QUALITY OF LIFE IN OLD ADULTS WITH DEMENTIA AND CAREGIVERS

IMPACT OF CARE-RECIPIENT RELATIONSHIP TYPE ON QUALITY OF LIFE IN COMMUNITY-DWELLING OLDER ADULTS WITH DEMENTIA AND THEIR CAREGIVERS

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TITLE: Impact of Care-recipient Relationship Types on Quality of Life (QoL) in Community-dwelling Older Adults Living with Dementia and Their Informal Caregivers

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LAY ABSTRACT

Living with dementia can take away more than just memory; it can significantly impact various aspects of an individual's daily life. Caring for people living with dementia (PLWD) can be rewarding but challenging, especially when the PLWD presents many complex issues as the disease progresses. Depending on caregivers' familial ties with those they care for, the consequences linked to PLWD and the caregiving journey may vary. For example, spousal caregivers are more likely to face social or emotional challenges than child-caregivers. However, what happens when extended family members, like grandchildren and siblings become informal caregivers? How does the dynamic change when two or more caregivers share responsibilities? There is limited exploration of these aspects currently. The thesis aims to address these gaps by investigating whether the different types of relationship shape the overall well-being and happiness PLWD and caregivers experience in their daily life across the dementia disease trajectory. I hope this thesis can contribute evidence for policies supporting PLWD and their caregivers as part of the system of aging in place.

ABSTRACT

Dementia contributes significantly to disability and dependence in older adults. As the global aging population continues to grow, the number of people living with dementia (PLWD) is expected to reach 78 million by 2030. Similarly in Canada, approximately 76,000 new dementia cases are diagnosed annually, and the number of Canadians living with dementia are expected to exceed one million by 2030 and reach 1.7 million by 2050. As a non-curable disease, dementia care research has gradually shifted focus from a disease-modifying treatment or a symptom-focus treatment to prioritize outcomes such as improved quality of life (QoL). This also applies to their informal caregivers, family members and friends, who play a vital role in dementia care. About 61% of PLWD in Canada live in the community and receive care mainly from their informal caregivers. The number of PLWD is projected to nearly triple over a 30-year period from 2020 to 2050, placing greater demands on Canada's health care system. Informal caregivers of PLWD dedicate more time and experience higher distress compared to those caring for older adults without dementia. As caregiving demands increase with disease progression, the QoL of informal caregivers is adversely affected, which in turn influences the care quality and subsequently affects the QoL of PLWD. Therefore, enhancing the QoL of PLWD and their informal caregivers warrants attention and is recognized by WHO as a primary goal of dementia research. While the care-recipient relationship type has been reported as an impact factor for QoL of PLWD and caregivers, the existing evidence is limited to single primary caregivers, spouses and adult children, and there needs to be more longitudinal evidence. Research, especially longitudinal studies involving broader typologies of care-recipient relationship and shared caregiving responsibilities, is needed.

This thesis comprises three manuscripts that examine the impact of care-recipient relationship type on the QoL among community-dwelling older adults living with dementia (i.e. PLWD) and their informal caregivers cross-sectionally and longitudinally. The selected datasets for this series of secondary analyses, the National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC), allowed us to analyze dyadic data involving a broader range of care-recipient relationship types. NHATS conducts annual in-person interviews with a nationally representative sample of Medicare beneficiaries ages 65 or older, while NSOC conducts periodical phone interviews with informal caregivers of NHATS participants. Together, NHATS and NSOC constitute the only national study providing both care recipient and caregiver perspectives on late-life care. Four types of relationship were identified: (1) care from a spouse/partner; (2) care from an adult child; (3) care from an informal caregiver other than a spouse/partner and adult child, such as child-in-law, sibling, etc. (referred as “other” caregiver); (4) care responsibilities shared by two or more caregivers (referred as “multiple” caregivers). Guided by the International Classification of Functioning, Disability, and Health (ICF) framework and Stress Process Model of Family Caregiving, the QoL of PLWD and their caregivers was assessed through multiple domains, including mental health, general health, functional limitations, and pain for PLWD, and positive emotional benefit, negative emotional burden and social strain for caregivers. PLWD’s dementia status was classified into probable dementia, possible dementia, and no dementia, as suggested by NHATS guidelines.

In Manuscript 1, a series of bivariate and multivariable regression models were constructed using data from NHATS (Round 5) and NSOC (II) to investigate cross-sectional associations among relationship types and QoL in PLWD (n=1230) and caregivers (n=1871). The findings revealed that PLWD cared for by an adult-child or “multiple” caregivers exhibited

higher functional limitations compared to those cared by a spousal caregiver, even after adjusting for socio-demographic variables (age, sex, race, income, education, marital status, living arrangement) and dementia status. Compared to spousal caregivers, “other” caregivers experienced a lower likelihood of negative emotional burden and social strain, while “multiple” caregivers also demonstrated lower odds of negative emotional burden. When comparing within single caregivers, adult-child caregivers were associated with lower negative emotional burden and higher social strain compared to the spousal caregivers. However, when accounting for care recipients’ dementia status, the association between adult-child caregivers and social strain diminished but a significantly higher likelihood of experiencing positive emotional benefit was observed in “other” caregivers. The study highlights variations in both PLWD and caregivers' QoL outcomes based on relationship types, with PLWD's dementia status influencing the association between care-recipient relationship type and caregivers' QoL.

In Manuscript 2, generalized estimating equation (GEE) was performed on data from NHATS Round 5 to 9 to assess the impact of care-recipient relationship type on the changes in PLWD’s QoL over a 4-years period. The results supported the findings of Manuscript 1, indicating that PLWD cared for by an adult-child or “multiple” caregivers predicted an increased risk of functional limitations both in unadjusted and adjusted models. In addition, there was a significant interaction between relationship type and education. PLWD with high school education or below and cared for by adult-child caregivers experienced a significantly higher risk of increasing functional limitations over the years compared to those with same education level but cared for by spousal caregivers. Similarly, PLWD who have a high school education and cared for by “multiple” caregivers exhibited a significantly higher risk of functional limitations than those with the same education level but cared for by spousal caregivers.

Manuscript 3 applied GEE on data from NSOC II & III and the companion NHATs Round 5 & 7 datasets. The objectives were to predict the impact of care-recipient relationship type on QoL in caregivers of PLWD over 2 years (2015 to 2017). Results indicated that over time, all three QoL outcomes (positive emotional benefit, negative emotional burden, and social strain) had higher odds of experiencing high burden compared to the baseline in 2015. Spousal caregivers consistently faced a higher risk of negative emotional burden and social strain than "other" caregivers over time in both unadjusted and adjusted models. This causal relationship aligns with the Manuscript 1 findings and contributes to the overall body of evidence. In addition, adult-child caregivers initially showed a significantly higher risk of social strain over time compared to spousal caregivers, but the significance of this difference diminished after adjusting for socio-demographics and care-recipients' dementia status.

The thesis uses well-organized national companion datasets to contribute to dementia care literature through cross-sectional and longitudinal analyses. It acknowledges the increasing role of "other" caregivers and shared caregiving responsibilities in dementia care, providing longitudinal evidence on QoL changes. It also recognizes the varied needs of PLWD with consideration of socio-demographics and highlights the impact of relationship types on QoL across multiple domains. Additionally, the findings provide insightful practical implications, emphasizing the importance of tailored interventions for specific caregiver subgroups, evaluation of the full spectrum of care demands, and exploration of policies and supportive resources designed for these needs.

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I am deeply grateful to my committee members, Dr. Lauren E Griffith, Dr. Ayse Kuspinar, Dr. Jenna-Smith Turchyn, for your constructive feedback and kind encouragement throughout my studies. I vividly recall my feelings after my first committee meeting; I was deeply impressed by your professionalism and dedication to the entire process. You have always been approachable and supportive, and I appreciate that greatly. Thank you for bringing valuable suggestions from your expertise, which has challenged me to think more critically.

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LIST OF ABBREVIATIONS AND SYMBOLS

AD8: 8-item Interview to Differentiate Aging and Dementia

ADAMS: Aging, Demographics, and Memory Study

ADLs: activities of daily living

ADRQL: Alzheimer Disease-Related Quality of Life

BPSD: behavioral and psychological symptoms of dementia

CI: confidence interval

CIND: cognitive impairment not dementia

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

FDA: Food and Drug Administration

GAD-2: 2-items Generalized Anxiety Disorder scale

GDS: Geriatric Depression Scale

GEE: generalized estimating equation

GPB: British Pound

HRQL: health-related quality of life

IADLs: instrumental activities of daily living

ICF: International Classification of Functioning, Disability, and Health

IRR: incidence rate ratio

NEB: negative emotional burden

NHATS: National Health and Aging Trends Study

NSOC: National Study of Caregiving

OR: odds ratio

p: probability

PCPs: personalized care plans

PEB: positive emotional benefit

PHQ-2: 2-items Patient Health Questionnaire

PHQ-4: 4-items Patient Health Questionnaire for Depression and Anxiety

PLWD: people living with dementia

QoL: Quality of life

QOL-AD: Quality of Life in Alzheimer Disease

QUALID: Quality of Life in Late-Stage Dementia

SD: standard deviation

SE: standard error

SF-12: 12-items Short Form Health Survey

SP: sample person

SS: social strain

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology guidelines

WHO: World Health Organization

yrs: years

SYMBOLS

β: beta

< : less than

DECLARATION OF ACADEMIC ACHIEVEMENT

Aiping Lai conceptualized the research design, purpose, and questions for all chapters in this thesis. Aiping Lai was responsible for data screening, cleaning, analysis, and preparation of the first draft for all chapters. The contributions of the supervisor and committee members to each chapter were outlined below.

Chapter 1 (Introduction) and Chapter 5 (Discussion)

Dr. Julie Richardson, as primary supervisor, provided conceptual expertise during the preparation of these chapters and offered feedback on the first drafts before they were submitted to the thesis committee for further review. The thesis committee members: Dr. Lauren E Griffith, Dr. Ayse Kuspinar, Dr. Jenna-Smith Turchyn, provided additional feedback based on their expertise in the area.

Chapter 2 (Manuscript 1), Chapter 3 (Manuscript 2), and Chapter 4 (Manuscript 3)

Dr. Richardson, as primary supervisor, suggested the data sources and approved the designation for applying for the data. She also provided conceptual and methodological expertise during the development of the research questions, methods, and data analysis. In addition, Dr. Richardson provided feedback on the first drafts of all three manuscripts before they were submitted to the committee members for further review. Dr. Griffith, Dr. Kuspinar, and Dr. Turchyn provided feedback on the research questions, methods, and the completed drafts of all three manuscripts. In addition, Dr. Griffith provided statistical advice on longitudinal data management and analysis. Dr. Kuspinar provided guidance on the selection of quality of life measurements for PLWD.

CHAPTER 1: INTRODUCTION

1.1 The increasing prevalence of dementia

Dementia, categorized as a neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), is an umbrella term encompassing a range of diseases that impact memory, other cognitive abilities and behaviour, ultimately leading to a significant interference with an individual's ability to carry out their daily activities [1]. Globally, dementia was documented as the 7th leading cause of mortality in 2019, according to the World Health Organization (WHO) [1]. It is recognized as a major contributor to disability and dependence among older adults [2]. While dementia is not an inherent aspect of the normal aging process, it is important to note that older age emerges as the strongest independent risk factor for dementia [2]. As the global aging population continues to grow, the number of people living with dementia (PLWD) is projected to reach 78 million by 2030 [2]. Much like many other nations, Canada anticipates a substantial surge in the prevalence of dementia in the coming decades as the population ages. In 2020, Canada had an estimated 597,300 PLWD. By 2030, this number is expected to approach 1 million, accounting for an overall 65% increase. Looking ahead to 2050, the number of PLWD will nearly triple the 2020 level, with over 1.7 million Canadians living with dementia [3].

While there have been recent advancements in the treatment of dementia, such as the full approval of a new drug called Lecanemab by the US Food and Drug Administration (FDA) in July 2023 for early Alzheimer's disease, the most prevalent type of dementia, dementia is still generally perceived as non-curable. This is because dementia is associated with not just one but many diseases that may have various causes with possibly an additive effect [2]. Consequently, WHO recognizes dementia as a longstanding global health challenge that we have been grappling with for years.

1.2 Informal caregivers: a key pillar of dementia care

Dementia care is not a solitary journey [3]. It relies significantly on the support of family members and close friends, often referred to as informal caregivers, who play a vital role in the care of PLWD [2]. According to a World Alzheimer Report [4], the annual global number of informal care hours provided to PLWD living in the community was approximately 82 billion hours in 2015, equivalent to an average of 2,089 hours per year or 6 hours per day. This amounts to more than 40 million full-time workers in 2015, a number projected to increase to 65 million by 2030. This trend is reflected in Canada, where approximately 61% of Canadian PLWD live in the community and primarily receive care from their informal caregivers, who can be family members, friends, or neighbours. On average, informal caregivers of PLWD in Canada provide 26 hours of assistance per week [5]. With the rising tide of PLWD in Canada, the demand for care hours provided by families could potentially rise to 1.4 billion in 2050, equivalent to approximately 690,000 full-time jobs. It is anticipated that there will be over 1 million informal caregivers for Canadian PLWD by 2050 [5].

Informal caregivers play a crucial role in assisting PLWD in various aspects of daily life, including activities of daily living (ADLs) such as bathing and dressing, instrumental activities of daily living (IADLs) like household chores and shopping, facilitating access to support services, and aiding in managing changes in mood, personality, and behaviours [3]. As the population continues to age and the prevalence of dementia grows, it becomes increasingly important for health systems and public agencies to consider offering increased direct support for caregiving rather than assuming family members will provide unpaid care for PLWD [6]. Recognizing the significant role informal caregivers play in dementia care, the provision of support to these caregivers stands as a central element in both national and international dementia strategies [7–9].

1.3 Quality of life of PLWD and their informal caregivers demands attention

Quality of life (QoL) is "the individual's perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards" [10]. It is a multidimensional and dynamic concept that encompasses various factors, including physical health, psychological well-being, level of independence, social relationships, personal beliefs, and the environment in which individuals live [11]. Given the pervasive effects of dementia [12], QoL is sometimes specifically conceptualized in relation to health and health related QoL (HRQoL) [13]. However, while there is likely an overlap between specific aspects of HRQoL and more general elements of QoL [14], it is crucial to assess QoL across multiple health and non-health domains, as it is a broad-ranging concept influenced in a complex manner by an individual's physical health, psychological well-being, level of independence, social relationships, and their interaction with significant environmental factors [10,12].

Quality of life is an important outcome from the perspective of PLWD and their caregivers [15,16], and the QoL of both parties can mutually influence each other [17]. In a recent announcement regarding the WHO dementia research blueprint, which marks the first WHO initiative addressing non-infectious diseases, there is a recognition that research on dementia care has shifted away from a primary focus on improving or maintaining cognition or mitigating behavioural changes to prioritize outcomes such as enhancing QoL [2].

With the increasing number of PLWD and, consequently, a growing population of informal caregivers, additional stress is placed on the health-care system. Many of these caregivers struggle to maintain their own health while also providing care to those they support. As dementia severity in care recipients progresses, leading to extended caregiving hours, the QoL of informal caregivers is often negatively affected [18–22]. This impact is especially pronounced for those informal caregivers who belong to the “sandwich generation”[23], a group caring for both the young and the elderly, which, in turn, can influence the quality of care provided and, subsequently, the QoL of the care recipient [17]. Therefore, enhancing the QoL of older adults with dementia and their informal caregivers demands increased attention, which is regarded as the primary goal of WHO’s blueprint for dementia research [2].

1.4 International Classification of Functioning, Disability, and Health (ICF) model in QoL research

The International Classification of Functioning, Disability, and Health (ICF) model is a universal framework offering a holistic perspective on health and well-being. It comprises three key components: body functions and structure, activities and participation, and contextual factors, encompassing personal and environmental factors. Developed by the WHO, the ICF provides a standardized language and systematic framework for describing health and health-related conditions [24]. Because the dimensions of health and functioning that QoL assessments address align with the health and health-related domains covered by the ICF, it is recommended to use the ICF as a conceptual platform for classifying and selecting the appropriate QoL measurements based on the specific research goals [25]. All elements within the ICF framework have the potential to impact an individual’s QoL and contribute to changes in their QoL over time [26]. It serves as a conceptual foundation for QoL studies in diverse populations, including older adults with dementia [27,28]. For PLWD, the ICF model acknowledges the various personal and social factors that can influence their lives. It also categorizes the various aspects of a PLWD’s life that are affected by dementia into different dimensions, such as physical, psychological, and social dimensions. This approach helps capture the complex nature of dementia and its impact on QoL. Therefore, ICF is considered as an important framework for dementia research [29–31]. Furthermore, ICF is also applied in practical dementia care. It is used to develop operational tools, such as personalized care plans (PCPs), which are employed in clinical-organizational care pathways, particularly for PLWD. These tailored tools define dementia care goals, interventions, and the health professionals responsible for addressing each identified need [29]. Hence, the ICF framework has been employed in the design of this thesis, not only for selecting appropriate QoL measures, but also for identifying determinants of QoL.

1.5 Caregiving model: The Stress Process Model

The "stress process of caregiving" model served as a guiding framework to investigate QoL among caregivers of PLWD. Developed by Pearlin and colleagues [32,33], this model posits that caregiving is inherently stressful, with the level of perceived stress being influenced by objective stressors, such as the severity of dementia, the duration of caregiving, and the number of caregiving hours[34]. Perceived stress is also shaped by subjective appraisals of these stressors and the unique characteristics of the caregivers, such as age, gender, race. Additionally, caregiver outcomes are further impacted by secondary stressors, such as the challenges of balancing work and caregiving responsibilities, and are mediated by the availability of coping mechanisms and support resources, including social support. As Daley [34] notes, caregivers may face similar objective demands, but differences in secondary stressors or mediating factors can result in varying outcomes for QOL.

Subjective caregiving experience can be negative or positive [35,36]. It can range from the negative burden, characterized by emotional distress, depression, anxiety, strained relationships with care recipients, and demands that interfere with social participation, to positive benefits, stemming from feeling of self-fulfillment, appreciation, satisfaction with the care recipients, and personal competence development [8]. Recent studies on dementia caregiver experiences have adapted Pearlin's models by integrating the concepts of negative and positive appraisals, but the core elements remain consistent with Pearlin's original framework [34,36,37]. Therefore, the stress model was chosen to capture the dynamic and multidimensional nature of dementia caregiving [38].

1.6 Care-recipient relationship type in QoL of PLWD

Maintaining QoL is the primary objective of care services for PLWD [39]. However, it has been argued that there is still limited understanding in this field, especially for those with more severe conditions [12,40–42], and whether QoL changes over time as dementia severity increases [12]. Studies on the factors affecting the QoL of PLWD, the changes in their QoL, the selection of suitable assessments, and the alignment between self-reported and proxy-reported measures has been a subject of contention. Research on the QoL of PLWD has primarily focused on assessment, using either generic or dementia-specific measures, with several options available [43–49]. While several standardized QoL assessment tools have been developed specifically for PLWD [48], such as the Quality of Life in Alzheimer Disease (QOL-AD), Alzheimer Disease-Related Quality of Life (ADRQL), Quality of Life in Late-Stage Dementia (QUALID), it is important to acknowledge that the complex and progressive nature of dementia presents challenges to comprehensive QoL measurement. Furthermore, a standardized assessment procedure for QoL is still in development, as the subjective nature of QoL measurement becomes much more complex when applied to individuals with cognitive deficits, such as those with dementia [50].

Understanding the factors influencing the QoL of PLWD is essential for identifying the pertinent domains or aspects of their lives that must be assessed to accurately measure their overall well-being and satisfaction. This approach is commonly employed in research and assessment to ensure that the selected domains for evaluating QoL align with the priorities of the individuals under study. A systematic review, utilizing meta-analysis techniques on 198 studies, examined factors associated with QoL, well-being and life satisfaction in PLWD [12]. The findings revealed that positive QoL was linked to factors such as relationships, social engagement, and functional ability. Additionally, living in the community, having a spouse as a caregiver, or receiving specialized and person-centered care in residential settings were associated with higher QoL. Conversely, poor physical and mental health, including depression and other neuropsychiatric symptoms, as well as diminished caregiver well-being, were linked to lower QoL. Subsequent studies have consistently reported that physical health, particularly ADLs, and mental health, especially depressive symptoms, have a significant impact on the QoL of PLWD [51–55]. Studies have also revealed that the QoL of PLWD is influenced by factors such as pain [53], awareness of memory function [56], and the continuity of the researcher [57]. However, research exploring the influence care-recipient relationship type on the QoL of PLWD remains limited.

Longitudinal evidence on predictors of QoL has gradually increased over the past decade, though it is still considered limited in comparison to studies on caregivers' QoL. According to Trigg [56], awareness of memory function not only directly impacts patient QoL ratings but can also obscure the effects of changes in other outcomes such as ADL function. A longitudinal study revealed that lower QoL in PLWD was associated with more severe depressive symptoms, low ADL functioning, and low IADL [55]. Another study consistently reported that higher Geriatric Depression Scale (GDS) scores were linked to lower QoL [54]. A recent study further demonstrated that the importance of psychological well-being in QoL changes over time. The group experiencing declining QoL had higher baseline levels of depression and loneliness, lower levels of self-esteem and optimism [58].

Yoshioka et al [59] investigated the impact of the care-recipient relationship type or kinship on PLWD in their study. They examined potential differences in the presence of behavioral and psychological symptoms of dementia (BPSD) among community dwelling PLWD with spouse caregivers versus non-spouse caregivers. Their findings indicated that PLWD with non-spouse caregivers were more likely to experience various behavioral and psychological symptoms, including behaviors such as hiding and/or losing items, rummaging, crying and/or screaming, and interfering with a harmonious home life[59, 60]. A systematic review [12] also revealed that community dwelling PLWD who had spousal caregivers experienced a higher QoL. However, as of today, there is still a lack of longitudinal evidence to support this finding. Additionally, research concerning the influence of the care-recipient relationship type on the QoL of PLWD remains limited. The previously mentioned studies primarily compared PLWD with spousal caregivers or non-spouse caregivers, including adult-child caregivers. Canadian surveys in 2011 showed that the primary caregivers were often spouses (46%) or adult children (44%), with a significant majority being daughters (71%) [61]. While the majority of informal dementia care is typically provided by spouses or children, accounting for approximately 65% in the United States [62], changing patterns in marriage and childbearing [63,64] have led to an increasing number of PLWD receiving care from other relations. These may include extended family members, neighbours, friends, or sharing care responsibilities with multiple caregivers [65,66]. A recent study referred to PLWD who had no living spouses or children at the onset of dementia as “kinless” [6] and suggested that older adults without close family support when they develop dementia constitute a diverse group with varied life paths and family backgrounds, sharing a common challenge that anyone might encounter in their late life. However, PLWD who have limited family support are currently insufficiently described in the existing geriatrics literature [67].

Hence, further research is necessary to investigate whether the factors influencing the components of QoL in older adults varies by different care-recipient relationship types, such as child versus spouse caregiving, immediate family versus extended family caregiving, or if they are the only caregiver or share caregiving responsibilities.

1.7 Care-recipient relationship type on QoL of PLWD's caregivers

Numerous studies have examined the factors that impact or predict the QoL of caregivers for PLWD. A systematic review[68] of quantitative and qualitative studies identified 10 key themes related to the QoL of caregivers for PLWD, including demographics, the caregiver–patient relationship, dementia characteristics, caregiving demands, caregiver health, emotional well-being, received support, caregiver independence, self-efficacy, and future outlook of the PLWD's disease progression. This review shows that the quality and level of evidence supporting each theme varies [68]. Another systematic review of qualitative studies [69] summarized five main themes pertaining to various aspects of QoL, including coping (emotion and problem coping), relationship with the PLWD (sense of loss and change in relationship), received support (both formal and informal), interference with life (control over caring situation, freedom, and independence), and health (physical, emotional and mental, and social health). Daley et al. [34] contributed to this body of literature by identifying specific role-related factors that influence QoL from the perspective of family caregivers of PLWD. Through qualitative analysis, they summarized that factors influencing QoL include perceptions of the relationship with and changes in the PLWD, the caring situation, and external factors beyond the caregiving dyad[34]. Caregiver depression and subjective burden [70], involvement in social networks and personal time [71], concern about the future, the need for support, and engagement in enjoyable activities [34,72], have all been recognized as factors that significantly influence caregivers' QoL. Additionally, factors associated with dementia, including the course of the illness, dementia severity, and the presence of neuropsychiatric symptoms, can negatively impact the informal caregiver's role and lead to a lower self-perception of QoL [71,73]. A systematic review, incorporating German-language literature, found that caregiver burden, health-related characteristics of informal caregivers, dementia-related characteristics, sociodemographic and contextual factors were all significantly and negatively associated with the QoL of informal caregivers [74]. However, while the importance of the care-recipient relationship has surfaced in quantitative literature, the literature pertaining to this topic remains limited [68,75]. Furthermore, a significant portion of this research primarily focuses on spouses or children caregivers. It is important to note that individuals in different caregiver relationships with PLWD often have distinct experiences, especially at the onset of dementia. For example, a systematic review on family relationships and Alzheimer's disease synthesized findings from 36 studies and highlighted that spousal caregivers often undergo a profound role shift, leading to feelings of loss, impaired communication, frustration, diminished intimacy, and a lack of support, with challenges in rebuilding marital closeness. In contrast, children caregivers reported heightened caregiver discomfort [76]. When comparing between offspring and spouse caregivers, it was found that spouse caregivers reported fewer family conflicts [76]. Furthermore, having a spousal relationship with the individual was associated with lower QoL for Alzheimer's disease caregivers [16].

While the greatest proportion of informal caregivers are typically spouses or adult children, it is important to examine those caregivers with other relationships to care recipients or those who share caregiving responsibilities. These caregivers are likely to assume a more significant caregiving role in the future, especially considering the shifting marital patterns among baby boomers, which include higher rates of divorce and fewer marriages compared to earlier generations [64]. Despite this importance, there is a noticeable shortage of research on "other" informal caregivers (such as extended family members or friends), and those who provide caregiving with others. Consequently, the effects of the caregiving experience on their QoL remain relatively under-explored compared to research on spousal and child caregivers.

Results regarding the influence of relationship type on caregivers' QoL have produced inconsistencies across various studies [77–80]. For example, Morrison [77] discovered that adult-child caregivers and those categorized as "other" caregivers exhibited higher QoL compared to spousal caregivers. Conversely, Vinas-Diez [78] and Rigby [80] reported lower QoL and a greater caregiver burden among adult-child caregivers compared to spousal caregivers. Given the conflicting nature of these findings, it suggests the existence of potential moderating factors that can influence the impact of the care-recipient relationship on caregivers' QoL, while also acknowledging that different study designs, samples, covariates, etc. across different studies can produce discrepant results. In addition, it is important to note that these studies primarily focus on sole caregiver types, particularly spouses and children. The concept of shared caregiving where responsibilities are distributed among multiple caregivers has not been explored in these studies.

