

Family Experiences of Mental Illness: A Meta-Synthesis

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ABSTRACT

Background: Caring for a family member diagnosed with mental illness requires a holistic support system. However, some families experience the feeling of burden, loss, and stigma affecting the entire family structure. Therefore, exploring the studies on the family experiences of mental illness is crucial.

Purpose: This meta-synthesis explored the available literature on the family experiences of mental illness.

Methods: An initial comprehensive search was conducted in the following databases such as Web of Science, Scopus, PsycINFO, CINAHL and Ovid-based MEDLINE using the keywords like mental illness, mental disorder, family, family member, qualitative studies and phenomenology. A total of five qualitative studies and one thesis dissertation published between 2001-2016 that elicited views of family members on their experience of mental illness were reviewed. A thematic analysis was used to identify, analyze, and report patterns among the data, allowing for specific organization and description and interpretations.

Results: Family empowerment emerged as the grand theme from the perceived effects of mental illness on the family, the process of coping and their perspectives on family empowerment grounded on family experiences.

Conclusion: Despite caring for a family member diagnosed with mental illness imposes threats, it further offers openness, readiness, and acceptance that empower each family to appreciate, acknowledge, and affirm the wholeness of a family member with mental illness.

Keywords: Family burden; family empowerment; mental health; meta-synthesis

BACKGROUND

The World Health Organisation (WHO, 2001) defines mental health as a state of social well-being where an individual realizes one's potentials, copes with the normal stresses of life, works productively and fruitfully, and contributes to the community. However, mental illness interferes with the person's thinking, feeling, social and daily functioning. As a result, a family member diagnosed with mental illness becomes a burden to the family. Mental illness comprises 12% of the total disease burden and has far-reaching effects on the family as members of the social system (WHO, 2013). Some mental

disorders acquired early in life, become chronic, recurrent and generate immense health burden. Individuals diagnosed with severe mental disorders cannot fulfill the societal roles expected from them at their age and intellectual ability (Borgo, Ramos-Cerqueira, & Torres, 2017). Severe mental illness is stressful, not only for the individual but also for the entire family as they live with their family rather than in mental health institutions and becomes a burgeoning family concern (Kizilirmak & Küçük, 2016; Mulud & McCarthy, 2017).

Mental illness has been an emerging phenomenon and a global burden (Charara et al., 2017; Elias & Paradies, 2016). Although addressing mental health problems is one of the functions of the government, the burden of care falls onto family members and the communities (Hsiao, Klimidis, Minas, & Tan, 2006). Family support provides caregiving roles to the mentally ill member from the admission to discharge (Zauszniewski, Bekhet, & Suresky, 2009). Stuart and Laraia (2005) mentioned that approximately 65% of mentally ill live with their families. Families provide caregiving support, long-term assistance with housing, financial needs, and rehabilitation. Hence, family support is an essential aspect of recovery and community integration, but the family also has specific needs to be considered – psychological, physical, emotional, social and financial. If these needs are not fulfilled, it leads to caregiver burden. Indeed, caring for a mentally ill person is very burdensome and has a tremendous impact on the caregivers' well-being and quality of life (von Kardorff, Soltaninejad, Kamali, & Eslami, 2016).

This meta-synthesis was conducted to explore the experiences among families having a family member with mental illness. Mental illness, which is widely stigmatized, does not have a much social support system as compared to physical ailments, victims of disaster or deaths. Therefore, caregivers have no choice but to carry their physical, emotional, spiritual and financial needs solitarily. Although few studies confirmed burden among the family of mentally ill relatives in general, there is still insufficient description about the family's perception about the illness and their specific process of coping and perspectives of the effect of the illness in the family system. Thus, it is essential to better understand the family's experiences in taking care of a family member diagnosed with mental illness to provide a broader insight into their shared experience.

PURPOSE

This meta-synthesis aimed to explore the family experiences of mental illness.

