





RESEARCH ARTICLE

Prevalence and determinants of loneliness in people living with dementia: Findings from the IDEAL programme

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Funding information

Economic and Social Research Council, Grant/Award Number: ES/L001853/2; Alzheimer's Society, Grant/Award Number: AS-PR2-16-001

Objective: To establish the prevalence and determinants of loneliness among people living with dementia.

Methods: Using data from the baseline wave of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study, we examined the prevalence and predictors of loneliness in 1547 people with mild-to-moderate dementia. Loneliness was assessed using the six-item De Jong Gierveld loneliness scale.

Results: About 30.1% of people with dementia reported feeling moderately lonely and 5.2% severely lonely. Depressive symptoms and increased risk of social isolation were associated with both moderate and severe loneliness. Those living alone were more likely to experience severe loneliness as were those reporting poorer quality of life. Marital status was not associated with loneliness nor were dementia diagnosis or cognitive function.

Conclusions: This is one of the few large-scale studies to explore the prevalence of and determinants of loneliness among people living with dementia. Social isolation, depression and living alone were associated with experiencing loneliness. Longitudinal studies are needed to determine the directionality of these associations.

KEYWORDS

Alzheimer's disease, depression, quality of life, social isolation, well-being

1 | INTRODUCTION

Worldwide around 50 million people are living with dementia and this is predicted to increase and reach 152 million by 2050.¹ Identifying factors that may help or hinder the ability to 'live well' with dementia is therefore valuable. The Institute of Medicine defines 'living well' as 'the best achievable state of health that encompasses all dimensions of physical, mental and social well-being' (p 32).^{2,3} Our recent comprehensive model examining factors associated with living well for people with dementia identified loneliness as one of the psychological

indicators that affected the ability to 'live well'.³ Loneliness is potentially modifiable and, as such, the aims of the current study are to identify the prevalence and determinants of loneliness in people living with dementia.

Loneliness may be defined as the discrepancy between expectations of the quantity and/or quality of relationships and what is actually experienced.⁴ It has been widely linked to depression and mental health⁵ and is a potential risk factor for the development of poorer physical health outcomes⁶ and mortality,⁷ and compromised quality of life, life satisfaction and wellbeing.^{3,8} In older populations, factors such

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as female gender, lower levels of education, living alone, marital status, lack of or low quality social relationships and poorer physical health have been identified as determinants of loneliness.^{9,10}

One area where there is potential for studies of loneliness in later life to be more inclusive is by encompassing people with dementia.³ However our current evidence base has focused either on loneliness as a potential risk factor for dementia, where findings have been mixed,^{11–14} or on its influence on cognitive function, where some but not all studies have reported that it is predictive of faster cognitive decline.¹⁵ Few existing prevalence studies of loneliness have included people with dementia.^{16–19} Where studies have looked at loneliness and dementia we can identify two approaches; (a) comparison of loneliness amongst those with or without dementia or (b) comparison of dementia status amongst those who are and are not lonely.^{20,21} Our focus is with the former approach as we wish to establish the prevalence and predictors of loneliness among people with dementia. A recent British study of 93 people with mild-to-moderate Alzheimer's disease, using the 11-item De Jong Gierveld loneliness scale, reported a mean score of 2.0 (scores of between 0 and 2 on the 11-item scale indicates no loneliness) suggesting that on average participants did not feel lonely.¹⁶ An earlier Swedish study examined social and emotional loneliness using two single-item measures in 154 people with dementia and 435 older people without a dementia diagnosis.¹⁸ People living with dementia were significantly more likely to report often feeling socially lonely than respondents without dementia, but no differences were observed for emotional loneliness; 46% of the participants with dementia reported often feeling lonely (social loneliness) and 53% said they experienced loneliness (emotional loneliness). A smaller European study explored the relationship between loneliness, social isolation and hallucinations in 22 people with Alzheimer's disease in comparison with 24 healthy controls using the UCLA loneliness scale.¹⁷ Participants with Alzheimer's disease reported greater levels of loneliness than the controls (mean scores of 61.3 and 50.1 on the 20-item UCLA loneliness scale, respectively). Studies of loneliness determinants have looked at specific symptoms of dementia such as neuropsychiatric symptoms or more specifically hallucinations rather than more established loneliness risk factors. No relationship was observed for neuropsychiatric symptoms in general,¹⁰ and experiencing hallucinations¹¹ was associated with loneliness for those both with and without dementia. Given the small number of studies and their focus on those with Alzheimer's disease our study has two research questions: (a) what is the prevalence of loneliness among people with dementia? and (b) what are the key determinants of loneliness in this group?

