

# **A mixed methods study exploring family members' anticipation of long-term care needs for people living with schizophrenia**

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# 1. Introduction & Background

## **What is the aim of my presentation**

- Feedback on findings

## **Rationale for the study**

- Schizophrenia imposes disproportionately large burden on patients and their families
  - Early onset
  - Deterioration in ADLs
  - Ability to sustain employment
  - Lifelong course
- Move towards deinstitutionalisation
  - Implied greater responsibility for families

- Challenge for low- and middle-income countries
  - Few community-based resources
  - Family has increase in responsibility for care
- The "on the ground" needs and concerns of families remain unidentified.
- Most research done in developed countries
  - Different challenges due to different context
  - Societal and cultural factors play a role

## 2. Study methods & Participants

- We conducted qualitative semi-structured interviews with 20 participants.
- Participants completed
  - basic socio-demographic characteristic questionnaire.
  - short version of the *Zarit Burden Interview (ZBI-12)*
- The study was conducted in the Western Cape.
- We used purposive sampling to recruit study participants.

- Participants were recruited from two sources to ensure that we have a diverse socio-demographic profile of participants:
  1. Family members of PLWS who are already participants of a Psychosis Research Program cross-sectional schizophrenia study.
    - These family members were identified as a primary support by the PLWS in the routine assessment of the PLWS and the person with schizophrenia gave us the family members contact details.
  - Participants from the Family Schizophrenia Support (FSS) Group for Schizophrenia (FSS).
    - One of the authors (LA) talked about the study at one of the FSS meetings and asked participants interested in the study to contact the authors.

- Ethics:
  - Human Research Ethics Committee of University of Stellenbosch approved the study
  - Participants were free to withdraw from the study at any point without prejudice
  - Identities protected
- Audio-recorded interviews were conducted in-person, telephonically or online, depending on participant preference.
- All audio-recorded data were transcribed verbatim
- Thematic analysis was used to analyse the data

# 3. Findings

- Qualitative findings
- The qualitative findings are clustered into six main themes:
  - *Planning around long-term care needs*
  - *Schizophrenia and all its layers*
  - *Concerns about independence and functionality*
  - *Isolation and Stigma*
  - *Access to care and resources*
  - *Doing the best you can*

## ***Planning around long-term care needs***

- Participants were concerned about the long-term care of the family member living with schizophrenia. Primary caregivers were particularly worried that there would be a time when they would no longer be capable of taking care of the person living with schizophrenia due to poor physical and psychological health associated with old age.

*"I'm worried about him for the long term. I'm thinking about a place for him to stay. I'm actually looking for somebody to help me because I'm really, really looking for a place for him to stay. I'm not sure if I can do it. I'm really looking for a place because I'm getting older, and I'm not getting younger."*

- Families felt that planning around the long-term care of the person living with schizophrenia was their responsibility and not that of the person living with the illness. “

*You know, outside and independent of him, you know, we're the ones thinking and worrying about him. Okay, what is the next step and the next step and the next step? I think for him to think and plan like that is very stressful. Yeah. So for him, he's kind of like one step at a time.*



- As a family some discussions and tentative plans around the long-term care of the person living with schizophrenia.
- In some instances, families made financial provision should something happen to them, but families were worried that the provision would not be sufficient.
- Other families reported that the person living with schizophrenia would be able to continue living in the home of the primary caregiver should the primary caregiver pass away. However, families were worried that once the primary caregiver died, the person living with schizophrenia would have shelter but no other means of support.
- Siblings of the person living with schizophrenia felt that due to their own families and other responsibilities, they would not be able to take over the caregiver role should their parents reach a stage where they were unable to fulfil the role of primary caregiver.
- Primary caregivers also felt that they could not expect the siblings to take care of the person living with schizophrenia.