METHODS

Meta-synthesis is a technique for combining the results of multiple qualitative studies to produce new insight and understanding (Beck, 2009; Sandelowski, 2008). The purpose of meta-synthesis is to identify similarities and differences of the findings and delve deeper into the phenomenon from various studies illuminate an integration of language as a “structure of artifact or culture that must be itself interpreted” (Sandelowski, 2008, p. 18). This interpretive meta-synthesis portrays a distinct, state of the art and direction for highlighting the emerging phenomenon grounded on experiences of family members that offer a novel interpretation of an emerging concept of family empowerment in mental health.

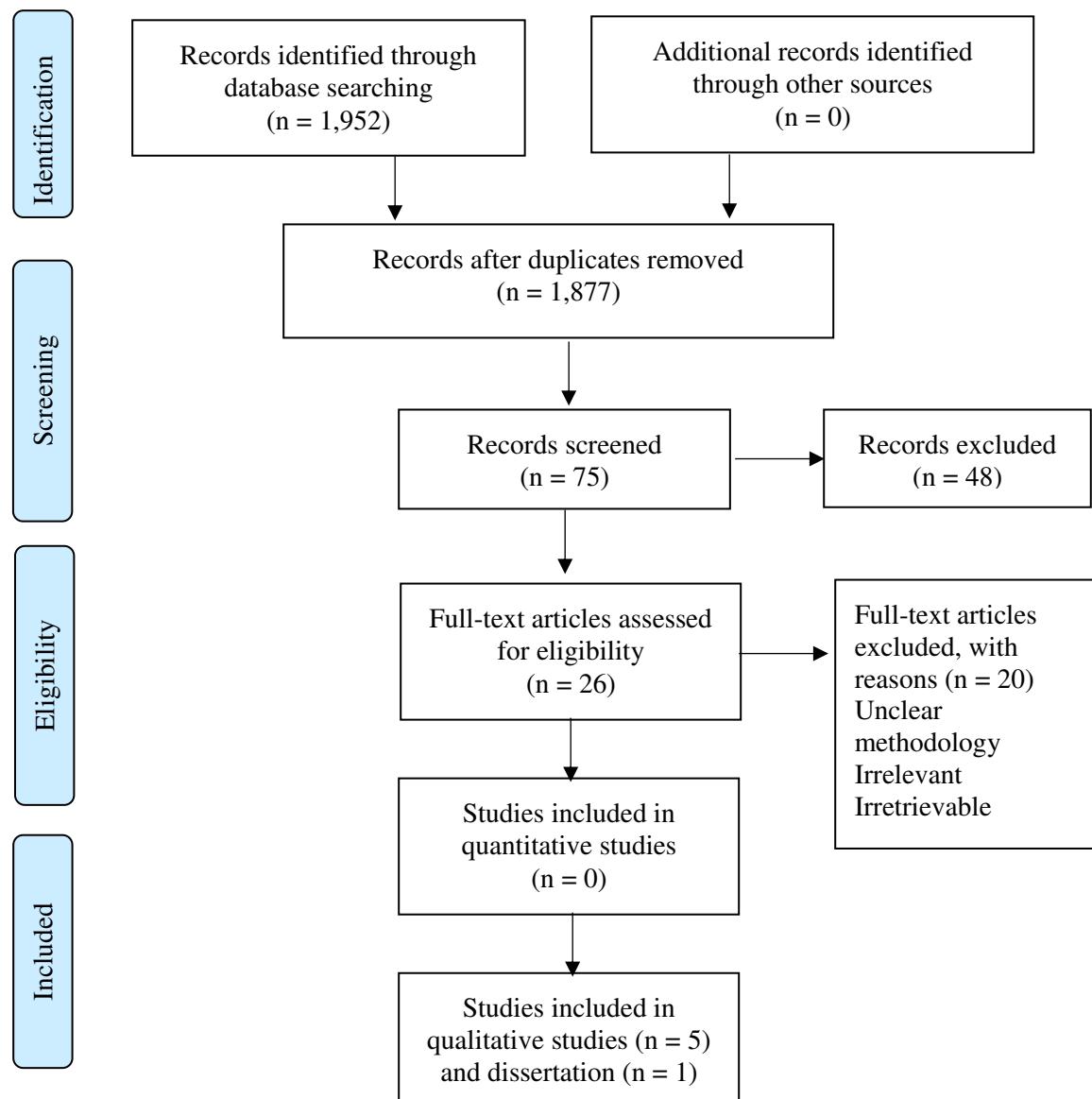


Figure 1. The search strategy selection of the included studies

An initial comprehensive search was performed in the following databases such as Web of Science, Scopus, PsycINFO, CINAHL and Ovid-based MEDLINE. The keywords were mental illness, mental disorder, family, family member, qualitative studies and phenomenology. A total of 1,952 studies were uploaded in the reference manager, and 1,877 were removed as duplicates. An additional manual search was also performed, but there were no available articles that accounted for the phenomenon of interest. There were seventy-five articles were further screened for general review which resulted in 26 eligible articles. Twenty articles were removed that did not meet the selection criteria including quantitative, book reviews, book chapters, editorial materials, proceeding paper, and commentaries. Also, there were irrelevant studies that did not reflect the experiences of family members and unclear methodology. For the final review, there were five qualitative studies published between 2001-2016 and one thesis dissertation that elicited family experiences of mental illness. The researchers extracted all the themes

from the reviewed articles and encoded using NVivo Plus 11 as shown in Table 1 in appendix (QSR International, 2016).

The approach to synthesizing the findings in a meta-synthesis is an iterative process to generate new insights about the phenomenon of interest. Various researchers surmised that summarising qualitative results can be aggregative or interpretive (Beck, 2009; Sandelowski & Barroso, 2008). In this meta-synthesis, the researchers used an interpretive approach in conjunction with a “holistic understanding and theory development” (Aguirre & Bolton, 2014, p. 281). A thematic analysis was used to identify, analyze, and report patterns among the data, allowing for specific organization and description of a series of foci and interpretations of the various aspects of the subject matter. The analysis was performed to recognize the themes and the following attributes via codes/descriptors in the disciplines and contexts to justify or express the idea.

