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‘Whom will I give him to? I must carry the difficulty as it is mine’:

Psychosocial difficulties experienced by care givers of patients with epilepsy in an urban township in South Africa

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Abstract

Epilepsy has been reported as one condition that can cause psychological difficulties and distress to care givers of patients suffering from the condition. This study explored psychological difficulties experienced by lay care givers of patients with epilepsy in an urban township in South Africa. Nine individual in-depth interviews were conducted with lay carers who provide care to their relatives, friends and neighbours who have epilepsy. A thematic data analysis method was used. Some fears, social concerns and worries affecting caregiving were reported. Community interventions that promote cultural sensitivity in mental health care and empowerment of these carers are needed.

Keywords

epilepsy; fears; social concerns; lay caregivers; South Africa

Introduction

There has been acknowledgement that the social, psychological and behavioural aspects of epilepsy are the least understood and most neglected in epilepsy research (Hermann and Jacoby, 2009). These difficulties are not solely experienced by people with epilepsy (PWE) but also by carers (Birbeck, Chomba, Atadzhanov et al., 2008; Yusuf, Nuhu and Olisah, 2013). Epilepsy has been described as a condition that is characterized as an ‘*emotionally straining experience*’ (Ryan and Räisänen, 2012: 216), and can cause severe burden for PWE and their carers (Canuet, Ishii, Iwase et al., 2009; Schachter, 2006; Wang, Zhao, Wu et al., 2009). It is also clouded by myths and misconceptions about its cause and treatment which have been reported world-wide through many decades and in different population groups (de Boer, 2010; International League Against Epilepsy (ILAE), 2003). For example, religious

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Declaration of Conflicting Interests

None declared.

people in the 13th century attributed the cause of epilepsy to demonic spirits and thought that it was contagious and that it could be passed on to others through the evil breath of the person suffering from the illness (ILAE, 2003). These superstitious beliefs about its cause, including the stigma related to illness, are reported as factors that have worsened the burden of care (Baskind and Birbeck, 2005; Kabir, Hiyasu, Abubakar et al., 2005; Sidig, Ibrahim, Hussein et al., 2009). Because care giving involves emotional bonding, duty and guilt, and is often given under difficult contextual constraints such as inaccessible or unavailable resource in the community (Dada, Okewole, Ogun et al., 2011), carers are compelled to make adjustments to their different roles and responsibilities towards optimal care giving (Raina, O'Donnell, Rosenbaum et al., 2005). They also experience a range of difficulties in their care giving roles (Oshodi, Adeyemi, Aina et al., 2012) and have been reported as '*the forgotten patients*' (Nuhu, Yusuf, Akinbiyi et al., 2010). However, little attention has been paid to investigating the impact of epilepsy on family members and other informal carers (Karakas, Cole, Montouris et al., 2014; Saengsuwan, Laohasiriwong, Boonyaleepan et al., 2013).

Context

The South African Democratic Government has put in place policies to redress inequities caused by the past colonial rule. However, poverty, unemployment and marginalisation are reportedly increasing and have had a great impact on the health of the marginalised population groups (Pelser, 2004). This has also been exacerbated by the rapid increase in urbanization (Stern et al., 2010), the quadruple burden of communicable and non-communicable diseases (Mayosi, Lawn, van Niekerk et al., 2012). Currently, the government has introduced a financial system referred to as the National Health Insurance (NHI) scheme which aims to enable equal access to essential health care and measures for re-engineering the Primary Health Care Approach (Oni, McGrath, BeLue et al., 2014). With the increasing burden of non-communicable diseases (Stern, Puoane and Tsolekile, 2010), epilepsy has not yet received urgent priority, as other chronic illnesses have. Although it is assumed that approximately one in every 100 South Africans suffer from the condition (Ackermann and Van Toorn, 2011), accurate data is difficult to obtain (Eastman, 2005). Risk factors such as meningitis, HIV/AIDS (Eastman, 2005) and neurocysticercosis affect proper management of epilepsy (Eastman, 2005; Ocana, Sablon, Tamayo et al., 2009; Qekwana, 2013).

