

Being a Parent and Caregiver in Schizophrenia: Experiences, Challenges and Transformations

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Abstract

Parents of individuals with schizophrenia often assume dual roles as parents and primary caregivers, facing substantial emotional, social, and practical challenges. However, caregiving as a lived experience remains underexplored, particularly in Latin America. This study aimed to explore how parents experience and make sense of their dual role as parents and primary caregivers of individuals with schizophrenia. An exploratory qualitative descriptive study was conducted with 14 primary caregivers of individuals receiving outpatient treatment for schizophrenia at Hospital del Salvador in Valparaíso, Chile. Following a psychoeducational workshop, participants took part in four focus groups. Data were analyzed using qualitative content analysis with ATLAS.ti. Rigor was supported through investigator triangulation and established qualitative quality criteria. Four categories emerged: (1) the emotional and social impact of diagnosis, including symbolic grief related to the perceived loss of the son or daughter as known before illness and stigma; (2) experiencing recovery, characterized by greater understanding of illness and treatment and strengthened caregiving skills, although acceptance remained gradual and fear of relapse persisted; (3) caregiving burden, marked by emotional strain and unmet needs for individualized psychological support; and (4) support networks, with parents valuing practical tools, information about social benefits, peer support, and professional guidance. Caring for a person with schizophrenia involves a dynamic, non-linear process of adaptation, learning, and meaning-making. Psychoeducation and peer support are valuable but should be complemented by individualized psychological support. Parents should be recognized as partners in care while their own emotional needs are addressed.

INTRODUCTION

Multiple studies have documented the substantial impact of schizophrenia on families (Awad & Voruganti, 2008; Caqueo-Úrizar et al., 2017). This burden spans emotional, social, and economic domains and may manifest as strained family relationships, caregiver psychological and physical distress, occupational disruption, and restrictions in social life (Brady & McCain, 2004; Provencher, 1996). Families often serve as primary caregivers, assuming responsibilities traditionally assigned to the clinical care team. In this context, Shiraishi & Reilly, (2019) identify negative impacts such as traumatic experiences, increased illness frequency, depletion of personal and social resources, uncertainty and unpredictability, family disintegration, interpersonal conflict, and exposure to discrimination. However, they also describe positive effects, including family solidarity, affirmation, affection, compassion, the acquisition of knowledge and skills, strengthened self-confidence, personal growth, and appreciation.

Parents who assume the role of primary caregivers are key actors in the successful treatment of schizophrenia, providing essential support across multiple domains. Their contribution includes emotional support, monitoring, and assistance with treatment adherence (Kamil & Velligan, 2019), as well as support with activities of daily living and financial and social assistance (Estradé et al., 2023). However, this role entails increased stress, potential depression, and financial strain (Prasad et al., 2024). A considerable body of literature has addressed central aspects of family caregiving, particularly

caregiver burden, family stress, and expressed emotion (Zanetti et al., 2018; Avraam et al., 2022). Qualitative studies have described the experiences of family caregivers, highlighting emotional distress and the impact on family relationships (Cleary et al., 2020; Kalayci et al., 2023). Despite these qualitative contributions, the broader literature has largely privileged quantitative approaches and outcome measurement over understanding the parental experience as a lived process marked by disruptions, ambivalences, and transformations in family relationships.

Understanding the dual experience of being both a parent and a caregiver in the context of schizophrenia requires access to dimensions of psychosocial impact that are not captured by traditional quantitative scales. Concepts such as caregiver burden and stress describe levels of tension or exhaustion, but they do not explain how these states are experienced in daily life or how they evolve over time, including dimensions such as sadness, meaning-making, and role reorganization. The qualitative literature suggests that the caregiving experience is characterized by dynamic, long-term processes of adaptation and meaning-making that are not fully captured by standardized measures.

For example, a bottom-up review of first-person accounts co-authored by academics and experts by experience (Estradé et al., 2023) identifies recurring experiential themes among family members and caregivers of individuals with psychosis, including the impact of diagnosis as a biographical disruption, experiences of loss and ambiguous grief, sustained emotional burden, feelings of invisibility within fragmented healthcare systems, and the desire to be recognized as active participants in care. This perspective of caregiving as a transformative process is particularly relevant for clinical practice, as it enables a deeper understanding of needs, conflicts, and potential intervention targets that extend beyond the measurement of burden or stress.

