

Original Research

## Exploring Caregiver Quality of Life in Dementia: The Role of Mealtime and Care Recipient Factors

David F. Bayne<sup>1, 2, \*</sup>, Willow Keefe<sup>1</sup>, Samantha E. Shune<sup>1</sup>

1. College of Education, University of Oregon, Eugene, OR, USA; E-Mails: [dbayne@ithaca.edu](mailto:dbayne@ithaca.edu); [wkeefe@uoregon.edu](mailto:wkeefe@uoregon.edu); [sshune@uoregon.edu](mailto:sshune@uoregon.edu)
2. Ithaca College, School of Health Sciences and Human Performance, Ithaca, NY, USA

\* **Correspondence:** David F. Bayne; E-Mail: [dbayne@ithaca.edu](mailto:dbayne@ithaca.edu)

**Academic Editor:** David G Smithard

**Collection:** [Dysphagia in Older People](#)

*OBM Geriatrics*

2024, volume 8, issue 3

doi:10.21926/obm.geriatr.2403289

**Received:** July 01, 2024

**Accepted:** September 22, 2024

**Published:** September 28, 2024

### Abstract

Informal caregivers play a critical role in supporting individuals with dementia, yet often face significant challenges that impact their own quality of life (QoL). This exploratory study investigates the multifaceted factors contributing to caregiver QoL, particularly focusing on care recipient factors including dysphagia, dietary restriction, dementia severity, and care recipient QoL. A total of 24 informal caregivers of persons with dementia (PWD) participated in an online survey assessing various factors believed to play a role in caregiver QoL including dysphagia severity, dietary restrictiveness, cognitive impairment, and caregiver QoL. Results revealed that increased degree of dietary restrictiveness, lower dementia symptomatology, and higher care recipient QoL were significant predictors of improved caregiver QoL. These findings highlight the complex interplay of factors influencing caregiver QoL and underscore the need for tailored interventions to enhance well-being in both caregivers and care recipients within community-based care settings.

### Keywords

Caregiver; quality of life; dementia; dysphagia; biopsychosocial



© 2024 by the author. This is an open access article distributed under the conditions of the [Creative Commons by Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium or format, provided the original work is correctly cited.

## 1. Introduction

The role of informal caregivers in supporting individuals with dementia demands immense dedication, compassion, and resilience. Caring for a person with dementia (PWD) is emotionally and physically taxing, often significantly impacting the caregiver's own quality of life (QoL) [1, 2]. Dementia, characterized by progressive neurodegeneration, manifests through evolving symptomatic expressions over time [3]. According to the World Health Organization, QoL reflects individuals' perceptions of their life situation within cultural and value frameworks [4]. Considering these definitions together, caregivers may experience shifts in their QoL as they undertake increasing care responsibilities to meet the growing needs of their care recipients.

While definitions of caregiver QoL vary, research suggests a link between caregiver QoL and caregiver burden which is directly influenced by factors such as perceived social support, availability of rest, and the relationship with the care recipient [5, 6]. Notably, caregivers of PWD often experience a decline in QoL over the course of their caregiving journey as dementia severity advances [7]. Caregivers are often faced with the challenge of adapting their care routines to the evolving needs of the care recipient, which can be emotionally taxing and physically demanding. Additionally, as dementia progresses, caregivers face an increasing number of challenges, ranging from cognitive and behavioral changes in the care recipient to managing daily activities and healthcare needs [3, 8, 9]. The QoL of the care recipient may play a pivotal role in influencing the caregiver's own QoL [6]. During disease progression, the care recipient's QoL may deteriorate, further intensifying undesirable health and well-being outcomes in the caregiver/care recipient dyad.

Previous literature shows that caregiver QoL is influenced by a range of factors, including the severity of the patient's symptoms, the level of cognitive decline, and the frequency of behavioral and psychiatric symptoms [3, 7, 10, 11]. Emotional stress, physical exhaustion, and social isolation can also significantly impact caregivers, often exacerbated by a lack of adequate support systems and respite opportunities [3, 8, 9]. These challenges can be particularly salient when mealtime impairment (e.g., dysphagia) places additional burden on caregivers of heterogeneous groups of older adults [12-16]. This may be even more magnified for caregivers of PWD, which has not been previously explored. As has been suggested in the recent Biopsychosocial Model of Mealtime Management [10], there is a complex interplay of biological, psychological, and social factors leading to mealtime difficulties among PWD that impact the caregiving experience. It may be crucial, then, to explicitly consider the multifaceted nature of dementia care in mealtime management to illuminate which of these factors may also be leveraged to enhance QoL for caregivers of PWD.

One particularly challenging aspect of dementia caregiving related to mealtime impairments is dysphagia, the difficulty or inability to swallow safely and efficiently. Dysphagia is a prevalent issue among people with dementia, affecting up to 93% of individuals at some point during the course of the disease [17, 18]. Dysphagia not only presents immediate risks, such as the risk of choking or aspiration pneumonia, but it also adds a layer of complexity to the caregiving process. Dysphagia can lead to significant dietary restrictions, often requiring caregivers to modify food textures and mealtime routines to ensure safety [19, 20]. This, in turn, may impact the overall well-being of both the care recipient and the caregiver [21]. Furthermore, the severity of dementia symptoms,

including cognitive and behavioral changes, can vary widely among PWD. Previous research has supported dysphagia as an independent contributor to general caregiver burden [12-16]. However, it is currently unknown how dysphagia contributes to caregiver QoL, particularly in light of the other known contributors to QoL.

