THE EXPERIENCES OF CAREGIVERS FOR OLDER PERSONS AMONG THE CHINESE IN URBAN KUCHING, SARAWAK

Raymond Chung Chiun Han

Master of Environmental Management
(Development Planning)
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THE EXPERIENCES OF CAREGIVERS FOR OLDER PERSONS AMONG THE CHINESE IN URBAN KUCHING, SARAWAK

RAYMOND CHUNG CHIUN HAN

A dissertation submitted in partial fulfillment of the requirements for the degree of Master of Environmental Management (Development Planning)

Faculty of Social Sciences
UNIVERSITI MALAYSIA SARAWAK
2012
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This declaration is made on the 16th day of July 2012.

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To all caregivers out there,

for you are not alone.
ABSTRACT

In most parts of the world, people have in recent years been living longer lives. There are various reasons for this, including advancements in medical science and better living standards brought about by rising wealth and development of nations.

While this is invariably seen as a positive development, and life expectancy at birth is often used as a yardstick to measure a country’s level of development, it nevertheless also has a downside. As people grow older, many will also become frail especially in later years. They will require aged-care facilities and end-of-life care, which may be provided in their own homes or in special purpose-built facilities including retirement homes, nursing homes and hospices.

Some will require caregiving, which refers to the process in which one or more persons assist them to carry out activities of daily life (ADLs) such as getting out of bed, moving around the home, washing and changing, eating and so on. Sometimes, the assistance may extend to helping with activities such as shopping, financial transactions and similar miscellaneous errands.

A major stakeholder in caregiving for the elderly frail is a member of the family. This could be a spouse, children, children-in-law, sibling or some other closely related member of the care recipient’s family.
This study has the objective of examining the experiences of caregivers from the urban Chinese population of Kuching. Interviews were conducted with eight caregivers, each of whom played a major role in caring for a frail elderly member of their family. The study explored circumstances that caused them to become caregivers, the things they do for their care recipients as well as the relationship between caregivers and care recipients. The study also explored the views of the caregivers in terms of the support services required for them. The implications of their experiences of caregiving for policy and social supportive services for both caregivers and the elderly persons are discussed before concluding the study.
ACKNOWLEDGEMENT

First and foremost, I am thankful for the opportunity recently to have had a major responsibility for my octogenarian father’s welfare and health. The three years that he lived with me opened up to me the world of the informal caregiver for a frail, elderly family member. It also gave me (and hopefully him as well) unforgettable moments of tears, joy and satisfaction which I will forever treasure.

To the respondents who made this study possible, many thanks for making time to talk to me and for sharing with me your very private experiences with your loved ones, and for introducing me to the remarkable lives of caregivers.

I would also like to thank UNIMAS, the university’s Centre for Graduate Studies and the Faculty of Social Science for their support and understanding in allowing me much needed additional time to complete my Masters in Environment Management postgraduate course. Special thanks also go to the SLUSE Programme Coordinator (Development Planning), Dr Wong Swee Kiong for her motivation and encouragement.

Most of all, I am very grateful to my supervisor, Associate Professor Dr Ling How Kee of the Faculty of Social Science, for her guidance, for sharing with me her extensive knowledge of the subject matter and for her patience and perseverance in never giving up on me.
Together, all of you have contributed to the successful conclusion of this study which I believe will make a contribution, albeit a small one, to the improvement of the informal caregiver's welfare and the elevation of their stature in society.

Raymond Chung Chiun Han
Kuching
July 2012
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ABBREVIATIONS AND CLARIFICATIONS

The following abbreviations are used in this report.

ADLs    activities of daily lives
CG      caregiver
CR      care recipient
ELC     end of life care

• unless noted otherwise, the term 'caregiver' as used in this thesis refers to an informal, unpaid primary caregiver for a frail elderly family member

• where used generally, the pronoun 'she' includes people from both the male and female gender

the female pronouns 'she' and 'her' is predominantly used as anecdotal information suggests that more females than males are caregivers
CHAPTER 1
INTRODUCTION

1.0 Introduction

This chapter introduces the subject of caring for the elderly frail in our society, how ageing in humans is not only inevitable but also brings with it the process of a weakening of the physical body. Caregiving for the elderly is then defined and the various stakeholders and issues involved are identified. The chapter proceeds with presenting the problem statements central to the research and the study objectives, and outlines the research methods of the study. It ends with an overview of the dissertation.

