



A lay carer's story about epilepsy in an urban South African context: They call it an illness of falling or an illness of fitting because a person shakes and eventually falls

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ABSTRACT

In South Africa, epilepsy is poorly understood and managed. The different cultural understandings and terms used to explain the condition across the diverse population groups exacerbate this problem. In this article, we describe the findings from a single story about epilepsy which we elicited through a semistructured interview guide in the respondents' natural setting. We used Kleinman and Benson's mini-ethnographic questions to explore the lay carer's explanatory models about epilepsy. Our respondent had different descriptors for epilepsy which include 'an illness of falling', 'an illness of fitting', and 'a thing'. His explanatory models concerning epilepsy were predominantly sociocultural, psychological, economical, and political in nature and were supported by personal examples from his past and present experiences. Key to this man's story is the reality of a strong cultural base of understanding epilepsy, with the added reality of an urbanized world in which people feel alienated from one another and do not necessarily share the same cultural beliefs and practices. Instead of viewing understandings of epilepsy as either 'traditional' or 'western', community-based health promotion interventions must therefore recognize both cultural issues and urban realities and should also incorporate approaches that foster a common ground for patients and carers with very diverse views. The findings of this one interview cannot be generalized but have implications for managing epilepsy in an urban African context.

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1. Introduction

Good and Good [1] state that "if we are to analyse the role of culture in shaping illness experience and behaviour, it is important that we attend to the stories we hear with great care". The authors further point out that this is important, partly because "most of what we know about ... illness, we know through stories we are told". According to Reverby [2], good medical practice involves the ability of the medical doctors to elicit a "thoughtful history by listening and hearing patient's real stories", no matter how they tell them, whether they are vague, and even if doctors have limited consultation time. Referring to the work of Paget (1982), Sandelowski [3] notes that listening carefully to even one story of an illness can reveal important information not only about the illness but also about life experiences more generally.

According to Kleinman (1988:49) in Hydén [4], "the illness narrative is a story that the patient tells and significant others re-tell to give coherence to the distinctive events and long-term course of suffering. The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering" (p.54). Hydén [4] further points out that when illness stories are told,

other people are enabled to comment on them and to provide new interpretations and suggestions. What the author means is that stories are a way of presenting, discussing, and hearing how people relate to the illness, thereby providing opportunities for articulating various events related through a story and discussing their meaning.

With regard to epilepsy, illness stories are socially and culturally constructed and may have a range of interpretations and meanings. Some of these may result in stigmatization of people with epilepsy (PWE) [5]. For example, an interesting feature of epilepsy narratives is that they are often told not by people who have epilepsy but by others. Indeed, many of the most dramatic experiences of epilepsy (grand mal seizures in particular) may not be remembered by PWE themselves and because of this, they are inserted into the narratives of those who witness and tell about seizures [1].

This story forms part of a larger study titled 'Perspectives on epilepsy on the part of patients and carers in a South African urban township', the broader findings of which will be reported separately. The study is set in one of the oldest townships in Cape Town, established in 1927 because of forced removals of Blacks by the policies of the White minority government. The burden and management of epilepsy are not mentioned in the situation analysis of the study setting, conducted in 2005 by Naidoo and Irlam [6]. Nationally, however, the burden of epilepsy is reported to be approximately 1 in every 100 South Africans [7,8]. Cultural beliefs regarding the cause and treatment of epilepsy also vary between communities in the country [9].

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1.1. What this study adds

There are very few studies looking at complex stories in Africa. We are not aware of any studies which look in detail at a single story which discusses issues of transition as clearly as this one. The story provides information not only about epilepsy but about the complex contextual factors that affect treatment, care, and health-seeking behavior in the context of poverty and displacement in a low-income area in Cape Town, South Africa.

2. Methodology

In this qualitative exploratory design, we chose to focus on particularities of a single story which is among many that we are collecting in line with Good and Good [1], who emphasize the importance of listening to stories. In particular, this story provides an in-depth exploration of relationships between different variables that affect health and health-seeking behavior. Our respondent provides a complex and multilevel perspective that we would not have gained through a larger study. Writing about the importance of listening to stories in their entirety, both Frank [10] and Charon [11] argue that a single story can open worlds of meaning. The analysis of a single story is not designed to give information about populations or groups in general. It focuses instead on the how and why of a person's experience [12]. Kleinman [13] also notes the importance of the single narrative for our understanding of the experience of illness and of caring for people who are ill. We used Kleinman's explanatory models of illness (EMs) [14,15] to conceptualize how our respondent explains epilepsy. Explanatory models constitute a way of understanding how people recognize an illness, explain it, and respond to it [16,17]. In addition, EMs are shaped and influenced by culture and are held by patients and their carers and provide personal and social meaning with regard to the illness experience [18–21]. Furthermore, EMs can affect coping, treatment choices, adherence, and therapeutic relationships [22,23].

