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FORMAL LONG-TERM CARE:
INFORMAL CAREGIVERS’ SUBJECTIVE WELL-BEING AND SERVICE UTILIZATION

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INFORMAL CAREGIVERS' SUBJECTIVE WELL-BEING AND SERVICE UTILIZATION

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A thesis submitted to the Nanyang Technological University
in partial fulfilment of the requirement for the degree of
Doctor of Philosophy

2019

Statement of Originality

I certify that all work submitted for this thesis is my original work. I declare that no other person's work has been used without due acknowledgement. Except where it is clearly stated that I have used some of this material elsewhere, this work has not been presented by me for assessment in any other institution or University. I certify that the data collected for this project are authentic and the investigations were conducted in accordance with the ethics policies and integrity standards of Nanyang Technological University and that the research data are presented honestly and without prejudice.

4 August 2019

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I have reviewed the content of this thesis and to the best of my knowledge, it does not contain plagiarised materials. The presentation style is also consistent with what is expected of the degree awarded. To the best of my knowledge, the research and writing are those of the candidate except as acknowledged in the Author Attribution Statement. I confirm that the investigations were conducted in accordance with the ethics policies and integrity standards of Nanyang Technological University and that the research data are presented honestly and without prejudice.

05 / 08/ 2019 Ho Moon-ho

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Date Assoc Prof Ho Moon-ho Ringo

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This thesis does not contain any materials from papers published in peer-reviewed journals or from papers accepted at conferences in which I am listed as an author.

4 August 2019

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Date

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Wayne Freeman Chong Weien

Dedication

First, to *God*, from whom comes all wisdom and knowledge.

Second, to my wife, *Lee Voon*, who ran this marathon with me.

Third, to my son, *Jerome*, without whom this thesis would have been completed a year earlier.

Last, to *Dad*, *Mom* and *Grandma*, who made all this possible with the well-being and mental health issues they gave me.

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List of Abbreviations

CB	Caregiver burden
CD	Caregiver depression
CHS	Caregiver health status
D	Distressed profile
LPA	Latent profile analysis
LTA	Latent transition analysis
LTCS	Long-term care services
ND	Non-distressed profile
T0	Baseline
T1	3-month post-stroke
T2	12-month post-stroke
WHO	World Health Organization

Abstract

This thesis was primarily motivated by the twin phenomena of falling formal long-term care service (LTCS) demand and unrelenting deleterious effects on informal caregivers' subjective well-being across urban societies. These phenomena run counter to the needs of ageing populations, that presents challenges of a rise in chronic degenerative illnesses and long-term disabilities, and associated crowding at acute treatment facilities. The limited effectiveness of increasing formal LTCS supply to meet these challenges has led to transformation of health care systems in order to influence demand for LTCS. Based on the premise that LTCS utilization decisions could be jointly taken by patients and their informal caregivers, this thesis investigated the extent to which informal caregivers' subjective well-being influences the utilization of public long-term health and social care services using three studies.

Taken together, the results obtained showed that there exist substantial associations between each of caregiver burden, depression and health status and LTCS use. Chapter 2 presented quantitative syntheses of reported research on this topic to-date. Research studies that involved fewer female (than male) informal caregivers reported 86% higher odds of caregivers experiencing higher depression levels associated with LTCS use by patients. I also found that there were unexpectedly few studies that provided quantitative data on this topic despite the many years of research involving informal caregiving in the context of LTCS. Using a longitudinal Singapore sample of stroke survivors and their informal caregivers, Chapter 3 showed that caregiver depression and caregiving burden are concurrent and prospective predictors of LTCS use respectively. After controlling for covariates, I found that caregivers who felt more burdened (found caregiving to be time consuming and difficult) at 3-month post-stroke, and those who were more depressed at 12-month post-stroke tend to have cared for users of stroke rehabilitation at 12-month post-stroke. Using the same sample, Chapter 4 showed that caregiver burden, depression and health status are useful indicators of latent caregiver psychosocial distress profiles that differ with regard to LTCS use. After controlling for covariates, I found that non-distressed caregivers at 12-month post-stroke tend to have cared for stroke rehabilitation service users at the same time point.

Theoretically, these results provide support for the concept caregiver resilience, and show that explanatory frameworks for LTCS use should include caregiver subjective well-being constructs, such as caregiver burden, depression and health status. Practically, these results are evidence of the importance of early caregiver psychosocial education and interventions, and provide support for integrated care service design and delivery that considers the patient-caregiver dyad as the recipient of care.

Chapter 1

Ageing and Changing Demography

The rise in the percentage of older adults and the corresponding decline in that of the young is a world population phenomenon (World Health Organization [WHO], 2014). The world population who are 60 years and beyond will increase by 56%. This number is expected to increase to 1.4 billion by 2030, as compared to 901 million in 2015. This trend is anticipated to continue, and the population above 60 years old will reach 2.1 billion by 2050 (United Nations Department of Economic and Social Affairs Population Division, 2013, 2015, 2017). Changing trends of morbidity as a result of such demographic shifts will result in morbidity moving from patterns of acute to chronic illnesses and disabilities. Around the world, endeavours aimed at transforming traditional models of healthcare, based on acute and primary care services, to new models of care, based on enhanced use of integrated long-term care services (LTCS), have emerged (Grabowski et al., 2010; Tsutsui, 2014).

The World Health Organization (WHO, 2014) ranks Singapore within the top five countries with the longest life expectancy at birth: with life expectancies of males to be 80.2 years and females averaging 85.1 years. Longevity has led Singapore to face a rapidly ageing population with 11.7 percent of its resident population aged 65 years old and above, in 2015 Singapore Department of Statistics (2016). Within the next decade, one in five Singapore citizens would be aged 65 years and above (Kim, Wai, & Low, 2015). Therefore, the Singapore government has announced plans to enhance the supply of LTCS and ensure the quality of these provisions to cater for the expected increase in demand (Ministry of Health, 2016; Ong, 2015).

Long-term Care Services (LTCS)

The United States Department of Health and Human Services defines long-term care services (LTCS) as a variety of services that supports individuals, who have difficulties with activities of daily living (ADL) resulting from chronic illness, disabilities both physical or mental or other issues relating to health, over a significant period of time (Favreault & Dey, 2015). The World Health Organization further elaborated that these services include medical and social assistances; and extends beyond ADL assistances to also include instrumental activities of daily living (IADL) assistances and health maintenance activities to preserve or develop one’s quality of life and physical and mental functioning (WHO, 2000; Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013).

The United States Department of Labor (2018) revealed that an average US citizen spent approximately 9.59 hours per day on ADLs such as bathing, dressing and medication management whereas they spent an average of two hours per day on IADLs such as meal preparation and house-keeping (Crowley, 2018). In Singapore, Duke-NUS Graduate Medical School found that 31,738 older Singaporeans, in 2010, had at least one ADL limitation and this is forecasted to increase to 82,968 older Singaporeans in 2030 (Kim, Wai, & Low, 2015; Thompson, et. al 2014).

Despite these definitions, there are various implementation challenges due to the widening age range of older adults, the varying expectations among people of different age cohorts as well as the diverse health and social issues faced by them (Crowley, 2018). For instance, Knickman and Snell (2002) found that baby boomers succumbed to more care hours, as compared to the old-old cohort of older adults aged above 80 years old, as they are at greater risk for acquiring disability earlier and require longer durations of LTCS (Corrada, Brookmeyer, Hill, Berlau, & Kawas, 2010). Crowley (2018) further revealed that older adults with dementia or Alzheimer's disease and those with functional loss also require earlier and higher levels of care as compared to those with other multiple chronic illnesses. These complexities pose difficulties in quantifying the quantity and level of care required at the population level, and, thereby, how LTCS would be defined (Qudrat-Ullah & Tsasis, 2017).

The location where older adults receive LTCS also evolved over the years. The WHO (2000) noted a shift among its member countries from the traditional hospital-based LTCS to community-based LTCS for older adults (Qudrat-Ullah & Tsasis, 2017). In many countries as with Singapore, formal LTCS, which are services provided by health or social care professionals, is broadly categorised into institution-based (nursing homes, sheltered homes and community hospitals), home-based (home nursing programmes, meals delivery, escort services and etc) and centre-based care (day care centres) (Kim, Wai, & Low, 2015).

Besides formal care arrangements, there is informal long-term care, which is usually provided by an older adult's family members, relatives, friends, neighbours or foreign domestic workers (FDW). These informal caregivers usually assist an older adult on a variety of tasks, from dressing, bathing and consuming medications to ventilator care and tube feeding (Reinhard, Given, Petlick, & Bemis, 2008).

In Singapore, most informal caregivers are female, between 45 to 59 years old, and married (Chan, Østbye, Malhotra, & Hu, 2012). About 65% of these caregivers are sons or daughters of the older adult they cared for (Chan et al., 2012). In 2013, FDWs were hired by 49% of Singaporean families to care for their older family members (Østbye, Malhotra, Malhotra, Arambepola, & Chan, 2013). These factors further expand the scope of LTCS.

Low Formal LTCS Utilization

Despite an increasing need for formal LTCS, the utilization rate is declining in many parts of the world (Alders, Comijs, & Deeg, 2017). For instance, in the Netherlands, official figures from the Ministry of Health, Welfare and Sport (2013) showed that although a significant proportion of the Dutch were utilizing institutional LTCS, the rate of utilization has drop significantly in recent years for adults over 80 years old. More specifically, de Meijer and colleagues (2015) noted that from 2000 to 2008, older adults with none or minimal disability were more adverse towards institutionalization. This accounted for a 67% drop in the utilization of institutional LTCS (de Meijer, Bakx, Doorslaer, & Koopmanschap, 2015). Likewise, in the United States of America (USA), Feder, Komisar and Niefeld (2000) reported that the number of nursing home residents has declined from 4.6% in 1985 to 4.2% in 1995.

Several countries in the Organisation for Economic Co-operation and Development (OECD) also observed similar trends of declining LTCS utilization. For instance, Estonia experienced a decline in home-based LTCS utilization rate of 27% from 2010 (*n* = 15,636) to 2016 (*n* = 11,413), and Norway experienced a 6% decrease in institutional LTCS utilization rate from 2010 (*n* = 44,397) to 2017 (*n* = 41,884) (OECD Statistics, n.d.).

In Singapore, Wee and colleagues (2015) found that although nursing homes appears to have a high occupancy rate, the actual utilization rate by people referred to community based LTCS are significantly lower than those in Western countries. Despite the best efforts put forth by the Singapore government, the utilization rate of LTCS was 50% at best (Wee et al., 2014). Liu, Eom, Matchar, Chong and Chan (2016) further support this trend where they found that only 53% of those referred to center-based LTCS (*n* = 418) and 52% of those referred to home-based LTCS utilized the services (*n* = 322).

According to the Behavioral Model of Health Services Use (See Figure 1.1; Andersen & Davidson, 2007; Andersen & Newman, 2005; Andersen, 1995), widely known as the “Andersen Model”, there are contextual and individual characteristics, each of which is divided into predisposing, enabling and need factors, which would determine if an individual would subscribe to health services. Predisposing factors are existing conditions such as socio-demographics (e.g. race, age, and marital status) that increase the propensity for, but which does not directly lead to, greater use of health services. Enabling factors are conditions that make health services accessible, such as income, living arrangements and the availability of a caregiver. Need factors are conditions, usually functional and clinical, that individuals and service providers would consider as requiring a health service, such as limitations in ADL. According to this model, health service use would, in turn, determine the individual's health outcomes.

Since the Andersen Model's inceptive suggestion in the 1960s that "people's use of health services is a function of their predisposition to use services, factors which enable or impede use and need for care", predisposing, enabling and need variables under contextual characteristics, consumer satisfaction, perceived and evaluated health as outcomes, and personal health practice and process of medical care as health behaviours, have been added to the original behavioral model (See Figure 1.1; Andersen, 2008).

Unfortunately, the Andersen Model does not adequately explain the decline in LTCS use (Alders, Deeg & Schut, 2019; Wee et al., 2014). Alders, Comijs & Deeg (2017) found an unexplained "time effect" when using groups of variables drawn from the Andersen Model to study LTCS use of older individuals across different timeframes in Netherlands (Alders et al., 2017; Alders et al., 2019). The authors found fewer admission to institutional care in the period of 2006-2009 as compared to 1996 – 1999, despite the patients in both periods being similar in terms of personal and health situations. This time effect was attributed to the changing perceptions on the attractiveness of institutional LTCS in their later study (Alders et al., 2019). Such dynamic and subjective component is neglected in the Andersen Model. The limited effectiveness of the Andersen Model in explaining service use has also been suggested to be due to its lack of psychosocial factors such as dynamic interpersonal interactions between caregivers and care recipients, and culture (Guendelman, 1991; Portes, Kyle & Eaton, 1992; Roh et al., 2017). Keith, Wacker, and Collins (2009), for instance, found that caregiver's and family members' perception and resistance had direct relationship with caregiver efficacy, which was associated with use of formal care services, while Wee and colleagues (2014) identified caregiver, rather than care-recipient, factors had greater influence over care-recipients' use of LTCS. Indigenous people in South Korea, in comparison with people in Western countries, underutilize LTCS and prefer home-based care to residential care because the care recipient could stay within the vicinity of the family (Kim and Kim, 2004; Kim, Cho, & June, 2006).

Deleterious Effects of Informal Caregiving

Traditionally, caring for the older adults has been a responsibility undertaken by informal caregivers (Lebel et al., 2001). Even with the availability of formal LTCS, many older adults who require assistance in activities of daily living prefer to rely on informal care. This phenomenon is especially common in Asia, where community-based services are preferred over institution-based ones, to keep seniors with or close to family.

In a meta-analysis, Vitaliano, Zhang and Scanlan (2003) reported that informal caregivers have 9% greater risk for health problems than non-caregivers. Like others who are engaged in activities that involves chronic exposure to high levels of stress, informal caregiving can lead to debilitating effects on the physical well-being of an individual (Cohen, Kessler, & Underwood-Gordon, 1997), and risky health behaviours such as substance abuse or having poor diet (Vitaliano et al., 2003).

Informal caregiving can also adversely influence the mental health of caregivers (Gilhooly et al., 2016). A longitudinal study in USA reported that spouses who were caregivers exhibited greater depressive symptoms when compared to spouses who did not take up the role of a primary caregiver (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003). Primary caregivers who are children of the care recipients have also experienced detriments to their psychological health since assuming the role of caregiving (Amirkhanyan, & Wolf, 2006). In a systematic review, Schulz, O'Brien, Bookwala, and Fleissner (1995) reported that the median rate of clinical depression among caregivers was 22%. This rate increased to 30% when self-reported measures were used.

Family dynamics are known to influence the burden experienced by family caregivers. Scharlach, Li and Dalvi (2006) found that family conflict mediates the effect of caregiver educational level and care recipient cognitive impairment on strain experienced by caregivers in the USA. In a later study of Japanese caregivers, Kusaba and colleagues (2016) reported that regardless of the extent to which a care recipient's cognition is impaired, adverse family dynamics strongly aggravate caregiver burden. It is, therefore, important to account for the family from various perspectives when providing an intervention for family caregivers as part of LTCS (Fukui, Sakka, Amiya, Sato & Kamibeppu, 2018).

In Singapore, it was estimated that there was a total of 13,700 caregivers aged 55 and above in 2016 (Gubhaju, Malhotra, Chan, & Østbye, 2017). Older family caregivers are in declining health themselves but are spending very long hours (up to 60 hours per week) caring for their family member (Gubhaju et al., 2017). Nine in ten caregivers aged 75 to 79 suffer from at least one chronic illness, while six in ten and three in ten of caregivers in this age range have poor or fair self-rate health and clinically significant depressive symptoms respectively.

Eom, Penkunas, and Chan (2017) found differences in self-perceived quality of life and well-being among informal caregivers in Singapore.

Caregivers who were adult children and spouses appear to have poorer well-being than caregivers who were more distant relatives and friends. The authors found that, when compared to other caregivers, spousal caregivers reported greater depression levels and poorer psychological health. They also reported that adult children caregivers experienced greater stress levels and significantly lower self-perceived general health than non-immediate family caregivers.

Østbye and colleagues (2013) found that instrumental support from an FDW moderates the adverse impact of primary stressors, such as the older adult’s impairments, on caregiver outcomes, such as self-esteem and self-perceived health status.

In a national survey of 1181 care-recipient/caregiver dyads in

Singapore, Ajay, Østbye and Malhotra (2017) reported that it was the insufficient preparedness of one’s caregiving role that increased caregiver burden, reduced care recipient and caregiver quality of life, and reduced the quality of care provided by the caregiver to the care recipient.

Informal Caregivers’ Subjective Well-being

In the field of positive psychology, subjective well-being is understood to refer to an individual’s response to life, which includes cognitive and emotional reactions. Research is accumulating evidence (Balatsky & Diener, 1993; Huebner and Dew, 1996; Myers, 2000; Diener, Scollon & Lucas, 2009; Diener et al., 2010) that shows that, despite individual differences, subjective well-being comprises three components:

1. Satisfaction with present life. Individuals scoring high in this area enjoy their work and have satisfying interpersonal relationships. Outgoing and gregarious, they are open to others. (Pavot, Diener, & Fujita, 1990). Positive self-esteem and healthfulness are present in individuals high in subjective well-being (Baumeister, Campbell, Krueger, & Vohs, 2003; Janoff-Bulman, 1989, 1992).
2. Relative presence of positive emotions. Individuals scoring high in this experience positive emotions more often, largely owing to their positive evaluation of the world around them, are optimistic and expect to succeed (Seligman, 1991). With their internal locus of control, they can experience the “flow” of engaging work (Crohan, Antonucci, Adelmann, & Coleman, 1989; Csikszentmihalyi, 1990).

3. Relative absence of negative emotions. Individuals with high scores in this area experience fewer negative feelings including anxiety, depression and anger. They maintain a moderate emotional outlook. They are usually positive, although negative moods may be present from time to time (Diener & Seligman, 2002).

The subjective well-being of informal caregivers of seniors has been understood and studied in terms such as caregiver psychosocial need (Cheng et al., 1994; Yates, Tennstedt & Chang, 1999; Harris, 2009), caregiver well-being (Eom, Penkunas, & Chan, 2017) and caregiver psychosocial health (Spaid & Barusch, 1991; Rapp, Shumaker, Schmidt, Naughton & Anderson, 1998; Chappell & Reid, 2002; Cunningham, Cunningham, Roberston, & Heyn, 2018). Five major concepts have been the subject of extensive investigations in the literature.

Caregiver burden. There is a body of established research which alludes to caregiver burden as complex with multiple dimensions and as a reaction or process. Research by Lu, Wang, Yang and Feng (2009) defines caregiver burden as a biopsychosocial reaction resulting from an imbalance of demands and resources which can include caregivers' financial resources, personal time, physical and emotional states, social roles, and formal care resources due to the many other roles they fulfill. Pearlin, Mullan, Semple, and Skaff (1990) understand caregiver stress to be a complex multifaceted process involving circumstances, experiences, and resources, with much individual variation. Their definition also indicates that this process results in various mental and physical outcomes. Research using the Pearlin Stress Process Model provides the most bearing in understanding the process of caregiver burden (Bookwala et al., 2004). Under this model, care is transformed into individual burden and can lead to physical and psychological responses in the caregiver. As well the model describes there are numerous stress factors influencing caregiver burden (Pearlin et al., 1990). Carretero, Garcés, Ródenas, and Sanjosé (2009) published a theory and empirical review of the current research with respect to the construct of informal care. Their conclusions indicate that despite multiple investigations, caregiver burden remains an ample term with still no homogeneity in its meaning and use (Carreterro et al., 2009). The authors suggested that caregiver burden be understood within a multi-faceted process that can encompass different explanatory theories (Carreterro et al., 2009).

Caregiver health status. Caregiver health status is a term used broadly and can be synonymous with other vocabulary such as health, quality of life, and well-being. Many studies show a direct correlation between caregiver health status and caregiver burden (Chung, Hsu, Wang, Lai, & Kao, 2007). Saban and colleagues (2016) reported that health status is very often viewed as a subset of caregiver burden. Research by Hong and Harrington (2016) uses the Caregiver Health Model which presents caregiver inputs based on caregiving situations and resources such as financial, mastery, social support and family harmony. Caregiver burden is then the outcome based on caregiving situations and resources. Perceived health of caregiver is an outcome based on caregiver resources as well as caregiver burden.

Additional literature references health status as an outcome based on the level of caregiver burden. Research by Hong and Harrington (2016) defines caregiver burden as the degree to which caregiving takes a toll on caregivers physically, emotionally, and/or socially. (Anderson & Elmståhl, 2008; Hong & Harrington, 2016). Similarly, research by Chang (2009) examined caregiver burden as an outcome which is assessed by understanding the extent to which caregivers experience perceived physical, economic, relational, psychological or emotional, daily life, and time management stress.

Caregiver depression. Depression in the context of caregivers can be described as an emotional state that reflects general feeling, self-perception, energy level, appetite and sleep, as well as feelings of anxiety and fear (Chang, 2009). The research presents caregiver burden and depression as outcomes. Some of the research views caregiver depression as an outcome that can be predicted by income insufficiency, gender, co-residence with the care recipient, longer daily caregiving hours, and poorer self-rated health (Arai, Kumamoto, Mizuno, & Washio, 2013). Research by Wang, Xiong, Levkoff, and Yu (2009) examine caregiver depression as an outcome that is influenced by care recipient physical condition and background as well as the caregiver's background and income.

Caregiver social support. Wang, Zhong, Ji and Chen (2016) defined caregiver social support as an interpersonal resource that caregivers may utilize when they are trying to cope with the everyday stresses and strains of life, arising from caretaking. According to The Stress Model, social support acts as a buffer to mediate the effects of caregiving stress (e.g. Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Pearlin et al., 1990). These interpersonal resources, which Hogue (1985) calls “Social Support Systems”, provide caregivers with monetary, emotional, physical, and cognitive support (House, Umberson, & Landis, 1988; Sarason, Pierce, & Sarason, 1990; Thoits, 1995).

Caregiver social support can be classified into two categories – formal and informal social support. Kaufman, Kosberg, Leeper, and Tang (2010) note that it is crucial to distinguish between the two given the complexity and multidimensional characteristic of informal social support. Shiba, Kondo and Kondo (2016) defined formal social support as professional services that caregivers use. Thus, formal social support refers to caregivers’ use of paid services provided by domestic helpers, doctors, nurses and social workers. Meanwhile, informal social support is based on the caregiver’s personal network such as relying on their family and friends for support. Amendola, Oliveira and Alvarenga (2010) added that social support is often offered by people or groups that caregivers usually have contact with. Both types of social supports are similar in terms of their functions. The main difference between formal and informal social support is that the former is a paid arrangement.

Caregiver-patient relationship quality. Caregiver-patient relationship quality is the understanding of the degree of closeness, comfort, and trust between the informal caregiver and patient. It focuses on the dynamic within the dyad, and examines the interactions between the caregiver and the patient being cared for.

Often, research studies on caregiver needs noted the nature of the caregiver-patient kinship (i.e. how caregiver and patients are related) but few went on to examine the possible effect(s) of the quality of the caregiver-patient relationship on caregiver needs. Recent research, such as Chong, Ho, Lou and Koh (2018), Francis, Worthington, Kypriotakis and Rose (2010), and Yeh, Wierenga and Yuan (2009), examined the quality of the relationship between informal caregivers and patients in attempt to gain a more holistic understanding on the demands of care needs from both patients and caregivers. Given that patients prefer to live at home rather than being institutionalized (Rantz, Marek, & Zwygart-Stauffacher, 2000), it becomes important to understand the quality of the caregiver-patient relationship so that the needs of both parties are addressed.

Integrated Care

In the past two decades, twin problems of low LTCS utilization and deleterious psychosocial effects of informal caregiving brought about by the ageing population, changing demography, and the growing prevalence of chronic conditions, have encouraged efforts to integrate LTCS provision for greater access, quality, and continuity.

Integrated care contrasts episodic or disjointed care. It is used interchangeably, with terms such as “seamless care” and “coordinated care”. Yet, there is no universally accepted model nor a singular definition for understanding integrated care conceptually. This is probably because of the various forms which integrated care can take, often dependent on the beliefs and viewpoints of the innumerable shareholders, embedded within the healthcare system.

The WHO (2016) reported from literature three key definitions of integrated care. The first, which is utilized by many national governments, embodies a process that deals with the various elements of integrated care. Accordingly,

> Integration is a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. With the result of such multi-pronged efforts to promote integration leading to benefits for people, the outcome can be called "integrated care" (adapted from Kodner & Spreeuwenberg, 2002, p. 3).

The second definition is focused on the experience of integrated care users and entails a description and purpose. In brief, "My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes" (National Voices, 2013, p. 3).

Thirdly, integrated care is defined as a health system, and is used by the WHO Regional Office for Europe.

Therefore, integrated health services delivery is defined as an approach

> to strengthen people-centred health systems through the promotion of comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through inter-sectoral and multi-sectoral actions (World Health Organization Regional Office for Europe, 2016, p. 10).

Underlying all three definitions is the principle that the needs of individuals, families and communities should inform integrated care (Shaw, Rosen & Rumbold, 2011). Evidence supporting such a perspective supports the call to focus on the needs of beneficiary stakeholders, in order to bring about consensus and collaboration between competing entities (Ham & Walsh, 2013). Having care delivery centred on users' needs clarifies the goals of integrated care, thus allowing assessment of its effectiveness. Furthermore, having user-centred goals helps decision-makers to avoid organizational or structural-based solutions (Lewis, Rosen, Goodwin, & Dixon, 2010).

To enhance access, quality, and continuity, Valentijn, Schepman, Opheij and Bruijnzeels (2013) presented four levels of integration in service provision; micro (clinical), meso (professional and organisational), macro (systems) and functional (micro-meso-macro) integration. At the micro level, person-centred service-delivery for coordinated interventions to address the spectrum of needs of a person is necessary. Professional and organisational integration is required to support and enhance interaction between organisations and professionals within and across systems, to maintain quality and continuity of services. Macro integration is defined as the combination of systems consisting of processes, structures and techniques to meet the needs of the people and the population across the care continuum. A functional integration of the micro-meso-macro levels can be achieved by linking key systems, such as financial or information systems, around the central processes of service provision to ensure accountability amongst policymakers, managers, professionals and patients, and to maintain the decision-making partnerships across the stakeholders.

The four integration types can also be described according to their underlying mechanisms. Integration based on management principles or affiliation is deemed normative integration; That which is exemplified by coherent regulations and policies across organisational levels is systemic integration. Integration may occur horizontally or vertically. The former happens when different organizational entities, upon reaching similar stages of their respective operation processes, converge to collectively provide goods and services. Some instances include, uniting acute hospitals or assimilating social organizations into health care organizations. The latter requires the deftness of organizational entities providing services at different stages since such entities function at a variety of levels under a single managerial hierarchy. Examples of vertical integration include, integrating principal care and support care, or integrating generic practice and community care. The integration process can also be virtual or real. Virtual integration occurs when developing partnerships, systems and predetermined preparations. Real integration happens during the union of organizations wherein their respective physical assets and infrastructure becoming mutually accessible.

Dorling and colleagues (2015), in their systematic review and meta-analysis of 53 individual controlled trials using a fixed effects model, found that compared with usual care, integrated care programmes were associated with a 19 percent decrease in hospitalization rates. The authors further established that in programmes for diabetic patients, there was a mean 0.5 percent decrease in blood glucose levels (HbA1c) associated with integrated care, as compared with usual care. Educating and empowering patients, cross disciplinary medical collaborations, synchronous care, and customized care plans were found to be critical components of any integrated care programme.

In 2009, the Agency for Integrated Care (AIC) was launched to integrate the Singapore LTCS sector. Its objective is to enhance care access, develop primary and community care, and support LTCS care recipients and their caregivers. The AIC coordinate referrals to LTCS and is a one-stop information service for anyone to enquire about intermediate and LTCS. The care needs of patients referred to formal LTCS are assessed by AIC referral coordinators, who also coordinate patients’ transition from acute hospitals back into the community. The AIC works with formal LTCS providers on care placements.

Individuals who receive LTCS via AIC referrals may receive government subvention after means testing.

In summary, integrated care potentially allows the needs of informal caregivers to be considered and incorporated into the design of care as a shared objective with that of patients' needs. This departure from the traditional paradigm of patient-centred care to dyad-centred care provides LTCS stakeholders a basis to redesign care and better cater to the evolving and complex needs of patients and their informal caregivers. To endeavour such a transformation of LTCS requires massive reallocation of resources. As such, it is only prudent that such endeavours be based on evidence of high quality regarding the association of formal LTCS use and informal caregivers' subjective well-being.

Aim of Thesis

The aim of this thesis is to elucidate the role of informal caregiver subjective well-being in explaining formal LTCS use. This shall have far-reaching implications on factors for LTCS use, and integrated care theory and design. Chapter 2 shall present, via a systematic review and meta-analysis of extant literature, a descriptive summary and quantitative synthesis of the association between informal caregiver subjective well-being, in the context of caregiver psychosocial need, and LTCS use. Chapter 3 shall show, via a series of logistic regression analyses of prospective data, the extent to which informal caregiver subjective well-being, understood as caregiver well-being, predicts LTCS use in the context of stroke rehabilitation. From a social health perspective, Chapter 4 shall present, via latent profile transition analyses of the same dataset, segmentation of informal caregivers based on subjective well-being fluctuations that occur in tandem with changes in stroke rehabilitation use over a 12-month period. Finally, Chapter 5 shall integrate and discuss the findings presented in this thesis in the context of integrated care design, service provision and service use factors. As a preview, Figure 1.2 summarizes the inter-relationships between the rationale, aim, research questions, findings, and contributions presented in this thesis.

Chapter 2

Introduction

Over the past decade, the meeting of caregiver needs has become an increasing concern of health and social care systems. Care systems are undergoing transformation to integrate caregiver services and programmes into existing ones that focus on the patient. Various approaches from different parts of the world have been initiated and upscaled to achieve these aims. In 2000, the Japanese government introduced the Long-Term Care Insurance System (LTCI) to allow the elderly to live in the comforts of their home for as long as possible. Oyama et al. (2013) found that home-nursing service use reduced caregiver burden, crucial for achieving the aim of the LTCI system. In Europe, Spijker et al. (2011) investigated the Systematic Care Program for Dementia (SCPD) and discussed the importance of monitoring caregiver needs to ensure that effective interventions are provided to relieve the caregivers of their burden. This will prevent delaying of patient’s institutionalization, ensuring that patients receive the quality care that they require for their condition. Similarly, in North America, Gaugler, Zarit, Townsend, Stephens, and Greene (2003) found that the daily cost to reduce caregiver burden and depression decreased when utilization of adult care services increased.

