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Social support and managing schizophrenia in Tanzania: Perspectives from treatment-engaged individuals and relative caregivers

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Abstract

Background: In lower-resource settings like Tanzania, people living with schizophrenia (PWS) rely on their families for much of their social support, thus leading family members to become their main caregivers. How PWS and their families understand and implement social support can profoundly impact recovery pathways. This study examines how PWS and caregivers of PWS in Tanzania describe receiving and giving social support. We describe, from the perspectives of treatment engaged PWS and unmatched caregivers, different types of social support experienced

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Appendix A. Supplementary data

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and provided and examine any differences in the types and expectations of social support expressed by PWS versus caregivers.

Methods: A total of 39 semi-structured in-depth interviews were conducted with PWS (n = 19) and caregivers (n = 20) recruited from outpatient psychiatric clinics in tertiary-level hospitals in Tanzania across two geographic regions. Thematic content analyses were based on four dimensions of social support (instrumental, emotional, informational, and appraisal).

Results: Results revealed four themes: 1) Financial and basic needs support from families is common yet critical for daily living (instrumental support); 2) There were mixed experiences regarding provision and receipt of love and acceptance with desires and calls for more encouragement and moral support (emotional support); 3) Caregivers try to provide knowledge, guidance, and reminders related to illness management for PWS but acknowledge their own gaps in understanding recovery promotion and effective caregiving (informational & appraisal supports), 4) A cross-cutting issue was calls for more social support from the wider community.

Conclusion: Social support is a multi-dimensional construct recognized by PWS and caregivers as critical for illness management, yet gaps remain, often due to lack of knowledge of how to bolster social support. Given the heavy reliance on families for social support in lower-resource contexts, psychiatric services can intervene with clinic-based psychoeducation for PWS and their families to improve quality of life and functioning.

1. Introduction

Schizophrenia is one of a diverse group of psychotic disorders that affects thinking, perception, feelings, and behavior, and is one of the leading contributors to years lived with disability globally largely due to early age at onset and often chronic course (Charlson et al., 2018). Schizophrenia is treatable if individuals have access to both pharmacological and psychosocial interventions that can help reduce symptoms, enhance functioning, and improve quality of life (Lancet Global Mental Health Group, 2007; World Health Organization (WHO), 2016). However, in low-resource settings where access to effective community-based psychosocial services is still limited and families are fundamental for recovery, the role of social support in the lives of people living with schizophrenia (PWS) is particularly critical (Eaton et al., 2011; Asher et al., 2017).

Adherence to pharmacological treatment is often essential for the alleviation of psychosis symptoms in schizophrenia, as is attention to the psychosocial needs of individuals living with a chronic psychotic disorder. Lack of social or family support has been reported as a major correlate of medication non-adherence for people with schizophrenia (PWS) (Semahegn et al., 2020). Support could include help accessing, paying for, and taking medications, and mitigating community stigma related to the illness. There are examples from lower-resource settings that higher levels of family and caregiver involvement, such as administration and supervision of medications, and positive attitudes of family members toward medication are predictors of medication adherence and overall patient recovery (Tham et al., 2016; Farooq et al., 2011). In India, individuals with poor social support were less likely to be engaged in clinic-based pharmacological treatment (Kumar et al., 2016).

Meanwhile, a study in Ethiopia revealed a significant association between the risk of relapse for PWS and low social support (Samuel et al., 2022).

Even with symptom remission, PWS may still experience multiple challenges in their domains of functioning such as cognitive and social impairment resulting from the chronic nature of the illness, lack of medication effects on recovery determinants or their side effects, and/or internalized stigma (Kharawala et al., 2021; Harvey, 2014). This has implications for the level of care and support they will need during their lifetime. The government of Tanzania's Persons with Disability Act (Parliament, 2010) mandates a hitherto cultural obligation to provide social support for family members with disabilities as follows; "every relative of a person with disability shall have an obligation to provide social support to such persons with disability including mental disability." The act goes further to include the collective obligations of the extended family, specifically for financial support, with proposed legal repercussions if they do not. The implications are significant because there are no free health services nor is there a social safety net for PWS in Tanzania, though there is evidence that Tanzanian families struggle to adequately purchase psychotropic medications (Iselelo and Ambikile, 2017). While the intent of the government policy is clear, the guidelines for its implementation are still in the implementation phase for PWS, and thus there is wide variability in the social support offered.

Social support is a broad construct that has been described as, among other things, the perception and actuality of receiving psychological and material resources, having positive social relationships, and/or being socially integrated into communities (Cohen and Wills, 1985). Cohen and Wills (1985) more deeply describe social support as being conceptually divided into four domains: *Instrumental* (the provision of tangible goods and services or tangible aid), *Emotional* (the provision of caring, empathy, love, and trust), *Informational* (information and advice provided to another during a time of stress), and *Appraisal* (the communication of information that is relevant to self-evaluation rather than the problem, constructive feedback).

