

## **Project Title**

Exploring caregiver experiences and coping strategies while caring for clients with schizophrenia: A systematic review

## **Project Lead and Members**

Project lead: Rae Wong Su Min

Supervisor: Dr Xie Huiting

## **Organisation(s) Involved**

Institute of Mental Health

## **Project Period**

Start date: 2018-09

Completed date: 2019-10

## **Aims**

This project aims to explore caregiver experiences and coping strategies while caring for clients with schizophrenia through the synthesis of available evidence.

## **Background**

Caregivers caring for clients with schizophrenia help to transit clients from hospitals to communities. As nurses constantly interact with caregivers, they must understand the caregiving experiences. However, studies exploring both caregiving experiences and coping strategies of these caregivers are uncommon.

## **Methods**

Utilising the Joanna Briggs' Institute's search process, primary studies were searched over multiple databases using pre-determined keywords, related terms and eligibility criteria. An initial search for related terms was sourced from Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed in October 2018. To further expand the search, the keywords and related terms found were utilized in a second search conducted across five major

healthcare databases, and the Singapore's Institute of Mental Health's (IMH) open access repository. Reference lists of identified papers were searched for additional studies. Eventually, 11 studies were selected and critically appraised such that findings were synthesized from studies with good methodological rigor.

## Results

Four themes were derived from the 11 articles, namely: (1) caregivers had negative experiences from caregiving, (2) impacts on caregivers' lives as an aftermath of caregiving, (3) caregiving also provided positive experiences and (4) caregivers utilised coping strategies. The first theme uncovered negative experiences caregivers had from caregiving such as various negative emotions, burden, and stigma. The second theme revealed that caregiving impacted on caregivers' physical health, mental health and finances. While caregiving could be challenging with its negative experiences and impact on caregivers' lives, not all was lost as caregivers also had positive experiences such as enhancement in their competency to provide care while adopting positive coping strategies such as leisure activities and volunteering with other groups, as uncovered in the third and fourth themes. These four themes portrayed that caregivers had a mixture of positive and negative experiences from caregiving, and that caregiving did not merely generate negative experiences and emotions. Besides, these themes also showed that similar to caregivers for clients with other conditions such as heart failures, amyotrophic lateral sclerosis, caregivers for clients with schizophrenia were burdened with caregiving's negative experiences and impact. However, though limited research existed about the positive aspects of caregiving, the synthesized findings suggested that caregivers for clients with schizophrenia experienced something positive from caregiving and volunteerism, which was not widely explored by researchers, could be a potential coping strategy.

## Lessons Learnt

Key lesson learnt: Caregivers are important for the client's recovery process. Hence, nurses should frequently update the caregiver about the patient's care. They should also teach the caregiver on how to look after the client, and also be a pillar of moral support and advice for caregivers.

Challenges: Meeting deadlines while struggling with other assignments and external commitments

Tips: Dare to be different, manage your time effectively, read widely and deeply.

## **Conclusion**

This review provided an understanding of the experiences and coping strategies adopted by caregivers of clients with schizophrenia. Stigma is prevalent not only among clients with schizophrenia but also their caregivers. Though most of the caregivers were middle-aged and elderly, possibly due to adult clients receiving support from immediate family members, an understanding of their experiences can aid nurses to establish therapeutic relationships with caregivers while educating them on caregiving skills. Future studies examining caregiving experiences could include a more diverse sample and examined the impact of specific coping strategies.

## **Additional Information**

Acknowledgements to Singapore Institute of Technology- University of Glasgow joint degree programme

## **Project Category**

Research

## **Keywords**

Research, Caregiving, Continuity of Care, Psychology, Institute of Mental Health  
Schizophrenia, Systematic Review, Caregiver Experiences, Coping Strategies

## **Name and Email of Project Contact Person(s)**

Name: Rae Wong Su Min

Email: raemin97@outlook.com



# Exploring caregiver experiences and coping strategies in caregivers caring for clients with schizophrenia: A systematic review

Rae Su Min WONG



Background


Caregivers caring for clients with schizophrenia help to transit clients from hospitals to communities. As nurses constantly interact with caregivers, they must understand the caregiving experiences. However, studies exploring both caregiving experiences and coping strategies of these caregivers are uncommon.

Aim

This systematic review aims to explore both caregiving experiences and coping strategies while caring for clients with schizophrenia through the synthesis of available evidence.

