Caregivers in distress: Using interRAI assessments to target and evaluate community based interventions

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Background: Informal caregivers have a fundamental role in our society with the provision of unpaid care for family members or friends that may otherwise be unable to live in their homes. However, caregivers may jeopardize their own physical and mental health leaving them unable to continue caring for older persons with complex health needs.

Objectives: Data from interRAI instruments and other sources were used to: a) develop and evaluate a caregiver survey; b) develop a screener to identify caregivers at risk of adverse outcomes; c) examine caregiver and care recipient predictors of long term care home admission and d) evaluate a respite intervention for distressed caregivers. The model of caregiver distress proposed by Pearlin et al. (1990) was used as a conceptual framework for this research study.

Methods: interRAI assessments serve as either the main or the secondary dataset used for analysis. In chapter three, the psychometric properties of the caregiver survey were examined using factor and frequency analysis and a reliability test. Information on the caregiver survey was used to develop and evaluate a caregiver screener using frequency analysis and logistic regression models in chapter four. In the next chapter, survival models and generalized estimating equations were used to identify caregiver and care recipient items in the RAI-Home Care (RAI-HC) as predictors of long term care home admission. The evaluation of a respite service examined changes in the caregiver distress index and items from the caregiver survey using paired t tests. Changes in the caregiver items of interRAI assessments of care recipient from the respite program and a similar cohort were compared using logistic regression models. Rates of long term care home admission and length of time before admission were compared using survival models.

Results: Three domains were identified in the caregiver survey: 1) psychosocial resources and well-being; 2) physical; and 3) mental health. This study also showed a significant association between care recipient depression and caregiver feelings of loneliness and poor self-esteem. The caregiver distress index developed as part of this research identifies low, moderate and high risk levels for adverse outcomes. Compared with the low risk group, caregivers in the high risk group were more likely to visit the doctor or nurse practitioner, self-report poor health, and report that the care recipient would be better off elsewhere. The RAI-HC predictors of long term care home admission were: care recipient MAPLe score, age, caregiver distress, caregiving dyad relationship, and living arrangements. There was an interaction between caregiver and care recipient coresidence and caregiving dyad relationship. A care recipient cared by a coresiding child caregiver was less likely to be admitted to a long term care home than a care recipient cared by a coresiding nonchild caregiver. In the respite program evaluation, an overall improvement in the frequency of mood items and positive symptoms were observed for all caregivers participating in the program. Caregivers in the moderate risk group experienced an increase in pain frequency and inability to go where they wanted in the spur of the moment. While the odds for improving caregiver distress was not affected by caregiver participation in the respite program, the odds of improvement in the caregiver ability to continue was notably higher for caregivers in the respite program. The length of time before institutionalization was greater for care recipients with MAPLe 5 in the respite program than for care recipients with MAPLe 5 receiving home care services from a local agency.

Conclusions: This dissertation highlights the complexity involved in caregiving experiences and the need for valid and reliable assessments for understanding caregiver issues and their needs. The caregiver distress index can be used to identify caregivers at risk of adverse outcomes that would benefit from respite and further assessments. Analysis including interRAI assessments for the care recipient and caregivers identified the positive impact of a respite program on caregiver quality of life and also for delaying institutionalization emphasizing the value of these assessments for the development, evaluation and allocation of resources for caregiver interventions.

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Dedication

I dedicate my thesis to my husband Gustavo Betini. Thank you for your support and wise words.

Obrigada meu amor.

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List of Abbreviations

AD – Alzheimer’s disease
ADL - Activities of Daily Living
ADL-H – Activities of Daily Living Hierarchy
CCAC - Community Care Access Centre
CDI – Caregiver Distress Index
CHA – Community Health Assessment
CHRIS - Client Health Related Information System
CI – Confidence Interval
CPS - Cognitive Performance Scale
CSI – Caregiver Strain Index
DRS - Depression Rating Scale
HC – Home Care
HR – Hazard Ratio
IADL - Instrumental Activities of Daily Living
LHIN - Local Health Integration Networks
LTCH – Long Term Care Home
MAPLe - Method for Assigning Priority Levels
MH – Mississauga Halton
OACCAC - Ontario Association of Community Care Access Centres
OR – Odds Ratio
ORE - Office of Research Ethics
RAI – Resident Assessment Instrument
SAS - Statistical Analysis System
SD – Standard Deviation
SE – Standard Error
ZBI – Zarit Burden Inventory

Chapter 1

INTRODUCTION

It is estimated that one third of Canadians aged 45 or older provide informal care for an older person (Turner & Findlay, 2012) that is often facing health problems that would otherwise result in institutionalization (Afram et al., 2014; Buhr, Kuchibhatla, & Clipp, 2006; Thomas et al., 2004). Thus, informal caregivers provide a valuable contribution to the sustainability of the health system and our society given the high costs associated with long term care home (LTCH) admissions and the desire of care recipients to live in their homes (Chari, Engberg, Ray, & Mehrotra, 2015; Forbes & Neufeld, 2008; Wimo, Jönsson, Bond, Prince, & Winblad, 2013).

A substantial increase in the aging population for most countries of the world is expected for the next 10 years (United Nations Population Division, 2013). In Canada, it has been estimated that 1 in 4 Canadians will be 65 or older in the same period of time (Government of Canada, 2015). As a result, informal caregivers will face an increasing demand to provide care for family members and friends with challenging health problems.

Unfortunately, informal caregivers are exposed to several stressors especially when providing care for someone with complex health needs (Health Council of Canada, 2012; Health Quality of Ontario, 2016). Apart from the amount and type of care provided, other factors related to caregiving experiences such as formal or informal support, quality of relationship with care recipient and coping skills influence their emotional and physical health (Goode, Haley, Roth, & Ford, 1998; Mackay & Pakenham, 2012; Martire & Schulz, 2001; Pearlin et al., 1990). Moreover, perceptions of burden and support have an impact on their ability to continue in their role, eventually leading to care recipient institutionalization (Caron, Ducharme, & Griffith, 2006; Colerick & George, 1986; Mittelman, Haley, Clay, & Roth, 2006). Thus, it is crucial to understand the intrinsic and extrinsic factors related to caring activities that have an impact on caregiver quality of life to better attend their unique needs.

Caregiver assessments are key for identifying their needs and preferences as well as the multiple aspects influenced by the provision of care. It is well known that informal caregiving may negatively affect caregiver well-being (Hilbrecht, Lero, Schryer, Mock, & Smale, 2015), mental health (Covinsky et al., 2003; Ferrara et al., 2008; Schulz et al., 2008), family relations or finances (Keating, Fast, Lero, Lucas, & Eales, 2014). However, it can also result in personal satisfaction and experiences of gratification (Bacon, Milne, Sheikh, & Freeston, 2009; Kruithof, Post, & Visser-Meily, 2015; López, López-Arrieta, & Crespo, 2005; Motenko, 1989). Although most caregiver instruments are used to evaluate negative feelings associated with caring activities (Chang et al., 2016; Onder et al., 2009; Savage & Bailey, 2004; Vitaliano, Strachan, Dansie, Goldberg, & Buchwald, 2014), the assessment of positive feelings is also relevant because it identifies factors that may empower caregivers and favor their ability to continue in their role (Buhr et al., 2006; Schulz et al., 2004). Thus, comprehensive caregiver assessments including multiple domains are needed for developing and evaluating interventions to improve caregiver's quality of life (Whitlatch, Zarit, & Eye, 1991; Zarit, Reever, & Bach-Peterson, 1980).

It is well recognized that care recipient health characteristics have an important impact on the caring demands as well as on caregiver health and well-being. One example is the association between Method of Assigning Priority Levels (MAPLe) scores, a measure of care recipient health care needs, and caregiver distress (Hirdes, Poss, & Curtin-Telegdi, 2008; Mitchell et al., 2015; Vu et al., 2014). The MAPLe algorithm, which is embedded in the Resident Assessment Instrument-Home Care (RAI-HC) and interRAI Community Health assessment (CHA), has been developed to help health care providers to identify persons with the most urgent need for care. This algorithm includes information on care recipient health associated not only with caregiver distress, but also with LTCH admission such as behavioral problems, cognition and activity of daily living (ADL) impairment. The latter have been shown to affect caregiver needs for assistance and burden (Grunfeld, 2004; Skarupski, McCann, Bienias, & Evans, 2009), whereas behavioral problems such as aggression and wandering have been reported as important causes of caregiver stress and depressive symptoms (Covinsky et al., 2003; Ferrara et al., 2008; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Schulz et al., 2004, 2008; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

The health characteristics used to calculate the MAPLe algorithm are frequently present in care recipients that are at a greater risk of LTCH admission (Buhr et al., 2006; Eaker, Vierkant, & Mickel, 2002) explaining the association between this algorithm and institutionalization (Hirdes et al., 2008; Mitchell et al., 2015; Vu et al., 2014). While caregiver emotional health and well-being have been also linked to care recipient institutionalization (Chenier, 1997; Colerick & George, 1986; Schulz et al., 2004; Zarit, Todd, & Zarit, 1986), it is unclear whether caregiver distress may predict LTCH admission independently of care recipient health care needs (Luppa et al., 2010; Pruchno, Michaels, & Potashnik, 1990). Further, the impact of caregiving dyad characteristics such as quality and type of relationship between caregiver and care recipient and coresidence on LTCH deserves further investigation.

Inclusion of information on LTCH admission for the evaluation of respite programs would be valuable, since this outcome may be affected by changes in caregiver related measures that would allow them to be able to continue (Dröes, Meiland, Schmitz, & van Tilburg, 2006; Knight, Lutzky, & Macofsky-Urban, 1993; Mittelman et al., 2006). In fact, other types of information on health care utilization (i.e., doctor and hospital visits) have been considered potential outcomes affected by caregiver interventions (Knight et al., 1993; Mittelman et al., 2006).

Some other measures used for evaluation of caregiver interventions are: quality of life indicators, feelings of emotional distress and depression since these outcomes may be responsive to strategies aiming to reduce burden (Sörensen, Pinquart, & Duberstein, 2002; Van Houtven, Voils, & Weinberger, 2011). However, most studies on evaluations of programs aiming to decrease burden or improve caregiver well-being have not shown significant changes in caregiver outcomes, especially in mental health related measures (Abbey & Parker, 2006; Acton & Kang, 2001; Shaw et al., 2009). This is unfortunate given that a lack of benefits is a threat for the provision of funding to related initiatives. The multidimensional aspects of caregiving and the unique needs of caregivers affects approaches to the development and evaluation of caregiver interventions as ‘there is not one size fits all’. In addition, assessments with poor sensitivity impede the observation of potential benefits to caregivers. More research is needed to link the understanding of caregiver issues, the development and validation of caregiver assessments, and their use for evaluating caregiver interventions effectively.

1.1 Rationale and research questions

Informal caregivers have a key role for the sustainability of a health care system, especially when considering the fast growth of the Canadian aging population. Caregiver experiences are influenced by a complex number of factors associated with caregiver and care recipient characteristics that ultimately affect their ability to continue on their role. The Pearlin (1990) stress model used in caregiver research will be used as a conceptual framework for this dissertation as it incorporates key elements that affect, and are affected by, informal caregiver experiences (Figure 1.1). This model includes the following elements: 1) background and context (e.g., the type and quality of relationship of the caregiver to the care recipient); 2) primary stressors (e.g., care recipient needs); 3) secondary role strains (e.g., family conflict, economic problems); 4) secondary intrapsychic strains (e.g., self-esteem, mastery, role captivity); 5) mediators (e.g., coping and social support) and 5) outcomes (e.g., depression, anxiety, physical health). Thus, this dissertation will support the progress of caregiver research by integrating these elements in the development and evaluation of caregiver assessments, examination of caregiver and care recipient predictors of LTCH admission and a respite program evaluation. A description of the chapters and its respective research questions is presented below.

The second chapter provides a scoping review of informal caregivers of the elderly. This literature review discusses the multifaceted issues involving caregiver’s role to identify gaps for the advancement of this field and link key topics that will be discussed in more detail in the following chapters (i.e.; assessments, predictors of LTCH admission, and caregiver intervention).

The following two chapters focus on caregiver assessments. More specifically, the goal of third chapter is to answer the question:

1) Is a caregiver survey, based on interRAI assessments, a reliable and valid instrument?

The fourth chapter describes a caregiver screener that was developed based on the caregiver survey to identify those that would more likely benefit from intervention and more comprehensive assessments. The research question of this chapter is:

2) Does the interRAI Caregiver Screener identify caregivers at risk of adverse outcomes?

The fifth chapter examines caregiver and care recipient predictors of long term care home admission. Specifically, it deals with the association of caregiver distress and caregiving dyad characteristics and care recipient needs with LTCH admission of long stay home care clients to answer the question:

3) Does caregiver distress influence LTCH admission after controlling for care recipient care needs and caregiving dyad characteristics?

The last study and sixth chapter provides an evaluation of a respite program for informal caregivers of high needs home care clients. It incorporates the knowledge of the previous studies in its approach for evaluation of the respite intervention. Thus, the last research questions are:

4) What impact did the respite program have in the caregiver's quality of life, their ability to continue on their role, distress and care recipient long term care admission? Which caregivers experienced most of the benefits?

It is expected that this dissertation will advance knowledge in caregiver research and provide evidence to assist policy and decision makers to better support caregivers in their role.

1.2 Search strategy

A literature review was conducted to identify relevant publications to be included in this dissertation. The following electronic databases: PubMed (Medline), PsycINFO, Scopus and Web of Science were used during the search. Several terms and keywords or a combination of them were used depending on the topic of the chapter. For example, for the chapter on assessments, a combination of the following terms and keywords, but not limited to, were used: "informal caregivers" OR "carer" OR "family caregiver" AND "assessment" OR "tools" OR "measures" AND "elderly" OR "older adults".

A search of articles within references of important articles was also used to identify other sources of information for the literature review. Moreover, key knowledge for caregiver research have been retrieved from books that are often cited in articles on caregiver research models such as “*Stress, appraisal, and coping*” from Lazarus and Folkman (1984). Reports on caregiver distress and related subjects released by organizations such as Statistics Canada and Alzheimer’s Society were also retrieved.

A scoping literature review on key subjects studied in caregiver research, particularly related to caregivers of older adults, is presented in the next chapter.

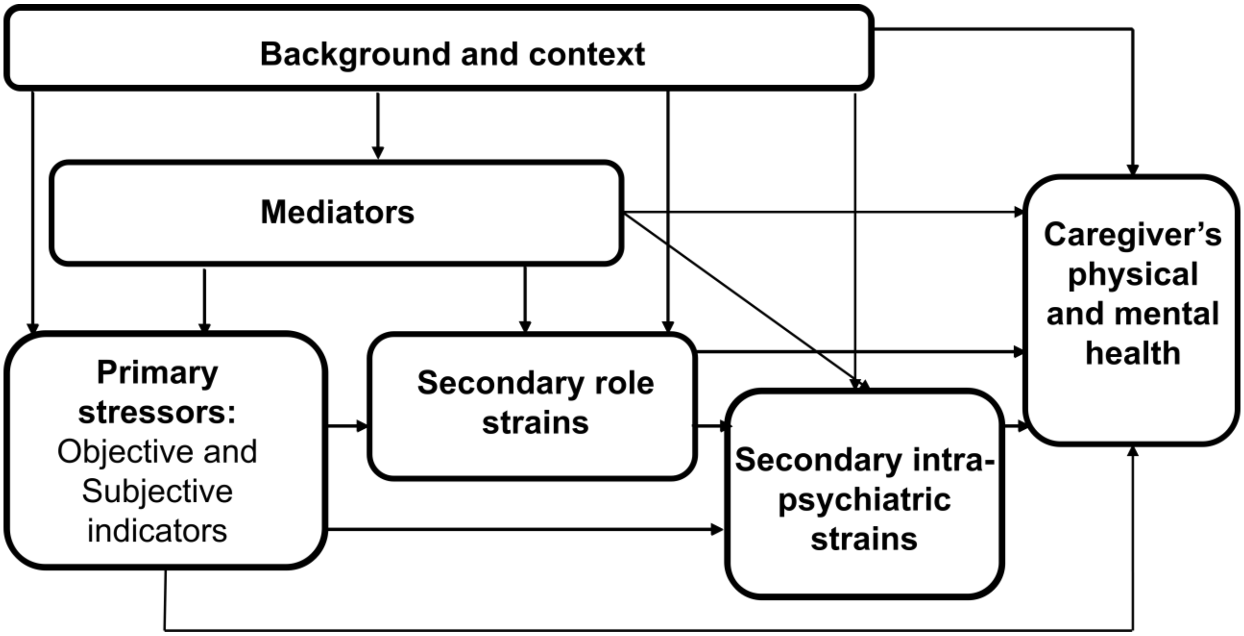


Figure 1.1. Summary of Pearlin’s stress process model (Pearlin et al., 1990)

Chapter 2

A SCOPING REVIEW OF INFORMAL CAREGIVERS OF THE ELDERLY

2.1 Introduction

Population ageing is a worldwide phenomenon that affects different aspects of the health system, including an increase in the demand for formal and informal care for the elderly (Ryan, Smith, Antonucci, & Jackson, 2012). Informal care, understood as unpaid care provided by family members and friends, has received much attention recently because of the growing recognition of its contribution to the health system (Levine, Halper, Peist, & Gould, 2010). However, informal caregivers often experience stress caused by caring responsibilities, financial difficulties, and changes in their personal relationships (Andrén & Elmståhl, 2007; Baronet, 1999; Mello et al., 2016) . Under these conditions, caregivers may become unable to continue in their role, thereby affecting the demand for formal services, care recipient's choice to live at home, and admission to a long term care home (LTCH) (Bookwala et al., 2004; Levine et al., 2010; Lieberman & Kramer, 1991; Yoo, Bhattacharya, McDonald, & Garber, 2004). Understanding the factors associated with the ability of friends and family members to provide care for the elderly is essential for informing policy and developing strategies focussed on providing support to caregivers and avoiding institutionalization of care recipients (Andrén & Elmståhl, 2007; Baronet, 1999; Mello et al., 2016)

A myriad of studies on predictors of caregiver burden and its effect on their ability to care have been published in the last 60 years. The study carried out by Clausen and Yarrow (1955), one of the earliest studies related to informal caregiving, focussed on caregivers of care recipients with mental illness. Although progress has been made in recent years, there are still many challenges for research on informal caregiving. Particularly important are (1) unclear understanding of the concept of 'burden', (2) underutilization of stress models as a framework of caregiver studies; (3) use of caregiver assessments without good psychometric measures; (4)

limited understanding of caregiver needs; and (5) inconsistencies in the methods used to develop and evaluate caregiver interventions (e.g., selection of participants, assessments).

The objective of this paper is to present a critical overview on the key topics involved in caregiver research, including the gaps between our understanding of the multidimensional aspects of caregiving, assessments and interventions. Given that most caregiver research is related to burden, the studies on its predictors and moderators (including positive aspects of caregiving) are reviewed first. Next, the impact of caregiving on caregiver outcomes and LTCH admission of the care recipient is discussed. Caregiver stress models and an overview of caregiver assessments used in caregiver research are presented followed by information on caregiver needs and examples of interventions.

2.2 Predictors of burden

One of the main topics of caregiver research is the caregiver and care recipient characteristics that predict caregiver burden. The knowledge of burden is relevant for the development of interventions that aim to improve caregiver well-being and their ability to continue in their role, allowing the care recipient to live longer in their homes.

2.2.1 Care recipient determinants of burden

Evidence related to care recipient characteristics that predict caregiver burden or distress is inconsistent. While some studies indicate that care recipient symptoms and care needs are associated with caregiver burden, others show that these characteristics are not necessarily linked.

Among those studies that report a relationship between care recipient characteristics and caregiver burden, behaviour symptoms appear as one of the major causes of caregiver perceived burden (Bédard, Pedlar, Martin, Malott, & Stones, 2000; Bergvall et al., 2011; Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010; Mioshi et al., 2013; Onder et al., 2009; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). More specifically, agitation, irritability, aggression, aberrant motor and night behavior seem to be the main sources associated with caregiver burden (Mackay & Pakenham, 2012; Papastavrou et al., 2007; Rinaldi et al., 2005). The constant need for watching over the care-recipient, due to the unpredicted nature of behavioural symptoms, have also been reported as a major cause for caregiver emotional distress (Mahoney, 2003).

Unfortunately, the majority of research on caregiver burden focusses mainly on caregivers who care for a care recipient with dementia or another type of mental illness. This may underestimate the relevance of other potential predictors of burden present among other groups of caregivers. A recent study reported that different levels of burden among caregivers were related to the care recipient diagnosis where those caring for care recipients with an acquired brain injury experienced higher levels of burden compared with caregivers of care recipients with dementia or cancer (Harding et al., 2015).

Other health issues such as impairment in activities of daily living (ADL) and instrumental activity of daily living (IADL) have also been reported as predictors of caregiver burden and depression (Grunfeld, 2004; Skarupski et al., 2009). There is also evidence that care recipient ADL impairment is an important predictor of informal care hours (Bergvall et al., 2011), suggesting a relationship between the need of this type of care and objective burden (i.e., burden as a result of activities and happenings related to the care provided (Montgomery, Gonyea, & Hooyman, 1985)).

The MAPLe (Method of Assigning priority levels) score, an algorithm from health assessments (RAI-HC - Resident Assessment Instrument Home Care and interRAI CHA -

Community Health Assessment), has been associated with caregiver distress in several studies (Hirdes et al., 2008; Mitchell et al., 2015; Vu et al., 2014). Interestingly, this algorithm includes items representing not only behavior symptoms of the care recipient but also ADL and cognitive impairment, explaining its correlation with caregiver distress regardless of care recipient diagnosis (Mitchell et al., 2015).

In contrast to the aforementioned studies, there is some evidence that care recipient characteristics account for a minor or absent effect in caregiver burden (Garlo, O'Leary, Van Ness, & Fried, 2010; Haley, Levine, Brown, & Bartolucci, 1987; Rinaldi et al., 2005; Stueve, Vine, & Struening, 1997; Zarit et al., 1980). In one longitudinal study, researchers did not find evidence linking increasing behavioural problems and decline in self-care of care recipients with a deterioration in the physical and mental health of caregivers (Goode et al., 1998). According to the authors, the lack of association between worsening in care recipient symptoms and decline in caregiver health measures could be explained by the absence of information on psychosocial resources used by the caregivers. This type of support could moderate the relationship between care recipient stressor and caregiver health outcome (Goode et al., 1998; Schulz & Martire, 2004).

It is also possible that caregivers may be able to adapt or become prepared for changes in care recipient health when those are not too large or are predictable minimizing caregivers susceptibility to distress (Nelson, Smith, Martinson, Kind, & Luepker, 2008). A study reporting the relationship between the health decline of stroke victims and an increase in subjective and objective burden of caregivers suggested that the latter was a consequence of large or unexpected changes in the neurological function of care recipients (Nelson et al., 2008). In contrast, Garlo and colleagues (2010) found that objective measures of functional impairment of care recipients with cancer, chronic obstructive pulmonary disease or heart failure were uncorrelated with caregiver reports of higher need for help, suggesting that caregiver perception of needed help is mitigated by their adaption to caring activities (Garlo et al., 2010).

Another possible explanation for the lack of relationship between caregiver workload and burden could be related to the multidimensionality of caregiver burden and its multiple definitions (Braithwaite, 1992; Byun & Evans, 2015). The unclear definition of burden and its poor assessment are important issues in caregiver research because they may produce misleading information on factors associated with burden. It is conceivable that differences in the findings related to the association between caregiver burden and care recipient health characteristics are consequences of the type of burden (objective vs. subjective) measured or whether this outcome was accurately measured (Bevans & Sternberg, 2012; Goldstein, Concato, Fried, Kasl, & al, 2004; Grunfeld, 2004; Pirraglia et al., 2005).

The general concept of burden has been modified in the last 60 years by differentiating burden between objective and subjective components (Hoenig & Hamilton, 1966, 1967; Hunt, 2003). Objective burden includes concrete events, happenings and activities, representing the direct consequences of caregiving activities on caregiver's life whereas subjective burden, or caregiver perceived stress, reflects the carer's appraisal of objective burden and the strain of caring (Hunt, 2003) which have different effects on physical and mental health (Schene, 1990).

In this dissertation, subjective burden is defined as caregiver perceived distress or their perception that demands related to caregiving exceed their resources. Objective burden includes the mental (e.g., vigilance, concerns) and physical demands (e.g., assistance with activities of daily living) related to the caregiver role. Unfortunately, most studies on caregiver burden do not differentiate these types of burden.

Although care recipient health problems may be considered a source of caregiver distress, several studies have shown that caregiver distress may not be necessarily driven by care recipient care needs (Dunkin & Anderson-Hanley, 1998). Instead, different aspects of caregiver's life and caregiving dyad may influence their burden appraisal. The next section will discuss determinants of burden related to caregiver and caregiving dyad.

2.2.2 Caregiver determinants of burden

Various sociodemographic characteristics of the caregiver have been investigated as predictors of caregiver burden (Baronet, 1999; Chiao, Wu, & Hsiao, 2015). These include ethnicity, age, relationship with the care recipient, coresidence and gender.

Caregivers from different races seem to have distinct ways to adapt to the distress related to their role. Several studies have reported that black caregivers are more likely to experience less burden (Horwitz & Reinhard, 1995; Stueve et al., 1997) and depression (Skarupski et al., 2009) than white caregivers. The reasons for these differences between ethnic groups are likely related to the diversity between cultural values, expectations and religious beliefes and their association with perception of burden (Chang & Hirdes, 2015; Hernandez, 1991). Unfortunately, the influence of cultural differences on caregiver outcomes represent a gap in caregiver research (Lero, Keating, Fast, Joseph, & Cook, 2007).

Studies on the association between burden and age of caregivers have yielded mixed findings (Baronet, 1999). While some studies indicate that younger caregivers may experience higher burden than older caregivers (Andrén & Elmståhl, 2007; Horwitz & Reinhard, 1995; Skarupski et al., 2009), others have reported the contrary (Horwitz & Reinhard, 1995; Rinaldi et al., 2005) or a lack of an effect (Andrén & Elmståhl, 2007; Kim, Chang, Rose, & Kim, 2012;

Noh & Avison, 1988). The inconsistent findings on the relationship between caregiver age and burden may be a result of the presence of variables related with burden (Baronet, 1999).

Elderly caregivers tend to be spouses, provide more hours of care, present with their own health problems and co-reside with their care recipient (Pinquart & Sörensen, 2011) while younger caregivers are more likely to be represented by adult children who often struggle with other issues such as employment stability and parenting their own children. Because of these key differences between these two groups of caregivers, their caregiving experiences are often affected in different ways. A study comparing spouse and children caregivers of care recipients with Alzheimer's Disease (AD) found that children caregivers face major changes in their life style as a consequence of their caregiving responsibilities like leaving their jobs (Mello et al., 2016). They also tend to experience more guilt (Conde-Sala et al., 2010) whereas spousal caregivers view their caregiving activities as part of their marital role (Conde-Sala et al., 2010). In regards to distress or burden, findings are unclear whether children caregivers (Andrén & Elmståhl, 2007; Conde-Sala et al., 2010; Skarupski et al., 2009) or spouses caregivers (Kim et al., 2012; Pinquart & Sörensen, 2003, 2011) are more likely to experience this problem.

A meta-analytic study comparing spouses, children and children-in-law caregivers suggested the higher psychological distress experienced by spouses is only partially explained by the amount of care provided (Pinquart & Sörensen, 2011). Thus, it is conceivable that burden differences between spouse caregivers and other family members are explained by other factors such as the quality of the relationship of the dyad and coresidence.

In fact, coresidence has been reported as having an impact on caregiver burden (George & Gwyther, 1986; Kim et al., 2012; Mello et al., 2016) and guilt. More specifically, in a study comparing children and spouses-caregivers, coresidence had an important influence in caregiver burden, while feelings of guilt among children caregivers were associated with not living with the care recipient (Conde-Sala et al., 2010). Caregivers coresiding may spend more hours providing attention to a care recipient due to the unpredictable nature of behavioural symptoms, resulting in emotional exhaustion (Mahoney, 2003). It is also worth mentioning that caregivers living with someone presenting with behavioral and psychological symptoms of dementia (BSPD) may under report the number of caregiving hours since they may not consider vigilance activities (such as watchful supervision or protective intervening, and constantly dealing with unpredictable behaviours) as caregiving activities (Mahoney, 2003).

In contrast to other demographic caregiver variables, the association between caregiver gender and burden has been more consistent. The majority of the studies on this subject have shown that females tend to experience higher burden than male caregivers. (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Kim et al., 2012; Mello et al., 2016; Pinquart & Sörensen, 2006a; Rose-Rego, Strauss, & Smyth, 1998; Skarupski et al., 2009; Thompson et al., 2004). Burden differences related to gender might be a consequence of differences in coping strategies, emotional attentiveness and caregiving tasks between male and female caregivers (Lutzky & Knight, 1994; Papastavrou et al., 2007; Rose-Rego et al., 1998; Thompson et al., 2004). Overall, female caregivers tend to provide more personal care and become more socially isolated, whereas male caregivers often receive more informal support (Miller & Cafasso, 1992; Papastavrou et al., 2007). However, this may not always be the case. A study on sons caregivers has shown that they also provide hand-on personal care by performing tasks such as bathing, dressing and feeding their parents (Harris, 1998). Moreover, a study comparing different measures of husbands and wives caregivers of care recipients with dementia reported that although the subjective distress associated with their role appears to be different, the objective measures indicated that, overall, they experience their caregiving role in similar ways (Fitting, Rabins, Lucas, & Eastham, 1986).

Higher levels of burden reported by female caregivers may be also a response to social expectations among various cultures that females should assume the caregiver role without question or searching for other options (Papastavrou et al., 2007). Thus, female caregivers may feel unsatisfied to assume this role (role captivity) due to family decisions as opposed to their own choice, affecting their level of satisfaction when engaging in the caregiving role (Marcén & Molina, 2012) thereby becoming emotionally distressed (Campbell et al., 2008). Moreover, lack of choice has been associated with emotional stress, physical strain and negative health outcomes of informal caregivers (Schulz et al., 2012).

2.2.3 Moderators of caregiver burden

The vast majority of studies about informal caregivers have focused on the association between negative aspects of caregiving and perception of burden, although positive aspects of caring activities may also moderate feelings of distress (Kruithof et al., 2015; López et al., 2005). Likewise, several factors that may or may not be related to caregiver characteristics moderate the impact of caring on their well-being.

Personality traits such as optimism, self-esteem, and mastery may affect caregiver appraisal or response to the stress related to their caring activities. A sense of self-mastery, for instance, can empower caregivers by making them feel capable of exerting their caring activities (Savage & Bailey, 2004). Also, certain personality traits may favour their ability to cope with challenging behaviors. While neuroticism has been positively related with caregiver burden and depression (Marziali, McCleary, & Streiner, 2010), extraversion and agreeableness were found to decrease burden in informal caregivers caring for individuals with dementia (Melo, Maroco, & de Mendonça, 2011).

Support provided through informal relationships such as family, friends and neighbours as well as through formal sources (e.g., health service providers, home care agencies) represent coping resources that may minimize the negative consequences of caregiving (Broady & Stone, 2015; Savage & Bailey, 2004; Yates et al., 1999). However, differences in the type and amount of formal care provided to care recipients seem to affect caregiver burden in different ways (Savage & Bailey, 2004; Winslow, 1997).

The strain caused by duration of care provided maybe also be buffered by caregiver social participation (Kramer, 1997a) while caregiver sense of community has shown to moderate the negative effect of the hours of care provided on their well-being (Hilbrecht et al., 2015).

While caregiver finance has been shown to be negatively associated with caregiver burden (Papastavrou et al., 2007; Spillman & Long, 2009) and well-being (Giordano et al., 2016; Hilbrecht et al., 2015), other studies reported no relationship of those variables (Andrén & Elmståhl, 2007). The negative association between income and burden may be a consequence of caregivers anticipating or experiencing changes in finances as a result of their caregiving responsibilities. For instance, family caregivers of care recipients with breast cancer reported financial problems related to prescription drugs expenses (Grunfeld, 2004). Moreover, caregivers have reported the need to be absent from work or leaving their job in order to assume or continue their role, consequently affecting their financial situation (Grunfeld, 2004; Lero, Spinks, Fast, Hilbrecht, & Tremblay, 2012; Lilly, Laporte, & Coyte, 2010). On other hand, sufficient financial support has moderated the impact of long hours of care provided on caregiver well-being (Hilbrecht et al., 2015). Caregivers with better financial support may be able to afford formal care and other services to alleviate the physical tiredness and emotional distress caused by caring responsibilities.

