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The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme

Christina R. Victor[a], Isla Rippon[a], Catherine Quinn[b], Sharon M. Nelis[c], Anthony Martyr[c], Nicola Hart[d], Ruth Lamont[c] and Linda Clare[c]; on behalf of the IDEAL Programme Team

[a]Department of Clinical Sciences, College of Health and Life Sciences, Brunel University London, Uxbridge, UK; [b]The Centre for Applied Dementia Studies, University of Bradford, Bradford, UK; [c]REACH: The Centre for Research in Ageing and Cognitive Health, University of Exeter, St Luke's Campus, Exeter, UK; [d]Alzheimer's Society, London, UK

ABSTRACT

Objectives: To establish the prevalence of loneliness among family caregivers of people with dementia and to identify potential risk factors for loneliness.

Methods: Using data from the baseline wave of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study, we examined loneliness in 1283 family caregivers of people with mild-to-moderate dementia living in Great Britain. Multinomial regression was used to examine the relative influence of a series of risk factors for caregiver loneliness.

Results: Almost half, 43.7%, of caregivers reported moderate loneliness and 17.7% reported severe loneliness. Greater social isolation and increased caregiving stress were linked with both moderate and severe loneliness. Better quality of relationship with the person with dementia along with increased levels of well-being and life satisfaction were associated with a lower relative risk of reporting both moderate and severe loneliness.

Discussion: This study examines the prevalence and predictors of loneliness in a large sample of family caregivers of people with dementia. Notably over two-thirds of caregivers in our sample reported feeling lonely. Interventions aimed at reducing caregiving stress and supporting meaningful relationships may go some way towards helping to reduce loneliness.

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Introduction

Loneliness is commonly defined as the discrepancy between expectations of quantity and/or quality of relationships and actuality (Perlman & Peplau, 1981). Weiss (1973) proposed that there were two types of loneliness: social and emotional loneliness. Social loneliness characterises the deficit in the amount and quality of relations, whilst emotional loneliness refers to the deficit in relationship closeness. Loneliness has been linked to poor well-being as well as depression, anxiety and mental health problems (Cacioppo, Hawkley, & Thisted, 2010; Courtin & Knapp, 2017), and is a potential risk factor for the development of poorer physical health outcomes (Valtorta, Kanaan, Gilbody, Ronzi, & Hanratty, 2016) and mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Although loneliness has been explored in a range of different populations, there are only a handful of studies focused on family caregivers (Chukwuorji, Amazue, & Ekeh, 2017; Ekwall, Sivberg, & Hallberg, 2005; Jones & Peters, 1992; McRae et al., 2009; Vasileiou et al., 2017) and few of these have examined loneliness in caregivers of people with dementia (Beeson, 2003; Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Clare et al., 2019; Jaremka et al., 2014).

Background: loneliness and family caregiving

People with dementia are often cared for by family members or friends who provide practical or emotional unpaid support (Schulz & Martire, 2004), and we use the term 'family caregiver' to encompass close friends providing care as well as family members. It is estimated that 4.9 million adults in the UK are carers: 4% of the total population (DWP, 2017), and the estimated number of carers looking after people with dementia is around 700,000 (Lewis et al, 2014). Partly as a result of population aging it is expected that the demand for informal care will continue to grow (Pickard, 2015). The UK government loneliness strategy identifies caregivers as a group potentially vulnerable to loneliness (DCMS, 2018). A range of factors underpins this potentially increased vulnerability. A meta-analysis examining influences on loneliness in older people identified the quality of social networks and contacts with friends as being of particular importance (Pinquart & Sorensen, 2001) and this may be especially pertinent to family caregivers given the additional limitations imposed by their caregiving responsibilities. A review of 38 studies examining correlates and predictors of loneliness in older people identified female gender, lower levels of education, low quality social relationships, poor self-rated health and functional status, poorer mental health and negative life events as relevant (Cohen-Mansfield, Hazan, Lerman, & Shalom, 2016). It is plausible that moving into a caring role brings about changes, for example, in the relationship between the caregiver and the person with dementia and in engagement with social networks, which may increase risk of loneliness. Longitudinal predictors of loneliness in population level studies include

CONTACT Christina R. Victor Christina.Victor@brunel.ac.uk

changes in spousal relationships (Dahlberg, Andersson, McKee, & Lennartsson, 2015; Victor & Bowling, 2012; Yang, 2018b). For example, a study of 9171 older adults in England found that change in closeness to a spouse or partner had a greater effect on change in loneliness scores over time than loss of a spouse or partner (Yang, 2018b). Furthermore, both closeness to spouse or partner and closeness to children were significant risk factors for future loneliness.