- In the minority cases, primary caregivers were of the opinion that extended family would take over their caretaker role should they no longer be able to fulfil their role. However, very few families had explicit conversations about the above. See below for the dialogue between the participant and researcher:

*Participant: "Um, if something should happen to me and my husband. I've got a sister and she will take him in. She loves him a lot."*

*Researcher: "He's so fortunate to have that, have you spoken to her about, should something happen to you, if she will be willing to take him?"*

*Participant: "No, I have not, but I will speak to her. But I'm so sure that she will look after him."*

## ***Schizophrenia and all its layers***

- When the person living with schizophrenia was first diagnosed, families initially felt surprised. Some families reported that, in hindsight, they noticed long before the diagnosis was made that their family member was 'different' and experienced difficulties.

*"I believe the diagnosis was last year, if I am not mistaken. However, from, I want to say from his teenage years, I mean almost as far back as I can remember, he has been, so he always had like an anxiety issue and social interactions were always very difficult, bullied at school, that type of thing."*

- For some, having a diagnosis helped them to have a better understanding of the family member living with schizophrenia and to have more patience and empathy. One participant described having a diagnosis as the following:

*"Before he was diagnosed, his life was full of ups and downs, and there was a lot of weirdness about his life. When he was diagnosed, we started to understand and realise what was going on with him and a light was switched on for us."*

- The unpredictability of the illness and the frequency of relapse emerged as a common theme. Families reported that in their experience, periods of stability and remission could very suddenly be replaced with periods of relapse.
- Families ascribed relapse mainly to treatment non-adherence.

*"So, when he comes out from the hospital, he only takes his medication for a day or two. But only a day or two, then he stops his medication. And then it is back to square one."*

- The majority of participants felt that they had no choice but to take a strong stance against non-adherence.

*“And then the other thing I'd like to say is, as soon as he got diagnosed, I told him straight that if I ever find out that he hasn't taken his medication, it's over. He has to take his medication, and he knows that if he doesn't take it, even if it is because he is told by voices not to take it, I will leave him. I have made it abundantly clear.”*

- On the other hand, families felt conflicted about monitoring treatment compliance. Families felt they needed to trust the PLWS to take their medication on their own, but this left them feeling anxious about the possibility of a relapse. Families were also concerned about the side effects of some of the medications and felt they needed to intervene and address their concerns with the healthcare professional. “

*I asked the doctor to take away the clozapine because he should not be sleeping from the morning to the evening. He keeps sleeping. He needs to take the broom and sweep. Then the doctor reduced the medication, and that worked for us.”* Two participants reported that they had to accept that their family members with schizophrenia were not willing to take medication.

- Co-morbidity adds another layer to the complexity associated with schizophrenia. Some families referred to their family members with schizophrenia having comorbid OCD or a personality disorder. Families found comorbid drug abuse particularly challenging to manage.
- Participants who had family members with comorbid drug abuse reported that the drug abuse and not per se the schizophrenia made it challenging for them to manage their family members at home.

- Some of the participants reported concerns over aggressive behaviour and safety.
  - Only one participant reported the occurrence of violence. The participant was physically injured when her son, living with schizophrenia, fought with his brother. The participant was injured by accident during the altercation between the brothers.
  - Families reported that they feel anxious when a family member with schizophrenia presents with aggressive behaviour.

*"He lives in a house with just females; he is the only male in the house. So, he seems to overpower us most of the time. And with my mom's age, me growing up, and things like that, I worry that I would never be able to move out of the house because of him."*

## ***Concerns about independence and functionality***

- Except for four participants, all families were living in the same home as their loved one with schizophrenia. All participants believed that the PLWS would not be able to function without family support, and the majority of participants were of the opinion that the PLWS could not live independently.

*“He will not be able to live on his own. To tell the truth, he would not make it.”*

- Family members living with schizophrenia required support to varying degrees, but most required daily supervision. Some families felt uncomfortable if their loved ones left home without supervision.



