating its potential to rectify epistemic imbalances for individuals from racialized communities. One of the key aspects of the PCREF is the provision of culturally appropriate independent mental health advocacy (IMHA) to ensure that people from racialised communities are central to decisions about their care and treatment. Salla et al. explore the pivotal role of culture, race, and racism in IMHA provision, through the conceptual lens of epistemic injustice. They argue that it offers a mechanism to challenge prevailing racialised epistemic injustices and offer a conceptual framework for culturally appropriate advocacy, with learning domains at both individual and organizational levels for its potential to be realized.

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[3] Allen, A., 2017. Power/knowledge/resistance: Foucault and epistemic injustice. In *The Routledge handbook of epistemic injustice* (pp. 187-194). Routledge.

[4] Crenshaw, K.W., 2017. *On intersectionality: Essential writings*. The New Press.

Whilst the majority of papers have focused on service user experiences of epistemic injustice, Moberg and Schön, use it as a lens to explore how staff might support adolescents as epistemic subjects in the implementation of a patient-initiated brief admission in Sweden. They found that top-down decision making to implement the initiative and their minimal involvement in decision-making limited the epistemic agency of staff. They argue that the reduced agency of staff has implications for the sustainability of this initiative designed to promote the agency of young people in defining their support needs.

Finally, three papers focus on Child Sexual Abuse and the Independent Inquiry into Child Sexual Abuse (IICSA), which investigated whether public bodies and non-state institutions have taken seriously their responsibility to prevent and better protect children from sexual abuse in England and Wales. Historical Institutional Abuse Inquiries have increased over the last three decades bringing opportunities for survivor and victim participation. Despite this, a knowledge gap has existed in understanding the implications of this participation, and learning from research approaches which can challenge epistemic injustice of CSA. Barker et al. elucidate how engaging a trauma informed approach to data collection it was largely possible to overcome longstanding concerns about addressing survivor needs and re-traumatisation. In doing so, their work embraces ideals of epistemic justice offering a nuanced insight to theory and politics of knowing through engagement with a historically excluded group. In their second paper, Barker et al. draw on efforts to create conditions to provide an affirming environment for survivors by delivering trauma informed training to non-specialist employees at the IICSA. Participants felt such organisational considerations facilitated safety and trusting relations with survivors, and the authors theorised elements of testimonial sensibility were secured through this therapeutic culture. Alyce et al. echo the significance of testimonial sensibility within a survivor approach to participatory research. They offer a nuanced and reflexive insight about the way this approach avoids hermeneutical barriers of misunderstanding and misinterpretation, which in turn provides the foundation for testimonial justice. It is an approach which imbued safety, minimised mistrust, and helped to remove the pain of epistemic silence.

This Research Topic has explored different forms of epistemic injustices and how epistemic justice can be advanced in mental health theory, practice, or research from different disciplinary perspectives. However, as various contributors make clear, advancing epistemic justice is a work in progress and needs to centre lived experience and seek to involve those who have been marginalised. A major limitation of this Research Topic is the absence of papers from low- and middle-income countries. We hope that this Research Topic is further developed with contributions from voices of experience in these countries.

Author contributions

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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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Legitimizing user knowledge in mental health services: Epistemic (in)justice and barriers to knowledge integration

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Including the voices and knowledge of service users is essential for developing recovery-oriented and evidence-based mental health services. Recent studies have however, suggested that challenges remain to the legitimization of user knowledge in practice. To further explore such challenges, a co-production study was conducted by a team of researchers and representatives from user organizations in Sweden. The aim of the study was to explore the barriers and facilitators to the legitimacy of user knowledge, as a central factor in sustainably implementing user influence in mental health practice. A series of workshops, with representatives of mental health services and user organizations were conducted by the research team to explore these issues. The analysis built on the theoretical framework of epistemic injustice, and the underlying aspects, testimonial, hermeneutic and participation-based injustice, were utilized as a framework for a deductive analysis. Results suggest that this is a useful model for exploring the complex dynamics related to the legitimacy of user knowledge in mental health systems. The analysis suggests that the legitimacy of user knowledge is related to the representativeness of the knowledge base, the systematic formulation of this knowledge in applicable methods, access to resources and positions within the mental health system and participation in the process of integrating this knowledge-base in mental health contexts. Legitimizing user knowledge in practice additionally challenges mental health systems to support readiness for change in working environments and to address the power and role issues that these changes involve.

KEYWORDS

mental health services, user involvement, co-production in research, epistemic injustice, user organizations, implementation, recovery

Introduction

The inclusion of users' knowledge is recognized as an essential component of the delivery and quality development of health care and social support, both in a Swedish and international context (1, 2). In the mental health field, including the voices and knowledge of users is essential for developing recovery-oriented and evidence-based services. The value of user knowledge and user choice has been reinforced in the growing body of research on recovery that increasingly guides mental health systems internationally (3–5). The importance of integrating user involvement in the mental health service system is further underscored in national policy and guidelines.

Recent studies have, however, suggested that while there is a positive discourse regarding user involvement, challenges remain to user knowledge being legitimized in practice (6). Users' participation tends to be reduced to tokenistic levels, where users are disregarded as epistemic partners in collaborative knowledge processes (6–8). Commonly, users highlight issues of dependency on professionals and not being considered as capable and trustworthy collaborators in shared deliberation (6, 9, 10). While imbalances of knowledge validation and power are recognized as barriers to participation in many domains of care and support, several studies have reported that greater levels of disempowerment, stigma and coercion in mental health settings may amplify barriers to user participation (11, 12).

While user knowledge perspectives are widely recognized as valuable in service development and provision, it is still unclear *how* user knowledge is to be incorporated into welfare systems (13). Accordingly, drawing on the framework of epistemic injustice, the aim of the study was to explore the barriers and facilitators to the legitimacy of user knowledge, as a central factor in sustainably implementing user influence in mental health practice.

User knowledge and the swedish mental health system

In Sweden, there are two primary actors in the mental health system. Social psychiatric services, provided by the municipalities, support people with mental health problems with residential support, occupational- and social activities, rehabilitation and case management. Psychiatric services, provided by the regional health care system, include inpatient treatment, psychotherapy, medication and outpatient care. Because of this division of responsibility, there is a continuing challenge in Sweden to coordinate these two service providers (14). Findings from previous studies indicate that user representatives provide a more holistic understanding of users' needs that contribute to developing structures for bridging gaps and methods for coordinating services (15).

The user movement in Sweden consists of a multiplicity of user-led organizations, connected to the domestic tradition of popular mass movements and supported in part with government funding (16, 17). The National Partnership for Mental Health (NSPH), an umbrella organization consisting of the country's largest service user associations in the field of mental health, has developed a number of initiatives that focus on systematically integrating the knowledge of users in services at individual, organizational and systemic levels. The development and implementation of User-Focused Monitoring (UFM), Peer Support workers in services, and tools for supporting personal recovery in the form of written materials or apps, represent practices developed to strengthen user influence and support the integration of user knowledge in practice.

User knowledge and epistemic injustice

The Recovery framework underscores the holistic nature of mental illness, promoting more emphasis on the situated, experiential knowledge of service users (3, 4). Experiential knowledge has been portrayed as complex, layered and holistic (5, 18). It entails social, emotional and embodied experiences of living with and managing an illness, as well as experiences of stigma and vulnerability. The knowledge perspective of users is not merely based on personal experiences but is constructed through a collective process, which involves sharing and distilling various perspectives. This knowledge form is therefore both personal and collective in nature (19). Technological developments have contributed to information now being more readily available, providing people with access to research studies, medical guidance and public discussion forums (18). In accordance with these descriptions, we conceptualize user knowledge as not limited to knowledge acquired through personal experiences but as situated knowledge perspectives that are continually co-constructed through merging lived experiences with collectively shared knowledge and scientific (e.g., medical) knowledge.

Despite the focus on acknowledging users as bearers of valuable knowledge, there is no consensus however on what aspects of user knowledge should be considered legitimate knowledge. Typically, user knowledge continues to be considered anecdotal and hierarchies continues to place constraints on the inclusion of users' knowledge perspectives in welfare services. Recent literature, drawing attention to the epistemically complex aspects involved in integrating user knowledge in the context of mental health care, suggest that challenges can be brought to light by applying Fricker's (20) conception of epistemic injustice (6, 9, 10).

The concept of epistemic injustice refers to an injustice done to people in their capacity as knowledge bearers, reasoners and questioners, in which their ability to take part in epistemic practices, such as providing knowledge to others (testifying) or making sense of their experiences (interpreting), is weakened (20).

As the description suggests, Fricker articulates two such wrongs: *testimonial injustice* and *hermeneutical injustice*. Testimonial injustice occurs when a persons' capacity as a reliable informant and conveyer of information and knowledge is breached. This devalued credibility is often due to identity prejudice. The speaker's membership in a negatively stereotyped group causes the hearer to view their accounts and arguments as less competent and sincere–and thus less trustworthy. Hermeneutical injustice occurs when there is a breach in shared conceptual, interpretative resources that puts people at a disadvantage when trying to make sense of their experiences. When shared modes of interpretation (such as concepts, ideas and narratives) are unavailable, these people are deprived of the capacity to use and develop the shared descriptive labels necessary for a mutual understanding of the phenomena they experience. Many theorists have expanded on the theory of epistemic injustice (21). One such elaboration, is the concept of *participant-based injustice* (22). Participant based injustice involves a (partial) exclusion of individuals or groups as collaborators in knowledge processes, i.e., in knowledge gathering, shared inquiry and deliberation, problem-solving and decision making.

Prior studies have illustrated that epistemic injustice is a valuable concept for analyzing barriers to the inclusion of user knowledge at an individual level (6, 9, 10). In this study, we apply these concepts to explore barriers to user knowledge integration in service development and provision.

Methods

The study builds on a co-production design that included six researchers from various disciplines and seven user organization representatives, as members of a research team. The user movement representatives hold central positions within the NSPH and have wide-ranging experiences of user involvement initiatives. An ambition of the study has been to integrate co-production throughout the research process, moving beyond consultation and toward knowledge production in partnership (23). The goal was to create a collaboration that was based on our complementary expertise [cf. Fleming et al., (24), p. 711]. The members of the research team have therefore been involved in all stages of the study, from initial formulation of the research proposal, to the study design, data collection, analytical procedures and in the communication of research results, contributing with their own competence and perspective.

TABLE 1 Representatives of the mental health service system–workshop I and III ($N = 14$).

Occupational	Quality development program director	6
	Department manager	3
	Unit manager	2
	Politician	1
	User influence coordinator	2
Region in Sweden	West	5
	East	3
	South	3
	Southeast	3

TABLE 2 User movement representatives–workshop II ($N = 14$).

Organization	NSPH (umbrella organization)	2
	Local NSPH associations	8
	Other local user organization	1
	User led enterprise	1
	Adult educational association	1
	User influence coordinator	1
Region in Sweden	West	4
	East	7
	South	1
	National	2

Co-produced workshops

Utilizing a co-production design, the team developed an interview framework and conducted a series of digital workshops (due to the pandemic) with I) user representatives and II) mental health program directors and practitioners. In total, we carried out three workshops (each of which approximately 3 h long). Two of these targeted program directors and practitioners representing the mental health service system, and one targeted representatives of the user movement. In total, there were 28 participants in the workshops. (see Tables 1, 2).

Participants were recruited through the network of the research team to form a purposive sample. The aim was to include individuals from a variety of regions in Sweden with substantial knowledge of the implementation of methods based on user knowledge in mental health practice. Most participants had experience of systematic user involvement attempts. In particular, the methods of UFM, The Recovery Guide and Peer support were discussed in the workshops.

- *The Recovery Guide* is a tool developed by the NSPH to support personal recovery. It is available as a printed format, mobile app and study circle. It is a workbook and the material builds on experiential knowledge of recovering from serious mental illness and presents recovery principles and strategies that can serve as tools for people attempting to participate in their care planning (25).
- *Peer support* involves people in recovery from mental illness who are trained and employed to offer support to others using psychiatric services due to mental health problems. In Sweden, the NSPH plays a central role in both the education, supervision and coordination of peer support (26).
- *UFM* is a method of reviewing care and supports, performed by people with experiential knowledge of mental ill health (27, 28). In Sweden, user organizations often organize UFM and train user monitors in evaluation methods. Based on a commission from a service organization, teams of user monitors conduct an evaluation of a service site or intervention from a user perspective (28, 29).

The user movement representatives and researchers in the team, as well as the interviewees participating in the workshops, are not a representative sample for all who we might have spoken with and there are certainly additional viewpoints that should be attended to. Smaller regions and cities or towns may, for example, not even have an organized user movement. While not representative of all perspectives, the participants were chosen based on their experience of these methods or other formalized, knowledge delivery projects involving user knowledge and influence.

The representatives from the mental health service system consisted of those representing municipal social psychiatric services and those representing regional psychiatric services. They were either higher-level department managers, or responsible for specific services, still others had a broad responsibility for quality development of services, including in these cases, a focus on user influence.

The user movement representatives included individuals who all had a specific role in the development and implementation of user influence initiatives. They were typically board members of either specific disability groups or the national association.

The interview framework was developed in the research team where we had introduced and discussed the theoretical framework related to epistemic injustice, and the study's ambition to focus on the "knowledge-question" and not simply implementation strategies. The resulting interview guide focused on exploring aspects of user knowledge in relation to the aim of user involvement, the implementation of different user involvement strategies, the effects of methods on the legitimacy of user knowledge and future ambitions.

Each workshop started with a joint introduction and discussion with all participants. In a next step, participants were divided into groups of 4–5 individuals, formed (by first, second and last author) to include a variety of perspectives representative of the total sample. Accordingly, heterogeneity was sought with respect to geographic location as well as forms of and roles in organizations. To conclude, a joint discussion was conducted, where participants shared and reflected on the issues discussed in the smaller group. During the workshops targeting officials and practitioners, the researchers and the user movement representatives of the research team were teamed up to share the interviewer role. The workshops directed primarily toward representatives of the user movement were also co-led but more directed by the professional researchers since the dual role of the research team members had to be acknowledged (30).

The workshops were recorded and transcribed verbatim. Regarding ethical considerations, verbal informed content was obtained from all workshop participants and no information trackable to unique individuals has been included in our results. Since no sensitive data was collected, ethical approval was not required.

Co-produced analysis

The recordings were watched and analyzed in mixed researcher/user representative pairs using a live-coding (31) consensus model (32). This analytical approach means that the workshops were coded while watching the film, a method that may support the preservation of the participant voice in group interviews (31). This was considered a fitting approach for our co-production design, where some of the participants are not trained in research methods. It further contributed to a dialogue that served to involve the complementary expertise of the researchers and the user movement representatives. Codes and illustrating quotes were discussed in the mixed pairs, and later in the larger project group, at two occasions. The compiled analysis from the live coding was compared to the transcribed recordings by the first author. The benefits of such a strategy of combining live coding with the coding of transcripts has been discussed in previous research (33). Following the submission of key points, quotations and categories related to the analytical framework by the smaller teams, an operative group of three researchers summarized the data sent in. The analysis was then discussed at a meeting where all were present and then the summary analysis was accordingly revised with the aim of

TABLE 3 Themes, categories, sub-categories and examples of codes.

Categories	Sub-categories
The theme of Testimonial (in)justice–the value and legitimacy of user knowledge	
Barriers and challenges For the legitimation of user knowledge	Lack of knowledge and commitment among decision-makers Insufficient establishment with front line managers and staff Stigmatizing beliefs
Factors promoting the legitimacy of user knowledge	Representativeness Describing and raising awareness of effects Formalized interventions based on user knowledge Ongoing cultural change
The theme of Hermeneutical (in)justice - the fit of formats and concepts	
Barriers and challenges for conceptual fit of user knowledge	Illness and deficit-focused mental health service models Organizational instability
Factors promoting shifts in conceptual frameworks	Safe and stable working environments User knowledge-based methods/materials Integration of a variety of knowledge perspectives
The theme of Participant based (in)justice–co-production on (un)equal terms	
Barriers and challenges for equal inclusion of user-knowledge perspectives in co-production	Unequal and unjust allocation of resources Professionals own the agenda Domination of top-down approaches
Factors promoting partnership between equal epistemic agents	Mutuality of commitment Stable resources Organizational infrastructures for systematic user involvement

creating a consensus document which would serve as the basis of the study results.

In order to explore barriers and facilitators for including user knowledge perspectives in mental health practice, data has been approached deductively, applying a 3 fold conceptual framework based on the theory on epistemic injustice and the three aspects described above. Table 3 illustrates how these themes have been generated through the organization of data in sub-categories and categories. The results are presented below in categories which emerged in the analysis in relation to the deductive focus in the workshops on barriers and facilitators for the legitimacy of user knowledge in mental health practice. Along with the descriptions of the categories, citations from participants are specified with numbers 1–28.

Findings

A number of barriers were identified relating to the three forms of knowledge injustices, connecting to the value of users' knowledge, the integrability of such knowledge perspectives within the prevalent conceptual paradigm, and user groups' access to influence in service and system development (see Table 3). However, the current data also provides a rich set of descriptions of positive progress and of factors and strategies supporting a more epistemically *just* development. The "in" prefix in *injustice* has therefore been placed in brackets in order to indicate that the concepts are applied to elucidate barriers as well as supporting phenomena. The three forms of epistemic (in)justices are to some extent intertwined but they have provided fruitful themes for representing key findings and presenting barriers and factors promoting integration of users' knowledge perspectives in the service system.

Testimonial (in)justice–the value and legitimacy of user knowledge

In the analysis, issues concerning the legitimacy of user knowledge are described in the theme *Testimonial injustice–the value and legitimacy of user knowledge.* This theme involves interviewees' perspectives on issues that hinder or enable user-knowledge to be validated, requested and taken into account in knowledge processes.

Barriers and challenges for the legitimation of user knowledge

From the discussions, it was clear how a general *lack of knowledge and commitment among decision-makers* to include user perspectives is both an effect of, as well as a contributing factor to low legitimacy of user knowledge. It was clearly noted that progress was underway, but still person-dependent and relying on individual enthusiasts:

> It's often very much about who is in charge and what response you get from the leadership and whether this is taken seriously and there is commitment to drive it further. And often it is dependent on individual enthusiasts, which can also make it quite complicated (1).

Due to this general lack of recognition of the value of user knowledge, inclusion of user knowledge was rarely based on any needs analysis or perception of necessity for quality development with regard to practice. Many expressed great frustration that user knowledge was most often merely regarded as a welcomed bonus when offered without conditions or costs: *"The leadership must stand up for this becoming part of ordinary practice. We must move beyond the idea that this is something extra to* *regarding it as part of our core mission" (9).* A problematic issue commonly noted as contributing to limited commitment among decision makers was the fact that user involvement initiatives were often tested in the format of projects with poorly defined expectations and that were too time limited for any positive results to become evident. The opportunity for user knowledge perspectives to be integrated and legitimized was consequently undermined. One interviewee described project funds as a *"poisoned gift"* (11) noting how there was a tendency for the project idea to be regarded as poor or without clear results when, in fact, it had not had the chance to be properly tested.

Many highlighted how laws, policy and guidelines emphasize that user knowledge perspectives need to be included in service development and delivery, but how it seems that decision-makers still lack basic knowledge on user involvement and regard it as an optional practice:

> It is a bit strange that already in guidelines over ten years ago it was stated that shared decision-making should be prioritized, but then… if you asked among really knowledgeable people in some regional contexts and development leaders, no one could really explain what it meant, so no one really knew what shared decision-making was (1).

Some suggested that decision-makers believe that they already live up to these guidelines by consistently focusing on the needs of users. This lack of understanding of what user involvement implies would then explain the lack of urgency for actually including users as knowledge agents. As one interviewee noted: "*We think that we always have had a user perspective, but it's something else to work from the users' perspective" (28).* It was commonly noted how the value of user knowledge was prioritized in system level documents but that this focus and organizational commitment was *insufficiently established with front line mangers and staff.* This was closely correlated with a lack of implementation efforts aiming to put policy into practice:

> Nowadays it is well established at higher levels and also politically correct that you have to make sure that you have user influence. Also, you have well formulated policy documents.… But the problem is rather to achieve anchorage downwards in the organization, to get these policy documents and establishment on the higher levels to seep down so that it reaches the individual user.... because that's where it may really have an impact (1).

It was also evident that *stigmatizing beliefs* about people with mental health problems contributed to the low legitimacy of these knowledge perspectives. Some spoke of the historical power imbalances and the lingering notion that staff should have a monopoly on knowledge. Some described how they were sometimes appalled by attitudes among staff who could, for example, declare how users were manipulative, untrustworthy and lacking in judgement. While it was noted that many staff members appreciated listening to recovery narratives in the context of staff trainings, this interest did not transmit to increasing their confidence in the users in their own services as competent knowledge bearers.

It was commonly highlighted how service users tend not to give weight to their own knowledge perspectives and view themselves as competent carriers of knowledge. Accordingly, self-stigma constituted a problematic aspect contributing to low legitimacy of user knowledge and thereby to testimonial injustice. One interviewee noted how *"users also need to discover that they have knowledge"* (21). Another interviewee said: "*Our users also often have very low self-esteem, are not used to being listened to and taken seriously, so you also have to work with self-assertion"* (9).

Factors promoting legitimacy of user knowledge

From the analysis, it was evident how *representativeness contributes to legitimacy.* Interviewees from both groups underscored how user knowledge needed to be *"valid for many"* (11) in order to be considered legitimate in knowledge processes on organizational or system levels. Preferably, knowledge processes should be anchored in the user organizations so that user representatives bring a *"palette of perspectives* (11)" into collaborative practice with professionals. Many noted how systematic methods such as UFM provided a fruitful strategy for presenting perspectives that represent experiences of a collective:

> UFM has raised the status of user knowledge. It feels like the user monitors' knowledge is valued higher as it is based on a group of users' experiences and not "just" their own. They have gathered what a group thinks, because otherwise, the user representatives usually get accusations like "What evidence do you have? You are only drawing from your own experiences" (7).

Many comments reflected how *describing and raising awareness of effects contributes to legitimacy of user knowledge.* The importance of advancing the research base on outcomes was identified to motivate implementation of interventions based on user knowledge. As noted by one interviewee: *"research and data that show that these are success factors in different ways, we will need that* (5)". In addition, the importance of not only building a research base but of consistently *disseminating* research evidence on outcomes was highlighted. Professionals who have first-hand experiences of positive outcomes, sharing good examples of how user knowledge has specifically benefited their practice, was also considered important. It was noted how "decision makers need to realize the value through concrete examples" (10). As one interviewee expressed:

> ... to get people to understand and show how user influence at the individual level, and also at the overall level, how it streamlines care and support processes, that is, how what you do becomes much easier and of higher quality if you make use of users' knowledge (1).

Interviewees described how a one-sided rights-perspective was insufficient for user knowledge to gain legitimacy. One interviewee noted how such a perspective sometimes drew attention away from efficiency gains:

> It is very common to talk about user influence as a kind of benevolent human right, which it of course is, but there is also something that is often forgotten, that it actually makes care and support more efficient (1).

It was noted that recognition of user knowledge among professionals could not be forced but how time must be allowed for managers to discover the benefits for the quality of their own practice and ultimately for the experiences of the users of their services. Not least, it was observed how implementing user knowledge perspectives has supported alliance-building with clients:

> The lived experiences have contributed to a more open climate in conversations with the clients… making it easier to reach people… we have access to a unique perspective that we then simply realize we cannot be without (8).

From the interviewees' descriptions, it was evident how legitimacy and testimonial justice was strengthened through the use of *formalized interventions based on user knowledge.* The value of user knowledge was discerned when mediated and applied within the frameworks of methodized approaches (such as UFM, peer support work or materials such as The Recovery Guide). In services where such methods had been successfully implemented, user knowledge perspectives had gained legitimacy and were systematically shared in client work, in staff training and in dialogue with staff.

Many interviewees noted how members of staff who had positive experiences of user involvement through various formalized initiatives typically acknowledged user knowledge as an invaluable element of an evidence-based practice:

> How cool it was that when we had a number of employees who were involved in this project and when they returned saying "how are we going to be able to work in any other way than this?" It was so incredibly natural that this evidence-based social service or knowledge-based social service, [were to include] that third component. It became so natural in all activities (6).

From the descriptions of the interviewees, it was evident how the user knowledge perspective was indeed steadily gaining legitimacy by an *ongoing cultural change.* While it was generally acknowledged that there is much work to be done for user knowledge to be fully legitimized, many noted a slow but positive development occurring over time, and expressed how a long-term view was necessary in order not to be discouraged by slow results. One interviewee noted, for example, how initiatives cannot be regarded separately, but that a variety of simultaneously occurring elements are "*pulling in the same direction,*" such as *"educations, policy development, research and an increasing focus on person centered care"* (13). While, as previously noted, problematic aspects of the short term projects was commonly discussed, some interviewees reflected that they might also be a contributing factor to this progress. Concordantly, it was noted as a fruitful approach for the user movement to direct resources toward services who were genuinely interested: *"where doors were already open or half open"* (3), who had autonomously begun promoting user influence. This approach may be understood as a way of tapping into the energy and this current of cultural progress.

Hermeneutical (in)justice-the fit of formats and concepts

Many descriptions in the data reflect problematic aspects of integrating users' knowledge perspectives within the formats for knowledge predominant within welfare and healthcare systems. In the analysis, issues relating to this lack of conceptual fit with the prevailing paradigm have been sorted into categories and collected within the theme *Hermeneutical (in)justice-the fit of formats and concepts.* Interpretive frameworks operate in a given context, that steer and delimit how we organize, order and navigate the world. It was clear from the analysis that different knowledge perspectives honored divergent understandings and values in relation to mental health and recovery.

Barriers and challenges for conceptual fit of user knowledge

From the discussions, it was discernable how *illness and deficit-focused mental health service models impede the desired paradigm shift.* Many comments reflected a poor fit between user knowledge perspectives, often expressed as narratives based on holistic views on health, illness and recovery that do not fit in with the welfare organizations that are structured based on diagnostic classifications and quality standards that relate to symptom relief, care consumption and compliance. One interviewee noted that the prevailing *"interpretive prerogative"* (7) granted to professionals constituted a particular challenge for such a shift. Many highlighted the stereotypical staff and user roles as a problem. As an illustrative example of such an "us and them" mentality, one interviewee described how staff at services about to implement peer support could ask *"where* *will the peer supporter sit and have coffee?"* (3). Accordingly, the conceptual spotlight of hermeneutical (in)justice drew attention to a discourse perspective, shedding light not only on how specialist knowledge outlines the boundaries for spoken and written language, but how it also generates and maintains structures, organizational logics and indicators of quality. From the interviewees' descriptions, it was evident that professionals were often unaware of these barriers, that they did not appreciate the importance of the user movement developing and implementing their interventions independently and delivering them in the formats that harmonize with the value base and knowledge contributions of users. One interviewee describes risks of user knowledge being co-opted and colonized by the prevalent paradigm based on deficit-based perspective on mental health:

> They want to cherry-pick-take over the methods developed by the user movement and run them themselves. With no understanding of the value of independence. Push it into diagnosis-based manuals. We have to reconquer recovery by means of The Recovery Guide (4).

In analyzing the data, it was also notable how interviewees rarely spoke about the influence of user representatives in terms of them being knowledge bearers. Whilst the questions were directed at barriers and facilitating factors for implementing user knowledge perspectives, responses commonly shifted focus toward technical and structural issues of implementation. This failing to construe the contributions of users' knowledge perspectives, even amongst those most committed to user involvement, may reflect a general lack of conceptualization of user knowledge within the interpretive frameworks prevalent in the welfare system.

It was commonly noted how change that requires quite radical restructuring of mindsets, as well as of practice, was hampered by *organizational instability*. As one interviewee noted, *"high staff turnover requires that attitudinal issues are constantly processed, and that staff training is continually repeated"* (12). In addition, it was noted by many how reevaluation of prevalent ways of thinking and working requires an openness to criticism. One interviewee reflected that paying heed to critical perspectives seemed easier for external, top-level decision-makers than for managers and staff actually performing the practice that is often subject for criticism: "*The closer you are to the services and the users, I can experience that it is more difficult to accept criticism"* (6).

Factors promoting shifts in conceptual frameworks

As noted, organizational instability was expressed as a barrier for introducing new perspectives. In concordance, a *safe and stable working environment*, where staff felt secure in their working roles was highlighted as a supportive factor. Interviewees' comments on this issue may be understood to reflect how a change of practice, that requires accommodation of new paradigms, takes time and space for people to reflect and process:

> You need to process it a bit before… as a staff member you are in the middle of something and you think that what you do is probably right and proper and so on, you need to process it about a bit in the workplace (1).

It also requires courage, especially when those novel perspectives may be challenging prevalent beliefs amongst staff that they have been performing their work according to best practice: "*If you have a staff group that feels good at work, I also think that it is easier to dare to let in other methods or dare to see things in new ways" (26).*

Many interviewees reported successful implementation of manualized interventions based on user knowledge. Common to these interventions was that they provided the holistic, recovery-oriented, bottom-up perspectives of service users with *knowledge-based methods/materials geared to prevailing structures of the mental health system*. Amongst these examples, the Recovery guide was highlighted. Since it is based on a recovery perspective, providing a holistic perspective on mental health and recovery, it postulates a bridging over organizational barriers:

> The Recovery Guide, of course, where we work more in a recovery-oriented way, where our employees gain knowledge about recovery, that we not only "store" patients and medicate patients, but it is about so much more and where patients then become very involved in their care and support, which of course they should be, it's their recovery process (3).

Likewise, UFM was highlighted as a formalized method structured according to the prevalent organizational logic that similarly to the recovery guide *"demanded co-operation"* (13) across organizational boundaries. It was also noted how these user-led mental health service evaluation processes commonly brought about constructive dialogues for improvement between user movement- and service representatives. Peer support workers, who according to the Swedish, user movement driven model, bring a broad and collective user knowledge base to their practice, further generated quite radical shifts in perspectives in the staff groups. One interviewee described how staff had become aware of and raised alarms about problems in service provision, noting how *"there had been some stormy awakenings"* (10).

From the discussions, it was evident that ongoing shifts in culture were not driven by adding experiential knowledge to professional expertise but through *the integration of a variety of* *knowledge perspectives,* that had the potential to synergistically expand spheres of knowledge. For example, some interviewees spoke in terms of fruitful co-learning processes that occurred when staff and users attended recovery trainings together:

> ... Going together with staff is the best! We have seen that this co-learning has had an effect. Before, we had all our training in a recovery-oriented approach for staff, but then we realized that if we include people with their own experience and they go together, it is far more rewarding (4).

Overall, many comments related to the positive effects of integrating holistic perspectives in organizational structures that served to promote a shift toward a holistic and recovery-oriented paradigm.

Participant based (in)justice-co-production on (un)equal terms

Comments that relate to issues of influence and power distribution in knowledge processes, reflecting whether or not user representatives participate in equal partnerships are sorted in categories and sub-categories together making up the theme *Participant based (in)justice-co-production on (un)equal terms.*

Barriers and challenges for equal inclusion of user-knowledge perspectives

Interviewees consistently highlighted a variety of power asymmetries that hindered user representatives from participating as equal partners in knowledge processes. A lack of resources in terms of time, money, people and administration was commonly highlighted as a major barrier for user involvement. It was evident how user movement representatives were constantly in a position of disadvantage in the face of the *unequal and unjust allocation of resources.* Even though it was commonly acknowledged that resources were limited at all organizational levels within the mental health system, influence over resource allocation resided, to a greater extent, within the realms of professionals than with the user organizations for which resource scarcity was noted to be particularly challenging:

> There has also been uncertainty about financing. It is always difficult when you try to run a larger operation that costs some money. Now we have some incentive funding, but they are often for one year at a time, it is not very stable to build on (8).

It was commonly noted how the user movement had low priority and was often subject to budget cuts. It was also noted that professionals received their pay when collaborating with user movement representatives during workdays, while the latter worked for free, causing strains on the user organizations and limiting the possibility to harness the potential of user knowledge: "*There is so much we could do to make use of and build on this knowledge, but we do not have the resources to manage*" (21). Many aspects of unequal allocation of resources were discussed, involving user movement representatives having less insight into the system, overview of the services and the decision-making routes, less access to established roles and functions in the system. Particularly, many noted the challenge of finding and preparing individuals that had the desire and capacity to participate.

As a major barrier for equal-terms partnerships, interviewees highlighted the lack of awareness amongst professionals of the disadvantaged position of the user movement in relation to power, resources and decision-making:

> They want to ride the train, but they do not want to pay for laying rails. They don't understand that the user movement needs some kind of infrastructure to be able to exist and run their services, they think we only consist of people who have as a hobby to come to a meeting a little now and then (29).

It was noted by another interviewee how "*professionals in possession of power did not perceive that they have the power, but they do, since they have the legislation in their hands*" *(7).*

The position of disadvantage of user representatives was also commonly highlighted in relation to the ways in which *professionals set the agenda* and delimit user movement autonomy. It was, for example, observed that professionals could specify which user representatives were invited to collaborate and under which terms collaboration was to take place. While acknowledging the importance of involving the "*right persons*" (19) in shared deliberation, interviewees observed an unwillingness of some professionals of even associating with the user movement:

> We notice that they want to pick out individuals from the user movement who they think are at the right level, so they do not want to associate with the user movement... but they prefer to pick-and-chose people with whom to communicate (19).

This proneness amongst seemingly committed professionals to fail in actually inviting users in knowledge processes that concern them was commonly noted. The following quote reflects the inclination to act as interpreters of users' values and needs, rather than inviting them to the table: "*But what creates value for the clients in these different contexts? And where are the ones we should ask what was value-creating? They are not invited*" (6). Similarly, it was observed how the user movement did not have power over the agenda and that professionals sometimes *"wanted to steer discussions"* (17) or delimit the issues in which users could have influence to insignificant matters. The occurrence of such tokenistic practice is exemplified in the following quote:

> So it was clear that the user organizations wanted to have influence in issues important to them, such as appointments of staff, while psychiatry thought yes, but it works so well if they can have a question-box and decide the color of the curtains, for example, which was much easier to take on board. So, I think that the willingness to let go of power and control is an important issue (7).

Another phenomenon noted that might be understood in terms of tokenism, was staff applying methods designed to support user influence in such a shallow way that no genuine sharing of power took place and user influence thus remained superficial. It was commonly discussed how the position of dependency of user representatives implied a need to adapt an agreeable and non-confrontational attitude in order to be invited to collaborate and thereby implicating a risk for co-optation. Handling this predicament was commonly described in terms of a tricky balancing act of being a *"critical friend"* to psychiatry (30) or *"To not get coopted but at the same time not be too confrontative"* (6). Expressing critical perspectives was often done at the risk of being excluded from collaboration:

> It can be a difficult balance between being a representative of a user association and at the same time being compliant with psychiatry. When, for example, user representatives have written debate articles that have a strong negative view of psychiatry, they may be deliberately excluded from working groups, influence councils, etc. (6).

In the face of this dilemma, many observed the need for some user movement actors to maintain an independent stance and for others to be more consensus-oriented in order to enable collaboration. Others described their endeavors to gain influence in knowledge processes from an unfavorable position in terms of having to persevere in the face of resistance from professionals. The importance of persistence and patience was noted in order to: *"horn oneself into various contexts"* and *"press in the practice of involving user perspectives"* (1).

Despite the intentions of those dedicated to respect user perspectives, many interviewees noted the risk of maintaining a *domination of top-down approaches.* Many appreciated how a greater power balance had indeed been achieved through NSPH as a national, well-resourced user movement organization. However, amongst the NSPH representatives participating in the FGIs, some noted the risk of NSPH becoming too established and thereby *"gaining a monopoly"* (29) on influence work and losing the rootedness amongst local user representatives.

In discussing power dynamics in relation to top-down approaches, it was underscored how staff too need to feel empowered in order to realize partnership and fair play. As one interviewee noted: "*Influence is also needed for the staff, so that they also feel that they have influence in these development- and change processes, as well as the users*" (2).

Factors promoting partnership between equal epistemic agents

From the discussions it was evident how *mutuality of commitment* was a prerequisite for equal partnership. For example, equality was supported in cases where user movement representatives could be involved in setting the conditions for collaboration. Accordingly, the analysis brought to light how accountability mechanisms sometimes were at work, supporting partnership and participation on equal terms. This occurred when formalized approaches for implementing user knowledge included some sort of mandatory counter performance. For example, as the following quote implies, access to the recovery guide material requires counter-performance from services: "*Now that we get requests from other regions, we have a whole list of things they need to commit to if they are to implement the Recovery Guide*" *(30).* Likewise, it was observed how UFM processes were more likely to lead to user influenced development work when an obligatory follow-up assessment was included in the commission:

> As enabling factors I would say … follow-ups of the UFM, and reviewing how has it affected the services, if they have made any changes, etc. Getting such questions makes them adhere to the recommendations (29).

In addition, it was noted how inclusive efforts needed to be employed by mental health system actors, going beyond inviting user representatives to join in *their* initiatives on *their* home turfs, but instead reaching out to people in their organizations and forums. As one interviewee noted: *"If they [the young service users] won't come to us, we have to find them and come to them."* (21).

Throughout the discussions, it was stated that equal partnerships required *stable resources*. The mandate to implement user influence requires that finances be budgeted for the work it involves in achieving systematic and structured partnerships. From the discussions, it was evident that such access to resources varied greatly between regions in Sweden. User organizations located in regions in which they were provided a steady inflow of resources had the possibility to establish sustainable structures, following concrete action plans and working proactively with the implementation of distinct methods:

> The success lies in the fact that it is a concrete way of working. So, it becomes a clear structure in how we should work with project groups and with steering groups and that there is a mandate to drive things forward. Before it was not so clear and then it mostly felt like we floated around (4).

As noted earlier, it was evident from the discussions how an ongoing cultural change is underway and how *organizational infrastructures for systematic user involvement* sometimes were in place, e.g., with user *"involvement embedded in management systems, ensuring sustainability"* (11). Earlier, the purpose of involving user perspectives had often been vague, but there is now a strategic thinking on what goals are to be achieved, on which actors should participate and what target groups needed to be reached:

> It didn't have any real purpose before [when user representatives participate in seminars]. Only information stacked on top of each other. Now there is strategic thinking about who should participate and listen. Now it feels like we're talking purpose (20).

Interviewees reflected on this progress noting that user representatives to a larger extent were now involved in entire development processes, from planning to follow-up stages. They were also more often involved in choosing which issues needed to be addressed and in which arenas collaboration was to take place.

Ideally, it was observed, that the *"user movement itself was strong enough to carry"* (5) their work. Otherwise, it was necessary that they were provided financial support but also other opportunities for education and team- and leadership training: *"We make sure that they get paid for travel and that they receive training. So that you do not come in with a knowledge deficit"* (10).

One success factor, related to organizational infrastructure was suggested to be the employment of user representatives with decisional mandates at system levels within the service organizations. As one interviewee noted, such a role implied having access to decision-makers and infrastructure and being able to independently move processes forward without dealing with gatekeepers:

> The biggest success factor is getting a user in at the system level. You have access to all decision-makers. You can run the work independently and do not have to toss around so much, just to get an approval (31).

Another interviewee noted how being co-located in the same corridors as staff and managers created a breeding ground for co-learning and co-production. In cases where such organizational infrastructures were in place, it was noted how an improvement in quality was evident, regarding the care as well as the working environment: As one interviewee concluded:

> Better care and better working environment. We can see this in evaluations. It produces a different climate in the discussions in the working groups, it breeds a better working environment (11).

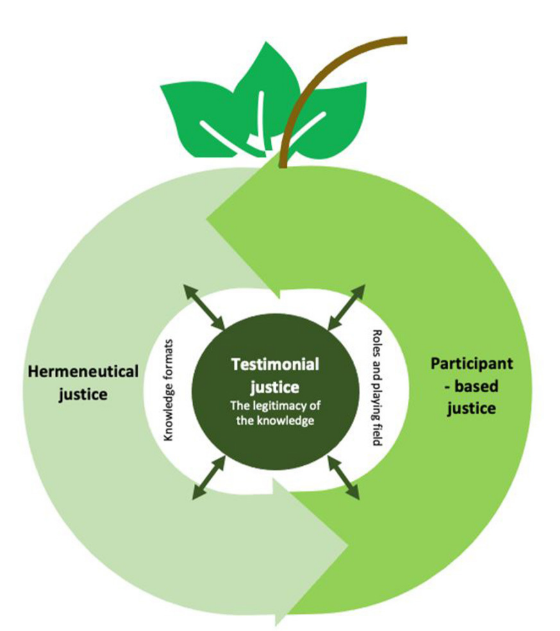

FIGURE 1
Model of interrelationships between the different forms of knowledge (in)justice.

Discussion

The analysis has clarified central barriers and facilitators to the legitimacy of user knowledge in mental health practice, applying the theoretical framework of epistemic injustice (6, 20, 22). In order to illustrate the three aspects that structure the analysis we suggest the following model (Figure 1) which has taken the form of an apple, as a metaphor for our focus on knowledge. It attempts to describe the interrelationships between the different forms of knowledge (in)justice. While a simplification of what is clearly a complex process, with many contributing factors that are not included here (meta-level issues regarding economy and resources for example), we found the model useful in both reflecting the interactivity in these concepts, and as a structure for considering these various aspects in the practical application of the results for future projects.

At the center of the model (the apple's core), we have placed *testimonial justice* which refers to the extent to which user knowledge is seen as legitimate, valued and credible at an individual and collective level. The extent to which a higher level of testimonial justice is achieved relates to the other justice forms, and is both influencing and being influenced by these. *Participant-based justice* relates to a more equal playing field, where different actors play on equal terms, with equal team structure and equal power distribution, in a joint construction of knowledge. Participant-based justice also has a two-way connection to *hermeneutical justice*. The knowledge formats and terminologies that are dominant and how quality and competence are defined in mental health systems is a critical focus for the constitution of an equal playing field for knowledge formulation, but also to the legitimacy of user knowledge. The double-sided relationships between all three forms of knowledge justice means that increased equality in one of these, have significance for all forms of knowledge justice. Altogether, the three knowledge (in)justices describe both barriers and facilitators that affect the extent to which user knowledge is legitimized and integrated in mental health practice.

A movement toward knowledge legitimacy and integration

The research team, as well as the interviewees, represented diverse perspectives, and many were able to place the discussions within a broad, historical context. A historic movement toward increased user influence was discussed in the workshops: From being seen as "disturbing" and critically opinionated patients, to being invited in to share stories of illness and recovery, to the position of the user as a "competent customer" and slowly progressing toward being seen as valuable partners in developing relevant services. In accordance with previous literature, the discussions centered on the idea that we are now in the midst of a progression from "influence" as the vision–to one in which a position as partners in coproduction has begun to dominate the discourse for practice, research and development of services (8, 34).

Co-production and co-learning were dominant in discussions of both successful examples and of factors important for the future. These types of knowledge-based contacts, where users and professionals received and produced knowledge in a partnership, seemed to directly impact the legitimacy of user knowledge. As the model above suggests, this process is complex and multi-directional, but inviting professionals and users into a learning context where diverse knowledge perspectives can meet, also contributes to increasing respect for user knowledge and a future willingness to integrate this knowledge form. The benefits of such joint knowledge production activities remain to be explored (35) but the current discussions highlighted the value of relation-building, and of how proximity or co-localization provided breeding grounds for dialogue and a spurring of change processes.

Closely aligned with this shift in vision for how patients or users might co-produce rather than just influence services, was a focus on how issues of influence might be viewed from a citizen, rather than user perspective, in a democracy context. From this standpoint, the issue of representativity was discussed in relation to the role of user organizations and the rights of individuals who may not choose to or feel represented by these organizations. The findings highlight previously noted risks of primarily involving participant ready individuals in that it may limit diversity (18, 36). Representation being a crucial aspect of democratic practices (37), the findings indicate that increased efforts are needed to ensure broad representation in order to uphold the democratic aim.

Systematic methods and relevant outcomes

The results suggest that the systematic methods which were an impetus for the research project, were considered by the interviewees and the research team as particularly effective for increasing the legitimacy of user knowledge and implementing user influence over time. Building methods for integrating and disseminating user knowledge (The Recovery Guide, UFM), as well as for providing services (Peer Support) were described as turning points for services who had previously committed primarily ideologically to user involvement and that could now integrate a concrete component in their practice. Although we cannot confirm the success of particular systematic methods in furthering the legitimacy of user knowledge, the framework suggests that developing specific forms of delivering user knowledge within the mental health system can function as a critical aspect in implementation processes. It was noted that the structural fit of these interventions provided a central facilitating factor. Working together with researchers to demonstrate outcomes of these methods for users and system quality improvements is recommended. This could potentially contribute to demonstrating the "added value" that might be associated with increased attention to user knowledge, which may support making user involvement a priority in economically stressed organizations. Simultaneously, awareness should be raised of the risks of professionalization and cooptation that are associated with such methods that involve close relationships with authorities. This might imply a neutralization of charged issues of importance for many service users, not least individuals struggling in the margins of society (38).

Financing and sustainable structures create legitimacy

The results suggest that the sustainability of initiatives to increase the legitimacy of user knowledge in mental health services is connected to the organizational and financial possibilities for doing so over time. Economic compensation for users who are not employed by the system is essential. The lack of compensation for the user representatives who contribute to advisory committees, work on quality assurance and development projects for example, makes them even more vulnerable to knowledge injustice. Permanent, rather than project-based funding was also considered crucial for stable implementation. Agreements with government agencies, national authorities and local and regional actors provided support for these user-based knowledge methods. In the end, as with many other change processes, the financing and responsibility for these services must come from the highest levels.

The results further suggest a need for stable welfare organizations and secure working conditions for staff, as a prerequisite for change. Readiness for change is also connected to information, communication and the involvement of front-line staff, as well as the leadership, in these change processes. The discussions also pointed to the fact that working environments not only relate to implementation questions. Many program representatives also described positive effects in the working environment of staff when a more user-inclusive culture developed.

Legitimizing knowledge is a process and power issues predominate

There is no one, static answer to the question of developing legitimacy for user knowledge. Knowledge is created over time, in contexts that influence the process. The opportunities for real participation in these contexts require shifts in power structures so that new forms of knowledge and new collaborations for learning can be integrated in mental health practice.

An important issue reflected in our results was the precarious balancing act user representatives had to perform in order to participate. They had to negotiate the tightrope of being cooperative but not too compliant and in providing fresh perspectives without being too critical. These findings resonate with previous studies focusing on user involvement of individuals in their care and support (6, 39). It further highlights the need to develop conditions and methodologies for an open exchange of experiences and opinions in order not to silence voices and miss out on important knowledge perspectives.

The results also suggest that perspectives on integrating user knowledge and allowing for influence are affected by attitudes that may not be readily apparent when implementing initiatives building on user knowledge. Interviewees described a "we already do that" mentality where staff perceptions of having succeeded in focusing on user influence were not necessarily reflected in users' experiences of having their perspective legitimized and included. Users themselves often lack confidence in their role as knowledge-bearers, and therefore maintain a passive voice, even when services are initially seeking their voice. Self-stigma may be thereby constitute an obstacle to participation. Even at the individual level therefore, epistemic (in)justice is worth considering when developing user influence.

Conclusions

The model presented above can be seen as an explanatory framework for understanding the complexity of legitimizing this unique form of knowledge in mental health services and thereby supporting user influence. It may also be seen as a framework for action, as it has emerged from the discussions we have had on an ongoing basis in the co-production team. The study and analysis have clarified, using the theoretical framework provided by epistemic injustice, many of the strategies that the user movement representatives have successfully struggled to develop in their work. The systematizing of a collective user knowledge base, presented in a form (method), that is relevant and adapted to a psychiatric context has characterized the specific methods we have considered. The issues of participation and power have additionally served to confirm the need for access to the "playing field" in a sustainable fashion, if the development and "packaging" of the knowledge is to stimulate a process that continues beyond the initial presentation of this knowledge. This was very clearly exemplified by the "Recovery Guide" implementation in which the authors in the user movement negotiated access to the mental health service in order to manage, follow-up and evaluate the implementation process.

The current analysis points to the legitimacy of user knowledge as related to the issue of representativeness, the systematic inclusion of this knowledge in applicable methods, stable resources, positions within the mental health system and participation in the process of integrating this knowledge base in mental health contexts. The results suggest that the focus must shift from the current paradigm, which primarily involves the importing of this knowledge into a professional system, to one in which the mental health system, including the national authorities, actively participate in developing cultures and organizational structures in which this knowledge base is valued and integrated in mental health practice. Further research is needed into how more isolated and independent users may gain influence and have their positions as active knowledge-bearers confirmed in practice.

Data availability statement

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

Author contributions

DR managed the research project and had main responsibility in designing the study. KG had the main responsibility in completing the analysis and writing up the manuscript, working in close collaboration with DR and HN. In these later stages, all authors took part in the analysis process in connection with group meetings and in reviewing and revising the manuscript. All authors were involved in developing the interview-guide, in performing the data collection and in the first stages of analyzing data.

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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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Perspective: Decolonizing postmodernist approaches to mental health discourse toward promoting epistemic justice

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Currently, it is possible to observe a slowly (but surely) growing volume of claims seeking to disprove Foucauldian ideas about knowledge and power as overlapping basic theories of epistemic justice. Prompted by these claims, alongside adopting tenets of Critical Race Theory to address injustices inflicted upon people facing mental health challenges, I propose applying decolonizing deconstruction to Foucault's terminology, toward identifying opportunities to enhance epistemic justice, primarily in direct interventions in mental health services.

KEYWORDS

Foucault, postmodernism, mental health, Critical Race Theory, decolonization, epistemic justice

Introduction

The rift between sociology, social philosophy, and psychiatry has been traced back to the 1970s, and is largely attributed to fundamental discrepancies between the theories, paradigms, and methodologies guiding each of these disciplines (1). One of the consequences of this split has manifested in mainstream psychiatry's broad dismissal of, or its self-preservation facing, the otherwise lively and impactful discussion surrounding post-modernity (2, 3). However, the widening preoccupation with epistemic in/justice in psychiatry and psychiatric epidemiology journals [e.g., (4–7)], signified also in the initiative to dedicate a distinct Research Topic thereto in *Frontiers*, marks an opportunity for identifying some of its notional origins and engaging in contemplation on the nuances of incorporating them into mental health discourse and practice.

Current assumptions about the postmodernist roots of epistemic in/justice in mental health services

In recent years, it has become increasingly common to cite some of Foucault's work on postmodernism as having laid the conceptual groundwork and inspiration for the formulation of epistemic justice theory and practice (8). This appears to make a great deal of sense in light of the supposition that knowledge is essentially never neutral, and dwells in all processes involved in the construction, manufacture, institutionalization, and application of power, organically inherent to Foucault's thought and to models advocating epistemic justice (9). Both Foucauldian interpretations and approaches driven by epistemic in/justice perspectives suggest that knowledge and power are inseparable. Both point to social structures of deviance, and to the professions tasked with treating those who "deviate" from what is delimited as "normal" as agents of disciplining powers that rely on the distinction between the "truth" of scientific reason and all other forms of knowledge (10). In this vein, mental health services have often been cited as playing an impactful part in sustaining social hierarchies and perpetuating a status quo (11). Discussing Foucault employing epistemic justice terminology has also been specifically useful toward identifying injustices imposed upon those diagnosed with mental illness, and for advancing the diversification of voices shaping mental health discourses and resisting Sanism (12). Foucault himself directly addressed epistemology as a space within which status and authority are granted (and thus also withheld) (13). The apparent theoretical parallels between Foucault and ideas of epistemic justice have even prompted claims that "Michel Foucault could well be considered a theorist of epistemic justice *avant la lettre*" [Allen (14), p. 187].

New approaches to the connection between Foucault and epistemic justice

Somewhat outside the immediate field of vision of prevailing literature, the assumption of overlap between Foucault's writing and the defining elements of epistemic justice is slowly but surely coming under criticism. This criticism takes an interesting analytical turn and applies the critical lens offered by some of the theoretical foundations of epistemic justice, namely, Critical Race Theory (15), to Foucault's philosophy itself. In doing so, some theorists point to an inconsistency between essentials of correcting epistemic injustice, namely, granting epistemic legitimacy and credibility to knowledge held by indigenous communities, sidelined social groups and experts by experience, and the seemingly heavy reliance of current debates on epistemic justice on postmodern ideas which are generated and developed primarily in privileged, Europocentric settings. The criticism drawn from this inconsistency encourages further conceptual developments of epistemic justice to keep in mind that "structuralism and post-structuralism are theoretical options born in the center of global imperialism" [Zondi (16), p. 21].

Reconsidering postmodernist ideas for the advancement of epistemic justice

Picking up where some of said critique leaves off, two steps toward promoting epistemic justice while building on postmodern suppositions about discourse, knowledge, and power in the context of what is considered mental illness and mental health are proposed.

Step I: Decolonizing deconstruction

The first step is applying decolonizing deconstruction to Foucault's ideas. Toward this, I refer to decolonization in its broader sense—i.e., questioning the underlying normative propositions of Western knowledge and explicitly prioritizing indigenous voices (17). In other words, decolonization as referred to in this effort is a set of assumptions regarding the need to undo and unlearn the damage caused by colonization, especially in terms of lost knowledge, silenced identities, and aggressive epistemic oppression (18). It is also a methodology that aspires to recover epistemic freedom among individuals and communities whose basic claims for self-definition have been subjected to outsiders' normative judgement and negation (19). In accordance, calls for decolonization position epistemic domination both as the result and the motivation for the colonization of the sort of knowledge that gains its justification from prejudices supporting the superiority of "white," "Western" and "modern" viewpoints over all other knowledges or ways of knowing the world (20). Consequently, I propose that Critical Race Theory can provide helpful guidance for such decolonization and renegotiation of ideas, specifically regarding those diagnosed with mental illness. While such individuals do not fall under the classic definition of "indigenous communities" victimized by colonialization in terms of localness or heritage, their shared historical collective prosecution, systematic oppression, institutionalized discrimination, and stigmatic delegitimization arguably render them an underprivileged group, not by ethnicity or culture but by collective exclusion and shared destiny[1]. The basic assumptions underlying such an effort may thus borrow from the tenets of Critical Race Theory (24), adapted to address the mental health/illness discourse, and would constitute:

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[1] Detailed discussions on the ability to apply Critical Race Theory to the analysis of disparities that are not primarily based on race without diminishing the impact of racism on mental health services are already available and inspire this suggestion (21, 22); as do recent arguments supporting such analysis as a means of observing discrimination whilst not nurturing a discourse that uses race as the ultimate explanation for social inequality (23).

1. the idea that the dominance of Western postmodern philosophy in the analysis of discourse cannot be veiled or merited by linking it to epistemic justice;
2. the notion that Western postmodern philosophy concerning the structuring of discourse should be subjected to the same questions that it itself raises regarding the relationship between science(/theory), status, discipline, and (theoretical) authority, and the links between knowledge and power that underly such a relationship;
3. the suggestion that Western postmodern philosophy regarding the association between discourse, knowledge, and power may itself be a social construct;
4. the emphasis on storytelling and counter-storytelling, or on the role first-hand narratives can play in introducing alternative perspectives on discourses of mental health and illness; and
5. the acknowledgment that "truths" may lay beyond widely cited theories and analyses, and that Western postmodern philosophy may have not reached its status in academic and professional communities had it not capitalized on the infrastructure of knowledge dissemination and legitimation wherein its theorists enjoyed a priori advantage and access as mostly Western, mostly white, mostly educated, and mostly male.

Embracing these principles, then, entails revisiting Western notions put forward by Foucault by opening them up to alternative interpretations, underlain by the unmediated perspective of those diagnosed with mental illness.

Step II: Focusing on testimonial epistemic justice

The second step would be redirecting some of the efforts so far inspired by Foucauldian ideas and reshaped by the decolonization and deconstruction performed in the first step toward the specific correction of testimonial epistemic injustices. Currently, literature tying Foucault's work to epistemic justice in the field of mental health more often than not addresses what can be framed as hermeneutical epistemic injustices and their relationship to sanctioned professional power [e.g., (11)]. These are the forms of epistemic injustice that lurk in the infrastructure of addressing the knowledge of members of marginalized groups, and results from an overall societal absence of skill or willingness to understand such knowledge, due to relentless exclusion of such groups from mainstream meaning-making platforms and activities. The less frequently addressed form of epistemic injustice, testimonial injustice, is the delegitimization and discrediting of an individual's account of experiences, due to bias and/or prejudice toward the social group to which s/he belongs (25). A deeper examination of the possible diverse manifestations of subjugation in micro-level encounters with mental health service-users can provide a plethora of opportunities to correct epistemic injustice, through mutual deconstruction of particular fallouts and experiences of testimonial oppression, and through employing a postmodern approach and its suggestions about the relations between discourse, knowledge, and power, as a starting point for discussion. Using Foucauldian ideas about such relationships as points of departure for dialogue with service-users and engaging in mutual examination of them, rather than keeping them in mind as underlying theoretical assumptions or treating them as secondary to the intervention process, may result in the correction of testimonial injustices so frequently prevalent in the area of mental health (26). This could begin with the foundational epistemic question "how do we know what we know about your situation, life history, challenges and strengths?" followed by, "What do we overlook or disregard in our handling of your situation, life history, challenges and strengths?" and "Why is that and what are we missing out on?".

Presumably, focusing on testimonial epistemic justice while fostering increasing epistemic trust will enable recognition and legitimation that go beyond issues of diverse representation and subvert the structure that disciplines both those diagnosed with mental illness and those socially mandated to treat her/him.

Discussion

Following the steps cited above could also achieve two additional goals: they could go a certain distance in grounding postmodern notions in real-life experiences of mental health services and expand theory through the entry of new, diverse voices, into the process of shaping our understanding of power structures. At the same time, they could enable the penetration of more structural theoretical understandings into the notional framework of epistemic justice, sometimes criticized for being over-individualistic and disregarding systematic factors fostering epistemic oppression, not least in the field of mental health intervention (27).

Whether interventions are articulated employing a postmodern approach and then decolonialized, guided by ideas of epistemic justice; or whether they are motivated by a desire to correct epistemic injustices and add a layer of postmodern perspectives to this effort, the status quo of mental health interventions stands to undergo transformation, as the practitioner and service-user allow themselves to engage in epistemic disobedience (28), taking various paths toward addressing knowledge and power; and contesting not only the relationship there between, but also actively diversifying their "knowledge about knowledge." This disobedience is a key to any effort to promote justice within the complex discourse underlying many mental health and mental illness intervention settings and social constructions. Otherwise, to paraphrase American novelist Thomas Pynchon, "If they can get you to keep asking the wrong questions, they will never have to worry about answers."

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

The writing of this paper and the ideas that are presented in it were formulated by LL.

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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“Poster girl”: The discourse constructing the image of “girls in distress” as existential epistemic injustice

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The present study is focused on understanding how the image of the girl designated “in distress” in official regulations guiding the provision of public social services to girls in Israel can be structured. The study takes a qualitative approach, and employs the critical-feminist paradigm to the analysis and interpretation of discourse, combining thematic content analysis and deductive critical discourse analysis. Its main findings disclose an organized process of establishing the normative authorities dominating the discourse on public social services for girls; classifying groups of service recipients to which a girl can belong; constructing their forms; and ultimately circumscribing the girls thereto, determining the performative acts on which receiving state assistance is conditional. Through discursive maneuvers of construction, the image of the girl is “born” as an undisputed “truth” deriving from the deviance attached to her every move. In this trajectory, basic epistemic injustices are perpetuated and solidified, and a new form of epistemic injustice—existential epistemic injustice—is revealed. This process’s implications are proposed.

KEYWORDS

girls, distress, social services, policy, epistemic justice, discourse

Introduction

“Language” is defined as “the words, their pronunciation, and the methods of combining them used and understood by a community” (1). According to the Sapir-Whorf hypothesis, language is subconsciously secured in societies’ communicative and interpretative habits (2). As such, language and its rules play an important part in establishing social and group identities. A language’s construction echoes the aspiration for finding order in social structures, and is often regulated by those who possess the power to control its content (3). “Discourse”, constitutes the practice of conceptualizing and exchanging ideas using language (4).

The present study addresses the construction of the image of girls in need of assistance from Israeli public social services, as it is reflected in the language and discourse prevalent in state regulations guiding such services. These girls are referred to in Hebrew using the term *na’arót beMetzuká* [“girls in distress”]. Our research approach can be identified as critical-feminist, incorporating ideas of Michel Foucault (5–8) and Judith Butler (9–11), insofar as these address the structural role of language and discourse in the evolution of gender forms and the social tasks assigned thereto. The study rests on the supposition, suggested as shared by both Foucault and Butler, by which there is no human depiction with an "identity" or "essence" that precedes discourse, and that any implied existence thereof is in fact the result of structural mechanisms, a central component of which is language. As will be shown, these assumptions will be applied toward gaining better understandings of the epistemic justice underpinnings of discourse practices, in general and with specific relation to girls dealing with distress.

According to Foucault (5, 6), power involved in acting, creating, and perpetuating social orders is applied through interventions in the lives of individuals, in ways that (1) subject individuals to the examination and surveillance of others who control the discourse; (2) shape what is assessed as individuals' social "particularity"; and (3) forcibly tie individuals to the particularity that determines their position within the oppressive social structure. Such power simultaneously bears disciplining and manufacturing attributes, and is definitively external to the subjects at whom it is directed. A prominent mechanism executing this power is *form*, which "categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him" [(7), p. 781]. So, *via* formative power, the individual takes on distinctive qualities, or definitions, that set her/him apart, that are integrated into her/his being and body, become an inseparable part of her/his existence, and are present in all of her/his actions (8).

Foucault (5) illustrates the inseparability of knowledge/power through the space of inspection. The power and control inflicted by inspection are often concealed, and are enabled through the acquisition of the status of rationality, objectivity and science. Accordingly, inspection becomes an antecedent of applying ritual and "scientific" actions to "fix" individuals based on the differences between them; and at the same time, these differences are prioritized, measured, "marked", and categorized by whomever controls discipline, thus reducing individuals to the traits that are inspected, or to mere faceless "cases". As with Foucault, institutions tasked with screening, classifying, and processing such "cases" (including prisons, schools, hospitals, and social services) are intended to create order among individuals by deeming them rational or irrational human material, worthy or unworthy of membership in the orderly world (12).

These processes run yet deeper within the social structure, as the predominance of the voice of what are established as scientific or professional authorities also delegitimizes interpretations of experts by lived experience, exacerbating testimonial epistemic injustices [discounting another's credibility based on bias toward the social groups to which she/he belongs, (13)]. In this sense, the distinction between rational and irrational, sane or insane, becomes grounds for discrediting the voice as well as the speaker. The particularities tied to individuals that are subjected to dominant discourse through processes of intervention, diagnosis, and inspection, obscure diverse identities (14). Individual accounts are devalued, based on predefined particularities that justify epistemic injustice as necessary for upholding the social order or even for providing effective treatment to those who'do not know what is good for them', and hence have little knowledge to offer to those tasked with assisting them (15). Regarding social structures and individual identities, Butler (16) contended that identities are neither natural nor static. They obtain social meaning only when repeatedly reenacted within the limits designated for them. For example, in *Gender Trouble*, Butler (9) claimed that gender is constituted as corporeal style, while it is in fact no more than a set of repeated performative actions, falsely creating the appearance of a suspended "natural" and "inalterable" fact. In this process, "material bodies" that matter are those sustained by specific appearances of sexuality marking bodies as socially comprehensible. In this vein, becoming understood socially entails obtaining meaning through systems of cultural signs (10). This means that there are no "material bodies" whose definition is not influenced by preceding cultural discourse (9). In terms of discourse, the "material body" is treated as a passive subject, marked by cultural forces external thereto. The forms inscribed onto the body, that are the consequence of the literal acts, sketch and delineate its acceptable boundaries. Butler argued that this does not mean that material bodies do not exist prior to inscription, but rather that materials and the social markings imposed thereupon are intertwined. The dominance and control over discourse thus becomes coupled with the privilege to create "social reality", and attach appearances of meaning to existing structure and form (10).

This "social reality" suggestibly constitutes exceedingly fertile grounds for the development of hermeneutical epistemic injustices [the broad societal difficulty to understand social groups' experiences, due to the continued exclusion of members of such groups from mainstream meaning-making process; (13)]. Not only do performative acts perpetuate existing epistemic hierarchies, but they also limit opportunities for systems to develop mechanisms needed to support virtuous hearing (17). In the absence of such opportunities, contestation against dominant discourse is easily brushed aside, and the language prevalent in systems becomes so organic to their functioning, that the power relations and epistemic injustices that underlie it become difficult to identify, and even more so contest (18). Policy can play a vital role in maintaining, shaping, or correcting epistemic injustices. Policy documents often fulfill a dual aim in this respect—they both reflect current dominant discourse and solidify it by turning discursive norms into written rules (19).

Resting on the above described conceptual frameworks, and in line with the suggestion that policy documents are telling and influential objects of research when it comes to the analysis of discourse surrounding marginalized populations (20), our research centered around two main questions: What is the image of "the girl in distress" that is reflected in official regulations guiding public social services for girls in Israel? How do the language and discourse constructing regulations and constructed therein delimit the status, essence, and presence of "girls in distress" in the public sphere?

While the study is anchored in the Israeli policy context, social services and the Israeli welfare state share their distinctive attributes with several other welfare states around the world [e.g., the United Kingdom, the United States, countries in southern Europe and certain areas in the Middle East; (21)], and consequent similarities characterize the main responses and treatment afforded to assist girls considered at-risk by public social services in these countries. This renders the study's findings, as well as insights attached to its methodology, plausibly highly transferable, as well as useful and thought-provoking, to other contexts as well.

Materials and methods

Sample of regulations and procedure of collection

All 23 State Social Work Regulations pertaining to public social services provided to girls in Israel were analyzed. State Social Work Regulations are intended to explain and organize the legal aspects of providing public social services in Israel. In them, are concentrated the official policies guiding services and shaping their nature, scope, and practice principles, as well as information about the procedures needed to apply policy and other institutional requirements attached to offering social services through departments of social services. In the absence of an up-to-date welfare services law in Israel and/or a defined basket of personal social services that the state of Israel is obligated to offer Israeli citizens, the State Social Work Regulations are the most pertinent documents that guide services in all areas of public welfare. They are divided into 20 chapters, all of which were screened for relevant content. State Social Work Regulations are publicly accessible online, thus no authorizations were required to gather or analyze them. The regulations analyzed for the present study were all published between 1987 and 2017.