Social support can play a critical role in the comprehensive management of schizophrenia, and it is often part of psychosocial interventions such as psychoeducation, case management, and social skills training which have been shown to decrease symptom severity, rehospitalization, and improve social functioning (Asher et al., 2017; Bighelli et al., 2021). Given the primacy of the family as the sole source of support in many countries without a government safety net for persons living with disabilities, including Tanzania, a deeper understanding of social support experiences among PWS and caregivers could help health services in lower-resource contexts understand how to leverage and enhance engagement with families to promote recovery. This is particularly important in cultural settings where there are already strong cultural norms for significant family involvement in healthcare (Hinton et al., 2019).

As part of a larger pilot clinical trial to evaluate the impact of a culturally adapted version of Family Psychoeducation on patient outcomes, our team conducted formative research to inform the design of the adapted intervention. For this paper, we examined the qualitative data on how individuals living with schizophrenia attending outpatient

psychiatric services and caregivers of those living with schizophrenia describe social support received and provided respectively in Tanzania. Specifically, the aims of this study are a) To describe the different types of social support experienced and provided to individuals living with psychosis via the perspectives of the affected individuals themselves and from the caregivers' perspectives; and b) To examine any differences in the types and expectations of social support articulated by the treatment-engaged population and by caregivers.

2. Materials & methods

The data for this study come from the parent project entitled: "Family Psychoeducation for Adults with Psychotic Disorders in Tanzania," a pilot randomized clinical trial ([Clinicaltrials.gov # NCT04013932](https://clinicaltrials.gov/ct2/show/study/NCT04013932)) funded by the National Institute of Mental Health #R34MH106663. This pilot study will inform a future trial to test the effectiveness of a culturally tailored Family Psychoeducation intervention on functioning, quality of life, and relapse for those participating individuals with psychotic disorders as well as caregiver burden for their relatives who participate in the intervention. This study and the culturally tailored version of Family Psychoeducation for use in Tanzania is called KUPAA, which means 'to soar' in Kiswahili [Kuwezeshana Kupata Uzima—supporting one another in wholeness]. The KUPAA study was carried out through a partnership between Muhimbili University of Health and Allied Sciences (MUHAS) and Duke University in two sites located in the regions of Dar es Salaam and Mbeya, Tanzania.

Before the pilot clinical trial, there was a formative qualitative phase to understand how family psychoeducation could address mental health care gaps in Tanzania and to culturally tailor the intervention. Formative data included a total of 80 one-time semi-structured interviews conducted with clinic outpatients with a diagnosed psychotic disorder, (unmatched) caregiver relatives of individuals with psychotic disorders, clinic-based providers, traditional healers, and government officials. This current study uses data from outpatients and caregivers.

2.1. Study setting

The study sites were two government health facilities based in the Dar es Salaam and Mbeya regions in Tanzania: Muhimbili National Hospital and Mbeya Zonal Referral Hospital. Muhimbili National Hospital (MNH), the national referral hospital, is in the coastal city of Dar es Salaam with a catchment area of about 5 million people. The Department of Psychiatry at MNH provides inpatient and outpatient care and has an inpatient capacity of 70. Mbeya Zonal Referral Hospital (MZRH) is in the city of Mbeya, 900 km from Dar es Salaam and is the only referral facility in the southern part of the country with a catchment area of about 4 million people. It is also a referral facility for the neighboring regions. The Psychiatry and Mental Health Unit has a 24-bed capacity and an outpatient service.

2.2. Participants

For the current study, the analysis focuses on 39 one-time semi-structured key informant interviews with clinic treatment-engaged individuals diagnosed with a psychotic disorder ($n = 19$) and caregiver relatives of individuals living with schizophrenia ($n = 20$). We

purposely selected participants in order to ensure a sample with various background characteristics (e.g., participant sex, study site location, length of illness for patients, and type of relationship with the patient for caregivers). We did this to achieve a sample representative of the those who access to services and because there might be varying experiences giving and receiving social support within these subgroups. The inclusion criteria and recruitment strategies were the same for both MNH and MZRH. Individuals with primary diagnoses of schizophrenia (ICD 10 code F20 Schizophrenia) attending outpatient services and relatives who were accompanying patients to services (which is typical for outpatient services in this setting) were recruited face-to-face on their appointment days while in the clinic waiting room or after an appointment but still in the department. Patients and caregivers were recruited separately and were not matched to maintain confidentiality. All participants were aged 18 years or older.

2.3. Data collection procedures

Bilingual, trained study staff conducted the key informant interviews (KIIs). The KIIs were conducted in Kiswahili, lasted approximately one and a half hours, took place in private office space on hospital grounds, and followed a semi-structured interview guide. Each participant was given 7500 Tanzanian Shillings (~USD \$3) for their study participation. Interview topics included: background information, telling your illness story, pathways to care, familial and community support, and how to adapt the family psychoeducation program for local use. Each KII was audio-recorded and then concurrently translated and transcribed directly into English (each transcript was reviewed for translation accuracy by the bilingual team members). Field notes were written on each transcript describing interview context and any notable features of the interview process.

