INTRODUCTION

Schizophrenia is a debilitating mental illness that affects people from all walks of life. Individuals attach meaning to their illness based on their cultural point of view. For some traditional black South Africans, causes of ill health are ascribed to culturally laden inferences. This study aimed to explore how black South Africans diagnosed with schizophrenia experience their illness from their cultural point of view. The study followed a hermeneutic phenomenological approach. In-depth interviews were conducted with three patients diagnosed with schizophrenia and on medication for their illness. Their stories were analysed using thematic content analysis. Five themes emerged during the study. Theme 1 related to “Naming Things”. The name given to their illness significantly affected the meanings that were attached to the illness. Theme 2 referred to “Being Without”. Losses as well as gains became apparent. Participants had lost their roles, independence and intimacy; however, they developed other coping strategies and some relationships became stronger. Theme 3 pertained to “Connections and Disconnections”. While participants were connected to their families and their community, they also felt disconnected due to the stigma perceived. Theme 4 was the theme of “Being Spiritual”. Spirituality played a vital role in how participants attached meaning to their illness, and it helped them to cope with challenges. Theme 5 was “Rainbow after the Rain”. The negative connotation of having a mental illness turned into personal, interpersonal and spiritual growth. The devastating illness became a gift to all participants; they demonstrated immense levels of resilience and they found their own way of being and relating. Culture played a crucial role during the initial stages of the illness; all participants sought spiritual help and it determined the meanings attached to the illness. This study proposes a need for mental health workers to explore the challenges that hamper openness within families and communities in order to lessen the perceived stigma experienced by the patients, and to acknowledge and encourage different coping and meaning-making structures, such as spirituality.

KEYWORDS Schizophrenia, patients, experiences, culture, Black South African.

Religion contributes immensely to the understanding and care of the mentally ill. The early Christian churches believed that mental illness was caused by demonic possessions and sacramental healing and exorcism was practised to heal the affected person (Huguelet & Koenig, 2009). Individuals diagnosed with mental illness reported that religion offers a sense of hope, comfort, love and compassion. However, some believe that their illness is a punishment from God, that their religious faith and practices are lacking or that they are being attacked by demons because they have sinned (Huguelet & Koenig, 2009). Most Africans perceive religion as fundamental to their lives and non-Africans at times misunderstand the spiritual view and beliefs of Africans (White, 2015). Religion has served as the structure around which all institutions such as cultural, economic, political and social organisations are built (Adeolu, 2003). However, White argues that urbanisation has resulted in the evolution of the African traditional religions.

There are reports that indigenous faith-based approaches to mental health remain marginalised within the healthcare system in South Africa (Mkhize, 2012). Studies in South Africa suggest that some Africans consider the soul as the seat of feelings; the mind is situated in the brain and is the initiator of action that is required for health (Mosotho, Louw & Calitz, 2011). Patients perceive the cause of their mental illness as dirty blood, bewitchment and bad luck (Motlana, Sokudela, Moraka, Roos & Snyman, 2004). Mufamadi and Sodi’s study (2010) also revealed that traditional healers identified some of the causes of mental illness as: ancestral dissatisfaction, witchcraft, untreated epilepsy, water in the brain and as heredity. Treatment ranged from herbs, ointments, rituals like uphasa to ritual dances. Traditional healers play a crucial role in the treatment of mental illness and they form part of the mental health multidisciplinary team at some South African institutions (Sorsdhal, Fisher, Wilson & Stein, 2010).

Saddock and Sadock (2014) describe schizophrenia as one of the most debilitating illnesses of the Western world affecting young adults. Schizophrenia starts slowly and progresses to a state where ambitions, potentials and hopes are destroyed. People with schizophrenia experience the illness as devastating and their future as unpredictable (McCann & Clark, 2004). Schizophrenia also redefines one’s identity (Estroff, 2004) and one has to adjust to the new role of being mentally ill (Brady & McCain, 2004). The disease leaves in its aftermath broken thoughts, inappropriate emotions and internal voices that often make existence a living hell (Saddock & Sadock, 2014). Johnson’s (2012, p 207) frustrations of living with schizophrenia are voiced as “a curse, this schizophrenia, because it has me asking questions… it has me questioning the basics of basics every 15 minutes over, and over again …”.

