



# Caregivers' Environmental Barriers in Caregiving in Adults with a Terminal Illness

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## Abstract

Caring for a patient at the end of their life can be highly demanding and becomes a challenge for caregivers. The participants were recruited using a convenience sampling of ten caregivers who provided the most care to an adult with a terminal illness. All interviews were recorded, transcribed verbatim and analyzed using the six steps of Interpretative Phenomenological Analysis (IPA). The findings showed that the environmental barriers caregivers had recognized were transportation, insufficient material resources, and remote home facilities. By acknowledging these barriers, healthcare professionals can design and implement therapeutic environments that are clinically relevant toward those most in need.

Keywords: Environmental barriers, terminal illness, adult, caregiver

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## 1. Introduction

Currently, there are very limited studies on environmental barriers in caregiving locally and globally. Therefore, this present study aims to reveal the family caregivers' experience of environmental barriers in taking care of adults with a terminal illness, as understanding the experience is essential to help the patient live as comfortable as possible, as well as to provide support to the caregivers. Terminal illness patients do not only suffer by themselves, but it also affected their family members. Caring for a patient at the end of their life can be highly demanding and being a burden and challenges for family caregivers. Family members such as the spouse, children and siblings often involve in providing such care. A study by Senden et al. (2015) expressed that family caregivers becomes responsible for the patient's well-being and for providing care for their loved one.

In addition, a previous study reported that taking care of the patient's symptom related to cancer disease and their personal care need is what triggers stress among the caregivers (Brazil, Bainbridge and Rodriguez, 2010). Meanwhile, a study by Bookman and Kimbrel (2011) reported that even though most of the caregivers achieve the feeling of satisfaction when able to provide the care for their loved one, sometimes they also feel burdened, socially isolated, strained and hopeless. According to a research by Much (2006), elder care required a set of services to respond to a broad range of often unpredictable medical, emotional, physical, personal care and financial possibilities. These needs often cause anxiety about things such as the ability to find and pay for immediate care. This kind of situation sometimes will become the burden and challenges for family members in the care of adults with a terminal illness.

## 2. Literature Review

Increased life expectancy and other demographic changes will increase the need for long-term care even greater over the next 50 years (Janette, Dill, & Cagle, 2010). Moreover, the older population and disabled constantly express a vivid preference to live, receive care, and die in their own homes (Stone, 2004). WHO (2004) define terminal illness as an illness for which there is no known cure. Many developed nations will face a public barrier over the coming decades in regards of how to enhance palliative and end-of-life care provision to meet the needs of rapidly ageing populations (Gardiner, Brereton, Frey, Wilkinson-Meyers & Gott, 2014). 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 the disease that is active and progressive that cannot be cured or there is no expectation of treatment recovery (Gonorazky, 2011). As the disease progresses, patients faced with the rapid deterioration in health, reduction in performance status, functional capacity, pain and psychological distress (Petkova et al., 2010) and impaired ability for self-care. Most of them often need to be in total dependency in all aspects from their family caregivers. Terminal illness patients do not only suffer themselves,

but it also affects their family members. As a result of the disease, all members of the family, including the patient face significant changes in their lives that requires adjustments and adaptation in coping with the numerous degree of loss (Sherman, 1998). A study from Tse Man Wah (2007) reported four major difficulties, including the relationship with the patient, emotional reactions to caring, physical demands in caregiving and restriction in social life.

Principle caregivers are outlined as persons who often provide the most aid with one or more of the essential activities of communication, mobility, transport, house chores and self-care (Australian Bureau of Statistics, 1999). According to the National Board of Health and Welfare's of Sweden, characteristics of high quality patient-focused care stress out communication between patients, health personnel and family members (Socialstyrelsen 2008). In Sweden, the patient's perspective is essential in caregiving and family members are only able to participate so far as the patient allows (Wilhelmsson, 2011). In this challenging era, family members are commonly asked to perform clinical care responsibilities that until recently would have been performed by trained healthcare personnel (Ryn et al., 2011). A study found that caregivers had reported of the negative feelings and experiences concerning the long-term care for the care recipient (Michalik & Valenta, 2012). Furthermore, because caregivers are challenged with both emotional difficulties and inadequate information, it is crucial for relatives to have knowledge, education, and assistance in their daily lives (Magnusson et al., 2002).