Process of analysis

Two methods of data analysis were chosen as appropriate for achieving the aims of the present study. The first was Thematic Content Analysis (TCA). TCA is a qualitative method employing strategies of systematic coding and categorizations of textual data, and is aimed at uncovering patterns in the use of certain words, the frequency of their appearance, and the relations between words and the discourse construct that they represent (22). To that end, all regulations were read and reread several times, and comments and remarks were attached thereto. In the initial readings, marking and commenting were intuitive. In later readings, categories revealed themselves and the texts were divided according thereto.

Following this, in the second stage of analysis, Fairclough's (23) principles of Critical Discourse Analysis (CDA) were employed to examine the veiled roles of language and discourse in constructing power relations and establishing the social status of the image of the "girl in distress". CDA is based on approaches to "discourse of power" and "discourse of racism" (24) that explain phenomena through the associations between discourse, power, oppression, and discrimination (25), and enable revealing possible outcomes of discourse in terms of creating or eroding solidarity (26). In the present study, CDA-associated deductive interpretation was guided by theoretical principles, described in the introduction, proposed by Foucault (5–8) and Butler (9, 10).

Namely, special attention was given to Foucault's (5, 6) three modalities of objectification, considered by many [e.g., (27, 28)] to be most closely related to the perpetuation of epistemic injustices: *subjectification*, through which dominant authorities who control discourse are established as normative, as are the roles and privileges attached thereto; *dividing practices* setting the rules of discourse that ensure the preservation of power by preventing the entry of "foreign" discourses into it, e.g., by deeming anything outside dominant "truths" as false; and *scientific classification*, by which idiosyncratic meaning is imposed on individuals, and actions are taken to sustain its uniformity.

To expose the specific qualities inscribed upon the image of the "girl in distress" in regulations and discuss the consequent implications of this inscription with regard to epistemic in/justices, a focus was also placed on Butler's idea of *discourse and performance*. In this vein, an attempt was made to track the construction of the gender image of girls within its cultural-political context and the form wherein the contours of this image are delimited; to identify processes of constructing the boundaries of sex and gender by stipulating compelled repeated performances; and to examine how repetitiveness contributes to the determination of the bounds of girls' images and social roles.

In practice, CDA was carried out by reading all of the texts once more, but this time from an interpretative-theoretical perspective. This resulted in a new set of categories, relating to roles, power relations and social positions.

Results

To illustrate the process of discursive construction unveiled in the present study, we chose to use an analogy of a machine (Figure 1).

The machine is comprised of seven cogwheels, rotating alongside each other, interlocked and interdependent for movement. The "machine" is bordered by an exterior wheel that symbolizes the discourse space of public social services for girls. Rotating within it are five wheels, each signifying a distinct discourse space attached to an individual type of service recipient that the "girl in distress" might be. These spaces are in turn bordered by names given to recipients of public social services, either inter alia or specifically, to girls. In each, the girl is labeled (explicitly or implicitly) as a beneficiary of assistance. Within these discourse spaces, the normative form of the image of service recipients becomes set, as does that of other figures related to it in the space of service extension.

In the center of the machine, as a byproduct of the rotating motion, lies the innermost cogwheel. While this wheel turns as a result of the movement of the wheels around it, at the same time, it is charged with keeping them turning. This wheel, that depicts the full representation of the "girl in distress", is created from the content of the surrounding wheels, and at the same time is expressed in them. The following describes the motion of the machine vis-à-vis each of its wheels and the process of construction that they produce and sustain.

Delineating the discourse space wherein normative authorities operate

The exterior wheel that the metaphorical "machine" borders on, is formed by establishing the subordination of discourse to the control of normative authorities. The normative status of these authorities is achieved and made apparent through the description of their active role vis-à-vis service recipients. The normative authority "Social Affairs and Social Services Ministry" exists in order to "*treat/care for children and youths who are in distress*" (Reg. 8.9, p. 1). Actions under the Youth (Care and Supervision) Law of 1960 (Reg. 8.11) and even "*society in Israel*" (Reg. 8.6, p. 1) are described similarly. The normative authorities ("the ministry", "the law", "society") are positioned as external to the "material body" of service recipients, and as having the privilege to make decisions about them and perform actions upon them. This solidifies their power to determine the actions to be performed by service providers, as agents mandated by normative authorities.

Naming service recipients

Once the normative authorities have been positioned facing an object of reference, the form of service recipients themselves is established, first by giving them names and attaching meaning(s) thereto. Regulations name five groups of service recipients to which girls can belong to, each tied to specific conditions set forth in categories justifying the need for intervention on the part of normative authorities and their agents. Such categories explicitly reflect a connection between age and peril: **Child** ("*from birth to the age of 18… in distress*"; e.g., Reg. 8.9); **Minor** (who is "*under the age of 18*"; e.g., Reg. 8.11, p. 2), and to whom one of the following situations apply: "*there is no one responsible for him, the person responsible for him is unable to care for him, or neglects caring for or supervising him* […];" (Reg. 8.11, p. 2); **Teenagers and youths** (aged 14–25), who

> *assemble in groups, were expelled from or dropped out of formal frameworks and loiter idly, and do not function or function with severe problems in adjustment, including asocial and criminal behavior. They mostly meet in the evening and nighttime, and belong to groups that evolve on their own in communities, against a background of non-functioning, feelings of deprivation, and rejection* (Reg. 3.22, p. 1-2);

Teens harmed by addictions (aged 12–24), whose "*routine functioning is damaged as a result of using drugs/alcohol/gambling, and who exhibit other and/or additional compulsive behaviors*" (Reg. 11.2, p. 2), and who "*uses […] and is characterized by physical and/or mental dependence*" (Reg. 11.2, p. 2); and **A girl or young woman** (aged 13–25), who is "*single […] whose behavior is characterized by self-destruction, and is deteriorating or in process of deterioration, and [who] experienced traumatic events, [either] mentally, emotionally, and socially*" (Reg. 17.1, p. 2). Delineating each group of service recipients to which the girl can belong implicitly involves, besides age and harmful situations, appearances of what each recipient, and the girl within her, is permitted or forbidden from being, if assistance is to be offered to her. Taking the definition of the "**girl or young women**" as an example, the reflection of what she is not allowed to be, is "married". But, she is also "not allowed" to express self-protection, self-enhancement, or other positive behaviors, as the link between traumatic events and self-destruction must be fully observable for her to receive assistance.

Distinguishing the various forms of service recipients within the service space

Once one "half" (normative authorities) of the described service space has gained the status of formative "truth", and in

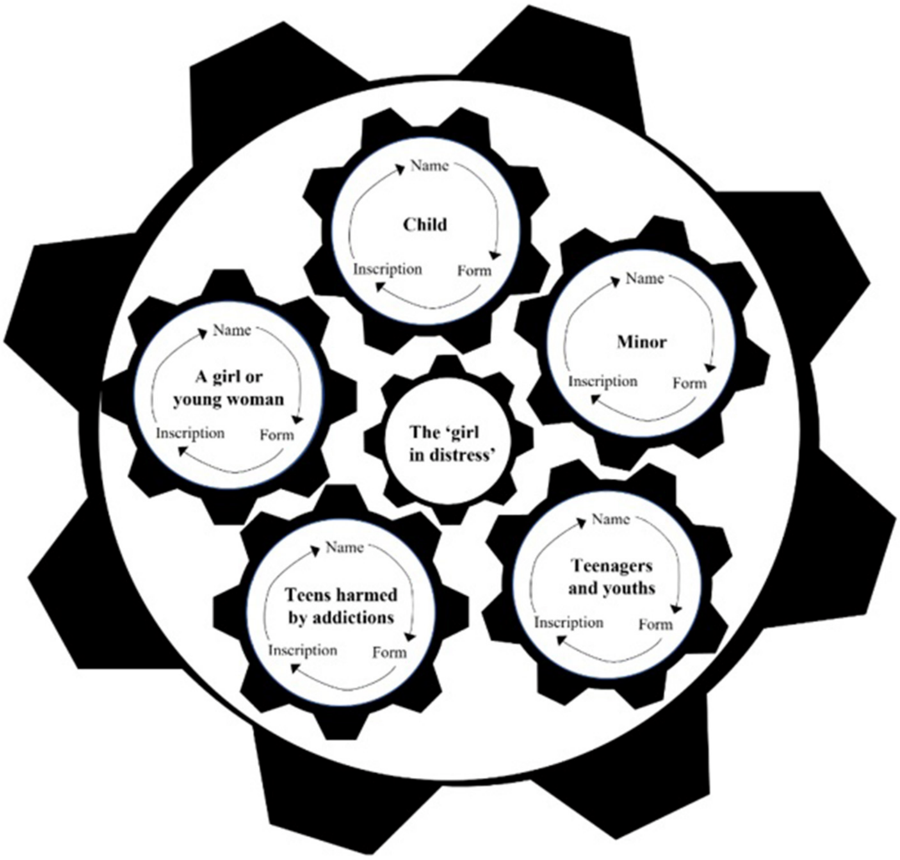

FIGURE 1
The "Machine."

order to coherently establish the service space, the "other half" (service recipients) correspondingly must be granted its own unique form of "truth" or existing form. This is done by applying various nuances to each group of service recipients to which the girl has to belong in order to receive assistance.

The emergent form of service recipient: Child

The terms repeated in regulations to describe children delineate the contours of a passive image. This service recipient is described as "*warded*", and as "*subjected*" to neglect, violence, risk, and distress (Regs. 8.17, 8.34, 8.2, 8.5, and 8.9). Accordingly, the service space for children is consistently displayed as that in which the child "is placed", "is supervised", "is organized", and "is treated". Another explicit "truth" established regarding children stipulates that "*a child's growing up in his natural family ensures his proper development…*" (Reg. 8.17, p. 1). The use of the word "natural" implies that the image of "family" has a self-explanatory and inherent form, stemming from the most basic structures of humanity. Regarding development as "proper", even without further explanation, implies that the "correct" way of developing can be measured and determined by normative authorities, and requires no elaboration, as it is granted the status of "truth" that precedes the discourse about children and families; as though "proper development" existed even before anyone defined it. Finally, the decisive premise that the result of growing up in a "*natural*" family is "proper development" is, once again, depicted as a "truth" that precedes discourse and is as such indisputable. If this is the case, what is to be "done" with children that do not grow up in their "natural" family? And what is there to learn about the family receiving services when development is not "proper"? Notably, the only form of children's families mentioned in regulations is a "natural family". In accordance, services extended to children by normative authorities are all designed to imitate it: "*A foster family is the model closest to the natural family…*" (Reg. 8.2, p. 1); "*The center serves as a temporary substitute for the child's natural family*" (Reg. 8.2, p. 2).

The emergent form of service recipient: Minor

Beginning with the initial delimitation of minors' form based on their age, terminology used to describe minors who receive assistance from public social services is by way of negation. While children are at an age between birth and 18, a minor is "*whomever has not [yet] turned 18*" (Reg. 8.11, p. 13). Consistently throughout regulations, minors are defined by what is extraneous to them, leaving they themselves void of content. Moreover, their eligibility for assistance is determined through actions performed on them by others, e.g., their family abuses or neglects them. Regulations do not include any reference to forms of minors that reflect other possible facets of their being, besides their being described as "*needy*" (Reg. 8.11, p. 1) or "*a victim*" (Reg. 8.6, p. 1), thereby attaching essentialism to such traits among minors who receive services. As stated in regulations: "*The law specifies certain circumstances under which there is need for external intervention in order to protect the minor*" (Reg. 8.11, p. 1). Such circumstances become indisputable "truths" about minors' needs, that implicitly precede discourse about them, and are recognizable using absolute, unmistakable, fully generalizable conditions.

The emergent form of service recipient: Teenagers and youths

The borders of the forms of teenagers and youths receiving services, are established by using terms that illustrate their separation from other groups in society, a distinction that renders them inherently anomalous. Terms such as "*alienated*" and "*antisocial*" (Reg. 9.1, p. 1) position them at the margins of functional society. Facing them, and regarding the objectives of interventions with them, is the repeated use of the terms "*normative*" and "*education*" (Reg. 9.1, p. 2). These repeated terms perhaps indicate teenagers' and youths' ability to cease being "deviant" and reintegrate into society by exhibiting socially acceptable rules of behavior. Their "deviance" is often described using the term "*natural environment*" (e.g., Reg. 9.1), as opposed to "*problems*" and a "*phenomenon*" (e.g., Reg. 3.22). In other words, this form of service recipient removes herself from what is "natural" (thus existing with idiosyncratic consensual meaning, preceding the discourse that describes it) to others, and may be welcomed back into what is "normative" when exhibiting behaviors that enable "*reintegrating them into society*" (Reg. 3.22, p. 3).

The content of the designation "teenagers and youths" is described by the repeated use of active verbs, all depicting actions that are essentially negative: "*[engaging in] criminal behavior*", "*loitering*", "*[having] dropped out*" (Reg. 3.22). The repetition of various terms meaning "idleness" across regulations (e.g., Regs. 2.4, p. 60; 3.22, p. 1; 9.1, p. 1) stresses the fact that the image of these service recipients engages in actions considered useless. While the form of their image, unlike the form attached to "children" or "minors", can contain their appearance as active figures, their activeness is delineated as categorically and absolutely useless and alienating, as a precondition for being considered eligible to receive services.

The emergent form of service recipient: Teens harmed by addictions

The outer contours of the form of the service recipient "teens harmed by addictions" is defined by describing various functions of its "material body". Such functions, or actions, are depicted by both active verbs (e.g., "*using [drugs]*") and passive language (e.g., "*to become addicted*"; Reg. 11.2). This phraseology reflects an internal contradiction in the form of these service recipients: On the one hand, they are victims of the problem, or the phenomenon, of addiction. On the other hand, they are implicitly blamed for taking the actions leading to their addiction. Accordingly, within the discourse space, as a condition for receiving services, the form of teens harmed by addictions who are eligible to enter the service space are expected to embody a paradox, and in this sense, the action engaged in by the body harms the same body that is also a passive victim of its own action. This duality enables the establishment of what is situated opposite this situation, i.e., what the normative authorities expect to achieve: "*gaining skills to cope [with the addiction]*", and "*reintegrating into the normative trajectory of life*" (Reg. 11.2, p. 3).

The emergent form of service recipient: Girl or young woman

The borders of the form of the service recipient "girl or young woman" are delineated by the description of two spaces wherein her image is presented as plausibly located: one, indoors, and the other, outdoors. The division there between is marked by the repeated use of words such as "*circle*", "*relationships*", and "*home*" (e.g., Reg. 17.1). The outdoors, described in terms of impartially assessed realities, are established as "*crisis*", "*danger*", and "*risk*" (Reg. 17.1). The indoor space is described as emotional and experiential, by using words such as "*emotions*", "*stress*", "*support*", and "*belonging*" (Reg. 17.1). Accordingly, the external, perceived as an objective evaluation of girls" and young women's states, obtains the status of "truth", while the internal is inter-subjective, "soft", and deriving from individual experiences. In the external space, the form of this service recipient is imagined to be passive and vulnerable in all areas of her life: "*a girl and young woman who was or is a victim of sexual abuse, a victim of violence in and outside the family*" (Reg. 17.1, p. 2). Her vulnerability is essential and overwhelming, and she is, throughout most regulations "*needy*" of "*protection*", "*support*", and "*empowerment*". Others know the truth about her, make decisions for her, and treat her.

However, regarding the inner space, while her image obtains the form of an active agent, her actions place her at continuous risk: "*a girl or young woman [...] whose behavior is characterized* *by self-destruction*" (Reg. 17.1, p. 2). According to this formula, her passiveness, as interpreted by others, holds the evident key to her protection, while her actions, which derive from her own decisions and interpretations, threaten her.

The "truth" about girls and young women eligible for assistance is established as follows: "*Among teenaged girls and young women there is a phenomenon wherein some have difficulties fulfilling the roles that are acceptable and typical for their age, as a result of their exposure to hardships in the family and in society*" (Reg. 17.1, p. 1). This solidifies expectations of girls (and young women) in Israel as preceding the discourse about them. In this "reality", the source of the "difficulty in fulfilling roles" is an absence of ability, or deprivation: "*These girls and young women are deprived emotionally and functionally, and often lack the capacity to forge stable bonds with their close environment*" (Reg. 17.1, p. 1). Here, what is "lacking" implies the existence of a "whole", and the "absence" stands opposite an unwritten "presence" that obtains a self-evident status of natural "fact". Who, then, is the girl who is eligible to become a service recipient? She is whomever her hypothetical normative counterpart, is not.

Pinning the figure of the service recipient down to its preassigned form

Thus far, we have seen how the discourse surrounding "girls in distress" in regulations includes the subjugation of groups of service recipients to which she may belong, to the normative authorities controlling the discourse surrounding the service space. The next stage then becomes the scientific classification of working with girls as an unquestioned discipline. Two elements of this process have already been displayed: By presenting assumptions about service recipients and their lives as "natural" truths that precede the discourse dictated by normative authorities; and by repeating them again and again, enabling discourse to take on the appearance of previous meaning, connected to common knowledge. These two maneuvers delimit groups of service recipients and designate coherent forms for identifying them according to a repeated internal logic. This fulfills Foucault's (5, 6) principle of the author: There is now a speaker of the discourse, with the legitimacy, knowledge, and power to shape services, to dictate the actions of their providers/agents, and to mark the acceptable borders of their recipients' forms.

For scientific discipline to be fully realized and services to be made available, these elements of the discourse must be tied *via* discourse to its subjects' individual particular identities.

For the service recipient "**Child**", this is done by repeating the phrase "*the child and the family*" in regulations (e.g., Reg. 8.9, p. 5), i.e., the child and her family are constantly presented as a single unit. When the family cannot be, or is not, what is acknowledged in the discourse as acceptable, the service fulfills its part of the symbiosis with the child, and the discourse shaping the service space is tied to the child's own particular identity. The service recipient "**Minor**", is defined, as aforementioned, through what it is not, automatically leaving a void to be filled by the dominant discourse, that is tied to minors' particular identity as it marks all that lies beyond them. Also, regulations regarding minors establish the constantly crucial involvement of the scientific discipline and its agents in the life of the minor receiving services, while pointing to her as being in a perpetual state of acute crisis ("*the social worker must be housebound, or carry a mobile communications device outside, ready to respond immediately to any call regarding a minor in need*"; Reg. 8.27, p. 2).

"**Teenagers and youths**" are tied to their own particular identities within the discourse established by normative authorities through the continuous use of the term "framework" (e.g., "*educational frameworks*", "*formal frameworks*"; Reg. 3.22). These frameworks can perhaps be analogized to a picture frame or a window frame, i.e., a mold that protects the edges of something, defines its borders, and is mostly inseparable from its familiar image. Accordingly, the frameworks in which services are provided are part and parcel of the discourse, and become what holds the form together. Another way this is done is by describing teenagers and youths as a social group with its own unique lifestyle that is idiosyncratic to it, in phraseology that is almost anthropological or zoological: "*Follow the times and area in which this population dwells, learn its ways of recreation and behavior...*" (Reg. 2.4, p. 60); "*It is the role [of the youth social worker] to go out to the population's natural habitat, in its own hours and time*" (Reg. 2.4, p. 60). The form of the image "**teens harmed by addictions**" is tied to the internal logic of splitting it, by external discourse, into the aforementioned paradox, i.e., between the girl that is both to blame and a victim of her own addiction, "savable" only by way of external intervention, without which she is presumably unable to create a separation between herself and "*the phenomenon*" (Reg. 11.2, p. 1), and is doomed to be trapped therein forever.

Finally, the form of the image "**girl and young woman"** is solidified and tied to her particular identity through repeated reference to the theme of "cycles of distress". For example: "*Removing the girl or the young woman from the cycles of sexual abuse and violence*" (Reg. 17.1, p. 3); "*Removing [...] from the circles of [...] distress...*" (Reg. 17.4, p. 2), and "*The responses are based on the unique needs [...] for removing the girls from the circles of violence*" (Reg. 17.1, p. 4). This decision depicts the risks posed to the girl as necessarily endless, correctible only through her removal by external authorities. As aforementioned, this state of affairs is created by the behavior of the girl herself: "*a girl or young woman that was/is a victim [...] and [who] employs one or more of the following behaviors...*" (Reg. 17.1, p. 2). The word "*and*" implies that to obtain assistance, the girl must fulfill not only the condition of victimization, but also exhibit self-harm. This framing restricts girls who were abused and need assistance to a victimhood < > guilt cycle, again disruptable only by external intervention. Interestingly, this intervention entails not only her removal from one circle/cycle, but also her placement in alternative circles/cycles, preselected for the girl by normative authorities: "*[treatment in the transitional home is aimed at] managing proper relationships in all the circles to which the girl belongs*" (Reg. 17.2, p. 2). In this sense, the decisive change that the girl receiving services can hope for, the only future foreseen for her within the particular identity that she must adopt as a condition for receiving services, is moving from circles in which she is the object of abuse, to circles wherein she is the object of protection.

The "birth" of the coherent image of the "girl in distress" and the performative preconditions for her receiving assistance

Now that the distinct, coherent forms of each group of service recipients to which the girl may belong to has been determined, it is possible to examine the qualities of the image of the "girl in distress" that is present in all of them, and that is the ultimate object of public social services provided to girls. Binding together splinters of the girl's form scattered across regulations, common threads that run through regulations reveal themselves, as they point to the performative acts in which she is expected to engage and perpetuate in order for her to be professionally comprehensible and receive assistance.

The first thread underscores her distinction from boys receiving services. In regulations wherein girls and boys are addressed separately, the girl is typically "*treated*" and "*removed from*" (e.g., Reg. 17.4), while the boy (or even the seldom-used "boy/girl") "*signs*", and "*takes*" (e.g., Reg. 11.2). These differing associations with activity vs. passivity are far more than semantic. They delimit the "girl in distress" in ways that restrict her activity, portraying her as the proverbial weak, unintelligent "damsel in distress". In order to be accepted as a recipient of services by normative authorities, she must perform accordingly. At the same time, unlike descriptions of services provided only to boys, some services for girls are designed to instill "*skills that will enable her to maintain a relationship with the opposite sex [. . .]*" (Reg. 17.1, p. 2–3). Here, the gender of the girl is equated with exclusive responsibility for relationships with boys and their sexually-particular "material bodies", possibly implying guilt when such relationships turn against her. They also establish a binary gender conceptualization wherein the "natural" is predetermined as exclusive attraction to the "opposite sex".

The second has to do with the repeated restriction of the "girl in distress" to domestic spaces of existence. Assistance to service recipients who may be "girls in distress" are denoted using words closely associated with this space, for example: "*a welcoming home*", "*a transitional residence*", or a shelter, described as "*a private home in a residential neighborhood*" (e.g., Reg. 17.3).

Conclusively, from the establishment of normative authorities, through the denoting of the various forms of service recipients within the service space, followed by the tying of these forms to recipients' particular identities, and ending with determining performative acts expected of "girls in distress" in order for them to receive public social services, what at first appears to be a simple description of girls granted assistance, can be viewed as none other than an object created by discourse, with or without taking its/her actual individual identities, voice, or circumstances into account. This object, constantly placed on the dichotomous independence/guilt < > dependence/victimhood track, is eventually "redeemed" only when (re)embedded in the performative acts expected of its "normative' counterpart: "*building a proper relationship and positive communication with members of her family; strengthening her ability to develop normative social bonds in accordance with her age [. . .] encouraging her integration into normative formal and social frameworks*" (Reg. 17.1, p. 3).

Discussion

The results of our interpretative analysis shed light on a systematic process of constructing the image of the "girl in distress" in regulations guiding public social services offered to her. They reveal how the language and terminology used in regulations can be viewed as a tool molding her form as weak, vulnerable, irrational, and perpetually troubled, yet "guilty" of actions that render her eligible for assistance. As is common in interpretative works, some of the analysis and the conceptualization of its results are intertwined in the presentation of the findings. We seek, however, to focus the discussion on three issues consistently appearing in regulations, the discourse reflected therein, and the insights that can be drawn about this discourse and its applications in terms of epistemic in/justice; and to address some of their possible meanings and implications.

The first issue is the repeated representation, description, and reference to "girls in distress" as passive, voiceless, individuals. The image of the "girl in distress" appears in regulations *ex nihilo*, as a formative silhouette structured only of conditions that she must fulfill in order for her distress to become apparent to others. If she fails to perform in compliance therewith, she will be rejected by normative authorities as not in "real" need of assistance, just as was plausibly done to her in other cultural or social spaces, following her failure to behave as is expected of girls her age. The "girl in distress's" distress, then, is not enough for her to turn visible: She must maintain the image determined for her, or else she will be left to fend for herself. Any experiences, individual identities, knowledge by experience or narratives that stray from this image and the contours determined for its form, are implicitly structured as irrelevant to the process of assisting or treating her. This, suggestibly constitutes a radical appearance of epistemic injustice, less discussed in mainstream literature. While, as noted earlier in this article, a common conceptualization of epistemic injustices groups them into either testimonial or hermeneutical injustices (13), the processes uncovered in the present study seem to echo what can be regarded as "existential epistemic injustice". This sort of epistemic injustice does not involve the willingness neither the capacity of listeners to accept the knowledge and experiences put forward by oppressed populations as legitimate and trustworthy (as would require the correction of testimonial injustice); nor does it pertain to societal or organizational skills to comprehend certain groups' social experiences due to "prejudicial flaws in shared resources for social interpretation" [s the correction of hermeneutical injustices would demand; (13), p. 148]. Rather, existential epistemic injustice is the state of negating not only the credibility of the speaker or the unique character of their narrative, but nullifying the very virtue of their existence as speakers. Existential epistemic injustice, thus addresses processes and mechanisms often hidden deep in the nuances of discourse, subjugation and inscription, which create a clear distinction between forms of speakers who are more or less victimized by epistemic hierarchies, and those rendered essentially invisible in the struggle for epistemic privilege and recognition. The image of the "girl in distress" that emerges from our analysis has her concrete, individual, experiential existence placed under question. If she does not express her distress in ways stipulated as preconditions for receiving assistance or treatment, she remains external to the arena where discourse is played out. Her voice does not reach the stage of being discriminated against; it is substituted with silence. This trajectory of epistemic violence (29) makes identifying testimonial or hermeneutical epistemic injustice all the more difficult. The distress that is not identifiable by normative authorities is situated beyond the structure designated to treat it. We propose that when this occurs, the girl's solitude is analogous with the empty space that her human image leaves behind in Israeli society, as she may continue to retreat into areas of hardship outside of most people's fields of vision.

In Butler's critique of Foucault, she wrote: "Although Foucault writes that the body is not stable and cannot serve as a common identity among individuals cross-culturally or transhistorically, he nevertheless points to the constancy of cultural inscription…" [(30), p. 604]. In this vein, according to her, while Foucault acknowledges that morality, sex, and other elements considered "natural" are in fact the result of cultural inscriptions on the body, he accepts the "material body" itself as a neutral platform that exists prior to the discourse and prior to cultural inscription. Butler proposed that even the coherence of the body is not independent of inscriptions. It follows, then, that the binary division, apparent in regulations, between actions associated with (and thus acceptable for) girls and those expected of boys, constitute a powerful inscription mechanism. The active body of girls receiving services is coherent only when performing the actions considered reasonable for it. If the girl is to be comprehensible to normative authorities, she must maintain the coherent image that authorities delimit for her.

Foucault (8) cited ways in which power is involved in the categorization of individual characteristics as "deviant". The "deviant" must thus be classified as such, and inspection thereof is justified as key to the maintenance of the social order. In the regulations that we analyzed, "girls in distress" are presented inseparably from the deviance attached to them. This deviance, both when described as needy passivity and as self-destructive activity, has the same end result: The girl must relinquish control to normative authorities over deciding what is best for her.

The second issue apparent throughout regulations has to do with the confinement of the girl to the physical or figurative domestic space. While the literature and direct experiences of woman show that for many girls, the meaning attached to the home portrays it as unsafe, sometimes even more threatening than other environments (31), the discourse found in regulations treats it differently: Solutions to the problems of "girl in distress" are widely described in terms referring to the home, or even designed as homes. In this sense, "home" becomes an essential element of the girl, outside of which her presence is not even imagined. Accordingly, using the process described by Foucault (7), the power of normative authorities operates on the individual that is the girl by intervening in her life, studying her, and encouraging her to become an "oppressable" individual by fostering her "particularity" and tying her thereto: The girl belongs in the home, and anything beyond it is outside of her reach.

Finally, throughout the regulations, the image and form delimited for the "girl in distress" depicts her as void of any national, cultural, or ethnic characteristics. Gender, age, and risk thus become the only "real" traits relevant to providing effective assistance to her. This could, in a way, be seen as a generator of equity, as all girls addressed in regulations are treated the same, regardless of their backgrounds. However, at the same time, the discourse reflected in regulations is blind to some of the most central identity, personal, and familial aspects of girls' lives. This stands out especially in the diverse, fraught, and conflictual context of Israeli society, so deeply entrenched in institutionalized gaps (32). Arguably, this exemplifies what can be referred to as oppression-by-dismissal or obscuring oppression (33), veiling structural factors frequently contributing to the discrimination and vulnerability that so many girls in Israel face (34). This issue is pivotal and deserves dedicated, in-depth discussion and interpretation, currently already taking place.

Some of the limitations of the present study should be taken into account when reviewing its findings. Firstly, as in all deductive analyses, our insights reflect the results of our own interpretations and readings into the theoretical principles applied. While this is organic to the paradigmatic approach to the present research, it is worthy of consideration. Secondly, while we believe that the understandings provided in this article can be applicable to a wide range of situations, it is left up to the reader to determine if and how they translate into her/his own specific context.

As a closing remark, it is important to note that although the results of our analysis and the interpretation thereof are presented as (and are in actuality) critical toward policymakers and the agents of their authority, they at the same time offer room for optimism. While policy must—though debatably—somehow mark who is and who is not eligible for services, this also gives the powers that design it the option of using discourse to rectify social injustices. Our suggestions also do not disregard broad facets of the milieu in which services to girls are provided. Providers of assistance and treatment to girls are, in a way, in some cases subjected to the very same discourse exposed in the present study. Categorically grouping them together with the elites dominating discourses flattens potential discussions on methods and allies in the movement toward shattering the shackles of oppression.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://www.gov.il/he/departments/policies/molsa-social-regulations.

Author contributions

LL and MC contributed to conception and design of the study, lead the analysis of the data, and wrote the first draft of the manuscript. RA, SP, and HK-E contributed to later drafts and advanced conceptualizations. The manuscript's submitted version was read and approved by all authors.

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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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Staff's experiences of implementing patient-initiated brief admission for adolescents from the perspective of epistemic (in)justice

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Background: The implementation of Patient-Initiated Brief Admission (PIBA) in child and adolescent psychiatry (CAP) in Sweden is ongoing. This intervention enables adolescents between the ages of 13–17 and with complex mental health problems to initiate a short care period for relief and support rather than the care apparatus being controlling in this process. Offering it is likely to promote epistemic agency, an exchange of knowledge and recovery from mental health problems.

Aim: The aim of this study was to explore staff's perspectives of PIBA for adolescents with complex mental health problems, and what facilitates or hinders its implementation.

Methods: Twenty seven employees, 21 women and six men, with various professions in CAP were interviewed and the material was analyzed thematically.

Results: Two overall themes emerged: "Staff's Experiences of PIBA" and "Managing Clinical PIBA Work." The results were discussed in relation to the theoretical frameworks of epistemic injustice and Normalization Process Theory (NPT). The main findings indicate that PIBA was generally viewed in a positive way, but that obstacles arose when it was actually put into practice. Findings also point at an overall lack of agency among staff when implementing this new way of working, at the same time as the need to adapt PIBA from an adult psychiatric intervention to one for adolescents in CAP is addressed.

Conclusion: This article offers insights into the views of psychiatric staff regarding the implementation of PIBA. If staff wish to support epistemic agency and recovery among adolescents, their agency may be an important aspect in the continued implementation. Furthermore, in order for PIBA to become normalized in a sustainable way, we suggest that the continued implementation should be characterized by a youth-friendly framework.

KEYWORDS

agency, epistemic injustice, recovery, implementation, power, patient-initiated brief admission, child and adolescent mental health care, participation

Introduction

In recent years, interest in young people's agency and position in health care and other welfare services has increased internationally (1, 2). A similar focus can be seen in Sweden, which has also led to a number of legal changes *via*, for instance, the incorporation of the Convention on the Rights of the Child (3) into Swedish law in 2020. This enhanced focus has also contributed to changes in knowledge asymmetries and the Swedish compulsory psychiatric legislation where the child's position and opportunities for increased rights have been described as important prerequisites for dignified and safe care (4). Giving young people with complex mental health problems increased agency and influence over their care is a task that in many respects requires delicate handling, while it places a great responsibility on the professionals [cf. (5)]. At the same time, promoting recovery is a central perspective in psychiatry which includes aspects of symptom management, participation, hope, meaningfulness, and autonomy (6). However, some patient groups return to psychiatric inpatient care where admissions may be protracted and risk being characterized by coercion and ineffective treatment (7). Also, these patients are more exposed to epistemic violations than others (8–10), which generally complicates agency and recovery. With the aim of improving young people's agency in psychiatric care, Patient-Initiated Brief Admission (PIBA) has been introduced in Child and Adolescent Psychiatry (CAP) in Stockholm. In summary, PIBA is a standardized crisis management intervention (11) drawing on increased autonomy for patients to self-assess if they require a briefer period of inpatient care, rather than the care apparatus being controlling in this process. One major difference compared to traditional admission is that it is nurses and not doctors that handle the enrollment, but also that no professional assessment is made concerning whether the admission is justified or not—this is determined entirely by the individual.

The adolescent signs an agreement together with his/her parents and caregivers from both outpatient and inpatient care that gives them the opportunity to initiate, regardless of the time of day, a care period of a maximum of four days three times per month. Since inpatient care can be perceived as difficult to access, PIBA has the potential to reduce the struggle for admission that sometimes occur between patients and care staff. Instead, through increased agency, PIBA may simultaneously expand the patient's interpretative precedence regarding the need for admission, making room for subjective needs and wishes for inpatient care. Through this (tentative) approach, we suggest that there is an explicit idea that PIBA may promote recovery and epistemic justice also for young people since they, to a greater degree, have the possibility to define and voice their needs rather than others defining and voicing these for them [cf. (12, 13)]. Providing PIBA to certain adolescents in CAP may change traditional structures of power and knowledge legitimacy. However, knowledge of its effects is so far limited.

The article explores staff's perspectives of PIBA for adolescents with complex mental health problems, and what facilitates or hinders its implementation. Two research questions have guided this purpose. (1) How do the staff understand their work with PIBA? and (2) What experiences do the staff have of implementing PIBA? To better grasp the implementation of PIBA in CAP, the study is based on the framework of Normalization Process Theory (NPT). In this context, NPT (14, 15) offers a model consisting of four core components (16): (1) *Coherence* (the sense-making of staff both individually and collectively when faced with operationalizing PIBA in their units), (2) *Cognitive Participation* (the relational work staff do to build and sustain a community of practice around PIBA), (3) *Collective Action* (the work carried out by staff to enact and implement PIBA) and (4) *Reflexive Monitoring* (explores the appraisal work of staff to assess and understand the ways that PIBA affect them and the adolescents). By primarily focusing on individual and collective behavior, these components aim to help us to understand implementation and, above all, to normalize new interventions in clinical settings. Since implementing PIBA in CAP may be a way of promoting epistemic justice and recovery (13) it is described as crucial in order to grasp the underlying factors that either facilitate or complicate this process, which is why implementation theories become useful when trying to describe the clinical work performed by staff.

The framework of epistemic injustice (17, 18) has been used to further deepen the understanding of the experiences of staff as well as to explore how they might support adolescents as epistemic subjects in defining their need for inpatient care. According to Fricker (17), epistemic injustice, and especially testimonial injustice, implies that someone is wronged in their capacity as a knower. Also, being subject to this is argued to be largely related to how different attitudes and perceptions are constructed concerning the social category to which a person is considered to belong. Certain categories tend to be more easily exposed to injustice than others, such as women, ethnic minorities and individuals in institutional care (10, 17). These categories often contribute to trivialized narratives, thus making a high degree of credibility impossible, while the notion that mental health problems complicate rational thinking makes it easier for epistemic injustices to become self-generating. The body of research on epistemic injustice is growing, and more attention is being paid to children and young people (19–22), and addresses the paternalistic view of how the care apparatus defines what is in the "best interests" of the patients (23) as well as the general absence of epistemic subjectivity and lack of a co-creative climate in an individual's encounter with care. What is also addressed is how the stereotypical image of mental health problems may undermine the self-knowledge of adolescents and diminish their capacity as knowledge bearers [cf. (24, 25)], which is why the field of epistemic research may be relevant when young people as epistemic subjects are examined in greater detail. Hermeneutic injustice is another aspect of epistemic injustice, meaning that someone's ability to understand their (social) experience is hindered due to biases in our shared resources for social interpretation. According to Fricker (17), hermeneutic injustice is the injustice of having some significant area of one's social experiences obscured from collective understanding owing to a structural identity prejudice in the collective hermeneutical resource. When exploring staff's collective experiences of implementing PIBA, this approach might be helpful when trying to understand their reasoning and certain strategies to manage the practical implementation work.

PIBA—From adult psychiatry to the context of adolescents

When trying to modernize the psychiatric system, it has been deemed necessary to incorporate new ways of promoting a more constructive care environment, where methods are continuously developed to optimize co-creation and participation. PIBA is described as a way of working with more complex mental health problems and is aimed at patients who have generally had a low degree of agency and self-determination in care. Since 2014, PIBA has been offered at several adult psychiatric clinics in Sweden. It initially started as a project addressing three different diagnostic groups—psychosis (26), emotional instability with self-harming and suicidal behavior (27) and eating disorders (28). In adult psychiatry, research shows coherent results regarding increased satisfaction and agency, fewer care days, increased suicide prevention work, reduced coercion in inpatient care and an improved care climate (29–32). These patterns of overall increased patient benefits may correlate with a recovery-oriented and person-centered approach (33–37). During the autumn of 2019, a political decision was made to implement PIBA in CAP in Stockholm with the ambition of increasing patient participation and agency among adolescents. Since December 2020, PIBA is offered to patients who meet the inclusion criteria, namely adolescents between 13 and 17 with an extensive need for care where more complex ill health, for example, self-harm, emotional instability, psychosis, and suicidal behavior, is common. Apart from parental consent, other prerequisites for receiving PIBA is that the adolescent has been admitted to inpatient care in the past year and has an expected great need for care ahead. Also, the adolescent needs to express his or her own desire to receive PIBA as well as demonstrate an understanding of the meaning of using it.

Setting—The context of CAP

The units in focus in this article are part of a cohesive child and adolescent psychiatric organization. There is a total of 13 local outpatient units, eight outpatient units with targeted interventions around, for example, trauma, emotional instability, and psychosis, an emergency room and three inpatient units with 10 beds in each. Most of the admissions are described as voluntary, even though inpatient care also cares for young people against their will, according to the Compulsory Mental Care Act (38). The need for inpatient care is described as being greater than what the places can cater for (39), and in this context, PIBA is thus viewed as fulfilling an important function regarding accessibility when an adolescent deems that an admission is necessary. PIBA currently affects four outpatient units and one inpatient unit and thus concerns about 130 employees. At each unit, a designated nurse is appointed who is expected to have an insight into the implementation process, while all staff must know the basics of PIBA and have completed a web-based staff training course to ensure this specific knowledge.

Materials and methods

As we wanted to investigate the staff's joint understanding of PIBA, it seemed appropriate to conduct focus group interviews to obtain this specific knowledge since it is valuable tool for collecting qualitative data (40). Altogether, five focus group interviews were conducted, one in each participating unit. Four of them were conducted in the outpatient units by the first author (JM). The second author (U-KS) conducted one focus group interview in an inpatient unit and an additional individual interview with a person in managerial position, who expressed a wish for this. By using a semi-structured interview guide inspired by the four core components of NPT (16) concerning the implementation process, the ambition was to follow the reasoning of the staff. The guide included questions such as "How would you describe PIBA?," "What are the prerequisites for implementing PIBA?" and "How does PIBA differ from regular work?." All the interviews were held at the five units between December 2021 and April 2022 and lasted between 35 and 80 min.

Description of the participants

In all, 27 interviewees, 21 women and six men, participated. They were recruited *via* the manager at each respective unit, and in each focus group there was a mixture of different professions such as unit managers, nurses, psychologists, care workers, counselors, and psychiatrists. Two of the nurses were also the designated contact persons for the implementation of PIBA.

Analysis

After transcribing the audio-recorded interviews verbatim, the material was read through to obtain an overall picture of the content. The coding of essential content, particularly touching on descriptions of the conditions for implementing PIBA and how this work has been carried out in CAP, was performed by the first author. After scrutinizing the transcripts, the material was categorized meaning that adequate units were selected, condensed, and analyzed iteratively as themes and sub-themes emerged in accordance with a thematic content analysis (41) influenced by the four core principles of NPT (16). After that, discussions were held with the second author until a consensus on the themes was reached. Further, to better understand aspects of knowledge and power shown in the material, the framework of epistemic injustice was used to deepen the analysis.

TABLE 1 Themes and subthemes.

The staff's experiences of PIBA	**Managing clinical PIBA work**
Understandings of the purpose of PIBA	Organizational readiness—Preparing for PIBA
A shared responsibility	From theory to practice—The importance of communication and collaboration
	Practical obstacles and ambiguities
	Implementing PIBA—"Just do it"?

Ethical considerations

This study was granted ethical approval (Dnr: 2021-02790). All participants were given oral and written information about the study prior to the interviews. Informed consent was collected in connection with the interviews, and participants were told that they could decline to answer questions or leave the interview context at any time.

Results

An analysis of the material revealed two main themes (see **Table 1**) and the following results are presented for each theme separately. Although these themes have different meanings, they are nevertheless intertwined to some extent. Important aspects are highlighted through a number of quotes followed by numbers that refer to specific focus groups. When a quote from the individual interview is used, the quote is, for ethical reasons, cited as belonging to the focus group made in the same unit.

The staff's experiences of PIBA

The interviews were largely characterized by discussions concerning the introduction of PIBA, and are here related to the different core components of NPT as well as aspects of power and agency addressed by the framework of epistemic injustice.

Understandings of the purpose of PIBA

A majority of the respondents expressed a coherent view of how PIBA matches the overall organization, although outpatient care portrayed PIBA in a more positive manner which was contrasted by inpatient care who more clearly discussed challenges with the implementation. PIBA was generally described as a complement to existing care and not as a solitary intervention, and using PIBA for preventive purposes where the contract enables faster access to inpatient care, reduces assessments in the emergency room and decreases destructiveness among adolescents was discussed in all interviews. Staff viewed the reduction of assessments prior to admission as something that promotes the agency of adolescents. In addition, avoiding acute phases in their mental health status was regarded as one of the basic principles, while the knowledge that inpatient care is within reach may contribute to increased endurance in an adolescent who is battling against poor mental health. Not having to persuade healthcare services that admission is necessary, rather than having to signal ill health in various destructive ways, was declared as one important aspect of using PIBA which connotes increased agency in a person's encounter with care.

> I think that it's an effective way of asking for help and support/and that it's a very...functional alternative to becoming destructive. This is how I think it can best be used. That instead of self-harming or threatening suicide...it's about "I need support *now*". And then you get it. (FG1)

However, depending on whether the interviews were conducted with staff in either outpatient or inpatient care, there were differences among the participants, consequently leading to an expression of uncertainty about the purpose. The perceptions of the staff were influenced by how long they had worked in psychiatry and their previous experience of the relevant target groups for PIBA in CAP. The work was more readily perceived as futile as there was no coherent understanding of the purpose of offering PIBA, or where it was not known who had the overarching responsibility.

> So, it's very vague, and I think it's because...we don't really know the purpose. Honestly, I'd say we don't know what we're doing here. Is it suicide prevention? Who assesses those situations? (FG5)

The staff discussed PIBA in relation to regular practice, where a more accessible inpatient care was understood to be an important aspect for the adolescents. An extension of this discussion included PIBA being seen as a promising tool to promote knowledge justice and recovery and how this is best utilized in practice. A number of respondents emphasized that one of the main benefits of having a contract is knowing that care is within reach, which may help curb admissions. For example, it was often stated that it is sometimes sufficient for adolescents to call the inpatient unit to "check" whether there is a vacant bed. According to the staff, this aspect has an important preventive function in itself without adolescents actually "using" PIBA.

> I think that PIBA...that its absolutely most important purpose is being an asset that you can reflect upon as a patient. You may not necessarily actually *use* it, but just as we have our telephone hotline, I think that PIBA is exactly the same type of experience for the patient...that it gives them a sense of security knowing that it's within reach. (FG1)

By implementing PIBA, the idea of exaggerating various destructive behaviors may thus be reduced which, in addition to an increased quality of life and control for adolescents, was said to benefit the entire CAP in terms of assurance that care is available in a more unconditional way. From an epistemic justice point of view, the respondents also emphasized how important being believed is for adolescents for them to be able to take that crucial step and ask for help when they consider that they are in need of it.

> It makes a huge difference when you're in the critical situation, you're not called into question and...and don't have to fight for someone to believe in you. (FG2)

Respondents had different views concerning their introduction to PIBA. Some remembered exactly in which context or by whom PIBA was first presented. Others described how they are generally flooded with information from different sources, which is why their introduction to PIBA was generally perceived as unclear. Some said that they had probably heard about the implementation at a workplace meeting while others thought they had first heard about it during a lecture and a few even said that they had not heard about it at all. In terms of cognitive participation, some of the staff explained that a lack of resources affected their ability to familiarize themselves with what they were supposed to do. This understanding permeated both outpatient and inpatient care where staff perceived the decision to initiate the implementation as unclear.

> It hasn't been that...instructive at all. I'd say that it hasn't been clear between managers here...and then you don't really know what the purpose is. (FG5)

The decision to implement PIBA was depicted as being sanctioned on a political level, and a common understanding was that the politicians were eager for the work to begin as soon as possible, or as one respondent put it, "it became damn urgent". Among staff in outpatient care, PIBA became an explicit tool to use in their work with adolescents.

> It was more imposed on them (inpatient care) as an...an extra thing on top of the tough job they're already doing...while it was more like an offer for us, and we just said "wow, this is great!" (FG1)

Thus, the implementation decision was made at a high level without the presence of the clinical staff, and this was generally perceived as having an impact on the employees' attitude to PIBA. As the quote above also shows, a number of the respondents underlined that this decision was "imposed" on inpatient care, where hesitation and resistance arose while also affecting the overall pace of the implementation process. At the same time, the staff felt that there was an expectation to quickly operationalize the political decision, which resulted in a lack of both structure and ownership of PIBA.

> I think that a certain organizational resistance is based on the lack of knowledge and that it's something that's just been 'thrown' at us. (FG5)

A shared responsibility

Although staff described the adolescents as the actual users of PIBA, the staff are themselves users of the method, which here addresses strategies for implementing PIBA and what becomes important to them during this work. During the interviews, it appeared essential to strive for a unified view of which adolescents that are eligible for PIBA to better understand how the staff should act in accordance with this new way of working. When discussing the target group for PIBA, the general view was that it was aimed at adolescents between 13 and 17 with rather complex mental health problems such as self-harming behavior, suicide attempts, emotional instability, and psychotic episodes. However, this understanding was not evident among staff in inpatient care, who requested clarifications about the adolescents that might be relevant for PIBA. In terms of identifying adolescents, the staff called for a joint effort rather than it being imposed on specific individuals. In addition, the fact that they did not wish to be alone in this work was mainly about protecting themselves from different self-destructive behavior which was described as sometimes occurring in contact with the adolescents. Drawing on this, the discussion then dwelled on the actual responsibility placed on an adolescent through a PIBA agreement. The staff emphasized in particular an adolescent's actual ability to make such a decision for him or herself in a situation where the adolescent needs help with their mental state, and that this process is largely related to age, maturity and acquired psychoeducation. By increasing the say that adolescents have in these decisions, it may be understood that the staff consider them as epistemic subjects rather than merely care recipients. However, there were concerns that, at too young an age, you cannot be expected to shoulder the responsibility that is required, resulting in a "conclusion" regarding who is best suited for PIBA.

> The optimal PIBA-patient is someone who already works with anxiety management, such as a DBT patient who's over 15/who's already been diagnosed./Someone who. . .can work with skills and has started with it and who wants to test the skills they've already acquired. (FG5)

Here, it seemed important to offer PIBA to motivated and determined adolescents who may use it to curb a deterioration in their mental health in time, rather than succumb to destructiveness. However, in relation to certain diagnoses, one respondent expressed the following:

> I'd say that the 'perfect patient' is someone who's. . .motivated. Those that know they want. . .to fight for their mental health. Um. . .I don't think that a certain diagnosis is relevant. It's mostly about. . .having to want it yourself. . .because we can't force anyone to use PIBA. It has to be a choice made by the patient. (FG5)

When discussing the advantages of PIBA, discussions about the disadvantages and concerns about offering it also followed. These concerns were manifested in various ways, but mainly addressed the dynamics and overarching structure of inpatient care, where the possibility of promoting epistemic agency was described as limited with the risk of adolescents becoming hospitalized and subjected to epistemic injustice and further paternalism. During the interviews, inpatient care was claimed to be a temporary element in a person's life, where "leaving" psychiatry is a goal in itself. Due to this, PIBA becomes a strategy to remain in care which is unsettling, according to the staff. When talking about this, it was suggested that PIBA might risk strengthening the identity of an adolescent as a "patient" by facilitating admissions for certain adolescents who often have extensive experiences of institutional care. Using PIBA may thus contribute to prolonged care periods, which is something that the staff needs to take responsibility for and monitor together in the midst of the overall implementation.

> Before admitting the patient. . .I think you should be vigilant about whether the patient risks hospitalization. . .that you identify patients who are at risk. In my experience, patients who are hospitalized begin their journey in inpatient care. And then they can't or don't want to be discharged. . .then the patient has become 'addicted' (to inpatient care). (FG3)

Managing clinical PIBA work

Incorporating a new way of working into an already pressured organization was portrayed as a challenge by all the respondents, with an emphasis on the general lack of resources in CAP. During the interviews, the implementation of PIBA in practice was often touched upon and particularly prominent was how to manage the overall responsibility of taking the theoretical understanding of PIBA and incorporating it into the clinical setting.

Organizational readiness—Preparing for PIBA

Preparing for PIBA was explained as an indispensable element in terms of creating procedures but also ensuring that the organizational changes permeate all levels of care in CAP. The perceived hasty political decision was described as decreasing the agency of the staff, which meant that they were not provided with the best conditions for preparing in a sufficient way. This was understood as having affected the stability of the implementation as well as the staff's attitude to it. The training that the staff were expected to receive—watching a PIBA video, receiving information orally and being shown the designated bed—was explained as important, although the majority of the respondents did not have the time to participate in or complete it. Also, when preparing for PIBA, the staff did not consider it to be an adult model that could be applied to CAP without adaptations.

> I think they've just tried to implement PIBA as it looks in adult psychiatry. Like 'this is what it looks like in the adult world, let's take it to CAP'. But then. . .you have to deal with parents (laughs), which becomes a completely different thing. So, I think you need to adapt the idea of PIBA for someone under 18. (FG5)

When trying to reach a consensus, the staff felt that they needed an established dialogue between outpatient and inpatient care. Some outpatient units described themselves as "ready" to implement PIBA, but that the inpatient care setting was prolonging the process. Inpatient care has had a number of challenges to deal with, for example, the structures for contract writing, securing training opportunities and keeping the PIBA bed vacant. At the same time, they are faced with high staff turnover and expectations of accessibility from adolescents, parents and other healthcare providers. Based on these conditions, the outpatient care staff can subsequently see that inpatient care would have needed more time to prepare *before* the outpatient units started the implementation.

> This is a consequence of. . .them getting PIBA in their lap. Their structure for this hasn't been clear. . .staff haven't felt safe. . .um. . .they haven't even. . .they don't know how to write (the contract). And then this is what happens. (FG1)

From theory to practice—The importance of communication and collaboration

Two different starting points for implementing PIBA emerged during the analysis. Since they were involved in the preparatory work, staff from outpatient care reasoned on a more theoretical level regarding how to put PIBA into practice. However, when speaking to the inpatient care staff, who provide the actual care, they, in turn, reasoned in a more practical way. Organizational affiliation may influence how your understanding of PIBA is formed, at the same time as practical conditions for the implementation affect the entire CAP with a certain focus on communication between outpatient and inpatient care.

> You probably need to sort of overcome all the obstacles and see how you can solve them. Because as things stand right now, it's all very unwieldy. We've had difficulties with communication. How should we communicate and with whom? Just sending information between unit managers and those with a responsibility for PIBA is a huge thing. There's a lot that's unclear. (FG5)

Lack of collaboration was thus explained as an obstacle to the implementation. Rather than being empowered by collective action and performing new and meaningful tasks, working with PIBA becomes something that needs to be balanced in the midst of managing ordinary working tasks. Feelings of inadequacy were said to affect the everyday management of staff and they also impinged the organizational attitude toward PIBA.

> You have to do it in a different way, there must be another 'setting' to make people want to work with this./To get to the point where staff's more likely to say: "we feel safe with this, we have a readiness to be able to take care of this." (FG4)

Practical obstacles and ambiguities

Discussions about practical obstacles regarding the implementation of PIBA permeated all the interviews. In particular, the staff highlighted that what they were unable to achieve in their preparatory work, has a clear impact on the continued implementation. However, the most pronounced obstacle was portrayed as the organizational confusion surrounding the PIBA bed in inpatient care. According to the staff, the hasty decision about implementation meant that CAP did not have time to map out or communicate where the bed would be situated, resulting in uncertainty and frustration.

> There was a lot of ambiguity about this bed and which inpatient unit it belonged to. One time, I found out that we no longer had it (PIBA) but we had told the emergency room that we couldn't enroll a patient because we didn't have any room since the PIBA bed was supposed to be kept vacant. And then someone said "but you no longer have PIBA in your unit". . .and I was like "oh, don't we?" And a month later someone said "but now you have PIBA again" (laughs). So that's how it's been./Also, at first, a patient could come (to the unit) 24/7 and then it changed so that patients had to come before. . .8 p.m. and then it changed again to 7 p.m. but that information wasn't communicated to the night nurses and. . .um. . .the patients didn't find out so they would appear at about 11 p.m. and were then told that they didn't have access to PIBA. So, this has been a process. (FG5)

The staff also highlighted aspects of trust in relation to what is to be expected from staff in inpatient care. Uncertainties have so far led to outpatient care not really knowing if someone actually engages with the adolescents when they choose to use PIBA. Offering PIBA to a young person, where planning and contract writing is done together with the guardians, means that the staff must be able to deliver on the promises that were given prior to admission. Advocating PIBA thus requires that various processes between enrollment and discharge continue and that access to inpatient care is guaranteed in order not to undermine the agency of an adolescent. These uncertainties risk affecting the staff's attitude with the result that PIBA is sometimes not considered at all.

> Unfortunately, I think that an obstacle is about. . .the very practical aspects that sometimes make me think 'she can just as easily go to the emergency room'. . .because. . .this PIBA bed may not be guaranteed. I don't really trust the organization surrounding PIBA. . .or the access to inpatient care. I feel that we may take another road. We'll solve this in some way or another. (FG1)

During the implementation, the staff have had to deal with missing information, for example, the respondents sometimes described that decisions were being made without them being able to identify by whom—external supporter, unit manager, section management or at an even higher level. Also, the staff currently experience ambiguities about what is expected of them and who has what responsibility in outpatient and inpatient care. A majority of the respondents claimed that the division of responsibilities and cooperation was unclear, and that it is important to illustrate *how* adolescents are identified, *who* is able to identify them and *who* to turn to if you have questions.

> If there's a disagreement among colleagues about this (PIBA)/then it must be handled in some way. . .somehow you have to agree if a patient's 'ready'. And who has the decision-making power? Is it the patient's main therapist or is it the doctor in the unit as well? (FG2)

Being in agreement was thus described as a prerequisite if PIBA is to function as favorably as possible, which addresses aspects of collective action as well as the power and hierarchy structure in CAP. Not being synchronized in this endeavor was described as undermining the stability of the implementation process as well as complicating the role of the contact persons for PIBA. Due to staff turnover, the stability that needs to exist around these staff members was said to be absent which is problematic since the contact persons are expected to participate at the meeting where the contract between adolescents, guardians and CAP is drawn up. Without this supportive function, the process is perceived as even more unclear and risks not being carried out.

> This makes me feel unsure. I have five patients who should be called to this meeting, but. . . I've mixed emotions about that (laughs). It has to be good for the patients./Um. . .and above all this meeting has to be actually carried out. . .because they're waiting and wondering "when will it take place?". We haven't received any feedback from any of them and they (inpatient care) don't know when it'll be. . .when this meeting can. . .take place. (FG5)

Also, the family's involvement in PIBA was explained as a complicated aspect during the implementation, where the overall organizational challenges have not helped. The staff described a situation where there was a conflict between parents and colleagues when trying to clarify *who* wanted to use PIBA—a decisive factor since the adolescent's agency is expected to control this. If there is uncertainty about how and by whom PIBA is utilized, the staff argued that there are no resources to respond to different wishes or handle complex situations when the adolescents come to the inpatient unit.

> Sometimes, the parents complicate PIBA admissions, and patients have told me that they came here (to the inpatient unit) only because their parents 'said so'. But also, sometimes parents come here signaling chaos which makes everything quite distorted. Whilst parents say they want their child to be admitted, the patient shows great reluctance shouting "I don't want to be here". . .which makes PIBA impossible. So, in those cases it turns into a matter for the social services. (FG5)

Implementing PIBA—"Just do it"?

Initially, some respondents thought that implementing PIBA would be fairly straightforward. However, the lack of organizational readiness has led to a re-evaluation concerning this. A number of participants described a general motivation to "just do it" but that the commitment needed from both outpatient and inpatient care has not been established. To avoid stagnation, the staff discussed the importance of keeping on trying rather than waiting for the best conditions, and if PIBA is really incorporated in the various units, there are also opportunities to address the management regarding practical difficulties.

> I think we just need to 'start doing' it and not be afraid and not. . .not think so much/and if we just do it, we can also give feedback to managers that 'this is how you could do' or 'this doesn't work' or 'we need *this* to make it work.' (FG3)

Going forward, it was considered crucial to have regular follow-ups and reminders about current adolescents, the criteria that apply to obtain an agreement and who the facilitator in each unit is, which constitutes reflexive monitoring. Since the implementation is characterized by a general confusion and uncertainty, not discussing PIBA often enough may, according to the staff, lead to PIBA being abandoned. Jointly monitoring the purpose and outcome of PIBA was claimed to be important since epistemic agency is not something that comes automatically by just implementing a method. Rather, this effort needs organizational and individual supervision, and being reminded of this at workplace meetings makes it possible to alleviate the risk of misunderstandings.

> There has to be someone who has control. . .like 'these are the criteria for PIBA, this is how you do it', um. . .because otherwise it's easy to forget. Sometimes we sit at treatment conferences and wonder 'how do we do this?'. And then you don't really know what to do because you don't do it (discuss PIBA) often enough. (FG2)

Among the outpatient care staff, the idea of "just doing it" was also translated into the overall importance of trying new things and seeing the early implementation phase as work in progress. At the same time, the importance of having a committed management that is continuously involved in the implementation at the same time as they have the ultimate responsibility for the monitoring of general progress concerning implementation was accentuated. Without a joint organizational approach and clear directives in the process going forward, the work will be made more difficult, according to the staff.

> If you're going to implement this, it's important that you're. . .that the entire clinic, right from the top. . . has the will. That 'this is what we're going to do.' And that it's also communicated to the emergency room and chief physician and. . .everywhere. And you have to work with that for quite some time before it settles. (FG5)

Discussion

The aim of this study was to explore staff's perspectives of PIBA for adolescents with complex mental health problems, and what facilitates or hinders its implementation. In semi-structured focus group interviews, outpatient and inpatient care staff shared these experiences, and a number of dominant themes have been identified and interpreted within the theoretical frameworks of epistemic injustice and NPT.

Conditions for implementing PIBA

When discussing the organizational conditions required for the implementation of PIBA, they were mainly described as insufficient which has contributed to the purpose of PIBA being perceived as fragmented. In CAP, the structure of the implementation has changed repeatedly, which the participants described as aggravating in terms of uncertainty and frustration. These factors risk affecting their view of PIBA as complicated, resulting in an incomplete or protracted normalization [cf. (14, 15)] meaning that important health benefits among adolescents here risk being lost [cf. (42)]. Basic prerequisites in the implementation process were about commitment among staff, time to get acquainted with PIBA, cooperation between outpatient and inpatient care as well as continuity for the designated facilitators of PIBA and adequate procedures for the writing of contracts. The absence of this organizational foundation may affect the general attitude toward PIBA.

Apart from the practical obstacles experienced by staff, the interviews also touched upon trust, professional expertise and leaning on each other's knowledge as well as stable care chains when facilitating PIBA in the clinical setting. These conditions were said to be imperative in order to ensure organizational cohesiveness and readiness as well as promoting the continued implementation and epistemic agency among adolescents. Linking this to implementation theories, NPT addresses how different components in this process are approached by clinicians as well as how these are adopted in existing procedures. It also presents facilitating and hindering factors for this endeavor in that it stresses that this new way of working needs to be adopted correctly (43) where a joint organizational approach requires careful planning with an understanding of each other's clinical everyday life. Here, staff presented different obstacles when working with PIBA—rather than relying on each other's knowledge in offering PIBA to adolescents, ambiguities such as not knowing the facilitators or which inpatient care unit is responsible for the PIBA bed were described as barriers to PIBA being used or considered. This might complicate the above-mentioned core components of NPT, which is a finding that is in concordance with previous research illustrating the importance of stability and an overarching commitment when initiating implementation work [cf. (44)].

Furthermore, since the decision to implement PIBA was sanctioned on a political level, the way the staff reasoned regarding this can be understood on the basis of both epistemic injustice and implementation theories. As mentioned above, PIBA has the potential to promote epistemic justice for adolescents by allowing them to themselves define their need of inpatient care. Another result is that staff, especially in inpatient care, are also actors in this process but that they, to some extent, lack hermeneutic justice where they describe that their needs and wishes regarding the implementation work are diminished and/or made invisible. In terms of epistemic injustice, the staff had limited access to information, resulting in loss of knowledge, and power [cf. (17)]. Also, their agency was virtually non-existent and they did not participate in shaping how the work with PIBA was to be realized in practice. This is particularly addressed by the staff in the results section when they discuss the feeling of having PIBA "thrown" at them, meaning that they feel that the political decision was "top down" (45), [cf. (44, 46)] because staff were not involved in the different decision-making processes. Trying to express an opinion on the clinical work—such as adapting PIBA from a system for adults to one for adolescents and voicing their collective dissatisfaction with the organizational conditions—one way of increasing the staff's agency and enhancing recovery orientation (47), is to reduce hermeneutic injustice (17) by recognizing staff as knowledge carriers as well as to underline the need for a "bottom up" perspective [cf. (44)]. However, it was implied that staff were not listened to when trying to voice dissatisfaction or concerns regarding practical matters and ambiguities during the implementation, and without acknowledging the coexistence of multiple perspectives concerning PIBA, for example, those of politicians, management and staff, the implementation risks failing due to resistance or abandonment which underlines the need for adopting both top-down and bottom-up approaches in order to facilitate normalization [cf. (43, 46)].

Adjusting PIBA to the youth context

In order for staff to facilitate agency and recovery among adolescents, it was considered important to adapt PIBA from the adult setting and thus make adjustments to the youth context [cf. (13)] that includes parents. Part of the recovery research on young people is about how care can be optimized and developed to best facilitate a recovery-oriented approach (33, 37). Here, a "youth-friendly" perspective (35, 36) is argued to be established in an overall biomedically dominated range of care, where PIBA has the potential to realize this view as well as becoming an extension of young people's right to agency and participation (1, 3–5, 34, 38). As an adolescent, being given the opportunity to use PIBA may be associated with increased psychoeducation which also stresses the general differences between adults and young people's identity development. This developmental process usually includes aspects of ambivalence and uncertainty that need to be taken seriously in young people's encounters with care [cf. (37)].

The involvement of parents at the admissions stage as well as transparency regarding how the adolescents use the contract were discussed by the staff, who wished for more adequate cooperation between CAP, adolescents and parents in order for PIBA to function optimally. Unlike adults who, may, without argument, renounce contact with family and relatives, adolescents were described as a part of the family system with a clearly limited legal space for self-determination [cf. (2)]. During the interviews, there was some uncertainty as to whether parents of adolescents with a PIBA contract risk persuading or otherwise influencing them to use it, which can understandably risk their agency and at the same time endanger their epistemic subjectivity. There were staff who had practical experience of having to manage the balancing act between, on the one hand, recognizing the young person's increased agency in the choice to use the inpatient care and, on the other hand, not knowing of this choice being in accordance with what PIBA stands for, but rather a choice, formal or informal, made by the parents. In reality, this can mean that the adolescents are met by the staff's confusion and uncertainty regarding the adolescents possibly being subject to parental guidance which may affect the admission in various ways, and especially the adolescents not being listened to [cf. (20, 24)] or seen as credible in their choice to use PIBA [cf. (21)].

Methodological considerations

When interpreting these findings, certain methodological considerations need to be discussed. The presence of a unit manager in four of the five units may have affected the other participants. A limitation may be linked to the (potentially) reduced freedom that comes with a manager's presence. Although in this context, the advantages have outweighed the disadvantages, especially as regards the possible uncertainties that may be clarified by people in managerial positions. A majority of the participants were from outpatient care, which means that the material and quotations may be perceived as uneven, since the perspective of inpatient care staff consists of a smaller sample. In light of the organizational limitations and differences in the work intensity between outpatient and inpatient care, the inpatient care staff were not interviewed as easily as the other staff. However, considerations were made that it was important to include the perspective of inpatient care as far as possible. Another reflection touches upon the fact that the units are in different phases regarding the implementation of PIBA, which may affect their understanding of and attitude toward the purpose of the method. Lastly, the main author has interpreted the material based on specific research questions linked to epistemic injustice and implementation theories, and thus omitted other possible themes than those presented here.