We have limited evidence as to the prevalence of loneliness among caregivers. Some studies such as those by Beeson (2003) report mean loneliness scores rather than prevalence. Their sample of spouse caregivers of people with dementia reported mean loneliness scores of 37.35 for caregivers and 33.06 for non-caregivers (UCLA 20 item score: range 20–80), Carers UK (2015), based on data collected from their members, estimate that 8 in 10 caregivers in the UK have felt lonely or socially isolated as a result of their caregiving situation. A recent survey by the AARP (formerly known as the American Association of Retired Persons) found that family caregivers in the USA were more likely to report loneliness in comparison with those in midlife or older people who were not family caregivers (prevalence of 42% compared to 34%) (Anderson & Thayer, 2018). In the UK the Office for National Statistics (ONS) reported, people who have caring responsibilities were 37% more likely to report loneliness than those who do not (Office for National Statistics, 2018). Caregivers aged 75 years and older in Sweden, reported lower levels of loneliness than non-caregivers using a single item question (8.3% reported recurrent or constant feelings of loneliness compared with non-caregivers) (Ekwall et al., 2005). These studies did not investigate loneliness prevalence across different types of caregiving relationships (e.g. spouse carers compared with adult children) or types of health problems that the cared for person has (e.g. dementia compared with physical conditions such as heart disease).

Prior findings suggest that loneliness may have an influence on caregiver well-being. We identified loneliness as one of the psychological factors significantly linked with 'living well' in a comprehensive model examining the ability of caregivers of people with dementia to live well (a composite measure of life satisfaction, quality of life and well-being) (Clare et al., 2019). An earlier study of 49 caregivers indicated that caregivers of people with Alzheimer's disease reported greater loneliness and depression in comparison to non-caregivers and that loneliness was predictive of depression (Beeson, 2003). Jones and Peters (1992), looking at caregivers of older people, concluded that loneliness measured using a single-item question independently contributed to elevated anxiety and depression but not stress (Jones & Peters, 1992). However, the evidence base regarding loneliness and caregivers is limited and inconsistent in terms of prevalence and predictive factors, with the majority of these studies examining the impact of loneliness on the health and well-being of caregivers (Beeson, 2003; Beeson et al., 2000; Chukwuorji et al., 2017; Ekwall et al., 2005; Jones & Peters, 1992). Therefore, the current study aims to address some of these limitations by using data from a large cohort of family caregivers of people with dementia in order to identify the prevalence of and risk factors for loneliness in this group.

Design and methods

Design and sample

This study analysed data from caregivers who took part in the baseline wave (2014–2016) of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study (Clare et al., 2014; Silarova et al., 2018). Participants with dementia and their respective caregivers were recruited through 29 National Health Service (NHS) Clinical Research Network sites throughout England, Scotland and Wales. The inclusion criteria required the people with dementia to have a clinical diagnosis of dementia (any sub-type), which was in the mild-to-moderate stages as indicated by a Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score of 15 or over, and to be living in the community at the time of enrolment. Family caregivers who were providing regular care to a person with dementia were approached to take part in the study if the person they cared for had agreed to take part. In total, 1547 people with dementia and 1283 caregivers agreed to take part in the IDEAL study. The caregivers self-completed the questionnaires while the researcher was interviewing the person with dementia, so that any queries or needs for additional support with completion could be addressed by the researcher. The assessments for the first wave of data were collected over the course of three separate visits. The analyses are based on version 2.0 of the IDEAL baseline wave dataset.

The IDEAL study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL study is registered with UKCRN, registration number 16593.

