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Family Caregivers' Perceptions of Schizophrenia and Community Members' Attitudes Toward Patients and Their Family Caregivers

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ABSTRACT
Schizophrenia is a complex disorder with no known single cause which makes family caregivers of patients to develop their own perceptions and interpretations of the condition. We aimed to find out family caregivers' perceptions and how they influence their treatment seeking behavior as well as attitudes of community members toward family caregivers and their patients. Qualitative data were collected from 24 family caregivers, of patients with schizophrenia who were residents of Greater Kampala Metropolitan Area. Findings indicated that family caregivers accepted schizophrenia as a chronic medical condition that could only be treated in a hospital. Community members got used to seeing patients with schizophrenia and accepted them with their family caregivers as part of their community. Study findings provide important information that could be used by social workers, other mental health workers and policy-makers to strengthen service delivery and mobilization of social support for family caregivers and their patients with schizophrenia.

KEYWORDS
Schizophrenia; perceptions; family caregivers; hospital; Uganda

Introduction

Schizophrenia, in its acute state, is the most impairing of all mental illnesses and primarily affects working-age populations (World Health Organization, 2022). The peak age of onset for the first psychotic episode of schizophrenia is in the early- to mid-20s for males and in the late-20s for females (American Psychiatric Association, 2013). The negative symptoms of schizophrenia impair the motivation and ability to establish and maintain social relationships including marriage for both male and female patients (Ozcan et al., 2014; Sarhan et al., 2022). According to the world mental health report of 2022, all over the world, people living with schizophrenia may not easily find employment opportunities due to other peoples' negative attitudes toward them (World Health Organization, 2022). The impairing nature of schizophrenia means that family caregivers hold different perceptions regarding its causes (Mathews et al., 2019).

One of the objectives of the World Health Organization action plan for mental health (2013–2020) includes enabling people with mental illness to continue living with their families and advocate the empowerment and involvement of family caregivers and other family members in mental health care (World Health Organization, 2013, 2022). Family caregivers refer to any relative, partner, friend or neighbor who has a significant personal relationship with and provide a broad range of assistance for, an older person or an adult with a chronic or disabling condition (Reinhard et al., 2008; Verity et al.,

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2021). These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care. In the context of severe mental disorders such as schizophrenia, caregiving is more complicated than in other disorders. In particular, the associated poor diagnosis, disability and stigma make caring for patients with schizophrenia stressful and discouraging (Häfner & Maurer, 2006; Ran et al., 2015). Family caregivers' perceptions about the causes of schizophrenia and how it affects a person diagnosed with schizophrenia under their care are important because they influence help-seeking, adherence to treatment, disease management and clinical outcomes (Caqueo-Urízar et al., 2015; Verginer & Juen, 2019). Factors that attempt to explain the causes of schizophrenia from a caregivers' perspective include family caregivers cultural background, religious beliefs as well as features of the mental health system available (American Psychiatric Association, 2013; Angermeyer et al., 2016; Holzinger et al., 2003). Similarly, genetic predisposition and psychosocial causes such as traumatic experiences during childhood are also perceived as causes for schizophrenia (Magliano et al., 2019; Mannarini et al., 2018). Some family caregivers also perceive schizophrenia to be a result of a brain disease and evil spirits (Agau & Bodilsen, 2017; Kisa et al., 2016; Mall et al., 2017). Depending on their perceptions, family caregivers seek treatment for a person diagnosed with schizophrenia under their care from either traditional, spiritual or conventional health care settings (Gabra et al., 2020; Mathews et al., 2019). Knowledge influences the way family caregivers perceive mental illness, schizophrenia inclusive, and research has shown that, even in Western cultures, there is a significant improvement in peoples' perceptions and attitudes toward mental illness over time which has been attributed to increased awareness of mental health issues (Henderson et al., 2020).

Caring for patients at home also implies that family caregivers need the support of their community members whom they interact with in their day-to-day life. This could be supported by a proverb in Africa which says that "it takes the whole village to raise a child." Therefore, it should take the whole village to support family caregivers of people diagnosed with schizophrenia under their care so as to enable them to live a functional community life (World Health Organization, 2022).

Community members' attitudes toward family caregivers and their patients are important because they are part of family caregivers' social network and a potential source of social support. However, many studies indicate that patients with severe mental illness such as schizophrenia are usually stigmatized in their communities which may result in limited access to community resources for them and their family caregivers. In most cases, stigma is a result of aggressive behavior of the patient while in other cases, it is a result of socio-cultural attitudes people hold regarding mental illness (Chidarikire et al., 2020; Knaeps et al., 2015; Marie et al., 2020; Reavley et al., 2017; Twesigye & Kagee, 2016). Due to stigma associated with mental illness, people living with schizophrenia experience more social exclusion compared to the general population (Clari et al., 2022). Furthermore, stigma and discrimination toward mentally ill people undermines their social support structures, and they are vulnerable to a downward spiral of lost resources and social exclusion that can worsen their mental health conditions (World Health Organization, 2022). Patients are also labeled by the community, including neighbors or extended family members, by using a term "madness," implying that the patients are hard to cure (Fitryasari et al., 2018). Furthermore, Klausen (2016) observed that a primary outcome of stigma for family caregivers and their patients was public ostracism and subsequent social isolation. Accordingly, exclusion from meaningful participation in everyday activities associated with work, friendships, and family led to poverty, a diminished social status for some family caregivers (Klausen, 2016).