RESULTS

The interpretive summary of metaphors of the selected qualitative studies are the hallmark findings of this meta-synthesis. The grand theme emerged as *Family Empowerment* with three sub-themes *Perceived effects: Emulating the burden and loss, Process of coping, and Perspectives on family empowerment* as shown in Figure 2.

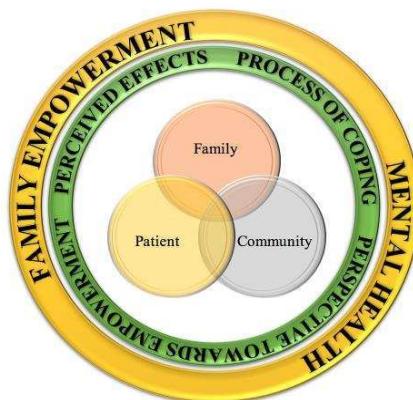


Figure 2. The grand theme of the reviewed studies

Perceived effects of mental illness: burden and loss

There are multifaceted effects of mental illness on the family including burden and loss. These perceived effects also impose threats to the quality of life and relationships within the family structure.

Social burden and stigma

These are the most commonly reported experience of the family that resulted in ineffective social relationships and poor interpersonal interaction. Social exclusion and withdrawal are central to a stigmatizing experience of the relative (Angermeyer, Schulze, & Dietrich, 2003). The majority of the respondents observed that friends, neighbors and even relatives gradually withdrew from the patient or the whole family. Some caregivers also reported that their social relationships are affected because they are not in the position to move and interact freely with others (Ae-Ngibise, Doku, Asante, & Owusu-Agyei,

2015). Over one in ten caregivers avoided social events (Girma et al., 2014), while other families reported that aside from the burden of caring for the patient, they felt ostracised and isolated (Marimbe-Dube, 2013). On a different note, guilt is one of the most spiteful experiences specifically among mothers having the responsibility for their children's upbringing (Angermeyer et al., 2003). One mother with two schizophrenic sons reflected, "professionals always ask for childhood experiences... which causes guilt and... is stigmatizing" (Angermeyer et al., 2003, p. 596). Another mother commented that parents' upbringing could also be a "contributing" factor to the illness (Stein & Wemmerus, 2001, p. 735). For adults who derive a strong sense of personal and social identity from their role as parents, this condition has challenged them what it means to be parents. They question their actions, recalibrate their expectations and even self-inflicting guilt on their child's illness.