Understanding the multifaceted factors that contribute to caregiver QoL in the context of dementia caregiving, particularly when dysphagia is involved, is of paramount importance. This exploratory study delves into the intricate relationships between caregiver QoL, dysphagia, dietary restriction, dementia severity, and care recipient QoL. We hypothesize that increased dietary restriction, increased dementia related symptomatology, increased swallowing/feeding difficulty, increased dysphagia-related caregiver burden, and decreased care recipient quality of life would result in decreased caregiver quality of life. While informal caregivers play a vital role in supporting individuals with dementia, their own quality of life (QoL) is often profoundly impacted by the caregiving experience. By investigating these factors, we seek to uncover unique dynamics and identify potential areas for interventions to enhance the well-being of both caregivers and care recipients in community-based care settings.

## **2. Methods**

### **2.1 Participants**

As an exploratory study interested in capturing a wide range of experiences, inclusion criteria for participation remained broad. Eligibility criteria included: (1) 18 years of age or older; (2) being an informal (e.g., unpaid) caregiver of a person with dementia; and (3) acting as an informal caregiver for a minimum of two months. Regarding dementia diagnosis, caregivers were asked whether their care recipients had a formal, medical diagnosis of dementia. To ensure confidentiality, however, medical records were not collected for participation in this study. Participants were not considered eligible for this study if they were younger than 18 years of age, received pay for their care support, and/or had not been providing care for a minimum of two months. Recruitment material for study participation was disseminated via online message boards for caregivers of people with dementia and speech-language pathologists (SLPs) that work with this population. Recruitment flyers were also posted in doctor's offices and community message boards. As the nature of this survey study did not require collection of any identifying information and had minimal risk, an information statement was presented to participants at the onset of the survey and consent to participate was assumed via completion of the survey. Participants did not receive any financial compensation for completion of the surveys. This study was completed with approval from the Institutional Review Board at the researchers' institution.

### **2.2 Data Collection and Outcome Measures**

#### **2.2.1 Procedures**

All caregivers completed an online survey that contained a demographics section, a section on the functional status of their care recipient, and a section on their own well-being. The survey was open for a period of five months, and took 12 minutes on average to complete. Demographic information collected included information about both the caregiver themselves and their care

recipients. Information collected regarding caregiver demographics included age, gender, relationship to the care recipient, employment status, and number of hours per week spent providing care. Demographic information about the care recipient included age, dysphagia diagnosis status, and the caregiver's subjective impression of the care recipient's dementia severity ranging from mild to very severe. Following completion of the demographic questionnaire, caregivers completed four questionnaires about their care recipients aimed at determining (a) the degree of the care recipient's swallowing difficulties (Eating Assessment-10; EAT-10), (b) care recipient's diet restriction (International Dysphagia Diet Standardisation Initiative Functional Diet Scale; IDDSI-FDS), (c) care recipient's cognitive status (Eight-item Informant Interview to Differentiate Aging and Dementia; AD8), and (d) care recipient's quality of life (Quality of Life in Alzheimer's Disease; QoL-AD). Caregivers completed an additional two questionnaires aimed at determining their level of dysphagia-related caregiver burden (Caregiver Analysis of Reported Experiences with Swallowing Disorders; CARES) and their perceived quality of life (Caregiver Quality of Life Scale). For the purposes of this study, and due to cognitive deficits associated with dementia, all questionnaires were designed to be completed by the caregiver of the PWD. Previous studies indicate that caregivers can reliably report on observable symptoms experienced by care recipients [22, 23].

EAT-10. The Eating Assessment Tool (EAT-10; [24]) is a validated, 10-item tool designed to quantify perceived swallowing impairment. Using Likert scale responses, the goal of the EAT-10 is to identify the extent to which patients experience eating-related problems, such as coughing when eating, pain when swallowing, and weight loss due to swallowing impairment. Participants are asked to determine if each eating-related problem results in "no problem" (score of 0) up to "severe problem" (score of 4) for a potential total score of 40 points. A score of three or higher is suggestive of increased risk of dysphagia.

IDDSI-FDS. The International Dysphagia Diet Standardisation Initiative Functional Diet Scale (IDDSI-FDS; [25]) is a validated tool that is utilized to capture the degree of dietary restriction utilizing the IDDSI framework. IDDSI-FDS scores range from 0 to 8 on a whole number scale, where a score of 0 indicates inability to eat or drink by mouth and a score of 8 indicating the individual follows an unmodified diet.

AD8. The Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) is a validated 8-item tool that screens for the presence of cognitive impairment [26]. The AD8 utilizes a clinical dementia rating score to examine memory, orientation, judgement, and function. An AD8 score of zero or one indicates normal cognition. An AD8 score of two or higher indicates the potential presence of dementia with a maximum potential score of eight. The AD8 is utilized to detect early cognitive changes associated with dementia, however it is not intended to diagnose dementia on its own [26].

QoL-AD. The Quality of Life in Alzheimer's Disease (QoL-AD) is a validated tool that can be completed by caregivers of PWD that seeks to determine the quality of life of the individual with dementia (QoL-AD; [27]). The QoL-AD utilizes 13 questions to examine demographic characteristics, cognitive and functional status, depressive symptoms, and participation in pleasant events. Participants can score a maximum of 52 points, with higher scores indicating better quality of life

with fewer depressive symptoms and higher levels of independent functioning in completion of ADLs.

**CARES.** The Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES, [28]) is a validated 26-item questionnaire consisting of two subscales: Part A, which examines caregiver response to behavioral and functional changes in the person with dysphagia (10 items), and Part B, which examines subjective reports of caregiver stress (16 items). Subscale A allows for a maximum score of 10 points and subscale B allows for a maximum of 16 points with each yes response receiving one point. In both subscales, a higher score is indicative of a higher degree of caregiver burden related to dysphagia care.

