

# Social Work/Maatskaplike Werk

**A professional journal for the social worker**

w: <https://socialwork.journals.ac.za/pub> e: [socialwork@sun.ac.za](mailto:socialwork@sun.ac.za) eISSN: 2312-7198 (online)

Vol. 60, No. 2, 2024

DOI: <https://doi.org/10.15270/60-2-1299>

## WE NEED SUPPORT: THE EXPERIENCES OF FAMILY MEMBERS CARING FOR A RELATIVE DIAGNOSED WITH SCHIZOPHRENIA

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Article received: 15/05/2023; Article accepted: 04/10/2023; Article published: 14/06/2024

### ABSTRACT

Family members living with and caring for a relative diagnosed with schizophrenia may experience severe challenges that can result in secondary stress and influence various life domains. This article is based on a study which aimed to explore and describe the lived experiences of these family members. The study applied a qualitative research approach with phenomenology as the strategy of inquiry. The study implemented voluntary snowball sampling to select participants for the study. Data collection consisted of unstructured interviews followed by thematic analysis to establish the findings of the research. These findings specified the challenges experienced by family members caring for a relative with schizophrenia. The findings also indicated the social support and social work interventions which can mitigate or prevent the adverse effects when family members care for a relative diagnosed with schizophrenia. Effective and comprehensive social work services, which are family sensitive and inclusive, are imperative. Active engagement with both the family carer(s) and relative diagnosed with schizophrenia can contribute to minimising these adverse effects.

**Keywords:** carers; deinstitutionalisation; family members; mental health; schizophrenia; social work

### INTRODUCTION

Mental disorders are one of the significant contributors to the global burden of disease (Chhipps *et al.*, 2015). The global prevalence of mental disorders is evident from the approximately 970 million people who suffer from the condition (World Health Organization, 2022). Yet mental disorders are not a priority in the public health context, especially in low- and middle-income countries (Abouzahr & Boerma, 2009). It is estimated that twenty-five percent of the South African population have mental health disorders (Swartz *et al.*, 2006) and almost a third of the

South African population have experienced a common mental disorder in their lifetime (Stein *et al.*, 2018). There is also a significant gap in treatment of mental disorders in South Africa as only one in four individuals with a common mental disorder receives any treatment (Petersen *et al.*, 2015).

## **SCHIZOPHRENIA**

The estimated global prevalence of schizophrenia is between 21 to 29 million people (Chen *et al.*, 2016; Ritchie & Roser, 2018). The estimated prevalence of schizophrenia in the African context is four to five million people (Purgato, Adams & Barbui, 2012). The literature on schizophrenia in South Africa indicates that one in every hundred people in South Africa may have schizophrenia (Albert, 2015). A rapid review report conducted by Davies *et al.* (2019) found that there is a high burden of mental disorders in the Western Cape. Furthermore, a psychiatric facility in the Western Cape reported high numbers of admissions of schizophrenia patients in comparison with other mental disorders (Jacob, 2015).

The personal, social and professional functioning of people with schizophrenia is severely affected and it is therefore acknowledged as one of the most devastating mental disorders (Habibi, Nayer & Zadeh, 2015; Rafiyah & Sutharangsee, 2011). A person diagnosed with schizophrenia may experience impairment in thought processes, which influences their behaviours and may result in conflicts that severely affect the family structure and order (Chen *et al.*, 2016; Ritchie & Roser, 2018). Schizophrenia affects a person's ability to remain independent in the various domains of psychosocial functioning; it affects the person's ability to perform their daily activities and engage with others. It also negatively influences the person's functioning at work, school, in parenting, self-care, independent living, interpersonal relationships and leisure (Khan Martin-Montañez & Muly, 2013). These impairments mean that there is a need for long-term support and care in patients with schizophrenia by families and caregivers, which may become a burden (Adeosun, 2013).

## **DEINSTITUTIONALISATION**

A policy of deinstitutionalisation from mental health institutions in South Africa led to significant challenges in the mental health care of people with mental disorders. This policy (Republic of South Africa, 2013) posited that patients in governmental mental health institutions should be discharged and that community-based services must be provided. This created the need for care from families and non-governmental organisations (NGOs). The outcome of this policy contributed to the discharge of 1,711 people with severe mental disorders and profound intellectual disabilities from governmental mental health institutions into the care of their families and NGOs between 2015 and 2016. Family members who then become the primary caregivers of a relative diagnosed with schizophrenia face a number of challenges, because they lack knowledge of mental disorders and they receive limited information and support from health care providers. They therefore, experience a significant burden in caring for a relative with schizophrenia (Azman, Singh & Sulaiman, 2019 Lippi, 2016). It is also evident that there are insufficient community mental health resources to assist families and mitigate the burden of care as proposed in the policy of deinstitutionalisation (Lippi, 2016).

## BURDEN OF CARE

The burden of care when caring for a person diagnosed with schizophrenia can lead to depression and anxiety, with 50% of family members/carers developing psychological problems of their own, to the extent that they also need help and support (Azman *et al.*, 2019). These ensuing psychological problems also have an impact on the independent living, productive activities and social relationships of family members (Galderisi *et al.*, 2014; Hsiao & Tsai, 2014). Families reported changes in household routines, disruption of family life, a decline in family relationships, and additional roles and responsibilities when caring for a relative with schizophrenia (Adeosun, 2013; Lippi, 2016). These authors contend that such changes negatively impact the health of family members, who experience fatigue, which in turn results in chaotic lifestyles and poor self-care when they have to care for and deal with the problematic behaviour of the relative with schizophrenia.

