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‘A Thing Full of Stories’: Traditional healers’ explanations of epilepsy and perspectives on collaboration with biomedical health care in Cape Town

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Abstract

The experience of epilepsy is profoundly culturally mediated and the meanings attributed to the condition can have a great impact on its social course. This qualitative study used Kleinman’s Explanatory Model framework to explore traditional healers’ perspectives on epilepsy in an urban township in Cape Town, South Africa. The healers who participated in the study were Xhosa-speaking, had experience caring for patients with epilepsy, and had not received any training on epilepsy. Six individual in-depth interviews and one focus group with nine traditional healers were conducted using a semi-structured interview guide. Traditional healers identified several different names referring to epilepsy. They explained epilepsy as a thing inside the body which is recognized by the way it presents itself during an epileptic seizure. According to these healers, epilepsy is difficult to understand because it is not easily detectable. Their biomedical explanations of the cause of epilepsy included, among others, lack of immunizations, child asphyxia, heredity, traumatic birth injuries and dehydration. These healers believed that epilepsy could be caused by *amafufunyana* (evil spirits) and that biomedical doctors could not treat the supernatural causes of epilepsy. However, the healers believed that western medicines, as well as traditional medicines, could be effective in treating the epileptic seizures. Traditional healers were supportive of collaboration with western-trained practitioners and highlighted that the strategy must have formal agreements in view of protection of intellectual property, accountability and respect of their indigenous knowledge. The findings suggest a need for interventions that promote cultural literacy among mental health practitioners. Research is urgently needed to assess the impact of such collaborations between biomedical services and traditional healers on epilepsy treatment and care.

Keywords

epilepsy; traditional healers; explanatory models; collaboration; South Africa

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Disclosure

We declare that we do not have any conflict of interest.

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Epilepsy is under-treated worldwide (Meyer, Dua, Ma, Saxena, & Birbeck, 2010; Newton & Garcia, 2012). Both because of this treatment gap and because there are many indigenous cultural explanations for epilepsy in different countries, some authors have suggested that traditional healers may have an important role to play in epilepsy management (Birbeck, 2010; Njamnshi et al., 2010; WHO, 2004). In South Africa, epilepsy management is reported to be poor in the public health sector (Keikelame, Hills, Naidu, de Sá, & Zweigenthal, 2012) and access to neurologists is difficult (Eastman, 2005). As in other African countries, some patients with epilepsy in South Africa consult traditional healers (Keikelame & Swartz, 2007; Eastman, 2005). Although there have been studies concerning issues likely to affect collaboration between traditional healers and the formal health system (Bührmann, 1984), most have focused mainly on mental health, HIV/AIDS, and TB (Campbell-Hall et al., 2010; Mngqundaniso & Peltzer, 2008; Sorsdahl, Flisher, Wilson, & Stein, 2010). As far as we are aware, ours is the first study to explore these issues in relation to epilepsy in an urban South African context.

Epilepsy has been associated with many myths and misconceptions about its cause and treatment over centuries and in different cultures and parts of the world (de Boer, 2010; ILAE, 2003). In the 13th century, Christians believed that demonic spirits caused epilepsy and that the condition was contagious and could be contracted via the evil breath of patients suffering from the condition (ILAE, 2003). Patients with epilepsy (PWE) were viewed as being “possessed” or “chosen” and their affliction could be treated through prayer (Helman, 2004).

In Africa, epilepsy has been given various names that relate to specific cultural beliefs. For example, epilepsy is called by its Swahili name “*kifafa*” in Tanzania (Jilek–Aall, Jilek, Kaaya, Mkhombachepa, & Hillary, 1997), Zaire (currently DRC) (Feierman & Janzen, 1992) and Kenya (Mbuba et al., 2012). Additional terms such as “*Nyuni, Nyago*”, “*Nyama ya dzula*”, and “*Vitsala*” are also used in Kenya to refer to seizures (Mbuba et al., 2012). A study in Indonesia found epilepsy was referred to as “*gila babi*” meaning “crazy pig”, convulsion sickness, and bad spirits caused by black magic (Conrad, 1992). Participants in a community survey on knowledge, attitudes and practices about epilepsy in Laos called epilepsy “mad pig disease” (Tran et al., 2007). The experience of epilepsy is culturally mediated and the meanings ascribed to the condition can have great impact on its social course (Aydemir et al., 2009).

