



Faculty of Medicine and Health Sciences

**AN EXPLORATION OF ADULTS' LIVED
EXPERIENCES AS CAREGIVERS IN KAMPUNG
MUARA TUANG, SAMARAHAN**

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Final Year Project Report

Masters

PhD

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An Exploration of Adults' Lived Experiences as Caregivers in Kampung Muara Tuang,

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Abstract

Introduction: A caregiver's responsibilities range widely from accompanying to assisting ADLs, short post-acute care after a hospitalization, to long-term constant ongoing care in chronically ill elderly. Caregiver burden is associated with caregiver's demanding responsibilities. It is important to address caregiver burden however not much is known about the experience itself especially in a rural area.

Objectives: The objectives are to identify the factors of caregiving, explore the impacts of caregiving on lives and relationships, and investigate the feelings of long-term caregiving.

Methodology: The research employed a qualitative methodology using descriptive interpretive research design by selecting participants with purposive sampling. The interview was conducted as one-to-one and was audio recorded. Informed consent was obtained from all the participants.

Findings: A total of 5 full-time caregivers were interviewed, 4 females, and 1 male. All the females are unemployed, while the male caregiver was employed. Three main themes were produced which are filial obligation, emotional distress, and acceptance of roles. Under each main themes, subthemes were presented to fully understand the experiences. Under filial obligation, it was found that caregivers felt a sense of responsibility, familiarity, and

companionship as factors of caregiving. While under emotional distress, “losing” the other person and denial emerged as impacts of caregiving on lives and relationships. Lastly, under acceptance of roles, caregivers reported feelings of long-term caregiving as a cultural norm and had personal expectations for themselves.

Conclusion: The findings contributed to understanding the caregiver’s lived experiences, especially in the context of a rural area where limited research has been conducted. By unraveling the factors, impacts, and feelings related to caregiving, this research provided insights that can assist the development of interventions and support systems to alleviate caregiver burden and enhance the overall well-being of caregivers in rural communities.

Keywords: caregiver, caregiver burden, filial piety, filial obligation

***Menyelami Pengalaman Orang Dewasa sebagai Penjaga Orang Tua di Kampung Muara
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Abstrak

Pengenalan: Tanggungjawab seorang penjaga adalah pelbagai, dari menemani hingga membantu dari segi aktiviti harian, penjagaan selepas keluar daripada hospital, hingga penjagaan berterusan jangka panjang kepada golongan orang tua yang sakit kronik. Beban yang dialami penjaga berkait rapat dengan tanggungjawab penjaga. Ianya penting untuk mengatasi beban penjaga, namun tidak banyak yang diketahui tentang pengalaman itu sendiri terutamanya di kawasan luar bandar.

Objektif: Objektifnya adalah untuk mengenal pasti faktor-faktor penjagaan, meneroka kesan penjagaan terhadap kehidupan dan hubungan penjaga, serta menyiasat perasaan penjaga terhadap penjagaan jangka panjang.

Metodologi: Penyelidikan ini menggunakan metodologi kualitatif dengan menggunakan reka bentuk penyelidikan deskriptif interpretatif dengan memilih peserta melalui sampel yang disasarkan. Temu bual dijalankan secara individu dan direkodkan. Persetujuan bertulis diperolehi daripada semua peserta.

Dapatan: Sebanyak 5 penjaga sepenuh masa telah ditemu bual, 4 wanita dan 1 lelaki. Semua wanita adalah tidak bekerja, manakala penjaga lelaki adalah bekerja. Tiga tema utama telah ditemui iaitu tanggungjawab sebagai anak, tekanan emosi, dan penerimaan peranan. Di

bawah setiap tema utama, sub-tema dipersembahkan untuk memahami sepenuhnya pengalaman tersebut. Di bawah tanggungjawab anak, didapati penjaga merasai rasa tanggungjawab, rasa kebiasaan, dan peneman/ saling menemani sebagai faktor-faktor penjagaan. Di bawah tekanan emosi, rasa "kehilangan" orang dijaga dan penafian muncul sebagai kesan penjagaan terhadap kehidupan dan hubungan. Akhirnya, di bawah penerimaan peranan, penjaga melaporkan perasaan penjagaan jangka panjang sebagai norma budaya dan juga ianya adalah jangkaan peribadi terhadap diri mereka sendiri atas dasar tanggungjawab.

