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Prisoners of Care: The Experience of Loneliness among Caregivers of Individuals with Alzheimer’s Disease

Więżniowie opieki: doświadczenie samotności pośród opiekunów osób cierpiących na chorobę Alzheimera

Abstract: Adjusting to an Alzheimer’s disease diagnosis is a complex process. Caregivers tend to experience feelings of loneliness and isolation, which in turn may

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have adverse effects on their well-being. Although the detrimental effects of caregiving on psychological and physical health are well documented, more research is needed to give a comprehensive portrait of the caregiving experience, especially in the areas of aloneness and social isolation. Loneliness remains a neglected aspect of the caregiving experience. Results from this study offer important insights into the caregiving experience for psychologists and other healthcare professionals.

Keywords: Alzheimer's disease; caregivers; loneliness.

Abstrakt: Przystosowanie się do choroby Alzheimera jest złożonym procesem. Opiekunowie doświadczają samotności i izolacji, co może niekorzystnie wpływać na ich samopoczucie. Mimo iż negatywny wpływ, jaki może wywrzeć sprawowanie opieki na zdrowie psychiczne i fizyczne, został potwierdzony w wielu badaniach, nie udało się jeszcze uzyskać kompleksowego portretu opiekuna i jego doświadczeń, zwłaszcza jeśli chodzi o doświadczenie samotności i izolacji społecznej. Samotność pozostaje zaniedbanym aspektem doświadczenia opiekuńczego. Wyniki tego badania oferują ważne informacje na temat doświadczenia w opiece zarówno dla psychologów, jak i innych osób zaangażowanych w pomoc osobom starszym.

Słowa kluczowe: choroba Alzheimera; opiekunowie; samotność.

1. Introduction

Alzheimer's disease (AD) is a chronic neurodegenerative disorder and the most prevalent type of dementia (Karantzoulis & Galvin, 2011). The most common symptoms of the disease include memory decline, aggression, apathy, hallucinations and depression (Alzheimer's Association, 2019). Because this disease is associated with age, it is estimated that Alzheimer's disease will affect a significant number of older adults, and will consequently impose a burden on health and social care systems around the world. The increasing number of people with AD will also impact many families because the majority of patients are cared for at home by informal caregivers, mostly family members (Lepore, Ferrell & Wiener, 2017). Due to the fact that the symptoms of AD worsen with the progression of the disease, older adults affected by the disease become more dependent on their families to provide assistance with tasks such as personal hygiene and eating (Fauth, Femia & Zarit, 2016). The physical and emotional demands associated with attending to the needs of an individual with AD can have adverse effects on caregiv-

ers. In fact, studies demonstrated that caring for a person with dementia is more stressful than caring for a person with a physical disability (Brodaty & Donkin, 2009). Caregiving has been associated with increased levels of anxiety, stress, depression, and with a diminished immune response, which leads to frequent infections (Lavretsky, 2005). Caregiving can also contribute to a higher risk of developing mental and physical health problems (Vitaliano, Zhang & Scanlan, 2003). Additionally, caregivers are less likely to engage in preventative health behaviours than non-caregivers, which may further contribute to their poorer health outcomes (Grunfeld et al., 2004).

It is projected that by 2030, the global number of individuals with AD or other types of dementia will increase to 65.7 million (Prince et al., 2013). In the context of increasing numbers of older adults with Alzheimer's disease, the predictors of caregiver burden have become the subject of considerable research (Pinquart & Sörensen, 2003). Thus, researchers have been trying to identify factors that can negatively impact the experience of caregiving. Among the established predictors of caregiver burden are certain sociodemographic characteristics such as being female, lower levels of education, and residing with the care recipient. Other factors that contribute to caregiver burden include depression, financial stress, higher numbers of hours spent providing care, and lower levels of social support (Adelman, Tmanova, Delgado, Dion & Lachs, 2014). Although a few studies have pointed to social isolation and the experience of loneliness as significant predictors of caregiver burden (Lee, Martin & Poon, 2017), little research has focused on the experience of loneliness and social isolation among caregivers of individuals with Alzheimer's disease.