The stigma associated with the initial diagnosis of schizophrenia is perceived as a second illness which leads to social isolation, invariably adding to the experience of the illness (Schulze & Angermeyer, 2003). Some studies (Ruiz, Saddock & Sadock, 2014) show that the social characteristics of the patient and their family are related to the degree of the stigma perceived by those diagnosed with the illness and their family. After having disclosed their mental illness at work, some people diagnosed with schizophrenia have to deal with colleagues and employers who tend to comment negatively towards them (Lee, Lee, Chiu & Kleinman, 2005). Parents experience challenges in disclosing their illness to their children (Fox,
2014). These parents cite one of the difficulties as finding the appropriate moment to disclose the information as well as the fear that other people may perceive them to be unfit to parent.

Level of education seems to be associated with the extent of the concealment of the illness. Schulze and Angermeyer (2003) report on instances where friends drifted away from the ill person because they felt that they had nothing more in common with the person and that it was no longer easy to communicate. People perceive a psychiatric diagnosis as a stain on their reputation; therefore, they keep their psychiatric diagnosis a secret (Schulze & Angermeyer, 2003). Psychiatric diagnosed are therefore inclined to keep their condition a secret as they tend to internalise the stigma of their illness, resulting in reduced self-esteem and self-efficacy (Watson, Corrigan, Larson & Sells, 2007).

Given the above considerations, and bearing in mind that few studies have been conducted to document the views and perceptions of South Africans about the meanings attached to schizophrenia, this study explored how Black South Africans diagnosed with schizophrenia experience their illness from their cultural point of view. In doing so, it described the experiences of individuals diagnosed with schizophrenia and the meanings that they attach to their illness from their cultural point of view.

Methods
To gather in-depth information regarding these experiences and meanings, a method that allows in-depth probing and flexibility was chosen. Phenomenology is described as “a discipline that focuses on people’s perceptions of the world in which they live and what it means to them”, and was therefore the most appropriate approach for this study (Landridge, 2008, p.4). Hermeneutic phenomenology seeks to clarify the conditions in which understanding occurs and it is commissioned with putting forward specific procedures for understanding (Breakwell, Smith & Wright, 2012). Interviews serve specific roles in hermeneutic phenomenological studies; they are used to explore and gather stories of lived experiences and facilitate the development of a conversational relationship between the researchers and the participant (Ajjawi & Higgs, 2007). Englander (2012) perceives sampling as one of the most important processes in hermeneutic phenomenology as it forms a vital part of data collection. Through purposeful sampling, three individuals diagnosed with schizophrenia and receiving treatment from the Soshanguve Community Health Centre were selected to participate in the study. Pseudonyms were provided to protect their identities. Inclusion criteria were: Diagnosed by a psychiatrist and fulfil the DSM-V criteria of schizophrenia; Black and SeTswana or SePedi speaking; Have the ability to engage in a logical conversation and to express their experiences; Be 18 years or older and have the ability to provide informed consent. Participants included “Sindi”, a 41-year-old unmarried woman diagnosed with schizophrenia in 2003. She has an LLB degree and had just written her law board exams. “James” is a 55-year-old married male; diagnosed in 1984; he worked as a messenger before his diagnosis “Leseka” is a 57-year-old unmarried man diagnosed in 1995. He was living with his younger sister at the time and had worked as a farm labourer before his illness. Interviews were conducted at the clinic where they obtain their medication, and lasted one to two hours.

Data collection
All interviews were conducted in SeTswana, which is a language that the participants were proficient in and it is also the researcher’s mother tongue. Fersch, (2013, p 90) insists that translating the text from a foreign language poses an “extreme case of hermeneutic difficulty”. The conversations were audiotaped and transcribed after the interview. Transcripts also included significant non-verbal observations. All recordings were deleted after information had been obtained.

