# Loneliness and social isolation among older informal caregivers: A review of the evidence from longitudinal investigations

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### Chapter 6

# Loneliness and social isolation among older informal caregivers

## A review of the evidence from longitudinal investigations

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## Population ageing and long-term care needs

As the world's population ages, the proportion of older adults will continue to grow over the coming years and decades. In consequence, more people are expected to live and age with multiple age-associated chronic illnesses, leading to greater demands for long-term care and higher health-care costs (de Meijer *et al.*, 2013). Increasingly, the policy response of Western governments has been to steer away from formal care while emphasizing the importance of informal care arrangements; older adults are encouraged to stay home longer instead of moving into long-term care facilities (Lindt, van Berkel, and Mulder, 2020). As people grow older, the possibility of remaining in familiar environments is related to the availability of home care which depends on older adults having access to a network of family and friends to provide the personal care and support without which the older person (i.e., care recipient) is unlikely to cope, including administrative help or domestic and personal care (Schulz *et al.*, 2020). It should be stressed that informal caregiving is unpaid, results from personal rather than professional relations, and often entails long-term care and support for a spouse or partner in need, other family members, or friends.

## Informal caregiver health and well-being

While caregiving can bring satisfaction and reward to some individuals, for many caregivers, it is an onerous experience that involves negative appraisals and perceived stress. Not only may caregivers feel as if the care demand never eases but many also concomitantly struggle with maintaining their social and financial well-being and become overstrained. As expected, current theoretical frameworks thus commonly view the burden associated with caregiving from the psychological perspective of stress and coping which has been widely applied in investigations of caregiver well-being (Myers, 2003). Specifically, as reviewed in detail in the next sections, there is growing longitudinal evidence on the potential contribution of informal caregiving to the

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development of social isolation and feelings of loneliness, two moderately related but distinct constructs indicating social needs that also differ in their determinants and health consequences (Newall and Menec, 2019). While loneliness refers to the subjective feeling that one's social relationships are of poorer quality (e.g., lacking emotional closeness or are fewer in number) than desired, social isolation indicates an objective lack of contact with others in one's social network (Holt-Lunstad *et al.*, 2015). On the one hand, a causal link between informal caregiving, social isolation, and loneliness is plausible given that informal caregiving can significantly limit the time and resources available for interactions with family and friends or participation in social and leisure activities, which may contribute to social isolation and loneliness. Becoming an informal caregiver, however, might also allow some individuals to counteract social isolation or feelings of loneliness by offering their help and assistance to those in need or through enhancing their social contact with people in similar circumstances (e.g., other caregivers).

## Prospective evidence on loneliness and social isolation among informal caregivers

An overview of the study design, data collection methods, and main findings reported in the ten studies reviewed here is provided in Table 6.1. In sum, three of the studies came from the USA, two from the UK, two from Germany, and one each from Canada, the Netherlands, and France. Seven studies recruited representative population-based samples; in the remaining three, the study samples were generated through non-probabilistic sampling methods. The overall reported sample sizes ranged from 129 to 8658; the study by Hajek and König (2019) was based on 21762 observations pooled over 12 years. The studies mainly involved middle-aged and older individuals (average age ranged from 49.4 years to 71.0 years across the studies; the proportion aged 65 year and older ranged from about 6.3% to 77.2%). The proportion of women in the samples ranged from approximately 42.9% to 70.3% with two studies not providing this information. Only five studies reported on the ethnic group composition of the study samples; the proportion of ethnic White participants ranged from 71.1% to 98.0%.

Seven studies used a dichotomous variable to quantify the presence of informal caregiving; two studies investigated the psychosocial impact of transitioning into a caregiving role; one study distinguished between current caregiving, former caregiving, and non-caregiving. Six studies examined spousal caregiving alone or in combination with other relationship types, and one study examined adult caregiving daughters of widowed parents, whereas three studies did not specify the caregiver–care recipient relationship type. The number of data collection waves used ranged from two to eight; however, the time between data collection points varied from as little as 2 months to 5 years. The overall follow-up period ranged from 6 months to 12 years.