Research also indicates that various caregiver groups have distinct appraisals and perceptions about what is important to evaluate in relation to their own QoL. Although no significant differences were observed in the overall evaluations of QoL between these groups (i.e. spouse-caregivers vs. non-spousal caregivers), they emphasized different QoL-related domains as being significant [81]. For example, non-spouse caregivers seemed to have more friends and perceived their own physical health as better than spouse-caregivers [81].This underscores the importance of considering the multifaceted nature of QoL when investigating the impact of care-recipient relationship type on caregivers of PLWD. To address this, it is important to assess the effects of care-recipient relationship type on distinct QoL domains. However, there is limited literature available on longitudinal studies in this regard. Therefore, the purpose of this thesis is to comprehensively examine the influence of various relationship types on QoL, both cross-sectionally and longitudinally, across different QoL domains.

1.8 Emergence of the research gaps and purpose

Dementia imposes a substantial burden on individuals, their families, healthcare, social welfare, and financial systems worldwide. The global cost of medical, social, and informal care associated with dementia in 2019 was estimated to exceed US$ 1.3 trillion, and this cost is projected to surpass US$ 2.8 trillion by 2030 [2,82]. Providing care and support for PLWD calls for targeted research to develop evidence-based and cost-effective services that address their QoL needs [2]. Considering the pre-existing relationship between care recipients and their caregivers, it is highly likely that the dyad will influence each other, affecting their responses to QoL, well-being, the strain experienced in the relationship, and the level of congruence or conflict related to the care provided [83,84]. However, despite recognizing that the care-recipient relationship type may be a substantial factor impacting the QoL of both parties, the existing literature remains fragmented, with conflicting findings, limited longitudinal evidence, and a lack of consideration for broader relationship types, such as extended family members or those sharing care responsibilities among multiple caregivers. This gap in the literature is particularly important given changing marital patterns among baby boomers, including higher divorce and separation rates, lower marriage rates, and evolving family structures characterized by fewer children and delayed childbirth compared to earlier generations [85]. Therefore, the focus of this thesis is to investigate the cross-sectional association between care-recipient relationship type and QoL among PLWD and their informal caregivers, as well as to explore the predictors of relationship type on longitudinal changes in their QoL.

1.9 Outline of thesis

1.9.1 Conceptual models and QoL domains selection

Following the ICF framework, this thesis assessed the QoL of older adults across four domains: mental health, general health, functional limitations, and pain. Mental health was evaluated using the 4-items Patient Health Questionnaire for Depression and Anxiety (PHQ-4), comprising a depression subscale from the 2-item Patient Health Questionnaire (PHQ-2) and an anxiety subscale from the 2-item Generalized Anxiety Disorder scale (GAD-2) [86]. General health was self-rated on a five-point scale ranging from excellent to poor. Pain was assessed using a dichotomous scale by asking whether the participants had been bothered by pain in the last month. Functional limitations were quantified as the total number of ADLs for which the participant received help in the past month. These outcomes were previously developed by Schwartz el al for their alignment with sub-domains of the 12-Item Short Form Health Survey (SF-12) [87], a widely recognized QoL assessment tool known for its strong connection to the ICF [88,89]. They are also consistent with an focus on mood and functional limitations in PLWD[43,90] and have been effectively employed in studies related to the QoL of PLWD using National Health and Aging Trends Study (NHATS) datasets [91].

The caregiver stress process was selected as a framework for identifying relevant QoL domains for informal caregivers of PLWD. The QoL measure included three primary outcomes: positive emotional benefit, negative emotional burden, and social strain. Each of these outcomes was assessed using items from the National Study of Caregiving (NSOC) questionnaire, and was dichotomized as “high burden” for the top quartile and “low burden” for the remainder. These measures are examined through exploratory factor analysis and their application in previous research which analyzed data from NHATS and NSOC, and found that the measurements used in this study account for a significant portion of the variance in caregiver burden, eigenvalues and variability for negative emotional burden, positive emotional benefit, and social strain are 5.45 & 28.71%, 2.68 & 14.13%; 1.38 & 7.27%, respectively[92]. These measures have been subsequently utilized in other studies leveraging NHATS datasets[93,94].

1.9.2 Data sources: NHATS and NSOC

This thesis conducted a series of secondary analyses of data on PLWD and their informal caregivers, sourced from two linked datasets: NHATS and NSOC. These datasets were sponsored by the National Institute on Aging (grant number NIA U01AG32947) and conducted by Johns Hopkins University [95].

The NHATS is structured around a conceptual framework that integrates elements from the ICF with the Nagi model of disablement[96]. NHATS is a population-based, in person survey designed to capture trends in late-life disability and individual trajectories by collecting data from a nationally representative sample of Medicare beneficiaries aged 65 years and older in the United Sates [96]. The participants were initially sampled in 2011 (Round 1) and refreshed in 2015 and 2022/2023 (Round 5 and 12/13). Since 2011, NHATS has annually collected information on the disablement process and its consequences, resulting in a total of 12 rounds available to date[95].

NHATS forms the basis for NSOC, a national telephone survey aimed at informal caregivers of NHATS participants who received assistance in self-care, mobility, medical, or household activities [95]. For older adults receiving assistance, a detailed helper roster was compiled, documenting the relationship and specific activities undertaken by each caregiver. When NHATS participants had more than five eligible caregivers, a random selection process was employed to choose five caregivers. The first three rounds of NSOC (I, II, and III) have been conducted with NHATS at periodic intervals in 2011 (Round 1), 2015 (Round 5), and 2017

(Round 7). The fourth round of NSOC (IV) began in 2021 (NHATS Round 11) and completed in 2022 (NHATS Round 12) [95].

Together, NHATS and NSOC constitute the sole national platform designed to investigate caregiving from the perspective of older adults and their caregivers [96].

1.9.3 Outline of included manuscripts

To fulfill the research objectives of this thesis, three manuscripts have been incorporated. The first manuscript (Chapter 2), titled "The Impact of Care-recipient Relationship Type on Health-related Quality of Life in Community-Dwelling Older Adults with Dementia and Their Informal Caregivers", seeks to evaluate whether there exists an association between the type of relationship and the QoL of care recipients (i.e. PLWD) and their caregivers. Additionally, it aims to explore whether PLWD's dementia status affects this correlation. To our knowledge, no prior study has utilized dyadic data to investigate how the QoL of PLWD and their caregivers may be influenced by varying relationship types. Leveraging linked data from the NHATS Round 5 and NSOC II, this study represents the first analysis to examine potential associations or patterns between the type of relationship and QoL, with the potential to establish a solid foundation for further investigations in longitudinal studies.

Given the absence of existing studies examining the influence of relationship types on PLWD's QoL and the inherent limitations of establishing causal relationships in cross-sectional studies, the second manuscript (Chapter 3), titled "Impact of care-recipient relationship type on quality of life in community-dwelling older adults with dementia over time", aims to address two key research questions: (i) Does type of relationship or caregiving being shared predict a change in PLWD's QoL over four years after adjusting for socio-demographics and dementia status? (ii) Does the effect of type of relationship or caregiving being shared differ by socio-demographics and dementia status? The findings of this study have the potential to offer insights into the role of care-recipient relationship types in shaping changes in QoL among PLWD over time. These findings can help prioritize resource allocation decisions for healthcare teams and policymakers, enabling the development of tailored interventions and proactive planning for future healthcare expenditures.

With the absence of longitudinal studies examining the predictive impact of relationship type on caregivers' QoL over time, the third manuscript (Chapter 4), titled “Impact of care-recipient relationship type on quality of life in community-dwelling older adults with dementia over time” aspires to bridge this critical research gap. This study seeks to assess how the type of relationship predicts changes in the QoL of informal caregivers of PLWD over two years. Alongside the two other manuscripts, this thesis aims to offer valuable contributions to dementia care research and its practical applications.

Several points require attention in this thesis: 1. Discrepancy in terminology: In Chapter 2, the term “Health-Related Quality of Life (HRQL)" was utilized, while subsequent chapters transitioned to "Quality of life (QoL)." This change was made to reflect that the term “QoL” rather than "HRQL" encompasses the broader impact of dementia on individuals. Dementia influences not only the health of individuals but also their relationships, daily activities, and surroundings. Similarly, the well-being of caregivers for PLWD is shaped by factors extending beyond the care recipients’ health. By selecting QoL, the intention is to acknowledge the condition’s comprehensive impact on PLWD and to provide a more inclusive assessment of the overall impact on the caregiving experience. 2. Change in Terminology for Dementia Classification: In Chapter 2, the term "dementia severity" was used, but in Chapter 3 and 4, it was shifted to "dementia status." The classification of dementia was derived from the original datasets, NHATS, wherein dementia was categorized into three types: no dementia, possible dementia, and probable dementia. This classification is more indicative of different statuses rather than varying levels of severity. Consequently, I have uniformly adopted the term "dementia status" throughout this thesis. 3. Structural differences among chapters: Discrepancies in structure among the three manuscripts (Chapters 2, 3, and 4) arise from adherence to diverse journal requirements. The Discussion section (Chapter 5) will bring together each manuscript, elucidating how they complement one another and contribute to bridging the gap in dementia care.

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CHAPTER 2: THE IMPACT OF CARE-RECIPIENT RELATIONSHIP TYPE ON HEALTH-RELATED QUALITY OF LIFE IN COMMUNITY-DWELLING OLDER ADULTS WITH DEMENTIA AND THEIR INFORMAL CAREGIVERS

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Title:

The Impact of Care-recipient Relationship Type on Health-related Quality of Life in Community-Dwelling Older Adults with Dementia and Their Informal Caregivers

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Abstract

Purpose: To assess whether there was an association between care-recipient relationship type and health-related quality of life (HRQL) of older persons living with dementia (PLWD) and their informal caregivers, and whether this association was affected by PLWD' dementia severity. **Methods:** This was a secondary data analysis study. PLWD (n=1230) and caregivers (n=1871) were identified from participants in the National Health and Aging Trends Study (NHATS) Round 5 and the National Study of Caregiving (NSOC) II, respectively. A series of bivariate and multivariable regression models examined the associations among relationship type and HRQL in PLWD and caregivers, adjusted for socio-demographic variables and dementia severity. **Results:** PLWD and caregivers' HRQL outcomes varied by relationship type. PLWD cared for by an adult-child caregiver, or multiple caregivers experienced higher functional limitations than those cared for by a spousal caregiver (β=.79, CI [.39, 1.19]; β=.50, CI [.17, .82], respectively). "Other" caregivers, such as extended family members or friends, had lower odds of experiencing negative emotional burden and social strain than spousal caregivers (OR=.20, CI [.09, .45]; OR=.43, CI [.20, .89]), respectively). Lower odds of experiencing negative emotional burden were also found with multiple caregivers. The effect of an adult-child caregiver on social strain was no longer significant when the dementia severity of PLWD was included in the analysis. **Conclusion:** The type of care-recipient relationship impacts the HRQL in both PLWD and their informal caregivers. Dementia severity of the PLWD appears to affect this association.

Keywords: Care-recipient relationship type; Health-related quality of life (HRQL); Dementia; Informal caregiver

Introduction

There are currently more than 55 million persons living with dementia (PLWD) worldwide [1]. As a common disease that mainly affects older adults [1], the number of PLWD has increased proportionally with the global growth of the aging population. The consequences of dementia can include many physical and mental challenges that can influence PLWD and their caregivers [2]. Notably, only 8% of PLWD in the United States do not receive help from informal caregivers such as family members, friends or other unpaid caregivers (hereafter referred to as "caregivers") [3]. Therefore, health-related quality of life (HRQL) among PLWD and their caregivers warrant increased attention.

HRQL and the International Classification of Functioning, Disability and Health (ICF) framework

HRQL is "a measure of the value assigned to the duration of life modified by impairments, functional states, perceptions and opportunities, as influenced by disease, injury, treatment and policy" [4]. HRQL is a multidimensional construct that encompasses the aspects of Quality of life (QoL) that impact health, referring to how an individual's daily function is affected by physical or mental health and their perceptions of their ability to live a fulfilling life [5].

The ICF is a systematic framework developed by the WHO [6] that closely aligns with this definition. It includes three following components: body functions and structure, activities and participation, and contextual factors (personal and environmental factors) [6]. Since the health and functioning dimensions covered by HRQL measurements are compatible with the health and health-related domains within the scope of the ICF, it is suggested that the ICF can be used as a conceptual platform to classify and select the appropriate HRQL measurement according to the relevant purpose of interest [7-8]. Therefore, the ICF model was applied as a framework to select the appropriate HRQL measures for inclusion in this study.

Care-recipient relationship type on HRQL

While maintenance of HRQL has been identified as the primary goal of care services for PLWD [9], HRQL investigations in PLWD have not been well established [10]. The importance of the relationship between the PLWD and caregivers has started to emerge but the existing literature focuses on the HRQL of caregivers [11]. Further research is needed to understand whether the impact of the factors which constitute HRQL in PLWD varies by different care-recipient relationship type (hereafter referred to as “relationship type”. e.g., formal vs. informal; child vs. spouse; immediate family member vs. extended family member). Another gap in HRQL studies with PLWD is the absence of a standardized assessment procedure because of the inherent difficulty in people with cognitive disorders [10]. In addition, studies of the impact of relationship type on HRQL mainly focus on spousal or children caregivers. Few studies investigate other relationship types, such as extended family members or friends, as well as those sharing care responsibilities with multiple caregivers [12-13]. Although most caregivers are spouses or children, it is important to examine other caregiver types or those who share the caregiving role with multiple caregivers. They are likely to play a more prominent caregiving role in the future given higher divorce rates, fewer marriages, lower fertility, and increased childlessness [14-15]. The findings of the impact of relationship type on HRQL in caregivers appear to be contradictory among studies [16-18]. Due to these conflicting findings, there may be other factors that influence the potential impact of relationship type on the HRQL of caregivers. Furthermore, there is growing evidence that PWLD’s dementia severity is related to the HRQL of both the care recipients and their caregivers [19-20].

Therefore, this study aims to assess whether there is an association between the relationship type and HRQL of care recipients and caregivers, and whether this association is affected by PWLD' dementia severity.

Methods

Data sources and sample selection

This is a cross-sectional study and a secondary data analysis. We created a dataset of participants from the National Health and Aging Trends Study (NHATS) Round 5 (77% response rate) along with their caregivers from its companion study, the National Study of Caregiving (NSOC) II (67% response rate). NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by Johns Hopkins University [21]. NHATS has been used for researching in older adults and their caregivers since it was launched in 2011 (see Supplementary Appendix A for a research brief of the NHATS). As a population-based in-person survey that measures late-life disability from a nationally representative sample of Medicare beneficiaries aged 65 years and older in the United States, the NHATS offers large sample sizes and has a comprehensive, validated disability protocol that is administered annually. It also serves as the foundation for NSOC, a national telephone survey for the informal caregivers of NHATS participants who received assistance in self-care, mobility, medical, or household activities [21]. To be included in the current study, care recipients must live in the community, and receive help with certain Activities of Daily Living (ADLs) from their caregivers at the time of enrollment. Activities include getting around inside, getting out of bed, eating, bathing/showering/washing up, getting to or using the toilet, and dressing. Correspondingly, caregivers who the NHATS participants identified as "helpers" assisting any activities were included and drew data from the NSOCII.

Measures

Dependent Variable: HRQL

As per the ICF framework, HRQL should be evaluated based on body function and structure, activities and participation, and contextual factors [6]. Body function refer to physical and mental health; Activities and participation refer to the execution of a task and involvement in life situations, and hence, activity limitations are considered as problems in this component. Contextual factors refer to personal and environmental factors, and therefore the individual's socio-demographic variables should also be considered in HRQL studies. In addition, the pain has profound effects on HRQL and community-dwelling PWLD are at high risk of experiencing pain [22]. Therefore, the present study assessed HRQL in care recipients using 4 main outcomes: mental health, general health, functional limitations, and pain. The 4 outcomes were previously validated through directly mapping onto the 12-Item Short Form Health Survey (SF-12) subscales [23], a common HRQL assessment reported having high linkage to the ICF [24-25]. Mental health was presented using the Patient Health Questionnaire for Depression and Anxiety (PHQ-4), a scale composed of a depression subscale from the 2-item Patient Health Questionnaire (PHQ-2), and an anxiety subscale from the 2-item Generalized Anxiety Disorder scale (GAD-2) [26]. General health was self-rated on a five-point scale from excellent to poor. Given a small number of participants answering "excellent" (47 out of 1230 participants), they were combined into the "very good" group. The pain was evaluated by asking whether or not the participants were bothered by pain in the last month. Functional limitations were presented as the total number of ADLs that the participant received help with in the last month.

HRQL of caregivers was assessed through 3 main outcomes: positive emotional benefit, negative emotional burden, and social strain. These outcomes were measured using items from the NSOC II questionnaire and substantiated through exploratory factor analysis, and applied in previous caregiver-related studies [27-28]. Positive and negative emotions were measured using the questions pertaining to the aspects of caregiving, health, and wellbeing. The social strain was measured using the questions asked about whether helping the care recipient kept the caregiver from participating in activities [28, 29]. Each outcome was coded as “high burden” for the top quartile and “low burden” for the remainder (see Supplementary Appendix B).

Independent Variable: Relationship Type

Four types of relationship were identified: (1) care from a spouse/partner; (2) care from an adult child; (3) care from an informal caregiver other than a spouse/partner and adult child, such as child-in-law, sibling, friend, etc. (hereafter referred to as “‘other’ caregivers”); (4) care from multiple caregivers, as opposed to a single caregiver.

Covariates: Socio-demographic Variables and Dementia Severity

Care recipients’ socio-demographic characteristics included age range, sex, race/ethnicity, annual income in quartiles, education, marital status, and living arrangements. Caregivers’ socio-demographic characteristics included age range, sex, race/ethnicity, annual income, education, marital status, and if they had a dependent child (<18yrs). The associations between these socio-demographic factors and HRQL outcomes have been reported in various studies [11, 14, 27-28, 30-31].

Care recipients’ dementia severity was classified into three levels- probable dementia, possible dementia, and no dementia- using a previously developed and validated approach [32].

Statistical Analyses

No variable had missing values for more than 5% of the analytic sample. Initial analysis began with applying box plots on each HRQL subscale by relationship type and summarizing the data.

Observation normality was examined using histogram and Shapiro test. Socio-demographics, dementia severity and HRQL subscales were examined by relationship type.

To examine whether relationship type impacted care recipients’ HRQL, bivariate regressions were performed for each HRQL subscale on each variable of interest, including relationship type and care recipients’ socio-demographics. Next, with the significant covariates from the bivariate regressions, the association between each HRQL subscale and relationship type was examined using a series of multivariable regressions: logistic regression for PHQ-4 as well as pain; ordered logistic regression for general health given a proportional odds assumption met; robust regression for functional limitations given unsatisfactorily addressing the residual normality requirements. Dementia severity was then added to each existing multivariable regression model, determining whether care recipients’ dementia severity affected the association between relationship type and their HRQL subscales.

To examine whether relationship type impacted caregivers’ HRQL, bivariate regressions were performed for each HRQL subscale on each of the variables of interest, including relationship type and caregivers’ socio-demographic variables. Next, with the significant covariates from the bivariate regressions as controls, the association between each HRQL subscale and relationship type was examined using logistic regression.

To examine whether the severity of dementia associated with older adults affected the association of relationship type and caregiver HRQL, we started by conducting logistic regression with each caregiver HRQL subscale as dependent variables, 3 types of relationship (spousal caregiver, child caregiver, “other” caregiver) as independent variables, and caregivers’ socio-demographic variables as covariates. We then added older adults’ dementia severity to the original models to compare the results.

Statistical analyses were conducted using STATA 16 software [33] with a significance level of 0.05.

Results

Sample Characteristics

As shown in Table 1, 1230 care recipients were included in the analyses. The majority of these care recipients were female (67.1%), in an age range of 80-84yrs (22.1%), Non-Hispanic White (60.2%), unmarried (56.8%), living with others only (37.3%), and identified as living with no dementia (55.2%). The majority had an annual income in the 2nd-3rd quartiles ≥$ 22,000 ≤$ 40,000; 27.1%) and had a high school education (29.5%). Care recipients received care from a spouse/partner 24.1% of the time, 28.6% received care from an adult child, 9.3% from "other", and 38.0% from multiple caregivers.

[Table 1 Care recipients' socio-demographics and dementia severity]

Table 2 lists the socio-demographic variables for caregivers. A total of 1871 caregivers were included in the analysis. The majority of these caregivers were female (66.5%), aged 65yrs or above (39.8%), Non-Hispanic White (58.7%), and were married or living with a partner (60.4%). The majority had an annual income in 2nd-3rd quartiles (≥$ 36,000 ≤$ 70,000; 25.8%), above high school education (36.1%), and had no dependent child (83.8%). Spouses/partners made up 15.8% of the caregivers, 18.8% were children, 6.1% were "others", and 62.2% were categorized as "multiple caregivers" whose care roles were shared among 2 or more caregivers such as children, friends, etc.

[Table 2 Caregivers' Socio-demographics]

Relationship type on care recipients' HRQL

The multivariate regression results on relationship type on care recipients’ HRQL outcomes are shown in Table 3. We categorized two groups in this study related to PHQ-4, lower frequency of symptoms (0-2) and higher frequency (3-12), due to approximately half of the participants in the scale of 0-2 and the small number of participants (about 5%) in the scale of 9–12. The results showed that functional limitations were the only outcome significantly related to the relationship type**.** Care recipients cared for by an adult-child caregiver or multiple caregivers experienced higher functional limitations than those cared for by a spouse/partner, holding all other independent variables constant (β=0.79, CI [0.39, 1.19]; β=0.50, CI [0.17, 0.82], respectively).

The association between relationship type and functional limitations persisted after including dementia severity as a control variable (β=0.67, CI [0.29, 1.05] for those cared for by an adult-child and β=0.45, CI [0.13, 0.76] for those cared for by multiple caregiver, respectively, table 4). Furthermore, the adjusted models showed an inverse relationship for care recipients who had intact cognition, which was associated with fewer functional limitations (Table 4).

[Table 3 Multivariable regression of care-recipient relationship type on care recipients’ HRQL adjusted for socio-demographics]

[Table 4 Multivariable regression of care-recipient relationship type on care recipients’ HQOL adjusted for socio-demographics and dementia severity]

Relationship type on caregivers’ HRQL

Table 5 illustrates the multivariable regression analysis results of relationship type on caregiver HRQL outcomes. “Other” caregivers and “multiple” caregivers were found to be less likely to experience negative emotional burden than spousal caregivers (OR=0.26, CI [0.13, 0.52]; OR=0.53, CI [0.35, 0.81], respectively). Compared to spousal caregivers, “other” caregivers were 51% less likely to experience social strain (OR=0.49, CI [0.26, 0.93]), suggesting that relationship type had an impact on caregivers’ HRQL outcomes.

To assess whether care recipients' dementia severity impacted the association between relationship type and caregivers' HRQL, models with or without dementia severity as covariates were generated on the sample of dyads using three types of relationships (spousal caregiver, child caregiver, "other" caregiver) (Table 6). In the fully adjusted models, care recipients' dementia severity was a risk factor for experiencing caregiver social strain, indicating that caregivers to recipients with possible dementia or no dementia were less likely to experience social strain compared to those providing care to recipients with probable dementia (OR=0.53, CI [0.31, 0.91]; OR=0.44, CI [0.29, 0.64] respectively). Furthermore, the significance of social strain maintained in "other" caregivers (*p* < .05 in both models) but diminished in adult-child caregivers after adjusting for dementia severity.

[Table 5 multivariable regression of care-recipient relationship type on caregivers' HRQL outcomes adjusted for socio-demographics]

[Table 6 Comparison between models with and without adjustment for care recipients' dementia severity]

Discussion

Findings from the current study revealed that relationship type was associated with HRQL of both care recipients and caregivers, which may be affected by care recipients' dementia severity.

Care recipients' HRQL by relationship type and the impact of dementia severity

A strength of this study was that it included 4 outcomes, mental health, pain, self-rated general health, and functional limitations, to evaluate care recipients' HRQL. The results suggested that care recipients' functional limitations were associated with the relationship type, and these associations were maintained regardless of their dementia severity.

While caregiving literature generally recognizes that family members, close relatives and friends of a patient may share care responsibilities, few studies fully consider such dynamics [13, 34]. This study showed that care recipients' HRQL outcomes were negatively impacted when the caregiving roles were shared among multiple members. Care recipients cared for by multiple caregivers experienced higher functional limitations than those cared for by a spouse/partner. This discrepancy was not explained by their dementia severity since the difference remained significant after adjusting for dementia severity. One possible explanation for this is that care recipients who are more functionally dependent require a higher level of engagement in caregiving activities and therefore require multiple caregivers. Additionally, communication among multiple caregivers may lead to misinterpretation of caregiving goals; another possible reason may be related to the expansion, increased complexity and intensity of the caregiver's roles and responsibilities in the middle to late stages of a caregiving trajectory [15].

Our study found that the care-recipients' dementia severity significantly associated with their HRQL outcomes, including mental health, pain, and functional limitations. Dementia was associated with a greater risk of poor mental health outcomes and a higher degree of functional limitations. An increasing number of studies have observed the co-occurrence between mental health issues such as depression and/or anxiety, and the development of cognitive deficits [35-36]. Cognitive impairment may affect one's concentration and memory capacity as well as decision-making ability, which are perceived as an important part of depressive symptomatology [35]. Moreover, the influence of depression on dementia severity interferes with individuals' abilities to perform ADLs [35]. The presence of functional limitations, a diminished capacity to perform ADLs required for community-dwelling older adults, may increase the risk of depression for older adults with cognitive impairment [37]. The findings of this current study support the idea that dementia severity affects mental health issues and functional limitations for the aging population. These symptoms may interact with each other and exacerbate the challenges on the affected individual [26, 35, 37].

However, this current study found that care recipients without dementia reported more pain than those with probable dementia, concurring with previous studies that have noted a decreased reporting of pain with increased cognitive impairment [38-39]. There are several explanations for this phenomenon: there are less validated and diverse ways to assess pain in this population; individuals with severe dementia have increased difficulty in verbalizing pain as a result of diminished communication abilities [30]; decreased validity in pain reporting due to memory loss [39]; and a decrease in the affective component of pain perception [40]. In addition, proxy respondents were used in this study when the respondent could not respond due to dementia severity, which may contribute to the differences in pain reporting. Thus it is important to have a more valid approach to assessing pain responses rather than asking cognitively impaired persons to provide a self-report of pain [30]. Behavioural/observation–based assessments like facial expression and sighing, are options for this testing [30].

Caregivers' HRQL by relationship type and impact of care-recipients' dementia severity

Evidence derived from the study demonstrated that caregivers' HRQL outcomes were associated with the relationship type. Moreover, the impact of care-recipients' dementia severity in these associations differed by the relationship type.

Although care recipients receiving care from multiple caregivers presented higher functional limitations, individuals who shared caregiving roles with other members were less likely to experience negative emotional burden compared to spousal caregivers. This finding suggests that care demands affect caregivers' health and ability to maintain personal and social obligations, and the sharing of these demands results in improved caregiver health and wellbeing [13]. Collective caregiving, family support and a solid commitment to care may have mitigated the difficult aspects of caregiving and turned the focus toward the rewards for caregivers [34]. This study adds to the literature by examining how care recipients and caregivers are affected when multiple caregivers share the caregiver role. These results will inform policymakers and researchers when they are evaluating the full range of care demands and allow a further exploration of shared care dynamics when they are designing policies and support services to alleviate caregiver burden and improve caregivers' HRQL. Beyond that, these are important findings to consider within policy development to support informal caregivers as part of the system of the aging place.

