'We have come out of one place: it is called Omega'

An ethnographic study on the role of context in understanding mental suffering among the !Xun and Khwe of South Africa

den Hertog, T.N.

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Informal care for people with chronic psychotic symptoms: four case studies in a San community in South Africa

Figure 8: Jacob, suffering from chronic psychotic symptoms, walks along the provincial road towards Kimberley. (Photo courtesy of A. Gilmoor)

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Abstract

Despite the internationally recognised importance of informal care, especially in settings with limited services, few studies focus on the informal care for people with mental health problems in low- and middle-income countries. Making informal care visible is important for understanding the challenges and identifying the needs to be addressed. This ethnographic case study explored the dynamics of informal care for people with chronic psychotic symptoms in a group of San living in poor socioeconomic circumstances in a township near Kimberley, Northern Cape, South Africa. Data were collected in 2013 and 2014 and included semi-structured interviews, informal conversations and observations. Using local terminology, four individuals with chronic psychotic symptoms were identified and selected during the research process. A total of 33 semi-structured interviews took place with their caregivers. Data were analysed using descriptive, interpretive and pattern coding to identify core themes and interrelations across the four cases. Results indicate that informal care is characterized by shared and fragmented care structures. Care was shared among family members from various households and unrelated community members. This allowed for an adaptive process that responded to local dynamics and the care recipients’ needs. However, informal care was fragmented as it was generally uncoordinated, which increased the recipients’ vulnerability as caregivers could redirect caregiving responsibility and withdraw care. Specific challenges for providing care were related to poverty and care resistance. To improve the living conditions of people suffering from psychosis-related mental health problems, community-based mental healthcare should broaden its scope and incorporate local strengths and challenges.
Introduction

Despite the pivotal role of informal care for people with a chronic illness in settings where services are scarce or unavailable, few studies on informal care in low- and middle-income countries have been conducted. The importance of informal care in low- and middle-income settings is evident for chronic physical illness (Ogden, Esim, & Grown, 2006) as well as mental health problems (Chadda, 2014). The low priority given to mental health at national levels and the scarcity, inequity and inefficiency of mental healthcare observed in many low- and middle-income countries (Saxena, Thornicroft, Knapp, & Whiteford, 2007), underline the importance of informal care for people with a mental health problem.

Informal care is an ambiguous concept used to distinguish informal community services (e.g. traditional healers and family organisations) from formal healthcare professionals (World Health Organization, 2008). It refers to household care, which is unlinked to formal programmes and usually provided by people living with the care recipient (Ogden et al., 2006). Informal care is also defined by general caregiving activities (e.g. psychosocial, health-related, and personal or nursing care) (Chepengo-Langat, 2014). In this study, we use the term ‘informal care’ to refer to a broad range of caregiving activities including providing basic needs that are unlinked to any formal organisational structures.

Studies in high-income countries primarily describe the effects of caring for a person with mental health problems as a care burden for households and caregivers, including emotional and psychological distress and financial costs (Awad & Voruganti, 2008; Hoenig & Hamilton, 1966; Loukissa, 1995; Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2005; Steele, Maruyama, & Galynker, 2010). The few studies on informal care for people with mental health problems in low-resource settings describe similar care burdens and highlight the economic strain on already poor households. For example, there is the family’s burden of a loss of income and additional costs due to the ill person’s destructive behaviour during psychotic episodes and costs derived from traditional and biomedical healing strategies (Duncan, Swartz, & Kathard, 2011; Jack-Ide, Uys, & Middleton, 2013; Marimbe-Dube, 2013; Mavundla, Toth, & Mphilane, 2009; Seloilwe, 2006; Van Der Geest, 2005). In addition, several studies have reported on stigma and its negative effects on the social and psychological well-being of caregivers (Marimbe-Dube, 2013; Mavundla et al., 2009). Some studies have reported additional caregiving difficulties based on the social environment, such as alcohol and drug abuse by care recipients and physical violence involving people with mental health problems (Read, Adiibokah, & Nyame, 2009; Seloilwe, 2006).

