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“By working together and caring for one another we can win this fight”: A qualitative exploration of a traditional healer's perspectives of care of people with epilepsy in a South African urban township in Cape Town

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ABSTRACT

There is a gap in knowledge about the construction of care in the Global South where biomedical care remains largely inaccessible to many people, resulting in people seeking health care from the indigenous sector of health care. As part of a larger study, in this article we present findings from a single individual interview with an indigenous healer using a semi-structured interview guide that was based on Kleinman's Explanatory Model Framework. Key themes that emerged from the thematic analysis of our indigenous healer's audio-recorded transcribed transcript were about “care”. The four overarching subthemes were the following: (i) care in the family, (ii) care in the community, (iii) care in the health system, and (iv) respondents' construction of care. A key feature of care, for this healer, is its explicit location in lineages of community – care is seen not as an individual or organizational issue, but part of the shared social fabric. We argue that it is crucial to attend to the lay understandings and practices of care which reflect diverse ways of understanding care and relationality in context. Future research is needed to close this gap.

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1. Introduction

As a chronic health condition, epilepsy commonly requires ongoing care from family members, health practitioners, and others in the community. As Kleinman [1] notes, care is a critical issue that influences human life in society in general as well as in health systems. Despite this, the issue of care has received relatively little attention in health research [1]. From a feminist perspective, McCarthy and Prokhovnik [2] (p.2) emphasize that “care is underpinned by notions of relationality and that it incorporates an embodied relational self, in which threats to the physical well-being of another may be experienced directly as implicating ones' own physical well-being”. Furthermore, Reach [3] (p.171) highlights that “care has a temporal dimension – taking care of oneself when one is a patient, or of someone when one is a caregiver needs in some way giving priority to the future”. On this basis, we argue that in a chronic illness such as epilepsy, the course of which may be of short or long duration, care may need to be provided over a prolonged period.

The emerging literature on care, as is the case with literature on many other issues affecting health, is dominated by writing from the Global North where, in general, there is relatively good access to biomedical care, and where biomedicine holds an undisputed status of

dominance among sectors of care [4,5]. Very little is known about the construction of care in the Global South, where access to biomedicine is more restricted, and alternative and indigenous healthcare systems continue to play a large part in people's lives. As part of our ongoing work on epilepsy and care in an urban South African context [6], in this article we use a case study of a South African indigenous healer to explore what care means in this different context. Through examining this healer's narrative, we suggest that though key features of care may be universal, it may also be important to attend to local understandings and practices of care which reflect diverse ways of understanding care and relationality in context.

We base our argument on an in-depth interview with a traditional healer who was a *sangoma* (diviner) as well as *inyanga* (herbalist) – whose cousin had epilepsy and died from the illness. The study was approved by the four local Health Research Ethics Committees (HREC).

2. Methodology

2.1. Research design

The data presented here form part of a corpus collected for our larger study. We interviewed and engaged with people with epilepsy, traditional healers, medical personnel, and community health workers as part of the study, as well as observed practices in a public health clinic. Details of the methods used to collect data have been reported by Keikelame and Swartz [6]. Data used in the current article were

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collected by MJK via a semi-structured interview guide, which used Kleinman's [4] Explanatory Model Framework as a basis. The participant was interviewed in his home in 2013, with the semi-structured interview guide being used as a framework, but with opportunity for the participant to speak freely. In this case, the interview lasted over 90 min and the participant, who for purposes of the article we will call Mr. A, spoke at length without interruption about his experiences. The interview was transcribed verbatim from isiXhosa (the language in which the interview was conducted) into English by a transcriber who was proficient in isiXhosa and English.

2.2. Data analysis

The transcribed interview transcript was analyzed by MJK and reviewed by LS using the Braun and Clarke [7] thematic analysis method. An inductive approach was used to uncover emerging themes from the data through reading and rereading, familiarization, and immersion [8]. In the process, MJK also kept reflective notes from discussions with LS, and this assisted recall of questions, to deepen the understanding of what Mr. A said.