A few studies have suggested that caregiver burden is negatively related to level of education (Papastavrou et al., 2007; Pinquart & Sörensen, 2011), possibly because caregivers with higher levels of education may have more access to information on coping strategies than less educated caregivers. This group of caregivers is also more likely to be in a better financial situation, which has been negatively associated with burden, confounding the association between education and burden.

The inconsistent results of the studies on the association between stressors and burden is evident particularly because the moderating influence of coping responses and resources on burden is not always clear or captured by these studies. Further studies should invest in better understanding the linkage between coping and caregiver characteristics for the development of tailored interventions.

2.2.3.1 Positive aspects of caregiving

The importance of positive emotions as part of the coping process during periods of stress has been previously described by Folkman (Folkman, 1997, 2008). Unfortunately, the study of the positive aspects of caregiving have been neglected in caregiver research in the past years despite the recognition that aspects such as rewards, self-esteem, uplifts, gains and satisfaction are also key elements of caregiving experiences (Kramer, 1997).

In a study involving caregivers of stroke care recipients the effects of positive caregiving experiences have been associated with caregiver life satisfaction even when burden was considered high (Krutihof et al., 2012). In another study, care recipient care needs and duration of the illness have not been correlated with caregiver satisfaction or their feelings of gratification of caregiving, indicating that these positive feelings are not directly related to the amount of care provided (López et al., 2005; Motenko, 1989).

Several studies have reported factors related to positive feelings experienced by caregivers. More specifically, the quality of the dyadic relationship prior to the care recipient's illness (López et al., 2005; Yates, Tennstedt, & Chang, 1999) and becoming a caregiver by choice (López et al., 2005; Schulz et al., 2012) were reported factors related to caregiver satisfaction (López et al., 2005). The current quality of the relationship between caregiver and care recipient has been associated with caregiver well-being (Quinn, Clare, & Woods, 2009).

The co-existence of distress and positive aspects related to caregiving reflects the complexity of the feelings experienced by informal caregivers. Thus, the recognition of positive aspects of caregiving is key for the better understanding of its role as a moderator of the impact of burden on caregiver well-being (Beach et al., 2000; Kruithof, Visser-Meily, & Post, 2012).

2.3 The impact of burden and caregiving experiences on caregiver health

Several studies have reported on the consequences of caregiving experiences and feelings of burden on caregiver mental and physical health (Vitaliano, 2010; Vitaliano, Katon, & Unützer, 2005; Vitaliano et al., 2014). Although the effects of caregiving on mental health have been more often reported than the effects on physical health, the latter has recently received more attention. A study on older caregivers of older adults showed that caregiver physical pain was associated with emotional and physical burden (Jones, Hadjistavropoulos, Janzen, & Hadjistavropoulos, 2011).

Depression is considered one of the major consequences of caregiver subjective appraisal of distress associated with care demands (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Cuijpers, 2005; Ferrara et al., 2008; Pinquart & Sörensen, 2003; Schulz et al., 1995) and its prevalence is higher than in the general population (Vitaliano, Zhang, & Scanlan, 2003). In addition, depression among caregivers has been linked with care recipient behaviour and lack of informal help (Clyburn et al., 2000) and caregiver's inability to continue caring (Schoenmakers, Buntinx, & Delepeleire, 2010). It is worth mentioning that mental health issues are present not only among caregivers of care recipients with dementia (Covinsky et al., 2003), but also among those caring for individuals with other disease diagnoses such as cancer (Sklenarova et al., 2015).

Unfortunately, some symptoms of depression in informal caregivers are not easily identified. For example, insomnia may be seen as a consequence of changes in the sleep routine related with caregiving activities instead of a possible symptom of depression (McCurry, Logsdon, Teri, & Vitiello, 2007; Rowe, McCrae, Campbell, Pe Benito, & Cheng, 2008). This is very concerning since poor sleep and other issues related to the caregiving, such as poor health and limited presence of someone to confide in, have been considered risk factors of suicide in older adults (Turvey et al., 2002). Thus, poor quality of life, social isolation, and neglected health increase informal caregivers risk of adverse outcomes (Schoenmakers, Buntinx, & Delepeleire, 2010). Although alarming, it is not surprising, that a recent study on the presence of suicidal ideation in caregivers of care recipients with dementia reported that 26% of them had contemplated suicide at least once in the previous year of the study (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2013).

According to Schulz and Sherwood (2008), a conceptual model on the trajectory of caregiver health decline begins with distress and depression, followed by psychological changes and harmful health habits that eventually cause illness, leading to death. Further, caregiving has been a risk factor for mortality. More specifically, a study on mortality among caregivers found that caregivers experiencing strain presented a mortality risk 63% higher than non-caregivers in the control group after adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease (Schulz & Beach, 1999).

Other health problems, such as lower immunity, are reported as indirect consequence of caregiver burden. A meta-analysis on caregiver physical health indicated that caregivers presented with higher levels of stress hormones and lower antibody responses than non-caregivers (Vitaliano et al., 2003). There is also evidence that frailty is accelerated among caregivers of persons with dementia compared to caregivers of individuals without dementia (Dassel & Carr, 2014).

It is not only the physical and emotional stress of caregiving activities that may have an impact on caregiver health. Caregivers may neglect their own health by avoiding medical appointments or hospitalizations due to lack of time or availability of a social network that can assist in the caring role while the caregivers are caring for themselves. A study of 150 spousal caregivers of care recipients with AD versus 46 married control participants found that caregivers providing ADL assistance presented a greater risk of 1) extended physical illness or disability, 2) unhealthy medical rating or, 3) hospitalization. Interestingly, in this study, caregivers facing more behavioural problems were less likely to be hospitalized, suggesting that caregivers may be avoiding medical care when their spouses present more challenging symptoms

(Shaw et al., 1997). Studies like these highlight the need to provide support for caregivers to ensure that their mental and physical health are not at risk.

2.4 Caregiver predictors of long term care admissions

Care recipient institutionalization may become an alternative when highly distressed caregivers feel unable to continue their caring activities (Afram et al., 2015; Luppa et al., 2010; Steven H. Zarit et al., 1986). Caregiver burden, in particular, has been linked with LTCH admission of care recipient in various studies, especially for caregivers of care recipients with dementia (Luppa et al., 2010). However, this may not always be the case, as this association is not always consistent across studies (Donnelly, Hickey, Burns, Murphy, & Doyle, 2015; Haupt & Kurz, 1993; Hébert, Dubois, Wolfson, Chambers, & Cohen, 2001; Lieberman & Kramer, 1991; Pruchno et al., 1990; Yaffe et al., 2002). A potential explanation for this inconsistency might be the use of different caregiver assessments across studies (Donnelly et al., 2015) and unclear definitions of burden (Braithwaite, 1992).

While some studies have reported that caregiver perceived burden is a predictor to LTCH admission (Zarit et al., 1986) others have stated that caregiver's perception of their ability to provide care seems to drive their decision to institutionalize rather strain or burden levels (Caron et al., 2006). A recent study comparing different reasons for institutionalization found that among caregiver reasons, burden, followed by inability to provide care were the main predictors of LTCH admission (Afram et al., 2015).

As mentioned earlier in this review, caregiver's ability to provide care may be affected by different factors such as financial constraint and poor physical or mental health. Thus, other caregiver measures, such poor well-being and life satisfaction that have been linked with a higher likelihood of care recipient institutionalization (Buhr et al., 2006; Mittelman et al., 2006) may be suitable alternatives to measure caregiver ability to continue on their role.

Caregiver mental and physical health may also threaten their ability to continue caring activities as they may limit physical activities required for executing caregiving tasks (Cohen et al., 1993; Gaugler et al., 2000; Hébert et al., 2001; Mittelman et al., 2006). Caregiver health, a reported reason for institutionalization, has been associated with poor self-reported health, more visits to the doctor, more comorbid illnesses, and higher distress (Buhr et al., 2006). These caregivers were also more likely to be older, have a lower income and lower life satisfaction (Buhr et al., 2006).

The relationship between caregiver and care recipient may also influence care recipient LTCH admission (Freedman, 1996; Scott, Edwards, Davis, Cornman, & Macera, 1997). Some studies have reported that spouses caregivers are less likely to institutionalize their partners than non-spouse caregivers (Sink, Covinsky, Barnes, Newcomer, & Yaffe, 2006; Yaffe et al., 2002). They are more likely to know the care recipient personality and be familiar with their behaviour patterns therefore being more prepared to deal with challenging symptoms. Also, non-spouses caregivers may be less committed to caregiving activities than spouses, often due competing responsibilities and less emotional closeness with the care recipient (Kesselring et al., 2001) leading to a higher likelihood of institutionalization (Colerick & George, 1986; Pot, Deeg, & Knipscheer, 2001).

In fact, some studies have shown that the relationship between caregiver and care recipient is a stronger predictor of institutionalization than the characteristics of the care recipient such as behaviour and neurological symptoms (Lieberman & Kramer, 1991; Vugt et al., 2005). Unfortunately, most studies looking at the influence of caregiver relationship with care recipient do not take into account whether caregiver co-resides with care recipient. This information could influence the role of the relationship on care recipient institutionalization in these studies, since it is known that coresidence is associated with higher caregiver distress (George & Gwyther, 1986; Kim et al., 2012; Mello et al., 2016). More research is needed to understand the impact of coresidence in LTCH admission, together with other caregiver factors and care recipient health related characteristics, as they seem to interact in their effects on institutionalization of older adults (Morycz, 1985; Weissert & Cready, 1989).

The perception of burden triggers changes in the physical and mental health of caregivers, which ultimately affects their quality of life. Negative outcomes may then, affect their ability to continue caring, leading to care recipient institutionalization whereas the impact of positive outcomes on their lives is less understood. Untangling the caregiver and care recipient contributors to burden, identifying moderators, as well as its impact on caregiver outcomes is needed for the understanding of the complex dynamic involved in caregiving. Stress models provide alternative ways to unravel this process.

2.5 Caregiver stress process models

Most of the stress models used as a theoretical framework in caregiver research are derived from models typically used in stress research (Folkman, 1997; Schene, 1994; Schulz & Martire, 2004). These models consider the objective burden as well as the care recipient's health characteristics as the stressors or chronic strains. In contrast, the subjective burden and its related outcomes (i.e., physical and mental health decline) are the result of the interactions with sources of stress not necessarily related to caregiving activities such as caregiver economic socio status (Pearlin et al., 1990).

The stress and coping model proposed by Haley and colleagues (1987) predicts changes in the emotional and physical health of caregivers where the stressor is represented by the care recipient's cognitive impairment, behavioural problems and disability in self-care (Haley, Levine, Brown, & Bartolucci, 1987). This model is based on the concept of the stress model proposed by Lazarus & Folkman (1984), which has been widely used to guide research on this topic. According to the latter, stress is not necessarily a result of the exposure to stressors, but instead is a result of the individual's appraisal of stress or their perception that demand exceeds their resources. In turn, these circumstances pose a risk to the caregiver's well-being. Further, the authors suggest that stress may be mediated by coping strategies and social support (Lazarus & Folkman, 1984).

In 1990, Pearlin and colleagues (1990) developed a conceptual framework to study stress in caregivers by using measures from 555 primary caregivers of a spouse or a parent with AD or a similar dementia. This stress process model contains four domains: background and context, the stressors, the mediators of stress, and the outcome of stress. One major difference from Haley's model is the distinction between primary and secondary stressors. According to Pearlin's model, primary stressors are represented by care recipient's health, behaviour and functional abilities, whereas secondary stressors are divided by 'role strains' (represented by family conflicts, social isolation and financial issues), or 'intrapsychic strains' (represented by self-esteem, mastery, loss of self, role captivity, competence and gain). According to the author, the distinction among types of stressors facilitates the understanding of how potential mediators may act in the stress process (Pearlin et al., 1990). Pearlin's model also include positive aspects of caregiving as a factor that may affect caregivers outcomes.

Vitaliano and colleagues (1991) proposed a model of burden (or distress) for caregivers, where distress is appraised by the individual in response to the caring responsibilities and depends on the exposure to stressors (i.e., care recipient symptoms) and the physical and psychological vulnerability of the caregiver (i.e., age, gender, physical health, personality). The latter variables are under less control, or not easily modified. Moreover, psychological and social resources of the caregiver also influence the burden or distress in both directions. For example, a positive outlook on life and coping processes may moderate the distress caused by caregiving as well as the presence of a social network available to provide assistance to the caregivers with their needs.

A noticeable difference between this model and other models discussed earlier is the inclusion of vulnerability characteristics of the caregiver as a variable directly related to caregiver distress. In Pearlin's model, vulnerability characteristics such as gender and age of the caregiver are mixed with other variables such as family and network in the 'background' domain while in Vitaliano's model the effect of vulnerability of caregivers on health outcomes is emphasized.

A stress model that incorporates the dynamic nature of caregiving was described by Goode et al. (1998), where changes in stressors and caregiver psychosocial resources may cause changes in the caregiver's physical and mental health status as a result of an direct or indirect interaction between stressors and resources on caregiver health. This model presents the idea that initial psychosocial resources of caregivers may act either as a moderator of the stressors or as a direct influence on caregiver health.

More recently, positive effects have received more emphasis in a model representing the health effects of caregiving (Martire & Schulz, 2001). This type of effect is reported to be a result of positive appraisal towards caregiving demands and include positive psychological, effective, behavioural, or cognitive responses. In this model, a positive pathway is triggered by caregiver positive appraisal of stress, leading to a decrease in the risk for developing mental or physical health problems whereas perceived distress leads to negative responses that increase the risk for mental and physical health problems.

Another model including positive outcomes associated with caregiving experiences was described by Mackay et al. (2012). These researchers applied the stress and coping theory proposed by Lazarus & Folkman (1984) as a framework in the research of informal caregivers caring for individuals with a mental illness by providing detailed definitions on the elements incorporated in each compartment of the model. The compartments are represented by background variables (care recipient and caregiver characteristics), interpersonal/cognitive and behavioral processes (coping and appraisal) and adjustment outcomes. Interestingly, the ‘adjustment outcomes’ include positive outcomes such as positive effect and life satisfaction, as well as negative outcomes such as distress. In addition, health is an outcome that can improve or deteriorate as a result of caregiving experiences.

The aforementioned models used to describe the pathways involved in the caregiver stress process present several similarities. All of them include care recipient health characteristics as a primary source of stress, whereas appraisal of caregiving demands triggers distinct pathways that ultimately affects caregiver health in different directions, depending on the appraisal. Although the majority of the models agrees that there are moderators of stress, they are not represented by the same variables. Additionally, some models are very simplistic in their representation (Goode et al., 1998; Haley, Levine, Brown, & Bartolucci, 1987; Vitaliano et al., 1991), while others provide more detailed information on the elements present in each component of the model (Mackay & Pakenham, 2012; Pearlin et al., 1990). More recent models have expanded the concept of consequences of caregiving by adding variables representing positive outcomes (Mackay & Pakenham, 2012; Martire & Schulz, 2001).

These models can provide valuable information when used a framework for caregiver research as well as for guiding the development and evaluation of caregiver interventions. Thus, the caregiver stress model proposed by Pearlin's et al.(1990) will be used as a framework for the research in this dissertation, especially for the chapter where information on the multidimensional aspects of caregiving is included. This model represents a classical stress theory extensively applied in caregiver research and it is based on the vast knowledge of the authors on stress processes (Pearlin, 1989; Pearlin, Menaghan, Lieberman, & Mullan, 1981; Pearlin & Johnson, 1977; Pearlin & Schooler, 1978; Pearlin et al., 1997; Pearlin et al., 2005).

2.6 Caregiver assessments

A myriad of caregiver assessments has been developed over the past 35 years with the aim of measuring different aspects of informal caregiver experiences with the majority of them evaluating the negative impact of caregiving, particularly burden (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003; Harvey et al., 2008; Michels, Boulton, Adams, Wee, & Peters, 2016; Vitaliano, Young, & Russo, 1991; Whalen & Buchholz, 2009).

However, assessments including 'burden' in their name often present items representing other domains (Schene, Tessler, & Gamache, 1994). After reviewing 21 instruments used to assess burden of caregivers of care recipients with severe mental illness, Schene et al. (1994) have found on average 13 dimensions per instrument represented by a scale or a single item. The most common dimensions included were labeled as follows: 1) 'worrying and the effect of care recipient's disorder on family routine', 2) 'effects on leisure', and 3) 'distress' whereas some of the least common dimensions were 1) 'effects on the physical health of the caregiver', and 2) 'caregiver's feeling of guilty and shame'. Additionally, the positives aspects of caregiving and knowledge about the illness were rarely present in these instruments. It is worth mentioning that the authors observed that none of the 21 burden instruments offer levels of risk that could be used in clinical practice to differentiate high versus low risk for negative outcomes based on the assessment of burden.

Whalen and Buchholz (2009) cite the following burden instruments that are commonly used in caregiver studies: Zarit Burden Inventory (ZBI) (Zarit et al., 1980), Caregiver Reaction Assessment (CRA) (Given et al., 1992), Caregiver Burden Inventory (CBI) (Novak & Guest, 1989), Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991) and Cost of care index (Kosberg & Cairl, 1986). Among these, CRA, ZBI and CBI have also been particularly used in studies of caregivers in palliative care (Michels et al., 2016).

Multidimensional instruments that measure several aspects of the caregiver's life may be of particular importance if the objective of the assessment is to understand how factors involved in a caregiver's life affect their experiences and perceptions of burden (Chou, Chu, Tseng, & Lu, 2003). However, the same type of instrument should be used with caution to evaluate interventions. That is, the sensitivity to change of the instrument may be inaccurate if the instrument outcomes mixes items that represent domains that could be affected differently by diverse interventions. According to Schulz (2002) specific measures should be used to identify changes within significant outcomes.

Studies reviewing caregiver assessments points out the lack of evidence on psychometric properties and information on sensitivity to change for several caregiver measures (Chou et al., 2003; Michels et al., 2016; Vitaliano, Young, et al., 1991). As aforementioned, the latter may be a consequence of the unclear construct of the instrument. Unfortunately, most studies carried out for the development of these assessments failed to provide a theoretical approach to explain the concept behind the development of the assessment (Chou et al., 2003).

Additionally, caregiver studies often include convenience sampling where participants are not representative of the general population. Thus, several studies for the development of caregiver assessments include participants caring for care recipients with a specific diagnosis (e.g., cancer, AD). For example, the Caregiver Quality of Life Index - Cancer (CQOLC) was designed based on a study with 263 caregivers of care recipients with lung, breast or prostate neoplasms. In a literature review of instruments used to measure the impact of caregiving of the elderly, most of the reported instruments were developed for assessing caregivers of (in descending order) 1) elderly with dementia; 2) overall elderly; 3) care recipients with cancer; 4) chronically ill care recipients; 5) psychiatric care recipients; and 6) stroke care recipients (Van Durme, Macq, Jeanmart, & Gobert, 2012).

Although cognitive impairment and behavioural symptoms of care recipients with dementia impose challenges to caregivers that are distinct from the challenges faced by caregivers of a care recipient with other health issues, a caregiver assessment should be able to identify the impact of caregiving in their lives regardless of the care recipient health characteristics (Yeatman et al., 1993). In this way, the instrument could be used in different care settings to identify caregivers at risk. Moreover, as previously discussed, there is strong evidence indicating that burden occurs regardless of the care recipient symptoms or functional status (Garlo et al., 2010).

The type of answers and questions of the caregiver assessment may interfere with the assessment accuracy. The Caregiver Strain index (CSI) (Robinson, 1983), used widely to assess caregivers of stroke care recipients, provides only dichotomous answers and therefore does not capture the nuances of the feelings associated with caregiving activities that could reflect changes as a result of an intervention. Moreover, the well-known ZBI scale presents questions that may result in acquiescence bias which would interfere in the evaluation of interventions. Thus, the inclusion of response sets that captures variations in caregiver feelings and questions that represent accurately the outcome measured are necessary features for an instrument sensitive to changes. Moreover, studies for the development of a valuable instrument should include representative sample of caregivers to allow for rigorous psychometric tests.

2.6.1 The 'Burden Interview'

The Burden Interview developed by Zarit (ZBI) and colleagues (Zarit et al., 1980) is undoubtedly one of the most common assessment used to evaluate caregiver burden (Michels et al., 2016), especially for those caring for care recipients with dementia (Bedard et al., 2003; Van Durme et al., 2012). Systematic reviews on instruments used to evaluate caregivers of care recipients receiving palliative care indicated a lack of information on the reliability and validity of ZBI for this cohort (Hudson et al., 2010; Michels et al., 2016).

The reason for the higher use of this assessment among caregivers of care recipients with mental illness is related to the ZBI origin, which was developed in a study including a small group (n=29) of caregivers of elderly people with dementia (Zarit et al., 1980). Although the first version consisted originally of 29 items, today there are several variations of ZBI used in caregiver research, such as short versions and the currently most common one with 22 items.

This scale has also been translated to several languages such as Portuguese, Spanish and Japanese (Taub, Andreoli, & Bertolucci, 2004).

One of the main criticisms about the ZBI relates to its unidirectional wording that may cause acquiescent response bias, where respondents have a tendency to provide affirmative answers to the questions (Dillehay & Sandys, 1990). Further, Garlo et al. (2010) argue that the ZBI does not have a well-defined threshold for high burden to identify caregivers that would be identified at risk of adverse outcomes. The lack of a clear threshold is likely a consequence of the variations in the sensitivity and specificity of the cut-off scores in different studies (Bédard et al., 2001; O'Rourke & Tuokko, 2003). Because ZBI is the most commonly used instrument to measure burden, some authors assume that the reliability estimates that have been generated by previous studies can be directly applied across populations and therefore they neglect the calculation of this measure in their study (Bachner & O'Rourke, 2007). As a result, the reliability of ZBI is not always reported across the studies applying this instrument (Bachner & O'Rourke, 2007). Moreover, discriminate and predictive validity of the ZBI have not been well established and external validation is still needed (Bachner & O'Rourke, 2007; Chou et al., 2003).

Another barrier to the effectiveness of ZBI in measuring caregiver burden is related to the different types of burden included in this instrument. More specifically, the ZBI measures 'personal strain' (subjective burden) and 'role strain' (objective burden), the latter being less sensitive to changes due to an intervention aiming to reduce distress (Knight et al., 1993; Kumamoto & Arai, 2004). Several studies have indicated that caregiver's perception of distress involved in their role may be different than the actual intensity or number of tasks performed by them (Garlo et al., 2010). Thus, the lack of distinction between objective and subjective burden in the ZBI scoring may yield unclear outcomes (Acton & Kang, 2001; Vitaliano et al., 1991).

In summary, although the ZBI has been widely used in caregiver research the lack of threshold for caregiver burden and the existence of two-factor measures may explain its poor sensitivity to change in intervention studies (Acton & Kang, 2001; Knight et al., 1993; Martire, Lustig, Schulz, Miller, & Helgeson, 2004). Thus, it is suggested that other caregiver measures should be used to select and evaluate changes in caregiver emotional distress.

2.7 Caregiver needs

The term ‘caregiver needs’ refers to an identified problem, whereas the term ‘unmet needs’ indicates that a certain service necessary to deal with the issue has not been received (Lambert et al., 2012).

An unmet need may lead to poor outcomes such as high burden and depression (Black et al., 2013; Heckel et al., 2015; Stirling et al., 2010; Wancata et al., 2005). Although research about the impact of caregiving on caregiver health outcomes is substantial, less focus has been given to studies on caregiver needs (Silva, Teixeira, Teixeira, & Freitas, 2013). For example, the number of instruments developed to assess needs is lower than the number of burden instruments (Deeken et al., 2003; Michels et al., 2016). In addition, most of these instruments have not been validated (Deeken et al., 2003) or present an unclear definition of ‘need’ limiting comparisons between studies (Lambert et al., 2012). Researchers have reported a distinction between ‘normative need’ (i.e., burden assessment) and ‘felt need’ (i.e., caregiver expressing which services they would like), the latter being associated with objective measures of distress (Stirling et al., 2010).

Informal caregivers report the need of services that offer: 1) respite from caring responsibilities; 2) emotional support and 3) social support (Silva et al., 2013; Wancata et al., 2005; Yedidia & Tiedemann, 2008). They also have expressed their need for more information on 1) coping strategies to better manage care recipient behaviour; 2) disease progress; 3) impact of care recipient disease on family; 4) legal and financial support; and 5) services available (Hirakawa, Kuzuya, Enoki, & Uemura, 2011; Silva et al., 2013; Stirling et al., 2010; Wancata et al., 2005; Yedidia & Tiedemann, 2008).

After interviewing 40 caregivers caring for care recipients with some degree of cognitive impairment, researchers reported that caregivers place highest priorities needs on: information about available services, stress management and coping strategies, and help with financial issues and insurance coverage (Yedidia & Tiedemann, 2008). The need for improving communication with care professional has been also reported as one key issue (Silva et al., 2013). Although care professionals may improve communication by providing information on the progress of the disease and what to expect, sometimes they may not be knowledgeable enough on specific topics nor familiar about the resources available in the community to direct caregivers (Jennings et al., 2015).

Interestingly, in a study on the needs of caregivers of persons with dementia, those caregivers with less education and more symptoms of depression were more likely to report unmet needs related to referral to community resources (i.e., Alzheimer's Society) that could provide key information on the impact of dementia (Black et al., 2013). These results are in alignment with research showing the association between caregiver low-self efficacy and their poor mental health (Gilliam & Steffen, 2006; Marziali et al., 2010).

Informal caregivers may need assistance in several aspects of their life. Particularly, caregivers caring for care recipients with dementia have expressed their unmet needs related to knowledge about care, related support services, respite, emotional and financial support (Lai &

Chung, 2007; Vaingankar et al., 2013). Their needs may also differ along the different stages of care recipient dementia. Those caring for care recipients with more severe dementia have expressed higher need for information on how to provide dementia care, such as dealing with behavioural and psychological symptoms (Hirakawa et al., 2011).

Other cohorts of caregivers have also reported multiple areas of needs. Family caregivers of elderly persons with depression receiving nursing interventions as part of home health care expressed needs for support and respite and also a desire to learn more about their tasks, role change and stress management (Farran, Horton-Deutsch, Loukissa, & Johnson, 1998).

However, caregiver ‘wants’ does not necessarily match with ‘needs’. It is not uncommon for caregivers experiencing distress to decline respite services. A study on caregiver attitude towards respite services found that 37% of the caregivers, although in need of respite as determined by higher subjective burden, did not ask for it. Some of the reported reasons were 1) care recipient resistance (did not want other person caring for them); 2) caregiver felt that they were the best person to take care of the care recipient; and 3) caregiver felt that caregiving is their responsibility. Additionally, caregivers of care recipients with early stage dementia reported that they often do not accept help due to fear of stigma and barriers in acceptance of the disease (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015). Further studies are needed to understand how to approach these caregivers and offer services that could alleviate distress without causing uneasiness (Van Exel, De Graaf & Brouwer, 2008).

It is pivotal to understand the unique needs of the caregivers, since there is not a single type of intervention that would be suitable for all (Sörensen et al., 2002). Moreover, a distinction between the assessment of their unmet needs and its impact on their well-being would facilitate tailored care planning. In fact, most interventions aim to minimize caregiver emotional distress instead of attend caregiver unmet needs (Gaugler et al., 2004; Gaugler, Kane, Kane, & Newcomer, 2005b). This gap on the assessment of caregiver needs as part of the development of interventions may explain, at least in part, the weak results on the effectiveness of interventions (Hogan, Linden, & Najarian, 2002; Sörensen et al., 2002a).

In summary, assessment of caregiver unmet needs in conjunction with caregiver mental health assessment would allow more refined and likely more successful interventions. Also, caregiver needs should be included in conceptual stress models (Gaugler et al., 2004) for better understanding the link between unmet needs and caregiver outcomes.

2.8 Caregiver interventions

Several studies have reported how different types of interventions, including a wide range of services and strategies, affect caregiver lives (Schulz et al., 2002). Examples of interventions include caregiver respite (Kosloski & Montgomery, 1995), counselling programs and (Mittelman et al., 1993), support groups (Mittelman et al., 1996; Mittelman et al., 2006; Whitlatch et al., 1991) to improve caregiver mental health and well-being (Mossello et al., 2008) while others may offer psychosocial strategies (Koivisto et al., 2016) to enhance a caregiver’s ability to execute their tasks and cope with the care recipient needs (Pusey & Richards, 2001; Tang & Chan, 2016). Interventions may incorporate multiple or single approaches depending on its aim.

Schulz and colleagues, divided the outcomes of caregiver interventions in four groups: 1) symptomatology (i.e., anxiety, depression); 2) quality of life; 3) social significance (i.e., service utilization, institutionalization) and 4) social validity (i.e., program recommendation) (Schulz et al., 2002). The majority of the studies on caregiver interventions evaluate changes in caregiver emotional and mental health, being depressive symptoms one of the main outcomes measured by assessments that are not caregiver-specific (Mosquera et al., 2016; Sörensen et al., 2002).

Unfortunately, most of studies on the effects of caregiver interventions on general well-being have shown only small or no effect on the measured outcomes (Peacock & Forbes, 2003; Pusey & Richards, 2001; Schoenmakers, Buntinx, & DeLepeleire, 2010b; Schulz et al., 2002; Sörensen et al., 2002; Zarit, Anthony, & Boutselis, 1987). Potential reasons are methodological in nature such as small sample sizes, selection bias during participant recruitment (Pusey & Richards, 2001) or the use of inappropriate assessments (Mosquera et al., 2016).

A recent meta analytic study on the tools used to measure the impact of elderly caregiving found that a significant number of instruments used to assess the impact of caregiving on caregiver's lives were not validated using criteria such as construct, predictive, criterion or convergent validity (Mosquera et al., 2016). Moreover, the evaluation of the effectiveness of interventions frequently fail to take into account factors that may moderate the impact of interventions such as caregiver and care recipient age, their relationship, caregiver gender, information on supports available, initial burden and characteristics of the study (Sörensen et al., 2002).

Evaluation and comparison of effectiveness of interventions may be complicated as studies present differences often methodological in nature or include distinct strategies that could influence outcomes (Gaugler, Jutkowitz, Shippee, & Brasure, 2016). While psychosocial interventions may include skill building psychoeducation, information-based psychoeducation, mood management for caregivers, and case management, outcomes may include changes in areas such as self-efficacy, anger, depression and burden. Moreover, each type of outcome may be measured by different assessments complicating even more any comparisons. One alternative is using meta-analytic methods for identifying key information on studies that evaluate similar interventions (Parker, Mills, & Abbey, 2008; Pinquart & Sörensen, 2006b; Sörensen et al., 2002).

A meta-analytic study on the effectiveness of caregiver interventions showed larger effects for those interventions that increased caregiver ability and knowledge on the care recipient needs compared to those addressing caregiver burden and depression (Sörensen et al., 2002). However, the impact of psychosocial interventions on caregivers often present contrasting outcomes. While a study demonstrated that improving caregiver knowledge on how to provide care or how to act in an emergency situation had a positive impact on caregiver mental health (Alves, Teixeira, Azevedo, Duarte, & Paúl, 2016) another study showed that providing education, support and counselling for caregivers of care recipients with AD did not affect their quality of life (Koivisto et al., 2016).

In the previous section, some of the most important needs reported by caregiver relates to the better understanding on care recipient disease and its progress, particularly for those caring for care recipient with dementia. Thus, it is not surprising that two meta-analytical studies on interventions for caregivers of care recipient with dementia indicated that studies including psychoeducational interventions showed positive effects on several caregiver outcomes (Parker et al., 2008; Pinquart & Sörensen, 2006b) highlighting the importance of assessing their unique needs.

Moreover, because caregivers have diverse needs, improvements in caregiver well-being and depression may be more likely to occur in studies that apply holistic interventions. A recent study showed that an intervention for caregivers of care recipient with dementia aiming to provide assistance in different aspects of their role, such as developing problem-solving skills, managing emotions and increasing their knowledge of dementia, resulted in a significant reduction of caregiver burden (Chen, Huang, Yeh, Huang, & Chen, 2015). In support of these findings, a systematic review of interventions aiming to assist caregivers of care recipient with dementia found that psycho-educational and multi-component interventions were associated to improvement in subjective well-being (i.e., anxiety, anger, distress, affect and morale) and depression, although burden was not affected (Parker et al., 2008).

