PROTOCOL

Cultural-Based Psychoeducation on Family Caregivers of Clients with Schizophrenia: A Scoping Review Protocol

Imas Rafiyah¹, Suryani Suryani¹, Laili Rahayuwati², Wandee Suttharangsee³

- ¹ Department of Mental Health Nursing, Faculty of Nursing, Universitas Padjadjaran, 45363 Bandung, Indonesia
- ² Department of Community Nursing, Faculty of Nursing, Universitas Padjadjaran, 45363 Bandung, Indonesia
- ³ Education and Innovative Learning Academy, Prince of Songkla University, Hat Yai 90110, Thailand

ABSTRACT

Introduction: Cultural-based psychoeducation is crucial for family caregivers of schizophrenic clients with different cultural backgrounds, but previous studies have not identified this clearly. This review will map out previous research related to cultural-based psychoeducation regarding family caregivers of schizophrenic clients. **Methods:** This is a scoping review protocol using the Arksey & O'Malley approach. Criteria will include the family caregiver, culture, psychoeducation, schizophrenia, and primary research using an experimental approach. Non-full text and non-English language articles will be excluded. The advance search techniques will use the keywords family caregiver, culture, psychoeducation, and schizophrenia on the CINAHL, PubMed, and PsycInfo databases. Screening will be conducted by deleting duplicates and by reading the title and abstract. The full text of relevant articles will be read in detail to determine eligible articles. **Discussion:** Data from included articles will be extracted and resumed on the table. Then, this data will be analyzed and presented in the table and graphic.

Keywords: Culture, Family caregiver, Psychoeducation, Schizophrenia

Corresponding Author:

Imas Rafiyah, MNS Email: imas.rafiyah@unpad.ac.id Tel: +62 812-8005-0455

INTRODUCTION

Schizophrenia is a chronic severe mental illness that affects brain function (1). Clients with schizophrenia experience symptoms such as hallucinations (2). Moreover, clients with schizophrenia might relapse and require rehospitalization which affects their ability to perform daily activities (1).

Around 20 million people across the world have schizophrenia, as measured in 2017. Although the prevalence of schizophrenia is not high, it is a global burden disease (3). People with schizophrenia experience disabilities that impact on their work life, social life, economic activities, and the loss of productive years.

Several reasons make a family caregiver crucial to the care of schizophrenic clients. These include changes in mental health service policies, limitations of mental health facilities, and the severity of the disease. On the one hand, shifting mental health service policies from hospital-based care to community-based care causes

the treatment of schizophrenic clients to be more community-focused (4). On the other hand, the lack of mental health services in the community, especially in developing countries, results in the family taking on a crucial role for their schizophrenic client (5). Moreover, characteristics of the disease such as positive and negative symptoms, relapse, rehospitalization, and violent behavior (6) make it necessary for family caregivers to provide long term care for clients of schizophrenia (7). Study shows that schizophrenic patients without family caregivers are more likely to end up homeless (8). Family members also provide primary care for ill family members voluntarily (9).

Long term care of schizophrenic clients has positive and negative impacts on the family (9). On one hand, caring for schizophrenic clients for a long time has positive effects such as consolidating relationships, positive thinking, spiritual belief, and self-growth (10). On the other hand, caring for schizophrenic clients has physical impacts such as fatigue, lack of concentration, or increased blood pressure (11), and psychological impacts such as feeling overburdened (13), loss, guilt, fear, (10), stress, anxiety, or depression (12). These problems are triggered by clients' severe symptoms (7), economic burden (14), and stigma (15).

Problems experienced by family caregivers of

schizophrenic clients result in a low quality of life due to the confusion of thoughts and feelings (16). This furthers the low quality care provided by family caregivers for schizophrenic clients (17). Those situations cause stressors on clients with schizophrenia that impacts their recovery as it may lead to high chances of relapse and rehospitalization (18).

Family caregivers need appropriate intervention from professional mental health workers to reduce their burden (10). Studies have presented some intervention evidence related to the distress of family caregivers. These are psychoeducation (19), home-based cognitive remediation (20), counseling (21), mutual support(22), community-based intervention (23), family-directed cognitive adaptation (24), brief cognitive behavioral stress management program (25), e-health intervention (26), and relaxation training (27). Psychoeducation is one of the interventions supported by some evidence.