Linking this background to our study setting, which is one the oldest African townships in South Africa, established in 1927, the problems affecting the health of patients with epilepsy and their carers could be worse. First, the setting is characterized by crime, and alcohol and drug abuse (Naidoo and Irlam, 2005). Second, the current population is 52,401 of which 99% is Black African, with about 40.21% being unemployed with 72% of households receiving a monthly income of about R3 200.00 (US\$263.133) (Lehohla, 2011). Third, factors such as lack of knowledge about the illness, reluctance of people to engage in helping behaviours because of lack of familiarity with one another, lack of knowledge about available support services, illiteracy and language barriers all pose serious challenges in care giving and understanding of the illness (Keikelame and Swartz, 2013a, 2013b). Fourth, available epilepsy support services are currently inaccessible to the study population. Based on this, we were interested to explore the lay carers' perspectives on epilepsy and their

subjective experiences of caring for their relatives or friends who have epilepsy. Our objective was to analyse and describe these experiences and challenges associated with their care giving role.

Methods

Design and selection of participants

We used an exploratory qualitative design to explore subjective experiences of lay carers of patients with epilepsy and the challenges they face in their care giving role. This approach would enable us to gain insider perspectives in order to understand the carer's experiences of epilepsy in their natural setting (Babbie and Mouton, 2001; Patton, 2002). These lay carers are regarded as important sources from which everyday ideas about the illness, support and advice are sought and first-hand experience of suffering is gained (Kleinman, 1980 in MacLachlan, 1997).

Our recruitment process commenced after gaining ethical approval from the four local research ethics committees. The first author (MJK) was assisted by two Xhosa speaking field workers to gain access to participants. These field workers were rendering volunteer home based care services and were residing in the study setting. MJK recruited some participants from the local community health centre which provides health care for the study population. Some were recruited via snowball (Gerrish and Lacey, 2010) because of the difficulty in gaining access to potential subjects and possibly because of the secrecy associated with the condition

Our criteria stated that only Xhosa speaking lay carers aged 18 years and older who had provided care or were currently providing care to a family member, a friend or a neighbour who has epilepsy would be included. Participants were also included even if they did not live in the same household with the person with epilepsy. They also did not have to specify the amount of time that they spend on care giving. A total of 12 participants were recruited, of whom 2 declined and 10 agreed to participate. In all, 9 were females and the 10th one was a male – whose interview findings have been reported elsewhere (Keikelame and Swartz, 2013b).

Ethics

MJK visited all recruited participants at their homes to gain their informed consent to participate in the study. She was accompanied by a Xhosa speaking field assistant whose role was to interpret the consent information leaflets. To ensure that participants were not in any way coerced to participate in the study, they were all given copies of a signed informed consent form which they would use to consult with others if they wished to do so, and time to ask questions. Because of the sensitivity of the topic and the stigma associated with the illness, participants were given enough time (between one and two weeks) before the interview appointment to think about their rights and responsibilities and their choice and decision to participate or to withdraw. Only two participants declined and their decisions were respected.

Data collection

A semi-structured interview guide was constructed in English by the first author and translated into isiXhosa by a Xhosa-speaking language practitioner. Because MJK is conversant in isiXhosa and has been working among Xhosa speaking people for more than twenty years, she conducted all nine individual face to face in-depth interviews at participants' homes between July 2012 and February 2013. Each interview was audio recorded with participants' consent and lasted between 60–90 minutes. All interviewees were reminded of their right to participate and to withdraw. Prior to conducting interviews, MJK arranged with local field assistants to visit recruited participants three days prior to the interview date to remind them of the set appointment date and time, because all of them did not have telephones. Each participant was given a R60.00 (\$10 US dollars) food voucher at the end of the interview as a token of appreciation for their time and for sharing their valuable personal information to enhance the purpose of study. MJK made notes of the conversations before and after the interview and extended them after the interview. These also included both authors' reflections which were later used in the data analysis process.

