4-18-2017 12:00 AM

Personal Constructs in Dementia Caregiving: The Family Caregiving Experience of People Living with Dementia in Saudi Arabia

Eradah O. Hamad
The University of Western Ontario

Supervisor
Dr.Andrew Johnson
The University of Western Ontario Joint Supervisor
Dr. Jeffrey Holmes
The University of Western Ontario

Follow this and additional works at: https://ir.lib.uwo.ca/etd

Part of the Gerontology Commons

Recommended Citation

Abstract

As observed globally, family (informal and in-home) caregiving of older adults with Alzheimer's disease or other forms of dementia has become a critical issue in the Arab region, including Saudi Arabia. This doctoral research psychometrically and conceptually evaluates an Arabic version of the Montgomery Borgatta Caregiver Burden Scale for use as a measurement tool to assess family caregivers of older adults living at home with dementia in Saudi Arabia. Currently, there is no published literature that addresses family caregiving for individuals with dementia in Saudi Arabia. Through further examination of family caregiving narratives, this research maps the personal and social construing of the family caregiver role of older adults with dementia in Saudi Arabia.

This doctoral research is guided by the theoretical framework and philosophical understanding of personal construct theory and employs an integrated mixed methods approach to data collection, analysis, and interpretation of findings from 20 Saudi Arabian family caregivers. The research is presented in five chapters, including three individual manuscripts and introduction and conclusion chapters. The first manuscript introduces personal construct theory with its underlying philosophy, fundamental concepts, and methods of assessment as a potential constructivist research approach to examine the personal, familial, group, and cultural construct systems that shape the context of dementia care within and across cultures. The defined gap in the first manuscript led to a mixed methods study to examine the construction of Western-based existing measure of "caregiver burden." The second manuscript, therefore, examines the items of the Montgomery Borgatta Caregiver Burden Scale and the construct of caregiver burden using the repertory grid technique and laddering procedure—the two constructivist methods derived from personal construct

theory—to identify culturally sensitive items of the scale in the target cultural context of Saudi Arabia. Alongside the conceptual and psychometric evaluation of scale items, the third manuscript further examines family caregivers' daily narratives and personal and cultural constructs that shape their caregiver role.

This research contributes to the international literature of family gerontology and research on caregiver assessment. It elaborates the assessment methods of personal construct theory to expand alternatives for research methodologies of measurement evaluation and validation. The research also promotes the therapeutic approaches of personal construct theory and other practical implications for the development of support programs for family caregivers and recommends an integrated system for health and social services and a national strategy for dementia care in Saudi Arabia.

Keywords: Dementia, Alzheimer's Disease, family caregiving, mixed methods research, personal construct theory, Saudi Arabia

Co-Authorship Statement

I, <u>Eradah O. Hamad</u>, acknowledge that this doctoral dissertation consists of three complementary manuscripts that represent the collaborative work of an international and multidisciplinary team of researchers and co-authors. As described in each of the three manuscripts, the primary contributor is the first author (Eradah O. Hamad), who researched the topic, reviewed related literature, designed the studies, completed the ethics applications, collected, transcribed, analyzed, and translated the data, and drafted the first versions of the manuscripts. The secondary contributors to the manuscripts are the listed co-authors, <u>Dr. Ahamd N. AlHadi, Dr. Jeffery D. Holmes, Dr. Marie Y. Savundranayagam, Dr. Christopher J. Lee, Dr. Elizabeth Anne Kinsella, Dr. Paul F. Tremblay, and Dr. Andrew M. Johnson</u>, who supervised the research, considered the theoretical and methodological perspectives of the design, discussed the research findings, and provided editorial support in revising and crafting the manuscripts for publication.

Dedication

This doctoral dissertation is dedicated to the one who granted me every moment of her life,

as a river of unconditional love, from the time I was born until now; my mother,

Noor.

The shadow owes its birth to light.

Through this journey towards my dream,

You were the light, so I had the shadow,

You were the inspiration, so I had the will,

To you, I dedicate this work.

أُمّي " نور"

يدينُ الظلُّ بانعكاسِه للنُّور ،

في رحلتي نحو حُلُمي ،

كُنتِ أنتِ النُّور فكان انعكاسُ ظلِّي ،

وكُنتِ أنتِ الإلهام فكانتْ إرادتي ،

إليكِ أُهدي

رسالة الدكتوراة.

Acknowledgments

Over the past four and a half years, I have had the privilege of gaining the guidance and support of wonderful people along my academic journey. Those people contributed to and extended their invaluable assistance in the preparation and completion of this doctoral dissertation. To those people, no words can express how blessed and grateful I am to have had them by my side throughout the journey. I must express my utmost gratitude to them all, because without them, I would not be the researcher (and person) I am today.

First and foremost, I extend my sincere gratitude to my mentor and my role model, **my supervisor**, Dr. Andrew Johnson, whose humanity, brilliant ideas, provoking feedback, continuous encouragement, energetic motivation, and confidence in me as a researcher enabled my personal and professional growth throughout all aspects of this journey. Observing him supervising, working in research teams, teaching, and responding to me and to other graduate students' questions and concerns were great hands-on learning experiences for me as an emergent scholar.

Second, I extend my appreciation to all members of **my advisory committee**, Dr. Jeffery Holmes, Dr. Marie Savundranayagam, Dr. Christopher Lee, and Dr. Elizabeth Anne Kinsella, for their time, effort, and inspiration to support my work by providing me with insightful comments and feedback along the way. I would also like to extend my special thanks to the members of **my examining committee**, Dr. Marie Savundranayagam, Dr. Joseph Orange, Dr. Lorraine Davies, and Dr. Norah Keating for their time and interest in my work.

Third, I acknowledge the effort of the staff of the Graduate Program of Health and Rehabilitation Sciences at the University of Western Ontario for their ongoing facilitation for the preparation and completion of this work. I would also like to extend my appreciation to

the Faculty and staff of the Psychology Department at King Abdulaziz University for the help and support they provided throughout the process and completion of my doctoral research.

Lastly, I truly and deeply thank **my participants**—all the family caregivers who took part in this doctoral work, especially those who took the time and effort to meet me face to face to take part in this study despite the difficulties they face with their busy lives and caregiving duties. Their responses and shared experiences are incredibly valuable to my work and to informing decision-makers of potential improvements that can be taken into consideration for better quality of care and support services for people affected by dementia and their families in Saudi Arabia. I would also like to thank Dr. Ahmad AlHadi, Dr. Fahad AlWahabi, and the Saudi Alzheimer's disease Association for the help they provided with recruitment and local logistical support when needed. I would also like to acknowledge the support of Dr. Sultan Alamri for his interest in my doctoral work and his invaluable conversations on the development of my future research plans.

Funding Acknowledgments

Table of Contents

List of Tables

List of Figures

List of Appendices

List of Abbreviations

AD: Alzheimer's Disease

ADI: Alzheimer's Disease International

ADL: Activities of Daily Living

ASC: Alzheimer's Society of Canada

CFA: Confirmatory Factor Analysis

CFI: The Comparative Fit Index

EFA: Exploratory Factor Analysis

FCA: Family Caregiver Alliance

IADL: Instrumental Activites of Daily Living

ICA: Interpretive Content Analysis

KAU: King Abdulaziz University

MBCBS: Montgomery Borgatta Caregiver Burden Scale

OB: Objective Burden

QUAL: Qualitative

QUAN: Quantitative

SA: Saudi Arabia

SADA: Saudi Alzheimer's Disease Association

SB: Subjective Burden

PCP: Personal Construct Psychology

PCT: Personal Construct Theory

PhD: Doctor of philosophy

RB: Relationship Burden

RGT: Repertory Grid Technique

RMR: The Root Mean Square of the Residuals

RMSEA: The Root Mean Square Error of Approximation

SCS: Self-Characterization Sketch

SRMR: The Standard Root Mean Square of the Residuals

WHO: World Health Organization

Chapter 1

1.1 Overview

Family (informal and in-home) caregiving of older adults living with cognitive and physical impairments has become a pressing issue in the Middle East, including the 22 countries of the Arab world (Ward & Younis, 2013), due to increases in the size of the older population and concomitant increases in diseases associated with advancing age, such as Alzheimer's disease (AD) and other forms of dementia (Prince et al., 2015). Caring for an older parent or relative living with AD at home is a challenging task and in some cases is equivalent to a full time job (Duxbury, Higgins, & Schroeder, 2009) taken on in addition to other roles in the caregiver's life (e.g., full-time worker, mother/father, wife/husband, and sister/brother). The caregiving experience may have an adverse effect on the caregiver's social life, financial status, and physical and mental wellbeing (Brodaty & Donkin, 2009). Among other negative impacts, family caregivers may also suffer due to a lack of knowledge and skills and the absence of adequate support to deal with the person's cognitive decline and behavioural and psychological symptoms associated with AD (Gitlin, Kales, & Lyketsos, 2012). Research demonstrates the importance of the role of the family caregiver in the overall treatment outcomes of the person living with AD (Whitlatch, Feinberg, & Stevens, 1999). The family caregiver's quality of life and ability to manage disease progression, symptoms, and other issues surrounding the caregiving experience are important factors for the quality of life of the person with AD and may delay the person's deterioration or time of relocation to institutional long-term care alternatives (Richardson, Lee, Berg-Weger, & Grossberg, 2013).

Research on different dimensions of family caregiving of older adults with AD and comparison of family caregiver populations from diverse cultural backgrounds has been facilitated by the development of self-reported assessment measures (Feinberg, 2002). The majority of these measures have focused on assessing the construct of "caregiver burden" (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Further, measurement of caregiver assessment is mostly derived from the experience of family caregivers in Western populations. While these measures may demonstrate acceptable validity within the populations for which they were developed, they may not be entirely appropriate when applied to populations with fundamentally different social or cultural norms. Several attempts have been made to re-validate some of the measures that are used in the Western literature, such as the Zarit Burden Interview (ZBI; Chou, Chu, Tseng, & Lu, 2003; Whalen & Buchholz, 2009), to assess caregivers from Eastern cultures, such as Asian populations (e.g., Chan, Lam, & Chiu, 2005; Lai, 2007; Seng et al., 2010). Although some of these measures have been shown to have good reliability and validity, the methodology used in these studies is primarily quantitative with a focus on literal translation and psychometric evaluation of the overall construct of burden (technical equivalence), regardless of the appropriateness of the scale items (conceptual equivalence). Thus, there is substantial need to apply qualitative research methods to the quantification and validation of measurement tools in the target cultures (Cheung, van de Vijver, & Leong, 2011). Qualitative methods, such as cognitive interviews and ethnographic observations, can also be used to refine the construct of caregiver burden as a construct in the target population.

1.2   Rationale

For older adults living with AD, cognitive deficits, related behavioural and psychological symptoms, physical disability, and the absence of a family

caregiver can all play a crucial role in maintaining health and quality of life. To provide appropriate support for family caregivers during their journey of care, their needs require consistent and accurate assessment. Currently, there are no validated measures to assess the experience of family caregivers caring for their relatives with AD and other forms of dementia in Saudi Arabia (SA), which is one of the largest states in the Arab region (Arabic-speaking countries) and the Islamic World (where Islam is the main religion). A translated and culturally adapted measure for assessing family caregivers in this context is required.

One of the most common assessment tools currently used in a Western context is the Montgomery Borgatta Caregiver Burden Scale (MBCBS; Montgomery, Borgatta, & Borgatta, 2000). A modified version of the MBCBS (Savundranayagam, Montgomery, & Kosloski, 2011) is used in the present research to assess the various aspects that might have changed in a caregiver's life due to his or her caregiving role and responsibilities. The scale measures three burden scores: *Objective Burden* (OB, e.g., disruption of a caregiver's life due to caregiving tasks), *Relationship Burden* (RB, e.g., relationships between caregiver and care receiver based on the demands of caregiving responsibilities), and *Stress Burden* (SB, e.g., emotional impact of caregiving). Due to the lack of published literature on the impact of family caregiving of older adults with AD and other forms of dementia in SA, the theoretical framework of personal construct theory (PCT; Kelly, 1955) is used to guide the research towards an in-depth understanding of the individual experience of caregiving in the SA context. PCT is suitable for examining the various aspects, anticipations, and expectations of family caregiving due to its emphasis on personal and group construal of a given experience (Hamad & Lee, 2013). More detail about PCT is provided in chapter two. An integrated mixed methods approach combining quantitative and qualitative methods to validate a quantitative measurement is also used to translate linguistically and culturally adapt an Arabic version of the MBCBS. The

constructive perspective of PCT and integrated collection of both types of data allow for better examination of the personal and social construction of scale items and caregiving narratives in addition to the psychometric evaluation of the construct of caregiver burden.

1.3   Key Issues in Family Caregiving for Dementia

According to the 2015 Alzheimer's Disease International (ADI) report, dementia is rapidly becoming a global crisis for the 21st century (Prince et al., 2015). By 2050, decreasing fertility rates and increasing life expectancy will create a situation in which there will be more older adults aged 65 and over than children under the age of 5. The number of older adults is expected to increase from an estimated 524 million (8% of the world's population) in 2010 to nearly 1.5 billion (16% of the world's population) in 2050, with most increases occurring in developing countries (National Institutes of Health [NIH], 2011). In North Africa and the Middle East, for instance, there are 31.11 million people over the age of 60 (ADI, 2009). As a result, cases of age-related neurocognitive diseases, such as AD (the most common type of dementia) and other types of dementia (e.g., vascular dementia, dementia with Lewy bodies, and frontotemporal dementia) have increased globally (Prince et al., 2015). In the following sections, dementia care by family caregivers is discussed from a global perspective, comparing experiences within the North American context (with a focus on Canada) and the Middle Eastern context (with a focus on SA). The discussion is divided into three key issues: prevalence of dementia among an older population, construction of family caregiving, and family caregiver assessment.

1.3.1   Prevalence of Dementia Within an Older Population

Approximately 46.8 million people globally are living with dementia (Prince et al., 2015). In Canada, it is estimated that there are more than 564,000 older adults

living with dementia in 2016. This number is expected to increase to 937,000 by 2031(Alzheimer's Society of Canada [ASC], 2016). In 2010, 1.15 million people were estimated to be living with dementia in North Africa and the Middle East, and it is expected that this number will increase to 2.59 million by 2030 (Prince & Jackson, 2009). Older adults with AD dementia may show severe cognitive impairment that interferes with independence on performing functional activities of daily living. The cognitive impairment can include one or more cognitive domains, such as memory, and visuospatial and language impairments (Albert et al, 2011). For spouses and adult children, caring for an older relative has become a frequent occurrence. Recently, it was estimated that over 4 million family caregivers in Canada provide approximately 80% of services to community-dwelling older persons (Canadian Caregiver Coalition, 2008). These unpaid services are often provided to older adults with health limitations, particularly AD, and this may create social and financial burdens that affect their physical and emotional health. However, research on the international prevalence of this caregiving phenomenon is limited. For example, in the Middle East, only about 10% of dementia cases are identified due to the small number of available specialists (e.g., neurologists and geriatricians) and low societal awareness of AD (Prince & Jackson, 2009). In SA, local estimates suggest that dementia affects over 50,000 older adults, many of whom depend on family caregivers. Therefore, caring for older adults with dementia has become a major concern to families, physicians, and the relevant authorities in SA (Al-Khateeb, 2013). Moreover, the government of SA has developed a new reform plan called *Saudi Arabia's Vision 2030* ("Vision 2030," 2016) and part of this plan is to transform the health care sector through 18 initiatives to improve the quality, effectiveness, and delivery of health care services. With the expected increase in the number of older adults affected by dementia in SA, it is assumed that this population and their families should be provided with appropriate options for care. These plans

would integrate the efforts of health and social care and develop targeted support programs for this population to ensure that their needs are assessed and met accordingly.

1.3.2   Construction of Family Caregiving

Globally, most older adults live in the community; therefore, family members (husbands, wives, daughters, daughters-in-law, sons, sons-in-law, and other family members) are the primary sources of support and care (Feinberg, 2002). In the past, caring for an older relative within the family was the norm (Kosberg, 1992; Szinovacz & Davey, 2008), but with the high prevalence of dementia within the aging population, older adults now need more care than before, and for longer periods of time (Kalaria et al., 2008; Muangpaisan, Hori, & Brayne, 2009). The capacity of the family to deal with the challenges of prolonged and intensive care is remarkable, but many families have limited resources (and ability) to provide care, especially as the cognitive and physical disabilities of the individual they care for become severe. Even when relocation of the older relative occurs, families continue to be involved in caregiving (Dunkin & Anderson-Hanley, 1998). In the later stages of disease, older adults with dementia are sometimes unable to communicate verbally, leaving family members to make all related care and life decisions.

Although family caregivers play a central role in the management of disease symptoms and individual daily activities, caregiving is a multidimensional process that requires varied tasks that may conflict with the different roles that a caregiver plays in his or her daily life (Teel & Press, 1999; Zarit & Zarit, 2007), and can even be viewed as an unexpected career (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). However, the impact of family caregiving can vary widely from one family to another, and from culture to culture, depending on individual differences in resources and ability, as well as social and cultural constructs

related to the experience of caregiving. Previous research has found that when caregivers provide care for their older relatives, the experience of caregiving may have negative consequences. Negative outcomes of caregiving have been well documented in the Western literature (e.g., Montgomery, Rowe, & Kosloski, 2007; Zarit, 1985; Zarit & Femia, 2008; Zarit & Zarit, 2007) and in some Middle Eastern literature (e.g., Boggatz & Dassen, 2005; Halabi & Zafar, 2010; Se´ouda et al., 2007; Sinunu, Yount, & El Afify, 2009; Ward & Younis, 2013). The negative effects on the quality of life of the caregiver can threaten quality of life for the care receiver. Researchers have reported an increased rate of "caregiver burden" (Grad & Sainsbury, 1963) among those who care for older relatives. Feinberg (2002) argues that "burden" is a broad construct that encompasses various (if not all) dimensions of caregiving, and as a term, it is less commonly used in practice than in research. Burden may include (but is not limited to) various types of stressors (e.g., physical morbidity, emotional wellbeing, and social and financial difficulties), which makes it difficult to determine the exact factors that predict burden (Dunkin & Anderson-Hanley, 1998). Feinberg (2002) further argues, as a construct, burden may not be culturally appropriate, as it may negatively affect caregivers from diverse populations. The use of the word "burden" may carry negative connotations about the role of the family caregiver. For example, in many Middle Eastern countries, caring for an older parent or relative is socially constructed as a source of pleasure, enrichment, and a way of showing appreciation for their parents' role as caregivers in the past (called "bir" in Arabic). Appreciation of parents is not only encouraged in Middle Eastern and Arab societies, but also in the holy book of Islam (Qur'an), the most common religion in this region (Osman, Shukri, & Othman, 2011). Although the use of the term burden may be controversial in some cultures, this term is used in Western caregiving literature and in Middle Eastern research. If caregiver burden is not adequately defined and assessed, the negative consequences associated with

caregiving can have direct and indirect costs for the community, economy, and health care system–both for the individual with dementia, and his or her family.

1.3.3   Family Caregiver Assessment

Assessing caregiver burden is crucial for implementing appropriate caregiver support, and so researchers in developed (industrialized) countries, such as Canada, have developed many self-report assessments. This research has also led to refinements to the construct of caregiver burden (Chou et al., 2003; Feinberg, 2002; Vitaliano, Young, & Russo, 1991; Whalen & Buchholz, 2009). These refinements include identification of the components and dimensionality of caregiver burden. In contrast, in Middle Eastern countries, there is a lack of knowledge about the effect of family caregiving, less attention has been paid to the construct of caregiver burden, and there is lack of dementia screening tools and caregiver assessment measures. One way to advance caregiver assessment is to translate existing validated Western scales. Culturally sensitive assessment measures are, however, essential for caregiving research, as well as for the creation of required national strategies, care options, and appropriate policies in the target society or culture. Such measures would need to take into consideration the definition of caregiving-related constructs used in creating the measure, and would also need to consider related contextual factors (e.g., age, gender, and income) from the perspective of caregiving experts and family caregivers.

1.4   Research Objectives

The two primary objectives of this research are:

1- To explore the feasibility of using an integrated mixed methods approach to measurement validation and personal construct methods for elucidating our

understanding of cross-cultural variations or invariance of different versions of the scale.

2- To assess the experience of SA family caregivers of older adults with AD and other forms of dementia to contribute to the development of appropriate intervention plans and national support strategies.

Secondary objectives are:

1- To contribute to the literature by enhancing the process of detecting and minimizing sources of measurement error due to difficulty in comprehending scale items (questions) and to adequately address the needs and expectations of the target population.

2- To facilitate comparison between SA family caregivers and caregivers from other cultural contexts (e.g., Canadian caregivers) using the SA cognitive map (personal and group templates) of caregiving and different versions of the MBCBS.

1.5 Research Questions

The aim of this study is to answer the following questions:

1- Is a translation version of the MBCBS applicable to the target population in SA, culturally conceptually, and linguistically?

2- Is the construct of caregiver burden (as measured by the MBCBS) culturally appropriate for measuring the impact experienced by SA family caregivers of older adults with AD and other forms of dementia? Could identified similarities or differences between SA caregivers' personal and cultural construct systems and those constructs used by the original culture of the developed scale (North American) lead to a modified version of the MBCBS (e.g., adding, deleting, or modifying items)?

3- How do personal and social constructs elicited from the narratives of SA family caregivers help us construct the role of family caregiver in the SA context? How can this construction be used to implement appropriate support for family caregivers of older adults with dementia in SA?

1.6 The Role of the Researcher: A Reflection on Personal Construct Theory and Family Caregiving

After a year of teaching and contributing to the Psychology Department as a teaching assistant at King Abdulaziz University (KAU), Jeddah, SA, I was awarded a full scholarship to continue my higher education (Masters and PhD) in a Western country. I chose Canada because of its multicultural values and its structured and diverse education system. My choice of Canada was a part of my epistemological understanding of the world, in which there is a reality out there, but different people construe different views and attitudes based on their own past and present experiences. People usually express these realities using their own language (e.g., verbal expressions or written phrases), which is an important component of the individual's experiences and culture. What's more, these individual constructions can be changed or modified over time as the person engages in new experiences, "i.e., living in SA where most people are the same (group oriented society) and moving to Canada, where individuals are different (individual-oriented society)."

I came to Canada with an interest in psychological measurement, focused primarily on how to comprehensively assess the characteristics that make a person different or similar to others with a view to providing better measurement and implementing appropriate support interventions for the target population. At that time, I only knew how to assess personal experiences through the use of structured psychological tests, "i.e., quantitative methods and statistical

analyses." My perspective of psychological measurement shifted when I read about the cognitive personality theory; PCT (Kelly, 1955) and its constructivist assessment methods. More particularly, I learned of repertory grid technique (RGT; also called the role construct repertory grid) as a novel approach for conversational and semi-structured testing of mental construing, where researchers can elicit test items from test respondents (Boeree, 2006). I appreciated the non-traditional sense of RGT as a research method for self-discovery; more specifically, its flexibility in working with both words (constructs) and numbers (ratings of personal constructs). Further, RGT can be a rich source of qualitative (interpretive) data that can be explored collaboratively with the respondents (Björklund, 2008). All previous reasons contributed to my personal growth as a researcher and methodologist during my doctoral journey.

Since the 1950s, RGT has become the most well-known element of Kelly's theory (Fransella, Bell, & Bannister, 2003) and has most often been used as an objective instrument to gather quantitative data about respondents. I contend that this way of using RGT loses the most important components of its theoretical basis. Kelly's research approach is one of the many psychotherapeutic constructivist approaches that share the assertion that human knowledge and experience entail the proactive participation of the individual (Mahoney & Lyddon, 1988). However, not all constructivists share the same view of epistemology (Domenici, 2008). Neimeyer (1993) writes, "constructivist psychotherapy is better viewed as a 'fuzzy set' with indistinct boundaries, whose members manifest considerable diversity and even occasional contradiction" (p.224).

My confusion in the past concerned the ontological position of Kelly's PCT: is it realist, relativist, or subjectivist? Domenici (2008) states that Kelly's approach was the first among several approaches to espouse a realist ontological position on the nature of knowledge, but with a constructivist epistemological view. That

is, reality exists, but we can only know it through our construction of it. I believe that Kelly approaches the interpretive view of the world rather than limited realism, as some researchers (e.g., Stevens, 1998) have proposed. Furthermore, in their *hermeneutic constructivist approach*, Chiari and Nuzzo (2000,1996) have identified similarities between their research perspective and Kelly's PCT. They argue that the philosophical traditions of hermeneutics and phenomenology have permeated PCT and social constructivist literature for at least the past 20 years. The hermeneutic constructivist nature of PCT opened a new horizon for my doctoral research and my belief in the importance of the balance between the ideographic and descriptive approaches to researching health-related phenomena, including family caregiving of older adults with AD. My journey towards my doctoral research started from this point of view.

In SA, where I originally come from, caring for an older adult (e.g., a parent or a grandparent) is often considered the social duty of family members, mostly adult children (e.g., honouring one's parents). Thus, placing a parent with dementia in a special care facility can be viewed as a source of offense to one's parent (e.g., dishounouring one's parents) and may cause deep feelings of sin, immorality, and social stigma. These familial and social norms, which are often rooted in religious teachings and familial norms of reciprocity (Abdelmoneium & Alharahsheh, 2016), taught in school and confirmed in society, have led to a paucity of residential long-term care facilities, such as nursing homes, elder day care centres, hospices, and palliative care centres in SA and other Arab and Islamic countries. In fact, there are only 12 eldercare homes (i.e., non-medical housing for older adults with no available family member support) in all of SA, and there is no formal (i.e., governmental) long-term care system. Instead, tertiary hospitals equipped with sophisticated modalities of care provide institutional care. These institutions are generally thought to be equipped to serve older adults with chronic illnesses and their families (Al-Shahri, 2009). Early in

my doctoral research, I learned that dementia is not an inevitable component of aging, and dementia care requires intensive effort, disease-based knowledge, and skill-based training. Thus family caregivers may suffer in silence and stumble between their personal construal of care, and a lack of formal support for education and alternative options for care. Since we know little about dementia care within the home in SA, any existing measures used in the assessment of the caregiving experience are unlikely to reflect the world in which these caregivers live. Therefore, PCT with its constructivist methods, is a fruitful framework to gain a better understanding of the dimensions of an existing measure by hearing from caregivers themselves using their own personal and shared constructs to describe their experiences.

1.7   Presentation of Research

This doctoral research is undertaken in response to a need for valid and culturally sensitive assessment measures to examine the multidimensional stressors associated with the experience of family caregiving of older adults with AD and for personal and cultural considerations in interventions and training practices to support and meet the needs of family caregivers. This research contributes to the international literature of family gerontology with an emphasis on reconstruction of an existing measure of the caregiver burden construct in the SA cultural context. This thesis is formatted as three related manuscripts, presented in chapters two, three, and four, bookended by introduction and conclusion chapters. The three manuscripts are varied in their orientation and content, encompassing one theoretical paper and two methodological and empirical papers, as part of a mixed methods research study.

In the present chapter, I addressed key issues surrounding dementia care by family caregivers, and explain the construct of caregiver burden within the current caregiving literature. I also set out a rationale, objectives, and the three main

questions for the research. At the end of the chapter, I reflected on my cultural assumptions and social construing of family caregiving, as a member of the SA cultural context. I also reflected on my decision to conduct this research through the lens of PCT, as this paints a picture of who I am as a researcher and methodologist, and describes the place from which I interpreted the findings of the mixed methods study research described herein.

Chapter two is the first of three integrated manuscripts, entitled *Assessment of caregiving constructs: Toward a personal, familial, group, and cultural construction of dementia care through the eyes of personal construct psychology.* This manuscript is intended to contribute to a conceptualization of family caregiving construct systems of older adults with AD. In this manuscript, we introduce PCT, its fundamental concepts and methods of assessment as a potential approach to examine personal and cultural constructs associated with the family caregiving experience, contributing to the conceptualization of the family caregiver role in the field of family and psychosocial gerontology across cultures. Further, the manuscript suggests alternative approaches for *reconstruing* caregiving-related constructs at the individual and group level, from the perspectives of health professionals, researchers, and family caregivers. The theoretical perspective, and the conceptual and methodological assumptions within this manuscript inform the design, data collection, data analysis, and discussion of the research in the subsequent two manuscripts (chapters three and four).

Chapter three presents the second of three integrated manuscripts, entitled *Reconstruction of a caregiver burden scale: Exploratory and content analyses to identify culturally sensitive items in Saudi Arabia,* and presents the core aspects of the mixed methods design of this dissertation. It describes the theoretical framework, methodological decisions, and methods of PCT within the mixed

methods design of the study. It also describes details of the procedures used in conducting this research, including: participant recruitment, data collection, data analysis, and discussion of findings.

Chapter four, entitled *"If he was not my father, I wouldn't do it": The confounding role of family caregivers for older adults with dementia in Saudi Arabia*, documents the experience of SA family caregivers and works in tandem with chapter three. It presents the second part of the mixed methods research study, wherein narratives of family caregiving of older adults with AD in SA were elicited and examined in depth. The content of this manuscript helps to articulate the unique constructs of family caregivers in SA. It also includes practical implications for strategies that enhance the daily tasks of this emergent role.

Finally, chapter five discusses emerging insights from this research and implications for family gerontology and presents an overall conclusion for this dissertation. A proposal for a future research agenda is also presented in this final chapter.

1.8   References

Abdelmoneium, A. O., & Alharahsheh, S. T. (2016). Family home caregivers for old persons in the Arab region: Perceived challenges and policy implications. *Open Journal of Social Sciences*, *4*(1), 151–164. http://doi.org/10.4236/jss.2016.41019

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *The Journal of American Medical Association*, *311*(10), 1052. http://doi.org/10.1001/jama.2014.304

Albert, M. S., DeKosky, S. T., Dickson, D., Dubois, B., Feldman, H. H., Fox, N. C., … Phelps, C. H. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7*(3), 270–279. http://doi.org/10.1016/j.jalz.2011.03.008

Al-Khateeb, S. (2013, February 23). Alzheimer's causing stress on families of patients. *Arab News*. Retrieved from http://www.arabnews.com/alzheimer's-causing-stress-families-patients

Al-Shahri, M. Z. (2009). Regional report from Saudi Arabia. Stand-alone palliative care facilities: A cultural viewpoint. *International Association for Hospice & Palliative Care*, *10*(5).

Alzheimer's Disease International. (2009). *World Alzheimer Report 2009*. Retrieved from https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf

Alzheimer's Society of Canada. (2016). *Prevalence and monetary costs of dementia in Canada: Population health expert panel*. Retrieved fromhttp://www.alzheimer.ca/~/media/Files/national/Statistics/Prevalenceand

CostsofDementia_EN.pdf

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career.* Academic Press.

Björklund, L. (2008). The repertory grid technique: Making tacit knowledge explicit: Assessing creative work and problem solving skills. In H. Middleton (Ed.), *Researching technology education: Methods and techniques* (pp. 46–69). Rotterdam: Sense Publishers.

Boeree, C. G. (2006). *Personality Theories: George Kelly (1905-1967).* Retrieved November 22, 2015, from http://webspace.ship.edu/cgboer/kelly.html

Boggatz, T., & Dassen, T. (2005). Ageing, care dependency, and care for older people in Egypt: A review of the literature. *Jornal of Clinical Nursing*, *14*(8B), 56–63.

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228.

Canadian Caregiver Coalition. (2008). *A framework for a Canadian caregiver strategy.* Retrieved from http://www.ccc-ccan.ca/media.php?mid=229

Chan, T. S. F., Lam, L. C. W., & Chiu, H. F. K. (2005). Validation of the Chinese version of the Zarit Burden Interview. *Hong Kong Journal of Psychiatry*, *15*, 9–13.

Cheung, F. M., van de Vijver, F. J. R., & Leong, F. T. L. (2011). Toward a new approach to the study of personality in culture. *The American Psychologist*, *66*(7), 593–603. http://doi.org/10.1037/a0022389

Chiari, G. & Nuzzo, M. L. (2000). Hermeneutics and constructivist psychotherapy: The psychotherapeutic process in a hermeneutic constructivist framework. In J. W. Scheer (Ed.), *The person in society: Challenges to a constructivist theory* (pp. 90–99). Giessen: Psychosozial

Verlag.