The caregiving experience may present distinctive cultural characteristics in Latin American contexts. Latino families tend to exhibit higher levels of emotional overinvolvement, characterized by intensive caregiving, prolonged parental bonds, and the centrality of family in the everyday lives of individuals with schizophrenia (Karno et al., 1987). Although these characteristics are not linearly associated with poorer clinical outcomes (Singh et al., 2013), they may shape experiences of responsibility, constant vigilance, emotional ambivalence, and exhaustion that differ from those described in Anglo-Saxon or European contexts (Hernandez & Barrio, 2015). However, most qualitative research originates from high-income countries, leaving an important gap in understanding how culture, family caregiving, and lived experience intersect in Latin American clinical contexts.

The present study drew on narratives generated through focus groups with parents who had completed a psychoeducational workshop. Family psychoeducation positions relatives as “partners in care” and addresses support needs beyond knowledge acquisition (Harvey, 2018), while providing a context for sharing and making sense of lived experiences (Millard et al., 2025). The study was not designed to evaluate the workshop or its effectiveness; rather, the workshop constituted the recruitment context and a shared experiential setting from which the focus groups were formed. The interactive format of the focus groups allowed participants to respond to one another’s accounts, compare individual caregiving

trajectories, and elaborate both shared and divergent meanings related to parenting and caregiving. References to the workshop were understood as participants' perceptions within their broader caregiving narratives, rather than as evidence of intervention effectiveness. The primary objective of the study was to identify and describe how mothers and fathers experience and make sense of their dual role as parents and primary caregivers within a Latin American clinical context, with particular attention to biographical disruption, persistent fears, emotional burden, and transformations in their relationships with their sons and daughters.

METHODOLOGY

Study Design

This was an exploratory qualitative descriptive study conducted with parents who had completed a psychoeducational intervention. However, the study was not designed as a formal evaluation of the intervention. Data were collected through post-intervention focus groups and analyzed using content analysis.

Ethical Considerations

The study was approved by the Scientific Ethics Committee of *blinded* (Approval No. 63/2021).

Consent to participate

All participants provided written informed consent and voluntarily agreed to participate in the study.

Recruitment

Between July 2021 and November 2023, four cycles of a psychoeducational workshop were conducted for family members and significant others of individuals with schizophrenia receiving outpatient care at the Psychotic Disorders Unit of *blinded*. The intervention aimed to provide knowledge about schizophrenia while creating a protected space for participants to share caregiving experiences and strengthen support networks. Each cycle included four to seven participants and comprised six weekly two-hour modules covering schizophrenia and its etiology, symptoms, treatment, the role of significant others, support networks, and society. An experienced nurse and social worker led most sessions, while a psychiatrist delivered the treatment module. At the end of each cycle, family members were invited to participate in the study and, if interested, received detailed information about the research procedures and ethical considerations.

Inclusion and Exclusion Criteria

Fourteen participants (primarily mothers and one father of a person diagnosed with schizophrenia) took part in the study. Two participants were recruited from the first and second workshop cycles, and five participants from the third and fourth cycles.

Given the qualitative nature of the study, the final sample size was determined according to the criterion of theoretical saturation (Martínez-Salgado, 2012), which in our case was reached with fourteen participants. This criterion refers to the stage of analysis at which no new units of meaning emerge from the data generated during fieldwork—in this case, through focus groups—that are necessary to understand the phenomenon under study.

Inclusion criteria were being the mother or father and primary caregiver of an individual diagnosed with schizophrenia receiving care at the outpatient clinic of *blinded* and having participated in the psychoeducational workshop.

Participants were excluded if, despite attending the workshop, they were not the primary caregivers of the individual with schizophrenia, or if they had an intellectual disability, severe psychiatric disorder, or severe neurological disorder.

Data Collection and Analysis

Parents of individuals diagnosed with schizophrenia who had participated in the psychoeducational workshop were invited to a separate session following completion of the intervention. The workshop sessions themselves were not included in the qualitative analysis. Focus groups were conducted by a member of the research team who had neither participated in the workshop nor been involved in the clinical care of participants' relatives. Four focus groups were conducted, one at the end of each intervention cycle. Each focus group consisted of a discussion session lasting approximately 60 minutes. With participants' authorization, sessions were audio-recorded in MP3 format and subsequently transcribed verbatim by the research team.

The transcribed material was analyzed using ATLAS.ti software (Version 9). A content analysis was conducted, coding explicit ideas and expressions as well as their manifest contexts (Guix, J., 2008), regardless of the linguistic or subjective meanings of the expressions. A coding framework was developed for each major theme emerging from the interviews, along with descriptive notes capturing the meanings and ideas identified during analysis. Codes were subsequently grouped into categories and subcategories to identify the main themes.