One of the main drivers of such integrated care efforts is the growing evidence that associates elevated levels of burden and depression, and worse health status on the part of caregivers, with increased physical and cognitive impairments, and behavioural problems on the part of patients. For instance, a meta-analysis of 228 studies (Pinquart & Sörensen, 2003) found that caregiver burden was directly and moderately associated with a patient's increased physical impairments and behavioural problems, and slightly associated with the latter's increased cognitive impairments. Similarly, these researchers found caregiver depression to be directly and slightly associated with the patient's cognitive impairments and physical impairments, while it is more strongly associated with a patient's behaviour problems. Rigby, Gubitz, and Philips (2009) found an association between high caregiver burden and lower cognitive function in patients with stroke and Parkinson's disease. Hirschman, Shea, Xie, and Karlawish (2004) established a strong association between higher caregiver burden and greater depression. Bass, Noelker, and Rechlin (1996) also found that problem behaviour predicted a 61% increase in caregiver depression.

The associations of these caregiver needs with a patient's long-term care service (LTCS) utilization[1], however, are unclear. On the one hand, care systems hope to reduce caregiver burden and depression and improve their health status via the provision of care. On the other hand, the increasing complexity of service utilization could be a daunting space for caregivers to navigate (Funk, Dansereau & Novek, 2019). The provision of integrated care may also uncover caregiver needs that care systems are ill-equipped to deal with. Care systems focus largely on patient's needs, but their needs can differ substantially from their caregiver's (Lopez-Hartmann, Wens, Verhoeven &

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[1] See Chapter 1 for a discussion on the concept of long-term care service utilization.

Remmen, 2011).

To-date, individual studies have reported conflicting findings on the association between caregiver needs and nursing home admission, home- and community-based care services utilization. Lai (2008) stated that caregivers who reported higher levels of caregiving burden were more likely to utilize formal LTCS and home support services, (odds ratio, *OR* = 1.07, 95% CI [1.04, 1.11]). McCann et al. (2005) found that greater caregiver burden was linked with an increase in the risk of nursing home placement. Hong and Casado (2015) established that the relation between service utilization and caregiver stress increased by 14.1% when state expenditure on home-based care services increases. Gaugler, Hepburn, Mittelman, and Newcomer (2009) reported a moderate decrease in caregiver burden after patient's institutionalization. However, Brown, Potter, and Foster (1990) reported an inverse relationship between caregiver burden and home services and nursing-home placement. Kim and Yeom (2016) found an increase of variance (48.9%) when adding home care service use to the model testing for caregiver burden. Phillipson, Magee and Jones (2013) found that non-users of residential respite care tend to have a lower caregiver burden. Meanwhile, Kumamoto, Arai and Zarit (2006) reported that as latent variables in a structural equation model, caregiver burden is predicted inversely by utilization of six care services under the Japanese LTCI System.

Similarly, examination of caregiver depression and its association with formal LTCS utilization are inconclusive. Kua and Tan (1997) established the presence of caregiver depression as a result of providing care for the patient. Chang (2009) found that home-care services helped to decrease the effect of patient’ needs on caregiver depressive mood. Bookwala et al. (2004) pointed out that caregiver related variables added 17.7% variance to the usage of community-based services, with higher depressive symptom predicting more LTCS use. Spijker et al. (2011) noted that caregiver depressive symptoms were significant predictors of the odds of institutionalization. Gaugler et al. (2009) further reported that caregiver depression slightly lowered after institutionalizing patients. However, Gaugler, Leitsch, Zarit, and Pearlin (2000), Schulz et al. (2004), and Zarit and Whitlatch (1992) pointed out that caregiver burden, and depression did not improve considerably after institutionalizing patient. This might be due to dissatisfaction with the nursing home environment. Tamiya et al. (2011) shared the same sentiment as the studies presented above. Mensie and Steffen (2011) who applied the Andersen Model to variable selection in their studies, reported that there is a lack of relationship between caregiver depression and 3-month respite usage.

Studies that looked at caregiver health status also presented a mixed review. Bass and Noelker (1987) found that caregiver health status deterioration was associated with formal LTCS utilization, rather than non-utilization. Mehta (2005), in examining caregiver stress among informal caregivers of older persons in Singapore, reported that high caregiver stress has an impact on the health status of the caregiver. Noimuenwai (2012) showed that caregiver health status improved after using adult day care services and Bonferroni post-hoc test further confirmed that the mean differences in baseline at the 1st month and 3rd month were significantly different. Kosloski and Montgomery (1994) presented that caregiver health status was associated with the use of doctors visit and group meals, only for caregivers who were children of the patient. Whitlatch, Feinberg and Sebesta (1997) found a negative correlation between caregiver health status and short-term use of in-home respite.

Measurement Issues

While some of the variations in the above associations may reflect a range of conceptualizations of each caregiver need discussed in Chapter 1, other variations may be a result of different measurement tools used.

Among the three caregiver needs, caregiver burden appears to have the greatest number of different measurement tools including Caregiver Stress Scale, Caregiver Strain Index, Caregiver Burden Scale, Caregiver Burden Inventory, Zarit Burden Interview (ZBI) and Self-Rated Burden Scale (Rigby et al., 2009). Among these tools, the ZBI is apparently the most frequently used (Rigby et al., 2009). The inventory has standard versions which encompass person strain and role strain as well as shortened versions which use a 5-point Likert-type scale in which the caregiver self-reports responses that range from 0 (never) to 4 (nearly always) (Ballesteros et al., 2012; Lai, 2008; Tanji et al., 2005). Hébert, Bravo, and Préville (2000) reported that the ZBI has an internal consistency of 0.92 as measured by Cronbach's alpha, and test-retest reliability of 0.89 as measured by both Mokken and Cronbach's α criteria. The ZBI, which exists in 47 different languages (Mapi Research Trust, n.d.), comprise two domains, personal and role strain, and assess the following areas: depression, mental health, negative affect, social support, and stress and coping (Hébert et al., 2000).

The Patient Health Questionnaire (PHQ-9) and Geriatric Depression Scale (GDS) are widely used instruments to measure caregiver depression. However, the Center for Epidemiologic Studies Depression Scale (CES-D) appears to be the more frequently used tool. The CES-D measures the overall depressive mood of the caregiver and uses a Likert scale that range from 1 (never) to 4 (often) (Chang, 2009). Many studies including research by Arai et al. (2013) use a 20-item version that takes 10 to 20 minutes to administer. Other studies deploy shorter CES-D versions such as a 10-item rapid screen (Hirschman et al., 2004). Components of the CES-D include depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite and sleep disturbance. The scale can be either interviewer- or self-administered. High internal consistency, and theoretically consistent divergent and convergent validity, in addition to strong factor loadings, characterize the outstanding psychometric measures of the CES-D (Radloff, 1997). Research by Hirschman and colleagues (2004) has found the CES-D to be used with older adults and scores are reported to be reliable with this population. Versions are available in over 20 languages with use in over 50 countries (Mapi Trust Research, n.d.).

Health status measurement tools are overwhelmingly deployed by self-reported and perceived health measures which may also be referred to as self-assessed health (Jowsey, Mcrae, Gillespie, Banfield, & Yen, 2013). In some instances, a single item measurement tool was used to assess perceived health status of caregivers.

Arai and colleagues (2013) assessed caregiver health status through a question “To what extent do you feel that you are physically fit?”, on a 5-point scale ranging from poor to excellent. Numerous studies have illustrated that single-item self-rated health (SRH) scales measures both objective and subjective aspects of health status (Meng, Xie, & Zhang, 2014). This is a scale ranging from 0 (worst) to 100 (best) where the respondent points out a value which best represents their health on the survey day. Because of the simplicity and single question nature such scales, they can be easily translated into other languages with application throughout several cultures.

Another approach to measuring caregiver health status utilizes subjective and objective methods. Subjective health is evaluated by a single-item indicator and symptom checklists while objective health is evaluated using the number of medical conditions, hospitalizations or doctor visits and medication use (Kim & Yeom, 2016). The Medical Outcomes Standard Form-36 tool uses a 36-item self-report form which evaluates physical and mental health (Klinedinst et al., 2009). Self-rated health measures have, in general, been positively correlated with objective health measures, and most consistently and accurately predicts depression in caregivers (Pinquart & Sörensen, 2007; Arai et al., 2013).

Importance of Study

Nonetheless, despite the growing literature that examines the association between patient's use of formal long-term care services (LTCS) and each of caregiver burden, depression, and health status, no systematic investigation and synthesis of these topics have been conducted. This leads to the proposal of a new systematic review and meta-analysis.

A systematic review is a literature review that uses a methodical way of secondary data collection for critical analysis of existing research studies, followed by synthesis of all the studies involved, to address a missing gap in the existing literature. With a defined research question, researchers search for relevant studies that fit a set of criteria. To address the research question, data from these studies are then extracted and synthesized qualitatively and/or quantitatively (Uman, 2011). A qualitative synthesis is an extraction of qualitative and quantitative data from included studies into descriptive summaries that (i) answer the research question, and (ii) informs on common study (e.g. country of study, LTCS type, measurement tool) and participant (e.g. ethnicity, main illness of patients) characteristics across studies. A quantitative synthesis, known as a *meta-analysis*, is an extraction of data from included studies into one combined ES estimate that informs the magnitude and direction of overall relations (i.e., omnibus tests) and provides precision on those relations (i.e., moderation tests). A meta-analysis allows the effect of study and participant characteristics on the relations of interest to be examined. A systematic review that involves both qualitative and quantitative syntheses to address the research question is referred to as a "systematic review and meta-analysis” (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009), which is the nature of the present study.

Theoretically, this study could assist with the formulation of a conceptual model of factors for integrated care service utilization in which the service user is not only the patient. Current models of healthcare service utilization such as the Andersen Behavioural Model (Andersen, 1995; Andersen & Davidson, 2007; Bradley et al., 2002; Andersen, 1968; Andersen & Newman, 1973; Aday & Andersen, 1974; Aday, Andersen, & Fleming, 1980; Andersen, 2008; Davidson, Andersen, Wyn, & Brown, 2004) and the Pearlin Stress Model (Pearlin et al., 1990) focus only on factors of an individual patient, without considering caregivers’ needs.

Practically, this study could have implications on the service design and delivery of integrated care services to both the patient and the caregiver. It may also provide insight into the conditions where functional and/or organizational integration of care services may be considered. For instance, if a patient’s dementia care service utilization is found to be unrelated to caregiver depression, then it should be unnecessary to consider the merging of a dementia intervention function in a facility with that of depression intervention in the same or in another facility.

Purpose of Study

The primary aim of the present study formulated using the Population-Intervention-Comparison-Outcome (PICO) method (Higgins & Green, 2011), was to determine if patient formal LTCS use is related to each of the three indicators of unmet caregiver psychosocial needs: caregiver burden, depression, and health status. To achieve this aim, this study conducted a systematic review and meta-analysis with three outcomes, following the "Preferred Reporting Results of Systematic Reviews and Meta-Analyses" (PRISMA) guidelines (Moher et al., 2009).

In this study, there were three relations of interest, namely,

1. the relation between formal LTCS use by the patient and the burden perceived by informal caregivers (that is, caregiver burden), and
2. the relation between formal LTCS use by the patient and the depression levels perceived by informal caregivers (that is, caregiver depression), and
3. the relation between formal LTCS use by the patient and the health status perceived by informal caregivers (that is, caregiver health status).

The target population (P) of this study is the informal caregivers of patients who need formal long-term care services. An informal caregiver is defined as a person who makes decisions on care arrangements or provides care to a person who is referred to or who is assessed to require formal long-term care services. An informal caregiver is usually, but not necessarily, a relative of the patient.

As intervention (I), formal LTCS refers to a broad range of health and social care services that are provided by care professionals on a sustained basis[2]. These services include, but are not limited to, day rehabilitation, social day care, day care, home nursing, home medical, home therapy, home help, home health, home hospice, nursing home, dementia care, dementia day care, respite care, community care, chronic care, hospice care, day hospice, hospice, residential care, and institutional care. Studies that compare (C) different types of LTCS and that compares a novel LTCS to usual care are eligible for inclusion.

The intended outcomes (O) are each of (i) caregiver burden, (ii) caregiver depression, and (iii) caregiver health status, respectively[3]. Different tools may measure each of these outcomes. If a relation was found between formal LTCS utilization and any one of these three outcomes, this study proceeded to identify the direction and magnitude of the relation.

A secondary aim of this study was to explore the effects of study and participant characteristics on the three relations of primary interest. While the selection of study characteristics to be coded may be considered straightforward in conventional systematic reviews and meta-analyses, the selection of participant characteristics in this study was guided by Babitsch, Gohl, and von Lengerke (2012), who, in their systematic review of the Andersen Behavioral Model, established the patient and caregiver factors which associations with healthcare utilization were most commonly examined in primary studies. Because these reviewers reported a lack of consistency in their findings

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[2] See Chapter 1 for a discussion on the concept of long-term care service utilization.

[3] See Chapter 1 for discussion on each outcome.

regarding the associations, and because this was the first review of the caregiver needs and formal LTCS use, no expectations on the results of the secondary aims were held.

Method

Protocol and Registration

The procedures of this study were guided by the Centre for Reviews and Dissemination for conducting reviews in health care (Centre for Reviews and Dissemination, 2008). A protocol that was drafted according to PRISMA-P guidelines (Shamseer et al., 2015) was registered with the International Prospective Register of Systematic Reviews (registration number: CRD42018108827).

Information Sources and Search

I conducted electronic searches of the following scientific databases on 7 September 2017: MEDLINE and PsycINFO. For reviews of healthcare interventions, systematic searching limited to MEDLINE, which is freely accessible via PubMed, has been shown to generate reliable results that can be used as inputs for subsequent decision and economic analyses (Halladay, Trikalinos, Schmid, Schmid, & Dahabreh, 2015). PsycINFO is a subject-specific database in behavioural sciences and mental health that potentially adds unique references relevant to the topic of the present study, although yields on top of MEDLINE might be limited (Halladay et al., 2015). In the MEDLINE search, the following limiters were applied:

1. article type: full text

2. source type: academic journals
3. source type: dissertations/theses
4. language: English

For each of the three relations of interest, I used the following keywords in the MEDLINE search respectively:

1. caregiver AND burden AND long-term care use
2. caregiver AND depression AND long-term care use
3. caregiver AND health status AND long-term care use

PsycINFO was searched similarly with the above limiters and keywords. I also conducted an electronic search of ProQuest Dissertations & Theses Global on 24 December 2017 and 13 January 2018. With the full-text article type and English language limiters applied, I used the search terms as I did in the MEDLINE search (see above), for each of the three relations, with one exception. Quotations for the phrase “long term care use” and “health status” were used in this search, otherwise, this search would yield an exorbitant number of hits (For instance, the use of “caregiver AND depression AND long-term care use” as search term yielded 77,043 hits).

For each of the three relations, a different second independent researcher re-performed the searches I conducted on the same day to verify them. All searches were verified correctly. Finally, two experts in the field of geropsychology were asked if they had knowledge of relevant but unpublished studies.

Study Selection and Eligibility Criteria

The title and abstract of each article were screened to ensure that included articles (a) were written in English, (b) collected empirical data, (c) collected data directly from informal or family caregivers (i.e. primary and non-proxy data), and (d) collected effect size data or sufficient quantitative data that allowed for the calculation of effect sizes of the corresponding relation. If an article reported no quantitative data on either formal long-term care service use nor the corresponding caregiver needs, and if it also reported no data on the other two caregiver needs, it was excluded. If an article reported data collected on any of the other two caregiver needs, it was included for review under the alternative relation(s) of interest. If the meeting of these criteria could not be determined from the title and abstract, the results and methods sections of the article were read. If the meeting of these criteria could still not be determined, then the entire article was read. If a dissertation/thesis was published as a journal article later, only the latter was included. If two or more articles reported results based on an identical dataset, only one of the articles was included, to avoid overrepresentation of any dataset.

Next, the references of included articles were manually searched to ensure retrieval of articles that were missed out from the computerized search. To ensure completeness, this step was replicated when new articles were discovered. For each of the three relations, another researcher independently re-performed the article selection process I conducted, to verify the list of included studies.

Data Extraction and Coding

The following qualitative characteristics were extracted from each research study found in an included article: author, publication year, data source, main finding, main statistical analyses, which of the three relations the study was included in, and whether the study was included in the qualitative synthesis, meta-analysis or both.

A coding manual (Supplementary material 1) was created on which to base the extraction and coding of quantitative characteristics. Variations to the labelling and measurement of caregiver burden, depression, and health status were extracted and coded if they pertained to the conceptualization of each of the caregiver needs described in this study. Formal LTCS use by patients was measured by either use vs non-use, or amount of use. The caregiver constructs were measured by either presence vs absence, or amount of caregiver self-perceived burden, depression, and worse health status, respectively.

The log odds ratio, *lnOR*, was the ES measure of choice. From each study, ESs were extracted or calculated from reported data and coded for each relation regardless of the type of analyses and other variables involved. The ESs were coded such that higher scores reflect a positive relation between increased use of formal long-term care service and higher caregiver burden, higher caregiver depression, or worse health status.

Aside from the ESs, study and participant characteristics were also extracted and coded. Based on literature, the quantitative study characteristics that were coded as categorical variables were: type of publication (journal article, dissertation/thesis), country of data collection, aim of study (patient factors for LTCS use, caregiver factors for LTCS use, both, others), study design (longitudinal, cross-sectional, cohort, correlational), LTCS type (community-based care, home care services, institutional services, respite, multiple services, information services), measurement tool of each caregiver need, grouping/measurement of LTCS use, theoretical model that guided the choice of study variables, analytic role of LTCS and each caregiver need. The quantitative participant characteristics that were coded as categorical variables were: whether more than 70% are female caregivers, whether caregivers were remunerated, whether caregivers held their role for the first time, whether caregivers stay with the patient and the main illness/health condition of the patient. The quantitative (study and participant) characteristics that were coded as continuous variables were: the total number of caregivers in the study, the mean caregiver's age, the mean patient's age, the percentage of female caregivers, and the percentage of female patients.

A two-hour training session was held to familiarize a masters-level coding assistant who works in the long-term care industry with the coding manual, show how to code approximately 10% of the included articles, and clarify doubts. This assistant and I then independently coded another 10% of the articles, met again for about one-and-half hours to check intercoder agreement, and troubleshoot discrepancies through discussions. The both of us coded the rest of the studies with the same protocol, with consultations where necessary. Finally, the coding results from both coders were compared and disagreements were surfaced. We had a 30-minute meeting to review the reasons for our different codes, and reach a consensus between us. Cohen's Kappa revealed a moderate to almost perfect agreement between the coding assistant and I (Kappas: .81 – .98, average: .89, all *p*s < .001; McHugh, 2012).

Risk of Bias / Quality Assessment of Individual Studies

The assessment of the quality of individual studies was based on three tools developed jointly by the National Heart Lung and Blood Institute (NHLBI) and the methodology team of a Cardiovascular Risk Assessment Work Group (CRAWG). These tools have been widely used in healthcare systematic reviews (Agency for Healthcare Research and Quality, 2013).

The tools were created to help reviewers focus on vital principles for critical appraisal of a study's internal validity. They comprised items for identifying possible methodological and/or implementational flaws, such as sources of bias (e.g. attrition), study power, confounding, causality strength in the interventions-outcomes relation, and other factors. Quality reviewers would choose "yes," "no," or "cannot determine (CD)/not reported (NR)/not applicable (NA)" in response to each item in the tool. When "no" was selected for an item, reviewers had to contemplate the possible risk of bias that might be caused by a design or implementation flaw of the study. Potential flaws were also denoted by CD and NR.

The CRAWG methodology team and the NHLBI also developed a guidance document for each of the three quality assessment tools. The guidance documents are distinct to each tool. They illustrated how the items are applied, and justified the inclusion of each item. Instances were given to explicate the purpose of the question and the suitable reviewer response for some items. The three quality assessment tools used in this study are included in Supplementary material 2, and the guidance documents may be retrieved from AHRQ’s webpage (Agency for Healthcare Research and Quality, 2013).

Each study was judged to be of “good,” “fair,” or “poor” quality by the reviewers using the study ratings on the range of item that came with each tool. Reviewers used the ratings on various items to examine the risk of bias in the study caused by study design or implementation flaws.

Generally, a “good” study is classified as having minimal risk of bias and its results are deemed valid. A “fair” study is exposed to some bias but insufficient to invalidate its results. A broad number of studies tend to fall into the fair-quality category, which varies in their strengths and weaknesses. A “poor” rating represents the presence of a substantial risk of bias. In the present systematic review and meta-analysis, studies that were rated poor were excluded for each relation of interest. An exception was made to consider poor quality studies if there were no further evidence available. However, the present study did not apply this exception as there were no instances where only studies deemed as poor-quality were available for any one of the three relations of interest.

I trained a master’s-level quality reviewer with a background in long-term care to use the quality assessment tools. The training provided (i) instruction for the reviewer to correctly identify designs of research studies, (ii) evidence-based research theory, (iii) quality assessment theory, (iv) item justifications in each tool, and (v) methods for making overall appraisals regarding quality ratings of “good”, “fair”, or “poor”.

I assessed the ability of the reviewer by assigning several articles with pertinent study designs after an in-person training session. She had to determine the appropriate study design, use the appropriate quality assessment tool completely, and submit the results to me to check against a key. A subsequent training session was held through telephone to re-examine and settle any remaining misunderstanding of the quality assessment procedures and instructions.

The reviewer and I used the appropriate tool to rate the quality of each study that met the inclusion and exclusion criteria independently. The reviewer and I discussed the article via a face-to-face meeting to reach consensus should the ratings differed. Cohen’s Kappa revealed a moderate to almost perfect agreement between the coders (Kappas: .75 –.86, average: .80, all *p*s < .001; McHugh, 2012).

Studies that were assessed to have poor quality were excluded from the syntheses unless its inclusion was required for moderation analysis, that is, any subgroup contained fewer than three studies.

Qualitative Synthesis

The number of included studies that display each sub-characteristic of the study and participant characteristics, and that were coded as categorical variables, were recorded for each relation. The total or grand mean across studies were calculated for the quantitative characteristics that were coded as continuous variables. The common characteristics across studies of each relation of interest were identified. The adjusted and unadjusted ESs obtained from each article are grouped by relation and arranged from the smallest negative value to the largest positive value. Finally, the median ES of each relation was computed and converted to odds ratio (*OR*) to ease interpretation.

Meta-analysis

Omnibus tests. As described above, aggregate participate data were coded and used in omnibus tests. To ensure generalizability of results, only articles that reported unadjusted effect size data or data that allowed the calculation of unadjusted effect sizes were included in the meta-analysis. Articles that reported only adjusted effect size data, that is, ES that are adjusted for other variables or data that only allowed the calculation of adjusted effect sizes were included in the qualitative synthesis but excluded from the meta-analysis. Articles that reported both adjusted and unadjusted effect size data were included in both the qualitative synthesis and the meta-analysis.

The meta-analyses were conducted using *Meta-Essentials,* which is a series of pre-written formulae and functions based in Microsoft Office Excel 2016 (Van Rhee, Suurmond & Hak, 2015). Separate meta-analyses were conducted with each of the three relations. Unadjusted ESs governing the three relations were extracted from each article. Where necessary, conversions were performed so that all ESs that were meta-analysed were represented as log odds ratios.

Where there were multiple effect sizes reported in any one article due to multiple timepoints, outcomes and/or comparisons made, a summary effect of each article was computed based on Borenstein's (2009) recommended formulae. This prevented overrepresentation of any study and avoided violation of the assumption of independent samples. If the total scale (e.g. Caregiver Burden Inventory) ES and separate dimension (e.g. role burden, task burden) ES were both reported, the total scale ES was chosen. Should the ESs for multiple dimensions be reported without the ES for the total scale being reported, the ESs for the dimensions were averaged to obtain the relation of interest's ES. Should multiple ESs from various subgroups (e.g. men vs. women) be reported, the average was computed by weighing each ES by the subsample size (Cooper, 2017).

The random effects model was used in omnibus tests and moderation analyses to evaluate the mean of the distribution of true effect sizes across the research studies. The weights were assigned to each study based on the inverse of the overall study error variance. As the means of each study were used to estimate the grand mean, both within- and between-study variances were used to calculate the overall study variance. The combined effect was calculated by the weighted mean of the studies. This model allows inferences to be drawn about a population of research studies that goes beyond the present sample of studies reported in the articles included (Lipsey & Wilson, 2001). It allows for systematic deviation of the obtained effect from the true effect, on top of study-level deviation from the true effect, which is afforded by the fixed effects model.

Moderation analyses. Moderation analyses were conducted in pursuit of the secondary aim of this study. These analyses were also warranted when the omnibus tests indicated substantial heterogeneity of the combined effect. After omnibus tests, the moderation of each relation by study and participant characteristics, which were measured by both categorical and continuous variables, were conducted with two exceptions. Characteristics that suffered from incomplete reporting, or had only one study in a subgroup, were not tested for their moderating effect on the corresponding relation.

Publication bias analyses. Using linear regression, the asymmetry of funnel plots based on standard error was assessed as recommended by Egger, Smith, Schneider, and Minder (1997). Furthermore, to obtain an adjusted ES that accounted for publication bias, the trim-and-fill approach was used (Duval & Tweedie, 2000). The extent that the analysis was sensitive to the largest studies was evaluated by removing the largest studies one-by-one, and computing the combined result from among the remaining research studies. To ensure the soundness of interpretation, these analyses were conducted within subgroups of homogeneous results only.

Results

Study Selection

The search and screening processes yielded 31, 14, and 15 articles for the relations between LTCS use and caregiver burden, depression and health status respectively. The coding and quality assessment processes reduced the number of articles for the relation between LTCS use and caregiver burden to 24, but did not change the number of articles for the other two relations. Figures 2.1 to 2.3 show flow charts of the inclusion and exclusion processes, for each of the three relations of interest. Each included article reported on only one research study.

Risk of Bias / Quality Assessment of Individual Studies

For each of the three relations, Supplementary material 2 shows the breakdown of quality assessment items for each study included in the review of relation. One study (Stone & Clements, 2009) was excluded because it was assessed to be of poor overall quality.

Qualitative Synthesis

Study and participant characteristics. The qualitative data describing study and participant characteristics extracted from each study are shown in Table 2.1. The quantitative data describing study and participant characteristics extracted from each study are summarized in Tables 2.2 to 2.7 for each relation. The adjusted and unadjusted ESs (*lnOR*) obtained from each study are grouped by relation and shown in Figures 2.4 to 2.6. The complete data extracted from the included studies of all three relations are found in Supplementary material 1.

Common characteristics. In each of the three relations, most of the studies were published as journal articles, collected primary data in the USA, investigated community-based and home care services, had use versus non-use as a grouping of LTCS use, adopted the Andersen Model, aimed to investigate caregiver factors for service use, and undertook cross-sectional designs. In most of the studies investigating each relation, informal caregivers were female and family members of the patients they cared for, were not remunerated nor first-time caregivers, while the patients had dementia.

LTCS use and caregiver burden. Of the 24 articles investigating the LTCS use-caregiver burden relation, 13 were North American (USA and Canada), and 10 were Asian (Japan, South Korea, Thailand, and Taiwan). The articles were published from 1987 to 2017, with 2009 as the median publication year. More than half (*k* = 14) of the articles reported cross-sectional study designs. This was twice the number of articles that reported longitudinal study designs.

The Zarit Burden Interview (ZBI) was most commonly used to measure caregiver burden across the studies (*k* = 16). Caregiver burden was a dependent variable in about half of the articles (*k* = 10) and was an independent variable in the other half (*k* = 11). The analytic role of formal LTCS as a dependent and an independent variable appeared evenly distributed (*k* = 11 vs 9 respectively). The age difference between patients and their caregivers is almost 20 years.

Taken together, the adjusted and unadjusted ESs ranged from -1.27 to 1.92. The median ES (*lnOR*) of 0.24 indicated that, on average, the odds (*OR* = 1.27) of experiencing higher burden was 27% higher among caregivers of LTCS users as compared to non-users. Most (*k* = 17) of the effects showed a positive relation between LTCS use and caregiver burden. A visual examination of the forest plot in Figure 4 showed three outlying ESs in the negative extreme, and one in the positive extreme. Because the adjusted effects accounted for a variety of different other variables, to enhance homogeneity across studies, only unadjusted effects were subsequently meta-analysed.

LTCS use and caregiver depression. Of the 14 articles investigating the LTCS use-caregiver depression relation, nine were North American (USA and Canada), and three were Asian (Japan, Thailand, and Taiwan). There was only one dissertation/thesis. The articles were published from 1996 to 2013, with 2009 as the median publication year. About 40% (k = 6) of the articles reported longitudinal designs and another 40% (k = 5) reported cross-sectional designs.

Six of the articles focused on home-based service use. The Centre for Epidemiological Studies Depression Scale (CES-D) was most commonly used as an assessment of caregiver depression (k = 10). Caregiver depression was a dependent variable in most (k = 9) of the articles. The analytic role of formal LTCS as a dependent and an independent variable appeared evenly distributed (k = 6 vs 8 respectively). The age difference between patients and their caregivers is about 13 years.

Taken together, the adjusted and unadjusted ESs ranged from -0.36 to 2.69. The median ES (*lnOR*) of 0.04 indicated that, on average, the odds (*OR* = 1.04) of experiencing higher depression was 4% higher among caregivers of LTCS users as compared to non-users. Most (k = 9) of the effects showed a positive relation between LTCS use and caregiver depression. A visual examination of the forest plot in Figure 2.5 showed three outlying ESs in the positive extreme. Because the adjusted effects accounted for a variety of different other variables, to enhance homogeneity across studies, only unadjusted effects were subsequently meta-analysed.

LTCS use and caregiver health status. Of the 15 articles investigating the LTCS use-caregiver health status relation, 12 were North American (USA and Canada), and two were Asian. These articles were published from 1987 to 2012, with 2000 as the median publication year. There was one article that reported on a randomised controlled trial.

Single item measures were most commonly used to measure caregiver health status. 10, three and two of these articles reported adjusted, unadjusted and both types of ES respectively. Caregiver health status was predominantly (k = 8) analysed as an independent variable, while formal LTCS use was analysed a dependent variable in most (k = 9) articles. The age difference between patients and their caregivers is about 15 years.

