Coping with Personal Care and Stigma: Experiences of Persons Living with Schizophrenia

Isaac Tetteh Commey (isaac.commey@ucc.edu.gh)
University of Cape Coast
Jerry Paul K. Ninnoni
University of Cape Coast
Evelyn Asamoah Ampofo
University of Cape Coast

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Abstract

Schizophrenia has an impact on social functioning and participation in everyday life. Yet, there is little data on the experiences of coping with personal care and stigma among people living with schizophrenia in Ghana. This study sought to fill this gap using a qualitative exploratory study. A non-probability sampling procedure, specifically criterion sampling, was used to access a total of nine persons living with schizophrenia. Data were obtained from semi-structured interviews and subjected to Colaizzi's descriptive phenomenological data analysis approach. The study revealed that people with schizophrenia could adopt specific personal measures to take care of themselves. Some of these subjective measures included Activities of Daily Living such as washing, sweeping, maintenance of personal and environmental hygiene and medication administration. Strict adherence to treatment regimens has helped to take care of themselves so long as they were in their lucid interval. Despite the anxiety, stress, fear and sadness associated with stigmatisation, participants coped with stigma by resorting to strategies such as avoidance, denial and wishful thinking.

Background

Schizophrenia is a chronic and severe mental illness that affects sufferers' social and economic lives and significantly burdens service users (clients) and their families globally. Difficulties in social contact in everyday life generally accompany a diagnosis of schizophrenia and limit the individual’s ability to participate in daily life activities. Persons living with schizophrenia have encountered challenges that have to do with the faculty of using one’s will [1]. Interferences characterise the condition in the affected person's perceptions, thoughts, feelings, and behaviours [2]. The illness affects over 21 million people worldwide [3]. Understanding schizophrenia has significant implications for health service planning and risk-factor epidemiology. Mental illness particularly, schizophrenia, presents a severe health care problem in many African countries [4]. The Mental Health Authority (MHA) of Ghana, in its 2019 report, put Schizophrenia as the top psychotic condition across the country [5].

One of the outstanding manifestations of schizophrenia is a disorder of volition [6], where these individuals find it very challenging to maintain their daily living activities. This contributes to why these persons are mostly seen in tattered clothes with unkempt hair in our communities. Indicators of personal care such as grooming, bathing, nail and hair care, dental care, maintenance of environmental hygiene and medication adherence are sometimes absent in the lives of persons with schizophrenia [7-8]. Other indicators include living a peaceful life without stress, self-esteeming, spiritual upliftment, well-being care and a sense of belonging. Self-care theory designates persons as self-sufficient and proposes that self-care is performed to regulate the functioning and preservation of health and well-being of people [9-10]. The capability of a person to perform self-care is affected by critical conditioning factors that include the health state of the individual, development state, sociocultural orientation, health care system, family system, patterns of living, environment, and resources [8]. Because of the disorders of volition associated with schizophrenia, individuals have unique needs for self-care all over the continuum of ailment. They, therefore, require specific self-care measures to help improve their health [10]. Additionally, since the

illness creates deviation from normal, exploring the personal experience of victims' needs for improved physical wellbeing is key [11]. Individual care, at times, becomes a challenge to people living with schizophrenia. A sizable number of them are taken care of by the family and significant individuals including mental health practitioners who have a fair knowledge of their condition [12].

Furthermore, it is worthy of note that people living with schizophrenia can engage in daily activities of living such as the washing of clothes and utensils, sweeping their compounds, taking their bath, general maintenance of personal hygiene and cooking for themselves and their families [13]. Others can also engage in meaningful jobs and contribute to society [14]. The concept of caregiving has been explored from the viewpoints of health professionals and the family [15-20]. These have often ignored the people who have lived the conditions over some time. This leaves a gap in the caregiving literature because 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 [21-23]. Hence, as health professionals, there is the need to understand how people with schizophrenia are coping with the illness, especially in their care, to tailor care to meet their health care needs.

