Original Article

Coping and Support Needs of Caregivers of the Mentally Ill: A Phenomenological Study in the Philippines

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Abstract

There are currently very few studies exploring the area of mental health in the Philippines. The topic on mental illness remains widely stigmatized that even the concerns of the caregivers of the mentally ill stay unexplored on the background. This qualitative study aims to help families, mental health professionals, and the general community, understand the different coping and support needs of caregivers of the mentally ill. The researchers employed a phenomenological method of identifying the coping and support needs of these caregivers whose mentally ill family members were admitted in a Mental Health Facility in Leyte, Philippines. Data collection was made through in-depth interviews with carers/caregivers/relatives of five (5) mentally ill persons. Library and internet desk research in its related literature were also employed. Results of the study revealed two major themes, namely 1) coping strategies of caregivers of the mentally ill, and, 2) support to caregivers of the mentally ill. In the theme of coping strategies of caregivers of the mentally ill, three sub-themes emerged, namely 1.1) religious practice, 1.2) being productive, preoccupied and proactive, and 1.3) acceptance and resolve. Several support programs and services such as provision of mental health education and counseling regarding facts about the illness, its treatment and management, and leniency on watcher requirements during hospital admission are among the recommended support needs identified by the caregivers of the mentally ill.

Keywords: Caregiving Experience; Mental Illness; Caregiver; Philippines; Phenomenological Research.

Introduction

Leaving mentally ill people untreated can create a huge toll of disability, suffering and economic loss. It's estimated that over one billion people globally have a mental, neurodevelopment or substance use disorder (GBD, 2016; IHME, 2017). Despite being critical to the overall well-being and physical health, diagnoses and treatment or support, remain much lower than this estimate (Whiteford et al. 2016; Ritchie, 2018).

Mental illness remains a stigmatized, under-researched topic in the Philippines. Few studies on the area of mental health are available, and at present, there is scant literature concerning the experiences of people living with and giving care to mental ill people. Even more scarce are the accounts of families and caregivers who mainly provide for their needs.

It is reported that one in five Filipinos will suffer mental illness (Magtubo, 2016). Currently, there are 700 psychiatrists and an estimated 1,000 psychiatric nurses for a population of 100,000 who can cater to the needs of these people. Further statistics showed that about 17% to 20% of

Filipino adults have experienced psychiatric illness, and 10% to 15% percent of children aged five to fifteen years-old suffer from a mental health disorder. There is a total of 50 outpatient care and 32 inpatient care mental health facilities in the country that provides primary interventions such as drug administration, psycho-diagnosis & therapy (WHO, 2018). The Philippine Health Information System on Mental Health (PHIS-MH), recently released some figures showing schizophrenia as the leading mental illness in the Philippines which has affected 42% of the study cohort (Coronel, 2018).

Despite the glaring statistics, only a few resources can be found on the caregiving experiences of people living with mentally ill persons, specifically their coping and support needs. This lack of knowledge is seen to be a result of the strong belief in spiritual and otherworldly causes of physical and mental problems widespread throughout the Philippines and the Western Pacific Region. This amplifies and reinforces the reliance of Filipinos on traditional and folk healers since they offer a cheaper and accessible alternative to mental health professionals. The early stages of the professionalization of counselors and psychologists in the country do not provide much help, thus, making mental health services inaccessible and momentarily prohibitive (Tuliao, 2014).

Given these, this research aims to help families, mental health practitioners, and society as a whole, to explore the lived experiences of primary caregivers and to recognize the things that help them sustain their caring role. Specifically, this research tries to:

1. Explore and describe the coping and support needs of caregivers of the mentally ill.
2. Formulate recommendations to support caregivers and families of mentally ill.

Materials and Methods

Theoretical Frameworks**:** This study utilized a combination of two theoretical frameworks, namely Four Stages in Caregiving Experience and the Family Stress and Coping Framework. The Four Stages in Caregiving Experience model was theorized by a sociologist named David Karp (Anusha et.al, 2017). Karp based his findings through his interviews with many family members about their experiences in the process of caregiving (Karp & Tanarugasachock, 2000). Karp argues that there are four interpretive stages which correspond to the paths that caregivers and mentally ill people take in the caregiving process.