2.4. Analysis

Thematic analysis was the broad analytic framework for qualitative analyses via an iterative process that included reading, coding, data display, data reduction, and team discussion (Braun and Clarke, 2006; Tolley et al., 2016). An Excel-matrix-based framework was used for coding, analysis, and identifying illustrative quotes, broadly aligned with the framework method (Gale et al., 2013). The top-level row had the main domain codes (demographics, telling your story, pathways to care, family, and community support, and adapting the family psychoeducation program). Under those headers were the individual research questions by sub-domain (a priori codes) as well a few cross-cutting content domains that came up frequently (financial/economic issues; any mention of money as a supportive mechanism, as a barrier to care, and/or as a way of gaining independence). A Tanzania-based team member led the patient data analysis (PS, first author) and a U.S.-based team member led the caregiver analysis (MD, second author). The initial coding process began with an initial reading of all the interviews by each relevant primary coder. After reading the transcripts for familiarity one time, each primary coder read the transcript a second time and began extracting and summarizing text from each interview question into the Excel sheet by subdomain. The coders also pulled illustrative quotes. The Excel sheet method allowed for more team-based data visualization. Inter-rater reliability was assessed iteratively as the study PIs (SK & JNB) also reviewed transcripts and the Excel sheet to review and confirm data summarization and coding. Discussions were held between both coders and

PIs to resolve any discrepancies of interpretation as well as confirming that all agreed data saturation had been reached for the outpatient and caregiver population groups. While the Excel sheet matrix facilitated the summarization tool, individual memos were also written for each social support theme.

To aid in synthesizing and organizing the social support concept for this analysis, we used the definition of social support with four domains by Cohen and Wills (1985): instrumental, emotional, informational, and appraisal support. We sought to use these commonly acknowledged domains of social support that have also been used in qualitative analyses conducted in East Africa (Tumwine et al., 2020; Rouhani et al., 2017). Memos were written for each of these social support domains by type of key informant which helped focus the identified themes (e.g. examining instrumental support from the caregiver perspective revealed it as an almost universal experience in our population).

2.5. Ethical approvals

All participants provided written informed consent. Ethical approvals were received from Duke University Health System, Muhimbili University of Health, and Allied Sciences (MUHAS), Mbeya Zonal Referral Hospital (MZRH), and the National Institute of Medical Research (NIMR) in Tanzania.

3. Results

3.1. Summary of key informant demographics and qualitative themes

The study recruited participants from a diverse range of ages, education levels, religions, and occupations. Among the 19 treatment-engaged participants living with schizophrenia (PWS) who participated in the study, 13 were men, and six were women. Participants ranged in age from 22 years to 48 years [exact ages are not shown for confidentiality]. Most participants were single, some were unable to articulate their marital status, and a few participants were currently married with one separated after the onset of their illness. More than half the participants had been living with their illness for more than ten years and few were formally employed (Table 1).

A total of twenty family member key informants were interviewed, 11 women and nine men, representing 10 parents, six siblings, one spouse, one adult child, one uncle, and one nephew. Participants' ages ranged from 20 to 78 years old with diverse occupations and education levels (Table 2).

Data analysis revealed four major themes organized across the four social support domains and data are presented as perspectives from PWS and caregivers with major differences in opinions highlighted. The themes include: 1) Financial and basic needs support from families is common yet critical for daily living (instrumental support); 2) Mixed experiences regarding provision of and receipt of love and acceptance with desires and calls for more encouragement and moral support (emotional support); 3) Guidance, reminders, and gaps in knowledge for recovery promotion and effective caregiving (Informational & Appraisal Supports), and 4) PWS and caregivers wish large community could provide more social support (cross-cutting support).

3.2. Instrumental support: financial and basic needs support from families is common yet critical for daily living

Perspectives from participants living with schizophrenia [PWS]: The vast majority of PWS (17 of 19) were almost fully dependent on close family members for financial support. Most PWS mentioned receiving financial support for basic needs such as housing, food, and clothes as the primary support they received from their caregivers. They also mentioned being financially supported by family members to buy medication and to pay for bus fare when attending clinic visits, as noted below.

“My family supports me by buying my medication and providing me with [basic] needs such that I can eat, be clothed, and have shelter. I get time to rest, and they also give me money to spend and enjoy my life.” (a 28-year-old man living with schizophrenia)

Although most participants focused on basic needs and medical support, one participant stated childcare was a valuable example of instrument support.

“The main support from the family is their patience with me. For instance, I have a little child, but he stays with my mother. Therefore, that patience and being able to stay with my child for me—it’s a huge support.” (a 21-year-old woman living with schizophrenia)

Perspectives from caregivers: Similarly, across caregiver interviewers, two types of instrumental support were consistently mentioned: financial, basic needs (food, clothing, medication, transportation, housing), and supporting social activities. All caregiver key informants mentioned transportation as a form of instrumental support that they provide, whether it was providing bus fare to the hospital or an actual escort to the hospital.