Again, one of the indicators of personal care is wellbeing. However, people with schizophrenia have been deprived of emotional and psychological well-being over the years due to stigmatisation. Stigma has widely been reported among people living with schizophrenia [24-25]. People living with these service users see them as different from other people and therefore call them with names which draws them away from the public [26-27]. One's ability to cope with negative evaluations and labelling whilst living with schizophrenia is a crucial indicator of quality personal care. There is considerable evidence to show that these persons have been deprived of a context-specific individualised and comprehensive assessment of their coping strategies adopted in dealing with the stigma associated with the condition. Therefore, it is imperative to know the subjective experiences of sufferers who have lived with the condition over some time. Studies that have focused primarily on the stories of people living with schizophrenia on coping with personal care and stigma are lacking. Therefore, it is unclear what the coping experiences of people with schizophrenia are regarding their care and stigma. This study, therefore, seeks to contribute to knowledge by addressing two specific issues comprising the experiences of personal care and context-specific experiences of coping among individuals living with schizophrenia in southern Ghana.

The paper is structured into five sections. Besides this introductory section, which provides a background to the study, section two focuses on a detailed description of the methods. Section three presents the study results, followed by section four, which discusses the study's results about relevant literature. Finally, section five concludes the study.

Methods

Study design and population

This exploratory-qualitative study adopted the Husserlian descriptive phenomenological design for the study due to the sensitive nature of the subject matter and the need to break new grounds as far as the subject matter is concerned. In addition, descriptive phenomenology is mainly employed in qualitative research when little is known about a phenomenon. The target population for the study included all persons living within the Cape Coast Metropolis with schizophrenia who had once been diagnosed and managed at the mainstream psychiatric hospital. The Cape Coast 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 an outpatient and inpatient basis.

The purposive sampling technique was used to access nine (9) individuals with schizophrenia when it was observed that no significant new information was being gathered from participants regarding the phenomena [28]. Data was collected using a semi-structured interview guide. Study participants were interviewed face to face at designated areas predetermined by the participants. All participants were contacted through telephone calls to explain the study in detail to them. Informed consent was ensured, and participants were aware that participation was voluntary. The date, time and place for the interviews were negotiated with participants. A period of one month (25th May – 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 sanitising. The study was granted ethical clearance by the Institutional Review Board of the University of Cape Coast (**UCCIRB/CHAS/2020/37**) after demonstrating how conditions of informed consent, anonymity, privacy and confidentiality will be maintained in the study.

Methodological rigour: This was ensured by adopting four key approaches which are credibility, transferability, dependability and confirmability [29]. Credibility, the accurate and truthful depiction of a participant's lived experience, was achieved in this study through continued engagement and observations to describe the phenomenon's context and minimise distortions that might interfere with the data. Transferability was also enhanced by using the purposive sampling method to purposefully select individuals who met the inclusion criteria and were willing to provide a detailed description to come out with robust data with a wide range of information through clear 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 review the transcribed material to validate the themes and descriptors identified. The reviewer did this with a wealth of experience in qualitative text. The aim here was that both analysts agree on the 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 analysed data was presented to the study participants to ascertain whether the narrative was accurate and a true reflection of their experiences

Data analysis

The seven steps in descriptive phenomenological data analysis by Colaizzi [30] were adopted for analysing the data collected. A step by step approach in the data analytical process has been presented in figure 1 as shown below.

Results Of The Study

The results of the study have been presented under this section. Table 1and figure 2 under this section present the demographic data on study participants and summary of the key findings of the study respectively. Aside figure 2, the findings have been presented in a text in relation to the sub themes that emerged from the data analysis.

Table 1 Demographic characteristics of the nine study participants with schizophrenia

Demographic Information	Frequency	Percentage (%)
Marital status		
Married	2	22.22
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		
Christianity	8	88.89
Islamic	1	11.11
Educational background		
Junior High	2	44.44
Senior High	4	44.44
Tertiary	3	11.11
No. of Years with Schizophrenia		
1-10	2	22.22
11-20	5	55.56
21 and above	2	22.22

Source: Field Work (Commey, 2020)

Key findings on experiences of personal care

Psychological care

The data revealed that respondents adopt bold measures in coping with schizophrenia despite the challenges associated with the condition. These measures enable them to maintain some level of resilience. Study participants verbalised that the strategy they adopt most often to cope with their situation is deliberately trying to take their minds off it. In other words, participants could prevent possible schizophrenic relapse by avoiding excessive thinking or worrying about their situation and its associated impact on their living conditions. A participant, for example, believes that accepting his condition and refusing to worry about it is a way to cope. "*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 negative things. The more I think about it; the more my condition gets worse….*" (Godswill, 49 years, Male Fisherman; 19th June 2020).