Kesimpulan: *Dapatan ini menyumbang kepada pemahaman tentang pengalaman hidup penjaga, terutamanya dalam konteks kawasan luar bandar di mana penyelidikan adalah terhad. Dengan mengungkap faktor-faktor, kesan, dan perasaan yang berkaitan dengan penjagaan, penyelidikan ini memberikan pencerahan yang boleh membantu pembangunan intervensi dan sistem sokongan untuk mengurangkan beban penjaga dan meningkatkan kesejahteraan keseluruhan penjaga di komuniti luar bandar.*

Kata kunci: penjaga, beban penjaga, kewajiban anak, tanggungjawab anak

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CHAPTER 1 INTRODUCTION

1.1 INTRODUCTION

In chapter 1, it describes the background of the research on ageing population globally and in Malaysia, roles of caregivers, and filial piety. Additionally, problem statement, research questions, research objectives, significance of research, operational and conceptual definition of terms used are also discussed in this chapter.

1.2 BACKGROUND

An informal caregiver is an unpaid family member, friends, or neighbours who care for a person suffering from an acute or chronic medical condition and needs support to manage activities of daily living (ADLs) (Reinhard et al., 2008). Physically and chronically impaired ill elderly are dependent on informal caregivers in performing ADLs. United Nations (2022) estimated by 2050, individuals aged 65 years and above will double that of children under the age of 5 years old. Something to take note of is that modern healthcare can prolong a person's life with the help of medical professionals, medications, and machines. However, living longer may not mean living better. Ageing is an unavoidable process, and according to Li, Yang & Anderson (2013), as a person's age increases, mortality rate also increases. This rounds back to the age population shift, and increase rate of mortality, causing informal caregivers expected to step up to care for their elderly members in the long run (European Union, 2018).

A caregiver's responsibilities range from accompanying to assisting in ADLs, short post-acute care after a hospitalization, to long-term constant ongoing care in chronically ill elderly (Reinhard et al., 2008; D'Amen et al., 2021). Edemekong et al. (2022) defined ADLs as fundamental skills required to independently care for oneself, such as, eating, bathing, and ambulating. These indicate a person's functional status where a poor ability to perform ADLs results in dependence on caregivers. This dependence may range from

ambulating assistance to total basic care such as bathing and feeding. It may sound easy and simple enough, but it is quite the opposite. As a person ages, they will experience a decline in physical, mental, and cognitive function. This decline renders them to rely on caregivers and causes difficulties, especially with demented elderly. For example, assistance with bathing does not adequately portray bathing a person who is resisting a bath, and helping with medications does not capture the struggles of medication administration (Reinhard et al., 2008; Sloane et al., 1995; Travis et al., 2000).

Filial piety is a significant cultural norm in Asia and can be seen in various families nowadays. Filial piety, or “xiao” is a traditional Confucian virtue in Chinese culture, referring to a family-centred cultural value that adjusts children’s attitudes and behaviours towards their parents to ensure parental well-being (Dong, 2016). Although it started as a Confucian virtue, it quickly became adapted into other religions, such as Islam and Christianity, highlighting the importance of “giving back” to family elders and amplifying filial piety across all generations (Tien, David & Alagappar, 2009). In Malaysia, it is common to see multiple generations living together under one roof and family elders being cared for by their married children (Ghazali et al., 2015). This in turn, leads the adult children to become informal caregivers for their elderly parents.

1.3 PROBLEM STATEMENT

Informal caregivers have complex and stressful responsibilities (Reinhard et al., 2008) as they are expected to care for their family members after acute case and long-term wise. However, there are still lacking in systems identifying informal caregivers needs, concerns, gaps, and barriers in Malaysia (Zubaidi et al., 2020). Caregiver burden must always be considered due to this nature. It has become increasingly prevalent as caregivers who often feel obligated by filial piety presents a challenge that needs to be addressed but the experience itself remains poorly understood especially in a rural area.

Therefore, there is a critical need to investigate and comprehend the factors, impacts and feelings of caregiving to develop strategies to alleviate caregiver burden and promote overall well-being for both, caregivers and care recipients.

1.4 RESEARCH QUESTIONS

The following research questions this research addressed are:

- a) What are the factors of caregiving?
- b) How does caregiving impact the caregiver's lives and relationships?
- c) What are the caregiver's feelings/ realization of long-term caregiving

1.5 RESEARCH OBJECTIVES

The objectives of the research are:

- a) To investigate the factors of caregiving
- b) To understand the impact of caregiving towards caregiver's lives and relationships
- c) To explore the caregiver's feelings/ realization of long-term caregiving

1.6 SIGNIFICANCE OF RESEARCH

The research benefits the caregiver, nursing research and can be used as evidence for nursing practice in the future.

1.6.1 Adult caregiver

The research assist caregivers in understanding the factors or motivation of caregiving, increased awareness in the effects of caregiving towards their health, social life, and relationship, and allowed the caregivers to work out a coping mechanism to deal with the effect. Other than that, this research also acted as a support system for the caregivers to realize that they are not alone in their experiences.