1. **Experiencing Emotional Anomie-** This characterizes the first few moments in the shared experience of the mentally ill and family caregivers. Family members may feel extremely puzzled and confused by the person's behavior and have no idea how to respond, emotionally or behaviorally.
2. **Getting a Diagnosis-** Caregivers struggle to empathize with their sick family member after a diagnosis has been made. They often believe that combining both medical treatment and utmost care to their family member will solve the problem.
3. **Perceiving Illness Permanency-** Once a clear picture of the family member's chronic illness is seen, the kinder emotions of concern and sympathy usually recede replaced by deeper feelings of anger and frustration. These hostile emotional reactions are likely to surface if caregivers perceive that their ill family member does not take responsibility for their recovery.
4. **Acceptance-** In the end, some caregivers may admit that the illness is beyond their control. Recognizing this can release family members of guilt by validating their withdrawal feelings.

On the other hand, the Family Stress and Coping Framework is a theory of stress, coping, and adaptation postulated by Hatfield (1987) who argued that the goal of the family is to adapt to the burden of taking care of someone who is mentally ill. This framework addresses the issue that most psychiatric studies on mental disorders have focused mainly on the welfare of patients, all the while overlooking the well-being of the persons devoted to them.

The three components of this model are: crisis, coping, and adaptation (see Figure 1).

1. **Crisis-** This term refers to any acute, or unforeseen events beyond an individual's usual method of response and ability to maintain balance and stability.
2. **Coping-** This denotes efforts that people employ to solve a problem and take control of a worrisome situation.

3. **Adaptation-** This signifies the connection between the person's own resources and external demands for dealing with them.

The authors of this study believe that the Family Stress and Coping Framework is suitable for explaining the interaction between family and patient in the context of mental illness. Hatfield (1987) purported that when coping is inadequate in reducing stress, it may result in psychological or physical morbidity. However, the model does not position itself inside the context of the family system but is more appropriate in explaining the micro level (or individual) experience of each distinct members of the family where it can draw out and collect individual responses.

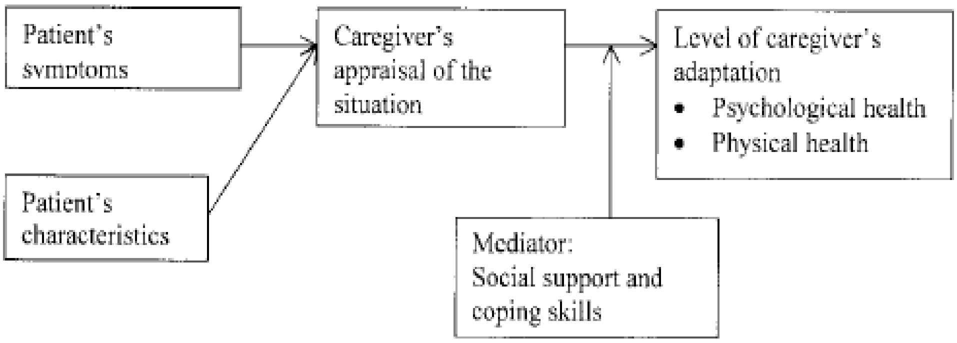

Figure 1: Family Stress and Coping Framework

Research Locale. This study was conducted from January to March 2018 at the Acute Crisis Intervention Service (ACIS) Unit of Schistosomiasis Hospital (SH) formerly Schistosomiasis Control and Research Hospital (SCRH) in Palo, province of Leyte in the Eastern Visayas region of the Philippines. ACIS is an immediate short-term psychological care which aims to assist an individual under a crisis situation to restore stability or equilibrium to their biopsychosocial functioning.

Research Design. Anchored on a qualitative research design, phenomenological method was employed for this research to explore the phenomenon under study which is the coping and support needs of caregivers of the mentally ill patients in the Acute Crisis Intervention Service. In this study, mentally ill individuals shall be referred to as those diagnosed with a mental illness for at least 6 months prior to the interview. The primary data were collected through in-depth interviews with caregivers or relatives of a mentally ill person who visit the said hospital. Library and internet desk research in its related literature were also employed.

Phenomenological researches are interested in the analytical and descriptive experience of phenomena by individuals in their everyday world (Eddles-Hirsch, 2015). Therefore, this study is more concerned with first hand descriptions of caregivers than in resolving why caregivers of mentally ill persons experience life the way they do. Phenomenological research differs from other modes of qualitative inquiry because it attempts to understand the essence of a phenomenon from the perspective of participants who have experienced it (Christensen et. al., 2010; Khan, 2014; Eddles-Hirsch, 2015). The focus, then, in this type of research, is not on the participants themselves or the world that they inhabit, but rather on the meaning or essence of the interrelationship between the two (Merriam, 2014). Thus, this phenomenological research seeks to uncover the essence of the coping and support needs of caregivers of the mentally ill patients at the Acute

Crisis Intervention Service (ACIS) Unit of the Schistosomiasis Hospital in Palo, Philippines.