Methods

1. SEARCH STRATEGY

JOANNA BRIGGS INSTITUTE

3 step-phase process from JBI was utilized in Oct 2018

- Databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycArticles, Ovid Journals, SAGE Journals Online
- Singaporean psychiatric articles: Institute of Mental Health's (IMH) open access repository
- Keywords and index terms based on the Population, Exposure, and Outcome framework:
  - Population:** "Caregiver", "carers", "family caregivers", "spouse caregiver" and "caregiving"
  - Exposure:** "schizophrenia" and "schizophrenic disorders"
  - Outcome(s):** "experiences", "coping", "coping strategies", and "coping skills"

2. INCLUSION AND EXCLUSION CRITERIA

INCLUDE:	EXCLUDE:
1. English-Language studies published from 2013 to present	1. Non-English language studies
2. Primary caregivers and spouse caregivers looking after clients with schizophrenia	2. Studies which are before 2013
3. Caregiving experiences while caring for clients with schizophrenia	3. Other experiences and/or coping strategies which are not specific towards caregiving for clients with schizophrenia
4. Coping strategies while looking after clients with schizophrenia	4. Coping strategies and experiences of clients with schizophrenia
	5. Other conditions which are not related to schizophrenia
	6. Articles based on treatment or interventions for schizophrenia, but not related to caregiving

3. STUDY OUTCOMES

Identification

Records identified through database searching\* (n = 505)

Additional records identified through other sources\* (n = 1)

\* Institute of Mental Health open access repository

Screening

Records after duplicates removed (n = 172)

Records screened for title (n = 172)

Records screened for abstract (n = 69)

Records excluded (n = 103)

Reasons:

- 1. Not relevant towards the research topic (eg: physical illnesses, abstracts, and posters) (n=43)
- 2. Introduction/evaluation/effectiveness of a treatment/ psychoeducation/ family support programme/ questionnaire/ instrument/ professional caregiver communication (n=30)
- 3. Caregiving experiences not related to caring for schizophrenia/caring process (eg: bipolar disorder, dementia, depression) (n=16)
- 4. Articles based on treatment or interventions for schizophrenia (eg: family therapy, drug treatment, psychoeducation), but not related to caregiving (n=12)
- 5. Client's experience of having schizophrenia (n=1)
- 6. Articles which are before 2013 or do not have a published year (n=5)

Records excluded (n = 25)

Reasons:

- 1. Caring for/ comparing between a multitude of mental illnesses but not specific to schizophrenia (n=10)
- 2. Experiences of individuals who may not be the client's caregiver (n=4)
- 3. Evaluation of a psychoeducation programme (n=1)
- 4. Experiences and/or coping strategies not related to caregiving (eg: communication of a diagnosis) (n=1)
- 5. Investigation of certain factors affecting caregiving experiences and/or coping strategies (eg: sociodemographic characteristics, posttraumatic growth, external stressors, family functioning, psychological morbidity, agitation, quality of life, emotional overvolvement) (n=9)

Full-text articles assessed for eligibility (n = 44)

Full-text articles excluded, with reasons (n = 33)

Reasons:

- 1. Systematic review proposal (n=1)
- 2. Investigation of certain factors affecting caregiving experiences and/or coping strategies (eg: sociodemographic characteristics, family functioning, coping styles) (n=12)
- 3. Results not relevant to research topic (eg: investigation of sociodemographic and clinical characteristics affecting stigma in caregivers, using caregiver experiences to measure patient outcomes) (n=10)
- 4. Experiences of individuals who may not be the client's caregiver (n=10)

Studies included in synthesis\* (n = 11)

Reasons:

- 1. Quantitative studies (n = 5)
- 2. Qualitative studies (n = 4)
- 3. Systematic reviews (n = 2)

Eligibility

Included

CRITICAL APPRAISAL:

Critical Appraisal Skills Programme (CASP)

Qualitative studies

Systematic reviews

JBI Appraisal Tool

Cross-sectional studies

Results

Theme 1: CAREGIVERS HAD NEGATIVE EXPERIENCES FROM CAREGIVING (10/11 studies)

Caregivers had negative caregiving experiences during their caregiving stints. They harboured negative emotions, felt burdened, and experienced stigma.

Theme 2: IMPACTS ON CAREGIVERS' LIVES AS AN AFTERMATH OF CAREGIVING (9/11 studies)

Due to caregiving, caregivers saw negative impacts on their finances and health. However, they experienced positive and negative impacts on their interpersonal relationships.

Theme 3: CAREGIVING ALSO PROVIDES POSITIVE EXPERIENCES (6/11 studies)

Despite having negative caregiving experiences, caregivers had positive caregiving experiences because of enhanced caregiving capabilities and positive feelings during caregiving.