Taken together, the adjusted and unadjusted ESs ranged from -3.98 to 0.39. The median ES (*lnOR*) of -0.05 indicated that, on average, the odds (*OR* = 0.95) of experiencing worse health status was 5% lower among caregivers of LTCS users as compared to non-users. More than half (k = 8) of the effects showed a negative relation between LTCS use and worse caregiver health status. A visual examination of the forest plot in Figure 2.6 showed two distinct outlying ESs in the negative extreme. Because the adjusted effects accounted for a variety of different other variables, to enhance homogeneity across studies, only unadjusted effects were subsequently meta-analysed.

Meta-analysis

Outliers. Because extreme ES may misrepresent meta-analytic results, the presence of outliers was explored in each relation. Using three standard deviations from the mean as the criterion (Cooper, 2017), no outliers were found for each relation.

Omnibus tests. As shown in Table 2.8, using random effects models, all the three relations were statistically non-significant at the level of .05. Caregiver burden (k = 12) was not significantly related to formal long-term care service use, $lnOR$ = 0.03, 95% CI [-0.48, 0.54], neither were caregiver depression (k = 8), $lnOR$ = 0.16, 95% CI [-0.30, 0.61], nor caregiver health status (k = 5), $lnOR$ = -0.01, 95% CI [-0.56, 0.54], ps > .05.

The homogeneity index (Q statistic) was statistically significant in all three relations. The I^2 statistic was greater than 60% in all three relations (Table 2.8). These results indicate a likelihood of substantial heterogeneity (Higgins & Green, 2011) across studies in each of the three relations[4]. Hence, the investigation of moderation effects may be valuable and was conducted.

Categorical moderation analyses. Table 2.9 shows the results of the categorical moderation analyses conducted.

LTCS use and caregiver burden. Among the study characteristics, country, LTCS type and theoretical model influenced the relation between formal LTCS use and caregiver burden. On average, the non-USA studies reported that the odds of experiencing higher burden were 40% higher among

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[4] I^2 values greater than 50% indicate substantial heterogeneity.

caregivers of LTCS users as compared to non-users, *lnOR* = 0.34, $p < .05$, 95% CI [0.05, 0.62]. This association was homogeneous across non-USA studies, $Q = 9.72$, $p > .05$. On the other hand, the formal LTCS use-caregiver burden relation was statistically non-significant among USA studies, *lnOR* = -0.45, $p > .05$, 95% CI [-1.26, 0.36].

The LTCS use-caregiver burden relation was positive and statistically significant in studies that did not involve nursing home services, *lnOR* = 0.33, $p = .001$, 95% CI [0.13, 0.52], and was sufficiently homogeneous across non-nursing home studies, $Q = 12.50$, p > .05. On average, studies that did not involve nursing home reported about 39% higher odds of caregivers experiencing higher burden among LTCS users as compared to non-users. The LTCS use-caregiver burden relation was negative in studies that involved nursing home services, *lnOR* = -1.20, $p < .001$, 95% CI [-1.32, -1.09], and was homogeneous across nursing home studies, $Q = 0.95$, $p > .05$. On average, studies that involved nursing home reported about 70% lower odds of caregivers experiencing higher burden among LTCS users as compared to non-users.

Theoretical model influenced the LTCS use-caregiver burden relation. On average, studies that adopted the Andersen Model reported about 38% higher odds of caregivers experiencing higher burden among LTCS users as compared to non-users, *lnOR* = 0.32, $p < .01$, 95% CI [0.09, 0.54]. This association was homogenous across studies. On the other hand, this LTCS use-caregiver burden relation was statistically non-significant among studies that adopted other theoretical models, *lnOR* = -0.40, $p > .05$, 95% CI [-1.31, 0.51].

Among the participant characteristics, the caregiver-patient relationship and main illness of patient were found to influence the LTCS use-caregiver burden relation. On average, studies in which caregivers could be in a variety of relationships with the patient, and where the patient suffer from multiple functional impairments reported about 43% (*lnOR* = 0.36, $p < .001$, 95% CI [0.22, 0.50]) and 38% (*lnOR* = 0.32, $p < .01$, 95% CI [0.20, 0.45]) higher odds of higher caregiver burden among LTCS users as compared to non-users respectively. These associations were homogeneous across studies ($Q = 2.42$, $p > .05$, and $Q = 0.55$, $p > .05$ respectively).

LTCS use and caregiver depression. The study design and whether there were 70% or more female caregivers in a study influenced the formal LTCS use-caregiver depression relation. Studies that were cross-sectional, and that recruited less than 70% female caregivers showed positive relations (*lnOR* = 0.78, $p < .05$, 95% CI [0.05, 1.52], and *lnOR* = 0.62, $p < .05$, 95% CI [0.09, 1.15] respectively), with indication of heterogeneity in the former ($Q = 4.11$, $p < .05$), but not the latter ($Q = 7.01$, $p > .05$). Studies that recruited 70% or more female caregivers showed a negative relation, *lnOR* = -0.20, $p < .001$, 95% CI [-0.29, -0.10], with an indication of homogeneity across studies, $Q = 2.43$, $p > .05$. These results indicate that, on average, cross-sectional studies reported 2.18 times higher odds of higher caregiver depression among LTCS users as compared to non-users. Studies that involved 70% or more female caregivers reported 18% lower odds of higher caregiver depression among LTCS users as compared to non-users, while studies that had less than 70% female caregivers reported 86% higher odds of higher caregiver depression among LTCS users as compared to non-users.

LTCS use and caregiver health status. Country influenced the relation between caregiver health status and formal LTCS use. Non-US studies reported a negative relation, $lnOR = -0.70$, $p < .001$, 95% CI [-0.76, -0.63], with homogeneity, $Q = 0.01$, $p > 0.5$, while US studies reported a positive relation, $lnOR = 0.22$, $p < .01$, 95% CI [0.07, 0.38], with homogeneity, $Q = 1.32$, $p > 0.5$. These results indicate that compared to non-users, non-USA service users were 50% less likely to have caregivers who reported worse health, while USA service users were 25% more likely to have caregivers who reported worse health.

The influence of other characteristics on each of the three relations of interest did not reach statistical significance.

Continuous moderation analyses. As shown in Table 2.10, none of the continuous variables investigated were significantly related to the effect sizes of each relation.

Publication bias analyses. Publication bias analyses were conducted for the (i) service type subgroups (nursing home involved, non-nursing home) of the LTCS use-caregiver burden relation, (ii) >= 70% female caregiver subgroups (yes, no) of the LTCS use-caregiver depression relation, and (iii) country subgroups (non-USA, USA) of the LTCS use-caregiver health status relation. Funnel plots and Egger regression were computed. The trim-and-fill approach was used to adjust the estimate of effect size for each subgroup. These results are found in Supplementary material 3.

Each funnel plot showed a distribution that resembles an approximate symmetrical inverted funnel. The Egger regression could not be performed in the nursing home involved (caregiver burden) and non-USA (caregiver health status) subgroups because each subgroup comprised only two studies. The degree of asymmetry in each of the remaining subgroups was not statistically significant by the Egger method, *p*s > .05. The imputed estimates were found to approximate those in the categorical moderation analyses. These results suggest that the meta-analytic results were not adversely affected by publication bias.

Discussion

The equivocal literature on the direction and magnitude of relations between formal LTCS use and each of informal caregiver burden, depression and health status, and the lack of a study that synthesizes the existing evidence on the above relations led to the present study. This is the first study to provide a systematic review and meta-analytic investigation of the above relations between formal LTCS use and each of the caregiver needs.

Main Findings

This study found that LTCS use associates respectively with caregiver burden, depression and health status in a non-trivial manner. The qualitative synthesis of the adjusted and unadjusted ESs uncovered modest positive associations in each of the relations, and the meta-analyses further revealed stronger associations that differed by subgroups (categorical moderators).

The most substantial evidence was found in the formal LTCS use-caregiver burden relation. In the qualitative synthesis, it was found that, on average, a one unit increase in LTCS use appears to be associated with elevated caregiver burden of approximately 27%. Meta-analysis found that studies involving nursing homes reported a medium-sized effect of 70% lower odds while those that did not involve nursing homes reported 39% greater odds of caregivers experiencing higher burden associated with LTCS use by patients. These findings reflect the vast quantity of research conducted on caregiver burden as both an outcome of and a factor for LTCS use. Among the three caregiver psychosocial constructs, the concept and measurement of the phenomenon of caregiver burden has been subjected to a tremendous amount of research scrutiny and contention (Bastawrous, 2013; Donnelly, Hickey, Burns, Murphy, & Doyle, 2015). It is noteworthy that the Zarit Burden Inventory has been translated into 13 languages. Among the LTCS types, nursing home is arguably a service type that has the longest history and has been subjected to the most scientific investigations. Institutions such as nursing homes fully discharge the informal caregiver of custodial responsibilities of the patient. On the other hand, community and home-based services stipulate the boundaries of responsibilities between the caregiver and LTCS provider, and require the caregiver to function as an important stakeholder.

The meta-analyses also revealed that the formal LTCS use-caregiver burden relation was positive in studies that used the Andersen Model to guide variable selection, studies in which the informal caregiver is of various relationships with the patient, and those in which the patient suffered multiple functional impairments. This is unsurprising given that the Andersen Behavioural Model remains the only theoretical model that has been developed to explain health services utilization, and that it focuses on individual patient factors. Other theories and models have different foci, and have had to be adapted for use in health services utilization studies.

Theoretically, this study provides strong evidence to consider including caregiver burden into the Andersen Model, regardless of caregiver-patient relationship and in the context of multiple functional impairments and formal LTCS use. In service delivery, seniors and persons with long-term care needs prefer to receive care in a familiar environment (Huang, Zhang, & Wang, 2019; Khongboon & Pongpanich, 2018). However, the use of community- and home-based services is, unfortunately, associated with increased burden on the part of informal caregivers who become important stakeholders of such services. Hence, this study points to a necessity for health and social services to become better integrated to meet the often-complex needs of caregivers of and patients with multiple functional impairments, regardless of the patient-caregiver relationship.

The qualitative synthesis showed that, on average, LTCS use appears to be associated with elevated caregiver depression. Meta-analysis clarified that studies that involved fewer female (than male) informal caregivers reported 86% higher odds of the caregivers experiencing higher depression levels associated with LTCS use by patient while studies that involved more female caregivers reported 18% lower odds of the same. This is surprising because it is well established that women have a higher prevalence of suffering from depression than men (Cyranowski, Frank, Young, & Shear, 2000; Ford & Erlinger, 2004). This finding of gender differences may reflect the underlying differences in individual’s perception of gender roles as dictated by social norms. Women are traditionally prescribed the caregiving role, which might suggest them being more comfortable in assuming the role (Hagedoorn & Revenson, 2018). In addition, the discomfort that males feel about sharing their personal feelings with others, may inhibit them from seeking support emotionally (Lai & Bai, 2016). This could, in turn, lead to male caregivers’ increased vulnerability to experiencing depression (Bai, Liu, Baladon, & Rubio-Valera, 2018). Therefore, targeted interventions should be designed for men who act as informal caregivers to patients with LTCS needs. Informal caregivers should be screened for depression as part of the intake of LTCS cases.

The qualitative synthesis of included studies showed that, on average, LTCS use is related to better caregiver health status. Meta-analysis revealed that non-USA studies reported 50% lower odds while USA studies reported 25% higher odds of caregivers experiencing worse health in relation to LTCS use. Changes in the interpretation of traditional Asian ideas of care, which rely on the concept of filial piety to take care of the old might have contributed to this result. Zhan, Feng, and Luo (2008) noted that having the ability to afford round-the-clock care, whilst having limited resources, is the current generation’s demonstration of filial piety. This expanded definition of filial piety that allows non-USA caregivers to maintain some distance from the direct strain of caregiving, could contribute to the lower odds of this group experiencing worse health in relation to LTCS use.

Other Findings

That most of the studies included in this systematic review and meta-analysis collected data in the USA and Japan reflects the growing needs associated with greying populations in these two countries. That most of the included studies investigated community-based and home care services reflects the preference of persons who needs LTCS to be cared for in familiar environments. Most of the included studies also adopted the Andersen Model in selection of variables, possibly because it is the only model available that deals directly with health services utilization, while the other explanatory models have slightly different foci although they have been adapted for use in healthcare utilization studies. This systematic review and meta-analysis also included more cross-sectional studies and studies that compare LTCS use versus non-use as the grouping variable. These findings suggest limitations in data collection resources and the use of health service operational data in research. Cross-sectional designs are less resource intensive, but unlike longitudinal designs, do not allow for dose-response inferences. Primary prospective studies that carefully measure the amount of LTCS use are urgently needed to allow for causality inferences associated with each of the three relations of interest. These studies will be very useful for theory building and service design.

Particularly noteworthy is the finding that with the eligibility criteria, only 37 studies were included in total in this review. Among these, there were only 27 studies that had examining caregiver factors for LTCS use as one of its main aims. Despite the importance of care integration, these findings may reflect the challenge of integrating social care and healthcare, family care and patient care.

Despite the relatively high number of articles that potentially report on each of the three caregiver needs, the number of articles that reported on each of three relations appears low. Individually, this finding reflects insufficient attention devoted to each of the three relation. Collectively, this finding reflects that the current state of care services and the research and evaluation of such services operates in a fragmented fashion, and that service designs that do not adequately consider caregiver needs.

Theoretical and Practical Implications, Limitations and Future Research

To summarize, this study provides evidence of non-trivial associations between LTCS use and factors of caregiver burden, depression and health status. These associations differed by LTCS type, percentage of female caregivers, and country, respectively. Evidence that associates caregiver's social support (Lou et al., 2011; Shiba et al., 2016), social activities restriction (Bookwala et al., 2004; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009) and quality of care relationship with patient (Eom et al., 2017; Yeh et al., 2009), with a patient's LTCS use is emerging. It would be of theoretical and practical importance to determine if there are combined caregiver psychosocial need characteristics that explain differing underlying profiles. The characterization of such latent caregiver profiles can potentially explain LTCS use. These profiles could also inform the design of person-centred caregiver interventions that could be a part of any mainstream LTCS.

As healthcare systems move towards integrating and providing holistic care spanning physical, psychological and social needs, the caregiver should not be forgotten. Care integration is often interpreted differently (Kodner & Spreeuwenberg, 2002). Because a patient's needs can differ from his informal caregiver's needs, one can understand patients' views from a care provider's perspective. Support services for patients' needs may not be always beneficial to their informal caregivers. Hence, integrated support services must consider caregivers' specific needs across the physical, psychological and social spectrum too. Integration in the form of cooperation between various professionals, across the cure and care sectors, or within and between primary, secondary and tertiary care settings, is required. Informal caregivers are important resources for persons who require formal LTCS, for instance, the frail senior, but their role as care providers is often overlooked (Leichsenring, 2004). Informal caregivers are often torn between being a caregiver and one in need of care. It is, therefore, essential that formal care providers acknowledge this precarious situation that the informal caregivers find themselves in, and design or redesign services accordingly.

Leichsenring (2004) shares a similar view to the result gathered from this study where, an informal caregiver who is supported, is an essential partner in the long-term care for the frail senior, because no system will be able to meet all the patient's needs. This triad of care, which involves healthcare professionals, patient, and informal caregivers is thus crucial in determining the betterment of the patient's condition. Without a physically and psychologically healthy informal caregiver, the quality of care that a patient receives would suffer. Therefore, the informal caregiver's needs must be considered and incorporated in all services aimed at delaying institutionalization.

This study was chiefly limited by the exclusion of articles not published in the English language. With Japan, Korea and several European countries as leaders of LTCS research, future research should include articles published in these languages of these countries. The number of articles could be optimised by also searching Embase, Web of Science and Google Scholar (Bramer, Rethlefsen, Kleijnen, & Franco, 2017) databases, although additional results might be modest (Halladay et al., 2015). The meta-analyses in this study were limited to reported data in journal articles and dissertations/theses. 18 and 10 articles pertaining to the LTCS use-caregiver burden and LTCS use-caregiver depression relations respectively were excluded in this study due to insufficient data reported. This analysis could be extended by requesting individual patient data from individual study authors. A meta-analytic structural equation modelling, where ESs of important variables involved in formal LTCS use are included, could also be conducted to better understand the possibility of latent structures involved in explaining formal LTCS use.

Further studies are required on designing integrated care services that explicitly include informal caregiver support with patient care. For instance, worse caregiver health status is associated with the patient's utilization of formal LTCS as shown in this study. The perceived and evaluated health of informal caregivers should be considered in care assessment and interventions should be designed that addresses this need. In this case, while caregivers may receive care directly or indirectly, service integration, that jointly takes care of patient and caregiver needs, should be endeavoured.

Future research can look at the effectiveness of specific LTCS interventions in improving caregiver's wellbeing while ensuring patient's care remains uncompromised. For example, a randomised controlled trial can be done to examine if there is a difference in improvement of caregiver needs when comparing home-based care with nursing homes in patients with multiple functional impairments. Similarly, future research can investigate the evaluation matrix used to ascertain the effectiveness of various LTCS programmes. The quality of LTCS programmes can also be examined through the degree of change in the caregiver needs and wellbeing of patients in addition to existing markers of change. This can facilitate the formulation of healthcare policies that services both the patient and their informal caregivers. This could ensure the development of a holistic healthcare plans that is an optimal balance between patient's needs and caregiver's needs with the limited resources that individuals have.

Chapter 3

Introduction

Historically, long-term care services (LTCS) in Singapore are home-based and delivered by family members receiving no monetary compensation (Teo, Chan, & Straughan, 2003). Despite decreasing family sizes and nursing homes serving more residents, family obligations to provide LTCS remains prevalent in Asia (Wong, Pang, & Yap, 2014). For the provision of LTCS to seniors, voluntary welfare organizations in Singapore are mainly tasked with delivering the services while the government funds, controls and sets goals for the LTCS industry (Chin & Phua, 2016). The Agency for Integrated Care (AIC) was founded by the Singapore Ministry of Health (MOH) in 2009, to facilitate greater collaboration and coordination of care between various settings and providers. The AIC recommends LTCS, assigns senior patients to residential and community-based services, and reintegrates these seniors back into the community (Haseltine, 2013). Furthermore, the Singapore government has keenly financed the development community based LTCS to enable family caregivers to remain as principal providers of LTCS and provide a platform for them to receive professional help, while still satisfying the needs of elderly care recipients (Chan, 2012).

Stroke and Rehabilitation in Singapore

In Singapore, cardiovascular diseases, such as stroke, have been the lead cause of fatalities and disabilities, accounting for 18.5% and 14.2% of total disability-adjusted life years in 1990 and 2017 respectively (Epidemiology &

Disease Control Division, Institute for Health Metrics and Evaluation, 2019). Stroke cases occur one in a thousand, and 3.65% of adults aged 50 years or older, have experienced it. Stroke survivors with physical disabilities, often need persistent care medically and socially, imposing psychosocial burdens on their families. Stroke survivors in Singapore are first medically stabilized. they are then sent for inpatient rehabilitation within the acute hospital they were admitted to, or at a separate community hospital. Once the patients have completed their in-patient rehabilitation, plans are made to allow them to undergo outpatient rehabilitation at a hospital outpatient clinic or a day rehabilitation centre. Home rehabilitation can also be organized if patients face inconvenience leaving their homes. The government also subsidizes the day rehabilitation centres' fees for patients who meet specific requirements for financial aid (Koh, Saxena, Ng, Yong, & Fong 2012).

Outpatient stroke rehabilitation is important in postponing institutionalization of stroke patients (Gaugler, Kane, Kane, & Newcomer, 2005) and in assisting caregivers with the difficulties of providing care (Zarit, Stephens, Townsend, & Greene, 1998). Bereft of such assistance, caregivers may face higher levels of mental (Malhotra, Malhotra, Østbye, Matchar, & Chan, 2012) and physical (Vitaliano et al., 2003) distress, possibly expediting the institutionalization of stroke patients (Tsuji, Whalen, & Finucane, 1995).

Despite the beneficial effects of stroke rehabilitation, its use remains low with only 33.3% of Singapore stroke patients recommended for rehabilitation treatment, utilizing outpatient rehabilitation services (Koh et al., 2012). In fact, two studies showed that outpatient rehabilitation, a year after patients were released from community hospitals, garnered only 28% and 4.3% participation (Koh et al., 2012; Chen et al., 2014). The proportion of Singaporeans aged 65 and above is projected to double from one in eight in 2015 to one in four in 2030 (National Population and Talent Division, 2016). There will be an increasing need for stroke rehabilitation and other forms of LTCS.

Andersen's behavioural model of health services use (Andersen & Davidson, 2007; Andersen, 1995) is an established theoretical framework, by which to understand the reasons that an individual hold in using or not using health services. It posits that some combination of predisposing, enabling and need factors explain health services use, which in turn, explains patients' health outcomes. The model has been expanded over time (Andersen, 2008) and now incorporates psychosocial factors in four domains – attitude, knowledge, social norms and perceived control - that explain a patient's LTCS use (Bradley et al., 2002). It has also been contextualized to the Singapore setting (Wee et al., 2014).[5] Studies have suggested the limited effectiveness of the Andersen Model in explaining service use due to its lack of consideration for dynamic interpersonal interactions between caregivers and care recipients, and important cultural factors (Keith et al., 2009; Wee et al., 2014; Roh et al., 2017). For instance, Bradley and colleagues (2002) argued that African Americans were

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[5] See Chapter 1 for further discussion on the Andersen Model.

more doubtful, then White Americans, of the quality of care provided by LTCS staff, and thus, preferred familial care, and rarely discussed caregiving burden.

In practice, LTCS are principally recommended according to patients' needs and caregiver characteristics (Li, Fann, & Kuo, 2011; Imai & Fushimi, 2012). However, patients who perceive less hindrance in activities of daily living (ADL), and who are less functionally dependent, are less inclined to use centre- and home-based LTCS in Singapore (e.g. Wee et al., 2014) and elsewhere (e.g. Bradley et al., 2002). It has also been reported that caregiver's characteristics such as education (Bookwala et al., 2004), age (Peek, Zsembik, & Coward, 1997), residency status (Cotrell, 1997), and mastery (Miller & Mukherjee, 1999) are predictive of formal care use and non-use.

Based on in-depth interviews with 55 caregivers and 16 care recipients who may be LTCS users or non-users in Singapore, Wee and colleagues (2015) found that the key determinants of LTCS use were family caregivers' attitudes, perceived control and social norms, availability of support, caregivers' capacity, and patients' self-determination. The low utilization rates of stroke rehabilitation in Singapore may explained by a myriad of factors, including caregivers' desire to manage within the family, low perceived affordability, social stigma, ambulation and transportation issues, caregivers' lack of available time and finances, and patients' loss of independence and dignity.

Caregiver Well-being and LTCS Use

Most recently, it was reported that the well-being of patients' informal caregivers is also associated with the use of a variety of LTCSs. Via a systematic review and meta-analysis, Chapter 2 showed that research studies that did not involve nursing homes reported 39% higher odds of caregivers experiencing higher burden associated with LTCS use by patients. I also found studies with more female than male caregivers reported 18% lower odds of the caregivers experiencing higher depression levels associated with LTCS use by patients. I further found that non-USA studies reported 50% lower odds of caregivers experiencing worse health status in relation to LTCS use. These findings suggest that, aside from established factors of the Andersen Model, LTCS use decision making is also influenced by informal caregivers' well-being (Liu, Eom, Matchar, Chong, & Chan, 2016).

However, most of the eligible studies reported in Chapter 2 collected data in Western contexts, which may be different from Asian Singapore. The only Singapore-based investigation of the LTCS use-caregiver well-being association found that non-immediate family and spousal caregivers, whose charges were nursing home residents or home-based service users, presented poorer self-rated health than caregivers whose charges were non-users of any formal LTCS (Eom et al., 2017).

The association of other attributes of caregiver well-being with LTCS use, in general, and with stroke rehabilitation use, in particular, has not been examined. Although detrimental outcomes on caregiver-perceived quality of care relationship with the patient, social support, and burden associated with caregiving burden (time and difficulty) continue to be reported (e.g. Haley, Roth, Hovater, & Clay, 2015), their associations with LTCS use, in general, and stroke rehabilitation use, in particular, have not been investigated.

Chapter 2 also pointed out that there is a scarcity of longitudinal research on factors for LTCS use, and of these, few examine the association of caregiver well-being with LTCS use (e.g. Bookwala et al., 2004; Chong, Li, & Chan, 2015). In the stroke rehabilitation literature, the handful of studies that investigate factors for stroke rehabilitation use focuses on the factors for institutionalization or assessing its efficacy in improving patients' activities of daily living (e.g. Teasell et al., 2018), and only two examined community-based rehabilitation (Obembe, Goldsmith, Simpson, Sakakibara & Eng, 2018; Mahak et al., 2018).

The Present Study

This study used a national prospective survey about stroke rehabilitation use in Singapore and measured six attributes of informal caregiver well-being – caregiving burden (time and difficulty), caregiver burden (personal and role strain), depression, health status, social support and quality of relationship with patient. I examined their associations with, and predictive ability of stroke rehabilitation use, 12 months after initial stroke diagnosis, before and after accounting for other established predictors of LTCS use. To the best of my knowledge, there is no reported longitudinal study on factors for community-based stroke rehabilitation use. Therefore, no specific hypotheses were held in this study.

Method

Data Source

This study analysed data from the Singapore Stroke Survey, which aimed to prospectively study the social, health and financial experiences among caregivers of stroke survivors in the immediate year after stroke onset. A total of 661 patients and their primary caregivers were recruited. 23 patients were subsequently dropped from the Survey for the following reasons: died during public tertiary hospital admission (Blake, Lincoln, & Clarke, 2003), wrong diagnosis (Lee, Merriman, Owen, Chew, & Tan, 1994), and one was discharged overseas, giving a final sample of 638 patients and 482 caregivers. Data was collected from the participants at three-time points: baseline (T0), 3-month (T1) and 12-month (T2) follow-up. Participants were recruited from December 2010 to September 2013 from all five public tertiary hospitals of Singapore, ensuring it is a representative sample.

The eligibility criteria for participation were as follows: the stroke patient must be a Singaporean citizen or permanent resident, above 40 years old, living in Singapore in the upcoming year, and not globally aphasic. They had to be diagnosed with stroke alongside confirmatory medical imaging, and exhibit symptoms a month before care was sought.

Informal caregivers (CG) were direct or distant relatives or friends, older than 21 years, providing fully or partially unpaid care or help in any form, and recognized by patients as their caretakers. The Singapore Stroke Survey was approved by the SingHealth Centralized Institutional Review Board, National University of Singapore Institutional Review Board and the National

Healthcare Group Domain Specific Review Board. Patients and caregivers provide their informed consent in writing after receiving a description of the Survey’s purpose and the procedures involved, in a language they understood (using translators if necessary). They were aware that they could cease participation at any time within the Survey’s one-year timeframe, should they wish to.

Other methodological details of the Singapore Stroke Survey, such as recruitment and follow-up procedures, can be found in previous reports (Tyagi et al., 2018a; Tyagi et al., 2018b).

Outcome Variable

Stroke rehabilitation use at T2 was used as the outcome variable in this study because previous research conducted with the same population found stark underutilization of stroke rehabilitation at this time point (Koh et al., 2012; Chen et al., 2014). The outcome variable was dichotomous, with service use coded as “1”, and non-use coded as “0”.

Explanatory Variables

The explanatory variables were six attributes of caregiver subjective well-being, namely: caregiving burden (time and difficulty), caregiver burden (personal and role strain), caregiver depression, caregiver health status, caregiver social support, and caregiver-patient quality of care relationship. I used two different measures of burden because of the lack of consensus in the literature as to what constitutes caregiver or caregiving burden[6]. Except for

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[6] See Chapter 1 for discussion on caregiver burden.

caregiving burden (time and difficulty), which was measured at T1 and T2 only, all explanatory variables were measured at all three-time points.

Measures

Quality of care relationship. The quality of the relationship between the stroke patient and the primary caregiver was assessed by using four items from the University of Southern California's Longitudinal Study of Three-Generation Families. The four aspects measured were relationship proximity, degree of communication, agreement of viewpoints and how well the two get along. Each item is given a score from 1 (*not at all*) to 4 (*very*), so higher scores reflected better relationship quality.

Social support. Social support was assessed by Pearlin's 8-item Subjective Social Support Scale (Pearlin et al., 1990). It has good internal consistency (α = .87). Response options were on a 4-point Likert scale where the total score can vary from 4 to 32.

Caregiver burden. The Zarit's Burden Interview (ZBI) assesses a caregiver's appraisal of caregiving impact by documenting their views about several negatively phrased questions related to caregiving (Bédard et al., 2001). A 22-item measure, the ZBI has been validated in Singapore with good psychometric properties (α = .93; Yap, 2010). I used the shorter 12-item version with the composite score ranging from a minimum of 0 to a maximum of 48.

Caregiving burden. The Oberst Caregiving Burden Scale (OCBS), previously used in stroke patients with good psychometric properties, is a 15-item measure to subjectively report the time and difficulty experienced by the caregiver related to the caregiving tasks. Higher scores represent more difficult and time-consuming tasks (Bakas, Austin, Jessup, Williams, & Oberst, 2004).

Caregiver health status. I defined health status as health-related quality of life in this study. I used the EQ-5D-3L scale to measure the quality of life of both patients and caregivers, which is a descriptive instrument comprising of functional and somatic components. The former consists of three items on mobility, self-care and performance of usual activities, whereas the somatic dimension covers pain/discomfort and anxiety/depression (Szende, Janssen, & Cabases, 2014). Each item is rated on a 3-point Likert scale and a multi-dimensional composite score calculated, which describes their current health state and its associated utility. This composite score is anchored by 0 (*death*) and 1 (*full health*).

Caregiver depression. To screen the patients and their caregivers for depression, the abbreviated 11-item version of the Center for Epidemiologic Studies Depression (CES-D-11) scale was used. The instrument comprises of statements or behaviours and the participants are required to indicate how often they felt like that on a Likert scale (Chan, Raman, Ma, & Malhotra, 2015).

Covariates

The choice of covariates was guided by the Anderson Model (Andersen, 1995; Bradley et al., 2002). The covariates were categorized as follows and considered in subsequent variable selection in the following sequence: stroke rehabilitation use at T1, predisposing factors, enabling factors, and need factors. The predisposing factors were patient’s age, stroke type and discharge destination. The enabling factors were caregiver’s sex, marital status, employment status, relationship with patient, utilization of healthcare service(s) in the past month, availability of domestic maid at patient’s home, stroke care as main responsibility of domestic maid, and caregiving and job conflicts. The need factors were patient’s cognitive status, depression, health status, disability level, and activities of daily living independence.

