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Quality of Life amongst Family Caregivers of Older Persons with Terminal Illnesses

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Abstract

The study aims to identify the constructs of quality of life amongst family caregivers who care for older persons with a terminal illness. A semi-structured interview was conducted with ten caregivers in Selangor, Malaysia. Data were closely analyzed using the Interpretative Phenomenological Analysis (IPA). Two superordinate themes emerged from the interview transcripts, i.e. "strengthening family bonds" and "improved sense of self-worth". The overall themes emerged indicates the constructs of the quality of life in relation the caring of the older person with terminal illnesses. This present study provides new insights for healthcare professionals. Therefore, they can promote the participation of the family members in providing the care for the older person who need the care for them to achieve their maximum quality of life.

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1. Introduction

Changes in health care and advancement in modern medicine have contributed to longevity. Subsequently, there are increasing numbers of the older population in Malaysia. For example, in Malaysia, the older population is

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expected to rise to 9.8% by 2020 compared to only 4% in 1998 (Razali et al. 2013). With increasing in age, they are at a higher risk of suffering from terminal illnesses and face various disabilities. Terminal illness such as malignant neoplasm, heart, and pulmonary conditions are expected to be a significant medical problem amongst this population. Terminal illness is defined as a disease that is active and progressive that cannot be cured or there is no expectation of treatment recovery (Gonorazky, 2011). Momtaz et al. (2010) found that 77.7% of their samples in the elderly population have at least one chronic condition. Most of the older patients with a terminal illness have impairments in quality of life resulting from the declining and the deterioration of the health status. The study by Albuquerque et al. (2015) has confirmed that currently there are no available curative treatments for patients with multiple sclerosis and that they have impairments in quality of life compared to healthy people in all areas. Meanwhile, a study by Simona et al. (2014) also found that patients with a chronic disease had a negative impact on their quality of life. Due to the deterioration of the health condition, the older person will reach to the point where they need to get the support and help from their family members to accomplish their routine daily activities. Family members such as the spouse, children and siblings often involve in providing such care. Family involvement in providing the care for older persons with a terminal illness is likely to maximize the quality of life of these older persons with a terminal illness. A study by Senden et al. (2015) expressed that family caregivers of an older person with cancer feels responsible for the patient's well-being and for providing care for their loved one.

Being a carer for an older person with a terminal illness is extremely complex and demanding. Caregivers usually faced various challenges and barriers while providing the care for the care recipient. A study by Marks et al. (2004) found that caregivers are at a higher risk for psychological and physical exhaustion. Pinquart and Sorenson (2003) also found differences among caregivers and non-caregiving peers where caregivers report higher levels of depressive symptoms and fatigue compared to the non-caregiving peers. Meanwhile, Michalik and Valenta (2012) found in their study that caregivers had reported negative feelings and experiences concerning the long-term care for the care recipient. The existence of the negative experiences, included the sense of exhaustion, depression, hopelessness and loss of the ability to enjoy free time.

However, many carers find that taking care of older persons with a terminal illness is a rewarding experience that eventually facilitates a sense of the quality of life. The study by Lkhoyaali et al. (2015) showed the benefits of caregiving in older persons with cancer family members. They said that caregivers have a feeling of satisfaction, personality enhancement, having the meaning of life and a greater appreciation of the family. Findings from the study by Stajduhar (2003), also reported that many family caregivers expressed positive impact on life-enriching experience resulted from providing the care for their loved one. Caregivers believe that they have an opportunity to give something back to the person they are caring for, and it also gives a sense of achievement when they can fulfill the final wishes of the patient. While providing the caregiving tasks, it also allows them to spend intimate times together with the patients and they can share the final moments that are meaningful in more efficient ways.

Besides this, a study by Haley et al. (2009) reported that the experiences in providing the care for the patients with disabilities can also bring families together and cause people to appreciate and see their life in various perspectives. The challenges and demanding tasks that they go through over a long period of time can teach themselves to become a stronger person. Meanwhile, the scarification and the contribution of their effort to reduce the patient's burden plays a significant role in achieving the patient's maximum quality of life and will also make them become a better person.

Studies that indicated the positive benefits of caring for the older person with a terminal illness are often conducted in Eastern and Western countries (Lkhoyaali et al. 2015; Haley et al. 2009 & Stajduhar 2003). However, the evidence regarding the benefits of caring for an older person with a terminal illness in Malaysia is limited and scared. Hence, the aim of the study is to identify the benefits of caregiving for older persons with a terminal illness and its impact to their of quality of life.

2. Methodology

This study involved a close examination of the experiences and perspectives of family caregivers who care for an older person with terminal illnesses. Since this study aims to explore in detail and understand about people's life experiences, therefore, a phenomenology approach was used in conducting this study as it is well suited to the objectives of the study.

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