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Understanding the caring network of podoconiosis patients in Rwanda: a qualitative study

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Introduction: Globally, a total of almost 4 million people live with podoconiosis in 32 potentially endemic countries including Rwanda. Podoconiosis is a non-infectious geochemical disease that causes massive swelling of the lower leg and is caused by long-term exposure to red clay soil found in tropical highland areas. The disease is a disabling neglected tropical disease (NTD) and is associated with profound stigma, discrimination and comorbid mental health conditions. Treatment interventions are commonly known as morbidity management and disability prevention. Both biomedical and traditional treatments are used by affected people. However, understandings informed by the social sciences of care in the context of NTDs are largely unexplored. This study explored the perspectives and experiences of care among care receivers (podoconiosis patients) and caregivers (family members, traditional healers) in the district of Huye, Rwanda.

Method: The study used qualitative methods including seventeen InDepth Interviews (eleven patients, two traditional healers, two care professionals, and two family members) and participant observation in a health centre and patients' houses.

Result: A caring network was found amongst the podoconiosis patients, their family members, care professionals and traditional healers. Caring network is not only about the medical treatments, but also about the caring relationship amongst them.

Discussion: Using notions of 'Network' and 'Collectives', from the care ethics literature the study shows that in addition to care work requiring professional know-how, it is also about the relationships between patients, their families, traditional healers, and biomedical care professionals.

KEYWORDS

neglected tropical disease, podoconiosis, Rwanda, care network, qualitative method

Introduction

Podoconiosis is a non-infectious geochemical disease that causes swelling of the lower leg, and is caused by long-term exposure to red clay soil found in tropical highland areas (1). The condition is characterised by lower limb lymphoedema, episodes of intense pain and severe disability (2). The disease is a disabling neglected tropical disease (NTD) and is associated with profound stigma (3), in turn to cause social isolation and exclusion, relationship difficulties including reduced marriage prospects, and negative feelings such as shame and lack of self-esteem and comorbid mental health conditions (4). Globally, a total of almost 4 million people live with podoconiosis in 32 potentially endemic countries of which 18 are in the African Region, 3 in Asia and 11 in Latin America (5). World Health Organization (WHO) acknowledged podoconiosis as one of the neglected tropical diseases (NTDs) under the category of 'other tropical conditions' (6, 7). However, only 4 of the 32 potentially endemic countries: Cameroon, Ethiopia, Kenya and Rwanda have mapped the distribution of podoconiosis. These four countries recognized podoconiosis as a priority NTD and have included it in their long-term health plans (8). Recent nationwide mapping in Rwanda revealed that podoconiosis cases were distributed in all 30 districts, with national prevalence of 68.5 per 100 000 population (9).

Podoconiosis severely disables those affected, who are mostly farmers in tropical African highlands. It is one of the most disabling tropical diseases and reduces productivity, causes stigma from the community and healthcare professionals, and affected people report low quality of life. Although it was thought of as disabling rather than a direct cause of excess mortality, a recent study in Ethiopia demonstrated that people with podoconiosis experience greater mortality than those without podoconiosis in similar community settings (10). The treatment interventions recommended by WHO are commonly known as morbidity management and disability prevention (MMDP) or disease management, disability and inclusion (DMDI). Treatment includes soaking feet, washing with soap, rinsing with clean water, drying and application of emollient, supervised use of single-layer, non-elastic bandages, foot and calf exercises, instruction to practice foot hygiene daily at home, instruction to elevate the foot of the bed or areas slept on, and instruction to use socks and shoes during waking hours (11).

Currently, an organization called Heart and Sole Africa (HASA) provides treatment to patients with podoconiosis in northern Rwanda. HASA is a non-profit organization located in Musanze District, Rwanda, whose vision it is to eliminate podoconiosis nationally. With support from IZUMI Foundation, HASA and Rwanda Biomedical Centre (RBC) have expanded care to eleven new sites in different regions of the country. Patients come to the clinic to soak, scrub, and file their feet. Washing the affected feet and lower legs primarily helps to reduce rates of skin infection. The treatment procedures are suitable for self-care, meaning that they can be performed by those affected, depending on the patient's situation.

