

Experiences of Persons Living Schizophrenia in Ghana

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Abstract

Living with a chronic condition such as schizophrenia comes with significant challenges. Yet, there is little data on the experiences of people living with schizophrenia in Ghana. This study explored the experiences of persons living with schizophrenia in the Cape Coast Metropolis of Ghana. The study adopted a descriptive phenomenological approach using purposive sampling technique to select nine (9) persons living with schizophrenia for the study. Data was collected using face-to-face in-depth interviews. Interviews were taped, transcribed verbatim, and analysed following Colaizzi's (1978) descriptive phenomenological data analysis approach. The study revealed that people with schizophrenia maintained their Activities of Daily Living such as washing, sweeping, maintenance of personal and environmental hygiene, so long as they were in their lucid interval. Study participants valued supportive relationship with family members, mental health practitioners, religious institutions and the social networks. Participants reported stigma and lack of job opportunities as some of the major challenges they faced. Non adherence to medication and stigmatization were perceived as common cause of relapse by participants.

Background

Schizophrenia is a chronic and severe mental illness which affects the social and economic lives of sufferers and poses a considerable burden on patients and their families. The condition is characterized by interferences in perceptions, thoughts, feelings and behaviors of the affected person (Nolen-Hoeksema, 2014). Schizophrenia affects over 21 million people worldwide (World Health Organization, 2016). The prevalence of schizophrenia is estimated to be four in 1000 persons (Saha et al., 2005; American Psychiatric Association [APA], 2009). Schizophrenia typically begins in early adulthood and normally runs a chronic course (Nolen-Hoeksema, 2014). Persons living with schizophrenia generally experience difficulties in their social functioning including difficulties in getting jobs, marriage and living independently leading to reduced quality of life (Corrigan & Watson, 2002).

Schizophrenia is among the top ten medical diagnoses of people occupying National Health Service (NHS) beds in England (Pillay & Moncrieff, 2011). Naber and Lambert (2009) posits that about one to two percent of all persons worldwide suffer schizophrenia.

There have been several interventions for people with schizophrenia to maintain a good quality of life (Morin & Franck, 2017; Chan, 2011). However, despite these interventions, a greater proportion of them often relapse and struggle to maintain a good quality of life (Abdelsalam & Gaber, 2017). Reoccurrence of signs and symptoms of schizophrenia after treatment continues to dominate the lives of persons suffering from Schizophrenia. This period of recovery and remissions have contributed to the phenomenon widely known in the field of mental health as the 'revolving door' syndrome. A phenomenon which denotes a cyclical pattern of short-term readmissions to the psychiatric units of health care centres by young adults with chronic psychiatric disorders (Garrido & Saraiva, 2012). There have been mixed

reactions by persons who have lived with schizophrenia over a period of time. These experiences of sufferers have been both positive and negative (Kazadi, Moosa & Jeenah, 2008).

A return or worsening of symptoms following a period of remission is often referred to as relapse (Joukamaa et al., 2006). Relapse has characterized lives of people living with schizophrenia; only in about 10 to 20 percent of people treated for schizophrenia do not suffer relapse (Sariah, Outwater, & Malima, 2014). Often, people suffering from schizophrenia have multiple relapses over time. The issue of relapse is particularly significant in mental health due to the relevance of mental stability in holistic health; thus, relapse is an issue of global concern (World Health Organization [WHO], 2013).

Living with schizophrenia poses a lot of challenges to the individual and their carers (Kannappan, 2009). It is stated that, in regular care, 80% of patients with a diagnosis of a first episode of schizophrenia have experienced relapse, often multiple times, within 5 years of treatment or remission from their first episode (Kazadi, Moosa & Jeenah, 2008).

Mental illness particularly, schizophrenia, presents a serious health care problem in many African countries (Roberts, Mogan & Asare, 2014). Mental illness is the most prevalent non-communicable diseases worldwide (Kessler, et al, 2009). It negatively affects both the patient and the family members financially and socially (Kessler, et al, 2009). Mental health has been shunned in Africa, and a number of reports reveal a higher prevalence of stigma and relapse in this part of the world (Barke, Nyarko & Klecha, 2011; Fournier, 2011; Kakuma, Kleintjes, Lund, Drew, Green, & Flisher, 2010; Mishra, Lucksted, Gioia, Barnet, & Baquet, 2009). Much attention has not been given to issues of mental health compared to other general medical conditions in Africa including Ghana. This may be attributed to the view that mental illness is not contagious or infectious.

The Mental Health Authority (MHA) of Ghana in its 2019 mid-year report, put Schizophrenia as the leading psychotic condition across the country (Duah, 2017). In Ghana, the concept of schizophrenia has been investigated from the point of view of healthcare practitioners, carers and families of persons suffering from schizophrenia (Pasadas & Manso, 2015; Omolayo, Mokuolu, Balogun, Omole & Olawa, 2013; Quinn & Evans, 2010; Li & Arthur, 2005). Studies have also been carried out on the experiences of people living with chronic conditions such as HIV/AIDS and other mental conditions such as dementia (Agyeman et al, 2019; Gyamfi, Hegadoren & Park, 2018; Dako-Gyeke, Dako-Gyeke, & Asampong, 2015; Wright & Mwinituo, 2010; Greeff et al, 2008; Emler, 2007). Furthermore, studies have also been carried out on the impact of mental illness, specifically schizophrenia on family members (Dadson, Annor & Yendork, 2018; Aryeequaye, 2016; Gerson et al., 2011; Teschinsky, 2000) and on care giver experiences in the management of persons living with schizophrenia (Gloria, Osafo, Goldmann, Parikh, Nonvignon, & Kretchy, 2018; Ae-Ngibise, Doku, Asante & Owusu-Agyei, 2015; Opoku-Boateng, 2016; Animwaa, 2013, McDonnell, Short, Berry, & Dyck, 2003).

However, studies exploring the experiences of the persons living with schizophrenia in Ghana are lacking. It is therefore not clear what the experiences of people living with schizophrenia are regarding the condition and the associated relapses and what meaning they make of their experience in Ghana. It is

argued that the service user is the primary source of any information regarding their lived experiences and the best person to define recovery and relapse (Patterson, Mullen, Gale & Gray, 2011; Mezey, Kavuma, Turton, Demetriou, & Wright, 2010; Till, 2007).