A systematic review of studies done in the Middle East indicated that stigmatizing attitudes toward people with mental illness, their family caregivers and sources of stigma were manifold (Alyafei et al., 2021). The experience of stigma by family caregivers and their patients was also reported to occur in the African context. In Ghana, family caregivers of patients with mental disorders and their patients were stigmatized by society, and being stigmatized meant that families had to solitarily bear the caregiving burden (Ae-Ngibise et al., 2015). Family caregivers in Tanzania described people around them as having negative attitudes toward them and people diagnosed with schizophrenia under their care, although the people diagnosed with schizophrenia were more stigmatized than their family caregivers (Iseselo et al., 2016). There were even people who believed that family caregivers could also develop mental illness and thus avoided associating with them (Perlick et al., 2014). The experience of societal stigma and discrimination is worsened by negative attitudes from close relatives toward family caregivers (Iseselo et al., 2016). The negative attitudes reduce opportunities of receiving social support for family caregivers from close relatives and other community members (Iseselo et al., 2016).

As a result of stigma, family caregivers experience loneliness and social isolation from their community members (Animwaa et al., 2013; Soltaninejad et al., 2015). According to Soltaninejad et al. (2015), family caregivers are looked down upon. Stigmatizing family caregivers was associated with receiving minimal support from members of their extended family and friends, as well as being blamed for their patients mental illnesses and abnormal behavior (Sanden et al., 2022; Soltaninejad et al., 2015). Klausen (2016) observed that a primary outcome of stigma for family caregivers and the people diagnosed with schizophrenia under their care was public ostracism and subsequent social isolation. Accordingly, exclusion from meaningful participation in everyday activities associated with work, friendships, and family led to poverty, a diminished social status for some family caregivers (Klausen, 2016).

Understanding family caregivers and community members' perceptions regarding patients with schizophrenia is important for proper planning of improved mental health service delivery as well as tapping and utilizing available community resources. This is also one of the aims of Primary Health Care (PHC) which was incorporated into mental health service delivery in Uganda (Mugisha et al., 2016). Primary Health care in Uganda refers to the first level of health care organized across a tiered system of health facilities, from the lowest (Health Centre II) to the highest (Health Centre IV), offering basic health services to the nearby population (Mugisha et al., 2016; Nsereko et al., 2011). PHC addresses the main health problems in the community by, providing promotive, preventive, curative, and rehabilitative services accordingly.

This study is part of a doctoral project on understanding social support for family caregivers of patients with schizophrenia in Greater Kampala Metropolitan Area, Uganda.

The aim of this study was to assess family caregivers' perceptions of schizophrenia and their community members' attitudes toward them and the people diagnosed with schizophrenia under their care. Three research questions were used to obtain data from family caregivers, and these were:

(1) Please tell me what you perceive about schizophrenia as a mental illness which your patient is suffering from.
(2) How do your perceptions influence your treatment seeking behavior? (Traditional/medical)
(3) How do people around you and the community at large perceive you as a caregiver and your patient?

Methods

Study design

This was a phenomenological study design which used in-depth interview guides to collect qualitative data. This method is good at describing the common meaning for several individuals recounting their lived experiences of a concept or a phenomenon (Denzin & Lincoln, 2017; Rubin & Rubin, 2012). Phenomenology is not only a description but it is also an interpretive process in which the researcher makes an interpretation of the meaning of the lived experience of the participants in the study (Bryman, 2016; Creswell, 2013). Phenomenologists focus on describing what all participants have in common as they experience a phenomenon (Bryman, 2016; Creswell, 2013).

Study population and sampling

The study population was of family caregivers of patients diagnosed with schizophrenia. Some of the patients were still admitted to Butabika hospital, while others had been discharged. Study participants were purposively selected with the help of a research assistant; who was a psychiatric nurse working in Butabika hospital. The rationale for using purposive sampling was to enable selection of primary family caregivers who had a practical experience of caring for patients with schizophrenia. Family caregivers who were selected were those whose contacts were available on the patients' files with the primary responsibility of caring for the patients and residents of Greater Kampala Metropolitan Area (GKMA). Twenty-four primary family caregivers (15 males and 9 females) consented to participate in the study after details of the study were explained to them.

Socio-demographic characteristics of primary family caregivers

Ten (10) of the participants were from Kampala, nine (9) were from Wakiso and five (5) from Mukono district, respectively. Fifteen (15) of the respondents were males, while nine (9) were females. Their ages ranged from twenty-seven to sixty (27–60) years, and nineteen (19) were married, three (3) were single, one (1) was divorced and one (1) was a widow. Eight (8) of them had attained tertiary education, seven (7) had primary education, four (4) had university education, three (3) had secondary education and two (2) had attained advanced level of education. Twenty-one (21) were house-held heads and only three (3) were not. Ten (10) were Anglicans, six (6) Catholics, five (5) were Born again and three (3) Muslims.