It is common practice that patients seek non-biomedical treatment such as herbal, magical, folk remedies and faith-based healing, also known as traditional medicine (12). In Africa, up to 80% of the population uses traditional medicine for primary health

care (13). In Rwanda, the use of traditional medicine is still popular despite the good accessibility and availability of conventional health services. According to a qualitative study conducted in Musanze district of Northern Rwanda, traditional medicine responds to health, social and financial needs which are insufficiently met by the current conventional health services provided by healthcare professionals (14). For their treatment, patients visit both healthcare professionals and traditional healers to receive care.

Even though the notion of care is talked about, care arrangements for podoconiosis patients have not been explored in depth. Integrated care means the participation of each stakeholder important for delivering care, and is thus a shared work. In shared care, it is key to understand how patients, care givers and families take part together using framings of relationality and interdependence. Such social scientific understandings of care are largely unexplored with respect to podoconiosis patients in Rwanda and those affected by NTDs in general. This study examines how care is delivered by focusing on the relationships between care receivers (podoconiosis patients) and care givers (family members, traditional healers).

Social scientific understandings of care

Annemarie Mol (15) argues:

'Care is a process. It does not have clear boundaries. It is open-ended ... Instead, it is a matter of time. For care is not a product that change hands, but a matter of various hands working together (over time) towards a result' (15; p.18)

Mol's logic of care can be used to understand the complexity of the process of 'foot care' amongst affected people and their caregivers. Care practices are ways of organizing life and daily practices. In any care work, the caring relationship between the caregiver and care receiver is vital. In the case of podoconiosis, it is more vital because of the disability inherent among recipients of care. There are two popular approaches to care practices in the field of disability: the 'disability studies' approach and the 'ethics of care' approach. Both approaches start by criticising existing practices such as rehabilitation and re-education, which are seen as biomedical interventions and relate the disability to individual or pathological factors from which the individual is to be rehabilitated. However, both the disability studies approach and the ethics of care approach claim that disability is not the result of individual causality. Rather, social and cultural factors cause the disability. Despite this common background, these approaches differ in terms of the dynamics of the relationship between caregivers and care receivers. Disability studies activists claim that the notions of care in existing practices are oppressive and paternal as disabled people are seen as dependent and passive (16). The approach stresses the autonomy and control disabled people must have in their everyday lives. The 'ethics of care' approach criticises the notion of an autonomous subject and posits a relational, affective and emotional subject supported by caring relationships. The focus is on the vulnerability and dependence within a caring relationship.

Although the relationship is asymmetrical, it is not one of domination (17, 18). Based on these two approaches, Winance (19) reached a different conception of care in which, 'care is shared work, carried out jointly by the collective' (19; p.111). In a caring relationship, there are some aspects which are relational and care receivers may be dependent. The relationship needs to be understood or studied to ensure effective care.

Care ethics is a further conceptual approach that understands care from a feminist perspective. The care ethics approach emphasises the importance of care in all our lives. The central understanding is based on the idea that humans are relational beings. We do not start out as autonomous individuals, rather we are dependent from the start of our lives in a society. We seek relationships with others. Our survival from birth is dependent on the care we receive from others. Importantly, care is equated with supporting people to meet their physiological needs for food, warmth, personal care, and mobility, meaning there is a need to support those who are unable to care for themselves.

Two notions: networked care and collectives are discussed in the care ethics literature. Networked care is also known as care within the dyad. Care is delivered by the immediate support network (family members or paid/unpaid care workers). Collectives are newly developed relationships, such as those developed beyond the immediate support network. An example of this is a disease patients' association. Care beyond the dyad, according to Barnes, suggests that a care system acknowledges that the care relationship does not only consist of two people, but also other members of the society (20). It suggests understanding reciprocity in care without a contractual basis (21). Families become involved in caring because of their nested obligations towards the person they are taking care of. On the other hand, care workers become involved to ensure the services expected from them by the caring services market. Barnes suggests thinking beyond this to where there are no family or economic obligations. In any care intervention, these two obligations help explain how care givers and care receivers develop a relationship.