2 | METHODS

2.1 | Sample

This study involved analysis of data from 1547 people with dementia who took part in the baseline wave (2014–2016) of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort

Key Points

- This is one of the few studies to explore the effect of loneliness on people living with dementia.
- Approximately one-third of people with dementia reported experiencing loneliness
- People with dementia experiencing social isolation and depression, and those living alone, were more likely to report feeling lonely.
- No relationship was observed between dementia diagnosis, cognitive function or marital status.

study.^{22,23} Participants were recruited through 29 National Health Service (NHS) sites throughout England, Scotland and Wales. The inclusion criteria for participation in the study required participants to have a clinical diagnosis of dementia (any sub-type), to be in the mild-to-moderate stages as indicated by a Mini-Mental State Examination (MMSE)²⁴ score of 15 or above, and to be living in the community at the time of enrolment. Exclusion criteria were a comorbid terminal illness, inability to provide informed consent and any known potential for home visits to pose a significant risk to researchers (see study protocol for full details).²² A total of 3105 people with dementia were approached to take part in the study, of whom 363 were ineligible and 1106 declined. Of the 1636 who consented, 8 subsequently proved ineligible and 81 withdrew. This resulted in a final sample of 1547 people with dementia (a response rate of 57% among eligible people with dementia).³ Data are drawn from version 4.0 of the IDEAL baseline 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 2014–11 684). The IDEAL study is registered with UKCRN, registration number 16593. Written informed consent was secured from all participants.

2.2 | Procedure

Information was collected by direct interview from people with dementia who were visited at home by a researcher on three separate occasions. All measures used in the current study were completed by the person with dementia and reflect self-reported experience.

2.3 | Measures

2.3.1 | Loneliness

Loneliness was assessed using the six-item version of the De Jong Gierveld Loneliness Scale.²⁵ Total scores range from 0 to 6, where a

score of 0 to 1 indicates no loneliness, scores of 2 to 4 moderate loneliness and 5 to 6 severe loneliness.²⁶ We selected this because it has been successfully used in two previous studies involving people with dementia^{16,18} and mindful of participant burden, takes less time to complete than the 11-item version. None of the studies identified reported problems with the acceptability of the scale.

2.3.2 | Covariates

We included as co-variables established factors associated with loneliness in the general population including age, sex, marital status, education and living situation (whether the person lived alone or with a spouse or others). The number of additional chronic health conditions was counted using the Charlson comorbidity index²⁷ and was grouped into four severity levels.²⁸ Depressive symptoms were assessed using the 10-item Geriatric Depression Scale (GDS-10),²⁹ with higher total scores indicating greater depressive symptoms. The six-item Lubben Social Network Scale was used to gauge social isolation by measuring perceived social support received from family and friends³⁰; total scores ranged from 0 to 30, where a score of less than 12 is seen to indicate a higher risk of social isolation. Life satisfaction was measured the Satisfaction with Life Scale.³¹ Possible scores ranged from 5 to 35, with higher scores indicating greater life satisfaction. Well-being was measured using the World Health Organization-Five Well-Being Index (WHO-5).³² 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. The QoL in Alzheimer's disease (QoL-AD) scale³³ which was developed specifically for people with dementia, was used to gauge QoL. Possible scores range from 13 to 52, with higher scores indicating greater QoL.

Dementia-specific factors were cognitive function at baseline as measured using the MMSE²⁴ and the type of dementia as recorded by the diagnosing clinicians at recruitment sites and retrieved from medical records when participants were enrolled into the study. Neuropsychiatric symptoms were not included in our analysis because information about these was provided by care partners, thereby excluding the 17% in our study who did not have a participating care partner.