Illustrative quotations were selected from the transcripts to represent the diversity of the sample and support each category. The research team met regularly to conduct investigator triangulation. Consensus was considered achieved when at least two-thirds of the authors agreed on the interpretation.

Trustworthiness and Methodological Rigor

The study adhered to the criteria for methodological rigor proposed by Guba and Lincoln (Morse, 2015).

RESULTS

Focus Groups 1 and 2 included two participants each, while Focus Groups 3 and 4 included five participants each. All but one participant were mothers of individuals diagnosed with schizophrenia; the remaining participant was a father. The analysis identified 42 codes, which were organized into four categories and fifteen subcategories.

Category 1: The Emotional and Social Impact of the Diagnosis

Participants described their emotional experiences during the diagnostic process and the perceived social impact of the diagnosis.

Subcategory 1: Symbolic Grief

Caregivers described feelings of loss associated with the significant changes brought about by the illness, portraying a grieving process related to the “loss” of the son or daughter they knew before.

Participant N°2 from Focus Group N°1

“For example, with the treatment he experienced positive changes, in the sense that before the process he did not want to talk, or have lunch with us, and sometimes he even thought we might put something in his food, that it would be spoiled and would harm him. Now, for example, he is affectionate with us and tries to help; in the ways he can, because he wakes up late and is not very active, but he helps me hang the laundry and take out the trash when he can. It is as if he wants to feel that his help at home is useful, that he contributes something. But I look at him and observe him and think, ‘he is no longer the (son’s name) he used to be.’ So yes, I believe that psychologically everything changes for you as well; your life changes, everything changes.”

Subcategory 2: Recognition of Social Stigma

Participants reported perceiving the social stigma associated with a diagnosis of schizophrenia.

Participant N°1 from Focus Group N°2

“And he called it schizophrenic... and he said it twice in the same moment... ‘this election has been very schizophrenic’ (referring to comments made by a politician on Chilean television regarding an electoral process). It bothered me because it felt like he was trying to caricature the issue... it simply was not the appropriate word.”

Category 2: Experiencing the Recovery Process

Participants described both factual and experiential elements related to accompanying their sons and daughters throughout the recovery process.

Subcategory 1: Learning to Recognize Symptoms

Participants described learning to recognize behaviors observed in everyday life, including reduced self-care, as manifestations of the illness.

Participant N°2 from Focus Group N°2

"They do not bathe, they are not interested in combing their hair, they do not care how they smell; they do not notice those things, but we do, and that is one of the symptoms."

Subcategory 2: Reinterpreting a Son's or Daughter's Behavior

Participants reported that the workshop had helped them better understand their sons and daughters by relating certain behaviors to symptoms of the illness.

Participant N°1 from Focus Group N°1

"It meant a great deal to me because I learned a lot about the illness and the symptoms my daughter had, and I was able to connect them with what she was experiencing. I understood that it was not that she was lazy or rebellious; rather, it was her illness that led her to behave that way."

Subcategory 3: Recognizing the Importance of Pharmacological Treatment

Participants perceived that the workshop enabled them to acquire knowledge about the pharmacological treatment of schizophrenia.

Participant N°2 from Focus Group N°2

"My experience was very positive; ... One thing that really caught my attention was the patients' medication, understanding what each medication looked like and what it did in the body. Also, learning how pharmacological treatments have evolved."

Subcategory 4: Acquiring Practical Caregiving Skills

Participants referred that the workshop provided them with tools for coping with their sons' and daughters' illness.

Participant N°4 from Focus Group N° 4

"For those of us who are caregivers, it teaches us to observe and recognize when our patient (the person we are caring for) may be heading toward a crisis; therefore, it teaches us how to respond."

Subcategory 5: Coming to Terms with a Son's or Daughter's Illness

Participants described a gradual process of accepting their sons' and daughters' diagnosis.

Participant N°1 from Focus Group N°2

"I am still in the process of accepting the illness that our children have... I say 'our' because I think she (addressing Family Member N° 2) must be going through the same thing, even though she has lived with it much longer than I have, but I think it is a long journey."

Subcategory 6: The Shadow of Relapse

Participants described a persistent fear that their son or daughter might experience another episode.

Participant N° 1 from Focus Group N° 2

"So, I always carry this internal fear that it might happen again. It is a fear I know I have to work on myself, because I understand you cannot live day by day like that. But as a mother, I was left with it, almost like a trauma. Sometimes the whole movie of what I lived through with him comes back to me, and I would not want to go through that again."