The authors utilized and modified the questionnaire used by Monyaluoe et al. (2014) and translated it to the local language of *Waray-Waray* in Leyte, Philippines for a better understanding of the participants. The questions were semi-structured followed by specific questions that probed deeper into their experiences in order to gain more valuable information. The interview and dialogue were also conducted in *Waray-Waray*. A pilot interview in the first week of February 2018 with the Leyte Normal University's guidance counselor and five Licensed Psychometricians was first conducted by the authors to test the questionnaire. One served as the facilitator while the other one served as the note-taker, observer and recorder. The pilot interviews lasted for 30-45 minutes on average. Revisions of the questionnaire were done as per the pilot informants' recommendations.

Data Collection and Sampling. The researchers utilized purposive sampling, considered as the most important kind of non-probability sampling (Welman and Kruger, 1999), to identify the primary participants. The authors selected the sample based on their judgment and the purpose of the research (Groenewald, 2004) looking for those who "have had experiences relating to the phenomenon to be researched" (Kruger, 1988 p. 150). Relatives, family members and or significant others of admitted ACIS patients were directly approached and asked to participate in the study.

Aside from the approval by the school-based Ethics Review Committee of the Leyte Normal University, and to ensure ethical research, the authors made use of informed consent (Holloway, 1997; Kvale, 1996). The authors developed a specific Informed Consent Agreement to gain the informed consent from participants, namely, a) that they are participating in the research, (b) the purpose of the research (without stating the central research question), c) the procedures of the research, d) the risks and benefits of the research, e) the voluntary nature of research participation, and f) the procedures used to protect confidentiality.

The Informed Consent Agreement form was explained to the participants at the beginning of each interview. Most potential participants signed the agreement and those who did not were not pressured to participate in the study. All who ended up being participants were in agreement with its content and signed.

A sample size of five (5) relatives and/or caregivers of mentally ill patients voluntarily participated in this study. To qualify as a participant, each participant stated that they were the principal caregiver of the patient i.e. someone who spends most of his time taking care of the patient for at least one year.

One researcher served as the facilitator of the discussions while the other one operated the voice recorder and took notes. Each interview lasted for about 30 minutes to 1 hour, all the while ensuring that there were no interruptions. The names of informants and their relatives in this study have been changed to protect their anonymity. The non-verbal reactions and observation during the interviews were also noted to blend with other field notes and recorded data. After having recorded the interviews, the audiotaped data were transcribed verbatim by typing and transferring it to the *Microsoft Excel* and *Word* program.

The transcripts were translated from *Waray-Waray* to English. In the process of transcription (Smith and Osborn, 2008), the participants' words were recorded as close as possible. To ensure the correctness of data, the transcriptions were checked against the voice record a number of times. The initial notes were transformed into short and summarized phrases aimed to grasp the critical points found in the text. The researchers encoded the emergent themes on the same computer applications while looking for connections between them. The transcript was subjected to repeated counterchecking against the participants' actual words to make sure that the connections work.

The process helped capture the thematic arrangement of concerns for each participant. The clusters were then assigned a name to represent the superordinate themes.

Results

The family members interviewed were parents, specifically mothers (3), spouse (1), and child (1) of the mentally ill person. There are four female participants who were between the ages of 30 to 65 years old. Four participants did not reach college level and only 2 of them have a gainful occupation. All participants attested to have been taking care of their patients for at least 2 years. Lastly, three (3) out of five (5) mentally ill patients suffered from schizophrenia while two (2) were diagnosed with Bipolar 1 Disorder.

Two major themes emerged, namely

1) coping strategies of caregivers of the mentally ill, and,

2) support to caregivers of the mentally ill. In the theme of coping strategies of caregivers of the mentally ill, three sub-themes emerged, namely 1.1) religious practice, 1.2) being productive, preoccupied and proactive, and 1.3) acceptance and resolve.

Theme 1: Coping Strategies of Caregivers of the Mentally Ill

Theme 1.1: Religious Practices: One common and perhaps a universal form of coping by the caregivers is praying to God. Praying on a regular basis relieves them of their frustrations and gives them hope. The presence of a Higher Being in their life signifies trust that in the end, everything will work out for their patient. They pray to God and plead the Saints to cure their family member and to give them guidance in managing their situation.

Theme 1.2: Being Productive, Preoccupied and Proactive: Caregivers also respond to their problems by being productive in every way possible. Most caregivers preoccupy themselves with work or anything that can momentarily take their mind off the problem such as gardening, taking strolls and helping others. In order to help themselves gain a wider perspective of the situation, they also try to plan for their future- they seek information and education from health care workers, they create work adjustments for their patients, borrow money to buy medicines, and take comfort in the fact that they have a strongly knit family. They believe that they have to go on with their daily lives despite the challenges; otherwise they might perish from hunger.