Hence, as health professional, there is the need to ascertain the meaning that sufferers attach to schizophrenic illness in order to tailor care to meet their health care needs. This study therefore sought to explore the experiences of persons living with schizophrenia in the Cape Coast Metropolis of the republic of Ghana.

Methods

Study Design: The qualitative study adopted descriptive phenomenological approach for the study.

Study Setting: The study explored the experiences of persons living with Schizophrenia in the Cape Coast Metropolis (Southern Ghana). The Central Region is one of the two regions in Ghana with a public psychiatric hospital known as the Ankaful Psychiatric Hospital. It is the only psychiatric hospital in central Ghana that provides mental health services to persons living with severe mental illness on outpatient and inpatient basis.

Study Population: The target population for the research included all persons living within the Cape Coast Metropolis with a diagnosis of schizophrenia.

Sampling and sample size: Purposive sampling technique was used to recruit nine (9) individuals with schizophrenia when it was observed that no significant new information was being gathered from participants regarding the phenomena. This phenomenon is often referred to as data saturation in qualitative studies (Morse & Field, 1998).

Data Collection instrument and Procedure: Data was collected using semi-structured interview schedule. The interview instrument was pre tested with no significant changes made to the schedule. Study participants were interviewed face to face at designated areas predetermined by the participants. All participants were contacted through telephone calls and followed up with home visits to explain the study in details.

Informed consent was ensured and participants were made aware that participation was voluntary. The date, time and place for the interviews were negotiated with participants. All participants who were contacted chose to be interviewed in their homes.

A period of one month (25th May to 22nd June, 2020) was used for the data collection exercise observing all appropriate Covid-19 preventive protocols, such as social distancing, wearing of nose masks, handwashing and hand sanitizing. A total of nine tape-recorded interviews with the nine (9) persons living with schizophrenia were carried.

Methodological rigor: This was ensured by adopting approaches postulated by Lincoln and Guba (1985), which includes credibility, transferability, dependability and confirmability. Credibility, the accurate and truthful depiction of a participant's lived experience, was achieved in this study through continued engagement and persistent observation to describe the context of the phenomenon and to minimize distortions that might interfere with the data. Transferability was also enhanced by using purposive sampling method, to purposefully select individuals who met the inclusion criteria and were willing to provide a rich description to come out with a robust data with a wide range of information through detailed and accurate descriptions of participants' lived experiences of schizophrenia by continuously returning to the texts. Dependability was also achieved by having an expert qualitative nursing researcher to review the transcribed material to validate the themes and descriptors identified. The aim here was that, both analysts agree on the findings related to themes and meanings within the transcribed material. Confirmability was achieved by documenting the procedures for checking and rechecking the data throughout the study. The collected and analyzed data was presented to the study participants, to ascertain whether the narrative was accurate and a true reflection of their experiences

Ethical considerations: The study commenced after an ethical clearance to carry out the study was given by the Institutional Review Board of the University of Cape Coast. To maintain confidentiality and anonymity, each participant was given a pseudonym during the interview and was used throughout the study. The data was secured on the computer with password protection and was only accessible to the researcher.

Data analysis

The figure below is a display of the step by step approach employed in the analysis:

[See figure in supplementary files]

All interviews were transcribed verbatim into written text for analysis. After each interview, the researcher listened to the audio recording over and over to make sense of what the participant said and also to determine whether some clarification was needed. There were instances where study participants were reached on phones to seek clarification and validations on certain responses given during the interview. The transcripts from the audio recorder were reviewed several times to obtain accurate accounts of the interviews. The seven steps in descriptive phenomenological data analysis by Colaizzi (1978) were followed for the analysis.

Firstly, familiarization with the data took place. To achieve this, the researcher familiarized himself by submerging in the data and carefully and read thoroughly each transcript several times to gain full understanding. Second, significant statements which were of direct relevance to the phenomenon under investigation were identified. An example of a significant statement regarding the impact of

schizophrenia included; *“..... this illness has really affected my work because if it had not been this illness, I know where I wanted to be in future would not have been this.*

The third step focuses on formulating meanings by identifying meanings relevant to the phenomenon. Several meanings were formulated from the significant statements which were generated at the second step. Examples of formulated meanings included; the economic impact of schizophrenia, labeling by people, religious support, family support available, reoccurrence of the condition etc.

The fourth step focuses on clustering of themes, where the researcher clustered the formulated meanings into themes that were common across all participants' accounts and were significant to the phenomenon under study. At this stage, bracketing was ensured so that the researcher's assumptions, presuppositions and what is already known pertaining to the phenomenon was put aside during the data analysis (Ahern, 1999; Gearing, 2004; Speziale & Carpenter, 2007). All that was known about schizophrenia and individuals who have lived with the condition over a period was written down and the researcher made sure he did not jump into conclusions based on what was known about the phenomenon prior to the study. As much as possible, the voice of the study participants was given the needed attention during the study. The fifth step is about developing an exhaustive description of the themes, where the researcher wrote a full and inclusive description of the phenomenon incorporating all the themes produced in step four. The sixth step of the analysis talks about the production of fundamental structure where the researcher condensed the exhaustive description down to a short, dense statement that captured just those aspects deemed to be essential to the structure of the phenomenon. Essentially, the sixth step is where the report of the study was generated. Finally, the seventh step related to seeking verification of the fundamental structure. This is where the fundamental structure statement (report) was returned to all study participants to ask whether it captured their experience. This was done via telephone calls and was duly recorded with the consent of the participants. Earlier steps in the analysis were modified in the light of this feedback. Issues other than the phenomenon of concern were not factored into the report. For instance, persons who had medical conditions such as diabetes mellitus and renal complications were given audience during the interview but their concerns regarding their medical conditions were not factored into the report which was explicitly on the experiences of living with schizophrenia. Consequently, the data were analyzed using the seven steps stated above.