Objectives of the study

This project explored components of care in the caring practices provided to podoconiosis patients in Huye district of Rwanda. Although several research projects are currently being undertaken on the lived experiences of podoconiosis patients, prior to these, very little consideration has been given to the care aspect of the disease. The study was carried out under the Social Sciences for Severely Stigmatizing Skin Conditions Foundation (the 5S Foundation) with the partnership of the University of Rwanda. The 5S Foundation aims to combat three skin diseases namely mycetoma, scabies and podoconiosis, in three African endemic countries (Ethiopia, Sudan and Rwanda) by bringing social science perspectives to bear on these diseases. This project specifically aims to understand the components of care in the network of care stakeholders (patients, family members, care professionals and traditional healers).

In Rwanda, patients take part in several intervention strategies to tackle the physical problems related with podoconiosis. In one of these care interventions operated in Huye district of the southern province of Rwanda, the initial training on 'foot care' to the patient is provided by Rwanda Biomedical Centre (RBC) and HASA but then care is managed by the government health professionals. The interventions are loosely known as 'foot hygiene' or 'foot care'. 'Foot hygiene' includes soaking feet, washing with soap, rinsing with clean water, drying and application of emollient. This project will explore how patients, family members and providers (care professionals and traditional healers) take part in a caring network. In any care work, how care is shared by all; meaning how patients, family members, and providers participate in it, is a significant concern. In the case of podoconiosis, caring is vital because of patients' physical disability and psychological stress. Better care can be planned for the future with insights from exploring care using social science.

Methods

Study setting

The study took place in the Rango health centre based in Huye district (formerly Butare), Rwanda and in participants' homes within ten kilometres of the health centre. Huye district is one of eight districts in the Southern province of Rwanda, with a population of 381,900. It has hilly landscapes from east to west. There are 79,744 people living in urban areas and 302,156 people in rural areas (22). The average rainfall is 1,200 mm. The soil condition, climatic features and seasonal rainfall are conducive for podoconiosis. Participants for the present study were recruited from Rango health centre from Rango B cell of Tumba sector in Huye district. Participants' households are located within 10 km of the health centre.

Study design

A qualitative study was conducted in March 2023. A weekly podoconiosis care programme is carried out in the health centre, supported by Rwanda Biomedical Centre (RBC) and Heart and Sole Africa (HASA). Seventeen In-Depth Interviews (eleven patients, two traditional healers, two care professionals, and two family members) and 20 hours of participant observation were conducted. Snowball sampling was used to recruit family members and traditional healers.

In-depth interviews were conducted in Kinyarwanda by a bilingual research assistant experienced in conducting qualitative research. A semi-structured topic guide was developed separately for patients, family members, traditional healers, and care professionals. The patients' topic guide was developed with more open-ended questions so that they could describe their experience in a narrative format: when they were first infected, how they initially reacted, what their family did, where they went for consultation first, experiences with traditional healers, and the

condition after the care intervention programme. The family members' topic guide were designed with questions like how they managed expenses for their relatives, how the family suffered after the relative developed podoconiosis. Traditional healers' questions included what their experiences with podoconiosis patients was like, what challenges they faced treating them, whether their methods of treatment were effective or not. The care professionals' topic guide was mostly about the design of the care intervention, what challenges they faced, what the impact of the care programme was, and what future plans existed.

The recruitment of patients and care professionals was completed in the first week of March 2023. Patients and care professionals were approached with participant information sheets and consent forms. Those who agreed to be interviewed, made their interest known immediately. Each interview was conducted during daytime, with care professionals interviewed at the centre and arrangements made for patient interviews at home at a mutually convenient time. The interviews ranged from 30 mins to 1 hour. They were audio recorded, transcribed and translated into English in Microsoft Word to facilitate data coding, text-searching and analysis. Data collection continued until no new themes emerged, i.e. until data saturation was reached. Observation was done on three consecutive Wednesdays during March 2023. Notes were taken about the activities, care practices, interactions between patients and care providers as well as between the patients.

A total of 17 participants were interviewed. Amongst them, there were 11 podoconiosis patients, 2 family caregivers of the patients, 2 traditional healers and 2 health centre care professionals. The age range of participants was 32-73 years.

Data analysis

Data were organised using manual coding techniques to categorise and generate themes. The method for generating codes involved using an integrated approach to developing code structure. This process involves both inductive development of codes and a deductive organising framework for code types.

Ethical issues

The study went through two ethical bodies, the Brighton and Sussex Medical School (BSMS) Research Governance and Ethics Committee (RGEC), and the ethics body of the University of Rwanda. Consent forms, Participant Information Sheets (PIS), and topic guides were all designed to include the suggestions and requirements of the two committees.