*Table 6.1* Characteristics and key findings from longitudinal studies of informal caregiving, loneliness, and social isolation

| | *Study design characteristics* | | | *Longitudinal results* | | | | |
|---|---|---|---|---|---|---|---|---|
| *Reference; Country, sample type* | *Caregiver (CG) relationship with care recipient and baseline CG sample size (n)* | *Baseline caregiver (CG) age (mean, SD, or % 65+), sex (% females), and ethnicity (% White or Majority population)* | *Baseline caregiving (CG) hours per week (mean, SD)* | *Psychosocial domain(follow-up period, years)* | *A*[a] | *B*[b] | *C*[c] | *D*[d] |
| **Li *et al.* (2021)**; Canada, population-based | Spouse (n=1293); Adult child (n=3933) | Spousal CGs (65+=56.5%; female=42.9%; White/ Majority=94.0%); Adult-child CGs (65+=6.3%; female=55.5%; White/ Majority=92.4%) | Spousal CG (mean=20.4, SD=39.5); Adult-child CG (mean=4.4, SD=10.7) | Social isolation (3 years) | yes | yes[e] | no | yes[j] |
| **Gallagher and Wetherell (2020)**; UK, population-based | Undefined (n=1349) | Mean age=52.8, SD=14.8; female=61.5%; White/ Majority=93.6% | NR | Loneliness (1–3 years) | no | NR | NR | NR |
| **Zwar *et al.* (2020)**; Germany, population-based | Undefined (n=551) | Male CGs (mean age=66.4, SD=11.10; Ethnicity NR); Female CGs (mean age=65.48, SD=10.2; Ethnicity NR) | NR | Loneliness and social isolation (3 years) | no | yes[f] | NR | NR |
| **Ross *et al.*, 2020**; USA, clinic-based | Spouse, parent, adult child, friend/other (n=129) | All CG types combined (mean age=48.6, SD=11.78; female=67.4%; White and non-Hispanic=71.1%) | NR | Loneliness (0.5 years) | NR | yes[g] | NR | yes[k] |

(*Continued*)

*Table 6.1* (Continued)

| | *Study design characteristics* | | | *Longitudinal results* | | | | |
|---|---|---|---|---|---|---|---|---|
| *Reference; Country, sample type* | *Caregiver (CG) relationship with care recipient and baseline CG sample size (n)* | *Baseline caregiver (CG) age (mean, SD, or % 65+), sex (% females), and ethnicity (% White or Majority population)* | *Baseline caregiving (CG) hours per week (mean, SD)* | *Psychosocial domain(follow-up period, years)* | *A*[a] | *B*[b] | *C*[c] | *D*[d] |
| **Hawkley *et al.* (2020)**; USA, population-based | Spouse (n=83) | Male CGs (65+=77.2%; White and other=85.6%); Female CGs (65+=58.9%; White and other=86.6%) | NR | Loneliness (5 years) | no | NR | NR | NR |
| **Smith *et al.* (2020)**; UK, population-based | Spouse, parent, parent-in-law, other relative, friend or neighbour (n=1375) | All CG types combined (mean age=62.0, SD=9.9; female=62.9%; White=98.0%) | All CG types combined (n=375, mean=56.8, SD=70.2) | Loneliness (8 years) | yes | NR | NR | NR |
| **Hajek and König (2019)**; Germany, population-based | Undefined (n=3148) | NR | NR | Loneliness (12 years) | no | NR | NR | NR |
| Joling *et al*. **(2018)**; Netherlands, clinic-based | Spouse (94.3% of n=192) | All CGs types combined (mean=69.5, SD=10.4; female=70.3%) | NR | Loneliness (2 years) | yes | NR | NR | NR |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| van den Broek and Grundy (**2018**); France, population-based | Adult daughters of a widowed parent (n=557) | Adult daughter CGs (mean age=49.4, SD=9.9) | NR | Loneliness (6 years) | no | yes[h] | yes[i] | NR |
| **Robinson-Whelen *et al.* (2001)**; USA, clinic-based | Spouse (n=91) | Current CGs (mean age=71.0, SD=7.5); Sex NR; Ethnicity NR; Former CGs (mean age=70.8, SD=10.1); Sex NR; Ethnicity NR | NR | Loneliness (4 years) | yes | NR | NR | NR |

Note:

[a] Significant adverse effect of informal caregiving role on loneliness and/or social isolation relative to a comparison group after full statistical adjustment;

[b] Significant adverse effect of caregiver background characteristics (e.g., demographics, health status) on loneliness and/or social isolation relative to a comparison group/reference level after full statistical adjustment;

[c] Significant adverse effect of care recipient characteristics (e.g., demographics, diagnosis) relative to a comparison group/reference level after full statistical adjustment;

[d] Significant adverse effect of caregiving level/intensity on loneliness and/or social isolation relative to a comparison group/reference level after full statistical adjustment;

[e] Male sex, older age, low personal income, worse general and mental health;

[f] Male sex;

g Being single/not married, unemployment, worse mental health;

h Being single/not married;

i Parental health limitation;

j Caregiving hours per week;

k Perceived stress, higher caregiving burden.