The findings we report in this paper are part of a larger project exploring patient and carer perspectives on epilepsy in an urban township in Cape Town, South Africa. In this article, we use Kleinman’s Explanatory Models (EMs) framework to explore traditional healers’ understandings of epilepsy and its management. In the initial formulation of the EM concept, Kleinman (1980) emphasised the fact that in health-related encounters there are commonly negotiations, explicit or otherwise, between patients and those who care for them regarding understandings of illness. There may well be overlap between patient and healer EMs. Subsequent applications of the EM concept have been used to explore beliefs about illness held by patients and healers from a wide range of backgrounds (Helman, 1994), often focusing on how notions of cause, symptoms, severity and treatment related to an episode of sickness are used by participants in the clinical process. Understanding folk EMs is crucial

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to providing appropriate care (Zhu, Liu, & Tardif, 2009). There may be wide variation of EMs within groups and the EM concept is not intended to essentialise or reify cultural views on illness but to be used as a tool to understand how people understand different aspects of illness (Kleinman, 1980).

Method

We used an exploratory qualitative research design to answer the question: "How do traditional healers understand and manage epilepsy?" This design is particularly appropriate for gathering data in the natural setting of participants because it enables the investigator to gain an "insider" perspective on the cultural contexts of participants; it also allows participants to share their views in safety and privacy (Babbie & Mouton, 2001; Gray, 2009), which is particularly important when studying a stigmatized condition such as epilepsy.

Study Setting

The study was conducted in one of the oldest suburbs of Cape Town, a culturally and historically important urban township, which was established and designated for Black Africans during colonial rule. The population is estimated to be 52,401 (Lehohla, 2011) and has high rates of unemployment (Naidoo & Irlam, 2005). Although the predominant spoken language is isiXhosa, the recent population census revealed that other spoken languages include Setswana, isiZulu, English and Afrikaans (Lehohla, 2011). As is the case with other chronic conditions, epilepsy is managed in Community Health Centres (CHCs), which offer health care to most patients from low-socioeconomic groups (Mash, Levitt, Van Vuuren, & Martell, 2008).

Sample

There were approximately 160 traditional healers practising in the study setting (Naidoo & Irlam, 2005). In South Africa, there are three types of traditional healers: "*sangoma*" (diviner), "*inyanga*" (herbalist), and "*umthandazi/umprofeti*" (faith healer/prophet) (Truter, 2007). These healers are popularly known among Xhosa-speaking people as "*amagqirha*" (Mzimkulu & Simbayi, 2006). In 2003, the South African Government formulated the Traditional Healers Practitioners Bill (THPB) to regulate their practice and to encourage them to form their own organizations (Pinkoane, Greeff, & Koen, 2008; Pretorius, 2004). This Bill was amended in 2007 (Bill 20 of 2007) and enacted into law as the Traditional Healers Practitioners Act (THPA) (No 22 of 2007) (Mbatha, Street, Ngcobo, & Gqaleni, 2012). Traditional healers such as herbalists, diviners, traditional surgeons (those who do circumcision) and traditional birth attendants can be registered under this Act, but faith healers have been excluded (Peltzer, 2009). Although these regulations are in place, only 60 traditional healers in the study setting were registered members of the South African Traditional Healers Organization (Naidoo & Irlam 2005). As Thornton (2013) notes, there is considerable diversity amongst traditional healers and it is a mistake to view them as a homogeneous group.

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Our sample consisted of 15 Xhosa-speaking traditional healers who were purposively recruited because they would be able to provide rich information to answer the research question (Babbie & Mouton, 2001; Gerrish & Lacey 2010; Ulin, Robinson, Tolley, & McNeill, 2002). Access to these healers was gained through assistance from an executive committee member of Traditional Healers Organization (THO). This approach enabled the first author to draw a sampling frame, which was used to identify 15 potential participants. The criteria for inclusion were any traditional healer who was Xhosa speaking (whether or not they had been caring for a person with epilepsy), and was older than 18 years. Preference was given to healers who resided in the study setting, whether or not they were registered members of the THO. Only one, who was recruited via the snowball technique, did not reside in the study setting. Of the 15 traditional healers included in the sampling list, four did not participate. One died during the recruitment process. Two declined to participate and the last did not fit the inclusion criteria.

Data Collection

Data collection involved individual in-depth interviews and one focus group discussion..

Individual interviews—A semi-structured interview guide was constructed in English and translated by a Xhosa language practitioner to isiXhosa. The interview guide was used to collect data from six traditional healers, a study sample deemed sufficient for in-depth qualitative interviews (Silverman, 2013). The duration of the interviews was between 45 and 90 minutes and interviews were conducted at participants' homes or workplaces. The interview questions were based on Kleinman's eight EM questions (Fadiman, 1997; Kleinman, 1980): (i) What do you call epilepsy? What names does it have? (ii) What do you think has caused the illness? (iii) Why and when did it start? (iv) What do you think the illness does? How does it work? (v) How severe is it? Will it have a short or long course? (vi) What kind of treatment do you think the patient should receive? What are the most important results you hope the patient will receive from this treatment? (vii) What are the main problems the illness has caused? (viii) What do you fear most about the illness?