Participants were approached and recruited once they fully expressed their consent for participation. All the participants could sign their names on the forms. Participants were informed that they had a right to stop or skip questions during the interview at any time, and that if they changed their mind about being part of the study they could withdraw. Participants were given unique identification numbers to maintain confidentiality and audio recordings were destroyed following anonymized transcription.

Results

Caring network

The podoconiosis programme reveals a caring network that brings out several dimensions of care between the patients and care professionals.

Patients' experiences in the health centre are shaped by the long history with the disease. Two things are prominent for the patients. One, the relationship with the care professionals and the nature of the intervention is different from their previous treatment experience. Two, solidarity is formed amongst the podoconiosis patients who visit the centre weekly.

Care professionals take a different approach with podoconiosis patients than with other clinic patients. They are more compassionate and spend more time with the patients to ensure the patients are listening to their instructions.

Both patient's and care professionals' perspectives are explained in the following.

Patients

Treated with no stigma at the centre

'We are treated like a regular patient there. No shaming, no shyness'

Patients who participated in the study mentioned that the intervention was friendly and accommodating. They did not experience stigma or 'bad looks' (because of the nature of the disease) from the care professionals. Previously, they were always stigmatised at the places they went for treatment.

'They don't show us that they don't want to touch us, they aren't like that. They treat us with love and passion' (P2).

Such an approach made the patients feel like 'regular patients' in the centre.

'We are not looked upon badly by anyone in the centre. We are treated like a regular patient there. No shaming, no shyness. Earlier I used to feel ashamed to visit the health centre because of the stigma. People used to give bad looks to us. Care professionals were afraid to come close to us. But Rango is different' (P4).

Patients mentioned that mutual trust is developed with the care professionals. It matters to the patients whether they receive the treatment publicly or secretly.

'There's no hide and seek for the treatment we receive. With the traditional healers before, there was always secrecy. Now I receive

treatment publicly in front of many other patients in the centre' (P5).

basic things. That's why we made this association to bring us hope' (P7).

Association with podoconiosis patients

'Being with other podo patients totally turned my negativity into a positivity.'

Since the patients started visiting the centre, they became a part of a group of patients. They were no longer alone or lamenting their low productivity and being neglected by society. After they found themselves amongst other patients, they found many other patients who had gone through almost the same negative experiences since the disease started. They eagerly waited for the Wednesday clinic. They felt that *'all of them are on the same boat'*. They shared, discussed, and tried to do something new with others.

'After getting involved and joining them, I can really say that that is a family to me. In my perspective, I see them the way I see my father that gave me life. We meet, discuss, and share ideas that can help us in our development' (P1)

Being together helps them to motivate each other, and encourage each other about the disease.

'When someone new comes in, and seems discouraged, we share our experience on how we were also worse before and that way the new person regains hope' (P2).

There are reasons why the patients relate to each other so quickly. The narrative of how they lived with the disease reveals commonalities: visiting several traditional healers, visiting hospitals, financial difficulties, harassment from neighbours and sometimes family members, and neglect.

'The life we lived are very similar. Our families had to suffer financially. We were bullied in the neighbourhood. Sometimes, people would not come near to us as they thought we were bewitched. Above all, we all are from low-income backgrounds' (P11).

Considering the patients' low-income backgrounds, patients formed a 'Podo patients association' amongst themselves. The primary aim for this association was to create a fund for their future needs. Each patient donates a monthly amount at any time of the month. The rules are made flexible because of the vulnerable economic situation of the members. The fund has been a great help for the patients already.

'It helps because sometimes we even borrow money and are able to get basic needs at home such as soap, cooking oil, and other

Patients elected three representatives to run the association, a president, vice-president, and treasurer. Besides collecting funds, the representatives also keep an update of patients' overall improvement. If some patients miss a Wednesday visit, representatives communicate with them through mobile phones or WhatsApp. If these patients need medical help at home, they tell the care professionals of the centre.

This bonding transformed patients' lives positively. Before being with the group in the care programme, they had been taken care of by people of their known network: family members, relatives, friends, neighbours, traditional healers, and care professionals. But now they became part of a group of podoconiosis patients who went through very similar difficulties because of the disease. Even though they were not known to each other closely, they became deeply attached to each other through their shared disease experiences. Being with other patients gave their lives a positive turn. One patient mentioned it as a *'life turning event'* (P6) in their life, and considered it *'god's blessings'* (P6).