Maltreatment of people with mental health problems, such as chaining and physical abuse, occurs in some settings and are rooted in local understanding of mental health problems, cultural practices and a lack of services to provide families with much needed support (Read et al., 2009).

The abovementioned studies indicate that informal care in low- and middle-income countries has context-specific challenges beyond caregiver burdens reported in high-income countries and warrants further research to bring these local realities to light. Our study aims to explore the dynamics of informal care for people suffering from chronic psychotic symptoms among the Khwe community of South Africa.
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Context of the study

The Khwe and !Xun are two San communities, approximately 1700 and 4500 in number, respectively (South African San Institute, 2010). Both groups currently reside in a township on the outskirts of Kimberley, the capital city of the Northern Cape province of South Africa. The Khwe and !Xun are originally from southern Angola and northeast Namibia and share a history of war and displacement (Den Hertog, 2013). Their militarised history started in the Angolan War of Independence (1961–1974) when they fought alongside the Portuguese. In fear of retributions by former enemies, the Khwe and !Xun fled the country after Angola’s independence in 1975. Those who ended up in northeast Namibia were incorporated into the ‘Bushman battalions’ of the South African Defence Force (SADF) along with the local Khwe and fought in the South African Border War (1966–1989). The Khwe and !Xun lived with their families on a military base in the Caprivi Strip and were dependent on the SADF for daily life: employment, everyday activities, schooling and general services (Gordon & Sholto-Douglas, 2000). Many of the Khwe and !Xun came to South Africa with the SADF after Namibia’s independence in 1990. In South Africa, they lived in a tented camp on a military base in Schmidtsdrift, but soon outlived their military purpose. Uncertainty about the future of the Khwe and !Xun increased due to the upcoming political change from apartheid to majority rule in South Africa (Sharp & Douglas, 1996). A third forced relocation seemed imminent as a local Tswana group claimed the land of the military base in Schmidtsdrift in 1992 (Douglas, 1997). After living in the tented camp for 13 years, the Khwe and !Xun finally relocated to a former farm, Platfontein, near Kimberley, with low-cost Reconstruction and Development Programme (RDP) housing. Platfontein is situated approximately 15km from the centre of Kimberley and is relatively isolated from other townships.

The history of the Khwe and !Xun left them facing a myriad of problems while trying to build a life in South Africa. Although living conditions have improved in terms of housing and proximity to a large city, the communities continue to feel marginalized and neglected by the local government based on the poor quality and limited number of houses and poor provision of services (Tempelhoff, 2014). Poverty is a structural problem as 97% of the Khwe and !Xun live on less than one dollar/day and have an unemployment rate of 95% (Dalton-Greling & Greyling, 2007; South African San Institute, 2010). Most families live on social grants or the income generated by one of the family members. Social conflict, violence and alcohol abuse have been reported since the Khwe and !Xun first came to Schmidtsdrift (Robins et al. 2001) and continue today. In addition, staff from the local health clinic, NGOs and community leaders indicate that HIV/AIDS and tuberculosis severely burden the communities, although statistics are not available (Dalton-Greling & Greyling, 2007; Govender, Miti, Dicks, & Ewing, 2013; Letsoalo, 2010).

War, displacement and poor socioeconomic and health conditions are detrimental to mental health outcomes (Desjarlais, Eisenberg, Good, & Kleinman, 1995; Miller & Rasco, 2004; Miller & Rasmussen, 2010; Patel & Kleinman, 2003; Porter & Haslam, 2005). Despite interest in San communities by scholars and NGOs, little to no attention has been given to mental health. The study reported here is part of doctoral research that aims to provide the first insights into local perceptions of mental health and mental healthcare among the Khwe and !Xun. A pilot study (Den Hertog, unpublished) identified ‘madness’ (á-tcó in Khwe) as severe mental health problem. ‘Madness’ was characterized as socially disruptive behaviour, abnormal talking, wandering around or the inability to care for oneself. The
focus on behavioural problems and specific symptoms such as violent behaviour, disrobing, incoherent speech and a lack of personal hygiene are similar to findings in other studies on mental health problems in African countries (Edgerton, 1966; Ventevogel, Jordans, Reis, & De Jong, 2013) and are often compared to behaviour related to psychosis.