Although loneliness is a common human experience and can occur across the life span, loneliness has traditionally been thought of as being prevalent in late adulthood (Victor, Scambler, Bond & Bowling, 2000). Loneliness is commonly defined as an emotional distress resulting from a person's perceived dissatisfaction with the quality or quantity of their social contacts (Perlman & Peplau, 1981). It is different from aloneness, which is defined as an objective absence of social ties (Ayalon, Shiovitz-Ezra & Palgi, 2013). Weiss (1973) suggested two types of loneliness: emotional loneliness (when a person lacks intimate and close relationships) and social loneliness (a consequence of an inadequate integration with social networks or a rejection by the community). More recent literature on loneliness emphasises that this state of loneliness is not driven by the number of friends or the amount of contact a person has with others, but is instead caused by their subjective perception of the situation (Rokach, 2012).

Investigating the experience of loneliness among caregivers seems to be of high importance, because of its negative consequences for mental and physical health and the overall quality of life (Richard et al., 2017). Loneliness is predictive of depression, sleep problems, increased coronary heart disease, stroke and mortality risk, and suicidal ideation (Holt-Lunstad, Smith & Layton, 2010). Studies conducted in the general population also indicate that loneliness has been associated with engaging in maladaptive behaviours such as smoking and alcohol consumption (Nieminen et al., 2013).

The diagnosis of Alzheimer's disease can significantly affect all aspects of the life of the dyad, including social interactions. As the couple has to adjust to their new roles, the disease forces both caregivers and care recipients to withdraw from previous habits, social activities and relationships. Reasons for their shrinking social network might be different. For example, some individuals might avoid social interactions because of being embarrassed by their declining memory and cognitive function (Singleton, Mukadam, Livingston & Sommerlad, 2017). Isolation can be also caused by social withdrawal, which is one of the most common changes in behaviour in Alzheimer's disease. As the disease progresses, the disease-affected individuals start avoiding friends and family members. In addition, care recipients become less interested in routine activities they used to enjoy, which may result in fewer social activities. Difficulties with language may further negatively impact interactions, because individuals with AD have problems with starting and maintaining a conversation (Alzheimer's Association, 2019). Caregivers may also experience a reduced social network because of the accumulation of caregiving duties. Furthermore, they often report feeling overwhelmed by their caregiving responsibilities. As a result, they often do not have the time and energy to visit with friends and family, or to engage in other activities (Schulz & Eden, 2016). Last but not least, the diagnosis of Alzheimer's disease is also very challenging for employed caregivers to receive. As the amount of tasks accumulates, many caregivers feel incapable of performing work activities, and decide to reduce their working hours or stop working (Skira, 2015). Considering the above-mentioned examples, Alzheimer's disease can significantly reduce social interaction and, therefore, can be a trigger for loneliness.

There is growing evidence that Alzheimer's disease is associated with loneliness and having fewer close relationships in later life (Rafnsson, Orrell, d'Orsi, Hogervorst & Steptoe, 2017). However, little research has been conducted to investigate the experience of loneliness among caregivers of individuals with Alzheimer's disease. In order to address this gap, we con-

ducted a qualitative study using semi-structured interviews, to gather detailed information from primary caregivers of people diagnosed with Alzheimer's disease. This study is important because it offers more insights into the caregiving experience, and provides a preliminary view of the experience of loneliness among older caregivers.

2. Methods

The present study analyses 30 qualitative interviews conducted with spousal caregivers of individuals with Alzheimer's disease. The study was conducted in Szczecin, Poland. Eligible participants were the primary caregivers for a person with Alzheimer's disease, living with the patient, and with no diagnosis of dementia. The median age of the interviewees was 78.3 years, with a range of 72 to 84 years. Similar to other studies that indicate that women predominate among caregivers (Sharma, Chakrabarti & Grover, 2016), the majority of participants in our study were also female (73%). Twenty-two of the respondents were caring for their husbands; eight were caring for a wife.