'Right when I was about to give up hope for everything in my life, coincidentally I became part of this group. Suddenly it seems like all my negativity was turning into positivity' (P3)

Care professionals – podoconiosis care programme

Three care professionals look after the podoconiosis patients at the Rango health centre in Huye. They received specific training on podoconiosis from Heart and Sole Africa (HASA) in

May 2022. HASA is an NGO that operates intervention programmes in a range of clinics in Rwanda. The interventions are loosely known as 'foot hygiene' or 'foot care'. 'Foot hygiene' includes soaking feet, washing with soap, rinsing with clean water, drying and application of emollient. HASA's biggest clinic is set in Musanze in the north-west of Rwanda. In Huye, HASA do not have any clinics, but the care professionals at Rango health centre were trained by HASA staff.

Compassionate approach

Since the beginning of the programme, care professionals mostly focused on how they approached podoconiosis patients. By approach, they meant how they communicate and interact with the patients. They had to think about their approach differently because podoconiosis patients are different from other patients. As it is a self-care intervention, they were looking for ways to motivate patients to receive training from the professionals. Most of the patients are scattered across Huye district, a few living near the

centre, and others far away. Podoconiosis is associated with severe mobility issue, so there were concerns about low attendance at the centre. During the interview, a care professional mentioned the approach had been 'Kwitaho' to the patients. *Kwitaho* is a Kinyarwanda word, meaning compassionate in English.

'Kwitaho (Compassion) comes from inside, not just from training' (C.P 2).

Podoconiosis patients' legs are swollen. Sometimes, there are bad smells from the infected leg. Care professionals were strictly instructed not to reject any patient because of bad odours.

They invested more time for the podo patients than the other patients. By giving more time, they indicated to the patients their care for them. Patients also felt that they were prioritized when they were given more time by the professionals.

We spend more time with podoconiosis patients because they are somehow rejected by their families, called different names to remove their dignity - they need a person to be close to them. So what we do is show them love and be close to them, we tell them how we care about them. (C.P.1)

They came up with the idea of giving a nickname to each patient. These nicknames are given based on unique characteristics or remarkable habits or feature. One patient was called 'doctor' because he had medicine-related knowledge. Another patient sang well, and so was named after Burna boy, a popular Nigerian singer. Nicknaming helps create a friendly and warm atmosphere in the centre, helping patients feel closer. Besides offering treatment, staff also listen to patients' life histories, family issues, and personal sufferings.

I always wait for Wednesday! We talk a lot and laugh. I feel like I am ready to listen to anything they want to tell me. They are now more open to me. They tell me their problems they face in their daily life, and I comfort them. (C.P2)

Health professionals also keep in touch with patients at other times of the week. They maintain an attendance book to keep track if a patient misses any session. They call these patients and check if they are well. If someone misses their session because of sickness, they make a visit to their houses.

Family

Family members are the first point of support for patients. Caring for their family member is their first and foremost duty, according to them. They go to considerable lengths to care for their relatives, trying multiple options (traditional healers and hospitals) for treatment. If they face financial challenges, they seek help from their social networks: from relatives, friends, neighbourhoods, the church, and state level organisations.

Traditional healers charged the most for their services. One family member (F1) said that she and her whole family were in misery managing the costs of healers.

I kept on renting the land and working hard to get enough money to give to the traditional doctor. I gave him like 80,000FRW but I finally fell into loss and stopped going there (F1).

The family's situation worsened after their relatives became affected, through treatment costs and loss of productivity of the affected person. Poverty spread through the family, and they started to lose their houses and property.

After his sickness it really affected me. Poverty really spread in my life I lost my property; my life has really become so hard and negatively affected due to the sickness of my son. If it had not happened, I would not be renting, I would have my own house (F2).

As patients had often been suffering from podoconiosis for a long time, it was not only one family member that had looked after them. One patient participant became affected at the age of 15. At first, his mother used to take care of him, but after several years, his mother died. Then his brother started taking care of him. After the brother got married, his wife is taking care of him. Six participants (P2, P3, P5, P6, P7 and P9) had more than one family member taking care of them.