Additional probe questions addressed the healers' perspectives on issues facing patients with epilepsy concerning marriage, driving, employment, sports and education, and contextual factors surrounding the individual, home, community and society that may influence the understanding and treatment of epilepsy. At the end of each interview, interviewees were given some time to reflect on the interview process and offered the opportunity to share any additional information. One participant chose to be interviewed in Setswana and another in English. During the transcription process, the first author replaced the names mentioned by participants during the recorded interviews with pseudonyms to protect anonymity. Field notes were written immediately after the interview and were later extended after reflection (Ulin et al., 2002). Participants were given food vouchers for the value of R60.00 (approximately six US dollars) as a token of appreciation for their time and contribution to the research study.

The focus group discussion—The first author sent letters to all traditional healers listed in the sampling frame to invite them to participate in the focus group discussion.

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Invitation letters were delivered by the field assistant to all participants. These letters stated the purpose of the focus group and the date, time, venue and duration of the discussion. Only nine agreed to participate and four of them had been individually interviewed. Participants were familiar with each other and also belonged to the same traditional healers organization and this appeared to enhance their sharing of subjective experiences freely with one another in a non-threatening manner (Gerrish & Lacey, 2010; Ulin et al., 2002). According to Lehoux, Poland, and Daudelin (2006, p. 2093), when the group has “common associational and status contexts” it is likely to establish good rapport, which can enhance group interaction.

A semi-structured focus group interview guide was constructed in isiXhosa and was used to collect data during the interview. The purpose of the focus group was to validate the findings from individual interviews (Flick, 2006) and to explore and clarify any conflicting information through direct interaction (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). The group was not informed of which of the members had been individually interviewed to avoid any influence on the participants’ interaction. Where reference was made to findings from the individual interviews, no direct references were made to the focus group members who had been interviewed.

The focus group discussion was conducted in isiXhosa by the first author at a local youth organization centre that was accessible to all. The duration was 120 minutes. A Xhosa-speaking assistant moderator was trained by the first author on her role during the focus group interview and a resource pack was prepared for her for reference. Participants were informed of the importance of confidentiality and anonymity and all agreed to sign a group informed consent form. The procedure for focus the group discussion was explained and ground rules were set and agreed upon by all. Participants’ profiles were completed and primarily consisted of demographic details. Refreshments were served and each participant received a transport voucher of R20.00 (approximately two US dollars). At the end of the focus group interview, the first author and the assistant moderator reflected on the process and their observations to enable the first author to expand on the field notes that would be used in the data analysis (Watt, 2007).

Data Analysis

The audio-recorded data from the focus group and individual interviews were transcribed from isiXhosa into English by a Xhosa-speaking language practitioner. Each completed transcript was checked by the first author for accuracy by reading the transcript while listening to the audio recorded interview. We used the thematic analysis method to identify key themes related to participants’ explanatory models of their perspectives and subjective experiences about epilepsy, its treatment and care. Our approach to data analysis was inductive and involved the following steps: (i) reading and re-reading the transcripts and listening to audio recorded data to gain familiarity with the data; (ii) generating data driven codes and themes; (iii) reviewing, defining and naming themes to give meaningful explanations of the data and to provide a clear sense of what each theme was about (Bradley, Curry, & Devers, 2007; Braun & Clarke, 2006). To increase rigour in data analysis, we incorporated the framework analysis method described by Ritchie and Spencer (1994) in

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Rabiee (2004, p. 657). Key themes that emerged from the two data sets were organized into tables and grouped into appropriate categories with quotations from transcripts and were compared for similarities and differences. Credibility of the analysis was enhanced by regular meetings to review and refine codes and themes of the two data sets and to reflect on how our own assumptions and professional orientations may have influenced the data analysis process (Adams, McCreanor, & Braun, 2013). The first author took notes of agreed upon key themes and also presented a preliminary draft report of the findings to the participating traditional healers to confirm the findings (Flick, 2006). The feedback meeting was held on 10 September 2013 at the local community library. Seven key themes emerged from the data, four of which are the central focus of this paper.

