

TRAVAILS OF MOTHER WITH TERMINALLY ILL CHILD: A MULTIPLE CASE STUDY

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ABSTRACT: This qualitative multiple case study explored the experiences of five mothers with a terminally ill child and their coping strategies while in the hospital for an extended period. The findings revealed that upon their child's illness, the mother's world seemed to crumble, causing them to shower their children with love and seek Divine intervention while trying to be strong for their child. The participants stressed the importance of seeking refuge in the lord, seeking help from government agencies, and remaining positive and hopeful. The study's implication suggest that it could serve as a model for medical social workers handling challenging cases and parents of terminally ill children who persevere through difficulties over several years. This study contributes to the literature on social work and the struggles faced by mothers with terminally ill children globally.

KEYWORDS: *Social work, travails, mother w/ terminally ill child, multi-case study, Philippines*

I. INTRODUCTION

Taking care of a terminally ill child is a challenging task for parents. In addition to physical and medical challenges, the entire family suffers from the impact of a lingering illness on the child. Mother, who often assume the role of primary caregiver, experience exhaustion, especially when they also have to take care of the household and a chronically ill child. As a result, many mothers give up their jobs, which can lead to social isolation and financial strain for the family (Bruce 2014; Park 2016). International research has identified various sources of stress for family members of critically ill patients, including psycho-social factors, parental uncertainty, and separation from family. The emotional and behavioral responses of the hospitalized child, as well as the disruption of the parent-child relationship, are particularly stressful for both mothers and fathers. Parents also experience role revision, which can lead to increase anxiety and a sense of inadequacy (De Whitte, 2018; Park et al., 2016). In the United States, there are 18 million children diagnosed with chronic illnesses, many of whom are cared for by parents or guardians (Coffey, 2006; Dabrowska et al., 2010; Wittenberg et al., 2013). Similarly, in the Philippines, childhood cancer is a significant concern, with an estimated 2,707 cases per year. The biggest government hospital in Davao City has a pediatric oncology unit that helps care for children with cancer. Despite efforts to help families of terminally ill children, there are still limitations to the available programs and services (Department of Health, 2017). To better support mothers and caregivers, more effective interventions are needed, which take a more holistic and multidisciplinary approach. However, this study has limitations, as it only gathered information from five mothers and did not include in-depth health or psychological analysis of the mothers of terminally ill children.

Objectives of the study

This study aimed to explore, know, and understand mothers' experiences with terminally-ill children. Furthermore, this study also knows the support system of the parents, relatives, friends, and the government in this kind of particular case.

II. LITERATURE REVIEW

Transactional Model of Stress and Coping Lazarus and Folkman (1984), emphasizes appraisal to evaluate harm, threat, and challenges, resulting in the process of coping with stressful events. This theory advocates that stress is experienced through thoughts, feelings, emotions, and behaviors, and that stress is an imbalance between demands and resources. Since every person is beset with requests, it has to match this with resources and skills available to them, which are the coping mechanisms. The theory advocates that mothers who appraise a stressors related to their child's ailment must balance the demands with the available resources they have to cope with or respond to the stressors. The stressors is often experienced as discomforting and influenced by various personal and contextual factors, including capacities, skills, abilities, constraints, resources, especially money and norms. This study describes how these mothers cope with stress.

In support with the transactional model of stress and coping is the comfort theory of Kolcaba (2007), which advocates four areas of comfort: physical, psycho-spiritual, environmental, and socio-cultural. Physical comfort refers to bodily comfort, psycho-spiritual to mental and spiritual well-being, environmental to the patient's space, and socio-cultural to emotional coping with loneliness and depression. Kolcaba motivates everyone in the healthcare discipline to bring comfort to clients and patients, especially those with lingering illnesses.

Consequently, Kubler-Ross(1970) is also used in this study. The author explains that each stage has a multi-faceted response to grief, particularly the loss of someone to which a bond was formed. Although, this conventionally focuses on the emotional response to loss, it also has physical, cognitive, behavioral, social, and philosophical dimensions. However, this is not limited to dying patients who need to cope with death and bereavement, but also to people undergoing deep-seated problems related to ailing family members. This is appropriate to understand the grief of mothers while taking care of their family and ill child.

Kubler-Ross model (1969) recognizes that people have to pass through their own individual journey of coming to terms with death, sickness, and bereavement, after which there is generally an acceptance of reality, which enables the person to cope. The strength of this theory lies on the focus of the grieving process. The key to understanding the stages is not to feel like one must go through everyone of them in precise order. Instead, it is more helpful to look into the adjustment process of mothers as a guide to increase their level of sensitivity and awareness concerning the illness of their children.