Reproductive role experience

Study participants expressed their views on sticking to activities of daily living to live with the condition. Participants disclosed that having lived with schizophrenia for several 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 they could take care of their daily activities such as meeting their personal hygiene needs, nutritional demands, and sleep despite their condition. The account shows that participants could go about their normal activities of daily living without any challenge.

"……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. I teach the children, as usual, interact with colleague staff in the school, and carry out my responsibilities as the head of my family. I enjoy my sleep and always take care of myself very well. It is only when the condition comes that I see some changes. (Terry, 58years, Male Teacher; 25th May 2020).

Another participant also added that:

…… "daily activities have never been my problem. When you came, you saw me washing; I had just finished cooking for my parents. They are inside eating. I will take my lunch after washing. I enjoy doing house chores. They keep me active and strong" (Favour, 32 years, Female Fashion designer; 28th May 2020).

Personal medical care

As part of the maintenance of personal care, respondents affirmed that they adopted some medical measures to help them stay healthy. These participants asserted that one of the major coping strategies had been medication adherence. In this regard, participants adhered to the treatment plan

given to them at the mental health facilities as part of their care. They explained that failure to comply with the treatment plan results in schizophrenic relapse.

"… 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 stronger and saves me from experiencing a relapse." (Forgive, 38 years; Female aviation security personnel; 9th June 2020).

Well-being care

Participants expressed that their belief in God keeps them going. This, according to them, sticking strictly to spiritual principles helps them gain some sense of hope and encouragement and thus prevents them from experiencing a relapse. In other words, their religious faith has been a source of hope in keeping them healthy. They indicated that their faith in God and religious activities in their places of fellowship relieve them and increase their understanding of well-being and help them remain resilient.

"……I am a good Christian. I have faith in God, which has been my source of hope all these years. Prayer meetings and church activities that take place at my church takes my mind off this illness and give me some form of relief. I believe I have not suffered from relapse all this while because of my constant church involvement." (Shallom, 20 years, Male student; 20th June 2020).

Another Muslim participant also shared his experience on the subject matter.

"…. Although I take my medications daily as instructed, I believe Allah is the true healer who can heal me of this condition. Whenever I go to the mosque and meet my fellow Muslim brothers for prayers, I experience great joy and relief. I feel like I don't have any problem in my life anytime I find myself amid Muslim brothers and sisters." (Bella, 43years, Female Teacher; 22nd June 2020).

Coping with Stigmatisation

Respondents specified that stigma is one significant negative experience they have had to cope with ever since they were diagnosed with this condition. They indicated that they have been at the receiving end of name-calling, labelling and neglect in the hands of people. Study participants believed that people in their community (public concern) are the ones who stigmatise them. It was clear from participants accounts that all these negative experiences did not come from family members. They indicated that the family members did not mistreat them at all. However, people who lived outside their homes were the ones who negatively evaluated them most often. Participants pointed out that

stigmatisation is associated with schizophrenia, just like any other chronic mental illness that sufferers cannot avoid once they live with illness. Although this phenomenon makes them sad, angry, anxious and puts them in a state of fear sometimes, they indicated that they have been able to deal with stigma by avoiding people who stigmatise them, denying the realities of what people say or do to them and focusing their mind on thinking positive all the times. One of the powerful stories on this subject matter can be found below:

"…….. this is my major challenge associated with this condition…over the years, I have come to recognise that people don't understand my condition…… they point fingers at me, call me with all sort of names and say negative things about me. One day, I stopped a car on my way to church, and just when I was about to board the car, one woman around the place quickly ran to inform the driver and the people in the car that I was a mad person, so the driver should not pick me. I had to walk to church that day. This sometimes makes me angry, anxious and sad. However, I avoid them; I live as if I did not hear what they said or did to me and focus my mind on hopeful thinking" (Beauty, 44 years, Female business woman; 22nd May 2020).

