SOCIAL SCIENCES IN HEALTH

journal homepage: http://kont.zsf.jcu.cz
DOI: 10.32725/kont.2024.007

KONTAKT / **Journal of nursing and social sciences related to health and illness**

Original research article

“Being a caregiver has changed my life”: the experience of family caregivers caring for a loved one in the first episode of psychosis

Andi Buanasari [1] *, Ralph Kairupan [2], Asep Rahman [3], Hendro Joli Bidjuni [1],
Novena Paulicia Pontoh [1]

[1] *Sam Ratulangi University, Faculty of Medicine, Nursing Department, Manado, North Sulawesi, Indonesia*
[2] *Sam Ratulangi University, Faculty of Medicine, Department of Psychiatry, Manado, North Sulawesi, Indonesia*
[3] *Sam Ratulangi University, Faculty of Public Health, Department of Public Health Sciences, Manado, North Sulawesi, Indonesia*

Abstract
Aim: Distress and confusion when caring for patients in the First Episode of Psychosis (FEP) will affect family caregiving roles and quality of life. The aim of this study was to explore caregivers’ experiences in caring for patients in the FEP.
Design: A qualitative design with a phenomenological approach was conducted to uncover the uniqueness of each individual’s experience.
Methods: Participant selection was conducted through purposive sampling, involving 12 family caregivers. Data collection was carried out through in-depth interviews and then analyzed using the Content Analysis method.
Results: Caregivers expressed responses in the form of blaming, Expressed Emotion (EE) responses, and help-seeking responses, with most participants combining alternative and medical treatments. Financial issues, psychological issues, perceived stigma, and disruptions in daily activities were changes caregivers experienced while providing care. However, caregivers found strength from internal motivation through prayer and external support from neighbors, extended family, and local government.
Conclusion: Participants experienced distress and changes in various aspects of their lives when caring for family members in the first episode of psychosis. Education and family intervention are essential to address the needs of families, including their psychological needs.

Keywords: Family caregivers; First-episode psychosis; Phenomenology; Psychosis

Introduction

Psychosis is a mental disorder in which a person has difficulty distinguishing between real and not real. This condition is characterized by hallucinations and delusions as the main symptoms. Meanwhile, the First Episode of Psychosis (FEP) is the time when someone experiences their first episode of psychosis, marked by a loss of contact with reality (Arciniegas, 2015). According to WHO data from 2022, schizophrenia psychosis affects approximately 24 million people, or 1 in 300 people (0.32%) worldwide, while the prevalence in Indonesia is 6.7 cases of psychosis per 1,000 households. The first episode of psychosis is a critical period because effective intervention and management during this phase can lead to better outcomes (Kim et al., 2020). Effective management during the early phase tends to lead to better responses to long-term treatment (Albert et al., 2017).

FEP can be challenging for families as caregivers. During this early phase, the family feels confused to understand about psychosis. The family describes painful emotions, especially guilt and isolation. They blame themselves for not realizing earlier that their relative was ill (Wainwright et al., 2015). Families experience feelings of desperation and distress which then penetrate their everyday caregiving role (Oluwoye et al., 2020). Stress on caregivers can increase Expressed Emotion (EE), incredibly Emotional Over-Involvement (EOI) and Critical Comments (CC), which are also associated with higher Family Burden in caring (Zanetti et al., 2018).

Caregivers report that the main conflicts experienced when caring for a family member during the first episode of psychosis are a lack of knowledge about the symptoms (56.4%) and family members refusing to take medication (43.0%). Additionally, caregivers also experience stress, anxiety, decreased socialization, and insomnia (Wan and Wong, 2019). Families with individuals experiencing psychosis tend to report extreme difficulties such as disengagement, rigidity, and chaos. Families also report negative thoughts about the illness, and decreased satisfaction with work, family, and social life. However, this study also demonstrates that positive coping can serve as a protective factor against the negative impact on quality of life (Gupta and Bowie, 2018).