Psychoeducation is a structured and systematic program provided by mental health professionals which includes the provision of information about the illness and details for how to adapt to stressful situations (28). Recently, psychoeducation for family caregivers has been modified with other aspects for increased applicability. Studies have described video-based psychoeducation (29), mindfulness-based psychoeducation (30), web-based psychoeducation (31), film-based psychoeducation (29), and culture adapted psychoeducation (32) as different forms of education for this matter. Culture is a critical aspect that should be recognized during the provision of psychoeducation (33).

Culture refers to a pattern of life developed by a particular ethnic group that is passed down from generation to generation (34). Family caregivers with different cultural backgrounds might have a different experience in caring for clients with schizophrenia (35). There may also be different illness perceptions (36), beliefs regarding the disease (37), and stress perception (38). Psychoeducation integrated culture will be effective for family caregivers of the schizophrenic client.

Studies of psychoeducation for family caregivers of schizophrenic clients has been carried out (37) (40) (41) (42) (43), but studies that integrate culture into education are limited. Moreover, the way previous studies have been carried out has not been clearly identified. The aim of this is to map out previous studies of cultural-based psychoeducation on schizophrenic clients to identify cultures, types of research, and the ways intervention is provided (such as by a provider, receiver, session duration, theory/model approach, or media), and to follow up and identify the outcomes carried out by the previous research. The result is useful for identifying specific cultural components that may influence intervention efficacy. This review will include a systematic process involving a large amount

of literature, so certain strategies and well-organized process are needed.

METHODS

The scoping review method used in this review follows the Arksey & O'Malley approach (44). It consists of five stages, namely identifying the research question, the relevant studies, the study selection, charting the data, and collating, summarizing, and reporting the result.

Stage 1: Identifying the Research Questions

The first step is to identify the research question that is built to support the literature search. Research questions should not be so broad as this results in the number of articles obtained being too large. On the other hand, the question should not be so narrow as this results in the number of articles obtained being too low (44). The problem posed in this scoping review is regarding how the research on cultural-based psychoeducation for family caregivers of schizophrenic clients has been carried out. Six sub-questions arise in planning this scoping review (Table I).

Tabel I: List of Research Questions and Operational Definitions

Research Questions	Operational Definitions
What cultures have been studied in the previous research?	Ethnic (Country)
What types of research that have been used in the previous research?	Primary research: qualitative, quantitative, mix methods
Who are the health professionals who have provided cultural-based psychoeducation?	Psychiatrist, Mental Health Nurse, Psychologist.
How cultural-based psychoeducation has been carried out in the previous research?	Number of sessions, duration of sessions, setting content of psychoeducation.
What are the outcomes that has been carried out in the previous research?	positive health outcomes and negative health outcomes.

Stage 2: Identifying Relevant Studies

To identify relevant studies comprehensively, it is necessary to have criteria for the articles to be reviewed, the source articles (databases), and strategies for finding suitable articles (44). The following is an explanation of how this process will be carried out.

a. Eligibility Criteria

Eligibility criteria in this scoping review includes the types of participants, the concepts used, the research context, and the type of sources. Inclusion criteria includes family caregivers as a population, the concept of culture and psychoeducation, the schizophrenic client as a context, and primary research, particularly in article sources. The year of publication and country will not pose a limitation since this review will map out previous studies. Furthermore, exclusion criteria include non-English and non-full text articles.

b. Databases

The databases used in this scoping review are CINAHL (Ebsco), PubMed, and PsycInfo. These databases present a lot of data on research results in the fields of health, nursing, and mental health.

c. Search Strategy

In the search strategy stage, there are three strategies to be conducted. Firstly, the terms used in the search will be determined. The terms to be used are developed from the research questions and key concept definitions (44). In this review, the terms are developed using a population, content, and context (PCC) approach including family caregivers as a population, the concept of culture and psychoeducation, and schizophrenic clients as a context (Table II). After obtaining the major terms, we look for other terms through MeSH and the synonym thesaurus. Furthermore, the Boolean term 'OR' is used for each other term in the major term, and the Boolean term 'AND' is used between the major term and the other major term. Based on the syntax obtained, an article search is carried out for each database with restrictions on the abstract available and the English language. After the articles are collected, the articles are exported to the endnote reference manager and screened by removing duplicate articles and are sorted by reading the article abstracts. Irrelevant article abstracts based on title, population, and research will be discarded.

Secondly, ten per cent of the relevant abstracts are taken, then the abstract and keywords are read. If no new terms are found, the search for articles will stop. If different terms are found, the keywords or index terms in the first stage are revised by including new terms. After this, the comprehensive search is continued using revised keywords or index terms.