Chiari, G., & Nuzzo, M. L. (1996). Psychological constructivisms: A metatheoretical differentiation. *Journal of Constructivist Psychology*, *9*(3), 163–184. http://doi.org/10.1080/10720539608404663

Chou, K. R., Chu, H., Tseng, C. L., & Lu, R. B. (2003). The Measurement of caregiver burden. *Journal of Medical Sciences*, *23*(2), 73–82. Retrieved from http://192.192.91.101/fdarticlee/old/2302073.pdf

Domenici, D. J. (2008). Implications of hermeneutic constructivism for personal construct theory: Imaginally construing the nonhuman world. *Journal of Constructivist Psychology*, *21*(1), 25–42.http://doi.org/10.1080/10720530701503868

Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. *Neurology*, *51*(1, S1), S53–S60. http://doi.org/10.1212/WNL.51.1_Suppl_1.S53

Duxbury, L., Higgins, C., & Schroeder, B. (2009). *Balancing paid work and caregiving responsibilities: A closer look at family caregivers in Canada*. Canadian Policy Research Networks. Retrieved from http://www.cprn.org/documents/51061_EN.pdf

Feinberg, L. F. (2002). *The state of the art: Caregiver assessment in practice settings.* San Francisco, CA: Family Caregiver Alliance. Retrieved from http://www.rosalynncarter.org/UserFiles/Caregiver Assessment 2002 FCA.pdf

Fransella, F., Bell, R., & Bannister, D. (2004). *A manual for repertory grid Technique* (2nd ed.). Chichester: John Wiley & Sons.

Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic

management of behavioral symptoms in dementia. *The Journal of American Medical Association*, *308*, 2020–9. http://doi.org/10.1001/jama.2012.36918

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet*, *281*(7280), 544–547. http://doi.org/10.1016/S0140-6736(63)91339-4

Halabi, A. K., & Zafar, J. M. (2010). Care of the elderly in United Arab Emirates. *International Journal of Geriatric Psychiatry*, *25*(9), 925–927. http://doi.org/10.1002/gps.2600

Hamad, E., & Lee, C. (2013). A Peronal construct approch to discovering the transition experience of studying abroad. *Personal Construct Theory & Practice*, *10*, 15–27. Retrieved from http://www.pcp-net.org/journal/pctp13/hamad13.html

Kalaria, R. N., Maestre, G. E., Arizaga, R., Friedland, R. P., Galasko, D., Hall, K., … Antuono, P. (2008). Alzheimer's disease and vascular dementia in developing countries: Prevalence, management, and risk factors. *The Lancet Neurology*, *7*(9), 812–826. http://doi.org/10.1016/S1474-4422(08)70169-8

Kelly, G. A. (1955). *The psychology of personal constructs*. New York: Norton.

Kosberg, J. I. (Eds.). (1992). *Family care of the elderly: Social and cultural changes*. California: Sage Publications.

Lai, D. W. L. (2007). Validation of the Zarit Burden Interview for Chinese Canadian caregivers. *Social Work Research*, *31*(1), 45–53. http://doi.org/10.1093/swr/31.1.45

Mahoney, M. J., & Lyddon, W. J. (1988). Recent developments in cognitive approaches to counseling and psychotherapy. *The Counseling Psychologist*, *16*(2), 190–234. http://doi.org/10.1177/0011000088162001

Montgomery, R. J. V., Borgatta, E. F., & Borgatta, M. L. (2000). Societal and

family change in the burden of care. In W. T. Liu & H. Kendig (Eds.), *Who should care for the elderly? An East-West value divide* (pp. 27–54). River Edge, NJ: World Scientific Publishing.

Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), *The handbook of gerontology: Evidence-based approaches to theory, practice, and policy* (pp. 426–454). Indianapolis, IN: John Wiley & Sons.

Muangpaisan, W., Hori, H., & Brayne, C. (2009). Systematic review of the prevalence and incidence of Parkinson' s disease in Asia. *Journal of Epidemiology*, *19*(6), 281–293. http://doi.org/10.2188/jea.JE20081034

National Institutes of Health. (2011). *Global health and aging*. Retrieved from http://www.nia.nih.gov/sites/default/files/global_health_and_aging.pdf

Neimeyer, R. A. (1993). An appraisal of constructivist psychotherapies. *Journal of Consulting and Clinical Psychology*, *61*(2), 221–34.

Osman, B. A., Shukri, A. S. M., & Othman, N. (2011). Filial piety in Confucianism and Islam: A comparative literary analysis of Qur'an, Hadith, and four Chinses classics. *Islam & Civilisational Renewal*, *3*(1), 133.

Prince, M., & Jackson, J. (2009). *The global prevalence of dementia*. London: Alzheimer's Disease International. Retrieved from http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf

Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015: The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013).

Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Reports*, *15*(7), 367. http://doi.org/10.1007/s11920-013-0367-2

Savundranayagam, M. Y., Montgomery, R. J. V., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist*, *51*(3), 321–331.

Se´ouda, J., Nehme, C., Atallah, R., Zablit, C., Ye´re´tzian, J., Le´vesque, L., … Ducharme, F. (2007). The health of family caregivers of older impaired persons in Lebanon: An interview survey. *International Journal of Nursing Studies*, *44*, 259–272. http://doi.org/10.1016/j.ijnurstu.2005.11.034

Seng, B. K., Luo, N., Ng, W. Y., Lim, J., Chionh, H. L., Goh, J., & Yap, P. (2010). Validity and reliability of the Zarit Burden Interview in assessing caregiving. *Annals of Academy of Medicine*, *39*(10), 758–763.

Sinunu, M., Yount, K. M., & El Afify, N. A. (2009). Informal and formal long-term care for frail older adults in Cairo, Egypt: Family caregiving decisions in a context of social change. *Journal of Cross-Cultural Gerontology*, (24), 63–76.

Stevens, C. D. (1998). Realism and Kelly's pragmatic constructivism. *Journal of Constructivist Psychology*, *11*(4), 283–308. http://doi.org/10.1080/10720539808405226

Szinovacz, M. E., & Davey, A. (Eds.). (2008). *Caregiving contexts: Cultural, familial, and societal implications*. New York: Springer Publishing.

Teel, C. S., & Press, A. N. (1999). Fatigue among elders in caregiving and noncaregiving roles. *Western Journal of Nursing Research*, *21*(4), 498-514–20.

Vision 2030. (2016). Retrieved from http://vision2030.gov.sa/en

Vitaliano, P. P., Young, H. M., & Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia. *Gerontologist, 31*(1), 67–75.

Ward, W. B., & Younis, M. Z. (2013). *Steps toward a planning framework for elder care in the Arab world. Springer briefs in aging.* Springer Science & Business Media, New York. http://doi.org/http://dx.doi.org/10.1007/978-1-4614-5978-1

Whalen, K. J., & Buchholz, S. W. (2009). The reliability, validity and feasibility of tools used to screen for caregiver burden: A systematic review. *JBI Library of Systematic Reviews*, *7*(32), 1373–1430.

Whitlatch, C. J., Feinberg, L. F., & Stevens, E. J. (1999). Predictors of institutionalization for persons with alzheimer's disease and the impact on family caregivers. *Journal of Mental Health and Aging*, *5*(3), 275–288.

Zarit, S. H. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. NY: New York University Press.

Zarit, S. H., & Femia, E. E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging & Mental Health*, *12*(1), 5–13. http://doi.org/10.1080/13607860701616317

Zarit, S. H., & Zarit, J. M. (2007). *Mental disorders in older adults: Fundamentals of assessment and treatment* (2nd ed.). New York: Guilford Press.

Chapter 2

2.1   The Family Caregiving Narratives

"… it is a full-time job beside my job. You know … it is burden but … it

is love… she is my mother… it is acceptance of God's will … it is my

responsibility to do it … but … I know… it needs me to keep a very

strict time management schedule, especially as a wife and a mother …"

This is how Nadia described her experience as a caregiver for her 90-year old mother who was diagnosed with AD four years ago. Nadia is a 50-year old high-school teacher, wife, and mother of three children. She currently lives with her mother (and her three children) due to her mother's health status. Nadia often feels exhausted and sometimes gets frustrated, because she does not know how to organise and manage the tasks of her role as caregiver alongside the other roles in her life. For Nadia, caregiving duties add responsibilities and additional load to her personal life. Her mother's case has been transferred from one physician to another, and Nadia finally feels that she can trust the information received from her mother's primary care physician who can fully explain to her what is going on with her mother. She has not discovered any community resources to support her role as a caregiver, and if there are such resources she has no time to join any activities outside of the home. Although she is the middle child and has six siblings who offer their help from time to time, Nadia feels enriched and most comfortable when she is taking care of her mother by herself, as she lived with her mother for most of her life—far more

than her siblings—before she got married. Indeed, Nadia often feels guilty and that she is not making enough effort to care for her mother. She has two private housekeepers: one for her and one for her mother. Nadia hopes to receive advice about how to deal better with her daily challenges, especially when her formerly wise mother starts to act in very uncharacteristic ways. For instance, "… *sometimes [in] the middle of the night she starts calling my brothers' names, as if they are at home, and I don't know what to do… she calls them her little babies ...*" Nadia will not accept non-home care (e.g., adult day-care, nursing home).

Mona is 37-years-old. She lives with her mother and her sister who works as a primary-school teacher. Her mother was diagnosed with AD with parkinsonian features, such as tremor, one year ago. Mona is a college graduate, single, and has quit her job to care for her mother. Due to behavioural challenges associated with her mother's disease, Mona has been unable to hire a private housekeeper. Mona reports, "… *she keeps putting pillows and blankets on the stove while I am cooking … it is hard to stop her, how can I tell her not to …*" Mona's mother left home on one occasion and became lost in the neighbourhood after Mona's brother came for a visit and left the door open. Fortunately, they found her safe, unharmed, and close to home. Mona is the youngest child and has five siblings and four of them are married and live in the same city. Although her sister sometimes provides back-up care for her mother, especially in the evenings and on weekends, Mona resents the lack of understanding and support from her other siblings and the challenge of daily (sometimes hourly) care.

It is very difficult for Mona to accept the changes to her mother's formerly strong personality. Mona does not know how her future will unfold, as she must take care of her mother. She thinks that as her mother's health deteriorates, adult day-care would be a relief and a solution that would preserve her aspirations (e.g., writing, working, and getting married). She has tried to set up a private day-care facility for

persons with dementia to help herself and others in the same situation, but the process proved too involved for her to manage within her current workload. Instead, Mona has started to write about her story as a caregiver and hopes to publish it so that others (including her siblings) can hear her voice and understand what it is like to be a caregiver. Caregiving, in her opinion:

> *"… is burden … but I know it is rewarding… she is my mother... it is burden*
>
> *because it is all on me and I can't do it all alone … it needs to be divided*
>
> *between us … my mind is scattered and I don't know what really my role is ..."*

The personal narratives of Nadia and Mona are two caregiver stories among many in the Middle East (e.g., Arab region), where family members, often adult children, are the cornerstone of providing eldercare. Informal (family) caregiving for persons who are cognitively, functionally, and physically compromised has become one of the foremost issues in global health (Keating & de Jong Gierveld, 2015) owing to an ever-increasing older population, concomitant increase in degenerative diseases associated with advancing age (e.g., AD), and the shift towards decreasing the costs of care that formal institutions provide.

In this paper, after reviewing research perspectives on dementia care and determining the gap in identifying personal and cultural constructs related to dementia caregiving, we present the theory of Personal Construct Psychology (PCP; Kelly, 1955) as a constructivist and flexible approach to gain a better understanding of the construction of dementia care in the target social or cultural group. We also present examples of constructs derived from personal narratives and constructions of family caregivers (e.g., Nadia and Mona), as well as resources associated with the different approaches and techniques on examining dementia-related constructs.

2.2   Perspectives on Dementia Care

Dementia is a chronic and progressive syndrome, and many persons with dementia show various changes in cognitive skills, personality, and ability to function well in daily life (Dunkin & Anderson-Hanley, 1998). Epidemiological studies show that approximately 46.8 million people are currently living with dementia around the world (Prince et al., 2015), with AD contributing to 60 to 70 % of cases (World Health Organisation [WHO], 2015). As a consequence of dementia-related changes and multiple morbidities, this population is increasingly dependent on informal caregivers, such as spouses, adult children, other family members, and friends. The impact of informal (and unpaid) care often starts from the day of diagnosis and continues through the duration of the illness, including physical, psychological, social, and financial difficulties (Dunkin & Anderson-Hanley, 1998). However, there are variations in the type and degree of impact on caregivers, including spouses and adult children caregivers (e.g., Savundranayagam, Montgomery, & Kosloski, 2011), and caregivers from various cultural populations (e.g., Dilworth-Anderson, Williams, & Gibson, 2002).

From a psychological and sociological perspective, family caregiving for relatives with dementia is perceived as an unexpectedly demanding occupation (Aneshesel & Pearlin, 1994; Gaugler & Teaster, 2006; Hasselkus & Murray, 2007) and a multidimensional process that causes major lifestyle changes (e.g., time off work, giving up of leisure activities, and less time to spend with other family members and friends, among other factors). In addition, the daily care needed requires varied tasks, such as decision-making, problem solving, and conflict management (Hasselkus & Murray, 2007). These new tasks can impact the caregiver's life and conflict with other roles that a caregiver plays in his or her daily life (e.g., as a worker, mother or father, friend, etc.; Teel & Press, 1999; Zarit & Zarit, 2007).

Within the gerontology and geriatric literature, some researchers have called the family caregiver "the hidden victim" or "invisible patient" (Medalie, 1994). The lack of formal support and the failure of the healthcare system to recognize the caregivers' needs can mean that their caregiving role expands beyond the support for basic and instrumental activities of daily living (e.g., toileting, feeding, shopping, and cooking) to include emotional (e.g., comforting and advocating), financial (e.g., money and bill management), and medical support (e.g., medications and geriatric case management). Moreover, while the majority of family caregivers live with the care receiver and provide informal daily care, many are also untrained and under-supported in performing these tasks (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Other researchers view the caregiver as the cornerstone of the care team and see them as partners with physicians in the care of the person with dementia (Silliman, 2000); therefore, routine assessments of caregiver needs is highly recommended (Adelman et al., 2014). However, examination of alternative approaches that go beyond the structured caregiver assessment tools and traditional psychological tests are recommended for a better understanding of the personal, group, and cultural constructions that determine the experience of dementia caregiving.

2.3   The Need for Theory and Assessment Methods of Caregiving Constructs

The assessment of physical, psychological, and social factors linked to the caregiving experience is an essential step in enhancing our knowledge of the quality of care for persons living with dementia, as well as the health and well-being of their family home caregivers. Behavioural and social research assessing the dimensions and consequences of dementia caregiving has been predominantly facilitated by the development and application of stress-coping models and caregiving relationship and interaction theories. While stress models (e.g., (Pearlin, Mullan, Semple, &

Skaff, 1990) focus on evaluating the immediate sources and mediators of stress on the process and outcomes of dementia care, conceptual models focus either on the dyadic relationship between the primary family caregiver and care recipient (e.g., Montgomery & Kosloski, 2013) or the triadic interaction among the person with dementia, the primary family caregiver, and the primary care physician (e.g., Fortinsky, 2001). Despite the insights these models and conceptual theories provide in addressing the impact of care provided to persons with dementia, the picture remains incomplete, particularly with regard to understanding the unique and shared personal, social, and cultural views of the meaning and impact of dementia care. Distinctive constructs, assumptions, and expectations held by family caregivers may be different from those held by formal caregivers or healthcare professionals. These constructs, which have not been socially or culturally investigated, usually shape the caregiving experience in either the formal or informal caregiving systems and may affect priorities and actions in the care decisions of the person with dementia.

Self-reported inventories and questionnaires are the most commonly used methods in caregiving research, particularly within the domain of *caregiver burden* (Chou, Chu, Tseng, & Lu, 2003; Vitaliano, Young, & Russo, 1991). These measures are usually constructed by caregiving experts (e.g., Montgomery, Stull, & Borgatta, 1985; Zarit, 1985) and are mostly derived from the experience of caregivers in Western populations. While these instruments may demonstrate acceptable reliability and validity within the populations for which they were developed, they may not be entirely appropriate when translated and applied to populations with fundamentally different social attitudes or cultural norms. For example, the construct "burden" (Grad & Sainsbury, 1963) and how it is linked to the care of persons with dementia has been well documented in the literature (Adelman et al., 2014; Campbell et al., 2008; Dunkin & Anderson-Hanley, 1998; Vitaliano et al., 1991). However, it has been argued that burden is a broad construct that encompasses various (if not all) dimensions of caregiving, and as a term, it is less commonly used

in practice than in research (Feinberg, 2002). Burden may include a wide array of stressors (e.g., physical morbidity, psychological distress, and social and financial difficulties), which makes it difficult to determine the factors that predict burden across various populations and cultures (Dunkin & Anderson-Hanley, 1998). Feinberg 2002 further argues that burden as a construct may not be culturally appropriate as it may negatively affect caregivers from diverse populations, especially those who perceive caregiving as a rewarding and fulfilling experience (Cohen, Colantonio, & Vernich, 2002; Roff et al., 2004). The use of the word burden may implicitly carry negative judgments about a caregiver's perceptions of the care they provide. To our knowledge there are neither standard definitions nor consensus in the literature about the construction of caregiver burden in populations from diverse cultural groups. Furthermore, in some cultures (e.g., Arab and Chinese societies) that place "caregiving (filial) obligations" (Holroyd, 2001) on adult children for their older parents, social (or religious) constructs associated with parental caregiving (e.g., *filial piety* in the Chinese culture or *bir* in most Arab cultures) may contradict the construct of burden. Conflicting results have been found in studies that assess the relationship between filial piety and caregiver burden. In one study, caregiver burden was claimed to be high in a sample of Chinese-Canadian family caregivers regardless of their traditional obligations towards family (Lai, 2009). In another study of Arab family caregivers, caregiver burden was found to be negatively predicted by filial piety (Khalaila & Litwin, 2011).

Given the wide individual and cultural variation, and the inadequacy of traditional research approaches in elucidating caregiving-driven constructs, constructivist approaches that explore interpersonal systems of meaning are likely to prove a more fruitful and practical way to explore the constructs and mental maps that shape dementia care, and at the same time help to differentiate individual views and shared meanings in both the informal and formal caregiving systems. Such an investigation may go beyond a specific model or structured measures to examine

the principles, values, attitudes, beliefs, and behaviours of the caregiver. It can also examine the willingness of formal caregivers or healthcare professionals to perceive and cope with other pressures of care. Thus, this paper proposes the theory of PCP and its methods as a constructivist and innovative framework for guiding the evaluation of caregiving constructs. This theory will help identify and assess personal constructs and generate *caregiving construct systems* or *caregiving mental maps* of these constructs. Such mental maps will allow for comparisons of caregiving systems across individuals and cultural groups. Construct systems, for instance, can be used to differentiate the conceptualization of the caregiving experience from one individual to another (e.g., male vs. female, spouse caregiver vs. adult child caregiver) and from one cultural context to another (e.g., ethnic or racial groups or individualistic vs. pluralistic societies). In other words, this theory can help us to articulate the personal or culturally prevalent (both negative and positive) constructs that shape the caregiving experience. The methods derived from this theory can be used to collect and explore personal and culturally prevalent constructs. These methods may also offer approaches that advance the understanding of the caregiver experience, including identification of the sources of "dementia caregiver distress" (Coon, Gallagher-Thompson, & Thompson, 2003), support for therapeutic interventions for caregivers, and more effectively targeted programs, policies, and community support services for family caregivers. This understanding may, in turn, assist researchers, program developers, and policy makers in their design of support systems that are both effective and efficient.

2.4   The Psychology of Personal Constructs

Although common elements can be recognized between PCP and other branches of psychology, such as personality assessment, psychotherapy, and other psychological theories (e.g., psychological constructivism theories), PCP is a division of psychology in its own right and not a subdivision of other psychology or theory.

PCP was developed by the American psychologist George Kelly in the 1950s. In this section, we present the theory, its underlying philosophy, the fundamental concepts and corollaries of the theory, and assessment methods derived from the theory.

2.4.1 The Philosophy, Theory, and Fundamental Corollaries of Personal Construct Psychology

Through PCP, Kelly (1955) advanced personal construct theory (PCT), which is concerned with an individual's construing (making meaning) of his or her life events, situations, and experiences. From Kelly's (1955) point of view, creative human exploration brings countless possible constructions of a particular reality. That is, events and life experiences are subject to as many alternative ways of construing as we can explore and create. Alternative ways of construing realities of the outside world represent the philosophy of *constructive alternativism*, the philosophical core of PCT (Caputi, Viney, Walker, & Crittenden, 2012). Consequently, when people construe their realities, they store them in the form (mental template) of *personal constructs* (their verbal language, such as words, adjectives, or phrases, and non-verbal expressions), and use these constructs to differentiate, integrate, and predict these realities. From this philosophical assumption and mental template comes one of the remarkable features of PCT: its abstracted, flexible, and content-free orientation. Because of this orientation, PCT is applicable to realities of all sorts, including the construction of the realities of people providing formal (e.g., Clinton, Moyle, Weir, & Edwards, 1995; Laubach, Brown, & Lenard, 1996) and informal care (e.g., Wills & Woods, 1997) for persons with dementia at all stages of the disease– as well as caregiving support programs and interventions.

"Person as a scientist" is a metaphor that Kelly (1955) proposes based on his theory. He views the person as a scientist. This means that a person (e.g., caregiver), like a scientist, constructs the meaning of his or her life by devising, testing, and continuously revising his or her personal theory to help him or her make sense of the

events he or she encounters (see Figure 2.1). The method of acting, making choices, experimenting, and revising a personal theory is similar to the scientific method used by the scientist to classify, categorize, and theorize a rigorous theory of discovering the truths about the universe in which he or she lives. Using his or her personal theory, the person anticipates future events (e.g., caregiver- care recipient relationship) by construing earlier events (e.g., child-parent relationship). A person's personal theory consists of a finite number of personal constructs, which may be organised within *personal construct systems* (e.g., family caregiver construct system) that vary in terms of their centrality or importance within the construing of an individual's overall reality (Winter, 1992).

As illustrated in Figure 2.2, Kelly (1955) organizes his theory into a *fundamental postulate* and *eleven corollaries* (also referred to as characteristics of personal constructs or construct systems). Kelly's fundamental postulate suggests that our experiences, thoughts, feelings, and behaviours, are determined, not just by the reality in the world, but also by our efforts to anticipate ourselves, other people (including our family and society), and the entire world, from moment to moment, day-to-day, and year-to-year (Boeree, 2006). In the process of construing realities around us ("construction corollary"), we usually move from theory to hypothesis.
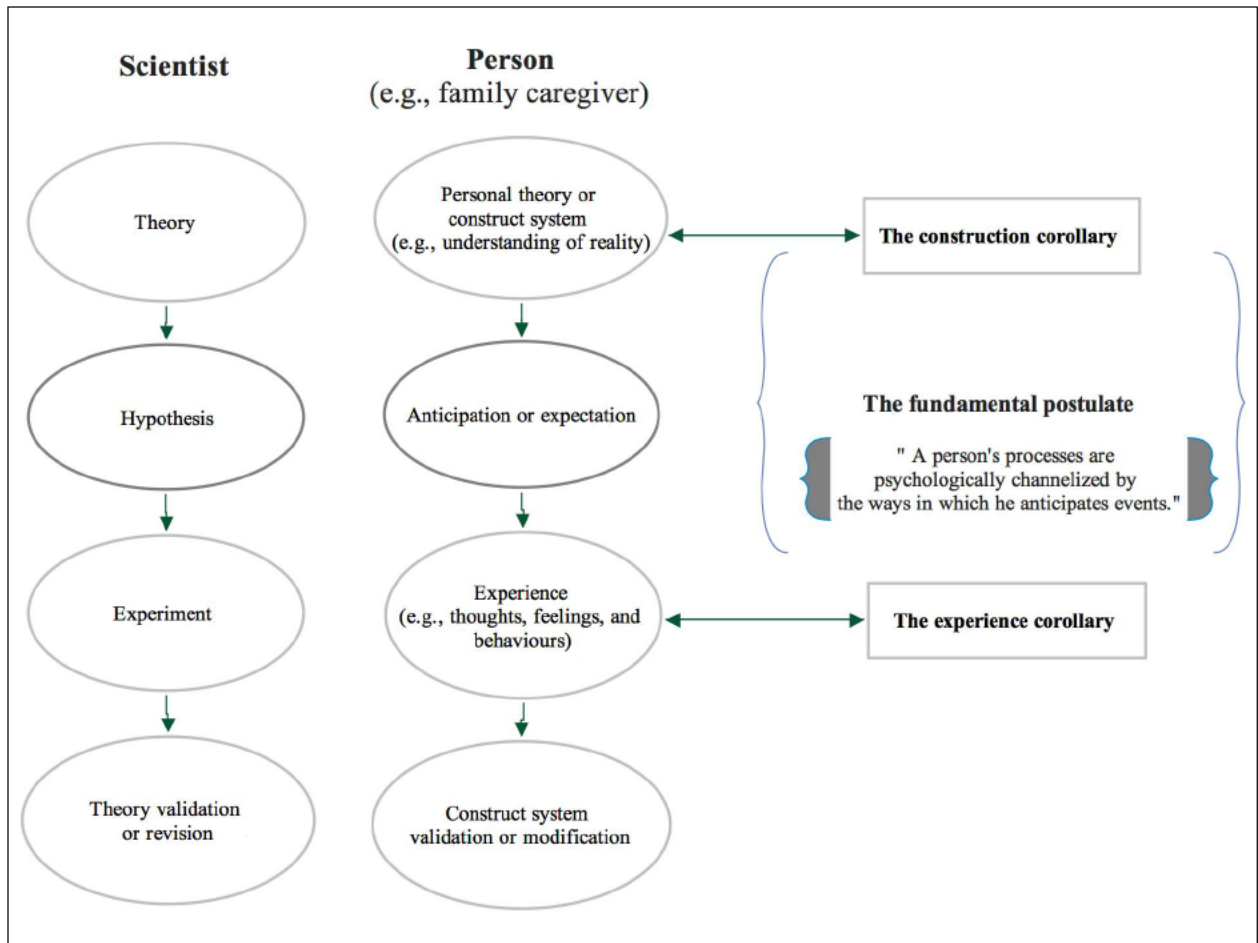
Figure 2.1. A person (family caregiver) as a scientist from the perspective of PCT, adapted from Boeree (2006).
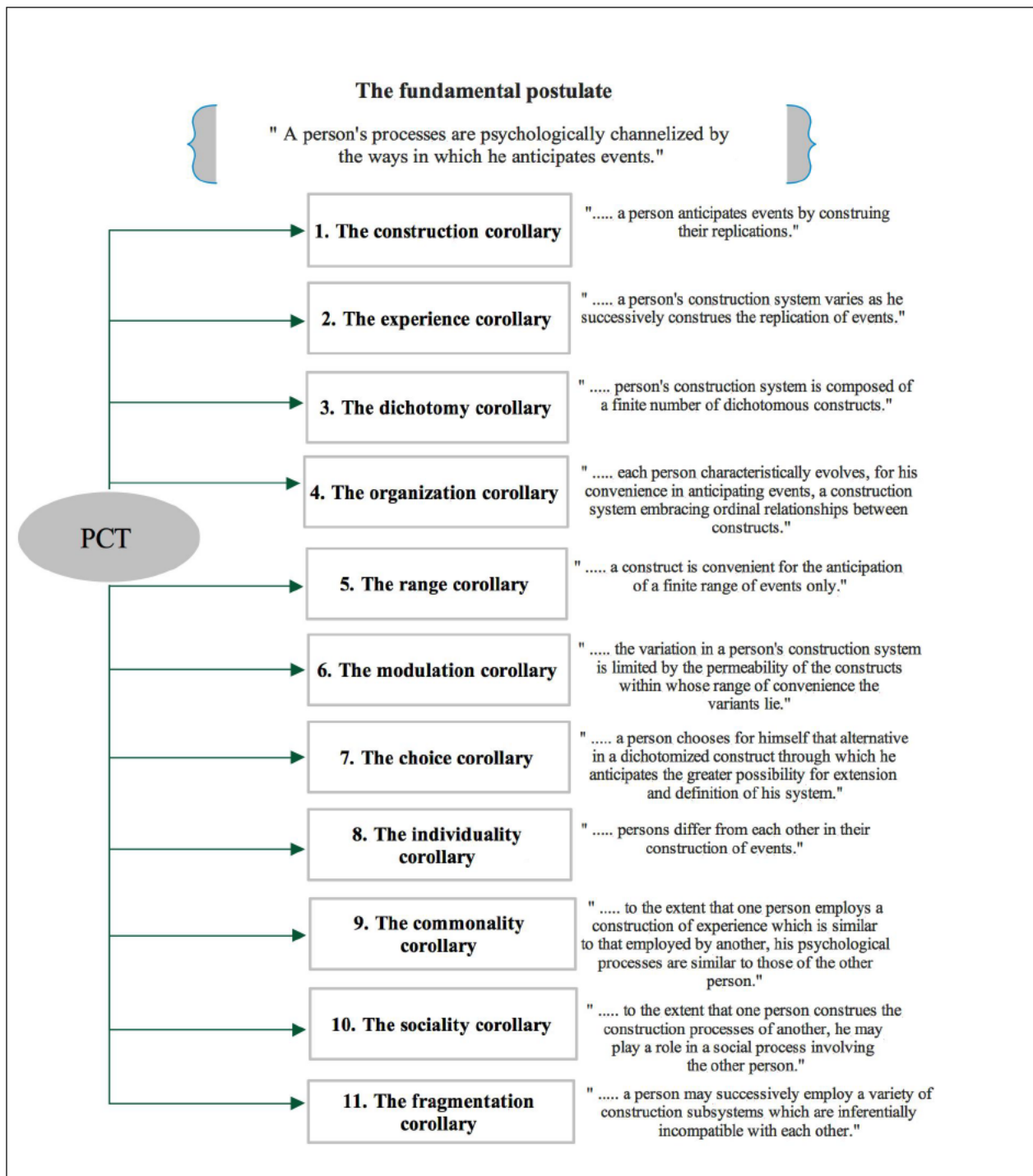
Figure 2.2. The fundamental postulate and eleven corollaries of PCT (Kelly, 1955).

In other words, we look for patterns and consistencies in our experiences and use our past experiences (e.g., wise and strong parent) for our future anticipations (e.g., wise and strong older parent). Thus, we typically expect things to happen as they have happened before – and when things do not happen the way they have in the past, we are forced to try to adapt ("experience corollary"). From each new experience, we revise our constructs for future anticipation. This is the step from experiment and observation to validation and adaptation or, sometimes, struggling to make the adaption. Based on the results of our experiments (e.g., the behaviour or experience in which we engage) we may continue our faith in our theory of reality, change our theory, or resist changing the theory regardless of its contradiction with the reality (Boeree, 2006). For example, consider the older parent (e.g., Nadia's mother), who was expected to continue to be a strong and wise person, but begins to show dependency due to cognitive and physical decline. The caregiver (Nadia) may feel that her role has expanded beyond her anticipated role of adult child and may have inconsistencies in her construct system that cause her to raise questions about what is going on or she may become *hostile* (e.g., heavy denial of her mother's changing behaviour or personality; Boeree, 2006). As Nadia may recognize this shift (with or without external help) in her expected role or "caregiver identity" (Montgomery & Kosloski, 2013), i.e., from adult child to part- or full-time caregiver, she will try to learn about the causes of these changes in her mother's behaviour and decline and may also struggle to understand these identity changes or adapt to the multiple roles ("fragmentation corollary") in her new experience.

A basic precept of PCT is that all constructs are *bipolar* (or dichotomous)*,* meaning that they have two ends or poles to show some sort of comparison (e.g., exhausted caregiver vs. energetic or active caregiver)*,* and this emphasizes the contrasting nature of personal constructs ("dichotomy corollary"); a person can determine the meaning of life events by comparing them to their opposites (e.g., care vs. neglect). Furthermore, the constructs are connected systematically in a hierarchical system

("organization corollary"), wherein some are *subordinate* to other constructs (action constructs, e.g., caregiving activities or action behaviours) and others are *superordinate* to other constructs (value constructs, e.g., caregiving beliefs or values). In addition, within this hierarchical system the relationship between these constructs is either very *tight* (when one construct frequently predicts the other, e.g., being rigorous and thus realistic) or *loose* (when a constructs are used in a more flexible way like in the process of creative thinking). Similarly, *permeability* of constructs allow for flexible thinking that is much easier to change (or *modulate*), and by contrast, *impermeability* of constructs allow for rigorous thinking that is hard to change (Boeree, 2006). Constructs may be highly idiosyncratic (e.g., Nadia's construct system) or widely shared (e.g., a family, social, or cultural caregiving system). In this manner, Kelly (1955) uses the term personal constructs to emphasize the assumption that these constructs are unique to each individual ("individuality corollary"). This implies that the poles for each of these personal constructs (e.g., frustrated vs. fulfilled caregiver or frustrated vs. careless caregiver) tend to be unique to each individual and may change over time as he or she interprets and anticipates his or her personal experience in the moment. Since everyone has different experiences, everyone's construction (of caregiving) is slightly different (Boeree, 2006). For example, Nadia's experience is likely to be different from Mona's experience. Despite their differences, personal constructs can also be similar in some ways. People (including caregivers) are all *meaning makers*, and if their construct system (e.g., understanding of reality, such as caregiving) is similar, there may also be overlaps in their experiences, behaviours, and feelings ("commonality corollary"). Because Nadia and Mona are family caregivers from the same society and culture (e.g., sharing assumptions of caregiving obligations towards their mothers) they may have some similarities in their construct systems (e.g., denial of the disease, feeling of responsibility for care, in-home care preferences, appreciating the wisdom of older people and family systems of care,

etc.). Similarly, people from the same social environment (e.g., primary care physicians, caregiving researchers, or policy makers) can communicate, understand, infer, and can therefore construe the personal constructs of people from within other social groups (e.g., family caregivers). Thus, these dissimilar individuals can still relate to each other and predict and understand their respective behaviours and constructions ("sociality corollary"). An equally significant aspect of personal construing in PCT is "cross-cultural construing" (Scheer, 2003), which may occur when people belonging to different cultures or ethnic groups live in the same place (e.g., family caregivers from ethnic minorities or caregiving researchers in an international research team) experience the same situation, live in the same environment, or use similar constructs (Scheer, 2003). Cross-cultural construing may also include examination of shared (or unshared) systems of constructs (e.g., individualistic vs. collectivistic construction of family caregiving), and this process is crucial to elucidate our understanding of dementia care and further help to develop a broader (or global) picture of dementia care in a multicultural society (e.g., Canada) as well as across countries or cultures (e.g., Western vs. Middle Eastern societies).