2.4 | Statistical analyses

Our analysis consists of three phases linked to our two research questions. To establish the prevalence of loneliness we classified participants into the three loneliness categories defined by the de Jong Gierveld scale (no loneliness, moderate loneliness and severe loneliness).²⁶ To establish loneliness determinants, 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. Finally, multinomial logistic regression was used to examine the determinants of loneliness in people with dementia and findings are presented as relative risk ratios (RRR) of reporting

moderate or severe loneliness in comparison with no loneliness. To investigate the influence of missing data, we imputed missing values using multivariate imputation by chained equations. Missing data ranged from 0.4% to 10.9%, and 33% of participants had missing data on one or more variable of interest. We included all variables from the analysis in the imputation model. Estimates from 30 imputed data sets were combined using Rubin's rules.³⁴ All data were analysed using Stata 14.2 (TX: StataCorp LP).

3 | RESULTS

Overall 93% of participants, 1445 out of 1547, completed the loneliness measure.

There were no significant differences in non-response to the loneliness questions across our included analytical variables except for marital status where the measure was more likely to be completed by the married (see Table S1). Table 1 shows the characteristics of the 1445 people with dementia who completed the loneliness measure. Most participants had a diagnosis of Alzheimer's disease (55.5%) and at least one additional chronic health condition (75%) and the mean age was 76 (SD 8.6). Just over half of respondents were male. The majority of respondents, 64.7%, were classified as not lonely, 30.1% as moderately lonely and 5.2% severely lonely (see Table 1). Loneliness was significantly associated with increased age, living alone, widowhood, depression and isolation, and with lower wellbeing, quality of life and life satisfaction. There was no relationship with type of dementia, cognition as assessed by MMSE score. Of those who reported severe loneliness, 39% lived alone, and of those who reported moderate loneliness 23% lived alone. This compares to 18.5% of the whole sample who reported living alone. Participants who felt severely lonely had a mean score of 10.1 (SD 6.3) on the Lubben Social Network scale, below the suggested threshold of 12, indicating that they are at high risk of being socially isolated.

3.1 | Determinants of loneliness

We undertook multi-variable regression analyses to identify the key independent loneliness determinants, with no loneliness as our reference category. In our final fully adjusted model two variables, depression and isolation, were associated with both moderate and severe loneliness and hinted at a 'dose-response' relationship. For depressive symptoms the RRR for moderate dementia was 1.18 (95% CI 1.08, 1.28) and (95% CI 1.14, 1.58; Table 2). Larger social networks, or less social isolation, was associated with a lower relative risk of moderate loneliness of 0.93 (95% CI 0.91, 0.95) and severe loneliness (RRR 0.86; 95% CI 0.81, 0.91). Respondents living alone had a higher relative risk of experiencing severe loneliness (RRR 5.01; 95% CI 1.65, 15.28) but not moderate loneliness. Better life satisfaction was linked with a lower relative risk of moderate loneliness (RRR 0.96; 95% CI 0.93-0.99) and higher QoL with lower risk of severe loneliness (RRR 0.87; 95% CI 0.81-0.94). Age, sex, education, marital status, wellbeing,