**Caregiver QoL Scale.** The Caregiver Quality of Life Scale is a validated 20-item questionnaire that characterizes quality of life of caregivers of PWD [2]. The Caregiver QoL scale investigates four major domains as they relate to QoL: the capacity to deal with difficulties associated with a diagnosis of dementia, participation in daily activities, the caregiver's psychological status, and the caregiver's feelings of distress. Caregivers can score a maximum of 100 points with a score of 0 indicating poor QoL and a score of 100 indicating good QoL.

### **2.3 Data Analysis**

Data analysis was completed utilizing IBM SPSS Statistics Version 26 (IBM Corporation, Armonk, New York, USA). For the subsequent analyses, caregiver QoL was the dependent variable with all the other outcome measures treated as independent variables (swallowing impairment, dietary restrictiveness, cognitive impairment, care recipient QoL, and dysphagia-related caregiver burden). EAT-10, IDDSI-FDS, AD8, QoL-AD, CARES, and the caregiver QoL scale scores were calculated via their respective standard procedures. For the quantitative analyses, the presence of diet restriction results based on the IDDSI-FDS scores were also dichotomized into "diet restricted" (IDDSI-FDS score: 1-7) and "diet unrestricted" (IDDSI-FDS score: 8).

Descriptive statistics were utilized to examine demographic information and describe the sample population according to the variables of interest. Pearson's correlation coefficient was utilized to determine the linear correlation between caregiver quality of life (Caregiver QoL Scale) and caregiver characteristics including: cognitive impairment (AD8), dysphagia severity (EAT-10), degree of dietary restriction (IDDSI-FDS), dysphagia-related caregiver burden (CARES), and quality of life of the care recipient (QoL-AD). Point biserial correlation coefficient was used to determine the correlation between caregiver quality of life and presence of dietary restriction (dichotomized IDDSI-FDS). Following completion of correlation analysis, a stepwise multiple regression was run to understand the independent predictors of caregiver QoL.

### **3. Results**

A total of 71 surveys were completed to some degree. Of these, 47 surveys were excluded due to incomplete responses on either demographic or questionnaire measures. Therefore, a total of 24 responses were utilized for data analysis representing 24 caregivers and 24 care recipients.

Table 1 presents caregiver demographic information, including dysphagia-related caregiver burden and QoL. The participant caregivers were primarily female (87.5%), white (87.5%), married

(66.7%), and working full time (54.2%), and a majority held a college degree or higher (75.0%). Participants' mean dysphagia-related caregiver burden score related to functional changes (CARES-A) was 4.33 (*SD* = 3.25), and dysphagia-related caregiver burden related to stress (CARES-B) was 7.0 (*SD* = 5.23). The mean caregiver quality of life score was 42.1 (*SD* = 18.9).

**Table 1** Caregiver demographic information (*n* = 24).

Characteristic	
Gender (female), <i>n</i> (%)	21 (87.5)
Age (range in years), <i>n</i> (%)	
18-24	0 (0.0)
25-34	4 (16.7)
35-44	2 (8.3)
45-54	5 (20.8)
55-64	7 (29.2)
65-74	5 (20.8)
75-84	0 (0.0)
85 & older	1 (4.2)
Race, <i>n</i> (%)	
Asian	1 (4.2)
Black	2 (8.3)
White	23 (87.5)
Additional Dependents (yes), <i>n</i> (%)	8 (33.3)
Relationship Status, <i>n</i> (%)	
Married	16 (66.7)
Separated	6 (25.0)
Widowed	0 (0.0)
Never Married	2 (8.3)
Relationship to Care Recipient, <i>n</i> (%)	
Spouse	7 (29.2)
Sibling	1 (4.2)
Son or Daughter	11 (45.8)
Son-in-Law or Daughter-in-Law	3 (12.5)
Grandchild	0 (0.0)
Other	2 (8.3)
Level of Education, <i>n</i> (%)	
No School	0 (0.0)
Completed 8 <sup>th</sup> Grade	1 (4.2)
High School Diploma	0 (0.0)
Certificate	5 (20.8)
Bachelor's Degree	7 (29.2)
Advanced Degree	11 (45.8)
Employment Status, <i>n</i> (%)	
Retired	4 (16.7)

Working Full Time	13 (54.2)
Working Part Time	2 (8.3)
Unemployed	2 (8.3)
Other	3 (12.5)
Hours of care per week, <i>M ± SD</i>	63.3 ± 65.5
Participated in support group (yes), <i>n (%)</i>	5 (20.8)
CARES-A, <i>M ± SD</i>	4.33 ± 3.25
CARES-B, <i>M ± SD</i>	7.00 ± 5.23
Caregiver QoL Scale, <i>M ± SD</i>	42.08 ± 18.88

Note. CARES = Caregiver Analysis of Reported Experiences with Swallowing Disorders; *M* = mean; *SD* = Standard Deviation; QoL = Quality of Life.