“[supports offered by informant] First of all by taking him to the medical center. Secondly by giving him the necessary needs such as food, shelter, and clothes.” (Caregiver—Uncle)

“[It] troubles me as she wishes to do or to have things that I may not afford. There may be a wedding party for her friend, and she wishes to attend it. So, you have to contribute to her needs, even if you don’t have that money at that particular time.” (Caregiver—Father)

In addition to instrumental support for ensuring payment for and access to prescribed medications, caregivers also frequently reported engaging in activities that would ensure medication adherence. These ranged from ensuring access to medications and making medicine easier to take or being present during times for taking medication as described in the following quotations. We note that it was not always clear in the transcripts whether the caregivers’ provision of support for medication was coercive or aligned with the requests for help with adherence from PWS which would indicate more autonomy.

“He does not have health insurance coverage, and he has his three younger siblings who also need school fees and others, but if it’s medicines, he must get medicines. Therefore, the entire burden is on me now because his father died” (Caregiver—Mother)

“I am trying hard to make sure that she takes the medication at the right time in the mornings and evenings. I do my best to mix the drugs with juice so she can take the medicines.” (Caregiver—Sister)

Both PWS and caregivers indicated how crucial family support was for daily living and that community support was more limited.

“There is a great difference. The family is to provide all support, and the community can help only when necessary.” (Caregiver—Brother)

“All of the persons with mental disorders are supported by their family members. Everyone carries his own load, and you cannot depend on someone from outside. You can only go to someone whom you know that can support you.” (Caregiver—Mother)

It was commonly mentioned that instrumental support was especially important when PWS experienced worsening symptoms (e.g., relapse). Caregivers highlighted how fully dependent PWS were on them and the implications on their time.

“We sometimes do not carry on with our own activities because we have to care for the patient most of the time. These patients are dependent, and so you will be forced to stop other activities for their sake.” (Caregiver—Mother)

“We provide a huge monetary assistance by ourselves. We deny ourselves a lot, we borrow money to make sure we support her” (Caregiver—Father)

Differences in Instrumental Support Perspectives: Differences in desired instrumental supports by caregivers did not vary by site but did vary by age, with older caregivers (ages 50–78 years), typically the parents, desiring that the PWS contribute more to the family due to years of dependency. In some instances, there were additional economic impacts on families when agitated behavior from PWS resulted in the destruction of property in the home or loss of income, as noted below:

“... As she becomes destructive to properties, she pulls me back economically” (Caregiver—Mother)

“All my businesses were spoilt; I have more than ten sewing machines for teaching people to sew. Neighbors used to tell people, “Don’t go to that place, her son beats people up when you go there ... I closed the business for about a week” (Caregiver—Mother)

“I wish my child to be fit and contribute to family issues [financial] ... so that we can move our family forward” (Caregiver—Father)

“I wish he could complete his college education, get a job, and start supporting himself and not be a burden to the family; and also help the family as well. I even wish we could exchange our situations and I take the sickness as my own” (Caregiver—Sister)

While many caregivers felt that they were giving all that they could, some PWS indicated gaps in their desired level of instrumental support. For example, some expressed their wish

for specific types of support such as opportunities to pay for additional schooling and/or start a small business to fulfill their educational ambitions and/or to enhance chances for independent living. This can also be interpreted as a bid for greater autonomy. This was particularly noted by PWS who acknowledged they were doing well as far as their illness was concerned.

“I need support to go for further studies, like going for a degree or diploma” (a 30-year-old man living with schizophrenia)

“If I got some money [from family members], I would do business especially now that I’m doing well, I think it would be good” (a 30-year-old woman living with schizophrenia)

3.3. Emotional support: mixed experiences regarding the provision of and receipt of love and acceptance with desires and calls for more encouragement and moral support

Perspectives from participants living with schizophrenia [PWS]: Over half of PWS described receiving emotional support from their caregivers and family members such as encouragement to take medication regularly to attain recovery, strengthening of their faith, and providing comfort.

“They support me and encourage me to use medication while continuing to believe that God will help me” (a 28-year-old man living with schizophrenia)

“A good day is when my boyfriend says, “I love you” and my mother of course, and my daughter.” (a 29-year-old woman living with schizophrenia)

However, over a third of PWS specifically highlighted lacking emotional support in the context of discussions about experiences with stigma at the community and family levels. These experiences included a lack of kindness, segregating practices, and name-calling using terms like “*crazy*” and other hurtful statements directed toward them.

“They [family] should be with you, help you buy medication, they should stay with you like in the past but now you are sick, they stigmatize you, thinking you’re sick all the time. They ignore you.” (a 30-year-old woman living with schizophrenia)

Perspectives from caregivers: The types of emotional support described by caregivers included ideas around expressions of love, fostering hope, providing support for healthy and positive living, and being emotionally close to their relative with schizophrenia. Love is represented by the caregiver’s provision of hospitality and trying to understand and be responsive to what their relative likes.

“You have to show him that you love him, don’t disappoint him, and always tell him “Now you are healed” while you know he is not [completely] healed. You should just create that hope in him even though you know he is not yet well” (Caregiver—Sister)

“We encourage her not to worry, and we pray to God that such problems may come to an end” (Caregiver—Father)

Accepting being physically present with their relative living with schizophrenia was one way that a variety of caregivers expressed being able to support both activities of daily living and more personal emotional needs.