Whitlatch (1991) pointed out some factors to be considered before an intervention takes place in order to obtain stronger effects: 1) goals that caregivers have for themselves; 2) initial levels of distress; 3) the chronicity of the stressors experienced by caregivers and 3) length of the intervention. In addition, the necessity for more precise measures to evaluate caregiver outcomes has been highlighted by other researchers (Acton & Kang, 2001). This is also crucial when selecting participants as accurate assessments are fundamental for identifying caregivers that are experiencing the issue targeted by the intervention. In addition, identifying the target population correctly increases the chance to obtain meaningful changes in the outcome evaluated by the intervention (Schulz et al., 2002).

The goals of the intervention should also be tailored for the different caregiving dyads. For instance, since AD is a degenerative disease, the expectations of the intervention should consider the degenerative nature of AD and its impact on caregiver distress with changes in the severity of the disease. In this case, minimizing the impact of the disease on caregiver well-being or delaying its decline would be a more realistic goal of the intervention than aiming for a complete elimination of the issues related to caregiving (Zarit & Leitsch, 2001).

In summary, interventions that: 1) include a combination of strategies (multi-components); 2) attend to the needs of caregiving dyad; and 3) have the active participation of caregivers, seem to produce better results than interventions that use a more restricted approach. Moreover, effective assessments that identifies a target population and their unique needs likewise well-defined outcomes are fundamental not only for developing but also for evaluating successful interventions.

Chapter 3

EVALUATION OF THE PSYCHOMETRIC PROPERTIES OF AN INFORMAL CAREGIVER SURVEY BASED ON INTERRAI ASSESSMENTS

3.1 Introduction

Informal caregiving is represented by a multidimensional construct that involves positive and negative experiences (Hunt, 2003; Pearlin et al., 1990). Informal caregivers are exposed not only to a myriad of stressors that affect their physical and psychological health (Pearlin et al., 1990; Vitaliano et al., 2014; Vitaliano et al., 2003), but also to experiences that may bring positive meaning in their lives, improve self-esteem and enhance life satisfaction (Beach, Schulz, Yee, & Jackson, 2000; Cadell et al., 2014; Kruithof et al., 2012).

Psychosocial resources, including appraisals, coping and social support, may moderate the effects of stress on caregiver health (Goode et al., 1998; Martire & Schulz, 2001; Pearlin et al., 1990; Vitaliano, Russo, Young, Teri, et al., 1991) complicating the understanding of the impact of informal caregiver experiences on physical and mental health. Thus, a comprehensive assessment that includes the key multidimensional domains involved in caregiver role is an essential component of caregiver research.

A substantial number of caregiver assessment instruments have been developed over the past 35 years (Deeken et al., 2003; Harvey et al., 2008; Schene, Tessler & Gamache, 1994; Van Durme et al., 2012); however, studies done to develop these instruments often failed to obtain a representative sample of informal caregivers or key information on various aspects of their lives (Keefe, Guberman, Fancey, Barylak, & Nahmiash, 2008). Moreover, while most assessments emphasize burden evaluation, fewer instruments have been developed to assess the quality of life of caregivers or their needs (Deeken et al., 2003; Harvey et al., 2008; Van Durme et al., 2012).

A review of tools used to measure the impact of informal elderly caregiving reported a lack of sufficient validation of many of the assessments (Mosquera et al., 2016). It is not uncommon that instruments developed to assess caregiver outcomes present untested psychometric properties or unclear definition of the outcome measured (i.e., objective vs subjective burden) (Bedard et al., 2003; Deeken et al., 2003; Vitaliano, Young, et al., 1991). The lack of association between caregiver burden scores and clinical mental health measures (i.e., depression symptoms) in most studies is noteworthy, since the uses of caregiver assessments should include identification of potentially treatable symptoms as a means of targeting interventions.

An effective assessment should allow caregivers to express different levels of psychological distress or mood related symptoms. For example, dichotomous responses (i.e., yes or no) to questions related to mood do not capture a wide spectrum of the item measured (i.e., sadness, distress, anger). This is a major problem since it limits the assessment ability to identify changes in caregiver mood that could result from an intervention (Deeken et al., 2003). The effectiveness of the assessment may be also compromised with the presence of unidirectional wording resulting in acquiescence bias (Dillehay & Sandys, 1990).

Sensitivity to change is fundamental for evaluating the success of an intervention involving informal caregivers particularly for 1) selecting participants that would potentially benefit the most from such interventions (Deeken et al., 2003) and 2) evaluating changes in the caregiver’s life as a result of an intervention. Yet, most caregiver assessment used to evaluate caregiver interventions have been unable to identify changes in caregiver burden, the major measure evaluated in caregiver research (Acton & Kang, 2001; Vitaliano et al., 1991).

Another limitation of existing caregiver research is that many studies were based on participants taking care of care recipients with a specific disease diagnosis (particularly dementia) which limits generalizability to other groups of caregivers (Van Durme et al., 2012; Weitzner, Jacobsen, Jr, Friedland, & Cox, 1999; Zarit et al., 1980). Caring for care recipients with health issues other than dementia (e.g., health instability, depression) can be also stressful and burdensome for caregivers, even though the challenges faced by them may differ (Hirdes, Freeman, Smith, & Stolee, 2012; Liptzin, Grob, & Eisen, 1988; Yeatman et al., 1993). In fact, the burden of caregivers of care recipients with depression may be as high as for those caring for care recipient with dementia (Liptzin et al., 1988). Nonetheless, the bulk of caregiver research has focused on the impact of caring for care recipient with dementia on caregiver burden (Van Durme et al., 2012).

The objective of this chapter is to examine whether an informal caregiver survey used to assess distressed caregivers of care recipients with diverse diagnoses and high care needs is a valid and a reliable instrument for assessing caregiver distress. For that, construct and convergent validity methods as well as a reliability test will be used.

3.2 Method

3.2.1 Design and sample

This is a non-experimental longitudinal cohort study involving informal caregiver participants of the Caregiver Recharge Services (CRS), an initiative funded by Mississauga Halton Local Health Information Network (MH LHIN). This program started in April 2012 in response to feedback provided by community representatives during the Integrated Health Service Plan (IHSP) engagement sessions. The community representatives identified that informal caregiver burnout is a significant issue. They also indicated that informal caregivers would not rely as heavily on long-term care if there were more supports available at home to provide the care their care recipients need. The CRS was developed in response to these identified concerns and offers flexible hours of respite to be used based on the needs of the caregiver. According to the CRS, an informal caregiver, is a volunteer, friend, neighbour, or relative providing unpaid, in-home care to an adult, sibling, spouse, parent or other relative with disabilities. Therefore, the term ‘caregiver’ used in this study refers to the aforementioned definition.

This program provided in-home service 24 hours a day, seven days a week. Eligible caregivers were able to use a minimum of 2 hours of service per visit to the maximum hours that were allotted to them at any time within the year. The maximum hours per year varied with the Caregiver Strain Index (CSI) score used to determine eligibility of the caregiver.

The in-home services were performed by personal support workers that provided assistance with 1) activities of daily living (e.g., ambulation, one person transfer, dressing/undressing, personal hygiene, bathing), 2) instrumental activities of daily living (e.g., homemaking, meal preparation, assistance with eating and medications) and also companionship (e.g., some recreational activities, redirection/prompting/cueing, prevention of wandering, safety checks). Personal support did not include intensive nursing care, medication administration, transportation or transfers that require two people. Thus, CRS provided respite to caregivers by offering assistance on activities that are usually performed by informal caregivers. The goal was to reduce caregiver distress and allow them to continue caring activities, consequently reducing avoidable admissions of care recipients to long-term care that often occurs due to caregiver distress.

The referral sources for the CRS were: Mississauga Halton Community Care Access Centre, community support service providers (e.g., Alzheimer’s society, Links2Care), hospitals, self/family, Health Links, physicians and other family health teams. Thus, caregivers seeking for respite from CRS were directed to this program by a wide range of health care providers.

During the two years of this study (April 2013 to April 2015) the respite was offered for a year period after which the caregivers needed to reapply again to participate in the program.

3.2.2 Selection criteria of participant caregivers

To participate in the CRS, caregivers were assessed using the Caregiver Strain Index (CSI) an instrument to evaluate caregiver burden with scores ranging from 1 to 13. (Robinson, 1983). Caregivers were eligible to participate in the program if their CSI assessment score was 9 or higher.

In addition to the CSI eligibility criteria, only those caregivers providing care for care recipients with a MAPLe (Method of Assessing Priority Levels) score of 4 or 5 were accepted into the program. This algorithm is an outcome measure of the Resident Assessment Instrument Home Care (RAI-HC) and the interRAI Community Health Assessment (CHA).

Caregivers of care recipients with an ‘end of life designation’ determined by an interRAI Palliative Care assessments were also eligible to participate in the CRS. All eligible caregivers were at least 18 years old and resided in the MH LHIN catchment area.

A number of assessment data sources were used for the study and are outlined below.

3.2.3 Care recipient assessments

All care recipients had an interRAI CHA, RAI-HC or interRAI Palliative Care assessment. These instruments are part of the interRAI suite of assessments developed by a group of researchers from over 35 countries around the world. They have been mandated or recommended for use in nine provinces and territories in Ontario as well as in several locations in the world such as in Europe, USA, the Middle East, Central and South America. Moreover, these instruments have well established reliability as reported by several studies (Carpenter & Hirdes, 2013; Hirdes, Ljunggren, et al., 2008; Landi et al., 2000; Poss et al., 2008).

3.2.3.1 interRAI Community Health Assessment (CHA) – In 2010, the Ontario Ministry of Health and Long-Term care (MOHLTC) initiated the use of the interRAI CHA by all community support organizations to evaluate the needs and preference of the clients receiving support services. The interRAI CHA includes a core assessment that may trigger the further assessment of specific problems using one of the four supplements available: functional, mental health, the deaf-blind, and the assisted living supplement. For the most part, care recipients in the CRS were assessed using the core and functional supplement.

3.2.3.2 Resident Assessment Instrument Home Care (RAI-HC) – The RAI-HC has been mandated in Ontario since 2002 for the assessment of Community Care Access Centres (CCAC) clients expected to be on service for more than 60 days. This comprehensive assessment has items that are compatible with other interRAI instruments such as the interRAI CHA. This compatibility allows for a crosswalk between items from these assessments, resulting in a larger sample size for the analysis linking the caregiver survey with care recipient information.

3.2.3.3 Clinical scales of interRAI CHA and RAI-HC

Several scales can be calculated using similar items in the interRAI CHA and RAI-HC. Evidence has shown the good validity and reliability of items and scales in these instruments (Hirdes, Ljunggren, et al., 2008; Morris et al., 1997; Poss et al., 2008). These scales represent different clinical aspects of the care recipient health and they are often related to outcomes and measures such as death, long term care admission or caregiver distress (Landi et al., 2000).

The Method for Assigning Priority Levels (MAPLe)

The MAPLe score is intended to assist health care providers in identifying those individuals who have the most urgent need for care (Hirdes et al., 2008). MAPLe scores range from 1 to 5 with higher scores indicating a higher priority for care. This algorithm can also be used to inform choices related to allocation of home care resources and prioritization of clients needing community or facility-based services. MAPLe scores were used as part of the eligibility criteria of this program mainly due to evidence on its strong association with caregiver distress (Health Council of Canada, 2012; Hirdes et al., 2008; Mitchell et al., 2015) and LTCH admission (Hirdes et al., 2008). Admission criteria to the CRS required that the care recipient had a MAPLe score of 4 or 5.

The Depression Rating Scale (DRS)

The Depression Rating Scale is a depression scale derived from a combination of assessor rated mood items present in interRAI assessments (i.e., interRAI CHA and RAI-HC) that has been tested against well-known interview-based depression scales (Burrows, Morris, Simon, Hirdes, & Phillips, 2000). This scale ranges from 0 to 14 where the scores are combined in four groups: 0 - ‘no depression’, 1-2 ‘some symptoms of depression’, 3-5 ‘possible depression’ and > 6 ‘possible severe depression’. The Depression Rating Scale has been evaluated in studies including care recipients from various settings such as home care (Dalby et al., 2008; Szczerbińska, Hirdes, & Życzkowska, 2012), long-term care (Huang & Carpenter, 2011; Koehler et al., 2005), acute care (Hirdes et al., 2002) and complex continuing care (Gruneir, Smith, Hirdes, & Cameron, 2005; Martin et al., 2008) and it has been also recently validated in the palliative care population (Fisher, Seow, Brazil, Smith, & Guthrie, 2015).

Activities of Daily Living Hierarchy Scale (ADL-H): The ADL Self-Performance Hierarchy Scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss. Early-loss ADLs are assigned lower scores than late-loss ADLs. Scale scores range from 0 to 6, with higher scores indicating greater decline (progressive loss) in ADL performance (Landi et al., 2000; Morris et al., 1997; Morris, Fries, & Morris, 1999).

Cognitive Performance Scale (CPS): A hierarchical index used to rate a person's cognitive status. The scale scores range from 0 to 6, with higher scores indicating more severe impairment. This scale has been validated against the Mini-Mental State Exam (MMSE) for the detection of cognitive impairment (Jones, Perlman, Hirdes, & Scott, 2010; Landi et al., 2000; Morris et al., 1994; Paquay et al., 2007; Wellens et al., 2013).

Some of the scales and other information were used to describe clinical health of care recipients with a caregiver participating in this study (Table 3.1).

Table 3.1 Characteristics of care recipients and their respective caregivers (n=316)

	% (n)
Caregiver characteristics	
Co-reside	94.3 (298)
Relationship – spouse	48.1 (152)
Relationship – Child/ child-in-law	44.3 (140)
Unable to continue caregiving	32.2 (108)
Distress, anger or depression	62.6 (198)
Has a secondary helper	17.7 (49)
Care recipient characteristics	
Gender – female	47.8 (87)
Primary language - English	72.8 (134)
Age group (years)	
<65	12.6 (40)
65-74	14.5 (46)
75-84	36.3 (115)
85+	36.3 (115)
Cognitive Performance Scale	
Intact or borderline intact	6.0 (19)
Mild/Moderate	57.9 (183)
Moderate/Severe	33.2 (105)
Very severe	2.8 (9)
Activity of Daily Living Hierarchy Scale	
Independent	11.8 (37)
Supervision required/Limited impairment	30.9 (97)
Extensive assistance required	37.7 (118)
Dependent/total dependence	19.4 (61)
Behavior Symptoms	
Wandering	10.4 (33)
Verbally abusive	10.1 (32)
Resists care	15.5 (49)

*Note: In some cases, the number of cases is less than the full sample size because missing data are excluded.

Table 3.1 Cont.

Disease diagnosis	% (n)
Dementia	57.3 (181)
Chronic obstructive pulmonary disease	10.1 (32)
Stroke	20.5 (65)
Congestive heart failure	6.9 (22)
Coronary heart disease	19.3 (61)
Cancer	7.9 (25)

3.2.4 Caregiver assessments

3.2.4.1 Caregiver Strain Index - All caregivers were assessed through CSI for determination of their eligibility. The CSI is a screening instrument developed to identify caregivers at risk of burnout. It includes 13 questions that reflect the perceptions of the caregivers on their responsibilities and also provide information on their emotional health (Robinson, 1983). The answers are dichotomous (yes or no) and higher scores are associated with higher risk of burnout.

3.2.4.2 The caregiver survey – This survey was developed by interRAI researchers based on other interRAI self-reported Quality of Life assessments, including the interRAI/Kendal Corporation Collage initiative “Wellness” assessment and the interRAI Quality of Life Self-report surveys for Home Care/Community Living, Senior Housing, and Mental Health. The Wellness Assessment is a self-rated assessment that addresses issues related to a person’s psychosocial, cognitive, health status, and daily functioning based on items from interRAI community assessments. The interRAI Quality of Life surveys are self-report surveys that address a number of issues, including self-determination, mood, social participation and community involvement, social ties, and belonging (Kehyayan, Hirdes, Tyas, & Stolee, 2015a, 2015b). All items from these self-report surveys were considered for the caregiver survey, with or without modifications. Over the course of a number of revisions, a pilot caregiver survey was finalized with a total of 82 items covering a range of domains including demographic information, physical and emotional health, caregiving responsibilities, well-being, and quality of life. The caregiver surveys were linked to 314 care recipient assessment being 170 interRAI CHA and 144 RAI-HC. All care recipient assessments were done as part of clinical practice within 3 months of their CSI assessment. The interRAI palliative assessment were excluded from the analysis due to the small sample size (n=20).

3.2.5 The caregiver survey interview protocol

Three health service providers (HSP), Links2Care, Home Instead, and AbleLiving, were responsible for introducing the caregiver study to caregivers during their first visit by providing a letter and asking caregivers consent to participate in the study. The consent would then be sent to University of Waterloo together with caregiver phone number and name. A University of Waterloo member (i.e., PhD student, undergraduate student volunteers, and research assistant) would interview the caregiver on the phone, taking in average 20 min for completion. All the interviewers were trained by an interRAI clinical educator. The surveys were completed before the caregivers received the first services and a second time, after at least 6 months of their participation on the study. The study was approved by the Office of Research Ethics from University of Waterloo (ORE # 18982).

3.3 Statistical Analysis

Validity and reliability tests were performed to evaluate the caregiver survey. The construct validity was examined using factor analysis whereas the association between caregiver survey items with care recipient Depression Rating Scale was evaluated as part of the convergent validity. All statistical analyses were carried out using Statistical Analysis System (SAS) version 9.4.

3.3.1 Construct Validity

The exploratory factor analysis (EFA) was used to examine if there is an association between the items in the survey and an underlying construct.

3.3.1.1 Preparing the dataset

As a first step, results of frequency analyses of 533 caregiver surveys were examined and a total of 24 items were removed based on low variability (i.e., at least 85% of the sample sharing the same response for the same question). In addition, a total of 14 items were removed because they could not be directly related to the presence of distress per se (i.e., gender, age, living arrangement, primary language, number of visits to the physician/hospital/emergency room, disease diagnosis, full time/part time job etc). For example, pain caused by a disease, rather than a disease diagnosis, could be related to caregiver distress. Thus, after removing 38 items, the initial factor analysis included 44 items.

Second, the distribution of missing values in the dataset was evaluated to determine whether they were randomly distributed. Third, an imputation method was used to replace missing values with mean values to avoid a decrease in the sample size without resulting in bias since the missing values were randomly distributed. Last, the scoring of reverse-phrased items was reversed.

3.3.1.2 Evaluation of the data appropriateness for factor analysis

Kaiser-Meyer-Okin (KMO) was used to measure sampling adequacy for extracting the factors. A KMO result equal to 0.86 indicated that a factor, or factors, could be extracted from the dataset (Beavers et al., 2013). Then, the Barlett's Test of Sphericity was performed to ensure that the dataset is appropriate for extracting factors. The null hypothesis (no factors) was rejected ($P < 0.0001$) confirming that factors could be extracted.

With regard to correlation between items, none of the variables were highly correlated (i.e., all lower than 0.60) with the exception of pain intensity and pain frequency, which presented a correlation of 0.74. Most of the items had low correlations ($r < 0.30$) and were appropriate for factor analysis according to Beavers et al. (2013).

3.3.1.3 Exploratory factor analysis

Parallel Analysis - A parallel analysis (PA) was performed to obtain the number of factors to be extracted (Figures 3.1 and 3.2). This method overcomes some of the limitations of the Kaiser's method, or mineigen greater than 1 criteria, such as misleading results due to sampling error (Hayton, Allen, & Scarpello, 2004). Parallel analysis is based on Monte Carlo simulation, where factors with actual eigenvalues greater than the average of the eigenvalues generated by random correlation matrices are retained (Hayton et al., 2004). A SAS Macro for parallel analysis was used (Kabacoff, 2003) including 100 iterations to obtain the plot between the actual and simulated eigenvalues (Figures 3.1 and 3.2).

Communality estimation: The communality estimate represents the proportion of the variance of a variable that is shared with other variables in the analysis (Hair Jr, Anderson, Tatham, & William, 1995). The estimates of communalities are supplied for a factor analysis because the proportion of the variance that is common among variables or unique for each variable is unknown. Thus, the prior communality estimate for each variable was set to its squared multiple correlation with all variables using the option PRIORS = SMC in SAS. The variance due to unique factors is eliminated by replacing the 1s on the main diagonal of the correlation matrix with estimates of the variables' communalities (R^2).

Rotation - The types of rotation, orthogonal or oblique, were tested by restricting the minimal loading of 0.30 based on the 'Table of Loadings for Practical Significance' provided by Hair et al. (1998)^{p112}. Items with loadings lower than 0.30 were removed and the analysis re-run until only items with at least 0.30 loading were represented in the final analysis. Both rotations produced loadings higher than 0.30 for the same items with few items loading in two factors. However, the oblique rotation was chosen as the most appropriate type of rotation because it allows the correlation among factors (Hair Jr et al., 1995), aligning with evidence on the interactions between variables representing different aspects of caregiver's life (Beach et al., 2000; Goode et al., 1998; Schulz & Martire, 2004). Thus, the oblique rotation, with 'promax' option in SAS factor procedure was chosen due to the nature of the variables representing caregiving experiences.

3.3.2 Convergent validity

The association between the Depression Rating Scale of the care recipient and caregiver mood items of the caregiver survey were assessed by considering the chi square test results of the frequency analysis in SAS (PROC FREQ). After preliminary analysis, the response set of the items representing quality of life and supports (i.e., section E of the caregiver survey), was dichotomized as 'never, rarely, sometimes' vs. 'most of time, always'. Only the statistically significant results were reported ($P < 0.05$).

3.3.3 Reliability

The reliability of the caregiver survey was assessed using internal consistency analysis. Specifically, Cronbach's alpha, a measure of internal consistency, was used to measure the reliability of the caregiver survey after latent variables with minimal loading of 0.35 were extracted as a result of the factor analysis. Cronbach's coefficient alpha determines the internal consistency by evaluating the average correlation among items within each factor (Cronbach, 1951).

A large overall alpha coefficients indicates that correlated items measure the same construct or concept providing evidence on the reliability of the survey (Tavakol & Dennick, 2011). According to Nunnally and Bernstein (1994), 0.70 is an acceptable reliability coefficient whereas smaller values are likely inadequate. The number of items, their correlation and dimensionality affect the alpha value (Cortina, 1993). The Cronbach alpha was obtained using the procedure 'CORR' in SAS with the 'nomiss'option which ignores missing cases.

3.3.4. Evaluation of positive statements

Frequency of analysis was performed to show the proportions of caregivers reporting 'most of time or always' as a response for positive statements by age group. This category (i.e., age) was chosen because it showed statistically different results among subgroups considered relevant for future research

3.4 Results

3.4.1 Construct Validity

The results of the parallel analysis indicated that 4 factors should be extracted although Figure 3.1 shows 2 factors are very closely related. Thus, the extraction of 4 factors was initially tested. Items with loadings higher or equal to 0.30 were retained based on Hayton (2004) and the analysis re-run. Changing the number of factors from 4 to 3 produced more interpretable results. For example, items related to physical health that were split in two factors merged to the same factor once 3 factors were pre-assigned. Also, a lower number of items presented loadings of 0.30 or higher (i.e, 31 instead of 44) as a result of changing the number of factors from 4 to 3. The plot of the parallel analysis in Figure 3.2 run after retaining only loadings of 0.30 or higher (31 items) clearly shows 3 factors whose actual eigen values were higher than the randomly generated eigen values (Figure. 3.2) providing additional evidence on the presence of 3 factors.

Figure 3.1 Comparison of actual versus simulated eigen values in parallel analysis including 44 variables, 533 observations, 100 iterations

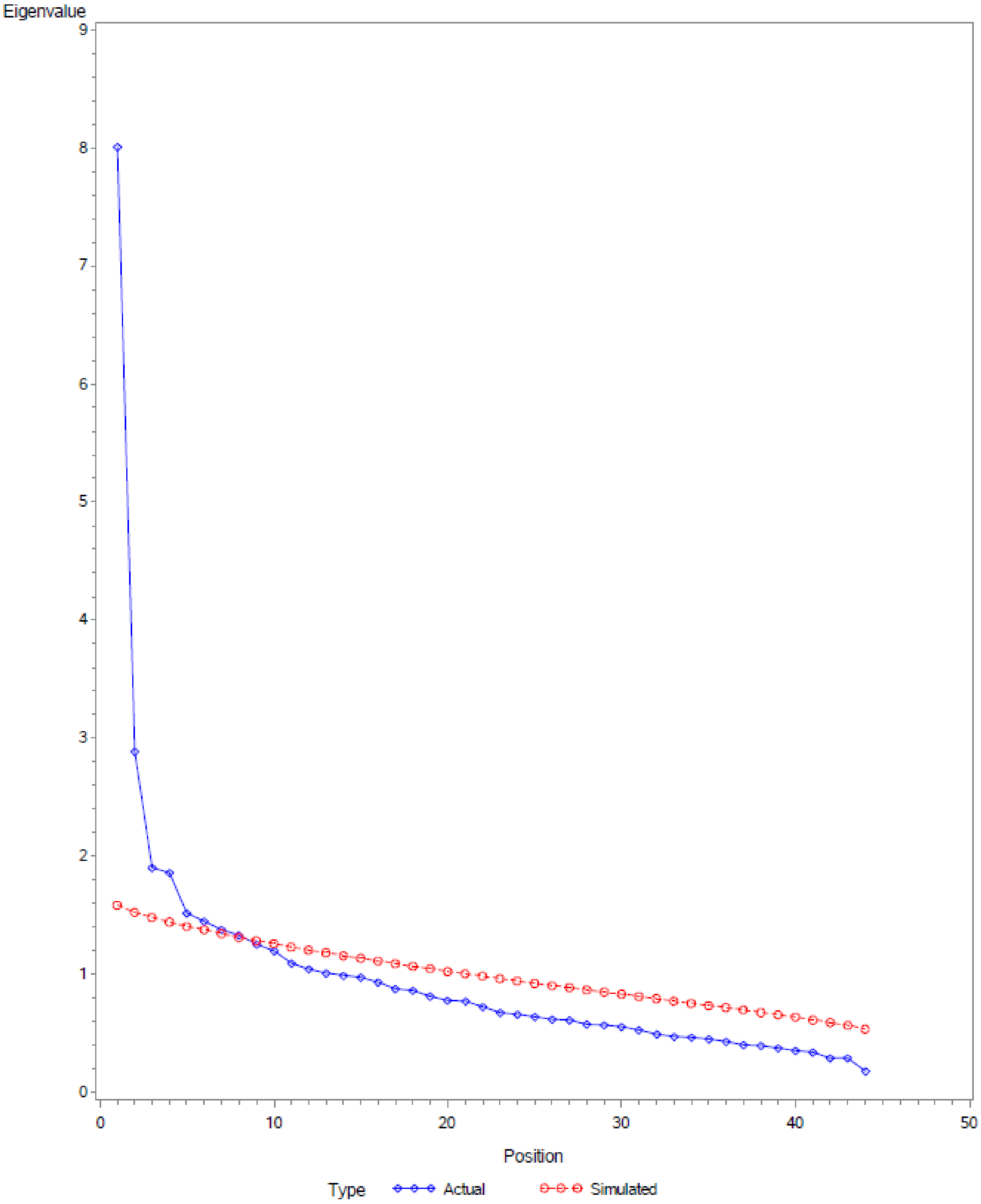
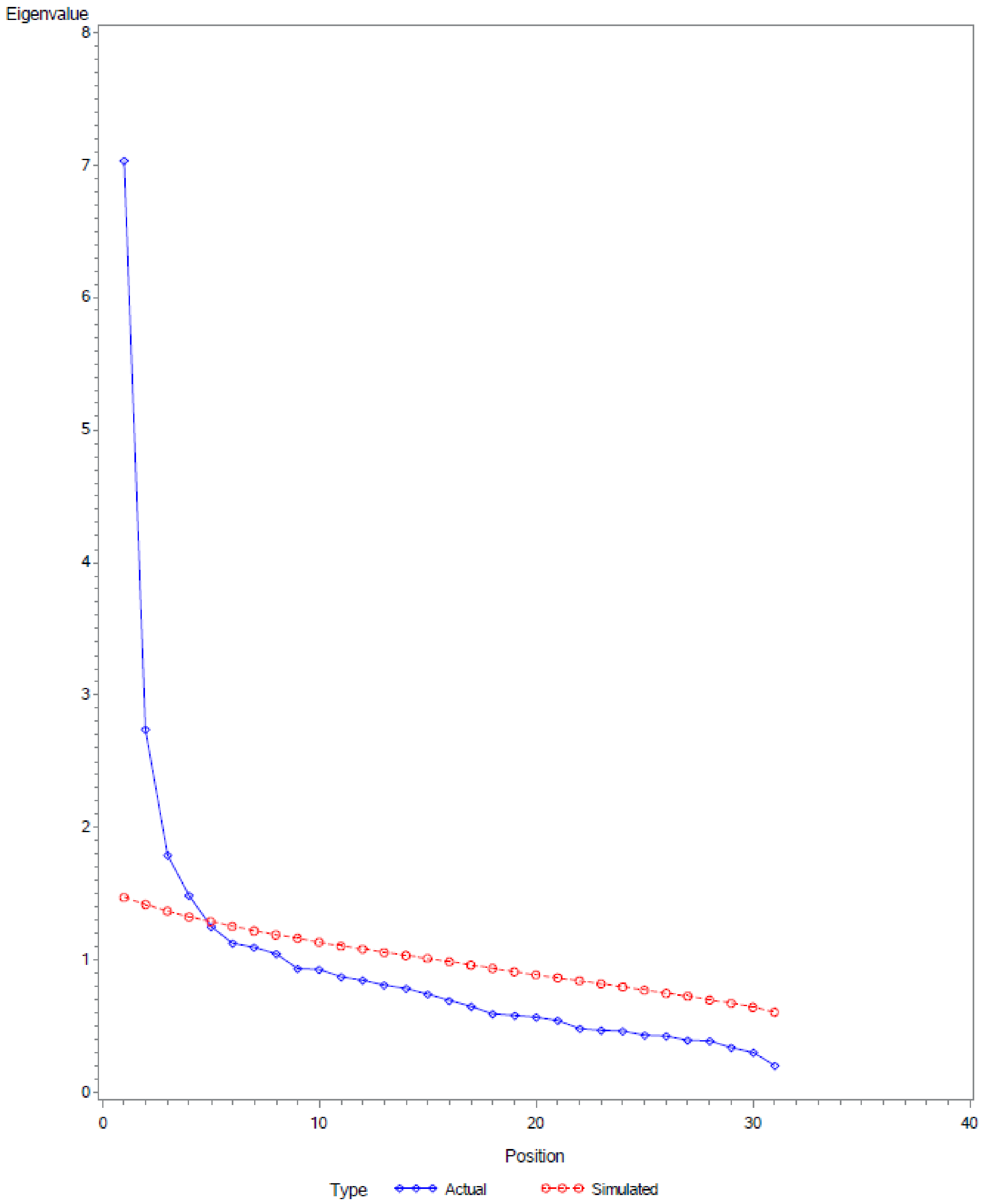


Figure 3.2 Comparison of actual versus simulated eigen values in parallel analysis including 31 variables, 533 observations, 100 iterations



An additional factor analysis was performed after removing items with loadings lower than 0.35 instead of 0.30 for verifying whether the number of factors would change. As a result, the number of factors remained the same as well as the remaining items (n= 25) loaded in the same factors, being consistent with previous results where loadings were higher/equal 0.30.

Thus, the final 3 factors included 25 items with loading higher than 0.35 representing aspects of caregiver’s life that were categorized as follows: physical health (factor 1), psychosocial support and well-being (factor 2), and emotional health (factor 3) (Table 3.2). Items with close loading values in two factors were kept in the final analysis because they likely represent a true correlation between distinct domains (i.e., emotional and physical). Moreover, the meaning of each factor and the ability to interpret the variables should be considered when determining the number of factors to be extracted (Hair Jr et al., 1995). The correlation between factors is presented in Table 3.4.

3.4.2 Reliability

The standardized Cronbach values are presented in Table 3.3 for the respective factors. All values were between 0.76 and 0.83 indicating respectively an acceptable and good internal consistency.