Theme 1.3: Acceptance and Resolve: Respondents manage their emotions by accepting the entire situation. Through acceptance, they are able to endure every struggle, sacrifice for their family and be the source of strength for everyone. Caregivers also emphasize the importance of holding on to one’s sanity and taking control of one’s emotions. According to one participant, if we do not hold on to our sanity, then we might also become (mentally) ill. Finally, they believe that people will not be given problems they are unable to solve, thus, they remain steadfast in seeking treatment for their patient.

***Theme 2:* Support to Caregivers of the Mentally Ill :** The most common support that caregivers seek is financial assistance. Due to lack of financial resources, caregivers resort to borrowing money which puts them in a lot of debt. In response to this, caregivers expressed their wish to have stable jobs where they can earn regularly to defray for the medical expenses of their patients. Another suggestion was, instead of paying for their medical expenses, they wish to receive free or subsidized and hassle-free healthcare assistance in the form of consultation and medicines from hospitals, Local Government Units, or Social Welfare. Caregivers struggle with the depressingly long queues, several documentary requirements and lengthy processing of medical assistance only to receive an amount barely enough to cover a month’s medical expense. They also recommend the provision of counseling and health education in hospitals to persuade their patients to end their vices. They also wish to receive effective and efficient medication and treatment from doctors to avoid the future relapse of the patient. Although they are already receiving such, they still feel that there must be a stronger antidote for their family member’s illness. Another form of support they seek was a more lenient policy on watchers due to the difficulty of finding a willing and same-sex companion for their patient. Longer hospital care (chronic) for patients, community assistance and moral support from other people were also some forms of support they seek.

Discussion

Despite all reasons to feel hopeless, caregivers and families of the mentally ill claim to have so much to be thankful for. The professional and institutional services they have received count as essential resources in fulfilling their roles as primary caregivers (Monyaluoe et al., 2014). The kindness of the people around them and the lack of discrimination have helped these families flourish and become unrestricted in giving everything they can for their patients.

In terms of coping, participants identified religiousness, engaging in productive activities, and strengthening their resolve as strategies that helped lessen the burden of caring for their mentally ill family member. However, it is evident on the findings presented that the negative caregiving experiences far outweigh the coping strategies of these caregivers. Almost all of the participants have a predominantly negative appraisal of the situation. They recognize only a few of ways of positively responding to it which significantly affects their adaptation towards the situation (Hatfield, 1987). Since their coping mechanisms are inadequate in reducing stress, this has resulted in psychological morbidity reported among some caregivers.

Finally, developing a stronger sense of belongingness (Sudarat et al., 2014) within the family and receiving various kinds of support, either moral or financial, have helped alleviate the heaviness of the situation. The entirety of the caregiving experience generally gave them more perseverance and compassion in their caregiving role. Despite the uncertainty of the future and the difficulty of access to medical care (Wang et.al., 2017), they still hope for a full recovery of their mentally ill family member.

Conclusions and Recommendations

This research revealed the interplay of various factors affecting the caregiving process including coping strategies and support needed by caregivers providing an in-depth understanding of the phenomenon. Consistent with the objectives of this study, the following recommendations have been proposed to effectively support caregivers of the mentally ill.

Mental health institutions should strengthen their health education and counseling services to families to help them gain sufficient understanding and awareness of the psychiatric diagnosis of the patient. Mental health education should be intensified to minimize stigma brought about by various psychiatric conditions, thereby increasing family & community involvement in patient's therapy. At the same time, patient and family counseling should be a continuous endeavor to improve compliance with the medication regimen and decrease patient's involvement in vices which pose as a huge risk factor for recovery.

Doctors and other health care providers must also clearly explain to families the important information about the drugs that their patients are taking to avoid misconceptions and fallacies regarding drug efficacy. The strict policy on watcher qualification is also something to be reviewed to accommodate cases of families who lack willing or available same-sex companions. It would also be beneficial to the family if institutions and health facilities expand the types of financial assistance they provide. Finally, health legislators in the Philippines should consider putting up mental health care facilities for chronic cases to help families address the difficulty in managing their chronically psychotic patients.

These recommendations are especially helpful in guiding mental health professionals, government and private institutions, and the community in creating policies and programs to assist caregivers of a mentally ill family member. Lastly, it would be helpful to conduct further research on the topic in order to improve and update the existing literature and enhance the understanding of caregiving in the mental health context.

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