The people in Platfontein use both traditional and biomedical healing strategies to address health issues (De Jager, Prinsloo, & Joubert, 2010; Letsoalo, 2010). The local healthcare clinic, situated at the centre of Platfontein, includes mental healthcare in their broad range of services. This is part of community-based mental healthcare initiated by the Mental Health Care Act (Ramlall, 2012). Although, South Africa’s mental healthcare is moving away from institutionalised care, it lags behind in providing adequate care at a community level. In addition to psychiatric care, adequate care would include psychosocial and rehabilitation aspects of care (Botha, Koen, Oosthuizen, Joska, & Hering, 2008; Petersen & Lund, 2011; Ramlall, 2012). The under-resourced and overburdened primary healthcare system is unable to provide comprehensive community-based mental healthcare (Petersen & Lund, 2011), which makes individuals with mental health problems largely dependent on the informal care provided by their families and the community as a whole.

**Methods**

A case study method was chosen to gain an in-depth understanding of informal care of people suffering from psychotic mental health problems as a real-life phenomena (Stake 1995, Yin 2009). The method allowed us to make underlying dynamics visible and understand how they shape context-specific challenges and opportunities. Data collection methods included semi-structured interviews, informal conversations and observations. Data collection took place in 2013, from March to May, by both authors, and in 2014, from March to April, by the first author.

**Case and participant selection**

This study took place in the Khwe community. Local terminology (á-tcò) was used to initiate the search for case studies with the assistance of the Khwe research facilitators. Case studies aim to develop a deep understanding of the particularities and context of a case (Stake, 1995; Yin, 2009). It is therefore inherent that a study contains one or a few cases, depending on the resources available. Five people with chronic á-tcò were identified. We conducted two case studies in each fieldwork period (four in total). Selection was based on the research facilitators’ familiarity with the individuals and their caregivers, as well as our first impression about the quality of care being provided. We aimed to study diverse cases, in terms of quality of care, as this would increase our opportunity to learn (Stake, 1995) about the dynamics of informal care. A caregiver was defined as a person who partook in any one of a broad range of caregiving activities, such as emotional and instrumental support, providing basic needs or nursing care. Caregivers were identified by the research facilitators, care recipients, caregivers, neighbours and through observation. The number of interviews depended on caregiver availability, and interviews were stopped when new insight on our topic of interest was no longer forthcoming.
Data collection and analysis

Semi-structured life-world interviews (Kvale & Brinkmann, 2009) were designed to discuss the caregivers’ views on their informal care and the lives of the care recipients. Interview guides with a list of open questions structured the interviews. Topics included: past and current relationships between the caregiver and care recipient, illness history and healing strategies, current living conditions, perceived need for and availability of care, people and organisations involved in care, opportunities and difficulties in the provision of care, and wishes for the future. Follow-up questions were used for further details.

The Khwe use the San language Khwe in daily interactions; Afrikaans is their lingua franca and English is spoken on rare occasions. The first author fully comprehends Afrikaans and is able to speak it at a basic level. The second author is a native English speaker. Research facilitators assisted with translation when respondents preferred to conduct the interview in the Khwe. To overcome translation and interpretation challenges, we used multiple local Khwe interpreters with whom we discussed the purpose of the study and reflected on the interview process and translation difficulties (Borchgrevink, 2003). Interviews were audio-recorded with permission and transcribed verbatim. In total, 33 interviews were conducted: 9 in Afrikaans, 4 in English and 20 in Khwe with translation from research facilitators.

Observations focussed on the care recipients’ daily activities, their interaction with community members and the caregivers’ activities. Researchers observed from a distance (observer-as-participant) and accompanied the care recipient (participant-as-observer) (Angrosino, 2007). Observations varied from brief time periods to 4 hours. Observations were combined with informal conversations with community members who interacted with care recipients. Brief field notes were written during observations and informal conversations. Daily reflections were written down as extended field notes.