3. Results

3.1. Participant characteristics

Mr. A, a male *sangoma* (diviner) and *inyanga* (herbalist), was 67 years of age. He passed Standard 8 (tenth grade) and could speak three African languages (isiXhosa, Setswana, Xitsonga). He was married and had five children. He had 7 years of training and had been practicing for 49 years. He migrated to Cape Town from one of the provinces in the country and has been residing in the study setting for 37 years. Some patients with epilepsy (PWE) and their close relatives consulted with him. He was receiving a pension grant and was a non-Christian.

3.2. What is care to Mr. A?

3.2.1. Care in the family/at home

Mr. A's conception of care was clearly rooted in issues of poverty, loss, and family vulnerability:

"I had an aunt. She had a boy child who had this illness [epilepsy]. My uncle and my aunt were the ones who took care of him from when he was pikanin [young boy]. When thinking of it, I think it is the illness that killed him because my aunt died and my uncle died, and there was no one to take care of him...my uncle's eldest son was too careless... I had a word that says, 'No, our brother [older brother] became careless because from our side, he wanted his things [the siblings' inheritance]. Even though he [younger brother] was a sick person [a PWE], sometimes he [younger brother] did not get food. A person with this illness must get food. If he does not get food he will leave you [he will die]."

3.2.2. Care at community level

Mr. A located care (or lack of it) within the context of a changing community:

"In this location, [a location is the name used in South Africa for a low-income urban setting in which Black people live] let me give you the absolute truth, there is no care. A person with this illness needs care. So, the people in this location, they live like Whites as I have observed. When they see another person who is like this, what fills them is only laughter. They do not have any care. Sometimes a person can go about sick till death because they do not care. A small thing can grow into a big one because there is no one who cares. But I believe by working together and caring for one another we can win this fight. You cannot win a fight if you do not care."

Here, Mr. A is referring to what he perceives to be the loss of what is termed "Ubuntu" in relation to care practices in urbanizing African communities. The concept of Ubuntu refers to an ethic of social reciprocity and mutual support, with the dictum "a person is a person because of other people" encapsulating the idea that personhood is dependent not on individual qualities but on how one relates to and cares for others. Mr. A's striking assertion, "they live like Whites", is an invocation of the idea that through urbanization and social change, urban Black South Africans have come to live individualistically and selfishly, thus abandoning the central ethic of Ubuntu and hence of care from an indigenous African perspective.

3.2.3. Care within the biomedical health system

When talking about care in the hospital, Mr. A conveyed the nature of care through a metaphor of a "lion" to highlight connections between power and powerlessness in relation to care:

"Why you hear people complaining about care in the hospitals, the problem is with the people who are working there... You see, if a lion shows up here, who will stand against it? Is it not that everybody will be afraid? He [the patient] will run away and everybody will run away because they see a lion... This is what I find kills hospitals..."

3.2.4. Care within Mr. A's health practice

Mr. A further provided his own perspective about "care", which demonstrated that, for him, care is embedded in social networks, sound relationships, altruism, and self-gratification for doing good to others:

"Care, from my experience and knowledge, when you as a patient arrives, I will ask you who you are, where do you come from... Why I do that is because I will also tell you who I am and where I come from so that when you get well after being helped you will know who helped you and where he [the healer] came from. You would say, I was attended this way and that way by this person...you will tell them that I went to so and so and I got help...people there like other people so much... Just your care made that person to get well... Care for me means that I should not be concerned about myself and not care for the sick... I must care for the patient more than I care about myself."

4. Discussion

Understanding care, what it is and how it should be given requires an appreciation of sociocultural constructions and meanings of care [9]. According to Kleinman [10] (p.1551), care should be understood as a process that involves psychological, socioeconomical, and political actualities which is provided by people who are complex, divided, and socially positioned. The aim of this article was to gain an in-depth understanding of our respondent's perspectives and subjective experience of care and caring for PWE who consult with him in an urban Black township in Cape Town. From an analysis of our respondent's qualitative verbatim responses, we discuss the main theme on "care" and the overarching subthemes that emerged from this single individual interview.

4.1. Factors affecting care in the family

The importance of understanding factors affecting care of PWE within the family is crucial because of the course of epilepsy and its impact on the person with the illness and the family. In their review of literature on family factors affecting children with epilepsy (CWE), Rodenburg et al. [11] found that factors such as family stress, relationship difficulties, and family dysfunction can have an impact on CWE. However, what we found was that family factors such as death

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