Results

Demographic Characteristics of the Respondent

The table below displays the demographic characteristics of study participants

Table 1
Results of Demographic Data (N=9)

Demographic Information	Frequency	Percentage (%)
Marital status	2	22.22
Married		
Single	7	77.78
Age (in years)		
20-30	1	11.11
31-40	3	33.33
41and above	5	55.56
Gender		
Male	3	33.33
Female	6	66.67
Religion	8	88.89
Christianity	1	11.11
Islamic	4	44.44
Educational background	4	44.44
B.E.C.E	1	11.11
WASSCE/NVTI	12	22.22
Diploma	5	55.56
No. of Years with Schizophrenia	2	22.22
1-10		
11-20		
21 and above		

In this research, three main themes are used to present the findings. These are:

1. Living with schizophrenia.
2. Perception and experience of schizophrenic relapse.
3. Coping with schizophrenia

The first theme describes the experiences of participants with regard to living with schizophrenia. This theme produced six sub themes:

1. Maintaining daily activities of living

2. Building and maintaining relationships
3. Experiences with medication
4. Seeking and receiving support
5. Experience of stigmatization
6. Acquiring and maintaining a working life

Activities of Daily Living

Study participants expressed their views on maintaining daily activities of living. All nine participants disclosed that having lived with schizophrenia for a number of years, they have come to accept that, the condition is part of them and something to live with them for the rest of their lives. They indicated that despite their condition they are able to take care of their daily activities such as meeting their personal hygiene needs, nutritional demands and sleep. Bella, Mercy, Sheila and Terry had this to say:

Bella

"Living with this condition you call schizophrenia has not affected the way I eat, sleep, bath, wash, among others. I eat very well; I enjoy my sleep and always take care of myself very well.

Mercy

"... The condition has not affected my daily activities at all. I do everything normal in the house. For example, I wash my clothes, sweep the compound and even arrange my brother's room nicely for him anytime his room is dirty. This has become my normal routine in most times.

Sheila

"It has not affected my daily activities in any way.

Terry

.....I have been living with this condition for several years without any interferences in the discharge of my daily activities both at home and when I go to school to teach. I do my things as expected of every human being. I maintain my home very well before going to school.....

Building and maintaining relationships

Relationship with Family

In exploring the relationship between study participants and their family members, the study findings indicated that, participants were able to maintain a good and positive relationships with people around them.

To the study participants, family members have good relations with them and have been supportive since they were diagnosed with schizophrenia. It is significant to note that mothers were seen to have had a good and positive relationship with most (six) of the participants compared to other family members. The accounts by participants revealed that these family members, especially mothers, show love towards them at all times and understand their condition. Below are narratives of how participants recounted the relationship they shared with family members:

Terry

Family members especially my parents and my siblings did not abandon me when I was diagnosed with schizophrenia. They rather encouraged and supported me in providing with some basic needs for my upkeep.....

Godswill also had this to say:

"... I am very close to my brothers, father and other siblings...we relate very well. My mother, for example, is the one who collects my medicine from the hospital for me and administers them to me when it is time to take my medication.

Forgive recounted:

.... My siblings and my mother are on good terms with me even with this condition.

Mercy added:

....My mother, for example, understands me better than any other siblings. She offers me help in terms of finances and other basic needs such as helping me to buy my medication when they get finished, providing food and shelter and encouraging me to stick to the treatment plan.

It is worth noting that, although six participants verbalized having a positive relationship with family members right from the first day of their diagnosis, three of the participants indicated having challenges initially with family members when they first got to know that they were living with schizophrenia.

Beauty also recounted:

.... At first, my family members, including my own parents thought I had been cursed by someone, that is why I have become a mentally ill person. In fact, they did not want to eat with me when I came home. They were of the view that, if they ate with me, they could also become mentally ill persons. It took the intervention of nurses who came to my house to educate them on my condition before they accepted to relate well with me.

Shallom added that:

....I greet them and do what I am supposed to do all the time.

Relationship with Mental Healthcare Providers

Participants also described their relationship experiences with mental health practitioners like nurses, doctors and other health workers in the mental health facilities. According to the participants, caregivers like nurses and doctors show a lot of concern about their conditions especially when they visit the mental health facilities. Participants revealed that in most cases, nurses and doctors complement what family members do for them.

Forgive had this to say in relation to her relationship with care givers:

.. As for the nurses and doctors, I think they are praying and wishing that I become completely free from this illness. This is because they call me on the phone to check up on me. The nurses are very good and caring. They are even part of the reasons why am feeling fine. They have been supportive and I am proud of them.

Shallom also added that:

.....The nurses, for example, do not joke with me at all especially when I visit the mental health facility. I don't know where I would have been by now had it not been the support of the nurses at the mental facilities. The nurses take good care of me ...

Favour said this:

.....The nurses and doctors at the mental facilities are very good to me. I remember any time I go to the hospital for example, the nurses will quickly attend to me and arrange a doctor to see me. I like the way nurses attend to me at the hospital.

Sheila also recounted her experience with care givers:

.....The staff have been supportive in many ways, at times they help me to get my medications and pay when I have the money. In fact, they have been a blessing to me all these years..

Marital Experience

On issue of marriage, the study sought to find out how living with schizophrenia has influenced participants' experiences with marriage and marital relationships. Findings from the study revealed that, two (Terry and Forgive) out of the nine participants were married and were happily living with their spouses. The married ones indicated that they had a positive marital relationship. The other seven who were not married shared various experiences with regards to marriage.

Terry reiterated:

.... You see, my current wife at times makes some funny comments about me but she does not use my condition to insult me or look down on me. We are living peacefully here.

Forgive added that:

".... If you get someone who really understands you, you will enjoy your marriage. In my case, my husband really understands me. He has been my source of encouragement."

Out of the seven participants who were not married at the time of data collection, *Sheila* and *Mercy* explained how potential suitors upon finding out about their mental illness withdrew from them.

Sheila

..... then he said, is this mental drug? I responded yes. Then he asked me if I am suffering from mental illness, which I said yes. Since then, he has not called me again.....

Mercy

.....This condition scares men from me... they don't want to marry someone with mental illness.