Table 3.2 Factor structure matrix rotated with promax criterion

Items	Item	Factor 1	Factor 2	Factor 3
In the last three days how often have you experienced the following?				
Dizziness	*b9a*	***0.44***	-0.96	0.16
Unsteady when walking	*b9b*	***0.55***	0.03	-0.13
Other pain	*b9d*	***0.75***	-0.03	-0.08
Difficulty falling or staying asleep	*b9h*	0.32	-0.14	***0.39***
In general, how would you rate your health?	*b1*	***0.44***	0.22	-0.03
In the last three days, how much has tiredness affected you?	*b8*	***0.58***	0.04	0.04
In the last three days, what is the highest level of pain intensity that you experienced?	*b10*	***0.75***	-0.04	-0.05
In the last three days, have you had shortness of breath?	*b12*	***0.42***	0.05	-0.04
In the last three days, how often have you experienced little or no pleasure in the things that you normally enjoy?	*b16*	0.14	0.09	***0.40***
In the last three days, how often have you been anxious, restless, or uneasy?	*b17*	0.28	-0.08	***0.51***
In the last three days, how often have you been sad, depressed, or hopeless?	*b18*	0.18	0.07	***0.57***
In the last three days, have you felt overwhelmed by your relative/friend's illness?	*c2b*	0.14	0.03	***0.52***
My relationships with family and friends are good.	*e1a*	-0.05	***0.61***	-0.10
I have people I can count on.	*e1b*	-0.05	***0.58***	0.00
I am hopeful about my future.	*e1c*	-0.01	***0.45***	0.30
I feel good about myself.	*e1d*	0.14	***0.55***	0.13
On the whole, my life is good.	*e1e*	0.01	***0.59***	0.22
I feel valued and respected by others.	*e1f*	-0.01	***0.64***	0.01
I play an important role in people's lives.	*e1g*	0.06	***0.60***	-0.20
I feel part of my community.	*e1h*	0.05	***0.38***	0.19

Table 3.2 Cont.

Items		Factor 1	Factor 2	Factor 3
I participate in meaningful activities.	*e1i*	-0.03	***0.37***	0.25
I can get the health services I need.	*e1j*	0.02	***0.51***	-0.08
If I need help right away, I can get it.	*e1k*	-0.04	***0.43***	0.04
I can be alone when I wish.	*e1o*	-0.22	-0.02	***0.57***
I can go where I want on the "spur of the moment."	*e1p*	-0.16	-0.03	***0.59***
Variance explained by each factor (%)		3.74	4.29	3.92

Table 3.3 Standardized Cronbach alpha values

	Standardized Cronbach alpha values (n)		
Standardized Cronbach alpha values*	0.77 (533)	0.83 (407)	0.76 (511)
Total number of items	7	11	7

*Bolded variables with loadings > 0.35 in Table 3.2 within each factor were used to calculate Cronbach alpha values. Cases with missing values were ignored.

Table 3.4 Interfactor correlations among three factors derived from caregiver survey

	Factor 1	Factor 2	Factor 3
Physical health (Factor 1)	1	0.31	0.44
Psychosocial resources and well-being (Factor 2)	0.31	1	0.50
Mental health (Factor 3)	0.44	0.50	1

3.4.3 Convergent Validity

Table 3.5 shows the proportion of caregivers responding ‘Never, rarely, sometimes’ for the following statements increased with increasing care recipient Depression Rating Scale ($P < 0.05$): ‘On the whole my life is good’, ‘I feel good about myself’, ‘I play an important role in people’s lives’, ‘I feel value and respected by others’ and ‘My relationship with family and friends are good’. In addition, a higher proportion of caregivers responding ‘yes’ to the question ‘In the last three days, have you felt lonely?’ was associated with higher care recipients Depression Rating Scale ($P < 0.05$).

Table 3.5 Relationship between symptoms of depression among care recipients and caregiver reported feelings of loneliness, distress, and feelings towards life.

	Care recipient Depression Rating Scale (DRS)			
	0, 1 or 2	3, 4 or 5	> 5	
Caregiver self-report items	None or some symptoms of depression	Possible depression	Possible severe depression	*P* value
Include only the answer 'yes' to the question below	%	%	%	
In the last 3 days, have you felt lonely? (n=120)	36.4	30.7	60.5	0.008
Include only the combined answers 'Never, rarely or sometimes' for the statements below:				
On the whole my life is good (n = 95)	27.4	40.9	44.5	0.04
I feel good about myself (n=96)	26.9	40.0	46.0	0.02
I play an important role in people's lives (n=58)	15.3	25.5	35.1	0.01
I feel value and respected by others (n=59)	14.2	32.0	34.2	0.001
My relationship with family and friends are good (n=37)	8.68	18.7	25.0	0.007

3.4.4 Evaluation of positive statements

Table 3.6 shows that the proportions of caregivers reporting ‘most of time or always’ for ‘I am hopeful about my future’ was significantly greater for younger caregivers ($P < 0.05$). In contrast, the proportion of caregivers answering ‘most of time or always’ for the statements ‘My relationship with family and friends are good’ and ‘ I feel valued and respected by others’ was greater for older caregivers. There was no statistical differences for the other statements among age groups.

Table 3.6 Percentages of caregivers reporting ‘always or most of time’ for positive statements by age group

	Caregiver age group			*P* value
Caregivers reported that ‘always or most of the time’…	< 60	60-74	75+	
	%	%	%	
My relationships with family and friends are good. (n=283)	80.0	92.5	93.7	0.002
I have people I can count on. (n=236)	73.7	72.5	73.7	0.96
I am hopeful about my future. (n=187)	72.0	55.1	61.4	0.02
I feel good about myself. (n=225)	70.7	66.6	72.5	0.64
On the whole, my life is good. (n=221)	70.5	64.4	75.6	0.23
I feel valued and respected by others.(n=258)	70.4	85.7	90.9	0004
I play an important role in people’s lives. (n=257)	84.3	83.7	74.0	0.14
I feel part of my community. (n=152)	46.7	43.5	56.9	0.17
I manage the stresses in my life. (n=234)	70.4	68.9	82.5	0.08

3.5 Discussion

This study evaluated the psychometric properties of a caregiver survey that includes 5 domains: background information, health, caregiver issues, well-being and quality of life and supports. Exploratory factor analysis yielded 3 factors representing 1) emotional health, 2) physical health and 3) psychosocial resources and well-being.

The results are in agreement with caregiver research models showing that caregiver experiences are represented by equivalent dimensions identified by the factor analysis (Goode et al., 1998; Pearlin et al., 1990). Moreover, the effects of caregiving experiences on caregiver physical and mental health, both represented by factors in this study, are particularly well known (O'Rourke & Tuokko, 2000; Pinquart & Sörensen, 2003, 2007; Vitaliano, 2010; Vitaliano et al., 2014; Vitaliano et al., 2003). In contrast, the impact of psychosocial resources on caregiver health related outcomes is less clear (Goode et al., 1998; Pearlin et al., 1990).

Interestingly, in this study some variables loaded equally in factors representing distinct domains. For example, 'caregiver difficulty falling or staying asleep', loaded in the factor representing emotional health and also on the factor representing physical health. The fact that this item loaded in both factors suggests that caregiver sleep issues are related to different aspects of a caregiver's life. This finding is consistent with other study that identified emotional and physical health, in addition to caregiver's disrupted routine sleep (McCurry et al., 2007; Rowe et al., 2008), as some of the major contributors of sleep disturbance among caregivers (McCurry et al., 2007; Rowe et al., 2008).

The results from the present study are also consistent with Pearlin's and also Goode's stress process models that describes possible mechanisms predicting changes in the mental and physical health of caregivers (Goode et al., 1998; Pearlin et al., 1990). Goode's model, less complex than Pearlin's model, considers coping responses, appraisal and social support as part of psychosocial resources that have direct or indirect influence on a caregiver's mental and physical health. In the present study the items representing appraisal, coping responses, and social support loaded in the same factor labeled as 'psychosocial resources and well-being'. Pearlin's model present a more detailed representation of caregiver stress model that also aggregates coping and social support in the same domain (i.e., mediator). The correlation between the 'psychosocial resources and well-being' factor with factors representing physical and mental health (Table 3.4) is consistent with similar linkages described by Goode's and Pearlin's models.

These outcomes have important meaning in the caregiving research, because they suggest that psychosocial resources and well-being related factors can potentially moderate the negative effects of caregiving on a caregiver's emotional and physical health. These results also align with Vitaliano's model of distress (Vitaliano, Maiuro, Bolton, & Armsden, 1987; Vitaliano, Russo, Young, Teri, et al., 1991), where psychological and social resources may decrease the risk of burden associated with caregiving.

It is possible that the 'psychosocial resources and well-being' factor in this study also relates to meaning in caregiving. A study of parents caring for a child with a life-limiting illness showed that meaning in caregiving was positively and significant correlated with variables corresponding to optimism, appreciation of life, and self-esteem (Cadell et al., 2014). In the present study, similar variables loaded in the 'psychosocial resources and well-being' factor indicating that they share a construct with similar meaning. In particular, the variables representing meaning in caregiving ('I play an important role in people's lives'), appreciation of life ('On the whole, my life is good') and 'self-esteem' ('I feel good about myself', 'I feel valued and respected by others') may reflect positive effects of caregiving. The co-existence of negative and positive feelings as part of caregiver experiences is consistent with Pearlin's model (1990), where personal gain may occur in the presence of role strains.

The present findings show that older caregivers reported more often feeling 'valued and respected by others' and also having 'good relationship with family and friends' than younger caregivers. These results aligns with a study on positive experiences in stroke caregivers which also reported 'feeling appreciated' and 'improved relationship with the person cared for or other family members' (Bacon et al., 2009) indicating a relationship between these positive aspects of caregiving.

In other hand, younger caregivers reported more often 'I am hopeful about my future' than older caregivers. This may be a consequence of older caregivers being worried about their aging related issues. There were not statistical differences among other positive statements reported by the different age groups suggesting that these experiences occur regardless of age. Although the caregiver research on positive effects of family caregiving is not vast, this study suggests that positive feelings may play a key role in promoting the well-being of caregivers as reported by other researchers (Kramer, 1997b; Kruithof et al., 2012; López et al., 2005; Motenko, 1989).

These findings also highlight the importance of positive emotions as part of the coping process during periods of stress as described by Folkman (1997, 2008). For example, in a study involving caregivers of stroke care recipients, the effects of positive caregiving experiences (i.e., self-esteem) was associated with caregiver life satisfaction even when burden was considered high (Kruithof et al., 2012). It seems that the co-existence of negative and positive feelings is one of the features of caregiving experiences where the balance between them will influence caregiver related outcomes.

Care recipient depression, represented by Depression Rating Scale categories, was related to caregiver survey items representing loneliness and feelings about life and esteem. These correlations provide evidence of the convergent validity of the survey and suggest that care recipient depressive symptoms may be related to psychological distress of caregivers. Further, these results agree with research reporting the impact of care recipient depression on caregiver quality of life and mental health (McCusker, Latimer, Cole, Ciampi, & Sewitch, 2007) after controlling for hours of care provided and care recipient comorbities and disabilities (Sewitch, McCusker, Dendukuri, & Yaffe, 2004).

The present findings also provide evidence for research on ‘depression contagion’ where depressive symptoms of one person causes the same type of symptom on their dyad (Coyne et al., 1987; Goodman & Shippy, 2002). Unfortunately, research on the consequences of caring for individuals with depression is scarce compared to studies on the burden of caring for care recipient with dementia (Sewitch et al., 2004), even though there is evidence that burden of caregiving for individuals with depression can be as high as for caregivers of care recipient with dementia (Liptzin et al., 1988).

It is important to note that the impact of depression among caregiving dyad may be affected by the stress associated with caring activities. Research has shown that caregiver burden may mediate the relationship between care recipient depression and caregiver depressive symptoms by exacerbating the latter (Jeglic et al., 2005). Moreover, care recipient depressive symptoms such as apathy and anger have been reported as major cause of caregiver distress feelings (Marsh, Kersel, Havill, & Sleigh, 1998). In contrast, there is evidence that the association between caregiver depressive feelings related to care recipient depression can be lessen by caregiver optimism (Given et al., 1993).

This study suggests that caring for individuals with depression may affect caregiver loneliness, feelings about life, and self-esteem. It seems that care recipient depressive symptoms make caregivers feel less appreciated about their role, consequently affecting their esteem and perceptions about their life. Additionally, symptoms of care recipient depression were associated with caregiver poor relationships with family and friends. In another study caregiver dissatisfaction with family support was reported by those caring for long term care home care recipients with depression (Soldato et al., 2008). Further studies including more sophisticated analysis are needed to better understand the relationship among caregiving dyads especially considering that care recipient treatment of depression may reduce caregiver burden (Martire et al., 2010).

One important strength of this study is the substantial sample size of self-report caregiver surveys completed compared with other studies where caregiver self-report instruments were developed. For example, in a review of self-reported caregiver instruments only 6 instruments out of 28 were developed based on studies with more than 300 participants (Deeken et al., 2003). In addition to the sample size, a large number of items pertaining to various domains allowed for the robustness of the analysis. Another strength of this study is the use of different methods to validate the caregiver survey. In addition, the inclusion of caregivers of care recipients with high needs instead of a specific disease favours the generalizability of the findings to a more diverse group of caregivers. Finally, the ability to examine the relationship between caregiver experiences and care recipient depression was only possible because of the linkage of the caregiver surveys with care recipient health information collected as part of a routine assessment. The linkage of the care recipient assessment and the caregiver surveys will also allow future research on the association of caregiver’s self-report feelings of distress with information of distress captured in the RAI-HC using assessor’s judgment.

The limitations of this study should also be acknowledged. Since informal caregivers participating in this study were caring for care recipients with high needs and presented high levels of distress (as required by the eligibility criteria of the respite program), the results are specific to this particular group of informal caregivers. Thus, the results may not be generalized to caregivers with low distress levels. Also, the study included only informal caregivers caring for clients with high needs (i.e., MAPLe 4 and 5). This may have precluded the examination of certain caregiver characteristics associated with care recipients with different levels of care needs.

In conclusion, the outcomes of this study demonstrated that the caregiver survey is a valid and reliable instrument. The results also highlighted the multidimensionality of caregiving experiences represented here by physical, mental health and psychosocial resources and well-being. This study also provides strong indication that care recipient depressive symptoms affect caregiver well-being. Findings of this chapter strongly indicate the need for assessing caregivers before recommending any type of intervention as their needs are unique to each individual. The knowledge produced in this study contributed for the development of the interRAI Family Carer Needs Assessment, a pilot caregiver instrument developed by interRAI in collaboration with Ireland government. This caregiver assessment, developed with the expertise and high quality of standards of interRAI, aims to identify the needs and preferences of informal caregivers for developing and evaluating interventions.

Chapter 4

DEVELOPMENT OF A SCREENER TO IDENTIFY DISTRESSED INFORMAL CAREGIVERS IN THE COMMUNITY BASED ON INTERRAI ASSESSMENTS

4.1 Abstract

Objective: Develop and evaluate a screener to identify caregivers at risk of adverse outcomes.

Methods: A total of 362 informal caregivers caring for persons receiving community based service with high care needs were interviewed using an interRAI based caregiver self-reported survey covering domains such as: background, health, caregiving issues, well-being, quality of life and supports. Care recipients were assessed as part of routine practice with the Resident Assessment Instrument – Home Care (RAI-HC) and interRAI Community Health Assessment (interRAI CHA). Items in the survey dealing with psychological distress were compared against the Caregiver Strain Index (CSI) and other outcomes to develop a caregiver screener. Three risk categories were identified and evaluated as potential predictors of adverse outcomes and health care utilization.

Results: The informal caregivers at high risk compared to the lower risk group were more likely to: 1) visit a doctor or nurse practitioner; 2) self-report poor or fair health; 3) report that the care recipient would be better off elsewhere; and 4) report that their life is ‘never, rarely or sometimes good’. Substantially more caregivers in the high risk group reported that they felt unable to continue in the role of caregiver, lonely, hopeless, and had financial concerns.

Conclusion: the Caregiver Distress Index (CDI) differentiates caregivers at risk of adverse outcomes. The CDI has the potential to identify caregivers that might benefit from further assessment and interventions such as respite from their caregiving responsibilities.

4.2 Introduction

Informal caregivers (e.g., family members, friends) are an integral part of the home and community care system in many countries. The unpaid care provided by informal caregivers is often a key factor for supporting those in need to remain at home for as long as possible and to avoid institutional care. The support provided by unpaid caregivers results in substantial cost savings for the health system by off-setting paid home care service and reducing the need for institutional care (Chari et al., 2015).

However, informal caregivers are often at risk of poor health outcomes especially when caring for persons with high care needs (Dassel, Carr, & Vitaliano, 2015; Vitaliano, 2010; Vitaliano et al., 2003). The ability of informal caregivers to continue providing care may be jeopardized when they are faced with increasing demands to provide care for individuals with complex health issues living in the community. Indeed, the sustainability of the home care system relies on the capacity of informal caregivers to function effectively in their role as providers of informal support.

Several studies have shown that informal caregivers may be vulnerable to the physical and psychological challenges of caregiving. For example, Dassel and colleagues found that caregivers for persons with dementia were more likely to be frail by the time of death compared with non-caregivers (Dassel et al., 2015). A major challenge for the health system is to identify caregivers at high risk of poor quality of life or health declines in order to provide appropriate supports to address their issues. However, most available instruments to screen caregivers are impractically long for initial assessment, lack cut-offs points for intervention, and/or lack construct validity (Schene, Tessler, et al., 1994; Schene, Tessler, et al., 1994; Vitaliano, Russo, Young, Teri, et al., 1991).

Moreover, most caregiver assessments are not designed to be compatible with assessment tools already in widespread use for assessment of home care clients.

A short screener that captures key aspects of a caregiver’s emotional health and flags the risk of adverse outcomes would help organizations to identify caregivers that would benefit from more detailed assessment. Such a screening and assessment system could identify areas of need (e.g., depression) and allow timely implementation of interventions to support the caregiver. This paper describes the development and validation of an informal caregiver screener compatible with the interRAI suite of instruments (Fries et al., 1997; Hirdes, Ljunggren, et al., 2008), to identify caregivers at risk of adverse outcomes.

4.3 Methods

4.3.1 Subjects

The informal caregivers in this study were participants of Caregiver Recharge Service (CRS), a respite program for informal caregivers offered through the Mississauga Halton Local Health Integration Network in Ontario (MH LHIN), Canada. The Caregiver Recharge Service was established to provide respite to caregivers by offering assistance with activities they usually perform in order to reduce caregiver distress and increase ability to continue caring activities.

4.3.2 Caregiver and care recipient assessments and sample size

In order to participate in this program, caregivers were assessed by trained interviewers using the Caregiver Strain Index (CSI) to assess caregiver distress (Robinson, 1983; Thornton & Travis, 2003). Eligible caregivers scored 9 or higher in the CSI assessment with a maximum score of 13. The eligibility criteria also included information on care recipient health using the interRAI

Community Health Assessment (interRAI CHA) or Resident Assessment Instrument – Home Care (RAI-HC) (Hirdes, Ljunggren, et al., 2008; Travers, Byrne, Pachana, Klein, & Gray, 2013).

In addition to the eligible CSI score, only caregivers caring for care recipients with a MAPLe (Method of Assigning Priority Levels) score of 4 or 5 or receiving palliative care were eligible to participate in the program. MAPLe is a decision-support tool used to identify community care recipients who have the most urgent need for care (Hirdes et al., 2008). MAPLe scores range from 1 to 5 with higher scores indicating higher care needs. It was used as part of the CRS eligibility criteria due to its association with caregiver distress (Chang & Hirdes, 2015; Hirdes et al., 2008; Mitchell et al., 2015; Vu et al., 2014) and long-term care home (LTCH) admission (Hirdes et al., 2008). A total of 236 caregiver surveys were linked to care recipient assessments using unique but non-identifiable numbers. All palliative clients were excluded from the analysis due to the low number of available linked caregiver assessments (n=20).

Once accepted into the CRS, based on the above criteria, caregivers were invited by the community service provider to participate in the Caregiver Recharge Service Evaluation study carried out by University of Waterloo researchers. Consenting caregivers were interviewed with a self-report survey based on interRAI items from its clinical assessment instruments and Quality of Life surveys (Kehyayan et al., 2015b). The pilot survey used in this study had a total of 82 items dealing with demographic information, physical and emotional health, caregiving responsibilities, well-being, quality of life and supports. A total of 362 caregivers completed the caregiver survey on the phone at baseline (i.e., CRS admission). Full ethics clearance for this study was granted by the Office of Research Ethics, University of Waterloo (#18982).

Only the interRAI-based surveys of caregivers with a CSI completed within a 90 days' interval between these assessments were used for the development of the screener. A total of 290 linked pairs were available (average time between CSI and survey = 37 days; SD 20.3).

4.3.3 Analysis

The initial step of the analysis involved identifying items in the interRAI-based caregiver survey representing psychological distress that were significantly correlated with the CSI scores. Thus, from 15 items in the interRAI-based caregiver survey that were correlated with CSI scores ($P < 0.05$), 11 were excluded because they did not represent feelings of emotional distress (e.g., physical activity, pain, full time job, financial issues). The final four items included questions related to the caregiver experiencing anhedonia (little or no pleasure in the things person normally enjoys), anxiety (anxious, restless, or uneasy), depressed mood (sad, depressed or hopeless), and feeling overwhelmed by caregiving responsibilities in the 3 days prior to completing the survey. The five possible responses for these questions are: 1) never; 2) not in the last three days, but do have the problem; 3) one day; 4) two days; and 5) every day in the past three days with scores ranging from 1 to 5, respectively. A series of chi-square tests was performed to evaluate different combinations of these item response scores and their association with CSI scores converted to a binary variable (i.e., 9, 10 to 11, 12, 13). The best distribution of the scores resulting from the sum of the four item responses and the binary CSI scores was obtained when assigning a score for the caregiver items responses '1' and '2', another score for responses '3' and '4' and a unique score for the response '5'. Thus, the resulting summary score of the four questions in the screener, Caregiver Distress Index (CDI), ranged from 0 to 8 with cut points zero, 1 to 4, and 5 to 8 based on the association with the CSI.

Next, logistic regression models were used to evaluate if the CDI cut-off points differentiate risk levels of various caregiver health outcomes (n=362), including: 1) physician visits; 2) self-reported health; 3) personal outlook; and 4) the caregiver reporting that care recipient would be better off elsewhere. These outcomes were chosen because they are related to different domains of caregiver's lives (Schulz & Sherwood, 2008).

The predictive power of the screener was evaluated after controlling for age and gender, which were included as covariates in the models. Chi-square analyses were also used to assess the relationships between CDI risk levels and caregiver variables such as financial concerns, ability to continue caring, physical pain, and loneliness (n=362). The reliability of the screener was evaluated using Cronbach alpha value.

4.4 Results

4.4.1 Sample description

4.4.1.1 Informal caregivers

Table 4.1 provides the main characteristics of the caregivers by age groups. The majority were female and caregivers in the over 75 age group were predominately spouses (86.4%) of the care recipient. Younger caregivers were more likely to be involved in full or part time work compared to the older age groups. About 28% reported some degree of financial concerns based on having to make trade-offs between necessities of life such as food, shelter, medications, home heat or cooling because of limited funds.

Table 4.1 Caregiver demographics, financial status, and health conditions on admission to the Caregiver Recharge Services

Age group (years)	All ages *% (n)* 100 (290)	< 60 *% (n)* 35.5 (103)	≥ 60 and < 75 *% (n)* 36.5 (106)	≥ 75 *% (n)* 27.9 (81)
Gender				
Female	72.2 (200)	70.0 (70)	79.0 (79)	66.2 (51)
Primary Language				
English	65.5 (190)	66.0 (68)	63.2 (67)	67.9 (55)
Relationship with care recipient				
Spouse	44.6 (100)	7.2 (6)	52.4 (43)	86.4 (51)
Child	36.1 (81)	66.2 (55)	28.0 (23)	5.0 (3)
Other	19.2 (43)	26.5 (22)	20.5 (16)	8.5 (5)
Paid Employment				
Part time or full time	33.8 (94)	68.0 (68)	23.0 (23)	3.9 (3)
Caring for				
Adult only	70.6 (205)	44.6 (46)	79.2 (84)	92.5 (75)
Adult and child	24.4 (71)	49.5 (51)	16.9 (18)	2.5 (2)
Economic Trade-offs*				
Yes	23.7 (67)	36.2 (37)	22.1 (23)	9.2 (7)
Physical Health**				
Diabetes	15.9 (46)	8.7 (9)	20.7 (22)	18.7 (15)
Depression	15.2 (44)	16.5 (17)	19.8 (21)	7.5 (6)
Cancer	6.5 (19)	2.9 (3)	7.5 (8)	10.0 (8)

* In the last 30 days, have you made trade-offs among purchasing: adequate food or shelter, clothing or prescribed medications, sufficient home heat or cooling, necessary health care or home care due to limited funds?

**Currently receiving treatment or being monitored for the health condition.

Note: In some cases, the number of cases is less than the full sample size because missing data are excluded.

4.4.1.2. Care recipients

More than half of care recipients were married (56%) and 35% were widowed. The mean age of care recipients in this study was 78 (n=236, SD 15.5), 50% were males, 59% had a dementia diagnosis, 41% had a MAPLe score of 5 and 55% of the care recipients needed at least extensive assistance for completion of activities of daily living. Chi-square tests showed that the proportion of care recipients with these health characteristics was not associated with the caregiver's risk levels of adverse outcome ($P > 0.05$).

4.4.2 CDI as a predictor of adverse caregiver outcomes and health care utilization

The predictive power of the CDI for adverse outcomes and health care utilization was assessed using logistic regression models that controlled for age and gender. The dependent variable response sets were collapsed as follows: 1) appointment with doctor or nurse practitioner in the last 90 days (any vs. none); 2) self-reported health (fair/poor vs. excellent/good); 3) caregiver reports that 'on the whole my life is good' (never, rarely or sometimes vs. most of time or always); and 4) caregiver reports that they 'believe that their care recipient would be better off elsewhere' (yes vs. no).

Table 4.2 shows that caregivers in the high risk group (i.e., CDI scores from 5 to 8) were more likely to have doctor/nurse appointments and poor or fair self-reported health ($P < 0.01$). They were also more likely to report that never, rarely or only sometimes 'on the whole, my life is good' and that they believed the care recipient 'would be better off elsewhere' ($P < 0.01$). While caregiver age group was significant for doctor/nurse appointment, self-reported health and the report of 'better off elsewhere', gender was not significant for any outcome predicted by the CDI.

The standardized Cronbach value calculated for the CDI was 0.75 indicating that this tool presents an acceptable internal consistency (Cronbach, 1951).

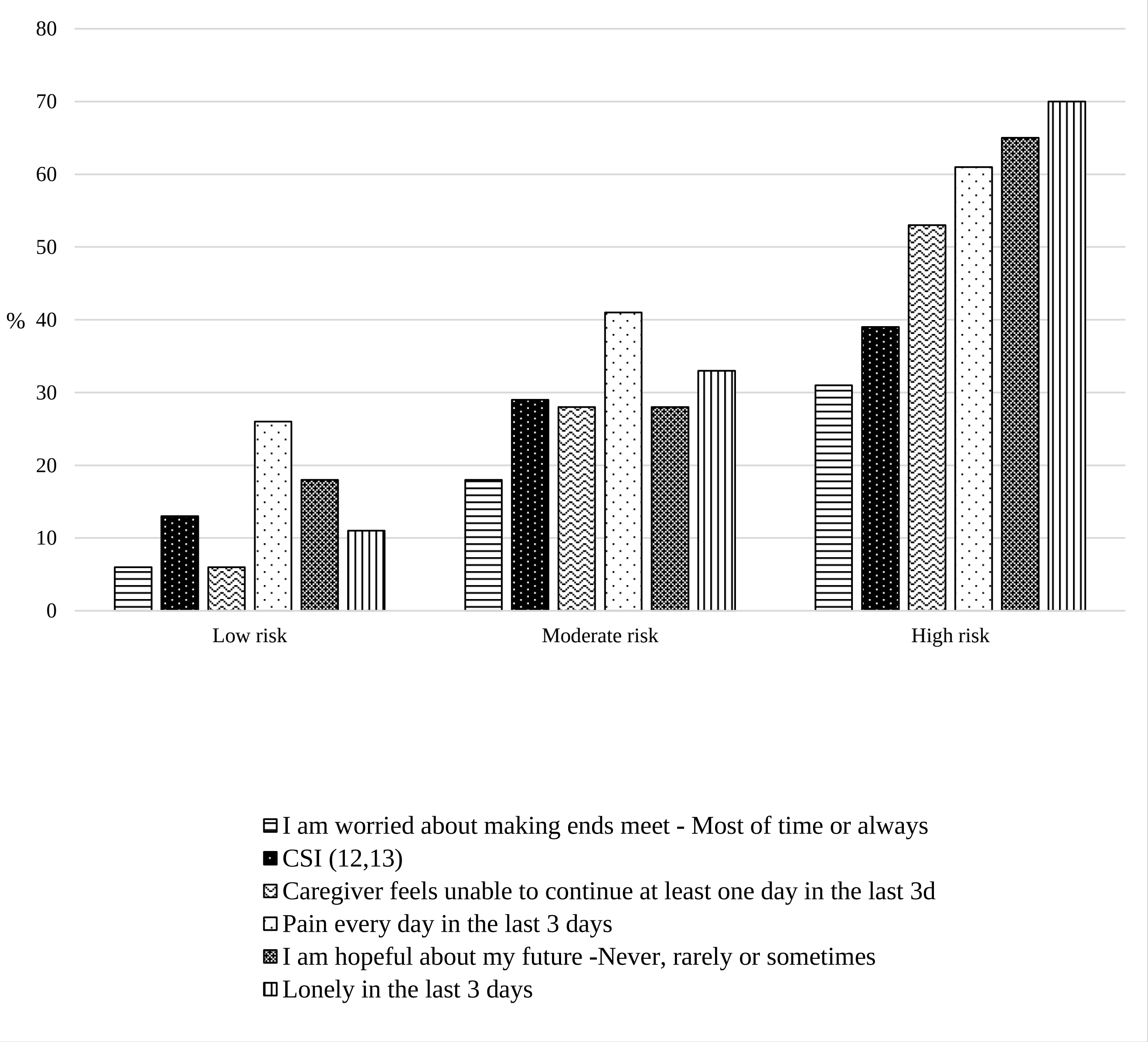
Table 4.2 Logistic regression models for selected outcomes associated with caregiver distress

Independent variable	Parameter estimate (SE)	Odds ratio (95% CI)	*P* value	C statistic
Caregiver - Doctor/nurse appointment (At least one appointment in the last 90 days)*				
CDI (1-4 vs. 0)	0.25 (0.31)	1.29 (0.69-2.40)	0.41	0.64
CDI (5-8 vs. 0)	0.93 (0.37)	2.54 (1.22-5.28)	0.01	
Age group (≥60 and < 75 vs. <60)	0.20 (0.29)	1.23 (0.68-2.18)	0.48	
Age group (≥75 vs. <60)	1.28 (0.39)	3.61 (1.68-7.77)	0.001	
Gender (female vs. male)	0.13 (0.30)	1.14 (0.62-2.06)	0.66	
Caregiver Self-reported health (Poor or Fair)*				
CDI (1-4 vs. 0)	0.62 (0.32)	1.85 (0.98-3.49)	0.05	0.66
CDI (5-8 vs. 0)	1.41 (0.35)	4.08 (2.03-8.20)	0.0001	
Age group (≥60 and < 75 vs. <60)	0.39 (0.29)	1.49 (0.84-2.64)	0.17	
Age group (≥75 vs. <60)	0.71 (0.32)	2.02 (1.07-3.82)	0.03	
Gender (female vs. male)	0.02 (0.28)	1.02 (0.58-1.80)	0.92	
Caregiver reports ‘On the whole, my life is good’ (Never, rarely and sometimes)*				
CDI (1-4 vs. 0)	0.63 (0.41)	1.88 (0.83-4.27)	0.13	0.72
CDI (5-8 vs. 0)	2.17 (0.42)	8.82 (3.82-20.37)	<0.0001	
Age group (≥60 and < 75 vs. <60)	-0.004 (0.32)	0.99 (0.53-1.88)	0.99	
Age group (≥75 vs. <60)	-0.33 (0.39)	0.72 (0.33-1.55)	0.40	
Gender (female vs. male)	-0.18 (0.33)	0.84 (0.43-1.61)	0.59	
Caregiver believes that care recipient would be better off elsewhere (Yes)*				
CDI (1-4 vs. 0)	0.72 (0.42)	2.06 (0.91-4.68)	0.08	0.64
CDI (5-8 vs. 0)	1.08 (0.44)	2.95 (1.24-6.99)	0.01	
Age group (≥60 and < 75 vs. <60)	0.76 (0.34)	2.14 (1.07-4.25)	0.03	
Age group (≥75 vs. <60)	0.41 (0.39)	1.51 (0.69-3.30)	0.30	
Gender (female vs. male)	-0.28 (0.33)	0.75 (0.38-1.45)	0.39	

*Interaction between age and CDI was not significant (*P* > 0.05).