---

* **Corresponding author:** Andi Buanasari, Sam Ratulangi University, Faculty of Medicine, Nursing Department, Kampus Unsrat, Bahu, 95115, Manado, North Sulawesi, Indonesia; e-mail: andi.buanasari@unsrat.ac.id
http://doi.org/10.32725/kont.2024.007

Submitted: 2023-11-13 • Accepted: 2024-02-09 • Prepublished online: 2024-02-12
KONTAKT 26/1: 83–88 • EISSN 1804-7122 • ISSN 1212-4117

The family experiences psychosocial problems such as stress, which can subsequently increase Family Emotional Expression (EE) and have an impact on the increased burden on the family in providing care (Zanetti et al., 2018). Expressed emotion (EE) describes the emotional attitude of family members toward each other, such as excessive criticism indicating hostility towards the sick family member and excessive emotional involvement (Butzlaff and Hooley, 1998). Previous studies have reported that families experience high levels of stress and highly expressed emotion (EE) during the first episode of psychosis (Sadath et al., 2017). A family with a high level of EE (Expressed Emotion) has an impact on the behavior of the patient, such as non-compliance with treatment, non-participation in family activities, reluctance to seek medical help, and a decrease in the patient's activities (Ng et al., 2020).

Family, as the primary caregiver, plays a crucial role in patient care and requires special attention. Family intervention during the first episode of psychosis, has been proven to have a positive impact on improving family relationships and enhancing the family's ability to cope with challenging circumstances (Loh et al., 2021). Family intervention also increases acceptance and understanding toward patients, enhances the family's ability to recognize early warning signs, and improves their problem-solving skills (Nilsen et al., 2016), reducing the risk of relapse, lowering the level of Expressed Emotion (EE) in caregivers, reducing caregiver burden, and increasing caregiver well-being when compared to families who receive only standard intervention (Claxton et al., 2017). This study aims to explore and gain a deep understanding about the experiences of caregivers who are taking care of family members with mental disorders during the first episode of psychosis.

Materials and methods

Design

This study was conducted through qualitative design with a phenomenological approach.

Participants

The selection of participants in this study was done through purposive sampling, where the selection of participants is intentionally based on the research objectives and predefined inclusion criteria (Afiyanti and Rachmawati, 2014). The determination of the number of participants in this study is guided by the focus of phenomenological research, which emphasizes the depth of data and the process. Therefore, it tends to be conducted with a small number of participants, typically around 10 or even fewer participants, depending on the achievement of data saturation (Polit and Beck, 2020). The study includes 12 families as participants, and the participant criteria are as follows: (1) families who are the primary caregivers of individuals with mental disorders, (2) families who have been caring for individuals with mental disorders for a period ranging from 1 to 5 years, calculated from the first appearance of symptoms, (3) capable of speaking Indonesian, (4) willing to participate in the study.

Data collection

In-depth interviews were conducted in the data collection process. The interview process took place at the hospital, involving families who accompany patients to the outpatient department and families in the emergency ward. Both of these locations serve as the first access points for patients and families at the hospital. To ensure participant privacy, the researcher utilizes a closed room within the hospital as the interview location.

The researcher prepares the interview environment to be as comfortable as possible and schedules the interview times according to the participants' availability (Creswell and Poth, 2016). The interview process begins with an explanation and the signing of an informed consent form by the participant if they agree to participate in the study. Data collection continues until the 12th participant, at which point data saturation is achieved. Each interview lasts 45–60 minutes per participant using the interview guidelines and is recorded using a digital voice recorder. Three participants need to be interviewed twice to gather comprehensive information. After the interview process has been completed, the researcher conducts a member check by confirming the accuracy of the data that has been collected with the participants to ensure data validity.

Data analysis

The data analysis technique used in this research was content analysis, following the data analysis steps of the phenomenological research method proposed by Colaizzi (Polit and Beck, 2020). The data analysis process begins by transcribing the interviews conducted with the first participant. Subsequently, statements from the transcript are categorized, and significant statements are grouped into keywords. These relevant keywords are then further organized into categories and themes. In the next stage, we create a comprehensive, systematic, and clear description (thick description) of the analysis results that have been generated (Creswell and Poth, 2016).

Results

This study involved 12 primary caregivers of People with mental disorder in the first episode of psychosis. Table 1 shows the characteristics of participants who care for individuals with mental disorders. The majority of caregivers are females aged between 41–60 years. Their highest level of education is typically secondary school, and most of them work as housewives. Mothers are the most common primary caregivers in the family.