Subcategory 7: Experiencing Destigmatization

Participants stated that their perception of the illness changed through their own experience, contributing to the deconstruction of previous beliefs associated with the social stigma of schizophrenia.

Participant N°2 from Focus Group N°1

"I used to think of those people as homeless-type individuals, lost people, the kind of people who burn houses or do things like that; that was what I thought a person with schizophrenia was like."

Then I realized, when I came here (referring to the hospital) and started to see how things really were, that it was not the way I had imagined, nor the way most other people imagine it."

Category 3: The Burden of Caregiving

Participants' narratives reflected fatigue and burden associated with their caregiving roles.

Subcategory 1: A Space for Expression and Support

Participants described the psychoeducation workshop as a space for emotional support and exchange, where they could share experiences of the illness, their own life stories, and the emotional burden of caregiving.

Participant N°3 from Focus Group N°3

"I may come here after a difficult day at work or stressed because of issues related to my son... and spending two hours in this workshop helps you release those feelings so that the following week you can keep fighting again."

Subcategory 2: Caregivers Need Care Too

Participants highlighted the need to strengthen psychological support for caregivers, considering the emotional and practical demands associated with caring for individuals diagnosed with schizophrenia.

Participant N° 2 from Focus Group N°4

"Sometimes it is not really about my own personal problems—those can be overcome—but seeing them suffering makes you sad, and then those depressive feelings come... You do not want to see them doing badly. Having support as a father or mother, so that we can cope with these things and remain strong in that sense."

Category 4: The Support Network That Sustains Caregiving

Participants identified support received from both peers and healthcare professionals as a fundamental component of their experience.

Subcategory 1: Tools to Support One's Child

Participants perceived that the workshop had increased their confidence and provided practical guidance for supporting their sons and daughters.

Participant N° 5 from Focus Group N° 4

"That is why I found these workshops so valuable, because they helped me support him (referring to her son), because I did not..., I did not know how to face ... how to help him, how to support him. Now I have learned."

Subcategory 2: Learning About Rights and Social Support

Participants valued the information provided during the workshop regarding social benefits associated with a diagnosis of schizophrenia, highlighting the knowledge acquired about resources such as disability pensions, disability identification cards, and referrals to day-care centers.

Participant N°1 from Focus Group N° 2

"I mean... regarding... the benefits available to our children... pensions, opportunities such as small business projects, how they can obtain a disability card, even for things like transportation. There are so many things that make you think, wow, this could really benefit my child."

Subcategory 3: The Network Woven Among Peers

Participants described developing empathetic relationships by sharing experiences and recognizing common challenges.

Participant N° 5 from Focus Group N°3

"I never imagined how useful this workshop would be for me because, first of all, I met mothers who were going through the same situation as I was; we exchanged experiences."

Subcategory 4: Gratitude Toward Those Who Care

Participants expressed gratitude for the knowledge and emotional support they associated with the workshop and the clinical team. They also acknowledged the support offered by their son's or daughter's healthcare team throughout the treatment process.

Participant N°2 from Focus Group N°1

"First, I thank God, and I thank the doctor, and also all of you (referring to the nurse and social worker leading the workshop) for all the help you have given us. As mothers, we come with the experience of living with our children, but without really knowing how to help them."

DISCUSSION

Our findings suggest that the experience of being a parent and caregiver of a person with schizophrenia is not a static condition but rather a dynamic and evolving process shaped by ongoing changes in the understanding of the illness, performance of the caregiving role, and perceptions of the future. Consistent with Estradé et al., (2023), who conceptualize diagnosis as a biographical disruption marked by experiences of loss and ambiguous grief, participants described their children's diagnosis as a form of symbolic grief. In this context, the changes that followed the first psychotic episode were often perceived as "the loss of the child they had previously known". This experience was accompanied by feelings of uncertainty and sadness, while also requiring parents to renegotiate their expectations regarding their child's development, autonomy, and future life course. These findings underscore the profound impact of schizophrenia not only on the individual diagnosed but also on the ways family members reconstruct meaning and adapt to a transformed reality.

Consistent with previous findings (Hsiao et al., 2017; EghbalManesh et al., 2023; Krupchanka et al., 2018), participants described directly experiencing stigma associated with schizophrenia. Parents not only perceived stigmatizing attitudes from their social environment, but also acknowledged that, prior to their children's illness, they themselves held similar beliefs and prejudices toward individuals with psychotic disorders. This experience appears to have fostered a process of critical reflection on their previous assumptions, enabling them to revise their understanding of severe mental illness and move toward a less stigmatizing perspective. In this regard, participants' accounts suggest that supporting their sons and daughters through diagnosis and treatment gradually transformed their beliefs about schizophrenia.