Conclusion and implications for practice

This article reflects on the implementation of PIBA in CAP, and underlines normalization, epistemic agency and the position of adolescents in mental health care. The results of the study imply that the majority of the staff interviewed were positive toward the overarching ideas of PIBA and viewed it as a possibility to increase agency and recovery among adolescents and to legitimize their knowledge about their mental health status. However, the interviews also show that obstacles arise when work with PIBA is to be put into practice, where reduced agency among inpatient care staff may be a complicating factor for a sustainable implementation since they are expected to strengthen the agency and recovery of adolescents simultaneously. The results thus highlights the importance of promoting epistemic agency—such as organizational conditions and participation in the decision-making process—among the staff involved in implementing PIBA. Without these conditions, promoting epistemic agency and recovery among adolescents' risks being reduced to merely a tokenistic vision rather than being properly put into practice. The paradigm shift toward recovery-oriented models in mental health care is ongoing and, to some extent, transcends CAP as well as other welfare services. Yet, since there is no sole manual for how agency and recovery are initiated and maintained, there needs to be a clearer understanding of what this entails when working with adolescents with complex mental health problems. Further, since it is not entirely obvious how the parents' involvement should be shaped when PIBA is used, this calls for more scrutiny in order for PIBA to facilitate epistemic agency rather than hindering it due to parental involvement. In addition, to ensure that care is designed in a youth-friendly way, further work is required where above all the structural challenges of inpatient care are focused on. Moreover, while little attention has been paid to the experience of adolescents using PIBA, this should be the focus of future studies.

Data availability statement

The datasets presented in this article are not readily available because participants of this study disagreed about their data being shared publicly. Requests to access the datasets should be directed to JM, jennie.moberg@socarb.su.se.

Ethics statement

This study was reviewed and approved by the Swedish Ethical Review Authority (Dnr: 2021-02790). Written informed consent was obtained from the individual(s) for their participation in this study.

Author contributions

JM elaborated the original theoretical proposal presented in this article and wrote the original manuscript. Both authors revised and edited the manuscript and were responsible for its final 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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Psychiatrization, assertions of epistemic justice, and the question of agency

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Thus far, the concept of epistemic injustice in the context of psychiatry has been discussed more widely by clinical academics than by authors with personal experience of psychiatrization. It is from the latter perspective that I critique the practice of attributing testimonial injustice solely to the "stigma against mental illness", and point to psychiatric diagnosing itself as a principal enabler and re-producer of this form of injustice. In relation to hermeneutical justice, I take a closer look at initiatives seeking to incorporate (collective) first-person knowledge into the epistemic systems that currently dominate mental-health service provision and research. Highlighting the incompatibility of psychiatric knowledge claims with first-person ways of knowing, I discuss some of the issues and challenges involved in achieving epistemic justice for psychiatrized people and advancing our collective knowledge base. Finally, I turn to the questions of identity and agency in these processes.

KEYWORDS

madness, psychiatrization, first-person knowledge, epistemic oppression, testimonial injustice, hermeneutical injustice, co-optation

Introduction

My first encounter with the idea of epistemic injustice was at a conference about narrative approaches in healthcare.[1] This concept, so simple and yet so profound, suddenly gave a name to the many struggles of psychiatrized people to have our knowledge count, not only in our individual lives, but also in our collective advocacy and research efforts. Engaging with the work of Fricker (2007) led me, a year later, to a conference called "Understanding Epistemic Injustice".[2] There, I realized how easy it is for a concept with the potential to become a change-making tool to be intellectualized to the point that it becomes an end in itself. Subsequently, as I began to investigate the use of "mad" people's testimonies in research, I pointed to the risk of overwriting and co-opting marginalized knowledge in the name of epistemic justice (Russo and Beresford, 2015; Russo, 2016). Unfortunately, this trend continues.

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[1] A Narrative Future for Health Care. London (2013). Available online at: https://medicalhumanities.wordpress.com/2013/05/07/a-narrative-future-for-healthcare-international-conference-guys-hospital-campus-of-kings-college-london-june-19-21-2013/.

[2] http://www.bristol.ac.uk/philosophy/research/epistemic-injustice-/

Thus far, the application of Fricker's work in psychiatric and mental health literature is characterized by descriptions of psychiatric patients' vulnerability to epistemic injustice, and by calls to "listen better" and "empathize more." These approaches typically leave the concepts of "mental illness" or "psychiatric disorder" unquestioned (see e.g., Crichton et al., 2017; Kurs and Grinshpoon, 2017; Scrutton, 2017; Bueter, 2019; Grim et al., 2019; Drozdzowicz, 2021; Ritunnano, 2022). The biomedical framing of human crises and the practice of psychiatric diagnosing are hardly ever considered as a foundation of othering, or as principal enablers of epistemic (and other) injustice.

The notion of epistemic injustice has been less elaborated by psychiatrized people ourselves than by clinical academics. Yet, to those who have adopted it, it has proved helpful as a simple and convincing way to frame the disqualification of our knowledge and our truths that we face individually but also collectively, as organizations and movements (LeBlanc and Kinsella, 2016; Roper and Gooding, 2018; Russo, 2019; Todd, 2021; White, 2021; Daya, 2022).

Fricker's conceptualization of epistemic injustice is certainly worth refining, as it cannot be universally applied to all epistemic marginalization. Its most important strength lies in the ways in which different oppressed groups can develop and use this concept in their respective liberation struggles. The principal question, then, is how to work toward epistemic justice. Below, I discuss some issues pertaining to achieving epistemic justice for psychiatrized people, advancing our collective knowledge base, and strengthening our epistemic claims.

I structured the text following Fricker's differentiation of testimonial and hermeneutic injustice. At the end I briefly refer to the potential of Mad Studies as a project toward hermeneutical justice. Exploring that prospect in more depth would exceed the scope of this text, as its primary goal is to provide a critical perspective on the biomedicalized approaches to epistemic justice in the fields of psychiatry and mental health.

Psychiatric diagnosing: The motor of testimonial injustice

Fricker states that "testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word" (Fricker, 2007, p. 1). In the psychiatric context, this form of injustice is often explained in terms of "the stigma of mental illness" to be resolved within individual encounters and through raising consciousness and empathy. A typical expression of this approach can be found in *The Routledge Handbook of Epistemic Injustice*, in the chapter that specifically addresses "mental illness." It concludes that "[a]dopting an attitude of listening rather than 'knowing best' would help to counter the stigma and sense of alienation and diminished agency that people with mental illness often experience" (Scrutton, 2017, p. 353). This suggestion can certainly do no harm. But can it, in the long term, counteract the amount of testimonial injustice that psychiatrically diagnosed people face? Scrutton's analysis, besides taking for granted the biomedical framing of "mental illness" as a health condition that some people simply have, also reduces testimonial injustice to (poor) clinical practice, to be remedied by improving relationships with patients. These presumptions detach the clinical encounter from its broader structural context and obviate the potential of the concept of epistemic injustice to bring about social change for psychiatrically diagnosed people.

Psychiatric diagnosing—whether subjectively experienced as helpful or oppressive—is not based on any replicable medical test (Kupfer, 2013), nor does it involve any consistent criteria or method. Yet it holds a massive amount of legal and social power. Kerstin Kempker, survivor of 3 years of forced detention and insulin shock treatment, reports:

> "The diagnosis is the power tool of psychiatry. It suddenly changes everything. Diagnosis is the crime that deprives me of my freedoms – caringly, preventively and for my own good, of course. Without a diagnosis nobody would be allowed to do that to me. It would be deprivation of liberty, bodily injury and attempted murder. With a diagnosis of schizophrenia or endogenous depression, it is a medical treatment." (Kempker, 1997, p. 69, own translation).

Not all diagnoses can elicit forced treatment, but treatment cannot be forced without a psychiatric diagnosis. It has been established that the diagnoses with the most power to coerce disproportionally land on multiply oppressed people and decisively depend on the social location from which they come into contact with services. The diagnosis of psychosis, for example, is given three to four times more often to African Americans than to Euro-Americans (Schwartz and Blankenship, 2014). Black people in England are almost five times as likely as white people to be detained under the Mental Health Act, and community treatment orders are imposed on "Black or Black British" people more than ten times as often as on white people (NHS Digital, 2021).

Psychiatric diagnosing readies entire social groups—and some far more than others—to routinely become subject to many subsequent wrongs. People labeled mentally disordered or ill are therefore not only *vulnerable* to testimonial injustice, but are being *systematically made into its objects*. And this practice, far from being obsolete, is currently taking place all over the globe. This well-organized and deep-rooted cycle of injustice is unlikely to be halted by improved and humanized encounters with individual clinicians. This view of epistemic injustice might correspond to Fricker's assertion that, in distinction to hermeneutical injustice, "the wrong of testimonial injustice is always inflicted from individual to individual" (Fricker, 2007, p. 138). Even though this is ultimately the case within all social interactions, it does not mean that testimonial injustice resulting from the ongoing psychiatrization of particular lives should be treated as an interpersonal matter only.

In their analysis of how legislation and the mental health paradigm work in synergy, Beaupert (2018) states:

> "[T]he medico-legal discourse of mental health laws, by consecrating this symbolic violence, operates to manipulate and nullify individual ways of knowing and being, and to radically diminish opportunities for the epistemologies of users and survivors to exert influence on societal systems and structures. Constructions of people with psychosocial disability as lacking capacity and 'insight' are central to these processes of dehumanization." (p. 16)

Beaupert's analysis makes clear that vulnerability to injustice arises, not from "mental illness", but from organized societal responses to what is labeled as "mental illness". It also demonstrates the need to change laws and abolish practices that enable and sustain testimonial injustice. Such a project goes far beyond improving clinicians' attitudes or collecting more evidence that testimonial injustice occurs within psychiatry. It requires political will and committed work on different levels and from many social actors. The *Convention on the Rights of Persons with Disabilities* (United Nations, 2007), as the first international treaty to prohibit forced detention and treatment based on psychiatric diagnosis, offers a good framework to underpin and lead such action (Minkowitz, 2007, 2010).

Knowledge claims of people deemed mad and struggles for ownership

According to Fricker, hermeneutical injustice occurs "when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (Fricker, 2007, p. 1) Following up this framing, I wish to discuss two closely intertwined issues regarding the (collective) knowledge of people deemed mad: the presumption of our inability to (collectively) articulate what we experience and what we know; and the question of who qualifies to work toward hermeneutical justice. Together, these two issues form a tight knot that is paradigmatic to the disciplines of psychiatry and mental health: speaking on behalf of others on the presumption that they are unfit to do so, and then taking over their agenda and acting in their name. This deeply rooted attitude normalizes a wide variety of practices, ranging from overt control and patronization to subtle forms of silencing that are much harder to challenge, as they appear supportive (Russo, 2012; Dimitrova, 2021).

The division between a hard-to-comprehend *them* who need skilled and knowledgeable *us* to put forward their epistemic claims is enshrined in the work of various experts (see for example Estroff, 1981, 2004; Hornstein, 2009). The fundamental contradiction between the declared aims of such undertakings and their ethics and methodologies is rarely at issue, including for those whose marginalized ways of knowing are at stake. Some authors argue that mental health professionals might need to provide "patients" with resources and tools to help them express their experiences, even while recognizing the risk of secondary epistemic injustices in such attempts; first-person reports can be "misdescribed or forced into imposed categories" (Drozdzowicz, 2021, p. 4). The suggested solution here is to develop phenomenological tools jointly with "patients" as well as tailor them to specific "mental illnesses" (Drozdzowicz, 2021). Such "biomedicalized participatory practices" (de Boer, 2021), and their repeated failure to uphold the distinctiveness of marginalized perspectives within the established hierarchies of knowledge, have already been documented and analyzed in the context of psychiatric and mental health research and praxis (Davidow, 2013; Staddon, 2013; Brown and Stastny, 2016; Carr, 2016, 2018, 2019; Fabris, 2016; Penney and Prescott, 2016). This body of critical work, mainly created by authors with first-hand experience of psychiatrization, offers important insights into how efforts to integrate first-person knowledge, in order to transform dominant structures of both mental health service provision and knowledge production, often end up sustaining those structures and ultimately reproducing inequalities.

Kristie Dotson's concept of "irreducible epistemic oppression" (Dotson, 2014) offers a helpful framework to further understand the incompatibility of psychiatric knowledge claims with collective first-person ways of knowing. Dotson identifies a specific form of epistemic oppression "that is not solely reducible to social and political factors but rather follows from a feature of epistemological systems themselves, that is epistemological resilience" (Dotson, 2014, p. 116). In their view, this form of oppression "can only begin to be addressed through recognition of the limits of one's overall epistemological frameworks" (2014, p. 116). Acknowledging such limits is rarely a viable option in the official knowledge production of a field that is on all levels (including funding) dominated by the biomedical model of mental illness. Efforts toward hermeneutical justice in psychiatry are therefore limited to attempting to upgrade the biomedical framework by incorporating "lived experience" as a historically missing perspective. While the absence of first-person knowledge is increasingly being identified, the distinctiveness of this epistemic source is not recognized—and its crucial mismatch with the dominant methods of knowledge-making on madness and distress is not being adequately addressed (Rose et al., 2018).

From the onset of psychiatry, those considered to be of "unsound mind" have not only generated and articulated our knowledge but have also documented it in various formats. Besides different oral traditions, the written sources include numerous biographical accounts and collections of essays, petitions, position papers, research reports, concepts of support and theoretical contributions.[3] However, this considerable body of knowledge is rarely explored on its own merits or given a chance to deepen and advance its own epistemology. When considered at all, our accumulated knowledge is likely to be seen only in connection with psychiatry and adapted to that context as a matter of course—even though it largely emerges in resistance to, and as an act of liberation from, that very context. This re-psychiatrization of first-person labor (both individual and collective) takes over the ownership of our knowledge and suppresses our agency as knowers. Regardless of its intentions, the continuous process of co-optation distorts and de-politicizes crucial aspects of this epistemic source that reach beyond the topics of madness and psychiatry and encompass relevant and valuable understandings of the world we live in. These circumstances turn Fricker's question about the collective capacity to articulate certain experiences into the question of *who* is entitled and resourced to work with those articulations, and in what kind of process.

The initiatives to include our knowledge—from consultancy to collaboration and coproduction—have thus far been restricted to the fields of psychiatric and mental health research. The hegemonial discourse of these fields channels all knowledge production, including inquiries of alternatives to psychiatry, into an ongoing dialogue with the biomedical model. The implicit demands of such environment impose firm limits on *what* can be researched and dictate *how* evidence-making should ensue (Faulkner, 2015; Russo, 2018). The collective first-person knowledge of people deemed mad transcends both the research questions and the methodologies of psychiatric and mental health research. The narrow focus of these research areas means that any attempt to subsume our knowledge, will inevitably

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[3] A selection of sources between 1620 and 2008 was assembled by The Opal Project: "Ourstory of Commitment: A living history." Available online at: http://www.theopalproject.org/ourstory.html.

miss crucial parts of that knowledge. To explore and deepen this comprehensive body of work with the respect which is its due requires a different epistemological framework. It is unlikely for such a framework to emerge within disciplines that were founded on the denial of "mad" people's rationality and remain reluctant to make room for our perspectives. There is dispute about the accomplishments of the past few decades of attempts (in Western countries) to bring our collective knowledge into a "science" that is used to study and treat us as its objects (Staddon, 2013). In these countries, the intellectual labor of "lived experience experts" is likely to be funded and supported only to enrich the dominant model of "mental illness", create better quality knowledge about "us", and improve treatments we supposedly need. This type of inclusion can foster the individual academic careers of people deemed mad but, in the long term, it actively delays and hinders our own theory-building and prevents us from creating sustainable structures to connect our work internationally and globally.

Fricker (2007) writes that "hermeneutical injustice, whether incidental or systematic involves no culprit" and that "no agent *perpetuates* hermeneutical injustice – it is a purely structural notion" (p. 158, emphasis in original). Leaving aside a debate about whether any human interaction can be of a solely structural or individual nature, what are the practical implications of this kind of framing in the context of official knowledge production on madness and distress? If no culprit is involved, how can we ever address hermeneutical injustice, particularly in projects that seek to involve first-person knowledge-holders within (Eurocentric) psychiatric and mental-health disciplinary frameworks, and on their terms?

Closing remarks

Even though the above exploration of the ways in which the concept of epistemic injustice is being considered in the fields of psychiatry and mental health is neither systematic nor complete, some general trends can be noticed. Testimonial injustice is mainly seen as intrinsic to "mental illness" and is commonly approached in terms of quality of contact with "patients." There is little willingness to question the role of the psy-complex[4] *per se* in the making of "psychiatric patients", and stop the practices of its professions that are foundational to testimonial injustice. At the same time, there is a growing eagerness to include "lived experience expertise" in mental health and even take on the task of articulating collective first-person knowledge. Such initiatives are not necessarily framed as work toward hermeneutical justice, but often do claim to foster marginalized knowledge. In the above section I have tried to highlight some of the fundamental contradictions intrinsic to these undertakings.

Finally, I'd like to open the question about the implications of identity in hermeneutical justice work. Psychiatrization intersects with the rest of our (unequal) lives and affects us differently. Also, whether being imposed, accepted or reclaimed in the psychiatric context, our diverse identities are fluid, and more often something to leave behind rather than hang on to or ontologize. But can the question of whether or not one has experienced psychiatrization be rendered irrelevant, or even secondary, in the attainment of hermeneutical justice? Has the work of finding common ground, understanding and politicizing oppression, and claiming rights ever been carried out by anybody other than those who have been subjected to that form of oppression? And why does something so obvious prove hard to respect in the case of people deemed mad or declared mentally ill? There are many social justice issues, both within and outside of the realm of psychiatry, that we should all stand up for. But when it comes to particular ways of knowing, standing up for justice might mean deliberately standing aside from, rather than in the way of, knowledge that has been silenced for so long and which seeks to find and articulate itself.

As stated above, in comparison to the number of publications by mental health and other experts, there is only a small number of references to epistemic injustice by authors whose own psychiatric experience is integral to their work. But already this body of work displays a different uptake of Fricker's concept—one which transgresses clinical context and positions psychiatrization within the broader human-rights framework (LeBlanc and Kinsella, 2016; Roper and Gooding, 2018; Todd, 2021; White, 2021; Daya, 2022). In this text I narrowly focused on the particular concept of epistemic injustice, but there are many more authors who address this same phenomenon using different terminology—such as for example, "psychiatric disqualification" (Carr et al., 2017, 2019).

To me, advancing our collective first-person ways of knowing is a matter of ethics (Russo, 2021), methodologies and, not least, independence from the psy-complex. The future will show whether Mad Studies, as a form of activist scholarship that seeks to flip the microscope away from "madness" (Costa, 2014) and to dismantle whiteness as norm (Gorman, 2013; Gorman et al., 2013; Eromosele, 2021; Joseph, 2021; King, 2021; Sharma, 2021), is up to such a task. In the meantime, I wish for Mad Studies to keep fostering hermeneutical justice—not as a desirable nor once-and-forever achievable state, but as an ongoing process which never shies away from taking an honest look at itself; which resists the seductiveness of having the last word; and which always stays open to those who have not yet spoken.

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

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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[4] For the explanation of psy-complex see https://www.encyclopedia.com/social-sciences/dictionaries-thesauruses-pictures-and-press-releases/psy-comple.

Publisher's note

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“Believe me, only I know how I feel.” An autoethnographic account of experiences of epistemic injustice in mental health care

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In Sweden, support and service for people with disabilities is provided under the Swedish disability legislation, which has a clear focus on the individual’s right to a life like that of any other citizen and on promoting equality and participation in society. Nevertheless, having a physical impairment makes it clear that equal mental health care is not provided in practice. This becomes particularly salient when there is a need for mental health in-patient care. In this article, the aim is to explore our own experiences of epistemic injustice in relation to mental health care provision in a situation where one of us has a mobility impairment that require the presence of personal assistants in everyday life. Critical personal narrative is applied to highlight the different, but intertwined experiences of a young female mental health user with a physical disability and her mother. Diary entrances, shared discussions and extracts from health care records are used to illustrate how epistemic injustice may occur in health care practices. In the analysis, we use Fricker’s concepts that relate to different aspects of epistemic injustice, to show how power is exerted. Healthcare professionals’ inability to value and integrate patients experience-based knowledge into practice where the lack of a holistic perspective visualizes what happens when people do not fit into predefined categories. Instead of strengthening patients’ rights, health care professionals discredit patients’ and family members knowledge, and thereby giving themselves epistemic privilege. People with the combined experience of both disabilities and mental health issues are vulnerable to epistemic injustice and epistemic harm since they are commonly denied both epistemic credibility and authority. Our results highlight the importance of counteracting resilient structures of social privilege and power and identifying and, in as far as possible, removing the mechanisms that exclude the epistemic resources of people with disabilities and their family members from being part of shared epistemic resources.

KEYWORDS

epistemic (in)justice, in-patient mental health care, disability and mental health, personal assistance, critical personal narratives, Sweden

Introduction

In Sweden, support and service for people with disabilities is provided under the Swedish disability act, Act concerning Support and Service for Persons with Certain Functional Impairments, LSS. Swedish disability legislation has a clear focus on the individual’s right to live a life like that on any other citizen, with an emphasis on promoting equality and participation in society. If people due to disabilities need support with care needs such as "… personal hygiene, meals, dressing and undressing, communication with others or other help that requires extensive knowledge about the person with a functional impairment" (1), they are given access to some degree of personal assistance. Personal assistance is an individualized support that entails user control (2) and is to be provided by a limited number of people (personal assistants).

In Sweden personal assistance is regulated by two different pieces of legislation- the LSS Act- and the code of statues. To obtain personal assistance, the person with disability must identify and describe the need for support and make an application. Then either an LSS-officers at the municipal level or officials at the Social Insurance agency at the state level, are responsible for conducting the social investigation that decide if a person can gain access to personal assistance. Psychiatric services are provided by the regional health care system, and include inpatient treatment, medication and outpatient care. Because of this division of responsibility between disability support and psychiatric support, there is a continuing challenge to (3) coordinate interventions from different service providers (4).

The consideration of basic rights is important from both a perspective of non-discrimination and for supporting full participation in society (5). The UN Convention on the Rights of Persons with Disabilities (UNCRPD) (6), which came into effect in 2008, is considered one of the main reasons for a shift in thinking about disability from a social welfare concern to considering a human rights issue (7). Social justice is central to the concept of equality. Viewed from a disability perspective, a prerequisite for social justice is equal participation in society. However, people with disabilities suffer both socioeconomic injustices, such as deprivation, and cultural injustices, such as non-recognition and disrespect (8). According to crip theory (9) a person's ability is fluid. Nevertheless, our ability is understood as normal or deviant in relation to how well it follows notions of compulsory able- bodiedness. The concept of able-bodiedness is a culturally compelling expectation, which implies that it is both taken for granted and considered as aspirational (9). Ableism affects people with disabilities opportunities to participate as well as identity formation, self-understanding, and self-worth. It affects both societal design and cultural beliefs.

In culture and the media people with disabilities are often stereotyped, and cast either as victims and objects of pity, or heroes and inspirational role models for overcoming their impairment (10). Disability discrimination is evident in the culture, both in terms of either lack of representation or undifferentiated representation in media, where people with disabilities are subjected to stereotyping (11). When societal or institutional patterns of cultural and symbolic value construct people as inferior, or just invisible, there is a lack in full partnership in social interaction and hence a state of misrecognition (8). In terms of identity, recognition and redistribution might be constructed as mutually exclusive, but from a status point of view they become integrated (8).

For many people with disabilities, their mental or physical issues play an important part in their sense of self. Thus, it becomes important to have a holistic approach to disability and understand disability as a dynamic interrelationship between an individual with a health condition and the environment in which they find themself (12). Already in 1977, the World Health Organization advocated for patients to participate in their healthcare (13). A patient-centered perspective requires that health care professionals holistically consider what is known about a patient and understand the patient as a unique human being before determining a diagnosis (14). The purpose of the UNCRPD is to promote, protect, and ensure the full and equal enjoyment of human rights and fundamental freedoms by all persons with disabilities and to promote and respect their inherent dignity. Article 4 in the UNCRPD clarifies that state parties should take all appropriate measures to eliminate discrimination based on disability. Nevertheless, mental health is unequally distributed depending on a range of discrimination grounds: gender, country of birth, disability, and sexual orientation (15). Persons with disabilities consistently display a higher prevalence of mental ill health (15, 16). A deterioration in mental health appears to have occurred over time among young people with disabilities (16). Between the years 2017 and 2020, the number of patients in Swedish child and youth mental health care increased by 13 percent (+15,800 patients) and the number of visits to psychiatry units increased by 11 percent (+110,000 visits) (17).

In this article, the aim was to explore our own experiences of epistemic injustice in relation to mental health care provision in a situation where one of us has a mobility impairment that require the presence of personal assistants in our everyday life.

Epistemic injustice

Epistemic injustice describes a situation where certain types of knowledge are not taken seriously for understanding, interpreting, or defining a situation. Epistemic injustice involves certain people being subjected to knowledge-based discrimination based on an attributed deficit of credibility in relation to possessing knowledge. Being subject to epistemic injustice makes it difficult for situated knowers to make sense of their own experience or understand what is in their best interest to know (18).

Fricker (19) distinguishes between two types of epistemic injustice: testimonial injustice and hermeneutical justice. Testimonial injustice occurs when hearers due to prejudice undermine, exclude or dismiss persons in their capacity as potential knowers. It also impedes speakers from expressing critical thoughts and ask critical questions. In addition, repeated transgressions can result in speakers staying quiet in situations where they should not, for fear of further marginalization. Hermeneutical injustice occurs when one-part lacks words or expressions to make themselves understood in a specific context or situation, and in which their own or others interpretative resources puts them at a disadvantage when trying to make sense of their experiences (18).

Even though epistemic injustice is enacted in micro-meetings these harmful actions often derive from epistemic practices which can be found on a structural level (18). Hermeneutical injustice is not committed by a single entity, "but is caused by a particular aspect of our collective hermeneutical resources: either an individual gap (in the temporary case) or a more extensive deficiency caused by structural identity biases (in the systemic case)" [(19), p. 231].

In the "credibility economy," the resources of credibility – knowledge and access to different concepts – are unevenly distributed between different individuals and social groups. This uneven distribution of resources can lead to hermeneutical marginalization, which implies that a socially disadvantaged group (19), such as people with disabilities, is blocked from gaining access to knowledge or communicating messages to more socially privileged groups (19). In epistemic exclusion, certain kinds of knowledge are not included in the shared knowledge bank (20). People are epistemically excluded when they are unable to access epistemic resources and/or contribute to the generation thereof. Epistemic privilege is enjoyed by dominant groups in society, since their forms of knowledge are preferentially absorbed into the epistemic resources that make up the background knowledge of a given community (21). Injustice arises because it systematically advantages certain parties, such as the health sector, at the expense of others such as marginalized groups and communities (22).

Materials and methods

Critical Personal Narratives (CPN) is used as the research methodology (23) to highlight the different, and sometimes intertwined narratives of a young, disabled, female mental health patient and her mother. In, CPN, also known as critical autoethnography, personal experience is used to criticize, analyze, unsettle and defamiliarize what is often passed off as the ordinary, or the routine.

Autoethnography is used as a tool to describe and deconstruct power relations and marginalization (24). Mutual experiences of living a life where political decisions, debates in the media, and bureaucratic decisions constitute a potential threat to one's way of life are an ongoing trauma, as described by Ryan (25), which is a reality that the two authors share and are forced to deal with.

We, as mother and daughter

In this study, our dual roles of the researchers and the participants of the study at the same time feature intensively and throw an issue of reflexivity of qualitative research. We both have similar and very different experiences of encounters with health care staff involved in provision of care. We are bounded by our mutual experiences of numerous encounters with a variety of health care professionals such as: psychiatrics, physicians, nurses, mental health nurses, and assistant nurses. We also have a mutual engagement in a local disability organization for families and children with mobility impairments. Nevertheless, our experiences differ in significant ways, both in relation to our respective roles (mother and daughter/recipient of personal assistance and psychiatric care) and in relation to our embodied experience (disabled/non-disabled person). One of us- the daughter is a young woman with a mobility impairment, in the beginning of university studies, transitioning from child and youth care to adult care. The other one- the mother is a middle-aged, non-disabled woman, with a background as a social worker and disability researcher. Sharing household, our lives are interconnected by mutual experiences of being in a vulnerable life situation, where access to personal assistants set the boundaries for our participation in society.

Living together creates opportunities for in-depth discussions about sensitive topics, knowing each other well makes it easier to be candid and being familiar with the situations referred to on a more detailed level give us a unique opportunity to provide two different perspectives on the same situation. In addition, being family members could make us influence each other's narratives. Being mother and daughter can undeliberate make us assume that we know each other's perspectives which could lead to not asking clarifying questions.

One of the biggest challenges of using CPN in studying disability and society is that we used our subjective experiences and feelings in the research. We may have some biases or personal experiences that are different from the experience of others. We treat this subjectivity as an approach to understanding our ways of knowing while exploring the issues of psychiatric health services.

Due to the emotional content of the text, it has been necessary for us to rest from the text for periods of time. Events narrated have been selected to illustrate critical incidents involving different actors in psychiatric care, at in-patient care units and out-patient care facilities. When care units are referred to in this text pseudonyms are utilized.

A third person perspective is utilized to critically analyze and reflect on our narratives. This gave us an opportunity to understand our narrative data and rethink the issues with a more objective point of view. Therefore, the daughter is called Amanda and the mother is called Anna.

We did not go through the application for ethical review because we did a textual-based analysis through our personal narratives. As authors and participants, both of us agreed to share our personal reflections and thoughts in this research.

The analysis began with the second author identifying critical incidents. Based on these incidents we discussed our experiences and the meaning and relevance in relation to access to equal care for people with disabilities. The second step was to complement our own narratives with notes from anonymized hospital records made by psychiatrists in charge of Amandas care. The third step was to create themes based on the chosen incidents and analyze them deductively by utilizing some of the core concepts that unpack the mechanisms of epistemic injustice, such as Fricker's (18, 19) concepts, testimonial injustice and hermeneutical injustice, which underline how power is exerted in a mental health care context by different care providers. In addition, to further clarify the relationship between disability, mental health, and epistemic injustice, concepts developed by the critical disability scholar Garland Thomson concerning misfitting were used (26, 27).

Results

The results are based on the themes discovered: "Believe me, only I know how I feel," Health care staff's reluctance to provide for basic care needs, and health care professionals perpetuating their epistemic privilege.

"Believe me, only I know how I feel"

Within adult psychiatry, many of the out-patient psychiatrists and unit managers for in-patient care held beliefs that in-patient care is not the right place for Amanda, even though she finds it necessary to be admitted to an in-patient care unit. The chief psychiatrist tried to persuade her that it was better to stay at home and cope with her ordinary out-patient care interventions. Although the chief psychiatrist responsible for Amandas care knew that the treatment was not effective, she was not willing to adjust the treatment plan. Due to experiences of severe anxiety, suicidal thoughts and impulses to self-harm, out-patient psychiatrists often agree to admit Amanda to an in-patient care unit. Nevertheless, those decisions are often questioned by chief psychiatrists at different in-patient care units that believe that in-patient care is not the right place for her, which result in Amanda being discharged although she has told them that she still has thoughts about self-harm. Particularly one of the chief psychiatrists at one of the in-patient care units routinely dismissed Amanda's testimony of suicidal thoughts and self-harm. Amanda consequently suffers testimonial injustice. Since both psychiatrists in outpatient and in-patient care foremost categorized Amanda as a disabled person, prejudicial stereotypes of disability and disabled people hindered them from listening to Amanda and taking her seriously.

A common denominator for the psychiatrists was their willingness to tell Amanda what they thought her mental health issues derived from. They said that her mental health issues were due to communicative difficulties within her family and lack of access to enough personal assistents. One of the psychiatrist responsible for inpatient care at one of the care units made the following assessment in the medical records:

> The patient appears calm and adequate in the ward, does not suffer from a serious mental disorder, is not depressed, not psychotic. A difficult home situation increases the patient's instability and negative thoughts. (Medical record entry from a psychiatrist, at an inpatient care unit, December, 2021)

In another entry in the medical record, from the same care occasion, the psychiatrist writes:

> 18-year-old woman discharged to her home and habitual state. Came in due to a burdensome social situation. (Medical record entry from a psychiatrist at an inpatient care unit, December, 2021)

In medical record entries made in connection with discharge from psychiatric inpatient care and follow-up in outpatient care, the psychiatrist in charge writes:

> In summary: young woman with cerebral palsy as main diagnosis. Anxiety and destructive behavior in connection with stress. Personal assistant during waking hours. (Medical record entry from psychiatrist at an inpatient care unit, December, 2021)
>
> Eighteen-year-old female with psychiatric diagnosis but mainly cerebral palsy who has come in for a check-up after discharge from *Gullvivan* [name of inpatient ward]. Received good care there. (Medical record entry from psychiatrist, outpatient care, January, 2022)

Instead of validating her experience of poor mental health, irrespective of origin, the psychiatrists chose to focus on her disability and the lack of adequate social support interventions, which they considered to be the main cause of her suffering.

> It is strange that health care professionals give themselves the right to define what the main diagnosis is and that representatives of psychiatric care focus on writing that the main diagnosis is cerebral palsy (the functional impairment), regarding which they have neither knowledge nor treatment responsibility.
>
> I am a whole person, neither just a body nor just a mind – I am so much more. There's nothing wrong with me, I'm not a defective person, although health care usually describes me as sick or broken. A neurologist at the children's and youth clinic used the word "defect" to describe how much mobility I have in my elbow joint; she wrote that I have an "extension defect in the elbow joint up to 20–30 degrees" (Amanda).

When Amanda attempted to describe her everyday life situation from her perspective, psychiatrists attributed her a credibility deficit based on her descriptions of her overall life situation. Instead of trying to understand the complexity of her everyday life situation, the responsible psychiatrists seemed to pay attention to those narratives that resonated with their preconceived perceptions about who belong in an in-patient care unit and benefit from psychiatric care. Accordingly, they communicated that Amanda's emotional distress would be manageable if she had access to either independent living with personal assistants or were placed in a service home with round the clock staff. By recasting and reducing Amanda's mental suffering to consequences of her disability, psychiatrists not only gave themselves epistemic privilege, they also caused epistemic harm by silencing Amanda and stripping her of agency (18).

In contact with mental health care, both Amanda and her mother, Anna, has learned that it is not enough for Amanda to say that she has suicidal thoughts. There must be visible, objective evidence of self-harm. The absence of visible injuries is considered "proof" that Amanda can deal with her mental health condition and is used to discredit the patient's verbal account of mental suffering and classify it as manageable. The outcome of Amanda's clinical assessment also depended on which psychiatrist was on duty at the time and day in question, which assessment unit that psychiatrist belonged to, and the availability of inpatient care. Amanda recalled a conversation at the in-patient care unit when she still belonged to child and youth mental health care,

> At the BUP (child and youth mental health care) emergency unit, the psychiatrist asks me to describe how I feel, and I begin. She listens and takes notes. She then explains that there are no openings that evening, but that my condition is serious. I keep saying that I feel very bad, and I state this repeatedly. Then she asks to see my arm, asks me to roll up my sleeve. She asks if I can do it myself. I declare that I cannot [roll up my sleeve] and cannot harm myself so that it shows. I can't seriously injury myself physically, but in these moments, that's all I want. My body does not obey, and therefore I can only injure myself superficially. My thoughts are just as destructive as those of a self-harmer.

When Amanda was admitted as a patient to an adult in-patient care unit, she had learned that it was important for her "to prove" that she was ill enough – otherwise there was a risk of her being discharged while thoughts of self-harm and suicide still remained. Amanda reflected:

> I'm sitting here with a lot of anxiety and have been thinking about hurting myself for 20 minutes. In the end, I do it mostly because I'm sad and lonely. I ring the red bell and, strangely, I expect it to be like in a casino – that something funny happens when you pull the red lever, but all that happens is that a bored assistant nurse comes in.
>
> The assistant nurse asks what I want in a hostile manner. I reply that I have harmed myself and that they should know about it. He says in a disinterested voice: "Show me." I show the small wound that I have scratched on the back of my hand, over the scars that reveal all the times I have scratched myself before. The assistant nurse says "Stop it, don't do that" and leaves the room. I know it's just that the wound is small and looks insignificant, really. But half to annoy him and half to get help, I ring the alarm again and hope not to meet the same assistant nurse again. Of course, the same tired face comes back through the door. He says: "What now?" "Yes, but the wound, aren't you going to do something about it?" "What?" "Yes, but I've harmed myself, aren't you going to clean it?" He cleans the wound, irritated – half because I want him to and half so that I won't call him again. "Don't do that again," he says, and it just feels like the same scene is playing out over and over.

Health care staff's reluctance to provide basic care needs

When Amanda expressed that she needed to utilize the toilet or eat breakfast, she knew that it would probably make the staff feel stressed and uncomfortable, which created a strained relationship that might affect her treatment. Although, assistant nurses and mental health nurses were less likely to ask questions, some of them showed their discontent and disbelief while helping Amanda. Not wanting to be perceived as a nuisance, Amanda found it difficult to ask for help:

> They will say something like "You'll have to wait, we are only a few assistant nurses in the care unit now. We'll come by as soon as possible." Then it takes anything between 15 and 30 minutes before someone comes. Sometimes they forget that they can't assist me on their own and then it takes another 15 or 30 minutes. It becomes even more difficult to decline help from male staff when I have been told that there is no other solution. Being upset when declining help can cause you to be perceived as a troublemaker, which can justify staff using forced medication in the form of sedatives. You can be labelled as "difficult," "uncooperative", or "unruly."

Psychiatric staff members were not used to provide physical care and some of them lacked a formal assistant nurse education. Both assistant nurses, mental health staff, and nurses lacked knowledge about mobility aids and expressed feelings of uncertainty when utilizing them. Thus, some of the assistant nurses and other mental health staff were reluctant to provide care and handle assistive devices. In addition, this was not among their regular duties, and when there was shortage of staff, it became hard for them to both perform their regular duties and function as personal assistants. Amanda perceived that interactions between her and some of the assistant nurses became tense since they displayed fear and pity towards her. Medical records also confirmed that having to perform tasks that was not considered as part of their ordinary duties created dissatisfaction among staff, which was expressed in the following journal entry:

> The undersigned [psychiatrist at outpatient care unit] has been in contact with the chief psychiatrist at *Gullvivan* [name of the inpatient care unit] and it appears that the patient has no assistance at the ward there and that the ward staff are not trained to be personal assistants to the patient. This has created negative sentiment among the staff against the patient. (Medical record entry from psychiatrist in outpatient care, December, 2021)

Amanda's primary reflections when she read the record entries were that they confirmed what she felt during her stay at that unit, where she experienced the interaction with mental health care staff as being tainted by her visible disability. Reading also made Amanda sad and distressed regarding future needs for inpatient care, since mental health care staff and managers at *Gullvivan* showed no ambition to make their care facilities more accessible neither in relation to psychosocial treatment nor as regards the physical environment. Amanda reflected:

> It feels difficult, reading that health care professionals find it problematic to help me. It makes me feel singled out and responsible for solving their problems. They often complain in front of me, which makes me agree to solutions that don't feel good for me. The environment also contributes to me feeling like a problem. The premises are not adapted for people with physical disabilities: the rooms are small and there is no space for my aids. None of the patient rooms are adapted for wheelchair users. Sometimes, this means four people will try to do a joint lift, where I am moved from my wheelchair to the toilet. If these four people do not communicate clearly with each other, the lift becomes risky, it feels uncomfortable, and I end up sitting crookedly on the toilet. The communication between me and the staff reduces me to a body or an object, to be moved from one place to another. No one thinks to ask me how it feels or what would work. If I get a question, it's if I'm okay with male staff helping with the lifting. If I say no, then there will be four women lifting my body, instead of a "strong man." It is difficult not to feel like a problem, which makes it even more difficult to say no to the help offered, in a situation that does not have an obvious solution and where both staff and patient end up in a deadlock.

As Amandas mother, Anna found it difficult to stay balanced, and not become too upset when she realized that Amanda did not receive proper care at in-patient care units. Sometimes Anna thought that her background as a disability researcher enabled her to stay calm and analyze her and Amandas encounters with health care staff as well as the health care system. At other times she felt that having knowledge about disability legislation and recognizing the discrepancy between law, policy documents and practice made her feel even more frustrated. Anna reflected:

> I easily, become frustrated with the Swedish health care system that cannot help Amanda who have complex care needs. It is obvious that patient-centered is one of those magic concepts and that equal care does not apply to her. When I went to visit her at the in-patient care unit yesterday, I instructed two assistant nurses in how to use Amandas assistive devices, so they could show their colleagues. The next day, Amanda tells me that it did not make any difference, and the routine is back to getting help from four female staff members or the care unit's "strong man."

Health care professionals perpetuating their epistemic privilege

When Anna or Amanda told health care staff that decisions made by officials at the Social Insurance Agency do not allow personal assistants to work when Amanda is admitted to in-patient care, they were met with disbelief. Although chief psychiatrists and unit managers did not tell them that they were wrong, they conveyed their disbelief through questions and advice, such as: Why do not you apply for assistance during hospital stay? or have you had any contact with the municipality? They can provide disability support.

A journal entry made by a one of Amanda's psychiatrists exemplify health care professionals lack of knowledge about other authorities and care providers responsibilities:

> The mother informs us that the Social Insurance Agency has decided that the patient does not have the right to assistance when she is admitted to health care facilities. The undersigned [the chief physician] is a little surprised and explains that staff in the psychiatric department are not used to providing physical assistance and that the company providing the assistance should have an agreement to do so even when the patient is admitted. (Medical record entry from psychiatrist, outpatient care, December, 2021)

In this situation, the chief psychiatrist lacked knowledge about current implementation of Swedish disability legislation and the process of gaining access to personal assistance. She stated that we must demand that our assistance company provided access to personal assistance during inpatient care. Despite explanations on our part, psychiatrists', and other health care professionals at different both in-patient and out-patient care units insisted that we must understand that care staff were not able to replace personal assistants. Some of them were under the impression that we did not understand the working conditions of care staff and thus informed us of a situation that although it was well-known to us, we did not find acceptable.

The negative consequences of needing support from both health care and social services becomes particularly salient when the provision of support was affected by decisions and guidelines from different authorities and care providers that were unaware of each other's competence and responsibility (4). Although this situation was familiar to Anna, she became both angry and frustrated since there was no single person from who to demand responsibility:

> The experience that stays with me is that the existence of a complex life situation is used as an excuse for health care providers to try to limit their responsibility and transfer it to the municipality – which is supposed to solve the situation, because there is no "mental illness." Everything takes time, time that we don't have. What happens when we can't take it anymore?

Over the years, Amanda and Anna have had numerous meetings with different welfare actors, where both Amanda and health care staff has given Anna the main responsibility for coordinating Amanda's care interventions. Anna has had this role since Amanda was granted personal assistance for the first time. Amanda was 6 years then and is 19 years old now. Anna often reflect upon the difference between making a phone call as a professional health social worker or researcher, versus making it as a private person. She possesses the same knowledge, but her input has been given different value when she is cast in the role as a professional. Even though she has had access to epistemic resources such as hermeneutical tools (medical discourse, familiarity with hospital work, LSS-legislation, social work), this was not sufficient to equalize existing power structures when she is viewed "only a parent," which downplayed the relevance of her combined experience-based and professional knowledge. Anna felt taken advantage of by health care staff as she was always expected to show up and be available when the health care staff thought she should participate in care planning and other care visits. Even though health care professionals considered Amanda's mental health issues was due to communication problems with her mother, they expected Anna to take responsibility for coordinating Amanda's various care efforts:

> As a parent, it feels like a moral obligation and an expectation from health care staff that I should always be available. When health care professionals feel reluctant to shoulder responsibility, representation is not questioned – then I am expected to act as an interpreter, mouthpiece, and representative. In other circumstances, I can be perceived as a potential threat, either depriving my daughter of her voice or speaking in my own interest. As a mother, I am expected to be there when it is convenient for health care providers.

Instead of seeking collaboration and shared responsibility with other care providers, health care professionals expected patients or parents to coordinate support and care interventions. Lack of knowledge about other authorities' or caregivers' areas of responsibility, combined with insufficient knowledge about the individual patient, made coherent care planning difficult and created a situation where the responsibility for coordination of support was placed on family members and the person in need of support. Thinking about her lifelong needs of care, increased Amanda's anxiety and she often got stuck with negative thoughts about an imagined future where she has to stand up for herself without the support from her mother:

> What happens when mum no longer is there to pick up the pieces of the broken healthcare system? A system that tells me that I don't belong there. That I would be better of living in an assisted living facility. Somewhere else where I no longer have to worry about being without help. Where they are better equipped to look after someone like me, they say. How can they even say that, when they

> don't know the first thing about me or even people like me cause I'm the first one they have ever met with a physical disability. Who will make sure my rights are still intact, and that I get a say in what I need from health care staff?

By assuming that Amanda and Anna were ignorant of the roles and duties of health care staff at inpatient care units, health care professionals simultaneously discredited their capacity as knowers while expecting Anna to take the main responsibility for coordinating social support with different health care providers. This line of reasoning places both the blame and the responsibility for the problem on patient and relatives. In addition, the psychiatrists did not question their own expertise. Even in situations when it was obvious that psychiatrists were misinformed, they did not take the chance to learn something new, instead they chose to retain their epistemic privilege.

Discussion

In this article, the aim was to explore our own experiences of epistemic injustice in relation to mental health care provision in a situation where one of us has a mobility impairment that require the presence of personal assistants in our everyday life.

In the backdrop of austerity politics (28), having a physical disability that requires technical aids as well as personal assistance reveals that equal health care does not, in practice, extend to people with severe disabilities that require both somatic and mental health care interventions. Although it is the duty of the psychiatry unit to provide equal and patient-centered care, the encounter indicates epistemic injustice that according to Dotson (29) derives from epistemic systems, from which individuals may be excluded to greater or lesser extent. As a stark contrast to having an intersectional approach, mental health care professionals tend to focus at one intersection at the time, and almost exclusively on Amandas disability.

This becomes particularly salient when there is need for mental health inpatient care. In mental health care facilities, rooms are usually inaccessible for people with physical disabilities. When Amanda needs space to move around with her wheelchair or utilize the bathroom, the environment needs to be adapted, e.g., furniture must be moved, which both staff and managers find difficult to do. This recurring task frames disability and the disabled person as problems that need to be fixed (30). Garland Thomson (26) has conceptualized this as the concept of a misfit or a situation of misfitting; "People with disabilities become misfits not just in terms of social attitudes—as in unfit for service or parenthood—but also in material ways. The disadvantage of disability comes partly from social oppression encoded in attitudes and practices, but it also comes from the built and arranged environment." [(26), p. 594]. It underlines that "the discrepancy between body and world, between that which is expected and that which is, produces fits and misfits" [(26), p. 593]. In line with the reasoning of Garland Thomson (27), the disability dominates and skews the perceptions of non-disabled people, meaning that they tend to reduce a disabled person's complex personality to a single attribute, i.e., disability.

To misfit in the public sphere is to be denied full citizenship (26), since equal access to the public sphere – which include institutions such as health care facilities – is denied. When personal assistance is not granted for inpatient care, the lack of an accessible toilet (*misfitting*) is transformed into an individual problem, where the situation defines the person – who thus becomes a problem (*misfit*) that health care workers are expected to solve. Without the support of managers, nurses and assistant nurses are forced to find a quick solution to a structural problem. When this happens, there is a great risk that health professionals' frustration is transferred to the patient, who becomes the scapegoat. Foucault (31) describes self-discipline as something that occurs everywhere in society where power is exercised – whether expressly stated and implied. At first glance, self-discipline can be perceived as the individual wanting to subordinate themself. When individuals discipline themself, they adapt to what the environment wants without any external pressure being needed, which means that the demands of the external power move into us and we are disciplined into subordination to get what we need (32).

Health care professionals' inclination to mistrust and devalue experience-based knowledge provided by people with experience of disability and mental illness or their family members contributes to testimonial injustice, which sustains the epistemic injustice whereby a significant area of knowledge is obscured from the collective understanding [(19), p. 154–155]. Thus, epistemic harm occurs both in relation to lack of adequate support with basic care needs in inpatient care and more indirectly by silencing the experience-based knowledge and devaluing its worth.

Instead of strengthening patients' rights, which could be reinforced and further developed by utilizing the experience-based knowledge that resides in people who have lived experiences, health care professionals dismiss their knowledge, thus giving themselves or other type of knowledge sources an *epistemic privilege*. As pointed out by Fricker (19), testimonial injustice can operate through individual actions and responses. Although we have both communicated – to several people belonging to different mental health care units – that the authorities' current decision on assistance for Amanda does not allow personal assistants to work when she is admitted to inpatient care, this is interpreted as our having misunderstood our rights to get support or having failed to seek adequate support from the authority in charge. This is a typical example of testimonial injustice, in which our experience-based knowledge is dismissed, perhaps because it is assumed that the information we provide (as a disabled person and an ally) is inherently untrustworthy in a way that information provided by health care staff is not. As a disabled person, Amanda is vulnerable to epistemic injustice. People with disabilities are commonly denied both epistemic credibility and authority (33).

When Amanda communicates her needs of assistance with basic care to staff at inpatient care units, they do not give her time to explain how she wants to be supported – instead they make decisions regarding how and when support will be provided. In those situations, health care staff – in addition to treating her as a problem (*misfit*) – give her an undifferentiated response: she is not seen as an individual with a physical disability, but as a member of the group "disabled people," irrespective of her individual circumstances. Since this type of testimonial injustice is inflicted systemically, it is even more damaging and insidious than if it were experienced at the hands of an individual (18, 19, 33, 34). Having claims and accounts epistemically downgraded unsettles a person's trust in the epistemic value of their own narratives and judgments and can, if internalized, impair their confidence in their overall agential capacity. It can also create a feeling of hopelessness and despair. Scully (33) argues that this becomes particularly harmful to disabled persons, who often have their status as people with the same moral value as others called into question.

Even in situations when health care professionals or civil servants agree with patients and family members, there is rarely any difference in practice, since the problem is recognized and described as a systematic error at a structural level, for which individual practitioners, civil servants, and organizations cannot take responsibility. Professionals' inability to value and integrate patients' experience-based knowledge into practice (35) becomes particularly salient in the transition phase from child to adult care, where the lack of a holistic perspective reveals what happens when people do not fit into the predefined categories of either welfare recipients or health care users. A complicating factor is that care is administered and shared between different authorities and organizations, with decisions made and enforced through different legislative acts and at different levels of governance (state, regional, and community level).

One of us is holding a faculty position as a disability researcher which has enabled us to have the opportunity to publish our article in an academic journal. We acknowledge this fact, as an epistemic privilege compared to other people whose lived experience remains untold due to lack of both financial and hermeneutical resources such as funding and knowledge about academic language and writing processes. Nevertheless, we believe that utilizing our epistemic privilege is justified in the sense that it enables us to provide an inside perspective on issues of epistemic injustice that need to be addressed. In this text health care professionals are not portrayed in a generous way, which is related to the fact that the narratives are based on critical incidents that highlight challenging situations in which their agency also depend on organizational structures. For us, the authors, it is important to show that epistemic injustice arises due to a systemic failure, in which both health care professionals and patients in many situations lack epistemic agency. Even in situations when individual health care professionals are willing to give up their epistemic privilege, this is not sufficient to change the routines and physical environment at care units, especially when it comes to the overall organization of mental health care.

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

Ethical approval was not provided for this study on human participants because this study is an autoethnographic study, which implies that the researchers analyze their own actions. In relation to the subject matter we have followed ethical guidelines and been careful in anonymizing other people and places. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

LH was responsible for the design of the study and he had the main responsibility for writing the text. LH and MH contributed to data collection. MH collaborated with the LH in the analysis and discussion. 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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Using participatory action research methods to address epistemic injustice within mental health research and the mental health system

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In this paper, we describe a model of research practise that addresses epistemic injustice as a central objective, by valuing lived experience and addressing structural disadvantages. We set out here the processes we undertook, and the experiences of those involved in an attempt to transform research practise within a study known as Co-pact. We do not discuss the findings of the research. Rather, we wish to build expertise on how to address epistemic injustice and offer examples of participatory research processes, central values, and practical procedures that we implemented.

KEYWORDS

epistemic injustice, participatory research, psychiatric care, mental health, mental health act

1. Defining epistemic injustice

The term 'social epistemology' has been used to describe attempts to understand the relationship between forms of knowledge and social life (1, 2). This includes the study of relationships between communities and knowledge, including the way groups might be organised so that they can create and deploy knowledge most persuasively and effectively (3). Fuller (4) maintains that knowledge can be seen as more than merely information about an independent phenomenon such as a risk, an illness or a treatment. The authors have investigated how forms of knowledge held by powerful groups intersect in intriguing and politically revealing ways with that of less powerful constituencies. Allied to this, Fricker (5) introduced the term 'epistemic injustice' to refer to a situation where someone (their perspectives and knowledge) is given less credence as a result of their social position. It can include actions such as excluding someone from participating in a discussion, silencing, or misrepresenting their views. In mental health care, for example, someone might be discredited, or their perspectives (lived experiences) might be regarded as unreliable. They may not have access to the same resources to make their views known and may be facing multiple disadvantages that require prioritisation for their immediate survival. When sharing knowledge, their perspective may not lead to any immediate benefit to the precarious situation in which they live and therefore may not be a priority.

Epistemic justice is about allowing or enabling people to think about their own experiences in ways that value those experiences, and support theorising about lived experience. The adoption of an epistemic justice framework recognises that knowledge is socially constructed and is valued irrespective of the source or social status of the person sharing their knowledge. The approach also endorses the view that multiple perspectives might exist and appear contradictory, but might all be valid and together to represent a more complete picture. This is an important acknowledgement when conducting qualitative research with heterogeneous populations, especially when diverse identities and contexts introduce contrasts in what matters and what is at stake.

As a corollary of this, Vaditya (6) writes of 'epistemic domination' which exists 'not because of objectivity or universality' of expert-led knowledge, but because its originators hold a 'privileged location within a historical, material and social setup of dominant power relations' (6, p. 272); in contrast, a 'situated knowledge' building process may help to end the epistemic oppression of disempowered groups. A similar notion of hermeneutical injustice is used to describe what happens when some groups are epistemically marginalised and excluded from being fully involved in the interpretation of knowledge that informs programme design and policy development (7, p. 163). This is not the same as prejudice or deliberate discrimination on the part of the actors in health and social care. Instead, the injustice results from 'socioepistemic structures' (8) which collectively disadvantage members of certain groups such that their opinion appears less credible or intelligible than that of others. More commonly, they are not central to knowledge production and interpretation. Marginalisation of this nature may lead to misunderstanding, imperfect and inaccurate ideologies, 'epistemic oppression' (9), and perhaps a lack in the progression of how information is used and understood; 'hermeneutical death' (10).

Fricker (5) has described two types of epistemic injustice, both based on wrongs done to someone in their capacity as a knower. The first type is testimonial injustice, which occurs when prejudice causes the hearer to assign a lower level of credibility to a speaker's word (5). The second type, hermeneutical injustice, happens when there is a gap in collective interpretative resources that leads to someone being disadvantaged when making sense of their social situation (5). Whilst testimonial injustice refers to the lack of credibility placed on a person by others, hermeneutical injustice refers to more structural prejudice, for example within a culture or organisation. A health assessor who does not recognise a person's identity, history, and forms of lived adversity (racism, poverty and unemployment), and thus diminishes the importance of these, demonstrates testimonial injustice. However, policies or guidance that prohibit asking about identity and racism, stipulates time limited assessments, or removes access to interpreters, are examples of hermeneutical injustice. Both are common in the mental health experiences and outcomes of black and minority ethnic groups in the United Kingdom, Europe, and North America (11).

2. Epistemic injustice in health care

Testimonial injustice occurs within the health system when healthcare professionals (including those in mental health care) are assigned more credibility than those living with a condition. Obviously, this is not inevitable, and depends on who is listening and their sensitivities. In clinical practise, research and mental health tribunals, professionals intend to hear the patient's view; however, their automatic thought processes and experiences may drive them to subtly negate or devalue the perspectives of the patient. The lived experience of a mental health patient can be dismissed as subjective due to experiential nature of their symptoms. Furthermore, the presence of hallucinations and delusions can be used to devalue knowledge beyond the symptoms that the patient has to share. Even though the content may hold meaning, this may be dismissed as a pathology. In contrast, the healthcare professional may be judged as having objectivity, expertise, authority, and professional credibility. An example of hermeneutical injustice within the healthcare system and in research is apparent when some patient populations are described as 'hard to reach', justifying their exclusion. The healthcare system as a structure, with policies and procedures, struggles to meet the needs of these populations, with responsibility placed for the lack of engagement on the patient. This may not be overt prejudice but rather exclusionary in nature. The patients themselves may not be aware of the structural inequalities. Hacking describes that the way we see things in the world become facts, and that we behave as if these facts are real, even though they are really born of a specific niche in time, political and social context (12). Some may see distress or a health condition as an entirely embodied biological phenomena rather than understanding these concepts as a product of history, the environment, and past and contemporary adversity, or taking an eco-social and development lens.

3. Co-pact case study

The Co-pact study recruited participants from racialised communities, who had been detained under the Mental Health Act (1983) in the last 2 years (13). The study aims to change local and national policy informing the current reform of the Mental Health Act. The protocol for how this work is being conducted has been published (13). Here we provide some rationale and pragmatic examples as to the choices made in implementing our protocol that speak to acknowledging and reducing epistemic injustice in mental health research.

We were interested in participants' experiences of being detained under the powers of the Act, as a starting point. Importantly, we consider these 'experience data' as important forms of valid and authentic knowledge that represent and reveal a real world occupied by the participant. Listening to such perspectives may help further the understanding of how to prevent detention in the future, and which structural and interpersonal processes lead to detention. We anticipate novel processes and mechanisms will be revealed, as marginalised world views rarely enter homogenised and normalised accounts of research data. These experiences might be dismissed as subjective because the research takes a qualitative form in which sampling is often purposive and not generalisable. Hierarchies of evidence may be invoked to diminish or discredit these views, privileging more normative and conventional research, in which marginalised groups are under-represented. These are all points or arguments that might be invoked to justify epistemic injustice. Thus, promoting experience data as a legitimate source of knowledge to inform both practise, service design, and policy was our first step.

The question of whose knowledge is given credence, and therefore worth and acceptability, needs to recognise that someone's personal experience, their truth, cannot be denied and that it has legitimate value. Co-pact employed photovoice methodology (14) to provide an opportunity to counter such thinking that is prevalent in mental health research which informs mental health systems. Instead, our study demonstrated the value of the information and experiences that patients contribute to the conversation. This experiential knowledge is valid in and of itself because it aids recovery, wellbeing and enhances self-esteem, as well as reinforces the importance of being valued as a human being. Having recognition is validation of self-worth (15). Such knowledge is crucial for training mental health staff and can enhance decision-making. From a social epistemological perspective patient voice becomes acceptable, worth listening to, and acting upon. It is serious knowledge.

Whilst there is much discussion about how participatory action research is defined (16), and what is considered as a participatory process, we consider that this work fits with the participatory action research paradigm. They way in which photovoice workshops were conducted, enacted participatory process, and built capacity amongst participants. The outputs from the photovoice workshops will inform a series of co-design workshops, resulting in action both at a local, or community level and at a national level. In person exhibitions to further engage policymakers will be co-produced with participants.

Eliciting authentic experiential data is not straightforward. We might anticipate people would be distressed if asked to share information verbally or may wish to avoid reminders (as with all traumatic events). We employed creative methods, specifically photo-elicitation around which a person might progressively narrate and construct a story of their experiences (photovoice) which are not immediately available for sharing, or when sharing is attempted, are overwhelming which leads to defensive avoidance. Creative methods are emotionally and behaviourally activating, allow for perspective taking and engage different brain regions. These processes enable traumatic or adverse memories to be activated, held non-verbally and worked through, as part of the narration process. As demonstrated in previous photovoice studies, the approach might be helpful and empowering to participants (17), if sharing their experience and deepening reflection facilitates improved self-understanding through taking a different perspective (18, 19), particularly for racialised populations (20).

It was important within the internal structure of the team that there was not a dominant narrative that steered the conversation and that a diverse range of views were represented and heard in all conversations. Many discussions were held surrounding how we address power dynamics in different spaces, not only between researchers and participants or people with lived experience, but also in terms of ensuring more junior members of the team had a voice. With regards to race, and profession it was important that we recruited a diverse range of local Principal Investigators (PIs) in the eight NHS trusts we were working with. We reached out to various networks in each trust to ensure that overall, we had men and women, different ethnicities and both psychologist and psychiatrists as PIs. This meant that in our team meetings a diverse range of perspectives were shared and heard. It is important for the sustainability of this type of work to build capacity, share knowledge across different NHS trusts and highlight best practise of how we can change the system to raise awareness of epistemic injustice.

People with experience of being detained in the last 2 years consented to participate in the three photovoice workshops. NHS ethics was obtained to conduct this research in eightNHS trusts in England. The first workshop was an introduction to the study (which incorporated training around the ethics of photography and the use of images), the aim of the second workshop was for individual participants to reflect on their experience and add captions to photographs that they had taken, and the final workshop allowed participants to share their experiences with each other. In the first workshop, participants' experience and resulting knowledge of the mental health act, and surrounding systems were acknowledged by the researchers. The researcher's lack of knowledge of living in the current climate with mental illness and being detained was also explored. Researchers were careful to identify their roles as providing a platform for participants to share their stories and be heard. It was important to consider the power dynamics between the research team and the participants. Although we framed the participants as being equal to the research team, there will always be inherent experiences and processes that set the two apart, for example the research team being employed by an academic institution. A member of the research team with lived experience of being detained under the MHA attended workshops where possible. Ideally, all workshops would have been co-facilitated with people with lived experience. However, limited resources and time meant that that wasnot feasible.

In between the first two workshops participants took photographs in response to prompts provided adapted from existing photovoice techniques (21), the researchers organised the workshops and made sure film from disposable cameras were developed. Participants were solely responsible for assigning context to the images in the second workshop, then shared their images and experiences with each other in the third workshop. Unlike a traditional facilitated discussion or focus group, the images acted as a focus point for participants to share specific personal experiences and enabled further sharing of experiences amongst participants. The emphasis of the discussion was on the participants' agenda as set by the photographs they had taken, as opposed to having a form of topic guide. More detail on this process can be found in the protocol for the study (13).

The Co-pact researchers were also interested in investigating and exploring any inequalities experienced by participants, which may have been tied to race. There were concerns that participants would be reluctant to disclose any inequalities that they had observed or experienced if they perceived the research team as being associated with their local NHS Trust or employed by the NHS. The research team, with guidance from the patient and public involvement research group (PPIRG), designed the photovoice workshops to be inclusive, safe spaces for participants. Participants were also asked to provide feedback about each workshop they attended, by answering short surveys containing questions written by the PPIRG. In the first workshop, a presentation was given by the research team, which acknowledged racial inequalities within the mental health system and how the research methods being used were different to traditional methods, and thus hoped for a sustained impact. It was explained that participation in the study was envisaged as the beginning of a collaboration between the participants and research team, should participants wish to remain engaged with the study after the workshops. Beyond the study, it remains important that participants have the option to have their names associated with their photographs during dissemination should they want to, rather than defaulting to sharing anonymised photographs which may be disempowering.

Throughout the photovoice data collection, participants appeared to perceive the photovoice workshops as safe spaces where they were empowered to contribute their experiences in an authentic and meaningful manner. Despite anticipations around re-traumatisation, many safeguarding issues concerned circumstances where participants made disclosures that were unknown to their clinical teams (such as eating disorders and being groomed). Participants also disclosed incidents where they had racially abused a member of staff, or other patients on a psychiatric ward. This indicates that participants were in a space where they did not feel judged and were able to share their experiences as a legitimate form of knowledge that would be heard and taken seriously. Researchers were trained in photovoice techniques and had weekly sessions with the wider study team to reflect and debrief of the experiences of conducting the workshops.

4. Participatory research as a vehicle to address to epistemic injustice

Participatory action research (PAR) is primarily concerned with the democratisation of knowledge curation, by ensuring that community members participate throughout the research process to produce authentic outputs which ultimately influence change. Therefore, the principles of how knowledge is curated and shared align with those of an epistemic justice framework. First developed to engage communities in expressing lived experience to inform policy in the early 1990s (22). Photovoice is well recognised as a form of participatory action research that elicits both visual data (photographs) and narrative data (participants' voices). Creative methodologies such as photovoice are useful to engage marginalised groups who have historically been subject to epistemic injustice, to encourage them to reframe and consider their experiences as legitimate form of knowledge that has the potential to inform policy and service design (20).

5. Participatory research and patient and public involvement

From inception, deliberate choices were made to exclude testimonial injustice and promote the voices of lived experience as an integral source of knowledge by using participatory action research methods of photovoice and co-design. The work conducted by Co-pact is not limited to the participants when providing a platform for voices from those with lived experience around detention (23). We have included carers in our PPIRG and advisory group, in which a vast number of professions are represented. The next phase of this work will entail local and national co-design events, in which we will engage several people from relevant communities. The approach taken here enables us to go beyond token service user consultation and fully enfranchise people with lived experience as knowledge creators.

Working within an epistemic justice framework alongside and promoting open interdisciplinary necessitated regular communication across the research team. Weekly meetings have been held throughout the programme of research to enable research team to learn and acknowledge complexity (24), sharing and coping with feelings of distress and discussing power dynamics, all of which can easily contaminate everyday team functions, particularly when focussed on delivering a funded research project. Researchers seeking to create environments where diverse contributions are acknowledged as legitimate forms of knowledge need to be prepared and take reflective supervision to ensure they sustain their health and wellbeing as well as that of the participants.

The study offset risk of testimonial injustice by ensuring people with lived experience of detention were included in the infrastructure of the study, at all levels. For example, the PPIRG is chaired by two Black women; one had experience of being a carer for someone with severe mental illness and one with experience of being detained under the Mental Health Act who was employed by the University of Oxford as a co-Investigator on the study. The Co-pact study also has an advisory board, co-chaired by a Black man, who is an academic with lived experience of detention and advocates for better mental health systems. They bring knowledge, experience, and expertise.

Members of the PPIRG, participants and the research team had joint ventures in raising the profile of Co-pact and our aims. They were interviewed on a radio show and have contributed to a video as a case study for exemplars of participatory work. One participant fervently vocalised how grateful to Co-pact he was for the opportunity to share his experience of detention, and by this hoped to influence service transformation. 'Knowledge is power' it is said by Francis Bacon, and knowledge from those who have been detained under the MHA, empowers them to influence positive change and radical transformation in research, policy and beyond—to society.

6. Conclusion

Approaching mental health research from a perspective grounded in social epistemology can have important benefits. It is commonplace that different actors in mental health care have different experiences and perspectives, and that these exist in a hierarchy of credibility. Typically, doctors, researchers, and allied professionals at the top, and informal carers and service users—especially those detained compulsorily under mental health legislation—are at the bottom. In the past, the knowledge of lay people has often been framed in terms which privilege professional understanding—notions such as 'health beliefs' or 'mental health literacy' are often explicitly formulated so as to bring laypeople into alignment with professional thinking. By contrast, taking participants' accounts seriously as knowledge in their own right can enable us to appreciate it in its full complexity and yield genuinely emancipatory and humane opportunities in research and service development.