Data analysis

We used the thematic analysis approach described by Braun and Clarke (2006) to analyse the data. All audio-recorded interviews were transcribed verbatim from isiXhosa into English by a Xhosa speaking transcriptionist. MJK read all transcripts several times to get a whole sense of the data and also listened to audio recorded data to ensure that the transcribed data captured the actual responses expressed by participants. Our approach to data analysis was inductive and involved familiarizing ourselves with the data, generating data driven codes and themes and reviewing, defining and naming themes to give meaningful explanations of the data and to provide a clear sense of what the theme was about. Thereafter, the main key themes that were identified from the data were organized into tables and grouped into appropriate categories with quotations from transcripts and were compared for similarities and differences. This organization enabled further in-depth analysis of themes to ensure that they were grounded in the data. During our regular feedback and debriefing meetings, we increased rigor by discussing, comparing and contrasting our codes and themes to gain consensus and to reflect on how our orientations might have influenced our data analysis (Adams, McCreanor and Braun, 2013). Thereafter, MJK visited each participant to confirm and to verify the findings to ensure that our analysis was consistent with what they had said (Flick, 2006; Ulin, Robinson, Tolley et al., 2002).

Results

Participants' demographics

Nine female participants were individually interviewed: Four had husbands/partners who have epilepsy. Two parents had adolescents who had epilepsy. One sibling had a sister who had died from epilepsy and two were volunteer carers. All belonged to different religions and only five were unemployed. Seven were receiving government grants. Their demographic background is presented below in Table 1. A summary of the type of carers and background information about their care recipients is provided in Table 2 (Appendix 1).

From our analysis of the nine interviews, seven key themes emerged. Because we were interested in the kind of fears that these carers reported, we will therefore provide key findings on two main themes which are central to this paper: (i) Carers' fears about the person's illness (epilepsy); and (ii) Carers social concerns and worries about caring for a person who has epilepsy.

Carers fears about the person's illness (epilepsy)—Participants provided a range of fears which they had about their relative or neighbour who has epilepsy. Partners/wives expressed fear of dying during a seizure attack, and fear of dying as a result of road accidents and from bewitchment/witchcraft related causes. Siblings' fears were related to fear of dying from the illness; fear of dying due to the course of the illness; and fear of genetic disposition to epilepsy. One parent had fear of road accident deaths while a volunteer carer had fear of contagion. These themes are discussed under the following subthemes:

Fear of partner dying during a seizure

We had four participants whose husbands/partners had epilepsy. However, in our analysis of their responses, we found that only two reported on three types of fears that they had about caring for their husband/partner.

One participant whose partner had epilepsy reported that she feared that her partner would die during a seizure attack. This participants' partner was 62 years of age and his epilepsy started in 1967. As articulated in her quotation below, we noted that the participants' fears may have stemmed from what she had heard from others or that she may have personally witnessed a person who actually died during a seizure attack. We also noted that besides her fears, she had strong religious beliefs which helped her to cope and to be hopeful that her partner would be relieved from suffering as a result of his epilepsy.

Things which I fear about fitting it's close to him waking up and it's close to him not waking up [fears that he may die during a fit] ...because with other people, the person fits and they never wake up again...but you must not be without hope. In everything you must let God lead the way and say God is there and He will make him stand... [Partner, #01, aged 54]

Fear of husband dying from road accidents

Another participant, whose 45 year old husband had epilepsy since 1989, reported that she feared that her husband may die as a result of road accidents:

I have a fear that he would die while he is driving...that he'd collide and get an accident... [Wife, #01, aged 39]

Fear of husband dying from witchcraft related causes

Only one participant stated that she feared the cause of her husbands' epilepsy was due to poison or demons (amafufunyana) – which apparently would cause harm to her husband's body and that her husband would eventually die as a result thereof. She reported that they were informed about the cause after consulting with some traditional healers for her husband's epilepsy:

The thing I fear about his illness is that as some traditional people said that it is poison or a demon (fufunyane)...it eats a person from the inside... So now I am afraid that he'll end up dead... that's what I am afraid of... [Wife, #01 aged 39]

Fear of child dying from road accidents

We had two parents who had adolescent children who had epilepsy. One parent was 42 years of age and had a 25 year old daughter who had epilepsy which started in 2001 when she was still attending school. The 62 year old parent's son was 23 years old and had epilepsy when he was seven years old, and is currently not attending school nor employed. However, only the parent whose daughter had epilepsy stated that she feared that her daughter may die as a result of road accidents:

I am afraid that one day I will be called and they will tell me that she has been hit by a car... I really worry, especially when she is going to school because she crosses the road..., taxis and all those things... [Parent, #01, aged 42]

Fear of dying from the illness and its course

We had one participant who was 55 years of age and had a sister who had epilepsy when she was seven years old and died from the illness in 2007, when she was 60 years old. She stated that she had fears about the illness itself and that a person may die from the illness because of its long course. We assume that these fears stemmed from her experience of her sister's illness and probably because of poor seizure outcomes:

I fear the illness [epilepsy] because I take it a person who has it doesn't live long... He /she fits until you see his/her life ends...we had hope that our sister would still be alive but she went with that illness... [Sibling, #01, aged 55]

In addition, this participant was of the view that her family could be susceptible to epilepsy because it runs in certain families. This perception therefore accounted for her family having fears that they may have a genetic disposition to the illness:

We had fear because we thought that it will be a sickness of the family because there are family sicknesses... [Sibling#01 aged 55]

Fear of contracting epilepsy

There were two participants who were volunteer carers. One was 39 years old and the other one was 35. One reported that she provided care to her neighbour's daughter who has epilepsy, while the other one was providing care to an older man who was her neighbour who also had epilepsy. Only one volunteer carer reported that she feared 'belching'. This perception is of concern since her fear may affect the way she responds to a person during a seizure attack:

I fear belching...you will pick it up... you must be alert that he does not belch towards you. [Volunteer carer, #01, aged 39]

Carers' social concerns, fears and worries—In our analysis of our participant's interview data, we noted that while they talked about what they feared most

about the illness of the person they were caring for, they also talked about some social concerns which accounted for their fears and worries. Four talked about stigma related actions towards their relatives who had epilepsy. Only one talked about her concerns with regard to her husbands' aggressive behaviour after a seizure. These are discussed below under the following sub-themes:

Fear of stigma

One parent was concerned about her 25 year old daughters' social participation and safety in sports. She said that she was not keen to allow her daughter to participate in sport because of fear of unpredictability of her daughter's seizures and that her daughter may be excluded from participation when others realize that she has epilepsy. This may show that this parent might be keeping her daughter's condition a secret:

I am afraid for her in everything, because this thing just happens when she is not expecting it...she likes sport but I am afraid for her... It is always with me that she might be playing some game and fall...other people won't understand, and maybe they will want to exclude her because they don't understand that she has this disease... [Parent; #01, aged 42]

Another parent whose 23 year old son had epilepsy was concerned about her son's friends who ridicule him about his condition and this caused her emotional pain:

There are many worries because wherever he goes you are concerned whether he has not fallen...and when you get there...he has lost his things because all those who helped him know about his illness and before he recovers they steal his cell-phone and money...things like that worries me...Another thing that really pains me...he has friends who when he has an attack, they ridicule him and insult him because of this. It hurts me... [Parent, #02, aged 62]

On the other hand, a volunteer carer who provided care for a neighbour whose 25 year old daughter had epilepsy stated that she had fear of stigma related actions towards school going adolescents. She said that she worried because some could not continue with their schooling as a result of being prejudiced by their peers. She was of the view that there should be interventions at schools to destigmatize the condition:

I fear it [fear of epilepsy] when it comes to adolescents of about 18 years...you see when they have fits their peers laugh at them... I worry about them... some even leave school because of those things because a child feels embarrassed at school and becomes a laughing stock of the whole school... I wish the education about epilepsy should also be directed at youth and to school children... [Volunteer carer, #02, aged 35]