Ethical Considerations

The first author presented the project proposal at a meeting held with the local executive of traditional healers organization to inform them about the study, to gain support and to network. The first author, who is not completely fluent in isiXhosa, the most common African language spoken in Cape Town, was accompanied by a Xhosa-speaking field assistant. The field assistant aided her by interpreting the patient information leaflet and consent form to eligible participants at each recruitment visit to ensure that the purpose of the study, the reasons for their recruitment, and their responsibilities and rights as participants were well understood. All recruited participants were given signed copies of consent forms to read and to share with family members or peers if they wished to do so. Requests for interviews to be conducted in other languages were respected. Ethical approval was gained from the four local health ethics committees: The Health Sciences Research Ethics Committee, University of Cape Town; the Health Sciences Ethics Committee, Stellenbosch University: the Provincial Government of the Western Cape (PGWC); and City Health Ethics Committees.

Results

Participants' Characteristics

Six healers were interviewed individually. Two were males and four were females. Their mean age was 65 years and 59 years respectively. Two female healers had been trainees ("*umkhwetha*") for more than ten years. Of the remaining four, all were *sangomas* with two males being *sangomas* as well as herbalists. All four had been practising for more than twenty years. Only one female trainee ("*umhkwetha*") did not reside in the study area. All six healers had treated and cared for a patient with epilepsy. Another female trainee ("*umkhwetha*") had a daughter with epilepsy. Among the two male healers, one had a nephew who had died from epilepsy and another had personally experienced an epileptic seizure. Four were registered members of THO. Two had never attended school and four had passed grade six. Four were receiving a government pension grant. One was employed as a cleaner and another, who was a trainee, did not disclose her means of income.

Out of nine focus group participants, six were female *sangomas* and two males were *sangomas* as well as herbalists. Only one female was a trainee ("*umkhwetha*"). The mean age was 63 years for men and 61.3 years for females. Three had never attended school and

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six had passed grade six. Five were registered members of THO. None of the healers in the individual interviews and focus group had prior knowledge of the national Non-governmental Epilepsy Organization and some had received lay training in HIV/AIDS and TB but not on epilepsy.

Names For Epilepsy

Participants in individual interviews were asked this question: "What do you call this illness (epilepsy)?" In their responses, three similar Xhosa names were reported: the illness of falling ("*isifo sokuwa*"), the illness of fitting ("*isifo sokuxhuzula*") and fits ("*ukuxhuzula*"). Only one participant said that epilepsy is also known as "sickness of fainting".

In the focus group interview, Xhosa names similar to those above (with the exception of fainting) were identified as names that are used interchangeably to refer to epilepsy. An additional name "*isithuthwane*", which is used by Zulu speaking people, was reported. Participants highlighted that these different names can lead to misinterpretation and confusion for those who are not familiar with them.

> Another one doesn't know when you say *isithuthwane* you mean the illness of falling but really you are talking of the illness of falling. Another one doesn't know when we say the illness of falling what do we mean? Then another one says he is fitting.… Again another one explains differently just like the names we have mentioned this way. [FGP]

Across all individual and focus group interviews, participants referred to epilepsy as "*lento*", which simply means "a thing". According to them, this use of "*lento*" reflected the fact that "epilepsy cannot be called by its name because it is a shameful illness".

The term "fainting" was further explored with participants who were asked whether fainting is another name for epilepsy. In response, they said that there is a difference between fainting and fitting and that fainting is an English word not a Xhosa word: "That fainting is not Xhosa … because when we talk of fainting that is not the Xhosa tongue … it's English" (FGP). To clarify the difference, two participants opted to explain fainting in their own African language. A Shangaan male participant explained that fainting in Xitsonga is known as "*sitsetsela*": "In Shangaan [Xitsonga] it is *sitsetsela* … yes. *Sitsetsela*. So fainting really, is when someone tells you something bad and you fall and you faint" [FGP]. Overall, participants seemed to distinguish between fainting (which they commonly seemed to view as stress-related) and epilepsy.

Presentation of Epilepsy

Regarding the question, "How does it work?" participants in individual interviews explained that it is difficult to understand how epilepsy works because: (a) it is not easily detectable, (b) seizures cannot be completely controlled, (c) seizures differ in duration and frequency, and (d) seizures are unpredictable and sudden.

> There are difficulties in understanding the illness because that illness is not an illness that is on the skin … [Female *umkhwetha*, aged 57]

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> Some people who do not understand this sickness .… They found that it comes and goes … because some of them they do a bit [fits are brief] and they become fed up because it keeps on coming … [Female *sangoma*, aged 66]

> You see … this thing is full of stories because sometimes while he is sitting like this … enjoying himself then all of a sudden he falls … [Male *sangoma*/herbalist, aged 67]

Participants further explained that there are certain warning signals prior to a seizure that their patients reported. This seemed to refer to an aura. Some patients experience "funny feeling in the stomach", "a throbbing sharp headache", "dizziness" or "an ugly cry".