Kelly (1955) claims that we choose how to construe or interpret reality ("choice corollary") even when reality places limits on what we can experience or do. Indeed, we choose to interpret reality in whatever way we believe will help us the most or that is within the *range of convenience* ("range corollary") of an event's bipolar contracts. Commonly, our choices are between a secure and an adventurous alternative (Boeree, 2006). Looking for support, a family caregiver (e.g., Mona) could, for instance, try to get help from community-based services like adult day-care or to get to know more family caregivers with the same experience in a local or virtual support group. On the other hand, other caregivers (e.g., Nadia) might prefer to define her understanding by making less adventurous choices (e.g., speaking with the primary physician, staying at home, pondering what might have gone wrong with the parent). Furthermore, some constructs (e.g., all older people are wise and their

opinions need to be taken into consideration) need to be changed as the life event, family, or society circumstances changed or new experiences are gained (e.g., progression of the disease). Such constructs can be evolved (or *modulated*) to accommodate new changes ("modulation corollary"), such as the need for adult children caregivers to deal with behavioural challenges and make care-related decisions that do not contradict with their respect of their older parents (care-related decisions vs. lack of respect). According to Kelly (1955), the disconnection (lack of prediction or repeated construction regardless of *invalidation*) between our old construct systems and the new experiences we gain cause anxiety and other psychological disorders. One of the therapeutic approaches Kelly (1955) suggests for problematic or poor personal construing is *reconstruction* or *reconstruing*. Reconstruction involves getting the client to revise his or her constructs (including core constructs) to make better predications, and to see things in a different way and from a new perspective.

In brief, the model underlying PCT is explicitly formulated by the metaphor that every person is a scientist with his or her own theory (personal construct system). Regardless of the coherence of a person's construct system, the person lives his or her life, anticipates events, determines behaviour, asks questions, and evaluates outcomes through the lens of his or her system of personal constructs. As new events, situations, experiences, and challenges are encountered, these may invalidate pervious assumptions, necessitating revisions to the individual's construct system. Frequent invalidation of personal assumptions may lead to a need for assistance in revising his or her construct system (Caputi et al., 2012). Understanding the experience of dementia care through the eyes of PCT can help us expand our knowledge by examining the personal construct systems of caregivers associated with dementia care and how it can be validated or reconstructed in the target population.

2.4.2 Assessment of Personal Constructs

To put his theory into action, Kelly (1955) developed two constructivist methods of assessment to elicit personal constructs and explore interpersonal systems of meaning: the repertory grid technique (RGT) and the self-characterization sketch (SCS). The constructivist nature of these techniques means that they focus on personal meanings and the ability of these meanings to aid in the identification, exploration, and evaluation of personal narratives and constructions within an individual's experience (Caputi et al., 2012). Although the main focus of these methods is the words or phrases (textual information) provided by the respondents, Kelly (1955) further recognizes the importance of both words and numbers in revealing the unique dimensions of an individual's experience, and in identifying general patterns across individual experiences (Fransella, 2005). Therefore, he proposed RGT as a flexible measurement method that allows for personal constructs to be either qualified (e.g., with few case studies) or quantified (e.g., with large sample sizes). RGT is an idiographic (e.g., for exploring unique experiences) and nomothetic (e.g., for exploring shared experiences) technique and, in contrast, SCS is purely a qualitative assessment of construct systems derived from personal narratives.

In Nadia's case, for example, RGT can be used as a person-centred technique to guide a semi-structured interview (Fransella, Bell, & Bannister, 2004). In this interview, a grid matrix can be developed where the rows represent the personal constructs that are identified (words or phrases used by Nadia), and the columns represent the elements (Nadia's roles, people, or situations that can be either suggested by Nadia, the interviewer, or both). The cells in the matrix indicate, on a rating scale (if relevant), the position of each element within each construct. There are various ways to elicit constructs from elements (Fransella et al., 2004). To elicit Nadia's personal constructs, the interviewer may use the standardized "triadic

elicitation" procedure (triadic opposite or difference or comparison of three elements at a time) suggested by Kelly (1955), or the "dyadic opposite" or "difference procedure" (comparison of two elements at a time) suggested by (Landfield, 1971). This will produce bipolar descriptions that are interpreted as indications of the constructs that Nadia uses to describe her experience. This process is repeated several times with other dyads or triads resulting in a two-dimensional matrix (see Figure 2.3 for a sample of a repertory grid). More advanced elicitation procedures can be used to elicit either hierarchical value-based (higher-order) constructs or act-based (lower-order) constructs. For instance, the laddering technique (Hinkle, 2010, also referred to as "value laddering"; Hill, 1995, or "laddering up"; Caputi et al., 2012) is designed to elicit participants' superordinate constructs or core values that carry implications of his or her identity (Caputi et al., 2012). "Laddering down" (Caputi et al., 2012; Jankowicz, 2003), also referred to as "act laddering" (Hill, 1995), can be used to elicit subordinate constructs that carry implications for a participant's actions or behaviours that may correspond to his or her core values or beliefs.

Either approach to the laddering technique, or a combination of both, can be applied to any pole of the elicited constructs (Hill, 1995). For example, working from elicited constructs toward a superordinate construct, a caregiver will be asked to answer *why questions* for each elicited construct (e.g., burden vs. rewarded caregiving experience). For subordinate constructs a caregiver can be asked *how questions* (e.g., in relation to burden vs. rewarding) regarding elicited constructs (e.g., primary care duties vs. back-up care). The laddering technique can be continued until the participant can ladder no further, i.e., he or she agrees that the uppermost response is a fundamental value (e.g., filial piety or God's will) within his or her hierarchical construction of caregiving.

			Elements (e.g., caregiver roles)										
			1	2	3	4	5	6	7	8	9	10	
			Myself as a caregiver	Myself as a mother/father	Myself as a sister/brother	Myself as a worker (e.g., teacher)	Myself as a friend	Myself as a daughter/son	Myself as a member of the care team	Myself in the past	Myself now	Myself in the future (e.g., I would like to be)	
	Constructs												
	Similarity pole	Contrast pole	Ratings (1 2 3 4 5)										
1													
2													
3													
4													
5													
6													
7													
8													
9													
10													

Figure 2.3. 10 × 10 grid matrix (family caregiver repertory grid).

Two important features of RGT are: (1) flexibility with the content and number of elements (e.g., 10 to 13 elements is most commonly used; Fransella et al., 2004); and (2) that the content of those elements can be produced in any language without worrying about the long procedure of adapting translated scales for various cultures. Elements used in a RGT can vary (e.g., social roles, people, situations, tasks, etc.) based on the context (e.g., target research phenomena or cultural group) that may determine the use of a RGT for elicited constructs (Fransella et al., 2004). These elements can also be either elicited from participants or supplied by the interviewer (based on previous knowledge or rationale for conducing the interview; Jankowicz, 2003). McCoy (1983) has argued that the flexibility and sensitivity of the RGT makes it particularly well suited to the needs of the values-free approach required in cross-cultural studies. Different objectives require different techniques of either eliciting or supplying elements or constructs (Fransella et al., 2004; Jankowicz, 2003). The chosen approach depends, for instance, on whether other people are construing their own worlds or whether the same issue is under study with members of different cultures (e.g., comparable groups on the same phenomena, such as North American family caregivers vs. Arab family caregivers). As an illustration of the application of developing or reconstructing caregiver assessment tools, the RGT can be applied as a semi-structured procedure to construct items (elicited constructs) for a new local scale (e.g., using common constructs among a specific cultural group as potential items) or to revise items (supplied constructs representing foreign constructs or labels) of an existing scale (e.g., using common constructs among a specific cultural group as potential revised items vs. items of the original scale). That is, both the respondent and the interviewer develop the grid matrix. For example, self-defined constructs derived by Nadia as guided by the interviewer can function as new or adapted scale items. More details of this application are presented in the in the next section.

On the other hand, SCS is a narrative exercise and can be employed on its own or

to enhance the picture we gain of a person through the use of RGT (Hamad & Lee, 2013). SCS requires a participant to provide a written character sketch (a short paragraph) about him or herself, usually in the third person (e.g., from the perspective of a friend who knows the person very well and better than anyone else) or as a character in a play, as if he or she were describing someone else (Fransella et al., 2004). Similar to RGT, elicitation of respondent constructs is the primary focus of this assessment. In addition, the analysis of this sketch will involve a deeper identification of the respondent's self-construction–in other words, where the respondent places him or herself with respect to the personal categories and dimensions that make up his or her world (Winter, 1992). For example, Mona might be asked by the interviewer to write a self-sketch, in the third person, to describe how she currently lives as a caregiver for her mother who has dementia, how she would like to live as a caregiver in the future, or how she imagines she would be if other roles in life along with her caregiving tasks were better managed. The elicited constructs can be open to various interpretations. However, categorizing these constructs using coding or thematic analysis is more suitable for the results of SCS and qualitative approaches to RGT (Caputi et al., 2012; Green, 2004). Statistical procedures, such as cluster analysis and principal component analysis, can be used to analyse the results of RGT (Jankowicz 2003). There are also software packages available for analysis and production of several reports and graphs from these grids (Fransella et al., 2004; OpenRepGrid, 2014). Overall, the produced constructs can provide the investigator with a graphic representation or mental map of one participant's or groups' construct system(s).

2.4.3 Family Caregivers as Case Studies

As represented in the stories of two caregivers, Nadia and Mona, assessment methods of PCT can be employed to elicit personal constructs that family caregivers use to describe their caregiving experience in a particular cultural context. Both

Nadia and Mona were living in an Arabic and Islamic cultural context in which construct systems are frequently shaped by religious and social norms of caring for older parents or relatives. As shown in Nadia's and Mona's narratives, consistent with most Arab societies, family caregivers are expected to embrace Islamic teachings (e.g., acceptance of God's will) and fulfil familial obligations (e.g., she is my mother, it is my responsibility to do it) and act in accordance with social norms (e.g., expectations of siblings, extended family members, and society). The two cases were part of a study that employed a mixed methods research design to examine the personal and social constructs used by adult children family caregivers to describe their experience of providing care for their relatives (parents and grandparents) living at home with dementia (Hamad et al., 2017). The theoretical framework of PCT and its constructivist methods (RGT and laddering procedure) guided the theoretical lens, data collection, and analysis. Content analysis was performed (manually and with the help of software) to deductively and inductively examines individual personal constructs (units of analysis) and generates common themes (common constructs or group constructions) that determine the caregiving experience in this cultural context.

In the quantitative part of the study, we compared the psychometric evaluation (factorial structure of three subscales) of an existing (translated) 16-item quantitative measure of caregiver burden (a common foreign construct) to the conceptual evaluation of caregiving constructs elicited from caregivers' interviews (with the use of RGT). The construct of caregiver burden was also examined using the laddering technique (both laddering up and down), which was found to be ineffective as a construct in this cultural context, because it may contrast with the personal meaning of caregiving (e.g., *additional load* or *burden but love* as in Nadia, and *rewarding burden* as in Mona). Figures 2.4 and 2.5 illustrate samples of a family home caregiver's mental map drawn from participants' constructs as related to scale items. The research findings explain how the conceptual evaluation of one subscale

(*Relationship Burden* subscale) may help differentiate between the group construction in the culture of the original scale (North American) and the target culture (Arab culture).

In the qualitative part of the study, further examination of family caregiving narratives was conducted to assess individual and group constructs that shape the role of family caregiver in this culture. Findings of interpretive content analysis reveal the contrasting nature of the family caregiver role (*frustrated nurse* vs. *qualified nurse* and *compassionate adult child* vs. *disloyal adult child*) within a family-oriented system of care. The research promotes the need for developing caregiver support programs that emphasize reconstruction (or revision) of caregivers' old theories (e.g., the expectation that their parent remain *wise* and *strong*) about caring for an elderly parent with dementia (e.g., the unexpected *full-disabled* and *child-like* parent) and developing new personal and social constructs more relevant to the *why* (or value laddering) and *how* (or act laddering) questions surrounding dementia care (*child-like* vs. *person with living with dementia*). Figure 2.6 provides further potential applications of PCT in caregiving research. Alternative approaches to PCT in dementia care-related research can also be found in Morris (2004) and Robbins and Bender (2006).
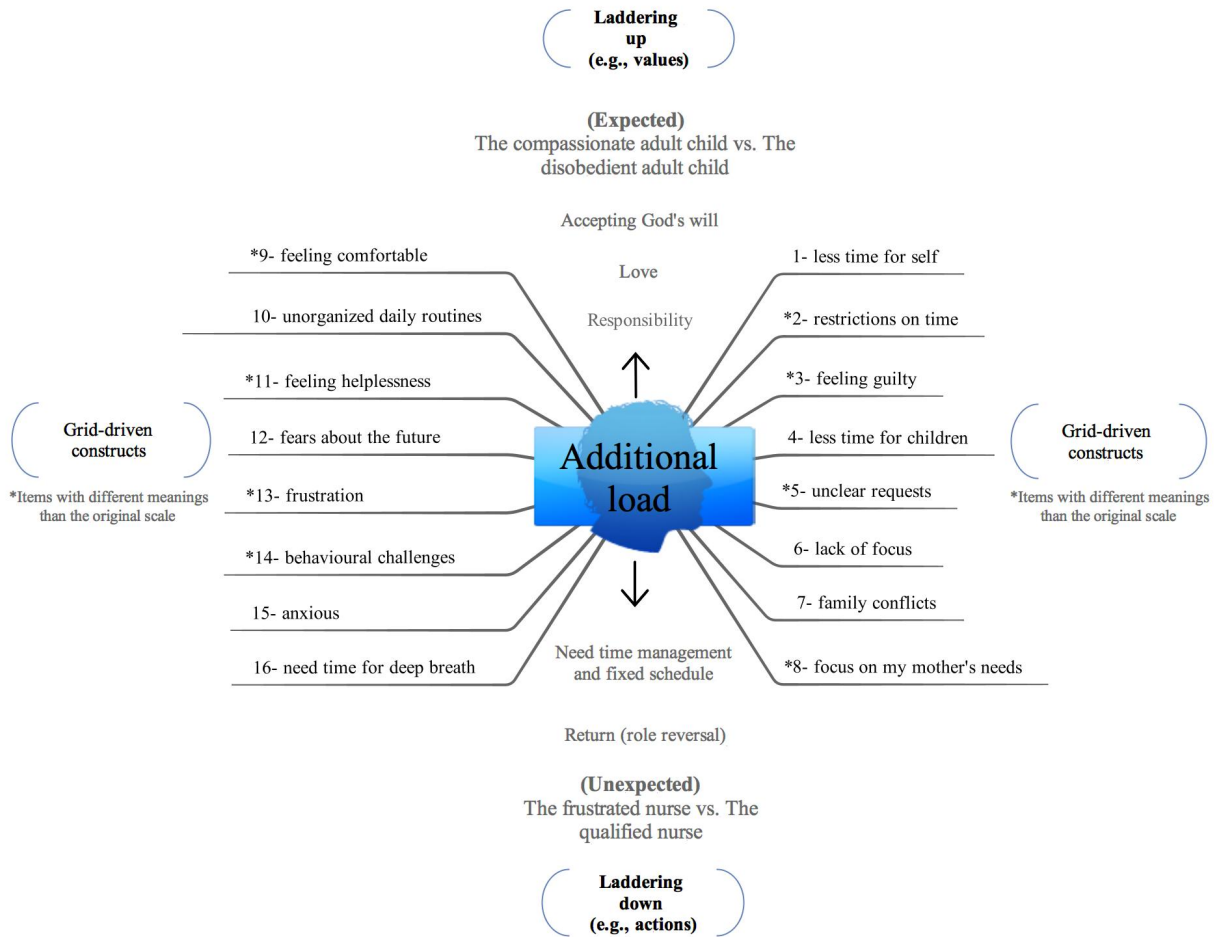
Figure 2.4. Sample of family home caregiver (Nadia's) mental map.
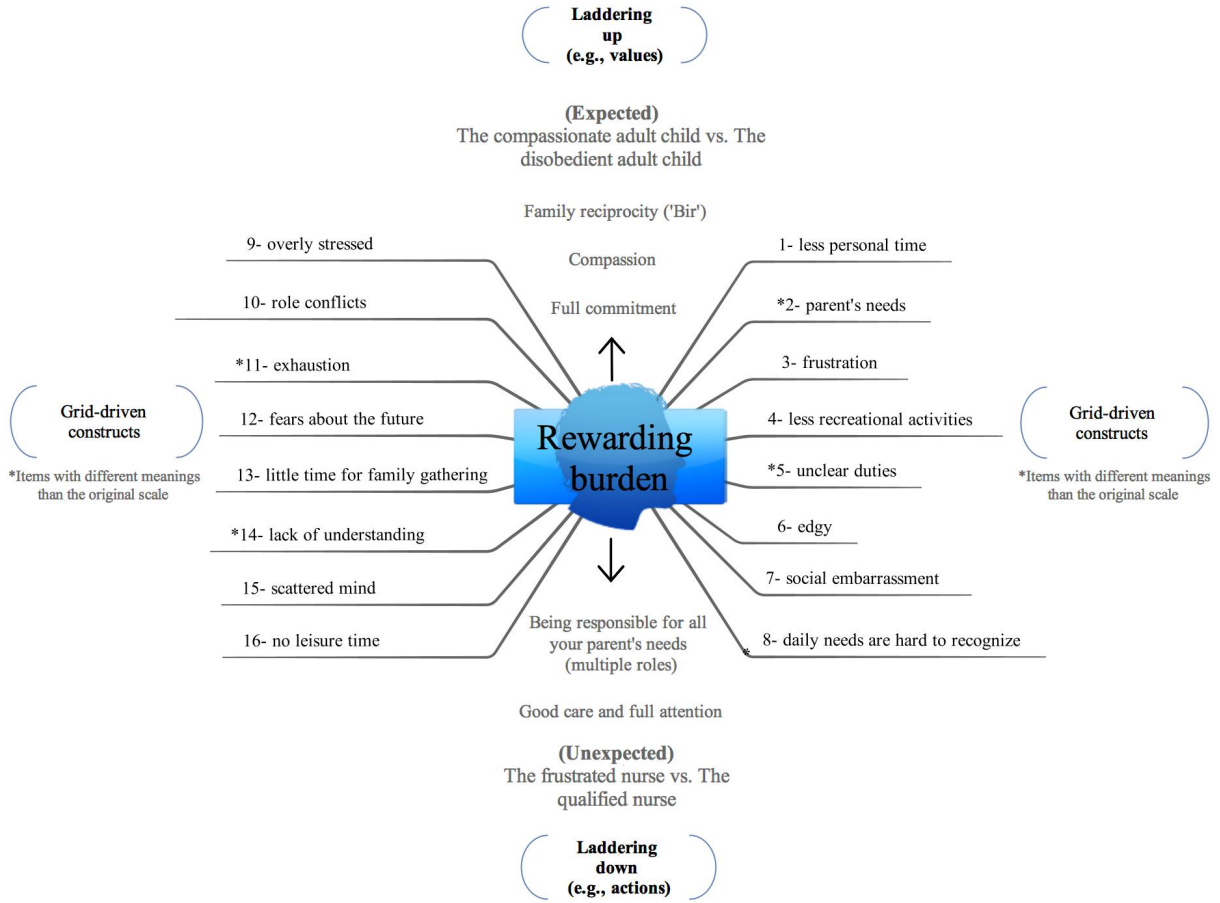
Figure 2.5. Sample of family home caregiver (Mona's) mental map.
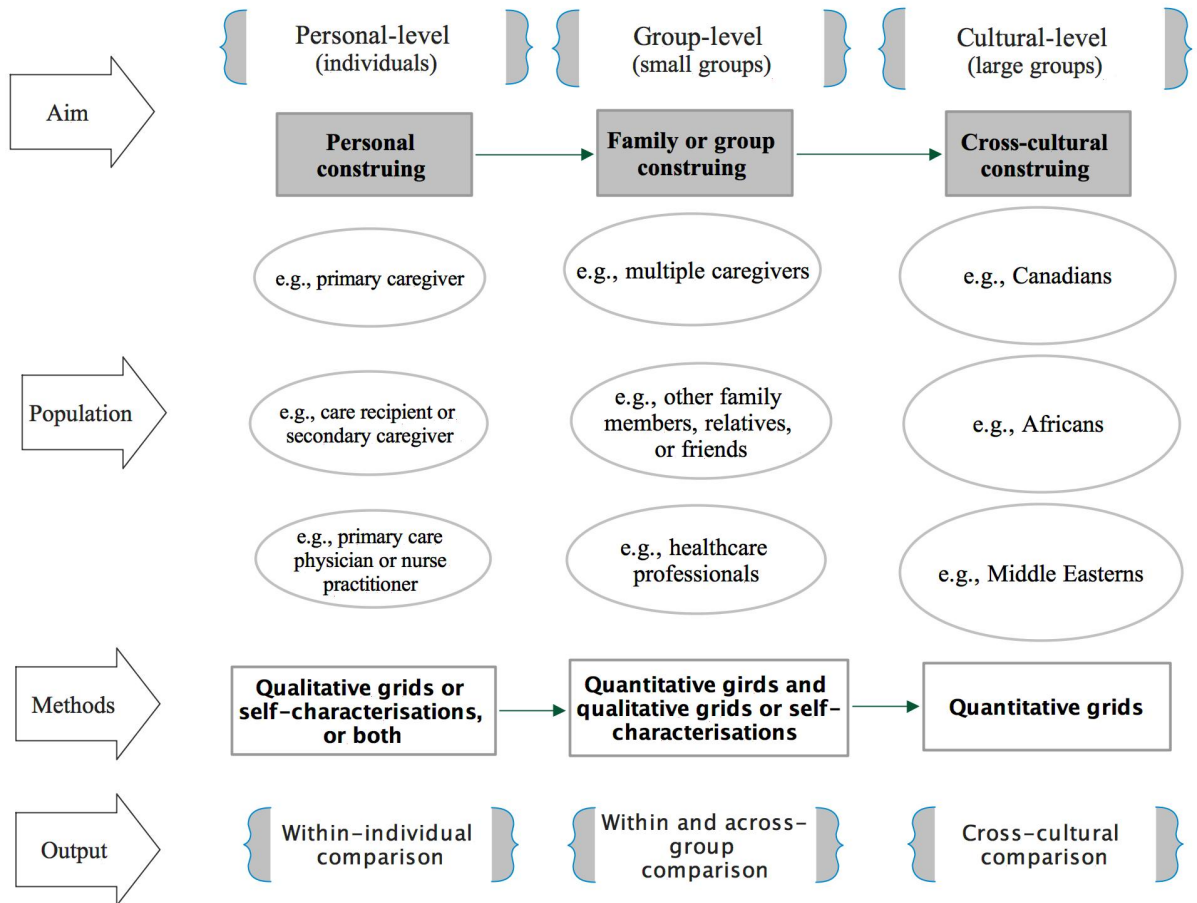
Figure 2.6. Potential applications of PCT in caregiving research.

2.5   Implications and Future Directions

In applied settings, clinicians, scientists, and researchers can use the assessment methods of PCT to understand how different persons and groups construe and map their view of themselves and the world. In clinical settings, PCT and its methods can be employed as an assessment process, as a distinct form of a therapeutic process, or both (Fransella, 2005). Because Kelly was a clinical psychologist, a great deal of his work was conducted in psychotherapeutic settings wherein he used the RGT and SCS as diagnostic tools to increase his understanding of how his clients view the world, and to track changes in their construct systems over the course of treatment. In this way, Kelly (1955) emphasizes that standard psychological tests and experimental procedures may not be easily readable and psychologically recognizable by populations with problematic aspects in their lives (Fransella et al., 2004). In PCT, the experience of stress or psychological disorder is characterized by particular features of construing. To encourage reconstruction of problematic (invalidated) personal construing, Kelly uses *role-playing* as part of therapy (Boeree, 2006).

As an example, consider role-playing in a therapy session with Nadia. The therapist might take the part of Nadia's mother or her sister and have Nadia express her feelings. After a while, the therapist might ask Nadia to reverse roles with him or her. In this way, Nadia will become aware of her own constructs and will better understand the constructs of her mother and siblings. Similarly, the therapist will begin to understand Nadia's construct systems or see ways in which she might need to reconstrue. Another way to help Nadia's reconstruction process would be to use the SCS to advise her to write a description of herself in the third person. Then the therapist can identify the problematic constructs with a focus on the core constructs in this sketch (e.g., helpless caregiver). Next, another description called the *fixed-role sketch* (of a pretend person; Boeree, 2006, or multiple selves; Caputi et al.,

2012) will be developed. For example, the therapist may write this sketch by examining Nadia's original sketch carefully and using revised (more suitable and less-judgmental) constructs to refer to the same range of elements (skilled vs. unskilled caregiver). By helping Nadia redefine her role as a caregiver, she will understand that a caregiver can be skilled in one area, yet unskilled in another, and this will allow for changes in her construct system (Boeree, 2006). If Nadia, for instance, feels that she is unskilled in an area of some importance to her caregiving experience, she can, with a little effort and time management, become a skilled caregiver. The same therapeutic techniques can also be used in group therapy to make sense of family shared meanings and construct systems about care and generational or gender roles, especially when discrepancies arise among family members (Procter, 2003).

Beyond clinical settings, it is worth noting that the blend of projective and objective assessment techniques in PCT is useful in a broad range of disciplines in the evaluation of various individual and group constructs. Since 1955, PCT has been extended to a variety of domains, including work with children (e.g., Ravenette, 1975), couples (e.g., Wijesinghe & Wood, 1976), social relationships (e.g., Kalekin-Fishman & Walker, 1996) organizational culture (e.g., Coopman, Hart, Allen, & Haas, 1997), and education (e.g., Hamad and Lee 2013). In a caregiving context, personal construct assessment techniques can be used to assess constructs of caring in health and social care systems, including the construing of formal caregivers, nurses, physicians, and other healthcare professionals (e.g., Clinton et al., 1995). Furthermore, the study of group or organizational construing (and reconstruing) can help to provide alternative constructs for dementia care that would lead to change in stereotypes of care, services, programs, and policies. Comparison studies of shared constructs can help evaluate the constructs of dementia care—not only for individuals living in the same culture, but also across cultures—to draw national and global mental maps of dementia caregivers in formal and informal care

settings.

2.6   Conclusion

The aim of this paper is to present how PCT can be adapted and used as a theoretical framework with its own philosophy, corollaries, and methods to explore the constructs used by informal caregivers and others involved in the context of dementia care. Personal constructs can be used to generate individual and group caregiving maps that can be compared and contrasted across families, care related groups, and cultural construct systems, and can enhance caregiving support programs, interventions, and polices within and across cultures.

2.7   References

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical Review. *The Journal of American Medical Association*, *311*(10), 1052. http://doi.org/10.1001/jama.2014.304

Aneshesel, C. S., & Pearlin, L. I. (1994). Caregiving: The unexpected career. *Social Justice Research*, *7*(4), 373–390. http://doi.org/10.1007/BF02334863

Boeree, C. G. (2006). Personality theories: George Kelly (1905-1967). Retrieved November 22, 2015, from http://webspace.ship.edu/cgboer/kelly.html

Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P., … Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International Journal of Geriatric Psychiatry*, *23*(April), 1078–1085. http://doi.org/10.1002/gps.2071

Caputi, P., Viney, L. L., Walker, B. M., & Crittenden, N. (Eds.). (2012). *Personal construct methodology*. John Wiley & Sons.

Chou, K. R., Chu, H., Tseng, C. L., & Lu, R. B. (2003). The measurement of caregiver burden. *JournalJournal of Medical Sciences*, *23*(2), 73–82.

Clinton, M., Moyle, W., Weir, D., & Edwards, H. (1995). Perceptions of stressors and reported coping strategies in nurses caring for residents with Alzheimer's disease in a dementia unit. *The Australian and New Zealand Journal of Mental Health Nursing*, *4*(1), 5–13.

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, *17*(2), 184–8.

Coon, D. W., Gallagher-Thompson, D., & Thompson, L. W. (Eds.) (2003). *Innovative interventions to reduce dementia caregiver distress: A clinical guide*. New York: Springer Publishing Company.

Coopman, S. J., Hart, J., Allen, M. W., & Haas, J. W. (1997). Detecting cultural

knowledge in organization members' personal construct systems. *Journal of Constructivist Psychology*, *10*(4), 321–338. http://doi.org/10.1080/10720539708404630

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist*, *42*(2), 237–272. http://doi.org/10.1093/geront/42.2.237

Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. *Neurology*, *51* (1, S1), S53–S60. http://doi.org/10.1212/WNL.51.1_Suppl_1.S53

Feinberg, L. F. (2002). *The state of the art: Caregiver assessment in practice settings*. San Francisco, CA: Family Caregiver Alliance. Retrieved from http://www.rosalynncarter.org/UserFiles/Caregiver Assessment 2002 FCA.pdf

Fortinsky, R. H. (2001). Health care triads and dementia care: Integrative framework and future directions. *Aging & Mental Health*, *5*(Suppl 1), S35–S48. http://doi.org/10.1080/713649999

Fransella, F. (Ed.). (2005). *The essential practitioner's handbook of personal construct psychology*. Chichester: John Wiley & Sons.

Fransella, F., Bell, R., & Bannister, D. (2004). *A manual for repertory grid Technique* (2nd ed.). Chichester: John Wiley & Sons.

Gaugler, J. E., & Teaster, P. (2006). The family caregiving career. *Journal of Aging and Social Policy*, *18*(3–4), 141–154. http://doi.org/10.1300/J031v18n03

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet*, *281*(7280), 544–547. http://doi.org/10.1016/S0140-6736(63)91339-4

Green, B. (2004). Personal construct psychology and content analysis. *Personal Construct Theory & Practice*, *1*, 82–91. Retrieved from http://www.pcp-net.org/journal/pctp04/green04.pdf

Hamad, E., & Lee, C. (2013). A Peronal Construct Approch to Discovering the Transition Experience of Studying Abroad. *Personal Construct Theory &*

Practice, *10*, 15–27. Retrieved from http://www.pcp-net.org/journal/pctp13/hamad13.html

Hamad, E. O., AlHadi, A. N., Tremblay, P. F., Savundranayagam, M. Y., Kinsella, E. A., Holmes, J. D., Lee, C. J., & Johnson, A. M. (2017). *Reconstruction of a caregiver burden scale: Exploratory and content analyses to identify culturally sensitive items in Saudi Arabia.* Manuscript submitted for publication.

Hasselkus, B. R., & Murray, B. J. (2007). Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia. *The American Journal of Occupational Therapy, 61*(1), 9–20.

Hill, R. A. (1995). Content analysis for creating and depicting aggregated personal construct derived cognitive maps. In R. A. Neimeyer & G. J. Neimeyer (Eds.), *Advnaces in personal construct psychology* (pp. 101–132). Greenwich, CN: JAI Press.

Hinkle, D. N. (2010). The change of personal constructs from the viewpoint of a theory of construct implications. (PhD dissertation, Ohio State University, 1965). *Personal Construct Theory & Practice*, (7 S1).

Holroyd, E. (2001). Hong Kong Chinese daughters' intergenerational caregiving obligations: A cultural model approach. *Social Science & Medicine*, *53*(9), 1125–34.

Jankowicz, D. (2003). *The easy guide to repertory grids*. Chichester: John Wiley & Sons.

Kalekin-Fishman, D., & Walker, B. M. (Eds.). (1996). *The construction of group realities: culture, society, and personal construct theory*. Malabar, FL: Krieger.

Kelly, G. A. (1955). *The psychology of personal constructs*. New York: Norton.

Khalaila, R., & Litwin, H. (2011). Does filial piety decrease depression among family caregivers? *Aging & Mental Health*, *15*(6), 679–686. http://doi.org/10.1080/13607863.2011.569479

Lai, D. W. L. (2009). From burden to depressive symptoms: The case of chinese-

canadian family caregivers for the elderly. *Social Work in Health Care*, *48*(4), 432–449. http://doi.org/10.1080/00981380802591759

Landfield, A. (1971). *Personal construct systems in psychotherapy.* Chicago: Rand McNally.