- The majority of families reported that the family member living with schizophrenia was unemployed and lived on a government disability grant.
- In the rare cases when the person living with schizophrenia was employed, it was challenging. One participant reported:

*"Miss, it is very difficult, so difficult. Often we (the family) wished that he could find a job, but then when he gets a job it only lasts two days or a week."*
- Families explained that the illness's unpredictability makes it challenging to find and maintain work.
- Some believe that when the PLWS experiences a period of stability and are in remission, they can work, albeit if they can find work. However, a relapse could interfere with their functionality at any time.
- Families experienced that even if the PLWS had informal work, they had to manage the income the PLWS earned.

- One participant reported that even though his loved one with schizophrenia is employed, the illness impacted his self-esteem, and this affects his confidence and performance at work.
- Families believe that it is important for the person living with schizophrenia to have something constructive to keep them busy and help them feel stimulated.
- Although, participants stressed that it was important not to put the PLWS under too much stress.

- Hope that the person living with schizophrenia will be able to function independently in the future is featured as a theme. One participant reported the following:

*“ I spoke to him and said to him – what will happen to you if something happens to mummy? When I am no longer around, you will have to stand on your own two legs.”*

- Some participants also hoped that the PLWS would be able to return to the level of functioning and independence they had before the onset of the illness.

*“I hope that he will be able to manage in the future, that he can help himself and be the way he was before (i.e. the illness)”.*

- Other families reported that they needed to accept and let go of the preconceived ideals they had for the family member living with schizophrenia.

## ***Isolation and Stigma***

- Isolation was a common theme that emerged from the data.

*"The only thing he has got no real friends, he's just got us as a family."*

- Families reported that the family members living with schizophrenia had very few or no friends, and some observed that the lack of social connections was present long before a diagnosis was made.
- The majority of participants thought that the community and extended family were uninformed about schizophrenia and that the family member living with schizophrenia is not seen and understood by people outside of the immediate family.

*"I think he's been in a very toxic environment because people tend to just see him as a patient."*

- People outside the immediate family discriminated against the person living with schizophrenia and insulted them.

*"And family do not actually, they say they do not want to be stuck with people that's crazy. And I mean, how can you diagnose someone as crazy if you haven't even lived with them."*

This made families feel it is their responsibility to shield the family members living with schizophrenia.

*"I'm very, very, oh, I'm very overprotective over him. And nobody can say nothing in front of me about him."*

## ***Access to care, resources and support***

- Families reported that private mental healthcare was too costly and unaffordable.
- In general, participants reported they felt helped in public mental healthcare hospitals. However, their family member living with schizophrenia was often discharged too soon due to a lack of bed space in government hospitals.
- Participants whose family members were admitted to public mental healthcare hospitals appreciated that some hospitals put to involve the family in the treatment process. Families reported that when they were called in for a family session, it helped them better understand the needs of the PLWS and they felt more educated about the illness.

- However, overall, families felt excluded when it came to decisions made about medication both in private and public mental healthcare.
- They experienced a lack of communication between the mental healthcare professional and the family.
- Participants reported that once the person living with schizophrenia was discharged from the hospital into the clinics, they felt particularly unsupported.

- Families expressed a need for appropriate follow-up services as this is when they need help the most to take care of their family member with schizophrenia.
- They felt that at the clinic level, there is a disproportionate focus on the medication and not on the psychosocial aspects of the illness and that families are provided with very little support, psychoeducation and resources to help them take care of the PLWS.

*“And then at the local clinic with both my children. You go to a psychiatric nurse, they say what's your problem, how do you feel, she takes the file, she goes to a doctor, she comes back, you get the medication.”*

- The lack of appropriate follow-up services left families feeling unsure of how to manage the person living with schizophrenia and left them feeling forced to involve the authorities, which is very traumatic for the families and the person living with schizophrenia.

*“My brother, like I said, he lives his females, right. So it's very easy for him to kind of assert authority over us. And at some point, we're not sure necessarily which steps to take. So it's always, let's call the police, right? But I can imagine for him as well, it might be a bit traumatic for us to always want to, you know, call the police on him. So if there are other, I do not know, like alternatives, we're able to also help him. Because the police have also taken him to Pollsmoor at some point, so that adds to his trauma as well. Just because he is mentally ill doesn't mean he doesn't have traumas that he also has to deal with.*”

- Families felt particularly traumatised by the experience of involuntary hospital admissions.