Participatory action research, and creative methodology such a photovoice may offer practical way to engage with and elevate the voices of people with lived experience in mental health research. In addition, embedding people with lived experience in the infrastructure of any research and facilitating continued and open dialogue around the interpretation and sharing of any findings in integral to addressing epistemic injustice.

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

RM finalised the manuscript and integrated comments over several iterations. CD drafted the first version. RM, BB, FK, DJ, and KB contributed text, introduced edits to improve the final paper, and reviewed and agreed to the manuscript prior to submission. 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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Epistemic injustice and mental health research: A pragmatic approach to working with lived experience expertise

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"Epistemic injustice" refers to how people from marginalized groups are denied opportunities to create knowledge and derive meaning from their experiences. In the mental health field, epistemic injustice occurs in both research and service delivery systems and particularly impacts people from racialized communities. Lived experience involvement and leadership are often proposed as methods of combatting epistemic injustice, a tool for ensuring the views of people at the center of an issue are heard and can inform decision-making. However, this approach is not without challenges. In this paper, we draw on our work as intermediary organizations that center lived experience perspectives to challenge epistemic injustice. We highlight two problems we have identified in working in the mental health research field: "elite capture" and "epistemic exploitation". We believe that these problems are barriers to the radical and structural change required for epistemic justice to occur. We propose a pragmatic approach to addressing these issues. Based on our work we suggest three considerations for researchers and our own organizations to consider when involving people with lived experience. These include reflecting on the purpose of creating knowledge, with a focus on impact. Embedding lived experience roles, with appropriate employment, support and remuneration, and acknowledging that it may be necessary to work alongside existing systems as a "critical friend" while developing new spaces and structures for alternative forms of knowledge. Finally, the mental health research system needs to change. We believe these three considerations will help us better move toward epistemic justice in mental health research.

KEYWORDS

lived experience, epistemic injustice, elite capture, epistemic exploitation, mental health

1. Introduction

"Epistemic injustice" is a form of systemic discrimination relating to the creation of knowledge (1). It occurs when people from marginalized groups are denied capacity as "epistemic agents" (i.e., as creators of knowledge), and are diminished or excluded from the process of creating meaning (2). Such exclusion creates conditions in which the lived experiences of marginalized people are primarily interpreted by people who do not share their social position (3). Consider the example of Cartwright, an early proponent of racial medicine, who observed enslaved Africans escaping from their slave masters. He interpreted this behavior as evidence of a mental illness called "drapetomania", ignoring more plausible explanations (4). Contemporary examples of such scientific racism are plentiful (5).

Epistemic injustice is common in mental health care and mental health research. Historically, the knowledge of people with "lived experience" of a mental health issue has been devalued in favor of clinical, academic, and professional knowledge (6). Those delivering mental health care, for example, psychiatrists, psychologists and other support roles, are afforded the assumption of credibility within the mental health system and are prioritized in shaping its policies. Concurrently, those receiving mental health care are often less influential, even when shared decisions are made or feedback is sought, despite the stakes being higher for them in terms of outcomes. More broadly, the evidence base of clinical guidelines tends to rely on positivist notions of a research "gold standard" hierarchy, which marginalizes experiential knowledge in favor of systematic reviews, meta-analyses and randomized controlled trials (7, 8).

"Lived experience involvement", "co-production" and other such terms are underpinned by a recognition of the epistemic power dynamics in the provision of mental health services and knowledge creation. As an approach, lived experience work recognizes that marginalized people are rarely afforded the opportunity to theorize their own experiences and generate solutions. Accordingly, we explore the experiences of two UK third-sector organizations, Black Thrive and the McPin Foundation, that prioritize "lived experience" to combat epistemic injustice. We draw from our work as intermediary organizations to discuss challenges we have identified in moving toward epistemic *justice* in the health and social care infrastructure and research ecosystem. The paper concludes with our perspective on taking a pragmatic approach to achieving progress. It is important to note that there are different views on what constitutes lived experience expertise (9), for the purpose of this paper it refers to the knowledge and skills gained through the experience of a particular issue or set of circumstances rather than academic or professional knowledge. In the context of our work, this often includes the experience of poor mental health and racialization.

2. Background

Our ability to acquire knowledge and understanding is influenced by our social positioning, identity, and experiences (10, 11). At the same time, when these characteristics are associated with a marginalized group, the knowledge acquired may be seen as less credible due to bias or prejudice against the group (1, 12). The exclusion of knowledge from marginalized groups creates a conceptual vacuum. This has real-world impacts as policy and practice decisions are being made in the absence of "conceptual resources" based on lived experience knowledge (or "standpoint").

Feminist standpoint epistemologists argue that knowledge and new conceptual resources can be created through struggle and critical engagement with oppression. These new conceptual resources dependent on, and developed by, marginalized communities expand our understanding of social situations. Consequently, models and theories developed from lived experience perspectives better recognize the complexity of marginalization and may generate tools for more equitable allocation of societal resources. As Toole says "a conceptual resource is developed to fill some gap in our conceptual understanding, but these resources travel only if they are found to be useful by those who are similarly situated" (11).

An example of this process is the rise of service user involvement in mental health research (13) and Mad Studies (14, 15). The knowledge created by psychiatric survivors has been instrumental over the past 25 years in enhancing mental health practice and research (16, 17). For example, both peer support in the community and peer support workers within mental healthcare were implemented based on research underpinned by survivor knowledge and leadership (18–20). Further, a more recent example from our work was research into the disproportionate impact (including mental health impacts) of the COVID-19 pandemic on marginalized communities (21) undertaken by community peer researchers in one borough of London, United Kingdom (22).

Organizations such as Black Thrive and McPin exist in an "intermediary" space between people with lived experience of mental healthcare, academia and/or practice. We may be asked by academic researchers to broker relationships with people with "lived experience' and to bring "marginalized" perspectives into academic systems. We have spent a combined 15 years championing the value of lived experience expertise, including in leadership positions, and can offer knowledge on the practicalities of doing so. We are seeing more interest in "inviting in" lived experience, with many funders now making it a requirement, however, this comes with the risk of tokenistic involvement. On the surface, people in the knowledge creation ecosystem may be eager (or coerced) to include lived experience. Nevertheless, it exists in the shadow of a positivist medical model of psychiatry which perpetuates epistemic injustice (6, 23).

There are significant barriers to the creation and legitimization of lived experience knowledge and research paradigms led by mental health survivors and service users. Knowledge production is mostly geared toward higher education institutions. Working outside academia, being employed in third-sector organizations or as independent research consultants inhibits the legitimation of lived experience research. In our experience on university-led research projects, lived experience contributors mostly work in *ad-hoc* roles contained in "advisory groups", with knowledge generation controlled by those in senior positions. Limited funding, short-term contracts and tight deadlines do not allow sufficient resources for training and development for some people with lived experience, and they face challenges within systems that are rigid in relation to academic culture or workplace expectations. These issues also limit the ability of academic teams to learn and invest in approaches such as co-production and community research. Those affiliated with a university-based research team, such as peer researchers using lived experience as part of their role, tend to be part-time and face assimilation pressures to maintain the status quo. In academia, "knowers" are expected to hold certain kinds of conceptual knowledge to navigate the system and follow traditional and mainstream approaches. Breaking away from these normative codes requires extensive efforts, including emotional labor (24) and there are challenges when bringing lived experience into existing, often harmful, structures.

3. Our concerns

We know there are challenges in achieving epistemic justice. We identify two mechanisms, "elite capture" (25) and "epistemic exploitation" (11), which limit the impact of lived experience in improving research to genuinely reflect, and be led by, the needs and experiences of people at the center of an issue.

3.1. Elite capture

Roles like "lived experience consultant" or "lived experience researcher" are subject to selection pressures. Social advantages determine who engages and excels in such positions. This elevation and maintenance of a small cohort of marginalized people can be considered "elite capture" (25). In mental health, lived experience involvement is reliant on normative conceptions of mental wellness. Those deemed "too unwell" (e.g., sectioned), "too mad" (e.g., holding alternative views), or "unskilled" (e.g., unable to communicate in ways valued by the system) are excluded. Those invited to contribute are those who can work within systemic constraints of academic and professional behavioral norms, forming an elite subset of a marginalized group. Similarly, the deference of powerful actors to a small "lived experience elite" may buttress the current system, leading to fewer voices, less diversity, narrower goals, and greater alignment between the "lived experience" and elite interests. This reduces the potential for radical solutions.

Nevertheless, we recognize that the experience of trauma *per se* is not adequate preparation for contributing lived experience to knowledge production. Other expertise, skills and resilience are also required. Having an "elite "group who can manage the burdens of lived experience involvement allows *some* influence in the structure of academia. These people can use their lived experience to gain insider knowledge of systems, enabling them to potentially advocate for more voices, translate jargon for others and to move into substantive (non-precarious) roles. In time, this may contribute to systemic change by embedding marginalized voices, but this alone will not lead to epistemic justice because it also relies on gaining patronage and approval from those in existing positions of power or privilege.

3.2. Epistemic exploitation

Epistemic exploitation is an epistemic injustice that arises from the expectation of dominant groups that marginalized people will educate them through testimony as to their oppression (11). Indeed, there are many cases in which lived experience is essentialized (26) and isolated from other knowledge and expertise. The "isolation" of lived experience expertise from other forms of expertise prevents people from providing other kinds of insight. It can lead to lived experience expertise being reduced to a testimony (epistemic exploitation), of limited influence and usefulness, distracting from the overall goal of equality and justice. As Lorde said,

> "This is an old and primary tool of all oppressors to keep the oppressed occupied with the master's concerns. Now we hear that it is the task of women of color to educate white women–in the face of tremendous resistance–as to our existence, our differences, our relative roles in our joint survival. This is a diversion of energies and a tragic repetition of racist patriarchal thought." (27)

Epistemic exploitation reinforces power imbalances. Those in power may fear their own authority and privileges (gained through study and professional experience) being undermined or devalued. They may worry about getting the "right" people involved, or for the need for "representative" people, creating barriers for marginalized people, including Black people and/or people who have experienced mental distress, who are more likely to have had their journeys in education and employment disrupted. Additional challenges arise when asking people to center their lived experience of systems and services that may have harmed them, such as a Local Authority or the National Health Service (NHS), particularly when those systems are unlikely to change.

Our organizations have recently worked together to address systemic change during an employment project based in south London. In the Black Thrive Employment Programme (evaluated by McPin), Black people with experience of living, or caring for someone, with a long-term health condition were part of a "working group". The group used their collective experience to make funding decisions about local employment support, redistributing power away from funders to local people. Peer researchers were recruited to deliver a developmental evaluation of the program and join its working group. The program created accessible resources, developed from working group discussions and decision making, i.e., "knowledge developed by knowers".

The working group is an example of where we have experienced elite capture. Members were selected as representatives of local people racialized as Black and with long-term health conditions. This group reflected on representing the "Black experience", a concept that they felt was homogenizing. The group also lost members over time. The remaining group was more effective at meeting project demands, which included making funding decisions in a way that replicated funder practices. At the same time, and possibly as a result, group members reported feeling pressured to make the "right decisions" (i.e., the ones that traditional funders would make). We sought to remedy this by recognizing the diversity of opinion and individual experiences, providing training, and concluding that the group could not be representative of the wider population and needed better terms of reference. Of interest, this group were engaged from conception in using a range of both lived experience and other skills, including graphic design, facilitation and networking, consequently limiting the impacts of epistemic exploitation.

4. Progressing epistemic justice

In practice, Black Thrive and McPin conduct, and support involvement in, research. But we also act as "critical friends", challenging academic orthodoxy and supporting people with lived experience to influence or to do their own research, including as embedded peer researchers. There are unintended consequences of this; we may contribute to elite capture or epistemic exploitation. As intermediary organizations with limited power in academic systems, we struggle to effect sustainable change through incremental involvement and increased recognition of lived experience expertise. However, through our experience of working in this way, we see three issues that academics and other researchers, including ourselves, should consider.

First, researchers must consider what the purpose of knowledge is. Research that includes lived experience should take a pragmatic approach to knowledge, considering it as a tool for action "which brings us into a more or less satisfactory relation with the world" (28). Pragmatism is an orientation which evaluates research in relation to the outcomes and other consequences it generates. It invites us to consider not "how" research is done but its effects. Incorporating lived experience into a research project does not guarantee that the consequences of the research are epistemically just or even have the potential to create justice. Researchers and organizations should reflect on whether the knowledge we create serves any useful purpose for those with lived experience. If social change is not a core aim of the research, then inviting lived experience into the research process can be oppressive in its own right.

Our understanding of who the knowledge serves is as important as the knowledge itself (28). We may find ourselves balancing lived experience against learned (or professional) experience alongside academic expertise, drawing on the strengths of all positions and highlighting their value to have real-world impact. At Black Thrive and McPin, we care about what new knowledge is intended to do, whose interests are served, and what its wider impacts may be (positive or negative), keeping in mind unintended consequences that may perpetuate epistemic injustice.

Second, a good proxy for the value placed on lived experience are conditions of employment and remuneration. Research organizations and funders must ensure more people with lived experience define the focus of research and occupy meaningful roles to make decisions. In many instances, academics and other professionals will argue that lived experience is central to their research while at the same time remunerating lived experience via temporary payroll arrangements and one-off payments. This casualization maintains a status quo where people in senior positions have more power to influence knowledge creation and limits the pool of people who can work in such precarious employment relationships. In this regard, Black Thrive and McPin operate differently, because we recognize the importance of life experience in understanding and changing systems of oppression and marginalization. We specifically recruit people with those experiences into substantive roles. In both organizations, most substantive staff have lived experience of mental health issues, caring responsibilities or, in the case of Black Thrive – anti-Black racism. We also have *ad-hoc* positions based on people's preferences to allow accessibility for those who prefer fewer hours or greater flexibility. If lived experience is central to research, then it should be reflected in the workforce and in our research methods. Driven by neoliberalism structural workforce issues favor consultancy models and commodify trauma and oppression, in turn limiting the radical potential of lived experience.

Third, working pragmatically may mean working with unjust systems rather than overhauling them. This can conflict with the political, activist roots of working from a lived experience perspective (9, 14, 15, 29). The irony is not lost on us. Radical change calls for the creation of "new rooms" (30) where hierarchies are flattened and diverse experiences are heard, rather than bringing lived experience into the same structures that created the current problems (6, 25). We have found new spaces and structures do not always accommodate the needs of marginalized groups within marginalized groups because of elite capture. A positive example of a "new room" is the recently launched International Mad Studies Journal, seeking to create spaces for alternative knowledge and marginalized voices, and operating outside the traditional academic publishing system (31). In working toward creating epistemic justice, we must reflect on the voices we hear, and more importantly, those we do not hear.

5. Conclusion

Epistemic injustice is prevalent across mental health care and research because the expertise of people with lived experience is devalued in favor of "professional" knowledge. Organizations such as Black Thrive and McPin operate between lived experience and academia. In this paper, we have attempted to share our experiences of some of the ways in which the potential impact of lived experience is diminished by wider research culture.

We highlighted the problem of elite capture, the idea that those who are able (and invited) to contribute lived experience may be unrepresentative of those who share the experience. Those who are brought in to contribute lived experience may become, or are selected based on, their alignment with the status quo. We also highlighted the issue of epistemic exploitation, long recognized by Black feminists (11, 27), where lived experience becomes a perpetual testimony with little influence or utility for justice.

Our observations remind us that incorporating lived experience expertise into dominant academic paradigms will not create systemic change. We proposed the following principles to help researchers and others progress epistemic justice. The first is for greater pragmatism when considering what the research will do and how it can potentially bring about social justice. Many people are tired of engaging with research that does not lead to change particularly when it is used to maintain the status quo. Secondly, researchers and their institutions must consider the terms under which they employ people with lived experience expertise. If lived experience is crucial then it must be remunerated with stable conditions of employment. The current "consultancy" model only creates space for a tiny minority who can afford such precarity. Finally, we believe that people with lived experience must be supported to pursue their own research priorities, not just to support the interests of others. This requires new spaces, not recreating the same structures that produced the current conditions.

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

CO, TM, VP, DR, and DB contributed to the conception and design of the manuscript. CO wrote the first draft of the manuscript. TM and DR wrote the second draft of the manuscript, VP and DB wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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Conflict of interest

Publisher's note

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The Patient and Carer Race Equality Framework: a model to reduce mental health inequity in England and Wales

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The Patient and Carer Race Equality Framework (PCREF) is an Organisational Competence Framework (OCF), recommended by the Independent Review of the Mental Health Act as a means to improve mental health access, experience and outcomes for people from ethnic minority backgrounds, particularly Black people. This is a practical framework that should be co-produced with and tailored to the needs of service users, based on quality improvement and place-based approaches. We aim to use the PCREF to address the longstanding epistemic justices experienced by people with mental health problems, particularly those from minoritised ethnic groups. We will outline the work that led to the proposal, the research on racial inequalities in mental health in the UK, and how the PCREF will build on previous interventions to address these. By taking these into account, the PCREF should support a high minimum standard of mental health care for all.

KEYWORDS

competency framework, public mental health, mental health inequality, ethnic minority, epistemic injustice

Background

People from ethnic minority backgrounds, particularly those who have Black African or African-Caribbean heritage, are disproportionately subjected to involuntary admission; have longer average lengths of stay in hospital; have higher rates of repeat admissions; may have higher rates of seclusion (1); are up to ten times more likely to be placed on Community Treatment Orders (CTOs) (2); are less likely to be offered psychological therapies and have higher drop-out from psychological therapy when they are offered it (3–5). These inequalities have developed in the context of White Eurocentric models of care, treatment and illness, as well as the historical context of colonialism.

In June 2017, the then British prime minister, Theresa May, commissioned the Independent Review of the Mental Health Act, chaired by Professor Sir Simon Wessely. This arose following longstanding concerns over the experiences of patients who had been detained under the Mental Health Act 1983 (amended 2007) (MHA), in particular those of Black African or

African-Caribbean heritage. The more recent increases in MHA detention rates, between 2008 and 2016, added to concerns that service users from some ethnic minority backgrounds were having poorer experiences of care within mental health services.

Shortly before this announcement, in 2016, the Crisp Commission noted that patients and carers should be supported to play an even greater role in their own care as well as in the design, provision, monitoring and governance of mental health services (6). It was argued that just as there is a Workforce Race Equality Standard (WRES) to reduce inequalities in NHS staffing (7), there should also be a focus on the patient and carer perspective regarding care. To address this, the final report recommended that a Patients' and Carers' Race Equality Standard (PCRES), akin to the Workforce Race Equality Standard (WRES), should be piloted in mental health services/care to improve the monitoring and experience of care for people from minority ethnic communities. The Crisp Commission began a shift from focusing on workforce issues to focusing on patient and carer needs. What they did not suggest, however, was a mechanism for how this might be achieved. The Independent Mental Health Act Review suggested that an organisational competence framework might be the way to achieve this, the Patient and Carer Race Equality Framework (PCREF).

This paper explores how the PCREF could be a mechanism to work toward achieving epistemic justice, by creating the conditions for the collective knowledge base of racialised or ethnically minoritised people to be advanced. Indeed, the independent review of the MHA described the PCREF as 'a new community-driven Organisational Competence Framework Tool' which should enable Mental Health Providers (MHPs) to understand what practical steps they need to take to meet the needs of diverse ethnic backgrounds'. In this sense, the PCREF aims to function as a race equity and accountability framework, to support MHPs to demonstrate how they are meeting core legislative requirements relating to inequalities, and how they can improve the cultural competence of their organisation.

Key roles of the PCREF include supporting MHPs to improve their interaction with racialised or ethnically minoritised people and to ensure institutional accountability so as to improve experiences of care and treatment. One of the implicit challenges in this is acknowledging and overcoming the existence of power asymmetries, encompassing not only uneven power relations between service users/survivors and mental health professionals more generally, but also the compounded disadvantage as a result of systemic racism. Fricker's theory of epistemic injustice provides a helpful foundation to explore and shape the forementioned roles of the PCREF, particularly the interactions and approaches to accountability between MHPs and people whose voices have been marginalised (8).

Introduction

This paper sets out by reviewing some of the main approaches to reducing racial and ethnic inequalities in mental health care, including training, stepped care and culturally adapted provision. It does so with the aim of identifying the strengths of such approaches, while also making the case for alternative approach to removing racial disparities. The authors present the PCREF as an approach which can play a vital role in improving access, experience and outcomes for racialised or ethnically minoritised people by providing an accountability framework which is located at strategic levels for each MHP, and is connected to actions across an organisation, providing a form of accountability to patients and carers. This paper describes the process from which the PCREF materialised, and details broadly its component parts. Emphasis is placed on elucidating the priorities and principles which underpin the PCREF.

Epistemic injustice recognises that the creation of knowledge is never neutral (9). Fricker advanced ideas of epistemic injustice to elucidate the means by which marginalised groups are silenced, their opinions and experiences invalidated, "*specifically in her capacity as a knower*" (2007, p. 18), and how opportunities for alternative knowledge production and meaning-making are excluded. In very few places, if any, will this be more visible than in mental health services. Understanding whether and how the PCREF can help to address this imbalance for racialised or ethnically minoritised people is an additional purpose of this paper (10). The following section locates elements of the PCREF within the conceptual framing of epistemic injustice. It aims to illustrate how far the PCREF can go to addressing epistemic injustice in mental health, including the potential limitations and opportunities. A discussion of the main themes is presented, reiterating the need to prioritise race equality in mental health.

Models aiming to reduce inequality in mental healthcare

There are existing interventions which attempt to reduce racial inequalities at both individual and organisational levels. For example, staff diversity training programmes have been implemented across various NHS trusts. These are intended to increase awareness of unconscious biases and to teach staff to mitigate their impacts on staff-patient interactions. However, existing evidence suggests that diversity (11, 12) and unconscious bias training in their current forms have limited effectiveness. Studies on unconscious bias training have found minimal positive (13) or even unintended, negative outcomes (14, 15), that may potentially reinforce bias. It is equally concerning that these approaches tend to focus on change at an individual level and have rarely been evaluated in terms of their effectiveness to produce change at the systemic level.

Given the absence of a strong evidence base, we must continue to explore and evaluate the underlying logic behind current and future interventions in the UK. Social epidemiologist Zinzi Bailey and her colleagues argue for an underlying approach based on "structural competency, cultural humility and cultural safety" (16). They cite policies employed within health and professionals' training programs in several countries, such as Canada and New Zealand, as examples. Pre-registration training should encourage a "lifelong commitment to self-reflection and mutual exchange in engaging power imbalances along the lines of cultural differences." Similarly, Hardeman and colleagues argue that health professionals already practising in the field can still "learn, understand, and accept" the current and historical basis of structural racism, encouraging cultural humility and furthering equity in clinical care and health research (17). The views above reflect the considerable ambitions behind these interventions and imply that an active learning process is needed to achieve them. While these programmes appear positive, it is unclear how such models would take effect in multicultural Britain, which developed from a unique and complex set of circumstances (18). Further, there remains very limited evidence of these training programmes being effective at reducing racial inequality at a system wide level (19).

Critics have questioned whether it is possible to facilitate comprehensive and sustainable learning within short-term interventions. As Byrne and Tanesini stated, one-off workshops and superficial cultural competence courses in medical education are insufficient to address unconscious racial bias (20). While common interventions such as mindfulness and implicit association tests (IAT) may be useful supplementary tools (21, 22), the potential for meaningful benefit can depend largely on the individual's own motivations (23).

Other areas of research have focused on holistic interventions which offer a wider range of options to patients, reducing the effects of structural factors. Bhui and colleagues' 2015 systematic review found that methods which improved access, engagement and outcomes for minority ethnic patients included complex interventions that engaged with social systems, stepped care and information and training for patients to support them to negotiate the mental health system (24). A further finding of this study was the importance of individual staff responsibility and monitoring which chimes with wider findings about the importance of individual and organisational accountability to achieving improved outcomes (25, 26). These findings were corroborated by the National Institute for Mental Health in England (NIMHE) community engagement project which used similar patient-focused strategies (27). Key improvements included better awareness and understanding of mental illness overall and how it is experienced by people from minoritised ethnic backgrounds; stronger engagement from services toward the community; better data provision and information dissemination to the community, and closer communication between the community and commissioners. Finally, user-led research has also emphasised that recovery is a dynamic process, requiring a flexible approach that focuses on engagement over a particular model of treatment (28, 29).

In terms of tangible policies, Penner and colleagues have suggested that a healthcare system of "aggregated" information could reveal patterns of neglect in individual patient care, such as one patient having repeated admissions for the same underlying issue (30). They argue that, by using algorithms tied to demographics such as socioeconomic status and race, it may be possible to identify mechanisms linked to systemic discrimination. This sounds appealing, however, the structure would need to include and be flexible toward patient reports (31). Of course, there is also the danger of this algorithm itself incorporating and reproducing unconscious biases (32).

Another in-depth, co-produced approach is the recently developed Culturally Adapted Family Intervention (CaFI) (33). The authors actively involved African-Caribbean people in their local communities and used Community-partnered participatory research (CPPR) (34) to find solutions related to psychosis and schizophrenia "with" the patients rather than "for" or "about" them (35). Using pre-existing models of family therapy, they added two further elements to strengthen its capacity to meet the specific needs of African-Caribbean service users and their families (36). These placed racism and discrimination, as well as alternative (non-Western) conceptualisations of mental illness, as central to the therapeutic process. The authors described the result as: "a focus on positive health and maintaining 'gains', better tailored relapse planning and using preventative strategies in an 'assets-based' approach toward community health. This catchment-specific approach enables setting bespoke criteria for good mental health outcomes in addition to standard ones." As a result, CaFI complements several existing models (such as Open Dialogue; (37)) that seek to reduce power imbalances, but it encourages a more detailed consideration of culture, marginalisation and discrimination.

Overall, there is considerable scope to improve outcomes following targeted interventions to reduce mental health inequalities. As outlined above, interventions should focus on behaviours and foster curiosity and lifelong learning, which requires systemic support.

A patient-focused race equality framework – the PCREF

The Mental Health Act African and Caribbean (MHARAC) working group of the Independent MHA Review asserted that, without a method for delivering them, the recommendations from the Crisp Commission would fail to be enacted, as with many other recommendations around race equality. The MHARAC group suggested that a competency framework approach was needed, similar to that taken by Roth and Pilling, a framework implemented to support the delivery of psychological services (38). Their paper sets out a method to summarise the evidence base, co-produce a set of competencies and develop these into a comprehensive model and training scheme. The idea arose for an organisational competency framework (the Patient and Carer Race Equality Framework, PCREF), practical guidelines, co-produced with and tailored to the needs of service users, based on quality improvement and place-based approaches.

The MHARAC group used evidence from a number of quantitative and qualitative sources to develop recommendations aimed at addressing the disproportionate detention of Black, Asian and Minoritised Ethnic people, particularly Black people, under the Mental Health Act 1983 (MHA). A mixed-methods approach helped to support this decision-making process:

1. Two Roundtable discussions at No.10 Downing Street with professional experts and Experts by Experience convened to explore the possible reasons for increased detention rates.
2. A series of 8 focus groups with people from Black, Asian and Minoritised Ethnic backgrounds were held across England and Wales.
3. A survey was conducted which received almost 2000 respondents from service users and carers (39–41).
4. Two working groups were set up to explore experiences with the MHA; one focused on people from Black African and Caribbean heritage (MHARAC) and the other focused on people from Asian and other Minoritised Ethnic groups (AME). A Service User and Carer Group (SUCG), oversaw and helped to integrate these workstreams. Some members of the SUCG were also core members on specific working groups.
5. As part of a suite of evidence reviews conducted for the overall Independent Review, the MHARAC group commissioned reviews on ethnicity and detention; substance use and workforce.
6. The MHARAC group used a formal consensus approach to derive coherent and evidence-based recommendations. This

utilised a quasi 'Nominal Group Technique' which has been previously used to develop clinical guidelines (42). The process began with each person independently generating ideas and then sharing these through a series of discussions. The group synthesised these ideas, taking into account the quantitative research and qualitative evidence from the survey and focus groups, in addition to feedback from the working group members. The group then collectively formed recommendations and prioritised them, according to those most likely to produce real and lasting change in racial inequity in Mental Health Act detention. Numerous recommendations were generated, however, it was accepted that only a limited number of recommendations could be put forward for inclusion in the review.

Discussions centred on the following:-

1. There should be expectation of equality of access, experience and outcome. Co-production and the ability to learn about, understand and address the needs of those from a different culture to the practitioner should be fully embedded across mental health institutions, clinical and research, from service development to delivery and from hypothesis generation through to data collection, implementation and review.
2. Institutions should provide the necessary resources to collect high quality data that is sensitive to both diversity and intersectionality.
3. Commissioners and service providers should be supported to understand and address the needs of their local communities.
4. Closer attention should be paid to the inequalities that exist within some minoritized ethnic groups over the lifespan and their relationship with poorer social, clinical and economic outcomes, e.g., higher rates of adverse childhood experiences (ACEs) (43, 44).
5. Certain minoritized ethnic groups have 2-4x the average rate of school exclusions (45); although this likely stems from longstanding systemic inequality, evidence-based preventive interventions should be implemented for at risk pupils and their access to mental health support strengthened through non-coercive pathways.

One of the main considerations driving the thinking behind the development of the Patient and Carer Race Equality Framework (PCREF) were the findings from the Barnett et al. (46) meta-analysis. This not only replicated the findings of higher rates of detention in minority ethnic groups from previous studies (47, 48), but also noted substantial heterogeneity in the samples of Black and other ethnic minority groups entered into the studies, and that despite this, these groups were treated as homogeneous. Barnett et al. concluded that this crude approach to classification has prevented the translation of research involving minority groups into effective interventions to reduce inequalities in care.

Barnett et al. also reported the explanations given by the researchers when they observed higher rates of detention amongst ethnic minority groups. Notably, 47% of the reviewed articles provided either no evidence or very weak evidence to support their conclusions. This is a significant problem: these explanations have informed future research and interventions, yet the authors were unable to verify the strength of most claims. Many of the untested hypotheses involved stereotypical cultural and demographic assumptions of minoritised ethnic groups, including drug use, language barriers, illness expressed as violence and stigma. Barnett et al. concluded that this situation was "problematic," having argued that such hypotheses possess little value when applied to heterogenous groups. Nevertheless, perspectives arising from these explanations are easily perpetuated and generalised into policy and commissioning.

The Barnett review indicated that for many years, researchers, clinicians and policymakers had been basing their decisions on flawed conclusions. It was postulated that this may explain why 40–45 years after the increased rate of detention of ethnic minority individuals in the UK was first noted (49–51), there have been few interventions which have reduced these disparities. The ensuing discussions formed the basis of the MHARAC group's recommendations, which are outlined in brief below.

1. The rise in use of the Mental Health Act 1983 (amended 2007) has been influenced by factors at various levels of governance (52). To improve access, experience and outcomes for people from minoritised ethnic backgrounds, there should be better standards of feedback, review and quality improvement procedures in mental health services across the UK.
2. Rather than simply being a set of competencies decided centrally to address racial disparity to which an organisation must adhere, the PCREF is a model of working which involves an organisation learning how to develop a system, using a competency framework approach, to address the racial inequality in its services, based on the needs of the local population. An organisational competency framework defines the skills, knowledge, and characteristics required from staff in an organisation in order to fulfil the strategic priorities of that organisation, in this case achieving equality of access, experience and outcome in mental healthcare for people from minoritised ethnic groups. Organisational competency frameworks are commonly used to improve individual and organisational performance in large institutions, but have not been applied to racial equality in mental health. Applying this successful approach to improving equality within mental health organisations should reduce racial disparity in access, experience and outcomes.
3. The first step to achieving this will be to ensure a minimum standard of data collection to reduce variability in data collection (2). Following this, each mental health Trust must develop its own competencies (38), co-produced with the local community and tailored to meet the needs of its unique population. This requires a change in the usual approach to service development which traditionally involves developing a service, then inviting those who will use the service to comment on it (a consultation approach). With the PCREF, the expectation is that from the outset, the local population are invited to develop a collaborative partnership with the provider mental health organisation and together devise services that will better meet the needs of the local population. By being specifically designed with and tailored to the needs of the local population, mental health services are likely to be more accessible; the experience more acceptable and the outcomes better than the current service offer. By developing services in

a more collaborative way, this approach gives those experiencing mental illness greater power in the relationship than currently exists between those providing mental healthcare and those receiving mental healthcare. The competency framework should include competencies focused on the policies, procedures and processes of the institution as well as the competencies expected of the individuals working within the organisation. Each organisation will go on to set co-produced internal standards based on these competencies and local data, with iterative review and an expectation of yearly improvement. It is this yearly improvement that can be subject to external scrutiny and quality assessment by regulatory and commissioning bodies.

4. In practise, there will be many commonalities between the competence frameworks developed by different organisations, however the priorities will differ depending on the needs of the local population. This has similarities to models proposed in the USA whereby benchmarking frameworks can be adapted and contextualised to local differences, but with a focus on cultural competency (53). Although developed to address issues within mental healthcare, this approach could be used in other organisations to support them in addressing racial inequalities.

The PCREF method is an organisational transformation approach using techniques based on/not dissimilar to those used to support transformation in large non-health organisations (54). Transformation is not simply organisational change, i.e., doing what the organisation does, but better, it is re-defining what the organisation does compared with what it does now (55). Focusing on achieving equity in mental health services, means that services will aim to move from providing good care to a proportion of its local population to providing excellent care to all of its population.

The PCREF aims for a maturity model approach (56) which can support an organisation with self-improvement, the focus of the improvement being the development of an equitable service. "*Maturity models (MM) are based on the premise that people, organisations, functional areas and processes evolve through a process of development or growth towards a more advanced maturity, going through a distinct number of levels.…The basic concept underlying maturity is that mature organizations do things systematically, while immature organizations achieve their outcomes because of the heroic efforts of individuals using approaches that they create and use spontaneously*." Maturity models are particularly useful for qualitative data where concrete and static solutions or circumstances are not available. A well-functioning organisation has in-built processes and procedures which are continuously improving; a poorly functioning organization has *ad hoc* processes and procedures which are uncontrolled; very person-dependent and easily corrupted. The aim of the PCREF is for organisations to become equity-led, that is, continuously improving processes designed to ensure racial equality in access, treatment and outcomes, through both incremental and innovative improvements and changes (Figure 1).

Epistemic injustice and the PCREF

Epistemic justice encompasses ways of working and thinking which offer priority and value to people less powerful, including the autonomy for marginalised voices to be central in the development of conceptual resources about lived experience. By following an approach rooted in epistemic justice it is recognised that knowledge is socially formed, and regardless of an individual's status or disposition, their testimonies should be validated and heard.

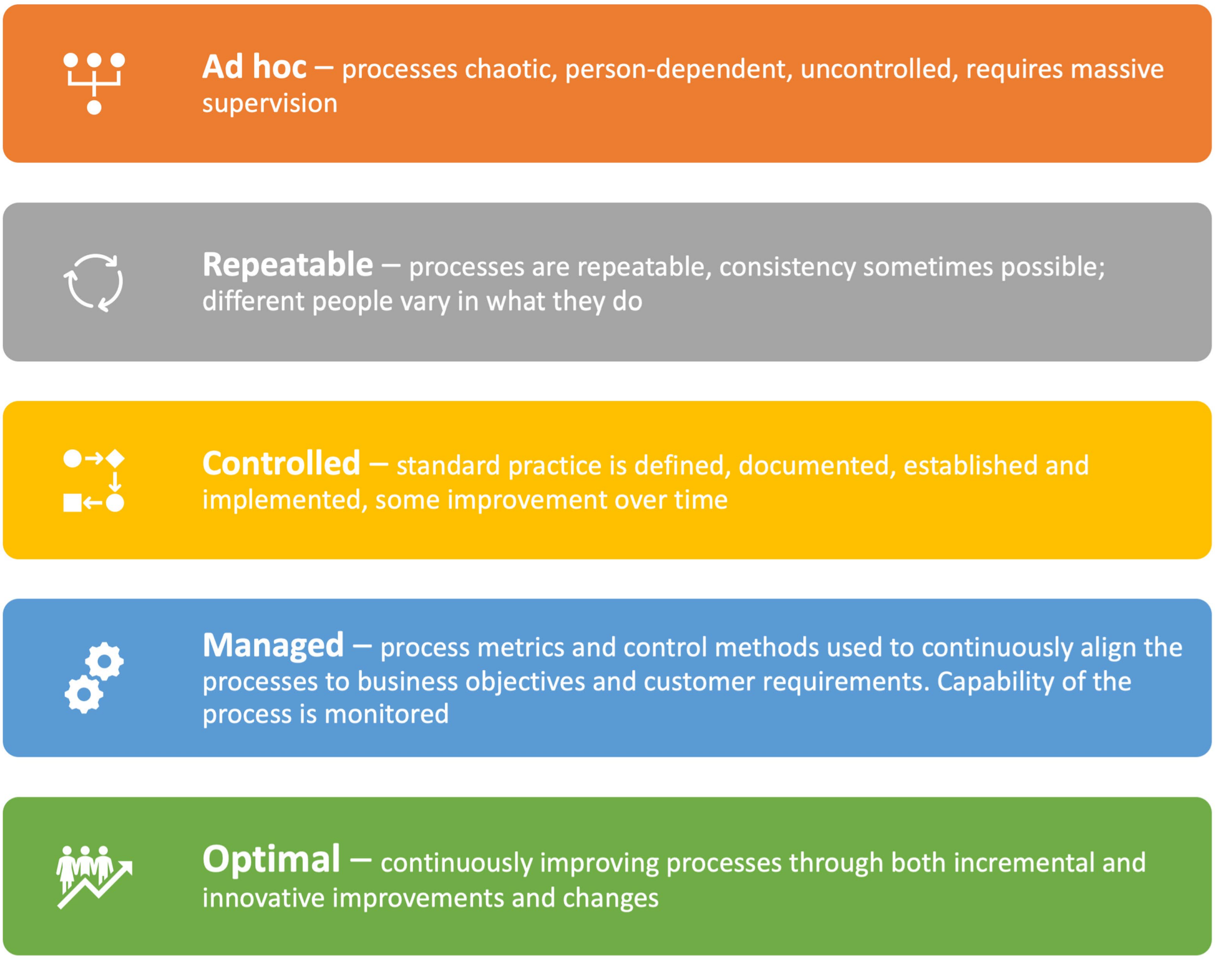
As a discipline which has favoured professional or clinical knowledge, mental health care is a key site for the study of epistemic injustice (57, 58). Such injustices can include being misrepresented, exluded from discussions or being silenced. Often the positions of psychologists, nurses, psychiatrists and other mental health professionals are viewed as reliable, whereas the positions of those with lived experience more often discredited. Framed within a system of Eurocentric frameworks and systemic racism, the silencing of racially minoritised service users is especially profound. It is against this background of micro-interactions and macro level dynamics that it is important to ask, what might the PCREF offer? Does it have a place in challenging epistemic injustice? If so, what might this be, and what could it look like?

As Russo points out, the focus in the application of Fricker's work across mental healthcare has largely placed emphasis on the need 'to listen better and empathise more'. Certainly, these are essential components which can allow racialised service users to indicate their experiences of care, mistreatment or trauma (59). However, across some race equality initiatives, such as those described earlier, (e.g., unconscious bias training), it is difficult to see a space for epistemic justice. It is therefore important to consider the sites where the PCREF can be more influential in fostering epistemic justice for racialised people and where there are likely to be limitations.

For the PCREF to become operational it will to some extent depend on data. This opens up a wider discussion about the way performance measures are identified locally and the kinds of data used as indicators. As Okoroji and colleagues have commented, there is a penchant within healthcare to rely on "positivist notions of a research 'gold standard' hierarchy, which marginalises experiential knowledge" (60). Numerical data on service access or outcomes in terms of equality monitoring can also be situated within positivist framework. Therefore, how much specificity and scope will the PCREF have to encourage MHPs to fully engage the testimonies of racialised lived experience, and the space and capacity for service user groups to be leading their own process of creating meaning.

Co-production is now viewed as one of the main approaches to engaging service user perspectives. Alongside partnership working, it is one of the features of the PCREF and the mechanisms through which engagement with racialised groups will occur. Ensuring at a strategic level that racialised people need to be involved in such processes is a step in the right direction. However, it is important to also recognise the possible limitations of co-production.

Rose and Kalathil refer to co-production as a 'third-space' which risks producing and reproducing already racialised hierarchies of knowledge (61). They present compelling cases of co-production which have perpetuated and engendered feelings of the 'racialised mad', 'minoristised' and 'othered'. They conclude that genuine knowledge production cannot happen in places where the markers of dialogue are constrained, be this government or academic spaces, where strong traces of hierarchical, White, Eurocentric thinking remain. They guard against co-production being merely tokenistic and not truly informative. Rose and Kalathil suggest co-production will



Ad hoc – processes chaotic, person-dependent, uncontrolled, requires massive supervision

Repeatable – processes are repeatable, consistency sometimes possible; different people vary in what they do

Controlled – standard practice is defined, documented, established and implemented, some improvement over time

Managed – process metrics and control methods used to continuously align the processes to business objectives and customer requirements. Capability of the process is monitored

Optimal – continuously improving processes through both incremental and innovative improvements and changes

FIGURE 1
The characteristics of well-functioning organisations, from a maturity model perspective (56).

not be able to democrastise knowledge and efforts must be found in service user movements (61).

The idea that service users can be involved in the co-design of culturally adapted services has paralells with the CaFI project described earlier, and is presented in the PCREF as an area of organisational competency. Such an approach clearly has advantages; evidence indicates there can be improvements to experiences, especially when support has been found to be culturally affirming (62). At the same time, as with CaFI, involving service users in the design of services at the outset is an improvement on typical models found in healthcare. While the limitations to co-production have already been addressed, Russo eloquently describes how conventional applications of epistemic injustice 'leave the concepts of 'mental illness' or 'psychiatric disorder' unquestioned'. This is a limitation which must be acknowledged with culturally adapted models which retain traditional biopsychosocial framing, and a point of consideration in relation to how far the PCREF can go to encouraging interventions which fully embrace the challenge of epistemic injustice.

The PCREF offers an opportunity to shape the way MHPs are accountable to patients and carers. However, a key emerging question relates to how far the PCREF can go in specifying the types of activities and data which will demonstrate some level of accountability. To some extent, this is not only a potential limitation of the PCREF but of the working parts which it has to incorporate within its framework, such as co-production. To address epistemic injustice, interventions must at least be considered across the remit of addressing testimonial and hermeneutical injustices.

The focus on partnership within the PCREF is a key area where epistemic justice could be realised. For example, establishing non-hierarchical partnerships with the Black Voluntary Sector (BVS), and service users movements, provides an opportunity for the collective knowledge base of Black people to be advanced. The BVS (also referred to as ethnocentric or ethno-specific support) has been identified as being particularly suited to racialised minority people. Keating has posited that the BVS offers the most relevant support to racialised groups because their work is based on different conceptual ideas about what it means to experience mental ill-health than do state services (63). Further, he argues that the BVS embraces the whole person when combating mental health problems rather than other models that define mental ill-health within a traditional biopsychosocial framework. Fernando makes a similar point when he suggests the BVS will bring in social and political issues within sessions, which are less likely to be brought into discussion within statutory provision. He suggests this means that a greater variety of personal problems can be considered including those which are racialised (64).

When considering Fricker's distinction between testimonial and hermeneutical injustice, the BVS can be viewed as an alternative space of knowledge production. BVS organisations offer a place for service users to search for understanding and organically develop their own meaning frameworks and resources. Hermeneutical injustices can hinder testimonial justice, as those racially marginalised may not have the professional language, legislative knowledge or medicalised frames of references or access to resources to be utilised when in hierarchial epistemic encounters. In a similar way as culturally appropriate group advocacy (65) may offer solidarity to generating collective hermeneutic resources, which can positively impact testimonial justice, by providing a means for equitable participation and shared meaning making, fully embracing the opportunities for partnership working with the BVS could do the same. For example at the South London and Maudsley Hospital Foundation Trust, a pilot site for PCREF, service users and carers are trained in quality improvement techniques, in the same way as staff members, so that they can generate QI ideas that enable them to develop services (personal communication).

Discussion

The consistent overrepresentation of Black African and Caribbean people in detention reflects wider systemic failures to respond to the needs of minoritised communities, and these disparities have not been reduced by major policy initiatives such as the 2005 Delivering Race Equality programme (66). We argue that these policies have not sufficiently understood the wide-ranging and intersecting factors that lead to structural inequity, which have resulted in inadequate prevention of mental health problems.

Not only could the PCREF achieve improved patient outcomes in access, experience and outcomes, but it also has the potential for economic benefits. An analysis suggested that in recent years, detentions under the MHA have increased substantially beyond the expected range, with the surplus alone costing approximately £75 million per year (52). This has had a disproportionately negative impact on Black people, who have consistently made up around 10% of total admissions over this period, despite only making up 3% of the UK population (52). This substantial inequality is a logical target for investment in order to ensure the NHS is more efficient in the long-term. If detention rates were proportionate to the percentage of Black African and Caribbean people in the population (3%), the basic annual cost to the NHS of detaining Black people would be reduced by an estimated £130 million (41). The PCREF should provide a means to help identify the causes of these inequalities and incentivise measures to address them.

The available evidence indicates the need for a PCREF approach. There is also a legal duty to address mental health inequalities. For example, the Public Sector Equality Duty under the Equality Act (2010) involves having "*due regard*" to the need to remove or minimise disadvantages suffered by people due to their protected (demographic) characteristics (67). Furthermore, in the United Nations' recent evaluation of the UK's adherence to human rights, they expressed concern about ethnic disparities in restraint, segregation and seclusion across settings, all of which take place under the MHA and the EHRC published guidance to support minimising and non-discriminatory use of restraint (68). The lack of improvement in ethnic disparities despite these imperatives, including the Public Sector Equality Duty, indicates that simply making recommendations is insufficient to bring about change. The PCREF represents a formal implementation method designed to aid transformation.

At its core, the PCREF will aim to further embed true co-production with service users and carers, and joint working between health, social care and voluntary sector services. These are also key priorities across national mental health policy, including the recent expansion of community mental health services (69), which draws on stepped care principles. While on the one hand it is recognised that it is too often the case that knowledge of people from minoritised ethnic backgrounds has drawn on the views of mental health professionals alone (70), the extent to which co-production can be a panacea to epistemic injustice, rather than just a modest improvement, will require each organisation to develop specific PCREF competences around how to ensure true co-production.

There are other areas where epistemic injustice might occur and where the PCREF might be able to support, for example, specific issues relating to cultural racism, when for example, the patient's view of the progression of their care may differ from that of the professionals providing that care (71). An aim of the PCREF is to amplify the patient and carer voice in treatment planning. The experiences of racialised people growing up and living in a society within which they are systematically disadvantaged are all too often not even considered and when they are, may be dismissed. There is a challenge to ensure that dialogues include experiences of racism and take account of the systematic failure to include racialised people in knowledge production. As the PCREF will provide a lead for the development of comprehensive monitoring structures, ensuring closer alignment between local patients' preferences and the care services provide to them, the opportunity is available to improve relationships between patients and clinicians, and increase the likelihood that they will engage with services, which may improve patient outcomes (72–74).

Finally, there is a need for continued advancement toward a mental health service that adequately reflects and engages with diversity in the UK. The need for this was identified as early as 1957, when a prominent ethnopsychiatrist outlined the divergence in psychosocial frameworks between first-generation Nigerian students and British psychiatrists (75). Mental health services still lack a mechanism to define, measure and evaluate cultural appropriateness. The required improvements in patient, carer and staff outcomes, as called for by the Old Problems, New Solutions report (76), cannot be realised without a bespoke framework that can regulate these issues at multiple levels of governance. The authors propose the PCREF can be part of the solution, but this will require genuine non-hierarchial relationships being developed with patients and carers and organisations. For a more meaningful attempt at addressing epistemic injustice in mental health this will require willingness to rethink the hegemonic model of 'mental illness' and bringing the knowledge of marginalised groups more to the forefront.

The PCREF aims to ensure that patients, carers, and the wider community, can be partners with mental health services in the delivery of support, care and treatment. This is the foundation of a high quality of care for patients of all backgrounds. Racial disparities in access, experience and outcome are both a symptom and a cause of unsatisfactory partnership working. By prioritising these areas, the PCREF should lead to more efficient mental health services, by promoting early intervention in the community thereby reducing the number of patients who present to secondary care in crisis.

Conclusion

This paper has demonstrated the need for a PCREF, illustrating the disparities present in the access, experiences and outcomes to healthcare and making the moral and legal arguments to solve these. This practical framework, co-produced with and tailored to local service users, is based on quality improvement and place-based approaches. The PCREF focuses on four basic principles outlined in the Independent MHA Review: using a rights-based approach; focusing on dignity and patient autonomy; maximising patient choice and the right to advocacy; and standardising the path of least restriction and justification of therapeutic benefits.

These proposals are "good to think with." Williams and Cooper suggest that mental health services require renewed emphasis on creating an environment of access to high quality care for all, including the consolidation of primary care, as part of healthcare delivery, and diversifying the healthcare workforce to more closely reflect the demographic composition of the patient population (77). The authors rightly term this as "putting more health into the delivery of healthcare." We agree that more qualified research is needed to identify tailored methods of raising awareness of implicit bias and unconscious discrimination in mental healthcare and providing organisations with strategies to minimise its occurrence (77). This is included as part of the MHARAC recommendations, since it is recognised and asserted that despite the need, there is a scarcity of high-quality research and data collection. In terms of addressing social determinants, health care providers should indeed be "proactively engaged in connecting patients" with supportive social services (77). We believe that the PCREF can achieve this whilst making "effective use of local community resources and strengthening our surrounding communities," as well as ensuring that "both community residents and institutions receive needed knowledge and technical skills to maximise the potential impact of interventions" (*ibid*). The model of the PCREF is therefore one of co-production with service users rather than a top-down approach.

We must emphasise that these recommendations are not calling for immediate radical restructuring. Rather, we are proposing incremental changes which should have impactful and, crucially, long-term accumulative effects. This is rooted in values of safe, equitable practise, ensuring that a high standard of care for all patients is at the heart of mental health service provision. The PCREF recommendation has been endorsed by the UK government who have funded four pilot sites.

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

SS: conceptualisation, visualisation, methodology, investigation, writing – original draft, and supervision. AK and KA: visualisation and writing – original draft. SG, AS, TL, and DE: conceptualisation, methodology, and writing – reviewing and editing. CT: writing – reviewing and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

Six authors took part in the 2019 Independent Review of the Mental Health Act (1983) African and Caribbean Group (MHARAC): SG as co-chair, SS as vice-chair, and KA, AS, TL, and DE as contributors. DE and SS are also co-applicants on the National Institute for Health Research-funded Culturally Adapted Family Intervention (CaFI) study.

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.

The handling editor CK is currently organising a Research Topic with the author AS.

Publisher's note

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The truth project paper one—how did victims and survivors experience participation? Addressing epistemic relational inequality in the field of child sexual abuse

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The last 30years has seen an exponential increase in Historical Institutional Abuse Inquiries.[1] One feature of these has been to place adult survivor voices at the center of Inquiry work, meaning that child abuse victims and survivors[2] are engaging with Inquiries, sharing their experiences, with this participation often presented as empowering and healing. This initiative challenges long held beliefs that child sexual abuse survivors are unreliable witnesses, which has led to epistemic injustice and a hermeneutical lacunae in survivor testimony. However to date there has been limited research on what survivors say about their experiences of participation. The Truth Project was one area of work of the Independent Inquiry into Child Sexual Abuse[3] in England and Wales. It invited survivors of Child Sexual Abuse to share their experiences including the impacts of abuse and their recommendations for change. The Truth Project concluded in 2021 and heard from more than 6,000 victims of child sexual abuse. The evaluation of the Trauma Informed Approach designed to support survivors through their engagement with the project was a mixed methods, two phase methodology. A total of 66 survey responses were received. Follow-up interviews were conducted with seven survey respondents. The Trauma Informed Approach was found to be predominantly helpful in attending to victim needs and minimizing harm. However, a small number of participants reported harmful effects post-session. The positive impacts reported about taking part in the Truth Project as a one-off

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[1] While the literature refers to Historical Institutional Abuse Inquiries and we also use that descriptor here, it is important to note that many victims and survivors, including IICSA's Victims and Survivors Consultative Panel, object to the use of the term historical and prefer non-recent abuse. This is due to the distancing quality that the term historical can evoke, while for many survivors the CSA experiences are anything but historic. Therefore in this paper, out of respect for our victim and survivor feedback, we will refer to IICSA as a non-recent institutional child sexual abuse inquiry (NRICSAI). Related literature refers to Historical Institutional Abuse Inquiries and will be referred to as HIA Inquiries.

[2] IICSA conducted substantial consultation on terminology at its outset and the consensus from people impacted by CSA was that they wished to be referred to as both victims and survivors as different people identify with each of these descriptors at different times. We have sought to reflect that preference in this paper by alternating between the two or using both terms at once.

[3] The results and interpretation presented in this study are based on research carried out by clinical and research staff at IICSA, and are not representative of the views of IICSA's Chair and Panel.

engagement challenges beliefs that survivors of child sexual abuse cannot safely talk about their experiences. It also provides evidence of the central role survivors should have in designing services for trauma victims. This study contributes to the epistemic justice literature which emphasizes the central role of relational ethics in the politics of knowing, and the importance of developing a testimonial sensibility when listening to marginalized groups.

KEYWORDS

institutional child abuse inquiry, child sexual abuse, trauma informed approach, epistemic justice, testimonial sensibility

Introduction

Prevalence and impacts of CSA

Definitions of Child Sexual Abuse (CSA) vary but most refer to "forcing or enticing a child to take part in sexual activities" (1). Prevalence rates vary; estimates globally suggest somewhere between 8–31% of girls and 3–17% of boys are victims of CSA (2). In England and Wales where this study was conducted, it is estimated that 3.1 million adults experienced CSA before the age of 16, equivalent to 7.5% of the population (1).

The long-term health impacts of CSA are significant (3). These include increased exposure to a range of mental health conditions; depression (4), anxiety disorders (5), psychosis (6), dissociative disorders (7), in addition to Complex Post-traumatic Stress Disorder (C-PTSD) and Post-traumatic Stress Disorder (PTSD) (8). There is also increased risk of chronic physical health conditions, including respiratory conditions (9), diabetes (10), and premature death (11).

Historical institutional abuse Inquiries

Over the past three decades, alongside growing awareness of the impacts of child abuse, there has been increased recognition of public institutions involvement in its perpetration and cover up (12). Increased awareness has arisen from media exposure and campaigning activism by victims and survivors (13). Over the past two decades there have been Historical institutional abuse (HIA) Inquiries conducted in all four countries of the UK, Australia, Canada, New Zealand, Ireland, the Netherlands, Sweden, Switzerland, Norway, Jersey, and Germany (12).

HIA Inquiries differ in focus, structure and remit; with some focusing on the failings of one institution, such as the Ryan Commission into Catholic Church administered residential care in Ireland, while others including the Australian Royal Commission have looked into the conduct of a broader range of institutions (14). However, one emergent common feature has been the shift in emphasis toward the centering of survivor perspectives, a shift that has been described as the "turn to testimony" (15). This "therapeutic turn" led to HIA Inquiries developing new forms of public engagement that augmented the traditional method of providing evidential testimony under oath at a Public Hearing.

However, while HIA Inquiries claim to have become survivor centered and their participation has been framed in therapeutic justice terms (16), there is limited evidence detailing what survivor participants report about their experience of engagement. One study, conducted following the Northern Ireland HIA Inquiry, highlighted the use of therapeutic discourse around healing and closure, and linked it to Transitional Justice frameworks focused on recognition and reparation for historical harms (17). The study found that there was mixed evidence about how victim centered their participation was, more than half said it was a positive experience, while a sizable minority found it to be exposing (39%) and led to longer term emotional consequences (29%). Almost half the participants described the experience as traumatizing (47%). The study concluded that participation should not focus exclusively on therapeutic outcomes for victims and survivors, but to take a broader perspective on victim needs. A further study looked at the experiences of participants in the Australian Royal Commission into Institutional Responses to CSA (18). The research included interviews with 26 survivors, with a majority reporting respectful and humane treatment, that contrasted with their previous experiences of minimization and denial by institutions. The recognition of participants by the Commission was argued to bestow a "dignification" that can counteract the traumatic shame of CSA, and positions Inquiries as public spaces in which "therapeutic politics" (19) can promote both personal healing and social change.

Epistemic injustice and the politics of knowing

One conceptual framework that can be used to understand the historic marginalization of CSA survivor testimony, and the shift toward survivor centered processes in HIA Inquiries is Miranda Fricker's work on epistemic injustice (20). Epistemic injustice refers to a person being "wronged specifically in their capacity as a knower" (21). Fricker's theory is specifically concerned with the ways in which the reliability of testimony is predicated upon the listener's evaluation of the credibility of the speaker. The credibility of the speaker is a key issue when the listener is drawing conclusions, based on the identity markers associated with the speaker as well as what they are trying to communicate (22). For example, in mental health, people with psychiatric diagnoses may be seen as less reliable because of long standing societal discourses about madness and unreason, making their testimony suspect by virtue of their association with this group (23). People who have experienced CSA have a long history of being described as unreliable witnesses to their own experiences, with institutional, disciplinary, and scientific power being deployed to undermine their testimony (24).

Examples of CSA survivor testimony being disregarded as unreliable can be found within the practices of the psy disciplines of psychology and psychiatry. False Memory Syndrome (FMS) is a psychological theory originally developed through experimental studies examining the capacity of research participants to be manipulated into believing fictitious things had happened to them, thereby creating “false memories.” Very quickly FMS theory was assimilated into criminal cases where it was used by the defense to argue that the complainant had been manipulated into believing she was abused by counsellors and therapists fixated on finding evidence of childhood trauma to explain psychological and psychosomatic complaints in adulthood (25). The development of a discourse suggesting some CSA survivors were falsely remembering sexual abuse had a profound impact on the public imagination and was picked on by the media as evidence of a moral panic around CSA (26). This “discourse of disbelief” (27) has been mobilized to undermine the testimony of survivors not only in family cases, but also in institutional settings, and has been characterized as a discursive contest about knowledge and pitting scientific evidence against survivor testimony (19). From an epistemic injustice perspective, the epistemic credibility of CSA survivor testimony has been undermined by claims to science of FMS psychologists. This has led to a hermeneutical lacunae where survivor knowledge have been superseded by widespread skepticism about the veracity of the extent of CSA in contemporary society (19). This knowledge gap creates a hermeneutical injustice (21) for survivors who lack a shared, socially sanctioned framework to discuss their experiences of CSA, leading to limited opportunities to disclose, seek help, and a lack of different forms of justice. The establishment of IICSA and other HIA Inquiries, therefore offer an opportunity to provide survivors with a form of testimonial justice, while also creating discourses that validate survivor identity and enable CSA to become an articulated, shared and destigmatized social concern (12).

Why this matters so much can be understood in relation to Fricker’s definition of social power; “a practically, socially situated capacity to control others’ actions, where this capacity may be exercised (actively or passively) by particular social agents, or alternatively, it may operate purely structurally” [(21), p. 14]. In this instance, survivors of CSA are subject to control over the believability of their testimony about abuse, with this social power being exercised indirectly by social agents in the form of scientific psychology, and research into false memories. However, while the capacity to control credibility is passive and indirect, psychologists are not necessarily directly intervening to question the testimony of an individual survivor, although they might be, the consequences are active and structural. In other words, by creating doubt about the testimony of non-recent CSA survivors in general, there are practical consequences for specific survivors when they try to access justice or disclose to other forms of authority about their non-recent abuse. The setting where we can see this structural form of social power play out most forcefully is the criminal justice system, where evidence about false memory and unreliable testimony is used routinely by defense barristers to cast doubt on the credibility of survivors, and in some cases this may include expert witness psychologists providing testimony to the research evidence and how this is relevant in a particular case (28). There are significant gaps between prevalence of CSA and reporting, prosecution and conviction rates; with estimates of around 500,000 children being abused in a single year in England and Wales, compared to police reports of 67,675 in 2021 cases, and 3,420 convictions for CSA related offences the previous year (29). Given this gap between estimated prevalence and conviction rates, it seems improbable, to say the least, that the over-reporting of non-recent CSA is a greater risk than under-reporting, and yet a wealth of social power, from psychological science, through expert witness testimony in courtrooms, is deployed to undermine survivor testimony. It is therefore crucial that Public Inquiries like Independent Inquiry into Child Sexual Abuse (IICSA), which operates a different form of social power and one that validates survivor testimony, are examined with an epistemic justice lens, to understand how they can offer restorative justice to a previously maligned and stigmatized group.

Research aims

The current HIA literature suggests that Inquiries increasingly aim to be survivor centered, that sharing their experience can have therapeutic outcomes, and that there is limited and mixed evidence regarding how well they attend to victim needs. Two questions arising from this are, how should HIA Inquiries address survivor needs and avoid causing harm? More specifically, are Trauma Informed Approaches (TIA) an effective model for engaging survivors in Inquiries and if so, in what ways?

A final research aim concerns analyzing the work of HIA Inquiries through an epistemic injustice lens. This allows concepts from the epistemic injustice literature to be operationalized in practical HIA Inquiry settings, and can enable insights into how elements of epistemic justice can be linked to the testimonial justice and trauma informed care that are offered at HIA Inquiries.

This study aims to address these questions by drawing on data generated from victims and survivors who participated in the Truth Project. A brief overview of the Truth Project, and the TIA literature will be presented to situate the findings in context.

Independent inquiry into child sexual abuse and the truth project

IICSA was established as an Inquiry in 2015 to investigate “whether public bodies and other non-state institutions have taken seriously their responsibility to protect children from sexual abuse in England and Wales, and to make meaningful recommendations for change, to ensure that children now and in the future are better protected from sexual abuse” (3). The Truth Project was a core part of IICSA, linked to one of the Inquiry’s terms of reference from the UK Home Secretary, to “consider the experiences of survivors of child sexual abuse, providing opportunities to them to bear witness to the Inquiry, having regard to the need to appropriate support in doing so” (30). The Truth Project was accountable to the Inquiry Chair and Panel, and a Restriction Order was put in place to ensure the anonymity of participants. There was a statutory obligation to report all allegations of child abuse to the police (31).

The Truth Project was piloted in 2015 and from 2016 to 2021, over 6,000 adult victims and survivors shared their experiences via face-to-face sessions, telephone and video calls, or in writing. It was

TABLE 1 Participant demographics.

Age		Gender		Ethnicity	
Over 65	9	Female	53	White/British	52
56–65	22	Male	11	Jewish	1
46–55	16	Non-binary	1	Romany/Trinidadian	1
36–45	11	No response	1	Gypsy/traveler	1
26–35	5			Black British	1
Under 25	3			British Indian	1
				Not answered/other	9

co-designed with the IICSA's Victims and Survivors Consultative Panel (VSCP), a group of CSA survivors who have expertise in the field. The experiences shared with the Truth Project were used for research to ensure survivors' voices were included, to add to the evidence in the field of CSA, to help IICSA in its development of recommendations to prevent CSA in the future and improve institutional responses (32).

Trauma informed approaches

TIAs are an organizational level intervention that recognize the health and social impacts of traumatic stress and have an awareness of the ways that institutions may reenact traumatic dynamics when delivering services to victims and survivors (33). TIAs recognize the impacts of trauma, while also structuring the organization and the practices of staff to minimize the risks of retraumatization.

TIAs have been applied in a range of settings, including: child welfare units (34), psychiatric inpatient units (35) justice systems (36) domestic violence shelters (37), and homeless services (38).

The evidence base for TIA implementation and impact is mixed. A recent systematic review of 32 TIA studies across a range of service settings for various typologies of abuse, found a significant reduction of PTSD symptoms in around half the studies examined (11 of 23) (39). A review of TIAs impact on child welfare settings, found implementation variability, with staff training being the most frequently evaluated form of intervention (40). In community adult mental health and addiction settings, the closest evidence base to the area investigated in this study, there is limited evidence available. Studies show some reduction in PTSD symptoms, improved service engagement and reduced use of emergency care, but no impact on other outcomes such as substance misuse (41–43).

Independent inquiry into child sexual abuse's model of trauma informed approaches

IICSA developed a TIA model for the Truth Project (TP) that was designed by psychology staff and members of the VSCP. VSCP members did an end-to-end walk through of the model to evaluate what it would be like for victims to participate, making adjustments to environmental and interpersonal features accordingly. For example, VSCP members booked on to a session to check the booking process offered choice and control. They attended and participated in a Truth session to evaluate the staff skills and environmental considerations. VSCP members had a background in sexual violence services and so imported this knowledge, service philosophy, and therapeutic orientation; as well as offering lived experience. The TIA model was therefore a hybrid drawing on the literature but also survivor expertise. It emphasized five components: (1) Recognizing that the experience of child sexual abuse is subjective and individuals should be respected; (2) Being aware that trust is not to be taken for granted, but fostered; (3) Empowering victims and survivors in their interactions with the Inquiry; (4) Prioritizing the safety and well-being of victims and survivors and working to prevent retraumatization; (5) Acknowledging the impact of child sexual abuse and institutional failures, therefore, looking out for staff wellbeing. The TIA was operationalized in a range of ways through staff training, and integration into all Truth Project processes such as communications policies, complaints processes, as well as building and website design. This was supported by a full-time consultation service delivered by clinical staff. Staff support and training have also been evaluated as part of this study and are described in another paper in this issue (Barker, Taggart, Gonzalez, Quail, Eglinton, Ford, and Tantam).

There was also a three-stage trauma model support service available to all Truth Project participants, delivered by a team of counsellors and support workers, and co-designed by the VSCP. Participants could opt-in to the service at any time, which a majority did (78%*), and utilize as much as they chose to. This included a support worker offering telephone-based support prior to the Truth session to plan around support needs, identifying any risks and session preferences; emotional support on the day of the session, and follow-up support after the session for up to 2–3 weeks.