Thirdly, the bibliography of abstracts and full papers are checked to identify whether they are appropriate articles or whether there are terms that differ from the specified keywords. If there are references that are not in the databases, the author or the search engine will be contacted.

Stage 3: Study Selection

After obtaining a certain number of articles from the search results, articles that answer the research question will be selected using certain strategies and a well-organized process. In this review, the selection will be made based on pre-determined inclusion and exclusion criteria. Inclusion criteria include the family caregiver

Table II: Major term based on PCC

PCC	Major Term
Population	Family caregivers
Content	Culture
	Psychoeducation
Context	Schizophrenia

culture, psychoeducation, schizophrenia, and primary research, particularly the experiment approach. Articles with non-English language and non-full text will be excluded. The selection also involves two people on the team who work independently. These two researchers will come to an agreed decision if there is a discrepancy in determining the articles for use. If there is still no agreement, a third person outside the team will become involved.

The screening process will follow the ScR PRISMA flowchart, including searching for articles through databases and additional sources after checking for and discarding duplicate articles. The title and abstract will be checked to determine remaining relevant articles. Relevant articles will be kept, and irrelevant articles will be discarded. After this, the full text of the relevant articles will be read in detail to carry out eligible articles. Finally, these articles that meet the criteria will be included in the review.

Stage 4: Charting the Data

The next stage is to map key items based on information obtained from eligible articles. In the extraction stage, data sources with appropriate objectives and research problems will be summarized logically by tables with the excel database program. During the data extraction process, data will be tested and revised as needed. The data on the table contains the author, year of publication, country, purposes, samples, method, intervention, and outcome.

Stage 5: Collating, Summarizing, and Reporting the Result

This stage includes collecting, summarizing, and reporting the results. As there is a possibility that there will be a large number of heterogeneous articles detailing different ways of intervention culturally based psychoeducation, it is not possible to predetermine the method of collating and summarizing the results. Thus, the evidence may be displayed in a narrative, a table, or a visual such as a map or diagram. For this review, the PRISMA-ScR will be used since it provides guidance on the reporting of scoping the review.

DISCUSSION

This is a protocol for conducting a scoping review of previous studies related to cultural-based psychoeducation on family caregivers of schizophrenic clients. This novel approach offers feasible ways for synthesizing many literatures on this topic area. This result of the scoping review will provide unique insight into the extent and scope of culturally adapted psychoeducation and will identify research gaps in it. Thus, the results of this review will offer directions for further studies on determining cultural-based psychoeducation intervention regarding family caregivers of schizophrenic clients.

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REFERENCES

- 1. Zoucha R, Narayan MC. Cultural implications for psychiatric mental health nursing. In: Varcarolis, Elizabeth M, Halter, Margaret J, editors. Foundation of psychiatric mental health nursing: A clinical approcah. 6th ed. St Louis, Missouri: Saunders Elsevier; 2010. p. 102–17.
- 2. Suryani S, Welch A, Cox L. The phenomena of auditory hallucination as described by Indonesian people living with schizophrenia. Arch Psychiatr Nurs [Internet]. 2013;27(6):312–8. Available from: http://dx.doi.org/10.1016/j.apnu.2013.08.001
- 3. James SL, Abate D, Abate KH, Abay SM, Abbafati C, Abbasi N, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: A systematic analysis for the Global Burden of Disease Study 2017. Lancet. 2018;392(10159):1789–858.
- 4. Thornicroft G, Bebbington P. Deinstitutionalisation. From hospital closure to service development. Br J Psychiatry. 1989;155(DEC.):739–53.
- 5. World Health Organization. Mental health policies and action plans . 2007; Available from: https://www.who.int/mental_health/policy/services/1_MHPolicyPlan_Infosheet.pdf?ua=1
- 6. Yosep I, Mediani HS, Lindayani L, Sriati A. How patients with schizophrenia "as a Victim" cope with violence in Indonesia: A qualitative study. Egypt J Neurol Psychiatry Neurosurg. 2021;57(1).
- 7. Koutra K, Simos P, Triliva S, Lionis C, Vgontzas AN. Linking family cohesion and flexibility with expressed emotion, family burden and psychological distress in caregivers of patients with psychosis: A path analytic model. Psychiatry Res. 2016;240:66–75.
- 8. Ran MS, Chui CHK, Wong IYL, Mao WJ, Lin FR, Liu B, et al. Family caregivers and outcome of people with schizophrenia in rural China: 14-year follow-up study. Soc Psychiatry Psychiatr Epidemiol. 2016;51(4):513–20.
- 9. Atri A, Sharma M. Psychoeducation: Implications for the profession of health education. Californian J Health Promot. 2007;5(4):32–9.
- 10. Young L, Murata L, McPherson C, Jacob JD, Vandyk AD. Exploring the experiences of parent caregivers of adult children with schizophrenia: A systematic review. Arch Psychiatr Nurs [Internet]. 2019;33(1):93–103. Available from: https://doi.