Discussion

This study explored the experiences of coping with personal care and stigma among nine service users living with schizophrenia in Cape Coast, Ghana. Before the study, there was limited knowledge regarding the subjective experiences of persons with schizophrenia in Cape Coast (Southern Ghana). This study delved into the personal lives of individuals with schizophrenia and explored vital issues that centred on how they have taken care of themselves and coped with schizophrenia-related stigma despite living with this illness. It has brought to the fore, managing experiences of personal care and stigma associated with living with schizophrenia.

It is very challenging to live with a chronic mental illness such as schizophrenia. However, in the midst of these challenges, study participants have the strategies they adopt in coping with schizophrenia. They believed that the condition had become part of their daily lives; therefore, they did not stress themselves about the negative manifestations of the condition. Giving much attention to the negative effects of the condition rather worsens their symptoms. Participants go about their daily activities as if they do not have any chronic illness. This suggests that if an individual with schizophrenia does not stress him or herself with the condition, the possibility of experiencing a relapse is minimal. It is believed that stress due to thinking excessively about an illness can lead to frequent deteriorations. Likewise, participants maintain a healthy environment by adhering to strict personal hygiene practices to stay healthy. In Great Britain, it was found that people with schizophrenia employ media (listening to Christian preachings and watching programmes), adhering to prescribed medication and drawing on faith to cope with the condition [31]. It can therefore be said that, these personal care strategies divert the mind of clients unto something more useful and therapeutic. It is worth noting that diversional activities play a crucial role in helping persons with schizophrenia to cope with the condition. Consequently, it is not surprising that a peaceful mind contributes to healthy daily living.

Pertaining to maintenance of activities of daily living, the findings showed that participants could do things in their rightful sense. It also suggests that they can do things independently without necessarily depending on others in discharging duties such as bathing, eating, washing, and other household chores. Being diagnosed with schizophrenia does not necessarily lead to an impoverished lifestyle [32]. Rather individuals with schizophrenia could have a normal lifestyle and perform activities such as washing, bathing etc. and even observe personal hygiene. Contrary to societal perception and evaluation of these persons, it is clear that they can be engaged in meaningful daily activity just like any other person in our societies once they are in their period of lucidity.

Several people hold the belief that, persons with schizophrenia cannot carry out activities unaided. However, participants autonomously managed their conditions with regular daily intake of prescribed medication having had adequate knowledge on the benefits of the medication in promoting recovery. Hence, medication was a decisive factor protecting individuals from experiencing a schizophrenic relapse and thus, contributes to coping with personal care. This means that, with adequate adherence to medication, participants with schizophrenia could maintain a level of resilience and feel more comfortable going about their normal daily activities. Persons who adhered to their medications had a quality of life compared to those who did not follow their treatment plan. Patients with schizophrenia manage their conditions through regular adherence to medication [33]. This, according to them, makes them strong and prevent them from experiencing a possible relapse [32]. Taking medications such as antipsychotics on daily basis is generally not a pleasant exercise in any given situation. However, these medications are taken as prescribed due to knowledge of the benefits the individual derives from them. Regular medication adherence helps persons with schizophrenia improve their care and cope with the condition.

Religion, including participating in religious activities, creates a sense of belonging, enables people to deal with difficult situations and gives them the strength to move on with their lives despite their condition. This may imply that; religion possibly provides positive coping to patients with schizophrenia and subsequently help in recovery. Religious coping has been the most common strategy used by people with schizophrenia to cope with daily activities associated with the condition [33]. This may be partly because, participants indicated that religious coping enhances self-esteem and reduces adverse effects associated with schizophrenia. Increased self-esteem has been shown to contribute to positive health outcomes. Religious faith also serves as a source of strength for persons with schizophrenia and assures them that they can survive complex events in their lives. Clients' belief in their maker improves their relationship with family and other people in their communities [34]. Persons diagnosed with schizophrenia cope well through religious activities such as exorcism or sacraments, which they believed could restore their mental and physical well-being to normalcy [34]. The implication is that people with schizophrenia will always depend on religion to manage the condition due to the relief or solace they derive from it. Religious faith and mental health are two inseparable concepts that have been widely explored and found to be crucial in the management of schizophrenia.

