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ORIGINAL RESEARCH

Beyond the Physical Demands: Loneliness and Social Isolation Among Female Spousal Caregivers of Persons with Alzheimer's Disease

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Background: Adjusting to Alzheimer's disease diagnosis is a complex process. Caregivers tend to experience feelings of loneliness and isolation, which in turn may have adverse effects on their well-being. The purpose of this study was to explore and describe the perspectives of female older adult caregivers of individuals with AD concerning the social isolation and loneliness.

Methods: The study uses a mixed methods design (N = 48), combining qualitative and quantitative research components to provide a more comprehensive understanding of the phenomenon.

Results: Based on the analysis, three main themes were derived: "social isolation due to caregiving responsibilities", "changes in social circle" and "balancing caregiving and social connection". There were significant negative associations between loneliness and depression.

Conclusion: While the detrimental effects of caregiving on psychological and physical health are well-documented, further research is needed to fully understand the multifaceted nature of the caregiving experience, particularly regarding loneliness and social isolation. This study addresses this gap by exploring the often-neglected aspect of loneliness among caregivers. The findings provide valuable insights for psychologists and healthcare professionals, enhancing their understanding of the challenges and needs of this population.

Keywords: Alzheimer's disease, caregivers, loneliness

Introduction

Alzheimer's disease (AD), a chronic neurodegenerative disorder, is the most prevalent form of dementia.[1] Characterized by memory decline, aggression, apathy, hallucinations, and depression,[2] AD predominantly affects older adults. Globally, 55 million people are currently living with ADRDs, and this number is expected to almost triple in 2050.[3] This demographic trend projects a substantial increase in the number of individuals living with AD, posing a significant burden on global health and social care systems.[3] Current treatments for the most common forms of dementia are limited to temporarily alleviating certain symptoms, as they can neither cure the disease nor alter its underlying progression. In addition, the progressive nature of AD leads to increased dependence on caregivers for assistance with activities of daily living, such as personal hygiene and eating.[4] As the majority of individuals with AD receive care at home from family members,[5] the impact of this disease extends beyond the individual to their families.

The physical and emotional demands of providing care for an individual with AD can have detrimental effects on caregivers. Studies have shown that caring for someone with AD is more stressful than caring for someone with a physical disability.[6] Caregiving has been linked to elevated levels of anxiety, stress, and depression, as well as a weakened immune response, increasing susceptibility to infections.[7] Furthermore, caregiving can increase the risk of developing mental and physical health problems[8] and may discourage engagement in preventative health behaviors, contributing to poorer health outcomes.[9]

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The rising prevalence of AD has spurred extensive research into the factors contributing to caregiver burden. Studies have sought to identify variables that negatively influence the caregiving experience. Established predictors of caregiver burden include sociodemographic factors such as being female, lower education levels, and co-residence with the care recipient, as well as depression, financial strain, increased caregiving hours, and limited social support.[10,11] While some research suggests that social isolation and loneliness significantly predict caregiver burden,[12] a deeper understanding of these experiences among AD caregivers remains limited. This gap in the literature highlights the need for further investigation into the specific challenges of loneliness and social isolation within this particular population.

While loneliness can be experienced throughout life, it has traditionally been associated with older adulthood.[13] Loneliness is often defined as the emotional distress arising from a perceived discrepancy between desired and actual social connections.[14] This subjective experience differs from aloneness, which refers to the objective absence of social ties.[15] Weiss[16] proposed two distinct types of loneliness: emotional loneliness, stemming from a lack of close, intimate relationships, and social loneliness, resulting from inadequate social integration or community rejection. However, more recent perspectives emphasize that loneliness is not solely determined by the quantity of social contact but rather by an individuals' subjective perception of their social situation.[17]

Examining the experience of loneliness among caregivers is crucial due to its detrimental impact on mental and physical health, and overall quality of life.[13,14,18] Loneliness has been linked to a range of adverse outcomes, including depression, sleep disturbances, increased risk of coronary heart disease, stroke, mortality, and suicidal ideation.[18–20] Furthermore, studies in the general population have associated loneliness with maladaptive behaviors like smoking and alcohol consumption.[21]

An AD diagnosis profoundly impacts all aspects of life, including social interactions. As families adjust to new roles and responsibilities, they often find themselves withdrawing from previous habits, social activities, and relationships. This decline in social engagement can stem from various factors. Some caregivers may avoid social interaction due to embarrassment associated with the care recipient's declining memory and cognitive function.[22] Additionally, social withdrawal, a common behavioral change in AD, can lead to isolation. As the disease progresses, individuals with AD may actively avoid friends and family and lose interest in previously enjoyed activities, further diminishing social interaction.[23] Furthermore, the accumulating demands of caregiving can strain caregivers' social networks. Overwhelmed by their responsibilities, caregivers often lack the time and energy for social interaction or leisure activities.[24] In summary, AD can significantly reduce social interaction through various mechanisms, contributing to feelings of loneliness and isolation for both individuals with AD and their caregivers.