In addition, one participant who had a partner who has been having epilepsy since 1990 highlighted her concerns on how her partner had been stigmatized by his family because of having epilepsy. She stated that her family excluded him from participating in family affairs and has been labelled as someone who is probably mentally ill or mentally challenged. According to her, her partner's exclusion causes her emotional pain. In our interpretation,

we were of the view that this may be painful for her since, as an African man, he may not be able to fulfil his roles as expected from his position:

My worry and concern is that he [the partner who has epilepsy] is not staying well at his home... to his mother he is not like her son at all because he is not treated well... Let me give you this example: Say you are my mother... and you don't care about me, even when others eat... when food is served I am not served, even during discussions they don't call me... I am ignored... When there is a count, others will be counted and I won't be counted. When Nosi asks: "What about him?" They'd say, "Just leave him, can't you see this person is not alright! All those things hurt..."
[Partner, #02, aged 53]

Worry about husbands' aggressive behaviour

A very disturbing social issue was reported by one participant whose 62 year old husband had epilepsy since 1981. She stated that her husband was behaviourally aggressive after a seizure. She reported that his behaviour was characterised by severe anger which led to violence. According to her, this had a negative impact on the family. Although the family sought assistance, those who intervened thought that there were domestic violence issues. However, she was of the view that the husband's behaviour was due to epilepsy. We assume that those from whom she sought support had poor knowledge about the illness or ineffective counselling skills. This could have probably resulted in the family adopting perseverance as a coping strategy:

My worry is that, after he fitted he becomes stubborn... we argue very easily... children then say 'Mama leave him because we already know him.' You see if he is waking up [recovering from a seizure]... he is dangerous sometimes... even a child, grandchild, makes him angry... He is short tempered... When he is angry he takes a sharp object and stabs me with it... It is like he sees something sort of like a witch... a person who will hurt him... if I called them [police] this week they would arrive and warn him, 'Tata you are old. Don't do this'... they don't know there is an illness at the centre... They are looking at domestic violence. They are trying to stop that... we just think for ourselves that it's his illness... we persevere.
[Wife, #02, aged 54]

Discussion

The findings of this study provide insights into the psychological difficulties and social concerns of caregiving for patients with epilepsy. Our carers were spouses, siblings, parents and those who do volunteer care work. We found that our participants expressed a variety of the kind of fears that they had about caring for their relatives or neighbours who had epilepsy. Fears of seizures have been reported as a difficult experience for patients with epilepsy and their carers (Saengsuwan, et al., 2013; Arthurs, Zaveri, Frei et al., 2010) – and that they can also increase care giver stress (Cushner-Weinstein, Dassoulas, Salpekar et al., 2008).

Among our participants, there was only one sibling who had fears about dying from illness, heritability thereof and fear of its course. Although this fear was expressed by this sibling,

Dunne (2013: 15) reports that most people who have epilepsy do not necessarily die as a direct result of their illness. We were of the view that her fears about the illness could be related to poor seizure outcomes and probably lack of knowledge about the illness. Our findings about fears of the illness and its long course were consistent with those reported by Ellis, Upton and Thompson (2000). With regard to heritability of the illness, it was interesting to note that this finding has been reported as one of the concerns among patients with epilepsy whose seizures were poorly controlled (Choi, Lee, Jo et al., 2011). Others have reported that epilepsy has been regarded as a family illness and that it has a high heritability which is assumed to increase with age (Kjeldsen, Kyvik, Christensen et al., 2001).