Families caring for a relative diagnosed with schizophrenia experience two types of burdens of care: objective and subjective burdens of care (Lasebikan & Ayinde, 2013). The objective burden of care affects the health of caregivers and leads to disruption of family life in domains such as work, leisure, family relations, social activities, social relations and family leisure (Igberase *et al.*, 2012). In addition to these objective burdens of care, family members experience problematic behaviours from relatives such as violence, threats of suicide and non-adherence to treatment. These disruptions exacerbated family members' experiences of practical problems which they experience daily when caring for these relatives. These daily practical problems include the financial burden entailed in caring for a relative diagnosed with schizophrenia; this results in reduced household income, which affects impoverished families particularly severely (Panayiotopoulos, Pavlakis, & Apostolou, 2013). Families often have to pay for out-of-pocket medical and other related expenses. Studies by Chan (2011), Lippi (2016), and Marimbe *et al.* (2016) reported that even though medication is provided without financial costs from governmental hospitals, some of the medication is often unavailable at these facilities and families then have to buy medication from the private sector for their relatives. The financial burden is exacerbated by the influence of care on the caregiver's employment. Often, caregivers cannot work full-time (Özden & Tuncay, 2018), abandon employment opportunities or reduce their working hours to spend time caring for their relatives (Ndetei *et al.*, 2009; Sabanciogullari & Tel, 2015). Family members often struggle to balance work and care responsibilities with consequent poor work performance and attendance (Caqueo-Urízar *et al.*, 2011; Stanley, Bhuvaneswari & Bhakyalakshmi, 2016). Furthermore, the responsibilities of caring can impact the mental and physical well-being of the carers themselves (Adeosun, 2013). Research found that there is a correlation between negligence of caregivers' mental and physical well-being, their experiences of mental exhaustion, a chaotic lifestyle, poor self-care and the risk of developing mental disorders themselves (Caqueo-Urízar *et al.*, 2017; Lippi, 2016; Riley-McHugh, Brown & Lindo, 2016; Stanley *et al.*, 2016).

The second burden of care is subjective, which refers to "the extent to which the caregiver experiences distress as a result of their caregiving role" (Igberase *et al.*, 2012: 32). The subjective burdens or "stressors" consist of the negative psychological impact on the caregiver and includes feelings of loss, depression, anxiety, anger, sorrow, hatred, stigma, uncertainty,

guilt, shame or embarrassment (Caqueo-Urizar *et al.*, 2011; Koschorke *et al.*, 2017). These feelings are derived from the consistent support and continuous care provided to relatives diagnosed with schizophrenia (Shah & Lodge, 2013). A study conducted by Riley-McHugh, Brown and Lindo (2016) in a Jamaican hospital found that families experienced anger, sadness, fear and depression when caring for their family member. Another study indicated that families are concerned about the health and well-being of their affected relatives, resulting in worry and tension (Caqueo-Urizar *et al.*, 2011). Ageing parents, in particular, worry about the care they can provide as they are getting older, especially regarding their children's future when they, as primary caregivers, are deceased (Sivakumar *et al.*, 2022). This study also reported that parents worry about their children's marital and employment prospects. Furthermore, studies found that caregivers often blame themselves for their family member's diagnosis and are hypersensitive about the perceptions of other people about the diagnosis (Caqueo-Urizar *et al.*, 2011; Korschorkel *et al.*, 2017). Parents as primary caregivers also feel overwhelmed by guilt, shame and self-blame, especially because they did not detect the symptoms of schizophrenia earlier (Lippi 2016; Worrall, 2008). Relatives accept responsibility for the behaviour of the family member with schizophrenia and experience feelings of condemnation and blame when the person does not adhere to societal roles and expectations (Korschorkel *et al.*, 2017; Lippi, 2016).

Support is vital to assist the family in adjusting and understanding the challenges and changes in family dynamics when caring for a relative with schizophrenia. Lack of support from or by mental health services results in relapse or readmission to psychiatric facilities of the person diagnosed with schizophrenia, because families do not have sufficient knowledge and support to provide effective care (Chan, 2011). Family support, such as social work support with relevant information on care and treatment of the illness (causes, symptoms, coping mechanisms), support and resources for both the relative diagnosed with schizophrenia and the family carer can mitigate these challenges experienced by families (Canada Health Act Annual Report, 2004). However, research reveals the inadequate assistance, support and community-based mental health resources offered to these families (Chan, 2011), especially among female carers in Africa (Asuquo & Akpan-Idiok, 2021). Many families experience numerous challenges in receiving and accessing support in mental health services in the South African context irrespective of the well-documented burden of care and need for support (Mothwa & Moagi, 2020).