The current study corroborates prior research findings that "other" caregivers have significantly higher HRQL than spousal caregivers. The care given by "others" appears to be less stressful and detrimental to mental health than spousal caregivers [16, 41]. Findings in the current study stated that "other" caregivers were less likely to report a negative emotional burden and social strain than spousal caregivers, whether or not care recipients' dementia severity was considered. Unlike caregivers in a primary kinship (such as child, or spouse), who often have a greater perceived social obligation to care for the care recipients, "other" caregivers are less bound by an obligation to enter a caregiving relationship but rather often do by voluntary desire [42]. As a result, spousal caregivers may experience a more significant negative caregiving experience compared to "other" caregivers. Another possible explanation for this finding is that 100% of the spousal caregivers in this study were living with the care recipients, demanding a greater responsibility and heavier care load compared to the "other" caregivers. It could also be that the spousal caregivers are more emotionally involved and older than other caregivers, and therefore the strain of caregiving is likely to be greater. These results verified the findings of a previous systematic review which confirms that closer kinship ties may be associated with increased caregiver burden which results in a poor HRQL outcome for the caregiver [43].

Although there are mixed results in studies which compared spousal and adult-child caregivers [16-17, 45], a converging opinion from cross-sectional, longitudinal studies, and meta-analysis reviews support the finding that spousal caregivers experience more depressive symptoms than adult-child caregivers when caring for older PLWD [12, 18, 44-45]. The current study compared three types of relationship and showed that adult-child caregivers were less likely to report negative emotional burden than spousal caregivers, despite higher functional limitations in their care recipients. However, adult-child caregivers reported more social strain which was not significant after adjustment for care recipients' dementia severity. Furthermore, severe dementia in care recipients was associated with greater social strain in caregivers in this study. This phenomenon is likely related to the increased amount of time required to care for PWLD. As a result, there is a loss of leisure time and increased social isolation [46]. The co-occurrence of functional limitations and mental health issues in PWLD may also increase the challenges in caregiving therefore exacerbating the caregivers' social strain.

Spousal and adult-child caregivers' varied responses to different HRQL domains may also be attributed to the fact that spousal caregivers were older and had more physical challenges in meeting care recipients' demands for increasing ADLs assistance and co-residing with the care recipients. Perceived loss of the spousal relationship and the impending loss of this person may also contribute to the higher psychological burden in spousal caregivers [44]. However, adult-child caregivers may recognize the impact of caregiving responsibilities, which limit their participation in social activities and are more likely to express caregiving stress. Spousal caregivers, who are mostly retired, have more time to commit to caregiving than adult-child caregivers who are more likely to have multiple social roles [18]. These findings provide evidence for the important influence of relationship type on caregiver HRQL, suggesting a distinction in caregiving challenges and supporting needs between spousal and adult-child caregivers.

Although the dementia severity of the care recipients influenced the perception of positive emotional benefit of "other" caregivers, the same effect was less significant in spousal or adult-child caregivers. Caregivers of older adults can experience both a positive and a negative impact due to caregiving, which may differ depending on the care recipient's level of dementia severity and relationship type [47]. Future studies need to explore the influence of relationship type on the perceived caregiving experience longitudinally, as well as how both positive and negative aspects interact with each other in caregivers for older PLWD. Therefore, the findings from this current study provide evidence for the influence of the dementia severity of care recipients on the association between relationship type and caregivers' HRQL. It suggests that the different aspects of HRQL should be considered when studying HRQL among different types of relationship.

Limitations

To our knowledge, this is the first study using dyadic data to examine how the HRQL of care recipients and caregivers are impacted by different relationship types. However, the study also has limitations. Firstly, the cross-sectional analysis limits the ability to make causal conclusions. A longitudinal study would help to establish a causal relationship between the impact relationship type on HRQL of both care recipients and caregivers. Also, the caregivers included in the NHATS and NSOC surveys are only caregivers assisting with ADLs/IADLs, and does not include other types of assistance being provided which may limit the generalization of the results obtained. In addition, the outcomes we used in this study, PHQ4, general health, functional limitations, and pain, are all constructs of HRQL. However, they may not be totally comprehensive. Lastly, proxy respondents were used in this study when the older adult could not respond due to dementia. The small percentage of proxy respondents (17.4%) included in this study is unlikely to have a substantial impact on the findings, however, the limits in analyses of subgroups of interest due to sample size constraints may have resulted in measurement bias.

Conclusion

The study shows that relationship type impacts the HRQL of both care recipients and their caregivers. The dementia severity of the care recipient appears to affect this association.

Chapter 2 Table 1. Care recipients' socio-demographics and dementia severity

Variables, count (percentage)	Care- recipient Relationship Type				
	Total (n=1230)	**By spouse /partner 296 (24.1)**	**By adult child 352 (28.6)**	**By "other" 114 (9.3)**	**By multiples 468 (38.0)**
Sex					
Male	405 (32.9)	172 (58.1)	58 (16.5)	38 (33.3)	137 (29.3)
Female	825 (67.1)	124 (41.9)	294 (83.5)	76 (66.7)	331 (70.7)
Age					
65 to 69 yrs	84 (6.8)	45 (15.2)	17 (4.8)	5 (4.4)	17 (3.6)
70 to 74 yrs	174 (14.2)	56 (18.9)	35 (9.9)	23 (20.2)	60 (12.8)
75 to 79 yrs	222 (18.1)	76 (25.7)	56 (15.9)	18 (15.8)	72 (15.4)
80 to 84 yrs	272 (22.1)	67 (22.6)	69 (19.6)	26 (22.8)	110 (23.5)
85 to 89 yrs	256 (20.8)	36 (12.2)	80 (22.7)	24 (21.1)	116 (24.8)
90+ yrs	222 (18.1)	16 (5.4)	95 (27.0)	18 (15.8)	93 (19.9)
Race/ethnicity					
Non- Hispanic White	735 (60.2)	230 (78.0)	185 (53.0)	54 (48.2)	266 (57.1)
Non- Hispanic Black	386 (31.6)	50 (17.0)	124 (35.5)	47 (42)	165 (35.4)
Hispanic	62 (5.1)	7 (2.4)	25 (7.2)	7 (6.3)	23 (4.9)
Other	39 (3.2)	8 (2.7)	15 (4.3)	4 (3.6)	12 (2.6)
Annual Income					
<1st quartile	305 (24.8)	15 (5.1)	128 (36.4)	46 (40.4)	116 (24.8)
1st-2nd quartiles	309 (25.1)	33 (11.2)	109 (31.0)	33 (29.0)	134 (28.6)
2nd-3rd quartiles	333 (27.1)	105 (35.5)	80 (22.7)	21 (18.4)	127 (27.1)
> 3rd quartile	283 (23.0)	143 (48.3)	35 (9.9)	14 (12.3)	91 (19.4)
Education					
Below high school	412 (33.8)	62 (21.0)	130 (37.1)	44 (39.6)	176 (38.0)
High school	360 (29.5)	81 (27.4)	113 (32.3)	30 (27.0)	136 (29.4)
Above high school	271 (22.2)	88 (29.7)	69 (19.7)	26 (23.4)	88 (19.0)
Bachelor and above	177 (14.5)	65 (22.0)	38 (10.9)	11 (9.9)	63 (13.6)
Marital status					
Married/living with a partner	532 (43.3)	296 (100)	47 (13.4)	17 (14.9)	172 (36.8)
Unmarried	698 (56.8)	N/A	305 (86.7)	97 (85.1)	296 (63.3)
Living arrangements					
Alone	249 (20.2)	N/A	111 (31.5)	44 (38.6)	94 (20.1)
With spouse/partner only	376 (30.6)	248 (83.78)	18 (5.1)	12 (10.5)	98 (20.9)
With spouse/partner and others	146 (11.9)	48 (16.22)	24 (6.8)	3 (2.6)	71 (15.2)
With others only	459 (37.3)	N/A	199 (56.5)	55 (48.3)	205 (43.8)
Dementia severity					
Probable dementia	371 (30.2)	59 (20.0)	127 (36.1)	34 (29.8)	151 (32.3)
Possible dementia	179 (14.6)	34 (11.5)	55 (15.6)	23 (20.2)	67 (14.4)
No dementia	678 (55.2)	202 (68.4)	170 (48.3)	57 (50.0)	249 (53.3)

yrs: years.

Chapter 2 Table 2. Caregivers' Socio-demographics

Variables, count (percentage)	Care- recipient Relationship Type				
	Total (n=1871)	Spousal caregiver 296 (15.8)	Adult-child caregiver 352 (18.8)	"Other" caregiver 114 (6.1)	Multiple caregivers 1176 (62.6)
Sex					
Male	624 (33.6)	121 (40.9)	99 (28.1)	30 (26.8)	374 (34.0)
Female	1,236 (66.5)	175 (59.1)	253 (71.9)	82 (73.2)	726 (66.0)
Age					
< 45 yrs	242 (13.2)	1 (0.3)	35 (10.2)	28 (25.0)	178 (16.5)
45 to 54 yrs	363 (19.9)	7 (2.4)	112 (32.8)	14 (12.5)	230 (21.3)
55 to 64 yrs	496 (27.1)	24 (8.1)	124 (36.3)	22 (19.6)	326 (30.2)
65 + yrs	728 (39.8)	263 (89.2)	71 (20.8)	48 (42.9)	346 (32.0)
Mean (SD)	60.2 (15.1)	74.7 (8.8)	56.7 (9.4)	57.6 (19.2)	57.6 (15.2)
Race/ethnicity					
Non- Hispanic White	1,050 (58.7)	219 (76.3)	182 (53.9)	52 (49.5)	597 (56.4)
Non- Hispanic Black	572 (32.0)	49 (17.1)	119 (35.2)	43 (41.0)	361 (34.1)
Hispanic	109 (6.1)	11 (3.8)	27 (8.0)	6 (5.7)	65 (6.1)
Other	57 (3.2)	8 (2.8)	10 (3.0)	4 (3.8)	35 (3.3)
Annual Income					
<1st quartile	467 (25.0)	31 (10.5)	112 (31.8)	38 (33.3)	286 (25.8)
1st-2nd quartiles	467 (25.0)	105 (35.5)	70 (19.9)	35 (30.7)	257 (23.2)
2nd-3rd quartiles	482 (25.8)	85 (28.7)	77 (21.9)	25 (21.9)	295 (26.6)
> 3rd quartile	455 (24.3)	75 (25.3)	93 (26.4)	16 (14.0)	271 (24.4)
Education					
Below high school	205 (12.0)	49 (16.8)	34 (9.9)	16 (14.3)	106 (11.0)
High school	457 (26.7)	88 (30.1)	71 (20.6)	38 (33.9)	260 (27.0)
Above high school	617 (36.1)	88 (30.1)	134 (38.8)	38 (33.9)	357 (37.1)
Bachelor and above	432 (25.3)	67 (23.0)	106 (30.7)	20 (17.9)	239 (24.8)
Marital status					
Married/living with a partner	1,119 (60.4)	296 (100)	161 (46.4)	37 (33.0)	625 (56.9)
Unmarried	735 (39.6)	N/A	186 (53.6)	75 (67.0)	474 (43.1)
Living with a child < 18yrs					
No	1,528 (83.8)	292 (98.7)	278 (80.4)	92 (82.1)	866 (80.9)
Yes	296 (16.2)	4 (1.4)	68 (19.7)	20 (17.9)	204 (19.1)

yrs: years.

Chapter 2 Table 3. Multivariable regression of care-recipient relationship type on care recipients' HRQL adjusted for socio-demographics

	PHQ-4			**Pain**			**General Health**			**Functional Limitations**		
	OR	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**	**β**	**p**	**95% CI**
Care- recipient Relationship Type (by spouse/partner as reference)												
By adult-child	0.90	0.652	0.57, 1.43	0.78	0.336	0.48, 1.29	1.40	0.108	0.93, 2.09	0.79	**0.000**	0.39, 1.19
By “other”	1.19	0.538	0.68, 2.07	0.57	0.060	0.32, 1.02	1.62	0.052	1.00, 2.64	0.46	0.057	-0.01, 0.94
By multiple caregivers	1.07	0.737	0.72, 1.59	0.78	0.259	0.51, 1.20	1.19	0.340	0.84, 1.68	0.50	**0.003**	0.17, 0.82
Sex (male as reference)												
female	1.32	0.053	1.00, 1.74	1.63	**0.001**	1.22, 2.19	1.03	0.835	0.80, 1.31	-0.05	0.692	-0.28, 0.18
Age (65 to 69 yrs as reference)												
70 to 74 yrs	0.52	**0.022**	0.30, 0.91	1.19	0.608	0.61, 2.30	0.92	0.752	0.57, 1.51	0.02	0.908	-0.38, 0.43
75 to 79 yrs	0.39	**0.001**	0.23, 0.67	0.63	0.143	0.34, 1.17	0.86	0.541	0.54, 1.38	-0.04	0.845	-0.43, 0.35
80 to 84 yrs	0.38	**0.000**	0.23, 0.65	0.51	**0.027**	0.28, 0.92	0.70	0.129	0.44, 1.11	0.09	0.663	-0.30, 0.48
85 to 89 yrs	0.43	**0.002**	0.25, 0.74	0.63	0.143	0.34, 1.17	0.71	0.154	0.44, 1.14	0.16	0.424	-0.24, 0.56
90+ yrs	0.36	**0.000**	0.21, 0.63	0.41	**0.005**	0.22, 0.76	0.40	**0.000**	0.24, 0.65	0.71	**0.002**	0.27, 1.15
Race/ethnicity (White as reference)												
Non- Hispanic Black	1.08	0.585	0.82, 1.43	0.68	**0.012**	0.50, 0.92	1.51	**0.001**	1.18, 1.94	0.17	0.184	-0.08, 0.43
Other	0.79	0.531	0.39, 1.63	0.75	0.444	0.36, 1.57	1.26	0.458	0.69, 2.31	-0.31	0.307	-0.90, 0.28
Hispanic	1.26	0.415	0.72, 2.21	1.11	0.744	0.59, 2.08	1.44	0.133	0.89, 2.33	0.41	0.135	-0.13, 0.95
Annual Income (Q1 as reference)												
1st-2nd quartiles	0.88	0.444	0.63, 1.23	1.29	0.183	0.89, 1.88	1.17	0.299	0.87, 1.58	-0.15	0.320	-0.45, 0.15
2nd-3rd quartiles	0.87	0.442	0.60, 1.25	0.84	0.371	0.56, 1.24	0.91	0.567	0.66, 1.26	-0.21	0.213	-0.54, 0.12
> 3rd quartile	0.79	0.300	0.51, 1.23	0.72	0.169	0.45, 1.15	0.71	0.082	0.48, 1.04	-0.08	0.683	-0.46, 0.30
Education (below high school as reference)												
High school	1.05	0.763	0.77, 1.43	0.91	0.584	0.65, 1.28	0.81	0.142	0.62, 1.07	0.01	0.930	-0.26, 0.29
Above high school	0.63	**0.009**	0.44, 0.89	0.99	0.966	0.68, 1.46	0.67	**0.009**	0.49, 0.90	0.12	0.445	-0.19, 0.43
Bachelor and above	0.49	**0.001**	0.32, 0.75	0.72	0.138	0.46, 1.11	0.61	**0.008**	0.42, 0.88	0.24	0.205	-0.13, 0.62
Marital status (married as reference)												
Unmarried	0.51	0.319	0.14, 1.91	1.28	0.720	0.34, 4.84	1.52	0.491	0.46, 4.98	-0.66	0.385	-2.14, 0.83
Living arrangements (alone as reference)												
With spouse/partner only	0.40	0.188	0.10, 1.56	1.16	0.836	0.29, 4.58	2.21	0.204	0.65, 7.48	0.44	0.567	-1.06, 1.94
With spouse/partner & others	0.48	0.295	0.12, 1.89	1.02	0.983	0.25, 4.04	2.20	0.208	0.65, 7.49	0.32	0.678	-1.19, 1.83
With others only	0.89	0.493	0.64, 1.24	0.84	0.349	0.59, 1.21	0.96	0.797	0.72, 1.29	0.79	0.000	0.51, 1.06
Constant	4.72	0.040	1.07, 20.77	3.95	0.079	0.85, 18.34				0.78	0.317	-0.75, 2.32

Logistic regression for PHQ-4 and pain; ordered logistic regression for general health; robust regression for functional limitations. Care recipients cared for by an adult-child caregiver or multiple caregivers experienced higher functional limitations than those cared by a spousal caregiver (β=.79, CI [.39, 1.19]; β=.50, CI [.17, .82], respectively). Bold values denote statistical significance at the p < 0.05 level

Chapter 2 Table 4. Multivariable regression of care-recipient relationship type on care recipients' HRQL adjusted for socio-demographics and dementia severity

	PHQ-4			**Pain**			**General Health**			**Functional Limitations**		
	OR	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**	**.β**	**p**	**95% CI**
Care- recipient Relationship Type (by spouse/partner as reference)												
By adult-child	0.85	0.507	0.54, 1.36	0.80	0.392	0.49, 1.33	1.39	0.114	0.92, 2.09	0.67	**0.001**	0.29, 1.05
By "other"	1.15	0.615	0.66, 2.01	0.59	0.079	0.33, 1.06	1.62	0.055	0.99, 2.64	0.40	0.088	-0.06, 0.85
By multiple caregivers	1.05	0.808	0.70, 1.57	0.79	0.272	0.51, 1.21	1.17	0.372	0.83, 1.66	0.45	**0.005**	0.13, 0.76
Sex (male as reference)												
female	1.39	**0.022**	1.05, 1.85	1.54	**0.005**	1.14, 2.07	1.02	0.865	0.80, 1.31	0.11	0.311	-0.11, 0.33
Age (65 to 69 yrs as reference)												
70 to 74 yrs	0.49	**0.012**	0.28, 0.85	1.22	0.550	0.63, 2.37	0.92	0.750	0.57, 1.51	-0.11	0.585	-0.51, 0.29
75 to 79 yrs	0.39	**0.001**	0.23, 0.66	0.64	0.158	0.35, 1.19	0.87	0.546	0.54, 1.38	-0.09	0.642	-0.48, 0.29
80 to 84 yrs	0.35	**0.000**	0.20, 0.59	0.58	0.080	0.32, 1.07	0.70	0.137	0.44, 1.12	-0.19	0.343	-0.57, 0.20
85 to 89 yrs	0.37	**0.000**	0.22, 0.65	0.74	0.347	0.40, 1.38	0.71	0.164	0.44, 1.15	-0.22	0.272	-0.61, 0.17
90+ yrs	0.30	**0.000**	0.17, 0.53	0.49	**0.028**	0.26, 0.92	0.40	**0.000**	0.24, 0.66	0.23	0.304	-0.21, 0.67
Race/ethnicity (White as reference)												
Non- Hispanic Black	1.06	0.690	0.80, 1.41	0.72	**0.035**	0.53, 0.98	1.52	**0.001**	1.19, 1.96	0.08	0.507	-0.16, 0.32
Other	0.81	0.572	0.39, 1.67	0.74	0.427	0.35, 1.56	1.27	0.446	0.69, 2.32	-0.30	0.272	-0.84, 0.24
Hispanic	1.23	0.483	0.70, 2.16	1.19	0.584	0.63, 2.25	1.45	0.127	0.90, 2.35	0.32	0.197	-0.17, 0.82
Annual Income (Q1 as reference)												
1st-2nd quartiles	0.91	0.594	0.65, 1.28	1.26	0.239	0.86, 1.83	1.17	0.297	0.87, 1.58	-0.05	0.732	-0.34, 0.24
2nd-3rd quartiles	0.91	0.617	0.63, 1.32	0.80	0.270	0.54, 1.19	0.90	0.529	0.65, 1.25	-0.08	0.627	-0.39, 0.23
> 3rd quartile	0.82	0.388	0.53, 1.28	0.69	0.119	0.43, 1.10	0.71	0.083	0.48, 1.05	0.02	0.908	-0.34, 0.38
Education (below high school as reference)												
High school	1.07	0.663	0.78, 1.46	0.88	0.466	0.63, 1.24	0.81	0.143	0.62, 1.07	0.09	0.517	-0.18, 0.35
Above high school	0.66	**0.021**	0.46, 0.94	0.92	0.687	0.62, 1.36	0.66	**0.008**	0.49, 0.90	0.29	**0.052**	0.00, 0.58
Bachelor and above	0.50	**0.002**	0.33, 0.77	0.68	0.084	0.44, 1.05	0.61	**0.010**	0.42, 0.89	0.36	**0.044**	0.01, 0.71
Marital status (married as reference)												
Unmarried	0.52	0.339	0.14, 1.98	1.33	0.672	0.35, 5.05	1.54	0.476	0.47, 5.05	-0.60	0.332	-1.83, 0.62
Living arrangements (alone as reference)												
With spouse/partner only	0.38	0.165	0.10, 1.49	1.26	0.740	0.32, 5.01	2.24	0.196	0.66, 7.59	0.32	0.616	-0.93, 1.57
With spouse/partner & others	0.44	0.246	0.11, 1.75	1.13	0.862	0.28, 4.51	2.22	0.202	0.65, 7.56	0.13	0.843	-1.13, 1.39
With others only	0.82	0.249	0.59, 1.15	0.91	0.602	0.63, 1.31	0.95	0.757	0.71, 1.28	0.58	**0.000**	0.32, 0.84
Dementia severity (probable dementia as reference)												
Possible dementia	0.57	**0.004**	0.39, 0.84	0.93	0.697	0.63, 1.36	0.94	0.732	0.68, 1.32	-1.03	**0.000**	-1.37, -0.69
No dementia	0.62	**0.001**	0.46, 0.83	1.62	**0.002**	1.19, 2.20	0.99	0.940	0.76, 1.28	-1.35	**0.000**	-1.62, -1.08
Constant	7.29	0.010	1.60, 33.21	2.74	0.205	0.58, 12.99				1.88	0.006	0.55, 3.21

The association between relationship type and functional limitations persisted after including dementia severity as a control variable (β=.67, CI [.29, 1.05] for those cared for by an adult-child caregiver; β=.45, CI [.13, .76] for those cared for by multiple caregivers, respectively). Bold values denote statistical significance at the $p < 0.05$ level

Chapter 2 Table 5. Multivariable regression of care-recipient relationship type on caregivers' HRQL outcomes adjusted for socio-demographics

	Positive Emotional Benefit			Negative Emotional Burden			Social Strain		
	OR	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**
Care- recipient Relationship Type (spousal caregiver as reference)									
Adult-child caregiver	1.01	0.969	0.65, 1.57	0.68	0.114	0.43, 1.10	1.40	0.127	0.91, 2.17
"other" caregiver	0.56	0.062	0.30, 1.03	0.26	**0.000**	0.13, 0.52	0.49	**0.028**	0.26, 0.93
Multiple caregivers	0.74	0.136	0.50, 1.10	0.53	**0.003**	0.35, 0.81	0.68	0.058	0.46, 1.01
Sex (male as reference)									
female	1.33	**0.025**	1.04, 1.72	1.38	**0.018**	1.06, 1.79	1.37	**0.015**	1.06, 1.77
Age (< 45 yrs as reference)									
45 to 54 yrs	0.97	0.877	0.65, 1.45	1.01	0.980	0.67, 1.51	1.71	**0.014**	1.11, 2.62
55 to 64 yrs	0.83	0.371	0.54, 1.26	0.92	0.713	0.60, 1.41	1.76	**0.013**	1.13, 2.74
65 + yrs	0.61	**0.032**	0.39, 0.96	0.65	0.063	0.41, 1.02	1.19	0.472	0.74, 1.91
Race/ethnicity (White as reference)									
Non- Hispanic Black	0.53	**0.000**	0.40, 0.70	0.64	**0.002**	0.48, 0.85	0.70	**0.012**	0.53, 0.93
Other	1.39	0.309	0.74, 2.63	1.40	0.315	0.73, 2.67	1.22	0.548	0.64, 2.30
Hispanic	1.09	0.731	0.68, 1.73	1.32	0.249	0.82, 2.11	1.43	0.130	0.90, 2.27
Annual Income (Q1 as reference)									
1st-2nd quartiles	1.18	0.336	0.84, 1.64	1.05	0.753	0.76, 1.47	1.25	0.199	0.89, 1.76
2nd-3rd quartiles	0.87	0.430	0.61, 1.24	0.65	**0.022**	0.45, 0.94	1.07	0.730	0.74, 1.53
> 3rd quartile	0.75	0.166	0.50, 1.13	0.46	**0.000**	0.30, 0.71	0.87	0.493	0.58, 1.31
Education (below high school as reference)									
High school	0.88	0.547	0.59, 1.32	0.74	0.136	0.50, 1.10	1.04	0.860	0.68, 1.60
Above high school	0.99	0.940	0.67, 1.46	0.73	0.117	0.50, 1.08	1.49	0.060	0.98, 2.24
Bachelor and above	1.11	0.637	0.73, 1.68	0.62	**0.029**	0.40, 0.95	1.61	**0.034**	1.04, 2.49
Marital status (married as reference)									
Unmarried	1.22	0.210	0.89, 1.66	1.39	**0.046**	1.01, 1.92	1.18	0.289	0.87, 1.61
Living with a child < 18yrs (no child as reference)									
Yes	0.70	0.051	0.49, 1.00	1.30	0.144	0.91, 1.86	1.14	0.458	0.80, 1.63
Constant	0.62	0.145	0.32, 1.18	0.86	0.662	0.45, 1.67	0.17	0.000	0.09, 0.35

With the significant covariates from the bivariate regressions as controls, the association between each HRQL subscale and relationship type were examined using logistic regression. "Other" caregivers and "multiple" caregivers were found to be less likely to experience negative emotional burden than spousal caregivers (OR=.26, CI [.13, .52]; OR=.53, CI [.35, .81], respectively). Compared to spousal caregivers, "other" caregivers were 51% less likely to experience social strain (OR=.49, CI [.26, .93]), suggesting that relationship type had an impact on caregivers' HRQL outcomes.