Socio-demographic characteristics of family caregivers are summarized in Table 1 below:

Data collection

The research assistant searched files of patients diagnosed with schizophrenia on different wards to identify those from GKMA and recorded phone numbers of their next of kin as indicated in their files. The research assistant called the individuals whose numbers had been recorded and explained to them about the study. She also informed them that the hospital had given permission to the first author as the primary researcher to conduct the study and more details about the study would be given to them. The first author called and made an appointment to meet with each family caregiver and explained more about the study. All the family caregivers who consented to participate in the study were interviewed by the first author in their naturalistic settings. In-depth interview guides with open-ended questions were used to collect data which were recorded, transcribed verbatim and translated into English for those that were in Luganda, the most widely spoken language in GKMA. To maintain confidentiality, each interview was given a number for identification purposes. Field notes and observations were also made during data collection and ultimately helped enrich the study findings.

Ethical approval

Clearance to conduct the study was granted by the Research and Ethics Committee of Uganda Christian University (UCU REC-2021-175), after which a clearance letter was obtained from Butabika National Referral Mental Hospital Institutional Review Board (IRB). Final approval was granted by Uganda National Council for Science and Technology (SS1038ES).

Researcher reflexivity

In this section, we will situate the first author, who was the primary researcher, and discuss her preconceptions, therefore presented in first person (I). I am a doctoral student of social work and mental health and a resident of GKMA. I worked in Butabika hospital about 12 years ago as a medical social worker, and much of my work involved working on cases that involved patients and their family caregivers. Being a resident of GKMA, accessing family caregivers' naturalistic settings was easy for me. Family caregivers were willing to share their experience with me after learning that I once worked in Butabika hospital. They were also happy to be interviewed in their naturalistic settings, and most of

Table 1. Characteristics of family caregivers.

Family Care giver ID	District	Gender	Age & Marital status	Level of educ.	House hold head	Religion	R/ship to patient	Main source of income	No. of dependants
1.	Kampala	Male	57 & Married	Tertiary	Yes	Muslim	Uncle	Self-employed	8
2.	Mukono	Male	58 &Married	Primary	Yes	Muslim	Brother	Employed	4
3.	Wakiso	Male	30 & Divorced	University	Yes	Anglican	Brother	Self-employed	4
4.	Mukono	Male	59 & Married	Secondary	Yes	Born again	Nephew	Self-employed	7
5.	Kampala	Male	54 & Married	Tertiary	Yes	Anglican	Brother	Self-employed	7
6.	Wakiso	Male	27 & Married	Primary	Yes	Catholic	Nephew	Self-employed	3
7.	Mukono	Female	32 & Married	Secondary	No	Catholic	Daughter	House wife	0
8.	Kampala	Male	52 & Married	Tertiary	Yes	Catholic	Father	Employed	5
9.	Mukono	Female	58 & Widow	Primary	Yes	Anglican	Mother	Self-employed	4
10.	Mukono	Female	52 & Single	Tertiary	Yes	Born again	Sister	Self-employed	4
11.	Wakiso	Male	40 & Married	University	Yes	Born again	Brother	Employed	7
12.	Wakiso	Female	45 & Single	Tertiary	Yes	Anglican	Mother	Employed	5
13.	Kampala	Male	42 & Married	Tertiary	Yes	Born again	Husband	Employed	5
14.	Kampala	Female	37 & Married	Tertiary	Yes	Catholic	Husband	Employed	4
15.	Kampala	Female	52 & Single	Primary	Yes	Catholic	Friend	Self-employed	4
16.	Wakiso	Female	49 & Married	Senior 3	No	Anglican	Mother	House wife	0
17.	Wakiso	Male	59 & Married	Tertiary	Yes	Anglican	Husband	Self-employed	7
18.	Wakiso	Female	39 & Married	Primary 6	No	Anglican	Sister	House wife	0
19.	Kampala	Male	50 & Married	Advanced level	Yes	Anglican	Brother	Self-employed	6
20.	Kampala	Male	34 & Married	University	Yes	Catholic	Brother	Employed	4
21.	Kampala	Male	60 & Married	Primary	Yes	Muslim	Brother	Self-employed	3
22.	Wakiso	Male	32 & Married	Primary	Yes	Born again	Son	Self-employed	8
23.	Wakiso	Male	38 & Married	University	Yes	Anglican	Brother	Self-employed	5
24.	Kampala	Female	40 & Married	Advanced level	Yes	Anglican	Brother	Self-employed	8

them were interviewed in Luganda. Some family caregivers said that no one from the hospital had ever visited them in their homes to discussed with them about their caregiving experience (Berger, 2014). It also increased their level of comfort as well as mine and greatly facilitated the process of building rapport. My status as a former medical social worker in Butabika hospital enriched the process of data collection and analysis. I approached the study with a lot of practical knowledge and experience about the area of mental health and addressed certain aspects of the study easily. Yet I had to be mindful that times had changed, especially with the trend of fast growing urbanization and improved technology. Thus, I had to guard against over relying on my past experience and was open to gaining new insights from the family caregivers as participants. During data collection, I wrote fieldwork notes to enable me to reflect on my interactions with family caregivers and fieldwork experience as a whole. The notes and reflections were used during data analysis and shared with my supervisors (second and fourth author) during our meetings for more clarity (Gearing, 2004).