Laubach, W., Brown, C. E., & Lenard, J. M. (1996). Nurses and physicians evaluate their intensive care experiences. *Heart & Lung : The Journal of Critical Care*, *25*(6), 475–82.

McCoy, M. (1983). Personal construct theory and methodology in interculutral research. In J. Adams-Webber & J. C. Mancuso (Eds.), *Application of personal constructs theory*. Toronto: Academic Press.

Medalie, J. H. (1994). The caregiver as the hidden patient: Challenges for medical practice. In E. Kahana, D. Biegel, & M. Wykle (Eds.), *Family caregiving across the lifespan* (pp. 312–330). Beverly Hills: SAGE Publications.

Montgomery, R. J. V., & Kosloski, K. D. (2013). Pathways to a caregiver identity and implications for support services. In R. J. V. Montgomery & K. D. Kosloski (Eds.), *Caregiving across the lifespan: Research, practice, policy, caregiving: Research, practice, policy* (pp. 131–156). New York: Springer-Verlag.

Montgomery, R. V, Stull, D. E., & Borgatta, E. F. (1985). Measurement and the analysis of burden. *Research on Aging*, *7*(1), 137–52.

Morris, C. (2004). Personal construct psychology and person-centred care. In G. M. M. Jones & B. M. L. Miesen (Eds.), *Care-giving in dementia: Research and applications*. Hove and New York: Brunner Routledge.

OpenRepGrid. (2014) [Computer software]. Retrieved from http://openrepgrid.org

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594. http://doi.org/10.1093/geront/30.5.583

Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015: The Global Impact of Dementia: An analysis of*

prevalence, incidence, cost and trends. London: Alzheimer's Disease

International. Retrieved from

https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

Procter, H. (2003). Family thaerapy. In F. Fransella (Ed.), *International handbook of personal construct psychology*. John Wiley & Sons.

Ravenette, A. T. (1975). Grid Techniques for children. *Journal of Child Psychology and Psychiatry*, *16*(1), 79–83. http://doi.org/10.1111/j.1469-7610.1975.tb01874.x

Robbins, S., & Bender, M. (2006). Making sense of dementia. In P. Caputi, H. Foster, & L. L. Viney (Eds.), *Personal construct psychology: New ideas*. Chichester: John Wiley & Sons.

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *59*(4), P185–P190. http://doi.org/10.1093/geronb/59.4.P185

Savundranayagam, M. Y., Montgomery, R. J. V, & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *Gerontologist*, *51*(3), 321–331.

Scheer, J. W. (2003). Cross-cultural construing. In F. Fransella (Ed.), *International handbook of personal construct psychology* (pp. 153–161). Chichester, UK: John Wiley & Sons.

Silliman, R. A. (2000). Caregiving issues in the geriatric medical encounter. *Clinics in Geriatric Medicine*, *16*(1), 51–60.

Teel, C. S., & Press, a N. (1999). Fatigue among elders in caregiving and noncaregiving roles. *Western Journal of Nursing Research*, *21*(4), 498-514–20.

Vitaliano, P. P., Young, H. M., & Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia. *Gerontologist*, *31*(1), 67–75.

Wijesinghe, O. B. A., & Wood, R. R. (1976). A repertory grid study of interpersonal perception within a married couples psychotherapy group. *British Journal of Medical Psychology*, *49*(3), 287–293. http://doi.org/10.1111/j.2044-8341.1976.tb02377.x

Wills, W., & Woods, B. (1997). Developing a specialist nursing service for family-caregivers of people with dementia: Dilemmas of role expectations, perceived dependency and control. In P. Denicolo & M. Pope (Eds.), *Sharing understanding and practice*. European Personal Construct Association Publications.

Winter, D. A. (1992). *Personal construct psychology in clinical practice: Theory, research and applications*. New York: Routledge.

World Health Organization. (2015). *Dementia Fact Sheet*. Retrieved from http://www.who.int/mediacentre/factsheets/fs362/en/

Zarit, S. H. (1985). *The hidden victims of Alzheimer's disease: Families under stress*. NY: New York University Press.

Zarit, S. H., & Zarit, J. M. (2007). *Mental disorders in older adults: Fundamentals of assessment and treatment* (2nd ed.). New York: Guilford Press.

Chapter 3

3.1   Introduction

Family caregiving (informal and in-home care) for older adults with cognitive,

functional, and physical impairments has become an increasingly important issue in

all parts of the world including the 21 countries of the Arab region (Algeria, Bahrain,

the Comoros Islands, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya,

Morocco, Mauritania, Oman, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia,

the United Arab Emirates, and Yemen) in the Middle East and North Africa. In this

part of the world, the relative proportion of older adults within the population has

increased (approximately 4.1% in 2010 to 12% projected in 2050; Sibai, Rizk, &

Kronfol, 2014) with concomitant increases in diseases associated with advanced

age, such as Alzheimer's disease (AD) and other forms of dementia (Abdelmoneium

& Alharahsheh, 2016; Ward & Younis, 2013). In the past, caring for an older adult

within the social institution of family, particularly within the extended family networks

in many social contexts, was the norm (Kosberg, 1992; Szinovacz & Davey, 2008).

However, with increasing rate of progressive cognitive decline and functional

disability associated with dementia, the caregiving of older adults now demands a

higher level of attention, longer periods of time, and intensive requirements of care

(Kalaria et al., 2008; Muangpaisan, Hori, & Brayne, 2009). Despite this fact, and

changes in family structure in the Arab region (e.g., declines in fertility rates and in

extended family networking), the capacity of families to manage the challenges of

long-term care is remarkable, especially considering that many families have limited

knowledge, training, support, and resources to provide appropriate care

(Abdelmoneium & Alharahsheh, 2016). Even with institutionalized care of older adults in the advanced stages of the disease, families continue to be involved in caregiving (Dunkin & Anderson-Hanley, 1998).

Previous research with self-reported measures for family caregivers on various aspects of the family caregiving experience (e.g., Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Chou, Chu, Tseng, & Lu, 2003; Feinberg, 2002; Dunkin & Anderson-Hanley, 1998; Montgomery, Stull, & Borgatta, 1985) has indicated that regardless of the positive outcomes associated with providing care (e.g., Cohen, Colantonio, & Vernich, 2002; Harwood et al., 2000; Roff et al., 2004), caregiving may be associated with negative consequences for the caregiver. Negative outcomes of caregiving, often quantitatively measured as "caregiver burden" (Grad & Sainsbury, 1963), have been well documented in the Western literature (e.g., Montgomery, Gonyea, & Hooyman, 1985; Montgomery, Rowe, & Kosloski, 2007; Zarit & Femia, 2008; Zarit, 1985). At the same time, research and knowledge translation on the impact of caregiving is still limited in the Arab region context. This paradox might be due to the relatively recent shift in demographics coupled with a lack of specialists, required skills, knowledge, social awareness (Halabi & Zafar, 2010), and adapted screening tools for older adults with dementia (Chaaya et al., 2016) and their caregivers. Thus, some scholars (e.g., Abdelmoneium & Alharahsheh, 2016; Halabi & Zafar, 2010) recommend more attention and research effort be focused on family care of aging adults in the Arab region. Because the impact of caregiving can vary widely from one family to another and from culture to culture due to individual differences, availability of resources, and variation in social and cultural constructs related to the experience of caregiving, there is clearly a need to examine the caregiving experience and its related constructs in various societies and cultures.

Feinberg (2002) argues that "burden" as a construct may not be culturally

appropriate, because it may carry negative connotations about the role of the family caregiver. For example, in Saudi Arabia (SA), one of the largest Arabic states in the Arab region, caring for an older adult is frequently constructed as a source of pleasure and enrichment and a way of showing appreciation and reciprocating to one's parents for their own caregiving contribution—a cultural norm known as "bir" in the Arabic language and Islamic teachings (Alobaidi & Aldamigh, 2001) or "filial piety" in the Chinese tradition of Confucianism (Osman, Shukri, & Othman, 2011). Although the use of the term burden may be controversial in some cultures, this term is frequently used in Western, Eastern, and Middle Eastern caregiving research to describe various aspects of the caregiving experience. In the interest of achieving better conceptual clarity and more precise assessments of stress levels associated with the caregiving experience, the Family Caregiver Alliance (FCA, 2006) has recommended that the term burden be avoided. Furthermore, the lack of proper definition and assessment of personal and cultural constructs associated with caregiving could lead to direct and indirect costs to the community, economy, and health care system for both older adults with dementia and their family caregivers.

Culturally sensitive assessment tools are essential to inform the development of care services and policies in the target culture. One way to advance research on caregiver assessment is to develop translated versions from existing validated Western scales that better reflect the perspective and uniqueness of people living in the target culture. Such tools would need to take into consideration the definition of caregiver burden used in creating the measure and related contextual aspects (e.g., dominant religious beliefs, social assumptions, norms relative to family networking, education, age, gender, income, and availability of support services) as understood by gerontological and caregiving experts and by family caregivers (as member of the care team). Thus, in validating relevant tools for different cultural contexts, there is a substantial need to apply qualitative research methods, such as focus groups, cognitive interviews, and ethnographic observations, in conjunction with the

standardization and validation of (imported) quantitative measures across cultures (Cheung, van de Vijver, & Leong, 2011; Weech-Maldonado, Weidmer, Morales, & Hays, 2001).

In the current study, we use a modified version (Savundranayagam, Montgomery, & Kosloski, 2011) of the Montgomery Borgatta Caregiver Burden Scale (MBCBS; Montgomery, Borgatta, & Borgatta, 2000; Montgomery et al., 1985) to assess various dimensions that might have changed in a caregiver's life due to his or her caregiving role and responsibilities (Farley, Demers, & Swaine, 2008; Savundranayagam, et al., 2011). An integrated (mixed methods) approach combining quantitative and qualitative methods was used to translate and validate a SA version of MBCBS. Thus, the three primary objectives of this study were: 1) to translate the MBCBS into Arabic and validate it in the SA context; 2) to examine differences in Western and Middle Eastern conceptualization of "caregiver burden" within the context of this existing measurement tool; and 3) to explore the feasibility of using an integrated (mixed methods) approach to measurement validation as a research methodology for cross-cultural measurement equivalence in order to facilitate the comparison between SA family caregivers and family caregivers from other cultures (e.g., American and Canadian caregivers) using the different versions (American and French Canadian) of the MBCBS.

3.2   Theoretical Framework

The present study uses personal construct theory (PCT; Kelly, 1955) as a theoretical foundation to explore the construction of the family caregiving experience in the target culture (Hamad et al., 2017). This exploration includes the examination of *personal constructs* (participants' words, phrases, or expressions) and individual *construct systems* ("individuality") and group (or familial) construct systems ("commonality") related to caregiving. From the perspective of PCT, family caregivers are seen as scientists; they have their own constructs or representations

of their world and ways of understanding current events and predicting future events that are based on past events or experiences (e.g., the child-parent relationship and a family caregiving system that characterizes the surrounding culture compared to caregiver-care recipient relationship due to the disease progression). The exploration of personal and group constructs in this study involved an exploration of the content (structured translated items and subscales) of the MBCBS through the use of two constructivist methods of PCT: the repertory grid technique (RGT; Kelly, 1955) and the laddering procedure (Hinkle, 2010; Hill, 1995). The personal (individual) and shared (common) constructs gained from these methods were used in comparison with the original MBCBS items and underlying constructs of subscales.

3.3 Methodology

3.3.1 Study Design

An embedded (mixed methods) instrument validation design (Creswell & Plano Clark, 2011) was used to integrate quantitative and qualitative data in order to develop and evaluate an Arabic version of the modified MBCBS. The embedded design combines the collection and analysis of quantitative and qualitative data within the traditional quantitative measurement validation design. The notation of the design can be written as QUAN (+ qual) = enhance scale validation (Creswell & Plano Clark, 2011). In this design, qualitative data provides additional information about the validity of the instrument, especially its content and construct validity, by focusing on the content and the meaning of the scale items (conceptual or qualitative equivalence) in addition to the quantitative item properties (technical or quantitative equivalence). To develop a validated Arabic version of the modified MBCBS, the study was conducted in two phases. The first phase included traditional scale translation, consisting of a forward-translation and independent review, and a back-translation and expert panel review to ensure meaning and wording clarity

(Weech-Maldonado et al., 2001). In the second phase, the translated Arabic scale (see Appendix A) was administered to the study sample and a personal construct elicitation of the scale items was conducted. Although it may be argued that the use of a Western scale as a jumping-off point may hinder the identification of SA-specific constructs, our contention is that this provides a unique opportunity to contrast Western and Middle Eastern conceptualizations of caregiver burden. More details about the methods and procedures used in the two phases of data collection are provided in the next sections. Both types of data were collected in a semi-structured interview format, and each type of data was analyzed separately and then merged for convergence and confirmation of both results (see Figure 3.1 for study design).

3.3.2 Participants and Procedure

SA family caregivers were invited to participate in the present study. For inclusion criteria, all participants were in-home family caregivers (of a family member who lives at home), such as a parent or other relative aged 50 years or older with a diagnosed AD or other forms of dementia. Participants were primary caregivers aged 18 years or over who provided at least one weekly activity of daily living (ADL; e.g., bathing, dressing, toileting) or instrumental activity of daily Living (IADL; e.g., cooking, driving, shopping), and had been caregivers to the family member for at least the past 6 months. Participants who did not meet the inclusion criteria were excluded from the study. A convenience sample of 20 family caregivers was recruited in several ways. Emails were sent to dementia specialists (e.g., geriatricians, neurologists) at King Saud University Medical City (Riyadh, SA) to share the details of the study with their patients via poster in the office waiting room. A recruitment poster (see Appendix B) was shared via the social media accounts of the Saudi Alzheimer's Disease Association (SADA). In addition, caregivers were contacted through client registry databases, through the SADA, and invited to participate in the study. Snowball sampling was also used such that family

caregivers who participated in the study were asked if they could refer other interested family caregivers (from other families) to the researchers. After participants read a letter of information about the study, and provided informed consent (see Appendix C) and demographic questionnaire (see Appendix D), they met with one of the investigators (first author) or a research assistant (a graduate medical student) to be interviewed at the SADA, geriatric clinic, or via telephone. The study was approved by the Health Sciences Research Ethics Board at Western University, London, Ontario, Canada (see Appendix E) and by the Institutional Review Board (IRB) of King Saud University, Riyadh, SA (see Appendix F). Verbal permission (through phone call) to translate the original scale for use in this study was obtained from Dr. Rhonda Montgomery (the copyright holder).

3.3.3 Methods

The modified MBCBS. The modified version of MBCBS (Savundranayagam, et al., 2011; see Appendix A) measures aspects of caregiver burden that can be categorized into three aspects of caregiver burden: *Objective Burden* (OB; i.e., disruption of a caregiver's life due to caregiving tasks; 6 items), *Relationship Burden* (RB; i.e., relationships between caregiver and care receiver based on the demands of caregiving responsibilities; 5 items), and *Stress Burden* (SB; i.e., emotional impact of caregiving; 5 items). The scale items are framed by asking caregivers to respond to a general question: "As a result of assisting the care receiver, have the following aspects of your life changed?" Items are answered on a 5-point Likert scale ranging from 1 ("not at all") to 5 ("a great deal"). The burden scores in each subscale are summed, with higher scores indicating greater burden.

The embedded instrument validation
(mixed methods) design
"QUAN (+ qual) = enhance scale validation"

Phase	Phase 1: Traditional scale translation	Phase 2: Pilot administration and personal construct elicitation	
Procedure	Forward-translation, independent review, back-translation, and expert panel review of MBCBS	Semi-structured interviews (demographic information questionnaire and the Arabic (translated) version of MBCBS) +	repertory grid and laddering procedures
Product	Arabic (experimental/translated) version of the scale	Sample characteristics and + responses to translated items	participants' personal constructs
Analysis	-	Technical evaluation using R software (descriptive statistics, + factor analyses, and reliability analyses)	Conceptual evaluation using MAXQDA12 software (content analysis of individual and group/common constructs)
Interpretation	-	Quantitative results +	qualitative findings

Figure 3.1. Study design.

Personal construct elicitation methods. Two methods, RGT (Kelly, 1955; see Appendix G) and laddering procedure (Hinkle, 2010; Hill 1995; see Appendix H) were used to elicit individual cognitive maps representing the personal construal of each individual's world or caregiving experience. More specifically, RGT and the laddering procedure were used for qualitative evaluation of the items in each subscale of the measure and the overall construct of caregiver burden. The RGT (Kelly, 1955) is a matrix that consists of elements or roles (columns) and constructs (rows). To elicit elements, participants were asked to generate a list of up to 10 roles in which they engaged in the past (e.g., "me in the past", "daughter"), in the present (e.g., "caregiver", "wife", "mother", "worker"), or in the future (e.g., "me in the future", "future self"). Construct elicitation (two poles) was based on asking the participants if each item on the translated scale is similar to, or different from, their caregiving experience. For example, for item 6 on the SB subscale ("have your caregiving responsibilities: made you nervous?"), participants were asked, "Does the word 'nervous' explain or describe your current situation?" If he or she answered in the affirmative ("Yes"), the word "nervous" became the first pole of the construct, and then he or she was asked to give a word that has a similar meaning to nervous (e.g., "edgy" or "becomes easily irritated") to make the second pole of the construct. If he or she answered in the negative ("No"), then he or she was asked to give a word that better explains the situation (e.g., "emotional stability"). This construct elicitation continued until all scale items were evaluated and completed. The participant's self-identified roles (elements) were then rated on a 5-point rating scale based on the two poles of each construct (1 or 2 indicates the left pole or the original translated item, 3 indicates a neutral response, and 4 or 5 indicates the right pole or the participant's elicited construct).

Following the RGT, the laddering procedure (Hinkle, 2010; Hill 1995), including "value laddering" (also termed "laddering up") and "act laddering" (also termed "laddering down") was applied to evaluate the construct of the scale (caregiver

burden). The purpose of this procedure is to explore the higher (fundamental) and lower (action) levels of constructs related to caregiving. For example, working from elicited constructs (e.g., burden vs. responsibility) toward a superordinate construct (e.g., a sense of duty), a participant was asked to answer *why questions* for each elicited construct. For subordinate constructs (e.g., spending more time and energy for my parent), a participant was asked *how questions* regarding elicited constructs. In other words, value laddering was used to *ladder upwards*, and act laddering was used to *ladder downwards*. The laddering continued until the participant could not ladder any further (i.e., he or she agreed that the uppermost response is a fundamental value within his or her general construction of caregiving).

3.3.4 Analysis Procedures

Applying a traditional psychometric approach to the translated scale. Traditional psychometric analyses were used for analysis of the quantitative data of the translated scale, and all analyses were done in R (version 3.2.2; R Core Team, 2016) using the "psych" package (Revelle, 2016). Descriptive statistics were calculated on the characteristics of the sample and are presented as frequencies and percentages for categorical data, and as mean and standard deviation for continuous variables. Different models of factor analysis (FA) and reliability analyses were performed to evaluate the similarity of the factorial structure of the translated scale with other versions of the scale that are published in the literature. Although our sample size is insufficient to make strong inferences about the factor structure, we believe that exploratory as well as confirmatory approaches to FA (Floyd & Widaman, 1995) will provide a provisional evaluation of the extent to which the translated version generally conforms to the factor structure (underlying dimensions or subscales in the translated version) of the three scale solution of the untranslated (original) version (Savundranayagam, et al., 2011). Reliability analyses were based

on Cronbach's alpha coefficient of internal consistency, with values of at least 0.70 suggesting acceptable internal consistency.

Content analysis applied to methods of PCT. For the qualitative data, individual caregiver constructs produced from participants' interviews (with the use of RGT and laddering procedure) were analyzed separately by the first author (a study investigator) and research assistant (a graduate medical student) using an initial eyeball inspection of the elicited constructs (e.g., getting familiar with the nature and rating of the constructs; Jankowicz, 2003) and interpretive content analysis (ICA; Drisko & Maschi, 2015). In the ICA analysis, both manifest and latent meanings were taken into consideration with reference to the SA context (e.g., referring to the Islamic teachings that place a very high value on the family and care of the older population). To facilitate the analysis, data was translated (from Arabic into English) and transcribed verbatim into Excel files and then transferred to version 12.1.0 of MAXQDA12 (qualitative and mixed methods data analysis software; MAXQDA12, 2016) to perform further analysis (e.g., highlighting codes, creating word clouds, and comparing constructs across participants). Participants' personal constructs (words or phrases) were used as units of analysis; thus, where possible, each response was translated into a string of "noun equivalents" to reduce the amount of analyzed data. After the two analysts reached an agreement about the generated codes of participants' constructs and overall conceptualization of coded data, data was illustrated on individual cognitive maps using version 9 of iMindMap (mind mapping software; iMindMap9, 2016). These cognitive maps present a visual representation of each participant's construct system (way of thinking) about the context of "being a caregiver", as compared with other roles in the participant's life. Although the content of these maps was data-derived (based on the participants' construal of their caregiving situations), the categorization of these maps was deductively derived from the predetermined subscales of the original scale. Individual maps were then aggregated (for commonality) into a group cognitive map by counting the number of

repeated constructs used by each participant. The results of this procedure were then expressed graphically as a group cognitive map and used to compare the experience of SA caregivers to the accounts of North American caregivers, and North American versions of the scale.

3.4   Results

3.4.1 Quantitative (Psychometric) Evaluation of Data

In addition to the content validity of the translated version of the scale, the results of the quantitative data include statistical data from the standard procedure of traditional psychometric analyses, such as descriptive statistics of the sample sociodemographic data and characteristics of scale items, FA procedures, and reliability analyses of scale items in comparison to the original scale and a translated scale in another cultural group (French Canadian version).

Content validity (experts' evaluation) of the translated version. The process of translating the original scale included forward-translation and an independent review (by the first and second author: a doctoral student and psychiatrist, and both are bilingual), back-translation, as well as a review by an expert panel, which includes the first author (bilingual doctoral student) and co-authors: test construction, occupational therapy, and family caregiving experts. The initial translation of the scale from English into Arabic was undertaken by two professional translators, and before starting, the translators were introduced to the objectives of the study, the demographic characteristics of the study population, and the targeted reading level of the translation. Once the scale was translated into Arabic, the scale was reviewed by two bilingual reviewers (first and second author). The review of the forward translation was followed by back-translation into English by two independent bilingual translators. The back-translators had no access to the original English version of the scale and did not consult with either the forward-translators or the

study investigators. The expert panel reviewed the back-translated version to detect any discrepancies in meaning or conceptual equivalence between the scale's original version and the back-translated version. The similarities and differences between the two versions were discussed and consensus among the experts suggested no correction or modifications to the back-translated scale. As a result of this evaluation, the translated (Arabic) version of the scale was introduced to study participants via study investigators (first author or a graduate medical student) who met either face-to-face, or via telephone, with each person individually, for approximately one hour and a half.

Characteristics of Family Caregivers. The sociodemographic characteristics of the sample are presented in Table 3.1 Twenty family caregivers from two Saudi cities (Riyadh and Jeddah) were interviewed. Due to some restrictions in Saudi society (e.g., refusal of face-to-face interviews, gender-match of interviewer) and circumstances in caregivers' lives (e.g., lack of time, transportation difficulties, inability to leave the person with dementia at home), 14 (70%) of the caregivers were interviewed face-to-face and 6 (30%) were interviewed via telephone. The average age of participants was 36.10 for caregivers and 77.70 for care recipients with probable diagnosis of AD (80%) or mixed dementia (20%). Most caregivers were female (65%), middle class (55%), adult children (90%), with college level of education (70%), living with the person with dementia (80%) in an extended family household (60% with 3 to 10 family members) and with an average of five years of caregiving experience for the person with dementia (Mean=5.70, SD=2.74). While half of the caregivers (55%) spent more than 8 hours assisting the person with dementia (75% of assistance with both ADL and IADL), approximately half (45%)

Table 3.1.

Characteristics of family caregivers (N=20)

Interview Style			
Face-to-face			14 (70%)
Telephone Interview			6 (30%)
City			
Jeddah			8 (40%)
Riyadh			12 (60%)
Age of CG		Age of CR	
Mean (SD)	36.10 (10.58)	*Mean (SD)*	77.70 (7.87)
Range	24-63	*Range*	64-90
Sex of CG		Sex of CR	
Female	13 (65%)	*Female*	11 (55%)
Male	7 (35%)	*Male*	9 (45%)
CG Marital Status			
Married			10 (50%)
Single			9 (45%)
Separated			1 (5%)
CG Employment Status			
Working full time			12 (60%)
Quit working			2 (10%)
Self-employed			2 (10%)
Working part time			1 (5%)
Retired			1 (5%)
Student			1 (5%)
Housewife			1 (5%)

Table 3.1.

Characteristics of family caregivers (N=20) (continued)

<u>CG Level of Education</u>	
College Graduate	14 (70%)
Postgraduate	4 (20%)
Vocational training	1 (5%)
High School	1 (5%)
<u>CG Family Income</u>	
Middle Class	11 (55%)
Upper Class	6 (30%)
Prefer Not to Answer	3 (15%)
<u>CG Relationship to CR</u>	
Adult Child (Daughter)	11 (55%)
Adult Child (Son)	7 (35%)
Grandchild	2 (10%)
<u>Number of Immediate Family Members</u>	
3 to 10	12 (60%)
11 to 18	7 (35%)
More than 18	1 (5%)
<u>Number of People Living at Home with the CG/CR</u>	
3 to 6	10 (50%)
7 to 9	10 (50%)
<u>Number of Children Living at Home with the CG/CR</u>	
No Children	8 (40%)
1 to 3	9 (45%)
More than 3	3 (15%)
<u>Caregiver Lives with the CR</u>	
Yes	16 (80%)
No	4 (20%)

Table 3.1.

Characteristics of family caregivers (N=20) (continued)

<u>Caregiving Period (In Years)</u>	
Mean (SD)	5.70 (2.74)
<u>Time Since Diagnosis</u>	
Mean (SD)	5.55 (2.87)
<u>Hours of Caregiving</u>	
More than 8 Hours	11 (55%)
Other (e.g., every other day, weekends, backup care)	5 (25%)
Less than 4 Hours	3 (15%)
5 to 8 Hours	1 (5%)
<u>Types of Care Provided to the CR</u>	
Both ADL and IADL	15 (75%)
Other (e.g., daily supervision, weekend supervision, daily activities)	5 (25%)
<u>Housemaid(s)</u>	
Yes	16 (80%)
No	4 (20%)
<u>Number of Housemaids</u>	
0	4 (20%)
1 to 3	15 (75%)
More than 3	1 (5%)
<u>Housemaid(s) Assistance for Care</u>	
Yes	4 (20%)
No	16 (80%)

Table 3.1.

Characteristics of family caregivers (N=20) (continued)

Family Support for Care	
Yes	18 (90%)
No	2 (10%)
Type of Family Support	
Physical and Psychological Support	5 (35%)
Other (e.g., backup care, care planning)	13 (65%)
Formal (non-family) Support	
Yes	11 (55%)
No	9 (45%)
Type of Formal Support	
None	9 (45%)
Programs of Alzheimer's Association	6 (30%)
Homecare Services	3 (15%)
Caregiving Advocacy (e.g., social media accounts for caregiver support)	1 (5%)
Private Nurse	1 (5%)
CG Physical Health Concerns	
Hypertension	2 (10%)
Back pain	3 (15%)
Stomachache	1 (5%)
Skin rash	1 (5%)
Diabetes	1 (5%)
CG Emotional Health Concerns	
Depression	1 (5%)
Concerns about the health status of the care receiver	2 (10%)
Fears of having memory problems	4 (20%)
No health concerns	7 (35%)

Table 3.1

Characteristics of family caregivers (N=20) (continued)

MBCBS Total Scores	
Objective Burden	
Mean (SD)	18.55
Range	(5.95)
Skewness / Kurtosis	7 – 26
Subjective Burden	-0.58 / - 1.12
Mean (SD)	
Range	11.50
Skewness / Kurtosis	(3.76)
Relationship Burden	5 – 17
Mean (SD)	-0.62 / - 0.99
Range	
Skewness / Kurtosis	
	15.95
	(3.20)
	10 – 22
	0.16 / -1.19

Note. CG = Caregiver, CR= Care recipient, SD= Standard deviation, ADL = Activities of daily living, IADL= Instrumental activities of daily living, MBCBS = Montgomery Borgatta Caregiver Burden Scale, OB= Objective burden, RB= Relationship burden, SB= Subjective burden.

received no formal (non-family) support. Instead, 80% of the entire sample had an average of 1 housemaid (private workers who are employed and paid by the caregivers) to provide help with the household chores (e.g., vacuuming, cleaning, washing and ironing, or other related services), with 20% of those (often untrained) workers providing help with the caregiving needs. Only two participants had a private nurse (living at home) to provide (mostly medical) help with the caregiving needs due to the advanced disease stage of the care receiver. For those who received formal support (55%), only 15% received basic in-home care services and 30% either navigated the programs provided by the SADA or acted as advocates for issues related to family caregiving (e.g., creating or participating in a virtual support groups via social medical platforms). For caregivers' own health concerns, most caregivers were concerned about either physical symptoms (e.g., hypertension, back pain, stomach ache) or psychological issues (e.g., concerns of the care recipient's health status and fears of experiencing future memory problems).

Scores on the Burden Scales. The level of SB (Mean=11.50, SD=3.76, range=5 to 17) and OB (Mean=18.55, SD=5.95, range=7 to 26) were the highest, with 65% and 60% of caregivers respectively, above the average score of the study population, respectively. The magnitude of RB (Mean=15.95, SD=3.20, range=10 to 22) was found to be lower than OB, but larger than SB, and 50% of caregivers were found to be above the average score of the study population. The percentages of participants' responses to scale items in each subscale are provided in Appendix I.

Factor analysis. Participants' scores on the translated scale were first subjected to parallel analysis (PA) to determine the number of factors that could be extracted for the data. In PA, the eigenvalues from a common factor analysis (study data) are plotted against estimated eigenvalues from random or stimulated data (Floyd & Widaman, 1995). Results of PA suggested that the scale had two distinct factors, both with an eigenvalue greater than one (6.22 and 1.65, respectively). A preliminary

two-factor analysis (FA) was also conducted to examine items' standardized loadings. After defining poor items (with loadings less than 0.30), further exploratory factor analysis (EFA) was undertaken to assess adequacy and compare the factor structure of the translated scale using four models: 1) two-factor model with all translated (original) items; 2) two-factor model (excluding four poor items); 3) two-factor model (excluding the five items of the RB subscale); and 4) two-factor model (excluding the five items of the RB subscale and one additional poor item from the SB subscale). As shown in Table 3.2, the summary table of the FA model solutions, the results of the two-factor model (model 4) have better fit indices for the translated scale than other models of EFA. The root mean square of the residuals (RMR) statistic for this model is smaller (at 0.12) and the comparative fit index (CFI) is larger (at 0.754), and both of these assessment measures indicate a better model fit of EFA. Furthermore, four models of a confirmatory factor analysis (CFA) were also conducted to confirm the findings of the EFA models (Harrington, 2009) as compared to the structure of three-factor model of the original scale (Savundranayagam, et al., 2011). The results of the two-factor model of CFA (model 7) indicate a better score (0.092) of standardized root mean square residuals (SRMR) and CFI score (0.856) which confirms the results of model four of the two-factor model of EFA (after the items of RB subscale and item 9 of the SA subscale were dropped in both EFA and CFA models). Although the fit indices are suboptimal, the final model presented within the analysis is the best model that could be constructed from these items within this sample. In addition, the correlation coefficient between the OB and SB subscales was found to be high (0.74). In contrast, the correlation of RB subscales was found to be very low with either the SB (0.01) or OB (0.05) subscales.

Reliability (internal consistency) analyses. A comparison of reliability scores (Cronbach's alpha) of the translated scale revealed that the two-factor model of EFA (model 4) has a higher reliability score (0.92) than the other models of EFA. In

addition, reliability scores of the subscales show that the OB subscale has a higher reliability than either SB or RB subscales (0.78 and 0.40 respectively), and the overall reliability score of the translated scale (with all translated items) is 0.88.

3.4.2 Participants' (Qualitative) Evaluation of Scale Items and Construct

The qualitative data of the study include the results of conceptual evaluation procedures for the content of scale items and construct of caregiver burden from the perspective (world of view) of study participants. These results include content analysis of the data gained from the RGT (grids) and laddering procedures (ladders). Because the results of qualitative data (personal constructs) were not examined in either the modified (Savundranayagam et al., 2011) or French version of the scale (Farley, Demers, & Swaine, 2008), these results were limited only to our sample and could only broadly be compared to the other results.