Transcribed interviews and field notes were read several times to become familiar with the data as a whole. Qualitative data analysis software (Atlas.ti, version 6.2) was used for descriptive and interpretive coding (Miles & Huberman, 1994) to order data and determine themes. After this initial phase, we decided to focus on the structure and organisation of informal care and factors facilitating and hindering informal care. An iterative process of discussion between both authors and returning to the data led to core theme identification. Pattern coding (Miles & Huberman, 1994) allowed for reviewing relevant data to have a deeper understanding of the themes and interrelated factors.

Ethical considerations

Permission for the study was obtained from caregivers. Care recipients were also involved, but at times seemed unable to grasp what was discussed. Interviews were preceded by written informed consent that explained and underlined the voluntary basis for participating in the study. Ethical clearance was obtained from the Humanities & Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (ref. number HSS/0054/013D). The South African San Institute, located in Kimberley, and traditional leaders were informed and gave permission for the study.
Findings

The four case studies revealed the diversity in the lives of people with psychotic symptoms and the care they receive. However, three patterns were identified across cases: shared and fragmented care, poverty, and care resistance. To illustrate local realities and to foreshadow these patterns, we start with a vignette (Ely, Vinz, Anzul, & Downing, 1997) about the life of Dala (pseudonym).

Dala’s everyday life

Dala’s psychotic condition made it difficult to elicit his perceptions and descriptions of his life; therefore, this vignette is constructed out of stories told by others and our observations.

Dala is a man about 30 years old who enjoys the company of others by joining conversations, hanging around with strangers (like us), going to church, assisting people with chores, and visiting various family members and acquaintances. His psychotic condition makes these interactions at times difficult. Although Dala talks a lot, he does not make sense most of the time. Dala’s odd behaviour sometimes causes bursts of laughter among community members, but in general people respond to him in a friendly manner and do not shy away from interacting with him. Dala lives in an RDP-house with one of his half-brothers (who was away working on a farm during our fieldwork) and spends his day wandering in the community. When Dala’s condition started, about 12 years ago, a half-brother, mother and uncle sought treatment from a traditional healer in Namibia as well as medical clinics in Schmidtsdrift and Platfontein. Unfortunately, Dala’s condition remains largely unchanged. At present, Dala receives medical treatment, but his medication intake is not supervised. Dala’s caregivers explain that he usually takes his medication and if he does not, it is very difficult to force him to do so. For his daily meals, Dala relies mostly on his mother who prepares his food. However, when there is no food available, Dala is sent to his aunt in the hope that she can provide him with the food. Dala receives a disability grant of 1200 Rand from the government. Several caregivers expressed concern about how Dala spends his money and his alcohol consumption in particular. On paydays, or ‘Platfontein verjaarsdag’ (Platfontein holiday) as it is ironically called, Dala participates in festive drinking activities which aggravates his symptoms. When caregivers attempt to control Dala’s behaviour including managing his money, personal hygiene, alcohol abuse, medication intake, and wandering outside Platfontein, they are confronted with resistance. Caregivers respond by resorting to strategies that avoid confrontation. One of Dala’s half-brothers, for example, tried to control Dala’s drinking behaviour by asking people not to sell him alcohol, but without success.

Shared and fragmented care

In all four cases, several people from various households were involved in caregiving, thus making informal care a shared activity. In general, the nuclear family was assigned the main responsibility for the individual with mental health problems. On many occasions, extended family such as uncles, aunts, cousins and nephews also played an important role in providing care. Caregivers frequently formulated their responsibility in terms of familial ties:
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I know him from that time when I was young. I think that I was really young at that time. [...] My brother told me ‘you see, this is your sister, this is the child of your sister... so, look at what happens, if something happens, it is your son’. (Dala’s uncle)