Statistical Analyses Plan

Missing values, multicollinearity and potential predictor identification. Missing values on the outcome variable resulted in the removal of the entire case. Missing values on the explanatory variables and covariates were treated with multiple imputations based on the guidelines proposed by Jakobsen, Gluud, Wetterslev and Winkel (2017). Multicollinearity in regression was assessed via the Variance Inflation Factor (VIF), and variables were removed if VIF was more than 10. Variables that were found to be correlated with the outcome variable at each time point at alpha = .10 level ($p < .10$), as indicated by point-biserial correlations, were identified as potential predictors and considered for inclusion into corresponding regression models.

Binomial logistic regression analyses. Categorical variables were dummy coded before they were added into the logistic regression models. A stepwise procedure with $p = .05$ as inclusion criteria and $p = .10$ as exclusion criteria were used to select predictors.

Time-lagged and non-lagged stepwise binomial logistic regressions were conducted. The non-lagged analyses aim to identify predictors of the outcome variable from the explanatory variables assessed at the same time point as the outcome variable, before and after controlling for the influence of covariates. The time-lagged analyses aim to identify predictors of the outcome variable from the explanatory variables measured at the same time point, and those measured at one or more previous time points, before and after controlling for covariates. Specifically, lag 1 analyses aim to identify predictors from the explanatory variables measured at 3-month and 12-month follow-up. Lag 2 analyses aim to identify predictors from the explanatory variables measured at each of the three-time points.

To control for the influence of covariates, block-wise stepwise binomial logistic regressions were conducted. Model 1 of the non-lagged, lag 1 and lag 2 analyses involved the selection of explanatory variables in block 1 via the stepwise procedures described above. Then, in Model 2 of each set of analyses, predictors were selected from the first category of covariates into block 1, while predictors from among the explanatory variables were selected into block 2. In other words, in Model 2 of the non-lagged analyses, predictors were selected from predisposing factors into block 1, while predictors from among the explanatory variables were selected into block 2. In Model 2 of the lag 1 and lag 2 analyses, stroke rehabilitation at T1 was tested for selection in block 1, while predictors from among the explanatory variables were selected into block 2.

Each subsequent model involved the selection of variables from an additional category of covariates into an additional block, with the explanatory variables in the final block. This blocking sequence was guided by the sequence taken by Bookwala and colleagues (2004) and considered the strong association of previous with current LTC use found by Chong and colleagues (2015).

Specifically, the non-lagged analyses comprised the following models (Mx), with their corresponding blocks (By).

M1: caregiver well-being (B1)

M2: predisposing (B1), caregiver well-being (B2)

M3: predisposing (B1), enabling (B2), caregiver well-being (B3)

M4: predisposing (B1), enabling (B2), need (B3), caregiver well-being (B4)

The lag 1 (L1) and lag 2 (L2) analyses comprised the following models (Mx), with their corresponding blocks (By).

M1: caregiver well-being (B1)

M2: 3-month use (B1), caregiver well-being (B2)

M3: 3-month use (B1), predisposing (B2), caregiver well-being (B3)

M4: 3-month use (B1), predisposing (B2), enabling (B3), caregiver well-being (B4)

M5: 3-month use (B1), predisposing (B2), enabling (B3), need (B4), caregiver well-being (B5)

The model fit of each resulting model that contained at least one predictor, was tested with the likelihood ratio test. In models with blocks, the change in likelihood ratio was tested for statistical significance at alpha = .05

level ($p < .05$). Data were analysed with SPSS version 24 software.

Results

Descriptive Statistics

In total, 482 patient-caregiver dyads were considered in the analyses. The baseline socio-demographic and clinical characteristics of the patients have been reported earlier (Tyagi et al., 2018a).

Most of the patients were 64 years of age or younger, male, Chinese, religious and married. Except for about 8% who chose to fully pay for their own wards, all patients were placed in government-subsidized wards for post-index-stroke episodes. Patients categorized as suffering from mild stroke by the National Institutes of Health Stroke Scale (NIHSS), constituted 58% of the stroke population. The remaining patients consisted of 36% who experienced moderate stroke and 6% who survived severe stroke. Based on the Barthel Index, about 45% of the patients were considered moderately to severely dependent, 38% were independent or slightly dependent, and the remaining, fully dependent. Less than half the stroke patients were assessed as cognitively impaired. The caregivers were 47 years old on average. The majority were spouses, while the rest were grown-up children, siblings, distant relatives or friends. More than half of the caregivers were married Chinese females. A little above one-third of all caregivers were also caring for more than one individual, and about 75% were residing with their stroke charges.

The descriptive characteristics of stroke rehabilitation use at 3-month and 12-month post-stroke, and of the explanatory variables, before multiple imputations are applied on the latter, are shown in Table 3.1. Of the dyads, 48% and 13.3% reported stroke rehabilitation use at T1 and T2 respectively. Analyses involving the outcome variable comprised up to 278 dyads due to the removal of entire cases with missing values on this variable.

Correlations

The point-biserial correlations of rehabilitation use and the six attributes of caregiver subjective well-being at each time point are shown in Table 3.2. No substantial associations ($r \geq .40$) were found between rehabilitation use at T1 and T2 and any explanatory variable. Substantial associations were found among the following explanatory variables measured at baseline: caregiver burden and caregiver depression; at T1: caregiver burden, depression, and caregiving burden (time and difficulty); and at T2: caregiver depression and health status.

Explanatory Variables

The results of the non-lagged, lag 1 and lag 2 logistic regression analyses are shown in Tables 3.3, 3.4 and 3.5 respectively.

M1. Before controlling for covariates, caregiver depression at T2, and caregiving burden (time and difficulty) at T1 significantly predicted stroke rehabilitation use at T2. A one-point increase in caregiver depression score at 12-month follow-up is associated with 1.11 higher odds (95% CI = [1.01, 1.22]) of the patient using stroke rehabilitation at 12-month follow-up. A one-point increase in caregiving burden at T1 is associated with 1.04 higher odds (95% CI = [1.01, 1.06]) of the patient using stroke rehabilitation at T2.

M2-5. In the non-lagged analyses, after controlling for predisposing factors (patient stroke type), caregiver depression at T2 still significantly predicted stroke rehabilitation use at T2, *OR* = 1.11 (95% CI = [1.01, 1.22]). No statistically significant predictor was found among the explanatory variables after further controlling for enabling and need factors.

In the lag 1 analyses, after controlling for stroke rehabilitation use at T1, caregiver depression at T2 significantly predicted stroke rehabilitation use at T2, *OR* = 1.13 (95% CI = [1.02, 1.24]). After further controlling for predisposing factors (patient stroke type), caregiving burden at T1 significantly predicted stroke rehabilitation use at T2, *OR* = 1.04 (95% CI = [1.01, 1.07]). After enabling and needs factors at both T1 and T2 were considered and added into the model as covariates respectively, none of the explanatory variables significantly predicted stroke rehabilitation use at T2.

In the lag 2 analyses, after controlling for stroke rehabilitation use at T1, caregiving burden at T1 significantly predicted stroke rehabilitation use at T2, *OR* = 1.04 (95% CI = [1.01, 1.07]). After the addition of each predisposing factor was considered, caregiver depression at T2 significantly predicted stroke rehabilitation use at T2, *OR* = 1.12 (95% CI = [1.02, 1.24]), after controlling for stroke rehabilitation use at T1. After enabling and needs factors measured at T1 and T2 were considered and added into the model, none of the explanatory variables significantly predicted stroke rehabilitation use at T2.

Covariates

In the non-lagged analyses, the statistically significant covariates in the final model were caregiver employment status and patient’s disability level. At T2, patients whose informal caregivers were not on full-time employment and who were more disabled were more likely to use stroke rehabilitation.

In the lag 1 analyses, the statistically significant covariates in the final model were rehabilitation use at T1 and caregiver employment status at T2. Patients who used stroke rehabilitation at T1 and whose caregivers were not on full-time employment at T2 were more likely to use stroke rehabilitation at T2.

In the lag 2 analyses, the statistically significant covariates in the final model were caregiver employment status at T2 and patient’s disability level at T1. Patients whose informal caregivers were not on full-time employment at T2, and those who were more disabled at T1 were more likely to use stroke rehabilitation at T2.

Discussion

To recapitulate, this study used a prospective dataset to examine the associations of six attributes of caregiver well-being with stroke rehabilitation use, before and after controlling for previous use, predisposing, enabling, and need factors of the Andersen Model (Andersen & Davidson, 2007; Andersen, 1995), in a group of stroke survivor-primary informal caregivers. This study responded to the call, in Chapter 2, to improve the Andersen Model, by adding caregiver well-being as a cluster of factors for LTCS use. Although previous studies on formal LTCS use have included caregiver characteristics as explanatory variables, these characteristics were limited to the background and sociodemographic statuses of the caregiver, such as primary caregivers’ relationship to the patient, the presence of secondary caregivers, and living arrangements (e.g., Tennstedt, Crawford, & McKinlay, 1993). They also tend to be based on cross-sectional data (e.g., Gill, Hinrichsen, & DiGuiseppe, 1998). By investigating caregivers’ subjective well-being as predictors of stroke rehabilitation use, this study generates pertinent information that supplements existing research on determinants of formal LTCS use, such as stroke rehabilitation. This study has two main strengths. Firstly, the entire stroke survivor population at all five public tertiary hospitals in Singapore was surveyed within a given timeframe. Secondly, longitudinal dyadic data was collected, allowing me to investigate the degree to which time-dynamic well-being attributes of caregivers, could predict changes in patients’ stroke rehabilitation use.

Stroke Rehabilitation Use and Caregiver Well-being

The findings of the present study regarding usage rates at 3-month and 12-month post-stroke are similar to those reported earlier (Koh et al. 2012; Chen et al., 2014). Together with the broader literature on LTCS use (e.g. Liu et al., 2016; Wee et al., 2014; Ow, Tan, & Goh, 2004), this study suggests that in Singapore, stroke patients, as with other patients who required long-term care, seek informal care first, and many who choose formal care return to informal care after a short stint of formal care.

Only a few statistically significant and no substantial associations were found between rehabilitation use at 3-month and 12-month post-stroke with each of the explanatory variables are important. These findings may be explained by the heterogeneity in each of the associations as with those found via meta-analysis (omnibus tests) and presented in Chapter 2. This is not surprising because it has been widely held that formal LTCS is highly context specific. That caregiver health status at baseline is positively associated with rehabilitation use at 3-month post-stroke is the only specific finding that is supported by the sub-group analysis presented in Chapter 2 regarding non-USA studies that investigated this association. However, because the other five associations between caregiver health status and stroke rehabilitation use were statistically non-significant and because this above finding is not replicated in our regression analyses, it should be interpreted cautiously.

That few substantial associations were found among the explanatory variables may reflect the conceptual distinctions among the six attributes. However, I also found some substantial associations between caregiver burden and caregiver depression. In a systematic review and meta-analysis of 55 studies, a large and positive association of subjective caregiver burden with depressive symptoms was found (del-Pino-Casado, Cardosa, López-Martínez, & Orgeta, 2019). Moreover, as caregiving outcomes, both explanatory variables are known to have similar predictors (e.g. Cheng, 2017), and as predictors, both variables are known to mediate between personality traits (neuroticism and extraversion) and health-related quality of life (e.g. Kim et al., 2017). Extant research does not provide a clear description of the concept of caregiver well-being and delineate its different attributes. Global measures such as the Caregiver Well-Being Scale (Tebb, Berg-Weger, & Rubio, 2013; Tebb & Tebb,

1995) and measures of specific attributes such as life satisfaction and depressive symptoms (Grant et al., 2013) and those used in this study continue to be used in research and clinical settings. Future research should clarify if a unitary conceptual of caregiver well-being exists in the context of integrated health and social care, and if so, what attributes it comprises.

Caregiving Burden and Caregiver Depression

Overall, the logistic regression analyses showed that, although with small effect sizes, two of the six attributes of caregiver well-being – caregiver depression, and caregiving burden (time and difficulty) – are concurrent and prospective predictors of stroke rehabilitation use at 12-month post-stroke, respectively. I also found that these associations remained even after rehabilitation use at 3-month was controlled for. However, these associations became statistically non-significant when enabling factors were added as control variables.

Caregiver depression has previously been found to concurrently predict the use of a variety of LTCS, before and after controlling for previous LTCS use (e.g. Bookwala et al., 2004). To my knowledge, however, this was the first study to find that caregiver depression also predicts stroke rehabilitation use at 12-month post-stroke specifically, before and after controlling for previous rehabilitation use. Witnessing that their loved ones continue to require stroke rehabilitation without signs of functional recovery after 12 months post-stroke can be emotionally distressing. This points to the importance of providing interventions aimed at assessing and tackling caregiver depression to users of stroke rehabilitation at 12-month post-stroke.

While it is known that caregiving burden (time and difficulty) is associated with LTCS use, in general, this was the first study that found it to prospectively predict stroke rehabilitation use, in particular. Caregivers who found it time-consuming and difficult to care for a stroke patient at 3-month post-stroke tend to have cared for outpatient stroke rehabilitation users *later* at 12-month post-stroke. Further analyses found the caregiving burden level at 12-month post-stroke ($M = 31.87$, $SD = 16.31$) and at 3-month post-stroke ($M = 33.15$, $SD = 13.75$), to have no statistically significant difference, $t(206) =$ $p > .05$, although the caregiving burden at 12-month post-stroke was not associated with stroke rehabilitation at 12-month post-stroke.

Theoretically, future research guided by the Andersen Model should aim to delineate the role(s) that caregiver well-being attributes, such as caregiving burden and caregiver depression, play in explaining LTCS use. For instance, understanding if caregiving burden is an enabling or a need factor, or if it is a contextual or individual characteristic would become important enhancements to the explanatory framework.

Future research should also aim to explain the continued use or non-use of LTCS. LTCS use differs from acute care services use in that its use is of a longer duration, and likely to comprise a suite of different clinical interventions and assistive services. The Andersen Model was conceptualised primarily from acute care services use and health outcomes. However, because of the longer duration involved in LTCS use, contextual and individual characteristics may undergo changes due to factors that are not contained in the Andersen Model. Moreover, caregiver well-being constructs, such as caregiving burden, may undergo changes in tandem with the degeneration experienced in chronic conditions such as stroke.

Practically, to enhance stroke rehabilitation use at 12-month post-stroke, the medium to longer-term benefits to informal caregivers brought about by a patient’s use of rehabilitation in the areas of time savings in care provision, and professionalism of rehabilitation professionals, maybe emphasized early in the recovery journey through mediums such as public education, and family case conferences.

Although the general ability of caregiver well-being to predict stroke rehabilitation use at 12-month post-stroke is limited in this study, the findings of our study suggest that caregiver burden and depression have some ability in influencing stroke rehabilitation use. Future research should explore and identify such segments of informal caregivers at different levels of burden and depression so that appropriate and targeted psychosocial intervention may be provided. In the light of other findings that indicate that high caregiver distress may lead to more adverse outcomes for stroke patients (Grant et al., 2013), it is likely important to intervene with both stroke patients and their family caregivers to optimize post-stroke recovery.

Enabling and Need Factors

Theoretically, that enabling factors were collectively found to be statistically significant predictors when caregiver well-being attributes were statistically non-significant indicate the relative importance of caregiver socio-demographics over caregiver well-being in predicting stroke rehabilitation use. That none of the caregiver well-being attributes were statistically significant in the final model of the non-lagged and lagged analyses shows that while 12-month caregiver depression and 3-month caregiving burden (time and difficulty) adds to the ability of 3-month stroke rehabilitation use in predicting stroke rehabilitation use at 12-month post-stroke, a parsimonious predictive model does not require the inclusion of the caregiver well-being attributes examined in this study.

Previous examinations of LTCS use factors that employed hierarchical regression guided by the Andersen Model are few and returned equivocal results. Bookwala and colleagues (2004) reported caregiver needs, such as task burden and change in physical health, to be statistically non-significant in the presence of enabling factors, such as household income and number of family-assisted tasks, in predicting the number of service hours used. Bullock (2000), however, reported that need factors, such as caregiver health status, had the highest predictive power while caregiver employment status, alone, had the least impact among significant predictors of formal LTCS use.

The recently implemented Home Caregiving Grant that provides a monthly cash pay-out for family caregivers to defray costs of eldercare and support services, including FDW salaries, is an enhancement of enabling factors for LTCS use in Singapore. Resident caregivers in Singapore are now better placed to manage well-being issues.

That patient’s disability level was the only statistically significant covariate among the need factors, which were added in the last block of the regressions, suggests that it is a single most important factor for stroke rehabilitation use. Regardless of the availability of other patient and caregiver data, the referral of stroke patients to rehabilitation should minimally be based on assessments of their disability levels.

Caregiver Employment Status

The logistic regression analyses showed that among the enabling factors, caregiver employment status at 12-month post-stroke was the strongest and most consistent predictor of rehabilitation use at 12-month post-stroke after controlling for other factors in the non-lagged and lagged analyses. This is clear evidence that cutting back on full-time employment by informal caregivers are predictive of stroke rehabilitation use. The transportation of the patient to and from day rehabilitation centers, the additional activities of daily living assistance provided to enable patient movement from the doorstep to the arranged transportation and vice versa, the provision of a conducive home environment for and participation in a patient’s home- or center-based rehabilitation therapy, have been what keeps an informal caregiver unemployed or under-employed (Wee et al., 2014).

Family caregiving arrangement is an important context in the study of factors for LTCS use, at least in Asian countries, where important LTCS use decisions are made jointly between the patient and his or her primary informal caregiver (Eom et al., 2017). To ease the load of informal caregivers, the

Singapore government announced a Caregiver Support Action Plan in 2019 that includes financial subsidies for senior mobility, employment foreign domestic workers to care for patients requiring LTCS, and skills training of informal caregivers. While these subsidies reduce the financial burden of caregiving, direct efforts aimed at reducing employment disruptions, and helping informal caregivers remain in the workforce for as long as possible are indicated by this study.

Limitations

This study had several limitations. I was interested in quantifying the experience of stroke survivors and their primary caregivers throughout a one-year observation period. Hence, I left out the small percentage (6%) of cases in which the stroke patient died during this one-year period. A comparison, via sensitivity analysis, on the baseline characteristics of the full sample and the sample of excluded cases has been reported earlier (Tyagi et al., 2018b). Considering, on the one hand, the goal of quantifying experiences, and on the other, the findings of the sensitivity analysis, I may generalize the findings only to those who still live, a year after index stroke.

Due to resource constraints, the recruitment of participants was limited to public tertiary hospitals. The private hospitals were not part of this study. However, stroke cases from these private hospitals contribute only a small proportion of the incident stroke cases in Singapore and are thus unlikely to make a difference to our analyses.

Community-based stroke rehabilitation use data was self-reported by informal caregivers. Although the Singapore Stroke Registry obtains epidemiological and clinical data on stroke cases diagnosed in Singapore, it does not pool patient service use data pertaining to utilization of community-based long-term care, such as stroke rehabilitation, which occurs in a variety of settings. Although the national healthcare claims record has data on patients who benefit from day rehabilitation centre subsidies and Medisave deductions for rehabilitation, the collection of such data began only in 2012, which was when participant recruitment in the Singapore Stroke Survey was almost completed. The inclusion of stroke rehabilitation service use data into the national claims record and the establishment of a national LTCS register are ways forward for greater service coordination and evaluation.

Conclusion

This study adds to the literature on factors for LTCS use by taking guidance from the Andersen Model to examine the predictive ability of caregiver well-being attributes on stroke rehabilitation use in Singapore. Higher caregiving burden at 3-month post-stroke and higher caregiver depression at 12-month post-stroke are prospective and concurrent predictors of stroke rehabilitation use respectively. Caregivers' cutting back on full-time employment is predictive of stroke rehabilitation use. Efforts aimed at the identification of primary informal caregivers at risk of depression at 12-month post-stroke, prevention and intervention targeted at caregiver depression, and reduction of caregivers' employment disruption are indicated by this study.

Chapter 4

Introduction

The understanding of health is undergoing transformation. In 1948, the World Health Organization (WHO) defines it as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” (WHO, 1948). This concept was ground-breaking because it eradicated the previously held definition of health as absence of illness and added physical, mental and social components to it. In the past 20 to 30 years, a non-static understanding of health, which includes one’s “ability to adapt and self-manage”, has emerged (Huber et al., 2016). Recent research indicated that self-management in chronic illnesses improves quality of life (Ahmadi et al., 2014; Benzo, Abascal-Bolado, & Dulohery, 2016; Chen, Tsai, Hsi, & Chen, 2016; Sugiyama, Steers, Wenger, Duru, & Mangione, 2015). However, studies of self-management in neurodegenerative conditions, including stroke, has been neglected. In stroke, and self-management for the stroke survivor, attention must be paid to informal caregivers’ self-management as neurodegeneration of the stroke survivor continues (Huis in Het Veld, Verkaik, Mistiaen, van Meijel, & Francke, 2015). Self-management necessitates an informed consideration of constraints and opportunities to live with the stroke survivor. As explained by the concept of social health (Vernooij-Dassen & Jeon, 2016), one’s well-being is a result of an ability to adapt to the difficulties and life changes the disease creates (Huber et al., 2016). Recently, it has been found that this concept of health includes six dimensions: social participation, mental functioning and perceptions, bodily functioning, spiritual and existential, quality of life and daily functioning (Huber et al., 2016). While operational definitions of this new concept of health are still being developed, measurement tools that assess the psychosocial aspects: quality of life, distress, and well-being, have been recommended (Huber et al., 2016).

As described in Chapter 1, despite the phenomena of population ageing and the rise in chronic illnesses all over the world, formal long-term care service (LTCS) use is on the decline and informal caregiving of older adults and persons requiring LTCS continue to be associated with deleterious effects. In the quest to better understand factors for formal LTCS utilization, and ways to improve utilization rates, some researchers have turned to examining the association between caregiver psychosocial health characteristics and LTCS utilization.

In Chapter 2, via a systematic review and meta-analysis, I showed that studies involving nursing homes reported 70% lower odds while those that did not involve nursing homes reported 39% higher odds of caregivers experiencing higher burden associated with LTCS use by patients. I found studies that involved fewer female (than male) informal caregivers reported 86% higher odds while studies that involved more female caregivers reported 18% lower odds of the caregivers experiencing higher depression levels associated with LTCS use by patients. I also found that non-USA studies reported 50% lower odds while USA studies reported 25% higher odds of caregivers experiencing worse health in relation to LTCS use.

Chapter 2 findings suggest that LTCS use decision making is often carried out by caregivers and patients together (Liu et al., 2016). That caregiver burden, depression and health status represented psychosocial needs in Chapter 2 also suggest that caregiver psychosocial health may influence LTCS use. Therefore, when investigating factors for the use of any specific LTCS, including stroke rehabilitation, the contribution of caregiver psychosocial health characteristics necessitates investigation, on top of other known ones.

Stroke Rehabilitation and Caregiver Psychosocial Health

In the stroke literature, earlier research has attempted to better understand changes in caregivers' needs spanning stages of disease development (King & Semik, 2006; Brereton & Nolan, 2002; Kerr & Smith, 2001). In early stages, caregivers ought to understand stroke, its consequences and how to manage the physical challenges involved (King & Semik, 2006; Brereton & Nolan, 2002; Kerr & Smith, 2001). Upon the stroke survivor's return to home, caregivers would require more help from community services, including having a worker to monitor the caregiving situation (King & Semik, 2006; Kerr & Smith, 2001). In the long run, caregivers recognize the intensive and regular nature of care provision and hence expressed the need for continuing support (Kerr & Smith, 2001). Greenwood, Mackenzie, Cloud, & Wilson (2008), suggested that more work in this area is required to shed light on the specific timing of caregivers' experiences and to guide changes to provision of health care and appropriate time-sensitive education and other interventions.

The *Timing it Right* framework informs when caregivers ought to be supported as they accompany stroke survivors across care environments. This framework describes five phases experienced in a stroke survivor's recovery journey: (1) acute care admission (event/diagnosis); (2) medical stabilization (stabilization); (3) preparation for discharge (preparation); (4) initial adjustment to community or home living (implementation), and (5) longer-term adjustment to community living (adaptation; Cameron & Gignac, 2008). Each phase highlights caregivers' needs for informational, emotional, and instrumental supports (Cohen, Underwood, & Gottlieb, 2000). Acknowledging different support sources, including health care professionals, and close ones, this framework develops caregiver programmes to deal with caregivers' needs across stages, increase preparedness, facilitates transitions, and reduces adverse results (e.g. burden; Cameron & Gignac, 2008).

Currently, studies involving family caregivers of stroke victims shows that caregiving can affect caregivers' psychosocial health adversely and more support than currently available are required (Han & Haley, 1999; Salter, Zettler, Foley, & Teasell, 2010; Rigby et al., 2009; Dowswell et al., 2000; King, Ainsworth, Ronen, & Hartke, 2010; Bulley, Shiels, Wilkie, & Salisbury, 2010; King & Semik, 2006; Grant, Glandon, Elliott, Giger, & Weaver, 2004; Brereton & Nolan, 2002; Kerr & Smith, 2001). Despite recommendations to acknowledge the changes in caregivers' needs and experiences across a patient's recovery journey to guide education, training and support programmes (Greenwood, Mackenzie, Cloud, & Wilson, 2008), few studies have explored the associations between caregivers' evolving needs for psychosocial support, on the one hand, and stroke rehabilitation use, on the other. Therefore, the present study aimed to address this gap in the literature.

Aside from Janssen and colleagues' (2017) examination of caregiver profiles in dementia and their association with quality of life, depressive symptoms and perseverance time, an integrated perspective of combined psychosocial health attributes that give rise to different underlying caregiver profiles is lacking. The importance of identifying such latent caregiver profiles is their conceivable ability to serve as factors for LTCS use. Moreover, to improve caregivers' psychosocial health and integrate patient and caregiver services, these latent profiles potentially allow for more targeted and personalized interventions.

Analysis Issues

Researchers have typically used one or two standard deviations (SD) from the mean of each characteristic measured as a cut-off for the profiles that arise from different combinations of characteristics to categorize persons into subgroups (Salmivalli & Nieminen, 2002). While this approach is effective in relating categories to degrees, no standard procedure exists for determining cut-off point locations, the number of profiles, or the difference indicated by a caregiver whose score is just above the cut-off point and another caregiver whose score is just below the cut-off point. These inadequacies make profile characterization and classification unclear.

The latent profile analysis (LPA) was developed more recently to overcome the abovementioned shortcomings. Respondents are classified into mutually exclusive classes from their observed variables of interests. Based on the patterns of responses on similar variables, the underlying subgroups are revealed when the classes are categorised through an interpretation of their responses within and between the assigned classes (Aldridge & Roesch, 2008). In such models, each indicator is assumed to follow a normal distribution within a latent profile and each individual is assumed to belong to one of the latent profiles. The proportion of individuals belonging to a particular latent profile and the probability of membership is estimated in each model. Under the assumption that the data is missing at random, partially missing data is estimated through maximum likelihood procedures in LPA models.

The latent transition analysis (LTA) examines the movement of LPA models longitudinally by estimating them at multiple time points. In this analysis, a transition matrix modelling the movement of profiles between time points examines if individuals of different latent profiles will remain in their estimated profiles or shift into other latent profiles. LPA and LTA have been known as, “person-centered analyses” due to the use of observed variables’ response patterns to classify persons to unobserved latent profiles (Collins & Wugalter, 1992; Masyn, 2013). These analyses have been used to study geriatric health behaviours that include changes in cognition function (Huang et al., 2019), physical activity (Mooney et al., 2018) and depression (Ni, Tein, Zhang, Yang, & Wu, 2017).

Study Goals

The current study had five main goals: first, to identify latent profiles characterized by caregiver social health characteristics, using LPA; second, to describe the profile stability and movement between profiles, over time; third, to determine if stroke rehabilitation use at 12-month post-stroke differed by the profile patterns; fourth, to explore if patient and caregiver characteristics explain the profile classification at each time point; and fifth, to investigate if the identified profiles at 3-month post-stroke influences the explanation of stroke rehabilitation use at 12-month post-stroke by stroke rehabilitation use at 3-month post-stroke, after accounting for the effects of patient and caregiver characteristics.

Method

Data Source

As with the study described in Chapter 3, this study analysed data from the Singapore Stroke Survey with three time points: baseline (T0), 3-month post-stroke (T1) and 12-month post-stroke (T2). Of the 661 cases recruited, there was usable data from 638 patients and 482 caregivers. This amounted to 378, 331, and 278 patient-caregiver dyads in T0, T1 and T2 respectively. The Methods section of Chapter 3 provides more information on this data source.

Latent Profile Indicators

Scores on caregiver burden, depression, health status (defined as health-related quality of life), quality of care relationship with patient, and social support were used to obtain and characterize the caregiver psychosocial health latent profiles. Missing data were assumed to follow missing at random mechanism. Maximum likelihood method was used to estimate the parameters. The Methods section of Chapter 3 provides more information on the measures used.

Outcome Variable

Stroke rehabilitation use at 12-month post-stroke diagnosis was used as the outcome variable in this study because previous research conducted with the same population found stark underutilization of stroke rehabilitation at this time point (Koh et al., 2012; Chen et al., 2014). The outcome variable was dichotomous, with service use coded as “1”, and non-use coded as “0”.

Covariates

Caregiver covariates included sex, marital status, relationship with patient, utilization of healthcare service(s) in past month, availability of domestic maid at patient’s home, housework as main responsibility of domestic maid, and stroke care as main responsibility of domestic maid. Patient covariates consisted of patient’s age, stroke type, discharge destination, health status, cognitive status and disability level. These data were either collected via a patient (P) or caregiver (CG) survey or taken from patients’ medical records (MR). Table 4.1 shows the variables of each category, their source, and their availability at each time point.

Statistical Analyses Plan

The statistical analyses were completed in four steps. First, cross-sectional latent profile analyses were conducted on the caregiver psychosocial health indicators and the numbers of profiles were decided T0, T1 and T2.

Statistical indicators of Akaike’s Information Criteria, Bayesian Information Criteria (BIC), sample-size Adjusted Bayesian Information Criteria (ABIC), Lo-Mendell-Rubin Adjusted Likelihood Ratio Test (LMR; Lo, Mendell, & Rubin, 2001), and entropy were employed to determine the model of best fit. Lower Akaike’s Information Criteria, BIC and ABIC values indicate a model of better fit, while higher values of entropy indicate higher classification accuracy. The extent to which competing solutions could be interpreted was assessed through latent profile separation and homogeneity (Collins & Lanza, 2010). The separation of latent profiles is high when each latent profile is characterized by a unique combination of caregiver psychosocial health indicators. The homogeneity of latent profiles is high when each latent profile matches a response set on the caregiver indicators.