> A person who has fits will hear it booming a lot in the stomach.… You will fall and fit like that… [Male *sangoma*/herbalist, aged 63]

> The girl that was here would say, "Mama here is this thing". I would say, "What do you feel?" She would answer, "It goes 'gungxu' (a funny sound) in the stomach.… Another one said he had that headache like there is lightning that happens.… When he is sitting with people he would give an ugly cry and then fall… [Female *sangoma*, aged 71]

> This one who feels themselves when they are about to fall sits down.… The other one will say they feel they are going to be dizzy. In fact that dizziness is when she's about to fit … [Female *umkhwetha*, aged 57]

An interesting common finding was that participants explained epilepsy as a "thing that is inside the body" which is recognized by a jerking of the body, turning of the eyes, foaming from the mouth, stiffening of fingers, urinating and losing consciousness.

Explanations of the Cause of Epilepsy

In their response to the question, "*What do you think is the cause of epilepsy*?" participants reported diverse biomedical and local cultural explanations of the cause of epilepsy in individual and focus group interviews.

Biomedical explanations included four broad subcategories:

i. blockage of the circulatory system, high temperatures, undiagnosed diabetes and stroke:

> The cause for a person to fit I can say it is veins … something in the veins get stuck then a person fits.… Temperature can be high.… The other would be having diabetes. Probably this diabetes hasn't been found yet, you find that they fit.… Another one sometimes they were about to be attacked by a stroke and fit from within [fitting from inside] … [Female *umkhwetha*, aged 57]

ii. Lack of immunization, unavailable immunizations, child asphyxia, birth trauma due to mal-presentation of the foetus and wound infections:

> This illness firstly it happens to a child … who didn't do well with those injections at the clinic.… Another one did not get that treatment of polio

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> and other things [other immunizations] properly from the clinic … or they ended [immunizations not available] so because of that your child is attacked with that illness … It may happen during childbirth … things that didn't come out properly … clogged saliva closed him he then suffocates and fits.… Sometimes a person is pregnant but the child is sitting wrong. … He comes out with a certain clot in the head at birth.… So I had another one with a big sore on the leg that doesn't heal.… This Mama arrived with that sore that was causing those fits … [Female *sangoma*, aged 71]

iii. Injuries to the brain:

> Some of them it's according to accident … he did bang his brain and the leakage goes in his brain. It's where the nerve started to shake. [Female *sangoma*, aged 66]

iv. Heredity:

> When others speak they say you get the illness because from your family in which you were born and there is someone who had the illness … [Male *sangoma*/herbalist, aged 67]

There were similarities and differences in biomedical explanations of epilepsy across interview types. Causes that were mentioned in the focus group but not individual interviews included: taking an overdose of seizure pills, poor adherence, dehydration in babies, haematoma due to internal bleeding, violence in old age, and parents not taking children who had accidental falls for early investigation.

> If someone has taken overdose of pills for epilepsy… Fits can be caused by lack of taking treatment when a person has epilepsy … when a child has lost water from the body.… You can get it from the family.… Epilepsy can be caused by accidents to the head and the clot stays in the brain … injuries when the baby … when the mother is giving birth.… When the baby falls accidentally by the head and is not checked … another one gets this baby in a way that is not right … or when we are sleeping the child falls we rub him and say, "No, it will be alright", but it stays in a person … [FGP]

On the other hand, causes such as high temperature, undiagnosed diabetes, stroke and infections were not mentioned by focus group participants.

Local cultural explanations—The most common themes that emerged in individual and focus group interviews were bewitchment, poison ("*idliso*"), evil spirits ("*amafufunyana*"), disobeying ancestors, punishment for moral transgression, witchcraft and African magic.

Participants believed that bewitchment could cause epilepsy. One participant related a practical example from his personal experience to illustrate what he believed caused his fits. He also said that he had fear and odd feelings in his stomach at the time of his first fit.

> I will talk about what has been happened to me … my uncle took off his shirt and gave it to me … his wife asked, "Why did you give it to him?" It didn't take a week

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> … it [fits] started. I was scared.… I see the shirt.… I feel a boom (sound) in the stomach and fall down … this thing amazed me.… They are shocked, the people I am going with.… A woman arrives and says, "What is happening with this child?" They say, "He just fell by himself." … "Did he urinate on himself?" They say, "No …" She says if it was the illness of fitting he would have urinated on himself.… I saw how illnesses come to people.… It was the one who scolded that I shouldn't be given the shirt … she had a bad heart. [Male *sangoma*/herbalist, aged 63]

Another participant reported that epilepsy can be caused by bewitchment which others refer to as "African magic".