Participants were recruited from a group of caregivers who signed up to receive financial aid from the local government. The research team obtained a list of individuals who were eligible to receive this financial aid, and who agreed to be contacted by the research team. In order to be eligible to receive financial help, a care recipient had to demonstrate they were physician-diagnosed with AD (by a neurologist or psychiatrist), and were at least 75 years old. Prior to recruitment, letters describing the study were sent out to caregivers, inviting them to participate. Of 124 potential participants who fulfilled the eligibility criteria, 30 (24%) agreed to participate in the study. All caregivers who participated in the study provided written informed consent. Upon providing the consent, a semi-structured interview to facilitate a discussion was used. All interviews were conducted face-to-face in the caregivers' houses and lasted between 90 and 120 minutes. The interviews were audio recorded and transcribed. The main purpose of the interview was to acquire information about the experience of caregiving. Topics included the challenges of caregiving, changes in the relationship, current caring needs, the caregiver's needs, reaction to the diagnosis, and plans for continuing care.

We employed a thematic analysis (a qualitative analysis technique) which aimed at identifying common themes in responses given by the participants (Boyatzis, 1998). Each excerpt cited in this article ends with a letter indicating gender (W for a woman and M for a man), and a number which indicates

the participants' age; C stands for a caregiver. Thematic analysis revealed three key themes that emerged from the transcripts, which could be encompassed under an overarching theme of 'being prisoner in your own house'. This describes the caregivers' constant struggle to balance their duties, such as grocery shopping, with providing care to their recipients. Other important themes that emerged from the interviews were related to changes in the social network, and feelings of loneliness in the relationship (emotional isolation); these were mostly due to the behavioural changes caused by Alzheimer's disease, including (but not limited to) social withdrawal and problems with language.

3. Results

A large majority of respondents (n = 27) described the length of time since the diagnosis as an important factor that significantly increased the amount of time they spent at home. A dominant theme was social isolation related to the challenges of performing daily activities, with the fear or inability to leave the house. Caregivers reported difficulties leaving the house because of their care recipients' reactions.

I am busy all the time. I don't have free time. Just quick grocery shopping, and I have to be back because my wife is worried that I've been gone for too long. I can't stay too long anywhere. I used to go out to play cards, but I don't anymore because I don't have time. [C03_M, 86]

We don't go outside. I can't run errands. [C06_W, 85]

I have no freedom. I can't go shopping. Just like with a child – he wants to go everywhere with me. [C12_W, 82]

Some caregivers were able to perform daily activities, but they were accompanied by the fear that something unfortunate might happen when they were not at home with the care recipient.

I can't leave him alone ... I mean I can, but I'm shaking because I don't know what he might do ... turn on the tap, burn the house? I do the grocery shopping like a crazy person – really, really fast. [C07_W, 83]

A few caregivers were able to leave the house but had to carefully plan when to do so. For example, one caregiver said, 'I go out only during the daytime

just to do some shopping, because in the evening she is very anxious. I can't leave her alone' [C22_M, 85].

Well, a lot has changed. I take care of him round the clock, do everything. If I need to go somewhere, or I want to visit someone or go to the hairdresser's, I need to ask my sister for help or have to ask somebody else. It's hard. [C09_W, 78]

Another dominant theme was described in changes related to the activities caregivers used to enjoy and their social activities. Providing care, and the symptoms of the disease, made it difficult or even impossible to continue maintaining their activities and hobbies.

Everything has changed since the diagnosis. We don't go out. Friends don't come to visit us. Most of our friends are already dead. [C17_W, 82]

I broke contact with my friends, with my lifestyle in general. You see ... I used to drive to different places, go on trips. People stopped visiting us. When my wife was fine, they would visit us. ... We used to meet for coffee every single Sunday. My social life has changed. Now when I call, they find excuses not to meet me. [C26_M, 82]

I can't go on holiday. I'm a prisoner in my own house. This is like a voluntary marital house arrest. [C18_W, 82]

I've become a homebody. We used to have an active social life before, and we really enjoyed spending time with other people, but now our social life doesn't exist. [C20_M, 86]

Only one caregiver mentioned that the reason why their social life changed is because she did not want to bother other people. Another caregiver mentioned that she would love to have guests more often, but it is difficult for her to pay attention to her guests' needs and her husband's needs at the same time.