The two participants' accounts above suggest that the diagnosis of mental illness has the potential to negatively affect a woman's opportunity for marriage.

Experiences with medication

Four of the respondents (Bella, Sheila, Shallom, and Godswill) indicated that taking medicine to support them had been part of them since they were diagnosed with schizophrenia. They recounted that the medicine has been part of their optimism because it is the only thing that suppresses the impact of the illness on them.

Bella :

.... Oooo the medicines are very good and they have been supporting me in staying healthy....

Sheila added that:

.... I am okay anytime I take my medicine. They are my source of hope. Due to this, I don't joke with my medication intake

Shallom also recounted that:

...since I was put on the psychiatric medications, I don't hear voices again. I am now able to live a better life. The medication has helped me a lot.

Godswill also added that:

...It has contributed to my recovery all this while.

The responses imply that medicine intake has been of great help to the study participants as far as the condition is concerned; suppressing the impact of the condition on the study participants.

Another basic thing derived from the responses of the participants was that although some had it a bit easier adhering to the medication intake, some participants found the intake of the medication a bit challenging. In other words, some participants recounted some adverse side effects associated with the medication. The side effects varied from one individual to the other. For example;

Beauty asserted that:

.....I feel hungry whenever I take my medicine. Also, anytime, I take the medicine in the night, I cannot teach the following day in school because I will feel drowsy throughout the day. I am sometimes unable to move about with my normal daily activities.

Favour also recounted:

.....The medicine makes me very weak and dizzy. Due to that, I sleep a lot..

It was noted from study that, although respondents had both negative and positive experiences with their prescribed medications, they continued to stick to treatment plan in order to remain healthy.

Seeking and Receiving Support

Family Support

Favour, Terry, Forgive and Shallom reiterated that, the family especially their mothers offer them some support while living with schizophrenia.

Favour

..... my mother especially tries very hard to encourage me not to think negatively about this condition.

Terry added:

.....as for my family, they always check on me to see how I am faring..

Forgive recounted:

..... I don't have any problem with family support. The people in my house have been very supportive. They even remind me of my review dates and give me transport fare to the clinic at times.

Shallom indicated:

..... I am a student and my family, especially my mother has been very supportive. She buys all my medication for me and encourages me when she sees that I am quiet or moody.

Support from other Institutions

Four participants asserted that their main source of support was from family. However, some institutions have been of great support to them. These institutions according to the respondents included the church and social welfare department. They provide certain basic needs to supplement what they received from family as well as mental healthcare practitioners. The following responses illustrate this assertion.

Favour asserted:

...the social welfare department offered financial support to me last year. They came to visit me with some mental health nurses, then I told them of my challenges in life..

Terry added:

... The church has been a great source of help to me. They pay regular visits to check how I am faring.....

Forgive again recounted:

"..... It is only my church that offers support to help me in this condition. My church helps me financially and sometimes too offer food items for my general up keep....."

Shallom added that:

... the social welfare department in Cape Coast once supported me. It was in cash. I even used some of the money for both medication and my general upkeep.

The responses suggest that participants receive financial and other forms of support from the social welfare department and the church. This means that apart from family members who offer support to these individuals with schizophrenia, other institutions like the church and social welfare departments have taken upon themselves to put a smile on the faces of individuals.

Perceived as Different: Experience of Stigmatization

On the issue of stigmatization, the respondents indicated that stigma is one major negative experience they have had in relation to living with the condition of schizophrenia. Almost all the participants were of the view that people in their community are the very ones who stigmatize against them. Participants shared their stories of how people in their various communities point fingers at them calling them with different names. They, therefore, labelled them as being different:

Beauty

.... People in my area call me a mentally ill person.the name calling is too much for me especially outside my home. I thank God for giving me the patience to contain some of the abusive words people utter when I go outside.

Mercy

..... Stigmatization is what kills my spirit. One day, whilst I was teaching, I could hear the children giggling behind me in the classroom and it disturbed my class a lot.....

Sheila

..... Stigmatization is the major negative experience associated with this condition... my colleagues at work point fingers at me and say all sort of negative things about me. They say my mind is not working etc..... One day I was going to church, I stopped a car and when I was about to board the car, one person in my area quickly run to inform the driver that I am a mad person so the driver should not pick me oooooo.... the driver left because of what he heard and I had to walk to church that day.

Forgive

".....People tell me that, as for me, my mind is not correct. They say I am mentally sick. Due to this, people sometimes fail to sell items such as food to me. "

Participants' accounts above suggest that stigmatization is associated with schizophrenia just like any other mental illness, however, the accounts point to the fact that most of the name calling and negative comments come from outsiders but not within their immediate homes. This has serious negative impact on participants' effort to maintain resilience.

Acquiring and maintaining a Working Life

The participants noted that living with the condition of schizophrenia has affected them negatively in terms of work and other job opportunities. This is because, during relapse, people with schizophrenia lose control of themselves, therefore they are unable to be active at work. Two participants (Terry and Mercy) verbalized being absent from work most of the time when they experience relapse. They further indicated that, long periods of absence from work often led to a reduction in their income, financial constraints and low job satisfaction.

Terry

As a teacher, I always had a sick leave to stay out of work as soon as there is a change in my behaviour at the workplace. This in a way is affecting my work because as a teacher, I am expected to always be in school and teach the students so they can pass their examination.

Mercy

"... This illness has made me inactive in terms of working. I cannot do any work. The sickness has made me lazy to the extent of lacking the urge to do any

Another meaning derived from the response was that some individuals living with this condition lose their job and other job opportunities. According to two other respondents (Sheila and Godswill), persons who suffer from schizophrenia sometimes lose their jobs because of the interruptions associated with the

illness. Others are also denied of jobs because of this condition, thereby making them unemployed at some point in their lives.

Sheila

...I used to work in the aviation department as a security staff. One day, I was told to go home and that I would be called back. I did not hear from them again. I lost my job because of this condition. It was a painful experience..

Godswill

.....I lost my job because of this condition. I was working with a certain company but they said I was talking to myself and threatening people at the workplace so they sacked me. .