Family members were considered to be the most important care givers because they knew the ins and outs of the daily lives of their relatives.

I can tell from my experiences of taking care of my son that there are two important things for him. One, regular diet, and two, as the disease is very stinky one, it must be a close person who will compassionately take care of their beloved son. There's no one closer than a family member to do that (F2).

Traditional healers

Traditional healers were an 'unavoidable option' in the present study. Before visiting a hospital or health centre, patients first went to them, because they were easier to visit since they lived in the neighbourhood, and there was no formal appointment system, since they treated patients privately in their own home.

Patients mentioned advice from relatives and neighbours that the disease might have a connection with witchcraft, and therefore suggest that patients consult a traditional healer.

Even though healers are easy options, their treatment methods may be ineffective, according to patient participants. After 10 years of consultation, they had rarely achieved any improvement. One patient (P8) said,

They are like ‘unavoidable options’ to us. In the last 10 years, I have been to almost four healers. They came with magic methods, herbal treatment, and many others. If the previous method would not work, they experimented with a different method. When they couldn’t, they would refer me to other healers. Never ever did they say to me that they are unable to treat it!

Because the healers did not tell patients that they could not treat the condition, they left room for hope, which is why some patients waited for as long as 10 years. Their situation became worse, and their families suffered because of the high expenses charged by the healers.

Discussion

Although there has been immense progress in controlling and eliminating NTDs, there is lack of research on how care is arranged or delivered to NTD patients, including podoconiosis patients. Little attention has been paid to the social and cultural factors that influence establishment of a caring relationship between different stakeholders and patients. This qualitative study explored several dimensions of caring relationships during a self-care intervention programme for podoconiosis patients in the city of Huye in Rwanda.

This study explored several dimensions of caring for podoconiosis patients, emphasising how different stakeholders, care professionals, traditional healers, and family caregivers participate in caring for the patient together. It focuses on how a caring network was established in the field setting of the study.

The study showed how patients received care from their immediate network. Family members took care of most of the patients. Patients also went to the traditional healers for consultation on the advice of neighbours and family members because of the perception that podoconiosis might be due to witchcraft. Patients also sought care from care professionals in hospitals or other formal healthcare settings. Family members, traditional healers, and care professionals were found to make up the immediate care network.

The study also explored the podoconiosis care programme, and found that two types of relationship were prominent. The first was between the care professionals and the patients and the second between the patients themselves. Even though care professionals are part of the immediate caring network, other patients are beyond the immediate network. At the beginning of the podoconiosis care programme, care professionals established a compassionate atmosphere to give a positive impression of the programme. As a result, friendly bonding developed between them. Even though the relationship with care professionals is not new in care activity, that amongst the patients is of critical importance. In the following, we discuss the relationships of patients found in the study against the notions of ‘Network’ and ‘Collectives’, two significant notions in recent care ethics literature. Characteristics of the notions of ‘network’ and ‘collectives’ are also discussed in the following, from the context of the present study.

Networks

In the care ethics literature, networks are known as the immediate support system. Care is given and received within networks of members that may include both paid and unpaid care givers (family members, friends, neighbours, or care workers), who may or may not meet frequently or live together (23). A key tenet of care networks is that responsibilities operate within the network as a whole, rather than being solely in one direction – from care giver to care receiver. While interdependency is multidirectional, the relationship is primarily defined by notions of responsibility or obligation from the care giver’s perspective. According to care ethics, networked care is regarded as unequal in that care receivers are considered to be dependent upon care givers (20). From this perspective, podoconiosis patients are dependent upon family members, traditional healers, and care professionals. The present study confirmed that care tended to be unidirectional: from care givers to care receivers.

In the present study, networked care mainly came from family members. However, podoconiosis patients also received care from traditional healers and general healthcare professionals. Their roles are discussed in the following to understand the characteristics of networked care for the podoconiosis patients.

Family members

Family members are the first point of support since their relatives become affected by podoconiosis. Family members were the care givers beside their relatives for the longest time, in our study from five to 20 years. All the patients who participated in this study, had been suffering for at least five years. In several cases, there had been changes of family members offering care. One participant (P3) became affected at the age of fifteen. His mother took care of him initially, but after seven years, she died, and his older sister took care of him. Another patient (P2) was cared for by his grandmother, mother, wife, and now an elder son, in what was like a ‘relay race’. At sequential significant points of the patient’s life, a new family member took over the care baton. The changes took place because the caregiver died or became overburdened by caring activities.