In practice, however, informal care was an adaptive system in which local dynamics, defined caregiver roles and activities rather than perceived responsibilities. Although structural elements of care were available in all cases, most care was initiated by care recipients, especially in terms of daily needs and social contact. Thereby, unrelated community members were also involved in caregiving and provided social contact, hand outs and supervision in times of crisis. One of our case studies, Christina, a woman of approximately 65 years old, spends her day visiting various community members for up to a few hours, mostly to enjoy their company. Two other case studies, David (approximately 35 years old and Christina’s son) and Jacob (approximately 30 years old), secure their daily needs in large part through irregular hand outs from family and unrelated people in Platfontein and people in Kimberley. These temporary and irregular caregivers are essential for the two men’s survival. In crisis situations, people may become temporary caregivers. For example, community members intervened when Jacob was assaulted in town and functioned as a safety-net in the absence of regular caregivers. Adaptive informal care was evident in response to scarce and irregular resources. When resources were scarce, care recipients were redirected to other caregivers. Sometimes, caregivers were temporarily unavailable due to employment. Most employment is security or farm work and requires men to be at the work location for a period of 3–9 months. In their absence, the care recipients rely on their remaining caregivers to provide care.

Shared and adaptive care structures have their own challenges as care becomes fragmented. Caregivers were often unaware of other caregivers’ activities. This made it possible for caregivers to withdraw and redirect caregiving responsibilities to other caregivers or service providers in the community:

Researcher: Who do you think is responsible for providing these things [food and clothing]?
Caregiver: You should get people from there to come here to help him
Researcher: Someone from outside [the community]?
Caregiver: Yes
Researcher: So there is not someone here in the community [who is able to provide these things]?
Caregiver: No
Researcher: Why are there no people who take care of him? Because there are people for Christina, but no people for David.
Caregiver: The family of David’s father should help but they don’t help. Christina is my sister that is why I help her. (Christina’s sister, David’s aunt)

Although redirecting care responsibilities facilitates care adaptability, it also creates vulnerability when there are only a few caregivers available. Following up on Jacob in the second year of the study, we learnt that two caregivers who regularly provided care had passed away leaving no one to fill the gap. Jacob was now more dependent on irregular hand outs, especially when his father was away working. Fragmented care also implied that care recipients were not continuously supervised, which increased their vulnerability for
(physical) abuse, robberies and traffic accidents. This was especially true when they left Platfontein:

> You know, what worries me a lot is maybe you can wake up the morning and you will see him lying dead on the street. Or in town, you will just hear that ‘no, he’s dead’. You don’t know what happens to him cuz he’s going places, he’s walking around, he’s not having security. (Jacob’s cousin)

**Poverty**

Poverty put considerable strain on informal care. Caregivers were especially concerned with providing the care recipients with their daily needs such as food and clothing. For David and Jacob, begging and scavenging at the municipality landfill were strategies to cope with their lack of caregivers. Facing reality and not seeing other options, caregivers accepted this as part of life. Jacob’s father remarked:

> Me and Jacob . . . If I got something, maybe food, then I must eat and I must keep half [of the food] for Jacob so he can come to eat. If I don’t have [food], then Jacob has to go to the dumpsite to eat. That is how we live. (Jacob’s father)

In terms of healing strategies, some caregivers explained how financial constraints limited access to traditional healing, which has high fees and requires travel expenses (people from Platfontein often travel to Namibia to visit a traditional healer). The burden of poverty was alleviated for two care recipients who received a governmental social grant, Christina (an old-age pension) and Dala (a disability grant), although managing money was an issue for Dala as mentioned earlier. The maximum amount for both grants is 1410 Rand per month (Government of South Africa, 2015). David and Jacob’s caregivers said that they had difficulty obtaining social grants because both men resisted medical treatment and filing for a South African ID – both actions that are necessary to apply for a disability grant. Caregivers also anticipated quarrels among fellow caregivers about who would manage the social grant and expressed concern over possible mismanagement, such as caregivers using the grant for their own benefit.