Four studies used versions of the De Jong Gierveld scale to quantify loneliness, two used the three-item UCLA loneliness scale, one used a shortened form of the New York University loneliness scale, and one used the NIH Toolbox loneliness scale. Two studies used different single item measures to quantify feelings of loneliness. On the other hand, one study only included in this review assessed self-perceived social isolation using the Social Isolation Index which combines structural/objective and functional/objective dimensions across several different domains, including community participation, social network size, living arrangement, and availability of social support. Among these longitudinal studies, two used specific panel regression models to exploit the longitudinal data structure and to reduce the challenge of unobserved heterogeneity. Based on these panel regression statistical models, consistent estimates can be generated.

### *Informal caregiving, loneliness, and social isolation*

Most of the studies reviewed here provide longitudinal information on the relative psychosocial impact of current caregiving per se, former caregiving, or transitioning into a caregiving role. However, the results appearing from these investigations are both diverse and inconsistent. Specifically, utilising data from the English Longitudinal Study of Ageing (ELSA), Smith *et al.* (2020) observed greater levels of loneliness among informal caregivers compared to non-caregivers over an 8-year follow-up after adjusting for potential confounding by gender, ethnicity, and multiple psychosocial factors. These findings seem to contrast the findings from three other population-based longitudinal studies, including one by Gallagher and Wetherell (2020) which examined the difference in the proportion of participants reporting being lonely often at baseline and follow-up; although significantly more caregivers, compared to non-caregivers, reported being often lonely at baseline, at follow-up, the difference between caregivers and non-caregivers proved to be statistically non-significant. Zwar *et al.* (2020) reached a similar conclusion when reporting that, for men and women combined, the potential influence associated with entry into a caregiving role on social isolation and loneliness turned out to be non-significant following full statistical adjustment. Lastly, although drawing on 12 years of follow-up data from the German Ageing Survey (DEAS), Hajek and König (2019) also failed to observe an association between informal caregiving and loneliness; specifically, transitioning into caregiving proved not to be associated with changes in the level of loneliness in the total sample (or either sex) after the analysis statistically controlled for participants' demographic characteristics, marital and employment status, as well as the presence of chronic health conditions.

A similarly variable picture emerges for findings on loneliness and social isolation in longitudinal samples involving specific caregiver relationship types, most often spousal caregivers. In this context, Li *et al.* (2021) found that spousal caregivers had a steeper increase in Social Isolation Index scores compared to adult–child caregivers in the Canadian Longitudinal Study of Aging (CLSA). Similarly, Joling *et al.*'s (2018) investigation of caregiving and social context showed that spousal caregivers who reported suicidal thoughts experienced more feelings of loneliness than those without suicidal thoughts. Another study by Robinson-Whelen *et al.* (2001) observed that both current and former spousal caregivers experienced greater loneliness than non-caregiving participants over a 4-year follow-up. In contrast to these studies, however, no associations were reported between spousal caregiving and loneliness for either husbands or wives in a population-based study undertaken in the USA by Hawkley *et al.* (2020). Similarly, van den Broek and Grundy (2018) failed to observe any statistically significant effects on loneliness of care provision by adult daughters of widowed parents, thus their analysis did not provide support for the hypothesis that the provision of personal care to widowed parents is associated with raised feelings of loneliness.