The responses suggest that study participants with schizophrenia are denied job opportunities and are sometimes sacked from their jobs due to their condition. Some of them also become absent from their work due to the challenges associated with the condition.

The second theme describes how participants perceived and experienced relapse in relation to schizophrenia. This theme also produced two sub themes:

1. The perception of relapse as illness reoccurrence
2. Experience of schizophrenic relapse

The objective of this second theme was to inquire into the perception of relapse by persons living with Schizophrenia. Under this section, two sub themes emerged from the data. They are; the perception of relapse as illness reoccurrence and experiences of schizophrenic relapse.

The perception of relapse as illness reoccurrence

Data from the respondents regarding their perception of schizophrenic relapse indicated that schizophrenic relapse is the reoccurring of their condition. To most of the participants, schizophrenic relapse occurs when they fail to take their medication. According to five participants (Bella, Favour, Terry, Forgive and Sheila), this condition has reoccurred several times in their lives. They saw relapse as the reoccurrence of signs and symptoms of their condition which were once under control. The following are accounts of five study participants:

Bella

.....Relapse is the coming back of this illness they call schizophrenia. Hmmmm.... that is how this sickness has been oooo... it goes and comes back....it is supposed to go completely but when it goes, it comes back again.

Beauty

.....Relapse means my condition has come back. It is when a person is treated and discharged of schizophrenia but the person is later seen on the streets exhibiting some traits that previously was shown when the person was being nursed in a hospital..

Favour

.....I believe that, there is schizophrenic relapse when the condition reoccurs several times in my life.

The responses showed that the study participants perceived schizophrenic relapse as the reoccurring of schizophrenia to the individual who has been diagnosed with schizophrenia.

Another inference made from participants' accounts was that individuals experienced schizophrenic relapse when they fail to constantly adhere to the treatment plan prescribed for them by mental health practitioners. Three of the participants (Beauty, Shallom and Godswill) noted that, they experienced relapse when they stopped taking their medication. This suggests that strict adherence to medication can reduce the risk for relapse.

Beauty noted that:

.... I usually experience a relapse when I stop taking my medication. For instance, after 13 years of resilience, I thought I was fine so I stopped taking my medicine without any medical advice. Suddenly, I started experiencing some strange things in my life. I took to the street, started talking and doing all manner of things like singing, laughing unnecessary, dancing

Shallom added:

"..... To me, relapse occurs if I don't take my medication. At times, I sense it but I cannot control myself unless I take my medication. So, I know that if I don't take my medication, I will suffer from relapse. Due to this, I usually take my medication.

Godswill reiterated that:

..... Anytime I stop taking my medication without advice from professional, I see those signs that led to my previous admission..... I talk unnecessarily, blame people without any cause, argue with people and sings a lot. n.

Furthermore, it was evident from almost all the participants that they experienced relapse as a result of stigmatization. They attributed their relapse to excessive thinking following a stigmatizing experience. Two participants (Favour and Mercy) explained that schizophrenia had to do with the mind so if an individual always thinks and worry about how he or she has been stigmatized in the community, the possibility of experiencing relapse becomes very high even if the person strongly adheres his or her medication plan .

Favour noted that:

..... I experience relapse anytime I think about how I am treated in my community. I think a lot because this condition has made people in my area point fingers at me. People don't come closer to me because they think I am mentally sick.... I find it difficult to forget about this condition. This thing makes me think excessively thereby resulting in relapse.

Mercy added:

.....When people say all those negative things about me, I find it very hard to forgive them. It leaves me thinking about my condition; sometimes throughout the night. I don't sleep at all.

The responses indicate that participants viewed failure to adhere to their prescribed medication and stigma as the major causes of schizophrenic relapse.

Experience of Schizophrenic Relapse

Participants shared their opinions on some of the experiences they go through in their relapse state. The data indicated that participants have varied experiences as far as schizophrenic relapse is concerned. The common thing almost all of the study participants go through during relapse is change in behaviour. Five participants (Mercy, Favour, Terry Sheila and Shallom) explained that individual differences exist; so, what someone experiences during relapse may not be the same as the other person as far as relapse is concerned.

Mercy

.....Any time I suffer from relapse, I sing at a point, hear voices telling me about the death of my younger sister which is not true..

Favour

.... I usually isolate myself from people. I also roam about and hear voices telling me to get up and go and attack people. Even if I decide not to go, the voice will be stronger and then I feel like some people are whipping me for being disobedient.....

Terry

.... *In relapse state, I become quiet, talk to myself, sometimes strip myself naked in the streets and do not stay in my own house. I sometimes roam, laugh excessively and stay quite without talking to anyone.*

Sheila

.....*As for me, when I relapse, I don't talk to anybody in the house. I remain indoors, sometimes without food for days. However, when my mother comes to force me to eat, a voice will tell me to attack her.*

Shalom

...When this illness comes, I leave home. I walk for a long distance. I don't know what tells me to walk for that long distance but I can walk for the whole day.

The responses suggest that participants have varying experiences during the relapse stage. It was indicated that, although participants give account of what happens to them when they experience relapse, most of them do not have control over what they do.

Finally, the third theme recounts the strategies participants used to cope with living with schizophrenia. This theme is also supported by four sub themes:

1. Coping through personal strategies
2. Using medical measures to cope
3. Coping through family support system
4. Coping through religious support

This theme presents participants' accounts of coping with schizophrenia. Thus, the research question was posed as "what strategies do persons living with schizophrenia adopt to cope with the condition?" Under this section, four sub themes emerged. These included personal coping strategies, using medical measure, coping through family support system as well as religious support.

Coping Through Personal Strategies

The data revealed that respondents adopt personal measures in coping with schizophrenia. These measures according to the respondents, help them to maintain resilience. Most of the participants (Bella, Beauty, Forgive, Mercy, Sheila, Shallom and Godswill) expressed that the personal strategy they adopt most often to cope with their condition is deliberately trying to take their mind off the condition. In other words, participants were able to prevent schizophrenic relapse by avoiding excessive thinking or worrying about their condition and its associated impact on their living condition. Bella for example believes that accepting her condition and refusing to worry about it is a way to cope.

Bella

I have come to accept that I have this condition and so I don't worry myself with thinking about the condition to experience a relapse..