From the results of the data analysis using content analysis, four themes were identified in this study, namely: (1) Caregiver's response to taking care of patients during the first episode of psychosis, (2) My life has completely changed since taking care of family with mental illness, and (3) Things that strengthen me through this hardship. The identified themes and sub-themes can be seen in Table 2.

Caregiver's response to taking care of patients during the first episode of psychosis

This theme is constructed from three subthemes that describe the responses that emerge from Family Caregivers when caring for patients in the first episode of psychosis, namely Blaming, Help-seeking response, and Expressed Emotion (EE). Participants expressed their responses when they first learned that a family member had a mental disorder, including self-blame for being too strict, feeling like a failure, and being inattentive. Additionally, some participants also blamed God, feeling that it was unfair, as evident in the following statement:

"Yes, I am grateful, but sometimes, you know, as humans, we're not always capable of dealing with it. Sometimes, it's like: 'Oh, why, God, when I'm loyal to my family, do I get handed problems like this?'" (Participant 5).

Table 1. Demographic characteristics of study participants (*n* = 12)

Variables	*n* (%)
Sex	
Male	2 (16.67%)
Female	10 (83.33%)
Age	
30–40 years old	2 (16.67%)
41–50 years old	5 (41.67%)
51–60 years old	5 (41.67%)
Religion	
Christian	11 (91.67%)
Muslim	1 (8.33%)
Education	
Primary education	4 (33.33%)
Junior secondary school	2 (16.67%)
Senior secondary school	6 (50%)
Occupation	
Cake vendor	2 (16.67%)
Housewife	5 (41.67%)
Farmer	1 (8.33%)
Tailor	1 (8.33%)
Massage therapist	1 (8.33%)
Minibus driver	1 (8.33%)
Craftsman	1 (8.33%)
Monthly income (Rupiah)	
<Rp1.000.000	5 (41.67%)
Rp1.000.000–Rp2.500.000	4 (33.33%)
Rp2.501.000–Rp5.000.000	3 (25%)
Marital status	
Married	12 (100%)
Unmarried	0%
Relationship with patient	
Husband	1 (8.33%)
Wife	1 (8.33%)
Father	1 (8.33%)
Mother	7 (58.33%)
Siblings	1 (8.33%)
Auntie	1 (8.33%)
Length of care	
1 year	5 (41.67%)
1.5 years	1 (8.33%)
3 years	2 (16.67%)
4 years	1 (8.33%)
5 years	3 (25%)

Table 2. Identified themes and sub-themes

Theme	Sub-theme
Caregiver's response to taking care of patients during the first episode of psychosis	Blaming
	Help-seeking response
	Expressed emotion
My life has completely changed since taking care of family with mental illness	Financial issues
	Disruption daily activities
	Psychological issues
	Perceived stigma
Things that strengthen me through this hardship	Internal coping
	External support

"He's stressed, and his dad often gets angry. I also feel guilty, maybe because we were too harsh, and that's why he ended up like this" (P12).

Another response is the Help-seeking response, which is the initial treatment chosen by caregivers when symptoms of mental illness appear in their family members. In this case, most participants have already taken the patient to the hospital during the early stages of the illness, but have also sought out Church prayer teams or alternative treatments. Some participants mentioned that the traditional healers were asked them to stop taking medication from the doctor while undergoing treatment.

"We initially went to the Church prayer team while also receiving medical treatment from a doctor. However, in contradiction, we were pressured to stop taking the doctor's medication because they believed that prayers won't work if combined with the doctor's medication" (P7).

Furthermore, caregivers also reported an Expressed Emotion (EE) response when caring for their family members. EE describes the caregiver's attitude towards the patient. Some participants reported high levels of Expressed Emotion, which manifested as hostility, such as anger, physical aggression, and restraining the patient. Critical comments were also expressed by family members, including speaking harshly and shouting at the patient.

"He makes his dad emotional, so his dad hits him until he is bruised. His dad thinks maybe by doing this, he can make him go back to being normal" (P3).