## **THE ROLE OF SOCIAL WORK IN SUPPORTING FAMILIES**

The role of social work in providing support services to family members is of the utmost importance to overcome the challenges that families experience when caring for a relative diagnosed with schizophrenia. The role of a social worker in dealing with mental health issues has evolved over time, with greater emphasis on the family perspective and the social workers as primary resources in the provision of mental health services (Starnino, 2009). Social workers can be partners in care with families caring for relatives with a mental disorder by providing psychoeducation programmes, which reduce the incidence of relapse of the patient or reappearance of symptoms, as well as improve patient recovery, and increase overall well-being and satisfaction for all family members. Bland's 2008 study on social work with the

family of a schizophrenic family member alludes to the importance for social workers to involve families in the overall treatment plan, addressing challenging emotions and establishing resources to support families. In a position paper on Social Work with Families in Mental Health Settings conducted in Ireland by Cuskelly *et al.* (2020), participants (family members) reported that they were not adequately informed about the availability of social work services. Moreover, families were frequently excluded from and disempowered by support services, despite being the primary caregivers for family members diagnosed with schizophrenia. Importantly, social workers working in the area of mental health need to understand the social context of these family members, recognise their strengths and understand their lived experiences while caring for a relative diagnosed with schizophrenia. Whilst recognising the important role of social workers, Wong, Wan and Ng (2016) highlight that social workers do not necessarily have the necessary professional skills, knowledge or training to support these families. The importance of social work support to families caring for relatives diagnosed with schizophrenia gave rise to this study, which aimed to explore and describe the challenges experienced by family members caring for a relative with schizophrenia. The study also provided recommendations for social work practice in providing support for these families to add to the body of knowledge in social work.

## **THEORETICAL FRAMEWORK**

The study was underpinned by the family systems theory (FST), which focuses on the family which functions as a unit when they deal with daily challenges such as caring for a relative diagnosed with schizophrenia (Paley, Lester & Mogil, 2013). The theory emphasises family members' exchanges of behaviours and interactions (Johnson & Ray, 2016). Families are interrelated and intertwined, and if something affects one family member it will also have an influence on the other members in the family (Skyttner, 2005; Republic of South Africa, 2021). Prolonged responsibilities when caring for a relative with schizophrenia influence the family's interrelated relationships negatively, which can result in feelings of guilt, depression and despair among family members (Leng *et al.*, 2019). FST enabled the researchers to comprehend the "how" and "what" of the family members' lived experiences when caring for a relative with schizophrenia.

## **RESEARCH METHODOLOGY**

The research question which directed the research was: "What are the lived experiences of family members who provided care for a relative diagnosed with schizophrenia?" The aim of the study was to understand the lived experiences of these families as carers. The specific objectives were to explore and to describe the challenges experienced by family members caring for a relative diagnosed with schizophrenia.

A qualitative research approach was implemented to understand the lived experiences of family members caring for a relative with schizophrenia. This approach provides rich insights into phenomena and focuses on how people construct their world and provide information on the "why" and "how" to describe their experiences, thoughts and perceptions (Creswell, 2013; Flick, 2018; Fouché & De Vos, 2012).

Phenomenology was the strategy of inquiry for this study because phenomenology focuses on the nature of the lived experience from the participant's perspective. This study accordingly sought to acquire a deeper appreciation of the meaning of their daily experiences from family members caring for a relative with schizophrenia (Patton, 2002; Ritchie, Lewis, Nicholls, & Ormston, 2013).

The population for this research study consisted of family members caring for a relative diagnosed with schizophrenia. Participants for the study were purposefully selected from a support group consisting of parents of family members diagnosed with schizophrenia residing in the Western Cape. Voluntary and snowball sampling were employed and the sample consisted of seven participants.

Face-to-face, in-depth unstructured interviews, which lasted 45 – 60 minutes, were utilised for data collection. The interviews were conducted at the participants' homes in Cape Town during 2018-2019. The interviews were guided by one broad question, namely: "Tell me, what are your experiences when caring for a relative diagnosed with schizophrenia?" During the interviews, the researcher asked probing questions about the context in which these experiences occurred and the meaning that participants attached to their experiences. The data were thematically analysed as described by Creswell (2013:193). An independent coder reviewed each transcript to identify a list of significant statements about how the participants experienced caring for a relative diagnosed with schizophrenia. The significant statements were then grouped thematically to describe "what" the participants in the study experienced and "how" they experienced it. This is called the "textural description" (what happened), where verbatim examples are compared and contrasted with findings in the literature. A compound description which presented the essence of what the participants experienced and how they experienced it was then compiled, comparing and contrasting the findings with the literature.

The trustworthiness of the data was ensured through a number of factors:

- 1) credibility, which was done through member checking to determine the accuracy of the findings by taking the final report or transcripts back to participants and determining whether these participants feel that they are accurate (Creswell, 2016);
- 2) transferability, enabled by providing thick descriptions of the findings with appropriate quotations;
- 3) dependability, in that an independent coder did the data analysis to validate the findings; and
- 4) confirmability, "the researcher could demonstrate that the data collected represent the participants' responses and not the researcher's biases or viewpoints" (Cope, 2014:89).

Ethical considerations for conducting the research as it affected the participants included confidentiality, autonomy and anonymity by using pseudonyms and ensuring no harm to participants by referring them for counselling should the need arise (Vanclay, Baines & Taylor, 2013). Participation was voluntary and participants were provided with consent forms to sign and informed of their right to withdraw from the research at any time. Ethical clearance was obtained from the Higher Degrees Committee of the Faculty of Community and Health

Sciences and the Humanities and Social Sciences Research Ethics Committee of the University of the Western Cape, ethics reference number BM19/7/1.