Data analysis
Thematic analysis was used to interpret the data, guided by the following steps (TerreBlanche& Kelly, 2009):

Familiarisation and immersion. The transcripts were read through repeatedly to extract the meaning from the stories.

Inducing themes. The stories were read again to determine the patterns or themes that emerged, and these themes were analysed for the possibility of alternative meanings.

Coding. Texts with similar meanings were grouped together. Different sections that were relevant to one or more themes were noted.

Elaboration. Themes were explored more closely in order to capture the nuances of meaning not captured by coding. Coding and elaboration continued until no further significant themes emerged.

Interpretation and checking. This is the final step, where the phenomenon under study was put together. Excerpts from the conversations were used to substantiate the themes. Contradictions were also noted.

Trustworthiness
Credibility in phenomenological studies depends on how vivid and faithful the description is to the experience that is being investigated (Laverty, 2003). The quality of a research study depends on the rigorous use of the systematic method of data collection and analysis, together with the transparency in documenting these (Ajjawi & Higgs, 2007). The use of anecdotes allows the themes emerging from the participants’ stories to be grounded in the data (Van Manen, 2006). Therefore, verbatim quotations were used during the discussion of the findings. The researcher also remembered her own preconceptions about psychosis from her black traditional perspective and noted how these influenced the trajectory of the questioning and comments during the interviews. This memory resonates with Morse, Barrett, Mayan, Olsen and Spier (2002, p. 10) argument that in hermeneutic phenomenological studies, “the research is only as good as the investigator”. This view is supported by Whitehead’s (2004) insistence on Heidegger’s notion of revealing one’s presuppositions to ensure sound textual interpretation.

Results
The five main themes extracted from the conversations included: Naming Things; Being Without; Connections and Disconnections; Being Spiritual; and The Rainbow after the Rain.

Naming things
From an African perspective, the names given to things play a crucial role in the meanings attached to the name. There is a SeTswana saying: leina lebe seromo; which is loosely translated as “a bad name is like an itchy rash”. All three participants attached meaning to schizophrenia according to what name they used for the condition. Leseka named his illness depression. He said: … they say … doctors here at Medforum … Not Medforum, at Louis Pasteur hospital … they said I must go to that hospital. They call it depression. Sindi mentioned that the traditional healer whom she had consulted earlier during her illness told her that she had mafufunyane (a culture-bound syndrome caused by bewitchment or spirit possession where a person’s behaviour is strange and unpredictable). However, Sindi preferred to call her illness being negative. She said: … and then I started being negative again. She added: I was so negative, thinking that people are conspiring against me. I didn’t speak to any of my family members. I was against any other, everyone. I would just hate
them. I didn’t face reality. She became paranoid and believed that people were out to get her. James named his illness bolwetse ba thlho, which is loosely translated as the illness of the head. He heard incomprehensible voices that were so debilitating that he had to isolate himself in an attempt to silence the voices. James controlled the noise in his head by keeping to himself. He stated that he felt better if he kept away from the outside noise. He claimed: “I think the main thing is that one should take care of oneself. One should avoid being in noisy places because that makes one feel bad.”

Being without

A diagnosis of schizophrenia brings with it significant changes in the lives of those diagnosed with the illness. All three participants experienced fundamental losses in most areas of their lives. This included loss of independence, loss of relationships and loss of roles. James felt that if he had not been ill, he would have been able to take care of himself. He said: “There are lots of changes… work … I haven’t been able to work since. Everything fell apart….” He is also convinced that his life would have been different if he had not been ill. He added: “I wouldn’t want to marry someone and not be able to provide for them. It wouldn’t be a good thing… If I was not ill, I would have been married and would have had my own house.” Leseka mentioned the loss of financial independence as being frustrating: “It disturbed me … eh … it interfered with my ability to continue work. I had challenges at work; it was really not nice. Sindi had to resign from her job due to her illness. She stated: “If I didn’t leave ESKOM, I would have been far in my profession. She added sadly: “I … my life would have been far, far, far away. Because I am still picking up the pieces … maybe I wouldn’t be here, I would be somewhere … I don’t know where…”