Bold values denote statistical significance at the $p < 0.05$ level

Chapter 2 Table 6. Comparison between models with and without adjustment for care recipients' dementia severity (Multivariable regression of three types on caregivers' HRQL outcomes)

	Positive Emotional Benefit			**Negative Emotional Burden**			**Social Strain**			**Positive Emotional Benefit**			**Negative Emotional Burden**			**Social Strain**		
	OR	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**	**OR**	**p**	**95% CI**
Care- recipient Relationship (spousal caregiver as reference)																		
Adult-child caregiver	0.95	0.866	0.54, 1.67	0.54	**0.047**	0.29, 0.99	1.76	**0.042**	1.02, 3.03	0.93	0.789	0.53, 1.63	0.51	**0.034**	0.27, 0.95	1.53	0.134	0.88, 2.67
“other” caregiver	0.49	0.051	0.24, 1.00	0.21	**0.000**	0.10, 0.46	0.48	**0.046**	0.23, 0.99	0.48	**0.047**	0.23,0.99	0.20	**0.000**	0.09, 0.45	0.43	**0.023**	0.20, 0.89
Sex (male as reference)																		
female	1.97	**0.001**	1.33, 2.93	1.53	**0.038**	1.02, 2.28	1.54	**0.024**	1.06, 2.25	1.93	**0.001**	1.30, 2.88	1.45	0.070	0.97, 2.17	1.41	0.080	0.96, 2.07
Age (< 45 yrs as reference)																		
45 to 54 yrs	0.86	0.685	0.40, 1.82	1.24	0.586	0.58, 2.65	1.30	0.502	0.61, 2.77	0.85	0.673	0.40, 1.81	1.21	0.623	0.56, 2.61	1.23	0.594	0.57, 2.65
55 to 64 yrs	1.04	0.917	0.48, 2.25	1.20	0.651	0.54, 2.65	1.69	0.190	0.77, 3.70	1.00	0.996	0.46, 2.17	1.11	0.799	0.50, 2.47	1.43	0.375	0.65, 3.18
65 + yrs	0.75	0.466	0.34, 1.64	0.81	0.611	0.36, 1.83	1.68	0.202	0.76, 3.72	0.72	0.419	0.33, 1.59	0.75	0.488	0.33, 1.71	1.46	0.359	0.65, 3.27
Race/ethnicity (White as reference)																		
Non- Hispanic Black	0.59	**0.014**	0.38, 0.90	0.62	**0.034**	0.40, 0.96	0.73	0.125	0.48, 1.09	0.59	**0.015**	0.38, 0.90	0.63	**0.040**	0.40, 0.98	0.66	0.057	0.44, 1.01
Other	3.33	**0.015**	1.26, 8.80	1.61	0.332	0.62, 4.20	1.29	0.593	0.51, 3.29	3.35	**0.015**	1.26, 8.91	1.68	0.295	0.64, 4.41	1.23	0.669	0.48, 3.17
Hispanic	1.59	0.210	0.77, 3.30	1.47	0.297	0.71, 3.06	2.08	**0.037**	1.05, 4.13	1.55	0.247	0.74, 3.24	1.42	0.353	0.68, 2.99	1.79	0.103	0.89, 3.59
Annual Income (Q1 as reference)																		
1st-2nd quartiles	1.46	0.142	0.88, 2.42	1.23	0.427	0.73, 2.08	1.48	0.122	0.90, 2.44	1.45	0.152	0.87, 2.40	1.24	0.428	0.73, 2.08	1.49	0.122	0.90, 2.47
2nd-3rd quartiles	0.59	0.052	0.34, 1.00	0.79	0.389	0.46, 1.35	0.91	0.725	0.55, 1.51	0.59	0.057	0.35, 1.01	0.78	0.376	0.46, 1.34	0.96	0.885	0.58, 1.61
> 3rd quartile	0.84	0.550	0.47, 1.49	0.69	0.241	0.37, 1.28	0.61	0.099	0.34, 1.10	0.85	0.565	0.48, 1.50	0.70	0.260	0.38, 1.30	0.65	0.144	0.36, 1.16
Education (below high school as reference)																		
High school	0.71	0.252	0.40, 1.27	0.58	0.063	0.33, 1.03	0.90	0.733	0.50, 1.63	0.71	0.254	0.40, 1.28	0.55	**0.042**	0.31, 0.98	0.83	0.551	0.46, 1.52
Above high school	0.93	0.798	0.54, 1.61	0.61	0.081	0.35, 1.06	1.59	0.100	0.91, 2.78	0.93	0.795	0.53, 1.62	0.61	0.075	0.35, 1.05	1.57	0.118	0.89, 2.75
Bachelor and above	0.97	0.925	0.54, 1.74	0.48	**0.018**	0.27, 0.89	1.34	0.334	0.74, 2.42	0.96	0.880	0.53, 1.72	0.46	**0.012**	0.25, 0.84	1.19	0.570	0.65, 2.18
Marital status (married as reference)																		
Unmarried	1.21	0.467	0.72, 2.04	1.93	**0.020**	1.11, 3.37	1.35	0.247	0.81, 2.22	1.22	0.459	0.72, 2.04	1.95	**0.019**	1.11, 3.40	1.38	0.216	0.83, 2.29
Living with a child < 18yrs (no child as reference)																		
Yes	1.13	0.689	0.61, 2.11	2.05	**0.025**	1.09, 3.83	1.27	0.446	0.69, 2.32	1.11	0.733	0.60, 2.07	1.99	**0.032**	1.06, 3.73	1.18	0.601	0.64, 2.18

Dementia severity (probable dementia as reference)																		
Possible dementia										0.76	0.328	0.43, 1.32	0.57	0.067	0.31, 1.04	0.53	**0.021**	0.31, 0.91
No dementia										0.84	0.395	0.56, 1.25	0.72	0.114	0.47, 1.08	0.44	**0.000**	0.29, 0.64
Constant	0.43	0.096	0.16, 1.16	0.63	0.378	0.23	0.13	0.000	0.05, 0.37	0.53	0.246	0.18, 1.56	0.96	0.941	0.32, 2.92	0.32	0.042	0.11, 0.96
	Without dementia severity adjusted									**With dementia severity adjusted**								

Logistic regression was conducted with each caregiver HRQL subscale as dependent variables, 3 types of relationship as independent variables, and caregivers' socio-demographic as covariates. Care recipients' dementia severity was added to the original models to compare the results. In the fully adjusted models care recipients' dementia severity was a risk factor for experiencing caregiver social strain (OR=.53, CI [.31, .91]; OR=.44, CI [.29, .64], respectively), indicating that caregivers to recipients with possible dementia or no dementia were less likely to experience social strain compared to those providing care to recipients with probable dementia.

Bold values denote statistical significance at the p<0.05 level

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Conflict of interest The authors have declared that no conflict of interests existed at the point of submission. The abstract was presented at the Gerontological Society of America (GSA) 2021 Annual Scientific Meeting and published at the society's journal.

Ethical approval NHATS was approved by the Johns Hopkins Bloomberg School of Public Health IRB. The access and re-use of the data were approved by NHATS under National Health and Aging Trends Study (NHATS) Sensitive Data Supplemental Agreements with Research Staff.

Consent to participate Participants provided written informed consent [48]

Consent to publish All authors have given their consent for publications.

Appendix A

Chapter 2 Table S1. NHATS Study Aims and Current NHATS Research

NHATS Study Aims	
Primary scientific aims 1	To promote scientific study of late-life disability trends and dynamics
Primary scientific aims 2	To advance our understanding of the social and economic impact of late-life functional changes for older people, their families, and society
Current NHATS Research	
Research area 1	Family and unpaid caregiving
Research area 2	Unmet need for assistance
Research area 3	Alzheimer’s disease and dementia
Research area 4	End of life care
Research area 5	Social engagement and participation
Research area 6	Medical care and health care spending

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Appendix B

Chapter 2 Table S2. HRQL outcomes and pertaining questions at NHATS or NSOC

Care recipients HRQL	Questions at NHATS
Mental Health (scored 0~12, higher score represents worse mental health)	“Over the last month, how often have you (a) had little interest or pleasure in doing things; (b) felt down, depressed, or hopeless; (c) felt nervous, anxious, or on edge; (d) been unable to stop or control worrying”. Each item is scored on a 4- point scale from “not at all” (0), “several days” (1), “more than half the days” (2) to “nearly every day” (3).
General Health (scored 0~4, higher score represents worse general health)	“Would you say that in general your health is excellent, very good, good, fair, or poor?” response is scored on a 5 scale.
Pain (scored 0~1, 1 represents pain)	“In the last month, have you been bothered by pain?” respond “yes” or “no”
Functional Limitations (scored 0~6, higher score represents more severe limitations)	“Whether you received help within the last month with any of the following activities of daily living (ADLs)”: (a) eating, (b) getting cleaned up, (c) using the toilet, (d) dressing, (e) getting around inside, (f) getting out of bed?
Caregivers HRQL	Questions at NSOC
Negative emotional burden (scored 0-34, a higher score indicates more negative emotional burden)	Over the last month, how often: a. had little interest or pleasure in doing things? b. felt down, depressed, or hopeless?
	c. felt nervous, anxious, or on edge? d. been unable to stop or control worrying?
	Over the last month, how often you feel • bored? • Lonely? • upset?
	• I gave up trying to improve my life a long time ago. • I often feel lonely because I have few close friends.
	• How much does the recipient argue with you? • How often does the recipient get on nervous?
	• Is helping emotionally difficult for you?

Social strain (scored 0-6, a higher score indicates more social burden)	In the last month, did helping the recipient ever keep you from • visiting in person with friends or family not living with you? • participating in club meetings or group activities? • going out for enjoyment? • working for pay? • doing volunteer work? • providing care for a child or other adult?
Positive emotional benefit (scored 0-38, a higher score indicates less positive emotional benefits)	• My life has meaning and purpose. • In general, I feel confident and good about myself • I like my living situation very much. • I have an easy time adjusting to changes. • I get over (recover from) illness and hardship quickly.
	Thinking about the last month, how often did you … • Feel cheerful? • Feel calm and peaceful? • Feel full of life?
	• How much do you enjoy being with the recipient? • How much does the recipient appreciate what you do for them?
	Helping the recipient has • made you more confident about your abilities. • taught you how to deal difficult situations. • brought you closer to them. • gives you satisfaction that they are well cared for.

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Kasper, Judith D. and Freedman, Vicki A. 2021. National Health and Aging Trends Study User Guide: Rounds 1-10. Final Release. Baltimore: Johns Hopkins University School of Public Health. Available at www.NHATS.org.

Freedman, Vicki A., Skehan, Maureen E., Hu, Mengyao, Wolff, Jennifer, Kasper, Judith D. 2019. National Study of Caregiving I-III User Guide. *Baltimore: Johns Hopkins Bloomberg School of Public Health*. Available at www.nhats.org

CHAPTER 3: IMPACT OF CARE-RECIPIENT RELATIONSHIP TYPE ON QUALITY OF LIFE IN COMMUNITY-DWELLING OLDER ADULTS WITH DEMENTIA OVER TIME

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Title:

Impact of care-recipient relationship type on quality of life in community-dwelling older adults with dementia over time

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Abstract

Introduction: Maintaining quality of life (QoL) has been identified as the primary goal of care services for people living with dementia (PLWD). **Methods:** A secondary analysis was conducted on five rounds of the National Health and Aging Trends Study (NHATS) over 4 years. A generalized estimating equation (GEE) was used to examine the prediction of relationship type on older adults' QoL through four domains: mental health, general health, functional limitations, and pain. **Results**: Older adults cared for by an adult-child or multiple caregivers predicted increased risk for functional limitations after adjustment for their socio-demographic and dementia status (IRR = 1.53, CI [1.26, 1.86]; IRR = 1.36, CI [1.14, 1.61], respectively). The interaction between the relationship type and education was significant. Older adults with a high school education or below, who were cared for by an adult child, had a significantly higher risk of increasing functional limitations over 4 years compared to those cared for by a spouse/partner (contrast = .50, P = .01, 95% CI [.07, .93]; contrast=.52, P = .03, 95% CI [.03, 1.02]; respectively). Similarly, older adults with a high school education, who were cared for by multiple caregivers, also experienced a significantly higher risk of increasing functional limitations than those cared for by a spouse/partner (contrast = .44, P = .03, 95% CI [.02, .85]). **Conclusion:** Our findings provide evidence of the significant contribution of relationship type on PLWD's QoL changes over time. They also help to prioritize resource allocation while addressing PLWD's demands by socio-demographics such as education level.

Keywords: quality of life, older adults, dementia, care-recipient relationship type, functional limitations

Background

"Dementia" is a general term for the impaired ability to remember, think, or perform daily activities.[1] With the prolongation of the human lifespan, dementia has become a significant public health issue.[2] In 2050, the number of people living with dementia (PLWD) globally is projected to increase by 204% from 50 million in 2018 to 152 million.[3] An estimated 6.5 million Americans aged 65 years and older are living with Alzheimer's disease, the most common type of dementia, and this number is expected to reach 12.7 million in 2050.[4] Without a cure or effective treatment for these diseases, maintaining quality of life (QoL) has been identified as the primary goal of care services for PLWD.[5]

Quality of Life is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[6] Quality of Life is a growing area of interest in dementia research. While several standardized QoL assessment tools have been specifically developed for PLWD[7], such as the Quality of Life in Alzheimer Disease (QOL-AD), Alzheimer Disease-Related Quality of Life (ADRQL), Quality of Life in Late-Stage Dementia (QUALID), it is important to acknowledge that the complex and progressive nature of dementia presents challenges to comprehensive QoL measurement. Additionally, the subjective nature of QoL measurement becomes significantly more difficult when attempted in people with cognitive deficits such as in PLWD.[8] Furthermore, while various factors impact the QoL of PLWD (e.g., socio-demographic characteristics, physical, psychological, etc.),[7,9] consensus on what factors influence QoL most in PLWD is needed in order to develop effective interventions. Moreover, factors impacting the QoL of PLWD vary across different living settings (care institutions vs communities) and differ based on stakeholder perspectives (PLWD vs PLWD's caregivers).[9] For community-dwelling older adults, “informal caregivers are ‘the most important resource available for people with dementia’.[10,11] About 61% of Canadian PLWD live in the community and receive care mainly from their informal caregivers,[12] who may be family members, friends, or other unpaid caregivers (e.g., nonrelatives not affiliated with a caregiving institution).[13] Given the existence of a preceding relationship between the care recipients and their caregivers, it is likely that the dyad will influence each other, including their responses to QoL and well-being, the strain they experience in the relationship, and the level of congruence and conflict about the care being provided.[11,14]

The care-recipient relationship type (i.e., the type of relationship/degree of kinship between caregivers and the care recipients, referred to from here on as “type of relationship”) is known to associate with QoL in informal caregivers of PLWD.[14-19] Compared to caregivers, evidence about the impact of relationship factors on the care recipients or PLWD is limited.[20] Existing information indicates that type of relationship influences the level of functional abilities in PLWD.[14] Care recipients cared for by adult-child caregivers had a higher risk of experiencing functional limitations than those cared by spousal caregivers.[14] However, the cross-sectional analysis does not allow for determining the temporal basis of relationships and limits the ability to make causal conclusions.[21] In addition, previous studies have found that PLWD’s QoL was influenced not only by their severity of dementia[22,23] but also by their socio-demographics (e.g., age, race, living arrangements).[24,25] Therefore, when evaluating the effects of type of relationship, it is also important to consider the potential impact of PLWD’s dementia condition and socio-characteristics.

Given the absence of existing studies regarding the impact of the relationship type on PLWD’s QoL and limitations in establishing causal relationships due to the nature of cross-sectional studies, longitudinal data-derived evidence is important to provide insights to healthcare professionals and caregivers. Therefore, we used five rounds of National Health and Aging Trends Study (NHATS) data (Round five to nine) to address these gaps. Specifically, we aim to address two questions:

(1) Does type of relationship or caregiving being shared predict a change in PLWD's QoL over four years after adjusting for socio-demographics and dementia status?

(2) Does the effect of type of relationship or caregiving being shared differ by socio-demographics and dementia status?

Methods

This was a longitudinal secondary analysis study.

Data Sources and Participants Selected

The present study used de-identified data from the NHATS Round five in 2015 through Round nine in 2019. As a population-based in-person survey that measures late-life disability from a nationally representative sample of Medicare beneficiaries age 65 and older in the United States,[26] the NHATS offers large sample sizes and has a comprehensive, validated disability protocol that is administered annually. NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and is conducted by Johns Hopkins University. The content of the NHATS was guided by a conceptual framework that blends the International Classification of Functioning, Disability and Health (ICF) with the Nagi model of disablement.[27] The NHATS participants were initially sampled in Round one in 2011 and replenished in Round five in 2015. Thus, using the NHATS Round five allows us to have a sample of the 2011/2015 cohort. When the older adult could not respond, the NHATS interviewed proxy respondents and collected information on reasons for using a proxy, the relationship of the proxy to the older adult, and proxy familiarity with the older adults' daily routine.[26]

We included older adults who live in the community and receive help with certain Activities of Daily Living (ADL)- getting around inside home/building, getting out of bed, eating, bathing/showering/washing up, getting to or using the toilet, dressing-from their informal caregivers at the time of enrollment. Informal caregivers in this study refers to "family and unpaid caregivers", who assisted a potential eligible participant with any ADLs and were either (1) related to the older adult whether paid or not, or (2) unrelated to the older adult and not paid to help.[28] Of 8334 older adults in the original NHATS Round five dataset, 1230 participants were identified as the eligible analytical sample in the current study. If a participant did not respond in one of the follow-up rounds, no attempt was made to contact those again in the next round.

Measures

Quality of Life Outcomes. We chose the ICF framework in selecting appropriate QoL measures as well as identifying determinants of QoL in this study. Previous evidence showed that all factors included in the ICF framework potentially affect an individual's QoL and contribute to changes in their QoL over time.[29] Guided by the ICF framework, older adults' QoL in this study was assessed in four domains: mental health, general health, functional limitations, and pain. A recent systematic review showed that mental health, functional limitation, and pain are essential factors associated with PLWD's QoL.[7] In our study, mental health was presented using the Patient Health Questionnaire for Depression and Anxiety (PHQ-4), a scale with a brief screening tool for depression and anxiety symptoms that is composed of two subscales-a depression subscale from the 2-item Patient Health Questionnaire (PHQ-2) and an anxiety subscale from the 2-item Generalized Anxiety Disorder scale (GAD-2).[30] The depression subscale of PHQ-4 measures how often the participant "had little interest or pleasure in doing things" and "felt down, depressed, or hopeless" over the past month. The anxiety subscale of PHQ-4 measures how often the participant "felt nervous, anxious, or on edge" and "was unable to stop or control worrying" over the past month. Responses to each question were recorded on a 4-point scale (scored 0-3), and the total score of the four items ranged from 0 to 12, with a higher score representing more depressive/anxiety symptoms.[26]

According to previously validated criteria, PHQ-4 can be categorized into low (0-2), mild (3-5), moderate (6-8), and severe symptoms (9-12).[30] However, considering the small number of participants in mild and moderate categories, we created a dichotomous indicator to categorize participants into two groups using a cutoff score of 3: low (0-2) and symptomized (3-12). General health was self-rated on a 5-point scale from excellent (0) to poor (4). Pain was evaluated by asking whether or not the participants were bothered by pain in the past month and scored as yes (1) or no (0). Functional limitations were presented as the total number of activities of daily living (ADLs) that the participant received help with within the past month and scored 0 to 6 with a higher score representing more severe limitations[26] (see Supplementary Appendix I).

Care-Recipient Relationship Type. The term "Care-recipient relationship" in this study represents the type of relationship between PLWD and their informal caregivers. An informal caregiver "includes any person, such as a family member, friend or neighbour, who is giving regular, ongoing assistance to another person without payment for the care given."[31] The type of relationship categorized four groups: (1) care from a spouse/partner; (2) care from an adult child; (3) care from an informal caregiver other than spouse/partner and adult child, such as child-in-law, sibling, friend, etc. (referred to from here on as "other caregivers"); (4) If NHATs care recipients indicated having multiple helpers/caregivers, they were assigned to the group of "multiple caregivers", as opposed to those with a single caregiver.

Dementia Status. To classify older adults' dementia status, a three-category dementia classification (probable dementia, possible dementia, and no dementia) was used, generated from the NHATS Round five (2015). For a non-proxy participant, cognitive function was assessed using a battery of cognitive tests that evaluated memory (immediate and delayed 10-word recall), orientation (date, month, year, and day of the week; naming the President and Vice President), and executive function (clock drawing test).[32] For proxy informants, cognitive function was assessed using the AD8 Dementia Screening Interview which assesses memory, temporal orientation, judgment, and function.[32–34] As per a previously developed and validated approach,[32] the participant was classified into the probable dementia group if there was a self or proxy report of physician diagnosis of dementia or Alzheimer's disease; or AD8 score ≥ 2; or at least two domains of cognitive tests met their respective cut points. If one domain of cognitive tests met cut point with no physician diagnosis of dementia or Alzheimer's disease, the participant was classified into the possible dementia group. Findings from a sensitivity and specificity analysis, conducted against a clinically evaluated sample in 2010 (Aging, Demographics, and Memory Study, ADAMS, Wave E),[35] demonstrated that the NHATS three-category dementia classification exhibited high sensitivity (85.7%) against ADAMS dementia diagnosis. Furthermore, it revealed reasonable good sensitivity (71.8%) against diagnoses of dementia or cognitive impairment not dementia (CIND), along with high specificity (83.7%) for persons classified as normal in ADAMS.[32]

Socio-Demographics

Older adults' socio-demographic characteristics assessed at Round five were used in analyses: age range (65-69 years, 70-74 years, 75-79 years, 80-84 years, 85-89years, ≥90 years), sex (male, female), race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, other), annual income in quartiles (<1st quartile, 1st-2nd quartiles, 2nd- 3rd quartiles, >3rd quartile), education (below high school, high school, above high school and below bachelor's degree, bachelor's degree or above), marital status (married or living with a partner, unmarried including separated/divorced/widowed/never married), and living arrangements (alone, with spouse/partner only, with spouse/partner and others, with others only). The associations between these socio-demographic factors and QoL outcomes have been reported in various studies[14,24,25]

Statistical Analyses

Categorical variables of type of relationship, dementia status, socio-demographic characteristics, and QoL subscales (pain, general health, PHQ4, functional limitations) were described using counts and percentages. Descriptive statistics were used to assess the changes in QoL subscales across five rounds (2015 to 2019). Baseline QoL subscales were examined by type of relationship using Chi-square tests for categorical variables (PHQ4, pain) and Kruskal–Wallis for ordinal (general health) and count variable (functional limitations). We used Bonferroni correction for multiple comparisons. The baseline variables of non-respondents through four years (Round six to Round nine) were compared to the included participants in Round five using Chi-square tests for categorical variables and Kruskal–Wallis for ordinal and count variables.

The generalized estimating equation (GEE) approach was used to compare the odds of participants in the four groups by the relationship types. The comparisons were over the four years across Round five-Round nine. The GEE approach takes into account the correlation of repeated measures within the same individual over the years and provides flexibility to retain the full sample of respondents (e.g., respondents with two or three consecutive time points of data can be included in the GEE analysis, while controlling for time point of administration).[36] With a logit link function for binomial variables (PHQ4, pain), a log link function for the ordered variable (general health) and count variable (functional limitations), we built models to estimate odds ratio (OR)/incidence rate ratio (IRR) and 95% confidence intervals (CI), with the group receiving care from a spouse/partner serving as the reference category. Two models were built with sequential adjustment for covariates: Model one adjusted for socio-demographic characteristics; Model two additionally controlled for dementia status. To disentangle the effects of potential interactions, we further tested for interactions between type of relationship with age, gender, marital status, dementia status, and education. Using Model two as a base model, each interaction term was tested in a separate regression model (i.e., Models three-seven). If a significant interaction term was found, a Sidak post-hoc comparison correction was then conducted to explore where the difference existed. All data were analyzed using Stata 16.0, and a two-tailed significance test with an alpha of 0.05 was set.

Results

Sample Characteristics

There were 1230 older adults in the analysis at Round five (see Supplementary Appendix II). The majority were female (67.1%), in an age range of 80-84 years (22.1%), non-Hispanic White (60.2%), unmarried (56.8%), living with others only (37.3%), and identified as living with no dementia (55.2%). Approximately 27.1% of the participants possessed an annual income within the 2nd-3rd quartiles (≥$ 22,000 ≤ $ 40,000), and 29.5% of the participants held a high school education. There were no significant differences in socio-demographic distribution and dementia status across the five rounds. The final retention rate for participants was 92.4%, 77.0%, 64.9%, and 54.7% for Round 6, 7, 8, and 9, respectively. Reasons of missing data include non-responses, moving to institutionalized settings, and deceased (see Figure 1). Compared to the overall baseline sample, non-respondents were generally younger and had a larger percentage of people living without dementia (see Supplementary Appendix III). Other variables (e.g. race, gender) were not found to be significant between the groups. The rate of proxy respondents included in this study was 17.4% in the baseline (NHATS Round five).

[Figure 1. Participants over 4 years period (from round five to round nine)]

Tables 1 and 2 show the baseline distribution of participants by care-recipients relationship types, as well as the socio-demographics, dementia status, and QoL outcomes. In Round five, 24.1% of older adults received care from a spouse/partner, 28.6% received care from an adult child, 9.3% from "other", and 38.0% from multiple caregivers. No significant differences were observed in the baseline QoL outcomes, including pain, general health, PHQ4 scores, and functional limitations, across the four groups. In general, older adults had more complaints of pain and tended to receive help with more ADLs over time, especially those receiving help with five or six ADLs in Round five (see Figure 2, Supplementary Appendix IV).

[Table 1. Baseline Socio-Demographics and Dementia Status by the Type of Relationship]

[Table 2. Baseline QoL Outcomes by the Type of Relationship]

[Figure 2. Changes in each QoL subscale cross five rounds]

Impact of Care-Recipient Relationship Type on Quality of Life Outcomes over Time

GEE analyses indicated that older adults cared for by an adult-child or multiple caregivers predicted increased risk for functional limitations (IRR = 1.58, CI [1.35, 1.85]; IRR = 1.40, CI [1.21, 1.63], respectively), and the prediction maintains after adjustment for socio-demographic characteristics (IRR = 1.59, CI [1.30, 1.95]; IRR = 1.36, CI [1.14, 1.63], respectively). After additional adjustments for baseline dementia status, the significance was maintained for these two groups (IRR = 1.53, CI [1.26, 1.86]; IRR = 1.36, CI [1.14, 1.61], respectively). There was no statistically significant relationship between the type of care-recipient relationship and other QoL outcomes, including pain, general health, and PHQ4 scores (see Table 3).

[Table 3. Results from GEE Models of Care-Recipient Relationship Type Prediction on QoL Outcomes over Four Years (2015-2019)]

No significant interaction effects were found between the type of relationship with any of the following: age, gender, marital status, or dementia status. However, the interaction term between the type of relationship and educational attainment was significant, indicating that the effect of relationship type on functional limitations is not uniform across education level. A pairwise comparison of changes using the Sidak post hoc test revealed that for older adults with a high school education or below, those cared for by an adult child experienced a significantly higher risk of increasing functional limitations over four years, compared to those cared for by a spouse/partner (contrast = .50, P = .01, 95% CI [.07, .93]; contrast = .52, P = .03, 95% CI [.03, 1.02]; respectively). Similarly, older adults with a high school education cared for by multiple caregivers experienced significantly more risk of increasing functional limitations than those cared for by a spouse/partner (contrast=.44, P = .03, 95% CI [.02, .85]). See Table 4.

[Table 4. Sidak Post-Hoc Results of Functional Limitations Differences among the Type of Relationship for 4-Levels Education]

Discussion

The pool of informal caregivers for PLWD has been expanding due to an increase in dementia prevalence and a shift in the traditional family structure from a gradual decline in marriage rates.[37] Despite this observation, impact of care-recipient relationship types on the QoL of care of recipients is nevertheless relatively unexplored.[14] To our knowledge, this is the first longitudinal study examining the effects of the type of relationship on changes in QoL over time in PLWD.

After controlling for socio-demographics and dementia status, we found that the type of relationship was associated with changes in the care-recipient's functional limitations, one of the QoL outcomes measured in this study. There were no significant differences in QoL outcomes at Round five by the type of relationship, including functional limitations. However, older adults cared for by an adult-child or multiple caregivers predicted an increased risk for functional limitations over a four-year period, compared to those cared for by a spouse/partner. Our findings suggest that the care-recipient relationship type predicts QoL changes in PLWD, which is consistent with our previous cross-sectional study[14] and further validates the causal relationship between the type of relationship and QoL of PLWD.