Theme 4: UTILISED COPING STRATEGIES (9/11 studies)

Caregivers adopted a myriad of coping strategies. However, it was reported that caregivers adopted more positive coping strategies than negative coping strategies.

Discussion and Conclusion

- This review provided an understanding of the experiences and coping strategies adopted by caregivers of clients with schizophrenia. Stigma is prevalent not only among clients with schizophrenia but also their caregivers.
- Though most of the caregivers were middle-aged and elderly, possibly due to adult clients receiving support from immediate family members, an understanding of their experiences can aid nurses to establish therapeutic relationships with caregivers while educating them on caregiving skills. Future studies examining caregiving experiences could include a more diverse sample and examined the impact of specific coping strategies.

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Major References

STUDIES USED IN THE REVIEW:

Brain, C., Kymes, S., DiBenedetti, D. B., Brevig, T., & Velligan, D. I. (2018). Experiences, attitudes, and perceptions of caregivers of individuals with treatment-resistant schizophrenia: a qualitative study. *BMC Psychiatry*, 18(1), 253. <https://doi.org/10.1186/s12888-018-1833-5>

Chang, K., Huang, X., Cheng, J., & Chien, C. (2016). The chronic sorrow experiences of caregivers of clients with schizophrenia in Taiwan: A phenomenological study. *Perspectives in Psychiatric Care*, 54(2), <https://doi.org/10.1111/ppc.12235>

Gater, A., Rofail, D., Tolley, C., Marshall, C., Abetz-Webb, L., Zanti, S. H., & Berardo, C. G. (2014). "Sometimes it's difficult to have a normal life": results from a qualitative study exploring caregiver burden in schizophrenia. *Schizophrenia Research and Treatment*. Retrieved from <http://link.galegroup.com.proxy4.athensams.net/apps/doc/A42247630/GPS?u=sgh&sid=GPS&xid=b68807c0>

Imkome, E. U., & Warassawapatti, K. (2018). Perspectives and experiences of primary caregivers of individuals with schizophrenia in Thailand. *Issues in Mental Health Nursing*, 1-7. <https://doi.org/10.1080/01612840.2018.1488312>

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013a). Caregiving appraisal in schizophrenia: A study from India. *Social Science & Medicine*, 98, 135-140. <https://doi.org/10.1016/j.socscimed.2013.09.005>

Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013b). Positive aspects of caregiving and its correlates in caregivers of schizophrenia: A study from North India. *East Asian Archives of Psychiatry*, 23(2), 45-55. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=csm&AN=107955356&site=ehost-live&scope=site&custid=ns206789>

Lam, P. C. W., Ng, P., Pan, J., & Young, D. K. W. (2015). Ways of coping of Chinese caregivers for family members with schizophrenia in two metropolitan cities: Guangzhou and Hong Kong, China. *International Journal of Social Psychiatry*, 61(6), 591-599. <https://doi.org/10.1177/0020764014565797>

Olwit, C., Musisi, S., Leshabari, S., & Sany, I. (2015). Chronic Sorrow: Lived Experiences of Caregivers of Patients Diagnosed With Schizophrenia in Butabika Mental Hospital, Kampala, Uganda. *Archives of Psychiatric Nursing*, 29(1), 43-48. <https://doi.org/10.1016/j.apnu.2014.09.007>

Onumera, J., Zhou, Z., & Kuipers, E. (2018). Informal Caregiving Relationships in Psychosis: Reviewing the Impact of Patient Violence on Caregivers. *Frontiers in Psychology*, 9, 1530. <https://doi.org/10.3389/fpsyg.2018.01530>

Suro, G., & Weisman De Mamani, A. G. (2013). Burden, Interdependence, Ethnicity, and Mental Health in Caregivers of Patients with Schizophrenia. *Family Process*, 52(2), 299-311. <https://doi.org/10.1111/famp.12002>

Tungpungkum, P., Napa, W., Chaniang, S., Srihachin, P., RN, A. P. N., Napa, W., ... RN, M. S. N. (2013). Caregiving experiences of families living with persons with schizophrenia: a systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 11(8), 415-564. <https://doi.org/10.1112/jbisri-2013-881>

OTHER REFERENCES:

Joanna Briggs Institute. (2014a). *Reviewer's manual*. Adelaide: The Joanna Briggs Institute.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(7):e1000097. [doi:10.1371/journal.pmed1000097](https://doi.org/10.1371/journal.pmed1000097).

Images from Videoplasty

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