Emerging evidence suggests a link between AD, loneliness, and reduced social connections in later life.[25] However, the experience of loneliness among AD caregivers remains understudied. To address this gap, we conducted quantitative and qualitative study to explore the experiences of primary caregivers for individuals with AD. Our study builds on previous studies investigating the experience of loneliness among older adults. The purpose of this study was to explore and describe the perspectives of female older adult caregivers of individuals with AD concerning the social isolation and loneliness. The study uses a mixed methods design, combining qualitative and quantitative research components to provide a more comprehensive understanding of the phenomenon.[26] The study focuses on spousal female caregivers in Poland, a country facing a dramatic demographic shift similar to its European neighbors. Due to declining fertility rates and increasing life expectancy, the percentage of older adults is projected to rise significantly; by 2030, 27% of the population is expected to be aged 65 or older.[24] This demographic trend directly impacts the provision of dementia care, as the vast majority of individuals with AD in Poland are currently cared for by family members. This reliance on informal care is likely driven by a combination of culturally strong family ties and the high cost of formal nursing home placement.

This study focuses specifically on female spousal caregivers of individuals with AD for several reasons. First, the majority of caregivers for individuals with Alzheimer's disease are women. Additionally, spousal caregivers, particularly women, often face greater challenges in providing care compared to adult children.[27] This is often due to factors such as increased caregiving hours[28] and closer emotional ties to the care recipient. Second, older caregivers of individuals with AD are more likely to experience adverse mental health outcomes, such as depression and anxiety, and report a lower quality of life compared to caregivers of individuals with other conditions.[29] This highlights the unique vulnerability of this population and the need to consider their specific needs, particularly regarding social contact, which may decrease also due to declining health.[30] The objectives were to investigate the degree of loneliness and social isolation experienced by older adult caregivers and to test the associations between caregiver's well-being and loneliness. It was hypothesized that loneliness negatively correlates with life satisfaction, depressive symptoms, and self-rated health.

Methods

Participants and Study Procedure

This was a mixed-methods cross-sectional study comprising a quantitative and a qualitative element. This study's data were drawn from a larger project (2021–2024) investigating the experiences, needs, and barriers of Polish Alzheimer's disease caregivers. A total of 51 female caregivers expressed their interest in participating in the study. Of these, 48 women met the inclusion criteria. Recruitment employed diverse strategies, including online advertisements, outreach to caregiver organizations and Email lists. This method was chosen to efficiently reaching a specific, often geographically dispersed, and time-constrained population like older adult spousal caregivers. Potential participants received invitations to complete a questionnaire outlining the study's goals, eligibility criteria, estimated time commitment, and researcher contact information. Confidentiality was assured, and participation was voluntary. To be eligible for this study, participants had to be informal, unpaid caregivers of individuals diagnosed with Alzheimer's disease for at least 12 months. Additional inclusion criteria included: a) self-identification as the primary caregiver for at least six months; and b) identification as the wife or a partner of the person with AD, c) aged 65 years or over. Ethical approval for the study was obtained from an ethics committee, and all participants provided written informed consent after receiving a thorough explanation of the project's purpose and expectations. No financial compensation was provided for participation.

Interviews were conducted in Polish between September 2022 and June 2024, lasting between 20 and 80 minutes each. The sequencing of topics was adjusted depending on the course of the conversation. The topics included challenges of caregiving, the impact of caregiving on a caregiver's various aspects of life, including relationships.

All interviews were audio-recorded. Recognizing the potential influence of researcher subjectivity in qualitative research, the authors maintained reflexive journals throughout the data collection and analysis process. This practice of reflexivity, considered essential in qualitative methodology, allowed for ongoing critical reflection on the researchers' own biases, experiences, and potential assumptions.[31]

Measures

Depressive Symptoms

Participants reported their depressive symptoms using the Polish version of the Geriatric Depression Scale (GDS), a 30-item questionnaire asking participants to respond yes or no in reference to how they felt over the last seven days. Scores of 0–9 are considered normal; 10–19 indicate mild depression; and 20–30 indicate moderate to severe depression.[32]

Loneliness

The Revised UCLA Loneliness Scale (R-UCLA) was used to assess loneliness. This instrument consists of 20 items. Respondents were asked to indicate how often they feel the way described in each item using a four-point Likert scale ranging from 1 (never) to 4 (often).[33] We summed up all items which resulted in a total score ranging from 20 to 80, with higher scores indicating greater loneliness (α =0.89).