Emotional and psychological burden

Sleeplessness, endless worrying, the feeling of embarrassment and exhaustion are some of the reported emotional disturbances. Some families developed depression and somatic illnesses (e.g., hypertension) due to severe emotional and psychological distress. Intense fear is another factor that affects the emotions. In the process of caregiving, some respondents described an experience of verbal and physical harm from those who are violent, assaultive and combative. Despite such experience, some families still ensure that they can meet the patient's needs (Marimbe-Dube, 2013). Some families even claimed they suffer more than those who are ill because of a sense of frustration, in which they mentioned that only the "death of the patient a way out for the burden to end (Ae-Ngibise et al., 2015).

Financial and economic burden

For some families, the financial burden is a result of having to leave their jobs for the caregiving role. The responsibility of caring lies within the family, and they have to ensure that they finance the patient's upkeep (Marimbe-Dube, 2013). Families would always want their ill family member to benefit from the optimal treatment and other relevant services but afflicted with financial constraints (Angermeyer et al., 2003). Majority of the caregivers are not employed, or some though employed but cannot sustain the daily expenses. Some would resort to selling their belongings, livestock, personal clothing, and others to support the need of the mentally ill. Also, respondents mentioned that the illness led to problems with work integration. One participant said: "My boss showed little understanding for the loss of working hours" (Angermeyer et al., 2003, p. 598).

Pervasive loss

Families perceived mental illness as such because it does not only involved the affected individual, but its effect spreads throughout the entire family. In a qualitative study of six families in Northwestern Ohio, the authors described the impact of mental illness in the family as a loss of a healthy life. The family reported the lost aspects of their ill-members' normal life that includes loss of skills and abilities, personal relationships, prized possessions and place in society. Parents in the study expressed a broad sense of sadness and frustration in their inability to bring back their child to "normal" (Stein & Wemmerus, 2001).

Process of coping: concealment vs. openness

In the review of the different studies, most participants reported to either conceal the illness or being open about the situation.

Concealment

Being secretive and minimizing contact with the community is one way that some caregivers, particularly those from culturally diverse backgrounds, coped with their situation (McCann, Lubman, & Clark, 2011). Girma et al. (2014) noted that caregivers are worried that other people would discover the patient's condition and felt the need to keep the illness a secret and isolate themselves. The fear of experiencing stigma from others deterred caregivers from being open about the problem (Marimbe-Dube, 2013). To avoid discrimination, many families conceal the illness from neighbors, friends, and relatives or disguise the illness as a depression (Angermeyer et al., 2003). Denial and blame from others also resulted in illness concealment (McCann et al., 2011). Caregivers especially women reported being blamed for the illness of the family member (Marimbe-Dube, 2013). Loss of status is also expressed by some caregivers who adopted a secretive style of coping (McCann et al., 2011). Loss of status accompanied by feelings of embarrassment, mainly when disturbing and dramatic situations occur during acute attacks. Loss of status also includes a troubled relationship and problems with work integration.

Openness

Some families adopted an open approach to coping with their situation. From being open, some caregivers responded to their family members' illness by disclosing their status and having contact with others (McCann et al., 2011). This coping approach includes openness to family, friends, and community. By doing so, support is strengthened, recognized and accepted. The type of support given varies from emotional support, financial and shared responsibility for care. Families also reported that although they are cautious at times about sharing their experiences with others, they understood that there is no wrong for having a family member diagnosed with a mental disorder. As a result, it nurtures the feeling of being listened to. Furthermore, families who do not have doubts keep on receiving emotional, psychological and practical support. One participant reported: "I have friends that ring me often to see how we are going. I have not hidden it. I may have at first, but I certainly don't know...I do get a lot of phone support" (McCann et al., 2011, p. 549).