### *Caregiver characteristics, loneliness, and social isolation*

The psychosocial influences of different sociodemographic and health characteristics among informal caregivers have been examined in several of the studies reviewed here, although the current evidence appears to be patchy and even inconsistent at times. Thus, in their analysis of population data from the CLSA, Li *et al.* (2021) observed that family caregivers aged 65 years and older at baseline experienced comparatively greater social isolation over the 3-year follow-up compared with both participants aged 45–54 years old and 55–64 years old. When social isolation was examined by sex, male caregivers were found to experience relatively greater increase in social isolation compared to female caregivers (Li *et al.*, 2021). These results partly corroborate earlier findings by Zwar *et al.* (2020) who reported that transitioning into caregiving was significantly associated with increased loneliness scores among male caregivers but not female caregivers. Further to this, *Li et al.* (2021) also reported an inverse relationship between personal income level and social isolation over time, but differences in social isolation scores over time by ethnic group (visible minority versus not) and education attainment (low versus high) proved to be statistically non-significant. In contrast, worse self-reported general and mental health were associated with comparatively more long-term social isolation in participants in the CLSA (Li *et al.*, 2021) and loneliness among family caregivers of individuals undergoing cancer treatment (Ross *et al.*, 2020). Similarly, Ross *et al.*'s (2020) study observed that unemployed family cancer caregivers experienced higher levels of loneliness compared to employed caregivers which contrasts an earlier finding reported by van den Broek and Grundy (2018) that change in employment status had non-significant influences on change in feelings of loneliness among adult daughters providing care for a widowed parent. However, the presence of a spouse or partner was found to be protective against loneliness, whereas the presence of children in the household was not (van den Broek and Grundy, 2018). This is partly in line with the findings reported by Ross *et al.* (2020) that, for any given time point across the 6-month follow-up period, family caregivers who were not married experienced higher levels of loneliness.

### *Care recipient characteristics and caregiver loneliness and social isolation*

Just two of the studies reviewed here prospectively investigated the influence of specific care recipient characteristics on caregiver feelings of loneliness. Drawing on representative data from the Family and Intergenerational Relationships Study (ERFI, the French component of the Generations and Gender Surveys), van den Broek and Grundy (2018) noted that, in a fixed effects regression model adjusting for age, cohabitation, the presence of children in household, employment status, and parental health limitations (i.e., limitations in performing everyday activities such as dressing or bathing due to physical or mental health disability) were significantly associated with daughters' raised sense of loneliness (as measured by the shortened De Jong Gierveld loneliness scale) over a 6-year period. The inclusion of personal care provision in the regression model did not materially attenuate the effect of parental health limitations; the effect of parental health limitations remained significant, suggesting that parental health limitations affect daughters' feelings of loneliness regardless of whether (only 4.5% of the sample provided personal care to their widowed parent) or not daughters provide personal care. In a final step, further adjustment for depressive symptoms in the analysis did not materially change the observed effects of parental health limitations, suggesting changes in daughters' feelings of loneliness (irrespective of whether they provided care or not) during follow-up were unlikely to be mediated by low affect. In contrast, a more recent analysis of data from the CLSA failed to observe statistically significant effects of care recipient's gender on family caregiver's social isolation over a 3-year follow-up; the analysis adjusted for a range of potential confounding factors, including the number of care hours per week albeit not the health condition of care recipient due to lack of available information in the CLSA (Li *et al.*, 2021).

### *Caregiving intensity, loneliness, and social isolation*

The evidence reviewed here points to a limited yet consistent association between indicators of caregiving level, or intensity, and psychosocial stress in informal providers of care. Thus, Li *et al.* (2021) observed a statistically significant, positive, linear relationship between the number of family caregiving hours per week at baseline and level of social isolation over three years in their representative population sample after adjusting for caregiver's sociodemographic characteristics, ethnic group, self-rated general and mental health, and the care recipient's gender. Similarly, in an earlier clinic-based study involving 129 family caregivers of individuals undergoing cancer treatment, Ross *et al.* (2020) reported significantly higher levels of loneliness over a 6-month period in caregivers who experienced greater perceived stress and more caregiver burden as indicated by low caregiver esteem, a negative impact of caregiving on personal finances, health, and schedule, and the caregiver's perceived lack of family support. These psychosocial influences of caregiver stress and burden were found to be independent of potential confounding by the caregiver's sex, his/her marital and employment status, mental health, participation in health-promoting behaviours, the quality of the caregiver–care recipient relationship (e.g., their shared values), and whether the care recipient was hospitalised or not for their cancer treatment.