Care recipients’ demographic information and EAT-10, IDDSI-FDS, AD8, QoL-AD results can be found in Table 2. Care recipients were primarily female (61.5%), all had a formal dementia diagnosis (100%), and a majority had feeding/swallowing difficulties as identified by their caregiver (70.8%). Just under half of the care recipients (45.8%) were rated by their caregivers to have severe dementia symptoms, which mapped onto the group’s mean AD8 score of 7.13 (*SD* = 1.42). On average, care recipients experienced a decreased quality of life with a mean score on the QoL-AD of 24.04 (*SD* = 5.33). Participants EAT-10 scores ranged from 0 to 34 with a mean score of 15.96 (*SD* = 12.04). A majority of the care recipients (79.2%) scored greater than three on the EAT-10, indicating increased risk of swallowing disorders. IDDSI-FDS scores ranged from 3 to 8 with a majority of care recipients being on a modified diet (66.7%). Although the majority of care recipients were reported to have some measure of feeding/swallowing difficulties by their caregivers (70.8%), only 37.5% of care recipients had a formal dysphagia diagnosis.

**Table 2** Care recipient demographic information (*n* = 24).

Characteristic	
Gender (female), <i>n (%)</i>	16 (61.5)
Age (range in years), <i>n (%)</i>	
Under 18	1 (4.2)
18-24	0 (0.0)
25-34	0 (0.0)
35-44	0 (0.0)
45-54	0 (0.0)
55-64	2 (8.3)
65-74	6 (25.0)
75-84	10 (41.7)
85 & older	5 (20.8)
Caregiver Reports Swallowing Difficulties (yes), <i>n (%)</i>	17 (70.8)
Dysphagia Diagnosis (yes), <i>n (%)</i>	9 (37.5)
Dementia Diagnosis (yes), <i>n (%)</i>	24 (100.0)
Caregiver Reported Severity of Dementia, <i>n (%)</i>	
Mild	3 (12.5)

Moderate	5 (20.8)
Severe	11 (45.8)
Very Severe	5 (20.8)
EAT-10, $M \pm SD$	15.96 $\pm$ 12.04
IDDSI-FDS, $M \pm SD$	6.38 $\pm$ 1.71
AD8, $M \pm SD$	7.13 $\pm$ 1.42
QoL-AD, $M \pm SD$	24.04 $\pm$ 5.33
IDDSI-FDS scores, $n$ (%)	
0	0 (0.0)
1	0 (0.0)
2	0 (0.0)
3	2 (8.3)
4	3 (12.5)
5	2 (8.3)
6	2 (8.3)
7	7 (26.9)
8	8 (34.6)
Presence of Diet Restriction, $n$ (%)	
Yes (Altered)	16 (66.7)
No (Unaltered)	8 (33.3)

Note. AD8 = Eight-item Informant Interview to Differentiate Aging and Dementia; EAT-10 = Eating Assessment Tool-10; IDDSI-FDS = International Dysphagia Diet Standardisation Initiative Functional Diet Scale;  $M$  = mean; QoL-AD = Quality of Life in Alzheimer's Disease;  $SD$  = Standard Deviation.

### 3.1 Relationship between Caregiver Quality of Life, Dietary Restriction, and Impact of Dementia

Table 3 represents the results of the correlation analyses between (a) caregiver quality of life and (b) degree of feeding/swallowing difficulty (EAT-10;  $r = -0.04$ ,  $p = 0.427$ ), presence and degree of dietary restrictiveness (IDDSI-FDS;  $r_{pb} = -0.367$ ,  $p = 0.046$ ;  $r = -0.45$ ,  $p = 0.013$ , respectively), degree of dementia-related symptomology (AD8;  $r = -0.415$ ,  $p = 0.022$ ), quality of life of the care recipient (QoL-AD;  $r = 0.423$ ,  $p = 0.020$ ), and dysphagia-related caregiver burden (CARES A & B;  $r = -0.178$ ,  $p = 0.202$ ;  $r = -0.333$ ,  $p = 0.056$ , respectively). Increased caregiver quality of life was significantly associated with increased level of dietary restriction, decreased dementia related symptoms, increased quality of life of the care recipient, and the presence of dietary restriction. However, caregiver quality of life was not significantly associated with degree of feeding/swallowing difficulty or dysphagia-related caregiver burden.



**Table 3** Variables associated with caregiver quality of life.

Variable	Correlation Coefficient <sup>a</sup>	<i>p</i> -value
EAT-10	0.040	0.427
IDDSI-FDS	-0.45	0.013*
AD8	-0.415	0.022*
QoL-AD	0.423	0.020*
CARES-A	-0.178	0.202
CARES-B	-0.333	0.056
Presence of Diet Restriction	0.367	0.046*

Note. AD8 = Eight-item Informant Interview to Differentiate Aging and Dementia; CARES = Caregiver Analysis of Reported Experiences with Swallowing Disorders; EAT-10 = Eating Assessment Tool-10; IDDSI-FDS = International Dysphagia Diet Standardisation Initiative Functional Diet Scale; QoL-AD = Quality of Life in Alzheimer’s Disease. <sup>a</sup>Pearson’s correlation coefficient (*r*) was calculated for all variables except for Presence of Diet Restriction, which used point biserial correlation (*r<sub>pb</sub>*). \*Significant correlation, *p* < 0.05.

A stepwise multiple regression was run to understand the independent predictors of caregiver QoL. All variables that reached a *p*-value of ≤ 0.05 in univariate analysis were included in the stepwise regression model with the exception of the dichotomous presence of diet restriction value, given its relationship to the IDDSI-FDS variable. Homoscedasticity was present upon visual inspection of the standardized residuals plotted against the standardized predicted values. Residuals were normally distributed as assessed by visual inspection of a normal probability plot. Results for the regression model are presented in Table 4. The stepwise linear regression model revealed three variables as statistically significant predictors of caregiver QoL. Degree of diet restrictiveness (per IDDSI-FDS scores), AD8 score, and QoL-AD significantly predicted caregiver quality of life,  $F(3,20) = 7.04$ , *p* = 0.002, accounting for 52.4% of the variability in caregiver quality of life scores, or a large effect size according to Cohen [29]. A correction for multiple comparisons was completed using a false discovery rate calculation which confirmed all variables in the model were significant using Benjamini-Hochberg Adjusted *p* values. Specifically, the model suggests that caregivers have a higher quality of life when caring for PWD with increased dietary restriction, who exhibit lower levels of dementia symptomology, and who have higher quality of life themselves.