III. METHODOLOGY

This study used a qualitative multiple case study approach to develop rich descriptions of the unique experiences of mothers with terminally ill children (Englander, 2012; McGrath, et. al., 2018). The research aimed to extract practical principles and methods of solving real problems experienced by these mothers. Qualitative research provided an opportunity to deeply penetrate the core of the participants' experiences and understand how they were affected by the illness of their child (Kaushik & Walsh, 2019). The research design aimed to obtain comprehensive descriptions that can be used in a reflective process and not from the measurement or explanation of its occurrence (Maxwell, 2016). The study employed a case study design that is appropriate for this research as it describes the meaning of the lived experiences of the five (5) participants about their being a mother of a terminally ill child. The data obtained through qualitative research is essential in developing an integrated understanding of phenomena that can then be translated into evidence for further quantitative research (Creswell, 2009).

IV. RESULTS AND DISCUSSION

Experiences of the Participants

The experiences of mothers of terminally ill children were analyzed and five key themes emerged. The first theme was that the mothers' world seemed to crumble and fall apart, with denial, anger, guilt, and disbelief being common experiences. Coping strategies were sought to eliminate emotional difficulties, but the cycle of grief and loss was difficult to manage (Kubler-Ross, 1969; Hamilton, 2017). The second theme was the mother's tendency to shower their sick children with love, becoming overprotective and emotionally strained, feeling guilty and responsible for their child's illness (Bovero, et.al, 2019; Gallo, 2019; Ferrell, 2016; Schaefer, et.al, 2020). The third theme was that the mothers brought their children closer to God, pleading and imploring for divine intervention (Schaefer, et.al, 2020; Taylor, 2019). Fourth theme was the day-to-day pain and agony of caring for a terminally ill child, which demanded the whole time and responsibility of the mother and father (Morrow, 2020). The final theme was that the mothers were confronted with the challenge of balancing their child's illness with the well-being of the whole family (Gheibizadeh, et. al., 2017). The stability and quality of family relationships were important to the well-being of the whole family, most especially to the sick child. The gestures of mothers in showing all their love to the ill child were supported by comfort theory, which advocates that when the specific needs of a person are met, they become more open to healing.

Coping with Life's Challenges

Four themes emerged from the analysis of data for research questions two: finding financial resources for treatment, putting on a brave face, agonizing over a child's suffering, and being on edge. Financial resources were difficult to find, and mothers felt like beggars, but they learned to seek help from government agencies and other sources. Having an ill child caused stress in all areas of life, and coping involved looking for financial resources, which was stressful but successful. Mothers put on a brave front and hid their worries to avoid discouraging their child, which was supported by resiliency theory (Pushpala; Wanner; & Pak; 2023). Coping with grief and loss is a personal experience, but health professionals can provide comfort and support to mothers and ill children. A mother's ability to cope is a result of therapeutic interventions, and interaction with service providers elevates the meaning-giving of events. Mothers have specific needs, and service providers help them cope (Bovero, et.al, 2019; Taylor, 2019).

Learning Insights

Three themes emerged from the analysis of research questions number three: seeking refuge in the lord, seeking help from the government agencies, and maintaining a positive and hopeful attitude. Seeking refuge in the lord involves accepting the child's illness, attaining meaning through spiritual or scientific explanations, and the importance of spiritual care for caregivers (Ferrell, et.al, 2016). Seeking help from government agencies refers to the availability of government programs and medical social workers who assist families in need (Feeg, et. al., 2016; Taylor, 2019). Social support is also vital in crisis situations, and healthcare providers should identify the needs of mothers and offer competent care and support (Bovero, et.al., 2019). Mothers expressed high levels of satisfaction with the services they received from healthcare professionals and government agencies.

V. CONCLUSION AND IMPLICATION

Social workers may provide psycho-social and spiritual support to mothers caring for terminally ill children, utilizing their expertise in case management and knowledge of inner and outer resources to assist mothers in navigating hospital procedures and accessing healthcare. Social workers may also involve fathers in the care-giving process, emphasizing the importance of partnership and family support in coping with stress. The coping mechanisms of mothers often involve faith, hope, love, and family support. Social workers may possess clinical skills in assessing and processing patients and caregivers in every stage of grief. They must work as part of the multidisciplinary team with other healthcare provider and future research could focus on the narratives of children and siblings of ill children, as well as the experiences and insights of social workers on end-of-life care.

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