## **DEMOGRAPHIC DETAILS**

The demographic details of the participants are illustrated in Table One.

**Table 1: Demographic details of participants**

Participant	Area of residence	Home language	Gender	Age	Level of education	Relationship to the family member	Years of experience caring for the family member
A	Claremont	English	Female	75	College	Mother	10
B	Rondebosch	English	Female	65	Postgraduate	Mother	21
C	Mfuleni	isiXhosa	Female	33	Grade 11	Sister	10
D	Cape Town	English	Female	57	High school	Mother	27
E	Mfuleni	isiXhosa	Female	64	Grade 8	Mother	16
F	Khayelitsha	isiXhosa	Female	35	Grade 12	Mother	22
G	Claremont	English	Female	64	Degree	Mother	7

The participants in the study were all females between the ages of 35-75 years. This correlates with the view of Asuquo and Akpan-Idiok (2021: 9) that “women are the irrefutable strength of informal caregiving.” The participants constituted a diverse group regarding age, race, household, education and socioeconomic background. Their caregiving responsibilities extended over a period of 7 to 27 years.

## **RESEARCH FINDINGS AND DISCUSSIONS**

The research findings are discussed according to four main themes with sub-themes which emerged from the thematic data analysis. The themes are illustrated with quotations from the participants and literature.

### **Theme 1: Worries and concerns of caregivers**

The burden of care on a family caregiver is complex and includes worry about the relative diagnosed with schizophrenia (Ivarsson, Sidenvall & Carlsson, 2004). These worries include the persistent concern about the whereabouts and safety of the diagnosed relative (Alfonso *et al.*, 2020).

The theme includes the following sub-themes regarding the relative diagnosed with schizophrenia: the constant worry about their whereabouts; constant concern about their safety and victimisation; concern about the family members' future, care and needs; and concern about aggressive and violent behaviour.

#### ***Sub-theme 1.1: The constant worry about their whereabouts***

The responses of two participants indicated that they worry about the whereabouts of the person and this was expressed as follows:

*We have to always watch him as he can do anything, anytime ... You see, if someone is leaving, there should be someone who is left with him and watch him constantly.*

*I am always watching him. When he goes out, when he talks and when he does things, I am always watching him... to make sure he does not get up into no good.*

It is clear from the findings that these participants were worried about their family members by constantly “watching out” and the constant need to know the whereabouts of the family member, which required high levels of attentiveness on the part of the participants, causing significant strain. Patients diagnosed with schizophrenia may experience hallucinations and delusions, which affect their thinking and behaviour and may result in unpredictable behaviour, so family members experienced that they have to keep a close watch on them all the time (Asma *et al.*, 2014; Schulz & Sherwood, 2008). The family members then experience feelings of exhaustion, frustration and being overwhelmed by the situation (Gater *et al.*, 2014).

Participants also experienced worry about the safety and victimisation of their relative with schizophrenia, as explained in the following sub-theme.

#### ***Sub-theme 1.2: Constant concern about their safety and victimisation***

Comments by participants showed their constant concern about the safety of their family members as one participant stated:

*People beat him up because of his behaviour, and now someone beat him. We were once called by someone who is a police officer that a mob would kill him because he is a rapist. And others will make videos of him, laughing. People are taking advantage of him because he won't know who beat him up. Sometimes he comes home injured; we are worried about his safety.*

Victimisation is higher in persons with schizophrenia than in the general population, because they are vulnerable and have impaired cognitive functions (De Freitas, Stumpf & Rocha, 2013). A study conducted in Jamaica by Jackson and Heatherington (2006) found that the community perceive people diagnosed with a mental disorder as mad, disruptive and frightening. A study on the prevalence and risk factors of victimisation in adult patients with a psychotic disorder by de Vries *et al.* (2019) indicated that people with a psychotic disorder are often victims of violence. Results from their meta-analysis review of 27 studies found that experiences of violent victimisation in adults with psychotic disorders are four to six times higher than the general community. The general perceptions of people which causes significant concerns for the safety of people with mental illness include beliefs that they are possessed by demons, bewitched, evil-spirited or cursed, and that the disease is a punishment from God (Burns, Jhazbhay, Kidd & Emsley, 2011). These perceptions or beliefs are often cited as common in explanatory models of schizophrenia in Africa (Asma *et al.*, 2011). Family members of a relative with schizophrenia may isolate their relative to avoid stigmatisation and discrimination (Iseselo, Kajula & Yahya-Malima, 2016). People with schizophrenia can often not fully integrate into society, because they have to deal with the social and psychological consequences of the stigma, which result in low self-esteem, poor social skills, social isolation and marginalization (Thornicroft, Brohan, Kassam & Lewis-Holmes, 2008). Social worker

services can assist families in coping with these experiences of fears about safety and stigmatisation. Community awareness and mental health literacy programmes presented by social workers are crucial in providing education about the realities of this condition, dispelling myths and misconceptions, and facilitating positive interactions between community members and those who have been diagnosed with the disorder. Social workers must actively combat the stigma around schizophrenia and champion the rights of individuals and families affected by this disorder, as emphasised by Corrigan *et al.* (2001).

Nevertheless, the picture that emerges is that attitudes and perceptions of the community contribute to the concern by families about the safety of their relatives with schizophrenia, as noted in the following sub-theme.