In addition to the High Expressed Emotion (EE) shown through negative emotions, some participants also reported positive EE, which is manifested as warmth, such as giving compliments, being more attentive, and showing more affection.

"Since he has been sick, we have become more attentive and affectionate. I have also noticed that his dad rarely gets angry" (P12).

My life has completely changed since taking care of family with mental illness

Participants discussed the changes that have occurred in their lives since their family member became ill and they had to become the main caregiver. The changes they experienced ranged from financial difficulties, as they couldn't work effectively due to caregiving responsibilities, disruptions in their daily activities, such as a decreased ability to socialize as they used to, and disturbances in their sleep and eating patterns.

"Yeah, I told her: 'You see, we're already struggling, so don't act like this, as it hinders our ability to work. We need to be more frugal now because we don't know where else to get the money from'" (P6).

"He can't be left alone. I've had less sleep, it's difficult to eat, and I even worry about leaving him, thinking he might misbehave or cause trouble when left alone. It's happened before; he's even stabbed someone else's child" (P8).

Another change experienced by caregivers is the emotional aspect. Caregivers admitted to feeling sad, confused about what to do, stressed, and experiencing hopelessness. This is exacerbated by the perceived stigma from caregivers, such as neighbors suggesting that the patient be restrained, and extended family members ostracizing them.

"At first it was so sad seeing him like this, and I couldn't accept it. I was confused about what to do because I didn't know anything about it at the time" (P3).

"The neighbors distanced themselves from us, as if we had done something wrong to them. They constantly make comments like: 'You know your child is ill, just keep them locked up at home'" (P7).

Things that strengthen me through this hardship

This theme describes how participants navigate challenges and strengthen themselves in caring for family members with mental disorders, especially during the first episode of psychosis – which is a new experience for the participants. Two categories make up this theme, namely internal motivation and external support.

The internal motivation is largely influenced by religious factors. Participants expressed a sense of surrender, entrusting everything to God because they believe that there will be something beautiful behind it all. Participants also perceived the challenges they face as opportunities for self-reflection and personal growth.

"Every struggle surely has a purpose from God, perhaps to make us reflect more on ourselves as individuals and as a family. Right now, it has brought us closer to God, relying on Him more. We simply believe that all of this is God's plan, and there is something good behind it" (P3).

Participants also explained that external support, such as financial assistance, moral support from neighbors, aid from the village government, and informational support from healthcare workers have been very helpful in the process of caring for the patients.

"We have no contact at all with other family members, but our neighbors are very kind, they always help, and the village officials always provide money and transportation assistance. Just a while ago, the church youth leader called to inquire about our well-being" (P8).

"I observe and ask the nurses here, so now I know, oh, this is what needs to be done when they have an outburst, oh, this is what to do when they are quiet or urinate. Because at home, I have to do it by myself" (P12).

Discussion

This study illustrates the experiences of caregivers in caring for their family members with mental disorders, particularly capturing their experiences during the first episode of psychosis. Caring for patients during the first episode of psychosis presents a significant challenge for families due to a lack of knowledge, leaving them confused about what to do, and where to go for help. This leads to profound changes in the family's daily lives (Kumar et al., 2019). In this study, three themes emerged from the experiences of families caring for individuals during the first episode of psychosis: (1) The caregiver's response to taking care of patients during the first episode of psychosis, (2) My life has completely changed since taking care of family with mental illness, and (3) Things that strengthen me through this hardship.

Being primary caregivers during the first episode of psychosis is a novel experience for the participants. Participants conveyed their reactions while caring for the patient, encompassing feelings of self-blame and directing blame towards God. Participants also expressed the feeling that they might be too harsh and have failed in raising their child. This is also related to Expressed Emotion (EE) in the family, particularly in the dimension of Emotional Over Involvement (EOI), which refers to overly self-sacrificing and exaggerated emotional responses (Amaresha and Venkatasubramanian, 2012). Previous systematic review studies have shown that EOI is positively correlated with feelings of guilt and shame (Cherry et al., 2017). Other EE responses exhibited by participants include hostility and critical comments. The burden of the caregiving process can increase family EE, as reported in previous studies involving 422 caregivers of individuals with mental disorders, with 23.9% reporting high critical comments and 35.1% reporting high EOI. Long caregiving periods and 3–4 episodes of schizophrenia are associated with increased EE in caregivers (Yimam et al., 2022). However, participants not only reported negative EE but also expressed positive EE (such as warmth). Previous studies have reported that families with high warmth tend to show low critical comments, higher maladaptive coping scores, and lower overall well-being scores compared to relatives with higher levels of warmth (Avraam et al., 2022).