Second, an LTA was conducted to characterize the movements of each latent profile over time. Third, measurement invariance, stationary transitions and order effects over time were formally tested in the following models using a likelihood-ratio test:

Model 1: A baseline model without any parameter restrictions was estimated.

Model 2: The equality of the parameters of the measurement model was fixed to examine if full measurement invariance could be assumed across the three time points. Measurement invariance can be assumed when there are no differences in model fit between Model 1 and 2.

Model 3: The transition probabilities across transition points were fixed as equal (i.e., the transition metrics between T0 and T1 was fixed to be the same as those between T1 and T2). Stationary transition probabilities can be assumed if there are no differences between Model 2 and 3.

Model 4: To test if the caregiver psychosocial variables displayed higher-order effects from the first time point to the last time point, a second-order effect was computed in Model 4a and a mover-stayer effect was computed in Model 4b. A second-order effect is a direct effect that being in a category of an initial class / profile membership has on later class / profile membership. In the current study, the second-order effect refers to the pathway from caregiver profile (T0) to caregiver profile (T2). There will be no second-order effects if there were no differences between Model 2 and Model 4a. In mover-stayer models, individuals' transition probabilities were used in grouping of *movers* and *stayers* classes (Nylund, 2007). Movers are individuals who change classes over time, while stayers are individuals who remain in the same class over time. There will not be any mover-stayer effect if there were no differences between Model 2 and Model 4b.

Last, the associations between stroke rehabilitation use, initial latent profile membership and the transitions in caregiver psychosocial indicators were examined using the manual three-step approach. The manual three-step approach was preferred over the one-step approach due to several limitations (Asparouhov & Muthén, 2014). Covariates were manually fitted into the latent transition model, and those with significant associations with the estimated latent profiles and rehabilitation use were retained in the final model. All models presented in this study were performed using Mplus v8 (Muthén & Muthén, 2017).

Results

Latent Profile Analysis

Latent profile analyses were used to identify latent profiles based on caregivers' health status, depression, burden, relationship quality and social support at T0, T1 and T2. The main objectives of this analysis were to detect if there were meaningful clusters, known as "profiles", of caregiver indicators, and determine and interpret the number of profiles required to represent heterogeneity across individuals' responses at each time point. Models with one to six latent profiles were estimated at each time point and were compared to determine the number of profiles that optimally balanced model fit and parsimony. The random sets of starting values were set at 1000 with 50 final stage optimizations for each model, and the percentage of solutions that converged to the maximum likelihood value was calculated. A higher percentage reflects greater confidence of identification for the maximum-likelihood solution. Solutions with less than ten percent of starting values identified across different random sets of starting values were considered as inadequate (Lanza & Bray, 2010). Hence, the five-profile model at T0, three- and six-profile models at T1, and the three-profile model at T2 were deemed as inadequate.

Table 4.2 compares the resulting model fit indices beginning with the one-profile model and proceeding to the six-profile model. The Akaike's

Information Criteria, BIC and ABIC values decreased when the number of profiles at T0, T1 and T2 increased. Entropy values indicate a good separation of latent classes (> .80) for all models. The LMR statistics at T0 suggested that the two-profile is superior to the one-profile model, four-profile is superior to the three-profile model and six-profile is superior to the five-profile solution. Both the LMR statistics at T1 and T2 suggested that the two-profile is better than the one-profile model.

The concepts of latent profile separation and homogeneity were explored next. High separation of latent profiles and high homogeneity was prioritized to facilitate the interpretation of competing solutions. Mean plots of one to six latent profile models are provided in Supplementary material 4. The caregiver psychosocial indicators are presented along the x-axes of each plot, while the y-axis present the standardized means of each variable. The standardized mean values of the two-profile models showed a more defined pattern of latent profiles when compared to the other profile models. For instance, clearer distinctions of depression, burden, and health status between groups of caregivers can be observed in the two-profile models. In addition, higher homogeneity was observed in the two-profile model, as there is a stronger correspondence between the caregiver psychosocial variables and the latent profiles. Considering the model fit indicators and interpretability of the models, the two-profile model was selected as the optimal latent profile solution.

Similar profiles were observed when the two-profile model plots were compared across T0, T1 and T2 (Figures 4.1, 4.2 and 4.3 respectively). The plots suggested that the caregiver psychosocial health profiles could be divided into the following two categories – “Non-distressed” and “Distressed”. The former accounted for most of the sample at T0 (81.2%), T1 (79.5%) and T2 (87.8%). This profile comprises caregivers with lower levels of burden and depression, and higher levels of health status, relationship quality and social support. The second profile comprises caregivers with higher levels of burden and depression, and poorer health status. The descriptive characteristics of these two latent profiles are shown in Table 4.3.

Latent Transition Analysis

Latent transition analysis was conducted next to explore movements between the two profiles. The possibilities of measurement invariance, stationary transitions and higher order effects were explored, and the model fit indices are presented in Table 4.4.

First, to explore measurement invariance, Model 1 with complete measurement non-invariance and Model 2 with full measurement invariance were compared. The likelihood ratio test (LRT) indicated a significant difference in model fit, $\chi^2(20) = 1314.03$, $p < .001$. However, Model 2 with full measurement invariance was selected and used in our subsequent analyses, as latent profile plots were similar across the time points (Nylund, 2007) and full measurement invariance allows a more straightforward interpretation of transition probabilities (Pan, Liu, Lau, & Luo, 2017).

Second, to explore if stationary transitions were reasonable, Model 2 used a transition matrix for each time point (e.g., one for T0 to T1 and another from T1 to T2) and Model 3 constrained the transition matrices to be equal across the time points. The LRT indicated a significant difference in model fit, $\chi^2(2) = 589.26$, $p < .001$. Model 2 with non-stationary transitions was chosen because the subsequent addition of covariates into the transition model was planned. Stationary transitions do not allow meaningful interpretations to be made (Nylund, 2007).

Third, to determine the presence of higher-order effects, Model 2 was compared to Model 4a for second-order effects and Model 4b for mover-stayer effects. Between Model 2 and 4, LRT indicated significant differences in model fit, $\chi^2(1) = 545.20$, $p < .001$ supporting a second-order effect. Similarly, LRT also showed significant differences in model fit between Model 2 and 4b, $\chi^2(2) = 466.77$, $p < .001$ supporting a mover-stayer effect. The second-order effect was chosen over mover-stayer instead of based on better model fit indices (i.e. lower Akaike’s Information Criteria, BIC and ABIC).

Last, a latent transition model with rehabilitation use at T2 as an outcome variable was conducted using the three-step approach (Asparouhov & Muthén, 2014). Caregiver demographics, patient variables and rehabilitation use at T1 were considered as covariates to the latent profiles and rehabilitation use at T2. Pathways that were not statistically significant were taken out of the model. Listwise deletion removed cases with missing latent profiles and covariates, resulting in 149 cases being reviewed in the eventual model. The transition probabilities of the latent profiles in the eventual model are presented in Table 4.5, the eventual model is displayed in Figure 4.4, and the parameter estimates of each latent profile transition pattern are shown in Table 4.6.

Notably, the second-order effect of the T0 latent profile on the T2 latent profile was statistically significant, $\beta = 2.26$, $p < .05$, after accounting for the effects of T0 patient depression, $\beta = -2.84$, $p < .001$, and T1 patient depression, $\beta = -4.41$, $p < .001$, on the T0 and T1 profiles respectively. Distressed caregivers at T0 were 76% likely to become non-distressed, and 24% likely to remain distressed, at T2. Non-distressed caregivers at T0 were more likely to remain non-distressed, than become distressed, at T2.

The profile transition patterns showed significant differences in stroke rehabilitation use. Among the eight patterns, those with non-distressed caregivers at T2 were associated with stroke rehabilitation use, rather than non-use, at T2, $\beta = 2.63$, $p < .01$, after accounting for the effects of T1 rehabilitation use and type of stroke.

T1 rehabilitation use was a statistically significant predictor of T2 rehabilitation use among non-distressed caregivers at T1, $\beta = 2.57$, $p < .01$, but not among distressed caregivers, $\beta = 1.00$, $p = .32$. Patients who were users of rehabilitation at T1 tend to have used rehabilitation at T2 only when their caregivers were not distressed at T1, but not when their caregivers were distressed. Stroke type was a statistically significant predictor of rehabilitation use at T2 for both non-distressed, $\beta = -2.20$, $p < .05$, and distressed caregivers, $\beta = -2.37$, $p < .05$. Patients with non-ischemic stroke types tend to have used rehabilitation at T2 for both non-distressed and distressed caregivers.

Discussion

To my knowledge, this was the first study that sought to understand profiles of informal caregivers using latent profile analysis (LPA), track changes in these profiles using latent transition analysis (LTA), and test associations of these profiles and profile transition patterns with LTCS use over a 12-month time frame. Specifically, this longitudinal study had five goals: first, to identify latent profiles characterized by caregiver psychosocial health, using LPA; second, to describe the profile stability and movement between profiles, over time; third, to determine if stroke rehabilitation use at 12-month post-stroke differed by the profile transition patterns; fourth, to explore if patient and caregiver characteristics explain the profile classification at each time point; and fifth, to investigate if the identified profiles at 3-month post-stroke influences the explanation of stroke rehabilitation use at 12-month post-stroke by stroke rehabilitation use at 3-month post-stroke, after considering the effects of patient and caregiver characteristics.

Latent Profiles Classification and Transition Stability

Results showed two distinctive profiles at baseline: distressed and non-distressed, characterized by caregiver burden, depression and health status. These groups followed a pattern in which most caregivers were categorized as non-distressed. At 3-month post-stroke, caregivers demonstrated similar categorizations. The non-distressed caregivers at baseline were likely to have remained non-distressed at 3-month post-stroke. The distressed ones at baseline, however, were likely to have become non-distressed, although some remained distressed. At 12-month post-stroke, the same two profiles were again obtained: most caregivers were classified as belonging to the non-distressed profile, and most caregivers had also gone through a transition that was akin to the transition shown between baseline and 3-month post-stroke. The baseline profiles showed a higher-order effect on 12-month post-stroke profiles, and the classification at 12-month post-stroke was largely determined by the status at baseline.

Research goal 1: latent profile characterization and classification. The characterization of the caregiver profiles adds support to the premise of this study, that caregivers' psychosocial health is an important consideration in the self-management of degenerative conditions, such as stroke. Based on the understanding that caregiver burden, depression and health status (or health-related quality of life) are centred on an individual self, while care relationship quality and caregiver social support are centred on an interplay between the individual self and at least one other individual, as presented in Chapter 1, that the profiles were differentiated by the former attributes, but not the latter, suggests that the concept of psychosocial health may be more intrapersonal than interpersonal in nature. While the operational definitions of caregiver psychosocial health should continue to be developed, patient-caregiver dyadic profiles should also be explored in future research for interventions and services to be designed in more integrated manners.

In the present study, the proportion of distressed caregivers of stroke survivors was 19%, 21% and 12% at baseline, 3-month and 12-month post-stroke respectively. The greater proportion of distressed caregivers at baseline and 3-month post-stroke may be explained by understanding the needs of stroke family caregivers using the *Timing It Right* framework. Family caregivers' needs for support change in tandem with stroke survivors' functional recovery and community reintegration (Cameron, Naglie, Silver, & Gignac, 2013). The baseline, 3-month and 12-month post-stroke time points of the present study coincided with the preparation, implementation and adaptation phases of the *Timing It Right* framework respectively. The needs of family caregivers are maximal in the preparation phase, when they prepare the stroke survivor for home discharge, and in the implementation phase - the initial months at home. There are also caregivers in the adaptation phase who have longer-term needs for support because they care for stroke survivors with greater cognitive and/or physical disabilities, or communication challenges.

The type and intensity of support needed by family caregivers vary in each phase (Cameron et al., 2013). For instance, in the preparation phase, family caregivers do well with getting involved in discharge planning, and appreciate emotional support that helps them to feel more relaxed and optimistic, whereas in the implementation phase, they find it necessary to learn to manage home rehabilitation and would like a sense of being cared for and connection and acceptance by peers. Nonetheless, caregiver psychosocial support should be accessible throughout the trajectory of stroke rehabilitation (O'Brien et al., 2014). Future research should confirm the presence, and if so confirmed, examine the magnitude and direction of this likely association between the caregiver psychosocial health profiles and the varying type and intensity of required caregiver support in each phase. If this association is confirmed, then the focus of care in each phase should address caregiver support needs in order to enhance the chance of non-distressed outcomes.

Research goal 2: latent profile transition stability. I found some stability across baseline, 3-month and 12-month post-stroke, in the classification results, and in the transition probabilities across the three time points. Firstly, independent LPA findings indicated that the caregiver psychosocial health profiles were similar over time. The caregivers were classified into two distinctive profiles across baseline, 3-month and 12-month post-stroke: a profile with high burden and depression and poor health status, and another profile with moderate overall indicator scores. While high levels of distress are common amongst studies that focus on informal caregivers of stroke survivors (Van Puymbroeck & Rittman, 2005; Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005), the consistency of caregivers' profiles across time is consistent with a study by Simon, Kumar and Kendrick (2009). In their research on informal caregivers of first-time stroke survivors, it was found that carers with the presence of psychological distress, as measured by The Revised Clinical Interview Schedule (Lewis, Pelosi, Araya, & Dunn, 1992), after patient-discharge continued experiencing distress 15 months later, while those who were not distressed at point of patient-discharge had a 92% chance of not becoming significantly distressed in the same time frame. This may suggest that caregivers' distress may be affected by carers' caregiving experiences at the onset, including appraisal or acceptance of situation (Rochette & Desrosiers, 2002; De Vugt et al, 2004), rather than merely a process of attrition (Simon et al., 2009).

Secondly, the LTA findings did not indicate significant differences in the transition probabilities across the three time points. Put differently, the transition probabilities between baseline and 3-month post-stroke were similar to those between 3-month post-stroke and 12-month post-stroke. While there exist longitudinal studies that evaluate caregivers' distress or well-being across time (e.g. Grant et al., 2002; Godwin, Ostwald, Cron, & Wasserman, 2013) based on observed measures, further research on the transitional probabilities of such caregiver distress or combined latent psychosocial health characteristics over time may be required to confirm the findings from this research.

Notwithstanding the above findings, the non-distressed profile appeared to be more stable than the distressed profile over time. As shown in Table 4.5, among the non-distressed caregivers, the probabilities of status stability exceeded .90 at each transition, but among the distressed caregivers, the probabilities of status stability did not exceed .34 at each transition. Most distressed caregivers at baseline became non-distressed by 12-month post-stroke although some remained distressed. Further analyses revealed that among the distressed caregivers at baseline whose patients were non-users of stroke rehabilitation, there was a .74 probability of them becoming non-distressed while their patients remained non-users of stroke rehabilitation at 12-month post-stroke.

This heartening finding may be explained by caregivers' adaptation to caregiving demands over time (Kramer, 2000; Stephens & Zarit, 1989; Townsend, Noelker, Deimling, & Bass, 1989), and the assistive and psychosocial support and training that some of them may have received. That some remained distressed could be due to their charges having greater cognitive and/or physical disabilities, or communication challenges hampering reintegration (Cameron et al., 2013). Future research should aim to explain the temporal stability of the non-distressed caregivers and the recovery of the distressed caregivers, and check if the lack of rehabilitative improvement of the patient is associated with the probability that some distressed caregivers remain distressed.

Latent Profile Transition and Stroke Rehabilitation Use

Research goal 3: caregiver profile transition pattern and rehabilitation use. Regardless of the pattern of profile transitions over the three time points, the non-distressed caregivers at 12-month post-stroke were likely to have cared for stroke rehabilitation users at 12-month post-stroke. This result suggests that stroke rehabilitation use is associated with reduced caregiver distress at 12-month post-stroke. This study was the first to find associations between latent profiles, indicated by combined caregiver psychosocial health characteristics, and stroke rehabilitation use. Future research should aim to confirm this evidence for caregiver psychosocial health profile to be added to explanatory frameworks of stroke rehabilitation and LTCS use.

Research goal 4: Explanation of caregiver profiles. Among the covariates, patient’s depression was found to explain the caregiver psychosocial health profile classifications at baseline and 3-month post-stroke. This finding is supported by previous research that showed that a patient’s psychosocial health is associated with a caregiver’s psychosocial health in the LTCS context (e.g. Pierce et al., 2017). The predictive ability of the baseline latent profiles on those profiles at 12-month post-stroke suggest that identification of at-risk caregivers, psychoeducation and psychosocial intervention to distressed caregivers should be provided as early as at the point of patient discharge from acute hospital.

Research goal 5: Moderating effect of caregiver profile. Stroke rehabilitation use at 12-month post-stroke was significantly predicted by stroke rehabilitation use at 3-month post-stroke and stroke type. Stroke rehabilitation users at 3-month post-stroke tend to continue to use stroke rehabilitation at 12-month post-stroke only when their caregivers were not distressed at 3-month post-stroke, but not when their caregivers were distressed. This finding shows that the caregiver profiles at 3-month post-stroke moderates the association between stroke rehabilitation use at 3-month post-stroke and 12-month post-stroke. Caregiver distress at the implementation phase may impact stroke rehabilitation use at the adaptation phase. On the flip side, experiencing caregiver distress early in a patient’s stroke recovery course is associated with subsequent non-use of rehabilitation, which may in turn give rise to further caregiver distress. These findings point to the importance of efforts aimed at psycho-educating caregivers of stroke survivors, identifying caregivers at risk of experiencing distress and intervening on distressed caregivers to be put in place as early as the preparation phase of a stroke patient's recovery journey.

Limitations

There are a few limitations to this study. The current study used five items as indicators of caregiver psychosocial health. Increasing the number of items is likely to produce a stable statistical model, although this may not be possible currently because, as discussed earlier, operational definitions of the new concept of health, are still being developed. Future research should attempt to examine if forthcoming operational definitions are good discriminators of caregiver health, in general, and psychosocial health, in particular.

As in any study, more covariates and distal outcomes could have been included to provide a richer understanding of the caregiver latent profiles and profile transition patterns found in this study. This study associated the profile transition patterns to stroke rehabilitation use at 12-month post-stroke. Future studies could explore distal outcomes of a greater temporal distance, such as rehabilitation use at 24- and 36-month post-stroke, without necessarily having to collect other patient and caregiver data at those time points. Such studies would shed light on the potential longer-term effects of caregiver profiles.

Conclusion

The present study extended previous research by providing evidence that distressed and non-distressed profiles of informal caregivers exist from the point of discharge of stroke patients, up to 12-month post-stroke. In order to encourage stroke rehabilitation use up to 12-month post-stroke, distressed caregivers should be identified, and appropriate support provided at the point of patient discharge. This support should continue to be provided up to 12-month post-stroke.

Chapter 5

Aim of Thesis Revisited

This thesis was primarily motivated by the twin phenomena of falling formal long-term care service (LTCS) demand and unrelenting deleterious effects on informal caregivers’ subjective well-being across urban societies. These phenomena run counter to the needs of ageing populations, that presents challenges of a rise in chronic degenerative illnesses and long-term disabilities, and associated crowding at acute treatment facilities. The limited effectiveness of simply increasing formal LTCS supply to meet these challenges has led to transformation of health care systems in order to influence demand for LTCS. Using three studies, this thesis investigated the extent to which informal caregivers’ subjective well-being influences the utilization of public long-term health and social care services.

Main Findings and Future Research

Taken together, the main findings presented in this thesis showed that among the five major concepts of informal caregivers’ subjective well-being, there exist substantial associations between caregiver burden, depression and health status and LTCS use.

The study reported in Chapter 2 is the first reported systematic investigation of the relation between each of caregiver burden, depression and health status and LTCS use. With the conceptualization of each caregiver construct as a psychosocial need, and based on reported empirical data of moderate to high quality sampled from journal articles and theses, this study provides a qualitative synthesis and meta-analysis of the magnitude and direction of each relation of interest. Chapter 2 showed that research studies that involved fewer female (than male) informal caregivers reported 86% higher odds of caregivers experiencing higher depression levels associated with LTCS use by patients. Studies involving nursing homes reported 70% lower odds of caregivers experiencing higher burden associated with LTCS use by patients. Non-USA studies reported 50% lower odds of caregivers experiencing poorer health status in relation to LTCS use. I also found that there were unexpectedly few studies that provided quantitative data on this topic despite the many years of research involving informal caregiving in the context of LTCS. That elevated burden and depression and poor health status of the informal caregiver indicate a need for the patient to use LTCS provided theoretical and practical bases for the studies presented in Chapters 3 and 4.

The studies reported in Chapters 3 and 4 are based on a population-based prospective cohort investigation of stroke survivors and their primary informal caregivers over a 12-month time frame in Singapore. These dyads were recruited from all government restructured acute hospitals and validated measures were used to assess stroke rehabilitation use, each of the five caregiver subjective well-being concepts, and many other patient and caregiver characteristics. Chapter 3 showed that, as caregiver well-being attributes, caregiver depression and caregiving burden are concurrent and prospective predictors of LTCS use respectively, albeit with low effect sizes. After controlling for covariates, I found that caregivers who found caregiving to be more burdensome (time consuming and difficult) at 3-month post-stroke, and those who were more depressed at 12-month post-stroke tend to have cared for stroke rehabilitation users at 12-month post-stroke. Other attributes of caregiver well-being, such as mastery, may influence stroke rehabilitation use, and should be explored in future research.

Using the same sample, Chapter 4 showed that caregiver burden, depression, and health status, characterize latent profiles that discriminate between distressed and non-distressed caregivers, who differ with regards to stroke rehabilitation use at 12-month post-stroke. After controlling for covariates, and regardless of the pattern of profile transitions over baseline, 3-month post-stroke and 12-month post-stroke, I found that caregivers in the non-distressed profile at 12-month post-stroke tend to have cared for stroke rehabilitation service users at the same time point. Furthermore, regardless of profile transitions, stroke rehabilitation use at 3-month post-stroke was strongly predictive of stroke rehabilitation use at 12-month post-stroke among non-distressed caregivers at 3-month post-stroke. This association is non-significant among distressed caregivers at 3-month post-stroke. These findings suggest that the five concepts of caregiver subjective well-being may be useful operational definitions of caregiver psychosocial health, which influences stroke rehabilitation use within 12-month post-stroke. Future research could employ factor analyses to confirm this suggestion.

The findings of Chapter 2 may appear to support those of Chapter 3 but not those of Chapter 4. Although the latent caregiver psychosocial health profiles presented in Chapter 4 are partially indicated by the observed caregiver burden and depression measures used in Chapter 3, the former is a combination of five individual attributes that used the two latter measures. The findings of Chapter 2 are based on syntheses of observed characteristics, not latent ones. Because the study presented in Chapter 4 is the first to use more recently developed latent profile and latent transition analyses to understand caregiver psychosocial health profiles, its results should be confirmed in future research.

Therefore, in summary, this thesis presented evidence that shows that elevated caregiver burden, caregiver depression, and poorer caregiver health status are non-causally associated with increased utilization of public long-term health and social care services. This thesis showed that increased caregiving burden and increased caregiver depression are prospectively and concurrently predictive of stroke rehabilitation use at 12-month post-stroke. This thesis also showed that non-distressed caregivers at 3-month post-stroke and 12-month post-stroke are likely to have cared for users of stroke rehabilitation at 12-month post-stroke.

Contributions to Literature

With the extent of the influence of caregivers' subjective well-being on formal LTCS clarified, how then, could the twin problems of falling LTCS demand and deleterious effects of informal caregiving be addressed? This thesis points to four potential solutions that are worthy of further investigations. The concept of *caregiver resilience* should be better understood, early caregiver subjective well-being education and intervention should be initiated, explanatory frameworks for LTCS use should include caregiver subjective well-being constructs, and integrated care service design and delivery should consider the patient-caregiver dyad as the recipient of care. Figure 1.2 summarizes the inter-relationships between the rationale, aim, research questions, findings, and contributions presented in this thesis.

Understand caregiver resilience. In Chapter 3, caregiver depression is predictive of stroke rehabilitation use at 12-month post-stroke, but in Chapter 4, non-distressed caregivers were more likely to use rehabilitation at 12-month post-stroke. This disparity across studies may be explained by the possibility of a coexistence of positive and negative caregiving experiences.

One such positive experience is *resilience*. Resilience is “positive adaptation to face adversity, flexibility, psychological well-being, strength, healthy life, burden, social network, and satisfaction with social support” (Dias et al., 2015). A depressed caregiver may not experience distress due to effective coping strategies and a sense of self-efficacy (Séoud & Ducharme, 2015). It has been documented that some caregivers are able to “bounce back” from adversity and manage the challenges associated with caregiving (Tugade & Fredrickson, 2004). There is also evidence that some caregivers do experience satisfaction and positivity in caregiving (Gray, Hahn, Thapsuwan & Thongcharoenchupong, 2016). Therefore, the findings of this thesis calls for further research into the possibility and nature of a coexistence of positive and negative caregiving experiences.

Educate and intervene on caregiver subjective well-being early. To my knowledge, the studies presented in Chapters 3 and 4 are the first that provide quantitative support to the importance of early and sustained psychosocial intervention to informal caregivers of stroke survivors. These results are supported by qualitative research reported previously associated with the *Timing It Right* (Cameron & Gignac, 2008) and *Conceptual Building Blocks* (Krieger, Feron & Dorant, 2017) programmes. Unfortunately, in the literature, the available psychosocial interventions for caregivers of stroke survivors and of other persons requiring LTCS are few and unstructured (Specht, 2014), and should be enhanced. Inadequacies in areas such as consensus among stakeholders on the need for caregiver support interventions, collaborative stakeholder engagement processes, and understanding of efficacy and cost-effectiveness evidence for such interventions have been implementation barriers (Tseung, Jaglal, Salbach, Yoshida, & Cameron, 2019), which might be overcome by implementation science approaches (Smith & Polaha, 2017). *Outreach counselling* is an example of an innovative early intervention (Krieger et al., 2017). Krieger, Feron and Dorant (2017), and Grant, Hunt and Steadman (2014) provide guidance on ways to develop caregiver interventions and should be consulted.

Current informal caregiver psychosocial training programmes are largely corrective in nature. Such programmes do not adequately assist caregivers to anticipate potential caregiving issues, nor prepare them sufficiently to manage such issues early. Unnecessary burden, depression and poor health status associated with caregiving may be minimised with early education.

Most of the currently available caregiver psychosocial interventions address individual and negative outcomes, such as depression and burden. Interventions aimed at nurturing holistic and positive caregiver psychosocial outcomes should be developed from measures of resilience, such as the Caregiver Resilience Scale (Maneewat, Lertmaharit, & Tangwongchai, 2016), and of gains, such as Gain in Alzheimer Care Instrument (Yap et al., 2010).

LTCS use explanatory frameworks. Theoretically, informal caregiver subjective well-being constructs add to the need factors of the prevailing Andersen Model (Mensie & Steffen, 2011; Bookwala et al., 2004) in health service use. Of the many perceived and evaluated needs that caregivers have, their well-being should not be neglected. For application to LTCS, a revised Andersen Model would suggest that the use of long-term health and social care services is a function of the caregiver and patient’s predisposition to use services, factors that enable or hinder use and factors that suggest need for care.

Caregiver characteristics should be distinguished from patient characteristics although they interact within the dyad. It is established that among the patient characteristics, disability level or number of activities of daily living limitations is strongly indicative of *need* for LTCS use. This thesis suggests that caregiver burden, depression, and health status as strong indicators of *need* for LTCS use among caregiver characteristics.

Caregivers and patients operate in different contexts, although some characteristics may be shared. Overall, separate but interacting caregiver and patient pathways should merge in joint decision-making regarding LTCS use and other health and social behaviours of the dyad. The emerging concept of health (Huber et al., 2016) is likely to give rise to a new set of outcomes that comprise psychosocial components. Figure 5.1 shows a behavioral model of LTCS use.

Because family dynamics is known to influence the experience of caregiver subjective well-being attributes such as burden (Scharlach, Li & Dalvi, 2006; Kusaba et al., 2006; Fukui, Sakka, Amiya, Sato & Kamibeppu, 2018), the interactions between caregiver and patient decision pathways may involve mechanisms of trust (Monir, 2019) and communication (Walczak et al., 2017). These mechanisms should be clarified in future LTCS use explanatory frameworks. Future explanatory frameworks should also include a time dimension to consider the illness and recovery trajectories of the patient and the psychosocial health trajectories of the caregiver.

Patient-caregiver dyad in integrated care. The results presented in this thesis, add further weight to the presence of this phenomenon: that patients and their informal caregivers engage in joint decision making regarding LTCS use. Informal care appears to be the first choice of care. Patients prefer to age in place, rather than be institutionalised. The consideration of formal LTCS use appears to begin when informal caregiving is no longer able to provide satisfactory quality of life to patients.

Therefore, informal caregivers' subjective well-being should be factored into integrated care service design and delivery. Caregiver needs may become more easily incorporated into care when community and family organizations and functions are merged with health care organizations and functions. Service integration could occur by first redefining service recipients to be the informal caregiver-patient dyad or the family. Clinically, geriatric and eldercare professionals should relook at guidelines and procedures that fits the dyad. For instance, with assurances established by guidelines, informed consent for medical procedures may be taken from a patient's primary informal caregiver, as a proxy, should the patient be unable or unwilling to decide.

Implications for Ageing Policy, Practice and Research in Singapore

For integrated care policy to stay relevant and integrated care services to be useful to the changing needs of Singapore's ageing population, it is vital to conduct regular reviews of the subjective well-being of informal caregivers. Policy- and practice-influencing research are likely to be population-based ones, but can also take the form of systematic evaluations of services. A consistent stream of such research is necessary to ensure the sustainability of outcome-informed policy and evidence-based practice that are useful and innovative.

The Agency for Integrated Care (AIC), working in close collaboration with its stakeholders in the health and social care ecosystem, may be best placed to take ownership of the iterative processes of research and policy recommendation, and of evaluation and service design and delivery. As Singapore's national integrator and referral agency of formal long-term care services, the AIC could systematise the collection of operational data (e.g.

claims), enhance data and database infrastructure, and establish linkages of its operational database with the national electronic health records and the various national disease registries (e.g. stroke, death). The AIC could institute rigorous evaluations of pilot services before they become mainstream. It could also facilitate the conduct of *deep dive* research studies either by commissioning an external institution or by providing competitive research grants such as through the AIC Intermediate Long-term Care Research Grant, within which the research is jointly designed by academia and industry. The knowledge created from such efforts, when disseminated, is likely to enhance the transformation and integration of the long-term care landscape.