Method

Participants

Ethical approval for the study was sought via consultation with IICSAs independent ethics research panel. People were eligible to participate in the study if they had attended a TP session. Eligible participants were identified through the Inquiry's Victims and Survivors Forum (VSF), a platform IICSA established to engage with victims and survivors in order to consult them on specific projects. A total of 66 individuals completed the mixed methods survey. The demographics of this group, shown in Table 1 below, differed when compared to the general population of Truth Project participants.[4]

Twelve participants were contacted for a follow up semi-structured interview. They were recruited using a purposive sampling strategy, identifying individuals who appeared to be able to offer further rich data, based upon what they had already shared. Further, individuals were selected to reflect the diversity of the sample; including ethnicity, gender, age and time since Truth Project session (44). Seven participants responded and completed the telephone

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[4] It was noted that there was a higher proportion of female respondents to the mixed-methods survey and a slightly lower proportion of white British participants, resulting in a more ethnically diverse sample when compared to Truth Project data (https://www.iicsa.org.uk/key-documents/26714/view/truth-project-dashboard-august-2021.pdf).

interview. Of these two were male and the remaining five were female, indicating a higher proportion of male participants than was seen in the overall sample. However, the majority of those who responded were white British and, as such, ethnic diversity was not reflected.

Of the 66 participants who completed this survey, the majority took part in the TP in person (50 people). Of the remaining participants, 10 took part over the phone, three over video link and three in writing. The majority had taken part in the Truth Project 1–3 years ago, with 15 people having participated more than 3 years ago, and eight having done so within the last year. Of this sample, 36 took up the support offer, while 30 did not.

Procedure

A mixed-methods survey was developed based on IICSA's model of TIA by two researchers who were not involved in the setup of the model but were IICSA staff (CB & SF). Participants were asked to rate the extent to which the Truth Project (1) Enabled them to feel empowered in their engagement (2) Treated them as an individual (3) Acted in a trustworthy way (4) Avoided retraumatization and (5) Created a safe environment for them in their engagement. They were asked five closed questions based on the extent to which the Inquiry fulfilled each of the five TIA principles, with a range from 1-not at all to 5-all of the time. In addition to ratings, participants were asked to provide details of instances where they felt the Truth Project either did or did not fulfill these aims. A further open question was asked about their overall view of how the TIA was implemented and for any other aspects of their experience with the Truth Project they wished to report.

A purposive sampling (44) strategy was used to identify participants for follow-up interviews. The semi-structured interview allowed for elaboration on aspects of participants' responses to the initial survey, in particular any issues raised by participants suggesting a negative experience.

Analysis

The qualitative data was entered into Microsoft Excel for thematic analysis. The semi-structured interviews were recorded, transcribed and analyzed, and then added to the survey data to produce one qualitative dataset. The amalgamation of different forms of qualitative data garnered from survey and semi-structured interview respectively, was done for pragmatic reasons due to the Truth Project's fixed lifespan and time limits on the study. However, attention was paid during analysis to how the semi-structured interview data could complement the larger number of survey responses, without overwhelming it.

Two authors (CB and SF) conducted the qualitative analysis, with another (DT) cross checking coding decisions to ensure reliability. Research supervision meetings were held throughout analysis to discuss emergent themes and to manage differences in coding. The qualitative data from both survey and interviews were analyzed using a six stage Thematic Analysis. The first stage required a thorough familiarization with the data, followed by a systematic identifying and labeling to group the data relevant to the research question. Key patterns or themes were identified followed by a review of those themes. The final two stages entailed a defining and naming of themes, leading to the final weaving together of the themes and narrative to provide the analytic conclusions (45). Given that some of the open-ended questions were generated based on the TIA model (trustworthiness, safety, retraumatization, empowerment and individual care), the data was not analyzed in a purely inductive way, but the data was still subjected to line by line coding to generate initial codes, before developing and refining themes across the dataset, and finally combining and defining themes. Rigor and trustworthiness were addressed in the analysis through the development of a reflexive audit trail of decision making, research supervision, use of data in the findings to promote confirmability, and ensuring credibility through engagement with the full data set before developing themes (46). The VSCP were also consulted throughout the analysis to check on their contributions to the model's development.

Findings

The findings are divided into eight themes. The six TIA related themes: overall experience of the TIA; retraumatization; individual recognition; trustworthiness; empowerment, choice and control; and safety, were all asked about directly in the survey. The other two themes; being believed, the long-term consequences and need for support, contain qualitative data that was not asked about but which emerged as themes during analysis. Quotes are attributed to pseudonyms to ease cross referencing and protect anonymity.

Overall experience of the trauma informed approaches

Five (7.6%) of participants indicated that a TIA is important when working with victims in an Inquiry setting. Of those who spoke about the approach, responses were positive:

> *"…it's just not going to work unless you are trauma-informed. It's a framework that's been very well constructed …" Thomas (interview).*

Many reflected upon the processes and approaches they found helpful. This varied from identifying behaviors used by Inquiry staff, such as listening and showing respect, to environmental considerations:

> *"Apart from the staff being obviously well trained it was the little acts of care like making water, drinks and tissues available. Making the offices quiet, comfortable, calm and private - that made a big difference to me and helped a lot." Kelly (survey response).*

Feeling retraumatized

When asked whether participants felt that their engagement with the Truth Project caused them to re-experience trauma, 36.3% ($n = 24$) reported that they did not feel traumatized at all or very little. However 39.4% ($n = 26$) reported that they did feel somewhat traumatized or felt traumatized most of the time, while 24.2% ($n = 16$) did not indicate either way.

In general, 9.1% ($n = 6$) participants reported that the nature of discussing their experience of CSA is, in itself, traumatizing. However they did not attribute this to having been heightened due to the approach taken by the Truth Project:

> *"I did not feel that anything the project did re-traumatized me. Just the act of talking about it all, some bits for the first time was, of course, very traumatic but this was not contributed to by the project." Kelly, (survey response).*

Others reported there was comfort in knowing what the Truth Project was about and what to expect. This prepared them ahead of their session and helped to prevent them from being re-traumatized as their experience was, somewhat, predictable:

> *"I didn't feel traumatized because it was what was written on the tin was inside." Barbara, (interview).*

Some participants questioned whether a degree of re-experiencing can be seen as part of the healing process:

> *"In some respects I think it was helpful to have had some degree of re-experiencing what had happened, because with distance and maturity I was more able to label and acknowledge what those feelings were, whereas previously I would not let myself go anywhere near them for fear of being overwhelmed." Amelia, (survey response).*

However, 10.6% ($n = 7$) found the process retraumatizing and 3% ($n = 2$) reported the after-effects as long-lasting. The consequences of being retraumatized were generally described in terms of ongoing mental health symptoms:

> *"I suffered a period of depression, PTSD and anxiety having been triggered as a result of sharing my experience with the Truth Project. This has lasted a number of years." Rachel (survey response).*

More commonly, responses from participants indicated that the majority still found benefit in having shared, despite the consequences for their mental health:

> *"For a few weeks after being at the project I had flashbacks, bad dreams and a lot of unknown fears, but I have to say it was worth every ounce of pain." Simon, (survey response).*

Being recognized as an individual

When exploring the extent to which their individual experience of CSA was recognized when engaging with the Truth Project, 84.8% ($n = 56$) felt the Inquiry acknowledged their individual experience of CSA and 6% ($n = 4$) felt that their individual experience was not acknowledged very much, while 9.1% ($n = 6$) did not indicate either way.

Some said they appreciated that the complexity of abuse and the various ways in which it impacts a person was acknowledged:

> *"(There was) recognition that abuse is complicated and often crosses various categories." Helen, (survey response).*

There was a recognition from those that provided qualitative responses that some of the Truth Project processes helped them feel someone had considered how a survivor might feel in that position. One example of this was that they did not need to repeat their story to various people if they did not want to, which was a key aim of the VSCP when they co-designed the model:

> *"The fact that I didn't have to keep repeating who I was, where I came from, and what happened to me helped me to know that I was an individual. I explained things once, and I didn't have to go over it again with another person, it was very helpful and I felt I was a person and not just another victim." Andrea, (interview).*

However, whilst many felt the Truth Project was able to identify and meet their individual needs, this was clearly within a structure which others appeared to feel was too standardized:

> *"They're coming at it from the angle that they don't really know what anybody's going to say or what situation anybody's in so they have to have a vanilla approach to everybody." John, (interview).*

Trustworthiness in the truth project

In relation to the principle of trust, 84.9% ($n = 56$) of participants reported finding the Truth Project trustworthy, while 6% ($n = 4$) said the Inquiry did not act in a trustworthy way and 9.1% ($n = 6$) did not indicate either way.

There was a recognition that trust must be earnt and that the Inquiry did earn this through the way in which they interacted with participants:

> *"I feel trust is gained and the support before, during and after made me feel at ease and I trusted the many amazing staff members throughout." Cathy, (survey response).*

In terms of earning trust, there were many comments about how this was achieved: 6% ($n = 4$) spoke about how confidentiality was maintained within the session and around the environment, as well as how information was handled; while 7.6% ($n = 5$) highlighted the clear communication (through media advertisements or in communication with the inquiry), and the predictability of the process:

> *"There was an integrity between what I was told I could expect at the interview, and what actually happened at the interview. It all matched up and really helped me to feel safe - that this was a process with people I could trust." Andrea, (interview).*

Feeling empowered and having choice and control

Regarding the question about feeling empowered by the Truth Project, 78.8% ($n = 52$) of participants reported feeling empowered to make decisions when engaging with the Truth Project, 10.6% ($n = 7$) did not, and 10.6% ($n = 7$) did not indicate either way.

Participants highlighted the need to feel heard as being a part of facilitating a sense of empowerment:

> *"Trauma survivors want to feel that someone has seen them and is holding them in their strength not as seeing them as fragile or incapable … we often get the message from people in our lives externally that something is wrong with us, we are too emotional or too fragile but we also believe this about ourselves … The truth project did that, held me in my strength." Diane, (survey response).*

When exploring the extent to which participants felt empowered by the Truth Project, there was a consistent theme around choice and control being important:

> *"I had choices about, you know, the times, dates and the gender that I talked to, yes I had those choices." Vicky, (in interview).*

Individuals appeared to view these principles as important because they were in contrast to the lack of choice or control in their experiences of CSA:

> *"I felt like I was in control of what was going on and that my input and that I was important. This felt like the polar opposite of my experience of abuse, where I was not in control, and I was insignificant and did not matter." Amelia, (survey response).*

One participant described in detail how they experienced each stage of their Truth Project journey and afterwards as empowering:

> *"I read the IICSA website a thousand times before I actually summoned up the courage to make contact … once I pressed the on-line button, I felt empowered. … The fact that I could have dedicated time to explain what had happened to me was empowering … Although my contribution was over three years ago, handing over the baton to the inquiry team was so empowering and has considerably helped me with my journey of healing … I feel that if they had not agreed to be on the panel to do their work, my story would have been buried in a secret, unspoken black hole. Sharing my story with a panel member is something I shall never forget - it was so empowering." Andrea, (interview).*

For others however there were mixed feelings because they felt organizations and agencies that they were referred to after the Truth Project, undid or compromised the feeling of empowerment they had built:

> *"After submitting my written statement and feeling like it was important to be heard, I didn't feel empowered by the police." Abigail, (survey response).*

Feeling safe

In exploring the principle of safety, 68% ($n = 49$) reported feeling safe all of the time when engaging with the Truth Project and 28.8% ($n = 19$) reported feeling safe "most of the time," while 3% ($n = 2$) reported that they felt safe "none of the time."

Safety, for one individual, was considered both as emotional safety and physical safety:

> *"I felt very safe emotionally and physically throughout." Christina, (in interview).*

A total of, 24.2% ($n = 16$) of participants identified specific actions that they felt the Truth Project was taking to promote safety:

> *"The care, empathy, body language, language, all made me feel safe." Sheila (survey response).*

Some participants, 4.5% ($n = 3$), described elements of the venue that increased their feelings of safety, such as the location of the session or the layout of the room:

> *"I loved the huge room I was interviewed in. It was like a hall. So much space made me feel safe." Andrea, (interview).*

Others considered this in terms of the boundaries and the support offer that was available to them.

> *"I always felt safe in the knowledge I could stop anytime and that everything was confidential and there would be support afterwards should I need it." Bryony, (survey response).*

Safety was also said to be impacted by external factors and concern about what would happen with the information they shared:

> *"From the time I made contact I felt safe, my only concern was the police contacting me because I knew they had to report it and this was the really big reason that put me off." Barbara, (survey response).*

Responses indicated that safety was, to a large extent, based on interactions with Truth Project staff. This included all staff, such as receptionists smiling and being welcoming, interactions on the phone, support given as well as staff in session.

> *"I felt that I was not judged, and that those around me were not shocked by anything disclosed therefore I felt safe from disclosing the information." Naomi, (survey response).*

Being believed

A central part of the Truth Project is that victim and survivor's accounts are not questioned or challenged and the information they provide is not verified or tested, 13.6% ($n = 9$) of participants discussed this theme.

Five participants indicated that this sense of belief facilitated engagement and shaped their experience, putting victims and survivors in a better mental space to share:

> *"The idea of the name 'the Truth Project' automatically sends the signal that whatever you say will be taken as the truth. The truth until proven otherwise." Vanessa (interview).*

A further 6% ($n = 4$) noted that this aided disclosure as there was no pressure to have to substantiate what they were sharing:

> *"Every piece of information was accepted at face value, they appear to trust implicitly what I disclosed." Shana (survey response).*

This sense of being believed helped shift how their experience was understood and framed, which helped the healing process:

> *"The abuse I suffered as a child was truly acknowledged in the session and by the support I was given before and after it. It had never been acknowledged as serious before even by my parents and I found my experience with the Truth Project immensely healing as a result." John (survey response).*
>
> *"It had always been something that I had tried to minimize, ignore and even deny it although I believe that it did cause me harm. To have the reality of that harm acknowledged has made a huge difference to me." Amelia (survey response).*

Long term consequences and support considerations

The majority of participants indicated that they considered the support during engagement with the Truth Project was helpful and appropriate. However, 16.7% ($n = 11$) did report that they needed longer term support following their Truth Project session:

> *"I feel that the inquiry is trauma informed but I wonder if it is aware of the long-term psychological damage that can be caused for people who open up for the first time ever and then leave the inquiry without any follow up support." Rachel (survey response).*

Without this additional support being available, some participants reported still experiencing negative consequences of having engaged with the Truth Project, at the point of their responses:

> *"More support needed for survivor's. My life has spiraled out of control and I have had another breakdown. I lost my job and am on the brink of losing my marriage. Having to fight another battle is a struggle, I'm doing it alone again …" Lauren (Interview).*

Of the 6% ($n = 4$) who reported to still be struggling with the impact of sharing their experience at the time of responding to the survey, two of them had experienced their session between 1 and 3 years prior to their engagement in this project. A further two were more than 3 years post session:

> *"I was very overwhelmed with the whole experience and apart from the support up until 2 weeks after I've been unable to get support since. I'm struggling more than ever and do regret doing the truth project now knowing how much it has affected me." Natalie (interview).*

Whilst the majority of participants felt that their engagement with the Truth Project was trauma informed, the process of having their information shared with the police and their subsequent interactions with police, were reported as not:

> *"The only negative experience I had was with the Police contact after my Truth session … I did find that upsetting and contrary to the rest of my experience." Amelia (interview).*

Discussion

Overall, these findings suggest that the hybrid survivor co-designed TIA employed by the Truth Project was well received by the majority of participants and facilitated their engagement. The data around the extent to which the Truth Project process was retraumatizing and to what extent the TIA was able to fully mitigate this risk was more mixed. Over a third of participants identified the Truth Project process as at times retraumatizing. The qualitative data suggests that for some participants, talking about CSA carries an inevitable element of reexperiencing that is difficult but manageable. For a small minority however, what engagement with the Truth Project brought up for them was retraumatizing in a way that had long lasting effects on their mental health. A final theme that was not directly asked about but which emerged in the qualitative data analysis was the importance of being believed in their contact with the Truth Project. Belief was linked to longer term healing from the impacts of CSA and previous societal responses to participants.

Historical institutional abuse inquiry scholarship and clinical implications

HIA Inquiries have become a new area of scholarship, with a particular focus on how participation is experienced by victims and survivors and to what extent their needs are taken into account (14, 17). This study adds to that literature and in evaluating the impacts of using a TIA, demonstrates that for many survivors support needs can be addressed via therapeutic means. However there are important caveats to this finding, both in relation to the minority of participants who identified the process as harmful, and also in the scope of what this study investigated in comparison to the broader literature. Based on these findings, while trust was established for the majority, choice and control were offered, and a number of participants described feeling empowered, the levels of retraumatization are of concern. Similarly to Hamber and Lundy's 2020 study in Northern Ireland (17), it would appear that while participation in these forms of HIA Inquiries confer meaningful benefits for victims, these are not without risk, and this needs to be explicitly communicated prior to participation. A key difference between this study and Hamber and Lundy (17), is that the scope of this study was focused on victim experience of the process and did not investigate wider justice needs.

While this study has focused on individual experience, there is support for victim needs being considered in a wider social and political context, with attention focused on a range of justice outcomes (16). This study also supports participation Inquiries as one way to promote healing for survivors of CSA, adding evidence for an approach that validates survivor testimony, and places dignity, as an antidote to shame, at the heart of participation (18, 47). The theme of being believed and having accounts validated, supports the benefits of participation in Inquiries as citizens in addition to survivors, and lends further evidence to these processes as forms of therapeutic politics that can lead to personal healing and social change (19). Based on the findings of this study, it appears that providing survivors with an opportunity to share their experiences offers a form of epistemic justice to repair previous injustices. This took the form of both testimonial and hermeneutical justice. The Truth Project offered a testimonial justice by addressing a previous "credibility deficit" (20) whereby the survivor has had their account invalidated as a result of being a child, evoking prejudice in the listener because of prejudice, or because of the relative credibility of the abuser who denies the allegation. A key form of hermeneutical justice offered is the public visibility of the Truth Project enabling survivors to feel less alone in their abuse, and to develop a new, destigmatised way of talking about non-recent CSA that was previously unavailable.

From a clinical perspective, several participants picked up on the detailed environmental context (room furnishings, refreshments and use of space), and interpersonal qualities of Truth Project staff as key to their overall experience. Through consultation with the VSCP, it became clear that a lot of this attention to detail arose through their "walk through" of the Truth Project process and their authorship of aspects of the model. While the TIA literature in general advocates survivor involvement in service design (33) this can often be backgrounded (48). Based upon these findings, survivor involvement in the design of TIAs are central to the translation of the components into a "felt" sense for Truth Project participants, particularly around creating non-clinical, welcoming environments. The VSCP can be seen to have helped IICSA develop what Fricker has described as a "testimonial sensibility" whereby they were able to take a "critical openness" to listening to survivor accounts. What is of importance is that this sensibility is not rule bound, or at least should not be when fully realized (20). Rather it relies on "the educated improvisations of a moral perceptual sensitivity [(20), p. 73], somewhat akin to other forms of improvisation in artistic endeavors. Given the IICSA staff group were largely made up of civil servants, there is likely to have been challenges for them and the VSCP in encouraging the development of an improvised approach to the development of an organizational ethical consciousness. Perhaps the TIA "rules" were necessary in supporting the imitation of this form of virtue, but there is evidence in the data that some survivors experienced the TIA being integrated in a seamless way, that suggests a less rigid approach. The work the VSCP did as the "in house" survivors, and keepers of knowledge of the dangers of epistemic injustices appears to have been key in creating a milieu where communicating belief was a central task.

This study goes some way to challenge a widely held belief that people can only talk about experiences of CSA in long term therapeutic interventions, and that anything else risks leading to destabilization (49). The majority of the current sample reported positive experiences from participation. The study supports the positive benefits of talking about CSA, in order to challenge stigma and silencing in services, and also wider society (24).

A final clinical implication for future Inquiries is the lack of longer-term support. While choice and control was raised as a positive component by some participants, engagement with the Truth Project was time-limited. This was raised by some of the participants who experienced some reemergence of post traumatic symptoms after their engagement. It may be that future HIA Inquiries can build in flexibility about what longer term support is available, to give participants more choice over the care they receive and to respond to people who have negative responses to participation.

Trauma informed approaches

The findings of this study, around the use of TIAs to support adult victims and survivors of child sexual abuse, fits broadly into the wider evidence base for TIAs. Similarly to a recently conducted systematic review (39) there is evidence from this study that the emphasis on staff training, interpersonal skills, environmental adaptation, and responding sensitively to trauma disclosure were all positively connotated by participants. TIA as a service model had meaningful connotations for many participants and they recognized the importance of a TIA implementation as highly relevant given the population and subject matter. While there is risk of branding over substance in TIA implementation (48) if properly operationalized, TIA as a service design model and philosophical orientation may be adaptable for other non-clinical service settings trauma victims and survivors engage with, such as justice and welfare systems. The TIA staff training implemented by the Truth Project was noticed by several participants and demonstrates that non-clinical staff can be trained in a TIA model and adapt their communication style to take account of trauma. The importance of survivor participation in the TIA development and in staff training was critical in the Truth Project.

Another finding that is pertinent for TIA research is the reported impact that it has when several participants in this study engaged in services such as some police services as a result of their contact with the Truth Project. This is a considerable challenge for service settings with significant safeguarding responsibilities, where the survivor has contracted to work in a TIA service setting but is then referred to external agencies who respond to trauma differently. This study would suggest the importance of making clear to victims and survivors at the contracting stage that external agencies may respond differently to trauma responses.

A final finding pertains to an additional theme, the importance of being believed. This has implications for the links between TIAs and epistemic justice, showing a potential gap in the constructs TIAs incorporate. Fricker suggests, "epistemic trust incorporates ethical trust … seeing a speaker in epistemic color entails seeing them in moral color" [(20), p. 76]. From this perspective not only is belief communicating the epistemic worth of a speaker, it also carries moral weight by recognizing their sincerity. There is no formal recognition of the need to believe trauma survivors in the TIA literature, it is incorporated in other constructs such as understanding the person through a trauma lens (33), but based on this study it could be explicitly included. The communication of belief could also form one part of the dignity conferring processes that are seen as an antidote to the inherent shame of sexual abuse (47).

The truth project and epistemic justice

Considering the research findings in light of the epistemic injustice literature, there are a number of themes of interest. As discussed above, the importance of being believed by the Truth Project was so central to several participants, that they brought it up unprompted. The Truth Project's most obvious achievement is through what is communicated by its name and the ethos of the methodology that arises from it, survivors were believed and not questioned. This granted them what Fricker describes as epistemic relational equality, to compensate for their historic blocking rom making an epistemic contribution (22). It can be argued based on this approach, that the epistemic inequality survivors of CSA have historically faced are linked to other forms of social and economic inequality. The Truth project's own data found a high proportion of survivors described the impacts of CSA on their educational and vocational development, also unsurprising given that outside the home the most frequently cited source of abuse occurred in educational settings (Truth Project dashboard). It is reasonable to wonder if the lack of epistemic equality arising from their CSA experiences are compounded by other, intersectional forms of epistemic injustices based on other aspects of their identity such as gender, mental health status, social class and social capital. One can see the CSA as an original injury that impacts development in ways that increasingly marginalize the person's epistemic worth, making it more challenging for them to be taken seriously as reliable witnesses to their own experience and simultaneously excluding them from a hermeneutical justice whereby they could make meaning of their CSA experiences through engagement with other survivors. One the of most consistently reported impacts of the Truth Project, both in this study and in other forms of feedback to IICSA, was how meaningful it was for people to realize they were not alone in what they had experienced.

It may be that the Truth Project can offer ongoing epistemic legitimacy to CSA by virtue of the scale of participation, however historical analysis would suggest that CSA occupies a paradoxical space in the public imagination, by turns hyper-visible and prone to outraged reactions, followed by periods of denial and disbelief (24, 50). It is likely to fall to activists in general, and survivors in particular, to continue to remind the public and public bodies about the scale of CSA and its impacts which the Truth Project has uncovered. This work carries with it complex demands of survivors, including the emotional labor and risk of retraumatization described in this study (13). A question it raises is that while it is laudable that the Truth Project has advanced the epistemic credibility of CSA survivors by offering a hermeneutical language whereby non-recent CSA can be spoken about by survivors in credible ways, it is another question entirely about whether they should be expected to do so. A key question for clinicians and researchers working in the field of non-recent CSA is what forms of advocacy are needed from them to support CSA survivors without coopting their epistemic claims and translating them into professionalized discourses (51).

This study also links to other scholarship in the area of epistemic justice and mental health. One recent study considered the legitimation of user knowledge in mental health services through a participatory research methodology (23). While they found evidence of support for user involvement in knowledge construction, there were limits to the reach of these forms of knowledge. Similarly in this study, while the Truth Project offered a platform of belief and validation of survivor testimony, it did not necessarily transfer to the epistemic demands of other settings such as the criminal justice system. So while the testimony was accepted as reliable within the confines of the Truth Project, it was not considered to have the same epistemic status as evidence provided at a Public Hearing, something which was similar to other Inquiries (17). This links to an important finding of this study that the TIA operated by the Truth Project was not replicated in adjacent organizations such as the police, that survivors were referred onto. This raises the possibility that the contingent nature of the epistemic legitimacy offered by the Truth Project could set survivors up to fail when they take their knowledge claims into other settings, with a different politics of knowing. Wider culture change to match the development of epistemic justice in one area of public life, needs to be matched by partner agencies, a finding picked up by another study which looked at staff attitudes to increased epistemic agency amongst inpatient adolescent service users (52).

One contribution this study has made to the epistemic injustice literature, is to operationalize some of the philosophical concepts in a way that can be applied. While Fricker suggests it is problematic to turn a testimonial sensibility into a form that makes moral knowledge codifiable, she does point out that rules can offer guidance for someone "en route" to full virute, while not being a substitute for it [(20), p. 73]. Based on the findings in this study it was possible to at least develop a set of rules for engaging ethically with CSA survivors through the TIA, and, crucially, the inclusion of the VSCP in developing a survivor oriented TIA.

The current study was limited in a number of respects. Most significantly was the independence of the evaluation, both perceived and actual. While none of the researchers were involved in the design and initial implementation of the original TIA in the Truth Project, all were involved in its later implementation and were Inquiry employees during the evaluation. From the participant perspective, they were recruited via an IICSA group, the VSF, and so will have been aware that it was the Inquiry itself seeking feedback, potentially skewing what was reported. However the presence in the sample of participants who had more difficult experiences with the Truth Project suggests there were a range of views reported.

Conclusion

This study was a mixed-methods survey based evaluation of a large-scale HIA Inquiry's engagement with adult victims and survivors of CSA. It focused on the implementation of a survivor co-designed TIA that was designed to address victim needs when they shared their experience with the Inquiry in a private capacity. The findings suggest that most participants in the study sample found the TIA addressed their needs and while there was some evidence of longer-term detrimental impacts, this was in a small minority of cases. While more focused research on outcomes needs to be undertaken, there is some support for the use of survivor co-designed TIAs in the support of victims and survivors of child abuse engaging with HIAs. An important component of the TIA was the survivor amendments to the model, which focused on aspects that may have been missed by top-down implementation. The wider significance of the Truth Project is that it challenges long held beliefs about the value of talking about CSA in a safe, supportive environment where belief, validation and dignity are prioritized. Fricker's work largely draws on exemplars of epistemic injustices and their antithesis from literature to elucidate her arguments (20). Findings from this study exemplify the process of moving from a position of experiencing prejudice and isolation as a knower, to feeling included in a wider network of meaning making in the field of CSA, and by virtue of participation achieving forms of testimonial and hermeneutical justice. It is suggested that future studies could operationalize Fricker's model through engagement with other groups who also face Epistemic Injustices.

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 IICSA independent ethics committee. The patients/participants provided their written informed consent to participate in this study.

Author contributions

CB: project manager, collected data, analysed data, and contributed to write up. SF: collected data, analysed data, and contributed to write up. RE: project leadership and liaised with organization. SQ: collected and analysed data. DT: research supervisor and led on write up. All authors contributed to the article and approved the submitted version.

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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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Epistemic citizenship under structural siege: a meta-analysis drawing on 544 voices of service user experiences in Nordic mental health services

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This paper presents a meta-analysis, drawing exclusively on qualitative research ($n=38$), which contributes to findings on mental health service user experiences of received provisions and/or encounters in contemporary social and mental health services in the Nordic countries. The main objective is to identify facilitators of, and barriers to, various notions of service user involvement. Our findings provide empirical evidence regarding service users' experiences of participation in their encounters with mental health services. We identified two overarching themes, professional relations and the regulative framework and current rule and norm system, in the reviewed literature concerning facilitators and hindrances of user involvement in mental health services. By including the interrelated policy concept of 'active citizenship' and theoretical concept of 'epistemic (in)justice' in the analyses, the results provide foundations for broader exploration and problematization of the policy ideals of what we call 'epistemic citizenship' and contemporary practices in Nordic mental health organizations. Our conclusions include suggestions that linking micro-level experiences to organizational macro-level circumstances opens up avenues for further research on service user involvement.

KEYWORDS

mental health organizations, epistemic injustice, meta-analysis, Nordic countries, service user involvement, service user experiences, active citizenship

Introduction and research questions

This paper presents a meta-analysis, drawing exclusively on qualitative research ($n=38$) published in the period 2017–2022, to contribute fresh findings on contemporary mental health service users' experiences of received provisions and encounters in the context of Nordic mental health organizations. More precisely, it covers research in Swedish, Norwegian, Danish, and Finnish welfare settings, but not those in Iceland, where service user involvement is less strongly promoted in national policies (1).

It is widely recognized that contemporary notions of individuals with mental illness are often strongly linked to subjects who are usually viewed as different, deviant, and marginalized (2, 3). Stigmatizing notions are embedded in the concept of mental illness that strip stakeholders of their capability and credibility as 'epistemic subjects', that is persons who are to be considered credible and reliable sources of knowledge and capable individuals (4, 5). Nonetheless, such theoretically marginalized epistemic subjects' contributions to knowledge policy and practice—as epistemic citizens—are both valued and sought in the development of high-quality mental health services in Nordic contexts. In this paper, mental health services and organizations are defined as any organizations and institutions that provide help and assistance for people with mental illness, such as primary health care and social service organizations, as well as those providing specialized care requiring referrals (e.g., psychiatric services).

A common feature of the Nordic countries' contemporary welfare systems is an ideologically driven prioritization and encouragement of *service user involvement* to strengthen service users´ influence on the design and content of received mental health and social services. However, different methods and strategies have been applied in efforts to achieve these goals in the four countries (1).

Service user involvement is related to *active citizenship*, rooted in notions regarding the division and sharing of responsibilities between citizens and the government [*cf.* (6)]. The state is widely regarded as having responsibilities to ensure the welfare of its citizens, while certain responsibilities are ascribed to the individual citizen, such as labor market participation (7, 8), not just in terms of being empowered in the role of being a 'patient' or a 'client' in a subordinated social position, but also in policy terms of being an *epistemically active citizen* [hereafter an *epistemic citizen*] [*cf.* (9)]. The (pro)active citizen is also regarded as having primary responsibility for making good and healthy choices, for instance in Swedish national *health* policy, which are expected to be based on (or closely aligned with) information and recommendations dispersed by the states' health organizations [*cf.* (8)]. However, epistemic *capability* is essential in order for citizens to take responsibility for their actions, knowledge acquisition, choices and participation in society [*cf.* (9, 10)]. Likewise, promotion of service user involvement presupposes that service users are capable and valuable sources of knowledge for the establishment of appropriate care regimes and processes for them. Thus, this policy goal has democratic underpinnings. Therefore, an overarching explanation for the prioritization of enhancing service user involvement in Nordic welfare policy is that it is related to the lagging political achievement of epistemic citizenship (choice and voice) in patients' encounters with welfare state organizations as representative institutions of the state.

In the politicized concept of service users' involvement, notions of person-centeredness are embedded that refer to the recognition of their expressed personal needs, experiences, and preferences. A prerequisite for embodying such a role as a service user is active involvement. Generally, service user-involving practices are intrinsically underpinned by Nordic welfare policies aligned with notions of empowerment, self-determination, and other positive aspects of service users' agency (1), but they are also linked with organizational-level development of welfare services' quality. Such ambition to raise services' quality is reflected in a commitment to evidence-based practice (EBP), which is stressed in organizational regulations and national-level policies (11–13). EBP refers to scientifically proven and efficient interventions/treatments in social service and healthcare practices. It theoretically rests on three equally important epistemic sources: service users' experiential knowledge, professional experience and practice, and the best attainable knowledge (14, 15). Hence, service user involvement is theoretically a crucial element of practices that are congruent with the epistemic triad model of EBP (12, 13, 16).

This paper focuses on research addressing service users' experiences of their encounters with welfare state organizations in Nordic contexts. This was motivated by considerable empirical evidence that although service user involvement is strongly, and ideologically, promoted in these countries, mental health service users often experience disempowering encounters in mental health organizations, and there is low recognition of experiential knowledge (12, 17–23). In sum, this suggests a potential conflict between political ideals and mental health service users' reality related to their value as epistemic citizens in their encounters with caregivers in 'professionalized spaces'. If so, use of individuals' experiential knowledge and involvement in their own care may be strongly promoted directly in policy constructs, and indirectly through the commitment to EBP in welfare services, but much less strongly in practice (14, 20, 23).

Recognition of needs to identify what mental health service users' experiences consist of (what they are) and meta-analytically *represent* motivated the research presented here. We consider that mapping successful and non-successful service user encounters with welfare actors, as revealed in empirical research, can potentially outline empowering, inclusive, and less inclusive welfare practices and structures as perceived from a stakeholder-perspective.

Against this background we seek to analyze and provide insights into the main facilitators of, and barriers to, mental health user involvement identified in contemporary research on service users' experienced encounters with professionals in social and mental health services in the Nordic countries. These experiences are analyzed through the interrelated theoretical concepts of epistemic (in)justice and notions of active citizenship. In doing so, we also scrutinize whether and how these encounters correspond to the ambitions of service user involvement and the increased emphasis on high-quality services in these welfare systems.

User involvement—a work in progress in Nordic welfare

A considerable body of literature and policy texts address the importance of service user involvement and their ability to influence and have an equal voice in decision-making processes, including decisions regarding how assistance and support should be carried out (13, 19, 20, 24–28). More recently, coproduction of services, i.e., service users' and professionals' joint involvement in decisions regarding plans and services, has been viewed as a normative ideal in social and mental health services. Coproduced welfare services are also considered to increase autonomy, redistribute power, and improve patients' recovery (17, 29, 30). Hence, research supports the hypothesis that the active involvement of service users increases the quality of welfare state services [*cf.* (14, 18, 19, 31, 32)].

The organization of mental health services is contextually bound to national traditions and systems, and may vary significantly across nations. However, the Nordic countries have similar systems, with provision of universal support services through taxation of income (33), and where a decentralization of 'soft' governance generally addresses municipal or regional responsibility for, and control of, the implementation of public health policy (Fosse and Helgesen, 2019 (34)). According to a recent scoping review by Ineland (1), there is high interest in these countries in the development of methods to enhance service user involvement in practice. Legislation on individual rights, in terms of service user involvement in social and health care, has been passed in all the Nordic countries, but is more limited in Iceland than in Sweden, Norway, Denmark and Finland (1). However, methodological and practical guidelines for approaching notions and practices of service user involvement are under development, from various perspectives, in all the Nordic countries (1, 13, 17, 19, 31, 32).

Practices that are intended to comply with the ideals of service user involvement can be found in different forms and at different levels. At the individual level, one example involves shared decision-making in encounters between service users and professionals. In such practice, professionals actively involve service users in the process of finding treatment options that are deemed most suitable (35). The purpose of such an approach is to empower the service user to 'take charge' of important decisions regarding treatment, which is also suggested to promote the continuation of treatment plans and recovery (30).

Another method, which is a quite new and as yet underused organizational approach to promote service user involvement and enrich welfare organizations with service users' experiential knowledge and perspectives, is to integrate a new occupational category of *peer supporters* in psychiatric services. Peer supporters are former patients with lived experiences of mental illness who have successfully recovered (36, 37). Their main function is to support patients in different welfare contexts by bridging the unequal power distribution between professionals and patients and promoting support aimed at more personal and person-centered care, thus mainly targeting the individual level of service user involvement (36, 38). However, they also function as beacons of self-recognition, empowerment, and hope of recovery for patients with mental illness (39–42). As Argentzell (36) highlights, peer-support workers' experiential knowledge and perspectives may induce a local recovery-oriented climate in an organization and provide an ethical compass for their colleagues onwards.

Another peer-to-peer approach to strengthen service user involvement and the quality of mental health services, primarily on an organizational level, is to incorporate service user-led monitoring and revisions (43). This involves evaluations of mental health service organizations by various methods, such as interviews with service users and/or surveys underpinned by holistic perspectives (covering multiple aspects of well-being) [*cf.* (44)]. Hermeneutically, the peer-to-peer evaluation of testimonial accounts of received mental health services, together with contributions from the new peer-support occupational role and shared decision-making, may theoretically have substantial potential to counter the unequal distributions of personal resources that are important markers of epistemic (in)justice. More specifically, the deployment of peers' insider knowledge may reduce inequalities in power relations, through the common ground of lived experiences of being a service user in a relatable social situation with other peers—as a person dependent on the quality and practice of welfare services that are constructed for an intrinsically vulnerable social group.

In the reviewed research, the main thematic incentives to politicize service user involvement in Swedish social and healthcare are underpinned by two democratic notions. First, the promotion of empowerment among stakeholders in order to control their own courses of personal recovery in professional encounters. Second, civic empowerment through redistribution of power to service users *via* user-led evaluations and the development of social and healthcare services where service users control, revise, and suggest improvements in contemporary organizations and services.

Epistemic injustice versus professional privilege and organization

Epistemic injustice as a theoretical term is not fixed, but rather a spectrum of situations in life where subjects (of various subgroups) are dismissed as equal knowers. The concept can be understood as profoundly associated with a range of normatively deviating social groups lacking credibility in normative daily life contexts.

Drawing on work by Fricker (4, 45), individuals' *testimonial* injustices and *hermeneutical* injustices are important factors to consider when searching for an understanding of, in this case, service users' experiences of received social and mental health services that fail or succeed, to meet their needs. Fricker later came to expand her original work on epistemic injustice, recognizing that distributive epistemic injustice refers to information as a type of resource that is systematically and structurally inaccessible for epistemically devalued social groups (45, p. 1318).

Hermeneutical injustice can be described as a (sub-)cultural disadvantage when navigating in particular social contexts, or 'spaces', due to the absence of compatible meaning-making resources (4, 45). Individuals' hermeneutical disadvantages influence their testimonial accounts (i.e., abilities to articulate the 'right' questions, personal experiences, and needs). In meetings between service users and professionals, the lack of medicalized knowledge and terminology (in healthcare encounters), legislative rights (in encounters with social services), or the coordination of services may lead to imbalanced epistemic encounters where subjects are dismissed as credible knowers (4, 46).

The general power relations between service users and professionals have been intensively researched. Power relations in an encounter favor the professional through imbalances in both social status and associated ascribed competence, drawing on both hermeneutic and testimonial credibility and authority (46). Further elements of epistemic injustice in meetings between service user and caregivers, besides the hermeneutical and testimonial imbalanced power distribution, have also been noted by researchers. These include informational injustice, as service users may be expected to participate in their own care, but based on the caregivers' premises, which emphasize the importance of medical knowledge and professional experience [and spaces], and locally situated taken-for-granted routines (5, 46, 47). In such cases, an encounter between a service user and professional is restricted to the service user being a cooperative recipient of, and source of information for, professional knowledge concerning their care. However, the service user is not expected, nor desired, to initiate discussions on alternative treatment options or reject the decisions or assessments of the caregiver (20). This kind of restricted participation leads to what Kurs and Grinshpoon (5) refer to as epistemic silence, a kind of epistemic injustice that occurs in what we define as passive participation, rather than the active participation that is promoted in guidelines or ambitions to enhance service users' involvement in contemporary policy and practice. Passive participation is hence not a reciprocal encounter, but one that merely demands service users' presence due to institutional routines and praxis.

Over the years, various studies have highlighted that not being 'heard' or 'understood' is a common experience among users of social or mental health services [*cf.* (21, 48, 49)]. This calls for enhancement of staff competencies in relational approaches to people with mental illness, which has great recognized importance for high-quality mental health services according to a systematic review by Staniszewska et al. (50). Further, this review concludes that all of 72 included studies (concerning practices and experiences in 16 countries in total) found that appropriate professionals' practices were crucial for service users to experience high-quality care. However, professional discretion is also bound to the local context of care and, hence, should be considered as a product of the 'system'—that is, the organizational context.

Demands for efficiency deriving from overarching organizational systems and regulations are prioritized in many rehabilitation contexts (3, 51, 52), which affects several aspects of service users' agency. Organizational regulations, guidelines, and resources can both weaken the alliance between professionals and service users, and strengthen them, depending on the local organizational context (31, 51, 53).

Method and data collection

Qualitative research and meta-analyses

This literature review is based on meta-analyses of qualitative research. It focuses primarily on qualitative empirical research and first-person testimonies as primary data because epistemic knowledge and hermeneutical accounts represent a spectrum of thoughts and situated experiences that are dynamic, complex, and difficult to capture through quantitative methodology, especially concerning mental health and illness (54). Humans interact with their environments, so a deep understanding of their experiences is not easily captured in a reductionist manner, such as that applied in many quantitative methodologies (54–56). In contrast, qualitative methods and methodologies highlight the importance of person-first accounts, thereby emphasizing the epistemological appraisal of lived experiences.

The fundamental goal of qualitative meta-analysis is to provide a comprehensive but concise account of research findings on a focal topic (55, 56). We decided to apply this strategy to search for common themes and patterns in findings of qualitative studies in order to aggregate knowledge regarding service user involvement and epistemic (in)justice for persons with mental illness in their encounters with welfare organizations. However, the form of knowledge production may vary depending on the purpose of a meta-analysis. In some cases the main aim may be to understand conflicting research conclusions or approaches, while in others (as in our review) it may be or to find essential elements that illuminate common denominators of sampled studies (55).

Our analysis and choice of study design are inspired by the work of Levitt (55) and Levitt et al. (57) and the guidelines on methodological integrity provided by the American Psychological Association (APA) for promoting the trustworthiness of the process and results of a meta-analysis. Two overarching principles (with various sub-categories) for the trustworthiness of meta-analytical work are *fidelity* and *utility*. Two key aspects of fidelity are *adequacy* (of studies included in a review to cover the focal topic sufficiently), and *groundedness* (of the analysis and construction of categories in the data). *Utility* refers to the correspondence between the aim and study design, and the study design's viability in relation to its stated purpose (57). These aspects are addressed in the following section by outlining and justifying the procedures applied in our study's initial phases.

Study design

An important aspect of methodological integrity is the umbrella concept of fidelity, which reflects the application of steps in the data selection process that avoid narrowing the rich variety of data under study to a few aspects (57). Accordingly, the first author, in collaboration with the university's library services, constructed several search strings that included synonyms and other conceptual varieties to increase the probability of finding a generous range of studies concerning users' experiences of Nordic social and mental healthcare services (see Appendix 1). Then, we searched a range of databases (SocINDEX, APA PsycInfo, Scopus, and PubMed), aiming to include studies rooted in diverse academic disciplines due to the complex life situations and needs of service users. The 'hits' were narrowed by using a "peer-review" checkbox, publication date spanning 2017–2022 and the additional criteria of "narrative," "focus group," and "interview" in the study designs. As illustrated in the flowchart shown in Appendix 2, the search strategy yielded 860 peer-reviewed studies in total, but despite the search criteria applied quantitative methodologies were used in many of the studies. In addition, some were conducted outside the Nordic countries due to authors having Nordic university affiliations. An additional mechanical search process was performed after importing the publications into Endnote software, using the search terms "narrative," "focus," and "interview" to select all the publications containing these terms in their titles or abstracts. In total, 523 abstracts were selected. The first analytical process to include or exclude publications began with reading these abstracts. Papers were excluded if:

(1) They addressed populations who did not have a mental illness as their primary diagnosis, but comorbidity (e.g., depression/lowered quality of life as a result of a non-psychiatric diagnosis, such as cancer, epilepsy, or arthritis).
(2) They applied quantitative methodology, or qualitative methods with a modest number of quotations from informants (service users), making it difficult to evaluate the groundedness of the authors' analysis in the presented data.
(3) The presented studies were methodological or evaluative, dealing for example with new projects (pilot studies), to maintain the focus of exploring experiential knowledge in previous and existing welfare provisions.
(4) The research participants were less than 18 years old. Due to the intrinsically different social and healthcare systems for adolescents, it was not deemed suitable to include a young population in the study design.
(5) They were published in 2017 or later, but declared that the presented data were collected before 2015. These were excluded to analyze recent situations and experiences. Studies published in the same timeframe that did not declare in the abstract or main text what year the data were collected were not excluded.
(6) The populations under study represented service users with drug abuse issues, and the papers did not focus on needs regarding social and mental health services.

(7) They were duplicates of included articles.

After this initial inclusion and exclusion process, 67 publications remained and were subjected to full-text readings, after which 38 peer-reviewed publications were included and further analyzed.

It should be mentioned that despite our Nordic perspective and interest in this study, Iceland was not included in the search strings used, because (as already mentioned) the emphasis on mental health users' involvement in welfare policy is modest in Iceland compared to Sweden, Norway, Denmark, and Finland. Thus, experiences of service user involvement in the deviating welfare context of Iceland could have potentially compromised the coherence of the review's findings (1).

Analysis

Overall, the analyzed dataset was comprehensive and touched upon several perspectives and aspects of mental health service user involvement and (indirectly) just and unjust epistemic encounters. As shown in Appendix 3, although many of the articles related to psychiatric care, overall they covered a great variety of contexts, service provisions, and testimonial accounts of encounters in social and mental healthcare services.

The initial analysis was conducted through a deductive approach. In accordance with directed content analyses (58), we explicitly searched for lived experiences of services and professional encounters. Sections in the articles touching on social networks or experiences of having a particular diagnosis were excluded from the analysis. In articles addressing both service users' and professionals' narratives and experiences, only quotations from service users were analyzed. Thus, our analyzed texts consist predominantly of quotations from research participants regarding their own experiences of social or mental health services. However, when relevant to the context, we also included the authors' discussions and elaborations in the articles' results sections in our analysis. These passages were checked for relevance against the presented informant quotations to assess the level of abstraction from the primary data. The quotations were also subjected to a coding process, in which we condensed them into several briefly descriptive codes, ranging in length from one word to a short sentence.

Before we started analyzing these codes a user committee comprising individuals with personal experiences of social and mental health services was contacted. They engaged in coproduced elaboration on a random sample of publications ($n = 7$) during a workshop session with the first author. The committee participants read and analyzed the data with an inductive approach. Later, we discussed the main findings the participants identified. These contributions were taken into consideration in the initial stage of our own analytical process, mainly targeting the relational and epistemic injustices in the data and were later confirmed by the authors after analysis of the complete material. The identified codes were reread several times until patterns were recognized and the codes could be organized into two overarching themes: *professional relations* and *the organizational context*. For a more tangible understanding of each theme, the codes under these respective themes were re-read, which resulted in the formation of sub-themes. We subsequently revisited the primary data to ensure that the (sub)themes reflected a valid level of correspondence and abstraction.

Results

The findings in this paper illuminate diverse experiences of being a service user with a mental illness in contemporary mental health organizations. We have identified two broad themes with recurring subthemes in the 38 analyzed studies. Findings show that narratives of mental health services users in the Nordic countries – negative and positive – and their experiences of participation and (in)justice are related to two explanatory aspects. One consists of the characteristics and quality of professional relations, while the other consists of the regulative framework and current rule and norm system of the services. Therefore, the analysis identifies constituents of service user involvement through individual experiences, relational encounters, and organizational prerequisites. We also examine how these constituents work together to give meaning to service users' testimonies and a position as citizens of epistemic worth. We argue that these relations represent pivotal aspects of the complexity embedded in defining, discussing, and understanding issues relating to epistemic justice within mental health organizations. Most, if not all, of the papers touched upon mental health patients reporting on their relations with professionals and the professional world. Positive experiences were predominantly connected to confidence and safety in professional encounters and characterized by, for example, continuity, responsiveness to individual needs, and the abilities to build trust, achieve a sense of uniqueness, and be recognized as a 'person' rather than a 'service user' (59, 60).

Taken together, professional relations between patients and professionals are crucial for service user involvement, empowerment, and consequently, epistemic justice. However, our analysis also suggests that the structural and organizational context strongly influences service users' intersubjective perceptions and experiences of involvement in various ways when positioned as 'service users of the welfare state' (1). In sum, the results section reports findings of positive and enabling, as well as negative and obstructing, experiences and prerequisites for service user involvement and patient-centered care in mental health services in Nordic countries. By doing so, our study adds fresh findings regarding evidence-based welfare services and the growing body of research on what attenuate and undermine mental health patients as epistemic citizens. As shown in Table 1, we summarize our main findings by differentiating between two overarching themes and several subthemes. In the following text we provide more detailed information (with empirical evidence) on how these themes and

TABLE 1 Overview of themes and sub-themes.

Themes	Sub-themes
Professional relations	Physical and emotional accessibility and availability Autonomy and safety
	Responsiveness to individual needs and preferences Empowerment and reciprocity
Organizational context	Information and knowledge distribution Continuity and organizational fit Co-productive working processes Ideology

sub-themes differentiate positive from negative user experiences within mental health provisional encounters.

Narratives and experiences associated with professional relations

One main finding of this scoping review is that numerous studies emphasize the importance of professional encounters and how welfare state systems – through their professionals – respond to mental health service users. This is crucial as the ability to establish empathetic relationships is commonly recognized as a keystone for quality in human service organizations (61). From a service user perspective, the quality of professional relations is also crucial for the development of trust and willingness to open up (60, 62, 63). The importance of relational aspects in mental health services is illustrated by a study of residents in supported housing for people with mental illness (64). The results show that easy access to professionals reduced patients' frequencies of hospitalizations, which the cited authors regarded as an indication that the availability of significant others to help them cope at difficult times improved their self-regulation experiences (64, p. 69).

A recurrent theme in our findings is that service users' experiential knowledge is valued, recognized, and called for, although the review does not provide clear information on the *extent* that service users, as epistemic sources, are listened to and involved in actual decision-making and work processes within the Nordic mental health sector. In a study of recovery-oriented intersectoral care in mental health, Jørgensen et al. (65) show that although health professionals acknowledge the value of involving mental health service users and relatives, and call for their opinions, care decisions are largely made paternalistically, and such voices are ignored. Instead, our review indicates that encounters and communication patterns characterized by an absence of stigma and imposition seem to be, in themselves, an aspect of epistemic justice [*cf.* (59, 66)]. In the following text, we present more detailed findings according to the themes and sub-themes outlined in Table 1 on service user narratives and experiences of influence, voice, relations and organizational settings.

Physical and emotional accessibility

The ability to encounter physically and emotionally accessible professionals is by far the most frequently reported aspect of professional relations and most explicitly differentiates positive from negative user experiences of the mental health sector. Although some positive examples are reported in the reviewed studies, these accounts were essentially challenged or overshadowed by experiences and narratives of a negative nature (62, 67–71). Other papers also report on ambitions and preferences of patients, emphasizing that they want to be recognized, listened to, and acknowledged as capable persons with valuable knowledge about their own current life situations, i.e., they addressed desires for epistemic recognition [*cf.* (4, 46)] and not to be ignored, dismissed, or condescendingly treated.

Moreover, inaccessible professionals are important elements of negative experiences, as shown for example by Pelto-Piri et al. (70) and Brännström et al. (72). This indicates that a lack of communicative staff, non-engaged professionals, inadequate meetings, and one-sided interactions cause feelings of being ignored and neglected by staff working on 'autopilot' (59, p. 544). Our review, however, shows that confidence, trust, and sustainable relations with professionals can make them feel 'unique', recognized (59, p. 543) and 'safe' (68, p. 596), which are recurrent themes of informants' descriptions. The following extracts are typical examples:

> The participants described experiences of feeling listened to; professionals were described as being "focused" and "present" and they "listened while still maintaining their professionalism" (59, p. 542).
>
> It makes me happy when the occupational therapist asks if we should bake a cake or go for a walk [in the meadows near the mental health center]. I can live on this kind of experience for weeks (68, p. 596).
>
> For all participants, descriptions of their relationships with ward staff permeated throughout the six components [under study] … underlining the centrality of developing personal relationships between patients and staff in creating a therapeutic ward atmosphere … (71, p. 344).

Another important finding is that, regardless of scale and specialization, organizations that value user-involvement and successfully implement it in their praxis (with utilization of users' experiential knowledge) have positive effects on service users' recovery (63, 73–75). What we depict as positive and reciprocal encounters also seem to enhance trust in the welfare system (60, 62, 76), motivation to use services (69, 77, 78), and users' control in their encounters with the professional world (63). In contrast, many of the reviewed articles indicate that patients experiencing professional relations as malfunctioning, distrusting and stigmatizing lead to negative feelings of being personally insignificant, worthless or de-humanized [e.g., (68, 76, 79, 80)]. Thus, our analysis suggests that service users' subjecthood plays a key role, due to strong associations between self-perceptions of being socially valued and positioned as a fellow human being who is worthy of epistemic recognition, which is manifested in the presence of reciprocal engagements with professionals.

Autonomy and safety

Our results show that the quality of mental health patients' relations with the professional world contributes considerably to their feelings of autonomy, safety, and security. In sum, the results stress the importance of creating a safe institutional environment and actively involving service users in their care by creating an open, confident, and safe place for dialogue (62, 81). Some studies found indications of negative outcomes (63, 82) related to unconducive group compositions or the absence of physical encounters, which were perceived as impersonal and barriers to trust and safety (62). The following excerpts are illustrative examples of how dismissing, non-engaged, and non-communicative professionals can contribute to patients' isolation and feelings that they are unsafe and bear responsibilities beyond what should be expected of an inpatient:

> We [inpatients] have a lot of people who go through periods of feeling very bad here … and we bear the responsibility for whether they will live until the next day when they indicate they have

> suicidal thoughts or have attempted suicide and the like … We don't really know if we're able to deal with this (70, p. 6).
>
> The participants do not experience a focus on their recovery process across sectors, and the medical treatment paradigm undermines their own perspectives on life. "The doctor filled me with medication, and I slept all the time. I said to him: Tell me, do you want me to sleep my life away? Yes, the doctor said" (65, p. 9).

A number of studies reported positive narratives and experiences (60, 66, 73, 74, 81, 83, 84). For instance, Björkvik et al. (73, p. 32) showed that service users' propensity to use dental health services was strongly related to their feelings of safety and their perceptions that their dentists understood and respected them. The delicate nature of interpersonal relations and their importance for users' feelings of safety and a sense of control are also evident in the following excerpts, indicating the significance of the help given and engagement shown by professionals:

> Without ES [psychiatric nurse], I would never have been here today. She called me an hour before picking me up and came together with me (73, p. 32).
>
> The group members described the feeling of being safe first and foremost as a feeling of trust and acceptance. These men had their triggers in the interpersonal field/ … /they emphasized confidentiality in the group more than their physical security [following an outburst, author remark] (82, p. 8).

These sub-themes thus illustrate differentiated perceptions and experiences based on the quality of interpersonal relations and professional accountability within mental health welfare contexts. Safe, confirmatory, and non-coercive contexts are described as prerequisites for reciprocal and respectful professional relations, which are fundamental elements of not only service users' involvement and sense of autonomy, but also their hermeneutical and testimonial credibility [*cf.* (4)]. Consequently, qualitative professional relations also have high potential for identity-building (78) and improvements in both self-esteem and recovery processes (73, 75, 77, 82). In contrast, non-successful encounters, characterized by limited reciprocity and service user influence, safety, and autonomy, increase risks for shame, dehumanization (being reduced primarily to a 'service user'), fears of airing one's opinions and sanctions, and reduced opportunities to foresee future steps of a given recovery or rehabilitation process [e.g., (65, 85–87)]. This is a significant obstacle for implementation of the fundamental ideals of service user involvement and epistemic citizenship in the Nordic countries. There are high risks that welfare contexts within them may not deliver provisions permeated by empowerment, coproduction and diverse forms of recovery if relations within them induce such negative and reductionist effects on personal autonomy and voice.

Responsiveness to individual needs and preferences

The third subtheme of how professional relations seem to differentiate positive from negative service user narratives is individual recognition, i.e., professionals' ability to respond to individuals' needs and preferences, in line with Nordic policy aims to enhance service user involvement [*cf.* (13, 23, 28)]. Jones et al. (79) and Hagen et al. (60) present negative and positive service users' narratives and experiences regarding their encounters with the professional world. The significance of professionals' responsiveness to individual needs is evident in the following two quotations of participants in the study by Jones et al. (79):

> [Professionals] need to hear me and be able to understand … I have PTSD and people [professionals] who do not know what PTSD is, cannot understand why I am like I am, nor can I get help then from someone who does not know what problems I have.
>
> I have had a lot of psychologists, contacts, and similar, but none of them have worked because they have followed these routines that they have, rather than looking outside the box, but then I got someone who listened to what I said, really … saw me as a person and listened to what I had to say … it was a huge help.

In their study on former suicidal inpatients, Hagen et al. (60) also address service user experiences related to professionals' responsiveness to users' testimonial accounts and individualized support. They suggest that to improve the quality of professional encounters, and provide more individualized care, professionals need to use more extensively not only their professional but also their personal qualities and act as empathetic fellow human beings. Some articles report patients feeling that their perspectives and experiences were overlooked, dismissed, or overshadowed by professionals, guided primarily by ideology or routines, potentially leading to neglect of their individual wishes and invalidation of their lived experiential knowledge (72, 88). In contrast, recognition of and responsiveness to individuals' needs and preferences can potentially enhance patients' recovery processes, as shown for example by a study of people who had common mental disorders and had experienced sickness absence (89, p. 9):

> One factor that emerged from the participants' experiences of professional support was the importance of being listened to and that someone believed in their story. This mutual respect was vital for achieving recovery.

Sunnqvist et al. (90) also touch on the importance of respectful and responsive meetings with people with mental illness in their study on prehospital emergency psychiatric units. Failure to provide such meetings may have negative consequences that leave patients feeling reluctant to seek care, in line with previous findings. In one example of their importance, a professional took time to talk calmly and respectfully with 'Patient 3', creating a trustful alliance, which made the patient feel safe: "So if it had not been for him, I would probably still have sat in my apartment … refusing to leave …" (90, 259). Coproduction of services in such cases is represented in terms of active agency (voice) and reciprocity and alliance (reciprocal relations) between service users and professionals. These are prerequisites for any form of coproduction in welfare contexts [*cf.* (19, 26, 27, 29)] and crucial for active participation in services.

Empowerment and reciprocity

The empowering potential and measures of reciprocity constitute the fourth subtheme of professional relations. Relations that acknowledge and promote involvement of service users and their experiential knowledge in daily routines are associated with positive outcomes, while opposite kinds increase risks for non-participation, us-them dichotomies, and lack of choices for service users accompanied by other disempowering practices, as shown by various authors [e.g., (68, 70, 76, 80, 85)].

Eldal et al. (76) highlight a recurrent theme in our review—the challenging service user position of engaging in professionalized spaces, due to the unequal power-distribution—that, at times, caused situations where service users' subjecthood was marginalized. One patient framed this as "scary" and "a risk" in their role as a service user (76, p. 796). Pelto-Piri et al. (70) also address relational aspects in terms of us-them narratives and provide vivid descriptions of service user narratives of being a burden or disturbance to professionals when asking questions or wanting something demanding consent, which causes disempowerment and increases patients' fear of conflict.

Some researchers have indicated ways that professional relations may also potentially help to re-distribute power, increase reciprocity and enhance patients' empowerment. Although it may be challenging, Møllerhøj and Stølan (68) argue that even the smallest professional initiatives may be important for motivation and meaning:

> The informants are very well aware of the power relations at stake, and the fact that the responsible consultant decides at the end of the day. However, the feeling and experience of some sort of negotiation and shared decision-making are important to patients [adjusting medical treatment] … (68, p. 596).

In terms of providing opportunities for involvement and positions as epistemic citizens, the review also reveals that relations reflect signs of genuine interest and recognition of service users as human beings, mutual trust, honesty, and reciprocity (78, 91–93). They also help to avoid feelings of shame, stigma, and anxiety (62, 73, 95) and increase individuals' sense of power and control (63, 77). In sum, the findings presented in this section provide nuances of the commonly held view of how public organizations—through *reciprocal* face-to-face encounters between professionals and service users—acknowledge people with mental illness, which is a pivotal aspect of service quality, and hence epistemically just encounters in mental health services. The reviewed articles indicate that reciprocity occurs in encounters where the social position and subjecthood of mental health service users are not epistemically challenged by, nor dismissed in, professionalized spaces and authority [*cf.* (4, 5, 46)] and where their epistemic citizenship can both be practiced and valued.

Narratives and experiences associated with organizational settings

In line with previous research, it is clear from our analysis that social and mental health organizations pose challenges when interacting with service users and patients with specific needs and preferences, due to their legal, moral, and institutional frameworks [*cf.* (96)]. A major reason for this is that institutional frameworks provide guiding principles for actions and engagement with individuals positioned as service users of the welfare state [*cf.* (3, 49, 51, 52)] that may exacerbate rather than ease difficulties in their recognition as human beings with individual biographical, cultural, and illness-related histories (92). The institutional frameworks of mental health organizations also serve to distribute power and influence among various organizational actors, which participating patients highlighted in the reviewed studies, as illustrated by the following conclusion of Møllerhøj and Stølan (68):

> Participants were aware of the fact that there was a care hierarchy in which the patient was at the bottom. They described powerlessness in relation to staff and there were some descriptions of oppressive behavior from the staff.

Although professional relations and organizational contexts are conceptually different, they are also intimately intertwined. Financial restraints, understaffing and paucity of local guidelines for patient-professional interactions or collaboration in inter-organizational teams will most likely negatively affect professional relations with service users. Thus, the physical absence of nurses in inpatient settings and interrupted service user-professional conversations, for example, have been treated as organizational, rather than relational, factors. Our findings suggest that being given sufficient information and the coordination of support structures contribute positively to service users' experiences, while a lack of coordinated and collocated services negatively affect their motivation and willingness to contribute to their recovery process (67). This results section reports findings that, from our theoretical and analytical standpoints, represent how service users experience their involvement and epistemic citizenship (participation, agency, and navigation) in mental health services and how these narratives are associated with the organizational context.

Information and knowledge claims

The ways that organizational contexts promote or limit service user involvement initiatives, as well as service users' experiences of agency, are most clearly related to issues concerning information, the forms of knowledge that are valued and acknowledged, and how the valuation and acknowledgement are manifested (81, 90, 93). As shown by the following quotation from a participant in a study on patients' experiences of caring encounters with a psychiatric mobile emergency response team (81, p. 445), adequate information has a preventive function and instills trust and safety in patients:

> They told me when to take the sleeping medicine … to wait until I was in bed; in that way, I would reduce the risk of falling … they also told me to contact the ordinary (psychiatric) mobile team or them before harming myself.

This quotation clearly shows that information in the form of self-care advice aided the handling of a situation before contact was resumed with regular caregivers. However, the literature commonly reported mental health patients describing ongoing or previous experiences with welfare services in terms of resistance and mistrust due to limited knowledge about the welfare system. This touches on important aspects of initiatives for service user involvement, as information has empowering potential for patients in mental health services:

> They [professionals] have become better and better at helping me because I am getting better and better at knowing what I am entitled to or not! (86, p. 195)

If service users cannot acquire information on entitlements in welfare services from professionals they must acquire it from other sources. Such lack of information can cause feelings of obscurity and insecurity in the 'helping alliance', with 'help' being perceived as deceptive. Such epistemic (hermeneutic) injustice due to the lack of information can arouse strong feelings in service users, of their lack of knowledge being acted upon by professionals, rather than being provided with answers and information [*cf.* (45)]. Several reviewed articles identified examples of negative effects and experiences due to insufficient or inadequate information and situations, when service users' experiential knowledge was neglected (66, 80, 85, 86, 91) or service users found it challenging to share, connect, or engage in genuine negotiations with professionals during treatment (83). Our results indicate that well-informed service users are both more motivated and hermeneutically better equipped to raise awareness of individual needs and preferences in professionalized spaces. Being well-informed also seems to empower users of mental health services as active citizens, challenging and resisting what are considered coercive and unethical practices [*cf.* (93)]. In contrast, the lack of information or patients not receiving information at all decreases motivation and strengthens the individual's role as a 'service user'. This reinforces the us-them dichotomy between professionals and service users due to practices that strengthen the difference in epistemic (hermeneutic and testimonial) authority between the parties:

> Some patients had excluded themselves from the planning and, due to lack of motivation or confidence, found it easier to adopt an outsider's role in their own care/ … /the participants agreed that patients need sufficient information on medication to participate, but that in practice, patient counseling is insufficient and unsystematic (85, p. 234).

Work by some authors, e.g., Roos et al. (75), showcases how a lack of information compromised patients' preparation for rehabilitation, causing them to constantly repeat themselves, which negatively affected their motivation and recovery processes (80). This is congruent with findings of previous research [*cf.* (35, 50)] addressing issues related to what Kurs and Grinshpoon (5) refer to as 'epistemic silencing'. In such cases, organizational routines or structures cause hermeneutical and testimonial injustice due to a lack of information and proper support, leaving individuals to opt-out from their own care and recovery process. Together with unclear role responsibilities and ambiguous rules and routines, a lack of knowledge and failure to integrate experiential knowledge into the work process have also been identified as major obstacles to service user involvement (86, p. 194). This confirms recent findings regarding hindrances for the realization of epistemic citizenship in mental health practices [*cf.* (17, 19, 31, 32)].

Continuity and organizational fit

A recurrent theme in the research participants' descriptions is a low degree of continuity and structure in their contact with mental health services, causing challenges in managing their mental illness. Lockersten et al. (80, p. 6) provide an illustrative example, of organizational misfit causing fear and halting of the recovery process for young adults with eating disorders:

> When treated in in-patient care, they were admitted with other patients who had been ill for a long time. These factors influenced the participants' hope for their recovery in the future. "I was admitted with patients that had been ill longer than I had been living."

Another example is provided by Stige et al. (95), addressing the link between time and psychotherapy. They conclude that imposing a strict time restriction might "… interrupt and end fruitful therapeutic processes prematurely, forcing clients to seek treatment elsewhere and start all over again with a new therapist—a strenuous and time-consuming exercise." Other studies show that repeated changes in staff, schedules, methods, etc. can complicate patients' contact with professionalized spaces. The following quotation from a patient in an outpatient clinic clearly shows that constant changes can results in different professionals making different assessments, decisions, or (rehabilitation) plans, allowing little involvement and causing both frustration and misunderstandings:

> Things that may be small, like wanting to get in touch with your psychologist, when it doesn't work, it adds a little to my heap of things. /—/There have been so many changes in my contact with psychiatry, which has been difficult in several ways, it hasn't been difficult just because of the way I feel, but it has also been difficult as a result of the way I have been treated and not taken seriously (72, p. 6).