Another observed response was help-seeking behavior when family members show signs of mental illness. Some families immediately seek medical care, while others choose to observe and confine the individual at home or try alternative treatments first. However, families who seek medical care often combine it with alternative treatments later, and some are even asked to stop medical treatment because it might affect the effectiveness of the alternative treatments. Several factors influence the help-seeking behavior of caregivers, including stigma and a lack of family knowledge (Wong et al., 2020). This problem needs to be addressed because appropriate intervention during the first episode can reduce the Duration of Untreated Psychosis (DUP) and prolong treatment engagement, leading to better outcomes (Weiss et al., 2022).

Another theme that emerged is related to the life changes experienced by caregivers when taking care of family members with mental disorders. Caregivers experience financial changes as well as changes in their daily life activities. The patient's inability to work during their illness forces the caregiver to work while providing care. The patient's employment status can affect stigma, patient dependency, loss, and the need for backup from caregivers (Charles et al., 2021). Previous systematic review studies revealed that 5 out of 7 studies indicated a financial burden in caring for individuals with mental disorders, characterized by financial constraints, productivity loss, and lost employment (Addo et al., 2018).

Another change was in the psychological aspect, where caregivers feel stressed, sad, and confused. Caregivers often experience psychological distress, especially during the first episode of psychosis, with feelings of shock, fear, and a tendency to keep what is happening at home a secret (Onwumere et al., 2019). This is usually because caregivers are confused about what to do due to a lack of information, especially regarding symptoms related to psychosis (Juneja, 2023). When compared to caregivers who care for chronic psychosis, the physical and social burden is higher in caregivers of patients with chronic psychosis compared to those caring for the first episode of psychosis, but not in terms of the emotional burden. Caregivers caring for those with first-episode psychosis exhibit more intense emotional responses (Sagut and Çetinkaya Duman, 2016). This emotional burden is exacerbated by the stigma felt by caregivers. Participants reported being shunned by neighbors and even asked to restrain their children because of having psychosis. This has also been reported in previous studies, where stigma and discrimination are experienced by most families during the first episode of psychosis, such as being shunned and experiencing difficulties in making friends and maintaining close relationships with extended family members (Kinson et al., 2018).

The last theme that emerged is how participants navigate and strengthen themselves to get through difficult times as caregivers. Internal motivation includes spiritual reinforcement, such as surrendering and praying to God. Caregivers often question the meaning of life and may feel despair when they have to care for family members with mental disorders, so they choose spiritual practices as coping mechanisms (Casaleiro et al., 2022). Another study stated that religious coping is associated with positive caregiving experiences, but on the other hand, those who rely more on religious coping may require more education and mental health services (Pearce et al., 2016). Additionally, a previous study also reported that parents who care for their sick children often use internal coping strategies, such as efforts to enhance emotional balance, like relaxation techniques (Sikorová and Bužgová, 2016).

Participants received external support from neighbors, local government, and healthcare workers. Some mentioned that other family members provide assistance, while others may not be as helpful. Previous studies have also revealed that although family support is limited, it can help caregivers get through difficult times (Hansen et al., 2020). Caring for a patient with a mental disorder, especially when it's a new experience, can indeed be challenging, and families often require a wide range of support and resources such as information, assistance in accessing government health facilities, and caregiving skills (Kumar et al., 2019). From the perspective of service users, they also explain their roles and responsibilities. For example, families provide emotional support and care, friends and the community facilitate recovery and promote good mental health in the community, and stakeholders provide access to healthcare services, help reduce stigma, assist in finding employment and education, and also improve the mental healthcare system (Pope et al., 2019).