Sometimes when we have a guest, I don't know what to do. Should I stay with my husband or should I focus on that person? The house feels like a hospital. [C11_W, 84]

Another dominant theme that emerged from the analyses was related to a feeling of loneliness due to changes in the relationship between the caregiver and the care recipient. When talking about their decreasing social network, most

of the caregivers expressed sadness yet understanding at not being visited as often as they had been. However, losing both contact and ability to exchange information with their spouses was challenging, and evoked various different emotions, ranging from sadness to anger.

He asks me the same questions all over again. It drives me crazy. I've become more stressed. ... I don't know why he gets upset, he was different before. It [the relationship] has changed significantly. I don't know if he listens to me, if he understands what I say. [C19_W, 84]

I can no longer talk to him like with an ordinary person. I miss having regular conversations. Sometimes I need to make a decision and I would like to consult with him, but I know it's now impossible. [C18_W, 82]

I used to have a friend, a partner. He was a normal person. Now I have nothing left. [W, 79]

It's like night and day. He always loved people ... he used to be the life and soul of the party. Now I have to encourage him to say something. He is socially withdrawn. [C05_W, 72]

The fact that there is no contact with him, that he doesn't understand me ... is terrifying. [C14_W, 79]

One caregiver indicated that the symptoms of the Alzheimer's disease are the biggest obstacle in communicating with her spouse.

Our relationship ... well, he keeps getting worse ... and now we can't get along; it's difficult ... now I don't understand what he is trying to say. Sometimes I get really angry because it's so hard to understand him, and then I have to remind myself that this man is sick, it's not his fault. [C21_W, 79]

When asked if participants had ever considered placing a spouse in a nursing home, a consistent response across all participants was that they would not do that. Some caregivers voiced the importance of family ties, but the majority believed that the admission to the nursing home would cause a quick deterioration of the AD symptoms. None of the caregivers used financial costs as an argument for not placing a care recipient in a nursing home.

I can't imagine that [placing him in a nursing home] ... he would be terrified. He would die quickly. [C09_W, 78]

I'm not considering placing her in a nursing home. We are a family ... She would go downhill quickly. [C25_M, 80]

4. Discussion

Loneliness among the spousal caregivers of individuals with Alzheimer's disease has received little attention, and it remains unexplored in existing research on caregiving. Previous studies indicated that a majority of older adults can expect a decline in the overall size of their social network and the frequency of their social contacts (Pinquart & Sörensen, 2003). Older adults may experience loneliness because their friends die, or because of their own physical health limitations that prevent them from being socially active. The deficit of contact may lead to loneliness, which is believed to be more prevalent in older than in younger adults. However, the ability to maintain social contact is further constrained among spousal caregivers of individuals with Alzheimer's disease. Therefore, they are at higher risk of experiencing the negative consequences of loneliness than other cognitively intact older adults.

This study sought to examine the caregivers' perspectives concerning their experience as a primary caregiver of a person with Alzheimer's disease. The literature consistently shows that caregivers face significant challenges that impact their physical and mental health. As the symptoms of the disease worsen, caregivers tend to focus more on care recipients, and have neither time nor energy to meet with friends and relatives. The disease also has a considerable impact on the relationship between spouses, because it reduces the disease-affected individuals' abilities to communicate. Our findings extend this work by showing that loneliness is a common experience among spousal caregivers.

We examined 30 spousal caregivers of individuals with Alzheimer's disease living in Szczecin, Poland, by conducting semi-structured interviews. Participants were insightful about their experiences, and their responses allowed us to identify three main themes that emerged from the analysis of the interview transcripts. These themes described (1) participants' difficulties in leaving the house (e.g., to do some shopping), and in providing care; (2) changes in their social network; and (3) the feelings of loneliness in the relationship, resulting from reduced verbal contact with the spouse.