Patients have also reported that such changes have sometimes led them to become over-responsible for their own treatments, which often made them feel less confident. Andersson et al. (89) found that such responsibility "… weighed heavy on them [patients] and was described as a source of worry over, for example, not being able to give the correct health information or suggest the most relevant intervention to the physician."

At least in part, patients' experiences of organizations failing to understand and acknowledge individual needs and preferences seem to correlate with insufficient communication channels. Eckerström et al. (66) also noted the disruptive consequences of employee turnover, which complicates the distribution of knowledge and ability to establish empathetic and sustainable interpersonal relations. Consequences of such factors, expressed by some patients, may include feelings of being "an object" or a sense of no longer feeling like a human (68, 80).

Coproduction in working processes

This sub-theme concerns service users' opportunities to engage directly with professionals, which we regard as organizational and structural factors [*cf.* (1)], and strongly influence their narratives and experiences of being recognized as an epistemic citizen. These findings are important as service user involvement and successful coproduction of services are considered crucial for the quality development of mental health services provided in the Nordic countries [*cf.* (1, 43)]. Our data suggest that the prevalence of coproduction in working processes, which may differ widely in scope, affects service users' overall experiences in their encounters in professionalized spaces (94).

Participants in the reviewed studies mainly reported negative experiences of shared decision-making or coproduction opportunities, emphasizing that they were inadequate or non-existent. Lindberg et al. (92, p. 640) reported patients' experiences of being "infantilized and patronized" by professionals [see also (86, p. 197)], which may have profound negative impacts on their self-esteem. Professionals have also been portrayed as homebound, mostly occupied in their offices, and as distant from patients, causing feelings of being "on the other side looking in but not seen" (63, p. 182).

However, there is considerable evidence in the reviewed literature that service users have mixed feelings and experiences (83, 92). Some articles suggest that patients may feel accepted, protected, and safe (as shown in previous sections), but at the same time miss having direct contact with professionals and experience limited choice (voice) and influence (63). These perceptions and feelings highlight vital, but contrasting, aspects of service user involvement initiatives and opportunities for users to draw on their experiential knowledge to add important insights for mental health organizations' praxis. One participant in the study by Derblom et al. (59) highlighted the potential dilemma involved:

> When you [staff] listen to me and process what I say, then you are the expert and I listen to you … because I trust that you are the expert; you know best and also want the best for me.

This quotation emphasizes the importance of knowing, understanding, and 'seeing' each individual for the ability to provide individualized assistance and support. Lofthus et al. (67) show that an apparent advantage of participating in an ACT program is that it helps prescription of the correct medication and its adjustment to provide the correct dosage. At the same time, individuals' rights might be neglected or even pushed aside due to the medication. However, Lofthus et al. (67) conclude that patients experiencing the most restrictions are the ones with the highest reported recovery. These results provide important nuances for ongoing discussions of service user involvement and epistemic justice within the discourse on mental health services.

Ideology

The fourth and final aspect of the relationships between the organizational context of mental health service provision and service users' narratives and experiences involves ideology and taken-for-granted assumptions about what is 'desirable' and 'appropriate' when providing assistance and support to people suffering from mental illness (80, 88, 95). One way in which ideologies are put into practice is through working methods. Røberg et al. (82) provide an illustrative example of how specific (psychoeducational) interventions, in combination with an accepting group atmosphere, can increase self-acceptance and reduce shame and stigma among (male) patients. However, when welfare organizations cannot individualize policy intentions, such interventions may have negative effects. One example is the study by Stige et al. (95), which illustrates how psychotherapy with a predetermined timeframe for recovery was experienced as a burden for many patients (88). One apparent aspect of 'ideology' and how it relates to research participants' experiences and narratives is associated with the ideological characteristics of service provision and a tendency to agglomerate humans with different backgrounds and needs into an impersonal category of 'service users'. The recovery process is then no longer individualized, but treated as a calculated cost-efficient intervention that service users' are responsibilized to manage [*cf.* (8)]. Participants in the study by Lockersten et al. (80, p. 6) provided further examples of the logic of welfare state organizations:

> With the experienced alteration from being treated as an individual to being treated as an illness, the participants often felt like an object during the transition, dependent wholly on a relationship that was restricted more to the registration of symptoms and less to what they felt would help them. They verbalized a sense of no longer feeling like a human.

The transition mentioned here was from a children's psychiatry clinic to an adult psychiatry clinic. This was a major change for young adults with eating disorders, who did not feel ready or willing to change the professional contacts who they had confidence in and had known them for a long time. Such transitions that are mandatory due to organizational structures pose risks for losses of confidence and trust in the system, as well as promoting fear of the adult (impersonal) world of psychiatry. Summing up, our findings show the importance of active collaboration within the welfare sector so that patients have the benefit of continuity and experience strong, transparent links and connections between different resources and mental health professionals [*cf.* (80, 82, 88, 95)].

Discussion

This study focuses on facilitators of, and barriers hindering, service user involvement in social and mental health services in the Nordic countries, which have been analyzed from perspectives of epistemic (in)justice and active citizenship (4, 5, 45). Drawing on a meta-analysis of contemporary research, our findings add new insights to the reciprocity between individual experiences and overarching ambitions for high-quality services expressed in each of the four included Nordic countries (11, 12, 19, 31, 32, 43, 97). They also extend insights by offering empirical evidence regarding two key explanatory factors that help to differentiate between service user experiences: professional relations and the organizational context. Although they are conceptually different, these factors are also closely intertwined. Particularly in financially restrained and understaffed organizations, vague guidelines on patient-professional interaction and/or collaboration in inter-organizational teams will most likely negatively affect professional relations with service users [*cf.* (3, 50–52)].

In line with a meta-analysis by Staniszewska et al. (50), a main conclusion of this study is that professional relations are prominent features of service users' narratives. Knowledge of these encounters' quality is crucial for understanding how individuals in the social and mental health sector experience help and support received from the perspective of being an epistemic citizen, and to what extent they are valued as capable individuals with epistemic worth. As an illustrative example, our findings show that the distribution of sufficient information, and successful coordination of support services, positively contribute to service user experiences, while a lack of coordinated and collocated services negatively affect professional discretion and, consequently, individuals' motivation, capacities, and willingness to contribute to their own recovery process [*cf.* (35)]. An interpretation is that individuals should be enabled to use their epistemic citizenship, for example by receiving information attuned with their hermeneutical resources, and thus enabled to take appropriate action in their current situation, like other (active) citizens. On a personal level this would also validate recognition of their epistemic agency. In addition, empowering and accessible environments—physically and emotionally—or the lack of them, seem to have a major impact on individual experiences of received services in highly professionalized spaces such as those in mental health organizations. By far the most frequently reported individual experiences related to this theme concerned the environmental barriers and facilitators for empowering and accessible care. However, it is important to note that positive accounts were strongly overshadowed by negative storylines (62, 67–71), as also shown in previous research.

Another important insight is that service users' sense of safety and trust seems to increase when their encounters take place in institutional environments where they experience personal sensitivity and engage in dialogue with professionals (62, 81). This is consistent with another important finding regarding the theme of professional relations; experiential knowledge among professionals seems to be valued, recognized, and/or requested, both implicitly and explicitly, by service users [*cf.* (36, 42)]. Consequently, we consider peer-support an important area for further empirical research. However, the review provides no clear evidence about if (and if so, how and to what extent) experiential knowledge is recognized and applied in day-to-day practice within different welfare organizations. These findings are important as professional relations play key roles in the realization (or failure to realize) the empowerment of service users through their involvement, and consequently epistemic justice. Moreover, the ability to establish and maintain empathetic relationships is commonly recognized as crucial for the establishment and maintenance of high-quality provisions in human service organizations (61). Paradoxically, according to both our analysis and previous research, this ability is lacking in many respects for citizens who need it most. The deficiencies seem to be due not only to a lack of quality in terms of activities or low frequencies of practices involving service users, but also to a lack of fundamental understanding of the critical needs of individuals with mental illness, not as patients, but as human beings. Hence we encourage empirical research attention to the slowly growing approach of engaging peer-support workers in Nordic mental health organizations.

Another conclusion is that service users' experiences of their encounters with professionals and the professional world seem to be closely linked to the organizational context. Our findings suggest that both professional and organizational aspects are important explanatory aspects to differentiate between positive/facilitating and negative/obstructing experiences of involvement. We conclude that the legal, moral, and institutional frameworks of mental health organizations [*cf.* (96)] seem to pose challenges for engaging with individual needs and preferences. Normative ideals regarding service user involvement and ambitions to equalize epistemic power between service users and professionals are strongly associated with the active citizen discourse in the Nordic countries. Against this backdrop, our findings provide new insights that may contribute to ongoing discussions on guiding principles for (professional) action and approaches when engaging with epistemic citizens positioned as service users of the welfare state. They strongly suggest that the ability to understand individuals' experiences of their engagements with mental health organizations should be regarded as an institutional element (linked to the rules, norms, and 'taken-for-granted' ideas) of these organizations (1, 25, 43, 50). The findings are also connected to the ongoing trend of including working models of service user involvement in quality-enhancing frameworks for practice [*cf.* (11–13, 18, 22)].

Linking micro-level experiences to organizational macro-level circumstances opens up avenues for further research related to epistemic (in)justice and service user involvement (8, 96, 98). To what extent do institutional contexts aid or obstruct recovery processes, well-being, and agency for mental health service users? How do mental health organizations' rule and norm systems accentuate, conceal, or mystify important ethical aspects of service provision relating to epistemic justice, service user involvement, distribution of power, and taken-for-granted assumptions or perceptions of 'service users' and 'professionals'? Addressing such research questions is important as their answers provide important insights into the moral and epistemic status of people with mental illness as active citizens in the Nordic progressive policy contexts and societies of today. Ultimately they also raise prospects for realizing service user involvement and epistemic citizenship among individuals who need mental health services in the Nordic countries.

When interpreting the results, some limitations should be kept in mind. First, due to the exclusion criteria in the study design we have not considered quantitative measures and findings, which might have added further nuances to our results. Neither have we included parents' or partners' experiences of active involvement in service users' care, which would have added important insights for our analysis, partly because they may provide at least partial channels for the most silent voices, which are often the ones we most need to hear. We should also note some strengths of the study. One is the triangulation in the analysis that was conducted with the local service user committee for collaborative work on a random sample of studies. This was an important contribution that enriched the analytical process with their lived experience and expertise. Moreover, the great heterogeneity of mental health service user groups and organizational contexts that were covered in the included studies probably provided a quite comprehensive and clear picture of contemporary practices and the barriers to and facilitators of service user involvement and epistemic citizenship in Nordic mental health organizations.

Conclusive remarks and recommendations for practice

In conclusion, this study provides empirical evidence of how ideological, professional and organizational factors may synergistically or antagonistically facilitate and/or constrain the ability of people with mental illness to act as equal epistemic citizens in professionalized spaces (1, 35). Our results show that resources required to empower service users' agency, i.e., the ability to comprehend and navigate within complex and sectorial mental health systems to obtain necessary support [*cf.* (4, 45)], are intrinsically connected to structural matters. The results indicate that possibilities for individual service users' to navigate as epistemic citizens are still rather scarce in Nordic mental health services, despite the ambitions to promote active citizenship and user involvement in Nordic policy and practice. These possibilities seem to be heavily constrained by structural aspects, i.e., ideological, attitudinal, and regulatory structures and routines, that must change to enable welfare organizations to provide fruitful and epistemically just relational encounters and support. Soft governance of mental health services in the Nordic countries enables the emergence of diverse locally situated strategies and hence implementation of varying methods and priorities in welfare organizations. It may be time for more stringent policy guidelines, and governance, for addressing mental health issues, as the stakeholders are still facing hardships in modern mental health services after decades of maltreatment and institutionalization. On an organizational level, clear guidelines on active service user involvement strategies should be incorporated followed by staff-education on citizen-inclusive ideologies instead of outdated mental patient-ideologies that belong in the era of institutionalization.

Author contributions

FN performed the initial search-process in the databases and is responsible for the inclusion- and exclusion-process of records in this study. FN and JI worked joint venture throughout 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

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1156835/full#supplementary-material

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The truth project- paper two- using staff training and consultation to inculcate a testimonial sensibility in non-specialist staff teams working with survivors of child sexual abuse

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This paper explores how trauma informed training and consultation for non-specialist staff at the Independent Inquiry into Child Sexual Abuse in England and Wales enabled them to work with survivors of non-recent child sexual abuse in the Truth Project and other areas of the Inquiry. The paper draws on data gathered from 32 semi-structured interviews with a range of Inquiry staff, including civil servants, legal professionals, senior operational managers, and researchers. The interview questions mapped on to the trauma informed principles embedded in the Inquiry and considered the efficacy and implementation of this training for engaging with survivors' voices, working with challenging testimonies and materials, and contributing to epistemic change. Findings included all staff having an awareness of what it meant to be trauma informed in an Inquiry context, talking about the principles in terms of value-based positions. Staff described an awareness of needing to attend to the idiosyncratic experiences of the individual survivor, and there was recognition that previous damage to survivor trust, through institutional failure, meant that demonstrating trustworthiness was a central task. Staff talked about the impacts of participation on some survivors, and the impacts it had on them to be exposed to trauma-related materials. There was acknowledgment of the limitations of the trauma informed approach but also recognition of the wider applications of this learning for other areas of their personal and professional lives. There is some support for the therapeutic culture developed at the Inquiry leading to what Fricker refers to as a testimonial sensibility, a quality of listening necessary for the establishment of epistemic justice. The discussion focuses on how this way of working can be applied to other public service settings and how epistemic justice concepts can be included in more traditional trauma informed care models to encourage an ethic of listening that has political and social, in addition to therapeutic, outcomes.

KEYWORDS

epistemic justice, child sexual abuse, staff training, Public Inquiry, trauma informed approach

Introduction

This article aims to evaluate the impacts of training staff in trauma informed approaches through an analysis of staff experiences at the Independent Inquiry into Child Sexual Abuse ('IICSA' or 'the Inquiry' hereafter). We consider staff perspectives on the Trauma Informed Approach (TIA) training and consultation they received, the impacts it had on their engagement with survivor and survivor testimonies, and the individual professional and personal reverberations such training engendered. We analyze their experiences via the lens of epistemic justice, using aspects of Fricker's work on testimonial justice to consider the tensions staff faced between offering a survivor-centered service while working in a civil service role (1). One of the key findings concerns how staff were able to bring aspects of their own values and life experience into their work at IICSA and a reciprocal shift in their world view around child sexual abuse (CSA).

IICSA was established as an Inquiry in 2015 to investigate institutional failures to protect children from sexual abuse in England and Wales. It also made meaningful recommendations in order to contribute to institutional change. From 2016 to 2021, over 6,000 adult victims and survivors participated in Truth Project sessions, in which they could share experiences about child sexual abuse without prompt and in their own words. The IICSA's Victims and Survivors Consultative Panel (VSCP), a group of CSA survivors who have expertise in the field, co-designed the Truth Project and contributed to ensuring that victim and survivor voices were represented throughout the process of receiving and processing these experiences.

The aims of this study were to understand the extent to which staff who may or may not have previously engaged with work relating to survivors were able to inculcate a trauma informed, testimonial sensibility in relation to survivor experience and testimonies. As the largest Inquiry of its kind to date, IICSA offers a hitherto unparalleled context within which to reflect on the ability of non-specialist staff-wide training programs to meaningfully equip individuals to deliver a trauma informed service in an Inquiry setting.

This article begins with a consideration of the meaning and implementation of trauma informed approaches in order to situate the particular training and practices of IICSA staff. It goes on to consider Fricker's work in relation to shifting staff orientations to epistemologies and justice, and the concomitant changes to survivor voice and testimones (1). It moves on to detail the research methodologies of qualitative, semi-structured interviewing, and engages with the qualitative interview data provided by 32 research participants and considers the key findings relating to application of trauma informed models, trust, individual experiences, empowerment, and personal growth. Finally it offers suggestions relating to policy and practice outside of specific therapeutic contexts.

Staff and trauma informed approaches (TIAs)

Trauma informed services are based on collaborative relationships between service providers and survivors (2). This is because the relational context in which abuse occurs means that any attempts to heal trauma requires forms of relating that are different from abusive dynamics. Trauma survivors often struggle to engage with services that replicate features of controlling and coercive relationships that mirror abusive relationships in childhood (3). Staff training and development is therefore a central feature of the organizational change process of embedding TIAs in frontline services.

Overall, TIAs provide inconsistent evidence in support of treating psychological outcomes (4). There is some evidence that they are effective in reducing Post-Traumatic Stress Disorder (PTSD) and anxiety symptoms but more research is needed to identify specific mechanisms of change, given the heterogenous nature of TIAs. While the majority of TIA interventions are delivered by clinicians with previous training in mental health, there is some support for non-specialist lay staff being able to effectively utilize TIAs if properly trained and supported (5, 6).

TIA staff training typically includes consideration of staff wellbeing and associated constructs such as secondary and vicarious traumatisation (7). The evidence about its effectiveness in this respect is mixed, with one study finding vicarious trauma symptoms increased following a training intervention (8). The authors of this study concluded that it was the increased awareness of the underlying trauma histories that drove service user's presenting difficulties and the need for an attitude and behavioral shift from control to care in a youth justice setting, that may have led to the shift. It is therefore important to consider staff wellbeing in any evaluation of TIA training and implementation, as staff outcomes may be more nuanced than expected.

Staff training and consultation at IICSA

IICSA undertook a particular form of TIA based on its status as a Public Inquiry. The Inquiry staff were multi-disciplinary with a majority being civil servants. Staff training and a psychological consultation service were central components of the TIA implementation. TIAs are an organizational level intervention that recognize the health and social impacts of traumatic stress and have an awareness of the ways that institutions may reenact traumatic dynamics when delivering services to victims and survivors (3). TIAs recognize the impacts of trauma, while also structuring the organization and the practices of staff to minimize the risks of retraumatization (9). Within IICSA, the TIA model was comprised of 5 key principles; (1) Recognizing that the experience of child sexual abuse is subjective and individuals should be respected; (2) Being aware that trust is not to be taken for granted, but fostered; (3) Empowering victims and survivors in their interactions with the Inquiry; (4) Prioritizing the safety and well-being of victims and survivors and working to prevent retraumatization; (5) Acknowledging the impact of child sexual abuse and institutional failures, therefore, looking out for staff wellbeing (9). This was implemented through staff training in the model, alongside ongoing clinical consultation and underpinned all work of the Inquiry.

All staff received training in TIAs on joining the Inquiry, as part of their induction. The half day training was delivered by two members of the clinical team. It included material on the neurobiology of trauma, PTSD and Complex PTSD (C-PTSD) symptoms, Dissociation, features of the TIA, and secondary and vicarious traumatisation. A further training programme was developed in on Complex Communications, which gave staff practical ways to engage with survivors via phone, email, or in person where there were complex needs and dynamics. This additional, optional training included trauma theory, impacts of abuse on interpersonal relationships, a model of abuse dynamics based on Karpman's Drama Triangle (10), and additional material on staff wellbeing. This half day training was also delivered by two clinicians. A final training was developed, 'Life after IICSA' which focused on the end of the Inquiry and was delivered by members of the VSCP and a clinician. It addressed staff and survivor needs as the Inquiry drew to a close; drawing on ideas from attachment theory, models of therapeutic endings, and encouraging citizen activism as a way to reintegrate to communities post IICSA.

The programme of staff training was supported by a psychological consultation service that was offered by a range of clinicians including; psychologists, counselors, and psychotherapists. Referrals concerned various aspects of contact with survivors, including telephone contact, email correspondence, and face-to-face contact arising from attendance at Truth project sessions. There was a separate safeguarding referral service which acted in parallel. Consultation took the form of one-off or multiple meetings with a designated clinician to discuss communication, or to formulate a survivor's needs based on their engagement. Often Inquiry staff were operating with limited information about the survivor as they were not required to provide any details about themselves, to protect confidentiality.

Staff wellbeing was also prioritized for staff across the Inquiry, originally through an employee assistance programme. However, this model evolved over the lifetime of the Inquiry, to include an additional web-based wellbeing hub, secondary and vicarious trauma workshops, reflective practice, debriefs and a compassion focused staff support group.

Trust and epistemic injustice

Fricker's work into *Epistemic Injustice* (1) provides a conceptualisation through which to understand the simultaneous overlaps and contestation between IICSA staff members' roles as representatives of institutional authority and as trauma-informed, compassionate individuals. Of particular relevance here is Fricker's clarification of testimonial justice, and the ongoing tension between viewing testimonial justice as "an intellectual or a moral virtue" (1, p. 120). Viewed as an intellectual virtue, testimonial justice is a process through which listeners (or 'hearers' in Fricker's terms) are required to seek the truth of experiences regardless of prejudicial understandings of moral aspects. By contrast, if viewed as a moral virtue then testimonial justice entails the hearer valuing the wellbeing of others above the importance of the individual facts of events. Fricker concludes that testimonial justice is "a hybrid virtue" because "correcting for prejudice is necessary for avoiding missing out on truths offered by an interlocutor and necessary for avoiding doing them an injustice in their capacity as a knower" (1, p. 126).

The following subsections consider two aspects that are germane to understandings of the TIA at IICSA and also in Fricker's work on testimonial justice: authority; and trust.

Authority

Research conducted by IICSA into victims and survivors' reasons for attending Truth Project sessions indicated that 50 per cent did so, at least in part, to prevent further abuse from happening (11, p. 46). Speaking their truth was a means by which victims and survivors could contribute to meaningfully changing institutional contexts and opportunities for safeguarding. A core outcome of the Inquiry's work was indicating the scale and extent of past failures to protect children. Survivor experiences established the authority of the Inquiry to make specific recommendations to contribute toward the prevention of CSA through providing a base of evidence. At a most basic level, the sheer number of experiences shared established that CSA continues to be a matter of national concern through demonstrating the extent of the scale of sexual abuse in England and Wales, and the considerable impacts it leaves on victims and survivors. Indeed, the Inquiry concluded that CSA is "endemic within England and Wales" (12, p. 1). Through the lens of Fricker's approach, survivors therefore contributed to the very authority of the Inquiry through providing testimonies of lived experiences.

After prevention, the next most commonly reported reason for attending Truth sessions was wanting to tell someone in authority (27 per cent) (11, p. 46).[1] Attendees also reported wanting to be believed (17 per cent); and wanting some resolution (17 per cent). Survivors therefore emphasized the importance of Truth sessions in enabling them to share their experiences with 'someone in authority' (11, p. 46). Viewed through Fricker's work (1), this might be understood as an opportunity for survivors to re-establish the epistemic validity of the speaker through participating in the formal sharing of testimony that might have been denied in prior experiences with institutions. It might also be understood as re-establishing the authority of the speaker themselves through being formally recognized by an institution as 'telling the truth.' These complexities of epistemic authority, truth, and trust, are all the more crucial given many survivors' prior experiences of institutional betrayal and being disbelieved (11).

IICSA reports identified the failings across multiple institutional contexts that facilitated the widespread sexual abuse of victims and survivors. The Report of the Independent Inquiry into Child Sexual Abuse (12) explicitly identified institutional factors that negatively impacted victims and survivors, including: inadequate measures being put in place to protect children; individuals and institutions portraying children as lying; and victims being blamed for the sexual abuse (12, p. 1). While there are more specific findings into institutional contexts (13), these overarching insights indicate the lack of trust that many survivors likely feel in relation to formal institutional structures, and make clear that survivors might have ambivalent feelings about interacting with organizations.

'Institutional betrayal' has been found to be a considerable factor in the experience of sexual abuse in organizational settings (11). Moreover, trauma-informed literature indicates that failures by institutions to understand the needs of victims and survivors may contribute to retraumatisation (11, 14). IICSA staff were therefore given the responsibility to ensure that the survivors whose experiences they received should not be let down once more, and to limit the likelihood of further betrayal.

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[1] This excludes 'Other' categories in which participants could provide reasons not listed in the 'reasons for attending.'

'Epistemic authority' emerges as an important lens through which to understand the layering of epistemologies and their relative authority as survivor experiences are shared and disseminated (1, p. 4). As both this and our preceding paper which addressed the experiences of survivors in the Truth Project (9) make clear, the Inquiry consistently amplified survivor experiences as the strongest form of epistemic authority: that these speakers voices conferred greater truth than others. This was a symbiotic form of collaboration in which the authority of the Inquiry was established through the collection of so many survivors' voices, and in which the epistemic authority of survivors themselves was maintained or re-established through being listened to by 'someone in authority' (15).

Trust

Trust and trustworthiness are interwoven within understandings of epistemic authority and testimonial justice, and similarly within the work of the Inquiry and the trauma-informed approach. Fricker understands epistemic trustworthiness as having two components: "competence and sincerity" (1, p. 45). From the outset, IICSA established that survivors would be allowed to speak their truth and that it would not be questioned. The Inquiry further embedded this trust in survivors through the Truth project which enabled survivors to share experiences in their own words, without established prompts or questions.

Survivors placed a great deal of trust in the Inquiry to respond to, store, and manage their data and the experiences they shared. Similarly, the Inquiry and staff trusted in the aggregated and anonymised data of survivor experiences, even if that did not take the form of specific details or the structured formatting of individual experiences. The likelihood of survivors sharing falsified experiences is very slim (16). In Fricker's terms, this was an act of "epistemic trust" (1, p. 44) embedding the commitment for survivors to be heard and believed in their own terms and minimizing possibilities for enacting testimonial injustice.

Available data indicates that survivors of CSA describe a reduced ability to trust others (16, 17), and especially for those sexually abused in institutional contexts, a reduced trust in institutions (18). However it is important to note that recent conceptualisations within survivor research indicate it is more accurate to suggest survivors assess the trustworthiness of others and can engage in trusting relationships depending on these judgments (19). IICSA research found that 37 per cent of Truth Project participants reported that CSA "shattered their ability to trust anyone" (12, p. 78). Similarly, Palmer et al.'s research report emerging from the Australian Royal Commission into Institutional Responses to Child Sexual Abuse detailed the systemic ways in which survivors had their trust in institutions diminished through consistently being disbelieved or deemed untrustworthy (20). For survivors, this indicates the level of confidence given to the Inquiry and the immense courage in coming forward to share experiences. For staff members, this indicates a challenge in embodying both the trustworthiness of the Inquiry, but also recognizing that their own trustworthiness might come under the scrutiny of survivors.

These understandings of authority, trust, and testimonial justice provide orienting points within which to understand the role of IICSA staff members. Staff members were the medium between survivors and institutional authority: a conduit through which survivors could be 'heard' both in terms of their experiences valued as testimony, and in leading to societal change.

This research into staff experiences therefore aims to increase understanding of the effectiveness of trauma-informed approaches for non-specialist Inquiry staff, and also to reflect on the practice of restoring epistemic justice to those who have suffered considerable institutional betrayal on a national scale.

Method

Participants

Ethical approval for the study was sought via consultation with IICSA's independent ethics research panel. Due to the study collecting evaluation outcome data, it was agreed by members of IICSA's research ethics panel. Participants were recruited on a voluntary basis, with an advertisement for the project being shared with managers across the Inquiry for discussion within their teams. Individuals willing to participate then made direct contact with the researchers in order to find out more about the project and sign up. The purpose of the study was explained, with details of right to withdraw and confidentiality, and consent was obtained prior to participation. A total of 32 IICSA staff members participated in the interviews. Due to staff turnover it is difficult to state the proportion of IICSA staff that took part in the research study. However, at any one point there were approximately 200 members of staff, giving a suggested proportion of 16%. As well as participating in the interview, all participants were asked to complete a short, anonymous google form, recording their demographic information. A total of 26 staff members completed this form. The demographics of this group are shown in Table 1 below. The demographics of the six staff that declined to complete the google form were not recorded.

Of the 32 participants who completed the interviews, 12 had worked for the Inquiry for more than 3 years and 14 had worked for the Inquiry for between 1 and 3 years. There were no participants who had been employed for less than a year. The participants represented teams across the Inquiry, including the legal team, communications, engagement, support and safeguarding, facilitators, operations, policy, research and facilitators. The majority of these staff were involved in the Truth Project either as all or part of their role. The exception to this were the legal team, who only had tangential contact with the Truth Project and were mostly involved in Public Hearings.

TABLE 1 Participant demographics.

Age		Gender		Ethnicity	
Over 65	0	Female	17	White/British	21
56–65	5	Male	9	Black Caribbean	1
46–55	4	Non-binary	0	Asian	2
36–45	5	Other	0	Black British	1
26–35	9	Prefer not to say	0	British Indian	1
Under 25	3				

Sixteen participants indicated that they had no prior experience of using a trauma informed model and 10 reported that they did. Participants held a wide range of professional backgrounds including: civil service, social work, teaching, psychology, legal services, policy and journalism.

Procedure

A semi-structured interview was used to gather data from the participants regarding their experiences of applying a trauma informed approach within their work for the Inquiry. This study aimed to give an expansive understanding of the ways in which training in trauma informed approaches changed how staff engaged with survivors of sexual abuse and their testimonies. As such, qualitative, semi-structured interviewing was the most appropriate approach in order not to bias participants' responses due to researchers' underlying assumptions, and to enable participants to develop insights that were most meaningful to them (21). These interviews were conducted by two IICSA staff members/researchers; these being a clinician (CB) and civil servant (MG).

Participants were asked to discuss their understanding of the trauma informed model, their experience of applying this and their perceptions of the responses to this of victims and survivors. They were also encouraged to give examples of where implementation of this had worked well and when it did not, as well as any impacts on their own wellbeing.

Analysis

Qualitative data was analyzed using a six stage Thematic Analysis (22) which involved those conducting the analysis to fully familarize themselves with the data before labeling data according to the research question. Following the identification of intial themes, these were then refined and woven together in order to provide the analytic conclusions. Thematic analysis was used due to the large sample size and the qualitative nature of the data collected. This was conducted by two authors (CB & SQ). A third author cross checked coding decisions to ensure reliability across the analysis (DT). Initially, data was systematically labeled according to the research question, including line by line coding to generate initial codes. These were then reviewed to identify key patterns and define themes. Three way research supervision enhanced the reliability of the coding approach and the data was consistently used and referred back to in order to ensure credibility of those themes identified (23). Quotations are used throughout the findings in order to support the emergence of the themes identified.

Findings*

The findings are divided into seven themes.[2] These reflect the five TIA principles of: recognizing individual experience; fostering trust; empowerment and choice; safety and preventing re-traumatisation; and staff wellbeing. There was also a general theme relating to overall experiences of applying the TIA and how this was received by victims and survivors and a theme around personal development, including how the TIA would be applied more personally by staff members in non-professional situations. Quotes are attributed to pseudonyms to ease cross referencing and protect anonymity.

Application of the TIA

All staff interviewed ($n = 32$) were able to describe the TIA model as developed by the Inquiry and how they apply this in their role, although with varying definitions and key words.

> *"Trauma informed is being aware of the, sort of, bigger picture around trauma and the impacts of trauma umm and I think, within IICSA it's a really positive thing that it's so multidisciplinary. That we've got teams within IICSA that are not all drawn from within the civil service… We've got external people who come in… Um, because I think it's important that the trauma-informed principles aren't just principles that are written on a piece of paper and people try to follow. I think you can only follow them in a, in a meaningful way if there is that knowledge of the bigger picture, what trauma is and what the wider impact and the wide reaching impact of trauma and how that can impact on people's interactions and sometimes behaviour, in a small number of situations, behaviour."* (Gabriella)

In addition to discussing the key principles that are outlined below, several other principles were identified by participants including: taking a person-centered approach, listening, being non-judgemental, empathic and respectful.

> *"I think the actual principles of the trauma informed approach is the way we should treat every human being anyway, is with that level of respect, you know, trying to build that trust, not treating everybody the same way, even if you think they may be the same. It's about listening and understanding their perspective and from you know their own subjective point of view rather than just having this just blanket objective policy that you just apply to every single person in the same way, and again it's about having those overarching principles but about being able to use your judgement and your common sense to be able to tailor them as necessary, so that you are giving that I suppose either a bespoke service or whether it's just listening to someone, speaking to someone on the phone, over email and I think you should try and apply that in every single thing that you do, regardless of role, because they are some very basic principals that are transferable."* (Holly)

Several participants described the overall quality of the model as having been a positive experience for victims and survivors.

> *"It has been well for me it's been michelin star for victims and survivors it's been an absolute michelin type service they've been given, yeah."* (Valarie)

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[2] The research findings coming from this study do not constitute formal recommendations by the Inquiry's Chair and Panel, and are separate from evidence obtained in investigations and hearings.

> *"I remember one lady saying that the police should learn from the model. Because being interviewed was horrific but had they followed the model, it would have made it so much better. So people have actually, victims and survivors that I've come across have actually loved the model."* (Linda)

The importance of an approach being embedded across an organization was also identified, as being demonstrated through all staff being trained in and having knowledge of the principles.

> *"Within the Inquiry, I can speak to another department or another area within the Inquiry and they will know exactly what I'm talking about when I'm talking about taking a trauma-informed approach which is a lot easier. It needs to be…in my opinion, for it to work in an organisation it needs to be… everybody needs to be doing it, not just individual departments or even individuals within an office or department doing it, otherwise it's not effective."* (Gary)

Further, there was also recognition that even in non-victim facing roles, such as teams that deal entirely with research and documentation, there was still an importance in all staff being trained in and understanding the TIA model.

> *"I think it's quite important to the work, so with legal I feel like a lot of the work that we do in terms of trauma and dealing with victims is more indirect so we don't necessarily have that direct interaction with them but it really is the core and the centre of all of the work that we do."* (Jacob)

Whilst there was a general sense that the TIA model had been effectively applied across the organization, there were some difficulties identified. These appeared to fall into two categories; training and wider organizational culture and policies.

In terms of training, individuals expressed the benefits of having a psychological consultation service which gave advice on implementing the model both within project work and in specific cases. However some participants noted that the TIA training, which occurred for each staff member during their induction to the Inquiry, should have been part of the mandatory training package that was repeated annually.

> *"I think it [TIA training] should have been done after we started because yes it was helpful but I really think you need to re visit and revisit not as just training but small group discussions so that its stuck for life so it reinforces what we're doing, the practise that you're getting right and it gives you ideas, that's what you need- ideas how when you're in the interview you can make the experience as good as it can be and promote trustworthiness, empowerment, safety you know how you can come out things from a cultural agenda perspective, we need to constantly constantly revisit."* (Shannon)

There was also a concern that, whilst trained in and given additional advice when needed, there was no monitoring or feedback with regards to implementation of the TIA model or how individuals could further develop their skills.

> *"I've never had for myself the equivalent of an observed lesson. I've never had anybody say to me, I was listening to the tape of that session, this was good, that could have been better, you know, you talked a bit too much here, whatever. Or have a conversation about it, the only time I've ever had any feedback, I mean yes we do the closed session debrief and I think that's valuable, that's not a situation for that to happen and apart from anything else there is the power relationship, you know, the (Truth Project) facilitators are unquestionably I'm afraid, hierarchically above assistant facilitators, I don't think it's right but it's a fact and so that's not a position where assistant facilitators will feel empowered to give a properly objective view of what the (Truth) session was like, so always you talk over practical things and stuff but then if you try and ask assistant facilitators how they think it's gone it will be all, you know, "oh well I think it's good". It's nothing really."* (Robert)

With regards to organizational culture, the Inquiry was independent of government but sponsored by a government department and employing civil servants. As a result, it was noted that there was sometimes conflict between the target driven culture of needing to get the job done, and the more trauma-informed perspective of needing to be flexible and adapt to individual needs.

> *"I think it [civil service] can be a barrier because I think the approach is, if i was to say it's a very civil service approach I think that there's a lot of things that are packed up in that…Overly hierarchical, complex bureaucracy, buck passing so an inability to take decisions because there's a concern about if you take the decision and it's the wrong decision, a focus upon process above substance sometimes, that would be what I would say are the main barriers because it's all quite process driven rather than "how do we get the job done?""* (Vera)

There were some reports that this resulted in increased complexity of tasks that might otherwise have appeared to have been straightforward.

> *"I think sometimes it can…I think too many people can be involved sometimes. If you send an email, erm – one experience that I had, I sent an email and there ended up being a chain of about…36 emails with one case, with over 10 people involved. And by the time I'd got to the bottom of the emails and worked out what was happening and everything, I was completely and utterly lost."* (Sarah)

Recognizing individual experience

A total of 37.5% ($n = 12$) of participants made specific reference to the need to recognize individual experience and to treat everyone as an individual when asked to identify the key principles of the TIA.

Feedback from some staff appeared to reflect how their work within the TIA model resulted in enhancing their knowledge of individual differences and how victims and survivors all react and respond to trauma differently.

> *"It's definitely made me understand that everyone thinks and feels differently which is why I think the trauma informed approach is in place everyone has a similar guideline and a similar approach to follow in the inquiry but it's definitely made me more considerate of how different things can make people react differently so what might trigger me might trigger someone else or what might be stressful to*

> *me might be stressful to someone else and so I think the trauma informed approach has helped me understand that."* (George)

This increased understanding seems to have really challenged individual expectations about what the response to a trauma should or does look like.

> "*There cannot ever be an objective measure of personal trauma. You know I've had participants who I think have been more powerfully affected by what you might think looking objectively from a distance to have been really quite a small thing than others who have experienced something which objectively looking from a distance people would say "oh yeah, that's proper trauma that is" so I don't think you can ever really judge "how traumatised has somebody been?", all that matters is what the effect has been on them. What their experience of it is."* (Robert)

For others, there was a sense that perhaps, in enhancing a TIA approach, we expect victims and survivors to be more vulnerable and to perhaps present as having more difficulties than, in reality, many do.

> *"I do think we, with the best of intentions, maybe lose a little bit of sight of the fact that our participants are resilient, capable people who are living their lives and are making a choice to come to us. I think sometimes we can become a little bit, um overly solicitous and I think, when you look at some of the feedback, you know, that we see through victim and survivor studies, we know that one of the many reasons that people don't speak and don't come forward is because of a fear of how they will then be perceived. It's a fear of that victim status being attached to them and a fear of them being seen as less capable, less strong and less resilient when actually the opposite is true and I think we know that and we say it but then, with the best of intentions, sometimes we become overly solicitous which could, sort of, reinforce those fears that in some participants.*" (Gabriella)

Fostering trust

In total, 37.5% ($n = 12$) of participants identified trust as being important when asked to identify the key principles of a TIA.

A key ingredient in fostering trust that was identified by several participants was transparency and that, in order to build trust with victims and survivors, Inquiry staff needed to be transparent about what they were doing and why.

> *"It's about being completely clear and transparent with them… otherwise our decisions would seem completely arbitrary and we're just making a decision because we feel that we should where as at least I can, I always refer to the protocol and I always provide a link to the protocol so that they can see for themselves why we have applied the redactions that we have applied. So yeah as I say, being completely transparent, being concise and being clear to them so that they can understand for themselves why we have done what we've done."* (Jacob)

There was also a recognition that, at times, being transparent means being open about things that cannot be done or questions that cannot be answered, rather than generating a false sense of hope.

> *"The trauma informed approach is to make sure that we're not making false promises as well, that we're as realistic as possible and it's about managing those expectations and sometimes we have to deliver bad news, your support has ended for example, we can signpost you, that's as far as we can go. Obviously it has to sit within the inquiry's remit as well, so we can't help everyone and I think it's about recognising that as well."* (Holly)

Alongside this openness, there was a recognition of the weight of responsibility on staff as individuals to follow through with what they say they will do, so as to not let victims and survivors down.

> *"I know I'm comfortable enough to say to a victim and survivor listen I can't answer that question or I'll get back to you and I'll seek advice and get back to them and again one thing is for that is that we do, when we say that we get back to people, we get back to people.*" (Andrew)

Similarly to Paper One, the biggest reported barrier to trust was the Inquiry's responsibility to report allegations to the police. This was identified as a key difficulty in both building trust and a trigger for trust breaking down.

> *"… as soon as you bring up the police that does seem to be a trigger point for when a lot of people will just choose to disengage… maybe if I didn't bring in the police right then or if I'd kind of led into it a bit more, kind of go into this section discussing around police involvement…A lot of the time it is having a conversation around taking details for a session. And then you're asking a serious question around police consent. And in their mind that means that an officer's going to be knocking on my door. So. And we can't say that's not going to be the case because it might. Even if we say, "please don't go and knock on their door, email them first", they might just go round and knock on the door, so…yeah. And that's…feeling that – do you want to do…making promises or assurances which you can't guarantee with 100% certainty.*" (Harry)

However, it was acknowledged that, even with knowing the potential impact of the role of the police, this information still needed to be discussed openly with victims and survivors.

> *"We have to give them the ownership of what they want to do. So quite often will just explain the remit of the inquiry, if they want to take part in the Truth Project, what that entails. We also inform that we will have to tell the police if they give us any information about abuse, but that will also be done anonymously so that they don't have to give their contact details, cause a lot of people do worry about that. They may of had a bad experience with the police, obviously we have to tell them, we have to be open and honest and tell them what we'll do with the information that they give us.*" (Laura)

Empowerment and choice

In total, 15.6% ($n = 5$) of participants referred to empowerment and the need to offer choice when asked to identify the key principles of a TIA. Below are details about environmental and comfort that were also identified as helpful by survivors in the first paper.

> *"We try to make it as pleasant as possible for them, so we give them the choice of setting out the room and anything that might make them feel comfortable, biscuits, tea, flowers, whatever, just to make it feel more homely, and their in control, I think thats the main thing, that the victim and survivor is in control of everything, were not controlling it, their the ones in control, their helping us, were not interviewing them or interrogating them or whatever, so I think from that perspective."* (Laura)

There was a considerable overlap between the principles of trust, empowerment and recognizing the needs of the individual. In particular, in acknowledging that different individuals will make different choices and that it is not for Inquiry staff to override their individual choices.

> *"It's their decision and their choice what they share, how they share, if they share. It's their decision if they complete a session or not. It's their decision if they want a break just to recharge, regroup and come again. It's totally their decision and it has to be about their decision. We're just, I don't want to say a bystander, we're just there to facilitate the journey. We're not there to direct the journey. So for me, it has to be about their choice, it can't be any other way."* (Valerie)

However, there was also a rationale for not offering too much choice and having boundaries within what is available, with boundaries being seen as positive containment as opposed to being restrictive.

> *"We want to give our participants as much choice as possible and to meet every need that we can possibly meet. But sometimes there's empowerment in setting an appropriately and sensitively set boundary. Um, because I also think you don't do people any favours when you behave in a way that gives the impression that there are no boundaries on your interaction with us."* (Gabriella)

Safety and preventing re-traumatisation

In total, 56% ($n = 18$) of participants identified safety and the need to avoid retraumatisation when asked to identify some of the key principles of a TIA.

It was clear that avoiding retraumatisation was a core value in many staff, and that people had a real motivation to help victims and survivors cope well with their experience of engaging with the Inquiry.

> *"The legal team that I work with are all quite sensitive, switched on women and we're not just robots and just got through the process to get the witness to give evidence and you know, in and out the witness box and thanks very much off you go. We want people to feel positively about their engagement with us as an Inquiry but also us as individuals."* (Hannah)

Many staff members were able to recognize signs of distress and offer examples of steps taken in attempts to create a safe environment in Truth sessions in which victims and survivors could share their experiences.

> "*…one woman who was in the chair, she was physically shaking. She was, she didn't know what to do with herself, she was fidgeting and she was shaking, she was literally… she wasn't at ease at all. So what I, what I did was spent a little time explaining how it was gonna work and explaining that it is about them and if they need to stop, well I give people, I say to them at the beginning, look you tell me as much or as little as you like, at any point, you change your mind, anything like that about the recording, at any point do you want a break, just have a cup of tea or go out and get a bit of fresh air or have a cigarette if they smoke, you're welcome to do that. And if it's too much and you want to leave, you can do that, you don't have to stay. You don't have to be here to tell me because it's about what you can cope with and just, just making sure that's alright and just check that they're okay. You know, check that, you know, if there's anything they need, do they need, if they're getting upset, do they need a break. And I think by the end of it, she had, she stopped shaking, she was calm and she was really comfortable."* (Valerie)

Some staff recognized that, as difficult as sharing was, for some individuals this was a cathartic process and working through sharing helped with healing.

> *"The key thing is being aware of the long term pervasive and not necessarily obvious effects of trauma on an individual and so trying to bear those in mind to ensure that we don't re-traumatise but that also we kind of provide opportunities for somebody who has suffered trauma to communicate effectively to heal this and obviously in an ideal world to have some sense of having been able to do something about their trauma by kind of giving witness… The sense I get is that people find the whole process much less intimidating and kind of traumatising than they expected it to and quite often, people explicitly say and if they don't say it you get a very strong sense of it, of the kind of "handing over a burden"* (Robert)

However, there was an acknowledgement that, whilst the approach may have avoided re-traumatisation for many, it could not avoid it for all.

> *"I have one person…who after ten minutes could not go on, unable to go on because he was retraumatised. It was the first time he had ever shared the story and he thought the would be okay but he wasn't so when we did the session within ten or 15 minutes but that's the only example of that kind."* (Shannon)

> *"There was a lady who, it was so traumatic for her, she started having chest pains. She was having chest pains so I actually had to stop the session, so I stopped it and just said to her, look you're obviously in distress, let's take a break. And she said, yes that would be good. She went to the toilet and she came back and she was still having chest pains so I actually said to her, look what we will do, let's stop the session, we can re-book and continue if you wish to do so, and if you don't want to come back, that's okay but for now, I don't want to put you through anymore trauma than you're going through because physical chest pains rings alarm bells in my head, a. because she's struggling but there's also a health implication there as well. So, I did stop and she did re-book and she did come back."* (Linda)

In this case, while the Truth participant showed signs of a strong physical reaction that might have been a precursor to a retraumatising experience, with the offer of choice and a relational approach from the facilitator, she was able to come back and complete her testimony. This is reminiscent of the finding in Paper one that suggested for some survivors, difficult experiences in telling their story should not be assumed to be retraumatising.

Staff wellbeing

In total, 18.8% ($n=6$) of participants referred to staff wellbeing as a key principle within a TIA.

The importance of staff wellbeing was clearly identified by staff members across a variety of teams, focusing upon the impact of this upon their engagement with victims and survivors.

> *"I think that there is a culture of care because that's you know that's about looking after those of us who work because if we're not looking after ourselves or we're not being looked after we can't offer a proper service to a victim and survivor coming through the door."* (Gemma)

Overall, most staff reported being aware of the various sources of support across the Inquiry and were able to identify where they would go for support if they needed it.

> *"I certainly feel the kind of like supported and protected in the information that I come across and what to do if it's kind of too much you know."* (Lily)

There were also a number of strategies identified for managing those situations that staff may find triggering.

> *"I think what I've learnt to do now myself is that if I'm reading a document and it is particularly sort of it hits close to home or something I think I will allow myself the time to take 10 minutes away from my work… get a fresh air or get a cup of tea and just let my line manager as well that I'm going to be doing this and I know they are very supportive of it but it was not something I was necessarily aware of that I could do at the beginning and it was something I had to figure out for myself. But I think yeah they are, everyone is really understanding but it's more of a case of just you have to be more vocal of it from the beginning just so that I'm aware that I can do that if something is particularly difficult then it's the case to sort of take a break."* (Shana)

However, there were some teams where individuals reported that measures to support staff wellbeing did not appear as evident.

> *"When I was working in the legal team…and I would listen to victims and survivors giving evidence or I'd have to deal with them behind the scenes and that was obviously very emotionally charged and very distressing. At the time there weren't any measures in place to ensure, the (clinical) team were there but they were there predominantly for the witnesses I don't think there was anything there for the legal team or the people who are behind the scenes making the hearing happen so I think in future that would be something that would be good to have because I don't think I thought about it until, thinking about it now retrospectively I'd come home and I'd be quite, I wouldn't say miserable I would just be quite deflated from the day, not having a chance to debrief."* (Alice)

These difficulties appeared to be particularly heightened when there was a pressure upon staff in relation to tight deadlines and the need for tasks to be completed quickly.

> *"When I worked as a (member of the legal team) I found it very difficult because the emphasis was on redacting a large volume of material and getting a lot of documents disclosed to core participants in a very short period of time, so the emphasis was very much on quantity, producing a lot of material and redacting a lot of material and I think there wasn't a lot of emphasis in ensuring that we're taking a trauma informed approach."* (Alice)

Staff wellbeing was also dependent upon the team in which someone worked, with recognition of strategies that were used across the Inquiry, but that the specific team approach or management style would impact upon how supported individuals actually felt.

> *"I'm not as confident in how well the Inquiry and we as a team, as a wider team and also as a research team work within a trauma informed approach with each other. I feel like we've got the structures, we've got like the framework, of you know, the wellbeing checks…and we've got mental health champions so it's kind of there but I feel it's almost, bear with me with my analogy, it's almost like the framework you know when you're putting a gazebo up and you've got your frame up but you haven't got the cover on yet and I feel there's a little bit of that with it in terms of staff. And I've thought about it a lot because I've had to, I've had some struggled with my responses to some of the content because I've had a period of being very immersed in Truth data and what I have found is, and obviously this is just my very personal experience now…I haven't really known where to go with that and yes, there is someone saying we've got (wellbeing service) and Im saying "well, I'm not sure about (wellbeing service) because I've done the wellbeing check which was ok, but it wasn't wasn't that useful"…I don't really want to un… to delve right down into it again with some counselling, I think that's very destabilising, I want someone, I need a pathway to help me that's very private and very confidential and puts me, my little bit of it in the centre to help me do my work and actually what's happening is I am trying to manage it on my own and some days are ok and some days aren't."* (Maria)

There was also a suggestion that accessing support should be a more formal requirement to ensure that staff wellbeing was prioritized.

> *"Before this job I worked at (another Inquiry) so I was and I think that that framework for how they looked after their staff, I thought was absolutely incredible and a few differences to (IICSA), the only thing I would say is I think is the, I would say it probably was trauma informed, the (other Inquiry) was more proactive on the support aspect for employees so we had a one hour consultation per month with a support worker which was mandatory and, not mandatory but highly encouraged most people took that up including myself and it wasn't waiting for someone to hit a point where they felt they needed to have to reach out… it was kind of set up and part and parcel of kind of the job that we did to make sure we had that hour to talk about, the same as (IICSA wellbeing service) it could be anything to do with your job or something else or secondary trauma, things like that so I have I would say yes I have before I think."* (Elizabeth)

Personal development

As well as feeling that involvement with the Inquiry had a positive impact upon victims and survivors, many staff identified the changes they had observed in themselves as a result of their work.

> *"It has its made me a more understanding person, someone who listens more and considers other people and also thinks ahead."* (George)

There was also an identification that individuals cannot be involved in this work and the boundary between the professional and the person become less clear, given the level of emotion involved. This was perceived as something beneficial that is relevant to future areas of work.

> *"I think something quite generally that I have found really helpful about the approach is how it encourages you to integrate professional and more human stuff, which I think sometimes in the workplace, I was working in (another country) before where there is a really strict line between professional and personal. So I find it really helpful for there to be an institutional integration of those things; we are not a robot doing work, we are human and that means X Y Z and kind of formally recognising those things and integrating them into the institution's work is so positive. That's definitely something I would personally take forward; making sure that I'm a policy adviser first but also a human too. Wearing two hats I think."* (Rachel)

For some staff, there was a recognition that their work within the Inquiry had changed them and their approach to thinking about CSA, often resulting in others being more open with them about their experiences and the staff members being able to offer more support. This was spoken about in positive terms as opposed to being a burden of the work.

> *"I think before I started on the Inquiry, no one spoke about it, but I think since working here, obviously people know what I do to a certain extent, everyone seems to be talking about it which I think is good. I think it's good and that's probably, hopefully what we're aiming for it to be more open, and obviously places where children can go and tell people about it so it's not so hidden. So I think it's definitely a good thing and I think working here has made a difference wider world.… I'm very surprised really, might be unusual but I would say at least ten people have disclosed to me that they were abused as a child, which obviously is not what you want to hear from your friends, but then again I think it's changed me as well because I've been supportive. I've not been talking in great depth about it, but just for them to tell me I think is probably a big thing for them."* (Laura)

Whilst disclosures were perhaps an unexpected consequence of working within the Inquiry, the knowledge and training relating to a TIA appears to have better equipped staff for managing these situations in non-professional contexts.

> *"I feel like it's sort of made me aware of the sort of um, how common, how common it is and how it impacts sort of sadly the majority of the population in some way or another and I think from that perspective it has given me the ability to sort of deal with it so for example I have, a lot of my friends are obviously aware of my job and the work I do and they have felt since me, I've only been here for a year, but since me being here a lot of my friends have come forward to me about their experiences and I just feel equipped to be able to sort of signpost them in the right direction but also just sort of taking that time to be sort of understanding to them and supportive to them and so I think that has really helped."* (Shana)

Discussion

This research indicates that IICSA staff could clearly identify TIAs and all could identify the core elements of these approaches, suggesting a baseline training was helpful in creating a shared orientation. There were interestingly diverse views on the relative vulnerability of different survivors, suggesting for some staff there was an overcaution around vulnerability that may have missed underlying forms of resilence. This fits with findings from survivor experiences in Paper One. More than half identified the importance of survivors' safety in sharing experiences with the Inquiry, with contact with the Police being a significant trigger point for many survivors, a finding that also corresponds with survivor perspectives in Paper One.

The qualitative data indicates the prioritization of survivor wellbeing when engaging with the Inquiry and the Truth Project. Staff described dealing with highly distressed survivors who at times displayed concerning psychological and physical reactions to the stress of talking about CSA. The descriptions of staff responses are sensible and appear to follow a TIA approach, suggesting that both the staff training and ongoing consultation provided was helpful in at least some cases in creating safety and responding to risk. Given that the majority of staff in this study were not clinicians, this is a considerable finding. Similarly to the survivor experiences, a more nuanced view of retraumatisation emerges, suggesting for some survivors reliving their distress in a truth session was not inevitably destructive in achieving their aim of providing testimony.

The qualitative data also indicates a more complicated landscape in relation to staff wellbeing, particularly within an outputs-oriented context such as the Inquiry. As in the survivor experiences in Paper One, there was a small but important minority who struggled with the CSA material in a way that indicates some negative impact. At the same time, many staff recognized positive changes in relation to personal development and changes in their relationships to others.

The findings will now be considered through a Epistemic Justice lens, followed by consideration of their implications for the TIA literature. Strengths and limitations of the study will also be discussed.

Testimonial sensibility

One aspect that emerged strongly in the data of IICSA staff experiences of TIAs is the curation of testimonial sensibility. Fricker conceptualizes testimonial sensibility as: "where a hearer gives a suitably critical reception to an interlocutor's word without making any inference" (1, p. 71). In the Inquiry's understanding, this 'critical reception' entailed a commitment to recognizing survivor testimonies as truthful and sincere, and without requiring challenge or clarification in order to verify. IICSA staff orientation to the credibility of survivors in some cases led friends to reveal their own experiences outside of the workplace.

Staff members consistently referred to the importance of receiving survivors' experiences in their own terms, without being guided or compelled by IICSA staff. Fricker's concept of "neutrali[s]ing prejudice in credibility judgements" is relevant to understanding this orientation of staff in relation to survivor testimonies, as well as testimonial justice (1, p. 122). 'Neutralising prejudice' involves removing judgments regarding the credibility of speakers in order to enable testimonial justice. While Paper One developed an understanding of the impacts of debates surrounding False Memories, the experiences of IICSA staff reveal the challenge of being the hearer of experiences we know to be true, and with which we would like to effect social change.

The experiences of IICSA staff reveal the complexities of requiring individuals to suspend or internalize emotional responses in order to present neutralized engagement. To be clear: the challenge was not a case of survivors not being believed, but rather that neutralizing credibility judgments entailed limiting the moral and emotional judgments of hearers in order to limit testimonial injustice. In this sense, testimonial injustice might emerge through an excess of moral and emotional engagement by the hearer. Receiving, synthesizing, and presenting the 'truth' of the considerable institutional failures to protect children from sexual abuse required staff to manage emotional responses to challenging material in order that emerging data might not be deemed prejudiced by individual sentiment.

However, individual staff members could not offer indications or guarantees to participants that there would be any specific social and political changes, nor any concrete actions taken on the basis of experiences shared. Moreover, facilitators were required to inform participants that any indication of ongoing criminal acts would be immediately handed to the police. Staff members thus occupied an interstitial zone between institutional authority and individual engagement that might raise considerable challenges. While testimonial justice is certainly a 'hybrid' of both moral and intellectual virtues, this very hybridity recognizes the competing tensions of impartiality and affective engagement embodied by IICSA staff.

Staff working at IICSA recognized the authority they had in relation to survivors and survivors' data. 'Authority' here captures multiple meanings. While explicit that sharing an experience with the Inquiry did not necessarily entail formal recognition of the individual facts of people's experiences, nonetheless sharing an experience with the Inquiry conveyed a sense to survivors that their experiences were being listened to by those in positions of power. This sense of formal authority became embodied by individual staff members in Truth sessions. At the same time, those working in other areas of the Inquiry enacted authority over the representation of survivors' experiences and management of survivors' data.

This framed IICSA staff members as representative of authority structures which might include both institutional opportunities for restitution, redress, and reform, but might also include coming to represent the institutional and organizational structures that initially facilitated the sexual abuse and failed the survivor. This challenge for staff of both representing organizational structures that failed to protect children from sexual abuse, and as embodying the possibilities for institutional reform captures the epistemic challenges of receiving and working with survivor testimonies.

As no individual staff member held authority over every aspect of the Inquiry, IICSA staff also placed their trust in 'the Inquiry' body overall to produce the most truthful and impactful findings and recommendations emerging from the collected testimonies and data. Located between the empathetic and engaged relationship to survivors and survivor data and the structural requirements to process and present findings as dispassionately as possible, staff members had to trust both that the testimonies they were given were truthful, and that 'the Inquiry' would produce meaningful change.

At the same time, individual survivors might view facilitators as enacting forms of epistemic authority over their experiences and consider that IICSA staff were seekers of dispassionate truths and might listen to their experiences with prejudicial skepticism. IICSA staff might also feel the responsibility associated with being in a position of epistemic authority, and conscious that the capacity to effect social change relied on their ability to effectively represent the experiences of victims. These complementary and competing formations of epistemic authority point toward the layering of 'trust' between survivors, staff members, and the Inquiry more broadly.

Trust

One of the most powerful themes to emerge in the data relates to the trust placed in staff, and the Inquiry more broadly, by survivors. This trust included the ways in which the Inquiry collected, stored, and deleted people's data, but also included trust that staff would try to diminish possibilities of retraumatisation. Staff members recognized the trust placed in them as individual representatives of the Inquiry, and evidently felt a responsibility to ensure that they maintained this trust.

A slightly more challenging area that the data points toward is the tension between the empathetic listening and support that constitutes important elements of TIAs and where survivors disclosed information which would be necessary to disclose to police. While staff understood why there was the need to contact the police if details were disclosed indicating that someone might be at risk of harm, they also understood that this mandate could deter survivors from engaging and might inflect or jeopardize the ways in which they related to the Inquiry. While further research would be needed here, available research indicates that many survivors of sexual abuse have negative experiences with the police and the criminal justice system more broadly (24). Moreover, telling survivors that their details might be shared with the police made manifest the power differentials between survivors and Inquiry and Inquiry staff which might otherwise be diminished through TIAs.

While the TIA worked to diminish the harm to survivors in engaging with IICSA, nonetheless the tensions between the institutional authority of the Inquiry and individual survivor vulnerabilities could emerge. This arose in the qualitative data in staff relating the importance of setting boundaries and limiting expectations for participants, which metonymically indicates an impermeable limit between survivor engagement and institutional responsibility. This sense also emerged in staff talking of survivors receiving a "michelin star" and "bespoke" service which indicates a transactional rather than relational element to participants' sharing experiences. This sits at odds with Fricker's conceptualisation of a Testimonial Sensibility, which emphasizes the "idea that our responses to others are learned and internalized through a process of epistemic socialization: a social training of the interpretive and affective attitudes in play when we are told things by other people." (25, p. 161). While survivors might receive an exceptional service, the transactional wording also recognizes that IICSA staff received salaries to conduct the work. It also gestures toward the limitations of institutional engagement, such that survivors might experience the outward presentation (similar to diners in a restaurant) while not being allowed to see the preparation or perceptions of the staff and institutional structures.

On the other hand, this process of 'epistemic socialization' was present for staff in the implementation of the TIA as evidenced by the shared understanding of core principles such as offering choice, safety and empowerment. The extent to which this was generalized for some staff to external roles can be seen in the broader shifts in attitudes to CSA their contact with survivors elicited.

Policy and practice implications for TIA implementation in inquiries and other settings

One of the novel features of this study is that staff trained in the TIA were not in the main experienced in working with survivors of CSA, and so had no pre-existing paradigm that had to be challenged. This is in contrast to many staff working in mental health settings where TIAs represent a shift from medicalised approaches where trauma is backgrounded (25). The lack of ambivalence about the TIA implementation here contrasts with other studies (8), suggesting that concerns about TIA training for non-clinical staff may be misplaced as they can come to the material unencumbered by competing allegiances. This finding validates other studies which also found evidence to support non-clinical staff training (5, 6).

A second practical implication is that the concerns about exposing staff to trauma related materials central to CSA appear to be overemphasized, but not absent, in the context of TIA implementation. For most staff interviewed, the impact on their own wellbeing was limited however for those who did struggle, additional support was needed. The suggestion that the wellbeing offer be made mandatory rather than optional is interesting, and links to the challenges of recognizing early signs of burnout, or vicarious and secondary trauma in oneself and others.

While CSA remains a highly psychologically disturbing and stigmatized area of social life, as IICSA itself found (26), there is encouraging evidence in this study to suggest, if well supported, staff can tolerate distressing CSA material and support survivors appropriately. This aligns with child abuse inquiry scholarship which has suggested that Inquiries serve an important function in spearheading wider societal recognition of child abuse (27), and can create new discourses that privilege survivor accounts over institutional expertise, the 'turn to testimony' (28). From this vantage point, IICSA staff might be considered a microcosm of evolving societal responses to victims of child abuse, suggesting new forms of validation and respect that have important dignity conferring functions for survivors (29). Caution should be employed however in overstating the value of a purely therapeutic sensibility in the absence of wider justice considerations (30). In addition the highly controlled and well resourced context of IICSA and the Truth Project may not be easily replicable in other environments, where survivors continue to face stigma and prejudicial treatment.

One broader policy implication for future Inquiries is that the training offered here was fairly brief and yet in combination with other forms of support, has had a substantial impact on staff practice and the wider environmental milieu. This means that future Inquiries into areas other areas of challenging social areas that require engagement with impacted citizens, can considerably enhance effectiveness in engagement and also attend to staff wellbeing by implementing a similar model of training and support.

Limitations of study and future research

Similarly to the Truth Project Paper One, this study was conducted by IICSA staff, with a risk of bias inherent. This was somewhat mitigated by the methodology of triangulating analysis via two researchers and a supervisor. What the insider status offered was access to the whole staff group and institutional support which may not have been possible for independent researchers.

The qualitative approach in this research study enabled participants to provide granular and reflexive insights into a topic that can be challenging and emotional. Complementarily, although pointing to wider learning on trauma informed approaches, the findings of this study are limited to the participants of this research. As such, they are not necessarily representative of wider populations, nor would it be possible to reproduce the study to test the validity of its findings. Lacking human resource data, we are unsure whether the participant characteristics of the sample are representative of the wider staff characteristics at the Inquiry. While there were standard themes asked of all research participants, the semi-structured approach to interviewing meant that questions and responses were not standardized. These limitations severely curtail the generalisability of the findings and the possibility of conducting rigorous quantitative analysis. Nonetheless, the depth of the insights provided by participants constitutes its own form of data validity that present difficulties with larger cohorts and withe more formal research approaches.

This study found much to recommend Fricker's work on Epistemic Justice as applied to the treatment of the testimony of survivors of CSA in Non-recent Child Abuse Inquiries and other contexts. One possibility is the use of the key areas outlined here- the promotion of testimonial justice through attention to an ethics of listening, neutralizing credibility judgments, and managing allegiance conflict for staff- could be implemented into TIA training and evaluation, which has been critiqued for a lack of operational and conceptual specificity (31).

Conclusion

This study found encouraging signs that non-specialist staff can be trained in TIAs and are able to work sensitively and safely with child sexual abuse survivors in a non-recent child sexual abuse Inquiry setting.

There was some concern about the impact of CSA material on staff wellbeing but less than is popularly presented as a barrier to working with trauma. There were a number of overlaps in findings with staff and Truth Project participants around a nuanced approach to retraumatisation, the interference of outside institutional influence on TIA effectiveness, and the centrality of relational factors in all aspects of communications. There was support for the application of Epistemic Justice in considering staff working with CSA survivors, particularly around the need for a testimonial sensibility that pays attention to the complexities around different forms of authority and the communication of a non-prejudicial listening that compensates for historic injustices in this field.

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 IICSA Independent Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

Author contributions

CB: principal investigator. DT: research supervisor and co-wrote manuscript. MG: project management and data collection. SQ and SF: data analysis and write up. RE: project oversight and organizational leadership. WT: co-wrote 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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A conceptual framework for culturally appropriate advocacy with racialised groups

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Independent mental health advocacy was introduced in England to protect and promote the rights of people detained under mental health legislation. However, shortcomings in access and delivery to racialised people, raising concerns about equity, were identified by a review of the Mental Health Act. The development of culturally appropriate advocacy was recommended. While the term culturally appropriate may be taken for granted it is poorly defined and limited efforts have conceptualized it in relation to advocacy. Ideally, advocacy operates as a liberatory practice to challenge epistemic injustice, which people experiencing poor mental health are at acute risk of. This is amplified for people from racialised communities through systemic racism. This paper argues that advocacy and culturally appropriate practices are especially relevant to racialised people. It clarifies the importance of culture, race and racism to the role of advocacy, and understanding advocacy through the conceptual lens of epistemic injustice. A central aim of the paper is to draw on and appraise cultural competency models to develop a conceptual framing of cultural appropriate advocacy to promote epistemic justice.

KEYWORDS

epistemic injustice, advocacy, culturally appropriate, mental health legislation, race, ethnicity, social justice, independent mental health advocacy

Introduction

This paper is concerned with independent mental health advocacy (IMHA) required by the Mental Health (Amendment) Act (MHA) 2007. In England after 2007, the purpose of this form of advocacy is to protect and promote the rights of people detained under the 1983 Mental Health Act. Advocacy is especially relevant to racialised groups, who face the double discrimination associated with their mental health status coupled with a racialised identity. Their worse experience and outcomes in relation to mental health services has been well documented and the need for advocacy to address this identified more than 20 years ago (1).