**Table 4** Independent determinants of Caregiver Quality of Life in caregivers of PWD requiring feeding assistance based on a multiple regression model.

Variable	Parameter estimate [95% confidence interval]	<i>p</i> value	Benjamini-Hochberg Adjusted <i>p</i> value
IDDSI-FDS	-0.473 [-8.798, -1.624]	0.007	0.021
AD8	-0.370 [-9.319, -0.488]	0.031	0.044
QoL-AD	0.343 [0.037, 2.393]	0.044	0.044

#### 4. Discussion

Informal caregivers of PWD are at increased risk for reduced quality of life, which can lead to negative health impacts for both the caregiver and the care recipient. However, the independent factors that contribute to this reduction in quality of life remain under investigation [30, 31]. One under-studied potential contributor in this population is dysphagia, which occurs in up to 93% of PWD [32]. The presence of dysphagia alone is suggested to contribute to reduced QoL in caregivers across a number of populations [33, 34]. The purpose of this exploratory study was to investigate the potential independent predictors of QoL among caregivers of PWD with some form of mealtime impairment. Consistent with the current literature base, we hypothesized that increased dietary restriction, increased dementia related symptomatology, increased swallowing/feeding difficulty, increased dysphagia-related caregiver burden, and decreased care recipient quality of life as factors that would decrease caregiver quality of life. Our hypotheses were partially supported. Factors that were revealed as predictive of caregiver quality of life included dietary restrictiveness, severity of dementia symptomatology, and recipient QoL. These results support the idea that caregiver QoL is influenced by multifaceted, likely interrelated, aspects of patient care and that dysphagia management may play a role in influencing caregiver QoL.

The present study found that a higher degree of dietary restriction, as measured by IDDSI-FDS, was predictive of improved caregiver QoL. This finding of increased degree of dietary restriction leading to increased caregiver QoL was unexpected based on our hypothesis and potentially in contradiction with the previous literature that has shown that increased diet restriction is associated with increased *burden*. Nevertheless, these seemingly conflicting findings suggest a potentially more nuanced relationship between dietary restriction, caregiver burden, and QoL. There is often a commonly held perception among family members that texture modified foods can lead to improved nutritional intake, weight, and swallow safety. In addition to improving nutritional intake and weight, caregivers may feel that provision of a modified diet is an active modifiable strategy to reduce perceived risk of swallowing related impairments, such as choking [35]. Supporting this interpretation and care partner perception, previous literature suggests that texture modified diets do indeed serve as a protective mechanism to increase patient safety with swallowing [36, 37]. Diet modification has also been shown to increase mealtime satisfaction and weight in adults with on texture modified diets, which may improve the caregiving experience from the perspective of the caregiver [38]. From a clinical perspective, these findings may be leveraged to encourage adherence to diet modification recommendations. Caregivers often experience increased emotional and psychological burden as they balance the risk of choking and meeting their care recipients' nutritional needs [39]. Therefore, when care recipients are on a more restrictive diet, it may reduce the worry over the risks associated with dysphagia, improving caregiver QoL. However, modified diets take time and effort; increased degree of dietary restriction has been found to be associated with increased caregiver burden [12]. Yet, while the presence of swallowing impairment has been established as a factor that increases general caregiver burden, the degree of swallowing impairment in relation to the degree of burden remains undetermined [13, 14, 16]. The findings of this study support the notion that dietary modification may actually increase aspects of caregiver QoL despite also potentially increasing aspects of burden. It may be crucial, too, to consider the sample population in this study. Notably, 70.8% of caregivers reported that their care recipient had some form of swallowing difficulty but only 37.5% of care recipients had a formal

diagnosis of dysphagia. The finding of increased caregiver quality of life related to increased diet modification may suggest that those on a modified diet have had formal support where diet modification was discussed. Thus, the provision of a texture modified diet may be a proxy measure for participation in dysphagia services, which can greatly alter the caregiving experience as related to dysphagia management. Lastly, texture modified diets may reduce the risk of overt signs and symptoms such as coughing and choking, thereby resulting in lower levels of caregiver distress and increased quality of life. The findings of this study suggest that perceived benefits of dietary modification may outweigh the burden associated with texture modified foods when considering impact on caregiver QoL. The current study's findings that dysphagia-related caregiver burden is independent from quality of life may suggest that caregivers of PWD can potentially maintain high QoL despite feelings of increased burden, at least as related to dysphagia management. Certainly, further investigation into the complex relationship between general burden, dysphagia-related burden, and quality of life in the caregiver/recipient dyad is warranted to elucidate understanding of the factors that contribute to each.

Consistent with previous investigations into the relationship between dementia severity and caregiver QoL [40-42], this study further establishes that increased severity of dementia symptoms is predictive of decreased caregiver QoL. Caregiver QoL has been shown to decrease in association with lower levels on Mini-Mental State Exam (indicating increased dementia severity) as well as with displays of behavioral and psychiatric symptoms accompanying dementia progression [11, 43]. The findings of this study add to the body of literature showing increased severity of dementia symptoms is predictive of declining caregiver QoL. Although dementia severity is not currently modifiable, findings from this study may indicate that caregivers would benefit from increased social and professional support to identify ways in which dementia symptomatology may be addressed effectively to reduce associated symptomatology.