Changing perspectives on family caregiving is key to maintaining government policies that encourages ageing within the community and controlling LTCS cost. Understanding the family caregiving dynamics via longitudinal studies on care recipients and caregivers, will shed more light on the process of caregiving. This will inform the development of specific interventions for seniors as well as their families. As family members are at the forefront of providing care for seniors, they postpone institutionalization of the care recipients. However, the departure from conventional family structures has affected the traditional dynamics of caregiving, suggesting a transition away from typical caregiving arrangement and availability of family caregivers (Cheng, Vaithianathan, & Li, 2018). The reduction in size of a Singaporean nuclear family will also lead to a decrease in the number of adult members available to care for seniors at home. Hence, it increases the probability of the person being involved in the caregiving process (Mehta, 2005).

Future research should also examine the subjective well-being and other psychosocial health needs of formal caregivers (healthcare professionals, foreign domestic workers) and the family and/or household that seniors live with, for a more holistic resolution of issues associated with an aging population. There may also be subjective well-being differences between inexperienced and experienced caregivers, which could be explored. In a recent study of female nursing home workers, it was found that those who were also unpaid informal caregivers experienced shorter sleep quantity and poorer sleep quality when compared to those who were not also unpaid informal caregivers (DePasquale, Sliwinski, Zarit, Buxton, & Almeida, 2019). Sleep determines health and well-being (Buysse, 2014). With an estimated 26% of the working-age population in Singapore having to care for both young and old, the emergence of a *sandwich generation*[7] (The Economist, 2010) is another demographic trend that influences formal long-term care service utilization.

Finally, expanding education programmes in gerontology and geriatrics is long overdue and should be considered a priority. In addition, researching on the integration of technology into the health care industry could help Singapore resolve her concerns with the shrinking work force owing to the aging population (Ministry of Finance, 2018). Hence, it is increasingly pertinent to have capacity development for the integration of technology with health

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[7] Those people "sandwiched" between the competing demands of caring for both their children and for their parents.

assessment.

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* References marked with an asterisk indicate studies only included in the qualitative synthesis.

** References marked with two asterisks indicate studies included in both the qualitative synthesis and meta-analysis.

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Tables

Table 2.1

Qualitative Characteristics of Included Studies (*N* = 37)

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Bass & Noelker, 1987	Study data are from a larger survey funded - respondents were referred from health and social service agencies, senior centers, civic groups, churches and other organizations in the Greater Cleveland metropolitan area and 10 non-metropolitan counties that were contacted for referrals.	Caregiver need characteristics account for significant variation in whether services are used, while family enabling factors are the most important predictors of the amount of services used.	multiple regression, bivariate correlation	✓		✓	✓		✓

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Bass, Noelker, & Rechlin, 1996	Case management agencies	The use of health care service by care recipients who are more disabled is related to lower levels of caregiver depression, health deterioration and social isolation.	Ordinary least squares regression		✓	✓			
Bookwala et al., 2004	2 waves of data from the Caregiver Health Effects Study, an ancillary study of the Cardiovascular Health Study	At Time 1, more caregiver depressive symptoms predicted greater service use; At Time 2, more caregiver activity restriction and depressive symptoms predicted greater formal service use	Correlational and regression analyses		✓	✓			✓
Brown, Potter, & Foster, 1990	Geriatric Assessment Program at the University of Nebraska Medical Center	Among measures of the older person's cognitive and physical abilities, only activities of daily living predicted increased use of services. When the measure of caregiver burden was added, it significantly improved the prediction of service use.	Logistic regression analysis	✓			✓		

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Bullock, 2000	Based on the secondary analysis of data from a larger survey of elders 60 and older, the Springfield Elder Project	Unemployed caregivers were less likely to use alternate options for assisting the elder and had a smaller number of secondary caregivers on average.	Linear regression			✓			
Chang, 2009	Using the 3rd year data from the Pilot Program for Long-term Care Development	The lack of moderating effect of home care on most interaction terms may be the result of a low rate of service use. Despite its low utilization, its ability to mitigate the negative impact of IADL on depressive mood reaffirms the necessity to conceptualize formal care as a type of social support and to examine its moderating function.	Correlational analysis; hierarchical regression model; multiple regression; contingency table (crosstab)	✓	✓		✓	✓	

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Cho, 2006	From the Caregiver Stress and Coping Study	Not all types of social support showed mobilization in response to stressors. Suggested that some types of social support such as formal service use remained stable over time. Analysis demonstrated that mediating and moderating effects of mobilized social support differed depending on the type of social support.	hierarchical binary logistic regression analyses, hierarchical ordinary least squares regression analyses, chi-square			✓			
Chou, 2010	4 designated home care service agencies in Tainan City, a Southern city in Taiwan.	Elder's disabilities, specifically memory and behavioural symptoms, is an important factor predicting the intensity use of both types of home care services.	Descriptive statistics, confirmatory factor analysis	✓					

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Crist, Kim, Pasvogel, & Velazquez, 2009	Dyads recruited at community events in a three-county area in southern Arizona and by referrals by providers and previous participants.	Contextual, personal and attitudinal factors were significantly associated with the use of HCS, and cultural/ethnic factors were significantly associated with confidence in HCS.	multiple regression, logistic regression	✓		✓			
Edlund, 1995	Physicians, hospital and clinic nurses, social workers, clergy, relatives and friends of caregivers referred subjects to the investigator. Subjects from a five-county area participated in the study.	Burden, spousal relationship, attitude toward service use, self-efficacy and the interaction of length of time caregiving and need for information explained 41% of the variance in the use of info services. Need for daily services, self-efficacy and the interactions of work and living arrangements and work and need for care explained 42% of the variance in the use of daily care services.	multiple regression, correlation	✓					

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Gaugler et al., 2009	MADDE: large multiregional sample of persons with dementia	Caregivers reported significant and considerable decreases in burden in the 6- and 12-month postplacement panels.	Multivariate regression model	✓	✓		✓	✓	
Gaugler, Zarit, Townsend, Stephens, & Greene, 2003	45 adult day programs in New Jersey	Daily costs to reduce caregivers' role overload and depression decreased with adult day service utilization over 1-year period.	Logistic regressions, one-way ANOVA and chi-square statistics		✓			✓	
Hawranik, 1998	Registrants with Manitoba Health, which administers a provincial health-insurance program for all permanent residents of the province.	A weak association between cognitive status and use of inhome services.	Logistic regression analysis	✓	✓	✓			

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Herrera, Lee, Palos, & Torres, 2008	Convenience sample from the South Bay region of San Diego, California, a county area with high concentration of Latinos.	Caregivers with greater long-term care use displayed lower level of familism, were knowledgeable about services, had a care recipient with health insurance, shared caregiving responsibilities and were less acculturated.	Spearman correlations, regression model, descriptive statistics	✓			✓		
Hong & Casado, 2015	2004 National Long-Term Care Survey	The cross-level interaction between service utilization and state expenditure on HCBS was significant.	Chi-square, multilevel modelling	✓					
Hong, 2009	2004 National Long-term Care Survey and Informal Caregiver data	Caregivers' network compositions signified heterogeneity in service use patterns. Care recipient- and caregiver-related needs contributed to distinguishing service use patterns.	Multinomial logistic regression and robust variance estimator	✓		✓			

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Huang, Shyu, Chang, Weng, & Lee, 2009	Convenience sample from one independent home care agency and three hospital-based home care agencies in North Taipei.	Willingness to use respite care was higher when the respite care services matched the needs of the caregivers as well as the caregivers perceived higher caregiver burden.	Chi-square tests, t-tests, Mann-Whitney tests, multiple logistic regression			✓			✓
Kim & Yeom, 2016	Convenience sample from 5 home care service agencies in South Korea	No sig influence of home care service use on reducing caregiver burden or on increasing caregivers' satisfaction. Although several factors were associated with caregiver burden and satisfaction, family functioning was the most unique factor to significantly affect both caregiving burden and satisfaction.	Hierarchical multiple regression analyses	✓					

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Kosloski & Montgomery, 1994	Collected as part of a larger study on family caregiving conducted in King County, Washington.	For the 4 discretionary services, neither the predisposing variables nor the enabling variable had a sig effect on service use. The need variables contributed sig only to the model explaining doctor visits.	Logistic regression analysis			✓			
Kumamoto, Arai, Zarit, 2006	Drawn from a list of 143 community-dwelling registered disabled elderly from Matsuyama Town in northern Japan	Home care services effectively reduce feelings of burden among family caregivers.	Structural equation modelling used to test the model, chi-square	✓					

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Kuzuya, Izawa, Enoki, & Hasegawa, 2012	Nagoya Longitudinal Study for Frail Elderly	Day-care service use was significantly associated with an elevated risk for long-term care placement within the 36-month follow-up period. Participants using a day-care service two or more times/week had significantly higher relative hazard ratios than participants not using such a service.	Multivariate Cox Regression	✓			✓		
Lai, 2008	Local telephone directory	Filial obligation is most likely manifested through facilitating the care receivers to make use of the services needed, particularly for caregivers who reported a high level of caregiving burden.	Logistic regression analysis	✓					
LeBlanc, Mullan, Wardlaw, Harrington, & Chang, 1998	Community-based AIDS organizations	Caregivers report that PWAs make substantial use of community-based support.	Logistic regression analysis		✓	✓			

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
McCann et al., 2005	16 adult day care service sites in metropolitan Chicago and from a federally funded Alzheimer's Disease Center.	Risk of nursing home placement increased significantly with the number of days of adult day care attendance.	descriptive statistics (main), Kaplan-Meier survival curves, sensitivity analysis, Cox regression	✓	✓	✓	✓	✓	✓
Mensie & Steffen, 2011	All participants resided in the Midwest and received in-home respite services managed by an Area Agency on Aging and funded through the National Family Caregiver Support Program.	The primary significant predictor of 3-month in-home respite utilization was the caregiving dyad's past in-home respite usage. Demographic predisposing variables and objective need variables were not associated with hours of respite use over 3-months, nor was level of caregiver depressive symptoms.	hierarchical regression, correlation		✓			✓	

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Moriwaki, Kanda, Kakamu, Kobayashi-Miura, & Inoue, 2017	2 home-visit nursing station in A city, Shimane Prefecture, a rural area of Japan.	Short stay users were positively associated with the personal strain, role strain and total scores of the J-ZBI and were negatively associated with age.	Logistic regression analysis, descriptive statistics	✓			✓		
Nakagawa, Yamada, & Nasu, 2014	Internet research company, Cross Marketing Inc.	Among the 5 burden components, none of them had a significant negative association with the amount of paid care services received. Low independent living skills and frequent abnormal behaviours related to dementia are positively associated with 4 of the 5 burden components. Male care-givers are negatively associated with emotional burden. Higher income was negatively associated with the time-dependent and developmental burden components.	correlation, multivariate logistic regressions treated as 5 univariate logistic regressions	✓					

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Noimuenwai, 2012	2 ADC sites - Somdet Chaophaya Institute of Psychiatry and Chiangmai Neurological Hospital	ADC improved caregiver-reported health after using ADC.	Repeated-measures analysis	✓	✓	✓	✓	✓	✓
Oyama et al., 2013	4 towns in the former Kimotsuki County, Kagoshima Prefecture. Current users of LTCI home-care services during the period between November 2001 and October 2003.	Low scores on the J-ZBI were related to outcome in both care-needs subgroups. The use of home-visit nursing service was related to staying at home continuously in the high care needs group.	X2-test, Fisher's exact test, Wilcoxon rank sum test, multiple logistic regression analyses	✓			✓		

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Pedlar, 1997	3 sources including a veteran population, a community-based memory clinic and a caregiver support group.	Results support the utility of taking caregiver attitudes into account in attempts to understand why families with a dementing disease exhibit low levels of community service use	Logistic and linear regression	✓		✓			
Phillipson, Magee, & Jones, 2013	Carers who contacted the 2 Commonwealth funded respite assessment and approval services in the Illawarra region between Nov 2008 and Nov 2009; local community and health services and the Alzheimer's NSW Telephone Helpline	Beliefs that service use would result in negative outcomes for the care recipient were strongly associated with non-use of both day care and residential respite care and were strongly associated with service non-use than other predisposing, impeding and need variables.	contingency tables, binary logistic regression	✓	✓		✓	✓	

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Savard, Leduc, Lebel, Béland, & Bergman, 2009	Data collected as part of a larger study SIPA, a demonstration project undertaken to evaluate a model of integrated services for frail seniors.	More regular attendance was associated with previous profession of ADC participant or spouse in a sector other than health care, receiving formal help for activities of daily living on days of expected ADC participation, participating for the whole day rather than half a day, lower participation in prevention and health-promotion activities, and lower caregiver burden among persons with cognitive impairment and higher caregiver burden among person without cognitive impairments.	Bivariate analysis; multiple regression analyses (main)	✓					

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Spijker et al., 2011	Seven community mental health services	No main intervention effect on institutionalization was found. The caregiver's sense of competence and depressive symptoms and the patients' behavioural problems and severity of dementia were the strongest predictors of institutionalization.	Chi-square tests and t-tests, multilevel logistic regression analysis, Kaplan-Meier survival analysis		✓				
Sugiura, Ito, Kutsumi, & Mikami, 2009	Data collected through anonymous, mailed self-report questionnaires administered from Aug 2002 to Sep 2002.	The effects of depression differed related to the caregiver's gender: Husbands relied more on family or home-care services when caring for their wives, whereas wives provided higher levels of care, positively accepted their role and did not seek to share caregiving but sought emotional support.	t-test; chi-square tests; multiple linear regressions (main)		✓				

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Tanji et al., 2005	Outpatient clinic for dementia, Department of Geriatric and Complementary Medicine, Tohoku University Hospital. Japan	Behavioural and psychological symptoms of dementia were significantly associated with heavy caregiver's burden which led to depressive symptoms, especially in spouse caregivers.	Pearson's simple correlation, one-way analysis of variance and Student's t-test	✓			✓		
White-Means, 1997	1989 National Long Term Health Care Survey collected by U.S Department of Health and Human Services Agency for Health Care Policy and Research	Use of formal in-home care decreases the expense of human-capital resources (health) of caregivers. Income status of 150 - 250% of poverty, residence in the South and large family networks decrease the likelihood of home health services use.	bivariate probit			✓			

Author, publication year	Data source (Reproduced from individual study)	Main study results (Reproduced from individual study)	Statistical analyses	Qualitative Synthesis			Meta-analysis		
				CB	CD	CHS	CB	CD	CHS
Whitlatch et al., 1997	One of California's Caregiver Resource Centers	The strongest predictors of caregiver depression were initial levels of depression, worsening of caregiver subjective physical health status and burden, and short-term use of in-home respite assistance	contingency table		✓			✓	

Note. CB: Caregiver burden; CD: Caregiver depression; CHS: Caregiver health status.

Table 2.2

Quantitative (Categorical) Characteristics of Included Studies Investigating LTCS Use-Caregiver Burden Relation (*k* = 24)

Characteristic	Number of studies
Study characteristics	
Type of publication	
Journal article	20
Dissertation/Thesis	4
Country	
Australia	1
Canada	4
Japan	6
South Korea	1
Taiwan	2
Thailand	1
USA	9
Aim of study	
Patients factors for LTCS use	2
Caregiver factors for LTCS use	12
Both	6
Others	4
Study design	
Longitudinal study	7
Cross-sectional study	14
Cohort study	1
Correlational	2
LTCS type	
Community-based care	7
Home care services	10
Institutional services	1
Respite	1
Multiple services	4
Information services	1
Caregiver burden measure	
Zarit Burden Interview (ZBI)	16
Caregiver Burden Inventory (CBI)	2
Taiwanese Caregiver Burden Scale	1
3-item burden measure	1
Single item measure	1
Author-developed measure	1
Caregiver Burden Scale	2
Grouping / measurement of LTCS use	
Use vs non-use	9
Amount of use	8

Both	6
Others	1
Theoretical model	
Andersen-Newman Healthcare Utilization Model	12
Stress and Coping Theory	1
Ecological perspective	1
Growth Curve Model	1
Smith's Model of Caregiving Effectiveness	1
Not reported	8
Analytic role of caregiver burden	
Covariates	3
Dependent variable	10
Independent variable	11
Analytic role of LTCS use	
Covariates	4
Dependent variable	11
Independent variable	9
Participants characteristic	
≥ 70% female caregivers	
Yes	13
No	7
Not reported	4
Caregivers remunerated	
No	24
1st-time caregivers	
No	24
Caregiver-patient relationship	
Family	11
Mixed	11
Not reported	2
Caregiver stays with patient	
No	1
Yes	2
Mixed	14
Not reported	7
Main illness of patients	
Cancer	1
Dementia	8
Functional impairments	6
Disability	3
Chronic diseases	1
Frail	3
Not reported	2

Table 2.3

Quantitative (Continuous) Characteristics of Included Studies Investigating LTCS Use-Caregiver Burden Relation (*k* = 24)

Characteristics	Number of studies	Total/Grand mean/%
Total number of caregivers	24	12,530
Mean caregiver’s age	22	58.71
Mean patient’s age	19	76.48
Percentage of female caregivers	20	75.00%
Percentage of female patients	17	66.00%

Table 2.4

Quantitative (Categorical) Characteristics of Included Studies Investigating LTCS Use-Caregiver Depression Relation (*k* = 14)

Characteristics	Number of studies
Study characteristics	
Type of publication	
Journal article	13
Dissertation/Thesis	1
Country	
Australia	1
Canada	1
Japan	1
Netherlands	1
Taiwan	1
Thailand	1
USA	8
Aim of study	
Caregiver factors for LTCS use	7
Both	2
Others	5
Study design	
Longitudinal study	6
Cross-sectional study	5
Randomized controlled trial	2
Cohort study	1
LTCS type	
Community-based care	4
Home care services	4
Institutional services	2
Respite	2
Multiple services	2
Caregiver depression measure	
Hopkins Symptoms Checklist	1
Center for Epidemiological Studies–Depression Scale (CES-D)	10
Geriatric Depression Scale (GDS)	2
Single item measure	1
Grouping / measurement of LTCS use	
Use vs non-use	10
Amount of use	2
Both	2

Theoretical model	
Andersen-Newman Healthcare Utilization Model	6
Stress and Coping Theory	1
Growth Curve Model	1
Smith's Model of Caregiving Effectiveness	1
Social Support Conceptual Framework	1
Not reported	4
Analytic role of caregiver depression	
Covariates	1
Dependent variable	9
Independent variable	4
Analytic role of LTCS use	
Dependent variable	6
Independent variable	8
Participants characteristics	
≥ 70% female caregivers	
Yes	6
No	6
Not reported	2
Caregivers remunerated	
No	13
Yes	1
1st-time caregivers	
No	14
Caregiver stays with patient	
No	1
Mixed	8
Not reported	5
Caregiver-patient relationship	
Family	8
Mixed	5
Not reported	1
Main illness of patients	
AIDS	1
Dementia	7
Cognitive impairments	1
Functional impairments	2
Disability	1
Multiple	1
Not reported	1

Table 2.5

Quantitative (Continuous) Characteristics of Included Studies Investigating LTCS Use-Caregiver Depression Relation (*k* = 14)

Characteristics	Number of studies	Total/Grand mean/%
Total number of caregivers	14	6,687
Mean caregiver’s age	14	59.51
Mean patient’s age	11	72.93
Percentage of female caregivers	12	65.50%
Percentage of female patients	10	54.47%

Table 2.6

Quantitative (Categorical) Characteristics of Included Studies Investigating LTCS Use-Caregiver Health Status Relation (*k* = 15)

Characteristics	Number of studies
Study characteristics	
Publication type	
Journal article	11
Dissertation/Thesis	4
Country	
Canada	2
Taiwan	1
Thailand	1
USA	11
Aim of study	
Patients factors for LTCS use	1
Caregiver factors for LTCS use	9
Both	4
Others	1
Study design	
Longitudinal study	3
Cross-sectional study	9
Randomized controlled trial	1
Cohort study	2
LTCS type	
Community-based care	6
Home care services	6
Respite	1
Multiple services	2
Caregiver health status measure	
Global health rating	1
Short Form Health Survey	1
General PWA health status	1
Health-related QoL	1
OARS-Multidimensional Functional Assessment Questionnaire	1
Author-developed measures	3
Single item measure	6
Multiple	1
Grouping / measurement of LTCS use	
Use vs non-use	10
Amount of use	3
Both	2

Theoretical model	
Andersen-Newman Healthcare Utilization Model	12
Smith's Model of Caregiving Effectiveness	1
Social Support Conceptual Framework	1
Not reported	1
Analytic role of caregiver health status	
Dependent variable	5
Independent variable	8
Not reported	2
Analytic role of LTCS use	
Covariates	1
Dependent variable	9
Independent variable	4
Mix	1
Participant characteristics	
≥ 70% female caregivers	
Yes	7
No	5
Not reported	3
Caregivers remunerated	
No	15
1st-time caregivers	
No	14
Not reported	1
Caregiver stays with patient	
No	1
Yes	5
Mixed	3
Not reported	6
Caregiver-patient relationship	
Family	8
Mixed	6
Not reported	1
Main illness of patients	
AIDS	1
Dementia	6
Functional impairments	3
Disability	2
Frail	1
Multiple	1
Not reported	1

Table 2.7

Quantitative (Continuous) Characteristics of Included Studies Investigating LTCS Use-Caregiver Health Status Relation (*k* = 15)

Characteristics	Number of studies	Total/Grand mean/%
Total number of caregivers	15	7,331
Mean caregiver’s age	13	58.52
Mean patient’s age	10	73.41
Percentage of female caregivers	12	70.00%
Percentage of female patients	7	59.72%

Table 2.8

Omnibus Tests: Log Odds Ratios of LTCS Use and Caregiver Needs

	Caregiver burden	*Caregiver depression*	*Caregiver health status*
lnOR	0.03	0.02	-0.01
95% CI	[-0.48, 0.54]	[-0.30, 0.61]	[-0.56, 0.54]
k	12	8	5
Q	312.48***	36.03***	10.70*
I^2	0.96	0.81	0.63

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 2.9

Categorical Moderation Analyses for Study and Participant Characteristics

Characteristics	Caregiver burden				Caregiver depression				Caregiver health status			
	k	*Q*	*lnOR*	95% CI	*k*	*Q*	*lnOR*	95% CI	*k*	*Q*	*lnOR*	95% CI
Study characteristics												
Country			0.04	[-0.80, 0.88]			0.13	[-0.63, 0.89]			-0.24	[-1.52, 1.04]
Non-USA	7	9.72	0.34*	[0.05, 0.62]	3	6.78*	0.55	[-0.20, 1.30]	2	0.01	-0.70***	[-0.76, 0.63]
USA	5	128.10***	-0.45	[-1.26, 0.36]	5	9.24	-0.10	[-0.39, 0.20]	3	1.32	0.22**	[0.07, 0.38]
Aim of study			0.18	[-0.24, 0.59]			0.10	[-0.26, 0.47]				
Caregiver and patient factors	3	6.73*	0.42	[-0.23, 1.06]								
Caregiver factors	7	114.75***	-0.22	[-0.89, 0.45]	4	27.77***	0.31	[-0.34, 0.96]				
Others	2	1.96	0.29	[-0.32, 0.90]	4	8.19*	0.01	[-0.44, 0.45]				
Study design			0.07	[-0.73, 0.87]			0.27	[0.82, 1.35]			0.00	[-0.15, 0.15]
Cross-sectional	6	7.94	0.37*	[0.03, 0.72]	2	4.11*	0.78*	[0.05, 1.52]	2	7.00**	-0.14	[-1.17, 0.88]
Longitudinal	6	248.11***	-0.37	[-1.06, 0.33]	6	9.25	-0.11	[-0.36, 0.14]	3	3.43	0.02	[-0.38, 0.42]
LTCS type			-0.44	[-2.12, 1.24]			0.07	[-0.62, 0.76]			-0.06	[-0.18, 0.06]
Day care					3	2.30	-0.17	[-0.42, 0.07]	2	3.33	-0.12	[-0.96, 0.71]
Others					5	33.37***	0.40	[-0.12, 0.92]	3	7.35*	-0.03	[-0.60, 0.54]
Nursing home involved	2	0.95	-1.20***	[-1.32, -1.09]								
Non-Nursing home	10	12.50	0.33**	[0.13, 0.52]								
Caregiver need measure			0.08***	[0.08, 0.09]								
Others	5	16.89**	0.09	[-0.55, 0.73]								
Zarit Burden Interview (ZBI)	7	225.03***	0.08	[-0.53, 0.69]								
Theoretical model			0.10	[-0.71, 0.91]			0.11	[-0.25, 0.47]				
Andersen	4	2.99	0.32**	[0.09, 0.54]	3	12.28**	0.37	[-0.45, 1.18]				
Others	3	53.80***	-0.40	[-1.31, 0.51]	3	9.51**	0.03	[-0.41, 0.47]				
Analytical role of caregiver need			0.05	[-0.11, 0.20]			0.05	[-0.27, 0.37]			0.00	[-0.15, 0.15]
Dependent variable	7	280.54***	0.10	[-0.47, 0.67]	6	18.09**	0.02	[-0.30, 0.34]	3	3.43	0.02	[-0.38, 0.42]
Independent variable	5	14.99**	-0.04	[-0.79, 0.70]	2	6.03*	0.58	[-0.71, 1.86]	2	7.00**	-0.14	[-1.17, 0.88]
Analytic role of LTCS use			0.13	[-0.08, 0.34]			0.05	[-0.27, 0.37]			0.07	[-0.39, 0.52]
Dependent variable	4	2.73	0.17	[-0.09, 0.44]	2	6.03*	0.58	[-0.71, 1.86]	3	10.70**	-0.28	[-0.98, 0.41]
Independent variable	8	285.48***	-0.10	[-0.75, 0.55]	8	18.09**	0.02	[-0.30, 0.34]	2	0.43	0.14	[-0.03, 0.32]
Original ES indicator			0.12	[-0.11, 0.35]							0.03	[-0.63, 0.73]
Cohen’s *d*	7	259.62***	-.17	[-0.86, 0.53]					3	7.67*	-0.31	[-0.93, 0.31]
Pearson’s *r*	3	0.53	0.12	[-0.16, 0.39]					2	1.31	0.22	[-0.07, 0.50]
Odds ratio	2	6.73*	0.43	[-0.25, 1.12]								

Characteristics	Caregiver burden				Caregiver depression				Caregiver health status			
	k	*Q*	*lnOR*	95% CI	*k*	*Q*	*lnOR*	95% CI	*k*	*Q*	*lnOR*	95% CI
Participant characteristics												
>= 70% female caregivers			0.09	[-0.06, 0.24]			0.17	[-0.82, 1.16]			-0.06	[-0.43, 0.31]
Yes	4	3.25	0.13	[-0.19, 0.45]	4	2.43	-0.20***	[-0.29, -0.10]	3	7.03*	0.06	[-0.50, 0.63]
No	6	267.32***	-0.01	[-0.54, 0.51]	4	7.01	0.62*	[0.09, 1.15]	2	1.88	-0.21	[-0.84, 0.43]
Caregiver-patient relationship			0.32*	[0.02, 0.61]			0.06	[-0.29, 0.42]				
Family	7	128.31***	-0.08	[-0.86, 0.70]	6	17.27**	0.02	[-0.33, 0.37]				
Mixed	4	2.42	0.36***	[0.22, 0.50]	2	11.64**	0.57	[-0.61, 1.74]				
Main illness of patients			0.27*	[-0.02, 0.56]							-0.13***	[-0.16, -0.10]
Dementia	5	123.61***	0.00	[-0.73, 0.72]					2	3.33	-0.12	[-0.96, 0.71]
Disability	3	6.73*	0.43	[-0.25, 1.12]								
Functional impairments	2	0.55	0.32***	[0.20, 0.45]					2	7.00**	-0.14	[-1.17, 0.88]
None	2	4.83*	-0.93	[-2.43, 0.58]								

* *p* < .05. ** *p* < .01. *** *p* < .001.

Table 2.10

Moderation Analyses: Meta-Regression Models Investigating Continuous Characteristics Associated with Effect Sizes

Characteristics	Caregiver burden			Caregiver depression			Caregiver health status		
	k	*β*	*B* (*SE*)	*k*	*β*	*B* (*SE*)	*k*	*β*	*B* (*SE*)
Study characteristic									
Publication year	12	.37	.03 (.03)	8	.29	.03 (.03)	5	-.69	-.03 (.02)
Participant characteristics									
Caregiver age	10	.10	.01 (.06)	8	-.25	-.02 (.02)	5	.50	.02 (.02)
Patient age	10	-.32	-.06 (.07)	7	-.24	-.04 (.06)	2	-.00	-.06 (.11)
% female caregiver	10	.19	.01 (.03)	8	-.51	-.04 (.02)	5	.27	.01 (.02)
% female patients	9	-.02	.00 (.06)	7	-.24	-.01 (.02)			

Note. None of the continuous variables were significantly related to the effect sizes of each relation.

Table 3.1

Descriptive Statistics of Stroke Rehabilitation Use and Caregiver Well-being Attributes at Each Time Point

Variables	*Mean*	*SD*	Sample size
Rehabilitation use			
(T1): *n* (%)	154 (48.00%)	-	321
(T2): *n* (%)	37 (13.30%)	-	278
Caregiver well-being			
Health status			
(T0)	77.60	14.25	372
(T1)	77.76	14.74	329
(T2)	79.92	12.38	276
Depression			
(T0)	15.86	4.01	354
(T1)	13.98	3.46	325
(T2)	13.56	3.08	275
Burden			
(T0)	25.13	8.57	351
(T1)	20.40	7.63	328
(T2)	18.35	7.11	272
Social support			
(T0)	26.48	4.37	369
(T1)	26.06	4.78	326
(T2)	25.19	3.86	275
Quality of care relationship			
(T0)	11.09	1.55	376
(T1)	10.86	1.62	329
(T2)	10.35	1.78	272
Caregiving burden (time and difficulty)			
(T1)	32.38	13.27	318
(T2)	31.90	16.24	278

Note. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.