For the caregivers interviewed, the caregiving experience significantly reduced the number of interactions with their family members, friends and acquaintances. The reasons varied, but the majority of caregivers indicated that it had become more difficult for them to leave the house because of the care recipients' behaviour (e.g. wandering). Their contacts were also reduced

because it was hard for the caregivers to focus on guests and care recipients at the same time. A few caregivers mentioned that their friends had stopped visiting them shortly after the diagnosis of Alzheimer's disease. We can speculate that friends and family members who have no experience of dementia may not know how to behave around someone with the condition. Therefore, future research could investigate the reasons why friends stop visiting after learning about the diagnosis of Alzheimer's disease. Future research should also employ a more diverse sample in terms of socioeconomic status, and collect data from more male caregivers in order to compare their experiences with those of female caregivers.

Also shared among the interviewed caregivers was the feeling of loneliness resulting from the changing nature of the relationship with the disease-affected spouse. Marriage is the most intimate relationship for most individuals (Levinger & Huston, 1990). Previous research demonstrated that caregiving causes disruptions in family dynamics and may decrease marital satisfaction (De Frias, Tuokko & Rosenberg, 2005), which is generally defined as a person's overall evaluation of his or her marriage. The presence of Alzheimer's disease in one partner can significantly affect marital satisfaction and cause the feeling of loneliness, as both members of the dyad have to adjust to their new roles. The burden of providing care to a spouse poses a threat to marital satisfaction and increases loneliness, mostly because of the behavioural and physical changes related to Alzheimer's disease, such as apathy and problems with communication (De Vugt et al., 2003). Our findings indicate that the disease also impacts emotional intimacy, defined as a deep sense of caring, expressions of liking and loving, sharing of private thoughts, and the capacity to communicate about the relationship (Waring & Chelune, 1983). In our study, caregivers frequently wanted to share their worries, discuss current problems, consult, or simply talk about the past. The caregivers emphasised that their relationship had changed significantly and was no longer as it used to be; or, as one of the caregivers stated, 'the relationship doesn't exist'. It is important to investigate the changes within the relationship, because studies have demonstrated that a lack of intimacy may contribute to a greater vulnerability to depression and feelings of loneliness (Waring, Patton, Neron & Linker, 1986). In addition, due to the spouse's physical impairment, a caregiver performed more responsibilities and had to reduce the number of activities that they had previously performed together. In our study, caregivers mentioned that they used to travel a lot and really enjoyed it. This reduction in activities that were enjoyable may also impact their marital satisfaction.

Even though caregivers mentioned the burden of providing care, none of them, when asked whether they had ever considered placing a spouse in a nursing home, was willing to do that. The participants were afraid that placing care recipients in a nursing home might deteriorate their physical and mental well-being. This draws attention to how important the commitment to caring for a spouse is. Due to increased life expectancy and the increased prevalence of chronic health conditions, a growing number of older couples have to face the transition to a caregiver–care recipient relationship. Because family care is often better than nursing-home care, it is important to support caregivers in a way that reduces their feelings of loneliness and burden.

This study's contribution to the literature should be considered within the context of its limitations. One such limitation is that the data came from a small sample of caregivers located in one geographical area. We used convenience samples of caregivers who were willing to participate in the study. Although convenience sampling is easier and less expensive to carry out than random sampling, relying on available subjects can lead to bias. This method does not allow the researcher to control the characteristics of the sample (e.g. age, race, gender or education). Therefore, the sample may be unlikely to be representative of the population being studied, and findings from the sample cannot be generalised to the population (Saumure & Given, 2008). However, despite the limitations, the study does provide useful insights into the caregivers' experiences. This study offers implications for policy, interventions, future research, and contributes to our understanding of spousal caregivers' experiences in providing care. Caring for an individual diagnosed with Alzheimer's disease can be difficult, and significantly reduces a caregiver's opportunities to leave the house. The interviewed caregivers often feel like they are 'prisoners in their own homes', and the results highlight the need to design interventions that could be applied in caregivers' homes. Previous research has already demonstrated that although caregivers often experience deterioration in their relationship, a sense of closeness can remain (De Vugt et al., 2003). It is therefore important that the interventions not only aim to decrease the burden, but also to foster caregivers' emotional intimacy and enhance the positive aspects of caregiving.