Lastly, results from the current study show that quality of life for caregivers of PWD is closely intertwined with the quality of life of the PWD. This finding is of crucial importance as health-related QoL in PWD deteriorates over time and doubles the risk of caregivers developing depressive symptoms [43, 44]. Because functional decline is an expected feature of dementia, it is imperative to identify factors that preserve and enhance quality of life throughout the trajectory of the disease for both the caregiver and the care recipient.

Ultimately, findings from this study demonstrate that caregiver quality of life is intricately tied to the multifaceted aspects of care within the caregiver/care recipient dyad. More work needs to be done to further elucidate which aspects of care are modifiable and could offer opportunity for increased QoL in the dyad. Strategies that enhance quality of life for caregivers, such as cognitive behavioral therapy, respite care, and promoting self-care may ultimately contribute to improved outcomes for care recipients [45-47]. Similarly, initiatives to enhance quality of life for care recipients, such as addressing their physical and psychosocial needs, increasing cognitive stimulation, and increasing opportunities for leisure may improve health and wellbeing of caregivers [10, 48-50]. Recognizing and addressing these interconnected factors is essential for creating a more holistic and sustainable caregiving ecosystem. The current study supports the interconnected nature of caregiver/care recipient well-being and highlights the importance of dyad-centred care that emphasizes preservation of QoL in both the caregiver and care recipient.

This study not only contributes to our understanding of the challenges faced by caregivers of PWD with dysphagia but also underscores the importance of clinical intervention that utilizes a

holistic approach to dementia care. This study's findings emphasize the need for tailored interventions and support systems that consider the multifaceted nature of caregiving and its impact on QoL for all parties involved. Ultimately, these findings highlight the need for targeted strategies aimed at preserving and enhancing the QoL of caregivers and care recipients.

#### **4.1 Limitations**

This study serves as a preliminary investigation into the relationship between caregiver QoL, dietary restriction, feeding impairment, dementia related symptomatology, and care recipient QoL. There are a number of limitations of this study that need to be addressed. First, there was a relatively small sample size with only 24 participants completing the entire survey. Second, data was collected via caregiver report. Although caregivers can reliably report on observable symptoms experienced by care recipients [22, 23], this method may not fully capture the experience of the PWD. Future studies may benefit from including additional objective measures to accurately reflect the perspective of persons with dementia. Furthermore, it must be noted that nonresponse bias may have played a role in data collection. Dyads that have lower levels of QoL and/or higher burden ratings may have been less likely to participate in a voluntary research study with no direct compensation. This nonresponse bias may partially account for the large number of incomplete surveys. Additionally, it must be acknowledged that data collection occurred during the COVID-19 pandemic which presented profound challenges to older adults, especially those caring for medically fragile individuals. The sociocultural context in which this data collection occurred may impact quality of life and may have contributed to the smaller sample size. Finally, due to the use of internet-based dissemination of this survey in caregiver forums, it is not possible to ascertain if the results from this study are reflective of the larger population of caregivers of PWD.

#### **5. Conclusion**

In conclusion, this study sheds light on the complex and interconnected factors influencing quality of life in caregivers of persons with dementia. The findings of the current study highlight the multifaceted nature of caregiver QoL, suggesting that various factors within the caregiver/care recipient dyad play a crucial role. Degree of dietary restrictiveness, severity of dementia symptomatology, and care recipient QoL were identified as significant contributors to caregiver QoL.

Contrary to the initial hypothesis, increased dietary restriction was associated with improved caregiver QoL. This unexpected finding underscores the complex nature of caregiving, where dietary modification, while potentially increasing burden, may also act as a protective mechanism, enhancing patient safety and, consequently, alleviating caregiver distress. The study emphasizes the nuanced relationship between burden, mealtime-related challenges, and QoL, suggesting that perceived benefits of dietary modification may outweigh associated burdens. Interestingly, dysphagia-related caregiver burden was not found to be predictive of caregiver QoL, challenging our initial hypothesis. This insight suggests that caregivers of PWD can potentially maintain high QoL despite feelings of increased burden associated with care of PWD, at least as related to dysphagia management. However, the study reiterates the negative impact of increased severity of dementia symptoms on caregiver QoL, emphasizing the need for enhanced social and professional support to address dementia-related challenges effectively. Through identification of factors that influence

caregiver QoL, this work and future work may also help identify which caregivers may need increased support.

Moreover, this study underscores the interdependence of caregiver and care recipient QoL, emphasizing the importance of a dyad-centred approach to care. In light of the inextricable link between caregiver QoL and care recipient factors, it may be more appropriate to shift our thinking to a care partnership where both in the dyad participate in treatment as a unit as opposed to discreet players. The recognition that caregiver QoL is influenced by various modifiable factors opens avenues for intervention within the dyad. This study contributes to the understanding of factors influencing caregiver QoL in the context of dementia care, emphasizing the need for holistic and sustainable dyad-centred caregiving approaches.

### **Author Contributions**

David F. Bayne: Conceptualization, Methodology, Data Collection, Formal Analysis, Writing – original draft, review and editing. Willow Keefe: Data Collection, Data Curation. Samantha E. Shune: Conceptualization, Methodology, Data Collection, Formal Analysis, Writing – review and editing. All authors have read and approved the published version of the manuscript.

### **Competing Interests**

The authors have declared that no competing interests exist.