As shown in Figure 4.1, several other variables were associated with the CDI (all Chi square values had *P* < 0.0001, except for ‘I am worried about making ends meet’ where *P* = 0.0002). In addition, the high scores on the Caregiver Strain Index were associated with the CDI (*P* < 0.001).

Figure 4.1 Associations of CDI risk levels with: 1) financial issues; 2) ability to continue caring; 3) hopelessness; 4) Caregiver Strain Index (CSI); 5) pain; and 6) loneliness.



4.5 Discussion

Caregivers with higher scores on the Caregiver Distress Index based on interRAI items were more likely to report their health was poor or fair and, as an objective indicator of health, have more doctor or nurse appointments. These findings are consistent with other studies that report high prevalence of poor health among family caregivers (Vitaliano et al., 2003) and higher health care utilization (Schubert et al., 2008).

Caregivers at higher risk of adverse outcome were also more likely to report that the person they are helping ‘would be better off elsewhere’, possibly suggesting that these caregivers were considering the option of long-term care placement for the care recipient. There is evidence that caregiver poor self-reported health and symptoms of stress are associated with long-term care admission of the care recipient (Buhr et al., 2006; Schulz et al., 2004).

It is possible that a substantial number of caregivers, particularly in the high risk group, were experiencing or could be at risk of depression as they were more likely to report loneliness, hopelessness and daily pain (Figure 4.1). This is concerning considering that depression affects quality of life and may lead to tragic outcomes when severe. A recent study showed that a substantial number of informal caregivers of care recipients with dementia (i.e., 26%) contemplate suicide, (O’Dwyer et al., 2013) highlighting the need of monitoring the mental health of caregivers.

Interestingly, the CDI also identified a potential moderator of adverse outcome. While caregivers with a negative outlook (i.e., less often expressing that ‘on the whole my life is good’) were at a higher risk of adverse outcome, looking at another angle, caregivers with a positive outlook (‘on the whole my life is most of time or always good’ and ‘I am most of the time or always hopeful about my future’) were more likely to be in the lower risk group of adverse outcomes. It is important to note that caregiver life satisfaction has been linked with positive caregiving experiences even when they report high burden (Kruithof et al., 2012). In addition, the presence of a large number of friends and close relationships has been associated with overall life satisfaction of caregivers (Haley, Levine, Brown, & Bartolucci, 1987b). According to Folkman, positive emotions have an important role in the stress process and are related to coping strategies (Folkman, 1997). More studies on this topic are needed to understand the influence of positive emotions on caregiver quality of life.

The results of the present research clearly demonstrate multidimensionality of the needs of caregivers in distress (e.g., poor perceived physical health, loneliness, financial concerns and negative personal outlook). These findings are consistent with interactions between various caregiver related domains described by stress process models involving caregivers (Goode et al., 1998; Pearlin et al., 1990). For example, the conceptual model of caregiver distress proposed by Pearlin and colleagues suggests that several secondary stressors, such as financial problems and constriction of social life, may be related with caregiver outcomes, including depression (Pearlin et al., 1990). As such, the CDI could be used to flag the need for further assessment of the caregiver to target interventions that match with their unique needs. For example, clinical treatment may be appropriate for caregivers affected by depression or pain, whereas caregivers experiencing loneliness might benefit from participation in a support group.

Not surprisingly, financial concerns were associated with risk of adverse outcomes. This result aligns with reported evidence of a growing number of studies on the financial challenges associated with caregiving (Chen, 2014; Siegel, Raveis, Houts, & Mor, 1991). Changes in policies that address this issue, such as paid sick and family leave and adequate guaranteed income, might well minimize financial burden for caregivers (Chen, 2014).

Concurrent validity was addressed by examining the association between the CDI and the Caregiver Strain Index scores. The two measures were strongly associated with each other; however, the CDI has the advantage of being fully compatible with interRAI standards for assessments that are widely used in Canada and elsewhere (Carpenter & Hirdes, 2013). Linking caregiver information from the pilot survey with the most recent care recipient interRAI CHA or RAI-HC allows for the assessment of caregiver needs at the same time that care recipient health is examined.

As a cross-sectional design, the present study does not allow for making causal inferences. Another limitation of this study is that all the participant caregivers presented with high levels of distress according to the Caregiver Strain Index scores. Hence, the performance of the screener should be tested in other groups of caregivers to capture a larger variation in the amount of care provided by informal caregivers as well as lower reported stress levels. On the other hand, the fact that the CDI was developed using items common to other interRAI assessments is an important advantage. The screener can be applied on its own or used in conjunction with an interRAI assessment of the care recipient to facilitate the design of an integrated care plan to address the needs of both persons in the dyad.

The most important finding of this study is that the CDI can identify caregivers at risk of adverse outcomes with a small number of items that could be implemented in a relatively straightforward manner. This screener has the potential to identify caregivers that would likely benefit from further assessment and intervention (such as respite care) with the goal of improving their quality of life and supporting them in their role as informal caregivers.

Chapter 5

CAREGIVER AND CARE RECIPIENT PREDICTORS OF LONG TERM CARE HOME ADMISSION

5.1 Introduction

For the first time in Canadian history, the number of individuals 65 years of age or older is higher than the number of individuals 15 years old or younger (Statistics Canada, 2015). This demographic shift combined with longer life expectancy has important implications for the role of caregivers in the society. In addition, as family sizes decline a lower number of child-caregivers may be available to provide care for their parents (Keefe, Légaré, Charbonneau, & Décarie, 2012). As a result, more individuals with high care needs will be relying on unpaid care provided by a smaller number of informal caregivers to continue living in their homes.

Caring for older individuals with high needs often results in considerable burden on informal caregivers (Turner & Findlay, 2012) that can increase distress, reduce quality of life, and hinder their ability to continue caring activities. This scenario often leads to the institutionalization of the care recipient (Buhr et al., 2006; Colerick & George, 1986; Tsuji, Whalen, & Finucane, 1995). Nonetheless, there is conflicting evidence on the influence of caregiver distress and well-being on the institutionalization of the care recipient (Luppa et al., 2010; Zarit et al., 1986). Some studies suggest that caregiver characteristics are important predictors of long term care home (LTCH) admission (Lieberman & Kramer, 1991; Pruchno et al., 1990). However, caregiver individual experiences and its influence on care recipient institutionalization may vary by caregiver gender and ethnicity (Morycz, 1985).

Care recipient institutionalization may be also affected by other factors related to the caregiver /care recipient dyad, such as coresidence and relationship (Chenier, 1997; Morycz, 1985). The relationship between caregiver and care recipient (i.e., spouse vs. non-spouse) as well as other caregiver related characteristics has been associated with care recipient institutionalization even after considering health characteristics of the care recipient (Colerick

& George, 1986; Lieberman & Kramer, 1991; Tsuji et al., 1995; Vugt et al., 2005). A study including caregivers of care recipients with dementia showed a significant influence of distress on caregiver decision to institutionalize the care recipient after accounting for characteristics of the care recipient (Lieberman & Kramer, 1991).

A combination of factors related to the caregiving dyad, caregiver emotional health as well as care recipient needs seems to play a key role in the institutionalization of older people (Morycz, 1985; Weissert & Cready, 1989). For example, the Method for Assigning Priority Levels (MAPLe), an algorithm representing care recipient heath care needs, has been shown to predict both, home care clients LTCH admission and caregiver distress (Hirdes et al., 2008; Mitchell et al., 2015). This algorithm, which is derived from the RAI-Home Care (RAI-HC), has been developed to inform health care provider decisions about the urgency of need for care among home care clients. The RAI-HC has been extensively validated (Landi et al., 2000; Morris et al., 1997; Kwan et al., 2000) and it is part of a suite of instruments created by interRAI a network of researchers dedicated to the improvement of quality and continuity of care across the health care sectors (Carpenter & Hirdes, 2013).

The relationship between the MAPLe score and caregiver distress is based on a combination of care recipients health characteristics that have been consistently associated with caregiver distress such as behaviours, activities of daily living (ADL) and cognitive impairment (Clyburn et al., 2000; Ferrara et al., 2008; Vu et al., 2014). In other hand, the association between MAPLe scores and institutionalization could be related to both the presence of care recipient health needs that may not be easily manageable in a home care setting as well as the presence of health characteristics that affects caregiver's distress and ability to continue (Buhr et al., 2006; Eaker et al., 2002; Mitchell et al., 2015).

Examining the influence of caregiver distress on long term care homes (LTCH) admission is crucial for understanding the impact of informal care on institutionalization, especially considering the economic value of their contribution to the health care system and the high cost of LTCH (Chappell, Dlitt, Hollander, Miller, & McWilliam, 2004; Hollander, Liu, & Chappell, 2009; Ostbye & Crosse, 1994). While several studies have shown that care recipient care needs and caregiver distress are linked to institutionalization, the influence of both factors on care recipient admission to LTCH after considering characteristics of the caregiving dyad that may influence institutionalization has not been examined using comprehensive assesments. Thus, the hypothesis of this study is that caregiver distress influences LTCH admission after controlling for care recipient care needs and caregiving dyad characteristics.

5.2 Method

5.2.1 Sample

A total of 94,956 long-stay home care clients initial RAI-HC assessments completed between April 01st 2013 and April 01st, 2014 as part of a clinical practice by 14 Ontario Community Care Access Centres (CCACs) were included in this study to be consisted with the timeframe used in other studies of this dissertation. Only assessments of individuals identified as residing in ‘Private home/apartment – with or without home care services’ (RAI-HC item cc5 in 1,2) were included in the dataset as other types of living arrangements such as assisted care living or group homes are not in the focus of this study. The hospital version of the RAI-HC was excluded from the dataset.

The majority of the assessments were completed by nurses or social workers working as case managers in the CCAC. The assessments have been sent to University of Waterloo by the Ontario Association of Community Care Access Centres (OACCAC) through license agreements between these two organizations. To guarantee the anonymity of the data the dataset does not include any identifier at the individual level.

Information on LTCH admissions was obtained from the Client Health and Related Information System (CHRIS), a web-based care recipient management system that collects information on home care clients admission and discharge. This dataset is sent to University of Waterloo by OACCAC through the same process and agreements used for sharing the RAI-HC assessments with University of Waterloo. Demographic and health related information of long stay home care recipients admitted and not admitted to LTCH is presented in Table 5.1. Ethics clearance for the use of secondary data has been provided by the Office of Research ethics from University of Waterloo (ORE#19917).

5.2.2 Clinical scales of RAI-HC

Several scales can be calculated using the RAI-HC. Evidence has shown the good validity and reliability of items and scales in this instrument (Hirdes, Ljunggren, et al., 2008; Morris et al., 1997; Poss et al., 2008). These scales represent different clinical aspects of the care recipient health and they are often related to outcomes and measures such as death, long term care admission or caregiver distress (Landi et al., 2000). Some of the scales that were used to describe care recipient clinical health from this study are presented below.

The Method for Assigning Priority Levels (MAPLe)

The MAPLe algorithm was derived from a study sample including close to 5,000 clients from 14 Ontario CCACs (Hirdes et al., 2008). The initial identification of variables for analysis and derivation of MAPLe included three steps. First, three binary dependent variables were chosen as indirect indicators of ‘need’ for additional services: presence of signs of caregiver distress, rating oneself or being rated by others as being better off elsewhere, and nursing home admissions. Next, independent variables were identified for the analysis. For that, among other things, the researchers performed a review of the literature on nursing home placement, and participated in a focus group meeting with clinicians, policy makers and service providers to identify risk factors of institutionalization and adverse outcomes among home care clients. After selecting the variables, the final analysis included 4 major steps: 1) identifying independent variables associated with the outcome variables for the decision-tree analysis; 2) performing the decision-tree analysis to obtain an algorithm; 3) combining groups with comparable levels of risk to simplify the decision-tree algorithm and 4) validating the MAPLe algorithm using RAI-HC data from 7 countries and across Canadian provinces. Some of the items selected as part of the final algorithm are related with: falls, behavioral symptoms, and cognitive, IADL and ADL impairment. Finally, the major findings of this study were the relationship between MAPLe scores with 1) caregiver distress and 2) LTCH admission.

The MAPLe score is intended to assist health care providers in identifying those individuals who have the most urgent need for care (Hirdes et al., 2008). MAPLe scores range from 1 to 5 with higher scores indicating a higher priority for care. This algorithm can also be used to inform choices related to allocation of home care resources and prioritization of clients needing community or facility-based services. MAPLe scores have been associated with LTCH admission (Hirdes et al., 2008) as well as with caregiver distress (Health Council of Canada, 2012; Hirdes et al., 2008; Mitchell et al., 2015).

Activities of Daily Living Hierarchy Scale (ADL-H): The ADL Self-Performance Hierarchy Scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss. Early-loss ADLs are assigned lower scores than late-loss ADLs. Scale scores range from 0 to 6, with higher scores indicating greater decline (progressive loss) in ADL performance (Landi et al., 2000; Morris et al., 1997, 1999).

Cognitive Performance Scale (CPS): A hierarchical index used to rate a person's cognitive status. The scale scores range from 0 to 6, with higher scores indicating more severe impairment. This scale has been validated against the Mini-Mental State Exam (MMSE) for the detection of cognitive impairment (Jones et al., 2010; Landi et al., 2000; Morris et al., 1994; Paquay et al., 2007; Wellens et al., 2013).

Table 5.1 Admission to long term care home within one year after first assessment versus client without admission by demographics, social and clinical characteristics of home care clients

		No admission (n=91,586)	LTCH admission (n=5,907)	*P* value
Caregiver characteristics		% (n)	% (n)	
Coresidence	Yes	57.0 (50,860)	55.4 (3,234)	0.01
Relationship	Spouse	49.0 (28,597)	32.7 (1,913)	<.0001
	Child	32.0 (43,719)	54.8 (3,204)	
	Other	18.8 (16,804)	12.3 (721)	
Other	Distress	21.4 (19,667)	41.6 (2,460)	<.0001
	Unable to continue	11.5 (10,582)	19.9 (1,180)	<.0001
Care recipient characteristics				
Marital status	Married	38.8 (35,580)	41.3 (2,441)	<.0001
	Widowed	40.9 (37,517)	46.6 (2,755)	
	Other	20.1 (18,489)	12.0 (711)	
Gender	Female	65.8 (60,327)	64.2 (3,795)	0.01
Age	<65	6.0 (16,004)	4.3 (255)	<.0001
	65-74	15.7 (14,382)	10.5 (620)	
	75-84	32.2 (13,382)	36.4 (620)	
	85-94	31.3 (28,716)	43.4 (2,568)	
	95+	3.2 (2,957)	5.30(313)	
MAPLe[a]	Low/Mild	18.7 (17,192)	2.6 (155)	<.0001
	Moderate	39.0 (35,761)	25.4 (1,504)	
	High	31.5 (28,933)	42.4 (2,509)	
	Very high	10.5 (9,700)	24.4 (1,739)	
CPS[b]	Intact or borderline	51.2 (46,948)	15.7 (931)	<.0001
	Mild/Moderate	43.1 (39,485)	71.2 (4,207)	
	Moderate/Severe	4.3 (4,021)	12.3 (728)	
	Very severe	1.2 (1,132)	0.7 (41)	
ADL-H[c]	Independent	51.5 (47,198)	32.0 (1,892)	<.0001
	Supervision	31.1 (28,852)	45.0 (2,659)	
	Extensive assistance	12.8 (11,757)	19.5 (1,151)	
	Dependent/total	4.48 (4,103)	3.4 (205)	
Dementia	Present	17.6 (16,190)	51.4 (3,036)	<.0001

[a]MAPLe: Method of Assigning Priority Levels; [b]CPS cognitive performance scale; [c]ADL-H: Activity of daily living Hierarchy

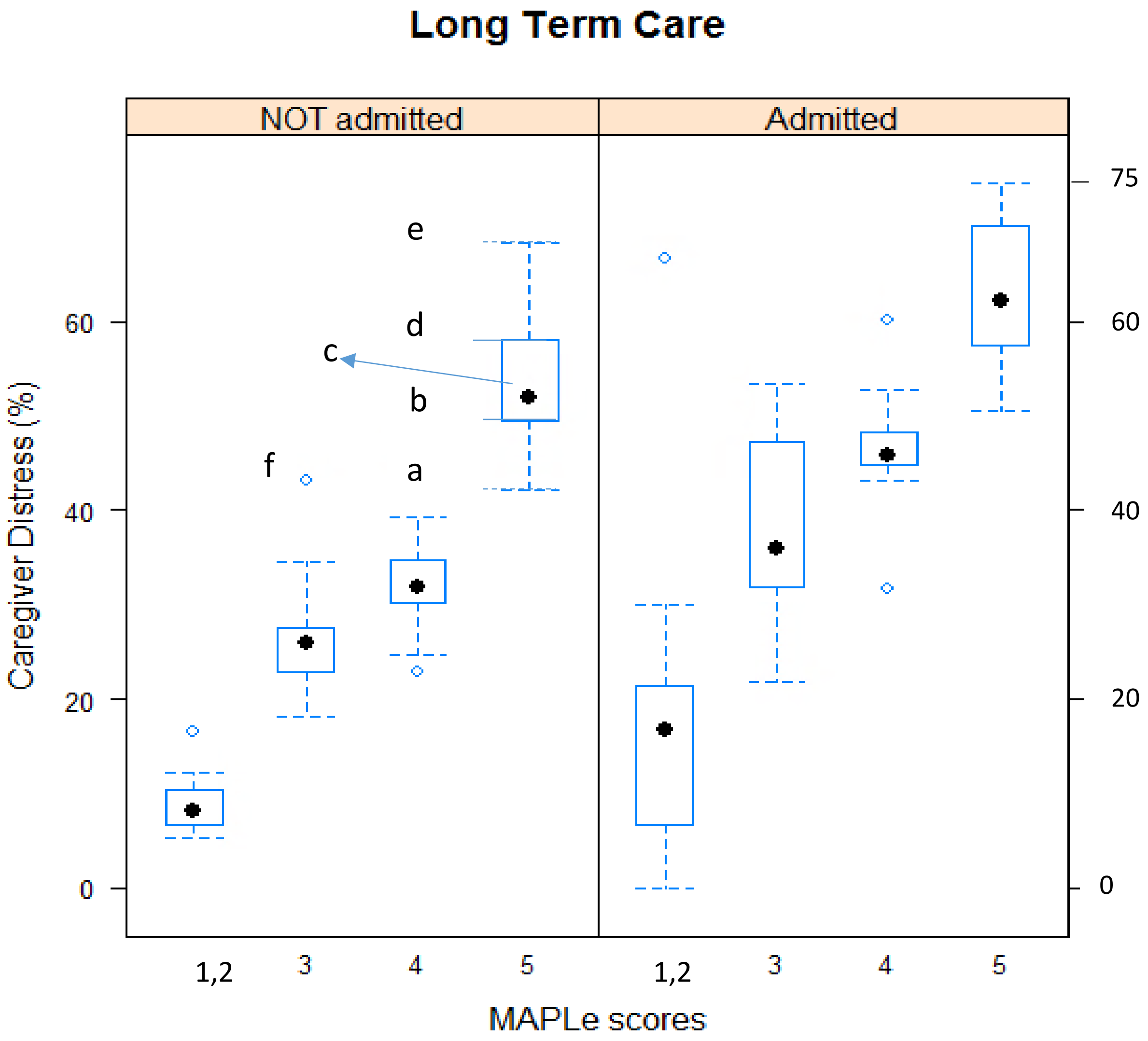
Note: In some cases, the number of cases is less than the full sample size because missing data are excluded.

5.3 Statistical analysis

In Ontario, 14 CCACs provide home care services for the community. Although CCACs share similar provincial guidelines for the provision of care, they also develop their own initiatives that may affect the amount of respite provided for caregivers or the care provided for their clients. In this context, the influence of caregiver distress on LTCH admission may be different for each CCAC as well as the relationship between caregiver distress and MAPLe scores. Thus, an exploratory analysis was performed to evaluate whether the association between caregiver distress and MAPLe scores vary among CCACs (n= 97,493). Figure 5.1 shows the distribution of the average proportions of caregiver distress by MAPLe scores for 14 CCACs. The results indicate that although the relationship between these variables seems consistent across CCACs the average proportion of caregiver distress by MAPLe varies among them. For example, Figure 5.1 shows that average proportions of distressed caregivers of care recipients of MAPLe 5 admitted to LTCH range from 50 to 75% depending on the CCAC, with a mean value of 63%.

Differences in correlations within clustered observations should be accounted in a multivariate model for predicting LTCH admission. The generalized estimating equation (GEE) model was used for predicting LTCH admission since it allows for clustering by estimating robust standard errors based on the variability of the data. The same approach was used for the survival model, where a model based covariance matrix estimate was used to account for the intracluster dependence (i.e., dependence of observations within CCACs). All statistical analyses were carried out using Statistical Analysis System (SAS) version 9.4.

Figure 5.1 Distribution of percentage of caregiver distress by MAPLe scores for care recipients admitted or not-admitted into LTCH among Ontario Community Care Access Centres (CCAC) clients



a) the sample minimum, excluding outliers, defining the horizontal dotted line at the bottom of each plot (i.e., minimal percentage of caregiver distress); b)the lower quartile (25th percentile), defining the lower limit of the box in each figure; c)the sample mean, represented by the heavy dot inside each box (i.e., mean value of percentage of caregiver distress of all CCACs); d) the upper quartile (75th percentile), defining the upper limit of each box; e) the sample maximum, excluding outliers, defining the horizontal line at the top of each plot (i.e., maximum percentage of caregiver distress); f) outliers, defining the empty circles

5.3.1 Generalized estimating equations (GEE) - A population-average model applying GEE (Liang & Zeger, 1986) has been chosen to adjust for agency-level (within subject) by considering the 14 CCACs as repeated subjects. The GENMOD procedure in SAS fits the population average model using GEE to estimate the regression parameters. The link function chosen for the model is the ‘logit’ because it corresponds to the binominal nature of the outcome.

The correlation matrix in GEE model accounts for the correlation of within-subject outcomes on dependent variable. The estimated correlations is used for reestimating regression coefficients and standard errors in the model (Burton, Gurrin, & Sly, 2004). However, it is not possible to know the best correlation matrix in a straightforward way (Burton et al., 2004).

As a first step, unadjusted models were used to evaluate the strength of association between the independent and dependent variable (LTCH admission) in the model. Variables were included in the unadjusted model based on results of frequency analysis and knowledge on predictors of LTCH reported in the literature. Items in the RAI-HC representing care recipient health characteristics associated with LTCH admission are included in the MAPLe algorithm. Therefore, in addition to MAPLe only caregiver, caregiving dyad and care recipient demographic information were included in the unadjusted models.

The “exchangeable” matrix was initially tested in the GEE analysis. This type of structure assumes that observations from the same subject are equally correlated (Ballinger, 2004; Burton et al., 2004). Preliminary analysis showed that the empirical and model-based estimates and respective standard errors of unadjusted GEE models were very close or similar indicating that the exchangeable matrix has been correctly specified as the choice of covariance structure (Hanley, Negassa, Edwardes, & Forrester, 2003). Finally, GEE generates robust standard errors that leads to reliable inferences even when the correlation structure is incorrect as long as the linear regression relationship is correct and the responses between subjects (i.e., CCACs) are uncorrelated (Burton et al., 2004).

The results of model-based estimates and standard errors derived from GEE were used for final interpretation instead of the empirical estimates since each cluster presented a large sample size.

5.3.2 Survival analysis

Regression analysis of survival data based on the Cox proportional hazards models were used to identify the variables significantly related to the hazard rates of LTCH admission. This type of model was chosen over a logistic regression model because it uses censored observations which are not incorporated in logistic models. The regression parameters in the Cox model were estimated by using a model based covariance matrix estimate to account for the intracluster dependence (Lee, Wei, Amato, & Leurgans, 1992). That is, the PHREG procedure from SAS 9.4 included 'COVS(AGGREGATE)' to compute the robust sandwich and model-based covariance matrix estimate. The 'aggregate' term requests a summing up of the scores residuals for each 'id' or cluster (i.e., CCAC). The model-based covariance matrix estimates have been chosen based on preliminary analysis.

Clients that were not admitted to a LTCH within 365 days of the initial assessment were right-censored meaning that this information was still used to estimate model parameters even though these clients did not experience the event. Survival was measured as time in days starting from initial RAI-HC assessment date until date of the event.

A test of proportionality was performed since one of the main assumptions of the Cox proportional hazard model is proportional hazards. The variables tested were: care recipient gender, age and marital status, MAPLe scores, caregiver distress, relationship with care recipient and coresidence. The Kaplan Meier curves produced as a result of PROC LIFETEST presented similar shape and the distance between them remained the same across time providing evidence of proportionality. Unadjusted variables were tested in the regression model before being included in the final Cox proportional hazard model for analysis.

Survival plots were generated by adjusting for the covariates significant in the regression model. The plots represent the survival probabilities for the reference groups of categorical variables. The reference groups correspond to the variable level with the highest hazard rates of LTCH admission. Since one of the objectives of the study is to examine the influence of caregiver distress on LTCH admission after controlling for other predictors, in Figure 5.4 caregiver distress reference group = ‘yes’ and in Figure 5.5 caregiver distress reference group = ‘no’.

5.4 Results

5.4.1 Generalized estimating equations (GEE)

The results of GEE analysis of unadjusted variables are presented in Table 5.2. Care recipient gender, marital status, age, and MAPLe scores where significant in the unadjusted models as well as caregiver distress, caregiving dyad coresidence and relationship.

Table 5.2 Generalized estimating equations (GEE) for unadjusted variables associated with long term care admission

Parameters	Estimate	SE	Odds ratio	95% CI	Z	Pr > |Z|
Care recipient characteristics						
Gender (ref. female)	0.06	0.03	1.06	(0.99-1.13)	2.28	0.02
Married (ref. 'no')	0.09	0.03	1.09	(1.05-1.16)	3.63	0.0003
Age group (ref. group 18-39 yrs)						
40-64 yrs.	1.14	0.27	3.12	(1.84-5.38)	4.18	<.0001
65-74 yrs.	2.01	0.28	7.46	(4.30-13.06)	7.10	<.0001
75-84 yrs.	2.55	0.29	12.8	(7.24-22.42)	8.83	<.0001
85-94 yrs.	2.75	0.29	15.6	(8.84-27.94)	9.47	<.0001
95+ yrs.	2.93	0.30	18.7	(10.38-33.44)	9.83	<.0001
MAPLe						
2	0.61	0.18	1.84	(1.29-2.61)	3.46	0.0005
3	1.99	0.18	7.31	(5.10-10.59)	10.79	<.0001
4	2.69	0.20	14.7	(9.97-21.54)	13.6	<.0001
5	3.40	0.21	29.9	(19.88-44.70)	16.3	<.0001
Caregiver characteristics						
Caregiver distress (ref. 'no')						
Yes	0.91	0.03	2.48	(2.33-2.64)	30.18	<.0001
Primary caregiver co-reside (ref. 'yes')						
No	0.05	0.03	1.05	(1.00-1.12)	2.06	0.03
Caregiving dyad relationship (ref. 'child')						
Nonchild	-0.25	0.03	0.78	(0.73-0.82)	-9.35	<.0001

Care recipient gender and marital status were not significant in the final model (Table 5.3). After removing these variables from the model, MAPLe scores of the care recipient and the presence of caregiver distress were associated with LTCH admission, as well as care recipient age, relationship between caregiver and care recipient and coresidence and interaction between the last two terms.

A variable combining the relationship between care recipient and the caregiver (caregiver is: ‘spouse’, ‘child’, or ‘other’) with the coresidence status (caregiver lives with care recipient: ‘yes’,’no’) was created to differentiate the types of relationship and their combination with coresidence. However, the relationship categories ‘spouse’ and ‘other’ were not statistically different justifying the combination of these two types of relationship into a single relationship category (i.e., ‘nonchild’ caregiver).

Further analysis showed the statistically significant interaction between coresidence and relationship suggesting that the effect relationship of type (child caregiver vs nonchild caregiver) on care recipient LTCH admission varies with coresidence. More specifically, the odds for LTCH admission is higher for care recipients of nonchild caregivers that co-reside while the admission odds of care recipients of nonchild caregivers is lower among those that do not co-reside (Figure 5.2). Characteristics of the care recipient such as MAPLe scores and age presented the largest odds for LTCH admission followed by caregiver distress, coresidence and caregiving dyad relationship.

Table 5.3. Generalized estimated equations (GEE) for long term care admission with estimates using model-based standard errors: predictors of long term care admission

Parameters	Estimate	SE	Odds ratio	95% Confidence limits	Z	Pr > |Z|
Age group (ref. group 18-39 yrs)						
40-64 yrs.	1.21	0.21	3.36	(2.20 – 5.10)	5.70	<.0001
65-74 yrs.	1.91	0.22	6.75	(4.30-10.48)	8.49	<.0001
75-84 yrs.	2.30	0.23	9.97	(6.35-15.64)	9.97	<.0001
85-94 yrs.	2.47	0.23	11.82	(7.53-18.72)	10.58	<.0001
95+ yrs.	2.61	0.24	13.46	(8.41-21.75)	10.77	<.0001
MAPLe (ref. 1)						
2	0.36	0.08	1.43	(1.08-1.87)	2.54	0.01
3	1.48	0.12	4.41	(3.25-5.92)	9.69	<.0001
4	2.07	0.13	7.89	(5.64-10.91)	12.30	<.0001
5	2.60	0.14	13.6	(9.58-19.10)	14.64	<.0001
Caregiver distress (ref. ‘no’)						<.0001
Yes	0.55	0.03	1.74	(1.63-1.84)	17.52	<.0001
Primary caregiver co-reside (ref. ‘yes’)						<.0001
No	0.26	0.05	1.30	(1.21-1.39)	7.25	<.0001
Caregiving dyad relationship (ref. ‘child’)						<.0001
Nonchild	0.09	0.04	1.09	(1.02-1.17)	2.60	0.009
Co-reside X relationship	-0.13	0.05	0.87	(0.78-0.98)	-2.32	0.02

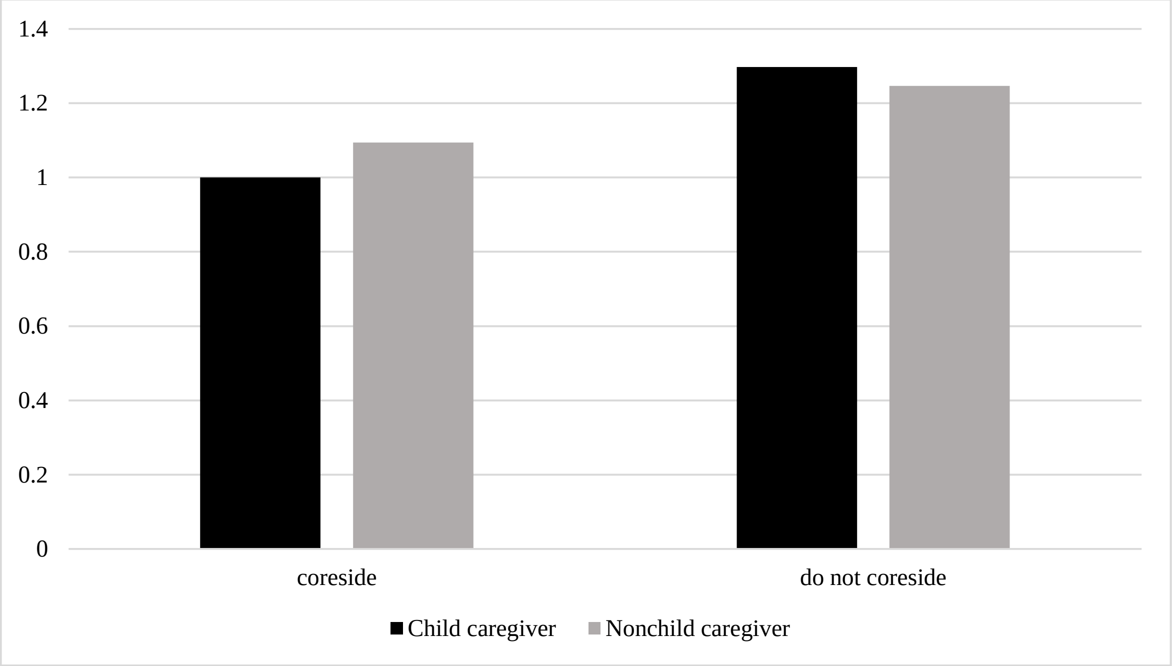


Figure 5.2 Adjusted odds ratios from GEE model for caregiving dyad relationship by coresidence

5.4.2 Survival analysis

Table 5.4 shows the results of regression models using survival data for unadjusted variables. All significant variables in the GEE model, MAPLe score, age of care recipient, caregiver distress, relationship with care recipient and coresidence, were also significant in the final regression model of survival data including the interaction between relationship and coresidence (Table 5.5). In addition, care recipient gender was also significant, although the hazard ratio for this variable was small (0.94) indicating its minor relevance as a predictor of institutionalization compared to the other variables in the model.