Persons with schizophrenia have been at the receiving end of name-calling, insults and discrimination over the years. There have been some negative comments, assessments and discrimination attributed to persons living with the diagnosis of schizophrenia by people who come into contact with them. Stigmatisation has been noticed to have characterised the lives of persons with schizophrenia. These individuals are highly discriminated against, especially in communities where they live, partly because society perceives them as mentally ill and a threat to the community. Thus, the community does not see the essence of associating with the "mad" people. Another reason people stigmatise these individuals may be due to the symptoms people with schizophrenia exhibit, especially in the relapse stage. Such manifestations scare people around, especially those in the catchment area where study participants reside [35]. Hence, most people in the community may consider them highly violent and can even kill people who may get closer to them. Society may permanently stigmatise them [36]. Stigma affects the wellbeing of people with schizophrenia because it leads to isolation and rejection of these victims.

Schizophrenia is the most stigmatised of all mental conditions because of its perceived dangerous and unpredictable [26]. This may be due to the fact that, people do not understand the course and treatment outcome of schizophrenia. As a result of stigma, these persons become angry, anxious, scared of the unknown and sad. People's perception of schizophrenia and how they label people with the condition make it very challenging for individuals living with the need to cope with it, especially when they step out of their homes [37]. They, therefore, respond to these unfortunate situations by using defense mechanisms such as avoidance, denial and resorting to wishful thinking [38-41]. They sometimes have no other choice of facing stigma rather than resorting to these strategies in maintaining their well-being. In some situations, they avoid people who negatively evaluate them, pretending as if they do not recognize their presence. In other instances, they deny the realities of the impact of stigma on their lives and also focus their minds on wishful thinking. All these strategies are adopted by persons with schizophrenia to help give little attention to the issue of stigmatization associated with the condition.

Conclusion

This study has shed light on how people with schizophrenia live and cope with their care and the stigma associated with their conditions in Ghana's resource-constrained setting. Participants in their lucid state lived an everyday life and could maintain daily living activities successfully. Again, study participants verbalised being labelled and seen as different within the communities in which they reside. It was evident in the study that persons with schizophrenia adopt personal measures that help them to live with the condition and cope with the associated stigma despite the challenges that the condition presents to them.

These findings are not dramatically different from those reported in the literature; however, the support needs of people with schizophrenia may differ from a cultural and spiritual point of view. African and, therefore, Ghana is highly religious, and people find solace in religious coping strategies.

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 to support clients who have challenges with personal care and stigmatisation.

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

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

Declarations

Ethics approval and consent to participate

Ethical Clearance was obtained from the Institutional Review Board (IRB) of the University of Cape Coast (**UCCIRB/CHAS/2020/37**). This clearance was provided after the board went through the research proposal and noticed that it met all the requirement for the issuance of ethical clearance. Because of the sensitive nature of the participants involved, the methodology was thoroughly scrutinised by the reviewers prior to the issuance of the clearance. Participation in the study was voluntary; participants were allowed to opt out of the study at any stage without any punitive measures. Furthermore, clients were taken through participant information and consent forms before the examination. They all signed the consent form before being engaged in the data collection. We therefore declare that; all methods of the study were performed in accordance with the relevant guidelines and regulations stipulated by the ethical review board of the university of Cape Coast, Ghana.

Conflict of interest

Authors declare that, this is the original manuscript which has not been submitted anywhere for review or publication. We therefore wish to also state that we have no conflict of interest.

Consent for publication

Prior to data collection, participants were informed that the study was aimed at improving care delivery. Thus, findings will be published for practitioners in the discipline, especially mental health nurses to improve practice. Therefore, audio recordings of interviews were done with the permission of study participants after they were reassured that their identities or anything that will make it easier for readers to identify them will not be captured anywhere in the article. Consent for publication was obtained from study participants for audio recording the interviews during the data collection process. This was included in the participants information and consent form which was part of the requirements for the award of ethical clearance by the institutional review board of the university of Cape Coast.