> There is something they say is African magic. A person puts things inside of you and then once those things are inside of you they fight with your blood, they make you fit.… In another person they [things put inside through African magic] come and they talk … their talking then disturbs the bones … it's as if he is having a stroke … he fits on his side … walking painfully … [Female *sangoma*, aged 71]

The same participant further said that traditional healers' approach to treatment of epileptic fits that are believed to be caused by bewitchment/African magic was different because these fits do not operate in the same way as fits caused by other factors.

> So we [traditional healers] have different ways of helping since it comes in different ways you must first search.… How did it enter and how did you get it? Is there a certain clot disturbing him that is going up his back or it's in the brain or he was fed something inside? You must try and get that thing out. When that thing is out he will be able to live and become right.… We give him herbs that will make him powerful.… We stretch his muscles.… We send him to the doctor so that he can check this thing in the brain what is it … [Female *sangoma*, aged 71]

Another participant believed that her daughters' epilepsy was due to poisoning ("*idliso*"). She said that this was confirmed by another traditional healer with whom she consulted.

> From my knowledge I think that a person maybe ate poison.… It's what is said to be "*idliso*" [putting something evil in the person's food] that is done by people.… I have a daughter who has epilepsy … another person [the healer] that I send her to said that she was poisoned … she had been bewitched … witchcraft won't come to you seeing it … Maybe I will come to your house … you make me food and pour it [poison] in there [in the food]. I eat because I don't know what is in there … that's what the person [the healer] said happened to my child … [Female *umkhwetha*, aged 47]

This same participant elaborated further as to how bewitchment can cause fits.

> Sometimes it is jealousy … maybe your child is studying or is clever in school.… They see that they must put a spell on him [bewitch the child to cause suffering] … or your child works for you … they see that he is the one you live by at home … or you see something that you were not supposed to see with your eyes … that happens with fitting.… It is said "*welamile*" … you saw something you were not meant to see … [Female *umkhwetha*, aged 47]

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Another participant said that children could get epilepsy when parents did not obey their ancestors.

> When parents didn't follow their calling to be a healer and then that is why the child gets that kind of sickness [epilepsy] … [Female *sangoma*, aged 66]

An interesting discussion in the focus group interview, which was not mentioned in individual interviews, was about "*amafufunyana*" (Ensink & Robertson, 1996; Niehaus et al., 2004; Robertson & Kottler, 1993; Sorsdahl, Flisher & Stein, 2010); Swartz, 1998). Participants explained the phenomenon as a form of witchcraft and black magic. One participant clarified the meaning thereof and said that it can cause fits. The participant further elaborated on the approach to treat a person whose fits are caused by "*amafufunyana.*"

> Another thing, fitting sometime there is these things called "*amafufunyana*" … a person fits having *amafufunyana* … a "*fufunyana*" is something a person is bewitched with … then now it is easy you hold him while you hold him … burn something for him even if you take an old towel or old cloth. The more he inhales that smoke he becomes lower … you see him stop more and more … that is "*ifufunyana*" … [FGP]

As the discussion progressed, another participant further explained how others view "a*mafufunyana*" and that older women are usually thought to be responsible for performing such evil acts.

> Others say "*ifufunyana*" is a dirty medicine that is done by people who mix dirty things from the grave all those things … other times a "*fufunyana*" speaks on its own … you hear someone talks who has "*fufunyana*" and say, "It was put in by *gogo* [old woman] or Mama" like this thing that *Tata* [father] finishes explaining. … That shirt he was given … it just came. It just came … it's those kinds of magic … [FGP]

Another participant elaborated on the symptoms of "*amafufunyana*".

> When a person has "*amafufunyana*", you will see a person running away saying that he is chased by a train.… He is the only person who sees the train. You [the carer or healer] do not see the train. He [the patient] is the only one who sees it' … [FGP]

Views About Collaboration With Biomedicine

Most participants in individual interviews and the focus group interview were supportive of collaboration with biomedical services and provided examples of strategies for enhancing collaboration. One participant said that traditional healers have tried to initiate referrals between the two systems, but these could not be accomplished due to lack of recognition.

> We have been asking for referral letters so that we refer from traditional to doctors. Because we are not licensed yet.… I think that's why we haven't got the communication … [Female *sangoma*, aged 67]

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On the other hand, another participant emphasized that the collaborative approach must have formal agreements that incorporate freedom of expression and respect for the knowledge of traditional healers and western trained health care providers.