Alzheimer's disease-related symptoms, such as social withdrawal or problems with language, are sources of distress for caregivers. Our results also point to the need for educating caregivers on how the contact with their spouses can be maintained while the disease progresses. While education about the disease and methods of coping may not be sufficient in itself, it has the potential to reduce the feelings of losing contact.

Findings from this study suggest that spousal caregivers do experience feelings of loneliness and social isolation. Given that there is an increasing prevalence of individuals with Alzheimer's disease, a continued exploration of the relationship between caregiving and loneliness is warranted. This study could be used as a stepping stone for other studies to investigate the relationship between providing care and feelings of loneliness among spousal caregivers.

References

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S. & Lachs, M. S. (2014). Caregiver Burden: A Clinical Review. *JAMA*, *311*(10), 1052–1060. DOI:10.1001/jama.2014.304
- Alzheimer's Association (2019). Alzheimer's Disease Facts and Figures. *Alzheimer's and Dementia*, *15*(3), 321–387.
- Ayalon, L., Shiovitz-Ezra, S. & Palgi, Y. (2013). Associations of loneliness in older married men and women. *Aging & Mental Health*, *17*(1), 33–39. DOI:10.1080/13607863.2012.702725
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications, Inc.
- Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, *11*(2), 217–228.
- De Frias, C. M., Tuokko, H. & Rosenberg, T. (2005). Caregiver physical and mental health predicts reactions to caregiving. *Aging and Mental Health*, *9*(4), 331–336. DOI: 10.1080/13607860500089674.
- De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., ... Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry*, *18*(2), 149–154. <https://doi.org/10.1002/gps.807>.
- Fauth, E. B., Femia, E. E. & Zarit, S. H. (2016). Resistiveness to care during assistance with activities of daily living in non-institutionalized persons with dementia: associations with informal caregivers' stress and well-being. *Aging and Mental Health*, *20*(9), 888–898. DOI:10.1080/13607863.2015.1049114.
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., ... Glosop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ: Canadian Medical Association Journal (journal de l'Association medicale Canadienne)*, *170*(12), 1795–1801. DOI:10.1503/cmaj.1031205.

- Holt-Lunstad, J., Smith, T. B. & Layton, J. B. (2010). Social Relationships and Mortality Risk: A Meta-analytic Review. *PLoS Medicine*, 7(7), e1000316. <https://doi.org/10.1371/journal.pmed.1000316>.
- Karantzoulis, S. & Galvin, J. E. (2011). Distinguishing Alzheimer's disease from other major forms of dementia. *Expert Review of Neurotherapeutics*, 11(11), 1579–1591. DOI:10.1586/ern.11.155.
- Lavretsky, H. (2005). Stress and depression in informal family caregivers of patients with Alzheimer's disease. *Aging Health* 1(1), 117–133. <https://doi.org/10.2217/1745509X.1.1.117>.
- Lee, K., Martin, P. & Poon, L. W. (2017). Predictors of caregiving burden: impact of subjective health, negative affect, and loneliness of octogenarians and centenarians. *Aging and Mental Health*, 21(1), 1214–1221. <https://doi.org/10.1080/13607863.2016.1206512>
- Lepore, M., Ferrell, A. & Wiener, J. M. (2017). *Living Arrangements of People with Alzheimer's Disease and Related Dementias: Implications for Services and Supports*. Research Summit on Dementia Care. <https://aspe.hhs.gov/system/files/pdf/257966/LivingArran.pdf>
- Levinger, G. & Huston, T. L. (1990). The social psychology of marriage. In T. Bradbury & F. Fincham (Eds.), *The Psychology of Marriage* (pp. 19–58). New York, NY: Guilford Press.
- Nieminen, T., Prättälä, R., Martelin, T., Härkänen, T., Hyypä, M. T., Alanen, E. & Koskinen, S. (2013). Social capital, health behaviours and health: a population-based associational study. *BMC public health*, 13, 613. DOI:10.1186/1471-2458-13-613.
- Perlman, D. & Peplau, L. A. (1981). Toward a Social Psychology of Loneliness. In: S. Duck & R. Gilmour (eds.), *Personal Relationships in Disorder* (pp. 31–56). London, UK: Academic Press.
- Pinquart, M. & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250–267. <http://dx.doi.org/10.1037/0882-7974.18.2.250>.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia*, 9, 63–75. e62. DOI: 10.1016/j.jalz.2012.11.007.
- Rafnsson, S. B., Orrell, M., d'Orsi, E., Hogervorst, E. & Steptoe, A. (2017). Loneliness, Social Integration, and Incident Dementia Over 6 Years: Prospective Findings From the English Longitudinal Study of Ageing. *The Journals of Gerontology: Series B*, gbx087, <https://doi.org/10.1093/geronb/gbx087>.
- Richard, A., Rohrmann, S., Vandeleur, C. L., Schmid, M., Barth, J. & Eichholzer, M. (2017). Loneliness is adversely associated with physical and mental health