2.1. Sampling procedure

Our participant was purposively recruited [24] from a group of patients with epilepsy and carers who attend a chronic illness clinic at the primary care setting that renders health-care services for the study population. We distinguished between and aimed to include different types of carers in our larger study – namely popular carers (family members, friends, or neighbors), folk carers (traditional healers such as herbalists and faith healers), and professional carers (Western-trained doctors, pharmacists, and other allied health-care professionals) [15] – in order to triangulate diverse views on the problem within the same population group. The inclusion criteria for popular carers included the following: any family member, friend, or neighbor who (i) is giving or has given care and support to PWE, (ii) speaks isiXhosa (isiXhosa is the dominant indigenous African language spoken in Cape Town), (iii) resides in the study setting, (iv) is aged eighteen years or above, and (v) is willing to participate in the study. During the recruitment process, the purpose of the study was explained to prospective participants who met the inclusion criteria. We also aimed to recruit 'information-rich' cases [24] which would provide insight and a deep understanding of the problem [24,25] and of the EMs about epilepsy. Only those who fit the criteria and aims and were interested in participating were included in the study and later visited at their homes to gain informed consent and to set interview appointments. Our participant was among the first to be interviewed. Our decision to share our respondents' story in detail was motivated by the richness of the information we obtained through the use of Kleinman and Benson's [26] mini-ethnographic questions, which may otherwise have been lost in a multistory cross-case analysis. The complexity of this person's story and cultural positioning gives a window into the multilayered experiences associated with epilepsy in an urban South African setting.

2.2. Ethics

A written informed consent and participant information leaflet were translated from English to isiXhosa by an isiXhosa-speaking language practitioner. This was read and interpreted to the participant by an isiXhosa-speaking field assistant to ensure that the participant understood the purpose of the study and his rights and responsibilities of participating. Confidentiality and anonymity were ensured by assigning predetermined identity numbers and pseudonyms to the audio-recorded interview data as well as the field notes to protect the identity of the participants. Written nondisclosure agreements were signed with the interpreter and the transcriber. All study documentation and transcripts were kept safely in a locked cupboard for confidentiality. The study was approved by the three local research ethics committees. Informed consent was obtained prior to the interview, and a signed copy was left with the interviewee [27–30].

2.3. Data collection

An in-depth individual face-to-face interview was conducted in isiXhosa (the participant's native language) at the participant's home by the first author, who is a black African female who has worked among isiXhosa-speaking communities in Cape Town for 19 years and knows the area well. A semistructured interview guide was constructed in English and translated into isiXhosa by an isiXhosa-speaking language practitioner and piloted prior to the interview at the local primary care setting by the first author among five patients with epilepsy and five carers who all speak isiXhosa. There were no questions that needed to be changed. The interview guide was based on Kleinman and Benson's [26] mini-ethnographic questions which the authors hoped would allow the participants to speak openly in an unstructured way, thereby enabling them to share experiences in the way they considered important [29,30].

Additional probe questions on psychosocial difficulties with regard to marriage, employment, and driving as well as recommendations of actions and solutions needed to address the difficulties were included. The interview commenced after gaining informed consent from the respondent and lasted for 90 min. The data were transcribed from isiXhosa into English by an isiXhosa-speaking language practitioner with experience in doing transcriptions. After the transcript was completed, the first author read the transcript and listened to the audio-recorded interview to ensure the accuracy of the transcribed data. The audio-recorded data were repeatedly listened to by the authors in order to cross-check against each other's interpretations.

While the first author is not a native isiXhosa speaker, she had enough knowledge of the language to be able to understand the thread of conversations in isiXhosa and to make herself understood in that language. The cross-cultural validity of the tool was ensured by (i) using the translated and piloted interview guide in the respondent's language during the interview, (ii) using an isiXhosa-speaking interpreter from the study setting to assist in gaining informed consent, (iii) using verbatim quotes to highlight the respondents' statements [31,32], and (iv) doing verbatim translation of the transcript to the respondent, a method Flick [33] refers to as a 'member check' (p. 205). Reflective field notes were captured by the first author after the interview to reflect on the process and to facilitate the data analysis [29,30].

2.4. Data analysis

After familiarizing ourselves with the data, we used Braun and Clarke's [34] thematic analysis method to analyze the qualitative data. We read the transcript to gain an in-depth understanding of the participant's story and began with open-coding of the data. As the aim was to provide meaningful interpretation of the participant's story, we attended to the words, language, and expressions used [1]. Thereafter, we selected the main categories emerging from the story and used

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