Several factors could contribute to the increased risk of functional limitations among PLWD cared for by an adult-child or multiple caregivers in comparison to those cared for by a spouse/partner: (1) Lack of consistency and attention in the complex care: Due to complexity of dementia care, PLWD often benefits from routine and consistent interactions.[38,39] Spouse/partner caregivers may provide a more stable and continuous caregiving environment, promoting a sense of familiarity and predictability that can support functional well-being. In the contrast, adult-child or multiple caregivers may face challenges in coordinating and sharing responsibilities. Adult-child caregivers often juggle caregiving responsibilities alongside other commitments such as work and family obligations. This was exemplified in a study where spouses reported significantly less burden than adult children in relation to the direct impact of caregiving on their lives.[40] When caregiving role was shared by different caregivers, each caregiver may adopt varying approaches and techniques in managing the needs of PLWD's ADLs/IADLs. These may lead to a potential gaps in providing consistent support and inadequate attention to PLWD's specific needs, which can contribute to a decline in functional limitation over time. (2) Possible learned helplessness: A previous study reported that PLWD might experience learned helplessness, a psychological state when someone has learned over time that their actions are ineffective and stop trying to do something for themselves because someone else intervenes and acts in their place.[41] Spousal caregivers may try to sustain or reconstruct couple hood by letting their partner continue with social and household chores and try to maintain former rituals and routines.[42,43] By comparison, interventions such as care tasks taken by an adult-child or shared among multiple caregivers may erode care recipients' self-confidence and discourage them from engaging in daily activities, which in turn can foster a decline in their physical functioning.[42,43] Though no significant differences were observed across the four types in terms of functional limitations in round five, adult-child and multiple caregivers exhibit a higher percentage of assistance in helping older adults with additional ADLs when compared to spousal caregivers (see Table 2). However, it's important to mention that an increase in depressive symptomatology, a key indicator of learned helplessness, was not detected in this study. Therefore, this aspect warrants further exploration through additional research endeavors.

There are no similar longitudinal studies with which we can compare our results, but previous studies reported that non-spousal caregivers had a greater desire or incidence of institutionalizing the care recipients.[44-46] People with adult-child caregivers were more likely to be admitted into nursing homes compared to those cared for by spousal caregivers,[45,46] and the reported reasons for nursing home placement were more related to care recipients' condition.[47] Although multiple factors are associated with nursing home admissions, activity limitations have been found to be strongly associated with future nursing home admission.[48] Moreover, indicators of functional limitations were among the strongest predictors in a meta-analysis review of predicting nursing home admission among older adults in the U. S.[49] Reinforcing this trend, a systematic review focused on predicting institutionalization revealed that 96% of the included studies underscored a significantly positive impact of functional impairment on the likelihood of being institutionalized.[50] Hajek et al.[51] expanded these findings by exploring the longitudinal predictors of institutionalization, highlighting the pivotal role of functional impairments in ADLs/IADLs in predicting the eventual need for institutional care.

While previous studies reported the association between depressive symptoms and functional limitations,[52,53] along with significant differences in functional limitation changes among PLWD cared for by different caregiver types in this study, notable distinctions in PHQ4 changes across caregiver types, as well as in other QoL outcomes-pain and general health, were not found. This suggests that while the caregiver approach to assisting with ADLs may vary across caregiver types, the impact of their care on PLWD’s emotions may exhibit similarities. In addition, the sensitivity of the measurement of each QoL outcome may play a role in these observations. Functional limitations were determined by simply counting the number of ADLs being assisted, whereas the other three outcomes were assessed through responses to a series of scaled questions. It is possible that within the context of dementia, there occurs a process of adapting to disability and gradually adjusting expectations (referred to as response shift).[54] Furthermore, sample variation could also be a contributing factor. Each PLWD is unique, and it is possible that some individuals may be more susceptible to functional limitations based on caregiver types, while other outcomes such as depressive symptoms may be influenced by factors not directly associated with caregiver types. The limited availability of longitudinal studies investigating PLWD’s QoL changes in relation to caregiver relationship types underscores the need for further exploration. More research is needed to clarify the role of these QoL outcomes in the context of PLWD and their caregivers.

This study reveals significant interactions between the type of relationship and education attainment in predicting PLWD's functional limitations. Prior research has not explored on the interaction of education and caregiver type, yet education is consistently linked to health-related factors and behaviors, especially in later life.[55,56] It is commonly believed that older adults with lower education attainment often correlates with higher likelihood of functional limitations.[57,58] Our findings suggest that education's impact on functional declines is associated with the care-recipient relationship type, particularly close kinship (e.g. spouse or children) rather than extended family. Shared caregiving roles might also influence this dynamic. The results might be in part attributable to the participants' characteristics differences among the groups. Functional limitations in this study were gauged by ADLs assistance, which was reported to differ based on age, marital status, and gender.[58,59] We observed variations in participants' demographics among groups, with implications for ADLs assistance. PLWD's education, as identified in our study, has not previously been recognized in the literature as a predictor of their QoL. It suggests the need for future research on caregiver type effects in the education- QoL association. Acknowledging the role of education and caregiver type on future functional decline will also allow for early identification of older adults with high care needs.

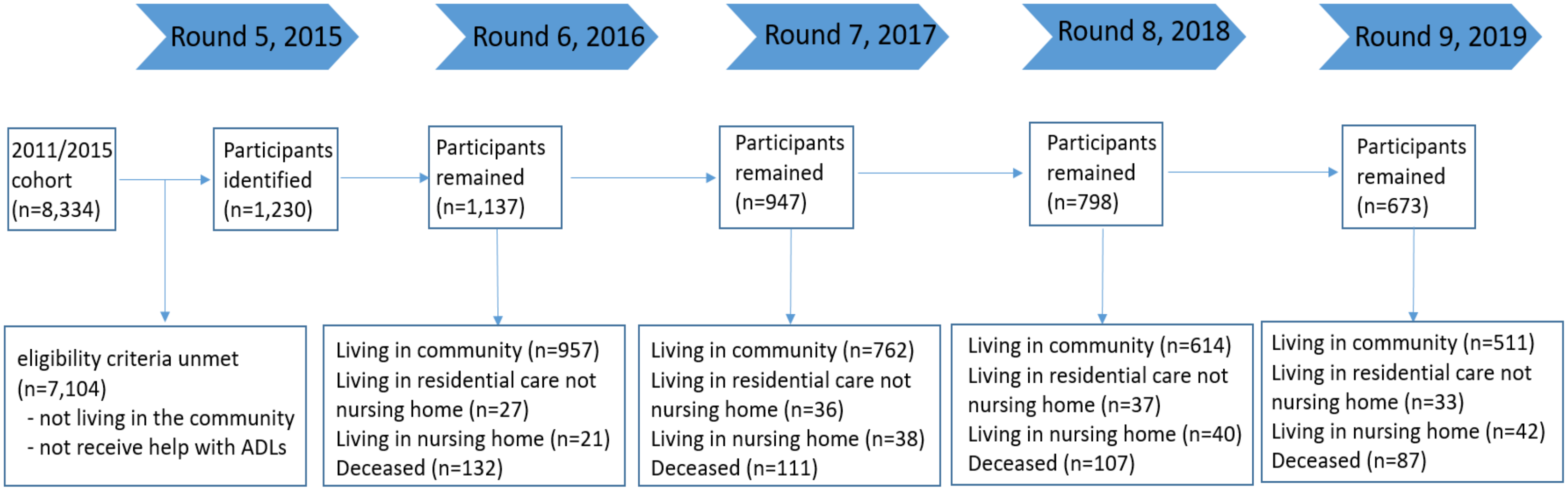
Limitations and practical implication

Some limitations in our study constrain broad interpretation. First, there is a high rate of loss to follow-up in Round nine (about 45%) in this four-year-period study. This can be attributed to the high death rate of over 35% among the sample. Additionally, the collection procedures set up in the NHATS survey, which sampled individuals residing in nursing homes and residential care, did not complete a sample person (SP) interview and were thus not eligible for a follow-up interview.[26] Therefore, the data can be considered missing at random. Second, the sample size restricted the number of covariates we were able to use (e.g. caregiver's co-residence status with the care recipients, care recipients' multi-morbidity), which may result in a biased estimate of our variable of interest and a possible heterogeneous group.[60,61] However, we used GEE in data analysis which resides in the unbiased estimation of population-averaged regression coefficients.[62,63] The use of GEE can give us relatively unbiased estimates on the prediction for how QoL would change by the type of relationship. Future research should have a larger sample and incorporate a broader scope of potential influencing factors to validate and generalize the results of this study. Third, 17.6% proxy respondents were included in this study when older adults could not respond to interviews. The degree of agreement between proxy and self-report depends partly on the domains of QoL being assessed, with observable domains (e.g. assistance in ADLs) having a higher degree of correspondence.[64] Therefore, the small percentage of proxy respondents is unlikely to have a substantial impact on the QoL outcomes assessed in this study. In addition, an analysis was conducted, and even after excluding the proxy respondents, the findings retained their statistical significance. Fourth, we acknowledged that the measures employed in this study, including PHQ4, general health, functional limitations, and pain, constitute aspects of QoL. However, it is important to note that these measures might not encompass all dimensions comprehensive. Furthermore, it should be noted that the duration and severity of dementia at the time of enrollment, caregiving duration, caregiving hours, and caregiving tasks were not included in this study, which may have affected our results. Future longitudinal studies, including factors such as caregiving outcomes for PLWD, may elucidate the expansion, increased complexity and intensity of the caregiver's roles and responsibilities in the middle to late stages of caregiving trajectory.[65]

Despite these limitations, our study provides significant evidence about the prediction of care-recipient relationship type on PLWD's QoL change, especially on their functional limitations change. Older adults' functional limitations reflect their degree of dependence[66] and are powerful predictors of nursing home admission.[48] Predicting the functional limitation changes is vital for the healthcare team and policymakers to develop tailored interventions and proactively plan for future healthcare expenses.

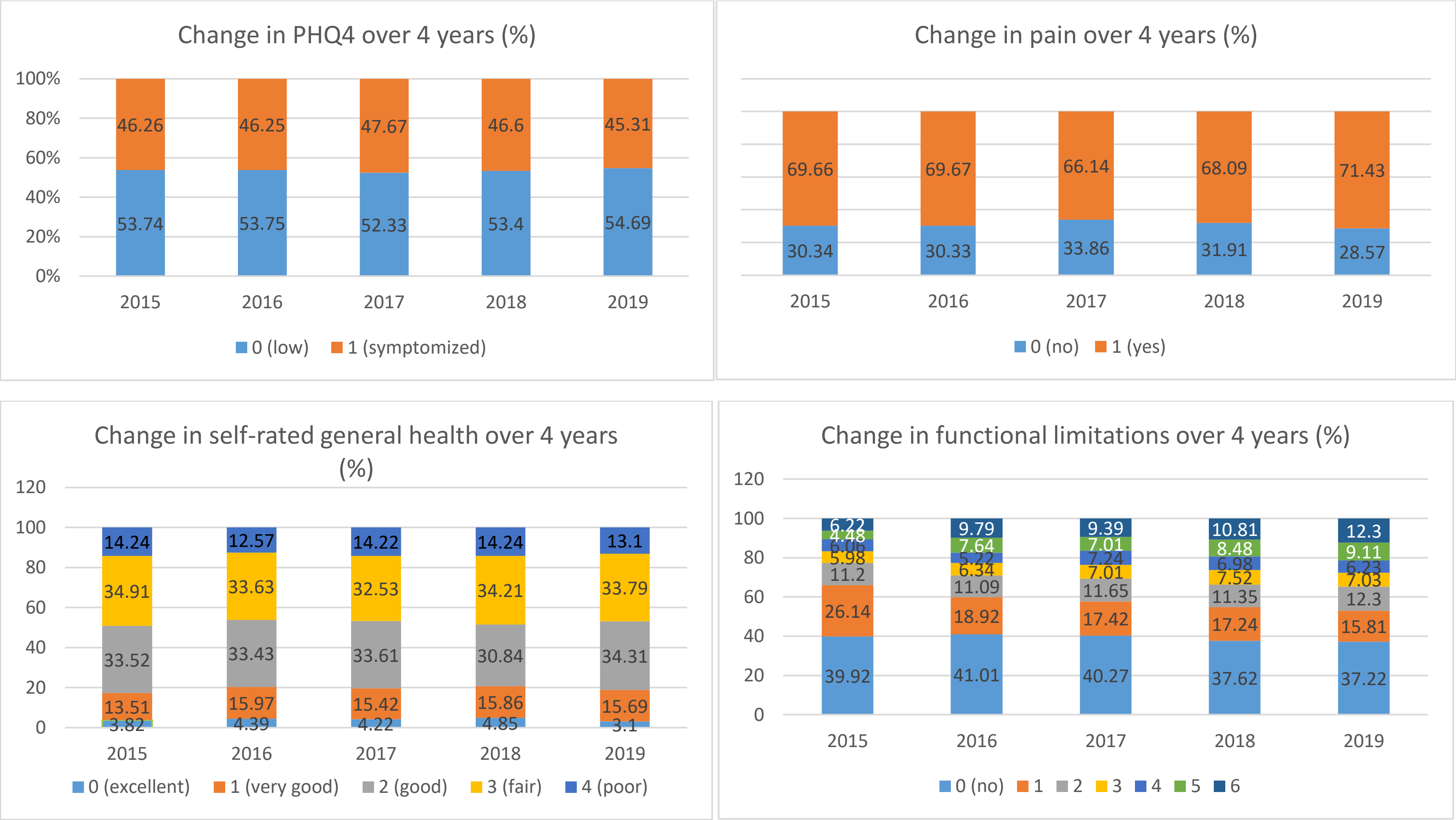
Conclusion

Our study provides significant evidence about the prediction of care recipient relationship type on PLWD's changes in functional limitations, an important QoL measure. Informal care is integral for developing a sustainable care system for PLWD. Our findings should contribute to raising awareness about the discrepancy in the QoL trajectory of PLWD with different types of caregivers. They provide evidence about the significant contribution of care-recipient relationship type on care recipients' QoL changes over time. They also help to prioritize resource allocation while addressing the demands for community-dwelling PLWD by socio-demographic characteristics such as education level.



Chapter 3 Figure 1. Participants over 4 years period (from round five to round nine)

Note: In 2015 Round five there were 1230 participants identified. In the following rounds, some were no longer living in community; some passed away or non-response. So the number of eligible participants who remained in follow-up rounds gradually decreased. In round nine, 511 participants can be used for analysis, which is less than 50% of participant included in the Round five



Chapter 3 Figure 2. Changes in each QoL subscale cross five rounds (Round five, 2015 to Round nine, 2019)

Note: PHQ4 Patient Health Questionnaire for Depression and Anxiety. PHQ-4 was categorized into two groups: low (0-2) and symptomized (3-12); General health was self-rated on a 5-point scale: excellent (0), very good (1), good (2), fair (3), and poor (4). Pain was evaluated by asking whether or not the participants were bothered by pain in the past month and scored as yes (1) or no (0); Functional limitations were presented as the total number of activities of daily living (ADLs) that the participant received help with within the past month and scored 0 to 6 with a higher score representing more severe limitations. The figure indicates that older adults had more complaints of pain and tended to receive help with more ADLs over time, especially those receiving help with five or six ADLs in Round five.

Chapter 3 Table 1. Baseline socio-demographics and dementia status by the type of relationship

Variables **count (percentage)**	Total (n=1230)	**Type of relationship**			
		By spouse/partner	By adult child	By "other"	By multiples
		296 (24.1)	352 (28.6)	114 (9.3)	468 (38.0)
Sex					
Male	405 (32.9)	172 (58.1)	58 (16.5)	38 (33.3)	137 (29.3)
Female	825 (67.1)	124 (41.9)	294 (83.5)	76 (66.7)	331 (70.7)
Age					
65 to 69 yrs	84 (6.8)	45 (15.2)	17 (4.8)	5 (4.4)	17 (3.6)
70 to 74 yrs	174 (14.2)	56 (18.9)	35 (9.9)	23 (20.2)	60 (12.8)
75 to 79 yrs	222 (18.1)	76 (25.7)	56 (15.9)	18 (15.8)	72 (15.4)
80 to 84 yrs	272 (22.1)	67 (22.6)	69 (19.6)	26 (22.8)	110 (23.5)
85 to 89 yrs	256 (20.8)	36 (12.2)	80 (22.7)	24 (21.1)	116 (24.8)
90+ yrs	222 (18.1)	16 (5.4)	95 (27.0)	18 (15.8)	93 (19.9)
Race/ethnicity					
Non- Hispanic White	735 (60.2)	230 (78.0)	185 (53.0)	54 (48.2)	266 (57.1)
Non- Hispanic Black	386 (31.6)	50 (17.0)	124 (35.5)	47 (42)	165 (35.4)
Hispanic	62 (5.1)	7 (2.4)	25 (7.2)	7 (6.3)	23 (4.9)
Other	39 (3.2)	8 (2.7)	15 (4.3)	4 (3.6)	12 (2.6)
Annual Income					
<1st quartile	305 (24.8)	15 (5.1)	128 (36.4)	46 (40.4)	116 (24.8)
1st-2nd quartiles	309 (25.1)	33 (11.2)	109 (31.0)	33 (29.0)	134 (28.6)
2nd-3rd quartiles	333 (27.1)	105 (35.5)	80 (22.7)	21 (18.4)	127 (27.1)
> 3rd quartile	283 (23.0)	143 (48.3)	35 (9.9)	14 (12.3)	91 (19.4)
Education					
Below high school	412 (33.8)	62 (21.0)	130 (37.1)	44 (39.6)	176 (38.0)
High school	360 (29.5)	81 (27.4)	113 (32.3)	30 (27.0)	136 (29.4)
Above high school below Bachelor	271 (22.2)	88 (29.7)	69 (19.7)	26 (23.4)	88 (19.0)
Bachelor and above	177 (14.5)	65 (22.0)	38 (10.9)	11 (9.9)	63 (13.6)
Marital status					
Married/living with a partner	532 (43.3)	296 (100)	47 (13.4)	17 (14.9)	172 (36.8)
Unmarried	698 (56.8)	N/A	305 (86.7)	97 (85.1)	296 (63.3)
Living arrangements					
Alone	249 (20.2)	N/A	111 (31.5)	44 (38.6)	94 (20.1)
With spouse/partner only	376 (30.6)	248 (83.78)	18 (5.1)	12 (10.5)	98 (20.9)
With spouse/partner & others	146 (11.9)	48 (16.22)	24 (6.8)	3 (2.6)	71 (15.2)
With others only	459 (37.3)	N/A	199 (56.5)	55 (48.3)	205 (43.8)
Dementia status					
Probable dementia	371 (30.2)	59 (20.0)	127 (36.1)	34 (29.8)	151 (32.3)
Possible dementia	179 (14.6)	34 (11.5)	55 (15.6)	23 (20.2)	67 (14.4)
No dementia	678 (55.2)	202 (68.4)	170 (48.3)	57 (50.0)	249 (53.3)

yrs years; ***unmarried*** single/widowed/separated/divorced

Chapter 3 Table 2. Baseline QoL outcomes by the type of relationship

Variables	Total	**Type of relationship**			
count (percentage)	(n=1230)	By spouse/partner	By adult child	By "other"	By multiples
		296 (24.1)	352 (28.6)	114 (9.3)	468 (38.0)
Pain					
Reporting pain	854 (69.4)	212 (71.6)	248 (70.7)	74 (64.9)	320 (68.8)
			chi2(3)= 2.0754, p= 0.557		
PHQ4					
Symptomized (PHQ4>2, ≤12)	553 (45.0)	117 (40.6)	159 (46.4)	59 (52.7)	221 (48.41)
			chi2(3)= 6.1942, p= 0.103		
General health					
Excellent	47 (3.8)	12 (4.1)	19 (5.4)	2 (1.8)	14 (3.0)
Very good	166 (13.5)	46 (15.5)	41 (11.7)	12 (10.5)	67 (14.3)
Good	412 (33.5)	99 (33.4)	117 (33.3)	35 (30.7)	161 (34.4)
Fair	429 (34.9)	99 (33.4)	123 (35.0)	46 (40.4)	161 (34.4)
Poor	175 (14.2)	40 (13.5)	51 (14.5)	19 (16.7)	65 (13.9)
			chi2 with ties (3)= 4.154, p= 0.2453		
Functional limitations					
Not receiving help with ADL	481 (39.1)	103 (35.2)	138 (40.4)	56 (51.4)	184 (39.9)
Receiving help with 1 ADL	315 (25.6)	111 (37.9)	67 (19.6)	21 (19.3)	116 (25.2)
Receiving help with 2 ADLs	135 (11.0)	38 (13.0)	35 (10.2)	12 (11.0)	50 (10.8)
Receiving help with 3 ADLs	72 (5.9)	13 (4.4)	25 (7.3)	2 (1.8)	32 (6.9)
Receiving help with 4 ADLs	73 (5.9)	9 (3.1)	29 (8.5)	6 (5.5)	29 (6.3)
Receiving help with 5 ADLs	54 (4.4)	9 (3.1)	23 (6.7)	4 (3.7)	18 (3.9)
Receiving help with 6 ADLs	75 (6.1)	10 (3.4)	25 (7.3)	8 (7.3)	32 (6.9)
			chi2 with ties (3)= 6.362, p= 0.0953		

yrs years; ***unmarried*** single/widowed/separated/divorced; ***PHQ4*** Patient Health Questionnaire for Depression and Anxiety; ***ADL*** activity of daily living

Chapter 3 Table 3. Results from GEE models of care-recipient relationship type prediction on QoL outcomes over 4 years (2015-2019)

	Model without adjustment for socio-demographics & dementia status				**Model 1**				**Model 2**			
	OR	**p**	**95% CI**		**OR**	**p**	**95% CI**		**OR**	**p**	**95% CI**	
PHQ4												
By adult child	1.18	0.19	0.92	1.52	0.95	0.77	0.66	1.37	0.93	0.69	0.64	1.34
By "others"	1.02	0.93	0.71	1.46	0.82	0.39	0.53	1.28	0.81	0.34	0.52	1.26
By multiples	1.15	0.25	0.91	1.47	0.98	0.92	0.72	1.35	0.99	0.94	0.72	1.36
Pain												
By spouse/partner												
By adult child	1.07	0.62	0.82	1.41	0.91	0.62	0.62	1.33	0.92	0.68	0.63	1.35
By "others"	1.09	0.68	0.73	1.61	0.82	0.41	0.50	1.32	0.83	0.45	0.52	1.34
By multiples	1.01	0.95	0.78	1.30	0.90	0.55	0.65	1.26	0.90	0.53	0.65	1.25
	IRR	**p**	**95% CI**		**IRR**	**p**	**95% CI**		**IRR**	**p**	**95% CI**	
General health												
By adult child	1.03	0.41	0.96	1.09	1.05	0.20	0.97	1.14	1.05	0.20	0.97	1.14
By "others"	1.05	0.26	0.97	1.14	1.03	0.50	0.94	1.14	1.03	0.50	0.94	1.14
By multiples	1.01	0.82	0.95	1.07	1.02	0.60	0.95	1.09	1.02	0.60	0.95	1.09
Functional limitations												
By adult child	1.58	**<0.01**	1.35	1.85	1.59	**<0.01**	1.30	1.95	1.53	**<0.01**	1.26	1.86
By "others"	1.10	0.48	0.85	1.43	1.25	0.12	0.95	1.64	1.21	0.16	0.93	1.57
By multiples	1.40	**<0.01**	1.21	1.63	1.36	**<0.01**	1.14	1.63	1.36	**<0.01**	1.14	1.61

P-values in bold indicate significant < 0.05. All models using “care by a spouse/partner” as a reference group.

Model 1 Generalized estimating equation (GEE) model with a logit link function for PHQ4 and pain, a log link function for general health and functional limitations, and adjusted for socio-demographic characteristics including age, gender, race, income, education, marital status and living arrangements; Model 2 additionally controlled for dementia status. Both models use group receiving care from a spouse/partner as the reference category; OR odds ratio; IRR incidence rate ratio; 95% CI 95% confidence intervals

Chapter 3 Table 4. Sidak post-hoc results of functional limitations differences among the type of relationship for 4-levels education

	Contrast	Std. Err.	p	95%CI	
relationship type @education					
(by adult-child vs by spouse/partner) 1	0.52	0.17	**0.03**	0.03	1.02
(by adult-child vs by spouse/partner) 2	0.50	0.15	**0.01**	0.07	0.93
(by adult-child vs by spouse/partner) 3	0.35	0.16	0.29	-.10	0.79
(by adult-child vs by spouse/partner) 4	0.47	0.18	0.12	-.05	1.00
(by others vs by spouse/partner) 1	0.43	0.21	0.39	-.17	1.03
(by others vs by spouse/partner) 2	0.06	0.26	1.00	-.67	0.79
(by others vs by spouse/partner) 3	-0.09	0.28	1.00	-.90	0.72
(by others vs by spouse/partner) 4	0.37	0.28	0.92	-.44	1.18
(by multiples vs by spouse/partner) 1	0.47	0.17	0.06	-.01	0.94
(by multiples vs by spouse/partner) 2	0.44	0.14	**0.03**	0.02	0.85
(by multiples vs by spouse/partner) 3	0.05	0.14	1.00	-.35	0.46
(by multiples vs by spouse/partner) 4	0.26	0.18	0.84	-.24	0.76

***1*:** below high school; ***2*:** high school; ***3*:** above high school below Bachelor; ***4*:** Bachelor and above

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Ethical Statement

Informed Consent

Participants in the NHATS provided written informed consent, according to NHATS Data Collection Procedures: Round 5, 2015. Available at https://www.nhats.org

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Supplemental Material

Supplemental material for this article is available online.