Poverty was a key component in the narratives of the participants as all of them were from lower-income backgrounds. One family member (F1) had to sell all their land and property to bear the expenses of the son. This was a common theme, and patients and family members became drained by the treatment expenses.

Despite the financial challenges and the exhausting caring activity, family members rarely stopped taking care of their relatives, but continued their role out of the obligations and responsibilities they felt towards their relatives.

One of the reasons for the expenditure was to search for appropriate treatment. After the patients became affected, they were advised to consult a traditional healer, since the disease was thought to have a connection with witchcraft. Since most of traditional healers practiced within the neighbourhood, patients tended to be taken to them.

Traditional healers

Traditional healers were the first to be consulted for advice and alternative medicine. The reasons to consult them included were

advice from neighbours, local beliefs about poisoning, and uncertainty as to whether the disease could be healed by traditional medicine or western medicine.

However, experience with traditional healers was not great. Participants rarely noticed any improvement in their condition, even after a long time, and healers were expensive. Even though traditional healers are amongst the immediate care network, relationships with them were rarely positive.

General healthcare professionals

Before the podoconiosis care programme, another priority for patients and their families was to visit a nearby hospital or health centre. This was also a frustrating experience for many, as the condition was not diagnosed, the condition of patients did not improve, and they felt that the healthcare professionals (who had not received podoconiosis-specific training) treated them with stigma and neglect.

The family was central to networked care amongst these stakeholders. Families provided care as a form of responsibility and obligations to their relatives. Neither traditional healers nor the general healthcare professionals provided benefit to patients.

Collectives

In contrast to the unidirectional care characteristic of networked care, 'collective care' suggest a different viewpoint in which care is generated through interactions amongst a number of stakeholders and people. While networked care is understood to focus on the needs of an individual (a podoconiosis patient in this study) and the shared responsibilities for meeting those needs by the surrounding people, collective care is the result of interactions between individuals who share similar needs by virtue of their circumstances (Barnes), so relationships are reciprocal. Based on this study, collective care was found amongst the podoconiosis patients receiving treatment and care from the podoconiosis care programme. The professionals who were part of this care programme also became part of the collective, because they tried to be more approachable to the patients to attract them into the care programme.

The core characteristic of the collective was that new relationships between patients and healthcare professionals arose, and were different to those found in the networked care. Notions of collectives were found in the relationship amongst the patients and the relationship between patients and the health professionals of the care programme.

Patients who had formed an explained how podoconiosis and its adverse impacts united them. They had all suffered in their personal and social lives, and undergone stigma since they first became affected by podoconiosis. Their dignity was compromised due to the physical disability of the disease. They discovered motivation and positivity amongst themselves after they came to the care programme. They further created an organisation to make concrete steps, such as saving

funds for themselves. They continued being members of the association so that future patients might also benefit from it.

The care professionals of the care programme are not like the general healthcare professionals mentioned in the networked care. The specifically trained care professionals took a compassionate approach so that patients did not feel stigmatized, but were treated as human beings at the health centre. Even though the treatment procedures are very simple, care professionals focused more on compassionate human-human bonding to deliver care. Each relationship highlighted relational aspects of care in which patients and healthcare professionals were equally and actively involved.

Conclusion

The results of this qualitative study highlight the importance of understanding caring networks within an intervention programme for podoconiosis patients in Rwanda. By examining how the stakeholders (care receivers and care givers) took part in the care programme, this study shows how compassionate care can be delivered. Care is about relationships as much as it is about professional knowledge. This study highlights the relationship aspects of care, and shows how patients who were once strangers can become united into an association. This demonstrates that care is not only about relationships with family members, traditional healers, and care professionals, but also about mutually supportive relationships between patients.

Data availability statement

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

Ethics statement

The studies involving humans were approved by Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC). 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

MR: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. GD: Funding acquisition, Validation, Writing – review & editing. PM: Supervision, Writing – review & editing. SZ: Conceptualization, Data curation, Methodology, Project administration, Supervision, Writing – review & editing.

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Conflict of interest

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