“Most of the time, we stay close to him and make sure that he is not alone, we normally involve him in conversations with visiting relatives, or sometimes going to the market with him to buy things, or even sending him alone to the market. You have to be close to him all the time, giving him a lot of company so that he does not feel isolated.” (Caregiver—Mother)

A nephew’s description of his uncle highlights overlapping instrumental (escorting) and emotional support via his physical presence with this uncle.

“He used to stay at the bus stop every day, he would not bath at all, he would stay there all day long and sleep there every day; I had to look for security guys to help me catch him and take him to the hospital because he was so strong. I realized, why shouldn’t I follow up on his treatments? Therefore, after his discharge, I started going with him to the hospital whenever the date came. It used to cause me pain because he is an educated, older relative, but we were caring for him as though he had no relatives just because we didn’t follow up on his treatments” (Caregiver—Nephew)

Most caregivers expressed acceptance of their relative’s mental health condition. A quarter of the caregivers felt embarrassed at times but most noted improvements when treatment was provided, allowing them to understand that some behaviors were part of the illness and not deliberate.

“Let me speak from my heart. I don’t feel embarrassed at all. Some people, when they see my child when mentally ill, try to embarrass me, but I don’t feel embarrassed. I understand it’s just a normal problem, which can happen anytime. I don’t feel embarrassed.” (Caregiver—Father)

The few who reported feelings of being embarrassed by the family member with a psychotic illness claimed it was due to observable actions (e.g., public nakedness, destruction of property) that required them to apprehend and physically restrain their relative. A few caregivers noted the importance of not focusing on past actions of persons with psychosis but more so on ways to support and assist them.

“... you just have to love them [person with psychotic illness]. Once you become a little too harsh towards them that is when you cause more problems.” (Caregiver—Mother)

“They should be treated equally just like normal people. They should not be despised. They should not be called bad names such as “crazy people.” When you call them that name; they get more confused and feel like they are not equal to other people. They should not be called bad names. They should be given good services. They should not be served food differently. They should just be treated like other people, ...in fact, they should be given more delicious foods on glass plates. If they are using the medications properly, they won’t break the plates. That

way they will feel part of the family. When you separate them, they feel bad. When you show them love and stay closer to them, they feel loved” (Caregiver—Mother)

Differences in emotional support perspectives.—There were differences by age and sex amongst caregivers on what types of emotional support were important to provide for family members with psychotic illnesses. Older caregivers, who were also primarily parents, were more likely to wish that the community would support their ill family members by valuing and loving them. Both male and female caregivers spoke of love. While some caregivers reported general acceptance and making efforts to involve PWS in social activities such as family conversations, and decision-making on family matters, most PWS indicated that they wished they had more emotional support. The perceived deficits in emotional support were linked to their experiences of segregation and illness-associated stigma.

3.4. Informational & appraisal support: guidance, reminders, and gaps in knowledge for recovery promotion and effective caregiving

Perspectives from participants living with schizophrenia [PWS]: Informational support includes giving advice, suggestions, or useful information to someone. Such supports have problem-solving potential. Appraisal support is essentially giving constructive feedback and affirmation to aid in self-evaluation. Participants mentioned some aspects of informational support, including being advised by the family members to adhere to medications and the importance of getting involved in spiritual matters. Being encouraged to work hard was also mentioned.

“They insist that I use hospital-based medication until the doctor tells me to stop.”
(a 28-year-old man with schizophrenia)

Participants mentioned that the psychoeducation provided by health care providers at the clinic was very helpful for self-understanding of the illness and treatment as well as a healthy lifestyle for better recovery. PWS expressed wanting even more guidance related to their mental health, particularly from clinicians. This included guidance on occupations as the means to help them regain their previously acquired skills or to acquire new skills to help them attain independence. Being independent was highly valued as it was related to respect—a number of participants believed that working would help change people’s attitudes towards those living with mental illness and they would be seen as less burdensome to the family. Some mentioned specifically the need to be equipped with vocational skills, problem-solving skills, assertiveness, and other skills on how to live and cope in the community.

“Occupational guidance will be helpful; for instance, I have been to school, but I still need more education. I need to be more independent and not depend on other people.” (a 30-year-old man living with schizophrenia)

“The guidance will be valuable to me because it will help me participate in community activities and do something in the community, which will cause people to value me in society.” (a 30-year-old woman living with schizophrenia)

Other aspects of informational support expressed included wanting recommendations regarding the use of faith-based services but without discouraging the use of hospital

medication as these were perceived as important as well. Guidance in their spiritual life was perceived to potentially increase hope and lead them towards ‘good’ behaviors that could help them avoid relapse like prohibiting substance use. PWS wanted families to support their participation in religious and spiritual activities alongside hospital treatment.

Perspectives from caregivers: The caregivers expressed their lack of knowledge about mental disorders, thus impeding their provision of informational support. They were eager for more information themselves on how best to support PWS so they could more effectively implement their caregiving role. Identifying signs of relapse was a frequently reported topic where they felt knowledge gaps.