Perspectives on family empowerment

Support and care from family members during periods of illness are significant for people with mental disorders. Moreover, families perceive that they have substantial roles in coping despite the considerable negative consequences it imposed on their quality of life (Larson & Corrigan, 2008). Based on their experiences, respondents provided their perspectives on various interventions towards empowerment.

Addressing negative public image

The negative public image of mental disorders is one of the causes of stigma. Most of the relatives participating in the focus group believe that those people suffer from mental disorders are violent and dangerous (Angermeyer et al., 2003). Relatives claim that the

media is responsible for disseminating this negative view. Media coverage of mental disorders is almost exclusively limited to showing persons as being violent. One participant narrated: "The media never portrays persons with mental illness living a normal life or as being creative. It would be good to show mentally ill people trying to live a normal life, not only murderers or homicides" (Angermeyer et al., 2003, p. 597). Also, unequal acceptance or status of mental and somatic illness by the public poses another negative image of mental illness. There are limited information and advice for mental health practitioners; and, when there is, it is usually in the context of negative headlines. Families felt that this negative image could be addressed through education, information, and promotion in understanding the disorder (Ae-Ngibise et al., 2015; Angermeyer et al., 2003)

Improved mental health care

Some families described the poor quality of mental health care. According to Angermeyer et al. (2003) relatives felt health professionals are insensitive to their needs, fears, problems, and worries. Also, the relatives believe that professionals regard them as an additional burden or source of irritation. In a similar vein, Ae-Ngibise et al. (2015), almost all the participants unanimously agreed that there is no external or community support in taking care of the patients. There should be improvements and changes in mental health care service delivery such as cooperation between and among the professionals and relatives, better education and training, adequate supervision and equitable distribution of mental health services. Family members also strongly felt that support groups for people with mental disorders and family members would help in the coping process.

DISCUSSION

This meta-synthesis illuminated the experiences among families having a member diagnosed with mental illness. Three themes with corresponding sub-themes emerged such as perceived effect, the process of a family coping with the illness and perspectives towards family empowerment. Burden and loss were the subthemes identified based on the family's perceived effect of mental illness. Burden encompasses almost all aspects of family life – psychological or emotional which also resulted in physical problems, financial and social burden. Furthermore, loss – specifically the loss of healthy life emerged as one significant effect of mental illness on the family.

In the process of coping with the illness, families adopted either concealment or openness approach. In being open with the family and friends, family members acquired support in various aspects – emotional, financial and sharing responsibility of care. Openness and contact with others enable them to obtain greater support and acceptance and help in de-stigmatizing the illness. However, transparency also leads to stigmatization, exclusion, withdrawal, and concealment (Angermeyer et al., 2003; Krupchanka et al., 2016; Larson & Corrigan, 2008; Muralidharan, Lucksted, Medoff, Fang, & Dixon, 2016; van der Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). McCann et al. (2011) mentioned concealment helps shield the caregiver and the patient from stigma and minimizes the likelihood of devaluation and exclusion. However, it denies the caregiver and family member from having contact with and receives support from others. Concealment reinforces social isolation and alienation from the community, and it heightens the family's overall burden of care. Concealment may also result in depriving the person to

access timely and adequate care of the illness (Krupchanka et al., 2016; van der Sanden et al., 2016).

Family empowerment is an essential indicator of a family's ability to access and effectively utilize the mental health system to meet their needs. In the family's perspective, their perceived burden of care and loss could be addressed through proper education and massive information dissemination about mental illness, thereby promoting empowerment. Family empowerment helps the family and community in solving the burden, loss and stigmatizing experiences with mental illness. Due to the paucity of evidence about family empowerment at a theoretical and philosophical underpinning, future scholarly work will be undertaken to explore this phenomenon of interest using various methodologies. Owing to the rigor of this meta-synthesis, the researchers maintained an audit trail, research team meetings for content validity, and expert peer review. Raw data from the quotations support the inferences drawn and grounded in the experiences of the family members.