Credibility

Credibility refers to how much the data collected accurately reflects the multiple realities of the phenomenon (Yin, 2003). In order to ensure credibility and enhance rigor for this study, methods of data collection were triangulated (interviews, informal conversations, observations and reflections). In addition to triangulation of methods of data collection, together with my research assistant, we listened to the recorded interviews to ensure that we both understood and agreed to what family caregivers as participants had said in response to the interviews, before data analysis was done. Rubin and Rubin (2012) advised that researchers should have a sturdy safety system that protects the data collected from the hands of any outsider, i.e., providing a protected password system for the filing and storing of research data (P. 85). Thus, the first author typed all the interviews into Microsoft word program in a personal computer which was pass-worded, and each participant was given a separate file.

Data analysis

Interpretive Phenomenological Analysis (IPA) was used to analyze data. The IPA approach enables a researcher to make a detailed analysis of personal accounts of participants followed by a presentation and discussion of the experiential themes that are typically paired with the researchers' interpretation (Cotterill et al., 2017). Specifically, the IPA extends beyond traditional phenomenology in its distinct commitment to idiography (Dowling & Cooney, 2012; Pietkiewicz et al., 2014). The social constructionist view in IPA asserts that reality is socially constructed by the persons who experience a phenomenon (Rahi, 2017). As a method, IPA can be used to analyze studies involving one or more participants, as well as a group of people experiencing the same phenomenon in the same context. When working with large samples, one can follow the same set of steps as outlined for working with an individual participant; however, the analysis of each case cannot be so detailed (Love et al., 2020; Smith et al., 2009). With large samples, the emphasis may shift more to assessing what the key emergent themes for the whole group were. Subordinate themes, also known as "personal experiential themes (PETS)", are smaller, more specific themes that emerge from the data, and often nested within broader themes (Smith et al., 2022). According to Smith et al. (2022), superordinate themes, also referred to as "group experiential themes (GETS)", are larger overarching themes that encompass multiple subordinate themes and provide a higher- level understanding of the phenomenon being studied. Data analysis was conducted as an iterative process that included multiple readings of transcripts. The first author began with the interview that was found most detailed and engaging and identified subordinate themes for each question until all the questions were covered. A code book was developed and subordinate themes numbered chronologically for each question. After identifying subordinate themes, the analyst should think of how they fit together; however, this level of analysis is not prescriptive, and the analyst is encouraged to explore and be innovative in terms of organizing the analysis (Smith et al., 2022; Vicary & Ferguson, 2024). After identifying subordinate themes, subsumption which refers to where an emergent theme itself acquires a super-ordinate status as it helps to bring together a series of related themes and numeration which reflects the frequency by which super-ordinate themes appear throughout the transcripts were used to identify super-ordinate themes for each question (Love et al., 2020; Mant et al., 2019; Marshall et al., 2020). Taking into account the frequency with which a theme is supported can be one way of indicating its relative importance (Kettell, 2018; O'Mahony et al., 2024; Smith et al., 2009). In this study, themes were identified manually from each family caregivers' transcript, and final analysis was done for the whole group with quotations from individual family caregivers, so as to maintain an idiographic focus (Dosanjh et al., 2021; Epstein et al., 2023). The first author analyzed and coded all the data after which files were shared with the second and fourth authors who independently reviewed the files. Discrepancies between the authors were discussed and consensually agreed.

Results

Four superordinate themes on descriptions of schizophrenia and attitudes of community members toward patients and their family caregivers were identified. These were as follows: (a) Schizophrenia is a very disturbing and difficult illness to understand, (b) Treatment is Only Sought from the Hospital, (c) Community members are familiar with seeing mentally ill patients and (d) Community members have no problem with family caregivers. Each of the superordinate them is discussed in detail.

Schizophrenia is a very disturbing and difficult illness to understand

Schizophrenia was perceived as a very disturbing and difficult illness to understand. Fifteen family caregivers described how schizophrenia had affected their patients under three subordinate themes: (a) schooling/career development, (b) challenges in finding a marriage partner and keeping in marriage, and (c) difficulty in finding and retaining a job.

Schooling/career development

Some of the patients after being diagnosed with schizophrenia could not continue with school. Patients were at different levels in their studies such as secondary school, undertaking training in a tertiary institution or at university level. Family caregiver 9, a 58-year-old, mother to a patient who had suffered from schizophrenia for the last 21 years stated:

> She could not continue with her formal education when she got the illness while in senior two. She used to score very low marks and was among the poor performing students in her class. So she decided to throw away all her books and said she was not going to study any more.

Similarly, family caregiver 12, a 45-year-old mother to a patient who was diagnosed with schizophrenia while at University and also her first born said:

> While in second year at campus, his academic performance started declining before he was diagnosed with mental illness and he had many course units to retake. He … stopped attending lectures and that was the beginning of a long journey for us. Among the many abnormal things he does, he watches the television most of the time and goes around telling people what he has summarized from different channels.

For family caregiver 20, a 34 –year-old brother to a patient who was a student at a religious institution said:

> While at the seminary, he started developing strange behaviors such as sitting outside at night to count all the stars in the sky … so, we took him to the hospital for treatment and life was never the same again and he never went back to the seminary to study.

Additionally, family caregiver 8, a 52-year-old male caring for his two children suffering from schizophrenia put it this way while talking about his daughter: “She did not sit her senior four exams because she was complaining of too much headache. We took her for a tailoring course but then the tutor said she was not following her instructions and was having trouble teaching her.”