Measures

Loneliness

The revised six-item version of the De Jong Gierveld Loneliness Scale (De Jong Gierveld & Van Tilburg, 1999) was used as a measure of self-reported loneliness among caregivers. Total scores range from 0 to 6, where a score of 0–1 indicates no loneliness, scores of 2 to 4 moderate loneliness and 5 to 6 severe loneliness (De Jong Gierveld & Van Tilburg, 1999).

Life satisfaction

Life satisfaction was measured using the Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985). It includes five positively worded statements rated on a seven-point scale from 'strongly disagree' to 'strongly agree': 'in most ways my life is close to my ideal'; 'the conditions of my life are excellent', 'I am satisfied with my life'; 'so far I have got the important things I want in life'; and, 'if I could live my life over, I would change almost nothing'. Possible scores ranged from 5 to 35, with higher scores indicating greater satisfaction with life.

Well-being

Well-being was measured using the World Health Organization-Five Well-Being Index (WHO-5) (Bech, 2004). Participants were asked how much of the time over the past two weeks they agreed with the following statements: ‘have felt cheerful and good spirits’; ‘calm and relaxed’; ‘active and vigorous’; ‘woke up feeling fresh and rested’; ‘my daily life has been filled with things that interest me’. Each item is rated on a six-point Likert scale from 0 (at no time) to 5 (all the time). The raw score was transformed into a percentage score where 0 signifies the worst possible well-being and 100 represents the best possible well-being.

Covariates

Demographic information was collected covering age, sex and education, based on the highest qualification achieved (no qualifications, school leaving certificate at age 16, school leaving certificate at age 18, university). Number of hours spent caregiving per day, living situation (whether or not they lived alone), caregiver kin-relationship to the person with dementia and the dementia diagnosis of person with dementia were recorded.

Relationship quality

Current relationship quality was measured using the Positive Affect Index (PAI; Bengston & Schrader, 1982). The PAI assesses the extent of positive affect that the respondent has for another person, with five questions addressing communication quality, closeness, similarity of views on life, engagement in joint activities and overall relationship quality. Possible scores range from 5 to 30 with higher scores indicating better relationship quality between the caregiver and person with dementia.

Social isolation

The six-item Lubben Social Network Scale was used to gauge social isolation by measuring perceived social support received by family and friends (Lubben et al., 2006). Total scores ranged from 0 to 30, where a lower score is seen to indicate a higher risk of social isolation.

Depressive symptoms

Depressive symptoms were assessed using the 20-item Center for Epidemiologic Studies Depression Scale-Revised (CESD-R; Eaton, Muntaner, Smith, Tien, & Ybarra, 2004). Possible scores range from 0 to 60, with a higher score indicating greater depressive symptoms.

Caregiving stress

Finally, caregiving stress was rated using the Relatives’ Stress Scale, a 15-item measure assessing the degree of distress and social upset experienced by a relative as the result of caring for a person with physical and/or behavioural difficulties (Greene, Smith, Gardiner, & Timbury, 1982). Scores ranged from 0 to 60, with a higher score indicating more severe caregiving stress.

Statistical analyses

We first report descriptive statistics exploring the prevalence of loneliness among caregivers. Examining risk factors for loneliness, we compared the baseline characteristics of respondents in the three loneliness groups using chi-squared tests for categorical variables and analysis of covariance for continuous variables. Next, using multinomial regression, we examined the relative influence of a series of factors on caregiver loneliness. The relative risk ratios (RRR) of reporting moderate or severe loneliness in comparison with no loneliness were calculated in each instance along with 95% confidence intervals (CIs). We did not include living situation in the fully-adjusted models as the numbers in each loneliness group were very small and no bivariate association was observed. To investigate the influence of missing data, we imputed missing values using multivariate imputation by chained equations. Missing data ranged from 0.9% to 6.9% and overall 22% of participants had missing data on one or more variables of interest. We included all covariates from the analyses in the imputation model. Estimates from 20 imputed datasets were combined using Rubin’s rules (Rubin, 1996). All data were analysed using Stata 14.2 (TX: StataCorp LP).