#### ***Subtheme 1.3: Concern about aggressive and violent behaviour towards participants***

Families can experience disorderly behaviour from a relative with schizophrenia, which results in an increased risk of aggression and violent victimisation (Monyaluoe, Mvandaba, Du Plessis & Koen, 2014). The following sub-theme describes the participants' experiences of aggressive behaviour by the relative with schizophrenia as well as expressing their concerns about their own safety, as well as the safety of other relatives, the relative diagnosed with schizophrenia and community members. The following five statements describe the aggressive and violent behaviour of the family member with schizophrenia directed towards them:

*So certain things made him angry if I disagreed with him, and so I prefer not to.*

*... if he asks for money and we don't have it, he will get angry and kick things around the house. He must get everything that he wants.*

*He does get angry, last week he was angry at the illness. He was angry at having mental illness... he shouted, before he used to break his cupboard doors.*

*He was violent then. He would often attack me. ... few occasions when he tried to stab me with the knife. There was once when I walked too close to him, and I found him in the garden, and he threw me into the glass window, and it cut me.*

*He was violent, using knives to stab us. Sometimes he would put a knife or axe under his pillow so that he could attack us.*

Participants expressed concerns about their own safety when they experienced dangerous situations and they referred to the aggressive behaviour when the family members did not get what they wanted or displayed aggression because of their illness. Violence directed at family members is quite common, with more frequent arguments and heightened tension between the patient and carer (Esbec & Echeburúa, 2016; Hsu & Tu, 2014; Young *et al.*, 2019). Monyaloue, Mvandaba, Du Plessis & Koen (2014) comment on similar results in their study and state that symptoms of danger and harm often include yelling, ridicule and criticism, followed by damage to property, violent threats of harm and physical violence directed at objects and families. A study by Labrum and Solomon (2017) found that at least 40% of family members had experienced some form of violence at the hands of their relatives diagnosed with schizophrenia, whom they realised they have no control over. This consequently results in impaired family

relationships and disconnection between family members (Labrum & Solomon, 2017; Onwumere, Parkyn, Learmonth & Kuipers, 2019). Social workers, however, have the ability through family systems theory to assist families in comprehending the ways in which caring for a loved one with schizophrenia can impact on their day-to-day routines, disrupt familial dynamics, cause heightened stress levels, strain interpersonal relationships, and necessitate the assumption of additional roles and responsibilities in the caregiving process (Adeosun, 2013; Lippi, 2016).

#### ***Sub-theme 1.4: Concerns about their future, future care and needs***

Other concerns that the participants expressed included concerns for the future of their family members diagnosed with schizophrenia. These concerns were expressed as follows:

*His future when we die. What is going to happen to him? Where is he going? I really don't know because he could be very isolated then. Sitting in a flat, you know. So, I don't know, I can't see the future where he is concerned.*

*The biggest concern as a parent with this kid is, what's going to happen when we are not around anymore. That is my first thought in the morning and my last thought at night.*

*I think about her future. Who is going to take care of her if I die? That is my worry because I think about when I am sick, I take care of myself. If I don't, she won't have anyone to take care of her. People won't like her.*

These findings indicated that the care, responsibility and future of the relative diagnosed with schizophrenia tend to weigh heavily on the participants' minds. These concerns or worries can often trigger high levels of stress and anxiety in the caregiver and add to the caregiver's burden of care and health. The participants seem to be preoccupied with concerns about the future of their family members, especially when they can no longer care for them (Knock *et al.*, 2011). They are well aware of the stigma associated with schizophrenia and the likelihood of abandonment and disowning that could happen if they were not around to care for the family member (Gurefe, 2007). Family members are also aware of the financial and emotional implications or burden when caring for a relative with schizophrenia and may therefore distance themselves from taking responsibility to care for this person. Re-institutionalisation, although not mentioned by participants, could be a real possibility for some of these family members diagnosed with schizophrenia and is therefore a significant worry for the family member who stated: "they won't have anyone to take care of her" or asked "what will happen when we are no longer around?". An added concern for family members is the lack of community mental health centres and support from mental health care facilities, especially within the South African context, where there is a lack of community resources and support (Lippi, 2016). These worries about the future care of a family members with schizophrenia are exacerbated when mental illness in families is perceived as having a supernatural source or as "spirit possession" (Fernando, 2012), which results in isolation of families and the relative with schizophrenia, especially within the African context (Gurefe, 2007).

Social workers can provide valuable assistance to ageing parents to address concerns regarding the care of children diagnosed with schizophrenia. Social worker services can focus on collaboration with parents to develop future care plans for their family members, thereby mitigating any “subjective burden” of concerns and ensuring the individual receives proper care (Sivakumar *et al.*, 2022). These plans can help reduce the subjective burden or the stress of uncertainty on parents (Caqueo-Urízar *et al.*, 2011; Koschorke *et al.*, 2017).

In contrast, our findings also showed that two participants were not overly concerned about their relatives and viewed them as more independent.