Most participants demonstrated similar responses and felt the same impact from caring for family members with mental disorders in the first episode. However, it appears that participants 1 and 5 showed more significant blaming responses, financial changes, and psychological impacts compared to other participants. This may also be attributed to their lack of adequate external support and insufficient information related to psychosis. Previous studies have confirmed that family caregivers who perceive the availability of social support experience lower psychological distress (George et al., 2020). Another study also showed that caregiver burden is related to the occurrence of depression among caregivers. However, adequate social support can reduce caregiver burden, especially among female caregivers and those with lower education and income levels (Sun et al., 2019).

Conclusion

This study provides an overview of the experiences of family caregivers when caring for their family in the first episode of psychosis. Participants reported drastic changes in their lives in terms of financial issues, psychological well-being, disruptions in daily activities, and feeling stigmatized by their surrounding environment. However, internal strength derived from religious aspects and external support became factors that strengthened caregivers in their caregiving role. The experience of caregiving during the first episode of psychosis is extremely challenging because participants still feel confused about what to do, leading to psychological responses that subsequently affect their help-seeking behaviors. These findings can serve as the basis for the development of education and family intervention programs to meet the learning needs of families in caregiving and address their psychological needs. This study has potential limitations. Not all the interviewed caregivers came from the nuclear family, which may potentially influence caregivers' experiences differently, especially in terms of psychological responses.

Authors' contribution

A.B. constructed research ideas and methodology, conducted interviews, performed data analysis, constructed the whole or body of the manuscript and wrote the manuscript in consultation with *R.K. R.K.*, assisted in data analysis, and conducted a critical review of the article before submission, not only for spelling and grammar but also for its intellectual content. *A.R.* and *H.B.* handled and prepared documents and permits for the research site, assisted in the data analysis process, and wrote financial research reports. *N.P.* assisted in the data collection process and created verbatim transcripts. All authors provided critical feedback and contributed to shaping the research, analysis, and manuscript.

Ethical aspects

The study was conducted in accordance with the ethical principles of research, which include voluntary participation, informed consent, anonymity, confidentiality, beneficence, non-maleficence, justice, and integrity. Additionally, the research has obtained approval from the research site, Prof. Dr. V. L. Ratumbuysang Mental Hospital, with approval number: 445/RSJ/194/2023.

Acknowledgments

We are very grateful to the participants who were willing to take part in this research, including the nurses who facilitated the data collection process.

Funding

Financial support for this work was provided by the Grant from The Institute for Research and Community Services of Sam Ratulangi University, Indonesia (Grant No: 226/UN12.13/LT/2023).

Conflict of interest

The authors have no conflict of interest to declare.

References

1. Addo R, Agyemang SA, Tozan Y, Nonvignon JJ (2018). Economic burden of caregiving for persons with severe mental illness in sub-Saharan Africa: A systematic review. PloS One 13(8): e0199830. DOI: 10.1371/journal.pone.0199830.
2. Afiayanti Y, Rachmawati IN (2014). Metodologi Penelitian Kualitatif dalam Riset Keperawatan. Rajawali Press, 258 p.
3. Albert N, Melau M, Jensen H, Hastrup LH, Hjorthøj C, Nordentoft M (2017). The effect of duration of untreated psychosis and treatment delay on the outcomes of prolonged early intervention in psychotic disorders. NPJ Schizophr 3(1): 34. DOI: 10.1038/s41537-017-0034-4.
4. Amaresha AC, Venkatasubramanian G (2012). Expressed emotion in schizophrenia: an overview. Indian J Psychol Med 34(1): 12–20. DOI: 10.4103/0253-7176.96149.
5. Arciniegas DB (2015). Psychosis. Continuum: Lifelong Learning in Neurology 21(3 Behavioral Neurology and Neuropsychiatry): 715–736. DOI: 10.1212/01.CON.0000466662.89908.e7.
6. Avraam G, Samakouri M, Tzikos A, Arvaniti A (2022). High Expressed Emotion and Warmth among Families of Patients with Schizophrenia in Greece. Healthcare (Basel) 10(10): 1957. DOI: 10.3390/healthcare10101957.
7. Butzlaff RL, Hooley JM (1998). Expressed emotion and psychiatric relapse: a meta-analysis. Arch Gen Psychiatry 55(6): 547–552. DOI: 10.1001/archpsyc.55.6.547.
8. Casaleiro T, Caldeira S, Cardoso D, Apóstolo J (2022). Spiritual aspects of the family caregivers' experiences when caring for a community-dwelling adult with severe mental illness:

A systematic review of qualitative evidence. J Psychiatr Ment Health Nurs 29(2): 240–273. DOI: 10.1111/jpm.12816.