Results

The majority (81%) of respondents were spouses or partners of the person with dementia and only 3% of caregivers lived alone. Table 1 shows the sample characteristics and the bivariate associations with loneliness for the 1195 caregivers who completed the loneliness measure; 38.6% of respondents reported no loneliness, 43.7% were moderately lonely and 17.7% were severely lonely. Caregivers who reported loneliness had smaller social networks, lower relationship quality, life satisfaction and well-being, and increased depressive symptoms and caregiving stress compared with those who did not report loneliness (all $p < 0.001$).

Predictors of loneliness

The fully-adjusted multivariable analyses identified several factors that were significantly associated with both moderate and severe loneliness (Table 2). Caregiving stress was an important predictor of both moderate (RRR 1.04, 95% CI 1.01–1.06) and severe loneliness (RRR 1.08, 95% CI 1.05–1.12) in comparison with no loneliness, alongside greater social isolation and poorer well-being and life satisfaction. Better current relationship quality was associated with a lower relative risk of severe loneliness in comparison to no loneliness (0.88, 95% CI 0.83–0.93) and moderate loneliness (RRR 0.95, 95% CI 0.91–0.99). For age, sex and education, the results were mixed. Female caregivers were less likely than male caregivers to report moderate loneliness in comparison to no loneliness (RRR 0.69, 95% CI 0.49–0.96). All results reported here refer to the imputed datasets.

Discussion

In this study, we examined the prevalence and predictors of loneliness in caregivers of people with dementia. Nearly two-thirds of caregivers, approximately 62%, in our study reported loneliness with 18% reporting severe loneliness. Findings indicate that greater social isolation, increased caregiving stress and poorer well-being were associated

Table 1. Characteristics of caregivers according to loneliness group.

		Loneliness (*N* = 1,195)			
Variable	Total (*N* = 1283)	Not Lonely (0–1) *N* (%)/M (SD)	Moderately Lonely (2–4) *N* (%)/M (SD)	Severely Lonely (5–6) *N* (%)/M (SD)	*P*
Total		461 (38.6%)	522 (43.7%)	212 (17.7%)	
Age group					
<65	369 (28.8%)	142 (30.8%)	138 (26.4%)	72 (34.0%)	0.138
65–69	208 (16.2%)	63 (13.7%)	95 (18.2%)	38 (17.9%)	
70–74	267 (20.8%)	93 (20.2%)	109 (20.9%)	48 (22.6%)	
75–79	223 (17.4%)	85 (18.4%)	89 (17.1%)	26 (12.3%)	
80+	216 (16.8%)	78 (16.9%)	91 (17.4%)	28 (13.2%)	
Sex					
Men	402 (31.3%)	149 (32.3%)	176 (33.7%)	48 (22.6%)	0.011
Women	881 (68.7%)	312 (67.7%)	346 (66.3%)	164 (77.4%)	
Education (*n* = 1232)					
No formal qualifications	265 (21.5%)	97 (22.0%)	97 (19.2%)	48 (23.5%)	0.358
School leaving certificate at age 16	274 (22.2%)	94 (21.3%)	112 (22.2%)	48 (23.5%)	
School leaving certificate at age 18	374 (30.4%)	122 (27.6%)	168 (33.3%)	60 (29.4%)	
University	319 (25.9%)	129 (29.2%)	128 (25.4%)	48 (23.5%)	
Marital status (*n* = 1272)					
Married	1,152 (90.6%)	407 (89.9%)	475 (91.4%)	190 (90.1%)	0.701
Unmarried	120 (9.4%)	46 (10.2%)	45 (8.7%)	21 (10.0%)	
Live alone (*n* = 1275)	40 (3.1%)	13 (2.8%)	16 (3.1%)	7 (3.3%)	0.946
Kin relationship					
Spouse/Partner	1,039 (81.0%)	355 (77.0%)	432 (82.8%)	181 (85.4%)	0.012
Family/Friend	244 (19.0%)	106 (23.0%)	90 (17.2%)	31 (14.6%)	
Dementia sub-type					
Alzheimer's disease	715 (55.7%)	266 (57.7%)	290 (55.6%)	115 (54.3%)	0.216
Vascular dementia	142 (11.1%)	52 (11.3%)	54 (10.3%)	23 (10.9%)	
Mixed Alzheimer's disease & Vascular dementia	263 (20.5%)	96 (20.8%)	104 (19.9%)	43 (20.3%)	
Frontotemporal dementia	45 (3.5%)	14 (3.0%)	16 (3.1%)	12 (5.7%)	
Parkinson's Disease Dementia	43 (3.4%)	15 (3.3%)	23 (4.4%)	2 (0.95%)	
Dementia with Lewy bodies	43 (3.4%)	11 (2.4%)	19 (3.6%)	11 (5.2%)	
Unspecified/other dementia	32 (2.5%)	7 (1.5%)	16 (3.1%)	6 (2.8%)	
Hours of care per day (*n* = 1235)					
Less than 1 hour	232 (18.8%)	98 (21.8%)	100 (20.0%)	17 (8.3%)	<0.001
1–10 hours	499 (40.4%)	192 (42.8%)	194 (38.7%)	87 (42.7%)	
Over 10 hours	415 (33.6%)	123 (27.4%)	173 (34.5%)	86 (42.2%)	
Other responses	89 (7.2%)	36 (8.1%)	34 (6.8%)	14 (6.9%)	
Depressive symptoms (*n* = 1201)	7.2 (7.9)	4.5 ± 5.7	7.3 ± 7.3	12.6 ± 10.2	<0.001
Caregiving stress (*n* = 1198)	19.2 (9.8)	14.9 ± 8.1	19.8 ± 9.2	27.0 ± 9.3	<0.001
Current relationship quality (*n* = 1249)	23.2 (4.7)	24.8 ± 3.9	23.0 ± 4.5	19.8 ± 4.9	<0.001
Social networks (*n* = 1232)	17.6 ± 5.5	20.3 ± 4.5	16.5 ± 5.3	14.4 ± 5.4	<0.001
Life satisfaction (*n* = 1240)	23.8 (6.5)	26.6 ± 5.5	23.1 ± 6.0	19.1 ± 6.7	<0.001
Well-being (*n* = 1247)	55.3 (19.8)	65.0 ± 16.6	53.1 ± 17.8	40.4 ± 19.3	<0.001