A study of the early implementation of IMHA identified that those people who most needed an advocate, and this included people from racialised communities[1], were the least likely to

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[1] We use the term racialised to acknowledge the historical, cultural, political and economic processes resulting in the construction and reproduction of groups based on racial identity. This is used in preference to the term Black, Asian and Minority Ethnic.

access one (2, 3). Furthermore, the Review of the Mental Health Act identified shortcomings in IMHA provision for people from specific racialised communities and recommended the introduction of culturally appropriate advocacy (CAA) (4).

This paper draws on the extant literature, and the experience of the authors in scoping and undertaking an evaluation of pilots to introduce CAA (5) to put forward a conceptual framing for CAA. It argues that the framing offered holds potential to improve conditions of epistemic injustice experienced by racialised people in mental healthcare.

In the background section, epistemic injustice and advocacy are briefly covered to pinpoint their relevance to mental healthcare and their parallel aims in addressing power asymmetries. The following section highlights a gap in the literature in relation to the conceptual framing of CAA. The paper then proceeds in the hope of starting a conversation about CAA. It begins by clarifying some of the core elements of culture and reasserting its importance in relation to mental wellbeing and poor mental health, and the specific relevance of cultural beliefs around rights and epistemic justice to advocacy. It moves on to discuss the necessity for any notion of culturally appropriate to be undergirded by an emphasis on dealing with race and racism. The paper then offers a critique of cultural competency and uses this to inform a definition of cultural appropriate advocacy. Drawing on the literature, steps are taken to propose 'possible' learning domains at an individual level, alongside organizational considerations to conceptually frame culturally appropriate advocacy as a mechanism to challenge epistemic injustice.

Background

Epistemic injustice

The theory of epistemic injustice developed by Fricker (6) as a foundation for social injustice has been identified as important in understanding and addressing the power asymmetries between survivors/service users and mental health professionals (7). Fricker conceptualized epistemic injustice as the wrong done to a person "*specifically in her capacity as a knower*" (2007: 18) reflecting prejudice based on social identity. Fricker distinguishes two forms of epistemic injustice, which she now refers to as discriminatory epistemic injustice (8) - testimonial and hermeneutic.

Testimonial injustice is a form of prejudice where the speaker is misjudged as a knower and whose credibility is seen as lesser, i.e., 'direct discrimination (2017, 53) (8) such that their testimony is ignored, dismissed or downgraded as being unreliable. This then justifies exclusion from decision-making about their lives and potentially compulsion (9, 10). Hermeneutic injustice, is a form of indirect discrimination, whereby the interpretation and meaning of experience, is disadvantaged by a lack of conceptual resources to understand the experience (11) or where forms of knowledge do not exist, are not fairly distributed or are marginalized reflecting dominant social norms (12).

As Hill Collins observes, epistemologies are embedded within social institutions and their practices, thus "accomplishing social inequality relies upon strategies of epistemic injustice that collectively reproduce epistemic oppression" (2017: 118) (13) Thus, mental health service user/survivor knowledge is subjugated to the 'official', i.e., normative, version that reflects dominant values and beliefs, described by LeBlanc and Kinsella as a form of pre-emptive silencing as a consequence of sanism (14) The power asymmetry in the value accorded to knowledge between mental health professionals and survivors/service users is clear (15), and very evident in the, often egregious, experience of people from racialised communities in relation to statutory mental health services (16). For people from racialised communities experiencing poor mental health, the knowledge, values and beliefs embedded in the mental health system not only reflect "a historical failure to draw on knowledge-systems in non-Western cultures" (2017: 31) (17) but also systemic racism and the hegemonic power of whiteness (18, 19).

Advocacy as a liberatory practice

People who experience poor mental health face a serious risk of epistemic injustice, with their knowledge and experience being dismissed or discredited, underpinning social inequalities. This risk is amplified by race, gender, sexual identity, and/or disability due to structural inequalities reflected in social processes of marginalization and discrimination. In this context, advocacy is situated within a challenging territory needing to situate cultural differences within the realms of socio-political-structural forces while ensuring service users are heard and their rights upheld.

Advocacy has been described as a liberatory practice because it is concerned with enabling marginalized voices to be heard and associated forms of knowledge possible (20). It takes many different forms including as social movements for greater justice and in mental health has evolved from collective action to an emphasis on individual level provision (21). Nonetheless, advocacy's roots are founded on the acknowledgement of power disparities, and the need for greater control and choice in relation to public services (22–24). Advocates, therefore, operate at the junction where differing conceptualisations of distress and rights are buttressed against the dominance of psy-disciplines (3, 25, 26).

Advocacy, as 'a liberatory practice (20), can be viewed as a mechanism to address epistemic injustice by ensuring that the testimony of people and alternative meanings of experience and preferences for support are promoted and heard (12). The view that health professionals are epistemically privileged by virtue of their access to specialized knowledge (27) has been contested through the activism of people with lived experience and the development of mad studies (15). Indeed, this has been countered by the recognition of the epistemic privilege of people who have lived experience of mental distress (28). Advocacy, by giving voice to meaning and experience, has the potential to democratize the relationships in care provision by reducing power asymmetries apparent in healthcare systems and fostering greater inclusion. It can be viewed as a critical component of an equitable approach, shifting power dynamics to ensure greater accountability and an equal basis for service users in decision-making.

Using findings from an evaluation of IMHA services in England, Newbigging and Ridley (12) concluded that advocacy can serve to legitimate the voice of people detained under mental health legislation, and thus, go some way to achieving testimonial justice. However, their analysis suggests that advocacy had little impact on achieving hermeneutic justice. They posit two reasons for this: first the context of compulsion and the associated feelings of fearfulness and disempowerment engender compliance with the dominant narrative of mental distress, and second, the increasing professionalization of advocacy has impacted on forms of advocacy that have stronger connections with activism and survivor/service user led groups. If advocacy is to realize its potential for addressing both forms of epistemic injustice attention needs to be paid to this in conceptualizing and implementing CAA.

A recommendation for culturally appropriate advocacy

Despite the valuable role advocacy can play in rebalancing power, a body of literature suggests that racialised groups are not content with advocacy provision (29). Research indicates there is limited engagement among racialised groups, and present models of advocacy are incongruent with their interests and concerns; such groups, for example, expressed greater emphasis on rights being asserted through activism and the need for collectivist practices (5). This contrasts with the mainstream model of statutory advocacy which is largely reactive to abuses, and gives primacy to individualism, independence and autonomy (30). While commissioning models and austerity can influence practice, this dissonance, alongside concerns about advocacy provision (31), and longstanding racialised inequality in mental healthcare, have led to calls for CAA (4).

CAA was recommended by the Independent Review of the Mental Health Act, to address the disproportionate rates of detention of racialised people and to improve their experience of mental health services (4). While calls for culturally specific initiatives are justified (32–35), the term itself is nevertheless enigmatic; it lacks robust definition (36) and there is minimal evidence on how it is translated into advocacy provision. Despite four decades of attention, reviews have found significant variation in what practitioners' feel cultural competence means in practice and to professional standards (37). Therefore, unpacking and comprehending such ambiguity can assist our efforts to conceptualize CAA.

Centralizing culture, race, and racism to the role of advocacy

Embracing culture

Mollah suggests a problem implementing cultural diversity initiatives stems in part from confusion about defining the term culture itself (37). Certainly, being culturally appropriate is not something exclusive to racialised diversity, however there has been particular emphasis on racialised people because of their negative experiences and poor outcomes in relation to public services. As Richardson and Fulton (38) comment '[a]lthough cultural competence is an inclusive notion it is especially important in relation to Black and minority ethnic communities because of their particular, rather than exclusive, needs' (p. 10).

Cultural appropriateness stems from the idea that specific and diverse needs are being met, and a service is grounded in commitment to equitable practices. Yet, culture is a challenging concept to come to grips with, public discourse conflates it with definitions of race and ethnicity, which are in themselves convoluted and imprecise. It is a nebulous and intangible term; Johada (39) described it as an elusive concept that can be whatever a person wants it to be. Culture conjures up various meanings and academic disciplines have their own slant on how it is interpreted (40, 41). Given this degree of uncertainty one may ask: how is culture relevant to racialised groups and advocacy?

Despite ambiguities about its meaning there is agreement that core elements form how we understand and define culture. Castro contends these include: common heritage and history passed from one generation to the next; shared values, beliefs, customs, behaviors, traditions, institutions, arts, folklore and lifestyle; similar relationship and socialization patterns; a common pattern or style of communication or language; geographic location of residence (e.g., country; community; urban, suburban, or rural location); and patterns of dress and diet (42). Of particular relevance is how culture exists in people's minds, which Holstede (43) proposed is part of our mental software.

For the purposes of this paper, we use a definition of culture that engenders a sense of cohesion between groups through shared patterns of belief, feelings and adaptation which people carry in their minds (44). This is illustrated by Spencer-Oatey (45) who states:

> Culture is a fuzzy set of basic assumptions and values, orientations to life, beliefs, policies, procedures and behavioural conventions that are shared by a group of people, and that influence (but do not determine) each member's behaviour and his/her interpretations of the 'meaning' of other people's behaviour. (p. 3)

This way of understanding culture is aligned with UNESCO's definition which sees culture as being based on 'distinctive spiritual, material, intellectual and emotional features of society or social group' (46). A non-essentialist stance is taken which views culture as being based on subjective perspectives; in doing so it presumes that cultural manifestations are dependent on context as individuals create and negotiate varied circumstances. In this way people from racialised groups may adhere to practices that are constructed as being culturally specific while others may not act in accordance with these codified ways.

Although culture is about similarities between groups and codified similarities, it can never be understood as being static and impenetrable as in an ever increasingly interconnected world cultures exist side by side influencing and informing one another's ways of living. Nevertheless, a position is taken that culture structures the way people view the world and the sets of beliefs, norms, and values concerning the nature of relationships, the way people live their lives, and the way people organize their environments. While this provides a framework for discussion, and while appreciating that culture is a fuzzy and broad concept, elements described here are pertinent to the diversity advocacy must embrace.

Culture and mental health

Although culture is a fluid concept it is a central part of how we understand mental health due to its established influence on health practices. As Hernandez remarks, "Culture influences what gets defined as a problem, how the problem is understood and which solutions to the problem are acceptable" (p.1047) (47). It has multi-layered dimensions which interact with class, religion, language, nationality and gender (48), each of which impinge on the way an individual engages with and experiences mental health services.

Mental health professionals and advocates must consider different dimensions of culture in their search for quality care. These dimensions can be physically observable, including forms of address, ceremonies and rituals, food, dress and music. It is nevertheless vital to have a deeper understanding of cultural forms which are hidden. People's assumptions, non-verbal cues, deeply embedded thoughts, perceptions, unconscious feelings and underlying assumptions are all part of culture (49). Various reviews (50, 51) have looked at the relationship between culture and mental health and highlighted its importance to the delivery of mental healthcare. Culture has been shown to influence emotional expression (52), idioms of distress (53) and assumptions about attitudes and responses to pain (54, 55), including levels of shame, which in turn influences help-seeking and engagement with professionals (56–58).

Culture informs people's ideas about hierarchical power structures which can have implications for autonomy within therapeutic relationships. Cultural differences are apparent in notions of collectivism as some groups are more likely to have community support structures which can be helpful for coping; while for some groups spirituality can be more pivotal to illness behavior (59–61). Evidently culture plays a central role in mental healthcare; misunderstandings can lead to reduced levels of trust and confidence (62).

Cultural differences can result in misinterpretations of experience and a dismissing of forms of support that people from racialised communities value. This is in a context of 'white' models of illness, assessment, care and treatment, and the impact of colonialism (63). Fricker's concept of epistemic injustice has been used to describe the downgrading or dismissing of experience on the basis of mental health status, reflecting a presumption of irrationality (8), and privileging dominant discourses of recovery and wellness (64). This is compounded for people from racialised communities, where racism, including exclusion from knowledge production, racial profiling, stereotyping, and ignoring linguistic and cultural diversity have contributed to the poor experience of mental health services by some communities, as reflected in the wealth of evidence of worse experience and outcomes than the majority population (65).

Values are a crucial dimension of culture as they are connected to ideas people hold about what is just and unjust, which is part of building trusting relationships. Cultural differences have been observed in the trust people have in public officials, with racialised groups reporting lower levels (66). This is noteworthy as trust is a component to help facilitate engagement in health provision. Similarly, racialised groups have different ideas about justice (67–69) and they are less likely to have trust and confidence in healthcare (70, 71), and they are more likely to perceive discrimination to be the reason for negative experiences (72). An understanding of these dimensions of identity and cultural differences are vital to the purpose of advocacy in recognition and redistribution of power and its overarching remit to protect and promote rights.

Fear is also a part of cultural beliefs which is relevant to mental health more generally and advocacy in particular. For Black groups especially, researchers have argued there is a fear of mental health services due to an expectation of being mistreated (73). It has been suggested that many Black people view psychiatric care as an extension of the way they are policed, and that mental health care is another strong arm of the state that enforces social control (74). When rights are felt to be so commonly abused, with an expectation of differential treatment, it is understandable that research shows how groups racialised as Black express a greater need for rights protection and enhancement (30).

Although there are observable cultural differences which run along blurred ethnic boundaries it remains vital to avoid reification and ascribe any sense of permanency to any racialised group. Culture is nevertheless significant to how we understand the differential experiences of racialised groups in mental healthcare. Ideas about rights, justice and service engagement are all part of cultural differences which are fundamental to how we construct the parameters of consideration for CAA.

Race and racism

Concerns have also been expressed that a focus on cultural differences obfuscates from the need to address racism (75). Cultural competence has often been introduced to eliminate ethnic inequality and tackle racism. Here there is potentially a muddle in the use of terms as culture is conflated with race and ethnicity in the sense a culturally appropriate intervention can deal with ethnic inequalities and tackle racism. The inequalities that racialised groups experience are not only apparent because of cultural differences. Rather, racial bias, which is directly attached to observable physical differences, in particular skin colour, which provide stimuli which can be perceived negatively, contributing to differential treatment (66). Thus a focus on race and racism is essential to the very foundations of CAA.

There is little doubt that ideas related to race and culture overlap. Hatred can combine cultural and biological factors as they intertwined so evidently in the treatment of Jewish people prior to WWII (76, 77). In relation to mental health, the two concepts converge; barriers to help-seeking are not simply a cultural nuance, they are infused with a fear among racialised people about the care they will receive because of their racialised identity (17, 78). Cases of historical mistreatment of racialised people by the state more generally and by mental health services contribute to cultural beliefs and values about mental health services (79, 80). Nevertheless, race and racism need to be central to any conceptualisation of CAA. Race remains the basis for differential treatment (81). Healthcare professionals are not immune to making racial biased decisions (82). Racial bias is systemic, having a tendency to surface when operating in environments where quick decisions are required, under pressure in stressful conditions (66).

Given this context, challenging racism is crucial. It is possible to be aware of cultural differences, yet this does not necessarily translate into challenging services which are discriminatory. For this reason, emphasis on tackling all forms of racism needs to be incorporated within any model of CAA. Advocates need to be able to comprehend the effects of their own attitudes. They also need the ability to take action to prevent and address racism in all its guises: overt, covert and institutional. While culture may often be used as a byword to embody race in policy initiatives it is explicitly put forward here that CAA must have a role in addressing racism.

CAA that encompasses a direct challenge to racism is well situated in interpretations of advocacy as a liberatory practice, reflecting a concern with social justice and epistemic justice. People from racialised groups are particularly disadvantaged by their positioning at the intersection of state power and individual freedom, and between bio-psycho-social hegemony and alternatives narratives of distress. In this way, CAA should be focused on action that not only protects rights, in the form of abuses under the MH Act, but also on promoting rights, in the sense of broader empowerment and a challenge to institutional and social inequality. A broader range of outcomes that include social equality have been identified by African Caribbean men in relation to the purpose of advocacy (29). Hence attention to race, racism and power should be seen as fundamental components of CAA. This challenges a concept of IMHA restricted by statute to issue-focussed and transactional engagement with service users. It highlights the importance of individual advocacy being situated within collective action on structural inequalities.

Culturally competent approaches

One of the earliest and most known definitions of cultural competence (CC), in relation to clinical practice, is that by Cross et al. (83). CC is analogous to culturally appropriate. This section draws on the former literature of CC, to provide a critique, and to elucidate components which are useful for framing culturally appropriate advocacy who refers to it as:

> 'A set of congruent behaviours, attitudes, and policies that come together in a system, agency, or amongst professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations (p. 13)

Although Cross' is the most widely cited there is no consensus on how CC should be defined. CC and other evolved forms of nomenclature (e.g., cultural awareness, cultural humility, cultural safety, culturally adapted, culturally responsive and culturally appropriate) each bring an element of conceptual confusion (34, 37). For example, Cross' conceptualisation of CC has been critiqued as it makes no reference to the acquisition of information and knowledge about different cultures (84).

Taking a general overview there is recognition that CC is about producing better health outcomes through the acquisition of varied competencies at an individual level while integrating standards across policies and practices. These sentiments were broadly captured following a review of evaluated programs whereby CC was summarized as including:

> "[A] set of skills or processes that enable mental health professionals to provide services that are culturally appropriate for the diverse populations that they serve". (p.14) (85)

Most ways of understanding CC acknowledge the existence of, and the need to account for cultural differences. CC models indicate that for service users' diverse needs to be met attention is required at three levels: structural, organizational and individual (86, 87). This goes beyond narrow understandings of CC which focus on workforce representation or ethnic matching. At the individual level CC typically includes the workforce having a particular set of skills and behaviors. For organizations, features include policies, practices and service design, while structural elements can include commissioning practices.

In most CC models the main aim is not to reflect the ethnic composition of a given population but to have a workforce that can operate to ensure equal outcomes by operating effectively in cross-cultural situations. To assist with developing a culturally competent organization initiatives at the individual level have generally comprised one of at least three components of learning: knowledge-based educational programs have focused on the provision of information such as diverging medical beliefs and practices or cultural interpretations of mental health and illness; attitude-based learning has sought to focus on issues of self-reflection and an exploration of bias, power and disparities; and skill based programs seek to improve communication skills and methods for interaction and how to elicit cultural differences in expectations.

However, CC which aim to build individual competencies have not come without criticism. Programs have often focused on either knowledge, skills or attitudes, missing other core elements of learning (88).

Approaches focused on attitudinal shifts, including cultural safety, cultural responsiveness or cultural humility (89) place emphasis on comprehending the historical, social, political and economic structures and power imbalances within which encounters between professional, and services users take place. While they entail self-reflection, encompassing ideas around humility, responsiveness and safety, they also hinge on the ability to listen and be respectful and open to patient's stories and interpretations. However, concerns about how humility and sensitivity can be quantified, and the singular focus on only attitudinal-based learning have been raised (90). Much has also been made of competency as a construct. Models focused at an individual level have been critiqued for viewing competence as an end-ability whereas a more progressive stance is that of viewing it as an ongoing process (91, 92). Fernando critiques approaches which aim to describe professionals as being competent, as this would mean a person must (a) have sufficient knowledge about all cultures; (b) be fully aware of how to go about eliciting a person's cultural background; and (c) possess attitudes of openness toward appreciating cultural differences (75). Hence, competency-based approaches are unlikely to be the standalone solution.

CC also requires organizational-level change. This can include positive action in recruitment where there is an identified need to ensure a more representative workforce alongside appropriate learning and coaching opportunities and robust attention to monitoring and evaluation. Cultural adaptations can also be considered at an organizational-level. Such adaptations to advocacy can help ensure existing practices respond to emerging needs (e.g., ethnic matching, change to a venue, modification of materials, changes to language metaphors or changes to types of practices including engagement approaches).

Individual and organizational level improvements should go hand-in-hand to improve the client's experience. Beck and colleagues (93) who describe culturally responsive services in clinical care. They suggest how health professionals should be able to recognize and value diversity and draw on the support of team members to make adaptations to clinical care to be culturally affirming for the service user. Hinton and Patel (94) outline similar dimensions when referring to culturally sensitive approaches where the focus is on the overall context of the service user. What is of importance is that any approach requires focus at multiple levels, the outcome of which should be the increased ability of individuals and organizations to work effectively in cross-cultural situations.

Defining culturally appropriate advocacy

With some exceptions, CC has been developed with clinical practice in mind (95). Even though this is the case, various components of CC are relevant to advocacy. Yet, as advocacy occupies a different space to other mental health professional roles there are several dimensions to consider before they can be transferred to the role of advocacy.

Indeed, a key differentiating factor of the advocate's role is that it is not about providing care directly. Advocacy is about supporting and/or representing the service user voice and it is a role embedded in liberatory practice (20), with the aim of building service user's capacity to self-advocate. Viewing advocacy within a framework of epistemic injustice means that attention has to be paid to the power relations in knowledge provision within which individual experience is located.

Independence from mental health services is another differentiating factor for advocacy, as it provides the conditions for scrutiny and for different understandings to the dominant discourse to emerge and to be promoted. Consequently, advocates can be viewed by statutory services as challenging and unduly critical (96). Also, as we will argue, CAA should not be limited to the narrow confines of ensuring the person has a voice (i.e., testimonial justice), as this risks ignoring the wider systemic injustices that have downgraded experience and the meaning of oppressive practices undermining good mental health.

These differences have implications for the skill sets associated with being culturally appropriate. Greater emphasis is placed on understanding and challenging wider institutional and structural inequalities. Representing and promoting service users' voices at the junction between state power and individual freedoms requires specific knowledge around rights-based frameworks, capacity for self-reflection, and insight and willingness to be able to hold services to account for performance at the individual and system level. In acknowledging these differences, and as an attempt to identify its parameters, we put forward the following working definition:

> Culturally appropriate advocacy entails an ongoing commitment by advocates and advocacy organisations, to respectively have the right knowledge, skills and sensitivities, and policies and practices, to challenge the abuse of rights and to work effectively in cross-cultural situations to protect and promote rights in order to achieve greater equality, and ultimately social justice.

This definition builds on ideas within CC and encompasses the need to pay attention to rights promotion and protection. It recognizes the need to focus on individual and institutional factors and how bias operates iteratively at different levels (97). While the definition draws on the need for varied competencies, it overcomes some of the conceptual challenges already identified in relation to definitions of CC. By focusing on the term appropriate, rather than competent, it elicits the expectations placed on the advocate to provide culturally affirming support but to also recognize the journey will never be complete. In this way, the definition overcomes the perception associated with competency which presupposed that a static end-goal can be reached by placing emphasis on the need to be open to ongoing learning.

Defining elements of culturally appropriate advocacy

This section will operationalize some of the key conceptual elements pertaining to the role of CAA. Considerations are defined at three levels for an individual advocate, advocacy organizations and structural factors.

Conceptual framing learning domains for culturally appropriate advocates

Based on a review of advocacy provision by the authors (5) and an evaluation of a culturally appropriate training pilot (98), a learning framework for culturally appropriate advocacy is an area in need of development. Similar frameworks (99) have been developed and applied to other professions within mental healthcare yet few of these have been evaluated, and advocacy has not been an area of consideration.

For advocates, we put forward the suggestion for learning across three domains: knowledge, sensitivities (attitude) and skills; the validity and interactive nature of which have some basis (91). While some models only focus on learning across one domain (e.g., knowledge), a more comprehensive and holistic approach is put forward to encourage wider learning and application. In accordance with the strength of evidence of effectiveness, the approach to learning should incorporate theory and research (100), and center the lived experience perspective. The aim of this section is not to document intricate parts of each learning domain. Rather it is to outline an approach which considers knowledge, sensitivities and skills as part of a culturally appropriate advocate's role.

We use knowledge to infer the cognitive element of any culturally appropriate approach that focuses on the acquisition of information. This includes, for example, advocates developing an understanding of broad aspects of culture and its relevance to (mental) health (e.g., pluralistic help-seeking); the social determinants of poor mental health; the ways in which bias manifests itself and mechanisms used to mitigate it. It is important to re-emphasize, this is not about having knowledge about all cultures, but developing an information base continuously about the specific ethnic groups in the geographic location where advocates operate. Further areas of knowledge include the need to develop an understanding of historical (ie. slavery and colonialism) and present power dynamics including personal power and culture (100). Research argues for an informed and deeper understanding of race, culture and ethnicity as socially constructed entities (5, 99) and the importance of having an intersectional lens and a non-essentialist approach. Other areas of knowledge acquisition may include the social and psychological effects of racism, community-based approaches and alternatives to mainstream support, and the contribution of social context (in hospital and in the community) to mental distress (89, 101), rights-based training and the manifestation of epistemic injustice in mental healthcare. Indeed, the areas covered are not intended to be exhaustive, but to illuminate knowledge as a learning domain and some of its constituent parts.

Sensitivity points toward the affective aspects of an advocate's role, and another domain of focus. While people can acquire knowledge, the right mindset needs to be in place for an advocate to use their learning and to be respectful of racialised differences. Hence, sensitivity is about the desire and effort of advocates which involves an attitude toward appreciating diversity. While many models use the construct attitude, we use sensitivity to encompass attitudes, humility, perceptions, values and aspects of behaviors. CC models have been critiqued for not placing enough emphasis on power and have promoted ideas about cultural safety and cultural humility (102). When using the term sensitivity we promote the necessity for self-reflection, to include an analysis of personal and structural power. This encapsulates ideas within cultural safety and humility models for there to be strength of awareness relating to socio-cultural factors, to facilitate a situation whereby advocates see one-self and their organizations as a cultural entity and that of the populations served. It is acknowledged here that sensitivity is a difficult metric to measure and therefore independent monitoring efforts are necessary at the organizational level, from client input, to reviewing advocacy performance.

The skills domain of the framework focuses attention on the way knowledge and sensitivities can be enacted. This can include the skill to identify when a person may need an interpreter and acting on this, or the skill and capacity to build positive and trusting relationships. It can include the communication skills to be able to elicit whether a person's cultural background has been factored into decision-making. Advocacy involves the skills to not only detect racism but to be proactive, involving critical thinking, including the commitment to critique hegemonic models of mental distress (103), as an element of an advocate's composite skills.

It is possible to explicate how the three learning domains (i.e., knowledge, sensitivity and skills) function interactively. If we take the scenario of a Somali man who feels he has experienced spiritual possession. An advocate needs to access knowledge to understand the significance of different cultural groups and their diverse explanatory models of mental health and self-defined outcomes. They would need to be sensitively attuned to view this as important. Advocates would also need the necessary skill to support and/or represent their client and engage with mental health professionals to encourage them to incorporate their explanatory framework into assessment and care, aiming to build a more developed understanding of client's valued outcomes and how these can be achieved. This example illustrates how the three learning domains can be applied to the role of an advocate. It is also starts the process of conceptually framing the role of CAA at an individual level, and how this can be aligned with the CAA definition provided.

Conceptual framing culturally appropriate advocacy organizationally

While advocates can play a vital role in resolving issues of epistemic injustice, attention also needs to be focused at the level of the advocacy organization. Any conceptual framing of CAA must expand beyond the level of the individual to include various domains at the organizational level, be this different advocacy delivery models, appraising outputs and outcomes, alongside policies and procedures.

The landscape of mental health advocacy provision is dominated by providers that specialize in a range of advocacy and their capacity and relationships with local communities is often under-developed. The following is particularly oriented toward improving the cultural appropriateness of their provision but should not be interpreted as precluding provision by culturally specific organizations which are likely to have a strong foundation in action to achieve racial justice.

Any conceptual framing of CAA must acknowledge the need for functioning organizational policies and procedures. It is by no means out of the realms of possibility for organizations to believe they are implementing progressive policies and procedures when their services can be discriminatory, for example, by inadvertently restricting service access. Embedded systems of data collection are not sufficient without appropriate evaluation, which should in turn inform service design. Service design and outcomes, based on models involving co-production with different groups and based on cultural differences among the service user population, should be common practice wherever appropriate. Other organizational factors, such as working environments, which may not be conducive for racialised people, need to be part of thinking in culturally appropriate ways. This may entail considering the racialised trauma experienced by advocates against the background of issues they encounter in their work.

CC includes an emphasis on organizational values and governance, considering the extent to which equality more generally or race equality in particular, are apparent in documentation, leadership and investment. Other domains include: communication, the need for interpretation or translation services in both written and oral forms to successfully engage and provide support; staff development, involving training, support and supervision, and whether positive action principles, especially around succession planning and client engagement, are implemented. CC frameworks also incorporate a domain centered on organizational infrastructure. This relates to workforce diversity, technology, it could also include linkages and alliances with experts in the field of CC, and partnership with Black led organizations. These are elements which can be transferred to any conceptual framing of CAA.

Service design is linked to the organizational conception of CAA. This can consider facility characteristics, including the access, availability and acceptability of provision, and the environment and location. This is pertinent to models which are viewed as culturally or ethnically specific. Service design can include partnership work, such as, targeted provision for organizations which have a remit to support individuals from specific ethnic backgrounds. Such organizations will have an advantage in terms of hermeneutic justice, although achieving this may well be constrained by the wider social and organizational context. These organizations, typically, undertake collective advocacy although they have been increasingly marginalized in the provision of formal individual advocacy. However, group advocacy is one element of service design which may form a key part of CAA approaches, and thus a consideration in its conceptual framing. It also provides the means to challenge the conditions of hermeneutical injustice. Solidarity is critical to generating collective hermeneutic resources, and by offering a space for interpretative and shared meaning-resources and concepts to be understood, developed and expressed, group advocacy can assist people historically excluded and hermeneutically marginalized (104). Racialised service users can utilize group advocacy settings to frequently come together using their lived experience to develop and share tools and strategies for interpretation and action. It is therefore necessary for advocacy organizations to review the delivery approaches and explore different methods of engagement to amplify service user's voice, and to use case information to inform other system players, including commissioners and NHS providers. Such actions and design considerations are fundamental to how CAA is conceived at an organizational level.

Structural and systemic factors

While the focus has been on individual and organizational factors, advocacy organizations are subject to the caprices of processes operating structurally. Austerity and a shift to neo-liberal managerialism can all impinge and place restrictions on the way advocacy operates, and mental health practices in general.

The role of commissioners also falls at this macro level of operation. Commissioners determine the scope and nature of advocacy provision and their role should not be under-estimated. As noted elsewhere (105), it is vital that advocacy services are based on engagement with, and a developed understanding of, the diversity of the local population. The very structure of advocacy, for instance case-based work, can be informed by the priorities of commissioners. At the same time, commissioners need to be attuned to racism and how bias operates through commissioning processes that may systematically disadvantage smaller community organizations that have both relationships, knowledge and sensitivity to provide independent advocacy services for specific populations. In the shifting world of commissioning and a re-energized focus on addressing inequalities in mental health, there needs to be accountability and transparency in commissioning advocacy.

A structurally specific framing of CAA acknowledges macro level factors, including the environment, the willingness of mental health trusts to engage and financial constraints within which advocacy organizations find themselves. Reduced finances can stymie approaches to pro-active engagement with service users as it impacts resource capacity. Similarly, opportunities for meaningful monitoring and evaluation at an organizational level can be hindered by the financial envelopes allocated by commissioners, and what is prioritized by local authorities. These matters are brought to the fore in the present framing of CAA as they impact directly on provision and have implications for epistemic injustice.

Discussion

Addressing epistemic injustice in mental healthcare is a clear priority. This is particularly the case for racialised people. Culturally appropriate advocacy has a key role in addressing this imbalance within power relations. We argue, that any framing of CAA needs to acknowledge the importance of culture against a background of western hegemony, while equally recognizing racism in all its guises.

The conceptual framing of CAA offered here is one the authors hope will promote further discussion. It offers a scaffolding of consideration at individual, organizational and structural levels, through which CAA can be situated. It does so through the lens of challenging epistemic injustice. Advocacy has already demonstrated it plays a role in relation to testimonial injustice. The focus on knowledge, skills and sensitivities across areas of racial, ethnic and cultural difference, conceptualized at an individual level consolidates advocacy's emphasis on testimonial injustice, while paying attention to the egregious position of racialised people in mental health care.

CAA has the potential to plug an evidenced gap relating to hermeneutic injustice. To do so, minimum efforts are required at all the levels at which CAA is framed. A willingness from advocates to provide a space for the development of shared meaning and resources must go together with a shift in how advocacy organisations operate, and the means with which they can operate.

When framing CAA at an organizational level, there is likely to be a strong call for practical considerations about how lawful requirements under the Equality Act 2010 can be met. This entails a real need to review service uptake, paying attention to feedback and appraising models of engagement, and where necessary adopting pro-active models of engagement. However, taking steps toward hermeneutic justice will require greater steps toward collectivism and solidarity. Part of this may come from enabling a collective voice, through approaches such as group advocacy, increased investment in and support for Black-led approaches; thus stretching the narrowly confined conceptions of IMHA.

Attempts to redress the resource deficit through solidarity and collectivism, must be supported through commissioning, and must have a channel to inform and drive system-wide change. For CAA to be effective there needs to be a listening ear on the part of Mental Health Trusts. This is a structural consideration in the framing of CAA. It is about leaders within Mental Health Trusts being receptive and accountable. There is some reason to be positive that changes in the Mental Health Act can provide the necessary apparatus. The Patient and Carer's Race Equality Framework (PCREF), another article in this special edition, may on the one hand provide the means to appraise delivery to racialised populations at a system-wide level. At the same time, it can provide the conduit through which CAA can inform the system about the experiences of people in mental health services, contributing to institutional accountability. However, codesign and partnerships with community and voluntary organizations for people from racialised communities, in full recognition of their key role in prevention and early intervention, will go some way to improving experience and outcomes and addressing wider social determinants.

Conclusion

CAA was a recommendation of the Independent Review of the Mental Health Act. It is unclear how the term culturally appropriate is conceptualized in relation to advocacy. Existing cultural competency frameworks do not encompass the specific functions of advocates and advocacy organizations and their position as a liberatory practice. This paper argues that advocacy and culturally appropriate practices are especially relevant to racialised people. It clarifies the importance of culture, race and racism to the role of advocacy, and draws on cultural competency models from across clinical practice to develop a conceptual framing of cultural appropriate advocacy.

CAA has implications for people experiencing mental health problems and racism, and professionals involved in care and treatment. If the potential of culturally appropriate advocacy to improve the experience of people from racialised communities in respect of mental health services in general and mental health legislation in particular, then we need to be clear that part of its role will be to address issues relating to race and racism. It is self-evident that while protecting and safeguarding rights in this context is essential, promoting the substantive rights of people from racialised populations will go further in achieving their better mental health and recovery and make major strides toward equality, greater social and epistemic justice.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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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Implying implausibility and undermining versus accepting peoples' experiences of suicidal ideation and self-harm in Emergency Department psychosocial assessments

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Background: Patients seeking emergency care for self-harm and suicidality report varying experiences from being believed and taken seriously to not being believed and taken seriously. Epistemic injustice provides a conceptual framework to explore how peoples' experiences of self-harm and suicidality are believed or not. We use an empirical method –conversation analysis – to analyze *epistemics* in clinical communication, focusing on how knowledge is claimed, contested and negotiated. In courtroom, police and political interaction, conversation analysis has identified communication practices implying implausibility in a person's story to contest and recharacterize their accounts.

Aims: To investigate communication practices in Emergency Department (ED) biopsychosocial assessments that may (1) undermine, imply implausibility and recharacterize or (2) accept peoples' experiences of suicidal ideation and self-harm.

Methods: Using conversation analysis, we micro-analyzed verbal and non-verbal communication in five video-recorded biopsychosocial assessments with people presenting to the ED with self-harm or suicidal ideation, and conducted supplementary analysis of participants' medical records and post-visit interviews. We present three cases where experiences were not accepted and undermined/recharacterized and two cases where experiences were accepted and validated.

Results: When peoples' experiences of suicidality and self-harm were not accepted or were undermined, questioners: did not acknowledge or accept the person's account; asked questions that implied inconsistency or implausibility ("Didn't you tell your GP that you were coping okay?"); juxtaposed contrasting information to undermine the person's account ("You said you were coping okay before, and now you're saying you feel suicidal"); asked questions asserting that, e.g., asking for help implied they were not intending to end their life ("So when you called 111 what were you expecting them to do"); and resistinged or directly questioned the person's account. Multiple practices across the assessment built on each other to assert *that the person was not suicidal, did not look or act like they were suicidal; that the person's decision to attend the ED was not justified; that an overdose was impulsive and not intended to end life; asking why the person didn't take a more harmful medication to overdose; that self-harming behaviors were not that serious and should be in the person's control*. Alternative characterizations were used to justify decisions not to provide further support or referrals to specialist services. At times, these practices were also delivered when speaking over the patient. When peoples' experiences were accepted, practitioners acknowledged, accepted, validated suicidality/self-harm and introduced a shared understanding of experiences that patients found helpful. Non-verbal feedback such as nodding and eye contact was central in acceptance of patients' accounts.

Conclusion: These findings advance our understanding of *how* peoples' experiences of suicidality or self-harm are undermined or accepted in mental health encounters in the ED. They have important clinical implications: patients report that when their experiences are not accepted or undermined, this makes them more distressed, less hopeful about the future and discourages future help-seeking when in crisis. Conversely, acknowledging, accepting and validating suicidality/self-harm and introducing a new ways of understanding peoples' experiences may make people less suicidal and more hopeful, generates shared understanding and encourages future help-seeking.

KEYWORDS

suicide, clinical communication, risk assessment, mental health, crisis care, Emergency Department (ED), conversation analysis (CA)

Introduction

Self-harm and suicide are public health priorities worldwide. In the UK, 1 in 5 adults has experienced suicidal thoughts (1) and 1 in 16 has self-harmed (2). Patients seeking emergency care for self-harm and suicidality report varying experiences from being believed and taken seriously to not being believed, not being taken seriously and feeling judged for seeking help (3). This is consistent with experiences of people seeking wider mental health support, i.e., they are sometimes not believed and their experiences are not taken seriously by healthcare practitioners (4–7). Disclosures of suicidality and self-harm may also be taken less seriously for certain groups of people, such as women and older adults nearing the end of life (8, 9). Interactions with healthcare practitioners can shape peoples' perceptions of whether they need and deserve medical attention (10). People describe a fear of being seen as "faking" or "just wanting attention" as a major barrier to seeking mental health care (11).

The fields of Philosophy and Sociology have theoretical and empirical tools for unpacking whether peoples' experiences are accepted or downplayed, dismissed and disbelieved. In the field of Philosophy, there has been increasing interest in the notion of *epistemic injustice,* which includes testimonial and hermeneutical injustice (12). According to the notion of *testimonial* injustice, a person's reports are dismissed or challenged because a feature of the person's identity triggers a negative stereotype, which leads to denying credibility and authority to that person as a knower. In other words, the person is thought to be unreliable in producing or sharing knowledge and thus the person's reports are overlooked, even when these are reports of the person's own experience. Examples would be discounting a woman's suggestions on how to conduct an experiment in a lab due to the stereotype that women are not good at science; or discounting a teenage patient's report that they feel suicidal due to the stereotype that teenagers are overly dramatic.

Another aspect of epistemic injustice is hermeneutical injustice. This is where a person is denied the conceptual resources to understand their own experience. An example would be how women who live in a misogynistic society in which the concepts of sexual harassment or domestic abuse are not available, lack the opportunity to understand their own adverse experiences as experiences of harassment and abuse.

Although the original notion of epistemic injustice has been developed to explain power asymmetries in social interactions due primarily to sexism and racism, the concept has recently been applied to the mental health context, where negative stereotypes can be associated with people seeking mental health treatment or with those diagnosed with mental illness (13). For instance, when reporting their own experiences, people may not be taken seriously due to having a history of psychotic symptoms (14) and are not credited with the capacity to understand and share their experiences. Historically, within traditional psychiatric diagnostic frameworks, psychotic experiences have been considered not real. However, more recent approaches reframe psychotic experience as "real" to the person even if not experienced by others.

From a philosophical perspective, applying the concept of epistemic injustice to the clinical encounter enables us to conceptualize the attitude of an epistemically privileged party – not as a lack of respect or a failure of empathy (which would not be specific enough) – but as an act of injustice toward the party who is epistemically subordinate. The injustice amounts to assigning reduced credibility to a patient's reports, effectively preventing the perspective of the patient from contributing to shared knowledge and decision making. As epistemic injustice concerns knowledge first and foremost, this does not simply tell us that dismissing a person's perspective due to prejudice is morally objectionable. Rather, it is problematic from an epistemic point of view because the opportunity to gather knowledge that would benefit both parties and society at large is missed.

When one party has expertise that the other party lacks, epistemic injustice does not rule out the possibility of disagreement between the parties. Rather, it situates disagreement in a context where both parties are recognized as agents with a valuable perspective. A practitioner will have clinical experience and expertise that can be harnessed to identify the best means of support for the person. A patient may lack clinical expertise, but has insights deriving from their experience of living with a mental health problem, including, e.g., how they reacted in the past to treatment options. In a particular domain, one party may enjoy greater authority, but both perspectives are valuable and worthy of attention.

Epistemic injustice as such is not an on-off concept, but the extent to which a person's perspective can be taken into account – and valued – admits of degrees and the framework allows for this. Epistemic injustice is based on the fact that the subordinate party is an epistemic agent and agency can be manifested in more or less sophisticated ways: some aspects of agency may not be fully developed, e.g., in a child or may be compromised by poor mental health. As such, epistemic injustice provides a conceptual framework to explore how peoples' experiences of self-harm and suicidality are discussed in mental healthcare clinical encounters. This conceptual framework can be paired with an empirical method developed in sociology – conversation analysis – to analyze *epistemics* in interaction. This involves analyzing how knowledge is claimed, contested and negotiated in communication (15, 16). Conversation Analysis has been used to micro-analyze how knowledge is negotiated in a range of naturally occurring video-recorded social interactions [e.g., Heritage (15–17) and Stivers et al. (18)].

In interpersonal communication, speakers continually mark levels of knowledge about a topic relative to one another (16). For example, asking a question ("How are you feeling?") can mark a lower level of knowledge on the topic (how they feel), relative to the person being asked. Similarly, asserting information ("I've been feeling really down.") can mark greater knowledge relative to the person being spoken to. Relative knowledge is not static: it shifts constantly during interaction depending on the topic being discussed (15, 16). For example, a healthcare practitioner might indicate they have more knowledge relative to the patient about what medication is appropriate to prescribe.

Sociologists distinguish between epistemic *status* and epistemic *stance* (16). Epistemic status involves *expectations* of knowledge, based on roles, e.g., doctor/patient, teacher/student, and experiences such as having studied a topic or having witnessed an event (**Figure 1**). For example, a teacher would typically be expected to know more about the topic of a lesson relative to a student. Similarly, a doctor would be expected to know more about diagnosis than a patient. This would mean that the teacher/doctor had a higher *epistemic status* than the student/patient on that topic. While a doctor would have higher epistemic status than a patient with respect to diagnosis, a patient would have higher epistemic status than a doctor on their experiences and emotions.

In contrast, epistemic stance involves *communication* of knowledge (**Figure 2**). For example, when a teacher corrects a student, they take a higher epistemic stance, or implicitly communicate that they know more about that topic relative to the student. Similarly, when a doctor *informs* a patient of their diagnosis, they take a higher epistemic *stance* on the topic of that diagnosis.

In social interaction outside of institutional contexts, conversation analytic studies have demonstrated empirically that speakers and listeners orient toward speakers have primary rights to know and report on their subjective experiences (17). In healthcare interactions, patients typically have primary epistemic

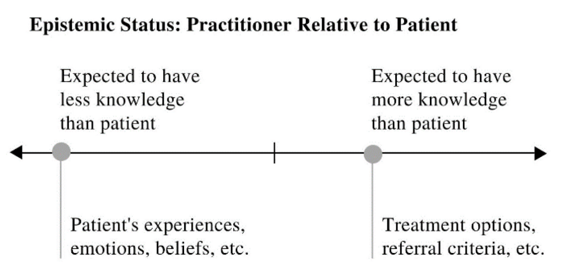

FIGURE 1
Linear representation of epistemic status with illustrative examples.

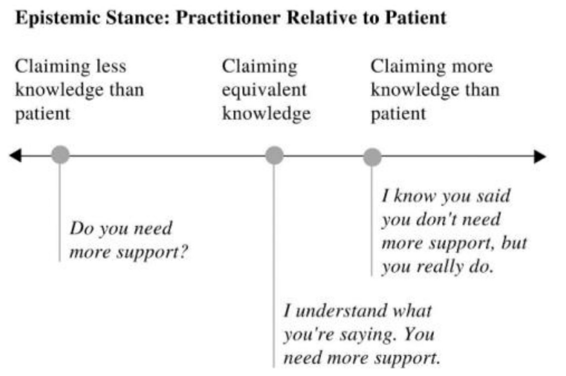

FIGURE 2
Linear representation of epistemic stance with illustrative examples.

rights to know and report on their experience of symptoms while healthcare practitioners hold primary epistemic rights over diagnosis and recommending treatment options [e.g., Heritage and Robinson (19)]. Communication practices can be used to undermine peoples' accounts of their experience. For example, there is a large body of literature examining communication practices in courtroom and police settings that seek and use evidence to undermine peoples' accounts [see Drew (20), Antaki et al. (21), Stokoe et al. (22), and Jol and van der Houwen (23)]. For example, police questions may subtly imply inconsistency or implausibility, e.g., "Didn't you just say that you were at home that evening?" (20, 22) or indicate objection or disagreement, e.g., "But how could you have known that?" (23). In political discourse and mass media, communication practices are used that contribute to a subtle erasure and rewriting of a person's experience [see Clayman and Heritage (24)]. For example, politicians may repeatedly assert unsubstantiated information about other people or newscasters may assume or presuppose a different characterization of events in interviews (24).

There is little research on epistemic communication practices in mental health contexts. As there are typically no physical tests or investigations, mental health practitioners rely heavily on communication to assess mental state and ask patients about their mood, thoughts, feelings, behaviors and physical symptoms. Suicidal ideation involves thoughts and feelings of not wanting to live. Meanwhile, self-harm in the UK, is defined as intentional self-poisoning or injury, irrespective of motivation or the apparent purpose of the act (25). Self-harm can take many forms, including cutting, overdoses, burning, and hitting.

Emergency departments are often the first point of contact with healthcare services for people with suicidal ideation or self-harm who are at increased risk of suicide (26). Hence, they offer a key support system. Medical needs are treated by generalist emergency department practitioners and mental health practitioners from liaison psychiatry teams then offer a biopsychosocial assessment to assess the person's current and future health and social care needs and make onward treatment referrals. This includes a suicide risk assessment in the context of a mental state examination to identify risk and protective factors to formulate suicide risk. Clinicians draw this together with information from other sources and make a structured professional judgment about the person's level of risk (e.g., high, medium, and low), drawing on this to develop a management plan.

There is limited research on *how* assessments are conducted and on peoples' experiences of risk assessment (27). Patients report varying experiences with some people reporting that they are believed while others report not being believed or that their experiences are not taken seriously (4, 5). Hence, the aim of this study was to use an empirical method, conversation analysis, to micro-analyze communication about suicidal ideation and self-harm in video-recorded biopsychosocial assessments in the Emergency Department (ED) to investigate communication practices used to (1) possibly undermine, imply implausibility and recharacterize peoples' experiences of suicidal ideation and self-harm or (2) accept peoples' experiences of suicidal ideation and self-harm.

Materials and methods

The study involved detailed analysis of five video-recorded ED biopsychosocial assessments for self-harm and suicidal ideation, participating patients' medical records and post-visit patient interviews. Self-harm was defined as intentional self-poisoning or injury, irrespective of motivation or the apparent purpose of the act (25).

Ethics

The study was developed in collaboration with a lived experience advisory group and obtained ethical approval from London Central Research Ethics Committee (17/LO/1234).

Treatment setting

The treatment setting was a liaison psychiatry team in the ED staffed by specialist mental health practitioners.

Video data and participants

After presenting to the ED, participants were assessed by medical staff in the ED and had their medical needs treated before being referred for a biopsychosocial assessment with the ED Liaison Psychiatry team. The biopsychosocial assessment involved an assessment of needs and risks, including the risk of harm to self and determined whether the person would be admitted to hospital or was safe to be discharged along with support required from other community based services.

Consent

Before the biopsychosocial assessment, patients were approached by a liaison psychiatry practitioner who assessed capacity to give informed consent and asked if the person would be willing to speak to a researcher. There was a multi-step consent procedure due to people presenting in a mental health crisis. If patients agreed to be approached, a researcher explained the study and obtained written informed consent before the biopsychosocial assessment. The practitioner re-affirmed consent during the assessment, and the researcher re-affirmed consent 1–2 weeks after the assessment.

Data

Data were from three sources (1) a corpus of 46 video-recorded Liaison Psychiatry biopsychosocial assessments collected between September 2018 and April 2019 in an ED in England [see Xanthopoulou et al. (28) and Bergen and McCabe (29)]. Two GoPro cameras were placed in the assessment room and the assessment was recorded with no researcher present. (2) Each patient's ED medical records including the written risk assessment and patient care notes were obtained after the assessment. (3) Patient participants were interviewed 2 weeks and 3 months after the assessment. A semi-structured interview explored patients' experiences of the assessment and their health and treatment after the assessment.

Detailed notes were taken summarizing the content of all video-recorded assessments. These notes were reviewed to identify assessments in which practitioners did not accept the patient's description of their experience of suicidal thoughts or self-harm and introduced an alternative characterization. Three assessments were selected as having particularly clear and recurring examples of this phenomenon. Two cases were then identified to compare these findings with communication when practitioners accepted peoples' experiences. Ultimately, this article focuses on five assessments: three assessments in which the patient's experiences were recharacterized by the practitioner and two assessments in which the patient's experiences were accepted by the practitioner.

Patients presented with suicidal ideation (*N* = 3) or after a suicide attempt (*N* = 2). Patients identified as white British (*N* = 4) and Indian (*N* = 1), male (*N* = 2) and female (*N* = 3), and were aged between 18 and 55. Five Psychiatric Liaison Practitioners (PLPs) participated: two were mental health nurses, two were occupational therapists, and one was a social worker. PLPs identified as white British (*N* = 4) and African (*N* = 1), male (*N* = 2) and female (*N* = 3), and were aged between 40 and 60.

Data analysis

Video recordings

Conversation analysis (30) was used to micro-analyze verbal and non-verbal communication. We sought to identify when a person's experiences were not acknowledged or accepted and the specific communication practices used to subtly recharacterize a person's description of their experience. We analyzed communication practices over the course of an assessment as individual practices may not immediately be seen as recharacterizing the person's experiences but multiple practices over the course of an assessment could be hearable as seeking and using evidence to discredit a person's characterization of their experience and introduce an alternative characterization.

We drew on conversation analytic findings from police, courtroom, and political settings to identify these practices. Data were also presented and discussed in data sessions to (1) a diverse group of five people with experience of receiving professional support for mental health and suicidal thoughts, and (2) a multidisciplinary group of six professionals from psychiatry, psychology, and philosophy.

We analyzed practitioner–patient communication about suicidal ideation and self-harm. We analyzed patient responses indicating lack of agreement with the practitioner's utterances and questions including: explicit disagreement; correcting the practitioners' talk and more subtle signs of patient disengagement including silence, minimal responses, quiet or flat voice quality, reduced eye contact, and not contributing to the forward progression of the assessment, i.e., not answering questions or sharing information to facilitate the practitioner conducting the assessment [see Peräkylä et al. (31)].

A range of communication practices were identified. The main practices are listed in **Table 1** and are discussed in detail using data extracts below.

TABLE 1 Communication practices used to recharacterize patients' experiences.

Communication practice	Studies in other settings	Examples (hypothetical, simplified)
Not accepting or acknowledging a person's characterization of events	Marquez-Reiter et al. (32)	Pat: I'm feeling suicidal. Pra: [**writing notes, no response**]
Question **implies inconsistency or implausibility**	Stokoe et al. (22)	Pat: I'm feeling suicidal. Pra: **Didn't you tell your General Practitioner** you were coping okay?
Question **embodies a compromising response** that could be used against the person's characterization	Drew (20)	Pat: I'm feeling suicidal. Pra: But you've felt like this before and **you got through it, right?**
Statement **juxtaposes information** that may undermine characterization or strengthen argument for alternative characterization	Drew (20)	Pat: I'm feeling suicidal. Pra: **You said** you were coping okay before, and **now you're saying** you feel suicidal.
Asserting an alternative characterization (sometimes repeatedly)	Clayman and Heritage (24)	Pat: I'm feeling suicidal. Pra: But overall **you've been coping okay**.
Questioning or resisting a person's characterization of events	Waring (33)	Pat: I'm feeling suicidal. Pra: **Really?**

To supplement conversation analysis of the video-recordings, we also explored and triangulated data from other sources:

1. Medical records: assessment summaries written by practitioners in the medical records after the assessment. Risk assessments and notes entered after the assessment in the patient's medical records were reviewed to identify how practitioners described the patient's account of their suicidal thoughts/feelings and self-harm This data was analyzed on a simple descriptive level and we report direct quotes from these sources.
2. Patient interviews: 2 week and 3 month post-visit patient interviews were reviewed to integrate patients' experiences on the assessment and interaction with the practitioner. Patient quotes are provided.

Findings

We present five cases in-depth: three cases undermining peoples' experiences and two cases accepting and validating peoples' experiences.

Implying implausibility and undermining peoples' experiences

Practitioners used specific communication practices to recharacterize, downplay and undermine patients' descriptions of their experiences. In each case, multiple communication practices built on one another to support an alternative characterization. In this section, we explore how this evidence is built across each biopsychosocial assessment and where patients' primary epistemic rights to know and describe their subjective experience is undermined across three cases.

Case 1 Patrick: recharacterizing the patient's experiences of misery, feeling suicidal, and undermining a decision to seek help in the ED

Patrick was brought to the ED by his university counseling service after he disclosed thoughts of suicide. Here, we examine brief extracts from Patrick's video-recorded biopsychosocial assessment and 3-month post-visit interview. At the start of the assessment, Patrick confirmed that he was "feeling suicidal" (transcript not shown) and described feeling fearful that he would end his life if he left his flat (see Extract 1). Transcription symbols are described in Appendix Table 1.

Extract 1

1 PR: What would have happened if you had gone for a walk.
2 PT: I don't kno:w.=I think, (2.0) I hadn't thought that far ahead,
3 PR: Mm.=
4 PT: =but li:ke (2.0) I was just- I figured, **if I leave here it's**
5 **the e:nd. I'm gonna kill myself.** So.

Later, after Patrick describes his experience, the practitioner asks what happened when the university counseling service got involved (transcript not shown). Patrick's answer is shown in Extract 2 (lines 51–53).

Extract 2

51 PT: We had a conversation: and then (.) >they spoke about the<
52 possibility of going to hospital,=and I tho:ught, prob'ly a
53 good idea.
...
61 PR: So they spoke about that possibil- What (.) From your point-
62 What made them think that um
63 (1.0)
64 PR: 'Cause they're- they see you because of mental health
65 reaso:ns, (.) and **what made them think that their i:nput**
66 **wouldn't be he:lpful for you.**
67 (0.5)
68 PR: **an:d that it would be helpful for >you to come to hospital.<**
69 from your point of [view.
70 PT: [They're not- They're not- I dunno.They're
71 not trained in any of this kind of stuff. They're kind of .hh
72 the go: between. Between (.) different places. And they
73 thought. (.) They'd be- I think- I think- >I mean I don't
74 know< for certain because I didn't ask them.
75 PR: Mm.
76 PT: But I think they tho:ught that (.) it would be good for me to
77 speak to someone (.) who knew what they were on about.
78 PR: .hh I see. **So they felt that they didn't have the- enough**
79 **trai:ning [to- to to talk to you and reassure you.**
80 PT: [Yeah.
81 PT: Mhm.

Patrick initially characterizes his decision to attend the ED as a "good idea" prompted by a recommendation from a university counselor (lines 51–53). The practitioner does not agree and instead asks a follow-up question (lines 61–69) indicating that it is not clear why it would be helpful for Patrick to come to hospital, and why his problems could not be addressed by the university counseling service. This introduces a potential alternative characterization, that attending the ED was not a good idea.

Patrick shows difficulty responding; after multiple restarts and expressions of uncertainty (lines 70–74, 76–66), he provides justification for the counselor's recommendation. The practitioner summarizes the university counselor did not feel they had the training to "talk to you and reassure you" (lines 78–79). This implies that talking and reassurance would have been enough to address Patrick's concerns, thereby positioning Patrick's concerns as not warranting presentation to the ED.

When discussing the reasons underlying his suicidal thoughts, Patrick describes feeling miserable. In Extract 3 below, a second practitioner asserts that he is either not miserable at times or able to give the impression that he is enjoying things (lines 4–6) then implies that Patrick's facial expressions provide evidence for this alternative interpretation (line 8) of Patrick's feelings.

Extract 3

1 PT: So I (.) feel like miserable kind of
(.) sums it up,
2 PR: **And yet in your fa:ce, you [know=**
3 PT: [Yeah,
4 PR: =**when you're speaking. You've-**
You've got a variation. haven't
5 **you. of- of your expressio:n,=and you**
know you smi:le and
6 **things like that.**
7 PT: >Yeah,< ((no nonverbal response))
8 PR: >**So you have times**< **when you clea:rly**
(0.3) aren't miserable,
9 **you're sort of enjoying things, or**
you're able to [give the
10 PT:
11 PR: **impression [that you are enjoying**
thi:ngs,
12 PT: [Yeah, ((small nod))

The practitioner does not accept Patrick's description of his emotions (feeling "miserable") at line 2. Instead, she cites his facial expressions ("you smile" lines 4–6) as evidence of an alternative interpretation; he has "times when" he isn't miserable (line 8) and is "enjoying things" (line 9). Presenting her observation of his demeanor (lines 4–6) as evidence that he is not always miserable, this challenges the patient's description of his emotional state [see Stokoe et al. (22)].

The contrastive formulation (line 2) and assertion of the alternative interpretation that he is "enjoying things or able to give the impression that you are enjoying things" (lines 8–9), paired with a lack of acceptance at line 2 (e.g., *okay*), discount Patrick's characterization. Patrick responds minimally (lines 3, 7, and 10), showing signs of disagreement and disengagement and passive participation, withdrawing from the conversation and not agreeing with the practitioner's interpretation "when you clearly aren't miserable, you're sort of enjoying things" in line 10 until after the practitioner self-corrects "or you're able to give the impression that you're enjoying things" (lines 11–12).

In **Extract 4**, later in the same assessment, a different practitioner asks what plan Patrick would have had if he had not gone to the ED.

Extract 4

47 PR: What- What plan would you have [had
if you-
48 PT: [I
just- Well I've got a
49 few events on. 'Cause I'm part of
rugby skiing and tennis.
50 And they were all putting events on tonight I co
51 to.
52 PR: **I see. So could we safely say, you**
know. you wouldn't end
53 **your life?**
54 (1.0)
55 PR: Or something that would have=
56 PT: =What tonight?
57 PR: Yeah. [Y-
58 PT: [I wouldn't have ended it
toni:ght. ((shakes head))
59 PR: ((nods)) **You wouldn't have. Okay. So**
maybe there was a bit
60 **of miscommunication because they-**
they brought you he:re
61 **because they were**
saying [Mhm **you were suicida:l, and=**
62 PT: =No I ((nod)) am.=But [I-
63 PR: **[You a:re.**
64 PT: But I've- I feel I can (3.0) I mean I
haven't done it yet,
65 PR: Mm. ((nods))

Patrick indicates he would have attended a sporting event, and the practitioner makes an inferential connection "So could we safely say…you wouldn't end your life" (34) implying that his answer provides evidence that he would not have ended his life (lines 52–53). Patrick pushes back against the question by requesting clarification "What tonight?" (line 56), giving a repetitional answer ("I wouldn't have") (35), and qualifying that he would not have ended it *that night.*

The practitioner repeats Patrick's statement without the qualification – sequentially deleting – "toni:ght" ("You wouldn't have") and makes another inferential connection ("So maybe there was a bit of miscommunication…") (34). He asserts that it may have been a miscommunication when the university counseling center said Patrick was suicidal. Patrick immediately resists this, asserting "I am," stating that he has not "done it yet" (lines 62 and 64).

Across the course of the assessment, the two practitioners undermine the legitimacy of Patrick's decision to seek help (**Extract 2**) and recharacterize Patrick as "not always miserable" (**Extract 3**) and "not suicidal" (**Extract 4**). Ultimately, Patrick was advised to visit a self-help website and continue to access university counseling. Over the next 3 months, Patrick returned to the ED twice; once for suicidal ideation and once for a pharmaceutical overdose with suicidal intent. In his 3-month post-visit interview, Patrick reported that he would not have gone to the ED again, but was brought back by university counseling services.

Case 2 Laura: recharacterizing the patient's experience of suicidal intent to justify no referral

In Case 2, a practitioner recharacterizes Laura's experience of suicidal ideation as brief and her act as impulsive. Table 2 summarises the communication practices used to characterize Laura's suicide attempt as impulsive. This is then used to justify a decision not to refer the patient to mental health services (anonymized). In contrast to impulsive acts of self-harm, practitioners treated premeditated suicide attempts as relatively more serious.

Laura was brought to the ED by ambulance after a pharmaceutical overdose. Earlier in the assessment, Laura said she visited her General Practitioner earlier in the day seeking mental health support but "they didn't help me" (transcript not shown). She reported that she later took a pharmaceutical overdose because she felt "very suicidal." She does not indicate that she took the overdose impulsively. In this section, we examine brief extracts from Laura's video-recorded biopsychosocial assessment and documents in her medical file, including a summary letter written for Laura's General Practitioner by the Liaison Practitioner.

Extract 5

1 PR: And then >what was the< intention
when you took the overdose.
2 What was=
3 PT: =To kill myse:lf,
4 PR: **To kill yourself. And then I hear that**
you called the
5 **ambulance straight away? Or: 111,**
6 PT: N::o, I got- I got on the phone with
111 and then they got an
7 ambulance.
8 PR: For you.
9 PT: For- For- Yeah.
10 PR: **So when you called 111 what were**
you expecting them to do:.
11 PT: All I expect- All I expected them to
get an ambulance out to
12 me to be honest? That's [(the way it
works)
13 PR: **[A::h. So**
would you say you took the
14 **tablets, at the spur of the moment,**
15 PT: Well I [took the tablets and then
later
16 PR: **[Thinking I wanna end my li:fe,**
17 PT: on, I told [them how many tablets I
had,
18 PR: **[And then-**
19 PR: **And then you got worried that you**
wanted to die, and then you
20 **called them.=**
21 PT: =Yeah.
22 PR: **So they would get you the [help. Is**
that
23 PT: [Yeah.
24 PR: **how, [Is that how it worked,**
25 PT: [Sort of, yeah.
26 PR: Yeah okay.
27 PT: I sort of wanted to di:e,
28 PR: Yeah. ((nod))
29 PT: Sort of didn't. Because I have the
two kids to live fo:r,
... ((discuss family relationships))
51 PR: **So it was a more of an impulsive**
thing, at the time,
52 PT: It was just I- I'd had enough. Of
people like Kate picking
53 on me.

In response to the practitioner's question in lines 1–2, Laura states her intention was "to kill my:self" (line 3). The practitioner does not accept Laura's answer (line 4) and asks her to confirm that she called for an ambulance "straight away." The question grammatically anticipates a compromising response, i.e., a response that would indicate she quickly sought life-saving support. When Laura does not immediately confirm (lines 6–7), the practitioner pursues, asking a question ("what were you expecting them to do:." line 10) that directly implies inconsistency between "wanting to end your life" and "calling 111" for help (22).

The practitioner makes an inferential connection ("So would you say," line 13) (34) between Laura's answer and the characterization that she took the tablets "spur of the moment" (line 14). The practitioner does not invite Laura

TABLE 2 Communication practices recharacterizing Laura's suicide attempt as impulsive.

Practitioner's characterization of suicidal act: "an impulsive thing"	
Practitioner communication practice	**Examples from Extract 5**
Asking questions that anticipate a compromising response (20)	"And then I hear that you called the ambulance straight away?"
Asking questions that imply inconsistency or implausibility (22)	"So when you called 111 what were you expecting them to do:."
Juxtaposing contrasting information (20)	"Thinking I wanna end my li:fe, ... and then you called them. So they would get you the [help."
Implying information provides evidence of an alternative characterization (21)	"A::h. So would you say you took the tablets, at the spur of the moment," ... "So it was a more of an impulsive thing, at the time,"

to describe her thought process. He instead invites Laura to confirm a characterization that her overdose was impulsive, which would be considered lower risk relative to a premeditated attempt. Laura does not agree [lines 15/17, see Schegloff and Lerner (36)] and asserts she disclosed the overdose "later on." The practitioner speaks over Laura in overlap (lines 13, 14, 16, and 18) as he continues to describe his characterization of events ("and then you got worried...") and does not acknowledge Laura's talk (lines 16, 18–20, and 22) [see Jefferson (37), p. 319].

Laura agrees with aspects of the practitioner's description ("you called them. = So they would get you the help" lines 21 and 23), but when the practitioner asks her to confirm the overall characterization (including taking the tablets "spur of the moment"), she indicates it is not completely accurate ("Sort of," line 25). She again attempts to describe her experience with conflicting feelings of suicidality and emphasizes the factors contributing to her decision to ultimately call for an ambulance as she has "two kids to live for" (line 29). The recharacterizations offered by the practitioner (that Laura wanted to die momentarily, then changed her mind and contacted an ambulance) does not leave space for the possibility that Laura may have experienced conflicting thoughts of suicide, both wanting to die and not wanting to die simultaneously.

Laura never agrees with the characterization "spur of the moment." The practitioner later asks Laura to confirm that the overdose was "an impulsive thing" (line 51). Laura again does not accept this characterization and describes reaching a point where she had "had enough" (line 53).

In the discharge letter to Laura's General Practitioner, the Liaison Psychiatry Practitioner writes: *[Laura] told us that [she] took the overdose impulsively because [she was] "Fed up with people picking on [her], especially [Kate]."*

Extract 6 occurs a little later in the same biopsychosocial assessment. The practitioner is asking a series of questions assessing to what extent the overdose was pre-planned (see lines 1–2).

Extract 6

1 PR: And the co-codamol. Was- Was it there
for your pa:in,
2 or wh- why: was it in your house.
3 PT: Uh well I originally had it for pain
relief.=
4 PR: =A[h.
5 PT: [But then I (.) took a ((inaudible))
of i:t, and I took an
6 overdose.
7 PR: ((nod)) I see. **Why didn't you take
your overdose on your:**
8 **Depakote [and- and other: (.)
medications,**
9 PT: [((shakes head))
10 PT: Because I didn't think it will:
have effect.