1.1 Preamble

Frail elderly people who are no longer able to fully care for themselves would need to be assisted in carrying out activities in their daily lives (ADLs). This allows them to continue living a life that is as complete and satisfactory as possible. The assistance involved may vary greatly depending on the extent to which the elderly person (the “care recipient” or CR) can still perform tasks for herself. That which she is no longer able to do will be carried out for her, in part or in full, by a carer (the “caregiver” or CG).
This study is a qualitative and exploratory one which examines the issues related to the provision of care services for frail elderly people, specifically the work carried out by informal (and often unpaid) caregivers who do not belong to any established healthcare institution. It compiles the difficulties and problems faced by a caregiver in rendering assistance to a care recipient, bringing together the experiences of a selected group of Chinese caregivers of elderly persons in Kuching. Questions are asked of these caregivers on the burdens they face and how these can be reduced, thereby making their caregiving role more bearable. The ways and means by which the caregivers can be supported and assisted are finally summarised into a recommendation that can be used as a basis for the development of a formal caregiver support policy.

1.2 Growing Old and Frail

Growing old is one of the certainties in human life. We all age with the passage of time. The fortunate among us may experience ‘healthy ageing’ in which a person remains in relatively good health even in old age. Others are brought down by ailments and diseases, rendering them incapable of independently carrying out activities of daily life (ADLs) (Lechner, 2005). Independence is lost and the assistance of others, sometimes on a round-the-clock basis, becomes necessary. These frail, elderly people would rely on others for such assistance to move around, eat, get dressed, bathing, going to the toilet and other ADLs in order to allow them to continue living complete and satisfactory lives. The level of
assistance involved may vary greatly depending on the extent to which the elderly person (the ‘care recipient’ or CR) can still perform the tasks for herself. What she is no longer able to do, will be carried out for her in part or in full by a caregiver.

Notwithstanding that people may conscientiously make efforts to stay healthy including taking necessary measures to remain in good health as they age, it is inescapable that physiologically and biologically, the human body, organs and limbs weaken as one grows old. It is simply part of the process of ageing. Then, there are also those who might not have been suffering from any debilitating diseases, but who become incapacitated due to accidents and mishaps, including those from among the elderly. They too would need caregivers.

‘Old age’ in humans is a relative term and itself revolves with time. As an example, a male person born in 1960 in the United States had a life expectancy at birth of 67 years. Fifty years later, a male infant born in 2010 in the same country could expect to live till around 76 years old (Figure 2a, Life Tables for the United States Social Security). Therefore, while a man 60 years old would be considered ‘very old’ in 1960’s United States, a similar person today would be considered to be relatively young.

While the threshold age marking the start of old-age for a person varies from country to country, it is usually taken to mean those who are either above 60 or 65
years of age. Among the elderly population of today, there is sometimes further classification into the ‘young-old’ (those 65-74 years old), the ‘old-old’ (75-84) and the ‘oldest-old’ (85 and above). The actual figures used may be linked to the retirement age and similar legal definitions in the particular country, which usually also determines such matters as eligibility for pensions and other benefits given out to the elderly.

1.3 Caregiving of the Elderly: definitions and options

What is caregiving? As applied to the elderly, it can be described as a ‘set of activities useful and often necessary to daily life that an elderly person is not – or most often no longer – able to provide for herself’ (Stark, 2007)

Who is a caregiver? Baroness Jill Pitkeathley (former chief executive of UK Carers, an organisation devoted to the plight of caregivers), in her 1989 book ‘It’s my Duty, Isn’t it?’, defines caregiver as ‘someone whose life is in some way restricted by the need to be responsible for the care of someone who is mentally ill, mentally handicapped, physically disabled or whose health is impaired by sickness or old age.