Environmental factors by definition affect large groups that in cooperates mutual living or working spaces (Woolf & Aron, 2013). A variety of aspects of the physical and social environment can impact people's health thus contribute as explanatory factors for health differences across countries. Moreover, environmental factors related to surroundings and location may in turn add to and increase socioeconomic and ethnic health inequalities (Bleich et al., 2012; Laveist et al., 2011). Nowadays, attention is given to the implications for health behaviors and social interactions that are created by the built environment. The built environment refers to the existence of (and proximity to) health-relevant resources as well as to aspects of the ways in which communities are designed and built (including transportation systems, urban planning and design features) (Woolf and Aron, 2013). Living in socioeconomically disadvantaged communities has been linked to higher rates of injury in both adults and children (Cubbin et al., 2000). However, only recently, healthcare personnel have been faced with the dilemma of how to create the most collective value with shrinking resources (Drummond et al. 2013).

### **3. Methodology**

This is a qualitative study which attempts to provide an exploration of one's life experiences in taking care of an adult person with a terminal illness. It was conducted using a phenomenology approach (Smith, Flowers & Larkin, 2009). The family caregivers were

approached either during hospital visits or over the telephone called to schedule an interview session and invited to participate. The detail of the study was briefed accordingly, and each respondent who agreed to be interviewed was asked to fill in a written consent form. The study was approved by the ethics committee in Universiti Teknologi MARA (UiTM). In-depth interviews were conducted with the caregivers about their challenges or barriers in taking care of adults with terminal illnesses. The participants were recruited using a convenience sampling of ten caregivers who provided the most care to an adult with a terminal illness. They held a caring role for adult people aged 50 years old and above.

The researchers designed the interview guide based on Kawa's Model (Iwama et al., 2009) in which it metaphors the river and its structured environment to symbolize the complexity of the phenomenon. The interviews were semi-structured and consisted of open-ended questions, guided by a questionnaire template developed for this study by the researcher. Participants preferred to share their story in chronological order. Thus, we obtained both a historical account of their experience and an account of the current issues and concerns experienced at the time of the interview. The interview sessions were approximately 30 minutes each. All conversations were recorded throughout the interview session using an audio recording device.

Finally for data analysis, interviews were transcribed verbatim and analysed concurrently using the six steps of Interpretative Phenomenological Analysis (IPA) as described by Smith et al. (2009) namely, transcript reading, text analysis, theme development, clustering of themes, analysis of other interviews following the first- fourth step, and finally, the authors searched for the similarities of themes across interviews. The results are revealed through themes. Some of the quotes from interview transcripts were selected to represent the emerging themes. Forward translations of transcripts were carried out with the Malay transcripts by a professional in the field.

#### **4. Results and Discussions**

This recent study revealed the findings conducted over ten participants with family members who were mostly involved in providing the care for adult persons with a terminal illness. The demographic characteristics of the ten family member caregivers are reported in Table 1.

Overall, of all the family caregivers who took part in the study, female caregivers were more than male caregivers who are eight and two respectively. This is in line with another study that had found that women constitute a majority of the informal caregivers of adults in need of assistance (Pinquart & Sörensen, 2005). The age inclusion criteria for this study was 18 years and older. Four participants were in a range age of 18 to 30 years, another four participants in a range age of 31 to 40 years old, meanwhile only two participants in a range ages of 41 and older. The demographic details of participants are as below in Table 1.

Table 1. Demographic characteristics of the participants (N = 10)

| Characteristic                   | N (%)  |
|----------------------------------|--------|
| <b>Gender</b>                    |        |
| Male                             | 2 (20) |
| Female                           | 8 (80) |
| <b>Age (years)</b>               |        |
| 18-30                            | 4 (40) |
| 31-40                            | 4 (40) |
| ≥ 41                             | 2 (20) |
| <b>Employment Status</b>         |        |
| Student                          | 3 (30) |
| Self-employed                    | 4 (40) |
| Housewife                        | 3 (30) |
| <b>Relationship to recipient</b> |        |
| Spouse                           | 2 (20) |
| Daughter                         | 6 (60) |
| Grandchildren                    | 2 (20) |

The findings presented using IPA revealed three themes. It is summarized in Table 2.

Table 2. Themes emerged from the interview transcripts

| Themes                             |
|------------------------------------|
| 1. Transportation                  |
| 2. Insufficient material resources |
| 3. Inconvenient home facilities    |

From this study, the respondents expressed three themes. These themes represent and illustrated a variety of underlying experiences, which are further detailed with quotes from the interviews (Smith, Flowers, & Larkin, 2009).