*My son is functioning independently, so I am not too worried.*

*He is very helpful; he is considerate and does for himself. He is quite motivated, which many aren't.*

While the bulk of the findings focus on the concerns of carers about their family member diagnosed with schizophrenia, these two participants noted the good prospects that derived from their caregiving, because they perceived their family members as being more independent. This is an indication that although there is a constant concern or worry about the family member (Kulhara, Kate, Grover & Nehra, 2012), experiences in living and caring for a relative diagnosed with schizophrenia are not always negative, but may also include dimensions of personal gains and gratification, such as finding meaning and a greater sense of inner strength for both carer and the person diagnosed with schizophrenia. Personal gain could suggest that participants were contented and perceived life through a positive lens and were proud of the achievements of their relative. These positive effects of caring included feeling fulfilled, enjoyment, a sense of responsibility and perceiving life positively (Cohen, Colantonio & Vernich, 2002; Kate, Grover, Kulhara & Nehra, 2013). These responses are a possible buffer against the negative experiences of constant concern and worries in caring for a relative with the diagnosis and are associated with a better quality of life in caregivers (Kate *et al.*, 2013).

Social workers, drawing on the tenets of family systems theory, are equipped to facilitate positive experiences and optimistic perspectives in families. Such interventions can serve to strengthen the familial bonds and foster a sense of unity among family members, particularly in times of crisis or when supporting a family member diagnosed with schizophrenia. Social workers can assist families by promoting family resilience and social support to navigate difficult circumstances, while also enhancing their overall well-being (Golics, Basra, Finlay, & Salek, 2013; Lawrence, 2012). It is worth noting that the family's positive or negative disposition can influence their ability to cope with the family members' diagnosis of schizophrenia for better or worse (in case of relapse). The family's response to the mental illness of a relative has a significant impact on the long-term outcome of the disorder, the functioning of the other family members, and their interpersonal relationships within the family. The social worker can therefore assist in mitigating the objective experiences of the family members by offering support to restore family and social relations (Igberase *et al.*, 2012).

## **Theme 2: Impact of caring on the participants' health**

Caregivers can experience a myriad of their own challenges, such as poor health, physical illness and psychological distress, which are characteristics of the demanding role of caregiving and the accompanying concerns and worries (Pinquart & Sorensen, 2007). Previous research has found that carers may themselves experience adverse health effects through neglecting their own health care, bad eating habits, or following a poor diet when caring for their affected family members (Burton *et al.*, 2003).

### ***Sub-theme 2.1: Influence on the participant's health***

The following two participants described how caring for a relative affected their health, especially their high blood pressure:

*I remember very well when he got sick, that affected my high blood pressure, and I got admitted to the hospital. It was difficult.*

*It was very difficult for me in my health. I have high blood pressure; I sometimes see that it is very high with [taking care of] him.*

The results show that there seems to be a strong correlation between the participant's health (high blood pressure) and the demands of a caregiving role. A study by Capistrant, Moon and Glymour (2012) on spousal care provision and hypertension indicated that there is a correlation between caregiving and a risk for cardiovascular disease (CVD). The CVD was the result of negligent health behaviour by the caregiver. A study by Ingber (2021) on caregiver's stress syndrome found that women, in particular, who spend nine or more hours a week caring for a spouse increased their risk of heart disease by 100%. Moreover, the age of the participants in the study, which ranged between 57 and 75 years of age, and the years in the caregiver role, with a range between 7 to 27 years, had a significant impact on their health. It is clear from these findings that the health of women who provide care to family members over extensive periods of time is compromised (Patel & Chatterji, 2015).

### ***Sub-theme 2.2: Experiences of stress***

Stress, as described by Fink (2010:5), refers to the “perception of threat, resulting in anxiety, discomfort, emotional tension, and difficulty in adjustment”. Family caregivers experience stress as a result of the provision of care as well as concerns about the future care of a relative with schizophrenia.

Participants commented as follows regarding stress in their demanding caregiving roles:

*It is a really difficult time... It is so stressful.*

*Those were the dark days; it was absolutely terrible... It is, at times, incredibly stressful.*

*It's very painful and stressful.*

A family member caring for another family member with schizophrenia feels overwhelmed and may experience anxiety (Ntsayagae, Poggenpoel & Myburgh, 2019; Sharif *et al.*, 2020).

Chronic stress, which transpires both physically and mentally in the caregiver, is evident when caring for a relative with schizophrenia (Bademli & Duman, 2016). Chronic stress results from physical and psychological strain over time and could be a result of experiences of stress in other life domains such as work, family relations and quality of life (Mulud & McCarthy, 2017; Schulz & Sherwood, 2008). Stress can also be the effect of adherence to medication and constant care, as per the findings discussed in sub-themes 1.1, 1.2 and 1.3. The findings made in these sub-themes could allude to the stress the participants experience and how it may lead to higher levels of vulnerability. If this happens, it could eventually cause mental and physical exhaustion, making it difficult for them to handle their caregiving responsibilities effectively. The evidence suggests that caregiver stress is strongly linked to adverse health outcomes in both the relative with schizophrenia and other family members, which could lead to challenges in family interpersonal relationships.

### **Theme 3: Experiences of participants' interpersonal relationships**

The participants shared their experiences on how caring for a relative with schizophrenia has affected their personal relationships. The following sub-theme emerged from the interviews.

#### ***Sub-theme 3.1: Family relations***

McFarlane (2016) notes that schizophrenia interrupts the organisation of most families. Families may experience various changes in their functioning, which include alienation of siblings, marital conflict, brutal disagreement regarding support versus behaviour control, and even divorce. Four participants shared their experiences on how their child's diagnose with schizophrenia, for example, disrupted or affected spousal/partner relationships.