Forgive added:

".....This sickness has come to stay with me, so I have purposed in my heart not to think about the negative things associated with this sickness.

Shallom also recounted:

..... I don't worry myself with what people say about my condition.....

Godswill

..... The negative things associated with this illness do not worry me. I have come to accept that schizophrenia has become part of me so I don't bother myself with the negative things people say about me....".

This finding indicates that study participants living with schizophrenia adopt personal strategies that enable them to stay healthy.

Using Medical Measures to Cope

Participants submitted that apart from their own strategy, medical measures also help them to stay healthy. All participants except Shallom and Godswill were of the view that one of the major coping strategies has been the medical strategy. In this regard, participants adhere to the treatment plan given to them at the mental health facilities. They explained that failure to adhere to the treatment plan results in schizophrenic relapse.

Terry asserted:

.....The use of psychiatric medication has been my source of relief. It has helped me to stay healthy.....

Sheila:

.....The benefit associated with the medicine makes me to quickly rush to the hospital for some whenever I notice that I am short of medicine.

Forgive also opined:

... The medication has helped me a lot; it is my food. I do not skip my medication for any reason because, it has saved my life. Despite the bad side effects associated with the medication at times, I still think it is what keeps me from experiencing relapse.

Another medical strategy that Shallom and Godswill stressed that they have adopted to remain resilient all these years was support system provided to them by the mental health practitioners. They believed that mental health practitioners encourage them, visit them and offer them the needed education on the need to follow treatment plan. The practitioners also do follow-up checks on them to ensure they cope well with the condition. They also educate them on the essence of medication and personal hygiene.

Shallom further verbalized that:

..... Mental health practitioners encourage people living with this condition. To be honest, anytime I see them around or have a phone call with them, I get relieved. This has helped me in coping with this condition.

Godswill

..... I have received a lot of education about my medication and condition from the mental health practitioners. This has helped me in staying strong.....

The responses suggest that medical support system is of great importance to the study participants. This implies that adherence to medication and directions offered by mental health practitioners provide a lot of support to participants living with schizophrenia in coping with the illness.

Coping through Family Support System

Most of the study participants submitted that, as part of their coping strategies about their condition, their respective family members especially their immediate family provide support which complements other strategies as far as coping with this condition is concerned. According to Beauty, Favour, Mercy, Forgive and shallom, their families, especially mothers have supported them in providing their needs, encouraging and seeing it to that they are always safe. They added that their respective families provide financial support which aids them in purchasing their prescribed medicine in managing the condition. This money provided by their family is used for regular reviews to mental facilities are all. Beauty for instance, recounted how her father supports her by paying her medical bills and offering words of encouragement.

Beauty

.... My family, especially my father and mother, help me with money to pay my hospital bills. As for their words of encouragement, I cannot talk about it because they have been doing enough. They go an extra mile by checking if am following the treatment plan given to me by the health professionals at the mental health facility.

Forgive added:

...My family members especially siblings have provided a lot of help. They help me by encouraging me a lot....

Mercy also recounted:

..... My mother has been of great help in coping with this condition. She provides me with food, shelter, money for my medicine and general upkeep. My other siblings from time to time come around to check up on me.

Shallom opined:

...My mother supports me with my medication. She has been my source of hope from the first day I was diagnosed with this condition.

This finding suggests that participants received emotional and financial support, attention and care from family members, especially mothers. This implies that family members are likely to contribute greatly to the maintenance of resilience among study participants.

Coping through Religious Support

Beauty, Favour, Terry, Mercy, Forgive, and Godswill all expressed that, their belief in God keeps them going. This according to them prevents them from experiencing relapse. In other words, their religious faith has been a source of hope in keeping them healthy.

Beauty

.....When I lost my son, I thought about it too much and it affected me, but when I decided to leave everything to God, I had some kind of joy within me. So, with that experience, I believe one day, my God will heal me completely.

Forgive

.....Prayers give me some form of relief and I believe I have not suffered from relapse for some time due to my prayers. God has the healing power so surely; he will heal me from this illness.

Godswill

.... I am a good Christian. I have faith in God and this has been my source of hope all these years.

Another meaning derived from the data as far as a religious support system is concerned, had to do with the support participants received from the church. Bella, Shallom and Sheila submitted that, the church and the mosque as institutions provide a lot of support in terms of money, food stuff and prayers. This according to the participants help them to cope with the condition."

Bella

"...My church has been very supportive since I was diagnosed with this condition. My church has encouraged me a lot in staying healthy through prayers. They visit me, share the word of God with me and pray with me.

Sheila

.....The church has been of great support in coping with this condition..

Shallom

".... My faith Allah tells me that God is the true healer. Although I take my medications as ordered, I believe that, Allah is the true healer who can heal me of this condition.

The responses showed that religious beliefs, the mosque and the church as institutions help people with schizophrenia with spiritual and material support in coping with the condition.

Discussion Of Results

The objective of theme one was to explore the experiences of persons living with schizophrenia. Thus, the research question was posed as "What are your experiences of living with schizophrenia?" Under this section, six sub themes emerged. This includes, experiences of maintaining daily activities of living, building and maintaining relationships, experiences with medication, seeking and receiving support, being seen as different (experiencing stigmatization) and acquiring and maintaining working life.

On Activities of Daily Living, all nine participants disclosed that having lived with schizophrenia for a number of years, they have come to accept that, the condition is part of them and something to live with them for the rest of their lives. They indicated that despite their condition, they are able to take care of their daily activities such as meeting their personal hygiene needs, nutritional demands and sleep.

The finding above supports earlier study by Bejerholm and Eklund (2006). They also found that, living with the diagnosis of schizophrenia does not necessarily lead to an impoverished lifestyle. Rather, individuals with schizophrenia lived a normal and fulfilling lives.