with both moderate and severe loneliness in comparison with no loneliness in caregivers of people with dementia. In addition, better current relationship quality reduced the relative risk of both moderate and severe loneliness. There was also some indication that male caregivers were more likely to report loneliness than female caregivers.

To set our results in context, we draw comparisons with two groups: older adults in general and caregivers specifically. The prevalence of loneliness in our group of caregivers, with 62% being moderate or severely lonely, is higher than in the general population of middle-aged and older adults in a range of comparable countries. A recent representative survey found that 35% of U.S. adults aged 45 years and over reported loneliness (Anderson & Thayer, 2018). A Norwegian study of older adults aged 65 years and over reported a prevalence of loneliness of 30.2% using the same scale as our study (Nicolaisen & Thorsen, 2014). Estimates from the Generations and Gender Survey of eleven European countries observed that the prevalence of loneliness ranged from between 10% and 20% in western and northern European countries to between 30% and 55% in Eastern European countries (Hansen & Slagsvold, 2016). Prior studies of loneliness in caregivers have used different measures to assess loneliness, which makes direct comparisons between studies difficult. However, the study of spousal caregivers of people with Alzheimer's Diseases reported higher loneliness scores than non-caregiving spouses (Beeson, 2003).

The quality of the relationship between the caregiver and the person with dementia may be a potential protective factor against loneliness. Caregivers with better relationship quality had a lower risk of reporting both moderate and severe loneliness in comparison with no loneliness. This is in accordance with previous studies of married couples which have demonstrated that better marital quality is associated with lower levels of loneliness both cross-sectionally and longitudinally (e.g. Ayalon, Shiovitz-Ezra, & Palgi, 2013; Stokes, 2017) and is concordant with findings that better relationship quality is associated with greater well-being in family caregivers of people with dementia (Quinn, Clare, & Woods, 2009; Rippon et al., 2019). This may reflect aspects of 'emotional loneliness' where there is a perceived loss of close relationships or in the quality of that relationship. The size of social networks was also an important predictor of both moderate and severe loneliness. Respondents who were more socially isolated or had smaller networks of friends and family were more likely to report loneliness. A Dutch study of 755 older people also observed that smaller social networks, poorer marital relationship indicators and presence of a long-term health condition in the spouse were associated with an

Table 2. Fully-adjusted regression model examining predictors of moderate and severe loneliness in comparison with no loneliness in caregivers of people with dementia ($N = 1{,}283$).