1.6.2 Contribution to nursing research

The research aids as a reference for future nursing research on adult caregivers' lived

experiences and its outcomes to their well-being. This research also contributes to further understanding caregiver burden and its effects.

1.6.3 Evidence for nursing practice

The research is used as evidence for a more holistic nursing practice and highlights the need for healthcare professionals to offer more support and guidance to caregivers.

1.7 DEFINITION OF TERMS

Definition of terms are discussed in table form as in Table 1. It is separated into operational definition and conceptual definition.

Table 1. Definition of terms

Terms	Operational definition	Conceptual definition
Activities of daily living (ADLs)	ADLs refer to basic daily living activities such as eating, bathing, and ambulating	Fundamental skills required to independently care for oneself, ie; eating bathing and mobility. ADL is used as an indicator of a person's functional status. Poor ability to perform ADLs results in dependence to caregivers (Edemekong et al., 2022).
Eating	Any instance where an individual takes in food through their mouth and swallows it, regardless of the amount or type of food.	Any instance where the caregiver assists or fully feeds the care recipient of any type of food either through mouth, or nasogastric tube.

Bathing	Washing oneself with soap or sponge bath; or in either a tub or shower, including the task	Fully or assist washing the care recipient in either a tub, sitting under a shower head using a
	of getting into or out of the tub or shower.	chair or commode, from wetting the body, to soaping, washing off the soap, and drying the body.
Ambulating	To walk or move about without any kind of assistance.	Moving the care recipient from one place to another by lifting and transporting, or assisting by holding arm and leading the way.
Informal caregiver	Unpaid family caregiver caring for their family members and/or elderly that needs assistance in Kampung Muara Tuang, Samarahan	Unpaid family members, friends, or neighbours who care for a person suffering from an acute or chronic medical condition and needs support to manage ADLs (Reinhard et al., 2008).
Adults	Adults aged 18 years and older	Caregivers within age range of 18 years to 59 years old.
Elderly	Older adults aged 60 and above with physical and/or cognitive impairment, need assistance or	Aged 60 or 65 years above (United Nation, 2019).

	dependent in performing ADLs	
Lived experience	Day-to-day responsibilities and feelings by the caregiver while caring for their care recipient	A depiction of a person's unique perception and decisions, as well as knowledge gained these experiences and choices (TalkingHealthTech, 2022).

1.8 SUMMARY

Malaysia is a multicultural nation and is not an exception to the moral obligation of filial piety. Children of a dependent elderly are expected to step up becoming a caregiver should anything happens, and females are almost always the main/ primary caregiver. Furthermore, caregivers are prone to caregiver burden due to their physically and mentally demanding responsibilities. This research helped to understand the motivating factors of why adult children become caregivers despite the caregiver burden.

CHAPTER 2 LITERATURE REVIEW

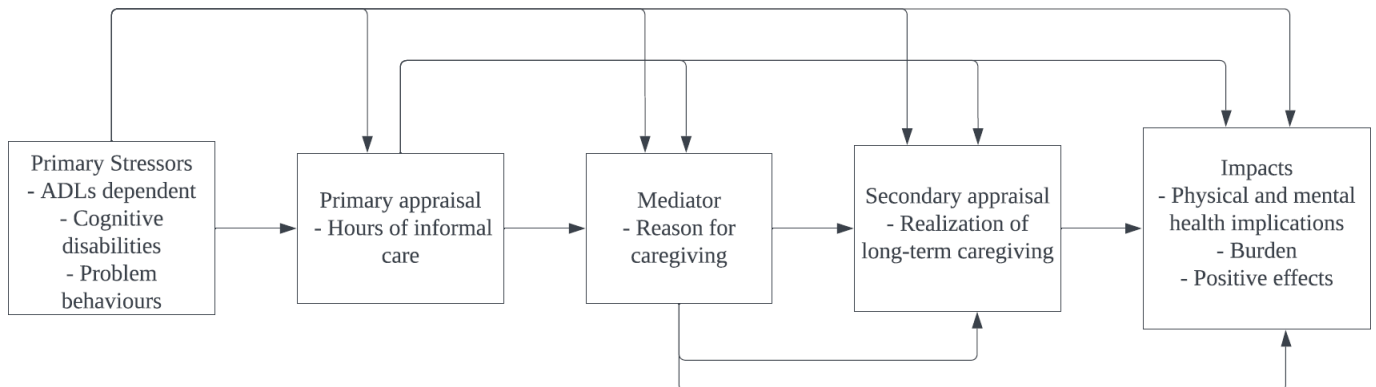
2.1 INTRODUCTION

This chapter presents the literature relevant to the area of research in relation to a conceptual framework adapted from Yates et al., 1999. The literature review critically explores and understands filial obligation, impacts of caregiving, and long-term caregiving. Several articles were selected for full-text screening of this review after being searched from databases: PubMed, Google Scholar, BMC Public Health, ScienceDirect and Elsevier using keywords such as “informal caregiver”, “filial piety” “family caregiver”, “filial piety”, “impacts of caregiving”, and “caregivers in Malaysia”.