- org/10.1016/j.apnu.2018.08.005
- 11. Carbonell E, Navarro-Přirez JJ, Mestre MV. Risk factors associated with the family care of people with serious mental illness. Med Oral Patol Oral y Cir Bucal. 2019;24(4):e438–43.
- 12. Dam K, Hall EOC. Navigating in an unpredictable daily life: a metasynthesis on children's experiences living with a parent with severe mental illness. Scand J Caring Sci. 2016;30(3):442–57.
- 13. Rafiyah I. Coping and burden of Indonesian family caregivers caring for persons with Schizophrenia.
- 14. Opoku-Boateng YN, Kretchy IA, Aryeetey GC, Dwomoh D, Decker S, Agyemang SA, et al. Economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana. BMC Health Serv Res. 2017;17(2):39-50.
- Gloria O, Osafo J, Goldmann E, Parikh NS, Nonvignon J, Kretchy IMA. The experiences of providing caregiving for patients with schizophrenia in the Ghanaian context. Arch Psychiatr Nurs [Internet]. 2018;32(6):815–22. Available from: https://doi.org/10.1016/j.apnu.2018.06.005
- 16. Caqueo-Urнzar A, Alessandrini M, Urzьа A, Zendjidjian X, Boyer L, Williams DR. Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia. Health Qual Life Outcomes. 2017;15(1):1–10.
- Daulima NHC, Triyaspodo K, Wardani IY. History of violence performed by family on people with mental illness following hospitalization. Enferm. Clin. 2019;29(2):346-350. Available from: http:// www.sciencedirect.com/science/article/pii/ S1130862119301421
- 18. Lucksted A, Mcfarlane W, Downing D, Dixon L. Recent developments in family psychoeducation as an evidence-based practice. J Marital Fam Ther. 2012;38(1):101–21.
- 19. Kumar K, Gupta M. Effectiveness of psychoeducational intervention in improving outcome of unipolar depression: Results from a randomised clinical trial. East Asian Arch Psychiatry. 2015;25(1):29–34.
- 20. Kumar D, Ashwini K, Hegde S, Prasanna L, Joseph B, Bose A, et al. Caregiver assisted home-based cognitive remediation for individuals diagnosed with schizophrenia: A pilot study. Asian J Psychiatr [Internet]. 2019;42(304):87–93. Available from: https://doi.org/10.1016/j.ajp.2019.03.010
- 21. Chen LF, Liu J, Zhang J, Lu XQ. Non-pharmacological interventions for caregivers of patients with schizophrenia: A meta-analysis. Psychiatry Res [Internet]. 2015;235:123–7. Available from: http://dx.doi.org/10.1016/j.psychres.2015.11.037
- 22. Chien WT, Bressington D, Chan SWC. A Randomized Controlled Trial on Mutual Support Group Intervention for Families of People With Recent-Onset Psychosis: A Four-Year Follow-Up.