On the issue of building and maintaining relationships, study participants reiterated that, family members have good relations with them and have been supportive since they were diagnosed with schizophrenia. It is significant to note that mothers were seem to have had a good and positive relationship with most (six) of the participants compared to other family members. The accounts by participants revealed that these family members, especially mothers, show love towards them at all times and understand their condition. Participants also described their relationship experiences with mental health practitioners like nurses, doctors and other health workers in the mental health facilities. According to the participants, mental health caregivers like nurses and doctors show a lot of concern about their conditions especially when they visit the mental health facilities. Participants revealed that in most cases, nurses and doctors complement what family members do for them.

Findings are consistent with that of Davis (2010). Davis found that people living with schizophrenia had united and close interactive living with family members.

A similar study in China by Wang, Chun and Xiong (2013) concluded that persons with schizophrenia build friendly relationships with mental health professionals like doctors and nurses. On the other hand, Johansson and Lundman (2002) concluded in their study regarding the subject matter that, patients with schizophrenia in Tasmania were ignored by health professionals.

Exploring participants' experiences with antipsychotic Medication, four respondents indicated that taking medicine to support them had been part of them since they were diagnosed with schizophrenia. They explained that medicines are always given to them to help them feel healthy and comfortable.

In support of the above findings, Karanci et. al, (2019) concluded that medication changed the general wellbeing of persons living with the diagnosis of schizophrenia from bad to good and is generally good for persons with schizophrenia.

On the experiences of marriage and marital life, it was evident among study participants that, people terminated their relationship with them when they got to know that they were living with schizophrenia. The participants' accounts suggest that the diagnosis of schizophrenia has the potential to negatively affect a person's opportunity for marriage. This finding goes in line with a study conducted in South Korea by Yu and Shim (2009) who explored the perception and experiences of marriage among couples with schizophrenia. They indicated in their study that, although persons living with schizophrenia often have very realistic views of marriage and are able to recognize benefits as well as demerits, participants had difficulties initiating and maintaining a marital life. Some females in the study verbalized experiencing restrictions and oppressions by their spouses that led to the termination of the relationship.

On seeking and receiving support, it was evident that, study participants receive support from their immediate families, the religious groups of affiliation and the social welfare department of the Cape Coast Metropolis. Participants indicated that, these institutions provide certain basic needs to supplement what they received from family as well as mental healthcare practitioners. Again, participants indicated that, they sometimes offer help in cash and sometimes in kind to them. The following responses illustrate this assertion

In relation to previous studies, Alexandra (2017) asserted in a similar study that, individuals living with schizophrenia faced a lot of challenges which include hostile interactions with family members. Again, Wang, Chun and Xiong (2013) concluded that government, as well as religious bodies, provide adequate and regular support in caring for people with schizophrenia.

On the issue of stigmatization, the respondents indicated that stigma is one major negative experience they have had in relation to living with the condition of schizophrenia. Almost all the participants were of the view that people in their community are the very ones who stigmatize against them.

Owoo (2017) also concluded that, persons with schizophrenia are highly discriminated against in their community. He further explained that stigma has prevented persons with schizophrenia from taking part in community social gatherings like wedding, naming ceremonies and funeral ceremonies.

Furthermore, in exploring participants' acquisition and maintenance of a working life, participants noted that living with the condition of schizophrenia has affected them negatively in terms of work and other job opportunities. In other words, the condition has interrupted their work, especially at the relapse stage.

Bradshaw, Armour and Roseborough (2007) found in New York that, persons with schizophrenia lacked job opportunities due to perceived limited social network. Their finding suggests that individual with schizophrenia were likely to suffer from obtaining employment.

The study further delved into the perception of persons living with schizophrenia and their and experience of schizophrenic relapse. The objective was to inquire into the perception of relapse by persons living with Schizophrenia.

Data from the respondents regarding their perception of schizophrenic relapse indicated that schizophrenic relapse is the reoccurring of their condition. To most of the participants, schizophrenic relapse occurs when they fail to take their medication.

A research by Sariah, Outwater and Malima (2014) recounted that discontinuation of prescribed antipsychotic medications leads to a relapse and maybe a stressor that causes severe and rapid relapse in persons with schizophrenia.

Participants further shared their opinions on some of the experiences they go through in their relapse state. The data indicated that participants have varied experiences as far as schizophrenic relapse is concerned. The common thing almost all of the study participants go through during relapse is change in behaviour. Five participants explained that individual differences exist; so, what someone experiences during relapse may not be the same as the other person as far as relapse is concerned.

Alsherif and AbdElrahman (2013) found that Persons Living with Schizophrenia always hear voices, laugh excessively, and talk alone when they relapse. It was indicated in the study that; relapse experiences of Persons Living with Schizophrenia are the same as the signs they experienced at the onset of the schizophrenic illness.

Finally, the study explored the coping strategies adopted by persons living with schizophrenia. Under this section, four key issues emerged. These included personal coping strategies, using medical measure, coping through family support system as well as religious support.

On the point of coping through personal strategies, data revealed that respondents adopt personal measures in coping with schizophrenia. These measures according to the respondents, help them to maintain resilience. Seven participants expressed that, the personal strategy they adopt most often to cope with their condition is deliberately trying to take their mind off the condition.

A study by Weisman (2005) indicated that Persons Living with Schizophrenia depend on personal strategies such as observing personal hygiene, playing games and engaging in daily living activities just to divert their attention from the negative aspects of the condition as strategies to cope with the condition.

Under using medical measures to cope, participants submitted that apart from their own strategy, medical measures also help them to stay healthy. Seven out of the nine participants opined that one of the major coping strategies has been the medical strategy. In this regard, participants adhere to the treatment plan given to them at the mental health facilities. They explained that failure to adhere to the treatment plan results in schizophrenic relapse.

Weisman (2005) confirmed this in a similar study by saying that adherence to prescribed medication is the major coping strategy of Persons Living with the diagnosis of Schizophrenia to cope with the illness.

In addition, most of the study participants submitted that, as part of their coping strategies in living with schizophrenia, their respective immediate family members provide support which complements other strategies. They added that, their respective families provide financial support which aids them in purchasing their prescribed medications and for transportation for regular reviews to mental facilities.

This was also confirmed by an assertion made by Wasserman (2010). According to him, the Persons Living with Schizophrenia depends on family support in coping with the condition.