9. Charles S, Kirkbride JB, Onwumere J, Lyons N, Man LC, Floyd C, et al. (2021). Carer subjective burden after first-episode psychosis: Types and predictors. A multilevel statistical approach. Int J Soc Psychiatry 67(1): 73–83. DOI: 10.1177/0020764020930041.
10. Cherry MG, Taylor PJ, Brown S, Rigby JW, Sellwood W (2017). Guilt, shame and expressed emotion in carers of people with long-term mental health difficulties: A systematic review. Psychiatry Res 249: 139–151. DOI: 10.1016/j.psychres.2016.12.056.
11. Claxton M, Onwumere J, Fornells-Ambrojo M (2017). Do family interventions improve outcomes in early psychosis? A systematic review and meta-analysis. Front Psychol 8: 371. DOI: 10.3389/fpsyg.2017.00371.
12. Creswell JW, Poth CN (2016). Qualitative inquiry and research design: Choosing among five approaches: Sage publications, 488 p.
13. George ES, Kecmanovic M, Meade T, Kolt GS (2020). Psychological distress among carers and the moderating effects of social support. BMC Psychiatry 20(1): 154. DOI: 10.1186/s12888-020-02571-7.
14. Gupta M, Bowie CR (2018). Family cohesion and flexibility in early episode psychosis. Early Interv Psychiatry 12(5): 886–892. DOI: 10.1111/eip.12384.
15. Hansen H, Stige SH, Davidson L, Løberg EM, Veseth M (2020). “Needing different things from different people” – a qualitative exploration of recovery in first episode psychosis. Soc Work Mental Health 18(1): 75–95. DOI: 10.1080/15332985.2019.1679324.
16. Juneja TK (2023). Understanding the information needs of clients and caregivers regarding early psychosis: A conventional content analysis. The University of Western Ontario, Electronic Thesis and Dissertation Repository. [online] [cit. 2023-01-22]. Available from: https://ir.lib.uwo.ca/etd/9585/
17. Kim SW, Nelson B, Yang YK, Chung YC (2020). Early intervention in psychotic disorders. Front Psychiatry 11: 574532. DOI: 10.3389/fpsyt.2020.574532.
18. Kinson RM, Hon C, Lee H, Abdin EB, Verma S (2018). Stigma and discrimination in individuals with first episode psychosis; one year after first contact with psychiatric services. Psychiatry Res 270: 298–305. DOI: 10.1016/j.psychres.2018.09.044.
19. Kumar G, Sood M, Verma R, Mahapatra A, Chadda RK (2019). Family caregivers’ needs of young patients with first episode psychosis: A qualitative study. Int J Soc Psychiatry 65(5): 435–442. DOI: 10.1177/0020764019852650.
20. Loh C, Liang W, Lee H, Koh A (2021). Multi-Family Therapy for First Episode Psychosis: Experiences of Families in Singapore. Front Psychiatry 12: 788827. DOI: 10.3389/fpsyt.2021.788827.
21. Ng SM, Fung MHY, Gao S (2020). High level of expressed emotions in the family of people with schizophrenia: has a covert abrasive behaviours component been overlooked? Heliyon 6(11): e05441. DOI: 10.1016/j.heliyon.2020.e05441.
22. Nilsen L, Frich JC, Friis S, Norheim I, Røssberg JI (2016). Participants’ perceived benefits of family intervention following a first episode of psychosis: a qualitative study. Early Interv Psychiatry 10(2): 152–159. DOI: 10.1111/eip.12153.
23. Oluwoye O, Cheng SC, Fraser E, Stokes B, McDonell MG (2020). Family experiences prior to the initiation of care for first-episode psychosis: a meta-synthesis of qualitative studies. J Child Fam Stud 29(9): 2530–2541. DOI: 10.1007/s10826-019-01695-z.