When an individual develops schizophrenia, their cognitive functioning is affected. Having a child diagnosed with schizophrenia is a devastating experience for a family caregiver who has many expectations of their child. Thus, family caregivers get financially drained as they seek for treatment from different places for their patients which affects their care giving.

Challenges in finding a marriage partner and staying in marriage

Schizophrenia is associated with a reduction in chances of finding a marriage partner. Most patients either remain single or lose their marriage if they develop schizophrenia when they are already married. Family caregiver 1, a 57-year- old male caring for his niece stated: " . . . My niece never got married because of mental illness. She just produces children whose fathers we do not know. Even her youngest child we named him 'Kirogote' because we do not know who his father is . . . ."

In addition, family caregiver 4, a 59-year-old male caring for his aunt put it this way: "Due to mental illness, my aunt never got married and has no children. She remained at home with my grandparents. So she considers me as her own son who cares for her though I am her nephew."

A similar reply was from Family caregiver 8, a 52-year-old male caring for his two children with schizophrenia who said:

> Can you imagine having two children with this type of mental illness and you have to take care of them for all their lives? As you know, I do not expect them to get married and have a families of their own and move out of my home.

However, there were patients who were once married, but due to schizophrenia, their husbands abandoned them. Explaining about abandonment, Family caregiver 3, a 30-year-old male caring for his sister said: "her husband used to complain about her behavior such as not keeping the home clean and caring for their child and they would be quelling most of the time. Eventually the husband left her and married another woman." Similarly, family caregiver 22; a 32-year-old male and a son to the patient stated: "Our father kept complaining about her illness coming back (relapsing) necessitating her to be taken back to the hospital so frequently. He said that he does not have money to keep taking her for treatment so he left her and married another woman."

Besides patients finding it a challenge getting a marriage partner and for those married having higher chances of being abandoned by their spouses, those who were married had conflicts with their spouses which were likely to end up in divorce. Family caregiver 4, a 37-year-old female and wife to the patient. stated: " . . . he is a very difficult man and at times tries to fight me when I complain about home expenses. He tells me that he married me and I have to take care of him and the children because I am working and I get money . . . ."

In addition, family caregiver 17, a 59-year-old male caring for his wife stated:

> I do not get on well with my wife most of the time. She conflicts with people at home and when I complain about her behavior she tells me we can as well end the marriage if I am tired of her. That is why I prefer staying in our up-country home in the village most of the time and only come to Kampala occasionally to see her and the children.

Caregiving can be made more burdensome when there is a conflict of interest between the patient and their primary caregiver who at the same time is their spouse. In cases where the patient is not married yet they have children whose fathers are not willing to care for them, it can be costly for a family caregiver to take care of both the patient and their child/children. Such a situation also compromises sources of social support for primary caregivers as the patients under their care are totally depended on them for the rest of their lives.

Difficulty in finding and retaining a job

Some family caregivers stated that their patients could not find a job or continue with the one they were doing either because it was too demanding or the patients' mental functioning was greatly impaired. Family caregiver 6, a 27-year-old male and nephew to the patient said:

> He started by doing uncoordinated things like on day he grabbed our employer's bottle of water and money and said they were his. He also did many other unusual things and we realized that it was becoming too much for us and decided to take him to Butabika hospital.

This reply was also given by Family caregiver 11, a 40-year-old male, and brother to a patient, who said:

> My brother has been very disturbed for many years and was even fired from his place of work because of his abnormal behavior. Even when you look at how he dresses and talks you know he has a problem and cannot hold any job despite his qualifications as an accountant.

Giving a similar reply on issues of employment, Family caregiver 14 a 37-year-old female who was a wife to a patient said: " . . . he has been sick for some years and not working. He used to do business and was getting some good money, but now he has no income and so I have to meet all the home expenses . . . ."

Another reply was from Family caregiver 17, a 59-year-old male and a husband to the patient who reported that: " . . . she would wake up early and say she is not going to work without any serious reason. We had a family business but she mistreated the workers by being so abusive and it affected their working relationship . . . ". Additionally, Family caregiver 15, a 52-year-old female who was a Good Samaritan and taking take of the patient said:

> He used to work from my verandah as a cobra and was getting good money . . . send money to his people in village to buy for him animals for rearing, but when he got the illness, he got so disorganized and was even losing people's shoes which they had brought for mending, now he is not doing any work.

Patients with schizophrenia cannot hold a meaningful job because of the abnormal/unpredictable behaviors they present. Their cognitive functioning is also greatly impaired, thus they are not able to make informed decisions. The disease also makes it difficult for them to participate, understand or remember important issues such as those related to particular job descriptions. Moreover, some patients experience frequent relapses and may require re-hospitalization from time to time which affects their employment record ending up being terminated from the job.

Family caregivers also gave their explanations regarding how their perceptions of schizophrenia influenced their treatment, seeking behavior for patients under their care.

Treatment is only sought from the hospital

All twenty-four family caregivers explained what they thought was the etiology of schizophrenia and how it influenced their decisions to continue seeking treatment only from the hospital. Family caregiver 2, a 58-year-old male caring for his sister said: "Traditional healers just deceive you and take your money and the patient does not improve. Moreover they ask for a lot of money." Similarly, Family caregiver 4, a 59-year-old male caring for his aunt said:

> I do not believe in traditional healers. They deceive you and just eat your money. They cannot tell you that I cannot manage this sickness, but just ask for things like goats and chicken and you come back when they have taken your things yet the patient is not any better.