Relationships are also negatively affected by schizophrenia. James’s relationship with his father had been tarnished by his illness. I wish that someone could explain that … he knows … they have explained to him that I am ill. Mhm. He just doesn’t want to understand. The untenable situation between him and his father pained James but he expressed the hope that the relationship could be restored. Since his diagnosis, Leseka had lost his ability to perform sexually and he thought that his low libido was caused by the anti-psychotic medication that he was taking. It is in connection with … what is that thing … issues of sex. You see, sometimes my penis bothers me with … with … it does not get a good erection.

Roles also change due to schizophrenia. Sindi had to give up her role as a mother to her daughter as she was not coping with the responsibility of parenting during the earlier stages of her illness. She blamed her daughter for her illness and had thoughts of harming her. She recalled the earlier experiences: “I remember I wanted to strangle the child. I was … when I was staying with her, I was close to kill my child (sic). At the time of the study, she felt that her illness was under control and that she was ready to have another child. However, she was unsure if having a child would be appropriate. She expressed fear that the medication that she was taking for schizophrenia might negatively affect the child or that she might transmit her illness to her child. She said: “I think that perhaps the child will be born with … I … I think that the child might be born with some disorder.”

Connections and disconnections

The theme of being connected or disconnected to self and to others was apparent in this study. Being diagnosed with schizophrenia allowed two of the three participants to be connected with their families and their communities. James experienced both a connection and a disconnection with family and community. On the other hand, a neighbour understood his illness and was nurturing towards him. Others in the community, especially the youth, mocked him and made demeaning comments. He recounted: “Yes. People talk … they talk a lot. They say I am crazy; it hurts a lot when people say that about me. They are the ones that make me get all messed up; especially people in my home town. He furthermore added: “They were saying that I have a mental illness and I shouldn’t be staying in the community. They said that I belong and should stay in hospital.” He shared that his father never acknowledged his illness and the conflict between the two escalated to a point where connections were completely severed.

In contrast to James, Leseka’s relationship with his nuclear family improved and he became closer to his children and wife, as it was a space where he felt safe. He shared: “We sit together and read the Bible and discuss the Word of God, you see.” He recounted the role of the church: “We are getting a lot of support from the church. That is where we get our support. When asked who else was there for him, he answered: “It’s just me and my wife at home. His community ostracised his family and they blamed his wife instead of supporting the family. Sindi felt comfortable and supported by her partner; however, there was a pseudo-connectedness in her family. She experienced her family as having discomfort with her illness and no one in the family ever mentioned mental illness. She expressed the wish that her family were capable of openly talking about her illness as this denied her of the much needed support from them. The discomfort within the family influenced her behaviour outside the family system. She never disclosed her illness to the community around her or anyone who was known to her. She commented on her stance regarding disclosing: “I never disclosed publicly to people, I am still … I think I will feel embarrassed. She added: “I talk to somebody I don’t know and it is easy. Be ca use I won’t say … (sic) you see here in my community, I won’t say hey, I get a disability grant. But when I meet someone I don’t know, I am able to say, hey, I am here to draw my disability grant. I can tell someone who doesn’t know me. Sindi showed signs of paranoia as she believed that people were conspiring against her and she therefore tried to avoid contact with others. She resigned from work in an attempt to avoid the negative thoughts that she had, especially in relation to her work colleagues. She recalled: “I was so negative, thinking that people are conspiring against me. I didn’t speak to any of my family members. I was against any other (sic). Everyone, I would just hate them. I didn’t face reality.”

