Seizure: European Journal of Epilepsy 61 (2018) 50–56

Contents lists available at ScienceDirect

Seizure: European Journal of Epilepsy

journal homepage: www.elsevier.com/locate/seizure

"I wonder if I did not mess up….": Shame and resistance among women with epilepsy in Cape Town, South Africa

Mpoe Johannah Keikelame*, Leslie Swartz

Department of Psychology, Stellenbosch University, Private Bag X1, Matieland, 7602, Cape Town, South Africa

ARTICLE INFO

Keywords:
Women with epilepsy
Shame
Resistance
Qualitative study
Individual stories
South Africa

ABSTRACT

Purpose: Literature shows that there has been more attention paid to epilepsy stigma, with less focus on issues of shame and resistance. This article provides an in-depth understanding of processes of shame and resistance strategies which emerged from the analysis of individual stories of four adult Xhosa -speaking women with epilepsy in an urban Black township in Cape Town, South Africa.

Methods: Our data collection method involved individual in-depth face to face interviews using a semi-structured interview guide adapted from Kleinman's Explanatory Model Framework. This framework enabled participants to openly share their experiences and perspectives of living with the illness. Their audio-recorded qualitative interview data were transcribed and analysed using a thematic data analysis method.

Results: Two main themes about processes of shame and resistance strategies emerged. Two women stories provided insights about the different types of emotions related to shame such as feelings of anger, guilt, regret and grief. Resistance strategies against actions of discrimination, unfair treatment and abuse were evident from the stories of the other two women with epilepsy. Being a bully was another form of violent strategy to fight victimization.

Conclusion: The findings demonstrate a need for a closer examination of these issues in future epilepsy studies in the study setting – and these should also be examined among men with epilepsy.

1. Introduction

The importance of paying attention to individualstories, especially of a stigmatised condition such as epilepsy, cannot be over-emphasised. For Kleinman [1] as cited by Fadiman [2] (p. 262), "every illness is not a set of pathologies but a personal story". This is crucial because stories enable us to gain an in-depth understanding of the individual's lived experience of the illness and its symptoms and how the illness disrupts the individual's life [3] (p. 52). In this article we present four individual stories of Xhosa -speaking women with epilepsy (WWE) – which are part of the findings from our larger qualitative research project which is the first to explore perspectives and subjective experiences of Xhosa -speaking adults with epilepsy and their carers in an urban Black township in Cape Town, South Africa, Kleinman's [1] Explanatory Model framework and his typology of systems of health care. Our sample of carers included traditional healers, popular carers (spouses, partners, parents, neighbours, friends, siblings) and home-based carers (HBCs).

In South Africa, social, economic, educational, employment and health inequalities of the past apartheid system are reported to continue to exist even post-democracy [4], and the system has left indelible poverty-related marks on affected population groups [5,6]. To curb this problem, the government provides financial assistance through a non-contributory pension, referred to as a disability grant, of R1500.00 (100USD) per month to disabled persons, the unemployed and people with epilepsy (PWE) [7]. Although these grants can be received by intended beneficiaries on a temporary or permanent basis [8], approval thereof is based on the assessment of western trained health care professionals (HCPs) – which often disadvantages the intended beneficiaries due to the HCPs lack of contextual information about the socio-economic backgrounds of the people concerned [9]. This situation is significantly worse for PWE as they are often suspected of faking their seizures to be deemed eligible for an income [9].

There is scant literature on shame and resistance in epilepsy research. Most of the literature on epilepsy reports on epilepsy stigma [10,11]. Hutchison and Dhairyawan [12] (p. 225) assert that "examining stigma without also examining shame is to miss much of importance - it is akin to studying threats as a social phenomenon while ignoring fear people have in response to those threats".

The aim of this article is to report on processes of shame and

* Corresponding author.
E-mail addresses: johannah.keikelame@gmail.com (M.J. Keikelame), lswartz@sun.ac.za (L. Swartz).

https://doi.org/10.1016/j.seizure.2018.07.021
Received 1 December 2017; Received in revised form 26 July 2018; Accepted 28 July 2018

resistance which emerged from an analysis of qualitative data obtained from individual interviews with four WWE. The objective is to describe and analyse these experiences to provide an in-depth understanding of the ways in which these WWE experience shame and resistance. We are of the view that our findings will stimulate further research on these aspects.

2. Methodology

2.1. Study design

This qualitative exploratory study was conducted between January 2012 and December 2014 and its conceptual framework was based on Kleinman's [1] Explanatory Model (EM) Framework [1]. For Kleinman [1], it is important to understand illness from both the biomedical and lay point of view because illness explanations are not only about the individual person's aspects of the illness experience, but they also include the social context of the ill person's experience. EMs are broad notions that include the person's aspects of experience and of experiencing the illness and the meaning, understanding and interpretation thereof [1,13] (Table 1).