Additionally, Family caregiver 9, a 58-year-old mother, caring for her daughter said: "At first I thought it was witchcraft or cultural things disturbing her, I took her to the traditional healers but they were just eating our money and the patient did not improve. Moreover they used to ask a lot of money, until we gave up." Another reply was given by Family caregiver 10, a 52-year-old female caring for her sister who said:

> Our mother sold part of our land and took her to a traditional healer . . . . . . relapsed. We contributed more money as a family and took her again to the traditional healer but she did not recover. When she relapsed again, we told our mother that we had no more money to contribute and our sister was not getting cured so we decided that we will only be taking her to the hospital.

Family caregivers' impression of traditional healers could be equated to that of a conman who extort money from unsuspecting people. Thus, traditional healers can drain resources of uninformed family caregivers who continuously seek treatment from them for the patients they care for.

There were also some family caregivers who had more than one patient in the family suffering from schizophrenia and for them it was very clear that it was a genetically transmitted disease and treatment had to be sought only from the hospital. Family caregiver 8, a 52-year-old male caregiver for his son and daughter suffering from schizophrenia informed in this regard:

> I have two children with the same illness. An elder brother whom the patient follows also has the same type of mental illness and he also gets treatment from Butabika. The health workers told me that the illness is genetic in the family.

Additionally, Family caregiver 19, a 50-year-old male brother to a patient stated: "Mental illness is in our family. That I cannot deny because two of my brothers suffer from mental illness and recently my sister also got mentally sick. So what else can I say? I have to make sure I take him to the hospital for treatment."

Another group of family caregivers had either family members or close relatives who were medical professionals and had educated them about schizophrenia. Thus, for them it was very clear that their patients needed to be treated in the hospital. Family caregiver 12, a 45-year-old single mother to the patient stated: " . . . his father is a doctor, but we are not married legally so we do not live together . . . he educated me about his illness and supports me in taking care of him." Additionally, Family caregiver 16, a 49-year-old female caregiver for her 28–year-old son and patient reported: "My elder brother is a medical doctor and he educated me about the illness my son is suffering from."

As for Family caregiver 13, a 42-year-old male church leader and husband to the patient, the reason for seeking treatment only from the hospital was because prayers could not cure his patient. He said: " . . . when she fell sick, we prayed a lot and believed God for her healing . . . but we did not see much change. In fact I had given up on her but then I decided to bring her in the hospital . . . ."

Caring for patients at home involves interaction with other community members. Thus, family caregivers explained how the patients diagnosed with schizophrenia under their care were perceived by community members.

Community members are familiar with seeing mentally ill patients

Thirteen family caregivers reported that community members where they lived knew that there were patients with mental illness within their community, though they could not specify which type of mental illness patients suffered from.

Family caregiver 1, a 57-year-old uncle to the patient said:

> The people around us do not care about her. They are not bothered at all even when she moves around carrying her dirty things in the bag they know that she is a mentally ill patient. They even greet her by name and ask her about her child. They have seen her for very many years and to them there is nothing new about her illness, and it has become a normal thing for them.

Similarly, family caregiver 9, a 58-year-old mother to a patient stated:

> People say she does not beat or disturb them and not even a threat to children, like other mentally ill patients whom they see around so they have no problem with her. They even offer her foods to eat or some money to buy things. And when she is re-hospitalized, they ask about how she is doing.

Additionally, Family caregiver 21, a 60-year-old male and a retired religious leader caring for his younger sister replied:

> Our neighbors and other people around us got to know that she has a mental illness and they understand her very well. There are even some homes where she goes and finds they have kept food for her knowing that she leaves home without breakfast. It is surprising that one day she fell asleep by the road side and people recognized her and supported her to sit on a boda- boda (motorcycle) and brought her to me and I thanked them and God.

These reports from family caregivers 1, 9 and 21 suggest that people who have lived in the same locality with family caregivers regard patients as part of their community and do not stigmatize them. Patients who do not present with aggressive/destructive behavioral tendencies are easily accepted by the community, and the attitudes of community members toward the patients may also be influenced by the relationship they have with their family caregivers.

Although the majority of family caregivers reported that community members were used to seeing the patients they cared for, there were some family caregivers who reported that their patients were stigmatized and feared in the community because of their behavioral tendencies. However, these family caregivers were fewer compared to those whose patients were accepted by the community. This reply was given by family caregiver 5, a 54-year-old brother to a patient who was stigmatized: " … the people around us fear him because he had a habit of raping women. At one time he was badly beaten and lost his teeth." Similarly, Family caregiver 6 a 27-year-old male nephew to patient stated: "At one time he attempted to beat someone, so people here including the local council chairman said they do not want him in their community and that I should take him back to the village … "

According to the reports from family caregivers, community members only fear patients who have ever been aggressive to them. Even when they have been treated and discharged, the community still recalls their aggressive behaviors before they were taken for treatment. Thus, patients' aggressive behavioral tendencies are the main reason for being stigmatized by the community who fear for their safety, not necessarily because they suffer from schizophrenia.

Besides accepting patients who were not a threat to them and only stigmatizing a few with aggressive behavioral tendencies, community members got on well with their family caregivers.