*“For me, it was hugely traumatic having to have a commissioner; I mean there's police-involved and I mean it was absolutely I would never do that again that was just the worst thing in the whole world, and yeah, there's just no support I mean you've got to watch this person going through all this and I mean once you've done it that's it, you know your hands are tied you can't get them out again which I understood right from the word go but naively I had imagined that actually there would be some help involved, you know, that things would happen. But there's just too many people and the system's too small.”*



## ***Doing the best you can***

- Taking care of a family member living with schizophrenia does not occur in a vacuum. Families also have other competing responsibilities, such as taking care of other family members and minor children.
- Families often felt conflicted and that they needed to balance the needs of the family member living with schizophrenia with those of other family members.
- Participants with younger children felt, at times, they needed to keep the family member with schizophrenia away from their minor children. This was mainly reported when the family member with schizophrenia was also abusing substances and showed signs of aggression.

*"I have a small baby that turns one next month. My brother is big and strong, and I need to think of my child."*

- For families, life goes on, and they have to deal with other aspects of life, such as losing a partner to death or separation, family members moving abroad, unemployment, work and financial stressors and physical health challenges. The caretaker role, as well as competing responsibilities, impacted family members.

*"It is a massive strain on me. I have to watch him, and my work is very strenuous. Sometimes, I have to work long 12-hour days, and I can't do that when he is ill. At times, I get called out at night, and when he does not take his medication, I am unable to leave him alone at home at night."*

- Extended family and friends would try to offer their support but could not always relate.

*"I think people don't always understand what this illness is about, and it really is it really it's quite a lot for family members to take on. You know, and it's just myself, you know."* One participant reported that her family were helpful but tended to give advice, which is not always appropriate. "I am very open with my family. The whole family understands. They struggle to cope with it themselves. They have lots of advice to give me, like I have to put him out on the streets."

- Families reported that, ultimately, they could only depend on themselves to take care of the family member living with schizophrenia.

*"I realised quite quickly on, don't live in a fairy tale world where you think somebody's going to swoop down and help you. It's not going to happen. You've got to sort it out yourself, the best you can. And that's all it is. It's just doing the best you can for the person, for yourself. And, you know, I mean, what else can you do, really."*

## 4. Summary of findings

- Lack of financial resources major stressor when it comes to plans around long-term care.
- Mainly tentative plans around the long-term care.
- No-one to stand in for primary caretaker.
- Families experience schizophrenia as a complex illness characterized by periods of relapse and unpredictability.
- Comorbidity and treatment non-compliance made it challenging for families to support the PLWS.

- Most families provided hands-on care and supervision for PLWS, this made it challenging to provide financially for the family - financial constraints made the role of caretaking particularly stressful.
- Families are concerned about PLWS isolation.
- Families reported that in general society is uninformed about schizophrenia.
- PLWS is not seen and understood by people outside of the immediate family.
- Families felt that it is their responsibility to protect the PLWS from discrimination and victimization.

- Families reported that being a participant in the PLWS treatment process helped them to take better care of the PLWS.
- In general families felt excluded from important treatment decisions made by healthcare professional.
- Lack of follow-up services at clinic level (i.e. post discharge from hospital) made families feel forced to involve authorities and make use of involuntary admission, which is traumatizing for PLWS and families.

- Taking care of a family member living with schizophrenia does not occur in a vacuum.
- Families often felt conflicted and that they needed to balance the needs of the family member living with schizophrenia with those of other family members.
- Dealing with other aspects of life, such as losing a partner to death or separation, family members moving abroad, unemployment, work and financial stressors and physical health challenges.
- Extended family and friends would try to offer their support but could not always relate
- Ultimately only depend on themselves to take care of the family member living with schizophrenia – doing the best they can.

# Thank you

- We welcome feedback and input from families.
- Please email feedback or comments to [sanjakilian83@gmail.com](mailto:sanjakilian83@gmail.com)