Grids. To seek convergence of quantitative analyses conducted on the translated (Arabic) scale items, common constructs generated from personal (individual) cognitive maps elicited from study participants were compared to the results of the translated (original) items and subscales. As mentioned in the previous section, the OB subscale ("impact of caregiving daily tasks" in our sample) was the most reliable (0.90) in our sample. Participants' constructs for this particular subscale showed similar meanings to the original items; however, participants' responses to several items (items 4, 7, and 13) in our sample were similar and classified based on gender or culturally related events. For example, in item 4, the "recreational activities" included familial or social activities (e.g., gathering with family or

Table 3.2
Comparison of fit indices for exploratory (rotate = "oblimin", fm="ml") and

confirmatory (overall fit) factor analysis of the translated MBCBS

Model	X^2 (df)	RMSEA (90% CI)	RMR	SRMR	TLI	CFI
Model (1) 2-factor solution (EFA) with all translated items	285.1- *(104)*	0.312	0.17	-	0.343	0.481
Model (2) 2-factor solution (EFA) excl. items 2, 5, 9, & 11	190.68 *(54)*	0.277	0.12	-	0.572	0.675
Model (3) 2-factor solution (EFA) excl. the RB subscale	158.45 *(44)*	0.249	0.14	-	0.663	0.749
Model (4) 2-factor solution (EFA) excl. the RB subscale and item 9 (SB subscale)	150.97 *(35)*	0.265	0.12	-	0.663	0.754
Model (5) 1 –factor solution (CFA) with all translated items	311.63 *(104)*	0.316	-	0.15	0.261	0.360
Model (6) 2-factors solution (CFA) excluding the items of RB subscale	80.86 *(43)*	0.210	-	0.10	0.701	0.766
Model (7) 2-factor solution (CFA) excluding the items of RB subscale and one item from SB subscale (item 9)	55.03 *(34)*	0.176	-	0.09	0.809	0.856
Model (8) 3-factors solution (CFA) with all translated items	282.59 *(101)*	0.300	-	0.21	0.335	0.440

Note. EFA= Exploratory factor analysis, *CFA*= Confirmatory factor analysis, X^2 *(df)* = Chi Square *(degrees of freedom)*, *RMSEA* = The root mean square error of approximation, RMR = The root mean square of the residuals, *SRMR* = The standardized root mean square of the residuals, *TLI* = Tucker Lewis index of factoring reliability, *CFI* = the comparative fit index.

friends), spiritual activities (visiting the holy mosques), and gender specific activities (time for gym or feminine activities like paying attention to nails, hair, skin, etc.). Similarly, in item 7, "social life suffering" is either related to less time for family gatherings or time with friends. In addition, showing up with the care recipient (e.g., the "formal wise person") at a family gathering was related to "social embarrassment" to the caregiver or "social pressure" to justify the changes that have happened to the care recipient.

In contrast to the OB subscale, the RB subscale had the lowest reliability score (0.40) due to several items that were questionable in our sample. In addition, the CFI score of the scale with all translated (original) items (0.481) was improved (CFI=0.754) when the items of the RB subscale (item 2, 5, 8, 11, 14), and item 9 ("have your caregiving responsibilities depressed you?") of the SB subscale were removed. The content analysis of participants' constructs of the RB subscale ("caregiving constraints" in our sample) showed that the common constructs used by our participants were conceptually contrasted with the overall conceptual meaning of the original subscale. Where the common theme of the original RB subscale is the "subjective demand burden"—i.e., the degree to which the care receiver being overly demanding, manipulative, making unreasonable requests, etc.—the common construction of the translated subscale shows that caregivers perceive their lives to be constrained by full commitment to (vs. manipulated or dominated by) care responsibilities for a "patient" or an "older adult with special needs." If there is "exhaustion" (vs. being taken advantage of) from increased responsibilities or "lack of understanding" (vs. conflicts with the care recipient) by the care recipient's special needs or "resentment" toward family members, it was often due to "misunderstanding of unclear requests or needs" (vs. unreasonable requests), and "acting in very uncharacteristic ways" (vs. beyond what the care recipient needs). For example, for item 8, while verbally nonaggressive behaviours (e.g., repetitive questions or requests) or physically aggressive behaviours (e.g., hitting or biting)

among care recipients were mentioned by some participants, "complete silence sometimes" or "no communication" was mentioned by others depending on the stage of the disease, or personality factors (e.g., quiet personality leads to fewer requests, or strong personality leads to aggressive behaviour) in some way as related to the former personality of the care recipients. With regard to item 9 in the SB (the "emotional impact" in our sample), although the mean score of this item is 1.75 and standard deviation is 1.12 (see Appendix H for item characteristics), participants' constructs showed symptoms of depression in their responses (e.g., sadness, crying or tearfulness, loss of enjoyment, and mood swings).

Other items in the SB subscale may also show similar meanings to the original items. See Figure 3.2 for a group cognitive map that compares participants' common constructs to the original items of the scale. Overall, participant roles ranged from a minimum of six roles to a maximum of ten roles, including the caregiver role ("my role now") and most common roles of friend (70%), sister (65%), and full-time worker (60%), with an average rating of 4 across all constructs indicating participants' preferences to use their own words or constructs to describe their unique situation.
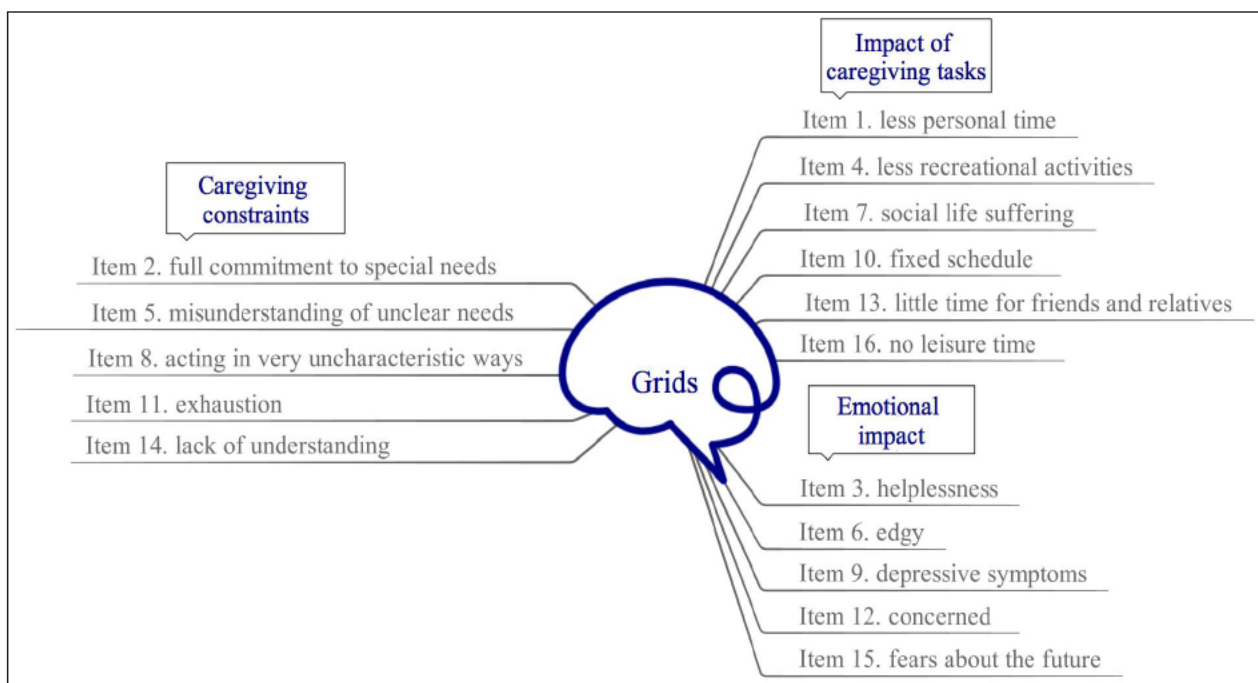
Figure 3.2 Group cognitive map (participants' constructs of scale items and constructs of subscales).

Ladders. For conceptual evaluation of the construct of caregiver burden, participants in our study were not comfortable with the use of the concept of burden. When the word burden was used (i.e., by four caregivers), it was adopted with caution and with direct reference to the word "rewarding" ("rewarding burden"), when the caregivers were the only primary caregivers (or felt that they were the only caregivers) responsible for providing daily caregiving tasks (or at least the required supervision). Although caregivers, as adult children and grandchildren, are socially "expected to care" for their older parents and grandparents, they describe their experience of "long-term caregiving" as an "unexpected effort" they had in their lives. Many indicated, however, that the word burden was a "very harsh" word to describe their experience and that it may contradict the blessing tasks they are committed to provide to their care receivers (parents or grandparents), which are characterized by "full commitment", "love", and "compassion" (as value constructs) and directly related to "God's will" (highest laddering or value construct). Thus, participants generally

preferred to use the word "commitment", "effort", or "responsibility" (vs. burden) to describe their situation. Many participants indicated that they felt "overwhelmed" by the changes and needs of the diseases and that they wanted to know how to handle the needs of the care recipient in a way that would "comfort" their parent with dementia. Participants indicated a need to learn "how to live with the disease" and "focus on my parent's needs" as a priority (first level of act construct); as well as a need to "master the caregiving skills" (second level of act construct), which need "patience, knowledge, and training". Participants indicated that a large part of mastering the skills required effort to "deal with the care recipient's memory and behavioural challenges" in the middle stages of the disease and to "severe physical disability" in the advanced stages of the disease, requiring "advanced medial care" (e.g, tube feeding, providing wound care) and in-home equipment (e.g., wheel chair, adjustable hospital bed). Another part of this effort frequently expressed by participants was the emotional feeling of not doing enough (or "guilt") related to the ability to do their best to meet their responsibility as adult children ("role reversal" or "parenting my parent"), and to make their parent feel "comfortable" in their later life; the feeling that caregivers themselves indicated they want to feel when they get older (see Figure 3.3 for aggregated laddering of "caregiver burden" as constructed by family caregivers in SA).
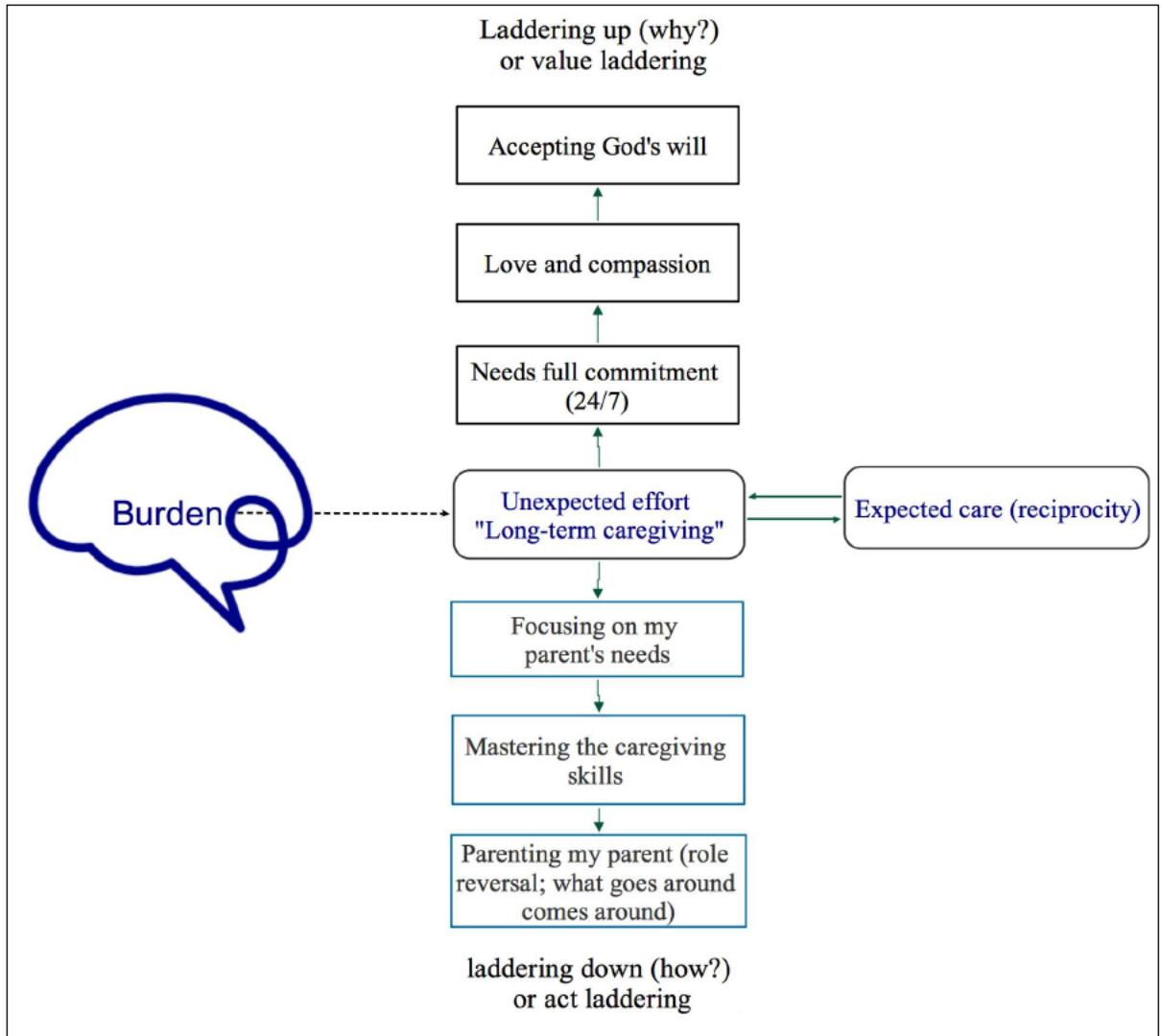
Figure 3.3 Aggregated laddering (participants' construction of "caregiver burden").

3.5   Discussion

Because there is no published literature on assessing the experience of family caregivers of persons with dementia in SA, we believe that this study is the first of its kind in this context. The aim of this study was to contribute to the literature on caregiver assessment by enhancing the process of validating an existing caregiver scale in the target culture in order to adequately address the needs, expectations, and construct system related to the investigated phenomenon (experience of family caregiving) in the target population (SA family caregivers). The constructive methods of PCT (RGT and laddering procedure) used in this study, in addition to the traditional quantitative methods (demographic information questionnaire and translated scale) of evaluating the psychometric properties of the scale were fruitful in examining the caregiving experience from the perspective of family caregivers. These methods were also helpful in facilitating a cross-cultural comparison of this population (SA family caregivers) with that of the original scale (American family caregivers) and other cultural groups for whom the scale was validated (French Canadian family caregivers). Through the use of personal construct methods, such a comparison is important for replicating the constructs and the meaning of the items and in designing and developing programs and support services that are socially and culturally related and meet the needs of the target population.

Overall, the results of this study are partially consistent with the findings of a local (unpublished) social survey (Alobaidi & Aldamigh, 2001) on the sociodemographics of dementia and its related factors (e.g., lack of knowledge and social awareness about dementia, family care system, living arrangements, hiring housemaids, role conflicts, supporting the care recipient with both ADL and IADL, and challenges in dealing with uncharacteristic behaviour of the care recipient) in SA. However, the care recipients in this study are mostly female (55%), which is slightly higher than the reported percentage of female in the survey (44%). Our results also affirm the

applicability of multiple dimensions of family caregiving across three cultures, and contribute to the identification of negative as well as positive consequences of family caregiving (e.g, Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Cohen, Colantonio, & Vernich, 2002; Dunkin & Anderson-Hanley, 1998; Etters, Goodall, & Harrison, 2008; Feinberg, 2002; Pearlin, Mullan, Semple, & Skaff, 1990). Regardless of religious and societal assumptions of elder care and positive outcomes caregivers may experience, the results also show that a comprehensive family caregiver assessment (e.g., holistic assessment and understanding of the caregiver's view and desired outcomes; FCA, 2006) is essential to ensure quality of life for both the caregivers and care receivers (Adelman et al., 2014). There is also a need for a potential care partnership plan that integrates the long-term care of AD and other forms of dementia between family caregivers (informal care) and formal care providers, including quasi-formal or community services, in cultures in which family are the primary care providers (Walker, 2000).

In our sample, the SB subscale and the OB subscale seem to have high impacts on SA caregivers (mostly female), similar to family caregivers in Western (e.g., del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011; Farley et al., 2008; Leggett, Zarit, Taylor, & Galvin, 2011; Montgomery et al., 1985; Savundranayagam et al., 2011) and non-Western societies (e.g., Lai, 2010; Daniel & Lai, 2007; Salama & Abou El-soud, 2012; Sinunu, Yount, & El Afify, 2009). However, some emotional impacts, such as "depression", may not be explicitly expressed by family caregivers, as in the case of item 9. This may be due to lack of clarity on the concept of depression, or "stigma" associated with mental illness within our sample, as has been shown to be the case in many Asian (Lauber & Rössler, 2007) and Arab families (Dalky, 2012). Another explanation is that admitting to having depression would mean that "I do not want to take care of my parents", which conflicts with the blessings and religious teachings of providing care to the elderly parent that caregivers were raised to embrace (Osman et al., 2011). Thus,

"sublimation" may also play a role in this, which may decrease the level of low mood and depression associated with the caregiving.

With regards to the RB subscale, although the study results do not confirm the three factor model of CFA (see Table 3.2) found in the original scale (Savundranayagam et al., 2011), the results of two factor model (model 4 of EFA and model 7 of CFA) are consistent with previous findings from a French Canadian study (Farley et al., 2008) in that the RB subscale was psychometrically inadequate and may not be recommended for use in caregiver assessment of either population (see Table 3.3). However, no further explanation about the appropriateness of the meanings or word clarity of this subscale was provided in the French Canadian study (Farley et al., 2008).

From the results of the caregivers' constructs used to describe this dyadic relationship in our study we argue that the relationship between an older person and a caregiver may be personally and culturally relevant and can vary from population to population (e.g., spouses vs. adult children, and male vs. female caregivers) and culture to culture (single vs. multiple caregivers, and individualistic vs. collectivistic caregiving system). Although caregiving for a person with dementia is demanding, words or phrases such as "to manipulate you", "unreasonable requests", "demands over and above what he or she needs", "taken advantage of by your relative", and "caused conflicts" may be negatively interpreted by adult children family caregivers who have strong familial norms of respect for their older parents or relatives, either because of their past memories or experiences (parent-child relationship) or assumed filial and social commitments to older persons in society (Osman et al., 2011).

Table 3.3

Reliability scores of the original and other versions of the MBCBS scale

Version/Subscales	OB	SB	RB	Authors
Original MBCBS				(Savundranayagam et al., 2011)
Spouses	0.85	0.86	0.87	
Adult children	0.93	0.90	0.89	
Translated				(Farley et al., 2008)
(French-Canadian)				
Spouses, adult children, and other relatives	0.91	0.66	0.58	
Translated				Current study
(Arabic-Saudi Arabian)				
Adult children and grandchildren	0.90	0.78	0.40	

Nonetheless, the challenges related to problematic behavioural symptoms seem to be a negative outcome for family caregivers across cultures (e.g., Chiu, Chen, Yip, Hua, & Tang, 2006; Donnelly, 2005; Fuh, 2006; Kar, 2009; Matsumoto et al., 2007), including adult children caregivers in cultures of both the original (Savundranayagam et al., 2011) and our translated scale. In addition, in a family-oriented caregiving system (similar to our sample), conflicts and disagreements (item 14) may be directed toward other factors than the dyadic relationship with the care recipient, such as family members involved in the caregiving relationship (e.g., partners, children, or siblings; Choi, 1993; Kim & Lee, 2003). Thus, cross-cultural clarity and conceptual validation may be enhanced through the inclusion of alternative items that reflect an understanding of culturally specific processes and constructs, rather than simply dropping items, or excluding a particular subscale (e.g., the RB subscale). We have provided a list of suggested items in Table 3.4.

Along with the findings related to the RB subscale, the examination of the construct

of caregiver burden in this study suggests that burden as a construct may not ring

true in the SA context, and should probably be avoided (FCA, 2006; Feinberg,

2002). SA caregivers and other family-oriented cultures with significant spiritual or

religious values (e.g., Chinese, African American; Dilworth-Anderson, Goodwin, &

Williams, 2004; Lai, 2010) may embrace positive, socially developed constructs

(e.g., role reciprocity, filial piety, wisdom of older persons, living arrangements)

associated with elder care before the dementia caregiving journey even arises. In

these cultures, understanding the personal and cultural constructs that inform the

relationship between the caregiver and care recipient, or the family caregiving

system in general, can help to identify contradictions between "old constructs" and

the need to "reconstrue" new constructs related to the new situation. Such an

examination of constructs can be helpful in differentiating between culturally

"expected", and "unexpected" care for a person with dementia. Further,

contradictions in caregivers' construct systems may arise not from the relationship

itself (e.g., old positive constructs associated with the child-parent relationship), but

from an inability to adapt to the new situation (e.g., the need to modify the old

constructs to inform the caregiving experience either with the care recipient or family

members).

Table 3.4

Suggested items for the RB subscale (caregiving constraints)

Items	Suggested items
Item 2	Made you feel as though your needs no longer come first?
Item 5	Frustrated you with unclear needs of your parent or relative?
Item 11	Changed your perceived role in your parent's or relative's life (e.g., from adult child to nurse)?
Item 14	Increased conflicts with other family members?

Note. Items are suggested based on the content analysis of participants' constructs (girds).

Negativity can arise in light of the older person's severe illness, lack of family networking support (e.g., marriage partners, children, grandchildren, and cousins), and inability to maintain other roles in life, such as employment (outside the home) and other challenges related to caregiving expenses. Moreover, such constructs ("as oldest adult child I am the one who is responsible for taking care of my parent" or "what goes around comes around") may prevent caregivers from seeking help either inside (family support) or outside (formal support) the family, even in a society with the appropriate services available. Support services are needed to help caregivers "reconstrue" and adjust to the new experience of long-term caregiving (Hamad et al., 2017). More advanced psychological (cognitive) approaches are also recommended for the same purpose (Cheng, Lau, Mak, Ng, & Lam, 2014). For potential formal care, instead of seeking help from untrained hired workers (housemaids) or private nurses (not covered by government or health or social insurance programs), advanced in-home care support services can also be critical for family-oriented caregiving systems (Walker, 2000).

There are several limitations of this study that should be emphasized. First, although this study is the first of its kind about caregiving experiences in the SA context, the

sampling frame of this study is geographically restricted to only two larger (urban) cities of two regions (Jeddah in Hejaz and Riyadh in Najd) based on the responses we received for participants (willingness to share caregiving experiences). Thus, more research is needed about the experience and challenges of family caregiving across populations (e.g., spouses vs. adult children) and in other areas of SA (e.g., rural areas vs. modern cities). Second, the sample size (N=20) may restrict the generalizability of the quantitative results to other regions in SA or other cultural groups; however, participants' responses (qualitative data) were structured by reference to participants' constructs as well as the predetermined categories or subscales of MBCBS. Theoretical foundation and methods of PCT may also provide a common basis for credibility and transferability of study results to other regions in SA or other cultures with similar constructions of familial values or social assumptions with respect to the older population. Furthermore, the qualitative data for the study was found to have reached saturation (the elicitation and analysis of the content of participants' constructs was continued, after participant 15, and data was collected and analyzed until no new constructs were expressed). Third, although we believe that the theoretical framework and methodological perspective adopted in this study have not previously been used to examine existing measures and related constructs, this framework and methodology may hold promise for similar research with other cultural groups. Because family is the main source of elder care in many family-oriented cultures, future studies should go beyond the traditional methodologies of cross-cultural measurement validation and use constructive methods to evaluate scale items and constructs associated with global gerontological phenomena in different cultures and contexts, from the perspective of the target culture. Such a constructivist investigation can offer caregivers an active voice in the research process, and assist policy makers to articulate the real needs of caregivers in their own terms rather than in pre-determined terms or categories chosen by caregiving experts or policy makers.

3.6   References

Abdelmoneium, A. O., & Alharahsheh, S. T. (2016). Family home caregivers for old persons in the Arab region: Perceived challenges and policy implications. *Open Journal of Social Sciences*, *04*(01), 151–164. doi:10.4236/jss.2016.41019

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *The Journal of American Medical Association*, *311*(10), 1052. doi:10.1001/jama.2014.304

Alobaidi, I., & Aldamigh, S. (2001). *Dementia in Saudi Arabia: Its spread and related factors*. Sultan bin Abdulaziz Foundation. Riyadh, Saudi Arabia.

Ankri, J., Andrieu, S., Beaufils, B., Grand, A., & Henrard, J. C. (2005). Beyond the global score of the Zarit Burden Interview: Useful dimensions for clinicians. *International Journal of Geriatric Psychiatry*, *20*(3), 254–60. doi:10.1002/gps.1275

Chaaya, M., Phung, T. K. T., El Asmar, K., Atweh, S., Ghusn, H., Khoury, R. M., … Waldemar, G. (2016). Validation of the Arabic Rowland Universal Dementia Assessment Scale (A-RUDAS) in elderly with mild and moderate dementia. *Aging & Mental Health*, *20*(8), 880–887. doi:10.1080/13607863.2015.1043620

Cheng, S.-T., Lau, R. W. L., Mak, E. P. M., Ng, N. S. S., & Lam, L. C. W. (2014). Benefit-finding intervention for Alzheimer caregivers: Conceptual framework, implementation issues, and preliminary efficacy. *The Gerontologist*, *54*(6), 1049–1058. doi:10.1093/geront/gnu018

Cheung, F. M., van de Vijver, F. J. R., & Leong, F. T. L. (2011). Toward a new approach to the study of personality in culture. *American Psychologist*, *66*(7), 593–603. doi:10.1037/a0022389

Chiu, M.-J., Chen, T.-F., Yip, P.-K., Hua, M.-S., & Tang, L.-Y. (2006). Behavioral and psychologic symptoms in different types of dementia. *Journal of the Formosan*

Medical Association, 105(7), 556–562. doi:10.1016/S0929-6646(09)60150-9

Choi, H. (1993). Cultural and noncultural factors as determinants of caregiver burden for the impaired eldelry in South Korea. *The Gerontologist, 33*(1), 8–15.

Chou, K. R., Chu, H., Tseng, C. L., & Lu, R. B. (2003). The Measurement of caregiver burden. *Journal of Medical Sciences, 23*(2), 73–82.

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*(2), 184–8.

Dalky, H. F. (2012). Perception and coping with stigma of mental illness: Arab families' perspectives. *Issues in Mental Health Nursing, 33*(7), 486–91. doi:10.3109/01612840.2012.676720

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Pancorbo-Hidalgo, P. L. (2011). Coping and subjective burden in caregivers of older relatives: A quantitative systematic review. *Journal of Advanced Nursing, 67*(11), 2311–2322. doi:10.1111/j.1365-2648.2011.05725.x

Dilworth-Anderson, P., Goodwin, P. Y., & Williams, S. W. (2004). Can culture help explain the physical health effects of caregiving over time among African American caregivers? *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 59*(3), S138–S145.

Donnelly, M. Lou. (2005). Behavioral and psychological disturbances in Alzheimer disease: Assessment and treatment. *Medical Journal, 47*(9), 487–493.

Drisko, J., & Maschi, T. (2015). *Content Analysis.* New York: Oxford University Press.

Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention. *Neurology, 51*(1, S1), S53–S60. doi:10.1212/WNL.51.1_Suppl_1.S53

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, *20*(8), 423–428. doi:10.1111/j.1745-7599.2008.00342.x

Family Caregiver Alliance. (2006). *Caregiver assessment: Voices and views from the field. Report from a National Consensus Development Conference (Vol.II)*. San Francisco, CA.

Farley, N., Demers, L., & Swaine, B. R. (2008). Development of the French Canadian version of the Montgomery Borgatta caregiver burden scale. *Canadian Journal on Aging*, *27*(2), 181–190. doi:10.3138/cja.27.2.181

Feinberg, L. F. (2002). The state of the art: Caregiver assessment in practice settings. *Family Caregiver Alliance*. San Francisco, CA. Retrieved from http://www.rosalynncarter.org/UserFiles/Caregiver Assessment 2002 FCA.pdf

Floyd, F. J., & Widaman, K. F. (1995). Factor analysis in the development and refinement of clinical assessment instruments. *Psychological Assessment*, *7*(3), 286–299. doi:10.1037/1040-3590.7.3.286

Fuh, J.-L. (2006). Study of behavioral and psychological symptoms of dementia in Taiwan. *Acta Neurologica Taiwanica*, *15*(3), 154–160.

Halabi, A. K., & Zafar, J. M. (2010). Care of the elderly in United Arab Emirates. *International Journal of Geriatric Psychiatry*, *25*(9), 925–927. doi:10.1002/gps.2600

Hamad, E. O., AlHadi, A. N., Lee, C. J., Savundranayagam, M. Y., Holmes, J. D., Kinsella, E. A., & Johnson, A. M. (2017). *Assessment of caregiving constructs: Toward a personal, familial, group, and cultural construction of dementia care through the eyes of personal construct psychology*. Manuscript submitted for publication.

Harrington, D. (2009). *Confirmatory Factor Analysis*. New York: Oxford University

Press.

Harwood, D. G., Barker, W. W., Ownby, R. L., Bravo, M., Aguero, H., & Duara, R. (2000). Predictors of positive and negative appraisal among Cuban American caregivers of Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*, *15*(6), 481–7.

Hill, R. A. (1995). Content analysis for creating and depicting aggregated personal construct derived cognitive maps. In R. A. Neimeyer & G. J. Neimeyer (Eds.), *Advnaces in personal construct psychology* (pp. 101–132). Greenwich, CN: JAI Press.

Hinkle, D. N. (2010). The change of personal constructs from the viewpoint of a theory of construct implications. (PhD dissertation, Ohio State University, 1965). *Personal Construct Theory & Practice*, (7 S1).

iMindMap9 [Computer software]. (2016). Retrieved from https://imindmap.com

Jankowicz, D. (2003). *The Easy Guide to Repertory Grids*. John Wiley & Sons.

Kar, N. (2009). Behavioral and psychological symptoms of dementia and their management. *Indian Journal of Psychiatry*, *51*(Suppl1), S77–S86.

Kelly, G. A. (1955). *The psychology of personal constructs*. New York: Norton.

Kim, J.-S., & Lee, E.-H. (2003). Cultural and noncultural predictors of health outcomes in Korean daughter and daughter-in-law caregivers. *Public Health Nursing*, *20*(2), 111–119.

Lai, D. W. L. (2007). Cultural predictors of caregiving burden of Chinese-Canadian family caregivers. *Canadian Journal on Aging*, *26*(Supplement S1), 133–147. doi:10.3138/cja.26.suppl

Lai, D. W. L. (2010). Filial Piety, caregiving appraisal, and caregiving burden. *Research on Aging, 32*(2), 200–223. doi:10.1177/0164027509351475

Landfield, A. (1971). *Personal construct systems in psychotherapy.* Chicago: Rand McNally.

Lauber, C., & Rössler, W. (2007). Stigma towards people with mental illness in developing countries in Asia. *International Review of Psychiatry (Abingdon, England)*, *19*(2), 157–78. doi:10.1080/09540260701278903

Leggett, A. N., Zarit, S., Taylor, A., & Galvin, J. E. (2011). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist*, *51*(1), 76–85. doi:10.1093/geront/gnq055

MAXQDA12 [Computer software]. (2016). Retrieved from http://www.maxqda.com

Matsumoto, N., Ikeda, M., Fukuhara, R., Shinagawa, S., Ishikawa, T., Mori, T., … Tanabe, H. (2007). Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community. *Dementia and Geriatric Cognitive Disorders*, *23*(4), 219–224. doi:10.1159/000099472

Montgomery, R. J. V., Borgatta, E. F., & Borgatta, M. L. (2000). Societal and family change in the burden of care. In W. T. Liu & H. Kendig (Eds.), *Who should care for the elderly? An East-West value divide* (pp. 27–54). River Edge, NJ: World Scientific.

Montgomery, R. J. V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations*, *34*(1), 19. doi:10.2307/583753

Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), *The handbook of gerontology: Evidence-based approaches to theory, practice, and policy* (pp. 426–454). Indianapolis, IN: John Wiley & Sons.

Montgomery, R. V, Stull, D. E., & Borgatta, E. F. (1985). Measurement and the

analysis of burden. *Research on Aging*, *7*(1), 137–52.

Osman, B. A., Shukri, A. S. M., & Othman, N. (2011). Filial piety in Confucianism and Islam: A comparative literary analysis of Qur'an, Hadith, and four Chinses classics. *Islam & Civilisational Renewal*, *3*(1), 133.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594. doi:10.1093/geront/30.5.583

R Core Team [Computer software]. (2016). *R: A language and environment for statistical computing*. R Foundation for Statistical Computing, Vienna, Austria. Retrieved from http://www.R-project.org/.