**Care resistance**

Caregivers described the care recipients’ strong will, denial of their condition and delusional ideas as typical behaviour for á-tcò. This became a major obstacle for providing care as care recipients resisted healthcare, personal and general hygiene, and lifestyle changes, such as avoiding substance abuse. It should be noted that the care recipients’ need for assistance in these areas varied. For example, Christina was generally capable of taking care of herself, whereas Jacob and David needed care in most areas. Caregivers described care recipients’ verbal and physical resistance as common responses when they attempted to enforce care:

> I want to go with Christina to the clinic but Christina don’t want to go. [If] I try in another way, like forcing her, then she gets angry. (Christina’s sister)

Although caregivers made initial attempts to enforce care, often after the onset of symptoms, the upsetting situation that arose and their ineffectiveness caused caregivers to abandon involuntary care. Only on rare occasions did caregivers continue to pursue
involuntary care. For example, Jacob’s caregivers mentioned that his condition sometimes deteriorates at which point they take him to the clinic against his will.

Care strategies were usually non-confrontational so caregivers provided care in a manner that did not result in conflict with care recipients. Examples included: accommodating a person’s request (e.g. buying groceries in town), carefully trying to persuade a person to do something (e.g. to wear clean clothes or take medication), attempting to control the environment (e.g. asking community members not to sell or give alcohol to the person), and accommodating care recipients’ specific preferences:

Caregiver: Dala doesn’t want me to visit him there [at his home] because . . . I don’t know, it is the sickness that makes him so . . . he decides when he wants to see me. [. . .]
Researcher: Okay so you never go to visit him?
Caregiver: If Dala is with his aunt . . . then I go to his place to see if the house is clean. If he is at home then I don’t go there because he doesn’t want to see me there. [. . .] If I’m there then I only clean the kitchen and living room. I can’t clean in his bedroom because he doesn’t want me to clean there. (Dala’s sister)

Non-confrontational care strategies have ambivalent effects as they maintain a relative peace between caregivers and care recipients, but simultaneously allow the care recipients’ maladaptive behaviour to continue. This is not only a concern for the care recipients’ general well-being but it also affects the caregivers’ emotional well-being. For example, caregivers are sometimes concerned about other community members’ views on the quality of care they are providing:

It’s like I’m taking care of her, but she likes to go to other peoples’ houses. So, I feel bad when people say I don’t take care of her, but I’m really trying. (Christina’s brother)

Discussion

Although leading rather autonomous lives, people with chronic psychotic symptoms were dependent on informal care to a great extent. This was especially true when a person was unable to care for him or herself in terms of daily needs, medical treatment and safety. In this study, informal care was characterized by shared and fragmented care, poverty and care resistance. These characteristics should be understood as dynamics generated by broader contextual factors.

Informal care in our case studies was shared and included family members from various households and unrelated community members. This contrasts with findings from other studies that described informal care as single-household activity (e.g. Duncan et al., 2011; Ogden et al., 2006) that in practice may be restricted to specific people, such as women (Akinlotola, 2006; Taylor, Seeley, & Kajura, 1996; Van Der Geest, 2005). Shared-care structures beyond single households were evident in a few studies (Addlakha, 1999; Seloilwe, 2006) and appeared to be well organised by caregivers. In our study, however, care was significantly more dynamic and care recipients often played a central role in orchestrating and demanding care. In part, this could be explained by the Khwe’s socio-historical context. Many family units live in close proximity to each other in Platfontein, which has resulted in the availability of several potential caregivers. In addition,
Platfontein’s relative social isolation and the general familiarity and acceptance of people with chronic psychotic symptoms, contribute to a relatively safe environment for the care recipients to wander around and demand care from various sources. Another contributing factor in Platfontein is the absence of stigma by association, which in other studies is reported as an obstacle to providing care (Marimbe-Dube, 2013; Mavundla et al., 2009). Caregivers in our study appeared unrestricted in their interactions with care recipients.

The shared-care structure reported in this study is an adaptive process that responds to local dynamics and care recipients’ needs. It does not, however, guarantee the availability of care. Care may be scarce due to a lack of resources, caregiver absence due to employment, sickness or death, or because caregivers redirect caregiving responsibilities. This affirms critiques of the assumption of the availability of informal care (Ogden et al., 2006; Seeley et al., 1993) and serves as a critical note for community-based mental healthcare that implicitly assumes the availability of informal care for daily caregiving activities.