Participants also perceived the psychoeducational workshop as a valuable component of this process, enabling participants to better understand the disorder and its symptoms and to interpret certain

behaviors from a clinical rather than a judgmental perspective. Although the present study was not designed to evaluate intervention effectiveness, these findings are consistent with evidence indicating that psychoeducational interventions reduce the risk of relapse, improve understanding of the illness, promote more adaptive coping strategies, and strengthen families' capacity to provide support to relatives living with psychotic disorders (Millard et al., 2025; Rodolico et al., 2022; McFarlane, 2016; McFarlane et al., 2003; Chien et al., 2024).

Similar to the findings reported by Millard et al. (2025), participants highlighted the importance of the parent support group as a space for emotional support and validation of their experiences. Sharing experiences with others facing similar challenges enabled them to reduce feelings of isolation, identify practical caregiving strategies, and develop a sense of belonging grounded in mutual understanding. In this context, group-based settings emerged as a significant source of social and emotional support for family members of individuals with schizophrenia, contributing to a reduction in the subjective burden associated with caregiving.

Despite the benefits of psychoeducation and peer support, participants expressed an unmet need for individual psychological support to address the emotional impact of caregiving. This finding is consistent with the study by Dimitriou et al. (2023), which reported that only a small proportion of parents (10%) receive any intervention from mental health services, despite recent evidence suggesting that such support would be beneficial in helping them better manage their children's illness (Forcheron et al., 2023). At the same time, this finding suggests that parents' needs extend beyond acquiring knowledge about the disorder and include opportunities to process emotions such as fear, guilt, frustration, and exhaustion. Consequently, our results reinforce the importance of developing comprehensive family-focused interventions that combine psychoeducational components, peer support, and psychological care aimed at promoting caregiver well-being.

Taken together, these findings show that parents should not be understood solely in terms of the support they provide to their sons and daughters or their contribution to the recovery process. They undergo their own process of grief, uncertainty, learning, and redefinition of the parental role. Importantly, the transformation described in their accounts was neither linear nor complete: greater understanding and confidence in caregiving coexisted with fear of relapse, emotional exhaustion, and continuing concern about the future. Recognizing parents as individuals whose lives, relationships, and identities are also reshaped by schizophrenia allows parental caregiving to be understood not merely as a set of responsibilities, but as a complex lived experience involving loss, adaptation, resilience, and ongoing vulnerability.

Strengths and Limitations

A major strength of this study is its contribution to the limited evidence from Latin American contexts on the experiences of parents of individuals with schizophrenia, providing context-specific insights into the challenges, needs, and adaptive processes associated with long-term caregiving. Some limitations should also be considered. Two of the four focus groups included only two participants, which may have

facilitated a trusting environment and more in-depth discussion of personal and emotionally significant experiences, but may also have limited the diversity of perspectives and group interaction. Nevertheless, the four focus groups generated rich accounts of parents' experiences and enabled the identification of common themes across participants".

CONCLUSIONS

The findings of this study indicate that being both a parent and primary caregiver of a person with schizophrenia involves a personal and relational transformation that is neither linear nor complete. Participants described experiences of symbolic loss, uncertainty, stigma, and persistent fear of relapse, alongside gradual changes in how they understood the illness, interpreted their sons' and daughters' behavior, and redefined their expectations regarding the parental role and the future. Greater understanding and confidence in caregiving coexisted with emotional exhaustion and ongoing vulnerability, showing that adaptation does not necessarily imply the resolution of grief or concern. Parents should therefore be understood not only as partners in care, but also as individuals whose identities, relationships, and life trajectories are reshaped by schizophrenia.

Within this broader process, participants perceived the psychoeducational workshop as a valuable source of information, peer connection, emotional validation, and mutual support. However, these perceived contributions did not eliminate the need for individual psychological support, which remained an important unmet need. Comprehensive family-focused care should therefore combine psychoeducation and peer support with opportunities for parents to process the fear, grief, frustration, and exhaustion associated with caregiving, recognizing their emotional well-being as important in its own right and not merely as a means of supporting the recovery of their sons and daughters.

Declarations

Consent to participate

All participants provided written informed consent and voluntarily agreed to participate in the study.

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Author Contribution

V.A. and A.C. designed the study, participated in the triangulation of results and wrote the main manuscript text. M.F. transcribed the focus groups and conducted the qualitative analysis. M.G. participated in the study design and triangulation of results. J.S. conducted the focus groups and participated in the triangulation of data.

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