Table 3.2

Point-biserial Correlations of Rehabilitation Use and Caregiver Well-being Attributes at Each Time Point

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1. Rehabilitation use (T1)	-																		
2. Rehabilitation use (T2)	.235**	-																	
3. Caregiver health status (T0)	.128*	.038	-																
4. Caregiver health status (T1)	.108	.071	.385**	-															
5. Caregiver health status (T2)	.005	-.045	.400**	.378**	-														
6. Caregiver burden (T0)	-.090	.034	-.345**	-.172**	-.099	-													
7. Caregiver burden (T1)	-.069	.020	-.161*	-.242**	-.126	.284**	-												
8. Caregiver burden (T2)	.007	.104	-.080	-.047	-.120*	.174*	.270**	-											
9. Caregiver depression (T0)	.027	-.025	-.299**	-.135*	-.083	.441**	.187**	.212**	-										
10. Caregiver depression (T1)	-.110	-.059	-.180**	-.365**	-.235**	.268**	.549**	.203**	.358**	-									
11. Caregiver depression (T2)	-.058	.130*	-.159*	-.284**	-.436**	.257**	.244**	.365**	.158*	.389**	-								
12. Caregiver relationship (T0)	.111	-.014	.131*	.109	.143*	-.182**	-.023	-.047	-.096	-.093	-.188**	-							
13. Caregiver relationship (T1)	.131*	.047	.129*	.176**	.034	-.226**	-.177**	-.053	-.168**	-.252**	-.097	.389**	-						
14. Caregiver relationship (T2)	.095	.051	.186**	.102	.159**	-.174*	-.152*	-.049	-.041	-.107	-.165**	.406**	.279**	-					
15. Caregiver social support (T0)	.123	-.039	.188**	.099	.125	-.271**	-.130*	-.172*	-.308**	-.279**	-.228**	.120*	.111	.083	-				
16. Caregiver social support (T1)	.047	.073	.083	.280**	.174*	-.081	-.152**	-.091	-.192**	-.369**	-.123	.032	.196**	.025	.201**	-			
17. Caregiver social support (T2)	.164*	.004	.064	.146*	.289**	-.002	-.036	.038	.024	-.150*	-.330**	.164*	.030	.254**	.106	.184**	-		
18. Caregiving burden (T1)	.045	.199**	-.117	-.175**	-.118	.173**	.499**	.285**	.081	.271**	.403**	.121	-.007	-.048	-.120	-.106	-.099	-	
19. Caregiving burden (T2)	.030	.095	.070	.019	-.010	.056	.027	.325**	.012	.090	.177**	.096	.041	.108	.026	-.076	-.078	.235**	-

Note. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.
* $p < .05$. ** $p < .01$.

Table 3.3

Non-lagged Stepwise Binomial Logistic Regression Results

	Predisposing factors		Enabling factors		Patient needs		Caregiver well-being	
Variables included	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]
Model 1								
Caregiver depression (T2)							0.10* (0.05)	1.11 [1.01, 1.22]
Model 2								
Patient stroke type (ischemia)	-0.95* (0.46)	0.39 [0.16, 0.94]					-0.98* (0.46)	0.38 [0.15, 0.93]
Caregiver depression (T2)							0.11* (0.05)	1.11 [1.01, 1.22]
Model 3								
Patient stroke type (ischemia)	-0.93* (0.46)	0.39 [0.16, 0.97]	-1.06* (.51)	0.35 [0.13, 0.93]				
Patient age	0.03 (0.02)	1.03 [1.00, 1.06]						
Caregiver full-time employment			-1.41*** (.44)	0.25 [0.10, 0.58]				
Caregiver health service doctor			0.28 (.17)	1.33 [0.96, 1.84]				
Caregiver maid at home (T2)			-.99* (.42)	0.37 [0.17, 0.84]				
Model 4								
Patient stroke type (ischemia)	-0.96* (0.46)	0.38 [0.16, 0.93]	-1.08* (.51)	0.34 [0.13, 0.92]				
Caregiver full-time employment			-1.09** (.41)	0.25 [0.10, 0.58]	-1.09* (0.43)	0.34 [0.15, 0.77]		
Caregiver health service doctor			0.28 (.17)	1.33 [0.96, 1.84]	0.29 (0.17)	1.34 [0.97, 1.86]		
Caregiver maid at home (T2)			-1.00* (.42)	0.37 [0.16, 0.83]				
Patient disability (T2)					0.46*** (0.11)	1.59 [1.38, 1.96]		

Notes. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke. Adjustments were made to the following non-lagged models: Model 2 (predisposing factors), Model 3 (predisposing and enabling factors), and Model 4 (predisposing factors, enabling factors and patient needs).

* *p* < .05. ** *p* < .01. *** *p* < .001.

Table 3.4

Lag 1 Stepwise Binomial Logistic Regression Results

	Rehabilitation use (T1)		Predisposing factors		Enabling factors		Patient needs		Caregiver well-being	
Variables included	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]
Model 1										
Caregiving burden (T1)									0.03** (0.01)	1.04 [1.01, 1.06]
Model 2										
Rehabilitation use (T1)	1.06* (0.44)	2.89 [1.20, 6.97]							1.14* (0.44)	3.12 [1.30, 7.48]
Caregiver depression (T2)									0.12* (0.05)	1.13 [1.02, 1.24]
Model 3										
Rehabilitation use (T1)	1.23 (0.59)	3.41 [0.96, 12.11]	1.25 (0.60)	3.48 [0.96, 12.57]					1.32* (0.58)	3.72 [1.09, 12.68]
Patient stroke type (ischemia)			-1.00* (0.48)	0.37 [0.15, 0.94]					-0.91 (0.49)	0.40 [0.16, 1.06]
Caregiving burden (T1)									0.04* (0.01)	1.04 [1.01, 1.07]
Model 4										
Rehabilitation use (T1)	0.93 (0.47)	2.53 [0.96, 6.67]	0.94 (0.48)	2.56 [0.95, 6.87]	1.23* (0.57)	3.41 [1.04, 11.18]			1.22* (0.55)	3.40 [1.07, 10.73]
Patient stroke type (ischemia)			0.98* (0.47)	0.38 [0.15, 0.94]	-1.32* (0.55)	0.27 [0.09, 0.79]			-1.21* (0.55)	0.30 [0.10, 0.88]
Caregiver full-time employment (T2)					-1.50** (0.50)	0.22 [0.08, 0.59]			-1.42** (0.50)	0.24 [0.09, 0.65]
Caregiver maid strokecare (T1)					1.34* (0.50)	3.79 [1.39, 10.40]			1.24* (0.55)	3.45 [1.12, 10.60]
Caregiver health service doctor (T2)					0.35* (0.17)	1.42 [1.02, 2.00]			0.33 (0.17)	1.39 [0.99, 1.95]
Caregiving burden (T1)									0.03 (0.02)	1.03 [1.00, 1.06]
Model 5										
Rehabilitation use (T1)	1.21** (0.40)	3.34 [1.53, 7.27]	1.21** (0.40)	3.34 [1.52, 7.53]	1.38** (0.43)	3.99 [1.70, 9.33]	1.51** (0.44)	4.52 [1.90, 10.72]		
Patient stroke type (ischemia)			-0.96* (0.48)	0.38 [0.15, 0.97]	-1.33* (0.55)	0.27 [0.09, 0.77]				
Caregiver full-time employment (T2)					-1.44** (0.47)	0.24 [0.09, 0.60]	-1.13* (0.45)	0.32 [0.13, 0.78]		
Caregiver maid strokecare (T1)					1.20* (0.51)	3.32 [1.19, 9.33]				
Caregiver health service doctor (T2)					0.33* (0.17)	1.41 [1.02, 1.95]	0.33 (0.18)	1.39 [0.97, 1.98]		
Patient disability (T1)							0.34 (0.19)	1.41 [0.97, 2.05]		
Patient disability (T2)							0.29 (0.17)	1.34 [0.96, 1.87]		

Notes. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke. Adjustments were made by adding covariates to the following Lag 1 models: Model 2 (rehabilitation use (T1)), Model 3 (rehabilitation use (T1) and predisposing factors), Model 4 (rehabilitation use (T1), predisposing and enabling factors), and Model 5 (rehabilitation use (T1), predisposing factors, enabling factors and patient needs). * $p < .05$. ** $p < .01$. *** $p < .001$.

Table 3.5

Lag 2 Stepwise Binomial Logistic Regression Results

	Rehabilitation use (T1)		Predisposing factors		Enabling factors		Patient needs		Caregiver well-being	
Variables included	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]	*B (SE)*	Odds Ratio [CI]
Model 1										
Caregiving burden (T1)									0.03* (0.01)	1.03 [1.00, 1.06]
Model 2										
Rehabilitation use (T1)	1.32** (0.47)	3.76 [1.47, 9.57]							1.41** (0.50)	4.11 [1.54, 10.98]
Caregiving burden (T1)									0.04** (0.01)	1.04 [1.01, 1.07]
Model 3										
Rehabilitation use (T1)	1.14* (0.45)	3.11 [1.25, 7.73]							1.20* (0.46)	3.31 [1.33, 8.26]
Caregiver depression (T2)									0.12* (0.05)	1.12 [1.02, 1.24]
Model 4										
Discharge destination (home)			-0.65 (0.37)	0.52 [0.25, 1.08]						
Caregiver full-time employment (T2)					-1.37** (0.43)	0.26 [0.11, 0.59]			-1.34** (0.43)	0.26 [0.11, 0.61]
Caregiver maid for strokecare (T1)					1.08* (0.46)	2.94 [1.18, 7.35]			0.99 (0.51)	2.69 [0.96, 7.54]
Caregiver relationship - spouse					-0.78 (0.43)	0.46 [0.20, 1.07]			-0.79 (0.44)	0.45 [0.19, 1.09]
Caregiver health service doctor (T2)					0.32 (0.17)	1.38 [1.00, 1.91]			0.32 (0.17)	1.37 [0.99, 1.91]
Caregiving burden (T1)									0.03 (0.01)	1.03 [1.00, 1.05]
Model 5										
Rehabilitation use (T1)	0.76 (0.42)	2.14 [0.91, 5.03]			0.93* (0.45)	2.53 [1.02, 6.28]	0.87 (0.48)	2.37 [0.88, 6.39]		
Caregiver full-time employment (T2)					-1.37** (0.45)	0.25 [0.11, 0.61]	-1.20** (0.44)	0.30 [0.13, 0.71]		
Caregiver relationship - spouse					-0.87* (0.42)	0.42 [0.18, 0.95]				
Caregiver health service doctor (T2)					0.33 (0.17)	1.39 [1.00, 1.93]				
Caregiver maid for strokecare (T1)					1.11* (0.43)	3.03 [1.29, 7.10]				
Patient disability (T1)							0.63** (0.18)	1.87 [1.27, 2.75]		

Notes. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke. Adjustments were made by adding covariates to the following Lag 2 models: Model 2 (rehabilitation use (T1)), Model 3 (rehabilitation use (T1) and predisposing factors), Model 4 (rehabilitation use (T1), predisposing and enabling factors), and Model 5 (rehabilitation use (T1), predisposing factors, enabling factors and patient needs).

* *p* < .05. ** *p* < .01. *** *p* < .001.

Table 4.1
Patient and Caregiver Variables

Variables	Source	Data collection time points T0	T1	T2
Caregiver psychosocial health				
Depression	CG	✓	✓	✓
Burden	CG	✓	✓	✓
Health status	CG	✓	✓	✓
Quality of relationship	CG	✓	✓	✓
Social support	CG	✓	✓	✓
Caregiver demographics				
Gender	CG	✓	✓	✓
Relationship with patient	CG	✓	✓	✓
Maritial status	CG	✓	✓	✓
Utilization of health service in past month	CG			✓
Patient rehabilitation use				
Rehabilitation use	CG		✓	✓
Patient physical and psychosocial health				
Depression	P	✓	✓	✓
Disability	P	✓	✓	✓
Activities of daily living independence	P	✓	✓	✓
Cognitive status	P	✓	✓	✓
Patient demographics and clinical parameters				
Age	P	✓		
Type of stroke	MR	✓		
Stroke severity	P	✓		
Availability of domestic maid at home	P	✓	✓	✓
Domestic maid for housework	P	✓	✓	✓
Domestic maid for strokecare	P	✓	✓	✓
Destination of discharge	MR	✓		

Notes. P: patient self-report; MR: medical records; CG: caregiver self-report. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.

Table 4.2

Model Fit Indices Derived from Latent Profile Analyses with 1 – 6 Profiles at Each Time Point

		Solutions					
	Model fit indices	1-profile	2-profile	3-profile	4-profile	5-profile	6-profile
T0							
	Log Likelihood value	-5526.41	-5422.33	-5323.67	-5247.09	-5191.94	-5142.07
	Free parameters (#)	10	16	22	28	34	40
	Entropy	NA	.809	.994	.938	-	.945
	AIC	11072.81	10876.65	10691.35	10550.17	-	10364.13
	BIC	11112.16	10939.61	10777.91	10660.35	-	10521.53
	ABIC	11080.43	10888.84	10708.11	10571.51	-	10394.62
	Solution %	100.0	100.0	12.0	100.0	4.0	14.0
	LMR	NA	202.48***	239.16	148.99***	-	172.13*
T1							
	Log Likelihood value	-4944.14	-4806.73	-4716.19	-4643.73	-4588.24	-4556.66
	Free parameters (#)	10	16	22	28	34	40
	Entropy	NA	.860	-	.948	.949	-
	AIC	9908.28	9645.46	-	9343.45	9244.48	-
	BIC	9946.30	9706.29	-	9449.91	9373.76	-
	ABIC	9914.58	9655.54	-	9361.10	9265.91	-
	Solution %	100.0	100.0	6.0	84.0	42.0	2.0
	LMR	NA	267.15**	-	224.11	107.87	-
T2							
	Log Likelihood value	-4006.95	-3902.26	-3734.73	-3689.68	-3642.61	-3611.40
	Free parameters (#)	10	16	22	28	34	40
	Entropy	NA	.946	-	.971	.961	.956
	AIC	8033.91	7836.52	-	7453.35	7353.23	7302.81
	BIC	8070.18	7894.56	-	7536.93	7476.57	7447.91
	ABIC	8038.47	7843.83	-	7448.14	7368.76	7321.08
	Solution %	100.0	100.0	2.0	16.0	16.0	10.0

Notes. AIC: Akaike's Information Criteria; BIC: Bayesian Information Criteria; ABIC: sample-size Adjusted Bayesian Information Criteria; LMR: Lo-Mendell-Rubin Adjusted Likelihood Ratio Test. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 4.3

Characteristics of Latent Profiles at Each Time Point

	Latent profiles				
Characteristics	*M*	*SE*	*M*	*SE*	*t*
T0	Non-distressed (*n* = 307)		Distressed (*n* = 71)		
Burden	22.20	0.55	36.83	1.36	-18.34***
Depression	14.69	0.23	20.16	0.74	-13.59***
Health status	80.89	0.87	65.14	2.43	9.47***
Relationship quality	11.25	0.09	10.50	0.26	2.67*
Social support	27.18	0.27	23.71	0.63	6.16***
T1	Non-distressed (*n* = 263)		Distressed (*n* = 68)		
Burden	18.06	0.43	28.88	2.00	-10.17***
Depression	12.55	0.24	19.22	0.76	-18.33***
Health status	80.44	0.98	68.08	2.58	6.35***
Relationship quality	11.06	0.11	10.13	0.29	3.89***
Social support	26.85	0.35	23.15	0.62	5.62***
T2	Non-distressed (*n* = 244)		Distressed (*n* = 34)		
Burden	17.46	0.45	24.99	1.67	-4.57***
Depression	12.63	0.12	20.15	0.74	-15.26***
Health status	81.81	0.77	66.28	2.50	7.51***
Relationship quality	10.43	0.11	9.72	0.39	2.00
Social support	25.59	0.23	22.31	0.81	4.19***

Note. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.
* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 4.4

Model Fit Indices of Model 1 to Model 4

	Model 1	Model 2	Model 3	Model 4a	Model 4b
Free parameters (#)	50	30	28	31	32
Log Likelihood value	-14110.19	-14224.62	-14224.82	-14221.17	-14220.74
H0 Scaling Correction Factor	1.40	1.50	1.54	1.47	1.47
AIC	28230.382	28509.25	28505.63	28504.34	28505.48
BIC	28529.279	28634.59	28622.62	28633.86	28639.17
ABIC	28370.584	28539.37	28533.75	28535.47	28537.61
Entropy	.731	.703	.703	.701	.673

Notes. AIC: Akaike's Information Criteria; BIC: Bayesian Information Criteria; ABIC: sample-size Adjusted Bayesian Information Criteria.

Table 4.5

Transition Probabilities of Distressed and Non-distressed Profiles

Transition Probabilities		
	T1	
T0	Non-distressed	Distressed
Non-distressed	.92	.08
Distressed	.78	.22
	T2	
T1	Non-distressed	Distressed
Non-distressed	.91	.09
Distressed	.66	.34
	T2	
T0	Non-distressed	Distressed
Non-distressed	.97	.03
Distressed	.76	.24

Notes. T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.

Table 4.6

Parameter Estimates and Odds Ratios of Latent Profile Transition Patterns Predicting Rehabilitation Use at 12-month Post-stroke (T2) with Covariates (*N* = 149)

Variables	Estimate	Odds ratio (*SE*)
ND- ND- ND & D- ND- ND[†]		
Rehabilitation use (T2)		
Rehabilitation use (T1)	2.57 **	18.63 (3.12)
Stroke type	-2.20 *	0.19 (2.11)
Rehabilitation use (T2) (thresholds)^	2.63 **	-
ND- ND- D & D- ND- D[†]		
Rehabilitation use (T2)		
Rehabilitation use (T1)	2.57 **	18.63 (3.12)
Stroke type	-2.37 *	0.02 (5.04)
Rehabilitation use (T2) (thresholds)^	-0.59	-
ND- D- ND & D- D- ND[†]		
Rehabilitation use (T2)		
Rehabilitation use (T1)	1.00	6.98 (7.00)
Stroke type	-2.20 *	0.19 (2.11)
Rehabilitation use (T2) (thresholds)^	2.63 **	-
ND- D- D & D- D- D[†]		
Rehabilitation use (T2)		
Rehabilitation use (T1)	1.00	6.89 (7.00)
Stroke type	-2.37 *	0.02 (5.04)
Rehabilitation use (T2) (thresholds)^	-0.59	-
Categorical latent variables		
Caregiver profile (T0)		
Patient depression (T0)	-2.84 **	0.04 (3.22)
Caregiver profile (T1)		
Caregiver profile (T0)	0.60	1.84 (2.76)
Patient depression (T1)	-4.41 ***	0.11 (1.66)
Caregiver profile (T2)		
Caregiver profile (T0)	2.26 *	8.00 (2.51)
Caregiver profile (T1)	1.63	3.97 (2.33)

Notes.

T0: Baseline; T1: 3-month post-stroke; T2: 12-month post-stroke.

D: Distressed profile; ND: Non-distressed profile.

[†] Latent profile transition patterns. For example, D- ND- D- denotes caregivers who transition from the Distressed profile at T0 to Non-distressed at T1, and then to Distressed at T2.

^ Profile-specific conditional mean. * $p < .05$. ** $p < .01$. *** $p < .001$.

Figures

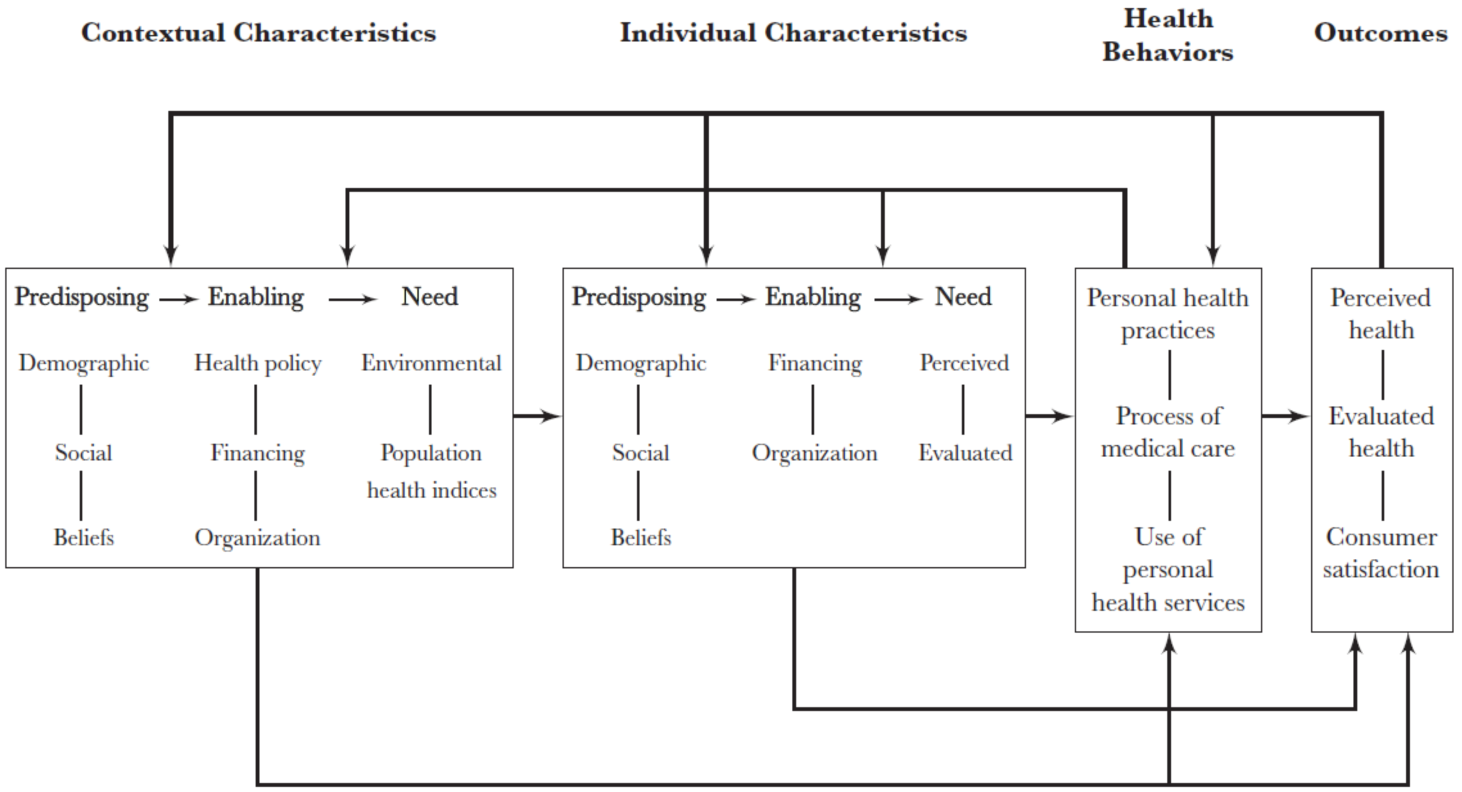
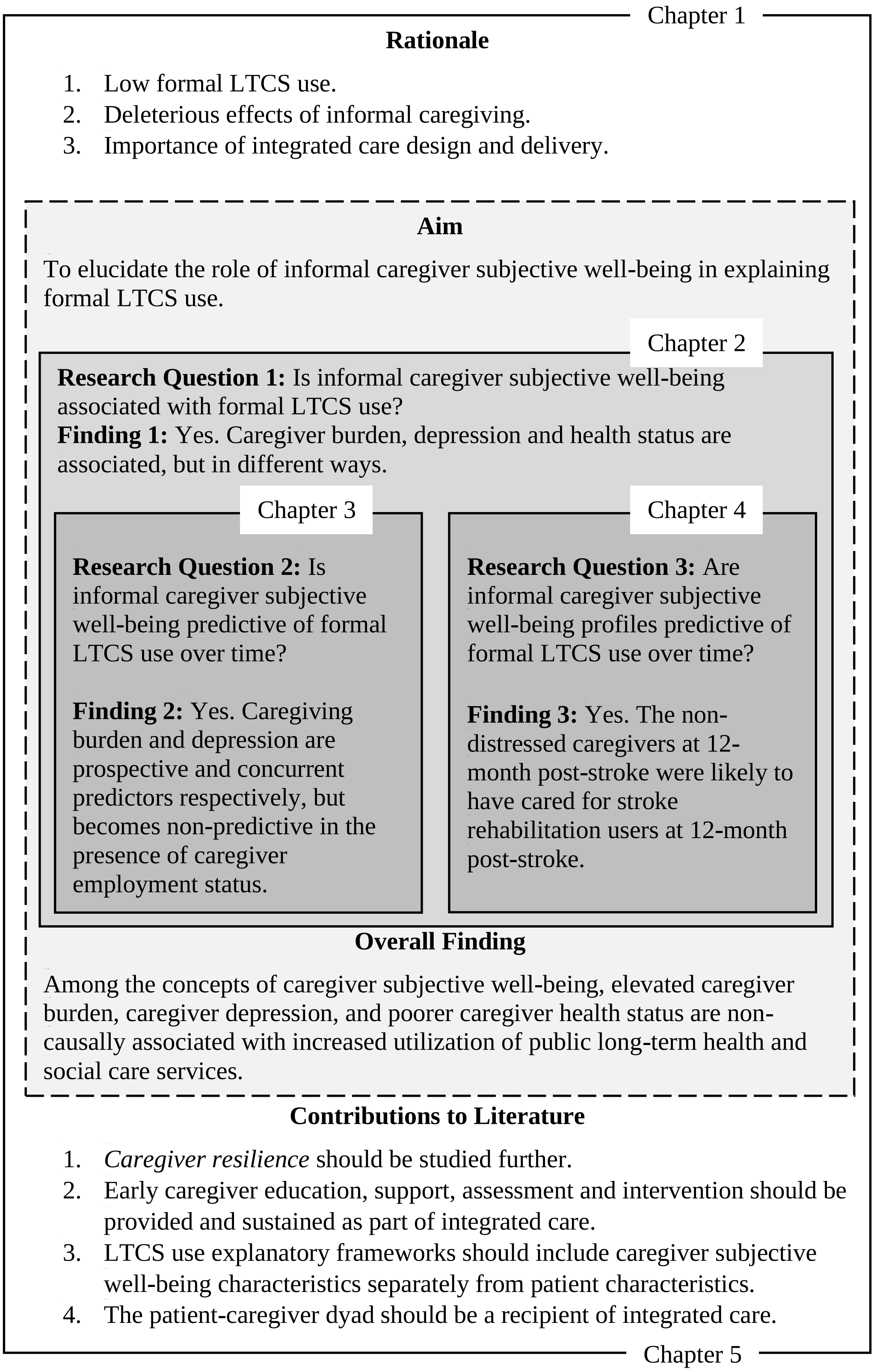


Figure 1.1. A Behavioral Model of Health Services Use (Reproduced from Andersen, & Davidson, 2007).



Chapter 1

Rationale

1. Low formal LTCS use.
2. Deleterious effects of informal caregiving.
3. Importance of integrated care design and delivery.

Aim

To elucidate the role of informal caregiver subjective well-being in explaining formal LTCS use.

Chapter 2

Research Question 1: Is informal caregiver subjective well-being associated with formal LTCS use?
Finding 1: Yes. Caregiver burden, depression and health status are associated, but in different ways.

Chapter 3

Research Question 2: Is informal caregiver subjective well-being predictive of formal LTCS use over time?

Finding 2: Yes. Caregiving burden and depression are prospective and concurrent predictors respectively, but becomes non-predictive in the presence of caregiver employment status.

Chapter 4

Research Question 3: Are informal caregiver subjective well-being profiles predictive of formal LTCS use over time?

Finding 3: Yes. The non-distressed caregivers at 12-month post-stroke were likely to have cared for stroke rehabilitation users at 12-month post-stroke.

Overall Finding

Among the concepts of caregiver subjective well-being, elevated caregiver burden, caregiver depression, and poorer caregiver health status are non-causally associated with increased utilization of public long-term health and social care services.

Contributions to Literature

1. *Caregiver resilience* should be studied further.
2. Early caregiver education, support, assessment and intervention should be provided and sustained as part of integrated care.
3. LTCS use explanatory frameworks should include caregiver subjective well-being characteristics separately from patient characteristics.
4. The patient-caregiver dyad should be a recipient of integrated care.

Chapter 5

Figure 1.2. Research Block Diagram.

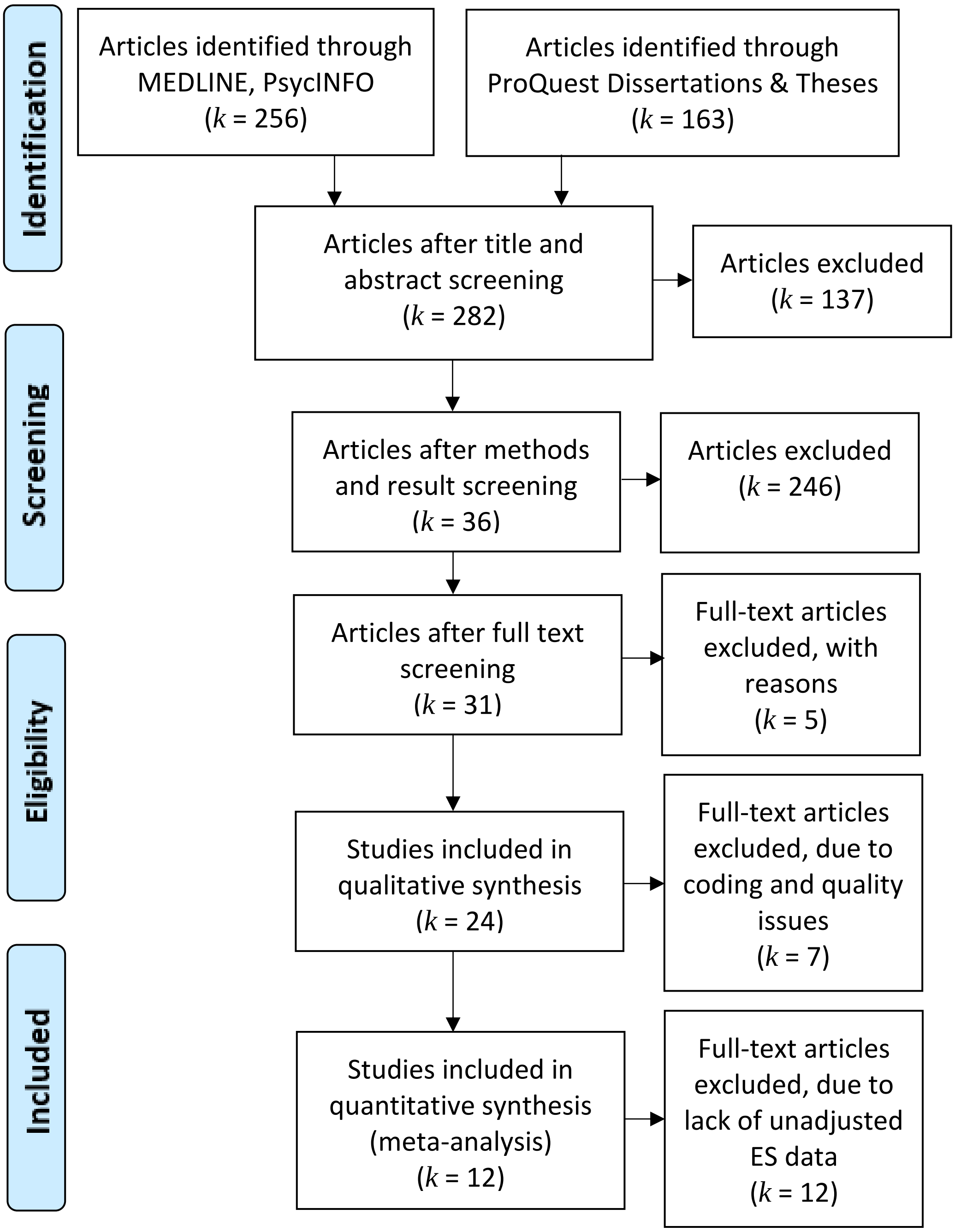


Figure 2.1. Study Selection: Caregiver Burden and LTCS Use.

(Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG, and PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, *6*(7), e1000097. doi:10.1371/journal.pmed1000097)

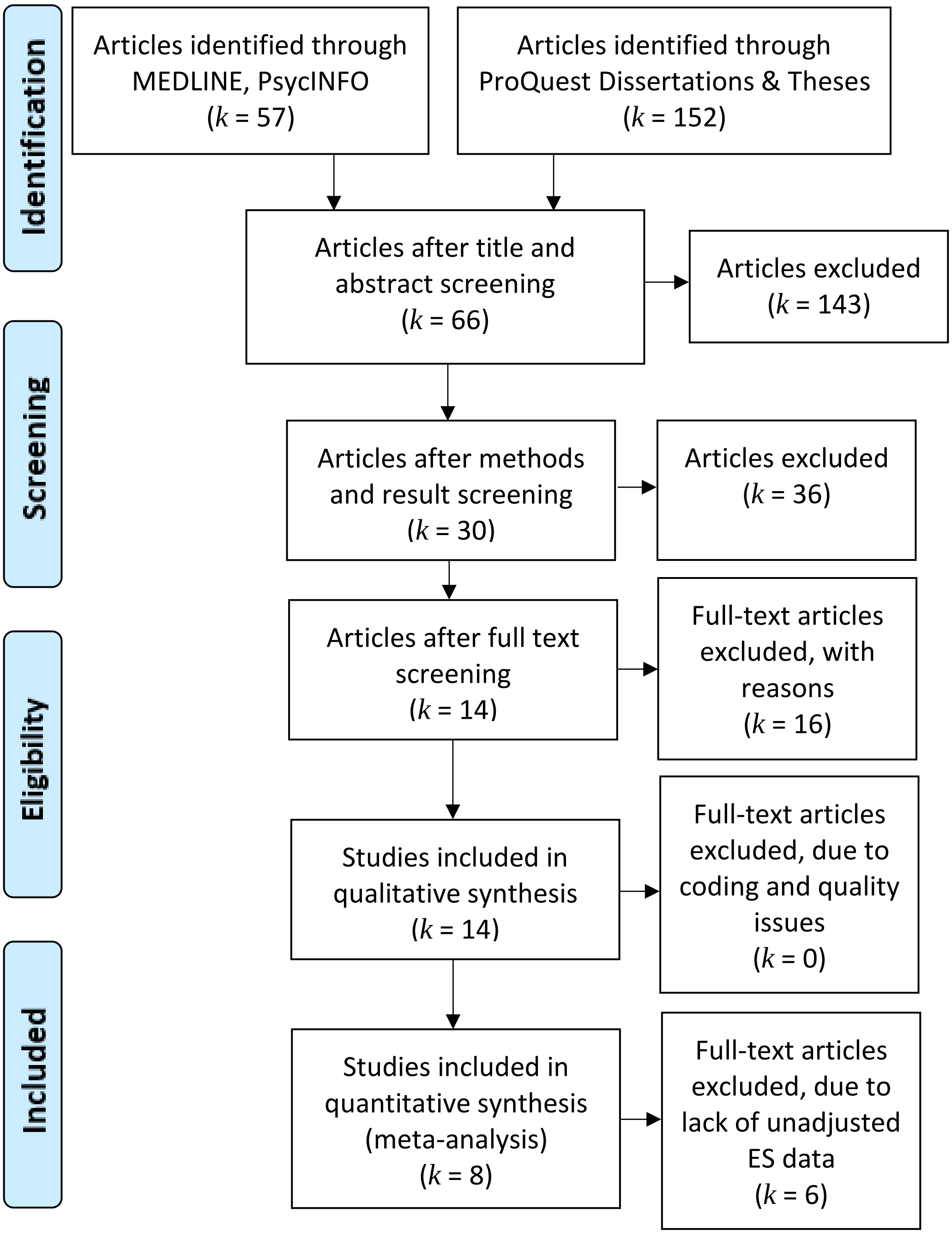


Figure 2.2. Study Selection: Caregiver Depression and LTCS Use.

(Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG, and PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, *6*(7), e1000097. doi:10.1371/journal.pmed1000097)

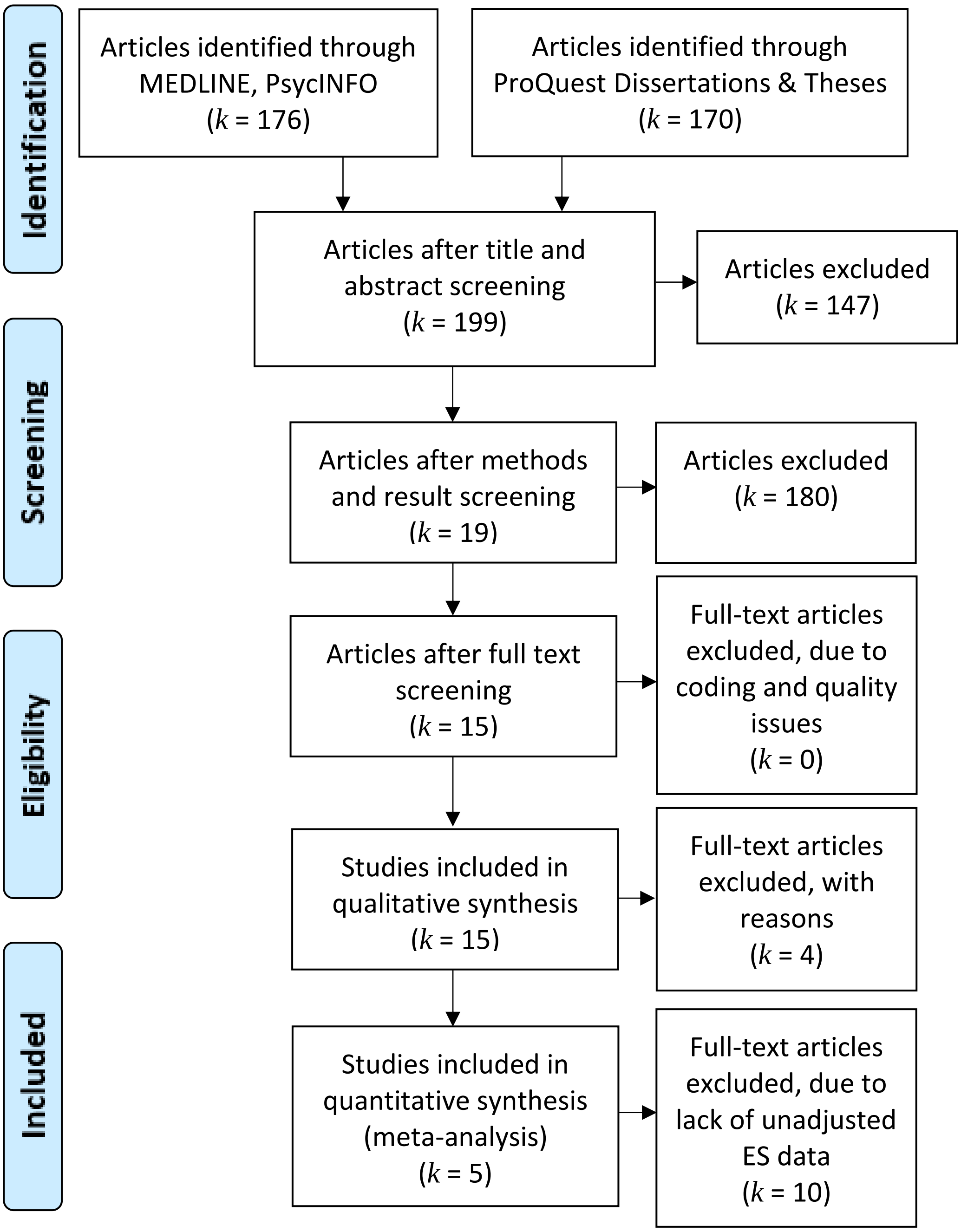
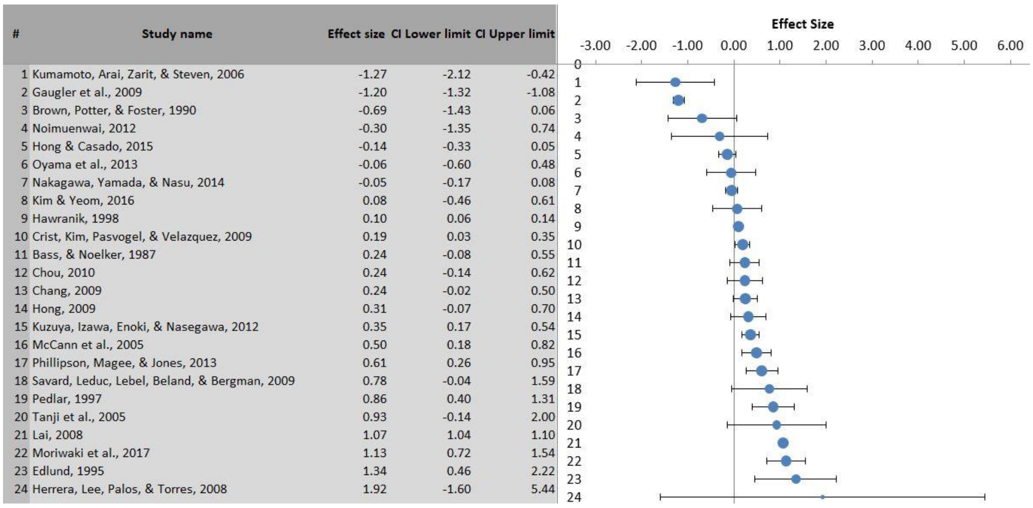


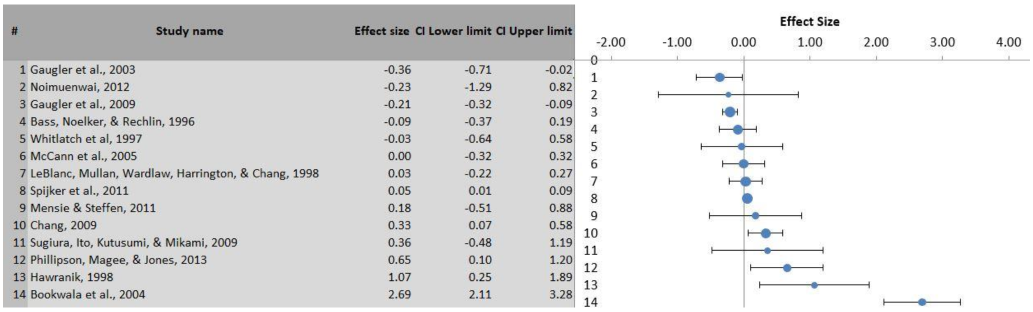
Figure 2.3. Study Selection: Caregiver Health Status and LTCS Use.

(Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG, and PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, *6*(7), e1000097. doi:10.1371/journal.pmed1000097)



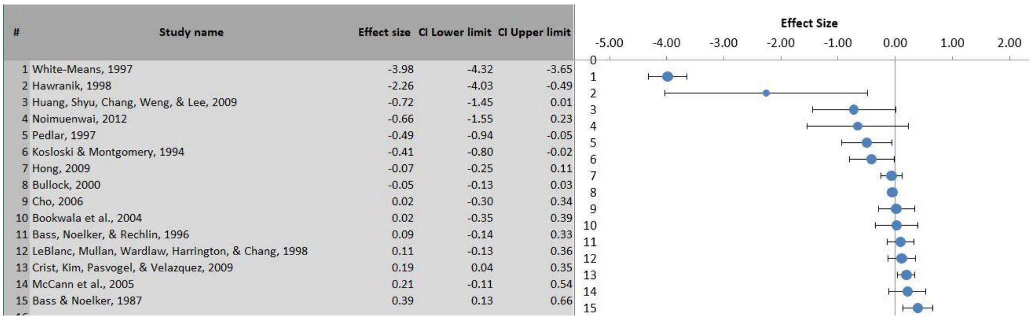
#	Study name	Effect size	CI Lower limit	CI Upper limit
1	Kumamoto, Arai, Zarit, & Steven, 2006	-1.27	-2.12	-0.42
2	Gaugler et al., 2009	-1.20	-1.32	-1.08
3	Brown, Potter, & Foster, 1990	-0.69	-1.43	0.06
4	Noimuenwai, 2012	-0.30	-1.35	0.74
5	Hong & Casado, 2015	-0.14	-0.33	0.05
6	Oyama et al., 2013	-0.06	-0.60	0.48
7	Nakagawa, Yamada, & Nasu, 2014	-0.05	-0.17	0.08
8	Kim & Yeom, 2016	0.08	-0.46	0.61
9	Hawranik, 1998	0.10	0.06	0.14
10	Crist, Kim, Pasvogel, & Velazquez, 2009	0.19	0.03	0.35
11	Bass, & Noelker, 1987	0.24	-0.08	0.55
12	Chou, 2010	0.24	-0.14	0.62
13	Chang, 2009	0.24	-0.02	0.50
14	Hong, 2009	0.31	-0.07	0.70
15	Kuzuya, Izawa, Enoki, & Nasegawa, 2012	0.35	0.17	0.54
16	McCann et al., 2005	0.50	0.18	0.82
17	Phillipson, Magee, & Jones, 2013	0.61	0.26	0.95
18	Savard, Leduc, Lebel, Beland, & Bergman, 2009	0.78	-0.04	1.59
19	Pedlar, 1997	0.86	0.40	1.31
20	Tanji et al., 2005	0.93	-0.14	2.00
21	Lai, 2008	1.07	1.04	1.10
22	Moriwaki et al., 2017	1.13	0.72	1.54
23	Edlund, 1995	1.34	0.46	2.22
24	Herrera, Lee, Palos, & Torres, 2008	1.92	-1.60	5.44

Figure 2.4. Effect Size Data of Included Studies Investigating LTCS Use-Caregiver Burden Relation (*k* = 24).



#	Study name	Effect size	CI Lower limit	CI Upper limit
1	Gaugler et al., 2003	-0.36	-0.71	-0.02
2	Noimuenwai, 2012	-0.23	-1.29	0.82
3	Gaugler et al., 2009	-0.21	-0.32	-0.09
4	Bass, Noelker, & Rechlin, 1996	-0.09	-0.37	0.19
5	Whitlatch et al, 1997	-0.03	-0.64	0.58
6	McCann et al., 2005	0.00	-0.32	0.32
7	LeBlanc, Mullan, Wardlaw, Harrington, & Chang, 1998	0.03	-0.22	0.27
8	Spijker et al., 2011	0.05	0.01	0.09
9	Mensie & Steffen, 2011	0.18	-0.51	0.88
10	Chang, 2009	0.33	0.07	0.58
11	Sugiura, Ito, Kutusumi, & Mikami, 2009	0.36	-0.48	1.19
12	Phillipson, Magee, & Jones, 2013	0.65	0.10	1.20
13	Hawranik, 1998	1.07	0.25	1.89
14	Bookwala et al., 2004	2.69	2.11	3.28

Figure 2.5. Effect Size Data of Included Studies Investigating LTCS Use-Caregiver Depression Relation (*k* = 14).



#	Study name	Effect size	CI Lower limit	CI Upper limit
1	White-Means, 1997	-3.98	-4.32	-3.65
2	Hawranik, 1998	-2.26	-4.03	-0.49
3	Huang, Shyu, Chang, Weng, & Lee, 2009	-0.72	-1.45	0.01
4	Noimuenwai, 2012	-0.66	-1.55	0.23
5	Pedlar, 1997	-0.49	-0.94	-0.05
6	Kosloski & Montgomery, 1994	-0.41	-0.80	-0.02
7	Hong, 2009	-0.07	-0.25	0.11
8	Bullock, 2000	-0.05	-0.13	0.03
9	Cho, 2006	0.02	-0.30	0.34
10	Bookwala et al., 2004	0.02	-0.35	0.39
11	Bass, Noelker, & Rechlin, 1996	0.09	-0.14	0.33
12	LeBlanc, Mullan, Wardlaw, Harrington, & Chang, 1998	0.11	-0.13	0.36
13	Crist, Kim, Pasvogel, & Velazquez, 2009	0.19	0.04	0.35
14	McCann et al., 2005	0.21	-0.11	0.54
15	Bass & Noelker, 1987	0.39	0.13	0.66

Figure 2.6. Effect Size Data of Included Studies Investigating LTCS Use-Caregiver Health Status Relation (*k* = 15).

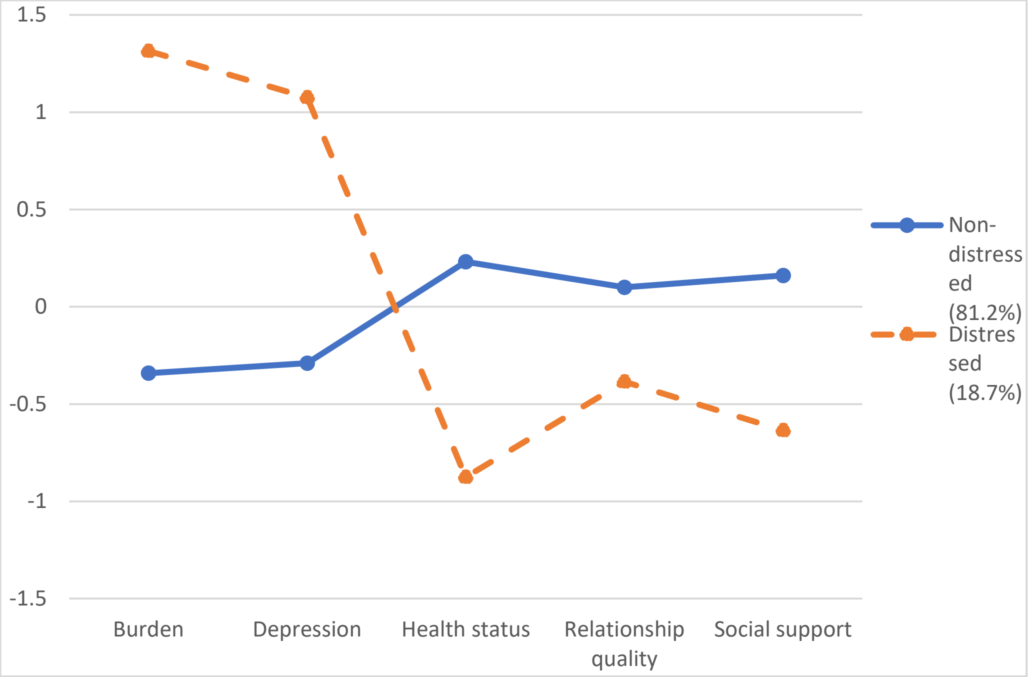


Figure 4.1. Profile Plots for the 2-Profile Model at Baseline (T0) (*n* = 378).

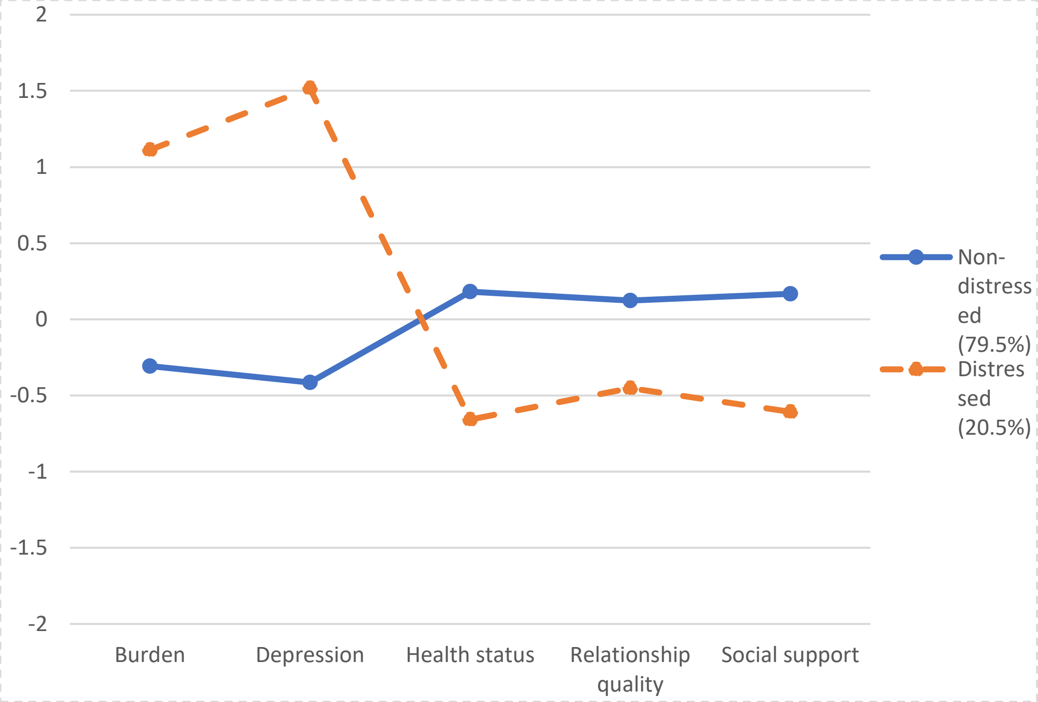


Figure 4.2. Profile Plots for the 2-Profile Model at 3-month Post-stroke (T1) (*n* = 331).

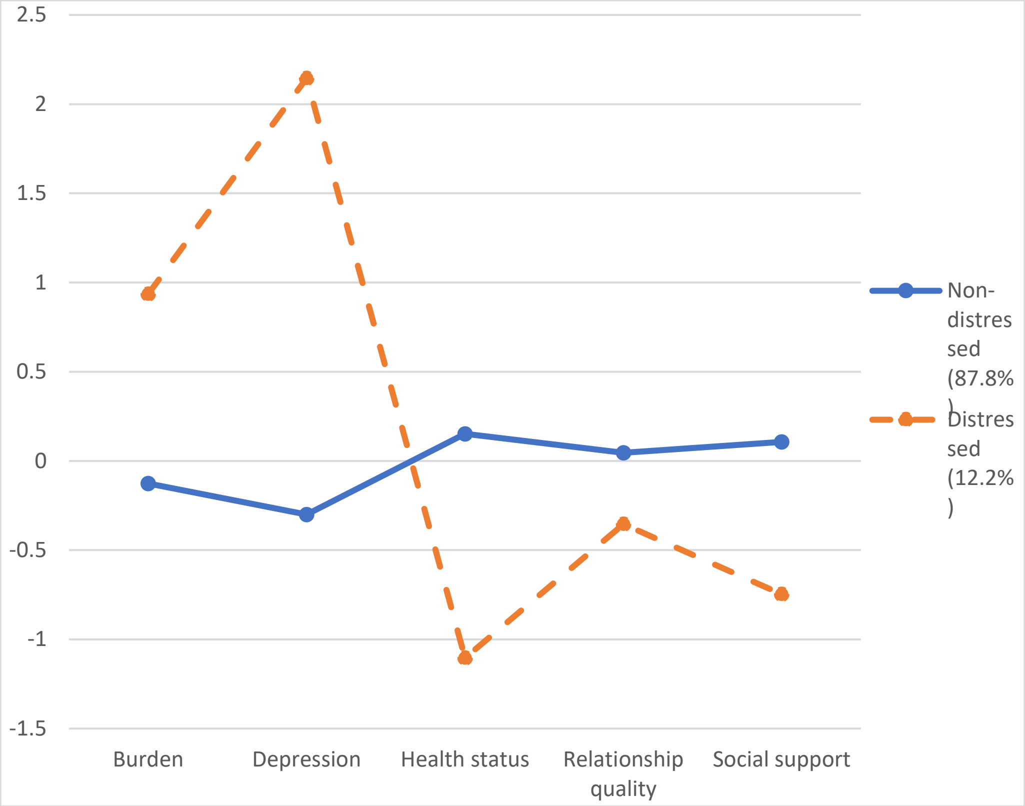


Figure 4.3. Profile Plots for the 2-Profile Model at 12-month Post-stroke (T2) (*n* = 278).

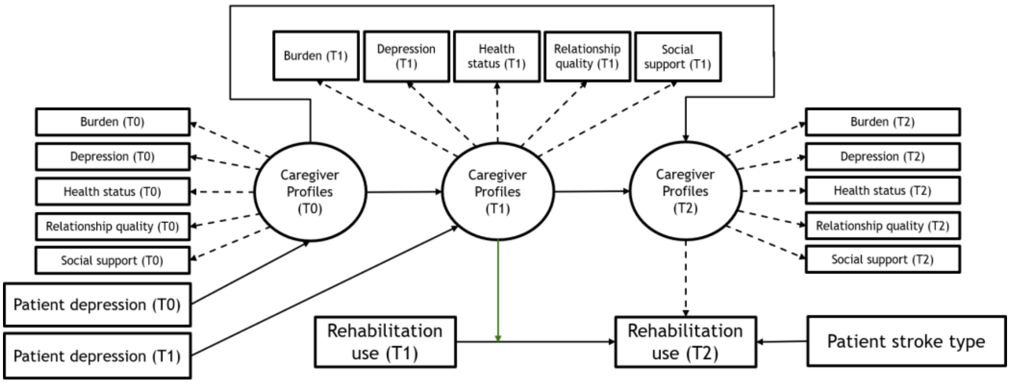


Figure 4.4. LTA Model Including Rehabilitation Use as Outcome and Covariates.

Note. The relation between the caregiver profiles (T2) and rehabilitation use (T2) represents profile-specific conditional means rather than *bona fide* regressive path.

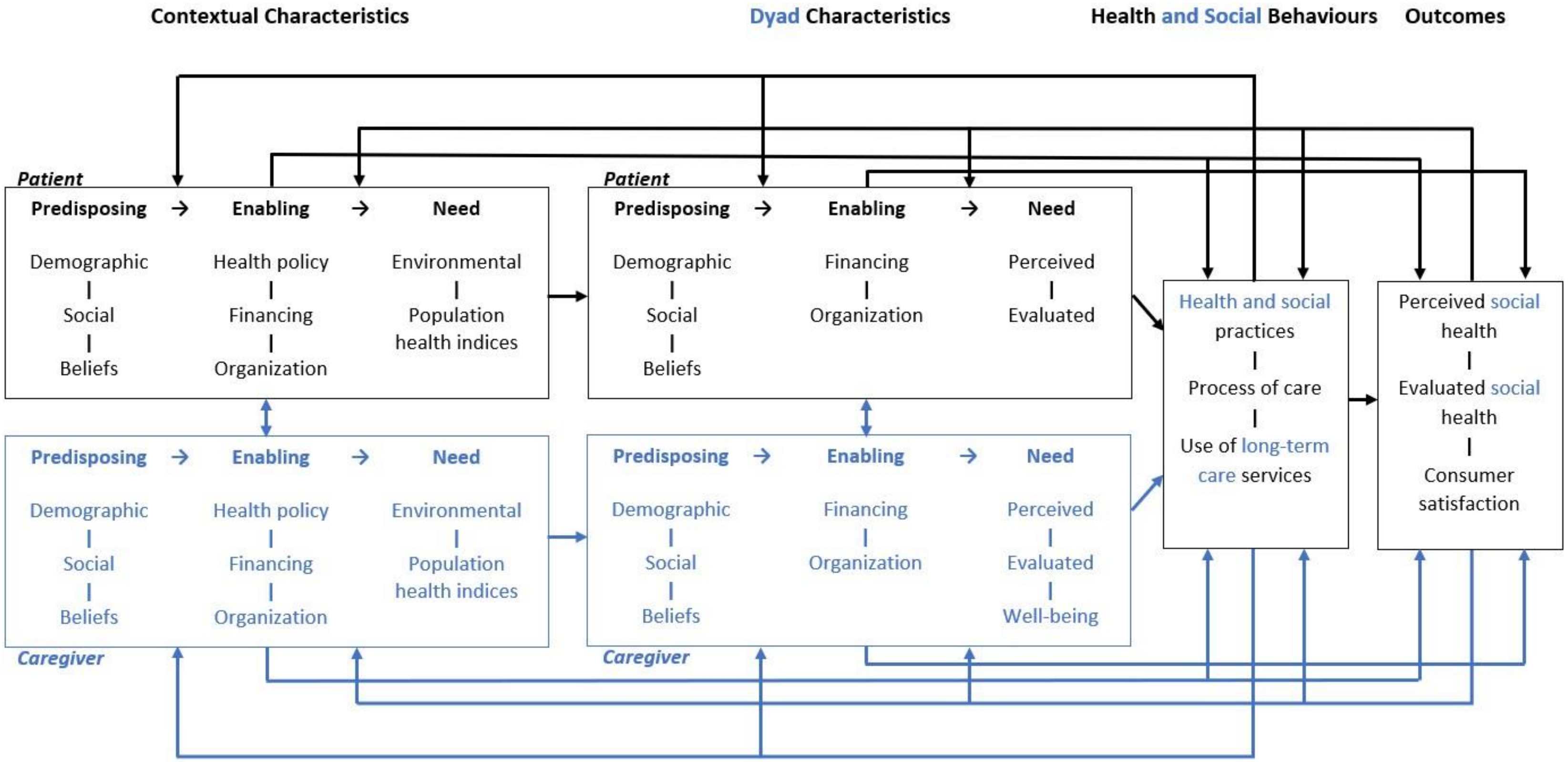


Figure 5.1. A Behavioral Model of Long-term Care Services Use.

Note. The additions and revisions to an earlier version of the Behavioral Model (Andersen, & Davidson, 2007) are shown in blue.