- and lifestyle factors: Results from a Swiss national survey. *PLoS ONE* 12(7), e0181442. <https://doi.org/10.1371/journal.pone.0181442>
- Rokach, A. (2012). Loneliness Updated: An Introduction. *The Journal of Psychology*, 146(1–2), 1–6. DOI: 10.1080/00223980.2012.629501.
- Saumure, K. & Given, L. M. (2008). Convenience sample. In L. M. Given (ed.), *The Sage Encyclopedia of Qualitative Research Methods* (pp. 124–125). Thousand Oaks, CA: Sage Publications.
- Schulz, R. & Eden, J. (2016). *Families Caring for an Aging America*. Washington (DC): National Academies Press (US). Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK396398/>.
- Sharma, N., Chakrabarti, S. & Grover, S. (2016). Gender differences in caregiving among family - caregivers of people with mental illnesses. *World Journal of Psychiatry*, 6(1), 717. DOI:10.5498/wjp.v6.i1.7
- Singleton, D., Mukadam, N., Livingston, G. & Sommerlad, A. (2017). How people with dementia and carers understand and react to social functioning changes in mild dementia: a UK-based qualitative study. *BMJ open* 7(7), e016740. DOI:10.1136/bmjopen 2017-016740
- Skira, M. M. (2015). Dynamic wage and employment effects of elder parent care. *International Economic Review*, 56(1), 63–93. <https://doi.org/10.1111/iere.12095>
- Victor, C., Scambler, S., Bond, J. & Bowling, A. (2000). Being alone in later life: Loneliness, social isolation and living alone. *Reviews in Clinical Gerontology*, 10, 407–417. <https://doi.org/10.1017/S0959259800104101>
- Vitaliano, P. P., Zhang, J. & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946–972. DOI: 10.1037/00332909.129.6.946
- Waring, E. M. & Chelune, G. J. (1983). Marital intimacy and self-disclosure. *Journal of Clinical Psychology*, 39(2), 183–190. [http://dx.doi.org/10.1002/10974679\(198303\)39:2<183::AIDJCLP2270390206>3.0.CO;2-L](http://dx.doi.org/10.1002/10974679(198303)39:2<183::AIDJCLP2270390206>3.0.CO;2-L)
- Waring, E. M., Patton, D., Neron, C. A. & Linker, W. (1986). Types of marital intimacy and prevalence of emotional illness. *Canadian Journal of Psychiatry*, 31(8), 720–725. DOI: 10.1177/070674378603100805
- Weiss, R. S. (1973). *Loneliness: The experience of emotional and social isolation*. Cambridge, MA: The MIT Press.