Appendix I

Chapter 3 Table S 1. Care-recipients' quality of life (QoL) outcomes and pertaining questions at the National Health and Aging Trends Study (NHATS)

QoL	Questions at NHATS
Mental Health (scored 0~12, higher score represents worse mental health)	"Over the last month, how often have you (a) had little interest or pleasure in doing things; (b) felt down, depressed, or hopeless; (c) felt nervous, anxious, or on edge; (d) been unable to stop or control worrying". • Each item is scored on a 4- point scale from "not at all" (0), "several days" (1), "more than half the days" (2) to "nearly every day" (3).
General health (scored 0~4, higher score represents worse health)	"Would you say that in general your health is excellent, very good, good, fair, or poor?" • Response is scored on a 5 scale: excellent (0); very good (1); good (2); fair (3); poor (4)
Pain (scored 0~1, 1 represents pain)	"In the last month, have you been bothered by pain?" • Respond "yes" (1) or "no" (0)
Functional Limitations (scored 0~6, higher score represents more severe limitations)	"Whether you received help within the last month with any of the following activities of daily living (ADLs)": (a) eating (b) getting cleaned up (c) using the toilet (d) dressing (e) getting around inside (f) getting out of bed? • Respond "yes" (1) or "no" (0)

Adapted from NHATS data collection instrument form. Available at www. NHATS.org

Appendix II

Chapter 3 Table S 2. Older adults' socio-demographic characteristics and dementia status

Variables, Count (%)	Round 5 (n=1230)	Round 6 (n=1137)	Round 7 (n=947)	Round 8 (n=798)	Round 9 (n=673)
Sex					
Male	405 (32.9)	372 (32.7)	299 (31.6)	251 (31.5)	211 (31.4)
Female	825 (67.1)	765 (67.3)	648 (68.4)	547 (68.6)	462 (68.7)
Age					
65 to 69 yrs	84 (6.8)	60 (5.3)	36 (3.8)	17 (2.1)	3 (.5)
70 to 74 yrs	174 (14.2)	134 (11.8)	112 (11.8)	88 (11.0)	72 (10.7)
75 to 79 yrs	222 (18.1)	190 (16.7)	150 (15.8)	125 (15.7)	107 (15.9)
80 to 84 yrs	272 (22.1)	199 (17.5)	178 (18.8)	154 (19.3)	129 (19.2)
85 to 89 yrs	256 (20.8)	214 (18.8)	175 (18.5)	152 (19.1)	127 (18.9)
90+ yrs	222 (18.1)	208 (18.3)	185 (19.5)	155 (19.4)	148 (22.0)
Race/ethnicity					
Non- Hispanic White	735 (60.2)	682 (60.0)	576 (60.8)	481 (60.3)	398 (59.1)
Non- Hispanic Black	386 (31.6)	353 (31.1)	285 (30.1)	246 (30.8)	216 (32.1)
Hispanic	62 (5.1)	59 (5.2)	53 (5.6)	42 (5.3)	34 (5.1)
Other	39 (3.2)	35 (3.1)	27 (2.9)	24 (3.0)	20 (3.0)
Annual Income					
<1st quartile (<13000)	305 (24.8)				
1st-2nd quartiles (>=13000 & <22000)	309 (25.1)				
2nd-3rd quartiles (>=22000 & <=40000)	333 (27.1)				
> 3rd quartile (>40000)	283 (23.0)				
Education					
Below high school	412 (33.8)				
High school	360 (29.5)				
Above high school below Bachelor	271 (22.2)				
Bachelor and above	177 (14.5)				
Marital status					
Married/living with a partner	532 (43.3)	415 (41.4)	336 (40.5)	277 (40.6)	232 (40.0)
Unmarried	698 (56.8)	587 (58.6)	494 (59.5)	405 (59.4)	350 (60.1)
Living arrangements					
Alone	249 (20.2)	228 (20.1)	199 (21.0)	169 (21.2)	148 (22.0)
With spouse/partner only	376 (30.6)	283 (24.9)	228 (24.1)	180(22.6)	162 (24.1)
With spouse/partner and others	146 (11.9)	117 (10.3)	97 (10.2)	84 (10.5)	63 (9.4)
With others only	459 (37.3)	374 (32.9)	306 (32.3)	249 (31.2)	209 (31.1)
Dementia status					
Probable dementia	371 (30.2)	340 (30.0)	258 (27.3)	194 (24.3)	141 (21.0)
Possible dementia	179 (14.6)	165 (14.5)	126 (13.3)	106 (13.3)	88 (13.1)
No dementia	678 (55.2)	630 (55.5)	562 (59.4)	497 (62.4)	443 (65.9)

% percentage

Appendix III

Chapter 3 Table S 3. Comparison between Non-response and Sample in Round 5

Variables, count (percentage)	Non-response (n=557)	Sample in Round 5 (n=1230)
Age		
65 to 69 yrs	40 (7.2)	79 (5.7)
70 to 74 yrs	95 (17.1)	137 (11.1)
75 to 79 yrs	92 (16.5)	210 (17.1)
80 to 84 yrs	125 (22.4)	276 (22.4)
85 to 89 yrs	107 (19.2)	275 (22.4)
90+ yrs	98 (17.6)	262 (21.3)
	chi2(5) = 16.1854 P= 0.006	
Dementia status		
Probable dementia	163 (29.4)	438 (35.6)
Possible dementia	83 (15.0)	187 (15.2)
No dementia	309 (55.7)	604 (49.2)
	chi2(2) = 7.6637 P= 0.022	

Appendix IV

Chapter 3 Table S 4. Changes in each QoL subscale over 4 years (2015-2019)

Variables, count (percentage)	2015	2016	2017	2018	2019
Pain					
Not reporting pain	372 (30.3)	303 (30.3)	280 (33.8)	217 (31.9)	166 (28.6)
Reporting pain	854 (69.7)	696 (69.7)	547 (66.1)	463 (68.1)	415 (71.4)
PHQ4					
Low (PHQ4>=0, <=2)	646 (53.7)	523 (53.8)	415 (52.3)	353 (53.4)	309 (54.7)
Symptomized (PHQ4>2, <=12)	556 (46.3)	450(46.3)	378 (47.7)	308 (46.6)	256 (45.3)
General health					
Excellent	47 (3.8)	44 (4.4)	35 (4.2)	33 (4.9)	18 (3.1)
Very good	166 (13.5)	160 (16.0)	128 (15.4)	108 (15.9)	91 (15.7)
Good	412 (33.5)	335 (33.4)	279 (33.6)	210 (30.8)	199 (34.3)
Fair	429 (34.9)	337 (33.6)	270 (32.5)	233 (34.2)	196 (33.8)
Poor	175 (14.2)	126 (12.6)	118 (14.2)	97 (14.2)	76 (13.1)
Functional limitations					
Not receiving help with any ADL	481 (39.9)	440 (41.0)	356 (40.3)	275 (37.6)	233 (37.2)
Receiving help with 1 ADL	315 (26.1)	203 (18.9)	154 (17.4)	126 (17.2)	99 (15.8)
Receiving help with 2 ADLs	135 (11.2)	119 (11.1)	103 (11.7)	83 (11.4)	77 (12.3)
Receiving help with 3 ADLs	72 (6.0)	68 (6.3)	62 (7.0)	55 (7.5)	44 (7.0)
Receiving help with 4 ADLs	73 (6.1)	56 (5.2)	64 (7.2)	51 (7.0)	39 (6.2)
Receiving help with 5 ADLs	54 (4.5)	82 (7.6)	62 (7.0)	62 (8.5)	57 (9.1)
Receiving help with 6 ADLs	75 (6.2)	105 (9.8)	83 (9.4)	79 (10.8)	77 (12.3)

CHAPTER 4: IMPACT OF CARE-RECIPIENT RELATIONSHIP TYPE ON QUALITY OF LIFE IN CAREGIVERS OF OLDER ADULTS WITH DEMENTIA OVER TIME

Prepared for:

Age and Aging

Title

Impact of care-recipient relationship type on quality of life in caregivers of older adults with dementia over time

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Abstract

Background: Dementia caregiving is a dynamic and multidimensional process. To gain a comprehensive understanding of informal caregiving for people living with dementia (PLWD), it is pivotal to assess the quality of life (QoL) of informal caregivers. **Objective:** To evaluate whether the care-recipient relationship type predicts changes in the QoL of informal caregivers of PLWD over a two-year period. **Methods:** This was a secondary analysis of longitudinal data. The data were drawn from two waves of linked data from the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) (2015: NHATS Round 5 & NSOC II; 2017: NHATS Round 7 & NSOC III). Caregivers were categorized into spousal, adult-child, “other” caregiver, and “multiple” caregivers. QoL was assessed through negative emotional burden, positive emotional benefits, and social strain. Generalized estimating equation modelling was used to examine whether changes in caregivers’ QoL outcomes differed across types of relationship over time. **Results:** 882 caregivers were included who linked to 601 PLWD. After adjusting caregivers’ socio-demographics , “other” caregivers had lower risk of negative emotional burden and social strain than spousal caregivers (OR=0.34, p=0.003, 95%CI [0.17, 0.70]; OR=0.37, p=0.019, 95%CI 0.16, 0.85]; respectively), and PLWD’s dementia status would not change these associations (OR=0.33, p=0.003, 95%CI [0.16, 0.68]; OR=0.31, p=0.005, 95%CI [0.14, 0.71]; respectively). **Conclusions:** The study demonstrates that spousal caregivers face a higher odds of negative emotional burden and social strain in QoL domains over time, underscoring the pressing need to offer accessible and effective support for informal caregivers of PLWD, especially those caring for their spouses.

Keywords: older adults, people living with dementia, informal caregivers, quality of life, care-recipient relationship type

Key points:

1. This study is the first to longitudinally explore how various types of relationship impact the QoL for informal caregivers of PLWD as their caregiving needs increase with the progression of the illness.
2. When developing interventions to improve caregiver QoL, we should tailor them to address specific caregiver subgroups, as defined by the relationship type or their level of risk.
3. While all caregivers may benefit from social and healthcare services, spousal caregivers of PLWD are groups with particularly high demands that warrant attention.

Introduction

Globally, the number of older adults living with dementia (PLWD) is rising steadily with nearly 9.9 million people developing dementia each year. This figure translates into one new case every three seconds [7], increasing the demand on caregivers and the healthcare system. In the UK, approximately 700,000 informal caregivers of PLWD contributed an estimated 1.3 billion hours of informal (i.e. unpaid) assistance [97], valued at GPB 13.9 billion [98]. The extended hours spent on caregiving may represent more demanding care situations, potentially resulting in an increased risk of caregiver burden [99]. Moreover, existing caregiving literature highlights the importance of cognitive impairment in PLWD, which has adverse effects on the psychological, physical, and social well-being of caregivers [19–22].

However, in addition to the negative outcomes of caregiving for PLWD, there are also positive aspects associated with this role [100]. Studies have reported that caregivers often experience positive outcomes from providing care, such as strengthened family relationships, reduced rates of depression, and increased life satisfaction [100–104]. The “stress process of the caregiving" model, developed by Pearlin et al [32,33,105], suggests that caregiving is a stressful experience. The extent of perceived stress among caregivers is influenced by objective indicators of stressors, such as the severity of dementia, the duration of care, and caregiving hours. It is also shaped by subjective appraisals of these stressors and caregivers' characteristics. Caregiver outcomes are further impacted by secondary stressors, such as challenges of balancing work demands and caregiving responsibilities, and are mediated by the availability of coping mechanisms and support resources, including social support. Therefore, dementia caregiving is a dynamic and multidimensional process [38]. To gain a comprehensive understanding of informal caregiving for PLWD, it is pivotal to assess the quality of life (QoL) of informal caregivers. This evaluation enables a subjective assessment of both the positive and negative aspects of caregiving [106,107].

The care-recipient relationship type (i.e. the type of relationship between caregivers and the care recipients, hereafter referred to as the "type of relationship") is known to influence the QoL of informal caregivers of PLWD [68,77,84,108]. Much of the research has focused on spousal and adult-child caregivers [109] where the latter reportedly had significantly higher QoL than spousal caregivers [77]. It is important to note that caregiving dynamics are evolving due to changing societal trends, such as baby boomers' marital patterns and family structures compared to previous generations [110]. As a result, caregivers with other relations to care recipients and shared caregiving roles are expected to have a more significant caregiving role in the future. Furthermore, the challenges and needs of informal caregivers change as dementia progresses [111]. However, there is a dearth of longitudinal studies that investigate whether and how the type of relationship predicts caregivers' QoL over time.

When evaluating the effects of the type of relationship on caregivers' QoL, it is essential to also consider the potential impact of caregivers' characteristics. Socio-demographic factors, such as age, gender, education, race, marital status, and co-residence with a dependent child (<18yrs), have been reported to play a role in the QoL of caregivers for PLWD [11,84,112]. Moreover, these factors can affect different aspects of caregiving, including both positive and negative aspects [113]. Additionally, it has been suggested that the effects of the type of relationship on caregivers' QoL may be influenced by socio-demographic variables, over time. A qualitative study [114] explored the long-term experiences of informal caregivers, specifically spousal and adult-child caregivers, caring for persons with Alzheimer's disease. The results showed that the caregiving experience was shaped not solely by gender or relationship type, but rather by the combination of the two over time. A Canadian study analyzing longitudinal data also found that caregivers' well-being is influenced by the intersection of gender, relationship type, and caregiving demands [115]. Spousal caregivers with very intensive care reported the highest depressive symptoms and lowest life satisfaction. Sons providing less-intensive care had the fewest depressive symptoms, while daughters in the same caregiving category reported the highest life satisfaction.

Therefore, this study aims to evaluate whether the care-recipient relationship type predicts changes in the QoL of informal caregivers of older adults with dementia over a two-year period. Specifically, the research questions are:

1) After adjusting for caregivers' socio-demographic factors, does the type of care-recipient relationship or shared caregiving predict changes in caregivers of PLWD's QoL over a two-year period?

2) Does PLWD's dementia status impact the prediction of care-recipient relationship type on caregivers' QoL change?

Methods

This was a secondary analysis of longitudinal data. The access and re-use of the data were approved by National Health and Aging Trends Study (NHATS) under NHATS Sensitive Data Supplemental Agreements with Research Staff (NHATS, 2015). The study's reporting adheres to the Strengthening the Reporting of Observational Studies in Epidemiology guidelines (STROBE) [117].

Data sources

The data were drawn from two waves of linked National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) (2015: NHATS Round 5 & NSOC II; 2017: NHATS Round 7 & NSOC III). NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by Johns Hopkins University. Together the NHATS and NSOC are the only national platform for studying caregiving from the perspective of older adults and their caregivers [96].

Sample selection

The care recipient sample in this study were NHATS Round 5 participants who live in the community and receive help with certain Activities of Daily Living (ADL) - getting around inside, getting out of bed, eating, bathing/showering/washing up, getting to or using the toilet, dressing- from their informal caregivers at the time of enrollment [96]. NHATS participants could identify up to five caregivers as helpers, but we only included the informal caregivers (i.e., family and unpaid caregivers) who were either 1) related to the older adults (relationship codes =

2-29 or 91) whether paid or not, or 2) unrelated to the older adult and not paid to help [118]. Sample selection criteria were the same for both waves. However, if the NHATS sample persons that caregivers cared for in Round 5 (2015) was marked as non-response in Round 6 (2016) or Round 7 (2017), no attempt was made to contact the caregiver for NSOC III.

Measures

Type of relationship: Informal caregivers are people who provide care to those who need it within the context of an existing relationship, such as a family member, a friend, or a neighbour [119]. If NHATs care-recipients only indicated having a single helper/caregiver, these caregivers were categorized into three groups: 1) care from a spouse/partner; 2) care from an adult child; 3) care from an informal caregiver other than a spouse/partner and adult child, such as child-in-law, sibling, etc. (referred to from here on as "other" caregiver). 4) If NHATs care-recipients indicated having multiple helpers/caregivers, each caregiver was included separately with a designation of "multiple" caregivers, as opposed to a single caregiver. Care from a spouse/partner is used as the reference category for statistical analyses.

QoL outcomes: Caregivers can have either negative or positive caregiving experiences [34,35]. Negative outcomes result when caregivers experience emotional difficulty, depression, anxiety, strained relationships with care recipients, and demands interfering with social participation. On the other hand, positive outcomes stem from feelings of self-fulfillment, appreciation, satisfaction with care recipients, and the development of self-competencies [120,121]. Consequently, caregivers' QoL should encompass both positive and negative aspects. Therefore, caregivers' QoL was assessed through three outcomes: negative aspects, including **negative emotional burden (NEB)** and **social strain (SS)**, and positive aspects, that is, **positive emotional benefit (PEB)**. The selection of these indicators was based on the "stress process of the caregiving" model[33] that recognizes the dynamic nature of caregiving stress and acknowledges the subjective aspects of stress. This approach aligns effectively with the WHO definition of QoL, which emphasizes an individual's perception of their position in life. These outcomes were measured using items from the NSOC questionnaire (see Appendix I), as described in our previous study [84].

Dementia status was classified into probable dementia, possible dementia, and no dementia, as generated from the NHATS Round 5 (2015). The measurement process was detailed in our prior study [122].

The following caregiver ***socio-demographic variables*** were used in analyses: age range (<45yr, 45-54yr, 55-64yr, ≥65yr), gender (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, other), annual income (<1st quartile, 1st-2nd quartiles, 2nd-3rd quartiles, >3rd quartile), education (below high school, high school, above high school, bachelor and above), marital status (married/living with a partner, unmarried), and whether having a dependent child (<18yrs). Socio-demographic variables contribute significantly to shaping caregivers' outcomes [32,120]. Research has shown that the relationships between caregiving intensity and quality of life vary substantially based on factors like race/ethnicity, gender, age, and annual family income [63,85]. Living arrangements, such as whether a caregiver lives with a child or not, have also been reported to impact QoL [93,121]. These variables have been identified as influential factors in caregivers' QoL and applied in previous studies [84,123].

Statistical analysis

Categorical variables, including the type of relationship, dementia status, socio-demographic characteristics, and the level of burden based on the QoL subscales (PEB, NEB, SS), were described using counts and percentages. Changes in “high” vs. “low” of QoL subscales over a 2-year period (from 2015 to 2017) were described using descriptive statistics. The association between baseline QoL subscale burden level and type of relationship was examined using Chi-square tests. Generalized Estimating Equations (GEE) with a logit link function was employed to investigate potential differences in QoL changes across four groups over a two-year period. The application of GEE enhances the robustness of our analysis by accommodating the longitudinal structure of the data, providing insights into group-specific variations in QoL trajectories over time. Three models were built with sequential adjustment for covariates: Model 1 was unadjusted; Model 2 adjusted for caregivers’ socio-demographic characteristics; Model 3 additionally controlled for care recipients’ dementia status.

To assess the robustness of our results, we compared the differences in baseline QoL and socio-demographics between missing data and the data initially included at baseline. All analyses were conducted using Stata 16.0, with a two-tailed significance test set at an alpha level of 0.05.

Results

In 2015 NSOCII, 1871 caregivers were included to the study, linked to 1230 older adults in NHATS Round 5. By 2017, 882 caregivers remained eligible for the analysis, linked to 601 older adults in NHATS Round 7 (see appendix II). Most caregivers were female (n=593, 67.54%), white (n=477, 55.85%), had no dependent child co-residency (n=734, 84.95%), married or living with a partner (n=515, 58.66%), had an education above high school (n=291, 36.42%), and were aged above 65years (n=365, 42.05%). Among them, 383 were single caregivers and were divided into three groups: spousal caregivers (n=173, 19.6%), adult-child caregivers (n=166, 18.8%), and “other” caregivers (n=44, 5%). Four hundred ninety-nine were multiple caregivers providing assistance to 218 older adults (see Table 1). Table 2 presents the demographic information of the older adults, including their age, gender, race, and dementia status. Compared to those with complete data, caregivers with missing data tend to be younger, while care recipients are older. Additionally, they are more likely to be unmarried (including single, widowed, divorced), and a greater number of care recipients are probable or possible dementia cases. Appendix II provides details regarding the reasons and differences for care recipients and caregivers missing in NSOC III (2017) compared to NSOC II (2015).

As shown in Table 3, overall the odds of being high burden for each of the QoL measures (PEB, NEB, and SS) was higher in 2017 compared to 2015 (OR= 63.62, p<0.001, 95% CI [46.76, 86.55]; OR= 48.69, p<0.001, 95% CI [36.50, 64.94]; OR= 51.44, p<0.001, 95% CI [38.58, 68.58]; respectively). A significant difference in SS was observed at baseline across four groups (Chi2 (3) = 15.703, P=0.001), with adult-child caregivers experiencing higher SS (Table 3). The same pattern persisted using GEE to assess the changes in QoL over time for the four groups. Adult-child caregivers exhibited a significantly higher risk of SS than spousal caregivers in the unadjusted model, but this was not statistically significant after adjusting for caregivers' socio-demographic variables and PLWD's dementia status (Table 4).

"Other" caregivers demonstrated a lower risk of experiencing NEB and SS than spousal caregivers (OR=0.34, p=0.003, 95%CI [0.17, 0.70]; OR=0.37, p=0.019, 95%CI 0.16, 0.85]) in the adjusted model, respectively (Table 4). This significant difference between "other" and spousal caregivers remained after additional adjustment for care recipients' dementia status (OR=0.33, p=0.003, 95%CI [0.16, 0.68]; OR=0.33, p=0.005, 95%CI [0.14, 0.71]; respectively).

Discussion

This study is the first longitudinal investigation assessing how different types of relationship and sharing caregiving approaches impact QoL outcomes across multiple aspects for informal caregivers of PLWD. Our results indicate that, in comparison to “other” caregivers, spousal caregivers showed a greater tendency for increased NEB and SS over time.

Type of relationship, which was referred to as “Kinship” in a recent systematic review, is reported as one of the important risk factors for the trajectory of caregiver burden for PLWD; being a spouse increases the risk of experiencing caregiver burden over time [124]. Our study demonstrates that spousal caregivers are more prone to experiencing NEB, which aligns with this review and our prior cross-sectional analysis [84] where spousal caregivers had higher odds of experiencing NEB than other caregivers. One of the primary contributing factors is cohabitation [124–126]. In our study, it is notable that all spousal caregivers lived with the care recipients, while other caregivers usually lived elsewhere. Additionally, spouses tend to be of an older age themselves, a factor consistently associated with an increased burden compared to younger caregivers, as evidenced by previous research [124,125,127,128].

Our findings provide evidence that type of relationship predicts SS over time, with spousal caregivers being more likely to experience SS. This aligns with our previous study that “other” caregivers had lower odds of experiencing SS than spousal caregivers [84]. This may be associated with the sense of “role captivity”, a situation where a caregiver feels trapped or constrained in their caregiving role which was often due to the demands of caring for a person with a challenging diagnosis such as dementia [129]. “Role captivity” was reported as one of the strongest predictors of negative caregiving experience according to the caregiver stress model[52,53]. Spousal caregivers often experience a greater obligation to their caregiving role, which can lead them to make sacrifices such as giving up leisure activities, reducing time with friends and family, and limiting employment opportunities [130,131]. As a result, they may find themselves feeling “trapped” in their caregiving role. Additionally, previous research has shown that caregiving motivations, particularly when it is a choice, can impact caregiver wellbeing. Lower QoL has been associated with caregivers who perceived a lack of alternative care options or feel that those options are insufficient [132]. Our findings imply the high need for social support to spousal caregivers to help them better manage their SS.

Although adult-child caregivers showed a significantly higher risk of SS over time than spousal caregivers in unadjusted model, this difference diminished after adjusting for their socio-demographics and their care-recipients' dementia status (Table 4). This finding is consistent with our previous cross-sectional study [84]. Existing literature has consistently reported that many factors, such as caregivers' race, age, and care recipients' cognitive functions impact the dementia caregiving experience [133,134]. Considering the notable differences in race, age, and education level between spousal and adult-child caregivers, along with the variations in dementia status of care recipients in these two groups, our findings provide evidence that the impact of care-recipient relationship type on caregivers' QoL trajectories can be influenced by caregivers' socio-demographics and care recipients' dementia status.

Research has indicated that the positive aspects of caregiving can be influenced by the caregiver's relationship to the care-recipient [135,136]. Our previous cross-sectional study also reported that "other" caregivers had a significantly higher PEB compared to spousal caregivers [84]. However, the current findings does not provide sufficient evidence to support the idea that the PEB for caregivers of PLWD differs based on the type of relationship. This paper uses a stress model [32] and focuses on questions that address caregivers' current experiences. However, the concept of positive aspects of caregiving is multidimensional and can also encompass self-efficacy, satisfaction, and competence [137]. The diversity in conceptual and operational terms makes it challenging to compare outcomes across studies. Future studies could consider to use more standardized measurements to explore this theme comprehensively.

Our hypothesis that shared caregiving would predict the QoL of caregivers of PLWD over time was not supported. This could be attributed to a relatively short follow-up period (only two years) and a limited number of observed time points (only two, in 2015 and 2017). Additionally, the heterogeneous nature of the structure of multiple caregivers, comprising spouse, adult child, and other types, may have contributed to the lack of significant findings. The study included caregivers of people with no-dementia as a comparison group to help detect differences and similarities in QoL outcomes across different caregiving situations. This approach offers a broad perspective in caregiving and allows the study to capture a wide range of caregiving experience. However, this may introduce heterogeneity into the sample, which could partially account for the lack of significant findings. Future studies could benefit from larger sample size, longer study durations, and more frequent observations at various time points to provide a more comprehensive understanding of the impact of shared caregiving on caregivers' QoL.

Limitations and Strength

Given the nature of secondary data analysis, the original data were not collected to answer the present specific research questions. While the 3 domains of QoL used in our study were substantiated through exploratory factor analysis and applied in previous caregiver-related studies, the use of these three specific domains does not fully address the broad scope of QoL issues that arise from informal caregiving duties. Future studies should explore other aspects of QoL (e.g., material well-being [138], health status [139] and use validated measures (e.g., Carer well-being and support questionnaire [140], Satisfaction with Life Scale [141] to substantiate the findings of this study. In addition, care recipients' multi-morbidity and health were not captured in this study. This may result in a potentially heterogeneous group, which may affect the generalizability of the study results to the caregivers of PLWD population. Future primary research should consider a broader scope of possible influencing factors to validate and generalize the findings of this study. Another limitation is that we only included baseline dementia status in the analysis, which was reported as the best predictor of cognitive change in a population of older adults [142]. However, the dementia status may have changed over time, which may have a degree of impact on the findings. The potential for generating false negatives and false positives in dementia classification may influence the direction and magnitude of findings, depending on the accuracy of capturing dementia status within each caregiver group. For example, if false negatives occur within the spouse caregiver group, this could result in an underestimation of the prevalence and impact of dementia-related stressors on their QoL, consequently leading to an overestimation of the impact of caregiver types on their QoL. Furthermore, some of sample attrition in this longitudinal analysis may have been selective, and we included only care recipients with consistent caregivers which results in the exclusion of 21% of the recipients in 2017. Care recipients who were non-respondents and whose caregivers changed in 2017 were older and had a greater number of being classified as probable or possible dementia compared to those being included (Appendix II). Even after conducting a sensitivity analysis comparing complete and missing data, no significant differences were found in caregivers' QoL measures (PEB, NEB, and SS). However, the higher dropout rates observed in the probable and possible dementia categories may bias the recipient sample towards milder cases. Furthermore, the reduction in sample size resulting from these dropouts may affect the study's statistical power, potentially leading to an insufficient detection of existing effects.

Despite the acknowledged limitations, our study analyzed two companion national datasets (NHATS and NSOC) to investigate the longitudinal impact of type of relationship and shared caregiving approaches on caregivers of PLWD. The study took into account caregivers’ socio-demographic and care recipients’ dementia status. The utilization of a GEE approach enhances the robustness of our findings.

Conclusion

In conclusion, the study demonstrates that spousal caregivers face a higher risk of negative emotional burden and social strain in QoL domains over time, even after accounting for sociodemographic variables related to caregivers' and care recipients' dementia status. These findings underscore the pressing need to offer accessible and effective support for informal caregivers of PLWD, especially those caring for their spouses, across the domains of public policy, research, and practical interventions.