2.2. Study setting

Our study was conducted in one of the oldest Black townships in Cape Town which was affected by the discriminatory and oppressive policies of the past colonial and apartheid rule. This situation resulted in major socio-economic, educational and health inequalities - and continue to exist even post democracy. In the different phases of our project, we found that: knowledge about epilepsy is lacking due to more attention being paid to Human Immuno-deficiency Virus (HIV) and Acquired Immuno-Deficiency Syndrome (AIDS) and tuberculosis (TB) [14]; that there are cultural beliefs about the cause and treatment of the illness and that some PWE combining western and traditional treatments and that different Xhosa names and cultural metaphors are used to explain epilepsy [14,15]. In terms of community-based care and support of PWE, we found that care is affected by factors such as migration, language barriers, lack of knowledge about support services [16], loss of indigenous communal values, known as "ubuntu" values due to urbanization [17] and lack of inclusion of epilepsy in local home-based care services [14].

2.3. Recruitment and sampling

A total of twelve adult PWE were recruited by MJK (first author) using snowball and purposive sampling methods [18] in distinct phases of the project, which entailed observations, individual interviews and focus group discussions. MJK was assisted by two local volunteer health workers to gain field entry and access to participants. This was important for establishing relationships because MJK did not reside in the township and needed to be introduced and to be orientated into the site. A list of names of 24 eligible participants was compiled by MJK. From this list, four PWE who initially gave consent decided not to participate. Eight had given their contact details and physical addresses but could not be traced and were therefore excluded. The recruitment criteria stated that only Xhosa -speaking adult PWE who resided in the urban township in which the study was to be conducted and who were willing to participate in the study would be recruited. This was because the majority of the residents in the township are amaXhosa and the most commonly spoken language is isiXhosa. After recruitment, each participant appointment for the interview was set over a two-week period to allow them to review their decision to participate or to withdraw.

2.4. Data collection instruments and procedure

Data were collected by MJK via a semi-structured interview guide between September 2012 and July 2013 at participants' homes to explore, interpret and understand the social context [18]. The interview guide was constructed in English by MJK and was adapted from Kleinman's [1] EM framework. It was translated from English into isiXhosa before data collection by a Xhosa -speaking language practitioner who was fluent in English and had experience in doing translations. The twelve PWE who had consented to participate in the study were individually interviewed in isiXhosa by the MJK – and they all gave permission for their interviews to be audio-recorded. The interviews lasted between 45 and 90 min. Each interviewee was given a food voucher of R60.00 (4.22USD) as a token of appreciation for their time and their valuable contribution to the knowledge base. These were given at the end of each interview.

2.5. Data analysis

The verbatim transcribed data of all twelve individual interviews

Table 1
Examples of interview quide questions for PWE adapted from Kleinman (1980) Explanatory Model Framework.

Column 1: Kleinman's (1980) Eight key Explanatory Model Framework questions	Column 2: Interview guide for PWE (adapted from Kleinman (1980) EM framework
What do you call the problem? What do you think has caused the problem? Why do you think it started when it did? What do you think the sickness does? How does it work? How severe is the sickness? Will it have a short or long course? What kind of treatment do you think the patient should receive? What are the most results you hope she receives from this treatment? What are the chief problems the sickness has caused? What do you fear most about the sickness?	1. What do people in your community call this illness (epilepsy)? [Probe for other names used to refer to epilepsy, what the names mean and why they are used] 2. From your point of view, what do you call your illness (epilepsy)? Are there other names that you use to refer to your illness? If yes, what names do you use and why? 3. What do you think has caused your illness (epilepsy)? Are there other things that you think may have caused your illness? If yes, please tell me more about them. 4 When did your illness start? Why do you think your epilepsy started at time it did? 5. What do you think your illness (epilepsy) does to you? How does it work? 6. From your personal point of view, how serious is your illness? Do you think your illness will have a short or long course? *[Probe for reasons]* 7. What kind of treatment do you think you should receive for your illness? *[Probe for reasons]* What outcomes do you expect from your epilepsy treatment? 8. What are the main difficulties you have experienced from having epilepsy? [*Probe for difficulties at home, community, society]* 9. How does epilepsy affect your life? [Probe for issues on driving, married life, employment, education) 10.What things make it difficult for you to understand your epilepsy? *[Probe for things that make it difficult for family, friends, community and society].* 11. In your opinion, what kind of actions should be taken to address the kind of things that makes it difficult for you to understand epilepsy? Who should take action and why? What are some of the things that may help to take such actions? What are some of the things that may make it difficult to take such actions? 12. What are the main things that you fear most about your illness?