Community members have no problem with family caregivers

Fourteen family caregivers reported that community members with who they live in the same residential area have no problem with them and some of their neighbors support them in caring for their patients.

This reply was from Family caregiver 7 a 32-year-old female caring for her mother, who reported: "They thank me for caring for my mother and have no problem with me. We have lived here for many years and the people around us are familiar with seeing her." Additionally, Family caregiver 8, a 52-year-old father whose son and daughter were both diagnosed with schizophrenia stated that: They sympathize with me and have no problem with me. They say it is a great loss for me to have two children with the same mental illness and they both dropped out of school." Family caregiver 13, a 42-year-old husband to a patient and a religious leader put it this way: "The people around us sympathize with me especially that some of our children are still so young and their mother is mentally ill and cannot take good care of them."

In contrast to community members having no problem with majority of family caregivers, some family caregivers who were tenants living in rented homes had problems with their neighbors. Family caregiver 14, a 37-year-old wife caring for her husband said: "We shifted from where we were staying after bringing him to the hospital because we had problems with the neighbors. Now in this new place nobody yet knows he has a mental illness." Similarly, Family caregiver 24, a 40-year-old female caring for her brother said:

> In this place we are still new. We shifted from where we were staying because they used to blame me. They would say that why do you stay with a person who is mentally sick? Why did you bring him here? He should be in the hospital because he can beat people or do other bad things.

Both Family caregivers 14 and 24 were not supported by their neighbors. In some places, tenants share facilities such as the compound with other tenants, which compromises their privacy. Some patients can even trespassed and go to the neighbor's home. Such an environment is not conducive for a family caregiver to live with a patient. Thus, they will end up not being supported by their communities or even stigmatized together with the patients under their care.

Discussion

The aim of this study was to assess family caregivers' perceptions of schizophrenia and their community members' attitudes toward them and the people diagnosed with schizophrenia under their care. Discussion in this section will focus on these areas as presented in the results section.

Schizophrenia is perceived as a serious disabling mental illness by family caregivers which makes their patients dependant on them for a long period of time. Moreover, most patients are diagnosed with schizophrenia around their productive years, a period also known as "the prime of life" (American Psychiatric Association, 2013; World Health Organization, 2022). After being diagnosed with schizophrenia, a patient cannot continue being productive such as pursuing career plans and have reduced employment and marriage opportunities (Marie et al., 2020; Sartorius et al., 2014). Barriers to employment for people with mental illnesses are multifaceted, and include those related to illness, treatment, and stigmatizing attitudes and discrimination (Reavley et al., 2017). Having cared for their patients for some years, family caregivers learnt that their patients were suffering from a chronic condition which can only improve with medical treatment. Some of the family caregivers got financially drained having initially sought care from traditional healers who charged them a lot of money yet their patients did not get cured. Moreover, some patients with a history of defaulting treatment or those who may not have transport to go for reviews on schedule end up in a relapsed state necessitating frequent re-hospitalization. According to the study findings, some of the family caregivers were educated on the causes of schizophrenia, others understood that it was a genetic illness running in their families, while some of them due to their religious beliefs had nothing to do with seeking treatment from traditional healers. According to Magliano et al. (2019), 61% of participants in a study in Italy cited genetic causes for schizophrenia. Family caregivers in Ethiopia who perceived schizophrenia to be a result of biomedical causes sought treatment from health facilities (Mall et al., 2017). The Diagnostical and Statistical Manual, of Mental Disorders 5th edition (American Psychiatric Association, 2013) states that schizophrenia is a genetically transmitted illness and can be passed on even to twins from their parents. Similary, a study conducted in Germany, Angermeyer et al. (2016), indicated that causes of schizophrenia were percieved to be genetic. Family caregivers in this study were also urban residents who are exposed to information of various types such as the internet and electronic media. It is believed that exposure to information leads to change in attitude and behavior, thus none of them believed in traditional/cultural causes of schizophrenia (Henderson et al., 2020). Knowledge influences the way family caregivers perceive mental illness and schizophrenia inclusively. Research shows that in Western cultures there has been a significant improvement in peoples' perceptions, and attitudes toward mental illness over time which is attributed to increased awareness of mental health issues (Henderson et al., 2020). Thus, family caregivers' perceptions about the causes of schizophrenia are important because they influence help-seeking, adherence to treatment, disease management and clinical outcomes (Caqueo-Urízar et al., 2015). All the factors put together, made family caregivers resolve to continue seeking for treatment only from a mental hospital. Moreover, Butabika hospital offers free services including meals and patients do not require an attendant to remain with them when they are hospitalized.

Greater Kampala Metropolitan Area (GKMA) as a geographic setting has its own unique living arrangements with some residents in the older age group having built their own houses and living as landlords in spacious residential homes. Some of them bought land and built, while others inherited it either from their parents or grandparents. In the context of GKMA, family caregivers in the above category are considered as "permanent residents" and these were the majority in this study. These older family caregivers have develop some form of bonding with their neighbors, and their residential areas are more of a community setup where most people know each other. The number of neighbors in a social network is larger for people who have been living at the current address for a longer time than others (van den Berg & Harry, 2015). Community members can easily relate with family caregivers as their neighbors, including supporting and accepting their mentally ill patients whom they consider as part of their community.