Laura explains that she purchased the co-codamol for pain relief (line 3). The practitioner then asks Laura to justify why she did not overdose on her prescribed medications, naming one particularly harmful medication (lines 7–8). The question implies implausibility that it was really Laura's intention to end her life ().

Extract 7 occurs later in the same assessment. In Extract 7, the practitioner characterizes Laura's suicide attempt as "impulsive" as he resists her suggestion of accessing a rapid response team if in crisis.

Extract 7

8 PR: And would you ask for help if
9 those thoughts came back and,
10 PT: I might ring the response team in.
11 To make sure I'm not taking
12 overdoses [and-
13 PR: [I- ((nods))
14 PT: to make sure ((inaudible)) it's
15 alright. [Yeah-
16 PR: **[You want the rapid**
17 **response team.**
18 PT: Yeah. If there- If there is any,
19 [I don't- I don't know.
20 PR: **[Well we'll talk about that but-**
21 PT: There was one where I used to live,
22 [A rapid response team,
23 PR: [Yeah. **I can appreciate that you**
24 **feel this but until Kate upset you,**
25 **you've been coping generally okay,**
26 PT: Yeah.
27 PR: **And then this happened and then**
28 **caused this impulsive um behavior.**
29 To kind of uh-
30 PT: Yeah.
31 PR: You took the overdose. So at this
32 point in time you say you don't have
33 any plans to do anything to cause you
34 harm.
35 PT: No.
36 PR: ((transitions to further risk
assessment questions))

The practitioner asks whether Laura would ask for help if she had suicidal thoughts (lines 8–9). Laura responds that she might ring the rapid response team (lines 10–15). The practitioner asks Laura to confirm (lines 16–17), indicating this is problematic (38) and flags that this may not be facilitated.

The practitioner acknowledges that Laura wants support from the rapid response team (lines 23–24 re lines 16–17) and speaks over the patient in interjacent overlap (lines 20 and 34). He asserts that until the triggering event Laura was "coping generally okay" (lines 24–25). He frames her overdose as "impulsive... behavior" that was "caused" by Kate (lines 27–29). Laura minimally agrees (lines 26 and 30) and the practitioner requests re-confirmation that she has no plans to harm herself (lines 31–34), a leading question that is designed for Laura to confirm she does not have plans to harm herself (39–41). This all works to build a case that the Rapid Response Team is not needed [see Anonymized (42)].

After Laura states that she has no plans to harm herself in response to the leading question, the practitioner transitions back to suicide risk assessment. Later, the practitioner recommends speaking to a friend or calling a charity helpline if she finds herself in a similar situation. In the risk assessment document, the practitioner writes: "*We have... encouraged you that if you are feeling low or have a fall out with someone you care about to try to talk to someone who will be kind, such as your landlord, or ring Samaritans. If you feel suicidal and this isn't enough we have advised you to ring 111.*" There is no reference to the rapid response team. There was no patient interview, which we have found was often the case when a person had a negative experience of the biopsychosocial assessment in the ED.

Case 3 Sasha: recharacterizing the patient's experience of food restriction shifts the burden of care

As shown in the extracts above, recharacterizations can be built up during an assessment and can be cited to justify decisions not to provide specialist care. In the following extracts, we demonstrate how these recharacterizations can be used to shift the burden of care off of the healthcare system and back onto the patient (43).

Sasha attended the ED seeking help for worsening symptoms of obsessive compulsive disorder (OCD) restricting her food intake and feeling unable to control her intrusive thoughts of suicide and the need to do things in blocks of eight. This included dietary restriction to 800 calories per day, which had resulted in the rapid loss of about 22 pounds and a Body Mass Index bordering underweight. Eating disorder behaviors are viewed by some as an extreme form of self-harm. In the ED biopsychosocial assessment, Sasha asked about specialist support for eating disorders multiple times. In this section of the article, we share brief extracts from Sasha's video-recorded biopsychosocial assessment and her 3-month post-visit interview. In Extract 8, Sasha describes her experience of food restriction.

Extract 8

1 PT: Because: **my obsessive behaviors have been getting worse and**
2 **worse as well.=They've now kind of spread into: (1.0) um (.)**
3 **areas of my life like eating:,**
4 PR: Mm. ((nod))
5 PT: Um (.) yeah Steve said that he was really concerned, (.) about
6 (.) the weight that I've lost so [rapidly: and I
7 PR: [Mm. ((nod))
8 PT: can feel my heart slowing do:wn:, and **I can feel the physical**
9 **symptoms from it.**
10 PR: Mm:.

Sasha describes her food restriction as an obsessive behavior stemming from her OCD (lines 1–3), thereby framing the behavior as a symptom outside her control. She emphasizes the speed of her weight loss, others' concern, and the physical impact on her body (lines 5–6 and 8–9). She positions the food restriction as a concerning symptom for which she is seeking help. She describes her experience of food restriction again in Extract 9A.

Extract 9A

1 PR: And and in terms of you:r understanding. What's your diagnosis
2 Sasha,
3 PT: Um: OCD, and (.) anxiety, I think, ((shakes head))
4 PR: Okay. ((nods))
5 PT: ((nods))
6 PR: And you- That- For you: that makes sense does it. ((nod))
7 PT: Yes. ((nod)) **The only thing that doesn't make sense is why:(.)**
8 **I'm feeling unable to eat:. [And restricting what I'm eating.**
9 PR: [Mm::. ((nod))
10 PR: Okay.
11 PT: And having (.) um (.) ((voice breaks)) kind of unpleasant
12 thoughts about my body shape? [and,
13 PR: [Mm:. ((nod)) Okay.
14 PT: that.

Sasha describes feeling "unable" to eat and that it "doesn't make sense" why she is experiencing these thoughts and behaviors. Sasha frames her food restriction as a serious problem, something she cannot control and needs help to address. In Extracts 9B, C, the practitioner indicates that the food restriction is not yet serious, something she may be able to control, and something she already has the resources to address. Extract 9B occurs immediately after Extract 9A.

Extract 9B

15 PR: Alright, Okay, **And I assume that you're rea:lly (.) try:ing?**
16 eating, ((nod)) as in you're (.) you know trying to give
17 yourself permission (.) to (.) you know, enjoy food.Whatever.
18 (.) 'Cause I guess if you're quite slim and you're worried
19 about losing more weight. **Now's not ((shakes head)) the time**
20 **to** start thinking Well I shouldn't have any custard ((smiles))
21 or I [shouldn't have any-So you're trying t-**Are you trying to**

22 PT: [((looking down, nods)) °Mm.°
23 PR: **just have what you fa-fancy when you-when you could (.) eat**
24 **it.**
25 PT: I- ((shakes head))
26 PR: Again it's e:asier said than [done but,
27 PT: [Whatever it is it's not letting
28 me.
29 PR: **It's not what, [Sorry.**
30 PT: [It's not letting me.
31 PR: **Right.**
32 **(2.0)**
33 PR: Okay.
34 PT: Like I- (1.0) haven't eaten anything today,
35 PR: Mm.
36 PT: And I've barely eaten anything since Monday, [Just-
37 PR: [Okay.
38 PT: Yeah. It's got out- out of control.
39 PR: **Mm::. Okay, ((nods, looks away))**
40 **(1.0)**

The practitioner immediately asks Sasha to confirm she is "try:ing" to eat and to give herself permission to "enjoy food" (lines 15–17). The question communicates an assumption that Sasha has the choice to try to enjoy food. This does not align with Sasha's previous descriptions that she is unable to eat (Extracts 9, 10). The practitioner then tells Sasha that "now's not the time" to think that she should restrict her food (lines 18–21).

Sasha pushes back on the presupposition that she has the choice to "try" to eat (lines 27–28). She frames the problem as a force outside of herself "Whatever it is. . ..it's not letting me." The practitioner does not show agreement or affiliation and responds with minimal acknowledgment ("Right.") and silence (lines 31–32). Sasha expands on her answer, providing an illustration (lines 34 and 36). She summarizes that her eating has gotten "out of control." The practitioner minimally accepts (line 39) but does not agree with or validate her experience. The practitioner looks away and there is a long silence.

In Extract 9B, the practitioner subtly communicates a stance that Sasha's food restriction is not yet serious and is something she may be able to control. Extract 9C occurs immediately after Extract 9B.

After the practitioner's minimal response (Extract 9B, lines 39–40) Sasha says she feels she will not be taken seriously until she is underweight (Extract 9C, lines 40–41). This also implies that the current practitioner is not taking her problem seriously. The practitioner resists this with an accusation, asking Sasha to confirm that she plans to "make" herself underweight so people will take her seriously (lines 43–44). This again recharacterizes Sasha's food restriction as within her control and implies that she may try to exploit this intentionally. Sasha again pushes back, stating that she does not want her weight to be the deciding factor in whether she receives care (lines 47–48).

Extract 9C

41 PT: But I feel like no one's gonna take me seriously until I'm
42 underweight. Which- (1.0) I don't know. I've=
43 PR: **=So you're gonna make yourself underweight, So people take you**
44 **seriously, Is that' what you're=**
45 PT: =I don't want that to happen. ((shakes head))
46 PR: No. | We wouldn't either.
47 PT: | I don't want that to be the deciding factor in whether I
48 get help for it or not.
49 PR: Mm:. ((nod))
50 PT: But I know it's tricky 'cause there's so many people °needing
51 help.°
52 PR: I was gonna say ((nod)) if you think there's a wait for
53 anxiety.
54 PT: Exactly.=
55 PR: =and mood problems, it- you know- eh for- **for the earlier**
56 **stages of catching and diagnosing eating disorder it's- it's**
57 **wo:rse and longer than that. So have you got anybody**
58 **supporting you: about eating. Anyone prompting: you: or**
59 **willing to sit with you:,**

Sasha acknowledges the burden on eating disorder services (lines 50–51) and the practitioner emphasizes the length of the waiting list for eating disorder services (lines 52–53 and 55–57). She describes the wait as "wo:rse and longer" than anxiety disorder services if a person is in "the earlier stages" of an eating disorder. Sasha has not described her eating problems as "earlier stages," so this further works to minimize and recharacterize her concerns. The practitioner then transitions to ask about friends and family supporting her at mealtimes (lines 57–59). Throughout the rest of the assessment, the practitioner repeatedly encourages Sasha to seek out social support (e.g., "it would be really good to collaborate with somebody in a bit of a buddy way").

Sasha did not receive a referral for specialist eating disorder services. After attending the ED, Sasha was encouraged by her parents to continue to seek specialist support and began treatment with an eating disorders specialist 3 months later. By then, she had lost a substantial amount of weight. In a 3-month post-visit interview, Sasha reported: "I did get the impression that some people weren't taking me seriously because I still looked vaguely normal. . . I've lost even more weight since then so kind of firmly within the anorexic range. So I think if – I don't know – Maybe if I'd been able to access the help sooner then it wouldn't have got to that stage."

Accepting and validating people's experiences

Below, we present two cases where patients' experiences were acknowledged, accepted (rather than contested or recharacterized), validated and where practitioners worked to develop a shared understanding with the patient about their experiences.

Case 4 Emily: accepting and validating the patient's thoughts of suicide

Emily presented to the ED with suicidal thoughts. In Extract 5, she describes feeling "I might be better off dea:d" but is seeking help because "I don't want to hurt anyone." In this section, we present brief extracts from Emily's video-recorded biopsychosocial assessment and her 1-week post-visit interview.

Extract 10

1 PT: I just always think 'A:ctually I'll go jump in front of the
2 tra:in.' [or whatever I'm doing.
3 PR: [Mhm. ((nods, eye contact))
4 **PR: ((continues nodding)) (0.5)**
5 PT: Yea:h. ((wipes face))
6 **PR: ((continues nodding)) (1.0)**
7 PT: Yeah that's- that's the kind of thought I have.
8 PR: **Mhm. It's a sca:ry thought.**
9 PT: I kno:w. [It's ho:rrible.
10 PR: [((nods))
11 PT: Or I'll be like, my anxiety will be ba:d. So (.) even when I'm
12 like (.) around the ho:use, [and I pick up a knife, [I'm like
13 PR: [((nods))
[((nods))
14 PT: >Okay I can just do this< now, [Or like (.) I can just hang
15 PR: [((nods))
16 PT: myself now, [I just- It's just like always going on in...
17 PR: [((nods))

Emily describes her suicidal thoughts in lines 1–2. The practitioner immediately accepts her description (line 3) and continues to nod as she gives Emily space to continue (lines 4 and 6). Nodding conveys affiliation, i.e., understanding and support of the person's perspective (44). The practitioner then validates her perspective by acknowledging these thoughts are "sca:ry" (line 8).

Emily does not show signs of disengagement (as in Extract 3) (31) or push back against the practitioner's response (as in Extract 4). She indicates this is a shared understanding of her experience ("I kno:w") and aligns with the practitioner's description ("sca:ry") by offering a similar upgraded description ("ho:rrible") (45).

Emily did not describe her suicidal thoughts further when given the opportunity at lines 4/6. However, immediately after the practitioner acknowledges her thoughts as scary, Emily shows a willingness to disclose more sensitive information, describing similar thoughts about ending her life in other ways (lines 11–12, 14, and 16).

In a post-visit interview, Emily described the assessment itself as "really really useful," particularly "getting off my chest how I was feeling." Emily reported she "felt quite safe when I went home" because of the conversations she had with this practitioner.

Case 5 Sam: building on the patient's characterization of his experience leading up to suicide attempt

It is common in mental healthcare encounters to negotiate about the meaning of and recharacterize a person's experiences in a more positive way. For example, practitioners can work to reframe patients' negative thoughts about themselves to facilitate a different understanding (46). Cognitive reframing is a therapeutic tool commonly used to manage negative assumptions and automatic thoughts (47), wherein the practitioner challenges the thought process and introduces alternatives. For example, a practitioner might challenge a patient's assumption that nothing will help them. This does not involve denying the person's emotions (e.g., hopeless) or experiences (e.g., of treatment-resistant depression).

In Extract 11, the practitioner introduces a new way of understanding the thoughts Sam experienced before attempting suicide. Sam was brought to the ED after an overdose with suicidal intent. He recently left the army and moved back to his mother's house. We present brief extracts from Sam's video-recorded biopsychosocial assessment and his 1-week post-visit interview.

Extract 11

1 PR: **I think, from what you've said, that you've been struck by**
2 **a NAT.**
3 PT: What's a NAT.
4 PR: **A NAT is a Negative Automatic Thought.**
5 PT: Mhm,
6 PR: And what's happened, is since you've left the army
... ((practitioner lists challenges patient is facing))
18 PR: Yeah? It's hard for you to get a job,
19 PT: ((nods))
20 PR: You struggle with your mom, 'cause your mom doesn't

21 understand the situation,
22 PT: Yeah.
23 PR: Yeah?
24 PT: Mhm.
25 PR: **So what happens is you get this build-up of negative thoughts**
26 **in your mind.**
27 PT: Mhm?
28 PR: Negative th[oughts. Negative thoughts.
29 PT: [Yeah.
30 PR: What happens with the build up of the negative thoughts?
31 PT: Yeah.
32 PR: Yeah? All of a sudden,
33 PT: Yeah. Yeah.
34 PR: **what will happen is, "What the heck. I'm opening up the ah-"**
35 PT: Paracetamol.
36 PR: **"medicine cabinet and I'm gonna take all the pills."**
37 PT: Yeah.
38 PR: **Those negative thoughts become the norm then don't they. It's**
39 **hard to get out of that sort of mindset.**
40 PT: Yeah I guess.
41 PR: **Yeah. What do you think of that?**
42 PT: You're right. One hundred percent you're right.

The practitioner proposes that Sam experienced a negative automatic thought (lines 1–3). He lists challenges Sam described earlier in the visit (e.g., unemployment and relationship with mother) (lines 6, 18, and 20–21) and gives Sam opportunities to confirm that the practitioner understood him correctly (lines 19, 22, and 24). He describes a build-up of negative thoughts (lines 25–26, and 28) and frames the pharmaceutical overdose as an understandable outcome (lines 32, 34, and 36). Sam responds with agreement and shared understanding (lines 29, 31, 33, and 35).

The practitioner does not recharacterize, contest or undermine Sam's experiences. Instead, he gives these experiences a name and introduces a new way of understanding them. He validates how difficult it can be to stop these thoughts (lines 38–39) and asks what Sam thinks of this understanding (line 41). Sam agrees fully, asserting "One hundred percent you're right."

In the post-visit interview, Sam described how he felt after the overdose; "I had no one to talk to, I had nothing to do... and then I spoke to him and the team [liaison psychiatry] and they understood... That's never happened before in my life. No one has actually understood me." Sam repeatedly emphasized how important this mutual understanding was and described it as the "most helpful" outcome of the meeting. When asked what he would do if he experienced another suicidal crisis, Sam responded; "Talk to someone first. I wouldn't do it. I'd talk to someone first."

Discussion

We identified communication practices used to either undermine, imply/assert alternative characterizations or accept and validate peoples' accounts of self-harm and suicidality. At times, these practices were also delivered when speaking over the patient. Practices that undermined or implied/asserted alternative characterizations were: not acknowledging or accepting the person's account; asking questions that implied inconsistency or implausibility ("Didn't you tell your GP that you were coping okay?"); juxtaposing contrasting information to undermine the account ("You said you were coping okay before, and now you're saying you feel suicidal."); asking questions that asserted a different characterization such as implying they were not intending to end their life because they rang a helpline ("So when you called 111 what were you expecting them to do" "So would you say you took the tablets, at the spur of the moment," "So it was a more of an impulsive thing, at the time?"); and resisting or directly questioning the person's account ("Really?").

Multiple practices were used across the assessment that built on each other to imply or assert that: the person was not really suicidal as they did not look or act like they were suicidal; the person's decision to attend the ED was not justified; that an overdose was impulsive and the person did not really intend to end their life; that self-harming behavior (restricting eating) was not that serious and should be in the person's control. Together, they were used to evidence inconsistency or implausibility in patients' descriptions of their experiences.

Importantly, we also identified communication practices that were used to acknowledge, accept and validate suicidality/self-harm and introduce a new way of understanding suicidal thoughts and a suicide attempt that patients found helpful as reported in post-visit interviews with patients. This involved practitioner continuers (such as "Mhm") which facilitate the patient in fully describing their experience, maintaining eye contact and other non-verbal feedback especially nodding. This also included validation by explicitly stating that the patient's experiences were difficult and putting forward a candidate understanding ("It's a scary thought") rather than remaining silent or asking questions that were designed to recharacterize, subtly undermine or challenge the person's account of their experiences.

The current findings contribute to an understanding of how peoples' accounts of self-harm and suicidality are undermined or accepted, a phenomenon which has been reported by patients and leads to negative consequences for them (4, 5). They also contribute to an understanding of the communication practices used when this does *not* happen, i.e., acknowledgment, acceptance, validation and creating meaning and new understandings. Patients report that feeling listened to and understood is vital for effective relationships with health care practitioners (48). However, many patients feel that they are not understood and feel judged for seeking help (3). The current findings show that acknowledging, accepting and validating peoples' experiences and developing a shared understanding with the person are critical but often overlooked in mental health assessments.

There are a wide range of – and often overlapping – reasons why peoples' experiences may be undermined or challenged which practitioners report anecdotally. These include: practitioner emotional discomfort with (repeated) exposure to despair and hopelessness; inadequate training and clinical supervision; compassion fatigue and burnout (a risk for people working in the ED); defensive practice which may be heighted after incidents where a practitioner's assessment and the patient report are not in agreement and the person ends their life; an "epistemic injustice repeat offender" who prefers encounters where they have the upper hand; vicious cycles, arising when patients sense that a practitioner is subtly resisting their account, leading patients to intensify their symptoms to be taken seriously, leading the practitioner to unintentionally respond by becoming even more skeptical. All of these reasons can contribute to patients being treated in a dehumanizing and counter-productive way.

It is important to consider the ED setting and the risk assessment activities underway in these assessments. EDs in the UK are high-pressure environments with 4 h targets for patients to be seen, treated and admitted or discharged. Assessing a person's mental state and suicide risk involves more than what people say when they are assessed by mental health practitioners on presenting to the ED. A range of factors are considered including, e.g., the person's social context (social isolation); life events (e.g., bereavement, divorce, domestic violence, and separation from children); family history (mental health problems and family member death by suicide); reports from family/friends/other clinicians about the person's behavior and mood; and the person's non-verbal communication. Sometimes, practitioners may feel there are gaps in the person's story that need to be filled. This makes for a complex judgment and times when practitioners and patients are not in agreement with each other about the degree of suicidality and corresponding risk management. Such cases where there remains unresolved divergence between practitioners and patients are not rare. They highlight the importance of not privileging the patient's perspective at the expense of the clinician's or vice versa, as both are unproductive. Communication that is based on collaboration and allows open discussion where there is a lack of shared understanding and disagreement between practitioners and patients is the aspiration not just in meaningful risk assessment but in healthcare communication in general (49). Alongside the pressures in the ED, the number of people seeking help for mental health problems has risen every year while numbers of hospital beds have decreased (50), This increases the pressure to discharge patients even though practitioners are aware of increasingly limited options for treatment (e.g., few in-patient beds, long waiting lists for referrals, high entry thresholds so many people do not meet the criteria for treatment in mental health services). If a person ends their life, practitioners can be called to give evidence in a coroner's court. Anecdotally, this results in defensive practice, with practitioners feeling helpless and experiencing "moral injury" as they are working in ways that contradict their moral compass (51).

Previous conversation analytic studies of epistemic injustice in mental health have been conducted in social work and substance use settings. Similar to our findings, Lee et al. (52) found two contrasting patterns (i) the worker aligns with the client, actively listening and working to demonstrate understanding and communicating this understanding back to the client, eliciting a deeper client account (ii) the worker assumes a stance of expert and refutes the client's account of her experience, ending with the client agreeing with the worker's version. In the current data, practitioners also worked to get patients to align with their alternative characterization. In a substance abuse setting, Auvinen et al. (53) analyzed a group discussion between two rehabilitation clients, a peer support worker and a social adviser. The discussion was based on a motivational interviewing approach which emphasizes the person's perspective and motivation to change. They found that sharing experiential knowledge, elaborating on personal experiences and developing intersubjective understanding can provide the conceptual resources for people to understand and describe their experience (thereby avoiding hermeneutical injustice).

The practices we focused on were previously identified in police, courtroom, and political settings (20–24). While in police or courtrooms, they are used to assess innocence or guilt, in the pressurized ED setting situated in a pressurized wider mental health services landscape, they can be used to generate alternative characterizations of peoples' experiences to justify decisions not to refer to specific mental health services. Practitioners are under pressure not to refer patients to overburdened mental health services (54) and are in a position where they must justify denying care in an under-resourced mental healthcare system [see Beale (51)]. Perhaps because of these pressures and lack of access to further care, an epistemic stance that conveys to patients that they have primary rights to know and report on their subjective experiences is even more important. If not, this risks leaving people feeling invalidated, guilty and negatively judged for seeking support and deters future help seeking (55). It also may lead to people being distrustful and unwilling to share what they think and feel with mental healthcare practitioners if they fear being misunderstood based on previous experiences, making it harder to identify optimal support. Some people may avoid seeking help if they have had a difficult interaction with practitioners, and will then miss out on attaining further support at times of future crisis (42). This is consistent with well-established evidence that positive therapeutic relationships predict better treatment engagement and treatment outcomes (56).

Practitioners describe feeling powerless to help patients navigate exclusionary referral criteria (e.g., not meeting threshold with respect to symptom severity for specialist mental health services, and simultaneously too risky for entry level primary care based services) and long waiting lists (3). At the same time, they are held liable for discharging people that are assessed as high risk of self-harm who subsequently die by suicide. Hence, they are under pressure not to report their clinical assessment of need and risk of harm when treatment is not available. As such, undermining and recharacterizing peoples' experiences may be unconsciously used to justify no further care where services are unavailable or inaccessible, reflecting a wider context of practitioners as gatekeepers, forced to ration mental health services in the UK National Health Service (43).

Candidacy for mental health services

Interactions with healthcare practitioners have a substantial impact on peoples' understanding of their own candidacy for mental health services, i.e., their perceptions of whether they have a problem that needs or deserves professional support, and are entitled to seek care (10). By recharacterizing a person's experiences (e.g., recharacterizing a suicide attempt as "impulsive," a person's food restriction as within their control), through their epistemic status and epistemic stance, a practitioner defines the person's experience in a specific way, e.g., as "impulsive," "not really suicidal," "not serious enough to be in the ED" or "in their control." As Beale (51) has written "We continue to behave as if risk is both predictable and quantifiable, persuading ourselves that certain stock phrases convey a protective coating. 'Fleeting thoughts of suicide,' for example, sometimes seen as the precursor to an 'impulsive' suicide attempt or act of self-harm. Although it is not without value to record these things in the course of trying to understand someone's state of mind, it is important to question the attached meaning. In writing 'no plans or intent' we make ourselves feel better about the unpredictable nature of suicide, hanging false hope on thoughts that come and go. Rather than admit that someone might end their life but we don't know when or how, we purport to know it is unlikely to occur." Based on this characterization, subsequent decisions not to provide further support/refer on to other services communicates that the person does not need further professional support.

Poor communication can leave patients questioning whether adverse mental health experiences were "all in your head" or "not true" (42), as these recharacterizing communication practices can be subtle and difficult for patients to recognize and contest. Hence, the impact on the person may go beyond claiming that the person does not need further professional support; it conveys that the person has a misplaced understanding of their own adverse experiences as "worse than they really are." There is an inherent power imbalance and the potential for patients to accept practitioners' claims at face value. This has a knock-on effect on subsequent help-seeking with patients reporting that when they do not feel their experiences were validated or they feel negatively judged for seeking help, they are less likely to seek help in the future even if their mental health has deteriorated further [see Anonymized (42)]. On a population level, this undermines efforts to promote early intervention and improve long-term mental health outcomes.

Hermeneutical injustice

Patients described their subjective experiences using concepts such as feeling miserable or being suicidal. Sometimes, the response was to undermine the appropriateness of those concepts, challenging their use with alleged counterevidence, e.g., when the practitioner implied that the patient could not have felt suicidal when he said he had plans for the evening or that he was able to given the impression he was enjoying things. Similar to Lee et al. (52), at other times, the response was to offer alternative expressions to describe the person's experiences, expressions that the practitioner found more appropriate, e.g., recharacterizing a suicide attempt as impulsive (because the person called an ambulance after an overdose) when the person had not described it in those terms and to persist with the alternative characterization despite the patient's resistance. This does not reflect a more nuanced understanding of suicidality that can include complex and conflicting thoughts, i.e., wanting to die coexisting with a fear of death. As a result of these challenges and recharacterizations, patients' feelings and thoughts as they experience them are minimized in further discussion and decision making. In some cases, the person may defer to the practitioner as the expert and stop using the contested concepts, for example, stop using the term "suicidal." In this way, patients may be subject to hermeneutical injustice as the practitioner does not accept the person's descriptions or does not negotiate with the person to develop a shared understanding of their experiences.

Testimonial injustice, medical records, and barriers to future access to care

Carel and Kidd (57) argue that people with mental and physical illness are more vulnerable to testimonial injustice because they may be considered "cognitively unreliable, emotionally compromised, or existentially unstable in ways that render their testimonies and interpretations suspect." For example, when a person reports feeling suicidal, their reports can be questioned and challenged more easily if the person has a known mental health issue. While the practitioner-patient interaction is critical in whether people are treated as credible knowers, what is entered in the person's medical record is also important. For example, one patient's suicide attempt was recharacterized as "impulsive" although she did not agree with this. While mental health is by its nature negotiated between patients and practitioners, recharacterizations in medical files are likely to go uncontested and potentially shape other healthcare practitioners' understandings of the patient. Where recharacterized and downplayed versions of patients' experiences are recorded, other practitioners may not recognize the patient's risks or may not consider the need for further support. For example, a practitioner might be less likely to consider providing a referral to eating disorder services if previous practitioners did not record the full extent of food restriction in the medical file.

Strengths and limitations

This is the first study we are aware of to subject the concept of epistemic injustice to empirical analysis using conversation analysis in mental health assessments for people presenting to the ED with self-harm and suicidality. However, we only analyzed five cases as this was an in depth analysis and assessments lasted up to 90 min. We specifically focused initially on cases where peoples' accounts were not accepted: hence, this is not intended to be representative of the wider dataset. The data were collected in one service and hence may not be representative of other services. Practitioner professional background and training may impact on communication. Given the small sample size, we could not explore this and it would be important to explore in future studies. While we interviewed patients about their assessment, we did not capture the practitioner's perspective on each assessment. This would have been helpful to understand their perspective on the patient's experience and their rationale for how they conducted the assessment. It was a challenge to comprehensively analyze practices across a full assessment. Longitudinal conversation analysis is a rapidly developing field (58) and is highly relevant to analyzing epistemic injustice as multiple communication practices build on each other during an assessment and in a person's mental health interactions over time with different professionals across multiple settings. Triangulating interactional analysis with interviews was informative in highlighting how each assessment was experienced by the specific patient. The longitudinal perspective also shed light on the downstream consequences for patients and carers of having their experiences undermined.

Future research

Future research should explore to what extent recharacterization could be minimized through further communication training or unconscious bias training, and to what extent a long-term solution may lie in increasing accessibility of mental health services for people that self-harm and experience suicidal ideation. Future research could triangulate multiple data sources, i.e., observation of interactions along with video-stimulated comments and interviews with patients and practitioners to investigate epistemic injustice more closely and the impacts on patients and practitioners over time. Analyzing interactions using conversation analysis may also shed light on empirical approaches to the study of epistemic injustice in other fields such as philosophy.

Conclusion

Multiple communication practices were used to evidence inconsistency or implausibility in patients' descriptions of their experiences across the assessment. At times, this included speaking over the patient during their accounts. These practices built on each other to imply or assert that: the person was not really suicidal as they did not look or act like they were suicidal; the person's decision to attend the ED was not justified; that an overdose was impulsive and the person did not really intend to end their life; that restricting eating (in the context of an eating disorder) was not that serious and should be in the person's control. Nodding and other non-verbal feedback was central in acceptance of patients' accounts. These findings have important clinical implications: patients report that when their experiences are not accepted or undermined, this makes them more distressed, less hopeful about the future and discourages future help-seeking when in crisis. Conversely, acknowledging, accepting and validating suicidality/self-harm and introducing a new ways of understanding peoples' experiences may make people less suicidal and more hopeful, generates shared understanding and encourages future help-seeking.

Data availability statement

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

Ethics statement

The studies involving humans were approved by the London Central Research Ethics Committee (17/LO/1234). 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

RM and CB led on conception of the study, with input from all other authors. RM collected the data. CB led the data analysis and all other authors participated in data analysis. CB wrote the first draft of the manuscript with sections written by LB and RM. RM and CB led on manuscript revision with all other authors contributing to manuscript revision. 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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Appendix

APPENDIX TABLE 1 Transcription conventions.

.hhh	Audible inhalation
hhh	Audible exhalation
:	Extended sound
-	Rising intonation
–	Falling intonation
?	Rising inflection
____	Emphasis (word or part of word underlined)
° °	Talk is quieter than the surrounding talk
< >	Talk is faster than the surrounding talk
UPPERCASE	Talk is louder than the surrounding talk
!	Animated tone
=	Latched utterance, no interval between utterances
[]	Beginning and end of overlapping talk
()	Transcriptionist doubt
(.)	A pause of less than 0.2 s
(0.0)	Silence measured in seconds and tenths of seconds

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Centring the voices of survivors of child sexual abuse in research: an act of hermeneutic justice

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Survivors of child sexual abuse (CSA) are known to hold silence and create distance between themselves and service providers for self-protection, as groomed behaviour or to protect the listener from vicarious trauma. Silence for many survivors has also been reinforced as a beneficial action by previous experiences of disclosing and being rejected, challenged, or disbelieved. How can researchers be sure the same dynamic is not playing out in research interviews? Generating reliable research data is an imperative and an act of epistemic justice that enables CSA survivors to testify to the suffering caused by abuse and subsequent trauma distress and to contribute to social discourse for change. Fricker, however, notes that the precursor to testimonial justice is hermeneutic justice. Hermeneutic justice pivots on the dual action of accurate understanding and interpretation, but CSA experiences may be beyond the comprehension of untraumatised listeners because their own frame of reference renders them unable or unwilling (even if unconsciously) to entertain the truth of such human depravity and cruelty. If survivors are not understood, their testimonies can be misconstrued or oftentimes excluded from the generation of epistemic knowledge, leaving the survivors unable to make sense of, and process, their experiences. These are crucial issues for researchers in the field of CSA and other crimes of sexual and gendered abuse. This study considers the operationalisation of a participatory research approach held within a lived experience research paradigm. Such methodologies advocate for peer involvement, which is becoming more widely recognised as supporting testimonial justice and the accurate understanding and interpretation of survivors' testimonies. The issue of validating the methodology and methods is considered, exploring a rigorous data audit and researcher reflexivity as contributors to trustworthy data. Peer and participant safety when researching through lived experience is addressed. Data from a doctoral research study are used to illustrate this article.

KEYWORDS

hermeneutic injustice, testimonial injustice, child sexual abuse, mad studies, participatory research, lived experience, trust

1 Introduction

Child sexual abuse (CSA) and the traumatic distress that victim–survivors live with may be beyond rational comprehension (Herman, 1992; Freyd, 1996; van der Kolk, 2014), but parts of society now seem ready to listen, as the final report of the Independent Inquiry into CSA has shown (IICSA, 2022). However, what action will emerge in the wake of the large-scale listening exercise at IICSA remains to be seen. Recently, there have been calls for detailed and focused research in the fields of gendered and sexual violence (James Lind Alliance, 2022). However, researchers need to be aware of how their own role in the research process may be shaping outcomes (Sweeney et al., 2009).

The need for robust data encounters at least one well-recognised barrier: the silence that CSA survivors hold around disclosure. Survivors have described experiencing misunderstanding, challenge, and rejection when disclosing the events of their childhood and CSA's trauma imprint of distress (Alaggia et al., 2019). These experiences reinforce the utility of silence and may have arisen from epistemic injustice, when what happened, and is happening, falls into "the gap in collective interpretative resources [which] puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (Fricker, 2007, p. 1). Fricker is talking of hermeneutic injustice, the precursor to testimonial injustice. These two elements comprise epistemic injustice. The words of one participant in a recent qualitative study of CSA illustrate exactly this: "I wish people could be in my skin for a day and just understand" (Tessa, CSA survivor and research participant).

Understanding is a crucial issue when conducting research studies with CSA survivors, and adaptive methodologies addressing this may be transferable to research studies investigating other forms of sexual and gendered violence. One approach is to work within participatory research paradigms. These include ethnographic (LeCompte and Schensul, 2010) and autoethnographic (Jones et al., 2016) methodologies, community-based participatory research (Minkler and Wallerstein, 2003), participatory action research (PAR) (MacDonald, 2012), and peer research (Bizieska and Johnston, 2015). Key to participatory research approaches is a blurring of the boundaries between researchers and participants, where people with lived experience become co-researchers at all stages of the research. Participatory studies often have a commitment to tackling marginalisation and exclusion. However, there remains a separation between researchers and participants because researchers in participatory paradigms tend not to have – or not to disclose that they have – lived experience.

This is where survivor research differs. Within survivor research, there is also a commitment to co-research with participants and to address exclusion, but the main researchers share an identity with research participants (Sweeney et al., 2009). Russo, therefore, described survivor research as the most extended form of participatory research, commenting that it "values first-person experience which it considers a true and legitimate source of evidence" (Russo, 2012). Similarly, Mad Studies describes a body of mad-positive knowledge that places first-person experience as central to our understanding of phenomena (Beresford and Russo, 2022). Thus, the unifying feature of survivor research and Mad Studies is the value placed on experiential knowledge as both an adjunct and a challenge to clinical and academic epistemology.

A recent qualitative study used a participatory approach to explore survivors' experiences of trust and trustworthiness. It was designed to not only address issues of epistemic injustice through privileging survivor accounts but also using a survivor research paradigm (Sweeney et al., 2009; Faulkner, 2017). This meant that survivors' experiences were more likely to be understood by the researcher due to a shared epistemic frame around CSA. (Re)building trust between CSA survivors and people in positions of authority is crucial in the provision of services, including but not limited to therapeutic or clinical practice (Parry and Simpson, 2016). However, to generate data that speaks to this need, participants needed to trust the researcher. Since the relationship between researcher and participant is short lived and yet designed to elicit sensitive and potentially shameful narratives, this presents an awkward problem. The study design addressed this central issue of survivor–participants' previous experiences of hermeneutic injustice, and this article presents and discusses how the study's participatory approach was a facilitator of testimonial justice. The study design centred the primary researcher's shared experience of CSA to overcome issues of shame and other reasons for participants holding silence, to flatten power hierarchies and to offer safety and agency to participants. This study considers the central issue of understanding and interpreting CSA data empathically and accurately as hermeneutic justice in action. Verification of the study findings as trustworthy, using a robust data trail audit and researcher reflexivity, are discussed. Finally, issues of researcher and participant safety and well-being are considered. This article focuses on evidence from the study that speaks specifically to epistemic and hermeneutic justice issues, while findings from the study regarding trust and trustworthiness in service provision are forthcoming.

2 Study design: key issues

2.1 The survivor of CSA

It is well documented that survivors of CSA hold silence around the abuse they have suffered because of groomed expectations of the negative effects of speaking out for themselves and their families (McElvaney, 2015). In the current study, Stella said: "There was a long period of time when I did not share any information [concerning CSA] with anyone and I was 37 before I ever shared anything with anyone." Additional contributing factors reinforcing silence include fragmented memories caused by trauma (Sinason and Conway, 2022) and a sense of shame (MacGinley et al., 2019). Many survivors who have attempted to seek help at earlier stages in their lives speak of encountering rejection, blame, challenge, and disbelief (McElvaney, 2015; Rouf et al., 2016; Alaggia et al., 2019), and this can result in withdrawal. Chloe tried to disclose to her family GP as a teenager, but his questioning had this result: "I did not feel like the trust was there so I just closed down and left and walked out." Chloe did not seek help again until her 30s. Additionally, survivors in this study spoke of their wish to protect others from the harmful effects of vicarious trauma until they were sure the listener was sufficiently resilient to hear narratives of abuse and trauma distress. Patrick said: "At first you are very cautious because first, what you are going to tell this woman is going to blow her mind."

Survivors know that it can be difficult for non-survivors to understand the complexity and nuance of their trauma-related distress. Jake said: "They [clinicians] do not understand, it's sometimes, it's the tiniest, littlest sort of subtle things that are the most painful, I was sexually abused for 6 years but it was that moment when my dad [non-abusing parent] did not trust me that was hardest." The experience of not being understood was foregrounded in reports by IICSA and the Truth Project (IICSA, 2022; IICSA: Truth Project, 2022). While these experiences arose within relationships of service provision, they may equally arise in the researcher–participant relationship involving abuse narratives and create dilemmas when shaping research studies.

2.2 Testimonial justice

Experiences of seeking help and then having disclosures challenged or rejected can arguably be considered a form of testimonial injustice. In this study, Jake said: "I tell you, I tried to disclose to teachers, um who kind of brushed it under the carpet, told me I was making too much of it. […] I do not think many people did not believe me, they just dismissed the experience and that I was using it as an excuse to be lazy." The GP that Chloe disclosed to said: "Are you sure, could you have [misconstrued] this?"

Scholarship-advancing theories of epistemic injustice, particularly in oppressed and marginalised populations (Dotson, 2014; Pohlhaus, 2020), posit that testimonial injustice rests on the listener failing to vest credibility in the speaker (McKinnon, 2016). One reason for this is that when a speaker voices a social experience that is beyond the comprehension of the listener, it renders the experience incomprehensible (Falbo, 2022). This then robs the speaker of the chance to make sense of their experiences, leaving them marginalized and excluded from discourse.

Survivors often wait many years before disclosing, and disclosures usually emerge piecemeal as trust is built with the recipient (Alaggia et al., 2019). Additionally, trauma memories are known to be fragmented and may not present as a chronologically smooth timeline (Sinason and Conway, 2022). This can make listening difficult for some recipients because it lies outside their frame of reference, and they cannot conceptualise what they are hearing. This can happen because of a lack of culturally sanctioned narratives around CSA for the speaker and listener to draw on, and so, the interpersonal injustice between two people links to a wider social injustice. Thus, the listener needs to engage in "reflexive critical sensitivity" (Fricker, 2007, p. 7) and trust in the speaker's testimony. The benefit of such virtuous engagement was evident in Yasmin's description of how she came to realise that so many of her difficulties were emanating from her CSA experiences:

> *"She [therapist] never lectured me or or or tried to dig in a way that was, that I got defensive, she was very listening and listening and listening and finally I decided, and also I told her I think there's something wrong with me, I think something is really really really wrong with me, either I'm bi-polar or I'm a borderline person or something is wrong with me, something is majorly wrong with this, and she was like what is this, what is this, where does it come from and she was always asking me and this when I realised that maybe this [CSA] is what everything is about."*

The sexual abuse of children is morally abhorrent, and yet it has been consistently difficult for modern societies to engage with (Rouf and Taggart, 2022), leading to pendulum swings between outrage and denial. Herman (1992) offered one explanation for this when she says of the wider issue of trauma: "The study of psychological trauma does not languish for lack of interest. Rather, the subject provokes such intense controversy that it periodically becomes anathema" (Herman, 1992, p. 7).

In another way, testimony can cause a recoiling from the evidence as it raises the possibility that the very fabric of society is ethically unsound (Herman, 1992; Fassin, 2009; van der Kolk, 2014). Recognising the scale of CSA creates a challenge to institutional structures that are "too big to fail", and the injustice of denial of the survivor's testimony is a small price to pay for the preservation of the status quo (IICSA, 2022). The interplay between institutional failures to believe victims and epistemic injustices in interpersonal contexts was explored in the work of the Truth Project (Barker et al., 2023).

2.3 The researcher's role

These many and varied issues mean that providing CSA survivors with a safe context for sharing testimony is essential. Testimonies must be received by researchers with the virtuous ability to listen. The operationalisation of such a "virtuous ability" (Fricker, 2003) offers validation to the survivor–researcher as an epistemologically virtuous agent. Coady forwarded the concept of a "learning mechanism" (Coady, 1992, p. 47) that enables the listener to gradually establish the trustworthiness of the particular speaker over a series of interactions. In this way, the survivor–researcher builds "critical capacities" which are non-inferential and operate innately, meaning that while listening, the capacity to believe and understand is unreflective but not uncritical. It is the very fact of the researcher having a CSA history that is the "learning mechanism," providing the ability to critically assess the survivor–participant's testimony as a true representation. Within this are the seeds of accurately presenting testimony in research data. The next issue is to find a shared understanding of "accuracy" between the reader and researcher, and this depends on the hermeneutics of the study.

2.4 Hermeneutics: accurate and sensitive interpretation

Hermeneutics is, in essence, an interpretation that seeks to make the "unintelligible both intelligible and communicable" (Dyer, 2010). Watts (2014) considers the juncture between two elements, interpretation and understanding, in qualitative research. He, like many others, rejects the notion of value-free interpretation because of the inevitable subjectivity of researchers because they are human. Instead, he advocates for the importance of the researcher shifting her proximity between "closeness" when understanding participants' words, and "distance" when conducting analysis using theoretically and methodologically informed viewpoints (Watts, 2014). To facilitate closeness, Ratcliffe's phenomenological perspective may be useful. He theorises that understanding traumatised people and others with extreme psychological distress requires a "radical empathy." This is a "way of engaging with others' experiences that involves suspending the usual assumption that both parties share the same modal space" (Ratcliffe, 2012, p. 483). Distance, on the other hand, is facilitated by the more traditional skills of the academic researcher. Interpretative Phenomenological Analysis (IPA) lends itself to the operationalisation of the hermeneutics of CSA testimony, given its foregrounding of interpretation. IPA has tackled the otherwise obfuscated issue of "not enough," "too much," and "incorrect" interpretation head-on. This article is not the place to play out the debates around IPA (see Smith, 2011; Smith, 2018; Nizza et al., 2021). However, IPA does provide a theoretically well-explored paradigm for survivor research, in that the virtues extolled in epistemic justice have been acquired through shared CSA experience and actively inform the interpretation in the "close" and empathic way these various scholars are advocating (Ritunnano, 2022).

Given these precursors, research into CSA needs careful consideration of how to create an environment where participants feel safe enough to offer their testimony in approximately a 1 h interview. The interviewer/researcher has the virtuous sensibility to offer hermeneutic justice. Participatory approaches that centre on lived experience offer one solution to this predicament.

2.5 Lived experience methodology

Lived experience as valid epistemology challenges the more traditionally established and valued positivist and (supposed) objective study of those receiving care (Sedgwick, 1982; Beresford, 2021). Lived experience is central to participatory ideology and methodology, and is "knowledge that is generated from people with direct experience of the social issue under investigation" (Taggart, 2022, p. 155). Ethnographic approaches, well established in mainstream academia, address issues of social and cultural import (LeCompte and Schensul, 2010) and have long held such experience as valid epistemology. Ethnographic approaches have been bolstered by positioning researchers' knowledge and sometimes shared identity through autoethnography (Jones et al., 2016). Recognising in this way the role the researcher's life experience plays in shaping research has been foregrounded since the 1960s (Bruyn, 1966). Participatory Action Research (PAR) has advocated since the 1940s (Baum et al., 2006) for the generation of knowledge by, and the implementation of policy for, the people directly affected by the issue under research.

Thus, lived experience as an organising principle for research is in no way new. Lineages of oppressed people have claimed their right to self-research and self-identify and take their place in discourses concerning their histories. Colonial, feminist, queer, disability, and gender studies are established as respected epistemology. Mad Studies is now recognised within this umbrella (Beresford and Russo, 2022). "Mad" is not an acronym or abbreviation but a simple reclamation of the term by those living with mental distress. Mad Studies is both academic and an activism-oriented resistance to hegemonic systems of psychological care (Sweeney et al., 2016). Proponents include people suffering iatrogenic harm by psychological and psychiatric services *plus* those who identify as "mad positive" (Spandler and Poursanidou, 2019), meaning those who align themselves with the scope and mission of Mad Studies. Survivor research is both an ally to and a forebear of Mad Studies (Sweeney, 2016; Beresford, 2016b), and both share the focus on trauma-informed research, which a growing body of writing advocates for when working within mental health contexts (Sweeney et al., 2016; Shimmin et al., 2017; Edelman, 2023).

Electing to research a population of survivors of CSA is a statement of the use of the orienting trauma-informed lens. This approach asks, "what happened to you?" (Sweeney and Taggart, 2018), rather than using a diagnostic category or potentially pathologised grouping via symptoms. Trauma-informed care advocates for transparency, safety, intersectionality (Crenshaw, 2017), active listening (Rogers and Farson, 1957), empathy, and understanding (Elliott et al., 2005; Huang et al., 2014; Sweeney et al., 2018). These principles are more readily operationalisable when all parties understand their utility and provenance as being the opposite of the primary abuse that gave rise to trauma distress in participants within the research process (Rose, 2009; Survivors Voices, 2022).

This article will now look in more detail at how lived experience methodology was operationalised in one study of CSA survivors' experiences of trust and trustworthiness.

3 Study design: operationalisation

3.1 Creating safety

The study design was informed firstly by the Charter for Engaging Survivors (Survivors Voices, 2023), produced by an abuse survivor-led charity, and secondly, by the guidance of an advisor who is a CSA survivor with more than 20 years of experience working with CSA survivors as a counsellor and trainer. Finally, ethics approval was obtained from the University of Essex (ref 18,014). The ethics application necessitated incorporated features to address the safety and support of the researcher and all participants and create an environment facilitating epistemic justice.

The Charter for Engaging Survivors calls for transparency as a counterbalance to the obfuscation and deceit of the original abuse and a flattening of power hierarchies in contrast to the abuse of power embedded in CSA. A key feature of this study was the explicit declaration of the CSA history of the researcher in every communication, which created a flat(ter) power hierarchy. This clear explication of identities speaks to openness and honesty and signalled to potential participants that their experiences would be understood and in no way stigmatised or demeaned. This was confirmed by Ruby, who said: "I feel it's also easier for me to talk to you because you have experienced something, like, we have a level playing field."

Participants were recruited using a "snowballing" method (Gilbert and Stoneman, 2016), whereby the researcher spoke to survivors already known to her and colleagues who worked with CSA survivors. This verbal invitation and explanation allowed for a personalised description of the research study, emphasising the importance and value of recruiting participants in a way that felt safe for all concerned. From these initial inquiries, survivors started contacting the researcher to ask for further information, which was given via email or personal communication. Initial contact was followed by emailing the participant information sheet and consent forms approved by the University of Essex Ethics Committee. Further recruitment was facilitated by a question at the end of each interview, asking participants to mention the study to survivor friends or colleagues and pass on the researcher's details. This gave choice and agency to potential participants, who could make contact if they were interested in participating. This may appear to be a standard method for recruitment, but was essential in this study because it meant that the researcher was not an unknown and distant person, but someone known to the recommending link in the chain. This "word of mouth" recommendation helped survivors feel more at ease in knowing who they were speaking to when the interview began. As Chloe said: "The first time I met you [at University via introduction], I knew I wanted to help you […] there was just something about you, I knew I wanted to help you."

The study was presented in all communications as an opportunity for "us" as survivors working together to gather and present data to inform service providers. This seemed to act as a motivator to participants, and their desire to be heard was evident. Yasmin said:

> *"I'm grateful for being asked to participate in this so thank you for listening and thank you for sharing also your personal stuff and also for meeting me exactly where I am, and not, that's also very big, to just being able to jump around things and being distant or this or that, just to blaaaaaah and babble on about it, so thank you."*

Yasmin is making another important point about the impact of trauma on memory, which can come in bursts, oftentimes with an emotional charge and without chronology (Sinason and Conway, 2022). This may be important when considering the flow of an interview. The researcher herself (SA) has lived experience of the past bursting into the present, where narratives and memory do not come in a smooth, well-considered flow, which meant she could appreciate participants' difficulties. Participants were understood and not demeaned for this, and this shared understanding lessened the need for, or expectation of, a narrative that started at the beginning and progressed through the middle to the ending.

Moments where emotions came to the fore were held sensitively. As the researcher (SA) understands the territory of abuse and trauma distress, such emotions did not scare her or give cause for undue concern. The material was not unfamiliar and so SA could tolerate the raw and sad experiences being recounted. It is possible that a different survivor–researcher might have struggled to receive the narratives, and it is recognised that every individual will have their own ideographic response in relationship to other survivors and when listening to testimony. Importantly, one can recognise that stigmatisation will almost certainly be avoided in conversations between CSA survivors.

Participants were pleased not to be closed down when emotions accompanied their narrative. Tessa said of her tears: "This is no worse than every day, it's just I had to get it out and this happens when I go to therapy because it comes out, […] so it's fine absolutely, I promise you." Other studies investigating CSA placed power in the hands of the researcher to close the conversation if their participant became distressed (Banyard et al., 2001), thus robbing the survivor of her agency (Sen, 2019).

3.2 Survivor agency

The semi-structured interviews were conceived as "co-constructed" in the feminist model (Oakley, 2005), to negate, or at least work towards flattening, the power hierarchy of researcher (professional/expert) and participant (Jenkins, 2019). The interview schedule was shaped in discussion with the advisor, himself a survivor (see above), and a pilot interview with him was undertaken. Issues and options for flexibility and choice were explored and discussed during these foundational meetings. These choices again aimed at reducing power imbalances (Lyons and Chipperfield, 2000). The researcher attended interviewer training to refine her active listening skills (Cegala et al., 2000; Weger et al., 2014). The researcher and participant opened their time together with gentle, reassuring introductions to build rapport. The interviewer described her motivation to conduct the study, her history as a survivor, and her wish that their time together might be a chance for them to discuss issues around trust, rather than a question-and-answer session. The interview schedule was shared and discussed with each participant at the start of the interview to see the range of topics the researcher felt might be of interest. However, the participants could speak about whichever topic was most pertinent to them. In total, 17 participants were interviewed. Because the value of the lived experience was enshrined in the shape of each interview, participants were given choice and agency in the generation of data they felt relevant to the topic. This is another issue the Charter for Engaging Survivors highlights as a counterbalance to CSA, where choice and agency are negated (Survivors Voices, 2023). Above, Yasmin is expressing her gratitude for the possibility of sharing her lived experience with the researcher in the hope that it will inform professionals working with survivors of child sexual abuse.

Choice extended to the participant and researcher (SA) discussing and choosing the location for the interview. Some participants chose a café; others chose the university, their therapy centre, or an online video call. Concerns for the safety of the researcher when meeting unknown participants were built into her side of agreeing to a location. This was not the only or primary concern but was held in balance with the participants' wishes.

These facets contributed to an environment of safety for the participant and the researcher. Tessa said: "I feel safe, I feel safe, I know you do this stuff and I know it's happened to you, and you have just got a nice vibe to me so, you know, so it's fine."

Perhaps the environment of safety contributed to a relationality characterised by trust between participants and researcher, which facilitated the sharing of detailed and sensitive data. As Chloe said: "If I trust you you'll get it all out of me, so obviously I must trust you." Tessa echoed this: "I do not expect you to do anything terrible, (laughter), I do not think you have got a hidden agenda." Tessa is pointing to this particular researcher (SA) having what Fricker (2003, p. 157) describes as a "sensibility" as an aspect of the "inferential model," where testimony is being believed with "critical openness." In this model, the listener does not simply listen with credulity to testimony, but has the developed virtue to be able to assess for truth while listening. Tessa knows her testimony will not be used against her materially or in any sort of shaming capacity. This is demonstrative of the survivor–researcher's capacity, and ability, to operationalise both testimonial and hermeneutic justice because of the necessary virtues developed directly as a result of her own history of CSA. This both evidences Fricker's theory and endorses Mad Studies as, at least, a suitable approach to research the sensitive and emotionally charged subject of sexual abuse.

Facilitating honest narratives addresses issues of testimonial justice, and the participants in this study were generous with the data they shared regarding their experiences of trust and trustworthiness. However, facilitating testimonial justice is only half of the dynamic underpinning epistemic justice: the other half is hermeneutic injustice, as delineated above. How can the researcher be sure that she is understanding her participants and interpreting their words accurately before going on to represent them in a framework of meaning that other readers can access?

3.3 Understanding

Finding a service provider or therapist willing, or able, to do this had been difficult for many participants: "You may never find that right person, you can probably go for years and years and years, go to different counsellors, different people and never find that right connection," as Chloe said. Yet, the need to be understood was clear in the interviews, as expressed by Tessa above: "I wish people could be in my skin for a day and just understand," and Helen: "I want understanding, of like why I'm ticking like the way I tick."

Finding someone who has the capacity to understand had proven difficult for many of the participants in this study. Chloe said:

> *"Do not tell me you [speaking of a doctor] understand, yeah, because you do not, you might have sympathy you have empathy, a lot of people have empathy over it and they think they know how it feels and 'cos once they find out they feel uncomfortable, […] yeah, and then they have that sort of feeling of uncomfort [sic] but you do not actually understand."*

Chloe, now working with survivors as a mental health nurse, said: "…and there's just no understanding, you can just see they [health professionals] do not understand any of it, I've sat in numerous reviews and I've said my piece as well and straight away they have [given a diagnosis], you are labelling someone with the wrong label and you know I've worked with people, young people who have been sexually abused […] and that they do not ever, I found they did not bring that into it … they [the doctors] sort of brushed over it… because they do not understand it." It can be argued that such doctors "brush over it" because the genesis of the issues, CSA, is not important in a biomedical formulation of the patient's mental health. Many, including the anti-psychiatry and the Mad movement, argue against that and instead suggest that such a view might be indicative of a history of denial (Beresford, 2016a). However, once it is recognised that the trauma of CSA is a harm in its own right, it no longer matters whether it fits the epistemological formulation or not: it warrants recognition on an ethical basis. The ethical listener would perceive the "moral colouration" (Fricker, 2003, p. 160) of the issue, irrespective of their worldview, but here they have lacked the "ethical socialisation" (p. 160) of seeing CSA as a central organising feature of survivor experience. This compares unfavourably with the survivor-centred approach, which arises from the survivor–researcher's socialisation by way of direct experience.

This is echoed by Jake, who is a CSA survivor–educator and therapist. He said: "I was training some psychologists and they said what model of recovery do you use, and I simply said I just ask people what they need and what help they'd like, and they said that's so radical and so amazing, I said no, I was thinking, no, it's just being a human being […] it's about humanity."

The recognition of the value of speaking with someone who has been through CSA is signalled in the earlier quotes and also by Betty, who said: "You've [the researcher] really gone there and you know, really looked into it and been absolutely honest and brutally honest and […] I thought you have been through all this […] so it sort of made me feel absolutely safe to tell you because you would get it."

Survivors in this study spoke repeatedly about a process of healing unfolding as a result of a listener understanding and that this enabled trust to flourish. They also said that understanding is crucial because it brings mutuality, which in turn symbolises a shared humanity, and through this, the self-worth of the survivor was affirmed. Betty discovered she could trust her GP and shared more of her history of CSA with her: "So she [GP] said, "Oh you have done really well" and somehow her saying it just made it feel like "Oh my god yeah", I had not realised that I've survived it and I've done OK you know […] she said it and it made it real."

This example directly illustrates how understanding by the listener results in a shift in self-conceptualisation, as Fricker posits: "A virtuous hearer may effectively be able to generate a more inclusive hermeneutic micro-climate through the appropriate kind of dialogue with the speaker" (Fricker, 2007, p. 171).

3.4 Interpretation

Understanding is the first component of hermeneutic justice, according to Dyer's definition given above, and interpretation is the second. In a participatory paradigm, it is imperative that a person of lived experience is offering the interpretation because of the power of the "double hermeneutic." This term emerged from the philosophy of phenomenology and denotes the recognition that in every living moment, a human being is making meaning from the information arriving in their consciousness, and a researcher is then making meaning of the meaning their participant has made (Eatough and Smith, 2017). This circles back to the value of someone with the radical empathy of lived experience accurately interpreting the words of the participant, and these two levels of interpretation are transparently presented in the study findings for the reader to have the opportunity to assess the validity of the data. This is more than an echo of the advocation for virtuous sensibility rendered above. Recognising the double hermeneutic gives the reader the opportunity to notice their own meaning-making process as they read, and this is a third hermeneutic level (Smith et al., 2009).

To match IPA's requirement for explicit interpretations, the study used to illustrate this article included both lengthy participant quotes alongside the interpretative argument from the researcher. This is called for in all IPA studies (Nizza et al., 2021). However, this study also included a 5,000-word appendix with further substantiating participant quotes footnoted in the findings chapters. In this way, the survivor's voice was evident in the study findings. Furthermore, the appendix and extensive quotes were intended as a mark of respect for the participants' generosity in sharing their narratives, which many times were raw and shaped by iatrogenic harm. This inclusion of extensive quotes meets the need for those wishing to audit the study as valid, provides a data trail from transcripts through to conclusions, and is in line with the JBI Checklist for Qualitative Research (JBI, 2017).

An example from the study may illustrate hermeneutics in operation:

"Listening included embodied engagement:

> *"how can you trust how can you trust someone who do not look in your face" [Helen].*

And when listening, a trustworthy other is not preparing their response. Listening is not just to use the survivor's words to springboard into their opinion or view. Staying with the survivor in their narrative was important. For Chloe, her trusted therapist:

> *"did not try to put their two pence in all the time" [Chloe].*

This metaphor suggests that Chloe appreciates her words being valued and the trustee not valuing their own words more than hers. This valuing appears in Jo's statement too:

> *"listening um, about taking seriously what someone else is saying not only thinking about your own self and your own response but really listening to the other person" [Jo].*
>
> *"just feeling that somebody is listening actually, taking it in and not just filing it away" [Anna].*

Not "filing it away" suggests the listening is engaged, and the words are not being dismissed, as in filed away, but also not being added to her medical notes or files. Her words are valued as live and relevant, not as indicators of disorder. In this way, these survivors found listening indicative of being given worth."

This excerpt reflects the researcher's (SA) endeavour to discover what meaning the participants were making of the capacity of service providers to listen and understand them before deciding if the person was trustworthy and thus able to be endowed with further CSA details. The meaning the researcher is making is the second hermeneutic in action – using metaphor ("filing away") as an insightful indicator of meaning. This section also reinforces the epistemic virtue of listening that contributes to the reversal of the marginalisation of groups who are not understood or epistemically valued. This avoids Fricker's "hermeneutical hotspots – locations in social life where the powerful have no interest in achieving a proper interpretation, perhaps indeed where they have a positive interest in sustaining the extant misinterpretation" (Fricker, 2007, p. 152).

3.5 Reflexivity in operation

Guidance on generating robust qualitative research often expounds on the need for reflexivity in the study design and process (Finlay et al., 2003; Mann, 2016; Dean, 2017). Most PhD studies require a statement of the researcher's stance and engagement with reflexivity. In this study, reflexivity proved essential as a tool for accurate data generation, but also to support the researcher. A reflexive journal was maintained, both written and in audio recordings, and the transcripts were notated with reflexive commentary as the iterative process of repeated reading unfolded. Towards the end of the study write-up, an autoethnographic chapter was written as an exercise in overviewing the process and the researcher's part in shaping the findings, discussion, and conclusion. This excerpt illustrates how reflexivity informed choices about data collection and inclusion:

Transcript three: Susanna

> *"After the pilot and first interview I found I was uncertain about the amount of time my own voice was taking up of the 1 h allotted. I realised that I had a lot to say of my own experiences of trust and trusting, and this was stealing valuable airtime from my participants. I reflected that I could perhaps gather this information a different way, because while I wanted to have myself in the research in a way that authentically represented my journey as a survivor, I also needed a reflexive practice to see where my experience aligned with, or differed from that of the participants. This gave rise to the interview conducted with me by my person-centred therapist, using my own interview schedule. This recording remained unlistened to until after the first draft of the findings. I decided not to include my words as data in order to keep my distance from the findings, but instead I have used it to reflexively critique when (and whether) my views have shaped my interpretations of individual moments within transcripts and the amalgamating of data into final chapters."*
>
> *"When I did listen to myself speaking, shocked is not too strong a word for what I felt. Almost everything I said echoed and mirrored the findings, but at the time I recorded it I had no notion that my experiences fitted the shape of the process flow chart, or the relationship between generalised and relational trust. I had no idea that my rough-hewn definition of trust would match the other participants' personal construct of trust (see conclusion). I remember during the interview feeling that I was rambling around the subject, tangentially answering the questions, and said at the end that I feared I had not been able to give any valuable data and did not have a clear overview of my own trust abilities or experiences. Even this statement was echoed by Anna at the end of her interview!"*

Working with narratives of trauma can be triggering (Sweeney and Taggart, 2018; Alyce, 2022a), and reflexivity enables a "stepping back" to check in with the unfolding of vicarious or triggered reactions to the work. Having a supervisor (DT) with lived experience was helpful and important in giving an overview of the way the study moved between domains of personal and professional (McWade, 2020). Furthermore, it created a context of ethical socialisation to the topic, and the hermeneutic spaces that were established together had epistemic justice as a central task. In this way, the research was about discovery but also epistemic support for survivor accounts, and as such, moved beyond issues of credibility to deeper concerns around dignity and worth. The researcher (SA) gained further reflexive support from an online survivor-researcher peer-support group run by Survivors Voices, authors of the Charter for Engaging Survivors (see above).

The role of survivor–researcher was helpful in the ways this article has illustrated, but it also brought challenges. During the first COVID lockdown in 2020, the researcher (SA) became physically unwell due to the stress of COVID-19, shingles, and perhaps spending uninterrupted hours transcribing and analysing transcripts. She was helped through this by her supervisor, giving her extra time to complete the work and with personal counselling. She scheduled additional time for self-care, using exercise and meditation as a grounding tool. By recognising the dual role of reflexivity as a method of generating trustworthy research and offering the capacity to protect and support, more time engaged in reflective practice became essential to carry the study to its completion (Alyce, 2022b; Alyce, 2023).

4 Conclusion

This article has presented an argument for good practice in the study of survivors of CSA by employing the lived experience of a survivor-researcher working within participatory paradigms and points to the necessity to support this approach with robust supervision and personal counselling. This modality has the ability to rebalance power hierarchies, create safety, allow agency and understanding for participants, and effect accurate interpretations. The robust implementation of this necessitates a well-documented data trail for audit and reflexivity to ensure the relevant proximity is adopted, while engaging with participants in person and analysis. This article has argued that when these elements are synthesised, Fricker's thesis of virtuous sensibilities facilitating epistemic justice through the avoidance of testimonial and hermeneutic injustice is supported. Future research is recommended to replicate the approach with other traumatised populations, such as domestic violence and sexual violence. The article adds to the literature on conducting trauma-informed research (Edelman, 2023) and provides a framework that can support survivor–researchers and participants to engage in this hard but critical work in ways that glean data otherwise lost in paradigms where shame prohibits the speaking of participant truths.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: unpublished research subject to PhD submission. Requests to access these datasets should be directed to DT, University of Essex, dtaggart@essex.ac.uk.

Ethics statement

The studies involving humans were approved by School of Health and Social Care, University of Essex. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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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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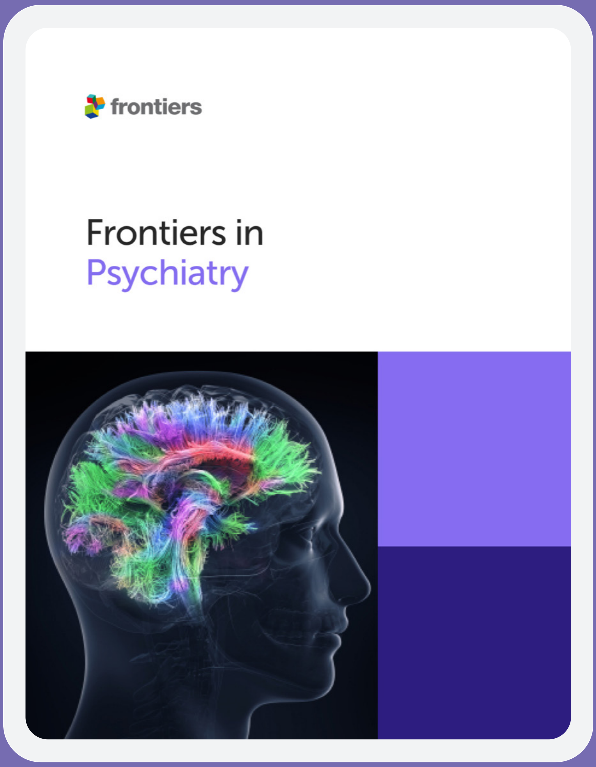

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