“When the situation gets worse, we bring him to the hospital and when he is admitted we come to take care of him, check him up, and bring for him whatsoever is necessary” (Caregiver—Wife)

One caregiver spoke of how the provision of information about the recovery process was essential guidance they wished to receive. By not knowing this information, they raised concerns that they may be negatively contributing to their relative’s recovery and further stigmatizing them.

“We as a family might be contributing to the non-recovery of the patient. We might not know about treating the patient in a way that can promote recovery. It might happen that we are locking up the patient when we are not supposed to do so. In this way, we don’t help her because we isolate her; she thinks she is not valuable to the family. She is thus stigmatizing herself and we are stigmatizing her too” (Caregiver—Mother)

There was largely a lack of appraisal support provided by the caregivers to PWS via constructive feedback. Facilitating hope by encouraging PWS to ‘keep fighting’ to decrease illness symptoms was the caregivers’ main form of appraisal support. Some participants indicated they actively provided affirmations for PWS to be optimistic about their condition with hope for recovery. In general, caregivers indicated they would like to provide more support but they themselves needed more education on mental illness and recovery from clinic-based providers.

3.5. Calls for more social support from the community (cross-cutting theme)

The last theme is related to perspectives on social support from communities, beyond the family. Both PLWS and caregivers touched upon how communities currently or could in the future engage with all types of social support.

Perspectives from participants living with schizophrenia [PWS]: PWS mentioned instrumental support from the community as a rarity. When available, it was provided during times of crisis, such as assisting family members as they trace and escort the PWS to the hospital. In addition, PWS perceived community support as necessary when they face illness-related difficulties outside the home. In these cases, the community can watch out for the family by reporting observations of illness relapse signs or alarming peer pressure influence to engage in substance use or other risky behaviors.

“The community will just take hold of you and tie you up, but never take you to the hospital because sometimes they don’t have the (financial) means. When they seize you, they take you to your mother and she is the one to take you to hospital” (a 45-year-old man living with schizophrenia)

“When they see I’m not in a good condition or I’m walking around with a group of boys or girls not having good morals, they can tell my mother or father. They can say tell them that your child is walking around with bad groups, you should help her” (a 29-year-old woman living with schizophrenia)

While instrumental support from the community was rare, so was emotional support and PWS wanted more understanding at the community level including kindness, being able to recognize illness, and being patient when they were ill. Most wished that stigmatizing practices such as name-calling should stop, to allow them to have a sense of inclusion.

“The community should encourage the mentally ill and avoid stigmatization. The community should recognize, care for, and protect the person with an illness. They should bear [be patient] with the mentally ill person” (a 25-year-old man living with schizophrenia)

PWS perceive the community as having few members who understand mental illness well enough to offer support. They noted that those with knowledge tended to be more supportive. In the absence of community mental health education, PWS perceived that more traditional beliefs about mental illness existed, and lay advice was to seek traditional treatment which some PWS did not like.

“The community can support them [family] in a big way, but some of the community members don’t understand about it [mental illness]. When they do understand that you have a mental disorder, they will catch you and take you to the hospital, but others [that do not know] might even kill you thinking that you are pretending [to be ill] while you are not even aware of yourself” (a 21-year-old woman living with schizophrenia)

Perspectives from caregivers: Covered under this theme was a constant desire from caregivers for any help from the community. However, the perception of a lack of community education by caregivers was also a barrier to them seeking support from the community. These sentiments can be interpreted as an internalized extended stigma on the part of caregivers, such that their concerns may prohibit sharing information about a relative’s mental illness.

“The best solution is not to laugh at them but encourage them. We have a neighbor who gives her money and can buy her some things in our absence. This makes her feel good. We do return some money to the neighbor if she asks for some from them in our absence. So, the community should accept her condition and help her. They should not tell her that they have no money, or she is bothering them” (Caregiver—Father)

“We are hesitant to do this [receive community support] because most of them are not aware of these things and so we might create another problem. That is why we

see it as a family problem, and we are just receiving assistance from the hospital. We are also trying not to expose our relative to other people because if he finds out that other people know about his illness it will create another problem because of the limited kind of knowledge available in the society” (Caregiver—Brother)

All caregivers expressed wanting to receive information from health care providers about proper caregiving that will allow them to improve treatment and recovery outcomes for their family members and for more community education on mental illness so the larger community could support recovery as well. There were not significant differences in perspectives on the role of communities between PWS and caregivers.

4. Discussion

This study provides an in-depth analysis of the social support domains experienced by and provided to PWS via the perspectives of the affected individuals themselves and from caregivers’ perspectives in Tanzania. Many psychosocial interventions for schizophrenia indicate the value of strengthening ‘social support’ without really exploring what that means in detail. An important example is the WHO mhGAP Intervention Guide which indicates that treatment for psychosis should include strengthening social supports with the implication being that (re)activating social activities with families and communities will lead to the “provision of direct or indirect psychological or social support” (World Health Organization (WHO), 2016). We think this treatment recommendation can be taken a step further. A clear description and understanding of social support, from those giving it and receiving it, has the potential to more strategically inform programs that aim to increase social support during recovery. This study revealed that perspectives from PWS and caregivers were largely aligned with some noted differences regarding perceptions of gaps in support, particularly emotional and informational support.