Similar to other studies in low- and middle- income countries, poverty restricts caregiving opportunities in terms of providing basic needs (Mavundla et al., 2009; Seloilwe, 2006). In the South African context, reform of municipal basic services and mental healthcare may further restrict the caregiving opportunities in poor households (Breen et al., 2007). Studies have also reported on financial constraints in relation to traditional and biomedical treatment for mental health problems (Jack-Idle et al., 2013; Marimbe-Dube, 2013; Van Der Geest, 2005). Caregivers in our study mentioned the cost of traditional healing, but not the cost of biomedical treatment as free biomedical care is accessible at the local healthcare clinic.

South Africa’s social care in the form of social grants aims to alleviate the burden of poverty for individuals with a disability. These grants are often an essential part of household income (Duncan et al., 2011). However, in this study, three people had no disability grants due to their resistance towards medical treatment and their caregivers’ non-confrontational care strategies. Furthermore, our findings revealed that the management of a social grant could become problematic as caregivers struggled to address the care recipients’ resistance to allow caregivers to manage the money. In addition, the widespread struggle for resources in Platfontein makes financial management of a social grant a potential source of interpersonal conflict among caregivers.

Care resistance was mentioned as an important obstacle to providing care, which is also commonly reported in other studies about informal care for individuals with psychotic symptoms (Mavundla et al., 2009; Ryan, 1993; Seloilwe, 2006; Sethabouppha & Kane, 2005; Van Der Geest, 2005). Caregivers often described non-confrontational responses as a means to prevent conflict with the care recipient. In a study about mothers of adult children with schizophrenia (Ryan, 1993), a mother described her experience as ‘walking on eggshells’. Having peace in the household seems to be an important strategy in living with or caring for a person with psychotic symptoms. In contrast, studies have also reported care strategies in which control is enforced through physical restraints (Read et al., 2009; Sethabouppha & Kane, 2005). Local responses to people suffering from psychotic symptoms follow common practice and this is often unquestioned (Read et al., 2009). In Platfontein, non-confrontational care, including unrestricted mobility for the care recipients, was common practice. Although this form of care exposed care recipients to harm at times when they wandered outside Platfontein, caregivers saw no other option and considered this approach to be the most appropriate way to care for people suffering from psychotic symptoms.
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It is evident that informal care dynamics are shaped by local contexts, such as socioeconomic, historical and cultural contexts, and may differ significantly among settings. The ethnographic case study approach allowed us to bring local realities of informal care to light and situate them in the context. It should be noted that we focussed on people suffering from chronic psychotic symptoms. Dynamics of informal care may be different for people who suffer from temporary psychotic episodes. This study’s findings indicate the need for local understanding of the following themes (i) the structure and organisation of informal care and its dynamics over time; (ii) caregiver challenges related to poverty and care resistance; and (iii) social contexts that may benefit care recipients (such as community acceptance), or expose them to harm (such as alcohol abuse, physical abuse, robberies and traffic accidents). Policies and formal mental healthcare services in low- and middle-income countries usually neglect these aspects of the lives of individuals with mental health problems and their caregivers, and give priority to psychiatric service delivery. Incorporating local challenges and strengths into service delivery will greatly benefit the quality of life of people suffering from chronic psychotic symptoms. Considering the pivotal role of informal care for people with a chronic (mental) illness, care and support for caregivers is an important step forward (Chadda, 2014; Ogden et al., 2006).

Conclusion

Informal care is an essential part of the care environment of individuals suffering from mental health problems. Additionally, the interdependent whole that shapes the care environment includes formal healthcare services, community and the broader social environment. Improving the quality of life of individuals with psychosis-related mental health problems demands a holistic approach that takes care environments into consideration. The adaptability of informal care is a key feature that enables timely and appropriate responses to local dynamics and care recipients’ needs. Strengthening and supporting informal care structures without compromising their adaptability is essential for improving the living conditions of care recipients and caregivers.

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