Chapter 4 Table 1. Caregivers' Socio-demographics 2015 Baseline

	Care- recipient Relationship Types				
Variables, count (percentage)	**Total (n=882)**	**Spousal caregiver 173 (19.61)**	**Adult-child caregiver 166 (18.82)**	**"Other" caregiver 44 (4.99)**	**Multiple caregivers 499 (56.58)**
Sex					
Male	285 (32.46)	76 (43.93)	45 (27.11)	7 (16.28)	157 (31.65)
Female	593 (67.54)	97 (56.07)	121 (72.89)	36 (83.72)	339 (68.35)
Age					
< 45 yrs	89 (10.25)	1 (0.58)	12 (7.36)	7 (15.91)	69 (14.11)
45 to 54 yrs	169 (19.47)	2 (1.16)	54 (33.13)	9 (20.45)	104 (21.27)
55 to 64 yrs	245 (28.23)	12 (6.98)	62 (38.04)	10 (22.73)	161 (32.92)
65 + yrs	365 (42.05)	157 (91.28)	35 (21.47)	18 (40.91)	155 (31.70)
Mean (SD)	61.62 (14.36)	75.72 (8.12)	57.32 (8.61)	58.77 (17.28)	58.36 (14.30)
Race/ethnicity					
Non- Hispanic White	477 (55.85)	122 (73.05)	79 (48.77)	18 (40.91)	258 (53.64)
Non- Hispanic Black	296 (34.66)	32 (19.16)	63 (38.89)	19 (43.18)	182 (37.84)
Hispanic	28 (3.28)	5 (2.99)	8 (4.94)	3 (6.82)	12 (2.49)
Other	53 (6.21)	8 (4.79)	12 (7.41)	4 (9.09)	29 (6.03)
Annual Income					
<1st quartile	234 (26.53)	18 (10.40)	60 (36.14)	16 (36.36)	140 (28.06)
1st-2nd quartiles	228 (25.85)	64 (36.99)	36 (21.69)	11 (25.00)	117 (23.45)
2nd-3rd quartiles	231 (26.19)	46 (26.59)	33 (19.88)	8 (18.18)	144 (28.86)
> 3rd quartile	189 (21.43)	45 (26.01)	37 (22.29)	9 (20.45)	98 (19.64)
Education					
Below high school	113 (14.14)	36 (21.05)	18 (11.04)	5 (11.36)	54 (12.83)
High school	203 (25.41)	47 (27.49)	37 (22.70)	17 (38.64)	102 (24.23)
Above high school	291 (36.42)	50 (29.24)	61 (37.42)	17 (38.64)	163 (38.72)
Bachelor and above	192 (24.03)	38 (22.22)	47 (28.83)	5 (11.36)	102 (24.23)
Marital status					
Married/living with a partner	515 (58.66)	173 (100)	69 (42.07)	10 (22.73)	263 (52.92)
Unmarried	363 (41.34)	N/A	95 (57.93)	34 (77.27)	234 (47.08)
Living with a child < 18yrs					
No	734 (84.95)	170 (98.27)	134 (81.71)	39 (88.64)	391 (80.95)
Yes	130 (15.05)	3 (1.73)	30 (18.29)	5 (11.36)	92 (19.05)

Chapter 4 Table 2. Care Recipients' Socio-demographics 2015 Baseline

Variables, count (percentage)	**Total (n=601)**	**By spouse /partner**	**By adult child**	**By "other"**	**By multiple caregivers**
		173 (28.79)	**166 (27.62)**	**44 (7.32)**	**218 (36.27)**
Sex					
male	207 (34.44)	100 (57.80)	20 (12.05)	15 (34.09)	72 (33.03)
female	394 (65.56)	73 (42.20)	146 (87.95)	29 (65.91)	146 (66.97)
Age					
65 to 69 yrs	51 (8.49)	32 (18.50)	8 (4.82)	2 (4.55)	9 (4.13)
70 to 74 yrs	101 (16.81)	34 (19.65)	18 (10.84)	14 (31.82)	35 (16.06)
75 to 79 yrs	121 (20.13)	49 (28.32)	28 (16.87)	5 (11.36)	39 (17.89)
80 to 84 yrs	129 (21.46)	37 (21.39)	34 (20.48)	10 (22.73)	48 (22.02)
85 to 89 yrs	112 (18.64)	17 (9.83)	38 (22.89)	10 (22.73)	47 (21.56)
90+ yrs	87 (14.48)	4 (2.31)	40 (24.10)	3 (6.82)	40 (18.35)
Race/ethnicity					
Non- Hispanic White	360 (60.40)	138 (80.23)	82 (49.70)	19 (45.24)	121 (55.76)
Non- Hispanic Black	192 (32.21)	28 (16.28)	66 (40.00)	20 (47.62)	78 (35.94)
Hispanic	29 (4.87)	4 (2.33)	10 (6.06)	2 (4.76)	13 (5.99)
Other	15 (2.52)	2 (1.16)	7 (4.24)	1 (2.38)	5 (2.30)
Dementia status					
Probable dementia	150 (25.00)	30 (17.34)	50 (30.12)	12 (27.27)	58 (26.73)
Possible dementia	78 (13.00)	16 (9.25)	25 (15.06)	6 (13.64)	31 (14.29)
No dementia	372 (62.00)	127 (73.41)	91 (54.82)	26 (56.09)	128 (58.99)

Chapter 4 Table 3. Caregivers' QoL outcomes

		Care- recipient Relationship Types			
		Spousal caregiver	**Adult-child caregiver**	**"Other" caregiver**	**Multiple caregivers**
Positive Emotional Benefit (PEB)	NSOC II				
	Low	115 (72.33)	99 (62.66)	35 (81.40)	345 (71.88)
	High	44 (27.67)	59 (37.34)	8 (18.60)	135 (28.13)
		Pearson chi2(3)= 7.832 P= 0.050			
	NSOC III				
	Low	120 (73.62)	107 (69.93)	32 (82.05)	337 (75.56)
	High	43 (26.38)	46 (30.07)	7 (17.95)	109 (24.44)
Negative Emotional Burden (NEB)	NSOC II				
	Low	105 (64.81)	107 (67.72)	33 (76.74)	357 (74.38)
	High	57 (35.19)	51 (32.28)	10 (23.26)	123 (25.63)
		Pearson chi2(3)= 7.1707 P = 0.067			
	NSOC III				
	Low	121 (74.69)	105 (68.18)	33 (86.84)	346 (75.88)
	High	41 (25.31)	49 (31.82)	5 (13.16)	110 (24.12)
Social Strain (SS)	NSOC II				
	Low	127 (73.84)	105 (64.42)	39 (88.64)	384 (77.42)
	High	45 (26.16)	58 (35.58)	5 (11.36)	122 (22.58)
		Pearson chi2(3)= 15.703, P= 0.001			
	NSOC III				
	Low	133 (77.78)	99 (61.49)	35 (89.74)	359 (75.74)
	High	38 (22.22)	62 (38.51)	4 (10.26)	115 (24.26)

Notes: Positive emotional benefit was assessed through 14 questions related to positive feelings about caregiving, life satisfaction, personal growth, and wellbeing. Scores ranged from 0 to 38, with higher scores indicating fewer positive emotion benefits. Negative emotional burden was measured through 12 questions concerning negative caregiving experience, mental health, and loneliness, with scores ranging from 0 to 34. A higher score indicates a greater negative emotional burden.

Social strain was measured using 6 questions related to participation, assessing whether they participated in activities, and whether caregiving responsibilities hindered their participation. Scores ranged from 0 to 6, with a higher score indicating higher social strain.

Each outcome were coded as "high burden" for the top quartile and "low burden" for the remainder. These outcomes have been previously substantiated through exploratory factor analysis and applied in previous caregiver-related studies. (3, 27, 42-43).

Chapter 4 Table 4. Prediction of Care-recipient relationship type on QoL changes over 2 years (2015-2017) (n=882)

	Model 1					**Model 2**					**Model 3**				
	OR	SE	P	95% CI		OR	SE	P	95% CI		OR	SE	P	95% CI	
Positive Emotional Benefit (PEB)															
2015 vs. 2017: OR=63.62, P<0.001, 95% CI [46.76, 86.55]															
Adult-child caregivers	1.07	0.28	0.783	0.65	1.79	1.15	0.37	0.662	0.61	2.17	1.07	0.35	0.844	0.56	2.02
"Other" caregivers	0.78	0.32	0.541	0.35	1.72	0.78	0.35	0.582	0.33	1.87	0.73	0.32	0.474	0.30	1.74
Multiple caregivers	1.00	0.24	0.984	0.63	1.61	0.95	0.29	0.867	0.52	1.74	0.89	0.28	0.706	0.48	1.64
Negative Emotional Burden (NEB)															
2015 vs. 2017: OR=48.69, P<0.001, 95% CI [36.50, 64.94]															
Adult-child caregivers	1.52	0.38	0.095	0.93	2.50	1.33	0.39	0.342	0.74	2.37	1.28	0.38	0.419	0.71	2.30
"Other" caregivers	0.59	0.20	0.119	0.30	1.15	**0.34**	**0.12**	**0.003**	**0.17**	**0.70**	**0.33**	**0.12**	**0.003**	**0.16**	**0.68**
Multiple caregivers	1.14	0.25	0.545	0.74	1.75	0.87	0.24	0.596	0.51	1.48	0.84	0.24	0.530	0.48	1.45
Social Strain (SS)															
2015 vs. 2017: OR=51.44, P<0.001, 95% CI [38.58, 68.58]															
Adult-child caregivers	**1.92**	**0.47**	**0.008**	**1.19**	**3.11**	1.12	0.36	0.718	0.60	2.12	0.97	0.32	0.916	0.51	1.84
"Other" caregivers	0.58	0.23	0.164	0.27	1.25	**0.37**	**0.16**	**0.019**	**0.16**	**0.85**	**0.31**	**0.13**	**0.005**	**0.14**	**0.71**
Multiple caregivers	1.24	0.25	0.289	0.83	1.85	0.78	0.23	0.404	0.43	1.40	0.67	0.20	0.188	0.37	1.21

Note:

Three Generalized estimating equation (GEE) models with a logit link function for each QoL outcomes and with spouse/partner caregivers as a reference group. Model 1 without adjustment for socio-demographics; Model 2 were adjusted for caregivers' socio-demographic characteristics including age, gender, race, income, education, marital status and living with a dependent child (<18yrs); Model 3 additionally controlled for care-recipients' dementia status.

OR: odds ratio; SE: standard error; 95% CI: 95% confidence intervals

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Appendix I

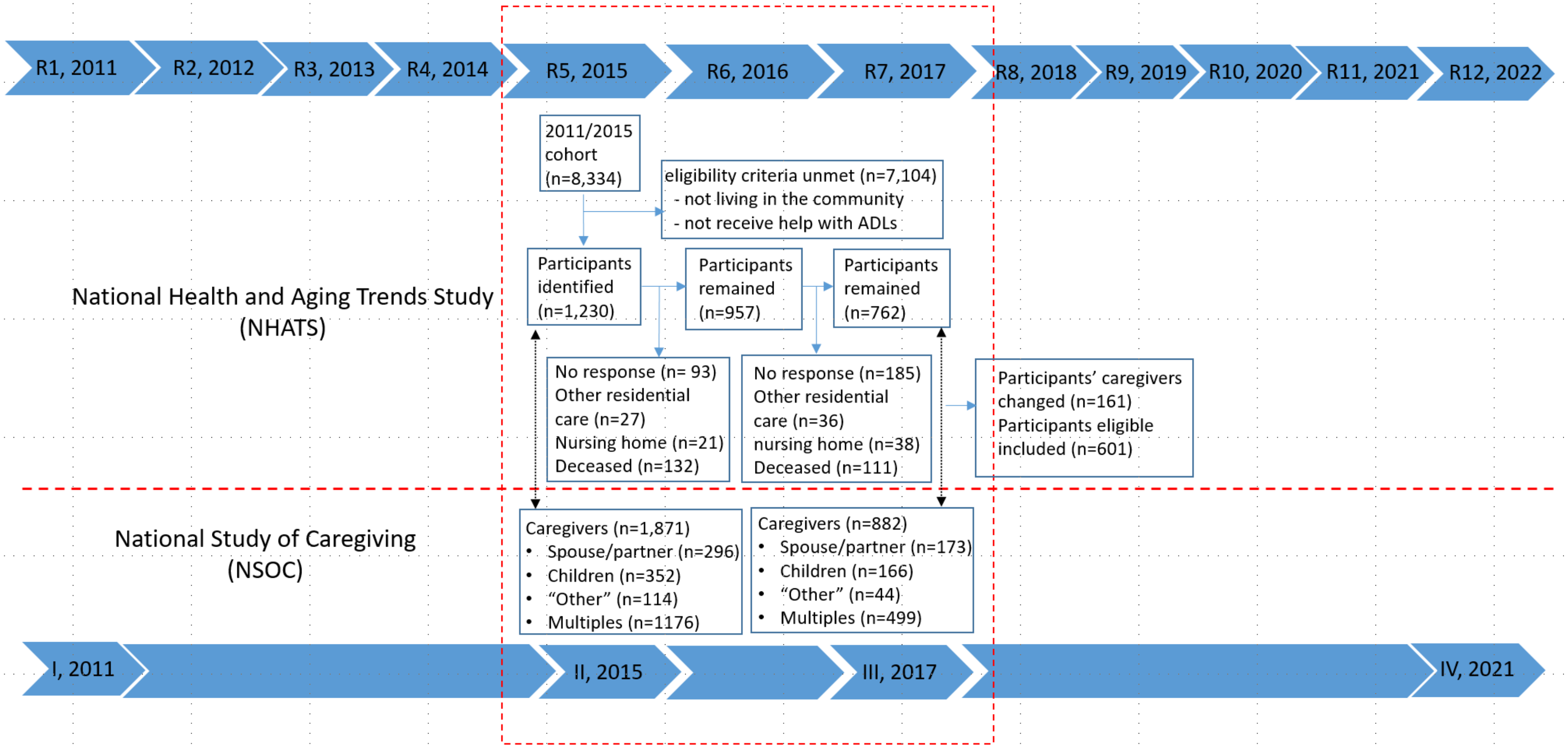
Chapter 4 Table S1. Caregivers' Quality of life (QoL) outcomes and pertaining questions at the National Study of Caregiving (NSOC)

QoL	Questions at NSOC
Negative emotional burden (NEB)	Over the last month, how often have you… 1 not at all; 2 several days; 3 more than half the days; 4 nearly every day
	• had little interest or pleasure in doing things? • felt down, depressed, or hopeless?
	• felt nervous, anxious, or on edge? • been unable to stop or control worrying?
	Over the last month, how often you feel… 1 every day; 2 most days; 3 some days; 4 rarely; 5 never
	• bored? • Lonely? • upset?
	Think about yourself, whether you… 1 agree strongly; 2 agree somewhat; 3 disagree somewhat; 4 disagree strongly
	• I gave up trying to improve my life a long time ago. • I often feel lonely because I have few close friends.
	Would you say… 1 a lot; 2 some; 3 a little; 4 not at all
	• How much does the recipient argue with you? • How often does the recipient get on your nerves?
	• Is helping emotionally difficult for you? 1 Yes; 2 No
Social strain (SS)	In the last month, did helping the recipient ever keep you from 1 Yes; 2 No
	• visiting in person with friends or family not living with you? • participating in club meetings or group activities? • going out for enjoyment? • working for pay? • doing volunteer work? • providing care for a child or other adult?
Positive emotional Benefit (PEB)	Think about yourself, whether you… 1 agree strongly; 2 agree somewhat; 3 disagree somewhat; 4 disagree strongly
	• My life has meaning and purpose. • In general, I feel confident and good about myself • I like my living situation very much. • I have an easy time adjusting to changes. • I get over (recover from) illness and hardship quickly.
	Thinking about the last month, how often did you … 1 every day; 2 most days; 3 some days; 4 rarely; 5 never
	• Feel cheerful? • Feel calm and peaceful? • Feel full of life?
	Would you say… 1 a lot; 2 some; 3 a little; 4 not at all
	• How much do you enjoy being with the recipient? • How much does the recipient appreciate what you do for them?

	Helping the recipient has 1 very much; 2 somewhat; 3 not so much
	• made you more confident about your abilities. • taught you how to deal difficult situations. • brought you closer to them. • gives you satisfaction that they are well cared for.

Adapted from NSOC data collection instrument form. Available at www. NHATS.org

Appendix II



Chapter 4 Figure 1. Informal caregivers over 2 years period (2015 to 2017)

Compared to those with complete data, caregivers with missing data tend to be younger, while care recipients are older. Additionally, they are more likely to be unmarried (including single, widowed, divorced), and a greater number of care recipients are probable or possible dementia cases. Details see Table S2 and S3.

Chapter 4 Table S 2. Comparison of caregivers in completed and excluded data

Variables, count (percentage)	Completed(n=882)	Excluded (n=989)	Chi-Square Test
Sex			
Male	285 (32.46)	339 (34.52)	Pearson chi2(1)= 0.88 P = 0.347
Female	593 (67.54)	643 (65.48)	
Age			
< 45 yrs	89 (10.25)	153 (15.92)	**Pearson chi2(3)= 14.03 P = 0.003**
45 to 54 yrs	169 (19.47)	194 (20.19)	
55 to 64 yrs	245 (28.23)	251 (26.12)	
65 + yrs	365 (42.05)	363 (37.77)	
Race/ethnicity			
Non- Hispanic White	477 (55.85)	573 (61.35)	Pearson chi2(3)= 6.01 P = 0.111
Non- Hispanic Black	296 (34.66)	276 (29.55)	
Hispanic	53 (6.21)	56 (6.00)	
Other	28 (3.28)	29 (3.10)	
Education			
Below high school	113 (14.14)	92 (10.09)	Pearson chi2(3)= 7.73 P = 0.052
High school	203 (25.41)	254 (27.85)	
Above high school	291 (36.42)	326 (35.75)	
Bachelor and above	192 (24.03)	240 (26.32)	
Marital status			
Married/living with a partner	515 (58.66)	604 (61.89)	Pearson chi2(1)= 2.01 P = 0.156
Unmarried	363 (41.34)	372 (38.11)	
Living with a child < 18yrs			
No	734 (84.95)	794 (82.71)	Pearson chi2(1)= 1.69 P = 0.194
Yes	130 (15.05)	166 (17.29)	
PEB			
Low	594 (70.71)	679 (72.54)	Pearson chi2(1)= 0.73 P= 0.393
High	246 (29.29)	257 (27.46)	
NEB			
Low	619 (73.43)	700 (75.03)	Pearson chi2(1)= 0.59 P= 0.442
High	224 (26.57)	233 (24.97)	
SS			
Low	655 (74.86)	701 (71.75)	Pearson chi2(1)= 2.27 P= 0.132
High	220 (25.14)	276 (28.25)	

Chapter 4 Table S3. Comparison of care recipients (i.e. PLWD) in completed and excluded data

Variables, count (percentage)	**Included (n=601)**	**Excluded (n=629)**	**Chi-Square Test**
Sex			
Male	202 (33.61)	198 (31.48)	Pearson chi2(1)= 0.64 P = 0.425
Female	399 (66.39)	431 (68.52)	
Age			
65 to 69 yrs	40 (6.66)	33 (5.25)	**Pearson chi2(5)= 16.82** **P= 0.005**
70 to 74 yrs	105 (17.47)	73 (11.61)	
75 to 79 yrs	115 (19.13)	101 (16.06)	
80 to 84 yrs	127 (21.13)	143 (22.73)	
85 to 89 yrs	118 (19.63)	144 (22.89)	
90+ yrs	96 (15.97)	135 (21.46)	
Race/ethnicity			
Non- Hispanic White	349 (58.46)	375 (59.90)	Pearson chi2(3) = 0.93 P = 0.818
Non- Hispanic Black	198 (33.17)	194 (30.99)	
Hispanic	31 (5.19)	33 (5.27)	
Other	19 (3.18)	24 (3.83)	
Education			
Below high school	211 (35.28)	201 (32.32)	Pearson chi2(3)= 2.99 P = 0.393
High school	163 (27.26)	197 (31.67)	
Above high school	136 (22.74)	135 (21.70)	
Bachelor and above	88 (14.72)	89 (14.31)	
Marital status			
Married/living with a partner	280 (46.59)	252 (40.06)	**Pearson chi2(1) = 5.33** **P = 0.021**
Unmarried	321 (53.41)	377 (59.94)	
Living arrangements			
Alone	120 (19.97)	129 (20.51)	Pearson chi2(3)= 7.58 P= 0.056
With spouse/partner only	198 (32.95)	180 (28.62)	
With spouse/partner and others	79 (13.14)	65 (10.33)	
With others only	204 (33.94)	255 (40.54)	
Dementia status			
Probable dementia	150 (25)	221 (35.19)	**Pearson chi2(2)= 22.34 P < 0.001**
Possible dementia	78 (13)	101 (16.08)	
No dementia	372 (62)	306 (48.73)	

Appendix III

Chapter 4 Table S4. STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No.	Recommendation	Page No.	Relevant text from manuscript
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	120	Impact of care-recipient relationship type on quality of life in caregivers of older adults with dementia over time
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	121	
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	122-123	
Objectives	3	State specific objectives, including any prespecified hypotheses	123	Therefore, this study aims to evaluate whether the care-recipient relationship type predicts changes in the QoL of informal caregivers of older adults with dementia over a two-year period. Specifically, the research questions are: 1) After adjusting for caregivers' socio-demographic factors, does the type of care-recipient relationship or shared caregiving predict changes in caregivers of PLWD's QoL over a two-year period? 2) Does PLWD's dementia status impact the prediction of care-recipient relationship type on caregivers' QoL change?
Methods				

Study design	4	Present key elements of study design early in the paper	125	This was a secondary analysis of longitudinal data.
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	NA	
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	125	The care recipient sample in this study were NHATS Round 5 participants who live in the community and receive help with certain Activities of Daily Living (ADL) - getting around inside, getting out of bed, eating, bathing/showering/washing up, getting to or using the toilet, dressing- from their informal caregivers at the time of enrolment. NHATS participants could identify up to five caregivers as helpers, but we only included the informal caregivers (i.e., family and unpaid caregivers) who were either 1) related to the older adults (relationship codes = 2-29 or 91) whether paid or not, or 2) unrelated to the older adult and not paid to help 118. Sample selection criteria were the same for both waves. However, if the NHATS sample persons that caregivers cared for in Round 5 (2015) was marked as non-response in Round 6 (2016) or Round 7 (2017), no attempt was made to contact the caregiver for NSOC III.
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	NA	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	126-127	**Type of relationship:** 1) care from a spouse/partner; 2) care from an adult child; 3) care from an informal caregiver other than a spouse/partner and adult child, such as child-in-law, sibling, etc. (referred to from here on as “other” caregiver). 4) If NHATs care-recipients indicated having multiple helpers/caregivers, each caregiver was included separately with a designation of “multiple” caregivers, as opposed to a single caregiver. Care from a spouse/partner is used as the reference category for statistical analyses.

				QoL outcome: negative emotional burden (NEB) and social strain (SS), positive emotional benefit (PEB). Dementia status: probable dementia, possible dementia, no dementia **Socio-demographic variables**: age range (<45yr, 45-54yr, 55-64yr, ≥65yr), gender (male, female), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, other), annual income (<1st quartile, 1st-2nd quartiles, 2nd-3rd quartiles, >3rd quartile), education (below high school, high school, above high school, bachelor and above), marital status (married/living with a partner, unmarried), and whether having a dependent child (<18yrs).
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	125	The data were drawn from two waves of linked National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) (2015: NHATS Round 5 & NSOC II; 2017: NHATS Round 7 & NSOC III). NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by Johns Hopkins University. Together the NHATS and NSOC are the only national platform for studying caregiving from the perspective of older adults and their caregivers.
Bias	9	Describe any efforts to address potential sources of bias	133	Details refer to the limitation section below.
Study size	10	Explain how the study size was arrived at	NA	

Continued on next page

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	137	Positive emotional benefit was assessed through 14 questions related to positive feelings about caregiving, life satisfaction, personal growth, and wellbeing. Scores ranged from 0 to 38, with higher scores indicating fewer positive emotion benefits. Negative emotional burden was measured through 12 questions concerning negative caregiving experience, mental health, and loneliness, with scores ranging from 0 to 34. A higher score indicates a greater negative emotional burden. Social strain was measured using 6 questions related to participation, assessing whether they participated in activities, and whether caregiving responsibilities hindered their participation. Scores ranged from 0 to 6, with a higher score indicating higher social strain. Each outcome were coded as "high burden" for the top quartile and "low burden" for the remainder. These outcomes have been previously substantiated through exploratory factor analysis and applied in previous caregiver-related studies.
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	127	Categorical variables, including the type of relationship, dementia status, socio-demographic characteristics, and the level of burden based on the QoL subscales (PEB, NEB, SS), were described using counts and percentages. Changes in "high" vs. "low" of QoL subscales over a 2-year period (from 2015 to 2017) were described using descriptive statistics. The association between baseline QoL subscale burden level and type of relationship was examined using Chi-square tests. Generalized Estimating Equations (GEE) with a logit link function was employed to investigate potential differences in QoL changes across four groups over a two-year period. The application of GEE enhances the robustness of our analysis by accommodating the longitudinal structure of the data, providing insights into group-specific variations in QoL trajectories over time. Three models were built with sequential adjustment for covariates: Model 1 was unadjusted; Model 2 adjusted for caregivers' socio-demographic characteristics; Model 3 additionally controlled for care recipients' dementia status.
		(*b*) Describe any methods used to examine subgroups and interactions	128	Generalized Estimating Equations (GEE) with a logit link function was employed to investigate potential differences in QoL changes across four groups over a two-year period.

		(*c*) Explain how missing data were addressed		
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed	128	Generalized Estimating Equations (GEE) with a logit link function was employed to investigate potential differences in QoL changes across four groups over a two-year period. The application of GEE enhances the robustness of our analysis by accommodating the longitudinal structure of the data, providing insights into group-specific variations in QoL trajectories over time.
		(*e*) Describe any sensitivity analyses	128	To assess the robustness of our results, we compared the differences in baseline QoL and socio-demographics between missing data and the data initially included at baseline.
Results				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	167	Compared to those with complete data, caregivers with missing data tend to be younger, while care recipients are older. Additionally, they are more likely to be unmarried (including single, widowed, divorced), and a greater number of care recipients are probable or possible dementia cases. Details see Chapter 4 Figure 1. Informal caregivers over 2 years period (2015-2017)
		(b) Give reasons for non-participation at each stage	167	See above
		(c) Consider use of a flow diagram	167	See above
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	128	Most caregivers were female (n=593, 67.54%), white (n=477, 55.85%), had no dependent child co-residency (n=734, 84.95%), married or living with a partner (n=515, 58.66%), had an education above high school (n=291, 36.42%), and were aged above 65years (n=365, 42.05%). Among them, 383 were single caregivers and were divided into three groups: spousal caregivers (n=173, 19.6%), adult-child caregivers (n=166, 18.8%), and “other” caregivers (n=44, 5%). Four hundred ninety-nine were multiple caregivers providing assistance to 218 older adults (see Table 1). Table 2 presents the demographic information of the older adults, including their age, gender, race, and dementia status. Compared to those with complete data, caregivers with missing data tend to be younger, while care recipients are older. Additionally, they are more likely to be

				unmarried (including single, widowed, divorced), and a greater number of care recipients are probable or possible dementia cases. Appendix II provides details regarding the reasons and differences for care recipients and caregivers missing in NSOC III (2017) compared to NSOC II (2015).
		(b) Indicate number of participants with missing data for each variable of interest	128	In 2015 NSOCII, 1871 caregivers were included to the study, linked to 1230 older adults in NHATS Round 5. By 2017, 882 caregivers remained eligible for the analysis, linked to 601 older adults in NHATS Round 7 (see appendix II).
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	128	Changes in "high" vs. "low" of QoL subscales over a 2-year period (from 2015 to 2017) were described using descriptive statistics.
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	129	As shown in Table 3, overall the odds of being high burden for each of the QoL measures (PEB, NEB, and SS) was higher in 2017 compared to 2015 (OR= 63.62, p<0.001, 95% CI [46.76, 86.55]; OR= 48.69, p<0.001, 95% CI [36.50, 64.94]; OR= 51.44, p<0.001, 95% CI [38.58, 68.58]; respectively).
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	129	A significant difference in SS was observed at baseline across four groups (Chi2 (3) = 15.703, P=0.001), with adult-child caregivers experiencing higher SS (Table 3). The same pattern persisted using GEE to assess the changes in QoL over time for the four groups. Adult-child caregivers exhibited a significantly higher risk of SS than spousal caregivers in the unadjusted model, but this was not statistically significant after adjusting for caregivers' socio-demographic variables and PLWD's dementia status (Table 4). "Other" caregivers demonstrated a lower risk of experiencing NEB and SS than spousal caregivers (OR=0.34, p=0.003, 95%CI [0.17, 0.70]; OR=0.37, p=0.019, 95%CI 0.16, 0.85]); in the adjusted model, respectively) (Table 4). This significant difference between "other" and spousal caregivers remained after additional adjustment for care recipients' dementia status (OR=0.33, p=0.003, 95%CI [0.16, 0.68]; OR=0.33, p=0.005, 95%CI [0.14, 0.71]; respectively).
		(*b*) Report category boundaries when continuous variables were categorized	132	Categorizing these outcomes into dichotomous variables (top quartile vs. remainder) may also pose bias due to cut-off selection, information loss, and reduced statistical power.