Being spiritual

Spirituality played an important role in the lives of all three the participants. Being spiritual enabled them to deal with the challenges of living with the diagnosis of schizophrenia. All three participants initially sought spiritual help to manage their illness; two consulted traditional healers and the third consulted a pastor. Sindi’s experience from the traditional healers was not positive: “You know, the witchdoctors have filled my mind with all the witchcraft stuff; they are still there.” She added that her mother called the pastors from church to visit them at home: “They prayed and prayed for me. But my mother said that she is happy that she took me to the hospital and I am healed.” She recounted her consultation with the second traditional healer, who recommended that her family seek medical treatment for her illness. “There are some things that the witch doctors are able to cure … I am not against them. But if you go to the witch doctors … you must know … you see. They took me to this other man and he told my family to take me to the hospital.” The healer stated that what Sindi had was mafufunyane (a culture-bound syndrome characterised by psychotic symptoms). This traditional healer further commented on Sindi’s condition: “He said even though the other traditional healer said it was amadlozi (ancestral spirits), this is not amadlozi … it is mafufunyane … He gave me a lot of things, he said I must burn them on the stove (hob). I must then inhale the smoke … Maybe to assist me to sleep or what.” James recalled his first visit to the traditional healer: “No, no, no. I
Prayer seemed to play a crucial role, and the belief that God would have been compliant since. The initial spiritual consultations were traditional medicine to drink. All three participants initially sought traditional healer that she was bewitched and she was given James was sceptical and was convinced that it was psychosocial traditional healer, who told him that he was bewitched. However, comfort, warmth and acceptance from the pastor. James consulted a he coped with the early stage of the illness. His family derived bewitchment. Prayers from the church had a profound effect on how spiritual factors. Leseka's illness was believed to be caused by stressors. All three participants attributed the cause of their illness to model for containing inner turmoil and coping with psychosocial (2014) argues that schizophrenia is a socially accepted explanatory ancestral dissatisfaction (Mufamadi et al, 2010; Sadock & Sadock Mkize, 1998), water on the brain, untreated epilepsy (Arnold & Roux, 2001). Many traditional black South Africans believe that schizophrenia is caused by bewitchment Mkize, 1998; Mufamadi et al, 2010; Sorsdal et al, 2010; Motlana et al, 2004) possession by evil spirits (Sorsdal, Fisher, Wilson & Stein, 2010; Mkize, 1998), water on the brain, untreated epilepsy (tsihafa) and ancestral dissatisfaction (Mufamadi et al, 2010; Sadock & Sadock 2014) argues that schizophrenia is a socially accepted explanatory model for containing inner turmoil and coping with psychosocial stressors. All three participants attributed the cause of their illness to spiritual factors. Leseka's illness was believed to be caused by bewitchment. Prayers from the church had a profound effect on how he coped with the early stage of the illness. His family derived comfort, warmth and acceptance from the pastor. James consulted a traditional healer, who told him that he was bewitched. However, James was sceptical and was convinced that it was psychosocial stressors that had caused his illness. Sindi was also told by the traditional healer that she was bewitched and she was given traditional medicine to drink. All three participants initially sought religion and spirituality to help with their illness; however, they later committed to taking medication as prescribed by a psychiatrist, and have been compliant since. The initial spiritual consultations were significant as it seemed to have contained the early and acute stage of the illness.

Prayer seemed to play a crucial role, and the belief that God would never forsake him made it easier for Leseka to make sense of his illness. However, all three participants were of the opinion that the treatment they had received from the hospital or the clinic was more effective in ameliorating the symptoms than the traditional medicine or prayer. The participants seemed53 to adopt the “both and” approach towards treatment of their illness as they needed to get an opinion from their spiritual practitioner first. Huguelet and Koenig (2009) argue that religion is a meaning system that guides one's perception and experiences, offers self- development and instils meaning, purpose and hope in the lives of those diagnosed with a serious mental illness. This “both and” approach is explained by Swartz (1998) as a complex and overlapping nature of people's healing systems, practices and beliefs. White (2015) notes that black Africans have a tendency of combining African beliefs and Christian beliefs. White further adds that urbanisation changes the way black Africans perform their traditional ritual practices. These changes in the practice of traditional ritual practices, which lead to changes in ancestral worship practices, emerge from changing social norms and economic status of black Africans (Wanamaker, 1997).