	Moderate Loneliness		Severe Loneliness	
	RRR (95% CI)	*p*	RRR (95% CI)	*p*
Sex				
Men	Ref.		Ref.	
Women	0.69 (0.49–0.96)	0.027	0.70 (0.42–1.16)	0.164
Age group				
<65	Ref.		Ref.	
65–69	1.63 (0.95–2.78)	0.076	1.23 (0.59–2.54)	0.579
70–74	1.21 (0.73–2.01)	0.468	0.99 (0.50–1.96)	0.975
75–79	1.07 (0.63–1.81)	0.812	0.72 (0.34–1.53)	0.391
80+	1.11 (0.65–1.89)	0.711	0.75 (0.35–1.59)	0.451
Education				
No formal qualifications	Ref		Ref	
School leaving certificate at age 16	1.48 (0.93–2.37)	0.098	1.26 (0.66–2.41)	0.481
School leaving certificate at age 18	2.12 (1.36–3.32)	0.001	1.81 (0.97–3.37)	0.063
University	1.52 (0.95–2.42)	0.082	1.18 (0.60–2.28)	0.629
Marital status				
Married	Ref		Ref.	
Unmarried	0.66 (0.37–1.16)	0.149	0.76 (0.34–1.71)	0.509
Kin relationship				
Spouse/Partner	Ref.		Ref.	
Family/Friend	0.73 (0.43–1.23)	0.236	0.43 (0.20–0.92)	0.029
Dementia sub-type				
Alzheimer's disease	Ref.		Ref.	
Vascular dementia	0.86 (0.53–1.40)	0.544	0.76 (0.38–1.52)	0.431
Mixed Alzheimer's disease & Vascular dementia	0.96 (0.66–1.40)	0.838	0.93 (0.54–1.60)	0.784
Frontotemporal dementia	0.87 (0.38–2.03)	0.753	1.14 (0.39–3.27)	0.813
Parkinson's Disease Dementia	0.75 (0.34–1.61)	0.455	0.19 (0.04–0.81)	0.025
Dementia with Lewy bodies	1.25 (0.51–3.04)	0.623	1.26 (0.40–3.89)	0.695
Unspecified/other dementia	1.56 (0.58–4.19)	0.379	1.22 (0.32–4.67)	0.773
Hours of care				
Over 10 hours	Ref.		Ref.	
1–10 hours	0.85 (0.59–1.40)	0.594	0.89 (0.54–1.46)	0.636
Less than 1 hour	1.37 (0.86–2.20)	0.188	1.03 (0.48–2.19)	0.942
Other responses	1.08 (0.57–2.03)	0.816	1.34 (0.56–3.22)	0.513
Caregiver stress	1.04 (1.01–1.06)	0.004	1.08 (1.05–1.12)	<0.001
Depressive symptoms	1.00 (0.97–1.03)	0.916	1.02 (0.98–1.05)	0.406
Social networks	0.86 (0.83–0.89)	<0.001	0.80 (0.76–0.84)	<0.001
Relationship quality	0.95 (0.91–0.99)	0.017	0.88 (0.83–0.93)	<0.001
Life satisfaction	0.97 (0.94–1.00)	0.029	0.96 (0.92–1.00)	0.049
Well-being	0.98 (0.96–0.99)	<0.001	0.96 (0.95–0.98)	<0.001

Note: RRR: relative risk ratio; CI: confidence interval.

increase in emotional and social loneliness (De Jong Gierveld, van Groenou, Hoogendoorn, & Smit, 2009).