#### 4.1 Theme 1: Transportation

The caregivers seem to have experienced the problem in acquiring transport to enable them to bring the patient to their hospital appointments. Patients with terminal illnesses were frequently admitted to the emergency department or attended hospital for treatment to alleviate worsening symptoms. Using the car without proper facilities for a long journey seems to be not suitable to carry the patients since they are very fragile and their condition can become worse. In the worst situations, they need the ambulance service to bring the patients to the hospital. However, the fee charge for the private ambulance service is quite expensive. This is illustrated by this caregiver:

*I could not attend the hospital appointments anymore. My father cannot even move or sit by himself. It's very difficult to bring my father to the hospital using my car. My father becomes extremely exhausted just from the journey to the hospital. We decided to stay at home.*

#### 4.2 Theme 2: Insufficient material resources

Meanwhile, some of the caregivers claimed that they were having difficulties getting the material resources such as medical equipment and supplies for the patients' needs. This has been illustrated by this caregiver. She said:

*I'm using the large size of colostomy bags. I am already searching in all pharmacies around here. There is no suitable size for him. The stools keep leaking under the bag. I always need to monitor him because his skin becomes irritated. He also got admitted because of infections.*

#### 4.3 Theme 3: Inconvenient home facilities

Apart from that caregivers also reported that the inconvenient home facilities increase their workload to take care of the patient at home. This is illustrated by the caregiver who was taking care of her father who has severe complications of the diabetes mellitus disease. She explained:

*My father's condition became worse. Now he depends on the wheelchair for his mobility. However, our home condition is not suitable for the wheelchair users. Therefore, we need to carry him, especially to go to the toilet. If he can use the wheelchair, of course it will reduce our burden since he can do it by himself. All we need to do is just minimal supervision to avoid any accidents.*

The present study has highlighted the nature of family caregivers' environmental barriers in taking care of an adult with a terminal illness. One theme that emerged in this study is due to the transportation issue. Most patients are staying at home because makes it easier for the caregiver to look after them. But, there were limited medical equipment and professionals for the patient to receive medical care at their homes. Hence, the patients with a terminal illness always need to go to the hospital for their critical illness management. However, to attend the medical appointments or in the case of an emergency, the caregiver's ability to bring the patient to the hospital is seen as a hard and difficult task to perform. The transport provided by the caregivers is not modified to be adapted to carry a bedridden patient. Using the transport without proper facilities seems to be not convenient to be used by patients with disabilities. As a result, most of the caregivers are unable to meet the needs of the patient to receive a proper medical treatment at the hospital. The study by Matthews et al. (2004) also found that the transportation resources specifically became a primary concern of the patients. Patients and their family members face the barrier to receiving a good quality care due to the lack of transportation resources. Furthermore, in a study of post-stroke patients, transportation selections were significantly important for safety, to attend hospital appointments, and increase independence (Marissa, Vento, Nakagawa and Linton, 2014).

Furthermore, the lack of resources or material needs of the patients also becomes a part of the barrier that is faced by caregivers. Caregivers claimed that it was difficult to find the material resources such as medical equipment to give the best care for the patients. Some degree of limitations to care that could be provided is a raised in the absence of equipment. This could relate to another core concept which is lack of financial means as well as insufficient supportive systems and the expensiveness of treatments (Tahrekhani, Sasani, & Naji, 2015). In Iran for example, such an issue puts a heavy burden on the patients' families due to insufficient supportive care thus consequently can lead to a financial crisis (Tahrekhani, Sasani, & Naji, 2015). However, by providing proper healthcare facilities it can lead to reduction in the number of hospitalization length; decrease the number of recurrence of the disease, and preservation of mental health and quality of life of both the patient and caregivers (Malakouti et al., 2004). Besides this, the government or other non-governmental organizations should look to this issue at hand and help to minimize the caregiver barriers to help them in providing the maximum quality of life in caregiving.

Meanwhile, the inconvenient home facilities also become a challenge for the caregivers in providing the care for an adult with terminal illnesses. Due to this issue, the caregivers need to provide their maximum physical demands in order to help the patients performing their tasks which lead to increase in caregivers' workload and burden to take care of the patient. This could be supported by a study that reported that the reduction of home environmental risks can improve functional performance of the patient with a disability and result in long-lasting benefits from both as a patient and their caregiver's quality of life (Serena et al. 2005). Therefore, this finding provides evidence for the health care professionals to assess the home environmental factor for ensuring home safety that motivates the patients to achieve their maximum independence that eventually will reduce the caregivers' burden.

## **5. Conclusion**

By acknowledging the difficulties and barriers in caregivers to supportive care for an adult with terminal illnesses, researchers and health care professionals can begin to design and implement therapeutic interventions that are clinically relevant and more likely to be effective toward those most in need. In addition, involvement and recognition of the potential contributions from other helpful sources may help to reduce the burden on the caregivers as well as to promote better care for the adult with terminal illnesses.

Future research should look into environmental intervention which includes adaptations and innovations that could be implemented for caregiving of the terminally ill patients. These interventions could be provided for the patient themselves or the caregivers. In addition, healthcare providers and policy makers can play a role by adopting

a trans-disciplinary approach by identifying and integrating existing resources that could maximize assistance for the patients and caregivers

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