As a way of supporting family caregivers, neighbors occasionally helped to transport patients to the hospital for reviews/re-hospitalizations (Anab et al., 2018; Iseselo et al., 2016; Mokgothu et al., 2015). Such support indicates a closeness that family caregivers share with their neighbors. People are also slowly getting to appreciate that patients with schizophrenia are not as dangerous as they have always thought and neither them nor their family caregivers should be stigmatized (Naamara et al., 2022).

Moreover, when patients adhere to their medication, they stabilize mentally which encourages community members to accept them as any other community member. Thus, patients with schizophrenia can live a normal life if they continue to take treatment (Videbeck, 2011). It is only a few patients who present with aggressive behavioral tendencies who may be stigmatized by their community members. Moreover, most patients suffering from schizophrenia tend to withdrawal to themselves and can be in a world of their own which makes them less of a danger to people around them. Thus, findings from this study contradict those by Fitryasari et al. (2018) who found that most patients with schizophrenia are stigmatized in their communities which affects their chances of recovery. According to (Fitryasari et al., 2018), patients are also labeled by the community, including neighbors or extended family members, by using a term "madness," implying that the patients are hard to cure.

Study limitations

The study was limited to family caregivers in GKMA, thus findings may not be generalized to other areas of Uganda. However, with fast spreading urbanization and globalization, findings from this study may have a lot of similarity to other areas of Uganda and other countries in Africa. Data were collected from only family caregivers who although narrated their own caregiving experience, they may not have clearly represented views of their community members. Obtaining views of community members preferably through focused group discussions regarding patients with schizophrenia and their family caregivers could enrich findings. The study focused only on patients with schizophrenia with no comorbidity, yet living in an urban environment exposes patients to many other health risks such as non-communicable diseases which also need to be studied.

Implications for social work practice

The ever increasing numbers of people with severe mental disorders such as schizophrenia globally and more so in low resource urban settings of countries in Africa such as Uganda are an area of great concern for social workers. Weather practicing in a clinical or community setting, social workers intervene in their clients' situations by involving other significant people in their lives from different levels of society. The reasons for involving other people in the intervention process range from the need to create awareness about mental health issues to mobilizing resources from their community members. Based on the strength perspective which underpins social work practice, resources for enabling family caregivers to carry on with their caregiving role are located within themselves, their families as well as in their community members (Saleebey, 1996, 2000, 2011). This study indicated that community members had no problem with family caregivers and their patients and, in some cases, were supportive of both of them. Thus, social workers should utilize these findings to educate communities about mental health issues such as how to prevent/minimize mental problems as well as how to promote good mental health practices. Social workers should encourage communities to continue supporting family caregivers and their patients. Supporting family caregivers and their patients' benefits both of them in that it minimizes stress on the part of family caregivers, promotes their mental health as well maximizing recovery and minimizing relapses for patients. Social workers should take advantage of the supportive environment to family caregivers in GKMA to facilitate formation of therapy groups at the community level. Through therapy groups, family caregivers share their caregiving experiences with other family caregivers and encourage those who may be at the verge of giving up on caring for patients. Family caregivers themselves should manage therapy groups and take charge of their own situation. In Uganda for example, therapy groups for people living with HIV such as those formed by the AIDS support organization (TASO) have been very instrumental in providing social support for people living with HIV who are enrolled on anti-retroviral therapy (Atuyambe et al., 2014). As the strength perspective states, despite the undesirable situations that one may be going through, an individual has underlying/underutilized resources within themselves to handle their challenges.

Implication for mental health policy development

Uganda still lacks a mental health policy and only has a draft which was developed in 2016. Developing a clear and favorable mental health policy requires the in-put of all stakeholders who include service users and their family caregivers. Thus, findings from this study should inform policy-makers about perceptions of family caregivers regarding schizophrenia and their community members' attitudes toward them and the patients under their care. Well-informed policy-makers will design a favorable mental health policy which will strengthen the mobilization of community resources for family caregivers and the patients under their care.

Conclusion

According to this study, schizophrenia still remains the most disabling of all mental illnesses and complicated for family caregivers to care for patients due to its early onset in most patients and destructive/abnormal behavioral tendencies exhibited by some patients. Thus, family caregivers perceived it as a very disturbing and difficult illness to understand which affected their patients negatively in different ways. Family caregivers opted to continue seeking treatment only from the hospital which implies that they perceived schizophrenia as an illness with medical causes. Renovation and opening up of Butabika hospital to be accessed by the general public for different purposes, including utilization of its land for developmental projects by both the government and the private sector has led to increased public awareness of mental health issues and mental illness. The out-reach programs and resettlement programs regularly conducted by the hospital staff to the surrounding areas have also mitigated stigma toward metal illness. Thus, as per findings from this study, increased awareness and improved service delivery has led to a reduction in stigma toward mental illness leading to acceptance of patients and their family caregivers by their communities. Patients are now regarded as members of their communities, especially those who were born or raised in those particular communities. Mental health workers, particularly those involved in community mental health out-reaches such as social workers and community mental health nurses, should utilize findings from this study, to strengthen mental health service delivery in different parts of the country.

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Authors' contribution

Winfred Naamara was involved in data collection and analysis and drafted the first manuscript.

Justus Twesigye and Winstons Muhwezi participated in conceptualization of the study and review of literature.

Byamah Mutamba critically reviewed the draft manuscript and approved the final version for submission to the journal.

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