		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA	

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Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	133	We included only care recipients with consistent caregivers which results in the exclusion of 21% of the recipients in 2017. Care recipients who were non-respondents and whose caregivers changed in 2017 were older and had a greater number of being classified as probable or possible dementia compared to those being included (Appendix II). Even after conducting a sensitivity analysis comparing complete and missing data, no significant differences were found in caregivers' QoL measures (PEB, NEB, and SS). However, the higher dropout rates observed in the probable and possible dementia categories may bias the recipient sample towards milder cases. Furthermore, the reduction in sample size resulting from these dropouts may affect the study's statistical power, potentially leading to an insufficient detection of existing effects.
Discussion				
Key results	18	Summarise key results with reference to study objectives	129-132	
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	133	Given the nature of secondary data analysis, the original data were not collected to answer the present specific research questions. While the 3 domains of QoL used in our study were substantiated through exploratory factor analysis and applied in previous caregiver-related studies, the use of these three specific domains does not fully address the broad scope of QoL issues that arise from informal caregiving duties. Future studies should explore other aspects of QoL (e.g., material well-being, health status and use validated measures (e.g., Carer well-being and support questionnaire, Satisfaction with Life Scale to substantiate the findings of this study. In addition, care recipients' multi-morbidity and health were not captured in this study. This may result in a potentially heterogeneous group, which may affect the generalizability of the study results to the source caregivers of PLWD population. Future primary research should consider a broader scope of possible influencing factors to validate and generalize the findings of this study. Another limitation is that we only included baseline dementia status in the analysis, which was reported as the best predictor of cognitive change in a population of older adults. However, the dementia status may have changed over time, which may have a degree of impact on the findings. The potential for generating false negatives and false positives in dementia classification may influence the direction and magnitude of findings, depending on the accuracy of capturing dementia status within each caregiver group. For example, if false negatives occur within the spouse caregiver group, this could result in an underestimation of the prevalence and impact of dementia-related stressors on their QoL,

				consequently leading to an overestimation of the impact of caregiver types on their QoL. Furthermore, some of sample attrition in this longitudinal analysis may have been selective, and we included only care recipients with consistent caregivers which results in the exclusion of 21% of the recipients in 2017. Care recipients who were non-respondents and whose caregivers changed in 2017 were older and had a greater number of being classified as probable or possible dementia compared to those being included (Appendix II). Even after conducting a sensitivity analysis comparing complete and missing data, no significant differences were found in caregivers' QoL measures (PEB, NEB, and SS). However, the higher dropout rates observed in the probable and possible dementia categories may bias the recipient sample towards milder cases. Furthermore, the reduction in sample size resulting from these dropouts may affect the study's statistical power, potentially leading to an insufficient detection of existing effects.
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	133	See limitation section above.
Generalisability	21	Discuss the generalisability (external validity) of the study results	134	The study demonstrates that spousal caregivers face a higher risk of negative emotional burden and social strain in QoL domains over time, even after accounting for sociodemographic variables related to caregivers' and care recipients' dementia status. These findings underscore the pressing need to offer accessible and effective support for informal caregivers of PLWD, especially those caring for their spouses, across the domains of public policy, research, and practical interventions.
Other information				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	NA	

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org

CHAPTER 5: DISCUSSION

Dementia is a leading cause of disability and dependency among older adults worldwide. It profoundly affects memory, cognitive functions, and behavior, hindering individuals' capacity to perform daily activities [1]. While enhancing the QoL of this population is widely acknowledged as a primary goal of dementia care, the paucity of longitudinal studies poses a challenge in comprehending the long-term changes in QoL [143]. Dementia affects not only the people living with the condition, but also the caregivers who provide care for them. As this incurable disease progresses, the caregiving demands gradually increase, leading informal caregivers of PLWD to report diminished physical health [144] and a reduced QoL [101,145] compared to caregivers of those without dementia. Furthermore, caregivers of PLWD more frequently encounter substantial negative psychosocial facets of caregiving, such as distress [5] and constraints on their social activities [102,144,146]. For example, 45% of caregivers for PLWD show symptoms of distress, a rate almost double that of caregivers for older adults with other health conditions [5]. In Canada, about 61% of PLWD live at home, and approximately 350,000 individuals are providing informal care for the 600,000 Canadians living with Alzheimer's disease and other dementias [3]. This number is projected to nearly triple over a 30-year period from 2020 to 2050, creating an increased demand on Canada’s health care systems [5]. Therefore, it is crucial to prioritize research on the QoL of PWLD and their caregivers, to assist policymakers and society in healthcare planning for future needs.

The reciprocity of caregiving between the caregiver and care recipient [134] emphasizes the importance of viewing both members of the dyad as a unit when evaluating the QoL for each. A recent review of dyadic relationships in dementia care highlighted that current research on this topic predominantly focuses on couple relationships, and suggests that the experiences of couples differ substantially from those of children or other caregiving networks [147]. Caring for a parent with dementia may be perceived by adult-child caregivers as just one among many responsibilities, such as raising children or working, while caring for a spouse with dementia can be particularly psychologically demanding [148,149]. Therefore, it is important to explore factors related to care-recipient relationship types in dementia care, including diverse caregiver typologies, the sharing of caregiving responsibilities among a network of caregivers, and the consideration of variations in socio-demographics. However, there are currently two notable gaps in the existing literature regarding the care-recipient relationship type. Firstly, the dearth of longitudinal studies requires a comprehensive understanding of the trajectories of QoL. Secondly, the predominant focus on the single primary caregiver has resulted in a lack of knowledge about how the distribution of caregiving responsibilities among multiple caregivers impacts the wellbeing of dyads. Addressing these gaps is crucial for a comprehensive understanding of the intricate dynamics between caregivers and care recipients. It is essential to identify target intervention opportunities in informal dementia care, while considering the evolving nature of care relationships [150].

This thesis consists of three manuscripts that examine the influence of care-recipient relationship type on the QoL among community-dwelling older adults with dementia and their informal caregivers. The investigation utilizes both cross-sectional and longitudinal secondary analysis across multiple rounds of two companion datasets: National Health and Aging Trends study (NHATS) and National Study of Caregiving (NSOC) [95]. Four types of relationship were identified: (1) care from a spouse/partner; (2) care from an adult child; (3) care from an informal caregiver other than spouse/partner and adult child, such as child-in-law, sibling, etc. (referred as "other" caregiver); and (4) care responsibilities shared by two or more caregivers (referred to as "multiple" caregivers). PLWD's QoL was assessed in 4 domains: mental health, general health, functional limitations, and pain. The International Classification of Functioning, Disability and Health (ICF) framework was used to guide the selection of PLWD's QoL domains because the multidimensional aspect of the ICF framework, including not only health-related domains but also social and environmental factors, align well with the complex nature of QoL in the context of dementia [24,25,151]. In addition, the Stress Process Model of Family Caregiving [32,33,105] was utilized to guide the measurement of caregivers' QoL. This is the most widely used framework for understanding the experience of informal caregivers for individuals with chronic illness. It allows for the examination of various factors, including stressors, resources, and outcomes, in revealing the dynamic and complex nature of caregiving [152]. Caregiver outcomes were evaluated based on their appraisals of the care situation in relation to available resources, such as supportive services and coping strategies. These appraisals can result in negative or positive subjective caregiving experiences. Accordingly, the measurement of caregiver QoL in this thesis encompassed three outcomes: negative aspects, including negative emotional burden and social strain, and positive aspects, namely positive emotional benefits.

Summary of findings from individual manuscripts

Chapter 2: The Impact of Care-recipient Relationship Type on Health-related Quality of Life in Community-Dwelling Older Adults with Dementia and Their Informal Caregivers

This is a secondary, cross-sectional analysis on 1230 care recipients (i.e. PLWD) and 1871 caregivers identified from NHATS Round 5 and NSOC II [84]. The purpose of this study was to examine whether there was an association between care-recipient relationship type and the QoL of both PLWD and their informal caregivers. The findings showed that PLWD cared for by an adult-child or multiple caregivers exhibited higher functional limitations, one domain of QoL, compared to those cared by a spousal caregiver. This distinction remained even after controlling for the care recipients' socio-demographics and their dementia status. Caregivers' QoL outcomes also demonstrated variations based on relationship types. “Other” caregivers, such as extended family members, experienced a reduced likelihood of encountering negative emotional burden and social strain, compared to spousal caregivers. Similarly, “multiple” caregivers demonstrated lower odds of experiencing negative emotional burden than their spousal counterparts. When comparing amongst single caregivers, adult-child caregivers were associated with lower negative emotional burden but higher social strain compared to the spousal caregivers. However, upon accounting for care recipients' dementia status, the association between adult-child caregivers and social strain did not remain significant, while the significance of “other” caregivers in the association with negative emotional burden and social strain persisted. It is also important to note that after considering dementia status, “other” caregivers demonstrated a significantly higher likelihood of experiencing positive emotional benefit compared to spousal caregivers. The study reveals variations in both PLWD and caregivers' QoL outcomes based on relationship type, with PLWD's dementia status influencing the association between care-recipient relationship type and caregivers' QoL.

The findings provide new perspectives in informal dementia care, suggesting potential variations in QoL outcomes and distinctions in different QoL domains based on the care-recipient relationship type for PLWD and their informal caregivers. Taking into account changes in family structure and dynamics, the study expands the research focus beyond the traditional primary caregiver typologies of spouses and children and incorporates a broader spectrum of caregiving relationships, including shared caregiving aspects and “other” caregivers. In addition, it adds to the literature by highlighting the influence of care recipients' dementia status in the association between caregivers' QoL and the type of relationship. However, this study is cross-sectional and therefore did not have the temporal relationship to determine a causal trend. The subsequent two studies employed longitudinal analysis on the impact of the type of relationship on the QoL of both care-recipients and caregivers over time.

Chapter 3: Impact of Care-recipient Relationship Type on Quality of Life in Community-Dwelling Older Adults with Dementia over Time

To evaluate how the care-recipient relationship type influences the change of QoL in PLWD over time, this study analyzed longitudinal data from five rounds of NHATS datasets (Round 5 to Round 9) [122]. The results showed that PLWD cared for by an adult-child or "multiple" caregivers predicted increased risk for functional limitations after adjustment for their socio-demographics (age, sex, race, income, education, marital status, living arrangement) and dementia status (probable dementia, possible dementia, and no dementia). These findings further corroborate the Chapter 2 cross-sectional study results from a longitudinal standpoint, underscoring the importance of promoting awareness regarding variations in the QoL trajectory among PLWD based on different types of caregivers. These results contribute robust evidence about the significant impact of care-recipient relationship types on changes in PLWD's QoL, especially functional limitations, over time.

Another finding from this study is that, after examining interaction terms between socio-demographics and relationship types, an interactive influence related to the care recipients' education attainment was observed. Among care recipients with a high school education or below, those with adult-child caregivers faced a significantly higher risk of increasing functional limitations over time compared to those with spousal caregivers. For care recipients with a high school education, those cared for by "multiple" caregivers also exhibited a significantly higher risk of functional limitations than those with spousal caregivers. No significant interaction of education attainment was observed between care recipients being cared for by "other" caregivers compared to those with spousal caregivers.

While there has been a notable increase in efforts in recent years to shift dementia care from perceiving it solely as a disease requiring management to prioritizing the QoL for PLWD, there is insufficient evidence about the impact factors on PLWD’s QoL, such as care-recipient relationship type. In addition, there is a dearth of longitudinal studies in this area [153]. This study serves as the first longitudinal investigation employing secondary analysis on national datasets to examine PLWD's QoL changes over time, specifically considering the impact of the dyadic relationship. It views QoL as a multidimensional concept and supports a need to prioritize resource allocation to address the caregiving demands of caregiving for community-dwelling PLWD, taking into consideration socio-demographic characteristics such as education level.

Chapter 4: Impact of Care-recipient Relationship Type on Quality of Life in Caregivers of Older Adults with Dementia over Time

This study is a longitudinal analysis on changes in caregivers' QoL over 2 years. Data were from NSOC II, NSOC III, and their companion study of NHATs Round 5 & Round 7. The results showed that over time, all three QoL outcomes (positive emotional benefit, negative emotional burden, and social strain) demonstrated higher odds of experiencing high burden compared to the baseline in 2015. Spousal caregivers had a higher risk of experiencing negative emotional burden and social strain than “other” caregivers over time. This tendency remained significant, whether or not accounting for caregivers’ socio-demographics (age, gender, race/ethnicity, annual income, education, marital status, and whether having a dependent child) and care recipients’ dementia status. This causal relationship aligns with the findings in Chapter 2 and contributes to the overall body of evidence.

In addition, adult-child caregivers initially showed a significantly higher risk of social strain over time compared to spousal caregivers, but the significance of this difference diminished after adjusting for their socio-demographics and care-recipients' dementia status. A comparison of spousal and adult-child caregivers revealed notable differences in their race, education, and age range. Variations in dementia status were also observed among care recipients in these two groups. Existing literature suggests that the dementia caregiving experience may be associated with socio-demographics factors and PLWD's cognitive function [16,34,115,133,134,154,155]. Therefore, it is plausible to propose that the observed changes in the relationship between caregiver type and social strain in this study can be explained, at least partially, by the combined impact of both caregiver and care-recipient factors.

The anticipated findings of having a significantly higher positive emotional benefit for "other" caregivers and lower negative emotional burden for "multiple" caregivers, as reported in the Chapter 2, were not sustained in this longitudinal analysis. These results could be attributed to various factors in this study, such as the relatively short follow-up period (only two years), the heterogeneous nature of the "multiple" caregivers, or the diversity in the conceptual term of positive emotional benefit. Moreover, the high percentage of missing data due to the exclusion of participants caring for recipients with non-response, deaths, and moving to institutionalized settings, combined with the inclusion criteria limited to those identified as caregivers in both 2015 and 2017, is also an important contributor to these nonsignificant findings.

Contribution of thesis work

As the first research analyzing dyadic data involving both PLWD and their caregivers to investigate the impact of relationship types on the QoL of dyads cross-sectionally and longitudinally, this thesis makes contributions both theoretically and practically. It not only advances the theoretical knowledge by reporting new empirical evidence regarding the impact of care-recipient relationship type on the QoL of PLWD and their caregivers, but also contains practical implications by providing knowledge transfer to the dementia care and caregiver support system. These two types of contribution are discussed in the next section.

Theoretical contributions:

Existing caregiving literature has predominantly focused on single primary caregivers. Considering the dynamic nature and evolving structure of families [110], the network of caregivers for PLWD has expanded beyond the traditional primary kinship types, such as spouses and adult-children. The datasets selected for this series of secondary analyses, NHATS and NSOC, allow us to analyze dyadic data involving both care recipients and caregivers with a broader range of care-recipient relationship types. NHATS conducts annual in-person interviews with a nationally representative sample of Medicare beneficiaries ages 65 years or older in the United States, while NSOC conducts periodical phone interviews with informal caregivers of NHATS participants to provide the perspective of family assisting older adults with daily life limitations. Together, NHATS and NSOC constitute the only national study providing both care recipient and caregiver perspectives on late-life care [156]. Instead of identifying a single primary caregiver to participate, NHATS interviews aim to include all eligible helpers for whom contact information is available. This design yields a caregiver sample that is representative of all eligible caregivers of NHATS participants and provides insights into how the distribution of caregiving responsibilities. Using data drawn from these national companion datasets, this thesis contributes to the current literature by evaluating different typologies of care-recipient relationship, including spouses, adult-children, "other" relationships involving extended family members, as well as shared caregiving approaches (i.e. “multiple” caregivers). The results indicate that spousal caregivers are associated with a higher risk of experiencing caregiving negative emotional burden than other relationship types, such as adult-child caregiver, “other” caregiver, or those who share caregiving responsibilities. This suggests a potential protection effect on QoL when caregivers are in extended relationship to the PLWD, or when two or more caregivers share care tasks. Conversely, the care-recipient relationship being spouses shows protection in QoL of PLWD, with recipients cared for by spousal caregivers linked to a lower risk of experiencing functional limitations compared to those cared for by adult-child caregiver or “multiple” caregivers. This recognizes the dynamic, evolving caregiver network and highlights the importance of a better understanding of how different care-recipient relationship types affect the QoL of both PLWD and their caregivers. This understanding can help identify new intervention opportunities and supportive services for dementia care and caregiving support system.

The challenges and needs of informal caregivers evolve as dementia progresses [157] while coping strategies develop gradually [18,158]. The availability of multiple rounds in NHATS and NSOC allows for the continuation of longitudinal analysis to examine and validate the cross-sectional association results in this thesis. Using the Generalized Estimating Equations (GEE) approach as the primary method, the thesis found a significant higher risk of having negative emotional burden on spousal caregivers compared to “other” caregivers over time. Although no significant longitudinal evidence validates the cross-sectional findings of lower negative emotional burden on adult-child caregivers and those who share caregiving responsibilities, this thesis adds to the literature by showing that the caregivers' change in QoL over time differs by relationship type, with spousal caregivers facing a higher risk of negative caregiving aspect than those who are in an extended relationship to the recipient. This emphasizes the need for further exploration of how care responsibilities are negotiated or distributed within a group of caregivers over time and how this impacts caregivers QoL and caregiving experiences [109]. Similarly, the cross-sectional association between PLWD being cared for by spouses and a lower risk of functional limitations in the QoL domain is further observed through GEE longitudinal analysis over 5 rounds of NHATS across 4 years. Guided by the ICF framework, a well-established multidimensional model for evaluating QoL, the evaluation of PLWD's QoL spans multiple domains, including mental health, general health, functional limitations, and pain. Consistent findings observed from cross-sectional and longitudinal analysis regarding PLWD being cared by spousal caregivers demonstrate a lower risk of functional limitations than those being cared by "other" caregivers significantly contribute to the current research gap on the impact of relationship type on PLWD's QoL changes. This insight can guide the identification of new intervention opportunities to improve the QoL of PLWD, emphasizing consideration of different domains and the structural aspects of the caregiver relationship.

Another significant contribution is the finding of positive aspects of caregiving in dementia care, addressing a topic that warrants further investigation. Positive aspects of caregiving for PLWD are increasingly recognized, with factors such as caregivers' socio-demographics and caregiving duration influencing these aspects [134,137,159–162]. Guided by the widely recognized Pearlin stress model in caregiving, the thesis comprehensively assesses the QoL of PLWD's caregivers through positive emotional benefit, negative emotional burden, and social strain. It is very interesting to note that “other” caregivers (e.g., child-in-laws or siblings) demonstrated higher positive emotional benefit after considering their socio-demographics and their recipients’ dementia status. While this has not been further validated in our subsequent longitudinal analysis, it highlights the need for further studies on how the positive emotional benefits for caregivers of PLWD vary based on the type of relationship and also suggests using standardized measurements to comprehensively explore this theme.

Practical contributions:

The findings of this thesis show that spousal caregivers of PLWD are associated with a higher odds of negative caregiving aspects compared to “other” caregiver types. This suggests that while all caregivers may benefit from social and healthcare services, spousal caregivers of PLWD are groups with particularly high demands that warrant attention. These insights help inform public policy decisions, especially with the reported increase in informal care provision, particularly for caregivers of PLWD dedicating over 20 hours per week in North America (including the U.S. and Canada) and U.K. [5,8,97,163]. The cross-sectional findings of adult-child caregivers experiencing higher social strain, but lower negative emotional burden, compared to spousal caregivers suggest distinctions in caregiving challenges and support needs based on different relationship type. It emphasizes the needs for tailored interventions to address specific caregiver subgroups when aiming to enhance the QoL of caregivers of PLWD. This practical insight can serve as a reference for policy makers, researchers, service providers, and practitioners to evaluate the full range of care demands. It also encourages them to further explore caregiving when designing policies and support services to alleviate caregiver burden and improve caregiver QoL.

As the first longitudinal study examining the impact of the type of relationship on changes in QoL over time for PLWD, this thesis introduces new perspectives into informal care for PLWD. It encourages policymakers to not only recognize potential discrepancies in various QoL domains, such as functional limitations for PLWD based on the type of relationship, but also underscores the importance of considering socio-demographic factors, such as education level, when evaluating their QoL and considering potential interventions. Combined with previous literature that reported healthcare providers can effectively differentiate between case severities in resource allocation even within a more limited budget [164], this thesis serves as a practical guide for targeted resource allocation. The findings of this thesis can guide targeted resource allocation, addressing the diverse needs of PLWD based on their specific relationship types within the context of socio-demographics.

Limitations and future research direction

Limitations:

The limitations of Chapter 2 to 4 have been delineated within each manuscript. Firstly, the inherent nature of secondary analyses imposes constraints on data collection for our research objectives. While the QoL measurements can be selected across various domains, the initial design of the NHATS and NSOC datasets lack common QoL scales for PLWD, such as the Short Form 36 (SF-36), Quality of Life in Alzheimer Disease (QOL-AD), Alzheimer Disease-Related Quality of Life (ADRQL), or Quality of Life in Late-Stage Dementia (QUALID), as well as QoL measures for caregivers, such as Carer well-being and support questionnaire (CWS) [165], Scales measuring the Impact of DEmentia on CARers (SIDECAR) [166], or Zarit Burden Interview (ZBI) [167]. This limits the comparison of findings with other studies. In addition, the dementia classification in the original datasets, while possessing high validity and reliability [96,168,169] and being used in many other NHATS related publications [170–173] operates as a status classification rather than a severity scale, such as the Mini-Mental State Examination (MMSE), Clinical Dementia Rating (CDR), or Global Deterioration Scale (GDS). This characteristic may potentially limit the depth of information provided by the categorical scale. Secondly, the presence of missing data over time results in a diminished sample size, impacting the inclusion of covariates (e.g., multi-morbidity and health condition) and reducing the size of subgroups. Despite a substantial number of participants included at baseline, factors such as relocation to institutionalized settings, mortality, and non-response contribute to a significant amount of missing data during follow-ups. This limitation affects the selection of covariates and the size of the sample, especially in the group where PLWD are cared for by “other” caregivers. Thirdly, the short duration of follow-up (two years from 2015 to 2017) and only two available time points (NSOC II and III) for caregivers' QoL change represent a constraint. NSOC was not conducted annually until 2021, and the fourth round was released in 2023. During the preparation of this thesis, only three rounds of NSOC were available, which were intermittently fielded in 2011, 2015, and 2017.This limits the comprehensive understanding of changes over time. Fourthly, participants' dementia status may evolve over time, but the analysis of this thesis only captures their status at the baseline. Continuing dementia progression may contribute to a decrease in QoL over time for PLWD [15,54], while also influencing the wellbeing and caregiving experience of their informal caregivers [174,175]. While this does not significantly impact the cross-sectional analysis in Chapter 2, it could influence the results of the longitudinal analyses in Chapters 3 and 4.

Future research:

Future research should focus on prospective studies, collecting data at multiple time points and tailoring designs to address specific research questions. By increasing the sample size to incorporate more covariates, such as dyads' health condition, caregiving duration and activities [176,177], we can gain a deeper understanding of the impact of care-recipient relationship type on QoL in PLWD and informal caregivers A larger sample size would also enable the analyses of subgroups, especially in the case of different care-recipient relationship types. This could validate the current findings of this thesis and reveal specific patterns or associations that may be masked. With more rounds of NHATS and NSOCS data available, this becomes possible. In addition, while the association between mental health (e.g., depression) and the QoL of PLWD is well recognized, the relationship between cognitive impairments and QoL of PLWD and caregivers is controversial [40,178,179]. Future studies should build upon the existing evidence presented in this thesis and further consider dynamic changes in dementia development over time, along with caregiving outcomes in response to these changes, such as caregiving complexity, intensity, and coping strategies. Furthermore, the NSOC will conduct annual data collection to align with NHATS, implying that more data will become available over time. With an increasing amount of historical data, future studies can consider employing analytical and machine learning-based approaches to facilitate more efficient and cost-effective conversations in terms of evaluating the caregiving tendencies, identifying potential impact factors, and more.

Another important consideration is to involve PLWD and caregivers more actively in the research to capture subjective elements of QoL through qualitative research methods. By taking into account individuals' own perspective in addition to objective criteria contributes to a more comprehensive understanding of QoL as a multidimensional concept [149,153]. Adopting a mixed methods approach, which integrates insights from individuals' experience through qualitative data with the robustness of quantitative evidence, allows for thorough exploration and adds richness and depth to the research. Furthermore, supplementing qualitative research with PLWD’s voices being heard aligns with the emerging human rights-based perspective and promotes a more ethical approach in research [153]. This approach not only offers valuable insights into the practical implications of QoL issues but also contributes to the development of tailored policies and supportive services that are more responsive to the needs of PLWD and their caregivers.

By incorporating these strategies, future studies can enhance the rigor and impact of the findings of this thesis, gradually mitigating the challenges associated with secondary analysis and small sample sizes over time.

Conclusions

This thesis examined the impact and prediction of care-recipient relationship types on the quality of life (QoL) in people living with dementia (PLWD) and their informal caregivers. Through cross-sectional and longitudinal analyses conducted in well-organized national companion datasets, the thesis contributes to the literature by acknowledging the increasing role of “other” caregivers and shared caregiving responsibilities. It provides longitudinal evidence on caregivers' QoL changes, recognizes positive aspects of caregiving, identifies research gaps, and reveals the impact of relationship types on PLWD’s QoL across multiple domains. Additionally, it highlights variations in caregivers’ QoL domains in response to increasing caregiving responsibilities.

The thesis findings not only offer valuable insights for policymakers and health providers but also provide evidence to support practical applications. These insights emphasize the importance of tailoring interventions to address specific caregiver subgroups, evaluating the full range of care demands, and exploring policies and supportive resources geared towards these demands. Furthermore, the study recognizes the varied needs of PLWD within the context of their socio-demographics and being cared for by different types of caregivers.

In conclusion, this thesis contributes considerably to dementia care by demonstrating the need for an integrated and holistic approach to informal care for PLWD and client-centered support to their caregivers.

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