Self-Rated Health

Self-rated physical and mental health was assessed with a single item: "In general, would you say your health is … ". Caregivers were asked to rate their physical and mental health on a scale from 1 (very poor) to 5 (very good). Higher scores indicated better mental and physical health.[34]

Life Satisfaction

Life satisfaction was measured using the Satisfaction with Life Scale (SWLS), a widely used, five-item instrument designed to assess global cognitive judgments of life satisfaction (α =0.80). Participants respond to each item on a sevenpoint Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree), resulting in a possible score range of 5 to 35. A score of 20 represents a neutral viewpoint, with scores between 5 and 9 indicating extreme dissatisfaction and scores between 31 and 35 indicating extreme satisfaction.[35]

Demographics

Standard demographic information was collected, including age, educational attainment, residential setting (urban vs. rural), and time since the AD diagnosis. Educational attainment was categorized as: less than high school, high school graduate or equivalent, and college degree or higher.

Analysis

The quantitative data were fully anonymized and transferred in SPSS version 28. The associations between depression, loneliness, self-rated health, as well as the demographic variables were examined using the Pearson correlation coefficient. A result with a p value <0.05 was considered statistically significant. There was no missing data identified among the observations obtained.

Qualitative Data

For the qualitative element of this study, the authors conducted thematic analysis of the data[36] using MaxQDA software (v.20.4.1). The interview questions were developed based on published literature on transnational caregiving and published in.[24] Initially, the dataset was coded to isolate fragments where participants discussed the impact of caregiving on their lives. After multiple readings of the transcripts to gain a holistic understanding, a preliminary list of codes was generated. These codes were then grouped into initial themes, ensuring internal homogeneity and external heterogeneity. Any discrepancies in interpretation were resolved through consensus discussions. Finally, selected quotes were translated from Polish to English following best practices for translation in qualitative research.[37]

Results

Quantitative Data

Table 1 presents the demographic characteristics of the sample, including age, education level, and time since diagnosis, as well as relevant test scores. Participants had a mean age of 72.1 years (*SD* = 4.9, range: 65–82). The average time since the partner's AD diagnosis was 2 years (*SD* = 1.3) ranging from 1 to 5 years. The majority of the 48 participants were high school graduates (56%, n = 27), while 35.4% (n = 17) had attained a college degree. Reflecting the demographics of the geographical

Table 1 Sample Characteristics (N = 48)

Variable	Female Caregivers
	M (SD)
Age (in years)	72.1 (4.9)
Education, n(%)	
Less than high school diploma	4 (8.3)
High-school graduate or equivalent	27 (56.3)
College degree and higher	17 (35.4)
Time since diagnosis in years	2.0 (1.3)
Self-rated health	3.75 (0.8)
Loneliness	31.4 (8.8)
Depression	4.8 (4.1)
Life satisfaction	28.8 (3.9)

Notes: Depression was measured using the Geriatric Depression Scale (GDS), range 0–30. Loneliness was measured using the Revised UCLA Loneliness Scale (R-UCLA), range 20–80. Life satisfaction was measured using the Life Satisfaction Scale (SWLS), range 5–35.

Table 2 Bivariate Correlations Between Study Variables

Variable	1.	2.	3.	4.	5.
1. Age					
2. Time since diagnosis	0.78**				
3. Loneliness	0.29*	0.08			
4. Life satisfaction	−0.36*	−0.25	−0.32*		
5. Depression	0.11	−0.01	0.50**	−0.58**	
6. Self-rated health	−0.22	−0.18	0.01	0.07	−0.16

Notes: *Indicates p <0.05, ** indicates p < 0.01.

area, all participants were white and native Polish speakers. Most participants resided in urban areas (83%). On average, participants exhibited normal scores on measures of depressive symptoms ($M = 4.8$, $SD = 4.1$), indicating they did not endorse significant depressive symptoms. They also reported good overall self-rated health ($M = 3.75$, $SD = 0.8$). However, their average loneliness scores were relatively high ($M = 31.4$, $SD = 8.8$), suggesting a greater feeling of loneliness. Despite this, they reported being generally satisfied with their lives ($M = 28.8$, $SD = 3.9$) as measured by life satisfaction scores.