Availability of data and materials

Due to the sensitive nature of the people recruited for this current study and the high level of stigma attached to this condition, raw data generated and the analysed data are not publicly available in this manuscript. However, on reasonable request, the corresponding author can make them available.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

ITC, JPKN and EAA contributed equally to this paper (development of the research concept, data collection, data analysis and drafting of the manuscript). EAA contributed to development of the research concept and critical review of the paper. ITC, JPKN and EAA were involved in data collection, data analysis and drafting of the manuscript. All authors approved the final draft of the manuscript before submission.

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Figures

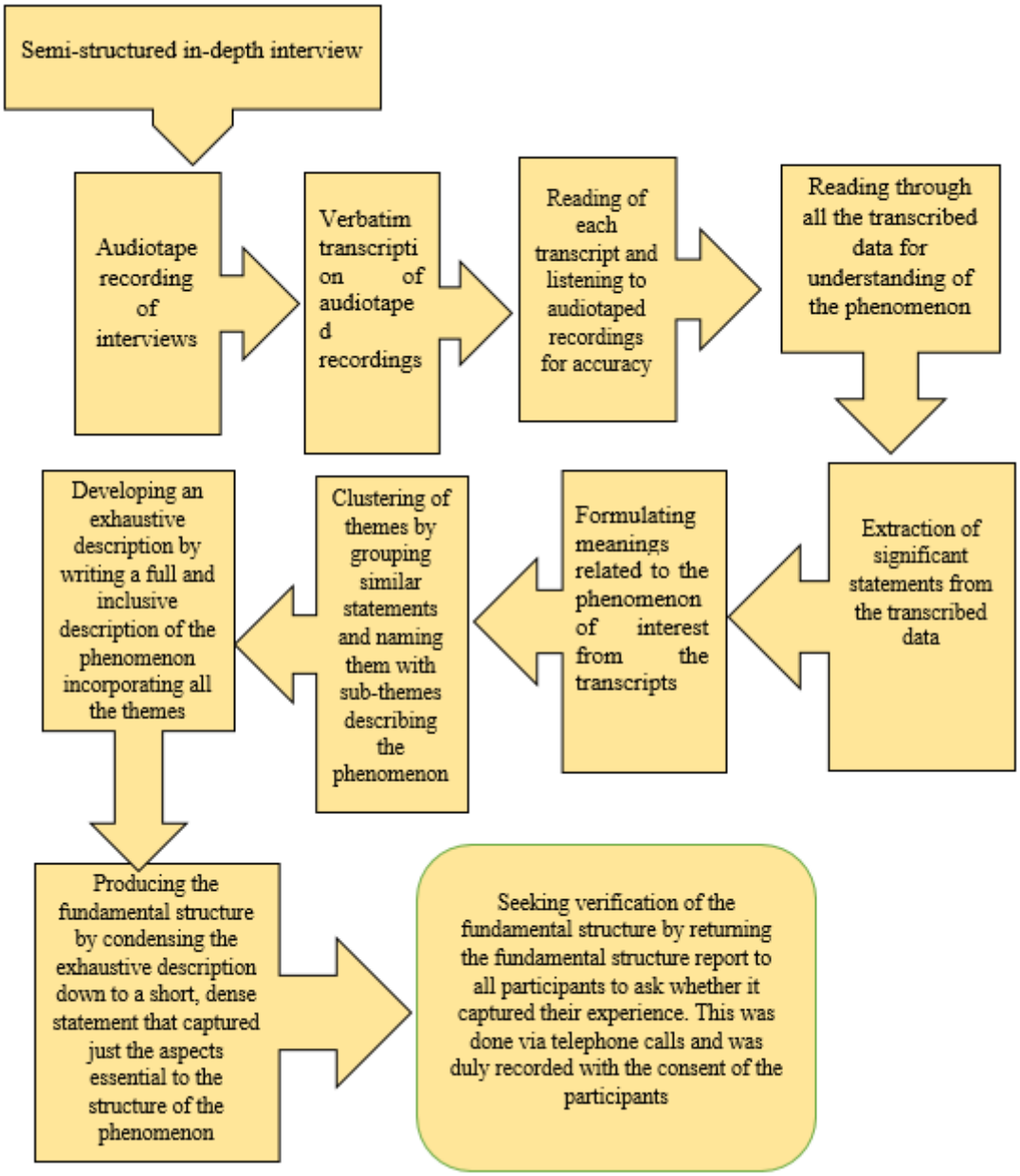

Figure 1

The step by step approach employed in the analysis of data on coping with personal care and stigma among nine persons living with schizophrenia