2.2 CONCEPTUAL FRAMEWORK

Figure 1. Conceptual Framework.

Adapted Caregiving Stress Appraisal Model by Yates et al. (1999)



The conceptual framework is adapted from Yates et al. (1999) caregiving stress appraisal model (CSA). The framework explores the relationship between stressors and well-being, leading to the impacts of caregiving on the caregiver. According to the framework, the impacts of caregiving result from primary stressors, which are the difficulties experienced directly in caregiving. In this adapted CSA model, primary stressors are ADLs dependent, cognitive disabilities, and problem behaviours. Meanwhile, reasons for caregiving are the

mediator factors in the research.

This conceptual framework consists of five interrelated factors, which are (1) primary stressors, a direct cause of stress for the caregiver which are ADLs dependent, cognitive disabilities, and problem behaviours; (2) primary appraisal, which is the hours providing informal care; (3) mediator, in which it can alter or lessen the effects of caregiving to the caregiver. Next, (4) secondary appraisal, the realization of long-term caregiving by the caregiver, whether they will make changes to their lifestyles or decide to use social resources such as hiring a care nurse or formal caregiver for the elderly as such. Lastly, (5) impacts, which is the impact of caregiving on the caregiver in terms of physical and mental health implications, burden, and positive effects. Further literature review involving filial piety or obligation, the impact of caregiving, caregiver burden and long-term caregiving are discussed below.

2.3 FILIAL PIETY OR OBLIGATION

Filial piety, or obligation, or “xiao”, is a virtue that holds a central place in Confucian ethics; where it is said to be the root of a person’s character (Sin, 2019). Dong et al. (2016) also refers xiao as a family-centred cultural value which adjusts children's attitude and behaviour towards the parents to ensure parental well-being. The character “xiao”, consists of an upper component that represents “age” and a lower component representing “child” which means the child supports and succeeds the parents (Bedford & Yeh, 2019). The building blocks of filial piety originated from ancestor worship (Hsu, 1975, as cited in Bedford & Yeh, 2019). Confucius refined filial obligations in family, virtue, and social relations (Bi & D’Agostino, 2004). The refined filial piety became the foundation of education, guideline for moral conduct and as Chinese social structure (Hwang, 1987).

In current modern society, filial piety is not only practised in Chinese culture, but it has become a cultural norm in Asia. Gans & Silverstein (2006) found that filial piety norms

show an accelerating decline with age. However, in a study by Kong et al. (2021) where the respondents' age is divided into three groups; “18-35”, “36-59”, and “60 and above”, it was found that older adults are still caring for their elderly more than the young adults. It poses a concern about how the elderly still need to care for the elderly.

In Malaysia, Tan, Noew & Sarvarubini (2020) found four themes regarding Malaysian Chinese views on filial piety: reciprocity, respect, respect, inherited value, and transformed cultural practice. In the first theme, reciprocity, Tan et al. (2020) discovered that filial piety is a way to show gratitude or “give back” to the parents for their efforts in raising them. The second theme, respect, is more in line with respecting the elderly as aligned with Confucian teaching, emphasising respect towards parents and the elderly (Tan et al., 2020; see also Liu et al., 2000). Next, in simpler terms, the third theme of inherited value means the children inherit filial piety virtue from their parents. According to Tan et al. (2020), children learn filial piety through the examples of their parents or elders that might tie the practice to religion. While the final theme transformed cultural practice, filial piety has undergone changes from past generations to modern times. Tan et al. (2020) stated that the tradition of children living with their parents is increasingly becoming difficult to maintain due to societal changes such as employment and nuclear families.

This review on filial piety shows it is a possible factor or motivator to be caregiver. Although in Tan et al. (2020) research findings, the fourth theme, transformed cultural practice, shows that filial piety changes over time, allowing the researcher to assume there will be other factors for being a caregiver.

2.4 IMPACT OF CAREGIVING

Reinhard et al. (2008) define an informal caregiver as unpaid family members, friends or neighbours who care for a person suffering from an acute or chronic medical condition