*Me and his father got divorced back at the time because of him. My husband didn't understand all this. He is not a compassionate person by nature, so he gave me an ultimatum. His behaviour was challenging after my son was diagnosed, and he said I must agree not to see him again or he wants a divorce.*

*I had a partner when my kid got the illness. He couldn't cope, we separated because of my kid's illness.*

*In the past, my husband and son had a difficult relationship when he was ill. You know my husband would say he has bad behaviour and wants to lose his temper. They didn't have a close relationship.*

*My husband kicked him out of the house.*

Swingler (2013) reports that schizophrenia is known to cause disruptions in interpersonal and family structures because mental illness significantly affects parents, children, spouses or partner relationships (Johnston, 2019), which is evident in our findings. Penning and Wu (2016) argue that romantic and family relationships can be negatively affected by schizophrenia. Some negative effects may include the disruption in family relationships, especially between spouses, which may cause families to experience deterioration of their relationships as they feel disconnected from each other and from extended family members, which can result in marital/partner conflicts, the inability of spouses/partners to fulfil conjugal

roles and ultimately result in separation (Caqueo-Urízar *et al.*, 2011; Caqueo-Urízar *et al.*, 2017; Swingler, 2013). Furthermore, the policy of deinstitutionalisation has interrupted the balance of the family system, causing possible relationship strains and conflicts. The occasional visits to institutions are replaced with the constant need to care for the family member, characterised by stress, exhaustion, worry, sadness and strain (as discussed in the previous themes), which inevitably weaken or threaten the unity of the family (Whittingham, Wee, Sanders & Boyd, 2013).

Social workers can expertly assist families in identifying and leveraging their families' unique strengths to gain a comprehensive understanding of their situation, that is, to help them define their situation and give it meaning by implementing a family systems approach (O'Connell, 2006). These families need insight into their situation to be receptive to appropriate support. Social workers can assist families in understanding their family dynamics when caring for a relative with schizophrenia to achieve this. Such family dynamics can include family conflict or cohesion, strong or weak relationships, sound or poor communication and flexibility (Anuradha, 2004). Social workers can enhance family communication, for example, by assisting family members to express their feelings, both negative and positive. Social workers are also instrumental in supporting family members to be flexible as they navigate through the difficulties of caring for a loved one with schizophrenia. Social workers can cultivate an environment of flexibility and adaptability through honest communication, where both the individual and their family can openly discuss the impact of the diagnosis on their roles and relationships, and the ability of the family to handle changes in interpersonal relationships. This information can contribute to a clear assessment of any family dynamics that could potentially be an obstruction in the functioning of the family caring for a relative diagnosed with schizophrenia.

#### **Theme 4: Social support networks available to participants**

The provision of support by healthcare professionals, social workers, community organisations and other service providers is essential for families and relative with severe mental illness to improve family quality of life and functioning, and to reduce levels of stress (Crabb, Owen, Stober & Heller, 2020).

The following comments describe participants' experiences accessing and receiving support from several resources. These included support from a higher being, churches, social support groups, healthcare professionals and the broader community.

*Even at church, the pastor used to come and pray here, and the church ladies. That really gives me hope.*

*I trust God that He will help us. That's the other thing that is giving me strength.*

*What gives me hope is that God will help us. And I will have the energy to pray to God to help us, and I will feel right and have hope.*

Three participants derived spiritual support from their belief in God, their church leaders and ladies in the church, which provided strength and hope. Sharif *et al.* (2020) state that one of the support mechanisms includes the person's belief that God is in control and, above everything,

that He can heal and take care of their concerns. The participants' experiences are similar to the findings by Grover, Pradyumna and Chakrabarti (2015) and Ntsayagae *et al.*, (2019), who found that families turn to religion as a support or coping mechanism, because they are optimistic and hopeful that God will help them through their carer journey. Our findings suggest that religion has a significant influence on how family members with relatives diagnosed with schizophrenia understand, treat and manage this illness (Smolak *et al.*, 2013) and assists them to make sense of the difficult situation.

Support from healthcare workers was described as follows:

*I mean, the saving grace was a psychiatrist at Valkenberg who was very supportive .....he kept my son in the hospital while she (our daughter) was in matric year because there is no way she could have made it through.*

*You have Valkenberg, and you have outpatient programmes you can attend. If it weren't for that outpatient programme I would never have survived this illness.*

These responses indicated that these five participants had received positive support from various support structures, which positively influenced their psychological and emotional well-being. The availability of good support for family carers could result in better adaptability within families, enhancing relationships within families from a family-centred approach to providing support services (Widiyawati, Yusuf, Devy & Widayanti, 2020). Through the provision of such support, the family becomes the most comfortable and supportive environment for the family member diagnosed with schizophrenia.

Support from social work professionals seemed vital in assisting the family carer in coping, (Ae-Ngibise, Doku, Asante & Owusu-Agyei, 2015) as formal support from social workers can reduce the burden of care for these carers.