When caregiving is required for a frail elderly member of the family, there are several options that are available:
a) the public sector, that is, places run by the government through their various agencies. These may range from basic facilities such as hospitals to more specialised institutions tailored for the elderly, including nursing homes and old-age homes. Often, the availability of these will depend on the development and wealth of the country or region. These usually cater only for those without homes/families or who are from the poorer segment of society. Eligibility criteria may apply, such as income means testing and availability of family care.

b) the private sector or the open market, such as care centres, nursing homes and hospices operated by business entities and health care providers. These are usually based on market demand, charge rates based on market conditions and offer greater choice and flexibility. Even though they are independent operators, they are subject to government regulations, guidelines and licensing.

c) non-government organisations (NGOs) including community groups, service organisations and religious bodies who operate care centres, homes for the elderly, hospices and the like. They often take in only the destitute and homeless. They are usually dependent on public donations and contributions and some may also receive grants from the government. The service provided may only be for members of the clan association and religion running the establishment.

d) care at home, which may involve one or more family members attending to the various needs of the elderly person. This is usually an informal and
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d) care at home, which may involve one or more family members attending to the various needs of the elderly person. This is usually an informal and
unpaid role for the caregiver(s). An external, non-family member, such as a nurse, healthcare worker or maid is sometimes engaged to look after the care recipient, but under the supervision and direction of the family caregiver, who will still be carrying the main responsibility for the overall wellbeing of the elderly person. In such instances, the caregiver could be children, grandchildren, nieces and nephews. A caregiver from within the family unit could also be someone from the same generation, such as a spouse, sibling, brother/sister-in-law or some other similar person related to the care recipient. In Asian societies, this practice is often seen as a cultural obligation as part of fulfilling one’s filial piety towards the older generation, especially parents.

The option finally selected by the family will depend on various factors, such as the level of care required, affordability and eligibility. Where specialised attention is required, the family home may no longer be an option. Financial means of the family often also determine where the care recipient will end up, as does the size of the family in regards to availability of someone to stay home and be the caregiver. In certain societies, the stigma associated with sending someone to an institution may rule out that option. The level and quality of care desired will also play a part, as families will often want only the best for the care recipient.
1.4 Problem Statement and Study Objectives

From the many varied issues relating to caring for the elderly frail, this study focuses on the experiences of the person who care for the elderly person. This person, the caregiver, has the major responsibility of either taking care of the elderly family member, or overseeing the care of this elderly person, and often both.

What are the issues that are encountered by this person? How did she end up being a caregiver, how has she fared in the task, and how does she see the caregiving role? These are questions to be explored followed by the difficulties they faced and how they can be assisted and supported in their caregiving role.

Specifically, who are these caregivers of the elderly and what type of lives do they live? What is the role that they perform, what are the things that they do for their care recipients? How does the caregiving responsibility impact on their own lives, and how can their caregiving role be made easier?

From these questions, the objectives of our study become clear:

1. to explore the experience of informal caregivers and capture their profiles
2. to determine how these caregivers can be supported and facilitated in their roles
This we will try to achieve through interviews with the respondents, each of whom has experienced caring for a frail, elderly family member.

1.5 Research Methods

This study adopts the qualitative approach. It is an exploratory study that strives to capture a comprehensive picture of the issues related to the provision of care services for frail elderly people, specifically the work carried out by informal, unpaid and often untrained family members who do not belong to any established healthcare institution. It explores the ‘travails’ faced by these caregivers while rendering assistance to their care recipients.

A total of eight respondents were selected to participate in one-to-one interviews. The researcher believes that this number of respondents is sufficient for a qualitative study of this nature. A 5-part semi-structured questionnaire is used as a guide for the interviews, consisting of both direct and open-ended questions.

While the general flow and structure of this questionnaire was followed as much as possible so as to ensure that the various issues were covered, the conversations themselves were intended to be free-flowing, informal and relaxed. This allowed the respondent to tell her story in a way comfortable and meaningful to her.