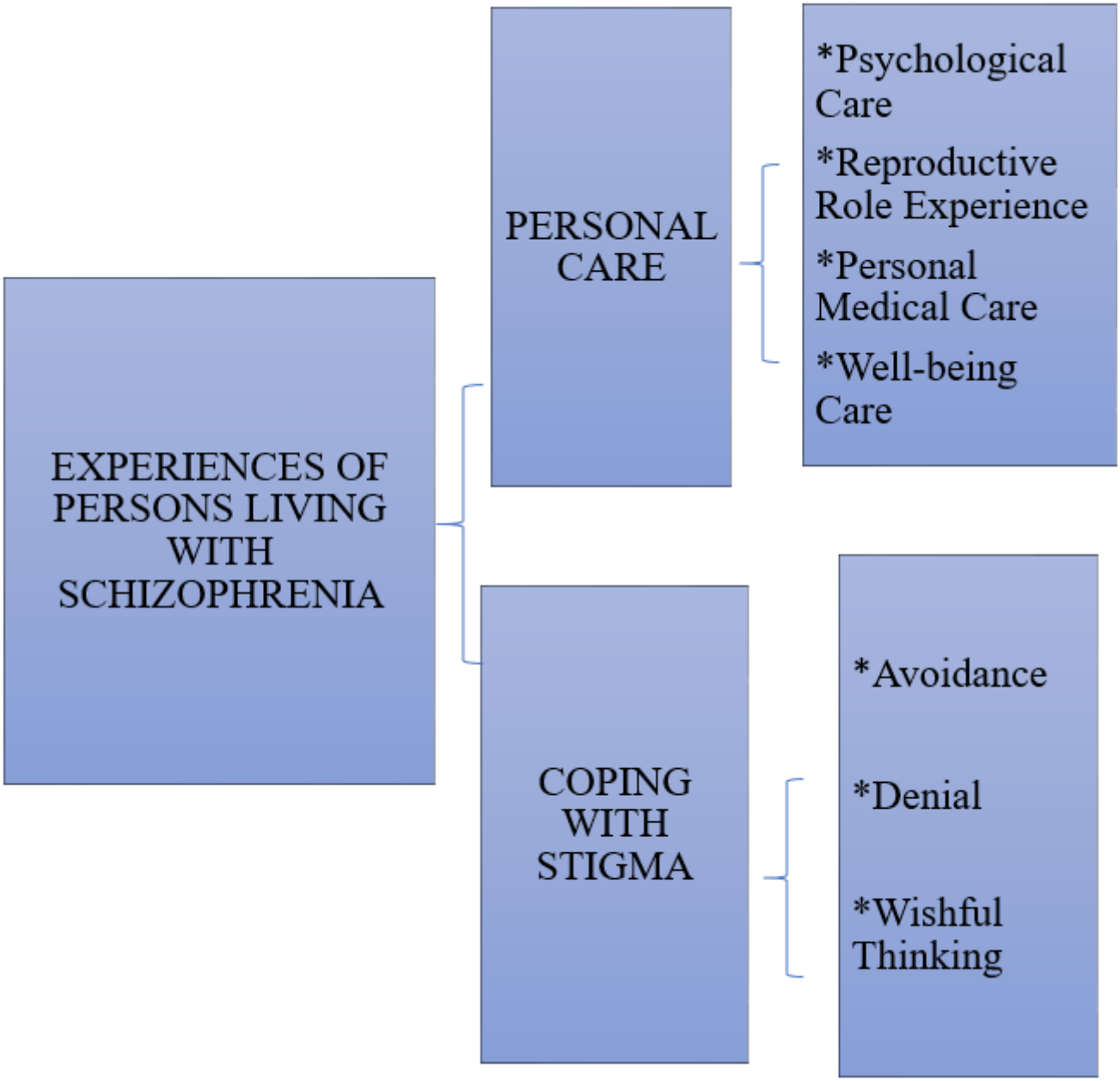

Figure 2

Summary of findings on coping with personal care and stigma among nine participants with schizophrenia