Table 5.4 Survival models for unadjusted predictors of long term care admission

Parameters	Estimate	SE	Hazard ratio	95% HR Confidence limits		Chi-square	Pr > Chisq
Care recipient characteristics							
Gender – (ref. ‘female’)	0.13	0.03	1.14	1.07	1.21	23.42	<.0001
Married – (ref. ‘no’)	0.13	0.04	1.14	1.08	1.20	24.54	<.0001
Age group (ref. group 18-39 yrs)							
40-64 yrs.	1.38	0.28	3.99	2.28	6.97	23.65	<.0001
65-74 yrs.	2.25	0.28	9.50	5.49	16.46	64.61	<.0001
75-84 yrs.	2.74	0.28	15.5	9.02	26.84	97.40	<.0001
85-94 yrs.	2.93	0.28	18.7	10.85	32.26	111.01	<.0001
95+ yrs.	3.11	0.28	22.5	12.93	39.22	121.13	<.0001
MAPLe (ref. 1)							
2	0.37	0.16	1.46	1.02	2.01	5.22	0.02
3	1.65	0.13	5.22	4.03	6.76	157.82	<.0001
4	2.39	0.13	10.92	8.45	14.10	335.06	<.0001
5	3.09	0.13	22.08	17.07	28.56	555.73	<.0001
Caregiver characteristics							
Caregiver distress (ref. ‘no’)							
Yes	0.89	0.03	2.44	2.32	2.57	1181.67	<.0001
Primary caregiver co-reside (ref. ‘yes’)							
No	0.06	0.02	1.06	1.01	1.11	4.56	0.03
Caregiving dyad relationship (ref. ‘Child’)							
Nonchild	-0.20	0.03	0.81	0.77	0.86	59.06	<0.0001

Table 5.5 Multivariate survival model for long term care admission

Parameters	Estimate	SE	Hazard ratio	95% HR Confidence limits		Chi-square	Pr > Chisq
Care recipient characteristics							
Gender (ref. ‘female’)	0.05	0.03	0.94	0.89	0.99	3.97	0.04
Age group (ref. group 18-39 yrs)							
40-64 yrs.	1.76	0.28	5.83	3.34	10.21	38.27	<.0001
65-74 yrs.	2.58	0.28	13.20	7.61	22.87	84.69	<.0001
75-84 yrs.	2.98	0.28	19.71	11.42	34.02	114.60	<.0001
85-94 yrs.	3.15	0.28	23.54	13.63	40.65	128.51	<.0001
95+ yrs.	3.31	0.28	27.60	15.82	48.16	136.51	<.0001
MAPLe (ref. 1)							
2	0.23	0.16	1.26	1.25	0.91	1.91	0.16
3	1.45	0.13	4.29	4.26	3.28	118.86	<.0001
4	2.14	0.13	8.47	8.47	6.54	261.18	<.0001
5	2.71	0.13	15.03	11.56	19.51	412.44	<.0001
Caregiver characteristics							
Caregiver distress (ref. ‘no’)							
Yes	0.58	0.03	1.80	1.71	1.90	446.52	<.0001
Primary caregiver co-reside (ref. ‘yes’)							
No	0.33	0.04	-	-	-	81.97	<.0001
Caregiving dyad relationship (ref. ‘child’)							
Nonchild	0.16	0.05	-	-	-	16.94	<.0001
Co-reside X relationship	-0.16	0.06	-	-	-	7.06	0.008

Figure 5.3 illustrates the interaction between the hazard ratio of LTCH admission for care recipients of child and nonchild caregivers and coresidence. The figure shows that the odds of LTCH for care recipients of child and nonchild caregiver that do not co-reside is similar. However, the odds of LTCH admission is higher for care recipients of nonchild caregivers that co-reside being this result consist with the same interaction found in the outcome of the GEE model.

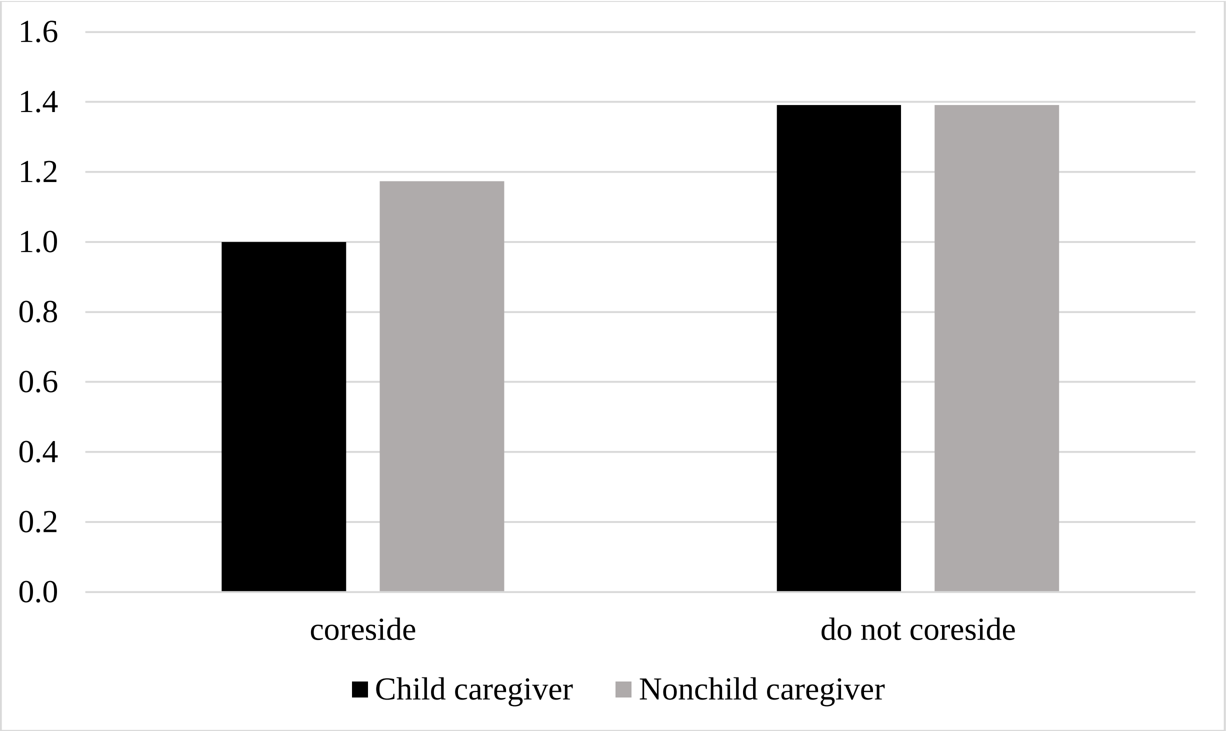


Figure 5.3 Adjusted hazard ratios from survival models for caregiving dyad interaction by coresidence related to LTCH admission

5.4.3 Comparison of survival curves by MAPLe – Distress vs. no-Distress

Before the survival analysis, the c-statistics of three logistic models including 1) only MAPLe scores, 2) only caregiver distress and 3) both variables were used to compare the accuracy of these variables for predicting LTCH admission in the logistic models. The c-statistics were 0.69, 0.61, 0.71 respectively for the models including: MAPLe scores only, caregiver distress only and caregiver distress and MAPLe, indicating that the model including the final selected variables has a higher predictive accuracy compared to the other models (Table 5.6). Even though MAPLe is a strong predictor of LTCH, the addition of caregiver distress in the model increased the c statistic indicating the influence of the later variable in predicting care recipient institutionalization. The c statistic was highest when all variables were included in the final survival model (Table 5.7).

Table 5.6 Logistic regression models for long term care admission based on MAPLe* and caregiver distress

Independent variable	Parameter estimate (SE)	Odds ratio (95% CI)	*P* value	C statistic
Model 1				
MAPLe scores (ref. ‘1’)				
2	0.48 (0.17)	1.62 (1.14-2.24)	0.01	0.69
3	1.80 (0.13)	6.10 (4.71-7.90)	<.0001	
4	2.53 (0.13)	12.5 (9.73-16.2)	<.0001	
5	3.25 (0.13)	26.0 (20.1-33.7)	<.0001	
Model 2				
Caregiver distress (ref. ‘no’)				
Distress	0.91 (0.03)	2.49 (2.36-2.63)	<.0001	0.61
Model 3				
MAPLe scores (ref. ‘1’)				
2	0.46 (0.17)	1.58 (1.14-2.20)	0.01	0.71
3	1.68 (0.13)	5.36 (4.14-6.96)	<.0001	
4	2.36 (0.13)	10.6 (8.22-13.7)	<.0001	
5	2.98 (0.13)	19.7 (15.1-25.6)	<.0001	
Caregiver distress (ref. ‘no’)	0.54 (0.03)	1.72 (1.63-1.82)	<.0001	

*MAPLe: Method of Assigning Priority Levels

Table 5.7. Logistic regression model based on final variables in the survival model only

Parameters	Parameter estimate (SE)	Odds ratio (95% CI)	*P* value	C statistic
Care recipient characteristics				
Gender – (ref. ‘female’)	0.00	0.99 (0.94-1.06)	0.95	0.74
Age group (ref. group 18-39 yrs)				
40-64 yrs.	1.65 (0.28)	5.25 (2.99-9.21)	<.0001	
65-74 yrs.	2.46 (0.28)	11.72 (6.25-20.35)	<.0001	
75-84 yrs.	2.87 (0.28)	11.77 (10.27-30.73)	<.0001	
85-94 yrs.	3.06 (0.28)	21.44 (12.39-37.10)	<.0001	
95+ yrs.	3.20 (0.28)	24.64 (14.07-43.14)	<.0001	
MAPLe (ref. 1)				
2	0.32 (0.17)	1.38 (0.99-1.91)	0.05	
3	1.58 (0.13)	4.87 (3.74-6.33)	<.0001	
4	2.25 (0.13)	9.24 (7.33-12.36)	<.0001	
5	2.84 (0.13)	17.24 (13.24-22.44)	<.0001	
Caregiver characteristics				
Caregiver distress (ref. ‘no’)				
Yes	0.59 (0.03)	1.81 (1.71-1.92)	<.0001	
Primary caregiver co-reside (ref. ‘yes’)				
No	0.33 (0.04)	-	<.0001	
Caregiving dyad relationship (ref. ‘other’)				
Child	0.15 (0.04)	-	0.0002	
Co-reside X relationship	-0.17 (0.06)	-	0.005	

Kaplan Meier survival curves for LTCH admission were stratified by MAPLe scores for comparison of probability of admission within a year after initial RAI-HC assessment for care recipient between distressed (Figure 5.4, group A) and no distressed caregivers (Figure 5.5, group B). This comparison was performed after controlling for the covariates that were considered significant in the final survival model. Thus, the figures show the survival probabilities for the reference groups of the categorical variables where only caregiver distress is different between the two models compared. Thus, except for caregiver distress, the reference group of each of the following variables in the model corresponds to the level with highest hazard ratio in the main survival model: age group = 95+ years, care recipient gender = female, care recipient is married = ‘no’, caregiver co-reside = ‘no’, caregiver relationship ‘nonchild’ = ‘yes’. The comparison of both figures shows that the presence of caregiver distress (Figure 5.4, group A, distress = ‘yes’) had an influence on LTCH admission when compared with the absence of caregiver distress (Figure 5.5, group B, distress = ‘no’) even after considering variables that were also associated with this outcome.

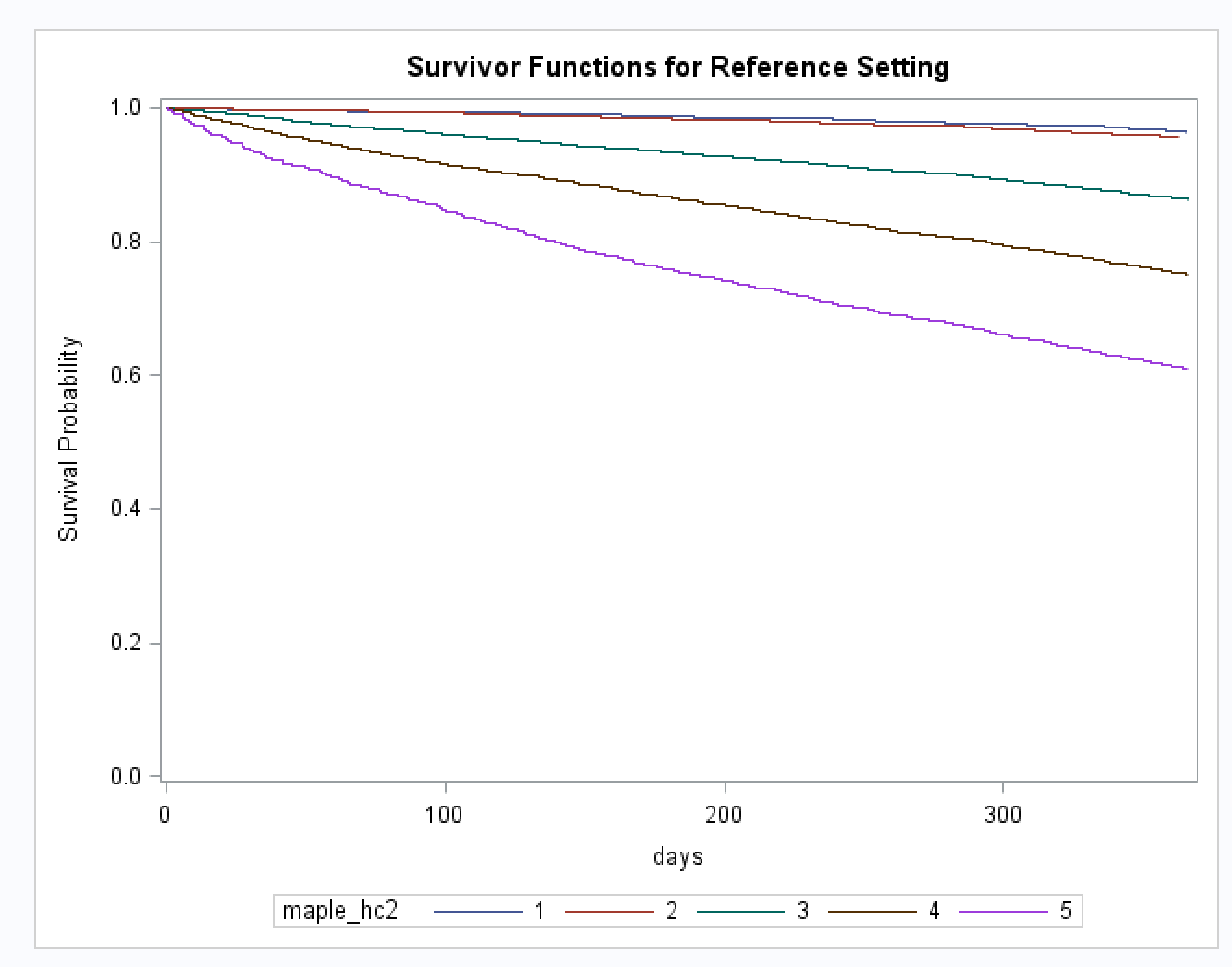


Figure 5.4 –Kaplan-Meier survival curves for long-term care home admission by MAPLe when other covariates are fixed (group A; caregiver distress = ‘yes’) (n=94,956)

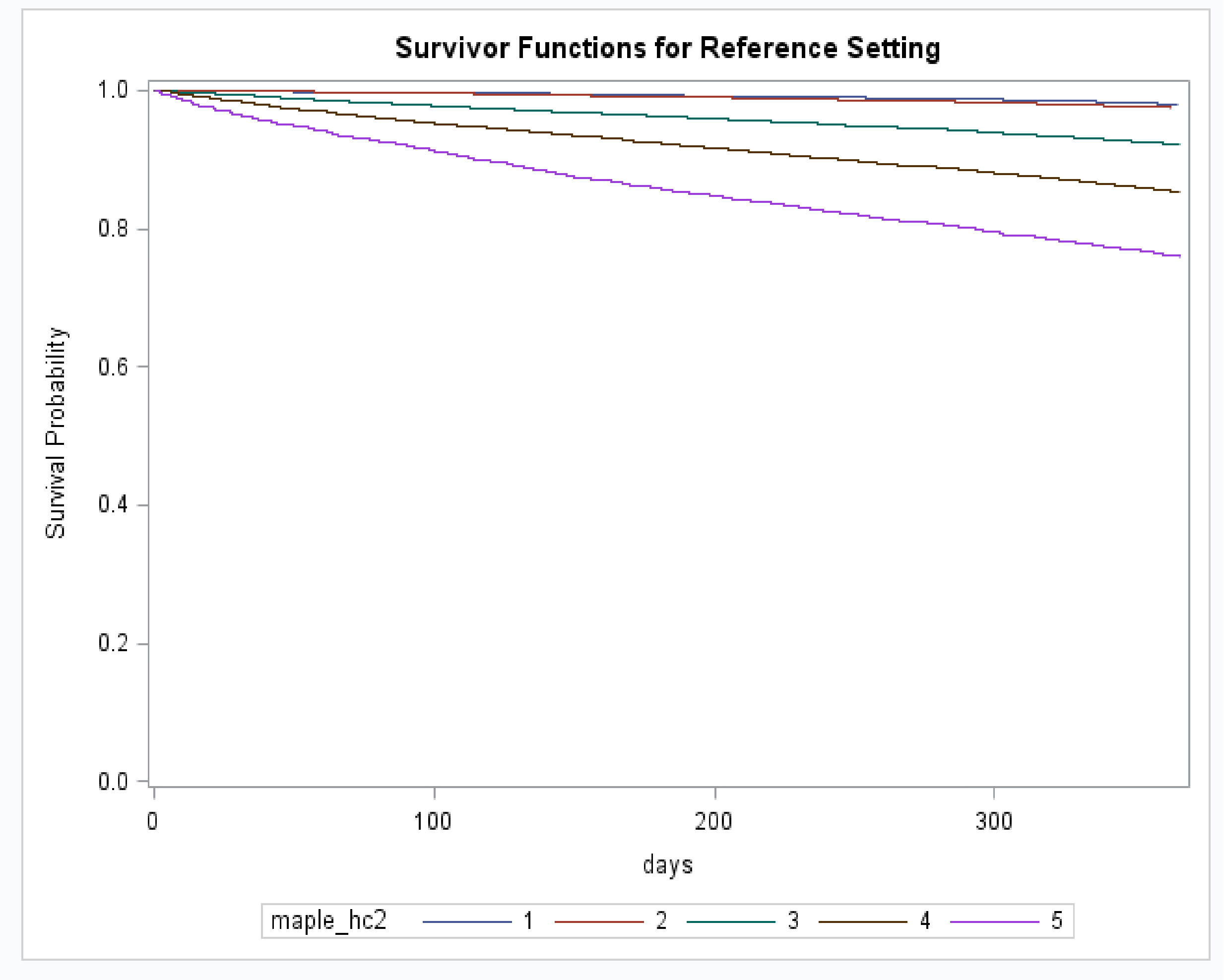


Figure 5.5 – Kaplan-Meier survival curves for long-term care home admission by MAPLe when other covariates are fixed (group B; caregiver distress = ‘no’) (n=94,956)

5.5 Discussion

Several studies have reported the influence of care recipient health characteristics on institutionalization (Eaker et al., 2002; Gaugler, Duval, Anderson, & Kane, 2007; Hirdes et al., 2008) while others have examined also the impact of caregiver related characteristics on LTCH admission (Buhr et al., 2006; Chenier, 1997; Donnelly et al., 2015). This study brings together information on care recipient health, caregiver and caregiving dyad characteristics and their association with institutionalization.

First, preliminary analysis was performed to examine the correlation between MAPLe, an algorithm representing care recipient health needs, and caregiver distress among 14 CCACs. The relationship between MAPLe score and caregiver distress agrees with previous reports on the same association (Hirdes et al., 2008; Mitchell et al., 2015; Vu et al., 2014) (Figure 5.1). This is an important finding giving that several studies reported that care recipient characteristic only accounted for a minor or even no effect on caregiver psychological burden (Cattanach & Tebes, 1991; Garlo et al., 2010; Haley, Levine, Brown, & Bartolucci, 1987; Rinaldi et al., 2005; Stueve et al., 1997; Zarit et al., 1980). In contradiction, other studies have reported that caregiver distress related symptoms are associated with care recipient ADL impairment and behavioral symptoms (Bédard et al., 2000; Bergvall et al., 2011; Conde-Sala et al., 2010; Grunfeld, 2004; Mioshi et al., 2013; Onder et al., 2009; Papastavrou et al., 2007; Skarupski et al., 2009; Van der Lee et al., 2014). These health characteristics are part of the MAPLe algorithm which may explain the association between this scale and caregiver distress.

The variations in the relationship between caregiver distress and MAPLe scores among CCACs are likely a result of different initiatives aiming to avoid or reduce LTCH admission as well as differences on resource allocation that would affect the support provided to caregivers and ultimately their distress levels. For example, the 2011 ‘Home First’ initiative where care recipients receive home care services after coming from hospital, may have been implemented differently in each CCAC.

The higher proportions of distressed caregivers among clients admitted to LTCH in the preliminary analysis also suggests that distress could play a role in institutionalization. Thus, caregiver distress, MAPLe scores and caregiving dyad variables were entered in the GEE and survival models having LTCH admission as an outcome. The care recipient with high MAPLe scores presented the highest risk of institutionalization in both models after controlling for aging and other variables. This result aligns with evidence that care recipient health characteristics such as psychotic symptoms and behaviour dysregulation, included in the MAPLe algorithm, are predictors of institutionalization (Buhr et al., 2006; Eaker et al., 2002). However, it is important to note that the MAPLe algorithm does not include only symptoms exclusively present among clients with mental health issues. That is, the association between MAPLe and LTCH could be also related with health care needs that surpass caregiver ability to provide care and when institutionalization becomes the most appropriate care recipient destination (Bergvall et al., 2011; Grunfeld, 2004; Skarupski et al., 2009).

Although caregiver distress was also a predictor of LTCH admission, the lack of interaction between care recipients with MAPLe scores indicates that caregiver distress influence LTCH admission regardless care recipient care needs. This finding is represented in the Figures 5.4 and 5.5 where likelihood of admission is higher for caregivers expressing distress even after controlling for other predictors. Other studies reported that caregiver characteristics influence care recipient institutionalization after considering care recipient health (Argimon, Limon, Vila, & Cabezas, 2005; Colerick & George, 1986; Tsuji et al., 1995).

Other factors may play a role in the caregiver decision to institutionalize besides the care recipient health characteristic. Research has shown that caregiver’s perception of their ability to provide care and feeling of burden are key factors contributing to their choice (Caron et al., 2006; Haupt & Kurz, 1993; Pot et al., 2001; Sun et al., 2013). This perception, or subjective burden, reflects the appraisal of the strain associated with caring responsibilities (Hunt, 2003) rather than the actual frequency or intensity of care provided (i.e., objective burden).

The association between caregiver distress and LTCH admission may also reflect the lack of respite services and resources available to support caregivers. The provision of in-home or out of home respite may not only help caregivers to deal with distress, but also delay LTCH admission (Gaugler, Kane, Kane, & Newcomer, 2005a; Kelly, Puurveen, & Gill, 2014; Lawton, Brody, & Saperstein, 1989).

Care recipient age, and caregiving dyad coresidence and relationship were significant in the GEE and survival models, indicating their influence on care recipient LTCH admission. Other studies also reported that care recipient age is positively associated with LTCH admission (Greene & Ondrich, 1990; Kosloski & Montgomery, 1995). On other hand, the impact of caregiver coresidence with care recipient on institutionalization has been less examined. In one particular study, care recipients of non-coresiding caregivers were more likely to be admitted to a nursing home (Tsuji et al., 1995).

It is not clear how the coresidence between caregiver and their care recipients influence caregiver responsibilities and their ability to provide care. Some studies have reported that caregivers that live with their care recipients tend to provide instrumental care and spend more hours overseeing care recipients' activities, especially those with behavioral symptoms (Mahoney, 2003; Tennstedt, Crawford, & McKinlay, 1993). Additionally, there is evidence on the negative impact of coresidence on caregiver burden or distress (Conde-Sala et al., 2010; George & Gwyther, 1986; Kim et al., 2012); however, this finding has not been consistently reported (Deimling, Bass, Townsend, & Noelker, 1989; Rinaldi et al., 2005).

The association between the type of caregiver relationship and care recipient institutionalization has been discussed in several studies, with most providing evidence that non-spouses caregivers are more likely to institutionalize their family member or friend (Colerick & George, 1986; Pot et al., 2001; Scott et al., 1997). A recent study on reason of care recipient long term care admission showed that spouse-caregivers reported more reasons related to themselves (e.g., burden), but child caregivers more often reported reasons related to care recipient health such as cognitive symptoms and fall incidents as motivations for LTCH placement (Afram et al., 2014).

One of the most interesting findings in the present study was that the impact of caregiver relationship with care recipient on likelihood of LTCH admission varies with caregiving dyad coresidence. This result was consistent between GEE and survival models where child caregivers that live with and care for their parents are less likely to institutionalize then nonchild caregivers with the same living arrangement. These findings demonstrate differences in the impact of coresidence on LTCH admission among child and nonchild caregivers, which is a neglected subject in past studies.

Although this research does not measure the reason for this finding some possible explanations can be provided based on past studies. One of the few studies of the influence of coresidence on distress among different caregiving dyad relationships has shown that child-caregivers that co-reside experienced less strain than child caregivers that do not co-reside (Deimling et al., 1989). According to the authors, child caregivers that co-reside may be in this situation due to special bonds with their parents as opposed to a child that is unwilling to co-reside. In addition, daughter caregivers coresiding with their parents have reported that the quality of their relationship as one of the reasons why they became their parents primary caregiver (Brody, Litvin, Hoffman, & Kleban, 1995). Interesting, son caregivers have reported that they assume this role motivated out of a sense of love and obligation (Harris, 1998). Thus, child caregivers that live and care for their parents may be more likely to be committed to their caregiver role, therefore less likely to institutionalize.

It is also possible that the majority of caregivers in the nonchild group is represented by older caregivers since this group includes spouses and likely some older relatives and partners that do not define themselves as spouses. If this is the case, the higher odds of institutionalization could be also related to caregiver aging related problems (Hébert et al., 2001) such as their own health issues that have been associated with institutionalization (Argimon et al., 2005; Buhr et al., 2006; Cohen et al., 1993). Spouse-caregivers are also more likely to be in the caregiver role for longer time compared to child caregivers, becoming more emotionally and physically vulnerable to the consequences of caring activities (Pinquart & Sörensen, 2011).

This study has limitations that should be acknowledged. The items on caregiver distress and ability to continue is a dichotomous variable which provide only a yes/no type of answer. Thus, it is not possible to distinguish levels of distress that could have yielded different associations with LTCH admission. In addition, although the RAI-HC provides some information on caregivers, this assessment focus is on the care recipient. Therefore, other caregiver information that may be related to caregiver’s reasons to institutionalize, such as their age and health status, could not be included in the analysis. It should be also acknowledgement that policy and other contextual factors that may affect LTCH placement were not considered in this study.

One of the major strengths of this study is the inclusion of not only care recipient health information, but also caregiver distress and caregiving dyad information such as coresidence and relationship allowing a more detailed examination of the potential predictors of LTCH admission. The study findings have important implications to researchers and policy makers since it shows that caregivers living arrangement should be considered when evaluating the potential caregiver predictors of LTCH admission for study purposes or developing interventions.

In summary, caregiver distress is a predictor of LTCH admission independent of home care recipient needs, although the later has a stronger association with institutionalization. In addition, caregiving dyad information such as living arrangement and relationship plays a role in LTCH placement. These findings are valuable for decision and policy makers as they present important implications for developing strategies to reduce or avoid LTCH admission. While the health decline of the care recipient is often unavoidable and institutionalization becomes the most suitable option, caregiver distress can be prevented by respite and support services. These interventions may improve their quality of life and provide them with skills to cope their daily challenges, ultimately allowing caregivers to continue caring for their family member and friends at home.

Chapter 6

EVALUATION OF A RESPITE PROGRAM FOR INFORMAL CAREGIVERS OF CARE RECIPIENTS OF HIGH NEEDS USING INTERRAI ASSSESSMENTS

6.1 Introduction

Several factors may negatively affect informal caregiver ability to continue on their role, such as poor coping skills, lack of formal and informal help and emotional support, and poor health (Buhr et al., 2006; Thomas et al., 2004). The lack of adequate support is particularly worrisome as it can lead to decline in caregiver's mental and physical health increasing the risk of adverse outcomes (Vitaliano, 2010; Vitaliano et al., 2003).

Diverse types of caregiver interventions have been developed to provide the support needed by informal caregivers to continue in their role. These interventions vary in nature and may assist caregiver in their caring related activities in different ways. They may have different aims such as to provide information on specific caring skills for dealing with behavior problems and health care needs, offer emotional help through counselling or support groups or offer respite through formal services (Sörensen et al., 2002). These resources may be provided on their own or as part of a multifaceted strategy that target multiple issues experienced by caregivers. However, the complexity involved in the caregiver role and the challenges that are unique for each caregiver complicate the development, implementation and evaluation of interventions as there is not a 'one size fits all'. Interventions that presents multiple strategies and incorporate flexibility and intensity in the services tailored to attend individual needs seem more likely to succeed (Gaugler, Potter, & Pruinelli, 2014).

Within the types of intervention, respite care involves the support provided to caregivers by assisting care recipient at home, adult day care or hospital/nursing home while caregivers can take a break from their caring responsibilities. However, studies of this type of intervention present conflicting results with a substantial number suggesting only a moderate or no impact at all of this type of intervention on caregiver outcomes or rate of care recipient institutionalization (Flint, 1995; Jeon, Brodaty, & Chesterson, 2005; Lee & Cameron, 2004; McNally, Ben-

Shlomooe, & Newman, 1999) . The lack of effect could be a consequence of inappropriate methods used for the development or evaluation of this type of program as well as conceptual limitations used in the research studies (Flint, 1995; Lee & Cameron, 2004).

A successful intervention evaluation depends on the collection of information associated with caregiver and care recipient outcomes and caregiving-dyad characteristics that may be affected by intervention or that may interfere in the results (Van Houtven et al., 2011). The framework for informal caregivers interventions developed by Van Houtven and colleagues (2011) suggests that caregiver and care recipient characteristics including demographics, physical and psychological health, economic status, and cultural norms, should be measured at baseline and also after the intervention. Moreover, care recipient outcomes such as hospital visits (Oktay & Volland, 1990), and length of stay of care recipients in the community (Kelly et al., 2014; Lawton et al., 1989) are potential measures for the evaluation of an intervention aiming to improve caregiver well-being. Some researchers believe that the latter outcomes maybe more responsive to an intervention targeting caregiver than measures of distress (Knight et al., 1993).

The quality and diversity of information required to evaluate an intervention for informal caregivers is key for successful evaluation particularly considering the complexity involved in the caregiving experiences. A meta-analytic study on the effectiveness of interventions for caregivers showed that the magnitude of an intervention effect varies with caregiver age, relationship with care recipient and caregiver gender (Sörensen et al., 2002). In this review, interventions not only had a higher impact on the burden of children caregivers, but also on care recipient symptoms when care was provided by spouse caregivers. The caregiving dyad relationship is particularly important for development and evaluation of respite programs given that they seem to use respite hours in different ways consequently affecting the outcomes differently (Berry, Zarit, & Rabatin, 1991).