The theme of connectedness and disconnectedness highlighted the ambivalence that people diagnosed with schizophrenia experience. Despite the connections the participants were able to forge with their families and their communities, they at times needed to distance themselves (disconnect) from others to control the inner turmoil that arose from the schizophrenic manifestations. Estroff (2004) argues that schizophrenia overtakes and redefines one's identity, and the perception that one has of himself/herself changes according to the inner self and the new identity which is characterised by some incapacities.

Stigma plays an important role in how people who are diagnosed with schizophrenia connect with others. This stigma could either be real or imagined. According to Watson’s (2007) model of self-stigma, people with mental illness tend to internalise the stigma of their illness. However, Michaels, Lopez, Rusch and Corrigan (2012) argue that not everyone who is diagnosed with schizophrenia self-stigmatises. This study supports the assertion by Phelan, Broment & Link (1998) that people who mostly self-stigmatisate have college degrees. White (2015) argues that according to traditional life, we are part of a community and whatever happens to one, affects the whole community; I am because we are. In this study the family that was open and willing to be part of the community felt the most support from the community.

The names that these participants gave their illnesses revealed the meanings that they attached to their illness. The importance of naming things and the significance of language is apparent in how these individuals explained and named their illness. These everyday nuances are easily taken for granted and could easily be missed if one disregards how things are said. What we name things represents the meanings attached to those specific things. This notion is affirmed by Gadamer's opinion that thought and language are inseparable (George & Klijn, 2013). Schizophrenia as a label is perceived to stand in the way of healthy self-regard All three participants labelled their illness according to what the illness represented to them. The names given were: Being negative, depression and bolwetse ba mantswe (the hearing of voices illness).

Finally, this study revealed the different coping strategies that are used to deal with a debilitating illness such as schizophrenia. As noted earlier, spiritual rituals such as prayer formed an important practice which gave meaning to their suffering. Other coping strategies included disconnecting from family members and the community in order to silence the internal turmoil caused by the voices. Each family adjusted and adopted new ways of existing that fit their respective family structures. They had to deal with loss of financial independence, loss of intimacy and loss of being a mother.
This is consistent with Ruiz et al’s (2014) assertion that people with mental illness always find ways of managing and dealing with the changed self.

The study revealed that individuals respond to what is happening in their lives based on the social spaces in which they find themselves. The three participants in this study were not restricted by the dominant narrative which assumes that black South Africans ascribe the causes and treatment of ill health to religion or spiritual factors. They did what worked for them. The participants’ invitation to look into their “mirror” and witness their experiences revealed the resilience and the determination to normalise what had initially been a burden.

CONCLUSION

This study highlighted the burden that people with schizophrenia carry and the diverse repercussions of being diagnosed with the illness. The fluidity of culture has been apparent in this study as it was evident that these participants adopted the “both and” attitude towards their illness. Spirituality informed how these participants understood their illness and they also used it as a coping strategy, especially during the difficult stages of the illness. Participants also elicited a need for distance and closeness and this was determined by their perception of stigma, either real or imagined. The level of self-stigma in this study was the highest in the participant who also had the highest level of education. This study also highlighted the degree of resilience observed in the participants. They became more appreciative of the relationships they had with their family members and the community. The notion of “I am because you are”, which is the cornerstone of Ubuntu, was evident in the relationships that some of the participants were able to foster with others.

Recommendations

This study recommends that mental healthcare providers be aware of the challenges that stigma poses on those diagnosed with schizophrenia. Mental healthcare providers should facilitate the discourse about schizophrenia in families, which might improve relations and encourage openness within families regarding schizophrenia. All the participants reported that it took them a while to connect and build rapport with the psychiatric nurses, and the current state of staff rotation made it challenging for them to trust and open up to the mental health nurses about personal issues such as their sexuality and the stigma they perceived. Therefore, allocating permanent mental healthcare nurses in the clinic might improve relations and encourage openness within the clinic.

Finally, it is recommended that mental healthcare workers be made aware of the significance of spirituality in managing mental illness in patients diagnosed with schizophrenia, and that traditional healers and/or spiritual health practitioners be made part of the multi-disciplinary team in clinics.

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