24. Onwumere J, Parkyn G, Learmonth S, Kuipers E (2019). The last taboo: The experience of violence in first-episode psychosis caregiving relationships. Psychol Psychother 92(1): 1–19. DOI: 10.1111/papt.12173.
25. Pearce MJ, Medoff D, Lawrence RE, Dixon L (2016). Religious coping among adults caring for family members with serious mental illness. Community Ment Health J 52(2): 194–202. DOI: 10.1007/s10597-015-9875-3.
26. Polit D, Beck C (2020). Essentials of nursing research: Appraising evidence for nursing practice: Lippincott Williams & Wilkins, 512 p.
27. Pope MA, Jordan G, Venkataraman S, Malla AK, Iyer SN (2019). “Everyone has a role”: perspectives of service users with first-episode psychosis, family caregivers, treatment providers, and policymakers on responsibility for supporting individuals with mental health problems. Qual Health Res 29(9): 1299–1312. DOI: 10.1177/1049732318812422.
28. Sadath A, Muralidhar D, Varambally S, Gangadhar BN, Jose JP (2017). Do stress and support matter for caring? The role of perceived stress and social support on expressed emotion of carers of persons with first episode psychosis. Asian J Psychiatr 25: 163–168. DOI: 10.1016/j.ajp.2016.10.023.
29. Sagut P, Çetinkaya Duman Z (2016). Comparison of Caregiver Burden in First Episode Versus Chronic Psychosis. Arch Psychiatr Nurs 30(6): 768–773. DOI: 10.1016/j.apnu.2016.07.011.
30. Sikorová L, Bužgová R (2016). Associations between the quality of life of children with chronic diseases, their parents’ quality of life and family coping strategies. Cent Eur J Nurs Midw 7(4): 534–541. DOI: 10.15452/CEJNM.2016.07.0026.
31. Sun, X, Ge J, Meng H, Chen Z, Liu D (2019). The Influence of Social Support and Care Burden on Depression among Caregivers of Patients with Severe Mental Illness in Rural Areas of Sichuan, China. Int J Environ Res Public Health 16(11): 1961. DOI: 10.3390/ijerph16111961.
32. Wainwright LD, Glentworth D, Haddock G, Bentley R, Lobban F (2015). What do relatives experience when supporting someone in early psychosis? Psychol Psychother 88(1): 105–119. DOI: 10.1111/papt.12024.
33. Wan KF, Wong MM (2019). Stress and burden faced by family caregivers of people with schizophrenia and early psychosis in Hong Kong. Inter Med J 49(Suppl. 1): 9–15. DOI: 10.1111/imj.14166.
34. Weiss A, Steadman S, Mercier HD, Hansel TC, Chaudhry S, Clark I (2022). Pathways to Care: How Help-Seeking Behaviors Relate to Duration of Untreated Psychosis and Treatment Engagement. Psychiatr Q 93(2): 473–482. DOI: 10.1007/s11126-021-09960-5.
35. Wong DTL, Tong SF, Daud TIM, Aziz SA, Midin M (2020). Factors influencing professional help-seeking behavior during first episode psychosis in schizophrenia: An exploratory study on Caregivers’ perspective. Front Psychiatry 10: 962. DOI: 10.3389/fpsyt.2019.00962.
36. Yimam B, Soboka M, Getachew Y, Alemu B, Ahmed G, Tesfaye E, Necho M (2022). Expressed emotion of caregivers among schizophrenic patients visiting Jimma University Medical Center Psychiatry Outpatient Unit, Southwest Ethiopia. Ann Gen Psychiatry 21(1): 27. DOI: 10.1186/s12991-022-00404-3.
37. Zanetti ACG, de Souza TM, de Souza Tressoldi L, de Azevedo-Marques JM, Corrêa-Oliveira GE, da Silva AHS, et al. (2018). Expressed emotion and family burden in relatives of patients in first-episode psychosis. Arch Psychiatr Nurs 32(3): 390–395. DOI: 10.1016/j.apnu.2017.12.003.