A successful intervention evaluation relies also on the effectiveness of the assessment used to identify the target cohort and changes in the key outcome measured before and post intervention. For example, selecting caregivers with high levels of distress would avoid floor effects (Knight et al., 1993). Thus, a valid and reliable tool is needed to ensure that distress levels are accurately identified. Unfortunately, most tools used to assess caregivers during intervention studies and used in practice have not been validated or are not caregiver specific jeopardizing the proper evaluation of the intervention (Mosquera et al., 2016). Moreover, the caregiver outcomes chosen as indicators of the impact of interventions are often not well defined and difficult to measure (Acton & Kang, 2001). Depression and burden are the most common outcomes measured during caregiver interventions (Mosquera et al., 2016; Van Houtven et al., 2011). However, depression has been suggested as being a more sensitive measures to identify intervention effects than burden (Knight et al., 1993).

Burden is not only poorly defined (Braithwaite, 1992; Brannan & Heflinger, 2001) but also has been measured by a substantial number of assessments (Platt, 1985; Schene, Tessler et al., 1994; Visser-Meily, Post, Riphagen, & Lindeman, 2004; Whalen & Buchholz, 2009). Consequently, results among intervention studies where caregiver burden is one of the key outcomes may not be comparable (Mosquera et al., 2016). Other caregiver related measures such as quality of life or mental health indictors could potentially be better measures of changes in caregiver outcomes as a result of an intervention. Unfortunately, few assessments emphasize quality of life indicators compared to the large number of assessment used to identify burden while most mental health assessments used in interventions studies are not caregiver specific (Deeken et al., 2003; Mosquera et al., 2016).

A well-defined caregiver outcome and its proper assessment are also key to identify participants that would be more likely to benefit from the chosen strategy (Pusey & Richards, 2001). That is, the caregiver related outcome measured as part of the intervention evaluation should be also part of the criterion used to identify caregivers to participate in the program (Acton & Kang, 2001; Whitlatch et al., 1991; Zarit et al., 1980). According to Deeken (2003), assessments should provide information to direct an intervention that later could be evaluated by the same assessments.

The other obstacle for proper intervention evaluation is the lack of assessments that are considered sensitive to changes. In fact, most instruments have not been tested for sensitivity to changes in the caregiver related outcomes or present low sensitivity which could jeopardize the success of the evaluation (Pusey & Richards, 2001). The Zarit Burden Interview, one of the most commonly used assessments in caregiver research, has been criticized as an instrument to evaluate changes in caregiver burden, since it includes both objective and subjective measures of burden that could lead to ambiguous results (Acton & Kang, 2001).

The objective of the present study is to evaluate a community based respite program that provide in-home respite services with three key objectives: 1) improve caregiver distress and well-being; 2) improve caregiver ability to continue in their role and 2) reduce avoidable long term care admissions of the care recipient. Multiple methods were used to evaluate whether the respite program achieved the expected goals.

6.2 Method

6.2.1 Design and sample

This is a non-experimental longitudinal cohort study involving informal caregiver participants of the Caregiver Recharge Services (CRS), a collaborative community service offered by the Alzheimer Society of Peel, Nucleus Independent Living and Links2Care. This initiative funded by Mississauga Halton Local Health Information Network (MH LHIN) started in April 2012 in response to feedback provided by community representatives during the Integrated Health Service Plan engagement sessions. The community representatives identified that informal caregiver burnout is a significant issue. They also indicated that informal caregivers would not rely as heavily on long-term care if there were more supports available at home to provide the care their care recipients need. The CRS was developed in response to these identified concerns by offering flexible hours of respite to be used based on the needs of the caregiver. According to the CRS, an informal caregiver is a volunteer, friend, neighbour, or relative providing unpaid, in-home care to an adult, sibling, spouse, parent or other relative with disabilities. Therefore, the term 'caregiver' used in this study refers to the aforementioned definition.

This program provided in-home service 24 hours a day, seven days a week. Eligible caregivers were able to use a minimum of 2 hours of service per visit to the maximum hours that were allotted to them at any time within the year. The maximum hours per year varies with the Caregiver Strain Index (CSI) score used to determine eligibility of the caregiver.

The in-home services was provided by personal support workers (PSW) that offered assistance with 1) activities of daily living (e.g., ambulation, one person transfer, dressing/undressing, personal hygiene, bathing), 2) instrumental activities of daily living (e.g., homemaking, meal preparation, assistance with eating and medications) and also companionship (e.g., some recreational activities, redirection/prompting/cueing, prevention of wandering, safety checks). Personal support did not include intensive nursing care, medication administration, transportation or transfers that require 2 people. Thus, CRS provided respite to caregivers by offering assistance on activities that are usually performed by informal caregivers. The goal of the program was to reduce caregiver distress and allow them to continue caring activities, consequently reducing avoidable admissions of care recipients to long-term care homes that often occurs due to caregiver distress.

The referral sources for the CRS were: Mississauga Halton Community Care Access Centre, community support service providers (e.g., Alzheimer's society, Links2Care), hospitals, self/family, Health Links, physicians and other family health teams. Thus, caregivers seeking for respite from CRS were directed to this program by different health care providers.

Referrals were sent to Central Registry, a one-stop point of access in the Mississauga Halton Local Health Integration Network for CRS and other programs. The care recipient eligibility for these programs are based on standardized criteria. The interRAI CHA assessment is administered by central registry to evaluate the care recipient needs and to direct them to the resources available.

During the two years of this study (April 2013 to April 2015) the respite was offered for a year period after which the caregivers needed to reapply again to participate in the program.

6.2.2 Selection criteria of participant caregivers

To participate in the CRS, caregivers were assessed using the Caregiver Strain Index (CSI), an instrument to evaluate caregiver burden with scores ranging from 1 to 13 (Robinson, 1983). Caregivers were eligible to participate in the program if their CSI assessment scores were 9 or higher, and if they were at least 18 years old and resided in the MH LHIN catchment area. More specifically, caregiver would be eligible for 168 hrs/year (when CSI 9 or 10), 267 hrs/year (when CSI 11 or 12) or 365 hrs/year (when CSI 13) to be used according to their needs.

In addition to the CSI eligibility criteria, only those caregivers providing care for care recipients with a MAPLe (Method of Assessing Priority Levels) score of 4 or 5 were accepted into the program. This algorithm is derived from the Resident Assessment Instrument Home Care (RAI-HC) and the interRAI Community Health Assessment (CHA). Caregivers of care recipients with an ‘end of life designation’ determined by an interRAI Palliative Care were also eligible to participate in the CRS. The interRAI CHA and RAI-HC assessments were administered within 3 months of their CSI assessment. The interRAI palliative assessments were excluded from the analysis due to the small sample size (n=20).

The care recipient assessments used in this study are outlined below.

6.2.3 Care recipient assessments

interRAI CHA and RAI-HC assessments of the care recipients from the CRS were obtained as part of the evaluation study. This dataset was used in analysis for 1) describing care recipient characteristics; 2) evaluating changes in the caregiver items; 3) examining predictors of LTCH admission and for 4) comparisons between care recipients in the CRS and long-stay home care clients. These instruments are part of the interRAI suite of assessments developed by a group of researchers from over 35 countries around the world. They have been mandated or recommended for use across Canada (including Ontario, Alberta, Saskatchewan, Nova Scotia, Newfoundland, and British Columbia) and also in several locations in the world such as in Europe, USA, the Middle East, Central and South America (Canadian Home Care Association, 2013). Moreover, these instruments have established reliability as reported by several studies (Carpenter & Hirdes, 2013; Hirdes et al., 2008; Landi et al., 2000; Poss et al., 2008).

6.2.3.1 interRAI Community Health Assessment (CHA) – In 2010, the Ontario Ministry of Health and Long-Term care (MOHLTC) implemented the use of the interRAI CHA by all community support organizations to evaluate the needs and preference of the clients receiving support services. The interRAI CHA includes a core assessment that may trigger the further assessment of specific problems using one of the four supplements available: the functional, the mental health, the deaf-blind, and the assisted living supplement. For the most part, care recipients in the CRS were assessed using the core and functional supplement.

6.2.3.2 Resident Assessment Instrument Home Care (RAI-HC) – The RAI-HC has been mandated in Ontario since 2002 for the assessment of home care clients from the Community Care Access Centres (CCAC) expected to be on service for more than 60 days. This comprehensive assessment has items and outcomes that are compatible with other interRAI instruments such as the interRAI CHA core plus the functional supplement. This compatibility allows for a crosswalk between items from these assessments, resulting in a larger sample size for the analysis linking the caregiver survey with care recipient information.

6.2.3.3 Clinical scales of interRAI CHA and RAI-HC

Several scales can be calculated using similar items in the interRAI CHA and RAI-HC. Evidence has shown the good validity and reliability of items and scales in these instruments (Hirdes, Ljunggren, et al., 2008; Morris et al., 1997; Poss et al., 2008). These scales represent different clinical aspects of the care recipient health and they are often related to outcomes and measures such as death, long term care admission or caregiver distress (Landi et al., 2000). Some of the scales that were used to describe care recipient clinical health from this study are presented below.

The Method for Assigning Priority Levels (MAPLe)

The MAPLe score is intended to assist health care providers in identifying those individuals who have the most urgent need for care (Hirdes et al., 2008). MAPLe scores range from 1 to 5 with higher scores indicating a higher priority for care. This algorithm can also be used to inform choices related to allocation of home care resources and prioritization of clients needing community or facility-based services. MAPLe scores were used as part of the eligibility criteria of this program mainly due to evidence on its strong association with caregiver distress (Health Council of Canada, 2012; Hirdes et al., 2008; Mitchell et al., 2015) and LTCH admission

(Hirdes et al., 2008). Admission criteria to the CRS required that the care recipient had a MAPLe score of 4 or 5.

Activities of Daily Living Hierarchy Scale (ADL-H): The ADL Self-Performance Hierarchy Scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss. Early-loss ADLs are assigned lower scores than late-loss ADLs. Scale scores range from 0 to 6, with higher scores indicating greater decline (progressive loss) in ADL performance (Landi et al., 2000; Morris et al., 1997, 1999).

Cognitive Performance Scale (CPS): A hierarchical index used to rate a person's cognitive status. The scale scores range from 0 to 6, with higher scores indicating more severe impairment. This scale has been validated against the Mini-Mental State Exam (MMSE) for the detection of cognitive impairment (Jones et al., 2010; Landi et al., 2000; Morris et al., 1994; Paquay et al., 2007; Wellens et al., 2013).

Information on the assessment (RAI-HC or interRAI CHA) of care recipient cared by informal caregivers participating in this study is compared with information of long-stay home care clients (MH CCAC) assessments (RAI-HC) administered in the same timeframe (Table 6.1).

Table 6.1 Characteristics of care recipients and caregivers in the evaluation study compared with long stay home care clients (MH CCAC)*

	Caregiver Recharge Services (n=316)	MH CCAC (2,982)	Pr > Chisq
Caregiver characteristics	% (n)	% (n)	
Co-reside - yes	94.3 (298)	66.3 (1,950)	<.0001
Relationship – spouse	48.1 (152)	31.4 (925)	<.0001
Relationship - child or child-in-lawn	44.3 (140)	53.3 (1,567)	
Unable to continue - yes	32.2 (102)	13.5 (401)	<.0001
Distress, anger or depression - yes	62.6 (198)	26.8 (801)	<.0001
Care recipient characteristics			
Gender - female	50.1 (157)	62.8 (1,874)	<.0001
Primary language - English	69.3 (219)	64.7 (1,930)	0.10
Age group (years)			0.02
<65	12.6 (40)	14.1 (423)	
65-74	14.6 (46)	11.1 (331)	
75-84	36.3 (115)	30.9 (922)	
85+	36.3 (115)	43.7 (1,305)	
Cognitive Performance Scale			
Intact or borderline intact	6.0 (19)	12.3 (367)	<.0001
Mild/Moderate	57.9 (183)	66.7 (1,989)	
Moderate/Severe	33.2 (105)	16.1 (482)	
Very severe	2.8 (9)	4.8 (144)	
Activities of Daily Living Hierachy Scale			
Independent	11.8 (37)	38.6 (1,152)	<.0001
Supervision required/Limited	30.9 (97)	27.7 (828)	
Extensive assistance required	37.7 (118)	21.6 (646)	
Dependent/total dependence	19.4 (61)	11.9 (356)	
Dementia	57.2 (181)	27.9 (687)	<.0001
Behavior Symptoms			
Wandering	10.4 (33)	4.8 (143)	<.0001
Verbally abusive	10.1 (32)	8.2 (246)	<.0001
Socially inappropriate	5.7 (18)	4.0 (121)	<.0001
Resists care	15.5 (49)	12.6 (376)	<.0001

*MH CCAC: Mississauga Halton Community Care Access Centre. Only RAI-HC from MH CCAC care recipients with Method of Assigning Priority Levels scores 4 and 5 were included in this analysis.

Note: In some cases, the number of cases is less than the full sample size because missing data are excluded.

6.2.4 Caregiver assessments

6.2.4.1 Caregiver Strain Index (CSI) - All caregivers were assessed through CSI for determination of their eligibility. The CSI is a screening instrument developed to identify caregivers at risk of burnout. It includes 13 questions that reflect the perceptions of the caregivers on their responsibilities and also provide information on their emotional health (Robinson, 1983). The answers are dichotomous (yes or no) and higher scores are associated with higher risk of burnout.

6.2.4.2 The caregiver survey – This survey was developed by interRAI researchers based on other interRAI self-reported Quality of Life assessments, including the interRAI/Kendal Corporation Collage initiative "Wellness" assessment and the interRAI Quality of Life Self-report survey for Home Care/Community Living, Senior Housing, and Mental Health. The Wellness Assessment is a self-rated assessment that addresses issues related to a person's psychosocial, cognitive, health status, and daily functioning based on items from interRAI community assessments. The interRAI Quality of Life surveys are self-report surveys that address a number of issues, including, for example, self-determination, mood, social participation and community involvement, social ties, and belonging. All items from these self-report surveys were considered for the caregiver survey, with or without modifications. Over the course of a number of revisions, a pilot caregiver survey was finalized with a total of 82 items covering a range of domains including demographic information, physical and emotional health, caregiving responsibilities, well-being, and quality of life and supports. The Caregiver Surveys at admission were linked to 314 care recipient assessment being, 170 interRAI CHA and 144 RAI-HC assessments.

Among 364 caregiver surveys completed at CRS admission, 169 caregiver surveys were matched with their respective surveys completed at follow-up. Some of the reasons of lost for follow-up were: care recipient deceased or admitted to long term care, caregiver declined CRS services before completing 6 months in the program, unability to contact the caregiver (e.g., wrong phone number) and caregiver did not want to participate in the study. Moreover, some caregivers were interviewed at program admission less than 6 months before the end of the study.

Although data on caregivers lost for follow-up interview was not systematically collected, data on the reason for discharge of the CR program provides relevant information related to caregivers lost for follow-up. The results of analysis on the discharge information (n=666) showed that 34% of the care recipients of the CR program either were admitted to LTC or died prior to completing the progam, whereas only 50% of the care recipients completed the year or finished their program hours. Among 16% care recipients/caregivers that were discharged before completing one year in the program, 6% declined services, 3% were directed to other services and 7% did not complete the year or finished their program hours due to unknown reasons.

6.2.4.3 Caregiver Distress Index (CDI) – This is a screener with four questions derived from the caregiver survey that yields a final score representing caregiver distress level. The development of this screener was performed using part of the dataset from this study and it is described in chapter 4. These screener questions represent caregiver symptoms of: anhedonia (little or no pleasure in the things person normally enjoys), anxiety (anxious, restless, or uneasy), and depressed mood (sad, depressed or hopeless) as well as feeling overwhelmed by caregiving responsibilities in the 3 days prior to completing the survey. The scores range from zero to eight and are split in three groups representing risk levels of adverse outcomes such as poor quality of life and poor health. The risk levels are low (score 0), moderate (scores 1 to 4) and high (scores 5 to 8). Caregivers in the high risk group were more likely to experience poor physical and mental health (see chapter 4).

6.2.5 The caregiver survey interview protocol

Three health service providers (HSP), Links2Care, Home Instead, and AbleLiving, were responsible for introducing the caregiver study during their first visit by providing a letter and asking caregivers consent to participate in the study. Consents were sent to University of Waterloo together with caregiver phone number and name. A University of Waterloo researcher (i.e., PhD student, undergraduate student volunteers, and research assistant) interviewed the caregiver on the phone, taking in average 20 min for completion. All the interviewers were trained by an interRAI clinical educator. A total of 364 surveys completed before the caregivers received the first services and a total of 169 follow-up surveys completed at least 6 months of their participation on the study were used for analysis.

The study was approved by the Office of Research Ethics from University of Waterloo (ORE # 18982).

6.3 Statistical Analysis

The evaluation of the respite services provided by CRS included three approaches aiming to answer different questions described as follows.

6.3.1 Changes in the Caregiver Distress Index (CDI) scores and caregiver survey responses between admission and reassessment

The objectives of these analysis were to identify changes in various aspects of caregiver life and also to examine whether these changes vary according to caregiver initial distress measured by the CDI.

The caregiver survey includes the four questions that are part of the Caregiver Distress Index (described in chapter 4), a screener used to identify informal caregivers at risk of adverse outcomes such as poor mental and physical health. The CDI scores at intake were used to categorize the caregiver in 3 groups: low (score zero), moderate (score 1 to 4) and high (score 5 to 8) risk. Only 140 completed surveys at intake were used for analysis due to missing values that did not allow the calculation of the CDI scores for intake or reassessment. Information on the caregivers risk level at CRS admission is presented in Table 6.2. This dataset include only information on caregivers that also participated in the follow-up interview.

Table 6.2 Characteristics of informal caregivers by Caregiver Distress Index

Caregiver Distress Index - Risk level	Low	Moderate	High	*P* values
	% (n)	*% (n)*	*% (n)*	
Caregiver characteristics	24.3 (34)	36.4 (51)	39.3 (55)	
Age				
< 60	35.3 (12)	44 (22)	37.7 (20)	0.74
60 - 74	38.2 (13)	32 (16)	43.4 (23)	
75+	26.5 (9)	24 (12)	18.8 (10)	
Gender				
Female	79.4 (27)	69.4 (34)	84 (42)	0.21
Primary Language				
English	67.6 (23)	66.7 (34)	72.7 (40)	0.77
Relationship with care recipient				
Spouse	37.9 (11)	32.5 (13)	61.5 (24)	0.06
Child	27.6 (8)	42.5 (17)	20.5 (8)	
Other	34.5 (10)	25 (10)	17.9 (7)	
Paid Employment				
Part time or full time	36.3 (12)	42 (21)	29.4 (15)	0.42
Caring for				
Adult only	76.5 (26)	72.5 (37)	69.1 (38)	0.75
Adult and child	20.6 (7)	27.4 (14)	27.2 (15)	0.73
Trade-off[a]				
Yes[b]	8.8 (3)	22.4 (11)	43.6 (24)	<.001
Mental Health				
Depression[b,c]	0	15.7(8)	40 (22)	<.0001
Loneliness[b]	8.8 (3)	41.1 (21)	72.7 (40)	<.0001
Physical Health				
Pain every day in the last 3 days[b]	33.3 (11)	37.2 (19)	58.2 (32)	0.03
Severe or horrible pain[b]	11.7 (4)	7.8 (4)	23.6 (13)	0.07
Unable to complete normal daily activities[b]	20.6 (7)	48 (24)	63.6 (25)	0.0002
Difficulty falling or staying asleep every day in the last 3 days[b]	29.4 (10)	37.2 (19)	61.8 (34)	0.01

[a] Based on the caregiver survey item: In the last 30 days, have you made trade-offs among purchasing: adequate food or shelter, clothing or prescribed medications, sufficient home heat or cooling, necessary health care or home care due to limited funds?

[b] *P* value according to Fisher Exact Test – *P* values according to Chi square test otherwise.

[c] Currently receiving treatment or being monitored for this condition.

Note: In some cases, the number of cases is less than the full sample size because missing data are excluded.

Changes in the items responses from intake and follow-up assessments were compared for all caregivers using paired t-test. Next, changes in the items responses were compared by CDI risk levels (i.e., low, moderate and high risk) to evaluate whether changes in the response for the items examined were different for each risk level.

The paired t-test determines whether the mean of a variable (i.e., caregiver item scores) are the same at intake and follow-up assessment. This test assumes that the differences between pairs are normally distributed, the variable is an interval, and samples compared are not independent. The Shapiro-Wilk test, used for small sample sizes, confirmed the normal distribution of the variables.

The scores of the items in the ‘E’ section of the caregiver survey (‘Quality of Life and Supports’) were reversed for the paired t-test and the ‘I don’t know’ answer was removed when present (i.e., 2%). These items present a response set that include the answers: ‘never’, ‘rarely’, ‘sometimes’, ‘most of time’ and ‘always’ which corresponds to the respective scores 4, 3, 2, 1, and zero. The negative mean values of the paired t test always represent an improvement or a positive change in the frequency of the experience reported regardless of the question asked.

6.3.2 Improvement of caregiver distress and ability to continue

Improvements in caregiver distress and the ability to continue in their role were evaluated as outcomes measures in logistic regression models. This information was obtained as part of the RAI-HC and interRAI CHA intake and follow-up clinical routine assessments of the care recipients participating in the CRS. The interval between intake and follow-up assessments for CRS clients was between 6 to 9 months. The same time frame was used for the interval between MH CCAC first intake and follow up assessments completed for clients with MAPLe scores 4 and 5, to be consistent with CRS assessments. All the assessors received the same training for completing the care recipient assessments regardless of working for MH CCAC or CRS as the interRAI training is standard for all organizations.

Three logistic models were built including 1) *improvement in distress*, *2) improvement in ability to continue* or 3) *improvement in distress and abilitity to continue* as a binary outcome. The dataset for each model included only assessments where the outcome variable was present in the first assessment. For example, for 'improvement in distress' model, the dataset included only intake assessments where caregivers reported 'yes' to the statement 'primary caregiver expresses feelings of distress, anger or depression'; therefore, the change from 'yes' in the intake assessment to 'no' to this statement in the follow-up assessment represented the probability modeled. The same approach was applied for evaluating a change in the answer for the statement 'a caregiver is unable to continue in caring activities', being the change from 'yes' (unable) to 'no' (able) the probability modeled. Both models included the following variables: care recipient age group (reference group younger than 65 years) and gender (reference: male), MAPLe score at intake assessment (reference: MAPLe 5), caregiver coresidence (reference: do not co-reside) and caregiver participation in CRS (reference: MH CCAC).

6.3.3 "I would recommend this program to others."

Caregivers were asked to respond to this statement '*I would recommend this program to others'*- *'never, rarely, sometimes, most of the time, always or I don't know'*. Only the answers at follow-up assessment were considered for program evaluation.

6.3.4 Rate of admission to LTCH and time to admission

The rates of long term care admissions as well as the number of days before institutionalization were compared between CRS and MH CCAC care recipients with similar

MAPLe scores. (i.e., 4 and 5) and cared by a distressed caregiver (i.e., caregiver ‘unable to continue’ or ‘distressed, angry, or depressed’ according care recipient assessment).

For CRS clients, only the LTCH admissions occurring between April 2014 and April 2015 were considered for this analysis since they were linked to initial care recipient assessments taken between April 2013 and April 2014, to ensure that caregivers could potentially use the respite hours from CRS for a year. The information on LTCH admission was obtained from the ‘Discharge summary’ document that was sent in a regular basis by CRS health service providers to University of Waterloo with information on caregivers and care recipient reason for discharge. Information on LTCH admission for MH CCAC clients was obtained for the same period of time: between April 2014 and April 2015. The information on LTCH admission was collected from the Client Health Related Information System (CHRIS). This software, stored by each CCAC as well as by OACCAC, includes information on community based client admission and discharge (including palliative care, home care and LTCH) and home care service utilization across Ontario.

Demographic, caregiver information and health characteristics of the care recipients from CRS and MH CCAC is presented in Table 6.3. The sample of assessments from CRS and MH CCAC include only care recipients with MAPLe 4 and 5 and with a distressed caregiver (i.e., caregiver ‘unable to continue’ or ‘distressed, angry, or depressed’ according care recipient assessment). Information from both organizations correspond to initial care recipient assessments administered between April 2013 and April 2014.

Table 6.3 Demographics, social and clinical characteristics of Caregiver Recharge Services (CRS) clients and long-stay home care clients (MH CCAC) with a distressed caregiver*

Variables in the care recipient assessment	MH CCAC (n= 1011)	CRS (n= 236)	*P* value
	% (n)	% (n)	
Caregiver characteristics	1011	236	
Co-reside - yes	80.8 (817)	94.4 (223)	<.0001
Relationship - spouse	42.2 (427)	50.0 (118)	0.003
Relationship – Child or child in lawn	45.5 (460)	45.3 (107)	
*Unable to continue - yes	39.9 (404)	41.9 (99)	0.57
*Distress, anger or depression - yes	79.2 (801)	89.4 (211)	0.0003
Care recipient characteristics			
Primary language English	55.9 (566)	63.9 (151)	0.02
Gender Female	56.7 (573)	54.3 (63)	0.14
Age (years)			
<65	13.7 (139)	6.78 (16)	0.01
65-74	11.7 (119)	15.7 (37)	
75-84	32.8 (332)	36.8 (87)	
85+	41.6 (421)	40.6 (96)	
Method of Assigning Priortity Levels			
High	59.5 (602)	55.1 (130)	0.21
Very high	40.4 (409)	44.9 (106)	
Cognitive Performance Scale			
Intact or borderline intact	10.8 (109)	5.93 (14)	<.0001
Mild/Moderate	61.4 (621)	53.8 (127)	
Moderate/Severe	21.7 (220)	35.6 (84)	
Very severe	6.10 (61)	4.66 (11)	
Activity of Daily Living Hierarchy Scale			
Independent	24.3 (246)	10.6 (25)	<.0001
Supervision required/Limited	32.0 (324)	33.9 (80)	
Extensive assistance required	29.6 (299)	34.7(82)	
Dependent/total dependence	14.0 (142)	20.7 (49)	
Dementia Present	25.4 (257)	39.8 (61)	0.0005

*either one or both present.

Note: In some cases, the number of cases is less than the full sample size because missing data are excluded.

A survival model using Cox proportional hazards was performed using PHREG procedure in SAS to evaluate whether the respite services had an impact on care recipient LTCH admission when compared with LTCH admission of MH CCAC long stay home care recipients. Care recipient age, initial MAPLe score (4 or 5), caregiving dyad relationship and living arrangement were covariates in the model.

The length of time between the care recipient assessment and LTCH admission was obtained for each organization, by MAPLe score, using the PROC MEANS. The confidence intervals were compared to determine if differences in the time before LTCH admission were statistically significant.

6.4 Results

6.4.1 Changes in caregiver survey items and CDI scores

The results of the paired-t test showed that caregivers in the follow-up presented improvements in the CDI scores (decreased scores) (Table 6.4). They also reported lower frequency of negative symptoms such as feeling overwhelmed by the care recipient disease and no pleasure in the things that they used to enjoy ($P < 0.04$). Table 6.4 also shows the increase in the reported frequency of positive outcomes such as feeling that they play an important role in people's lives and participation in meaningful activities.

Table 6.4 Change in caregiver survey items using paired t-test for all caregivers

	mean*	95% CL mean	SD	t value	*P* value
CDI score					
All caregivers (n=139)	-0.43	(-0.85 – -0.01)	2.51	-2.05	0.04
In the last three days, how often have you felt little interest or pleasure in the things					
All caregivers (n=142)	-0.36	(-0.66 – -0.05)	1.86	-2.30	0.02
In the last three days, how often have you felt overwhelmed by your relative/friend's illness?					
All caregivers (n=160)	-0.26	(-0.52 – -0.01)	1.66	-2.00	0.04
I play an important role in people's lives.					
All caregivers (n=149)	-0.19	(-0.33 – -0.05)	0.88	-2.69	0.01
I participate in meaningful activities					
All caregivers (n=159)	-0.24	(-0.45 – -0.02)	1.37	-2.19	0.03

*negative mean values represent an improvement while positive mean values represent a worsening in the follow-up assessment related to the intake assessment;

When the caregivers were assigned in groups according to the CDI risk levels, improvements in the psychological distress items were observed only for the high risk group (i.e. CDI levels) (Table 6.5). In addition, caregivers in this risk group also improved their perception related to access to needed health services. However, for the moderate risk group, no improvements were observed. Instead, caregivers in this group reported an increase in pain frequency and also in their inability to go where they want on the 'spur of the moment'. In the low risk group, there was an increase in CDI scores and in the number of days that caregivers feel anxious, restless and or uneasy and also overwhelmed by their friend or relative's disease.

Table 6.5 Change in caregiver survey items using paired t-test by risk levels according to the Caregiver Stress Index*

	mean	95% CL mean	SD	t value	*P* value
CDI score					
Low risk (n=34)	1.38	(0.73-2.03)	1.85	4.34	0.0001
Moderate risk (n=51)	-0.11	(-0.73 – 0.50)	2.19	-0.38	0.70
High risk (n=55)	-1.85	(-2.48 – -1.22)	2.33	-5.89	<.0001
In the last three days, how often have you felt little interest or pleasure in the things you normally enjoy?					
Low risk (34)	0.38	(-0.02-0.79)	1.18	1.89	0.06
Moderate risk (n=51)	-0.31	(-0.75 – 0.12)	1.55	-1.44	0.15
High risk (n=55)	-0.91	(-1.52 – -0.29)	2.27	-2.96	0.004
In the last three days, how often have you felt anxious, restless, or uneasy?					
Low risk (n=34)	0.85	(0.36-1.33)	1.39	3.56	0.0011
Moderate risk (n=58)	-0.10	(-0.57 – 0.37)	1.80	-0.44	0.66
High risk (n=55)	-0.41	(-0.82 – -0.01)	1.51	-2.05	0.04
In the last three days, how often have you felt sad, depressed, or hopeless?					
Low risk (n= 34)	0.35	(-0.09-0.79)	1.27	1.61	0.11
Moderate risk (n=51)	0.12	(-0.30 – 0.54)	1.61	0.57	0.57
High risk (n=55)	-0.85	(-1.27 – -0.43)	1.55	-4.07	0.0002
In the last three days, how often have you felt overwhelmed by your relative/friend's illness?					
Low risk (34)	0.61	(0.20-1.03)	1.18	3.05	0.004
Moderate risk (n=58)	-0.02	(-0.46 – 0.43)	1.77	-0.08	0.93
High risk (n=55)	-1.01	(-1.42 – -0.61)	1.50	-5.00	<.0001
I can get the health services I need.					
Low risk (34)	-0.12	(-0.45-0.22)	0.97	-0.70	0.48
Moderate risk (n=55)	0.15	(-0.11 – 0.42)	0.95	1.16	0.25
High risk (n=55)	-0.31	(-0.61 – -0.01)	1.07	-2.06	0.04
I can go where I want on the "spur of the moment."					
Low risk (34)	-0.20	(-0.61-0.20)	1.17	-1.02	0.31
Moderate risk (n=58)	0.36	(0.01 – 0.71)	1.31	2.06	0.04
High risk (n=55)	-0.03	(-0.28 – 0.20)	0.90	-0.30	0.25

Table 6.5- Cont.

	mean	95% CL mean	SD	t value	*P* value
Pain frequency in the last 3 days					
Low risk (33)	-0.18	(-0.36-0.72)	1.53	0.68	0.49
Moderate risk (n=58)	0.56	(0.09 – 1.04)	1.81	2.38	0.02
High risk (n=55)	-0.20	(-0.72 – 0.32)	1.95	-0.76	0.45

*negative mean value represents an improvement while a positive mean value represents a worsening in the follow-up assessment related to the intake assessment

6.4.2 Improvement of caregiver distress and ability to continue in role

The variables a) MAPLe score at intake assessment was significantly associated with improvement in caregiver distress ($P < 0.05$; c statistic= 0.67. Participation in the CRS and coresidence did not have an effect in the outcome measured. However, the right direction of the result and the low *P* value (i.e., 0.07) indicates that the lack of significance could be due to the small sample size (Table 6.6).

In contrast, in the second model where the improvement in caregiver ability to continue in their role was the response variable, participation in the CRS and coresidence were both associated with the outcome ($P < 0.05$; c statistic = 0.75) (Table 6.7). More specifically, caregivers participating in the CRS or not coresiding with the care recipient presented higher odds of becoming able to continue at follow-up assessment. Care recipient gender and age, and caregiver relationship with care recipient were not significant in both models ($P > 0.05$).