The most commonly mentioned type of social support described by both PWS and caregivers was instrumental which included financial support for basic needs such as food, clothing, and shelter, but also for transportation, and the purchasing of medication. The Persons with Disabilities Act states that individuals are entitled to effective medical care that would prevent any occurrence of impairment, which “may cause permanent functional limitation” (Tanzania, 2010). Unfortunately, due to the recent implementation of government cost-sharing policies in healthcare, adults with psychosis are not necessarily able to access historically free psychotropic medications at all public health facilities in Tanzania (note: there is variation across regions of the country with some health facilities having transitioned to cost-sharing while others are still providing free medications). Without medication due to an inability to purchase it, the chance of relapse increases and can impact the quality of life of both PWS and their families as they manage crises (Leucht et al., 2012; Sun et al., 2007). The value of instrumental social support from families cannot be overstated.

Emotional support was also mentioned frequently, described as an encouragement to take medication regularly, providing comfort, and words of support to strengthen their faith/hope in attaining recovery. Even with many caregivers discussing their efforts to provide emotional support, some PWS indicated wanting and needing more of this type of support.

Explicit communication from providers to families about the importance of this expression could be helpful, as well as skills building in family communication so PWS and caregivers can share their needs and expectations with each other. Related to family communication and areas for clinic-based education, some PWS wanted more informational support about occupational strategies, and how to get include more spiritual elements (e.g. praying) that could support their recovery alongside clinical treatment.

When participants talked about perceived deficits in emotional, informational, and appraisal support from families and the larger community, this was often linked to experiences of segregation and illness-associated stigma. These gaps in support were attributed to a lack of information/knowledge among caregivers and the community on how to improve someone's recovery process and support them. PWS were eager to receive more social support across all domain types and caregivers were especially open to providing more informational and appraisal support if given appropriate training and more guidance on how to do so.

Community-level social support, particularly instrumental support, for PWS and their families is perceived as something rare and if present is offered by very few community members and only during times of crisis. In Tanzania, there is evidence of some negative aspects of family members serving as caregivers including psychosocial problems such as decreased quality of life and social isolation (Iseselo et al., 2016). Wider community knowledge about mental illness including psychosis could help combat the lack of social support felt by many of our participants. While PWS and caregivers often expressed that they were doing the best they can, they yearned for more—more education from clinical providers (informational) and more acceptance and material support from the community (instrumental and emotional).

4.1. Study limitations

This study had a few limitations. First, our sample of key informants was purposefully recruited from outpatient psychiatric services meaning we missed the perspectives of those not in treatment who are also more likely to have less social support. The insights provided in this study are also not representative of relatives of PWS because these caregiver key informants were already attending clinic with their patient-relative, indicating a level of instrumental support (escorting to the clinic). We also note that our patient population key informants were all stable enough for informed consent and thus we missed those who may have been in more need of social support (in crisis/active relapse was an exclusion criterion). This stable outpatient population could have also been higher functioning than all PWS accessing services or untreated in the community. It is also possible that these participants did not feel completely free to share during the interview because although confidentiality was assured by the interviewers, the interviews took place on the grounds of the hospital. Broadly speaking, the transcripts from caregivers had more depth and details as they were more verbose than the PWS and thus their perspectives might be overemphasized even though we strove for an analytic balance regardless of depth of content. This could be due to a number of reasons, but one was that interviewers indicated that some participants seemed drowsy, likely due to medication side effects, and others may have had mild cognitive deficits that made it more difficult for them to fully express themselves, thus impacting the

depth of detail provided and focus. Finally, there could be response bias from caregivers who revealed relatively high levels of acceptance and low stigma (more socially acceptable answers). We tried to address this issue and others by not matching patients and relatives in our recruitment for these interviews so they could each feel freer to share. We also note that there are many positive aspects of caregiving for the caregivers that may not be fully captured in our study because the focus was on PWS receiving social support (Kulhara et al., 2012). A strength of the study was the wide socio-demographic variability we achieved in our sampling and confidence that we reached data saturation given the repetitive concepts identified across transcripts by type of key informant.

4.2. Implications

Beyond a deeper understanding of social support for PWS in Tanzania, there are programmatic and policy implications of the data. Due to Tanzania's limited mental health workforce, of 1.3 per 100,000 population, working with families to support the recovery goals of PWS is logistically and culturally essential (World Health Organization (WHO), 2020). Therefore, mental health services should include dedicated resources for strengthening families' ability to provide social support (e.g., psychoeducation). Likewise, addressing the financial burden caregivers might be experiencing and how this affects other types of social support can be directly discussed by peer family groups or with providers (e.g., in Tanzania, patients can apply for financial exemptions from payment based on the economic status of the family with the help of social workers, or aligning patients' and relatives' understanding of occupational goals and income generation during treatment goal planning). In addition, while this study focuses more on the role of families, there is also a growing movement for creating opportunities for more peer social support which could complement and potentially fill some noted gaps in support.