Factors related to the caregiving role, such as caregiving stress, also increased the likelihood of experiencing loneliness. This is echoed by findings from qualitative interviews with family caregivers of people with dementia and other long-term conditions (Vasileiou et al., 2017). The study identified four linked themes: shrunken personal space and diminished social interaction caused by the restrictions imposed by the caregiving role; both lack of or loss of social relationships and also decreasing satisfaction with existing occasions of social interaction; relational deprivations and losses; and feelings of powerlessness, helplessness, and a sense of sole responsibility. Prior studies have examined the risk factors for depression in caregivers of people with chronic conditions and have also identified stress and characteristics of the caregiving situation as key risk factors (Pinquart & Sörensen, 2004).

Established predictors of loneliness, such as being female, living alone, marital status, lower socio-economic status and depressive symptoms were not observed in the current study (Cohen-Mansfield et al., 2016; Dahlberg et al., 2015). This may in part be explained by the very small proportion of caregivers in our sample who were not married or in a partnership or who lived alone. In our study, we found that female caregivers were less likely to report moderate loneliness than male caregivers. This is in contrast to some population level studies and may reflect a combination of other risk factors in the caregiving situation. Previous studies have demonstrated that, while more females reported greater loneliness, gender was not a significant predictor of loneliness once other factors were considered (Victor, Scambler, Marston, Bond, & Bowling, 2006). Similarly, Yang (2018a) found that gender alone was neither a necessary nor sufficient condition for loneliness at older ages or across the life course.

Strengths and limitations

This is one of the first large-scale studies to examine the prevalence and predictors of loneliness in a large sample of family caregivers of people with dementia. Our large sample size enabled us to control for a much wider range of explanatory factors than has been explored previously. Nevertheless, there are several limitations. Firstly, as this is a cross-sectional study it is not possible to say with certainty whether or not specific factors lead to increased loneliness. However, as IDEAL is a longitudinal study, we will be able to examine the effect of loneliness further as the caregiving role continues once longitudinal data become available. Secondly, we were unable to consider cultural and ethnic differences as the sample consisted almost entirely of white British caregivers. It will be important to consider caregivers from black and minority ethnic groups in future studies of loneliness as prior studies of family caregivers have observed ethnic differences in receipt of informal support, quality of the relationship with the care-recipient and psychological health (Pinquart & Sörensen, 2005).

Implications

The results of this study have significant implications and could potentially inform the design of interventions aimed at addressing loneliness in family caregivers. Nearly two-thirds of caregivers in our sample reported loneliness, with generic factors such as social isolation and carer specific factors such as caregiving stress and, poorer relationship quality increasing the risk of loneliness. A review of befriending and peer support schemes aimed specifically at caregivers of people with dementia reported that these were largely ineffective at both reducing loneliness and improving mental health, in part due to low uptake or withdrawal from schemes (Smith & Greenwood, 2014). Our findings suggest that interventions focus upon building carer resilience and maintaining relationship quality may be a more effective means of addressing carer loneliness than those focussed upon loneliness per se. There are existing caregiver interventions that focus upon building resilience but these are usually addressing more clinical issues such as depression and anxiety. Including loneliness as an outcome measure for such interventions would provide an indication of whether such interventions might address loneliness as well. Additionally, a comprehensive recent overview of interventions designed to help alleviate loneliness concluded that these should be person-centred and focused on the specific needs of the population group in question, in this instance caregivers of people with dementia, and should support the development and maintenance of meaningful relationships (Victor et al., 2018).

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Disclosure statement

No potential conflict of interest was reported by the authors.

Data availability statement

The IDEAL data will be deposited with the UK Data Archive following completion of the study in March 2020. Details on how the data can be accessed after this date will be made available on the project website www.idealproject.org.uk.

ORCID

Christina R. Victor http://orcid.org/0000-0002-4213-3974
Isla Rippon http://orcid.org/0000-0002-9743-2592
Catherine Quinn http://orcid.org/0000-0001-9553-853X
Sharon M. Nelis http://orcid.org/0000-0001-9055-3837
Anthony Martyr http://orcid.org/0000-0002-1702-8902
Linda Clare http://orcid.org/0000-0003-3989-5318

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