> Working together with the hospital is good … since the law is free … a person with the knowledge he has … can express it … this is what will make us to be able to respect each other.… There must be agreements … [Male *sangoma*/herbalist, aged 63]

All participants were of the view that collaboration is important because there are certain illnesses that either party cannot treat. In addition, they said that they could intervene where support was needed because patients' follow up appointments were often longer than a month apart, whereas traditional healers were always accessible.

> We could work together with them because there are illnesses [that we can't treat]. … Doctors will be defeated by this [illness caused by bewitchment] … the doctor will give an appointment for the next month.… I am always here … [FGP]

Discussion

In this study of traditional healers' views of epilepsy, healers provided several different terminologies referring to epilepsy, suggesting the potential for confusion and misinterpretation. Healers had a range of explanations that included biomedical causes of epilepsy as well as notions that epilepsy could be caused by bewitchment, witchcraft and "*amafufunyana*". They said that epilepsy in children could be caused by ancestors as punishment for their parents. Most were supportive of collaboration with western practitioners.

Previous studies in other parts of Africa have shown that the terminology for epilepsy varies among different population groups and cultures (Mugumbate & Mushonga, 2013; Millogo et al., 2004; Mushi et al., 2011). In our study, epilepsy was referred to as "*isifo sokuwa*", "*isifo sokuxhuzula*", and "fits". Reference to epilepsy as a fainting illness was consistent with findings from Tanzania (Mushi et al., 2011). In addition, "*isithuthwane*", which is a Zulu name for epilepsy, was also identified. These findings highlight the diversity of spoken languages in the study setting, which can affect the ways in which health care is accessed and engaged with. Language barriers pose many challenges, particularly in South Africa which has eleven official spoken languages, with most health care professionals being proficient in only one or two of these languages (Levin, 2007; Schlemmer & Mash, 2006, Watermeyer & Penn, 2009). Even when patients and providers are of the same ethnicity, they may use quite different idioms and terms for describing illness (Keikelame & Swartz, 2013a, 2013b).

The most common finding across all interviews was that epilepsy was referred to as a "thing", "*lento*". Participants explained that this was because epilepsy is a shameful illness and using "*lento*" is a way of hiding the illness. This view may reflect the stigma and secrecy that surrounds epilepsy (Baskind & Birbeck, 2005a; de Boer, 2010; Diop, de Boer, Mandlhate, Prilipko, & Meinardi, 2003).

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Many of our participants' explanations of the causes and descriptions of epilepsy were consistent with those of biomedicine, reinforcing the view that EMs do not exist in sealed-off, homogenous groups. There were also some anomalies, such as the belief that epilepsy is associated with lack of immunizations for polio and other conditions. Alongside biomedical explanations, local cultural explanations of the cause of epilepsy included bewitchment, witchcraft, poisoning and black magic. Similar findings have been reported in other studies (Baskind & Birbeck, 2005b; Kendall-Taylor, Kathomi, Rimba, & Newton, 2008; Mushi et al., 2011; Stekelenburg et al., 2005). Our participants used "bewitchment" and "witchcraft" interchangeably when they spoke about the cause of epilepsy. Ivey and Myers (2008a) distinguish between the two concepts. They state that witchcraft involves secretive and evil actions that use mystical powers to harm others or their property, while bewitchment is an epitome of evil magic, but this distinction did not seem to be held by our participants.

Our participants described "*amafufunyana*" as a form of bewitchment where "dirty things from the grave" are mixed and given to the person. This is also referred to as "ants of the grave" and is often used to refer to schizophrenia and psychosis (Lund & Swartz, 1998; Mzimkulu & Simbayi, 2006). Other authors state that "*amafufunyana*" is also referred to as "nerves" (Lund & Swartz, (1998). Its symptoms include, among others, aggression, fits, hysteria, anorexia, agitation and catatonia (Ivey & Myers, 2008a). Our participants explained that a patient whose fits were caused by "*amafufunyana*" would report hearing voices, seeing things that others do not see, and believing that an old woman is responsible for the illness. Witchcraft or sorcery is "*ubuthakathi*" in isiXhosa and is often performed by a witch, "*umthakathi*" (Thornton, 2013). Thornton states that bewitchment accusations are rife in South Africa even though legal protection is in place. As noted in the results, one participant believed that older women, "*gogos*," could be accused of witchcraft actions. These bewitchment accusations against older women were reported as a form of elder abuse and lack of respect for the elderly in previous research (Keikelame & Ferreira, 2000). Together, these findings suggest that older women who present with a history of fits should be examined for signs of such abuse.