Epilepsy stigma has been well documented (Admi and Shaham, 2007; Baskind and Birbeck, 2005; de Boer, 2010; ILAE, 2003; VanStraten and Ng, 2012; Viteva, 2013). Our findings with regard to stigma related actions towards patients with epilepsy are consistent with literature. For example, stigma related actions towards adolescents such as bullying, being laughed at, and being treated differently, have been reported by Kerr, Nixon and Angalakuditi (2011). These authors further report that as a result of these actions, some parents restrict their children to stay at home— partly to protect her from being stigmatized— and also because of the unpredictability of the seizures (Ahmad, 2011). Some of these findings were also reported by Keikelame and Swartz (2007) in their study exploring parents' understanding of their children's epilepsy in Cape Town.

There were some cultural myths regarding fear of contracting epilepsy through belching. We noted that this finding was also reported by another lay carer in the same study setting (Keikelame and Swartz, 2013b). This finding is of concern since such misperceptions can increase stigma towards patients with epilepsy and may also lead to inappropriate helping behaviours when a person has a seizure attack.

An interesting finding reported, though, was about fear of bewitchment related causes (ufufunyana). Authors reporting on bewitchment highlight witchcraft related causes which are evil acts that are performed by witches and can cause harm and death (Bührmann, 1992). *Amafufunyana* or “ants of the grave” is a term that is often used by Black psychiatric patients to refer to schizophrenia and psychosis (Lund and Swartz, 1998; Mzimkulu and Simbayi, 2006). Writing about the psychology of bewitchment and the experience thereof, Ivey and Myers, 2008 highlight that symptoms of amafufunyana include, among others, aggression, fits, hysteria, anorexia, agitation and catatonia. We are of the view that this participants' fear of bewitchment could probably be linked to some psychological symptoms that this carer may have witnessed in the process of caring for her husband who has epilepsy.

One disturbing finding was about behavioural difficulties as a result of epilepsy. A study done by Ito, Okazaki, Takahashi et al. (2007) reported on sub-acute postictal aggression in patients with epilepsy. These authors reported that this aggressive behaviour was found in one male who was 62 years of age who threatened to beat his wife with a bamboo stick – and showed remorse after the aggression had ceased. Our findings show that similar symptoms were reported by our participant whose husband was of the same age. This finding is of serious concern, more so that witness description on routine clinical

investigations in primary care settings in Cape Town has been reported to be poor – thus inhibiting doctors in making a proper diagnosis (Keikelame, Hills, Naidu et al., 2012). Therefore, presenting symptoms such as these may be missed if carers do not have knowledge about epilepsy and when they are not adequately counselled about the illness.

Despite these psychological difficulties and social concerns, we noted that wives/partners used coping strategies such as ‘being hopeful that God will solve or change the situation’, ‘by perseverance’ and ‘endurance’. While spiritual or religious coping may be used to deal with stress– this may be a negative step when a person holds ‘beliefs in a punitive God’ and delegates God to solve one’s problems (Tedrus, Fonseca, De Pietro Magri et al., 2013: 386). We also noted that these women remained in the relationships despite these issues and that perhaps their strategies may be revealing their lack of power and capability to address the difficulties and concerns they had.

Limitations

Our data was drawn from a small cohort of carers and cannot therefore be claimed to be representative of the entire population. We recruited participants from only one study site in an urban township in Cape Town which is predominantly Xhosa speaking. The results can therefore not be generalised to the care givers of Xhosa speaking patient with epilepsy in other urban townships. Some of the family members did not want to participate in the study. As such, their perspectives on the illness have not been captured. The importance raised by participants of broader social factors in care and illness does however resonate with other studies of illness and caregiving in similar contexts (Kagee, Remain, Hoffman et al., 2011; Kagee, Swartz and Swartz, 2014).

Conclusion

Our study provides a glimpse of some psychological difficulties and social concerns of lay carers (wives, partners, sibling, parents and volunteers) who provide care for their relatives, friends or neighbours who have epilepsy. While these findings are from participants in one of the oldest urban settings in Cape Town, they suggest that there are some socio-economic and cultural mediating factors which affect their care giving role –especially since managing epilepsy has been reported to have a great impact on care givers (Ramagalia, Romeo, Viri et al., 2007; van Andel, Westerhuis, Zijlmans et al., 2011). A number of coping strategies that can help care givers have been reported (Oshodi et al., 2012; Wagner, Smith, Ferguson et al., 2010). However, it would be important that careful consideration should be taken to ensure that they are designed to meet specific needs of carers. The study findings provide insightful information which adds to the body of existing knowledge, especially on the importance of designing appropriate interventions for promoting cultural sensitivity in mental health care.