CONCLUSION

Family caregivers of mentally ill patients experience high levels of burden and loss in which they cope with either positive (openness) or negative (concealment) attitude. From their perspective, family empowerment helps the family and community in addressing the burden, loss and stigmatizing experiences with mental illness. There is a need for the development of education campaign and information dissemination to understand better the concepts and therapeutic interventions for mental illness along with family empowerment. Through such campaigns, it will facilitate the development of tailored-fit strategies in addressing the burden of care and loss among the family members. The government should continue to assess, monitor, and evaluate their funded mental health programs to meet the needs of the patient and their family. The development of a community treatment program will also strengthen collaboration among healthcare providers, families, and the entire community.

REFERENCES

Ae-Ngibise, K. A., Doku, V. C., Asante, K. P., & Owusu-Agyei, S. (2015). The experience of caregivers of people living with serious mental disorders: A study from rural Ghana. *Global Health Action*, 8, 26957. doi:<http://10.3402/gha.v8.26957>

Aguirre, R. T., & Bolton, K. W. (2014). Qualitative interpretive meta-synthesis in social work research: Uncharted territory. *Journal of Social Work*, 14(3), 279-294. doi:<http://doi:10.1177/1468017313476797>

Angermeyer, M. C., Schulze, B., & Dietrich, S. (2003). Courtesy stigma-a focus group study of relatives of schizophrenia patients. *Social Psychiatry Epidemiology*, 38(10), 593-602. doi:<http://10.1007/s00127-003-0680-x>

Beck, C. T. (2009). Metasynthesis: A goldmine for evidence-based practice. *AORN Journal*, 90(5), 701-702, 705-710. doi:<http://10.1016/j.aorn.2009.06.025>

Borgo, E. L. P., Ramos-Cerqueira, A. T. D. A., & Torres, A. R. (2017). Burden and distress in caregivers of patients with panic disorder and agoraphobia. *Journal of Nervous and Mental Disease*, 205(1), 23-30. doi:<http://10.1097/NMD.0000000000000614>

Charara, R., Forouzanfar, M., Naghavi, M., Moradi-Lakeh, M., Afshin, A., Vos, T., . . . Mokdad, A. H. (2017). The burden of mental disorders in the Eastern Mediterranean region, 1990-2013. *PLoS One*, 12(1). doi:<http://10.1371/journal.pone.0169575>

Elias, A., & Paradies, Y. (2016). Estimating the mental health costs of racial discrimination. *BMC Public Health*, 16(1), 1205. doi:<http://10.1186/s12889-016-3868-1>

Girma, E., Moller-Leimkuhler, A. M., Dehning, S., Mueller, N., Tesfaye, M., & Froeschl, G. (2014). Self-stigma among caregivers of people with mental illness: Toward caregivers' empowerment. *Journal of Multidisciplinary Healthcare*, 7, 37-43. doi:<http://10.2147/jmdh.s57259>

Hsiao, F. H., Klimidis, S., Minas, H., & Tan, E. S. (2006). Cultural attribution of mental health suffering in Chinese societies: The views of Chinese patients with mental illness and their caregivers. *Journal of Clinical Nursing*, 15(8), 998-1006. doi:<http://10.1111/j.1365-2702.2006.01331.x>

Kizilirmak, B., & Küçük, L. (2016). Care burden level and mental health condition of the families of individuals with mental disorders. *Archives of Psychiatric Nursing*, 30(1), 47-54. doi:<http://10.1016/j.apnu.2015.10.004>

Krupchanka, D., Kruk, N., Murray, J., Davey, S., Bezborodovs, N., Winkler, P., . . . Sartorius, N. (2016). Experience of stigma in the private life of relatives of people diagnosed with schizophrenia in the Republic of Belarus. *Social Psychiatry and Psychiatric Epidemiology*, 51(5), 757-765. doi:<http://10.1007/s00127-016-1190-y>

Larson, J. E., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic Psychiatry*, 32(2), 87-91.