Revelle, W. (2016). Package 'psych.' Retrieved from https://cran.r project.org/web/packages/psych/psych.pdf

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *59*(4), P185–P190. doi:10.1093/geronb/59.4.P185

Salama, R. A. A., & Abou El-soud, F. A. (2012). Caregiver burden from caring for impaired elderly: A cross-sectional study in rural Lower Egypt. *Italian Journal of Public Health*, *9*(4), 1–10. doi:10.2427/8662

Savundranayagam, M. Y., Montgomery, R. J. V., & Kosloski, K. (2011). A Dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist*, *51*(3), 321–331. doi:10.1093/geront/gnq102

Sibai, A. M., Rizk, A., & Kronfol, K. M. (2014). *Ageing in the Arab Region: Trends, Implications and Policy options.* Beirut, Lebanon. Retrieved from

http://www.csa.org.lb/cms/assets/csa publications/unfpa escwa regional ageing overview_full_reduced.pdf

Sinunu, M., Yount, K. M., & El Afify, N. A. (2009). Informal and formal long-term care for frail older adults in Cairo, Egypt: Family caregiving decisions in a context of social change. *Journal of Cross-Cultural Gerontology*, (24), 63–76.

Walker, A. (2000). Sharing long-term care between the family and the state: A European prspctive. In W. T. Liu & H. Kending (Eds.), *Who should care for the elderly? An East-West value divide* (pp. 78–106). Singapore University Press.

Ward, W. B., & Younis, M. Z. (2013). *Steps toward a planning framework for elder care in the Arab world. Springer briefs in aging.* Springer Science and Business Media, New York, NY. doi:http://dx.doi.org/10.1007/978-1-4614-5978-1

Weech-Maldonado, R., Weidmer, B. O., Morales, L. S., & Hays, R. D. (2001). Cross-cultural adaptation of survey instruments: The CAHPS® experience. In M. L. Cynamon & R. A. Kulka (Eds.), *Seventh Conference of Health Survey Methods* (pp. 75–81).

Zarit, S. H. (1985). *The Hidden Victims of Alzheimer's Disease: Families Under Stress*. NY: New York University Press.

Zarit, S. H., & Femia, E. E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging & Mental Health*, *12*(1), 5–13. doi:10.1080/13607860701616317

Chapter 4

4.1   Introduction

It is well known that with the rapid increase of population aging across the globe, the rates of aging-related neurodegenerative diseases, such as Alzheimer's disease (AD) and other dementias, are also increasing. According to the World Health Organization (WHO, 2016), dementia is one of the major global causes of cognitive deterioration and functional disability among older adults and results in a variety of physical, psychological, social, and financial impacts for families who seek to fulfill the caregiving needs of this population. Because the experience of an individual with AD and other dementias can be different for each person (Alzheimer's Australia, 2016), the experience of family members (e.g., spouses, adult children, relatives, or friends) can also vary both within and across cultures (Dilworth-Anderson & Gibson, 2002; Montgomery & Kosloski, 2013; Zarit, 1985). Broadly speaking, individuals in the same familial or social context are influenced by family norms and social values that are embedded within the larger cultural context (Szinovacz & Davey, 2008). Family members living in a specific social context may have common traditional expectations, and attitudes towards care, as well as common cognitive constructions (or construct system of values and actions) regarding the everyday practice of care (e.g., child care and eldercare).

Along with the global increase of AD and other forms of dementia (Prince et al., 2015), rapid growth of this population has been recognized recently in Saudi Arabia (SA), one of the largest countries in the Arab region. Disease-specific organizations such as the Saudi Alzheimer's Disease Association (SADA) were established in

---

2009 to draw the attention of decision-makers in health sectors and the broader society to the emerging needs of this population and their families. However, insufficient databases and limited research efforts remain barriers to the implementation of a national strategy and the development of appropriate support services. This may be due to firm religious teachings and social norms that rely heavily on family and kinship networks as a cornerstone of providing care to older relatives in Arab families (Sibai, Rizk, & Kronfol, 2014). Research is needed to gain a better understanding of how the everyday lives of family caregivers in SA are affected by their role of providing care to their relatives who live with AD at home. Qualitative constructivist methods of assessment are proposed as a foundation for opening a window to individual interpretations, perceptions, observations, and understandings of personal experiences of in-home family caregiving in a specific cultural context (e.g., the SA cultural context). Consequently, using the theoretical framework and assessment methods of Personal Construct Theory (PCT; Kelly, 1955), the aim of this qualitative study is to examine personal and cultural construct systems associated with the role of family caregivers as constructed in the narratives of everyday caregivers who provide care to older adults living with AD at home in SA.

4.2   Literature Review

Dementia is a broad term that describes a progressive neurological syndrome caused by many diseases in the brain, such as AD, which is the cause of approximately 60 to 70% of dementia cases (WHO, 2016). As described in the Diagnostic Statistical Manual of Mental Disorders (DSM-5), older adults with dementia (or what is called major neurocognitive disorder), share common features of cognitive, emotional, behavioural, and physical functions that may interfere with the person's independence in performing activities of daily living (American Psychiatric Association [APA], 2013). Accordingly, the need for assistance from a

family member or relative to enable the performance of these everyday occupational

activities is frequently necessary, which creates an additional role, emergent

occupation (Moghimi, 2007), or new identity (Montgomery & Kosloski, 2013) for the

family member as a "caregiver." From the perspective of occupational science, an

"occupation" can be defined as an activity of everyday life (e.g., activities of daily

living) that has a name (e.g., informal or unpaid family caregiver) and given values

(e.g., eldercare values) within an individual's experience or culture (Hasselkus &

Murray, 2007; Moghimi, 2007). The new identity (e.g., caregiver identity) associated

with the occupation of caregiving may go beyond the expectations of the pre-existed

familial role or identity (e.g., a spouse or adult child) and expand to new unfamiliar

activities (e.g., personal and medical care), which may result in identity

discrepancies between the old and new role (Montgomery & Kosloski, 2013). Thus,

the daily and sustained occupation of caregiving can be very challenging for many

families, who may not have the knowledge, necessary occupational skills, and

resources to provide practical and effective care that corresponds to the changes in

the person's cognitive and physical abilities over the course of the disease.

Although the impact of the everyday family occupation of caring for older adults with

AD seems similar in many families and cultures, caregiving research (e.g., Liu &

Kendig, 2000) indicates that family caregiving is perceived differently between

societies of the West (e.g., North America) and societies of the East (e.g., South

Asia). Comparing and contrasting perceptions of caregiving across cultures and

ethnic groups can improve our understanding of family caregiving of older adults

with AD and help us better tailor programs and care options that meet the needs of

particular cultural groups (Choo et al., 2003). Within North American contexts, for

example, it has been noted that a family caregiver is considered a "hidden patient" or

"hidden health care team member," because they are pursuing an "unexpected

career" (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995) in meeting dementia-

related occupational demands (Corcoran, 2003; Moghimi, 2007). Thus, the

experience of caregiving in these cultures is well-documented as a stressful experience (Family Caregiver Alliance [FCA], 2006; Pearlin, Mullan, Semple, & Skaff, 1990). This view of caregiving is supported by survey results of 32,800 employed Canadian caregivers (Duxbury, Higgins, & Schroeder, 2009). This survey reported that caregivers spent an average of 30.3 hours in employment in addition to 34.4 hours in caregiving per week. For those caregivers, the role demands are equivalent to a second full-time job, which places individuals at risk of physical and psychological morbidity due to "work-life conflict" (Duxbury et al., 2009) or "role overload" (Aneshensel et al., 1995). In contrast to the negative consequences of care, caregiving was also viewed as a "labor of love," especially for those who wanted to, or chose to, provide care for their relatives (Duxbury et al., 2009). In another study from the United States, Bookman and Harrington (2007) pointed out that despite research efforts and support services provided to caregivers, they were still under-supported, forming a "shadow workforce" in the American geriatric system. To fill the gap, family caregivers often act as geriatric case managers, paramedics, and patient advocates in providing the type of care that is often offered in healthcare or hospital settings which goes beyond the personal care expected to be provided in home settings.

On the other hand, "filial piety" is a familial construct (also referred to as "familism" in some cultures; Miyawaki, 2016) that is emphasized in both the teachings of Confucianism and Islam (Osman, Shukri, & Othman, 2011) and is present in many collectivistic contexts, such as those found in Chinese and Arab families. Filial piety assures personal satisfaction for individuals, harmony within the family intergenerational relationships, and regulation of children's and parents' attitudes and behaviours towards each other. Family caregiving, in this view, is constructed as a partner's or adult child's "duty" or "obligation" (Arokiasamy, 1997; Glass, Chen, Hwang, Ono, & Nahapetyan, 2010; Lai, 2010; Shaji, Smitha, Lal, & Prince, 2003; Sibai et al., 2014). This familial obligation implies that physical and emotional care,

as well as financial security, of parents is prioritized (under all circumstances) over an adult child's personal gratification (Kaindl, 2009). Family-centered constructs of some Eastern societies may play a role in decisions and preferences of care, such as choosing in-home services as a source of support and refusing to access other services outside the family or home (Glass et al., 2010; Khan, Khan, & Mufti, 1999; Miyawaki, 2016). However, with the need for ongoing and intensive care for older adults living with AD, cultural values may not prevent the stressors associated with the demands of caregiving in these populations; rather, negligence toward one's parents can be a source of guilt and public shame (Hooyman & Kiyak, 2011). Personal constructions associated with the pre-existing familial identity and new emerging occupation are not often disclosed by existing structured measures of caregiving, which asserts the need for better constructivist understanding of the occupation of caregiving in specific cultural contexts.

4.3   Theoretical Framework and Methodology

This qualitative study is a secondary data analysis of a mixed methods measurement validation study focusing on the convergence of the technical (quantitative) and conceptual (qualitative) evaluation of scale items driven from the construct of "caregiver burden" in a convenience sample of SA family caregivers caring for relatives with AD (Hamad et al., 2017). The aim of the current study is to gain a better understanding of the caregiving experience in SA through an examination of the overall construal (cognitive templates) and meaning that caregivers attribute to their role as elicited from their narratives (daily observations and experimentations of caregiving). The theoretical perspective of PCT derived from Personal Construct Psychology (Kelly, 1955) guided this study. Considering PCT as a subset of the *hermeneutic constructivist approach* (Chiari & Nuzzo, 1996), PCT with its assumption of bipolar constructs (e.g., good versus bad) and focus on a person's worldview and language in anticipating life events, is assumed to be

compatible with the nature of the contrastive aspects of the caregiving experience (e.g., pitfalls versus rewards, memories versus current experimentations, help inside the home versus help outside the home). The repertory gird technique (RGT; Kelly, 1955) and laddering procedure (Hinkle, 2010; Landfield, 1971) are two constructivist assessment methods of PCT suggested for the individualized examination of a caregiver's construct system (Hamad et al., in press). The two methods are used in this study as techniques to elicit caregivers' personal constructs through a semi-structured interview format.

The study took place in the cities of Jeddah and Riyadh, SA. Twenty family caregivers (of a convenience sample) volunteered to participate (thirteen women or daughters and granddaughters and seven men or sons) and met the inclusion criteria: self-identified as in-home family caregivers of an outpatient parent or relative aged 50 years or older with AD or other form of dementia (based on clinical diagnosis). Participants were at least 18 years old and were primary caregivers who provide help with at least one weekly activity of daily living (ADL) or instrumental activity of daily Living (IADL), and had been caregivers for at least the past 6 months. Consent forms and letters of information were read and signed by participants before the beginning of the interview. Participants met individually with one of the study investigators (the first author or a research assistant) in a variety of settings (e.g., at the location of SADA or a geriatric clinic). Fourteen caregivers were interviewed face-to-face, and six were interviewed via telephone due to some restrictions in the SA society (e.g., gender-match of interviewer and circumstances in caregivers' lives). All interviews took approximately one hour and a half and were audiotaped. The procedure, measures, and informed consent mechanisms were evaluated and approved by the Health Sciences Research Ethics Board at Western University, London, Ontario, Canada and by the Institutional Review Board (IRB) of King Saud University, Riyadh, SA.

For data analysis, this study employed interpretive content analysis (ICA; Drisko & Maschi, 2015) to examine inductively personal constructs (units of analysis) used by participants to describe their role as caregivers. To facilitate the analysis, all of the audiotapes were transcribed in Arabic and read several times to obtain a thorough understanding of the detailed meanings within the data and how the data is related to the SA cultural context. Emerging themes were then translated into English. To establish the trustworthiness of findings, the first and second author (two bilingual researchers who are originally from SA and also familiar with the Canadian context of care through their graduate studies in Canada, referred to as "cross-cultural construing" in PCT) discussed the themes until they reached agreement about the generated themes. Findings were also checked independently by an external auditor, a SA geriatrician who was also familiar with the Canadian health system (Creswell & Miller, 2000). Neither the SADA nor the external reviewer had previous access to the study data. Visual constructions (figures) of emerging themes illustrated in the next section were used to map the researchers' interpretations of participants' construing (referred to as "sociality corollary" in PCT). These illustrations were drawn with the support of a professional artist, who is also familiar with the cultural context of the Arab region.

4.4   Findings

Of the twenty participants, eighteen were adult children and two were grandchildren, who ranged in age from their early twenties to mid-sixties. Twelve worked full-time, and fourteen had a college level of education. Sixteen participants were living with their relatives living with AD in the same household. Eleven of the persons with AD were mothers or grandmothers and nine were fathers or grandfathers who ranged in age from 64 to 90. Two superordinate themes emerged from the analysis of the laddering procedure of participants' interviews (value and act-related constructs). Two predominant confounding roles (associated with the caregiver role) were

identified: (1) the "compassionate adult child" versus the "disobedient adult child"; (2) the "frustrated nurse" versus the "qualified geriatric nurse or case manager" (see Figure 4.1). The first theme reveals the caregivers' unexpected work in a "full-time or around-the-clock job" to care for a "patient with multiple chronic illnesses" or "fully disabled patient." The second theme reveals the expectation that the caregiver will embrace Islamic teachings (e.g., God's will) and the familial obligation (e.g., reciprocity of family roles) to "take care of an elderly parent." From the analysis of participants' grids (constructs elicited from the RGT of participant interviews), subordinate themes related to the two conflicting roles (nurse versus adult child) were also revealed.
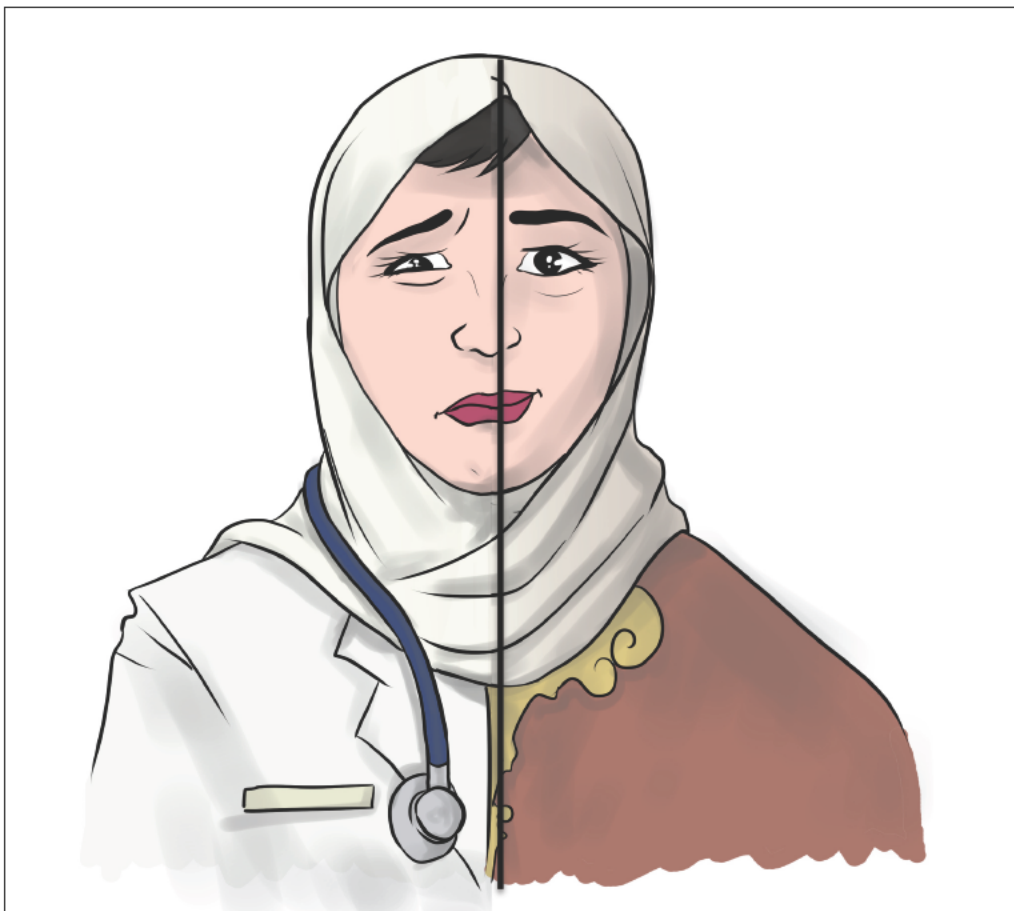
Figure 4.1. The confounding role of a SA family caregiver (frustrated nurse versus compassionate adult child).

Although both superordinate and subordinate themes were identified in all of the participants' narratives (referred to as "commonality corollary" in PCT), they also included shades of unique construct systems expressed by some participants (referred to as "individuality corollary" in PCT).

For the purpose of data illustration, themes and subthemes are presented separately in this section; however, as shown in Figure 4.2, themes and subthemes overlap and interact in a continuum of contrasted constructs that represent predominant ups and downs identified in the caregiver's role and journey of care. Short excerpts elicited from participants' interviews
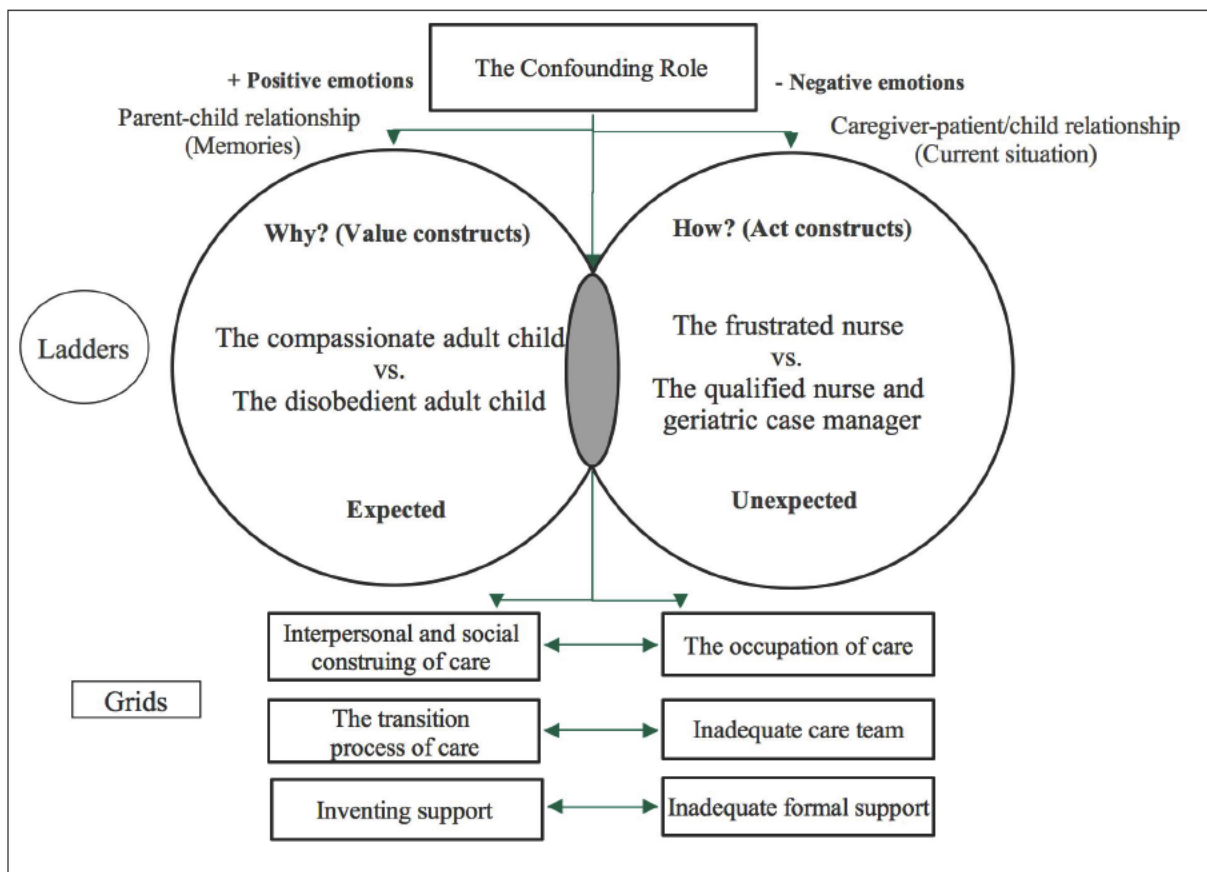
Figure 4.2. The continuum of the confounding role of a SA family caregiver.

demonstrate examples of the themes and subthemes identified in the study and are presented in the following sections. For the purpose of confidentiality, all participants' names were replaced with numbers (e.g., P #) with their age and gender identified in brackets. A longer excerpt of the caregiver's confounding role and its related constructs from one participant's account is presented in Appendix J.

4.4.1 The Frustrated Nurse

"I am the one who does everything, but above all I am the nurse."

(P# 2, 37 year old, female)

Figure 4.3. The construction of the "frustrated nurse."

In response to "how" questions (act ladders or constructs) on the effect of care in the participant's daily life (i.e., decreased time to oneself, changed daily routine, left with almost no time to relax, etc.) many participants indicated that the role of nurse was placed ahead of other roles in their lives (see Figure 4.3). Constructs that characterized the parent or grandparent as a vulnerable person, with decreased capabilities were very common. Participants frequently used descriptions, such as he or she is "like a child," "completely disabled," a "changed person," who they "try very hard" to communicate with. Three subthemes were identified in the construction of this role: 1) the occupation of daily care; 2) inadequate care team; and 3) inadequate formal support.

4.4.1.1 The Occupation of Daily Care

"*I am on a long sick-leave right now. It is a job besides my job.*"

(P #11, 50 year old, female)

Figure 4.4. The construction of "the occupation of daily care."

As illustrated in Figure 4.4, the construction of the occupation of daily care was a major subtheme. Many participants identified that their tasks went beyond what they expected to do for their parents as they aged, including dimensions of basic daily activities or household chores. Participants used words, such as "additional responsibility" and "extra duty" to describe the extra chores required. Further, participants often described themselves as "nurses" and care receiver as a "patient" or a "child." Eleven of the participants indicated that the daily routine of care took more than eight hours per day (with an average of five years of care provision). For all participants, the occupations of care ranged from personal and hands-on care (e.g., "I feed him or her," "I go with him or her to the toilet") to advanced nursing tasks to manage illness symptoms that a patient with moderate to severe dementia and other chronic illnesses may have (e.g., "I deal with his or her sleep disturbances," "I move and lift him or her onto a bed," "I check his or her blood pressure"). A number of participants also discussed dealing with emergency

situations (e.g., "he or she had episodes of seizures," "he or she choked on food").
All participants indicated that they had no previous knowledge of how to perform
these tasks, and that their daily caregiving was often associated with "fears of
making mistakes" and "physical or psychological risks" for either the care receiver or
caregiver.

Variations were commonly depicted among participants in approaches to meeting
their care responsibilities (ten of the participants were married, nine were single, and
one was separated at the time of the study). Some participants decided to reduce or
modify their daily work routine (e.g., "I changed my work hours for him or her"),
others decided to leave their job temporarily (e.g., "I usually take short vacations
from my work"). Quitting the job completely was the optimal option for a few
participants who had no support for the daily tasks (e.g., "I left my job to take care of
my mother or father and my siblings support us financially"). The few participants
who had support and shared caregiving with their siblings or hired live-in
housekeepers or nurses (four participants reported the assistance of a housekeeper,
while two participants indicated in-home nursing support) reported that when they go
to work or for a short vacation they often continue to "worry" or feel a "sense of guilt,"
even when their parent is under the supervision of other caregivers.

4.4.1.2 Inadequate Care Team

"No one can do it alone. Alzheimer's needs a team of carers and medical consultants."

(P #19, 27 year old, male)

Figure 4.5. The construction of an "inadequate care team."

Beyond personal care and nursing tasks, the majority of participants depicted the daily life of their parent as demanding communication and management capabilities from a team of carers and healthcare professionals (see Figure 4.5). For example, inside the home, many participants expressed the need for a "family care plan," or "fair division of care tasks between siblings" and "financial coverage" for out of pocket expenses of "disease and other illnesses' medication," "medical equipment," and "hired qualified companions" for the parent. The majority of participants hired a housekeeper (mostly for help with household chores). For formal support outside the home, a number of participants indicated that their parent required a better "medical plan" and team of "professional medical consultants" to help track the health status regarding the course of the disease, medication doses, and alternative care options. In addition, many participants reported frustrated efforts to seek answers from practitioners about their parents' diet, daily occupational, physical, and social activities, language and swallowing difficulties, resistance to care, and behavioural disturbances. Feelings of "self-insufficiency" and "low mastery of skills" towards self, as well as "resentment," and "low satisfaction" with the effort of others (e.g.,

physicians, siblings, or hired companions, such as housekeepers or nurses) were common constructs among participants. Only five participants of the twenty participants had care plans and back-up care when needed, and participants arranged those plans after many attempts.

4.4.1.3   Lack of Formal Support

"*Caregivers need more attention and support from the health care system.*"

(P #20, 24 year old, male)

Figure 4.6. The construction of an "inadequate formal support."

For all participants, as indicated in Figure 4.6, the emergent of the nursing tasks in addition to lack of knowledge of practical caregiving skills were related to limitations of formal support from the healthcare system. Participants indicated that they adapted to their parents' needs through various approaches, such as "learning by doing," "experimenting," "asking other experienced caregivers," and "self-navigating" to access available medical care and social services. The majority of participants reported challenges with the health system as related to determining the diagnosis, lack of public awareness (e.g., "we realized that there was something wrong with my mother's/father's behaviour and memory"), lack of availability of AD specialists or memory clinics (e.g., "we didn't know where to go to assess my mother/father"), and

conflicting medical opinions (e.g., "different physicians had different opinions"). Many participants also reported challenges related to the care received from physicians and other healthcare professionals (e.g., "you wait for months to get an appointment for follow up," "physicians only give you medications and you do the rest with daily care challenges," "some healthcare professionals have no idea about Alzheimer's") and in emergency cases (e.g., "you wait for hours in emergency rooms with your parent"). As a consequence, some participants preferred to go to follow up appointments without their parent present in order to "save time and energy" at the clinic, especially in the moderate to late stages of the disease when the patient was "hard to control" or "can't walk or move." In addition, a few participants reported access to in-home medical services "after institutionalization" of their parent and with "basic care" only. Relocation to a nursing home was not an optimal option for the majority of participants; instead they expressed a desire for holistic "in-home medical services," "social care policies," "assistive technology for home," "day care for elderly," and "rehabilitation centres." They also indicated a need for care options that allow their family member to "stay active and connected with others," and to have a "safe place" to go while the caregiver is at work.

4.4.2 The Compassionate Adult Child

"*I do it with love and compassion. It is my duty, and she deserves it.*"

(P# 2, 37 year old, female)

Figure 4.7. The construction of "compassionate adult child."

As shown in Figure 4.7, participants' responses to "why" questions (value ladders or constructs) regarding their care for an elderly parent or relative, frequently indicated the use of positive constructs, such as "it is my pleasure to give back what he or she did for me," "he or she was very strong and wise." Three subthemes were identified from this prominent theme: 1) interpersonal and social construing of care; 2) the transition process of care; and 3) inventing support.

4.4.2.1 Interpersonal and Social Construing of Care

"I am thinking of my kids and myself when I get old too. What goes around comes around."

(P #8, 34 year old, female)

Figure 4.8. The construction of "interpersonal and social construing of care."

Describing their rationale for doing what they do, many participants passionately, and some tearfully and mournfully, reported that an adult child is "responsible" for embracing Islamic teachings (e.g., "what God asks us to do") and meeting familial reciprocal commitments (e.g., "what my parents raised us with") and social norms (e.g., "what our extended family or society expect us to do") to provide parents with the "right" of being cared for by adult children (see Figure 4.8). In light of this, the majority of participants stated that they were "glad", "honoured", and "very willing" to "pay back" what their parents and grandparents had done for them in the past. Four participants noted the unexpected "overload" or "burden" was still "rewarding." Regardless of both the pitfalls and uplifting dimensions described by participants, with the lack of understanding and the ambiguous progression of the disease, it was very hard for many participants to distinguish between their strengths (e.g., "what can I do better to comfort my parent?") and limitations (e.g., "when do I need to stop and not make him or her feel angry at me?," "when do I need to ask for formal help?").

Variations among participants (who all have at least three immediate family members) were also noted regarding which adult child should take the primary responsibility for care. For example, while one participant described the feelings of being "scattered" and "overwhelmed" with multiple roles in life (e.g., wife, mother, and full-time worker) and having siblings who could share the caregiving, she preferred to take the primary responsibility; indicating that otherwise, a sense of "guilt" would be felt. Similarly, "weekend visits" were "not enough care," as reported by one participant who shared the caregiving with her older sibling during the weekdays. On the other hand, two participants noted that they either received no help (e.g., "nobody cares about how I feel") or did not receive the help they think they need (e.g., "they rarely offer help") regardless of the number of siblings they have.

4.4.2.2 The Transition Process of Care

Figure 4.9. The construction of "the transition process of care".

"Role reversal is psychologically challenging, and you need to change and re-adapt again each time you think you are adjusted to it."

(P #3, 32 year old, male)

As illustrated in Figure 4.9, although the majority of participants described their strong desire to pay back and provide care, accepting the new situation and learning to live with the new person (e.g., "a man or woman with stolen memory") was frequently depicted as a challenging transition for both participants and their families. Recognizing the disease started for many participants with "heavy denial" and "trying to prove the diagnosis to be wrong." In the larger society around them, participants depicted "social pressure," especially from family, to accept the parent as an "Alzheimer's patient" rather than "he or she is just getting older and becoming more forgetful," "insane," or "a bewitched person." Many participants reported that over time they "lost hope" and tried despite the frustrations, to "learn to adapt" to the needs of the new situation. Many participants indicated that every new stage of the disease required "extra effort to adapt" to the parent's cognitive, physical, and personality changes. Feelings of "social embarrassment" in family gatherings or public places due the parent's (who was in the moderate stages) "uncharacteristic behaviours" were also described by some participants. Participants caring for a parent in later stages of the disease indicated feelings of "sadness," "grief," and "incompetence," due to "meaningless communication" with the parent. With regard to family relationships during the transition process, some participants reported that their parents' illness became a motivation for "family solidarity" and "intergenerational unity," for instance when family gathered each week to visit or assist the parent or grandparent, when this was not the case before the illness. For other participants, the consequences of the new situation were described as "making the parent's needs always as priority," "social isolation," and "less time for family and friends."

4.4.2.3 Inventing Support

"I usually try home remedies recommended by others for bedsores, besides medications, and sometimes it works."

(P #1, 63 year old, female)

Figure 4.10. The construction of "inventing support."

To cope with the duties of care and the needs of the parent or grandparent living with AD, many participants disclosed "personal trials" for developing coping approaches (see Figure 4.10). Some of these approaches included the use of un-prescribed medications (e.g., "taking medical advice from family members or other caregivers"), traditional herbal medicine or food supplements (e.g., "trying home remedies and traditional herbs"), or other advice found in the media or from public sources (e.g., "newspapers, websites, and public social media accounts"). Other approaches described by participants included "turning to God" and "prayers," with requests to develop "patience and tolerance" to face this disease, which was a "gift" for some and "punishment" for others. "Reading books about the disease" and "reaching services through disease-specific and other social organizations" were also coping strategies identified by a few participants. However, the majority of participants identified the best source of advice as "asking people [caregivers] who are in the same situation." Barriers, such as "it needs transportation," "takes time and effort," and "it is hard to leave the parent alone" were also articulated by many

participants in relation to attending face to face support groups organized by the SADA. A few participants took an advocacy role and created a virtual support group through WhatsApp Messenger (a free messaging application for smart phones) to be used as "relief from such emotional stress" and as a "24/7 helpline" for providing advice to caregivers. Overall, finding support was a challenging experience identified by the majority of participants. However, for some, searching for support was seen a source of personal growth (e.g., "I am stronger than before," "I learned a lot from living with this disease") and fulfillment ("I feel satisfied when he or she looks happy and well," "I want others [caregivers] to get educated and provide better care for their parents").

4.5   Discussion and Practical Implications

This study is unique in its contribution of a qualitative constructivist examination of personal and cultural constructs associated with the family caregiving experience of adult children caring for their relatives living with AD in the SA context. Given the nature of the RGT and laddering procedure and its underlying theory, we were able to analyze the content of twenty caregivers' accounts and draw a cognitive map of the shared constructs that describe the challenges that caregivers confront in their daily experimentations with the occupation of AD daily care. Due to the lack of research in both the Arab and SA cultural context in family gerontology, our findings are briefly discussed against relevant constructs of caregiving defined in the internationally published literature, particularly in North American and Asian contexts. In addition, the findings are also compared against concerns articulated in a recent documentary called "Alzheimer" (Sandokji, 2016), produced by the SADA and narrated by seven SA family caregivers who take care of their parents living with AD at home. Consistent with qualitative research design, our findings may be transferrable to social groups who share similar characteristics with our sample either in other local areas in SA or potentially in other family-oriented societies.