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Table 1

Summary of individual participants' characteristics

Type of Carer-N=9	Age	Religion	Education	Employment	Income
Wife, 1	39	United Presbyterian	Grade 11	Full time	Child support grant
Wife, 2	54	Methodist	Grade 7	Part time	Child support grant
Partner, 1	54	Zion	Grade 8	Unemployed	Disability grant
Partner, 2	53	Assemblies Missionary	Grade 8	Unemployed	Disability grant
Parent, 1	42	Baptist	Grade 10	Unemployed	Child support grant
Parent, 2	62	Methodist	Grade 7	Pensioner	Pension grant
Sibling, 1	55	Dutch Reformed	Grade 12	Full time	
Volunteer, 1 carer	39	His People	Grade 11	Unemployed	Selling goods
Volunteer, 2 carer	35	Zion	Grade 6	Unemployed	Child support grant

Table 2

Summary of types of carers and background information about care recipients

Carer and age	General information
Partner, 1, aged 54	She cares for her partner aged 62, whose epilepsy started in 1967, and her niece, aged 27, who has had epilepsy since 2004. She has four children and two are attending school. Her partner receives a government pension grant and she receives a disability grant. She earns extra income from selling clothes. She attends the Zion Church and passed grade 8.
Parent, 2 aged 62	Her son, aged 23, has epilepsy, which started when he was seven years old and is currently not working. She was married and her husband died. She passed grade 7 and worked as domestic worker – but has since retired and she now receives an old age pension. She attends the Methodist church.
Partner, 2 aged 53	She has been living with her partner who has epilepsy for 38 years, and one son, aged 38 years. Her partner has been having epilepsy since 1990. She passed grade 8. She had stroke and is now receiving a disability grant. She attends the Gospel Missionary Assemblies Church.
Wife, 2 aged 54	Her 62 year old husband has had epilepsy since 1981. They have three daughters aged 21, 18 and 17 who are attending school. She is employed as a domestic worker and attends the Methodist church. She passed grade 7. Her husband receives a government pension grant. She also receives a child support grant for one grandchild.
Volunteer carer, 1 aged 39	She is married and has two children aged 22 and 14. She passed grade 6 and has been caring for a male neighbour, aged 56, who has epilepsy. She has not received any training in home based care. She earns income through sewing and selling goods. She attends the Zion church.
Volunteer carer, 2 aged 35	She cares for a neighbour's daughter who has epilepsy. She is unmarried and has a 14 year old child and receives a child support grant. She worked as a volunteer carer in one of the NGOs which rendered hospice care for HIV/AIDS and cancer patients for 5 years. She passed grade 11 and attends His People Church.
Sibling, 1 aged 55	She had an older sister who had epilepsy when she was seven years old and died from the illness in 2007, at the age of 60. Her sister had three children who are now under her care. She is a member of the Dutch Reformed Church and passed grade 12. She is currently working as a quality control checker in one of the factories. She has one child aged 30 years old and a four year old grandchild.
Wife, 1 aged 39	Her husband, aged 45, has been having epilepsy since 1989. The husband works in a factory and she works as a cleaner in one of the hospitals and passed grade 11. She has three children aged 10, 8 and 2, and two are attending school. She attends the United Presbyterian Church. She also receives a child support grant.
Parent, 1 aged 42	She is unmarried and has 4 children aged 25, 16 and seven year old twins. She passed grade 10 and was a volunteer carer for two years. She is currently unemployed but runs a child day care and receives a child support grant. She attends the Baptist Church. Her 25 year old daughter has epilepsy which started in 2001 and has left school because of her illness.

NGO: non-governmental organisation