Marimbe-Dube, B. (2013). *The perceived impact of a relative's mental illness on the family members, their reported coping strategies and needs: A Zimbabwean study*. Master's Thesis, University of Cape Town. Retrieved from https://open.uct.ac.za/bitstream/handle/11427/5930/thesis_hsf_2013_marimbe_bd.pdf?se

McCann, T. V., Lubman, D. I., & Clark, E. (2011). Responding to stigma: First-time caregivers of young people with first-episode psychosis. *Psychiatry Services*, 62(5), 548-550. doi:http://10.1176/ps.62.5.pss6205_0548

Mulud, Z. A., & McCarthy, G. (2017). Caregiver burden among caregivers of individuals with severe mental illness: Testing the moderation and mediation models of resilience. *Archives of Psychiatric Nursing*, 31(1), 24-30. doi:<http://10.1016/j.apnu.2016.07.019>

Muralidharan, A., Lucksted, A., Medoff, D., Fang, L. J., & Dixon, L. (2016). Stigma: A unique source of distress for family members of individuals with mental illness. *Journal of Behavioral Health Services and Research*, 43(3), 484-493. doi:<http://10.1007/s11414-014-9437-4>

QSR International. (2016). *NVivo qualitative data analysis software* (Version 11.4.0): QSR International Pty Ltd.

Sandelowski, M. (2007). From meta-synthesis to method: Appraising the qualitative research synthesis report. In C. Webb & B. Roe (Eds). *Reviewing Research Evidence for Nursing Practice* (pp. 88-111): Blackwell Publishing Ltd.

Sandelowski, M., & Barroso, J. (2008). *Handbook for synthesizing qualitative research*. New York: Springer.

Stein, C. H., & Wemmerus, V. A. (2001). Searching for a normal life: Personal accounts of adults with schizophrenia, their parents and well-siblings. *American Journal of Community Psychology*, 29(5), 725-746. doi:<http://10.1023/a:1010465117848>

Stuart, G. W., & Laraia, M. T. (2005). *Principles and Practice of Psychiatric Nursing*. (8th ed). St. Louis, MO: Mosby.

van der Sanden, R. L. M., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. R. (2016). Stigma by association and family burden among family members of people with mental illness: The mediating role of coping. *Social Psychiatry and Psychiatric Epidemiology*, 51(9), 1233-1245. doi:<http://10.1007/s00127-016-1256-x>

von Kardorff, E., Soltaninejad, A., Kamali, M., & Eslami, S. (2016). Family caregiver burden in mental illnesses: The case of affective disorders and schizophrenia—a qualitative exploratory study. *Nordic Journal of Psychiatry*, 70(4), 248-254.

World Health Organization. (2001). *Strengthening mental health promotion*. (Fact Sheet, No. 220). Geneva, Switzerland: World Health Organization

World Health Organization. (2013). *Comprehensive mental health action plan 2013–2020*. Geneva, Switzerland: World Health Organization. Retrieved from <http://www.who.int>

Zauszniewski, J. A., Bekhet, A. K., & Suresky, M. J. (2009). Relationships among perceived burden, depressive cognitions, resourcefulness, and quality of life in female relatives of seriously mentally ill adults. *Issues on Mental Health Nursing*, 30(3), 142-150. doi:<http://10.1080/01612840802557204>

*Appendix**Table 1. Summary of thematic metaphors*

Study	Perceptions	Process	Perspectives
Angermeyer et al., 2003	Interpersonal interaction problems Financial burden	Concealing the illness	Changing negative public image
McCann et al., 2011	Negative public image Poor access to social roles	Open disclosure approach secretive approach	Improving mental health care Increase understanding of the mentally ill and their family
Girma, et. Al., 2014	Worried that people blame the parents for the illness of their children	Non-disclosure of the illness and avoided being seen with the patient to lessen self-stigma	
Stein, et al., 2011	Loss of a normal life		Support the family member to get back on track and to get along with the world
Al-Ngibise et al., 2015	Emotional disturbance Social relationships are negatively affected Economic Burden Not enough external support	Prayers Hoping for a miracle The anticipation of a new treatment	Community empathy Educational support from healthcare workers
Marimbe-Dube, Bazondlile, 2013	Psychological/ Emotional Impact Physical Impact Financial/ Material Impact Social Impact	Concealment Confrontation Resignation Alcohol use Seeking spiritual assistance	Financial subsistence Support groups Information and training for caregivers