Traditional healers explained epilepsy as "a thing inside the body." Some researchers in the field of psychology have suggested that the concept of "the thing inside" may be reflect what they term "the embodiment of bewitchment" (Ivey & Myers, 2008b, p. 83–84), wherein individuals who believe in and ascribe the cause of their illness to bewitchment may report feelings of odd sensations in the stomach. One participant in this study who had a personal experience of a seizure that he thought was due to bewitchment stated that he felt a "booming sound" in his stomach and fear prior to the seizure.

As in many other African cultures, in this group ancestors are believed to play a crucial role in the lives of their families by protecting them from misfortunes (Munthali, 2006; Ngubane, 1977; Hammond-Tooke, 1989; Thornton, 2013). In previous research, it has been reported that ancestors are believed to cause suffering in children when parents disregard them (Munthali, 2006). Our participants also explained that one cause of epilepsy in children is a lack of parental respect for ancestors. According to Janzen in Munthali (2006, p. 376), in other African cultures, misfortunes caused by ancestors do not require medications but can be treated by treatments referred to as "kinship therapy".

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The majority of our participants were supportive of collaboration with western trained health practitioners, consistent with findings reported by Pouchly (2012) in other studies conducted in South Africa. Traditional healers have been recognized as pillars of epilepsy care because of their ability to counsel patients and their position as custodians of culture (Winkler et al., 2010). In KwaZulu-Natal province in South Africa, a 48-bed hospital founded by a traditional healer uses traditional and western treatment for psychosocial disorders (Shizha & Charema, 2011). However, many challenges remain regarding the possibilities for collaboration in the health care system (Janse van Rensburg, 2009; Pinkoane, Greeff, & Koen, 2008). For example, sick certificates issued by traditional healers are not recognized. Our findings show that there are also referral and communication challenges. Regarding these challenges, our participants emphasized that collaboration must incorporate their right to freedom of expression of their indigenous knowledge and practice. The findings suggest that collaboration must be developed through a well-planned strategy that is based on inclusive participation, transparency and acknowledgment that the two knowledge systems, indigenous and bio-medical, can complement each other to achieve improved health outcomes (Campbell-Hall et al., 2010). Caution must be taken in view of strategies that may be interpreted as exploitative of traditional healers (Owusu-Ansah & Mji, 2013).

Limitations

Our study was limited by the small sample and the results cannot be generalized to the entire population of traditional healers in the study setting. There could have been a sampling bias because the field assistant who helped in recruitment of other healers was a member of the THO and may have recruited only those who were known to her. The first author was also known by some of the participants and this may have influenced their responses during the data collection. Bias in analysis and interpretation of the data also could have resulted from the authors' cultural and professional backgrounds, the first author's position as a board member of the local branch of the national non-governmental epilepsy organization, and her observations and informal conversations in the field.

On the other hand, because the focus group participants knew each other well, they were able to discuss contentious issues in more depth. Familiarity of participants in focus group interviews has been reported as a positive factor because it can enable active participation and openness in a non-threatening environment (Ulin et al., 2002). In addition, the focus group had some members who had been individually interviewed and this provided an opportunity to clarify and validate some issues from individual interviews (Flick, 2006).

Conclusion

The study of cultural factors in epilepsy needs to take into account local beliefs and practices, explanatory models of healers and patients, as well as the culture of the wider medical system. The participants provided both biomedical and local cultural explanations of epilepsy and also shared their perspectives on collaboration. Our study has implications for practice in terms of working collaboratively with these healers. First, there is a need for interventions that promote cultural literacy (Zarcadoolas, Pleasant, & Greer, 2006). Second, given the nature of the past exploitative experiences during colonization and a lack of clear

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guidelines on protection of traditional healers' intellectual property rights in the country (Ross, 2010), strategies and plans for collaboration must comprise formal agreements that embrace human rights. Traditional healers must also not be granted an inferior status because of their lack of professional qualifications in formal terms (Shizha & Charema, 2011). Collaboration requires a willingness to engage as equals with different areas of expertise (Rhodes, Small, Ismail, & Wright, 2008).

Part of the difficulty in this field is that traditional healers in South Africa have not yet received full recognition in western health care systems. In addition, the training of sangomas involves a process called *ukuthwasa*, which is undertaken over a number of years (Swartz, 1998; Thornton, 2009). According to Mlisa (2009), *ukuthwasa* is a religious phenomenon that is difficult for outsiders to grasp and is also an integral part of indigenous knowledge systems (IKS). In order to engage in respectful collaboration and relationships with traditional healers (Berg, 2003), health care providers need to be orientated towards a culture-centred approach (Campbell-Hall et al., 2010). Further research on the process of collaboration with traditional healers is urgently needed.

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