Table 6.6 Logistic regression model for improvement in caregiver distress (from ‘yes’ to ‘no’) (n = 324)

Independent variable	Parameter estimate (SE)	Odds ratio (95% CI)	*P* value
Caregiver Recharge Services (ref. no)	0.54 (0.31)	1.75 (0.93-3.17)	0.08
MAPLe 4 at intake (ref. 5)	0.56 (0.27)	1.72 (1.02-2.99)	0.04
Caregiver co-reside - no (ref. yes)	0.64 (0.36)	1.91 (0.94-3.88)	0.07
Caregiver relationship – other (ref. child)	-0.24 (0.17)	0.61 (0.31-1.18)	0.14
Care recipient age group			
65-74 (ref. <65)	-0.32 (0.55)	0.72 (0.24-2.14)	0.56
75-84	0.57 (0.44)	1.77 (0.74-4.22)	0.19
85+	0.12 (0.48)	1.13 (0.44-2.91)	0.79
Care recipient Gender - female (ref. male)	-0.36 (0.28)	0.80 (0.39-1.22)	0.21
C statistic	0.67		

Table 6.7 Logistic regression model for improvement in caregiver inability to continue (from ‘yes’ to ‘no’) (n=145)

Independent variable	Parameter estimate (SE)	Odds ratio (95% CI)	*P* value
Caregiver Recharge Services (ref. no)	2.56 (0.58)	13.0 (4.14-40.88)	<0001
MAPLe 4 at intake (ref. 5)	-0.18 (0.42)	0.83 (0.36-1.89)	0.66
Caregiver co-reside - no (ref. yes)	1.47 (0.63)	4.38 (1.25-15.3)	0.02
Relationship – other vs. child	0.20 (0.52)	1.22 (0.43-3.45)	0.70
Care recipient age group			
65-74 (ref. <65)	-0.57 (0.85)	0.56 (0.10-2.99)	0.50
75-84	0.16 (0.66)	1.17 (0.31-4.21)	0.80
85+	-1.08 (0.72)	0.33 (0.08-1.23)	0.13
Care recipient Gender - female vs. male	0.47 (0.44)	1.61 (0.67-3.85)	0.28
C statistic	0.75		

The model combining changes in distress and ability to continue also indicated that caregivers participating in the respite services presented higher odds to improve the combined outcome (Table 6.8).

Table 6.8 Logistic model with changes in caregiver distress and inability to continue in their role combined (change from ‘yes’ to ‘no’) (n=397)

Independent variable	Parameter estimate (SE)	Odds ratio (95% CI)	*P* value
Caregiver Recharge Services (ref. no)	0.62 (0.29)	1.87 (1.05-3.33)	0.03
MAPLe 4 at intake (ref. 5)	0.36 (0.25)	1.44 (0.87-2.38)	0.14
Caregiver co-reside - no (ref. yes)	0.64 (0.34)	1.91 (0.98-3.73)	0.06
Relationship – other vs. child	-0.35 (0.31)	0.70 (0.38-1.29)	0.26
Care recipient age group			
65-74 (ref. <65)	-0.56 (0.51)	0.57 (0.21-1.56)	0.27
75-84	0.31 (0.39)	1.36 (0.63-2.94)	0.42
85+	-0.25 (0.42)	0.77 (0.33-1.79)	0.55
Care recipient Gender - female vs. male	-0.11 (0.26)	0.88 (0.52-1.49)	0.65
C statistic	0.65		

6.4.3 “I would recommend this program to other.”

For the statement ‘I would recommend this program to others’, among all caregivers, 86% (n=116) responded ‘always’, 11.6% (n= 16) responded ‘most of the time’ and 4.3% (n=6) responded ‘never, rarely, sometimes or don’t know’.

6.4.4 Rate of admission to LTCH and length of time before admission of CRS and MH CCAC clients.

The results of the regression model of survival data shows that the hazard ratio of LTCH admission did not differ between care recipients of CRS and long-stay home care clients (MH CCAC) (Table 6.9). However, care recipient MAPLe 5, a non-child caregiver, caregiver not coresiding with respective care recipients and care recipients older than 65 presented higher hazard ratios of LTCH admission than their respective reference groups. Chi-squared analysis also did not show significant difference for LTCH admission rates between the two groups (Table 6.10).

Table 6.9 Survival model for long term care admission (n=1,245)

Parameters	Estimate	SE	Hazard ratio	95% HR Confidence limits		Chi-square	Pr > Chisq
Caregiver Recharge Services (ref. ‘yes’)	0.24	0.21	1.27	0.83	1.94	1.27	0.25
Care recipient characteristcs							
Gender – (ref. ‘male’)	0.30	0.18	1.35	0.94	1.94	2.74	0.09
Age group (ref. group 18-64 yrs)							
65-74 yrs.	0.94	0.47	2.57	1.03	6.41	4.07	0.04
75-84 yrs.	1.35	0.41	3.87	1.74	8.61	11.0	0.001
85+ yrs.	1.35	0.41	3.86	1.72	8.66	10.7	0.0011
MAPLe (ref. 4)							
5	0.63	0.16	1.88	1.36	2.59	14.7	0.01
Caregiver characteristics							
Primary caregiver co-reside (ref. ‘yes’)							
No	0.71	0.20	2.05	1.38	3.02	12.9	.0003
Caregiving dyad relationship (ref. ‘child’)							
Not a child	0.46	0.20	1.58	1.07	2.35	5.35	0.02

Table 6.10 Comparison of long term care admission rates and time to admission of Caregiver Recharge Services (CRS) and long-stay home care clients (MH CCAC)* among distressed caregivers (n=1,245)

	Intake Assessment		Admissions to LTC		Rate of LTCH admission			Number of days to discharge to LTC	
MAPLe	MH CCAC	CRS	MH CCAC	CRS	MH CCAC	CRS	*P*<Chisq	MH CCAC	CRS
	n		n		%			Mean days (Lower and Upper 90% Confidence interval)	
4	602	130	52	15	8.64	11.5	0.30	143.9 (111.4-176.3)	196.6 (160.7-232.5)
5	409	106	68	15	16.6	14.1	0.54	139.7 (114.2-165.3)	228.8 (170.8-286.8)*

*Mississauga Halton Community Care Access Centre
**Absence of overlapping confidence intervals between MH CCAC ad CRS indicates statistical significant difference

The time before LTC admission within one year after first RAI-HC assessment was lower for MH CCAC clients with MAPLe scores 4 and 5 compared to CRS clients, although only the later showed statistical difference according to the confidence interval values suggesting that this respite program delayed institutionalization for care recipients with the highest care needs (MAPLe 5) (Table 6.10). Although not statistically significant, the confidence interval values for days before institutionalization for CRS due not overlap the mean value for MH CCAC care recipients with a MAPLe 4, indicating that a lack of significance could be a function of sample size.

6.5 Discussion

This study evaluated the impact of in-home respite services on caregiver distress, ability to continue in their role, as well as changes in other aspects of their lives. The influence of respite use on LTCH admission of the care recipient was also examined. The use of various methods and measures for evaluation of caregiver intervention relates to the multiple aspects involved in caregiver's life that may be affected by respite. This approach also follows the recommendations and framework proposed by Van Houtven (2011) to guide interventions and evaluation.

First, changes in the response of caregiver survey items were assessed for all caregivers participating in the follow-up interview. The overall decrease in the frequency of caregiver feeling overwhelmed as well as their lack of pleasure in things that they normally enjoy may be linked to the increase in the frequency of their participation of meaningful activities and positive feelings related to their caregiver role. These results also indicate that caregivers may be using their respite hours to participate in activities that they value. It would be important to obtain further information on this matter in future studies since other studies have shown that caregiver tend to use their respite hours to perform house chores or work instead of using their hours for leisure or social activities (Berry et al., 1991).

Caregivers in this study were caring for care recipients with high care needs, a situation that may have restricted their opportunities to socialize. In support to this potential issue, a substantial number of caregivers reported loneliness (Table 6.2). In fact, the intense provision of care for older adults with high needs often affects caregiver's social activities such as visit with friends, vacations and church attendance (Haley, Levine, Brown, Berry, & Hughes, 1987). Thus, it is not surprising that this particular cohort of caregivers increased their participation in meaningful activities after joining the respite program and also presented a decrease in the CDI scores suggesting positive changes in psychological distress.

In the present study, the evaluation was also performed after grouping caregivers according to their distress (i.e., CDI risk levels). The results show that caregivers were affected differently depending on their distress level. This finding not only shows the positive impact of the intervention on caregiver distress and the risk of adverse outcome, but also highlights the importance of using effective assessments to identify caregivers that would be more likely to benefit from interventions (Acton & Kang, 2001; Schulz et al., 2002; Whitlatch et al., 1991). Unfortunately, several studies evaluating the impact of respite programs on caregiver psychological distress or depression failed to show significant results (McNally et al., 1999; Shaw et al., 2009; Yates et al., 1999). The inappropriate target population, inadequate provision of respite (i.e., low number of hours and lack of flexibility), poor evaluation methods (Lee & Cameron, 2004; McNally et al., 1999) and the unattended needs of caregivers may explain the absence or weak result on the studies reporting the impact of respite programs on caregivers outcomes (Li, Seltzer, & Greenberg, 1997). In the present study, the eligibility criteria was key for targeting the appropriate population whereas the flexible hours of respite was a important feature of the CRS program for attending the unique needs of the caregivers.

Caregivers with higher distress levels also positively changed their opinion on receiving the health services that they need. This is a key outcome for a policy and health care system perspective as suggests caregiver satisfaction with provision of public health care. Moreover, at follow-up assessment, 96% of all caregivers indicated that they would recommend this program to others ‘always or most of time’ suggesting their contentment with this program. This is a remarkable high percentage even considering that caregivers participating in the follow-up study could be more likely satisfied with the program. Moreover, this result is in agreement with other studies where caregivers recognize the practical benefits of respite programs (e.g., time to rest and relax, time for other activities etc.) (Jeon et al., 2005).

The lack of improvement in the CDI score for the moderate risk group or the small change in the CDI score for the high risk group may indicate that this type of intervention was not attending some of the caregiver needs. According to Sorensen (2002), caregiver interventions may be divided in two categories: 1) interventions to reduce the hours of care provided (i.e., respite) and 2) interventions to improve caregiver well-being and coping. Thus, it is conceivable that other causes of caregiver psychological distress were not affected during intervention because they were unrelated to their need of formal help. Instead these feelings may be related to caregiver concerns associated to the progress of the care recipient illness and uncertainties about their future (Gaugler, Zarit, and Le, 1999; Zarit & Leitsch, 2001). This emphasizes the need for multidimensional approaches intervening in different areas of caregiver needs particularly considering the promising outcomes of multidimensional interventions (Chen et al., 2015; Parker et al., 2008).

A decline in physical health represented by an increase in pain frequency and an increased inability to go where they want on the ‘spur of the moment’ for caregivers in the moderate risk group may also have affected the lack of improvement in the CDI scores and other quality of life indicators. Several factors such as a decline in caregiver or care recipient health could explain the change in caregiver role captivity (the extent to which caregiver feels confined by their caring activities); however, there were insufficient data to test this hypothesis. Changes in the health status of the care recipient may also have influenced the increase in CDI scores, caregiver anxiety and their report of feeling overwhelmed by the care recipient disease during the follow-up assessment of caregivers in the low risk group.

The lack of detailed information to explain the negative changes in caregiver’s lives highlights the need for including care recipient and caregivers assessments in longitudinal studies used to evaluate interventions (Van Houtven et al., 2011). This type of information is needed to capture the dynamic process involved in caregiving experiences during an intervention period.

It is possible that a shorter interval between intake and reassessment could have captured greater differences in the outcomes measured; however, it is not clear which is the optimal lag time between caregiver assessments. Studies on evaluation of respite programs have used different intervals of time between baseline and follow-up assessments (Kosloski & Montgomery, 1993). This may affect the sensitivity of the assessment instrument, since a certain time may be needed for the intervention to cause an impact on the outcomes while the effect may dissipate if the follow-up assessment is taken to long after the intervention is implemented.

In the second approach, improvement in caregiver distress according to care recipient assessment between admission and follow-up assessments was examined. In contrast to the CDI scores, a self-report screener, the caregiver items in the care recipient assessment represent the assessor perception of caregiver distress instead of caregiver self-reported answers. Interestingly, a MAPLe score of 4 at intake was positively associated with improvement in distress. This result is also consistent with evidence on the relationship between MAPLe scores and caregiver distress (Hirdes et al., 2008; Mitchell et al., 2015; Vu et al., 2014). Moreover, this result may also indicate that a 'yes/no' type of answer is not appropriate to capture changes in distress levels. As shown by the CDI, although in a lower level, distress was still present at reassessment.

One of the most striking results of the evaluation of this intervention relates to the higher odds of improvement in caregiver ability to continue on their role for participants in the CRS. This outcome may be related to the help received for attending the needs related to care recipient ADL impairment, as this type of impairment was particularly high for this group of care recipients (Table 6.3). Moreover, several studies have shown that the lack of support with ADL has a strong influence on caregiver ability to provide care (Gaugler et al., 2000, 2007, 2003; Luppa et al., 2010).

Interestingly, caregivers that did not co-reside were also more likely to become able to continue on their role. A study on type and time used on respite activities suggested that respite programs seem to be more effective when caregivers can use a number of uninterrupted number of hours to perform certain household activities (i.e., work, chores) or for relief from their caring activities (Berry et al., 1991). Thus, it may be that caregivers that do not co-reside are more likely to have commitments with their own families or job related activities and therefore would benefit from respite hours for performing other activities. Unfortunately, a scarce number of studies have investigated how caregivers use their respite hours.

The lack of impact of CRS on improvement in caregiver distress contrasts with its strong effect on caregiver ability to continue on their role raising the question on the appropriateness of certain outcomes measured during respite interventions as some are more sensitive than others (Kosloski & Montgomery, 1995). As mentioned by other researchers, caregiver distress or other outcomes such as burden often measured during interventions, may not be the most adequate outcome to be measured since they may not be necessarily resolved by a respite program (Zarit & Leitsch, 2001). For example, some of the major sources of burden is related to care recipient behaviors (Gaugler et al., 2010). An intervention that provide PSW hours as a form of respite like in this study, may allow caregiver to continue as they receive support with ADL. However, this type of support may not be enough to resolve caregiver distress associated with care recipient behavioral problems or worries about their own future, especially among those caring for someone with a degenerative disease.

The last approach used for the respite evaluation compared rates of LTCH admission and time to admission among long-stay home and CRS care recipients with caregivers unable to continue or distressed at the intake assessment (Table 6.9, 6.10). The results suggest that the CRS delayed institutionalization for care recipients with the highest MAPLe score. In agreement, another study reported 22 days delayed institutionalization of care recipients with dementia cared by a caregiver receiving respite services for a year (Lawton et al., 1989). However, the number of delayed days for both studies is substantially lower than the 228 delayed days reported by a study where the caregiver intervention consisted of family counselling, support group participation and ad hoc counselling (Gaugler, Reese, & Mittelman, 2013). Higher number of delayed days before institutionalization (i.e., 329 days) were also observed when caregivers of care recipients with AD participated in support groups and received counselling compared to the control group (Mittelman et al., 1996). This remarkable difference between the outcomes of the present study and these studies could be related to differences in the nature of the intervention. The studies showing longer delay before institutionalization include interventions that provide education, resources information as well as emotional support whereas the current study provides respite to caregivers. Thus, it is possible that addressing other caregiver needs, in addition to their respite needs, could potentially provide stronger results related to delay to LTCH admission. According to Spillman & Long (2009) interventions that aim to reduce physical strain and financial hardship of the caregiver would also reduce LTCH entry, as these factors were reported as the main predictors of caregiver distress in their study.

It is possible that the lack of difference in the LTCH admission rates for CRS compared to MH CCAC admission rates is related to differences between CRS and MH CCAC clients. The higher proportions of clients with dementia and ADL dependency in the CRS may have blurred the effects of the respite on LTCH admission as these factors may influence this outcome (Gaugler et al., 2000, 2007, 2003; Luppa et al., 2010).

As a non-experimental design, this study does not have a control group. Another limitation of this study is the lack of information on the number and allocation of respite hours used through the year as the flexibility of the respite hours provided was the main feature of the program. Moreover, it was not possible to distinguish caregivers of CRS that were also receiving services from MH CCAC.

The caregiver survey interview was conducted in English. Therefore, possibly caregiver who do not speak English as their first language were not able to participate in this study or needed a proxy to answer the questions reducing the participation of immigrant caregivers. Also, the results from this study cannot be generalized to caregivers caring for care recipients with MAPLe scores lower than 4 or caregivers with low levels of stress as these criteria were part of the eligibility to participate in this program.

This study has several strengths. Both caregivers and care recipients were evaluated using comprehensive assessments that provided key information for the intervention evaluation. Moreover, the longitudinal nature of this study allowed the analysis of changes in caregiver items in the survey and in the care recipient assessment. In an attempt to overcome the lack of control group, information on caregivers of comparable cohort of care recipients were selected for logistic regression analysis allowing the comparison of estimated rates of LTCH admission as well as changes in caregiver items in the care recipient assessments of CRS and MH CCAC. The compatibility between items from the interRAI CHA and RAI-HC allowed the linkage between assessments originated from community support services agencies and CCAC.

In conclusion, this respite evaluation provides evidence on the benefits of this type of intervention to informal caregiver's quality of life and also on their ability to continue on their role. This study also highlights the value of using a caregiver screener, the CDI, for identifying caregivers that would be more likely to benefit from respite interventions. Moreover, evidence on the delay in LTCH admission of care recipient of high care needs (i.e., MAPLe 5) emphasizes the merit of this type of program not only for caregivers and care recipients that desire to live at home but also for the health care system. Last, this study demonstrates the use of a multiple approach to identify several benefits of a respite intervention. This type of evidence is key not only for encouraging implementation of similar programs across Ontario and Canada, but also for justifying future funding of similar initiatives. This study also suggests that the impact of respite may be more evident among more distressed caregivers. Also, there is an indication that formal support is especially benefitial for caregivers that do not co-reside with their care recipient. Future studies are needed to better understand which caregivers would be more likely to benefit from respite and how caregivers use their respite hours.

Chapter 7

GENERAL DISCUSSION AND SUMMARY

The six chapters of this dissertation report research related to the challenges experienced by informal caregivers, particularly those caring for older people. The literature review reported inconsistencies among studies on factors associated with caregiver burden. It also pointed out how several studies reported the lack of relationship between caregiver subjective burden and care recipient health needs. Conflicting findings may be at least in part a result of different definitions and assessments of burden used in these studies. The issues related to the lack of consistency on burden definitions has been extensively discussed elsewhere (Braithwaite, 1992) and although some attempts have been made to narrow down and better define this concept (i.e., subjective and objective) (Hoenig & Hamilton, 1966, 1967; Poulshock & Deimling, 1984) the unclear and unrestricted use of this term still hinder the advancement of caregiver research.

The scoping review also highlights the methodological flaws and gaps in caregiver research studies evaluating caregiver outcomes and interventions. Some of the problems reported such as small sample size, lack of longitudinal studies, and lack of information on care recipient health were not present in the studies included in this dissertation. Also, contrary to several caregiver studies, the studies on this dissertation include assessments with tested psychometric measures. In addition, the caregiver survey used to obtain information on the caregivers did include positive aspects of caregiving, a valuable information that does not receive enough attention in caregiver studies.

There is no doubt that caregiving experiences are part of a multidimensional construct where intrinsic and extrinsic factors associated with their role have an impact on caregiver's life. The complexity surrounding caregiving experiences is illustrated in chapter three through the evaluation of a caregiver survey. The factors analysis indicated three dimensions involved in caregiving experiences: 1) physical health; 2) mental health and 3) psychosocial resources and well-being. This finding is consistent with several models used in caregiver research showing that caregiver ability to manage their caring responsibilities is influenced by several factors, including access to resources, coping strategies and personal characteristics (i.e., traits, vulnerability) that may change over time. This study provides evidence of the co-existence of negative and positive feelings as part of caregiver experiences as described in Pearlin's model (1990), where personal gain may occur in the presence of role strains. The study also shows the association of caregiver isolation and poor self-esteem with care recipient symptoms of depression.

Chapter four describes the development of a screener that identify three levels of risk of adverse outcomes. In this study, these outcomes are represented by the caregiver's poor quality of life, such as poor self-rated health and their report that life is never or only rarely or sometimes good. Caregivers in the high risk group were also more likely to visit the doctor and nurse practitioner and state that the care recipient would be better off elsewhere. Other key findings of this chapter relate to other caregiver issues more likely to be experienced by those in the high risk group (e.g., higher pain frequency and intensity, loneliness, hopefulness and financial concerns). These findings have particular relevance for developing assessments to identify caregivers more susceptible to poor outcomes associated to caregiving.

Caregiver distress and care recipient care needs, represented by MAPLe scores, were associated with care recipient LTCH admission in Chapter five. This association is present even after controlling for care recipient aging, and characteristics of the caregiving dyad represented by relationship and coresidence. Another interesting finding emerged from this study. The effect of caregiving dyad relationship on LTCH admission was influenced by caregiving dyad coresidence where care recipients cared by and living with a child-caregiver were less likely to be admitted to a LTCH than a non-child caregiver that co-resides with a care recipient. However, it is not possible to determine the reasons for this result justifying further studies on this topic.

The sixth chapter evaluated a respite intervention using different approaches. First, positive changes in the overall distress and in other caregiver information was observed when including data on all caregivers in the respite program for analysis. Changes in the caregiver distress index scores between admission and reassessment were observed particularly for those in the high risk levels whereas caregivers in the moderate risk group experienced increased pain and a decline in their ability to go where they want in the spur of the moment. In a second approach, changes in caregiver distress and ability to continue recorded in the care recipient assessments (RAI-HC and interRAI CHA) at admission and follow up assessment were compared to changes in the same items of assessments from long-stay home care clients. The results showed that the respite intervention had a positive effect on caregiver ability to continue in their role. As a last approach, rates of LTCH admission of care recipient in the CRS were compared with long-stay home care clients in MH CCAC. The results indicated that the respite intervention had a positive effect on the length of time before admission for the care recipients with highest needs. This study suggests that interventions should be evaluated using a multidimensional approach that reflects the inherent complexity of caregiving.

7.1 Implication for research

The advancement in caregiver research relies on studies such as the caregiver study described in this dissertation. As shown in the caregiver study, the use of valid and reliable assessments is key for identifying factors involved in caregiver experiences and its consequences to their physical and mental health. Moreover, the caregiver study also demonstrated that it is fundamental to apply a 1) theoretical framework that represents the multidimensional aspects involved in caregiving and 2) longitudinal designs that allow the examination of this dynamic process. Information on care recipient health as well as the caregiving dyad relationship and coresidence information should also be reported in caregiver studies as this dissertation provides evidence on their influence on caregiver outcomes.

In addition, the interRAI assessments performed as routine clinical assessments in Canada and other countries offer an invaluable source of information to be used in caregiver studies. These assessments could be used particularly as part of informal caregiver intervention studies, as the respite evaluation demonstrated that the use of key sources of information for development and evaluation of a respite intervention identified meaningful outcomes.

7.2 Implication for policy

In July 2016, the Ministry of Ontario announced an investment of $20 million for caregiver respite provided by home care organizations. Thus, it is fundamental that policy makers and organizations funded to support caregivers find effective ways to identify caregivers with higher needs that would be more likely to benefit from respite and other type of interventions. Within this context, this dissertation not only generated information to better understand caregiver issues and their needs, but also developed and validated a caregiver screener, the caregiver distress index (CDI), for identifying caregivers at risk of adverse outcomes. During the writing of this dissertation, the CDI has been implemented at Hamilton Niagara Haldimand Brant CCAC for assisting care coordinators to allocate respite hours among distressed caregivers of long-stay home care clients. In addition, other two CCACs and 5 community support agencies are also in the process of CDI implementation.

Preliminary results of the CDI implementation at Hamilton Niagara Haldimand Brant CCAC has shown that proportionally more caregivers with higher CDI scores experience conflict with family and symptoms of distress, depression or anger and care for someone with high care needs -providing evidence on the validity of this screener for future studies. While the CDI is not the only outcome from this dissertation that can be used by policy and decision makers, it can certainly be effective for informing decisions on how better direct resources to caregivers. Even more important, the use of the CDI gives caregivers an opportunity to express their feelings and needs to the care providers.

This dissertation reports on the use of interRAI assessments in different ways. The MAPLe, an algorithm from the interRAI-HC and RAI-HC, has been used as part of the eligibility criteria of the Caregiver Recharge Services (MH LHIN) to assist health care providers in identifying caregivers in distress. The CDI has currently been used by this respite program to add information on the caregiver distress levels. The combination of MAPLe and CDI scores is an example of the use of interRAI measures for targeting caregivers that would be more responsive to interventions.

In addition, this dissertation showed the value of using information from the interRAI CHA and RAI-HC assessments for respite program evaluation. These assessments not only provide information on caregiver distress and ability to continue but also on characteristics of the caregiving dyad and care recipient health characteristics that are key for tailoring and evaluating interventions. While developing effective interventions is fundamental, demonstrating its benefits for caregivers and care recipients are imperative when justifying and applying for funding.

Thus, home care and community organizations that currently conduct interRAI assessments can use these instruments beyond the evaluation of the care recipient health by incorporating the information collected on caregivers to develop a family centred care plan.

This dissertation also indicates that the respite intervention represented by personal support worker's assistance on activities that are usually performed by caregivers does not address other relevant caregiver needs that could be causing distress. For example, caregivers may be distressed because of financial concerns, inability to handle care recipient symptoms, or worries about their future. Thus, understanding caregiver needs through comprehensive assessments is key for developing customized interventions that consider the multiple aspects involved in caregiving.

7.3 Implication for assessing caregiver and evaluating interventions

The large number of assessments developed to evaluate caregivers reflect the complexity of the caregiver issues. Among all instruments, researchers should use those with strong psychometric properties that have been developed using a solid theoretical foundation, such as the interRAI instruments. Moreover, although most assessments were developed to evaluate caregiver outcomes, the use of assessments to identify their needs would allow researchers and policy makers to better understand the root of the caregiver issues and invest in programs that are more likely to succeed.

Effective assessments are key elements of interventions used to identify 1) target populations; 2) multiple factors involved in caregiving experiences; 3) caregiver needs; and 4) changes in potential outcomes. Therefore, implementation and evaluation of interventions should include a conceptual framework that represent the dynamic process of caregiving experiences. As a result, interventions based on a strong conceptual framework combined with valid and reliable assessments will be better designed and evaluated and more importantly, more likely to benefit caregivers. More detailed recommendations are provided below.

7.4 Recommendations for developing and evaluating effective interventions.

The key recommendations arising from this research are:

- Use a valid, reliable and sensitive assessment for identifying those caregivers more likely to be responsive to interventions. The Caregiver Distress Index can be used as an initial screener not only for this purpose, but also for identifying the caregivers that would benefit from further evaluation.
- Next, a comprehensive caregiver assessment should be used for gathering information for developing, tailoring and evaluating target interventions. The interRAI Family Carer Needs assessment is a new instrument being pilot tested internationally for this aim.
- More specifically, a caregiver assessment should obtain information on: caregiver unmet needs for: respite, training, social interaction, formal and informal support and financial assistance.
- In addition, information on direct and indirect factors involved in caregiver role should be obtained for assessing their interference on the outcomes of interventions. For example, it

is important to understand whether caregivers can count on their social network and what are their coping skills (i.e., knowledge on the disease, ability to provide care).

- Characteristics of the caregiving dyad such as coresidence and type and quality of relationship should also be identified as they also influence caregiver experiences.
- Health care prodivers should use the outcomes of the caregiver assessments to customise interventions by including a holistic approach that addresses the unique needs of caregivers. For example, care plans may include the participation of a variety of professionals (e.g., social worker, personal support worker, psychologist) that would address caregiver's needs with respect with issues like respite, emotional support, assistance with ADL.

Regarding the intervention outcomes, the evaluation should include:

- Outcomes that could be influenced by changes in caregiver ability to provide care, such as care recipient health measures (e.g., changes in the manifestation of certain behaviours as a result of caregiver receiving training), and institutionalization. Care recipient health assessments such as the RAI-HC and the interRAI CHA provide a valuable source of information not only on the health characteristics of the care recipient that could affect or be affected by caregivers, but also on caregiving dyad characteristics that could influence caregiver outcomes. For example, the lack of improvement in caregiver distress may be related to care recipient health decline. Therefore, it is crucial to link the information on caregiver outcomes with the trajectory of care recipient health and use of health care services.
- Not only measures of the overall change in caregiver distress or burden, but also measures associated with the specific goals of the interventions. For example, if the

intervention involves provision of education on how to deal with care recipient disease, an assessment on caregivers caring skills should be also performed.

The interval between intake and follow-up assessment:

- Should be long enough for the caregiver to adapt to any changes that an intervention may cause to their routine, but also short enough for the effects of the intervention to be identified before it dissipates or be annulled by the occurrence of any stressful event. Although the literature is not clear on the interval between intake and reassessment for evaluation purposes, an interval between 3 and 8 months seems a reasonable suggestion based on the knowledge yielded by the CRS evaluation study.

7.5 Strengths and limitations

This dissertation has limitations that should be acknowledged. First, the literature review was a scoping review rather than a systematic review. Therefore, some articles related to the subjects discussed may not have been included in this chapter. In the studies for the evaluation of the psychometric features of the caregiver survey, development of the caregiver screener and intervention of the respite program, only caregivers and care recipients eligible to participate in the respite program were included in the study. Thus, the generalizability of these studies is limited to distressed caregivers caring for care recipients with high care needs based on the MAPLe scores. Moreover, the lack of interpreters for the caregiver survey interview may have limited the participation of immigrant caregivers. Also, in chapter six, the lack of a control group for the intervention evaluation is a disadvantage of using convenience sample in a non-experimental study design. The lack of data on the number of hours of respite used by the caregivers precluded the examination of the possible association of this information with caregiver outcomes.

The study of predictors of LTCH admission only included dichotomous variables representing caregiver distress and their inability to continue. Thus, the type of response ‘yes/no’ may have limited the accuracy of these variables as predictors of LTCH admission.

This dissertation also has several strengths to be mentioned. First, chapter three, four and six include information on caregivers caring for care recipients with high care needs and not with a specific diagnosis. By selecting care recipient based on their care needs, findings from these studies maybe generalized to a similar cohort living in the community and other settings instead of a cohort with a specific health diagnosis. In addition, although this cohort of caregivers was mainly represented by persons dedicating a substantial amount of hours on caring activities, interviewers were able to schedule an interview by offering alternate hours through the day and the week allowing the completion of the caregiver survey by individuals that possible would not participate in this study otherwise.

Another strength of this dissertation relates to the quality and quantity of information on the caregivers obtained through the caregiver survey and the respective interRAI clinical health assessments of care recipients. The interRAI expertise used for the development of the caregiver survey certainly brought a strength to the studies in chapter 3, 4 and 6, where this survey was used for different purposes. The reliability and validity of the interRAI instruments demonstrated in past studies provides reassurance on the high quality of the data used in all chapters. Moreover, the compatibility between interRAI CHA and RAI-HC items is an important feature of interRAI assessments where similar items exist in different assessment types. For chapters 3, 4 and 6 the linkage of these assessments yielded a larger dataset for analysis.

In chapter 3, the linkage of the caregiver survey and the care recipient interRAI CHA and RAI-HC allowed not only the convergent validity of the caregiver survey but also the emergency of interesting findings such as the correlation between caregiver poor esteem and mood related symptoms with care recipient depressive symptoms. The caregiver related items in the RAI-HC from chapter 5 also allowed the evaluation of predictors of LTCH admission beyond care recipient health characteristics by including caregiver distress items and information on caregiving dyad (i.e., coresidence and relationship).

The multifaceted approach of the respite intervention evaluation is also a noteworthy strength of this study. The respite program was evaluated by using multiple interRAI assessments that allowed comparisons among similar cohorts of care recipients, changes in caregiver's distress related symptoms and comparison in rates and time to LTCH admission.

In summary, this dissertation investigated the various aspects involved in caregiver's experiences and how they influence their well-being as well as their ability to continue in their role. A caregiver screener has been created to identify risk of adverse outcomes. Although this is a straightforward tool to be used by community and home care organizations to identify caregivers for interventions, the use of a comprehensive assessment is essential since caregiver's needs are unique for each individual. Thus, the development and evaluation of effective interventions relies on the use of valid and reliable assessments that capture the multifaceted aspects of caregiver's lives. Such interventions would be more likely to attend caregiver's needs, allowing them to continue on their role without jeopardizing their own health.

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