The deinstitutionalisation of people with mental illness from psychiatric facilities created the expectation that families would have to provide the majority of support to their relative with schizophrenia and, therefore, spend significant time caring for the family member (Patel & Chatterji, 2015). Yet a limited number of families are adequately prepared emotionally, physically and financially to take on this caring responsibility, even if the strength of the family is acknowledged (O'Grady, 2004). Furthermore, contrary to our findings, a study by Akbari, Alavi, Irajpour and Maghsoudi (2018) found that there is compelling evidence that family caregivers of relatives with mental disorders receive limited social support or any kind of professional assistance. It was also noted that caregivers are primarily women, and we need to acknowledge their primary role. Although this study did not focus on the specific role of women as primary carers, Thurer in 1983 already highlighted the important role of women as primary carers and consequently considered deinstitutionalisation a women's issue. Bachrach, (1984) states that deinstitutionalisation has affected the lives of women who have been charged with the responsibility of caring for those with mental illness and suggests that the effects of such policy initiatives on the lives of women as carers should be examined.

## CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS OF THE STUDY

This study found that caregivers experience substantial objective and subjective burdens of care when caring for a relative diagnosed with schizophrenia. These objective and subjective burdens exert the most significant impact on caregiving roles and include constant care, worry, stress and financial difficulties. They impact the caregiver's employment opportunities as well as their health and relations with community and family members (Caqueo-Urízar *et al.*, 2016; Igberase *et al.*, 2012).

There are also implications for social work practice when family members care for a relative with schizophrenia. The primary role of social work professionals is to assist the family member diagnosed with schizophrenia with their functional recovery, which will enhance their independence and lessen their dependence on other family members (Harvey & Bellack, 2009; Slade & Longden, 2015). The social worker therefore supports the individual diagnosed with schizophrenia to restore their psychosocial functioning by (i) enhancing their abilities and skills to master their daily routines such as personal care and independent living; (ii) enhancing their social and community participation, which will also contribute to destigmatising schizophrenia in communities; and (iii) assisting them with developing the social competence to socialise effectively with family members and member in the community. Such functional recovery does not only assist the individual diagnosed with schizophrenia, but also supports the family members caring for them (Poon, Joubert, Mackinnon & Harvey, 2018; Fox, Ramon & Morant, 2015). The family is thus not the sole focus of social work interventions, but also the person diagnosed with schizophrenia.

The findings of this study indicated that there is a correlation between the burden of care and gender. The responsibilities in caring for a person with a mental illness are more extensive among female caregivers and have a negative impact on women (Del Rio-Lozano *et al.*, 2013; Schulz & Sherwood, 2008). There is an assumption in society that women must provide caregiving (Scerri, 2014). Cascella, Carbó and Garcia-Orellan (2020) estimate that 80% of the caregivers in the world are female, and they experience six times more symptoms of depression and anxiety than those who have no such responsibility. The study's findings on gender raise the question of whether deinstitutionalisation is a women's issue. It is therefore recommended that research should be done on this. It would be useful to do a comparative study with family members caring for a relative diagnosed with schizophrenia focusing specifically on gender roles, age and duration of care. The findings on gender also indicate that social work practice should prioritise the assessment of the social needs of every family member, with particular emphasis on the primary caregiver. The range of factors that can impact on the caregiver's ability to care for a relative with schizophrenia should be investigated, such as the caregiver's age, health, family circumstances and the potential effects on family relationships, as well as their mental and emotional well-being. It is essential for social workers to take all of these factors into account when providing services and to ensure that the caregiver can provide the best possible care to their loved one with schizophrenia.

We propose recommendations to social work practice that can facilitate the reintegration of mental health patients into their communities. We would like to emphasise that social workers must not ignore the burden and strain of caring for a family member, although evidence from

our study indicated that caregivers received support from various health providers. Professional social work services have major implications for family members caring for a relative diagnosed with schizophrenia in most areas of their daily functioning. Social work intervention strategies must therefore not only focus on symptom remission in the patient, but also enable family members to participate in various life domains while also taking care of a relative diagnosed with schizophrenia. Too often the caregiver and the family are the “hidden” patients, whom healthcare workers tend to overlook (Tshililo & Davhana-Maselesele, 2009). Our findings emphasise the importance of post-discharge support services by social workers to families and relatives diagnosed with schizophrenia. Social workers can provide information to families and patients when the patient is discharged from a facility. This information should include clear instructions or explanations regarding follow-up sessions with psychiatrists, adherence to medication, support, coping mechanisms, care plans (when the carer is no longer able to care for the family member) and information on actions necessary if there is a relapse in the medical condition. These explanations should include referrals to appropriate community resources, such as support groups for family members and patients diagnosed with schizophrenia in their communities, which could inevitably reduce the burden of care on caregivers.

Social workers can provide support on the basis of family system theory, with the central notion that the family cannot be fully understood through its individual members or subsystems in isolation from each other (Milberg, Liljeroos, Wåhlberg & Krevers, 2020). Our findings support the relevance of applying family system theory in rendering social work support to families through individual and family counselling, awareness initiatives and support groups. Such support can have a positive impact on family relationships, reduce anxiety, help families create coping mechanisms among family members, and create a balance between disruption and stability. If social work support services focus only on one family member, i.e. the carer, they will be ineffective; it would also be a missed opportunity to assist the entire family with support to adapt when they experience challenges in caring for a relative diagnosed with schizophrenia (Milberg *et al.*, 2020). In sum, this study has documented the challenges experienced by family members caring for a relative diagnosed with schizophrenia as well as addressing aspects that social workers can consider when supporting family members.

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