Under coping through religious support, study participants reiterated that, their belief in a higher power keeps them from experiencing relapse. In other words, their religious faith has been a source of hope in keeping them healthy.

A previous study by Cheng (2017) revealed that persons with the diagnosis of schizophrenia cope well with the illness through religious activities such as exorcism or sacraments which they believed could restore their mental and physical wellbeing to normalcy.

Conclusions

The study came out with the following conclusions: Participants in their lucid state lived a normal life and could maintain daily activities of living successfully. Secondly, most participants maintained a cordial and peaceful relationship with family, and healthcare providers. Again, study participants verbalized being labelled and seen as different within the communities in which they reside. It was evident in the study that, non-adherence of medication and stigma are the common risk factors for episodes of relapse among study participants. Furthermore, study participants cope with the condition by adopting measures which include strict adherence to prescribed medication, personal strategies, religious coping and support system from family and mental health practitioners.

Recommendations:

Based on the findings of the study, the following recommendations were made:

NURSING PRACTICE

Community psychiatric nurses should continue to intensify their home visits to individuals living with schizophrenia in their catchment area.

EDUCATION

The mental health authority (MHA) of Ghana should intensify health education on issues relating to schizophrenia to create awareness on issues affecting the lives of Persons Living with Schizophrenia.

POLICY

Authorities at Cape Coast metro health directorate should establish a counselling centre within its premises to house accredited religious ministers and professional psychologists to provide the needed assistance to meet the needs of clients with schizophrenia and their families

SUGGESTIONS FOR FURTHER STUDY

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- A research can be conducted on gender differences with regard to the experience of Persons Living with Schizophrenia to find out if differences exist between males and females living with schizophrenia.

Declarations

Ethical Clearance was obtained from the Institutional Review Board (IRB) of the University of Cape Coast. All other ethical protocols for vulnerable populations prescribed by the various institutions where data were collected were followed. Efforts were taken to protect the participants from physical and psychological harm. Written consent was sought from the participants after a thorough explanation of the research process had been provided. Participation in the study was voluntary, participants were given the opportunity to opt out of the study at any stage without any punitive measures. . Pseudo names were used in order not to link participants to the data. Furthermore, clients were taken through a participant information and consent form prior to the study and those who consented to be part of the study were recruited for the study.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors

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Figures

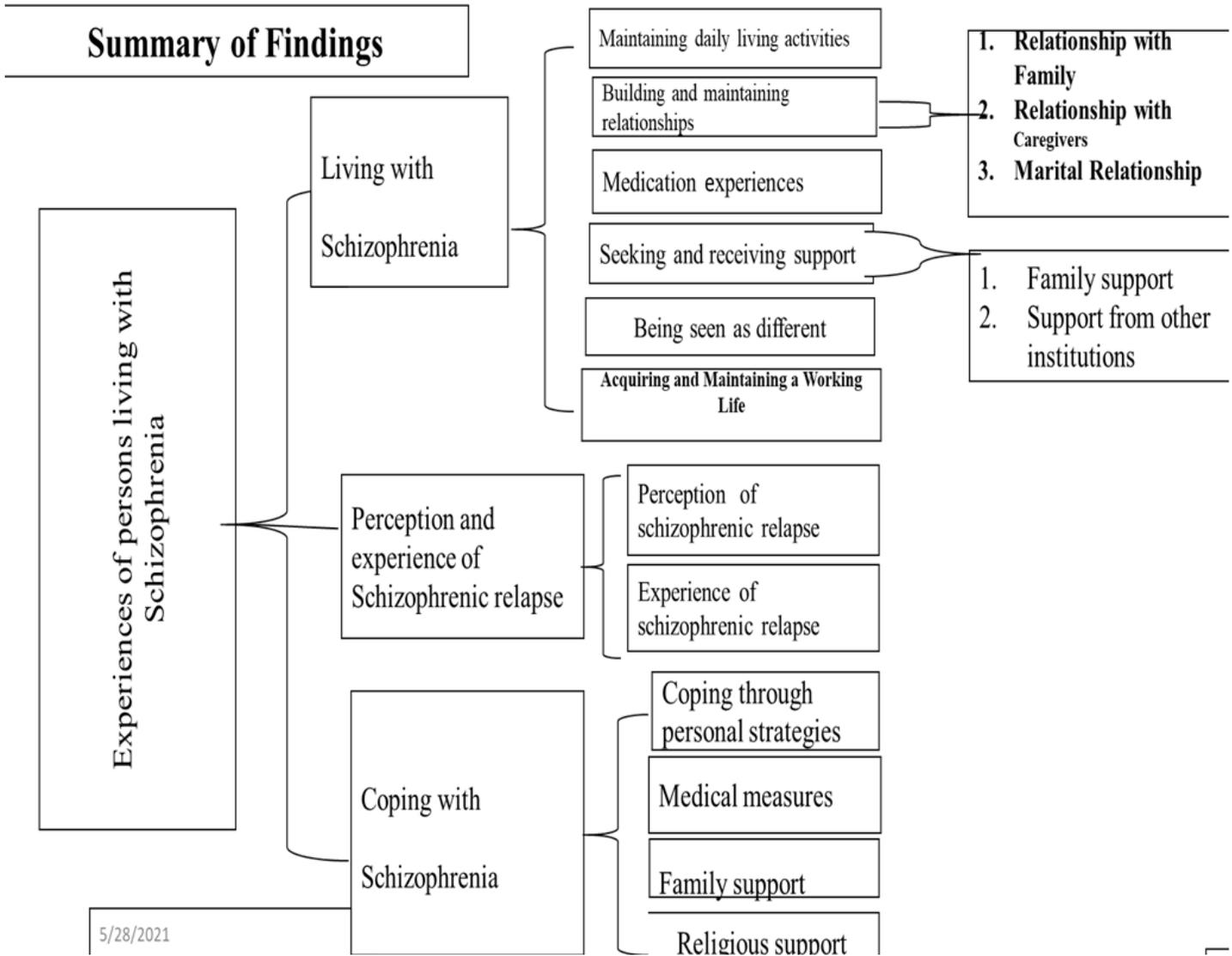


Figure 1

Summary of findings

Supplementary Files

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