## Potential explanatory pathways

Informal caregiving is a complex adult life-course role activity which may bring satisfaction, rewards, and enjoyment for some assuming this role, yet for others, it is associated with a high burden and responsibilities (Lindt, van Berkel and Mulder, 2020). The extent to which many caregivers may end up socially isolated or feeling lonely is likely to depend on different moderating factors (e.g., the caregiver–care recipient relationship type, the caregiver's gender, state of health) and mediating biopsychosocial pathways (e.g., psychobiological processes of stress and coping) operating alone or in combination (Lindt, van Berkel, and Mulder, 2020 and McAuliffe, Ong and Kinsella, 2020). For example, strain resulting from prolonged caregiving may culminate in psychological morbidity, including symptoms of distress and depression (Del-Pino-Casado *et al.*, 2019) which can affect the quality of personal relationships and engagement in social activities, thus contributing to social isolation and loneliness. Specifically, spousal caregiving is related to particularly high stress levels; spousal caregivers tend to be older, are most likely to live with the care recipient, tend to provide more hands-on care and for longer hours, and find less respite (Schulz *et al.*, 2020). Spouses are also more likely to care for a person with dementia than adult children; the care recipient's decline in cognitive and functional status, behavioural disturbances, and care dependency are important risk factors for adverse emotional reactions, including anger, grief, and loneliness in these caregivers (Cheng, 2017). Especially among older caregivers, intense feelings of loneliness and social isolation may also result from poor physical health and long-term conditions that limit daily functioning and frequent social contact with others (Lindt, van Berkel and Mulder, 2020). Moreover, informal caregivers' decreased engagement in health-promoting behaviours is related to less physical activity, greater likelihood of smoking, drinking alcohol, and poor sleep patterns; poor sleep quality may induce feelings of loneliness and reduce social engagement (Byun *et al.*, 2016 and Kim and Woo, 2022). If sedentary behaviour, smoking, and excess body weight induce negative self-evaluations in informal caregivers or make them more susceptible to negative stereotyping, their ability to form or maintain quality relationships with others might be further compromised (Hajek and König, 2021 and Jung and Luck-Sikorski, 2019).

## Quality of findings, gaps in the evidence, and recommended future research

This review reveals that the available longitudinal evidence on social isolation and loneliness in informal caregivers is still limited in extent and methodologically heterogeneous. Reported findings are patchy and invariably conflicting. Not only does this diversity in research design hamper any meaningful synthesis of findings across studies, accounting for the apparent discrepancies in results remains challenging. Overall, although with clear exceptions, the quality of the evidence is compromised by the lack of detailed information available in several studies on specific caregiving contextual, moderating, and mediating factors, such as those outlined in established stress–process models; the lack of concomitant measurement of social isolation and loneliness; the potential impact of selection (e.g., in non-probabilistic samples) and attrition (e.g., in population-based samples) biases; the possibility of reverse causality in studies with limited follow-up periods; and potential residual confounding attributed to poorly measured or unaccounted confounding factors.

Partly as a result, several gaps may be identified in the current evidence that should be addressed in future investigations. For example, it is not clear how, or to what degree, any long-term effects of informal caregiving on social isolation and feelings of loneliness maybe moderated by the caregiver and care receiver relationship or other contextual factors and characteristics (e.g., the caregiver's health or available socioeconomic resources, length of time spent in the caregiving role, the care recipient's diagnosis, needs, or behaviours). Moreover, it is unclear how the impact on social isolation and loneliness maybe further shaped by different caregiving transitions (e.g., entry into, or exit from, caregiving).

Where possible, future investigations need to make more explicit use of available conceptual frameworks, such as stress and coping models, for aligning the study focus with the study design, methods, and analysis. The utilisation of these models would also allow researchers to systematically assess where further analyses may be needed and plan accordingly. For example, diverse sociocultural factors, including social norms that dictate spouses to take on caregiving responsibilities before others, may influence entry into an informal caregiving role (Phillips and O'Loughlin, 2017) and shape caregivers' experiences of social isolation or feelings of loneliness. However, few of the investigations reviewed here were able to generate meaningful evidence on the caregiving experiences of different cultural groups within European and North American multicultural contexts due to small sample sizes. Thus, it is imperative that further investigations based on both underrepresented societal groups (e.g., different minority ethnic groups within Western societies) and samples from other parts of the world (the latter would also facilitate cross-country comparisons) are undertaken using adequate population samples and culturally validated outcome measures, including established and widely used instruments, such as the De Jong Gierveld or the UCLA loneliness scales (Penning, Liu, and Chou, 2014).

In conclusion, this chapter reviewed the evidence from available European and North American longitudinal studies investigating social isolation and loneliness in both representative and non-probabilistic samples of informal caregivers. Despite important shortcomings, and the significant need for better-designed studies, the evidence suggests that informal caregiving may be independently associated with greater subsequent feelings of loneliness and social isolation. These findings add to growing evidence on the psychosocial challenges experienced by informal caregivers and have the potential to contribute to the development of effective policies and interventions that aim to prevent or reduce the negative impact of this vital role on those assuming it.

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