Table 2 presents the bivariate correlations among all study variables. As shown in the table, loneliness was significantly positively correlated with depression ($r = -0.50$, $p < 0.01$), and negatively correlated with life satisfaction ($r = -0.32$, $p < 0.05$).

Qualitative Data

The themes that emerged from the qualitative interviews are represented in this section using verbatim quotes to illustrate the theme. Based on the analysis, three main themes were derived: “social isolation due to caregiving responsibilities”, “changes in social circle” and “balancing caregiving and social connection”.

Theme 1: Social Isolation Due to Caregiving Responsibilities

The study found that a significant majority of caregivers (n = 32) experienced increased social isolation after their care recipient’s diagnosis. This isolation stemmed from the challenges of providing care, which often made it difficult to leave the house. Caregivers felt restricted by their care recipient’s needs and anxieties, leading to a loss of freedom and independence. This experience is illustrated by the following quotes:

> I’m constantly busy these days. There’s just no free time. He is worried I’ve been gone too long even if I just go to do some shopping. I used to enjoy going out, but that’s not happening anymore.

Another caregiver stated:

> It feels like these four walls are closing in on me. I don’t remember the last time I saw my friends.

These quotes convey the sense of confinement and dependence experienced by caregivers, highlighting the impact of caregiving on their social lives and personal freedom. Even when caregivers managed to engage in activities outside the home, they often experienced significant anxiety about their care recipient’s well-being during their absence. This constant worry is conveyed by one participant:

> I can’t leave him alone. Well, I can, but I’m a nervous wreck the whole time. I’m constantly worried about what might happen – will he leave the water running, run away?

This caregiver’s words highlight the emotional toll and sense of hypervigilance that can accompany even brief periods away from the care recipient. The fear of potential accidents or dangerous situations creates a sense of restriction.

While some caregivers managed to leave the house, they faced significant limitations and had to strategically plan their outings. One caregiver explained:

> I’m pretty much housebound after dark. He gets really anxious in the evenings, so I can’t leave him alone. It means I have to squeeze everything in during the day – shopping, appointments, you name it.

Another caregiver shared:

> My life's been turned upside down. It's constant care, 24/7. I can't even pop out for an appointment or to see a friend without having to rely on someone else, like my sister, to step in. It's tough, to say the least.

The restrictions imposed by caregiving led some to feel trapped and isolated:

> Holidays are out of the question. I'm basically a prisoner in my own home. It's like I've been sentenced to house arrest, but by my own marriage vows.

Theme 2: Changes in Social Circle

Many caregivers found that their previous activities and hobbies were severely curtailed or even eliminated due to the demands of caregiving and the impact of their care recipient's condition. This loss contributed to a diminished quality of life and further social isolation. The participants described how their social lives had dramatically changed following their husbands' diagnoses. Many felt isolated and disconnected from their former social circles. One participant summarized this experience:

> Life's been completely different since the diagnosis. We're pretty much stuck at home now. No more going out, and friends rarely visit. I guess that's what happens when most of your friends are gone now.

This sense of social withdrawal and changes in social circle was echoed by others:

> My whole life changed after my husband got sick. I lost touch with friends, gave up things I loved. You know, I used to be on the go all the time. But people stopped coming around. They used to visit when my husband was healthy. we used to host small parties. Now when I call them up, it's always one excuse after another. Our social life has vanished.

Theme 3: Balancing Caregiving and Social Connection

The caregivers' narratives reveal a profound shift in social connections following the onset of caregiving responsibilities. While some caregivers expressed a desire for social interaction, they also described the challenges of balancing their caregiving responsibilities with the needs of visitors:

> It's tricky. I want to have people over, but it's hard to juggle everything. Like, when we have a guest, I'm always torn between spending time with them and attending to my husband. And with his condition, the house feels more like a hospital than a home, which makes it even harder to relax and socialize.

Another caregiver stated:

> I crave connection but now every visit is a calculated decision. I can't sit down with my friend without him interrupting us.