Evidence-based interventions such as family psychoeducation which can explicitly address informational support and emotional support could be scaled to enhance efforts to strengthen social support for PWS (Lyman et al., 2014; Lucksted et al., 2012; Aldersey and Whitley, 2015). Individual health providers and social workers during patient intake, family conference meetings, and/or discharge planning could also assess and share strategies for addressing the four domains of social support within existing clinical services (e.g., is there someone who can help pay for your medication (instrumental), provides you comfort and who accepts you (emotional), gives you helpful feedback when you try something new (appraisal). Informational support was largely seen as needing to start with the clinicians ensuring families (in addition to PWS) are well educated so they can be a resource to their relatives. Community-level education and stigma-reduction campaigns would also be needed to enhance social support from the community. The evidence base on effective interventions to reduce community-level stigma is mixed to date (Corrigan, 2016), and stigma might be getting worse for those with psychotic disorders in some settings (Pescosolido et al., 2021). However, the calls to continue stigma reduction in LMICs are clear and newer interventions are being tested (Thornicroft et al., 2016; Jankowski et al., 2023). In Tanzania, World Mental Health Day often gets significant attention in the media and this is one opportunity for general awareness. In tandem with stigma reduction work would be clear community-level psychoeducation about how to support someone living with psychosis in your community

(e.g. an example shared during our study was wanting the community to help during crisis situations, this might best be accomplished more at the neighborhood level with some previous introductions and relationship-building prior to a crisis situation). This type of community intervention would benefit from more research.

5. Conclusion

Globally, the evidence for social support improving recovery outcomes for PWS is well established, but the depth of understanding of how exactly social support is experienced and perceived by PWS and caregivers in this Tanzanian context adds nuance that can help clinicians and programs more thoughtfully target psychosocial services in a resource-limited setting. In Tanzania, social support from families for PWS is both a legal and cultural obligation and hearing the voices of those affected is important for understanding the existing strengths in families and gaps that could be further improved. That said, some of the findings such as PWS wanting more clear expressions of love are probably universal. Finally, individuals living with schizophrenia are part of communities and those communities need the resources (education) to strengthen their ability to facilitate a social environment conducive to optimal recovery.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Socio-demographic characteristics of participants living with schizophrenia in Dar es Salaam and Mbeya, Tanzania (n = 19).

Age	Sex	Marital Status	Education Level ^a	Employment status	Years of living with psychosis
<i>Dar es Salaam site</i>					
20s	F	Single	Primary	Subsistence agriculture	4
20s	M	Single	Form 6	Student	2
20s	M	Single	University	Student (postponed)	2
20s	M	Single	University	Unemployed	5
30s	F	Married	Primary	Housewife	1
30s	F	Unknown	Form 4	Catering services	13
30s	M	Married	Form 6	Unemployed	17
40s	F	Separated	Primary	Commercial painter	12
40s	M	Unknown	Primary	Unemployed	15
40s	M	Single	Form 6	Shop salesperson	25
<i>Mbeya site</i>					
20s	M	Single	Form 3	Subsistence livestock producer	<1
20s	M	Single	Form 3	Unknown	10
20s	F	Unknown	Form 4	Petty trade	6
20s	F	Single	Diploma	Unemployed	12
20s	M	Single	Primary	Subsistence livestock producer	10
30s	M	Married	University	Teacher	11
30s	M	Unknown	Primary	Unemployed	15
40s	M	Unknown	Diploma	Teacher	15
40s	M	Single	Primary	Mason	15

KEY.

^aPrimary—first 7 years of education; Form – descriptor of the class level in secondary school that comprises six years, four years ordinary level (1–4), and two years advanced level secondary school (5–6).

Table 2

Socio-demographic characteristics of participants who are caregivers for persons living with schizophrenia in Dar es Salaam and Mbeya, Tanzania (n = 20).

Age	Sex	Education Level*	Employment status	Relationship to a PWS
<i>Dar es Salaam site</i>				
60s	F	College	Associate professional	Mother
70s	F	College	Petty trade	Mother
30s	F	Primary	Unemployed	Sister
60s	M	College	Retired associate professional	Father
40s	F	Form 4*	Subsistence Agriculture	Wife
30s	M	Form 4	Petty trade	Brother
70s	F	Primary	Unemployed	Mother
60s	M	Form 4	Subsistence Agriculture	Father
50s	F	Form 4	Subsistence poultry production	Mother
60s	F	Diploma	Retired Administrator	Sister
<i>Mbeya site</i>				
60s	M	Diploma	Skilled Agriculture	Father
60s	F	Primary	Unemployed	Mother
60s	F	None	Subsistence Agriculture	Mother
20s	M	Form 3	Unknown	Nephew
30s	M	Diploma	Unemployed	Brother
20s	M	Degree	University Student	Son
60s	F	Primary	Subsistence Agriculture	Mother
30s	M	Form 6	Unknown	Brother
70s	M	Primary	Retired	Uncle
50s	F	Primary	Petty trade	Sister

KEY:

* Form – descriptor of the class level in secondary school that comprises six years, four years ordinary level, and two years advanced level secondary school. Ranges from Form 1 to 6.