Potential implications for better caregiving outcomes are also discussed in this section.

Findings of this study confirm that family caregiving of older adults with AD in SA, is both a global (Prince et al., 2015) and a local challenge (Sandokji, 2016). In particular, the findings highlight the significance of the everyday occupations of family caregivers (Hasselkus & Murray, 2007; Moghimi, 2007), and show how these encompasses a set of meaningful values (as depicted in the constructs related to the role of compassionate adult child) and the organized demands of occupationally and medically-related activities (as described in the constructs related to the role of frustrated nurse). Montgomery and Kosloski (2013) propose that with the emergence of the new role or occupation of caregiving, there are gradual changes in a family member's identity as a consequence of the transitional nature of the relationship with the parent (e.g., from adult child as in mother-daughter relationship into caregiver as in caregiver-care recipient relationship). As noted by the SA "Alzheimer's" documentary (Sandokji, 2016), as well as described by many participants in our study, the transition to a "nurse" identity corresponds to the advanced medical care that is undertaken by family caregivers with insufficient support from the healthcare system. Seeking better quality of life for relatives with AD through "financial coverage," (or healthcare insurance) "social care policies," and alternative community-based options for care, such as "day care for elderly" and "rehabilitation centres" were suggested in both the documentary and our study. Constructs referring to "nursing," or "health related" tasks (e.g., managing medications, helping with assistive devices, preparing food for special diets, and operating medical equipment) were also highlighted in the results of an online survey of 1,677 American family caregivers conducted by the American Association of Retired Persons (AARP; Reinhard, Levine, & Samis, 2012). "Personal responsibility to avoid institutionalization" was, for example, one of the main reasons most participants in the survey referred to in relation to taking on nursing tasks despite "feelings of

pressure" associated with such tasks. In both the present study and the Reinhard et al. (2012) survey, there was an indication that tasks of caregiving (or nursing) occupations often go beyond the personal preferences and cultural expectations of providing daily personal care or assistance with household chores, especially when the condition of the older adult with AD becomes moderate to severe. For example, participants in this study frequently reported the performance of advanced nursing tasks, such as dealing with sleep disturbances, moving and lifting, and monitoring chronic diseases, which were often performed through personal experimentations. A lack of appropriate training for such caregiving occupations was reported in both studies. The challenges associated with caregiving as an emerging familial occupation asserts the need for better understanding of, and preparation for, the caregiving occupation. The current study contributes to this aim in the SA context.

Despite variations in individual construing, the construction of caregiving in SA as an "obligation" that needs to be fulfilled to meet "God's will" and the expectation of "reciprocity" towards parents (Osman et al., 2011) was depicted by all participants, suggesting the construct of "compassionate adult child" (versus "disobedient adult child"). Thus, caregivers in SA could be better prepared for recognizing the necessity (and construction) of an associated identity of "qualified nurse or geriatric care manager" (versus "frustrated nurse"). From the perspective of PCT, constructs of transition such as frustration, anxiety, guilt, and other psychological problems may emerge from a person's invalidation of an old personal construct system (e.g., old identity of family member) to a new experience (e.g., new identity of caregiver) using the same old constructs rather than developing new constructs that may better accommodate the new situation (Boeree, 2006). Educating family caregivers in everyday language at the individual as well as familial and societal level about *reconstructing* or revising their old theories (personal construct systems) about caring for an elderly parent. This reconstruction process will further facilitate the development of new personal and social constructs more relevant to the "why"

questions of issues surrounding the caregivers occupation. Both, the reconstruction of old personal theories and development of new personal theories, could be included as key components of caregiver educational support programs. To produce more insightful and client-centred approaches for occupation-based education, alongside critical thinking, stress management, and problems-solving strategies of occupational therapy (Moghimi, 2007), there is a need to provide caregivers with insights into "why" questions, such as: normal brain aging versus progressive brain disease; feelings of disloyalty versus asking for help; child-like person versus person with living with dementia; and pharmacological treatments versus traditional herbs. Caregivers at risk of harm to their psychological well-being can be educated to seek referrals to individual or family (group) psychotherapy (Cheng, Lau, Mak, Ng, & Lam, 2014; Coon, Gallagher-Thompson, & Thompson, 2003), while innovative approaches, such as online or telephone support (Gallagher-Thompson et al., 2012) that respond to the challenges of leaving the home when caring for a person with AD may also be important.

With regard to preparation for caregiving occupations, providing caregivers with in-depth and skill-based training that responds to the "how" questions (e.g., moving and lifting older adults, environment modifications to facilitate activities of daily life, strategies for coping with cognitive decline and behavioural issues) can help the primary caregivers or their hired companions (housekeepers or nurses) and the family care system at home adjust to the situation to better maintain the older adults' quality of life and respond to their disease-related cognitive and physical changes (Corcoran, 2003). Education can take the form of workshops or *role-playing* (a therapeutic technique suggested by PCT; Boeree, 2006). However, in light of the circumstances of caregivers' lives, the educational delivery methods should go beyond traditional face-to-face methods and include audiovisual and virtual methods of training (Gallagher-Thompson et al., 2012; Lewis, Hobday, & Hepburn, 2010). Additional help to caregivers can be provided though improved arrangements related

to navigation, communication, and interaction with professionals in both the health and social care system. Further, team-based approaches, long-term support of in-home rehabilitation therapies and high quality community-based home care services (Callahan et al., 2016) are required to ensure better quality of life for both family caregivers and care recipients with AD.

4.6   Conclusions and Future Research

This study contributes to the literature that the experience of adult children family caregivers of older adults with AD, in the SA context, may carry a heavy load that goes beyond personal and basic activities of care to include the work of unpaid nursing and geriatric case management. However, further research is needed to explore the individual and group construing of the family caregiving experience in SA across various groups (e.g., spouses versus adult children, male caregivers versus female caregivers) as well as care contexts (e.g., healthcare professionals versus family caregivers). To support family caregivers in SA, great investment in structuring family-centred support programs, and conducting research and program evaluation is required. Support programs that incorporate education of dementia-related issues and performing the tasks of caregiving occupations are suggested. A national AD and other dementias strategy that integrates efforts of formal and family care of older adults living at home is also vital to enhance the quality of care delivered through health and social care systems. Such work has the potential to empower caregivers and increase their confidence and satisfaction in fulfilling their long-term familial obligations as enacted through the occupation of caregiving.

4.7   References

Alzheimer's Australia (2016). *About dementia and memory loss*. Retrieved from
https://www.fightdementia.org.au/about-dementia

American Psychiatric Association. (2013). *Diagnostic and statistical manual of
mental disorders* (5th ed.). DSM-5. Washington, DC: Author.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995).
Profiles in caregiving: The unexpected career. *Profiles in caregiving: The
unexpected Career.* Academic Press.

Arokiasamy, J. T. (1997). Malaysia's aging issues. *Medical Journal of Malaysia*,
52(3), 197–201.

Boeree, C. G. (2006). *Personality theories: George Kelly (1905-1967)*. Retrieved
November 22, 2015, from http://webspace.ship.edu/cgboer/kelly.html

Bookman, A., & Harrington, M. (2007). Family caregivers: A shadow workforce in the
geriatric health care system? *Journal of Health Politics, Policy and Law*, *32*(6),
1005–1041. http://doi.org/10.1215/03616878-2007-040

Callahan, C. M., Boustani, M. A., Schmid, A. A., LaMantia, M. A., Austrom, M. G.,
Miller, D. K., … Hendrie, H. C. (2016). Targeting functional decline in Alzheimer
Disease. *Annals of Internal Medicine*, *Nov 22*. http://doi.org/10.7326/M16-0830

Cheng, S.-T., Lau, R. W. L., Mak, E. P. M., Ng, N. S. S., & Lam, L. C. W. (2014).
Benefit-finding intervention for Alzheimer caregivers: Conceptual framework,
implementation issues, and preliminary efficacy. *The Gerontologist*, *54*(6),
1049–1058. http://doi.org/10.1093/geront/gnu018

Chiari, G., & Nuzzo, M. L. (1996). Psychological constructivisms: A metatheoretical
differentiation. *Journal of Constructivist Psychology*, *9*(3), 163–184.
http://doi.org/10.1080/10720539608404663

Choo, W.-Y., Low, W.-Y., Karina, R., Poi, P. J. H., Ebenezer, E., & Prince, M. J. (2003). Social support and burden among caregivers of patients with dementia in Malaysia. *Asia-Pacific Journal of Public Health*, *15*(1), 23–29. http://doi.org/10.1177/101053950301500105

Coon, D. W., Gallagher-Thompson, D., & Thompson, L. W. (Eds.). (2003). *Innovative interventions to reduce dementia caregiver distress: A clinical guide*. New York: Springer Publishing.

Corcoran, M. A. (2003). *Practical skills training for family caregivers*. Family Caregiver Alliance. Retrieved from https://www.aota.org/-/media/Corporate/Files/AboutOT/consumers/Caregivers/Skills.pdf

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice*, *39*(3), 124–130. http://doi.org/10.1207/s15430421tip3903_2

Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease and Associated Disorders*, *16*(Suppl 2), S56–S63. http://doi.org/10.1097/00002093-200200002-00005

Drisko, J., & Maschi, T. (2015). *Content analysis*. New York: Oxford University Press.

Duxbury, L., Higgins, C., & Schroeder, B. (2009). *Balancing paid work and caregiving responsibilities: A closer look at family caregivers in Canada*. Canadian Policy Research Networks. Retrieved from http://www.cprn.org/documents/51061_EN.pdf

Family Caregiver Alliance. (2006). *Caregiver assessment: Voices and views from the field*. *Report from a National Consensus Development Conference (Vol.II)*. San Francisco.

Gallagher-Thompson, D., Tzuang, Y. M., Au, A., Brodaty, H., Charlesworth, G., Gupta, R., … Shyu, Y. (2012). International perspectives on nonpharmacological best practices for dementia family caregivers: A review. *Clinical Gerontologist*, *35*(4), 316–355. http://doi.org/10.1080/07317115.2012.678190

Glass, A. P., Chen, L.-K., Hwang, E., Ono, Y., & Nahapetyan, L. (2010). A cross-cultural comparison of hospice development in Japan, South Korea, and Taiwan. *Journal of Cross-Cultural Gerontology*, *25*(1), 1–19. http://doi.org/10.1007/s10823-009-9108-8

Hamad, E. O., AlHadi, A. N., Tremblay, P. F., Savundranayagam, M. Y., Kinsella, E. A., Holmes, J. D., Lee, C. J., & Johnson, A. M. (2017). *Reconstruction of a Caregiver Burden Scale: Exploratory and Content Analyses to Identify Culturally Sensitive Items in Saudi Arabia.* Manuscript submitted for publication.

Hamad, E. O., AlHadi, A. N., Lee, C. J., Savundranayagam, M. Y., Holmes, J. D., Kinsella, E. A., & Johnson, A. M. (in press). Assessment of caregiving constructs: Toward a personal, familial, group, and cultural construction of dementia care through the eyes of personal construct psychology. *Journal of Cross-Cultural Gerontlogy.*

Hasselkus, B. R., & Murray, B. J. (2007). Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia. *The American Journal of Occupational Therapy, 61*(1), 9–20.

Hinkle, D. N. (2010). The change of personal constructs from the viewpoint of a theory of construct implications. (PhD dissertation, Ohio State University, 1965). *Personal Construct Theory & Practice*, (7 S1).

Hooyman, N., & Kiyak, H. A. (2011). *Socialgerontology: A multidisciplinary perspective* (9th ed.). Peason.

Kelly, G. A. (1955). *The psychology of personal constructs*. New York: Norton.

Khan, L. A., Khan, S. A., & Mufti, M. H. (1999). Care of the elderly: Parallel thinking. *Saudi Medical Journal*, *20*(985–86).

Lai, D. W. L. (2010). Filial Piety, caregiving appraisal, and caregiving burden. *Research on Aging*, *32*(2), 200–223. http://doi.org/10.1177/0164027509351475

Landfield, A. (1971). *Personal construct systems in psychotherapy.* Chicago: Rand McNally.

Lewis, M. L., Hobday, J. V, & Hepburn, K. W. (2010). Internet-based program for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, *25*(8), 674–9. http://doi.org/10.1177/1533317510385812

Liu, W. T., & Kendig, H. (Eds.). (2000). *Who should care for the elderly? An east-west value divide*. Singapore Uinversity Press and World Scientific Publishing.

Miyawaki, C. E. (2016). Caregiving practice patterns of Asian, Hispanic, and non-Hispanic White American family caregivers of older adults across generations. *Journal of Cross-Cultural Gerontology*, *31*(1), 35–55. http://doi.org/10.1007/s10823-016-9281-5

Moghimi, C. (2007). Issues in caregiving. *Topics in Geriatric Rehabilitation*, *23*(3), 269–279.

Montgomery, R. J. V., & Kosloski, K. D. (2013). Pathways to a caregiver identity and Implications for Support Services. In R. J. V. Montgomery & K. D. Kosloski (Eds.), *Caregiving across the lifespan: Research, practice, policy* (pp. 131–156). New York: Springer-Verlag.

Osman, B. A., Shukri, A. S. M., & Othman, N. (2011). Filial piety in Confucianism and Islam: A comparative literary analysis of Qur'an, Hadith, and four Chinese classics. *Islam & Civilisational Renewal*, *3*(1), 133.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594. http://doi.org/10.1093/geront/30.5.583

Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer report 2015: The global impact of dementia: An analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

Reinhard, S. C., Levine, C., & Samis, S. (2012). *Home alone: Family careigvers providing complex chronic care*. AARP Public Policy Institute. Retrieved from http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

Sandokji, A. [Saudi Alzheimer]. (2016, June 8). *Alzheimer documentary* [Video file]. Retrieved from https://www.youtube.com/watch?v=Idjj3JoBKx0

Shaji, K. S., Smitha, K., Lal, K. P., & Prince, M. J. (2003). Caregivers of people with Alzheimer's disease: A qualitative study from the Indian 10/66 Dementia Research Network. *International Journal of Geriatric Psychiatry*, *18*(1), 1–6. http://doi.org/10.1002/gps.649

Sibai, A. M., Rizk, A., & Kronfol, K. M. (2014). *Ageing in the Arab region: Trends, implications and policy options.* Beirut, Lebanon. Retrieved from http://www.csa.org.lb/cms/assets/csa publications/unfpa escwa regional ageing overview_full_reduced.pdf

Szinovacz, M. E., & Davey, A. (Eds.). (2008). *Caregiving contexts: Cultural, familial, and societal implications*. New York: Springer Publishing.

Zarit, S. H. (1985). *The hidden victims of Alzheimer's disease: Families under stress*.

NY: New York University Press.

World Health Organization. (2016). *Fact sheet on dementia.* Retrieved from

http://www.who.int/mediacentre/factsheets/fs362/en/

Chapter 5

5.1   Emerging Insights and Concluding Thoughts

This doctoral dissertation consists of three related articles that emphasize the significance of examining the construct systems of dementia care in various social groups and cultural contexts. The core theme of this research is the personal and group construction of the family caregiving experience of older adults with Alzheimer's Disease (AD) and other forms of dementia within the social and cultural context of Saudi Arabia (SA). A mixed methods research design was chosen to examine the personal and social constructs used by family caregivers to describe their caregiving experience. The factor structure of an existing quantitative measure of "caregiver burden" (Montgomery Borgatta Caregiver Burden Scale; Montgomery, Borgatta, & Borgatta, 2000) was used in comparison with caregiving personal constructs in addition to content analysis of narratives elicited from family caregivers. The theoretical framework of personal construct theory (PCT; Kelly, 1955) and its constructivist methods was used to guide the theoretical lens and data collection and analysis in all three manuscripts presented in this dissertation. In light of research findings, this chapter discusses emerging insights from the three manuscripts and concludes the dissertation. Within the examination of research strengths and limitations and the researcher's personal growth during the research journey, a proposal for a future research agenda in the field of caregiver assessment and family gerontology is also presented.

The first manuscript (Chapter Two) of this doctoral work, entitled *Assessment of caregiving constructs: Toward a personal, familial, group, and cultural construction of dementia care through the eyes of personal construct psychology*, was developed after completing a narrative review of current literature on global perspectives of dementia care and determination of a gap in identifying personal and cultural

constructs related to the emerging occupation of family caregiving of older adults with AD and other forms of dementia in various cultures. The review led to a presentation of PCT as a constructivist and flexible approach to gain a better understanding of the construction of dementia care in the target social or cultural group and to a proposal for the implication of PCT methods and therapeutic approaches to generate (and reconstruct) individual and group mental maps that shape dementia care. PCT and its methods is a novel and innovative framework to guide the examination of caregiving-related constructs among family caregivers. In this research, the focus was on examining the caregiving construct systems of a convince sample of 20 family caregivers who provide daily care at home for their relatives with dementia. Further applications of PCT are described in the next section of this chapter.

The second manuscript of this doctoral work (Chapter Three, entitled *Reconstruction of a caregiver burden scale: Exploratory and content analyses to identify culturally sensitive items in Saudi Arabia*) arose from the defined gap in Chapter Two and led to a mixed methods study to examine the construction of an existing measure of caregiver burden and identify culturally sensitive items of the scale in the target cultural context (SA). In addition to the psychometric data of the translated scale, the theoretical framework of PCT and its methods helped to facilitate the examination of the content of scale items in comparison to participants' personal constructs. The results of the study provide further explanation of how the conceptual evaluation of one subscale (RB) may help differentiate between the construction of caregiver (relationship) burden in the culture of the original scale (North American population) and the target culture (SA population). Although this study is the first of its kind in the context of SA, there is a need for further research with larger sample of caregivers for generalization of findings. Such an application is presented in the next section, where a future plan is proposed.

The third and final manuscript (Chapter Four, entitled *"If he was not my father, I wouldn't do it": The confounding role of family caregivers for older adults with dementia in Saudi Arabia*) presented the findings and further examination of the construction of family caregiving in SA. Family caregivers' daily narratives were examined alongside the conceptual evaluation of scale items that was addressed in the mixed methods research design described in Chapter Three. The content analysis of participants' narratives revealed the contrasting nature of the family caregiver role (frustrated nurse vs. compassionate adult child) within family-oriented caregiving system. The study findings suggest the need for integration of both the formal (health system) and informal (family) care of older adults with dementia to provide better care; thus, the study may help inform a national plan for dementia and caregiver support programs with an emphasis on education of dementia-related issues and skills-based training on performing the daily tasks of the emergent occupation of family caregiving in SA. This study uses only two constructivist (qualitative) methods of PCT. This research suggests that there is an opportunity to apply other approaches and methods of PCT for a more in-depth understanding of the family caregiving role.

5.2   Future Directions

The study of aging-related diseases and family gerontology is still in its infancy in the Arab region, including SA. This is a significant problem, given that (as noted in Chapter One), there are only 12 eldercare homes (i.e., non-medical housing for older adults with no available family member support) in all of SA, and there is no formal (i.e., governmental) long-term care system in SA. Thus, there truly is no other option other than family-based care – and supports need to be put in place to facilitate family caregiving.

Considerable effort and work are required to develop the services and support programs that can meet the proposed needs of the aging population and their

families in the region. In the case of eldercare services in SA, such efforts are crucial in order to guide the country's vision of 2030 ("Vision 2030," 2016) to improve the healthcare system. These services might include a variety of family supports, such as homecare, community care, respite care, transportation, and rehabilitation support. The present research supports the conclusion that even the most dedicated caregiver cannot provide continuous care for 24 hours a day, 7 days a week – and these individuals must be provided with resources that will ease the psychological, social, emotional, and financial stresses that caregiving can produce.

Concurrent with this, the field of aging in other areas of the world is undergoing constant change, and there is great potential for creative and innovative research, as well as knowledge exchange within and among the education and health and social care sectors at both the local and international levels. As an emergent scholar, methodologist, and educator in the field of measurement and methods with a focus on family gerontology and caregiver assessment, the next step following my doctoral research is to expand the area of my research focus and create a long-term and short-term research plan. To expand the focus of my research, I have enrolled in the Gerontology Certificate Program at Ryerson University (started from September 2016) to help me view aging-related diseases and caregiving experiences from a boarder bio-psycho-social perspective. My future plan for research is to build upon the strengths, limitations, and potential implications that have been raised and addressed in my doctoral research (personal and cultural construction of family dementia care) within the broader gerontological perspective and educational experience I will gain from the Gerontology Certificate Program.

In the long-term, I aspire to design local and international assessment tools, program evaluation measures, best-evidence guidelines, and early care plans for the sandwich generation who provide both child and elder care in addition to their full-time jobs. I intend to work with family caregivers who are not only struggling with the

effects of aging-related neurocognitive disorders but are also seeking to provide better care and to restore hope and meaning in their lives. The doctoral work that I have conducted (with international and multidisciplinary team of researchers and co-authors with the support of two local Saudi Universities and the Saudi Alzheimer's Disease Association) has illustrated that multidisciplinary work and group collaboration are needed within aging and caregiving-related studies, to achieve this goal. Dementia care is complex, and is influenced by many inter-related health, familial, and social factors. However, there are solutions for every challenge when proactive and collaborative work are prioritized and where there are opportunities for the integration of knowledge, research, and services within and across teams and sectors. Interdisciplinary and multidisciplinary teams should allow for better person and family-centred geriatric care system in the community. Effective communication between healthcare practitioners, gerontology researchers, and health educators from various aging-related disciplines (e.g., neurology, psychology, sociology, and health and rehabilitation sciences) can result in better assessments, practice guidelines, support programs, and services, that are intended to meet the needs of this population. The concept of system integration was, for example, presented in Ontario's Senior Strategy, entitled *Living Longer, Living Well* (Sinha, 2012) developed by Dr. Samir Sinha, a geriatrician (with a degree in medicine) and gerontologist (with a degree in sociology) who is the provincial lead for the strategy. The same idea can also be applied to the delivery of dementia care services at local and international levels. International examples of system integration for dementia-affected populations was recommenced in the 2013 report produced by Bupa and Alzheimer's Disease International (Pot & Petrea, 2013).

In the short-term, I plan to further investigate some of the limitations and recommendations of the three manuscripts included in this dissertation. Based on the recommendations of methodological and therapeutic implications of the first manuscript (Chapter Two), I plan to examine personal construct systems of various

samples, including recruitment of family caregivers with different demographic characteristics than my sample (e.g., caregivers from rural areas and caregivers with different social status and educational levels) and healthcare professionals (geriatricians and primary care providers) to gain a better understanding of dementia care-related construct systems within and across groups involved in care provision. In addition, there is a potential application in investigating construct systems of dementia care before and after providing educational or support programs for family caregivers or healthcare providers. Examples of applying PCT-driven methodology and methods can be found in Fransella (2005) and Caputi, Viney, Walker, and Crittenden (2012).

Given the identified limitations of the second manuscript (Chapter Three), I plan to conduct a larger study using an electronic version of the translated caregiver burden scale I used in the study. This study will be distributed via social media platforms and thus will include a larger sample of family caregivers (up to 200 participants) and from various areas of SA. The electronic version of the scale will also include new items (e.g., "frustrated you with unclear requests from your parent's or relative's," and "increased conflicts with other family members?") intended to mitigate the weaknesses of questionable items of the *Relationship Burden* subscale addressed in the manuscript. Advanced approaches to factor analysis will be applied to the psychometric data of the study (see Harrington, 2009, for potential analytic strategies).

As a follow up to last manuscript (Chapter Four), I plan to further examine critically caregiving constructs elicited from other purely qualitative methods of PCT, such as self-characterization sketch (SCS), where caregivers write short paragraphs (written personal construal) about their current occupation of care from the perspective of a third person. Further information about SCS can be found in Caputi et al. (2012). These short paragraphs and visual (constructed) illustrations (figures) of caregiving

daily situations used in this manuscript can be the first step towards publishing a booklet series for family caregivers and healthcare professionals in SA. Moreover, I plan to explore current polices related to eldercare in health and social services in SA to examine the ways in which they promote or create barriers for the delivery of services and daily tasks of family caregivers. Such an examination can lead to the development of a dementia care action plan and national strategy created from international criteria of dementia national plans (see Pot & Petrea, 2013, for potential criteria).

In conclusion, I contend that there are many possibilities for future research examining dementia care in various familial, social, and cultural contexts, and from either a post-positivist (e.g., large quantitative studies), or a constructivist perspective (e.g., small qualitative studies), or some combination of both, due to the uniqueness of issues surrounding dementia care as well as shared aspects of care among formal (health and social) and informal (family) systems of care at both national and international levels. The next step in my research journey will involve not only conducting research, but also advocating for the development of better assessment tools and best-practice guidelines in the hopes of working toward more empowered caregivers who can communicate and collaborate with dementia-friendly health and social care systems and communities. I believe in the potential of the findings of this research to influence decision makers in the SA health and social care system to commit to proactive approaches for how future (formal and informal) occupation of dementia care will be shaped and produced in families, societies, and communities.

5.3   References

Caputi, P., Viney, L. L., Walker, B. M., & Crittenden, N. (Eds.). (2012). *Personal construct methodology*. John Wiley & Sons.

Fransella, F. (Eds.). (2005). *The essential practitioner's handbook of personal construct psychology*. John Wiley & Sons.

Harrington, D. (2009). *Confirmatory factor analysis*. New York: Oxford University Press.

Kelly, G. A. (1955). *The psychology of personal constructs*. New York: Norton.

Montgomery, R. J. V., Borgatta, E. F., & Borgatta, M. L. (2000). Societal and family change in the burden of care. In W. T. Liu & H. Kendig (Eds.), *Who should care for the elderly? An East-West value divide* (pp. 27–54). River Edge, NJ: World Scientific Publishing.

Pot, A. M., & Petrea, I. (2013). *Bupa/ADI report: Improving dementia care worldwide. Ideas and advice on developing and implementing a national dementia plan*. London: Bupa/ADI. Retrieved from https://www.alz.co.uk/sites/default/files/pdfs/global-dementia-plan-report-ENGLISH.pdf

Sinha, S. K. (2012). *"Living Longer, Living Well": Highlights and key recommendations*. Retrieved from http://healthcareathome.ca/centraleast/en/news/Documents/Seniors_Strategy.pdf

Vision 2030. (2016). Retrieved from http://vision2030.gov.sa/en

Appendix A: The Arabic Translation of the Modified Montgomery Borgatta Caregiver Burden Scale (MBCBS).

<div dir="rtl">مقياس مونتقمري لعبء مقدم الرعاية</div>

As a result of assisting the care receiver (parent or relative), have the following aspects of your life changed? Have your caregiving responsibilities:

<div dir="rtl">كنتيجة لتقديم الرعاية لقريبك، كيف تأثرت الجوانب التالية من حياتك؟ هل أدت مسؤولياتك في الرعاية إلى أنها:</div>

	Not at all مطلقا1	A little قليلا 2	Moderately أحيانا 3	A lot كثيرا 4	A great deal كثيرا جدا 5

1- Decreased time you have to yourself? (**OB**)
<div dir="rtl">قللت من الوقت المخصص لنفسك ؟</div>

2- Increased attempts by your relative to manipulate you? (**RB**)
<div dir="rtl">زادت من محاولات قريبك في التحكم بك ؟</div>

3- Created a feeling of hopelessness? (**SB**)
<div dir="rtl">ولدت لديك شعورا باليأس؟</div>

4- Kept you from recreational activities? (**OB**)
<div dir="rtl">حالت بينك و بين ممارسة الأنشطة الترفيهية؟</div>

5- Increased the number of unreasonable requests made by your relative? (**RB**)
<div dir="rtl">زادت عدد الطلبات الغير معقولة من قبل قريبك؟</div>

6- Made you nervous? (**SB**)
<div dir="rtl">جعلتك عصبي المزاج؟</div>

7- Caused your social life to suffer? (**OB**)
<div dir="rtl">سببت لك المعاناة في حياتك الاجتماعية؟</div>

8- Caused you to feel that your relative makes demands over and above what he or she needs? (**RB**)
<div dir="rtl">جعلتك تشعر بأن قريبك يطلب أشياء كثر مما يحتاج؟</div>

9- Depressed you? (**SB**)
<div dir="rtl">جعلتك مكتئبا؟</div>

10- Changed your routine? (**OB**)
<div dir="rtl">غيرت من نظام حياتك اليومي؟</div>

11- Made you feel you were being taken advantage by your relative? (**RB**)
<div dir="rtl">جعلتك تشعر بأنه يتم تحميلك فوق طاقتك من قبل قريبك؟</div>

12- Made you anxious? (**SB**)
<div dir="rtl">جعلتك قلقا؟</div>

13- Given you little time for friends and relatives? (**OB**)
<div dir="rtl">أعطتك القليل من الوقت لتقضيه مع الأصدقاء و الأقارب؟</div>

14- Caused conflicts between you and your relative? (**RB**)
<div dir="rtl">سببت لك خلافات بينك و بين قريبك؟</div>

15- Caused you to worry? (**SB**)
<div dir="rtl">جعلتك مشغول البال؟</div>

16- Left you with almost no time to relax? (**OB**)
<div dir="rtl">لم تترك لك وقتا للاسترخاء؟</div>

Appendix B: Recruitment Poster (Arabic and English)

Alzheimer's Caregiver?

Would you like to participate in an Alzheimer's awareness study?

A research team is conducting a research study to help increase our society's knowledge about challenges and obstacles faced by family caregivers of older adults with Alzheimer's disease or related dementia. If you are interested in taking part in this study or would like more information, please read the study eligibility criteria or you can contact the research team.

Please call:
or email:

To be eligible to participate in this study you must meet the following criteria:
A Family caregiver aged 18 years or over who provides help to patient (aged 50 years or older) with Alzheimer's disease or related dementia at least one weekly activity of daily living for at least the past 6 months.

All information will be treated as *private* and *confidential* and your name will never be associated with the information you provide. Interview times will be based on your schedule and will be *compensated* for your time.

Appendix C: Letter of Information and Consent Form (Arabic and English)

Western
HealthSciences

<div dir="rtl">

نموذج معلومات الدراسة
(المرحلة الثانية)

عنوان الدراسة: المواءمة الثقافية والتقييم السيكومتري للنسخة العربية من مقياس مونتـِومري لأعباء مقّدم الرعاية

الباحثون الرئيسيون :

إرادة حمد ، مرشحة دكتوراة
تخصص القياس و طرق البحث ، برنامج الدراسات العليا لعلوم الصحة و إعادة التأهيل
كلية العلوم الصحية ، جامعة ويسترن
لندن أونتاريو ، كندا
البريد الإلكتروني : ▮▮▮▮▮▮

د. أندرو جونسون ، دكتوراة ، أستاذ مشارك (المشرف الأكاديمي)
رئيس قسم القياس و طرق البحث و المشرف على برنامج الدراسات العليا لعلوم الصحة و إعادة التأهيل
كلية العلوم الصحية ، جامعة ويسترن
لندن أونتاريو ، كندا
البريد الإلكتروني : ▮▮▮▮▮▮

الباحثون المساعدون :

د. أحمد الهادي ، أستاذ مساعد ، استشاري الطب النفسي و العلاج النفسي
المشرف على كرسي سابق لأبحاث و تطبيقات الصحة النفسية
كلية الطب ، جامعة الملك سعود
مستشفى الملك خالد الجامعي
الرياض ، المملكة العربية السعودية
البريد الإلكتروني : ▮▮▮▮▮▮

يقوم على إجراء هذا المشروع البحثي المتعدد الثقافات فريق بحثي من جامعة ويسترن بمدينة لندن أونتاريو كندا ، و جامعة الملك سعود بالرياض ، المملكة العربية السعودية. لقد تمت دعوتك للمشاركة في هذه الدراسة بصفتك مقدم/ة رعاية لشخص كبير السنّ في أسرتك يعاني من مرض ألزهايمر أو أحد الأنواع الأخرى من الخرف. الغرض من هذه الدراسة هو تقييم تجربتك كمقدم/ة للرعاية وقياس مدى الضغوطات التي قد تعاني منها و تكون ذات صلة بمسؤولياتك في تقديم الرعاية. سيتم إجراء هذه الدراسة باستخدام "مقياس مونتـِومري لأعباء مقّدم الرعاية" ، كما سيقوم الباحثون بتقييم مدى إمكانية و ملاءمة استخدام النسخة العربية من هذا المقياس لتقييم تجربة مقدمي الرعاية الأسرية في المملكة العربية السعودية.