### **References**

1. Srivastava G, Tripathi RK, Tiwari SC, Singh B, Tripathi SM. Caregiver burden and quality of life of key caregivers of patients with dementia. *Indian J Psychol Med.* 2016; 38: 133–136.
2. Thomas P, Lalloué F, Preux PM, Hazif-Thomas C, Pariel S, Inscale R, et al. Dementia patients caregivers quality of life: The PIXEL study. *Int J Geriatr Psychiatry.* 2006; 21: 50–56.
3. Alzheimer's Association. 2022 Alzheimer's disease facts and figures. More than normal aging: Understanding mild cognitive impairment. Chicago, IL: Alzheimer's Association; 2022.
4. World Health Organization. WHOQOL user manual programme on mental health division of mental health and prevention of substance abuse world health organization. Programme on mental health. Geneva, Switzerland: World Health Organization; 2012. pp. 1–106.
5. Goldsworthy B, Knowles S. Caregiving for Parkinson's disease patients: An exploration of a stress-appraisal model for quality of life and burden. *J Gerontol B Psychol Sci Soc Sci.* 2008; 63: P372-P376.
6. Zhang W, Rand S, Milne A, Collins G, Silarova B. The quality of life of older carers and the people they support: An international scoping review. *Health Soc Care Community.* 2022; 30: e3342-e3353.
7. Dourado MC, Sousa MF, Santos RL, Simões JP, Nogueira ML, Belfort TT, et al. Quality of life in mild dementia: Patterns of change in self and caregiver ratings over time. *Rev Bras Psiquiatr.* 2016; 38: 294-300.
8. Ismail Z, Smith EE, Geda Y, Sultzer D, Brodaty H, Smith G, et al. Neuropsychiatric symptoms as early manifestations of emergent dementia: Provisional diagnostic criteria for mild behavioral impairment. *Alzheimers Dement.* 2016; 12: 195-202.

9. Ismail Z, Gatchel J, Bateman DR, Barcelos-Ferreira R, Cantillon M, Jaeger J, et al. Affective and emotional dysregulation as pre-dementia risk markers: Exploring the mild behavioral impairment symptoms of depression, anxiety, irritability, and euphoria. *Int Psychogeriatr*. 2018; 30: 185-196.
10. Bayne DF, Shune SE. A Biopsychosocial model of mealtime management in persons with dementia, an asset-based approach to patient-centered care. *Geriatrics*. 2022; 7: 112.
11. Kamiya M, Sakurai T, Ogama N, Maki Y, Toba K. Factors associated with increased caregivers' burden in several cognitive stages of Alzheimer's disease. *Geriatr Gerontol Int*. 2014; 14: 45–55.
12. Davis C, Namasivayam-MacDonald AM, Shune SE. Contributors to poststroke dysphagia-related caregiver burden. *Am J Speech Lang Pathol*. 2021; 30: 1061-1073.
13. Namasivayam-MacDonald AM, Shune SE. The burden of dysphagia on family caregivers of the elderly: A systematic review. *Geriatrics*. 2018; 3: 30.
14. Namasivayam-MacDonald AM, Shune SE. The influence of swallowing impairments as an independent risk factor for burden among caregivers of aging parents: A cross-sectional study. *Geriatr Nurs*. 2020; 41: 81-88.
15. Rangira D, Najeeb H, Shune SE, Namasivayam-MacDonald A. Understanding burden in caregivers of adults with dysphagia: A systematic review. *Am J Speech Lang Pathol*. 2022; 31: 486-501.
16. Shune SE, Namasivayam-MacDonald AM. Swallowing impairments increase emotional burden in spousal caregivers of older adults. *J Appl Gerontol*. 2020; 39: 172-180.
17. Alagiakrishnan K, Bhanji RA, Kurian M. Evaluation and management of oropharyngeal dysphagia in different types of dementia: A systematic review. *Arch Gerontol Geriatr*. 2013; 56: 1-9.
18. Espinosa-Val MC, Martín-Martínez A, Graupera M, Arias O, Elvira A, Cabré M, et al. Prevalence, risk factors, and complications of oropharyngeal dysphagia in older patients with dementia. *Nutrients*. 2020; 12: 863.
19. Carnaby GD, Harenberg L. What is “usual care” in dysphagia rehabilitation: A survey of USA dysphagia practice patterns. *Dysphagia*. 2013; 28: 567-574.
20. Sura L, Madhavan A, Carnaby G, Crary MA. Dysphagia in the elderly: Management and nutritional considerations. *Clin Interv Aging*. 2012; 7: 287-298.
21. Hoffman GJ, Burgard S, Mendez-Luck CA, Gaugler JE. Interdependence in health and functioning among older spousal caregivers and care recipients. *West J Nurs Res*. 2019; 41: 685-703.
22. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: Can proxies provide reliable information? *Soc Sci Med*. 2003; 56: 95–109.
23. Oczkowski C, O'Donnell M. Reliability of Proxy Respondents for Patients with Stroke: A Systematic Review. *J Stroke Cerebrovasc Dis*. 2010; 19: 410–416.
24. Belafsky PC, Mouadeb DA, Rees CJ, Pryor JC, Postma GN, Allen J, et al. Validity and Reliability of the Eating Assessment Tool (EAT-10). *Ann Otol Rhinol Laryngol*. 2008; 117: 919-924.
25. Steele CM, Namasivayam-MacDonald AM, Guida BT, Cichero JA, Duivestijn J, Hanson B, et al. Creation and Initial Validation of the International Dysphagia Diet Standardisation Initiative Functional Diet Scale. *Arch Phys Med Rehabil*. 2018; 99: 934–944.
26. Galvin JE, Roe CM, Powlishta KK, Coats MA, Muich SJ, Grant E, et al. The AD8: A brief informant interview to detect dementia. *Neurology*. 2005; 65: 559–564.

27. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of Life in Alzheimer's Disease: Patient and Caregiver Reports. *J Ment Health Aging*. 1999; 5: 21–32.
28. Shune SE, Resnick B, Zarit SH, Namasivayam-Macdonald AM. Creation and initial validation of the caregiver analysis of reported experiences with swallowing disorders (Cares) screening tool. *Am J Speech Lang Pathol*. 2020; 29: 2131–2144.
29. Cohen J. A power primer. *Psychol Bull*. 1992; 112: 155–159.
30. Cifu DX, Carne W, Brown R, Pegg P, Ong J, Qutubuddin A, et al. Caregiver distress in parkinsonism. *J Rehabil Res Dev*. 2006; 43: 499–508.
31. Karg N, Graessel E, Randzio O, Pendergrass A. Dementia as a predictor of care-related quality of life in informal caregivers: A cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatr*. 2018; 18. doi: 10.1186/s12877-018-0885-1.
32. Affoo RH, Foley N, Rosenbek J, Kevin Shoemaker J, Martin RE. Swallowing Dysfunction and Autonomic Nervous System Dysfunction in Alzheimer's Disease: A Scoping Review of the Evidence. *J Am Geriatr Soc*. 2013; 61: 2203–2213.
33. Nund RL, Ward EC, Scarinci NA, Cartmill B, Kuipers P, Porceddu SV. Carers' experiences of dysphagia in people treated for head and neck cancer: A qualitative study. *Dysphagia*. 2014; 29: 450–458.
34. Plowman-Prine EK, Sapienza CM, Okun MS, Pollock SL, Jacobson C, Wu SS, et al. The relationship between quality of life and swallowing in Parkinson's disease. *Mov Disord*. 2009; 24: 1352-1358.
35. Makhnevich A, Marziliano A, Porreca K, Gromova V, Diefenbach MA, Sinvani L. Oropharyngeal dysphagia in hospitalized older adults with dementia: A mixed-methods study of care partners. *Am J Speech Lang Pathol*. 2023; 32: 234-245.
36. Atherton M, Bellis-Smith N, Cichero JA, Suter M. Texture-modified foods and thickened fluids as used for individuals with dysphagia: Australian standardised labels and definitions. *Nutr Diet*. 2007; 64: S53-S76.
37. Cichero JA, Steele C, Duivesteyn J, Clavé P, Chen J, Kayashita J, et al. The need for international terminology and definitions for texture-modified foods and thickened liquids used in dysphagia management: Foundations of a global initiative. *Curr Phys Med Rehabil Rep*. 2013; 1: 280-291.
38. Wu XS, Miles A, Braakhuis AJ. Texture-modified diets, nutritional status and mealtime satisfaction: A systematic review. *Healthcare*. 2021; 9: 624.
39. Habermann B, Shin JY. Preferences and concerns for care needs in advanced Parkinson's disease: A qualitative study of couples. *J Clin Nurs*. 2017; 26: 1650-1656.
40. Conde-Sala JL, Turró-Garriga O, Piñán-Hernández S, Portellano-Ortiz C, Viñas-Diez V, Gascón-Bayarri J, et al. Effects of anosognosia and neuropsychiatric symptoms on the quality of life of patients with Alzheimer's disease: A 24-month follow-up study. *Int J Geriatr Psychiatry*. 2016; 31: 109-119.
41. Heßmann P, Seeberg G, Reese JP, Dams J, Baum E, Müller MJ, et al. Health-related quality of life in patients with Alzheimer's disease in different German health care settings. *J Alzheimers Dis*. 2016; 51: 545-561.
42. Montgomery W, Goren A, Kahle-Wroblewski K, Nakamura T, Ueda K. Alzheimer's disease severity and its association with patient and caregiver quality of life in Japan: Results of a community-based survey. *BMC Geriatr*. 2018; 18: 141.

43. Garzón-Maldonado FJ, Gutiérrez-Bedmar M, García-Casares N, Pérez-Errázquin F, Gallardo-Tur A, Torres MM. Health-related quality of life in caregivers of patients with Alzheimer disease. *Neurología*. 2017; 32: 508-515.
44. Morimoto T, Schreiner AS, Asano H. Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age Ageing*. 2003; 32: 218–223.
45. Danucalov MA, Kozasa EH, Afonso RF, Galduroz JC, Leite JR. Yoga and compassion meditation program improve quality of life and self-compassion in family caregivers of Alzheimer's disease patients: A randomized controlled trial. *Geriatr Gerontol Int*. 2017; 17: 85-91.
46. Lee M, Ryoo JH, Crowder J, Byon HD, Williams IC. A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. *J Adv Nurs*. 2020; 76: 475-489.
47. Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Annemans L. Effectiveness and cost-effectiveness of an in-home respite care program in supporting informal caregivers of people with dementia: Design of a comparative study. *BMC Geriatr*. 2016; 16: 207.
48. Fitzsimmons S, Buettner LL. Therapeutic recreation interventions for need-driven dementia-compromised. *Am J Alzheimers Dis Other Dement*. 2002; 17: 367-381.
49. Kim SK, Park M. Effectiveness of person-centered care on people with dementia: A systematic review and meta-analysis. *Clin Interv Aging*. 2017; 12: 381-397.
50. Nyman SR, Szymczynska P. Meaningful activities for improving the wellbeing of people with dementia: Beyond mere pleasure to meeting fundamental psychological needs. *Perspect Public Health*. 2016; 136: 99-107.