Discussion

While much research exists on the challenges of caring for someone with Alzheimer's disease, the loneliness experienced by spousal caregivers has not received enough attention. It is known that older adults often see their social circles shrink due to factors like losing friends or facing health issues.[30] However, spouses caring for partners with Alzheimer's disease (AD) face a unique set of challenges that intensify their risk of loneliness and social isolation. The constant demands of caregiving can severely limit their ability to stay connected with others. This isolation, combined with the emotional strain of watching their loved one decline, puts them at even greater risk of experiencing detrimental consequences of loneliness and social isolation compared to their peers.

This mixed-methods study explored the experiences of 48 individuals caring for a spouse with AD, focusing on their experience of loneliness and social isolation. As the disease progresses, caregivers often find themselves increasingly consumed with their loved one's needs, leaving little time or energy for socializing with friends and family. Our findings build on this knowledge, revealing that loneliness is a pervasive experience among spousal caregivers of individuals with AD. Participants provided rich insights into their functioning, enabling the identification of three core themes:

"social isolation due to caregiving responsibilities", "changes in social circle" and "balancing caregiving and social connection". The results directly support the "wear and tear" theory.[38] This suggests that the unique combination of sustained demands and social isolation experienced by older caregivers leads to a cumulative psychological burden rather than successful habituation. Caregivers demonstrated persistent or deepening loneliness and emotional strain, which is consistent with the "wear and tear" model and other studies investigating caregivers' experience of providing care.[39]

The caregiving experience profoundly impacted participants' social interactions, leading to a marked reduction in contact with family, friends, and acquaintances. Several factors contributed to this decline. Primarily, caregivers reported increased difficulty leaving their homes due to care recipients' behavioral challenges, such as wandering. Furthermore, managing visitors while simultaneously providing care proved challenging, hindering social engagement. Notably, some participants shared that friends ceased contact shortly after the onset of their husbands AD. This suggests a potential discomfort or lack of understanding among those unfamiliar with AD regarding appropriate interactions with individuals with the condition. Further research is warranted to explore the specific reasons behind this withdrawal of social support following an Alzheimer's diagnosis. This could inform the development of interventions aimed at promoting understanding and maintaining social connections for both caregivers and care recipients. We also found a significant relationship between depression and loneliness.

This study's contributions should be considered in light of its limitations. Primarily, the findings are based on a small, geographically constrained convenience sample of female caregivers in Poland. The sample consisted exclusively of female caregivers, which reflects global trends where women disproportionately bear the burden of providing informal care for the older adult population. Secondly, while convenient and cost-effective, this sampling method introduces potential bias and limits generalizability. The lack of control over participant characteristics (eg, age, education, socioeconomic status) may result in a sample that is not representative of the broader population of spousal AD.[40] Consequently, caution should be exercised in generalizing these findings to other contexts. Future research should employ a larger and more diverse group of caregivers and implement a longitudinal design to investigate changes in loneliness and well-being over time, providing deeper insight into the dynamic progression of psychological burden throughout the caregiving trajectory.

Despite these limitations, this study offers valuable insights with implications for policy, intervention development, and future research, enhancing our understanding of the challenges and needs of spousal caregivers for individuals with AD. Specifically, the findings highlight the restrictive nature of caregiving, with participants often experiencing social isolation and confinement to their homes. This underscores the necessity for interventions that can be effectively delivered within the home environment. This study is among the few studies exploring caregivers' experience of caring for someone with AD through a mixed-methods design in Poland. The novelty of this work lies in applying a mixed-methods design to a specific and often overlooked group: spousal caregivers of persons with AD experiencing loneliness. While caregiver burden is a well-established concept, our integrated approach provides a uniquely comprehensive and nuanced understanding of their psychological and social isolation, moving beyond the scope of purely quantitative studies. This dual approach allowed us to argue how and why loneliness manifests among Polish spousal caregivers.

Conclusions

To conclude, the increasing prevalence of Alzheimer's disease necessitates further exploration of the complex relationship between caregiving and loneliness. Our findings confirmed a link between isolation and depressive symptoms while providing rich qualitative insight into the specific experiences of spousal caregivers. The results are also consistent with the "wear and tear" model of stress, demonstrate that high levels of emotional strain and social isolation persist among spousal caregivers. This study can serve as a foundation for future research investigating the correlation between providing care and experiencing loneliness among spousal caregivers.

Data Sharing Statement

The dataset used and analyzed during the current study are available from the corresponding author on request.

Ethics Approval and Consent to Participate

Ethical approval for this study was obtained from the University of Szczecin, Poland. The study adhered to the Declaration of Helsinki.

Consent for Publication

The participants informed consent included publication of anonymized responses/direct quotes.

Disclosure

The author declares no competing interests.

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