- Front Psychiatry. 2018;9(December).
- 23. Chatterjee S, Naik S, John S, Dabholkar H, Balaji M, Koschorke M, et al. Effectiveness of a community-based intervention for people with schizophrenia and their caregivers in India (COPSI): A randomised controlled trial. Lancet [Internet]. 2014;383(9926):1385–94. Available from: http://dx.doi.org/10.1016/S0140-6736(13)62629-X
- 24. Friedman-Yakoobian MS, Mueser KT, Giuliano AJ, Goff DC, Seidman LJ. Family-directed cognitive adaptation pilot: Teaching cognitive adaptation to families of individuals with schizophrenia. Am J Psychiatr Rehabil. 2016;19(1):62–74.
- 25. Ata EE, Doğan S. The effect of a brief cognitive behavioural stress management programme on mental status, coping with stress attitude and caregiver burden while caring for schizophrenic patients. Arch Psychiatr Nurs. 2018;32(1):112–9.
- 26. Sin J, Henderson C, Spain D, Cornelius V, Chen T, Gillard S. eHealth interventions for family carers of people with long term illness: A promising approach? Clin Psychol Rev [Internet]. 2018;60(January):109–25. Available from: https://doi.org/10.1016/j.cpr.2018.01.008
- 27. Schizophrenia and epilepsy: Effectiveness of relaxation training for caregivers of patients. Prof Med J. 2017;24(05):757–66.
- 28. McFarlane WR. Family interventions for schizophrenia and the psychoses: A review. Fam Process. 2016;55(3):460–82.
- 29. von Maffei C, Gurges F, Kissling W, Schreiber W, Rummel-Kluge C. Using films as a psychoeducation tool for patients with schizophrenia: A pilot study using a quasi-experimental pre-post design. BMC Psychiatry. 2015;15(1):1–7.
- 30. Chien WT, Bressington D, Yip A, Karatzias T. An international multi-site, randomized controlled trial of a mindfulness-based psychoeducation group programme for people with schizophrenia. Psychol Med [Internet]. 2017;47(12):2081–96. Available from: http://ristekdikti.summon.serialssolutions.com/2.0.0/link/0/eLvHCXMwrV1LT9wwEB6VrVTBASivLizIXFEDm8R1nBNCVekKaU-FC5fl8UNEsAktu5f-h_5nZhxnYVmJU2-RY-WhsWc-ez5_A5Amp8PojU_lpNHDMjViaDUiZJvnXJZUHDltdckzOv58dSvRyKOx-BnlhXQ0Jpi785LedZtG0675GWITQXpqnJ8__o6ojhTlW0N
- 31. Chan SKW, Tse S, Sit HLT, Hui CLM, Lee EHM, Chang WC, et al. Web-based psychoeducation program for caregivers of first-episode of psychosis: An experience of Chinese population in Hong Kong. Front Psychol. 2016;7(DEC):3–8.
- 32. Shin SK. Effects of culturally relevant psychoeducation for Korean American families of persons with chronic mental illness. Res Soc Work Pract. 2004;14(4):231–9.

- 33. Maura J, Weisman de Mamani A. Culturally adapted psychosocial interventions for Schizophrenia: A review. Cogn Behav Pract [Internet]. 2017;24(4):445–58. Available from: https://doi.org/10.1016/j.cbpra.2017.01.004
- 34. Fuentes A. What Is culture? Why we believe. 2019;1(6):77–96.
- 35. Smith ME, Lindsey MA, Williams CD, Medoff DR, Lucksted A, Fang LJ, et al. Race-related differences in the experiences of family members of persons with mental illness participating in the NAMI family to family education program. Am J Community Psychol. 2014;54(3–4):316–27.
- 36. Subramaniam M, Abdin E, Jeyagurunathan A, Chang S, Samari E, Shafie S, et al. Exploration of illness perception among patients with mental illness in a multi-ethnic Asian sample. Psychiatry Res. 2018;267:516–27.
- 37. Tarakita N, Yoshida K, Sugawara N, Kubo K, Furukori H, Fujii A, et al. Differences in etiological beliefs about schizophrenia among patients, family, and medical staff. Neuropsychiatr Dis Treat. 2019;15:137–42.
- 38. Kung WW. Culture and immigration-related stress faced by Chinese American families with a patient having schizophrenia. J Marital Fam Ther. 2016;42(3):409–22.
- 39. Mottaghipour Y, Tabatabaee M. Family and patient psychoeducation for severe mental disorder in Iran: A review. Iran J Psychiatry. 2019;14(1):84–108.
- 40. Sin J, Gillard S, Spain D, Cornelius V, Chen T, Henderson C. Effectiveness of psychoeducational interventions for family carers of people with psychosis: A systematic review and meta-analysis. Clin Psychol Rev [Internet]. 2017;56(September 2016):13–24. Available from: http://dx.doi.org/10.1016/j.cpr.2017.05.002
- 41. Öksüz E, Karaca S, Özaltın G, Alpay M. The effects of psychoeducation on the expressed emotion and family functioning of the family members in first-episode schizophrenia. Community Ment Health J. 2017;53(4):464–73.
- 42. Ran MS, Chan CLW, Ng SM, Guo LT, Xiang MZ. The effectiveness of psychoeducational family intervention for patients with schizophrenia in a 14-year follow-up study in a Chinese rural area. Psychol Med. 2015;45(10):2197–204.
- 43. Tabelero V, Tomasi E, de Avila Quevedo L. A randomized controlled trial of the effectiveness of a psychoeducational intervention on family caregivers of patients with mental disorders. Community Ment Health J. 2018;54(2):211–7.
- 44. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. Int J Soc Res Methodol Theory Pract. 2005;8(1):19–32.