توقيع المشاركـ/ة _____   ديسمبر 2014/يناير 2015

</div>

معلومات الدراسة

في حال اختيارك للمشاركة في الدراسة ، ستتم مقابلتك بشكل فردي من قبل أحد الباحثين في الدراسة. سيكون الباحث الذي يجري المقابلة هو الشخص الوحيد المتواجد معك خلال إجراء المقابلة إلا إذا رغبت بوجود شخص آخر معك خلال إجراء المقابلة. قبل إجراء المقابلة ، سيشرح لك الباحث جميع المعلومات المتعلقة بالدراسة بالتفصيل. في حال موافقتك على المشاركة ، سيطلب منك الباحث الإجابة عن بعض الأسئلة حول الكلمات المستخدمة لوصف تجربتك في تقديم الرعاية و ذلك بغرض فهم تجربتك كمقدم/ة للرعاية بشكل أفضل. بالإضافة إلى ذلك سيطلب منك ملء استبيان ديموغرافي قصير. سوف تستغرق المقابلة ساعة واحدة تقريبًا ، وسيتم تسجيلها ولكن يمكنك طلب وقف التسجيل في أي وقت.

مخاطرالدراسة

لن تكون هناك أي مخاطر من مشاركتك في هذه الدراسة ، ولكن قد يكون هناك شعور بعدم الراحة في الحديث عن بعض التفاصيل التي تخص تجربتك في تقديم الرعاية. إذا شعرت بعدم الراحة فيمكنك طلب وقف المقابلة في أي وقت. كما أن باستطاعتك عدم الإجابة عن أي من الاسئلة التي قد تثير لديك شعورًا بعدم الراحة إن قمت بالإجابة عنها.

فوائد الدراسة

بصفتك ذو خبرة في تقديم الرعاية ، قد يؤدي تقييم تجربتك من خلال هذه الدراسة إلى تعزيز وعي المجتمع وزيادة معرفته حول رعاية كبار السن المصابين بالخرف.هذا بالإضافة إلى أن نتائج هذه الدراسة سيتم عرضها و نشرها في المؤتمرات و المجلات العلمية ذات الصلة بموضوع الدراسة مما قد يساعد الرعاية الصحية المحلية و كذلك المجتمع الطبي لإبداء المزيد من الاهتمام للتحديات و الصعوبات التي يواجهها كبار السن والقائمين على رعايتهم من أفراد الأسرة في مجتمعاتنا العربية.

الخصوصية

سيتم تسجيل المقابلات خلال الدراسة ، ولكن يمكنك طلب إيقاف التسجيل في أي وقت خلال الدراسة ، ولا يزال بإمكانك المشاركة حتى لو لم تبدي الرغبة في تسجيل المقابلة. معلوماتك الشخصية التي ستفصح عنها خلال الدراسة لن تنشر وعوضا عنها سيتم استخدام أرقام و رموز لتمييز إجاباتك عن غيرك من المشاركين. كما سيتم الاحتفاظ بنموذج الموافقة والأوراق والتسجيلات في مكان آمن وذ لك بغرض مناقشتها في وقت لاحق من قبل الفريق البحثي المشارك في الدراسة فقط. في حال نشر نتائج هذه الدراسة فإنه لن يتم استخدام اسمك أو نشر أي معلومات تكشف عن هويتك بدون الحصول على إذن منك. و في الصفحة الأخيرة من "نموذج الموافقة على المشاركة في البحث" سيكون لديك الفرصة لاختيار ما إذا كانت لديك الرغبة أن يستخدم الباحثون إجاباتك لأغراض المشاركات البحثية في المؤتمرات و النشر العلمي من عدمها ، مع العلم أنه لازال بإمكانك المشاركة في هذه الدراسة حتى في حال اختيارك الإجابة بـ (لا) عن أي من هذه الأسئلة.

المشاركة تطوعية

مشاركتك في هذه الدراسة تطوعية تمامًا. اختيارك لعدم المشاركة أو سحب موافقتك على المشاركة في أي وقت خلال إجراء الدراسة لن يؤثر على خدمات الرعاية الصحية الحالية أو المستقبلية المقدمة لك أو لمن تقوم على رعايته ، كما أن اختيارك لعدم المشاركة لن يعيق وصولك إلى مجتمع الرعاية الصحية المحلي.

توقيع المشارك/ة ــــــــــ   ديسمبر 2014/يناير 2015

أسئلة حول الدراسة

في حال كان لديك أي أسئلة أو استفسارات أخرى حول الدراسة يمكنك التواصل مع أحد الباحثين المدرجة أسماؤهم في الصفحة الاولى من هذا النموذج حول معلومات الدراسة. و في حال كان لديك أي أسئلة حول حقوقك كمشارك/ ة في البحث أو عن خطوات سير هذه الدراسة ، فيمكنك الاتصال بمكتب أخلاقيات الأبحاث بجامعة ويسترن ، كندا

███████████████████████

توقيع المشارك/ة _____   ديسمبر 2014/يناير 2015

عنوان البروتوكول : المواءمة الثقافية والتقييم السيكومتري للنسخة العربية من مقياس مونتيﻮمري لأعباء مقدم الرعاية

نموذج الموافقة على المشاركة في البحث

أَقَرَّ أنا _____ (اسمك)
بأنني قد قرأت نموذج معلومات الدراسة ، و قد تم إيضاح طبيعة الدراسة لي ، وبناء عليه أوافق على المشاركة في هذه الدراسة بعد أن تمت الإجابة عن جميع أسئلتي بشكلٍ مُرضٍ.

اسم المشارك/ة: _____ (كتابة الاسم)

	لا	نعم	أوافق على استخدام إجاباتي في هذه الدراسة لِ
			أغراض بحثية
			أغراض تعليمية
			الملصقات العلمية و العروض التقديمية

توقيع المشارك/ة : _____

التاريخ : _____

(اختياري)

يرجى كتابة معلومات الاتصال الخاصة بك للتواصل معك في حال موجود مقابلات لاحقة أو دراسات مستقبلية

البريد الإلكتروني / رقم الهاتف : _____

— — — — — —

الشخص الحاصل على الموافقة : _____

الاسم : _____

التوقيع : _____

توقيع المشارك/ة _____   ديسمبر 2014/يناير 2015

Western
HealthSciences

LETTER OF INFORMATION (PHASE 2)

Study Title: Cultural Adaptation and Psychometric Evaluation of an Arabic Version of Montgomery's Caregiver Burden Scale

Principal Investigator (Supervisor):
Andrew M. Johnson, PhD
Associate Professor and Chair
Health and Rehabilitation Sciences
Western University
London, Ontario, Canada
Email:

Principal Investigator (Doctoral student):
Eradah Hamad, PhD Candidate
Health and Rehabilitation Sciences,
Measurement and Methods
Western University
London, ON, Canada
Email:

Co-investigator:
Ahmed AlHadi, MD, PhD
College of Medicine, King Saud University
King Khalid University Hospital
Riyadh, Saudi Arabia
Email:

This cross-cultural research project is being conducted by a research team from Western University, London, Ontario, Canada and King Saud University, Riyadh, Saudi Arabia. You have been invited to participate in this study, because you have been identified as a family caregiver of an older person with Alzheimer's Disease and/or other types of dementia. The purpose of this study is to assess your experience as a caregiver and to measure the stress that you may have, related to your caregiving responsibilities. This study will be undertaken using a caregiver assessment tool called Montgomery's Caregiver Burden Scale. The researchers are also evaluating the appropriateness of the Arabic version of this tool so that it can be used to assess family caregivers in Saudi Arabia.

Study Information

If you choose to participate in this study, you will be interviewed individually by one of the study investigators. Only the interviewer will be present unless you would like someone else to be there. The interviewer will describe the study to you in detail. If you agree to participate, you will be asked to answer a few questions about words that you may use to better understand your experience as a caregiver. In addition, you will be asked to complete a short demographic questionnaire. The interview will take approximately one hour. This interview will be tape recorded, but you may request that the recording be stopped at any time.

Participant's Initials: _____

Risks or Discomforts

There are no known risks to participating in this study. However, you may feel uncomfortable talking about certain details related to your caregiving experience. If you feel uncomfortable, you may choose to stop the interview at any time. You may also decide not to answer any questions with which you feel uncomfortable.

Benefits

The results of this research will be presented at meetings, presentations, and in scholarly journals. You are an expert about what it is like to be a caregiver, and your experience may enhance society's awareness and knowledge about caring for older adults and help the local healthcare and medical community pay more attention to challenges and obstacles faced by older adults and their caregivers.

Confidentiality

The interviews will be recorded, but you may ask the researcher to stop the recording at any time. You may still participate if you do not want to be recorded during your individual interview. Your name will never be published, and numbers or codes will be used to identify your responses. The consent form and transcripts of the recordings will be locked in a secure place for future consultation by the research team only. If the results of the study are published, your names will not be used and no information that discloses your identity will be released or published without your permission. On the last page of the consent form, you will be given the opportunity to choose whether or not the researchers can use your responses for teaching, research, and publication purposes. You can still be in the study if you check "No" for any of these questions.

Voluntary Participation

Your participation in this study is completely voluntary. Deciding not to participate, or choosing to withdraw your consent, will not impact current or future healthcare, nor will it restrict your access to the healthcare community.

Questions about the Study

If you have any further questions or concerns about this study, you may contact any of the investigators listed on the first page of this letter. If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics

Participant's Initials: _____

PROTOCOL TITLE: Cultural Adaptation and Psychometric Evaluation of the Arabic Version of the Montgomery's Caregiver Burden Scale

CONSENT FOR PARTICIPATION IN RESEARCH

I _____ (YOUR NAME) have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

Name of Participant: _____ (PRINT NAME)

I give permission to use my responses for:	YES	NO
Research purposes		
Teaching purposes		
Posters/Publications/Presentations		

Signature of Participant: _____ (SIGNATURE)

Date: _____

Please enter your contact information for a possible follow up interview or future studies (optional):

Email/Phone Number: _____

PERSON OBTAINING CONSENT

Print Name and Title: _____

Signature: _____

Participant's Initials: _____

Appendix D: Demographic Questionnaire (Arabic and English)

<div dir="rtl">

استبيان ديموغرافي حول مقدم الرعاية (من أفراد الاسرة)

شكرًا لموافقتك على المشاركة في هذه الدراسة. يرجى منك اختيار/كتابة المعلومات التي تقدم أفضل وصف لحالتك.

نود التنويه إلى أنه يمكنك الاعتذار عن الإجابة عن أي من الأسئلة المطروحة عليك في هذا الاستبيان، كما يمكنك التوقف عن المشاركة في هذه الدراسة في أي وقت مع ملاحظة أن المعلومات المطلوبة في هذا الاستبيان ستستخدم لأغراض بحثية فقط.

٢) كم هو عمر قريبك كبير السن (مُستقبِل/ة الرعاية) ؟	١) كم هو عمرك ؟
_____	_____

٣) ما هو جنسك ؟

أفضّل عدم الإجابة _____   أنثى _____   ذكر _____

٤) ما هو جنس قريبك كبير السن (مُستقبِل/ة الرعاية) ؟

أفضّل عدم الإجابة _____   أنثى _____   ذكر _____

٥) ما هي حالتك الاجتماعية ؟

أرمل/ة _____   متزوج/ة _____   أعزب/عزباء _____

أفضّل عدم الاجابة _____   منفصل/ة _____   مطلق/ة _____

٦) ما هي حالتك الوظيفية ؟

أعمل لحسابي الخاص _____   أعمل بدوام جزئي _____   أعمل بدوام كامل _____

أعمل من المنزل (مثل الخياطة ، التصنيع ، معالجة النصوص) _____   ربة منزل _____   متقاعد/ة _____

أفضّل عدم الإجابة _____   أخرى _____

</div>

٧) ما هو مستواك التعليمي ؟

ابتدائي_____ متوسط_____ ثانوي_____

تدريب مهني_____ جامعي_____ دراسات عليا_____

أخرى_____ أفضّل عدم الإجابة_____

٨) كم يبلغ دخلك السنوي (تقريبًا) ؟

_____ أفضّل عدم الإجابة_____

٩) ما صلة القرابة التي تجمعك بقريبك كبير السن (مُستقبِل/ة الرعاية) ؟

زوج/ة_____ ابن/ة_____ زوجة ابن/زوج ابنة_____

حفيد/ة_____ أخرى_____

١٠) كم عدد أفراد عائلتك المباشرة (بما فيهم الأخوة والأخوات) ؟

_____ أفضّل عدم الإجابة_____

١١) ماهو عدد الأشخاص الذين يعيشون معك في منزلك (بما فيهم أنت) ؟

_____ أفضّل عدم الإجابة_____

١٢) ماهو عدد الأطفال الذين يعيشون معك في المنزل ؟

_____ لايوجد أطفال في المنزل_____ أفضّل عدم الإجابة_____

١٣) هل تعيش/ين مع قريبك كبير السن (مُستقبِل/ة الرعاية) ؟

نعم _____   لا _____

١٤) منذ متى وأنت تقدم/ين الرعاية لقريبك كبير السن (مُستقبِل/ة الرعاية) ؟

_____

١٥)   منذ متى تم تشخيص قريبك كبير السن (مُستقبِل/ة الرعاية) بمرض ألزهايمر (أو النوع المصاب به من الخرف) ؟

_____

١٦) كم عدد الساعات التي تقضيها يوميًا للعناية بقريبك كبير السن (مُستقبِل/ة الرعاية) تقريبًا ؟

أقل من 4 ساعات _____   من 5 إلى 8 ساعات _____   أكثر من 8 ساعات _____

أخرى _____

١٧) ما نوع المساعدة التي تقدمها لقريبك كبير السن (مُستقبِل/ة الرعاية) ؟

أنشطة الحياة اليومية (مثل التغذية ، الذهاب إلى الحمّام ، الاستحمام) _____

المساهمة في أنشطة الحياة اليومية الأخرى (تقديم الأدوية ، إعداد الوجبات ، التسوُّق) _____

جميع ماسبق _____   أخرى _____

١٨) هل لديك عاملة منزلية ؟

نعم _____   لا _____   أفضّل عدم الإجابة _____

إذا كانت الإجابة بـ نعم على السؤال السابق ، فكم عاملة منزلية تَسكن معك في المنزل ؟

_____

إذا كنت تملك عاملة منزلية فهل تقوم العاملة المنزلية بمساعدتك في العناية بقريبك كبير السن (مُستقبِل/ة الرعاية) ؟

نعم ــــــــ   لا ــــــــ

١٩) هل يقوم أفراد أسرتك بدعمك في مسؤوليات تقديم الرعاية لقريبك كبير السن (مُستقبِل/ة الرعاية) ؟

نعم ــــــــ   لا ــــــــ   أفضّل عدم الإجابة ــــــــ

إذا كانت الإجابة بـ نعم على السؤال السابق ، يرجى التحديد

دعم في الأمور التي تتطلب مجهودًا بدنيًا ــــــــ   دعم مالي ــــــــ   دعم نفسي ــــــــ

أخرى ــــــــ

٢٠) هل تتلقى/اين دعمًا آخر (من خارج الأسرة) في مسؤولياتك في تقديم الرعاية (مثل خدمات الدعم الصحية أو الحكومية) ؟

نعم ــــــــ   لا ــــــــ   أفضّل عدم الإجابة ــــــــ

إذا كانت الإجابة بـ نعم على السؤال السابق ، يرجى التحديد

خدمات الرعاية الصحية المنزلية ــــــــ   مجموعات الدعم ــــــــ   أفضّل عدم الإجابة ــــــــ

٢١) ما هي أبرز مخاوفك الصحية (إن وُجدت) ، أو مشكلاتك الصحية التي تمَ تشخيصها ؟

ـــــــــــــ   لاتوجد أي مخاوف أو مشكلات صحية ــــــــ   أفضّل عدم الإجابة ــــــــ

Family Caregivers Demographic Information Questionnaire

Thank you for agreeing to participate in this study. You may refuse to answer any of these questions, and you may discontinue your participation at any time. Please select/write the information that best describes your status. This demographic information will be used for research purposes only.

1- What is your age?	2- What is the patient's age?
_____	_____

3- What is your sex?

Male __   Female __   Prefer not to Answer __

4- What is the patient's sex?

Male __   Female __   Prefer not to Answer __

5- What is your marital status?

Single __   Married __   Widowed __
Divorced __   Separated __   Prefer not to Answer __

6- What is your employment status?

Working full time__   Working part time __   Self-employed __
Retired __   Housewife __
Homeworker (e.g., sewing, manufacturing, word processing) __
Other: _____   Prefer not to Answer __

7- What is your level of education?

Primary school __   Middle school __   High school__
Vocational training __   College graduate __   Postgraduate __
Other: _____   Prefer not to Answer __

8- What is your annual income (approximately)?

_____   Prefer not to Answer __

9- What is your relationship to the patient?

Spouse   Child   Child-in-law
Grandchild   Other: _____

10- How many family members do you have in your immediate family (including brothers and sisters)?

_____   Prefer not to Answer __

11- How many people are living in your home (including you)?

_____   Prefer not to Answer __

12- How many children are living in your home?

_____   No children __   Prefer not to Answer __

13- Do you live with the patient?
Yes   No   Other:_____

14- How long have you been the primary caregiver for the patient?
_____

15- How long has the patient been diagnosed with Alzheimer's disease and/or dementia?
_____

16- How many hours do you spend caring for the patient daily?
Less than 4 hours   5 to 8 hours   More than 8 hours Other:_____

17- What type of assistance do you provide to the patient?
Activates of daily living (e.g., feeding, toileting, bathing) __ Instrumental activates of daily living (e.g., managing medications, preparing meals, shopping) __ Both __   Other: _____

18- Do you have housemaid(s)?
Yes __   No __   Prefer not to Answer __

If yes, how many housemaid(s) do you have?
_____

If yes, does your housemaid(s) help you in taking care of the patient?
Yes __   No __

19- Does your family support your caregiving activities?
Yes __   No __   Prefer not to Answer __

If yes, please specify
Physical support __   Financial support __   Emotional support Other: _____

20- Do you receive other support for your caregiving activities, from outside your family (e.g., formal support services)?
Yes __   No __   Prefer not to Answer __

If yes, please specify
Home health care   Support groups   Other: _____

21- What, if any, are your major health concerns and/or diagnosed health conditions?
_____   No health concerns/conditions __ Prefer not to Answer __

Appendix E: University of Western Ontario Ethics Approval

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Andrew Johnson
Department & Institution: Health Sciences\Health & Rehabilitation Sciences,Western University

HSREB File Number: 105687
Study Title: Cultural Adaptation and Psychometric Evaluation of the Arabic Version of Montgomery's Caregiver Burden Scale
Sponsor:

HSREB Initial Approval Date: October 30, 2014
HSREB Expiry Date: May 31, 2016

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Advertisement	Recruitment Email	2014/08/18
Advertisement	Recruitment Email Reminder	2014/08/18
Data Collection Form/Case Report Form	Grid and Laddering Form	2014/08/18
Instruments	Montgomery Burden Scale	2014/08/18
Other	Study Design	2014/08/18
Revised Western University Protocol	Revised Ethics Protocol (clean)	2014/10/21
Revised Letter of Information & Consent	Revised LOI for Phase 3	2014/10/21
Revised Letter of Information & Consent	Revised LOI for Phase 2 (tracked changes)	2014/10/21
Recruitment Items	Recruitment Poster	2014/10/21
Instruments	Revised Demographic Questionnaire	2014/10/21

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing and submitting an HSREB Updated Approval Form in a timely fashion.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

This is an official document. Please retain the original in your files.

Appendix F: Institutional Review Board (IRB) of King Saud University

بسم الله الرحمن الرحيم

Kingdom of Saudi Arabia
Ministry of Higher Education
King Saud University
Code 034
College of Medicine
& King Khalid University Hospital

المملكة العربية السعودية
وزارة التعليم العالي
جامعة الملك سعود
رمزها ٠٣٤
كلية الطب
ومستشفى الملك خالد الجامعي

Date: 28.12.2014 التاريخ: No.: 14/4490/IRB الرقم:
06.03.1436

Ms. Eradah Hamad
PhD Candidate
Health & Rehabilitation Graduate Program
Western University, London, Ontario, Canada

Subject: **Research Project No. E-14-1360**

"Cultural Adaptation and Psychometric Evaluation of an Arabic version of Montgomery's Caregiver Burden Scale"

Dear Ms. Hamad,

I am pleased to inform you that your above-mentioned research project was reviewed by the Institutional Review Board on 23 December 2014 (01 Rabi-I 1436). The project was **approved**. Work on this project may begin. However, please remove Western University email and details from Arabic consent form.

We wish you success in your research and request you to keep the IRB informed about the progress and final outcome of the study in a regular basis. Please quote the project number shown above in any future transactions or follow-ups related to this study.

If you have any question, please feel free to contact me.

Thank you!

Sincerely yours,

/rubie

Appendix G: Repertory Grid Technique (Interview), adapted from Kelly (1955)

	Constructs	Elements Participants' roles							
Scale items	Participants' constructs								
	1 2 3 4 5								
	1 2 3 4 5								
	1 2 3 4 5								
	1 2 3 4 5								
	1 2 3 4 5								
	1 2 3 4 5								
	1 2 3 4 5								
	1 2 3 4 5								

Appendix H: Laddering Procedure (Interview), adapted from Hinkle (2010) and Hill (1995)

Laddering Technique

Value Laddering

A fundamental construct/item ....

Why?

A superordinate construct/item ....

Why?

A superordinate construct/item ....

Why?

An elicited construct/item ....

How?

A subordinate construct/item ....

A subordinate construct/item ....

A subordinate construct/item ....

A subordinate construct/item ....
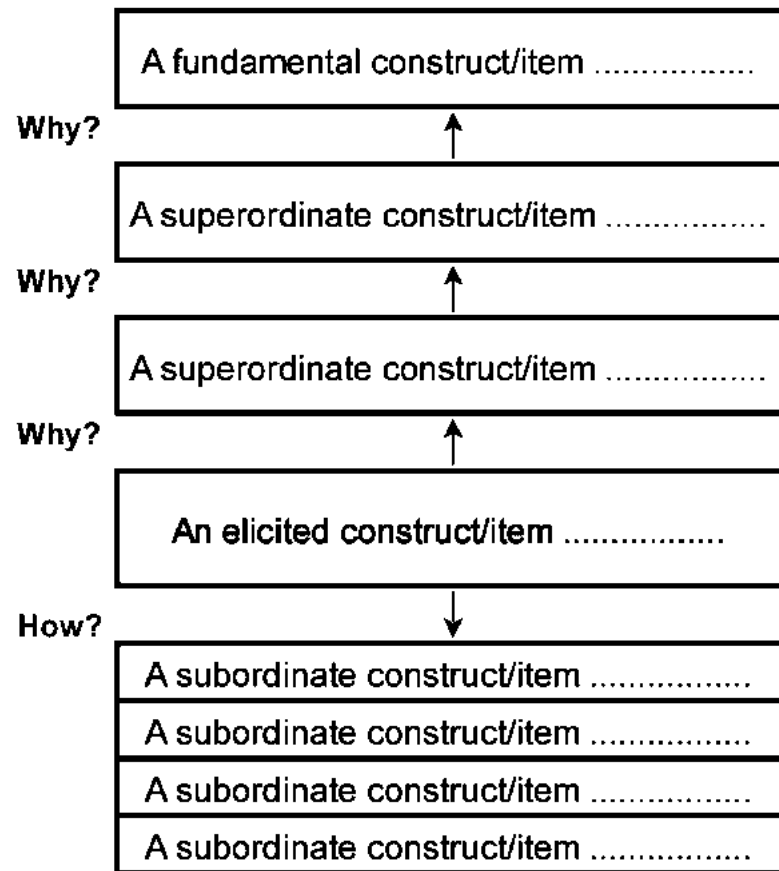
Act Laddering

Appendix I: Item Characteristics of the Translated MBCBS.

Items I (Subscale)	Mean	SD	1 %	2 %	3 %	4 %	5 %
Item 1 (OB)	3.45	1.19	10.0	05.0	35.0	30.0	20.0
Item 2 (RB)	3.05	1.10	10.0	15.0	45.0	20.0	10.0
Item 3 (SB)	2.55	1.19	25.0	20.0	35.0	15.0	05.0
Item 4 (OB)	3.15	1.23	15.0	15.0	15.0	50.0	05.0
Item 5 (RB)	3.55	1.32	10.0	10.0	25.0	25.0	30.0
Item 6 (SB)	2.55	0.94	20.0	15.0	55.0	10.0	00.0
Item 7 (OB)	2.85	1.31	25.0	10.0	25.0	35.0	05.0
Item 8 (RB)	3.10	1.17	10.0	20.0	30.0	30.0	10.0
Item 9 (SB)	1.75	1.12	65.0	05.0	20.0	10.0	00.0
Item 10 (OB)	3.50	1.36	10.0	15.0	45.0	15.0	25.0
	3.45	1.15	05.0	10.0	45.0	15.0	25.0
Item 11 (RB)	2.95	1.15	15.0	15.0	35.0	30.0	05.0
Item 12 (SB)	3.25	1.21	10.0	20.0	15.0	45.0	10.0
	2.80	1.15	15.0	25.0	30.0	25.0	05.0
Item 13 (OB)	1.95	1.05	40.0	35.0	20.0	00.0	05.0
Item 14 (RB)	2.65	1.09	20.0	20.0	35.0	25.0	00.0
Item 15 (SB)							
Item 16 (OB)							

Appendix J: An Excerpt from One Participant's Account (P# 16, 27 year old, female).

P#16 began talking about her caregiving experience with a very mournful and shaky

voice referring to her role as a "nurse":

> *"I am a college graduate, I used to be very ambitious, but I am very frustrated right now. I wish I could continue my education and go to work like other women my age, but I don't. Actually I can't do anything, because of my caregiving responsibilities. Although I have no previous medical education and I understand nothing about nursing, I am a 24/7 nurse for my father [72] since he was diagnosed with viral hepatitis ten years ago. Five of the ten years are with Alzheimer's too." He is in the severe stage of Alzheimer's now. He doesn't even move or talk, almost paralyzed. He needs very advanced medical care. His room is like a hospital room. I give him medications and feed him through a feeding tube inserted in his stomach, but most of the time I feel afraid of feeding him or administering medications more than what he really needs. Sometimes I can understand him if he is not feeling comfortable from his eye movements, his tears, or when he bites or scratches me. My mom is old and sick too. She has diabetes and hypertension and she can't help. One of my brothers can help me, sometimes, but only when I feel severely overwhelmed and can't handle it any more. I am very exhausted and often have back pain, because of carrying and moving my father all the time. The in-home medical services team visits my father every other week, but when they come, they just make a regular check on him and do body massage for him. That's all. We tried to hire a private nurse, but it costs approximately 7,000 SAR [more than $2,000 CAD] per month, and we can't afford that."*

She continued with a description of her role as an "adult child":

> *"I am very compassionate and honoured to take care of him. I love him, he is my father, and he was my guardian. Actually, he was everything to me and everybody loves him in the family. I have nine siblings, and I am the youngest. They are married except two brothers living with us in the house with my mom and the housemaid [helps with the house chores]. I feel very isolated though! My siblings are living their lives. I miss the family and friends' gatherings very much, but I know my father needs me and I can't leave him without me being with him. My father used to be a strong, very strict, and stubborn man, because he used to work at the armed force, but he was kind too. He used to drop me off and pick me up from school, carry my backbag, and open the car's door for me. Now, I do everything for him in return! It's bir [filial piety] and I am still feeling guilty for not doing enough for him. Sometimes I can't control myself and cry, but I get out of his room very fast, however, I know he can feel it, even if he doesn't talk."*

Curriculum Vitae

EDUCATION

Certificate Program in Gerontology   2016-Presnet
The Change School of Continuing Education, Ryerson University,
Toronto, Ontario, Canada

Doctor of Philosophy   2012-Present
Measurement and Methods Field
Graduate Program in Health and Rehabilitation Sciences
Faculty of Health Sciences, The University of Western Ontario,
London, Ontario, Canada
Research Title: *Personal Constructs of Dementia Family Care:*
The Family Caregiver Experience of People with Dementia in Saudi
Arabia (Defense April, 2017)
Supervisors: Dr. Andrew Johnson and Dr. Jeffrey Holmes
Advisory Committee: Dr. Marie Savundranayagam,
 Dr. Christopher Lee, and Dr. Elizabeth Anne Kinsella

Master of Science   2010-2012
Measurement and Methods Field
Graduate Program in Health and Rehabilitation Sciences
Faculty of Health Sciences, The University of Western Ontario,
London, Ontario, Canada
Research Title: *Personal Constructs of Saudi Arabian Graduate Students*
Studying at a Large Canadian University: A Personal Construct Theory
Approach
Supervisor: Dr. Christopher Lee
Advisory Committee: Dr. Andrew Johnson and Dr. Jennifer Irwin

Bachelor of Arts   2001-2005
Psychology Program
Faculty of Arts and Humanities, King Abdulaziz University,
Jeddah, Saudi Arabia

AWARDS, GRANTS, AND SCHOLARSHIPS

Graduate Student Scholarship for Studying Abroad   2008-Present
King Abdulaziz University, Jeddah, Saudi Arabia

Faculty of Health Sciences Graduate Student Travel Award   2015 & 2016
Faculty of Health Sciences, The University of Western Ontario
London, Ontario, Canada

Travel Grant   2014 & 2015
Canadian Association on Gerontology, Canada

Saudi Arabian Cultural Bureau Excellence Award   2014 & 2015
Saudi Arabian Cultural Bureau, Ottawa, Ontario, Canada

PUBLICATIONS

Peer-Reviewed Articles

Hamad, E. O., AlHadi, A. N., Lee, C. J., Savundranayagam, M. Y., Holmes, J. D., Kinsella, E. A., & Johnson, A. M. (in press). Assessment of caregiving constructs: Toward a personal, familial, group, and cultural construction of dementia care through the eyes of personal construct psychology. *Journal of Cross-Cultural Gerontology.*

Hamad, E. O., Savundranayagam, M.Y., Holmes, J. D., Kinsella, E. A., Johnson, A. M. (2016). Towards a mixed methods research approach to content analysis in the digital age: The combined content analysis model and its applications to healthcare Twitter Feeds*. Journal of Medical Internet Research, 18(3), e60. doi:10.2196/jmir.5391*

Published Abstracts

Hamad, E. O., Johnson, A. M., & Kinsella, E. A. (2016). *Reconstruction of existing constructs: A personal construct theory approach for cross-cultural construing of quantitative measures*. Abstract published in Personality and Individual Differences, 101, p.483.

Hamad, E. O., & Johnson, A. M. (2013). *Assessing caregivers of cognitively impaired older adults: A mixed methods research study*. Abstract published in International Journal of Qualitative Method, 12, p.733-34.

PRESENTATIONS

Refereed Conference Presentations

Hamad, E. O., Alamri, S. H., & Johnson, A. M. (October 2016). The integrated model for dementia care in Saudi Arabia (IMDC-SA): A suggested solution to challenges faced by people with dementia and their family caregivers. *45th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG2016).* Montreal, Quebec, Canada.

Hamad, E. O., AlHadi, A. N., & Johnson, A. M. (October 2016). "If he was not my father, I wouldn't do it": The confounding role of a frustrated nurse and compassionate adult child—Saudi Arabian family caregivers. *45th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG2016).* Montreal, Quebec, Canada.

Hamad, E. O., Johnson, A. M., Lee, C., Savundranayagam, M. Y., Holmes, J. D., Kinsella, E. A., & AlHadi, A. (October 2015). Do we share the burden of care? Cross-cultural measurement construction
of Montgomery's Caregiver Burden Scale*. 44th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG2015).* Calgary, Alberta, Canada.

Hamad, E. O., Johnson, A. M., & Kinsella, E. A. (July 2015). Reconstruction of existing constructs: A personal construct theory approach for cross-cultural construing of quantitative measures. *2015 conference of the International Society for the Study of Individual Differences (ISSID).* University of Western Ontario, London, Ontario, Canada.

Hamad, E. O., & Johnson, A. M. (October 2014). Tweeting eldercare: Concurrent content analysis of Twitter chats on caring of older adults. *43rd Annual Scientific and Educational Meeting of the Canadian Association on Gerontology (CAG2014).* Niagara Falls, Ontario, Canada.

Hamad, E. O., & Johnson, A. M. (June 2013). Assessing caregivers of cognitively impaired older adults: A mixed methods research study. *12th Annual Advances in Qualitative Methods (AQM) Conference.* University of Alberta, Edmonton, Alberta, Canada.

TEACHING EXPERIENCE

Teaching Assistant   2013-2015
Occupational Therapy, Becoming a Professional
The University of Western Ontario, London, Ontario, Canada
Instructors: Prof. Lisa Klinger, Dr. Carri Hand

Teaching Assistant   2011
Research Methods and Analysis in the Health Sciences
The University of Western Ontario, London, Ontario, Canada
Instructor: Dr. Andrew Johnson

Instructor   2007-2008
General Psychology
Islamic Analysis of Human Behaviour
King Abdulaziz University, Jeddah, Saudi Arabia

VOLUNTEER EXPERIENCE

Group Mentor   2016-Persent
Virtual support group of family caregivers of people
with Alzheimer's disease and other dementias, Saudi Arabia

Peer Reviewer   2015 & 2016
Conference Abstracts (Psychology Division)
The Annual Scientific and Educational Meeting of the Canadian
Association on Gerontology (CAG), Canada