TABLE 1 Participant characteristics by loneliness group

Variable	Total (N = 1547) N (%)	Loneliness (N = 1445)			P
		Not lonely N (%)	Moderately lonely N (%)	Severely lonely N (%)	
		935 (64.7%)	435 (30.1%)	75 (5.2%)	
Age group					
<65	136 (8.8%)	66 (7.1%)	53 (12.2%)	13 (17.3%)	.011
65 to 69	178 (11.5%)	107 (11.4%)	52 (12.0%)	10 (13.3%)	
70 to 74	260 (16.8%)	157 (16.8%)	74 (17.0%)	15 (20.0%)	
75 to 79	369 (23.9%)	234 (25.0%)	91 (20.9%)	16 (21.3%)	
80+	604 (39.0%)	371 (39.7%)	165 (37.9%)	21 (28.0%)	
Sex					
Men	871 (56.3%)	542 (58.0%)	236 (54.3%)	38 (50.7%)	.253
Women	676 (43.7%)	393 (42.0%)	199 (45.8%)	37 (49.3%)	
Marital status					
Married	1138 (73.6%)	727 (77.8%)	302 (69.4%)	42 (56.0%)	<.001
Single/divorced	140 (9.1%)	80 (8.6%)	40 (9.2%)	12 (16.0%)	
Widowed	269 (17.4%)	128 (13.7%)	93 (21.4%)	21 (28.0%)	
Education (missing = 35)					
No qualifications	423 (28.0%)	232 (25.4%)	135 (31.8%)	20 (27.0%)	.199
School leaving certificate at age 16	269 (17.8%)	167 (18.3%)	72 (17.0%)	16 (21.6%)	
School leaving certificate at age 18	516 (34.1%)	322 (35.2%)	145 (34.2%)	22 (29.7%)	
University	304 (20.1%)	194 (21.2%)	72 (17.0%)	16 (21.6%)	
Living situation (missing = 6)					
Live with someone	1256 (81.5%)	796 (85.4%)	335 (77.4%)	45 (60.8%)	<.001
Live alone	285 (18.5%)	136 (14.6%)	98 (22.6%)	29 (39.2%)	
Dementia sub-type					
Alzheimer's disease	858 (55.5%)	534 (57.1%)	235 (54.0%)	33 (44.0%)	.465
Vascular dementia	171 (11.1%)	102 (10.9%)	42 (9.7%)	13 (17.3%)	
Mixed Alzheimer's disease and vascular dementia	326 (21.1%)	194 (20.8)	100 (23.0%)	15 (20.0%)	
Frontotemporal dementia	54 (3.5%)	32 (3.4%)	15 (3.5%)	3 (4.0%)	
Parkinson's disease dementia	44 (2.8%)	24 (2.6%)	13 (3.0%)	3 (4.0%)	
Dementia with Lewy bodies	53 (3.4%)	27 (2.9%)	17 (3.9%)	5 (6.7%)	
Unspecified/other	41 (2.7%)	22 (2.4%)	13 (3.0%)	3 (4.0%)	
Comorbid conditions (missing = 107)					
No comorbidity	343 (23.8%)	212 (24.1%)	95 (23.0%)	13 (21.3%)	.052
Mild (1-2)	723 (50.2%)	458 (52.1%)	199 (48.1%)	24 (39.3%)	
Moderate (3-4)	278 (19.3%)	155 (17.6%)	90 (21.7%)	15 (24.6%)	
Severe (five or more)	96 (6.7%)	54 (6.1%)	30 (7.3%)	9 (14.8%)	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
GDS-10 (missing = 169)	2.7 (2.9)	2.1 (1.9)	3.4 (2.4)	5.5 (2.6)	<.001
Social isolation (missing = 90)	15.1 (6.2)	16.4 (5.9)	13.3 (5.8)	10.1 (6.3)	<.001
Life satisfaction (missing = 43)	26.1 (6.1)	27.6 (5.2)	24.0 (6.4)	19.5 (6.8)	<.001
QoL-AD (missing = 145)	36.8 (5.9)	38.3 (5.2)	34.9 (5.6)	29.1 (6.4)	<.001
Well-being (missing = 26)	60.9 (20.6)	65.8 (18.5)	54.8 (20.3)	38.7 (23.3)	<.001
MMSE (missing = 71)	23.2 (3.6)	23.3 (3.6)	23.2 (3.6)	23.6 (3.8)	.783

Abbreviations: GDS-10, Geriatric Depression Scale; MMSE, Mini-Mental State Examination; QoL-AD, quality of life in Alzheimer's disease scale.

TABLE 2 Fully adjusted regression model examining predictors of moderate and severe loneliness in comparison with no loneliness in people with dementia (N = 1547)

	Moderate loneliness		Severe loneliness	
	RRR (95% CI)	P	RRR (95% CI)	P
Sex				
Men	Ref.		Ref.	
Women	1.00 (0.76-1.30)	.977	1.04 (0.57-1.89)	.907
Age group				
<65	Ref.		Ref.	
65 to 69	0.73 (0.42-1.26)	.255	0.66 (0.22-1.93)	.444
70 to 74	0.68 (0.41-1.14)	.143	0.84 (0.31-2.30)	.737
75 to 79	0.55 (0.34-0.91)	.021	0.55 (0.20-1.50)	.242
80+	0.55 (0.34-0.88)	.014	0.33 (0.12-0.91)	.032
Education				
No qualifications	Ref.		Ref.	
School leaving certificate at age 16	0.83 (0.56-1.22)	.336	1.42 (0.62-3.23)	.407
School leaving certificate at age 18	0.92 (0.66-1.29)	.642	1.30 (0.62-2.72)	.583
University	0.74 (0.50-1.10)	.137	1.23 (0.53-2.84)	.624
Living arrangements				
Living with someone	Ref.		Ref.	
Living alone	1.42 (0.85-2.38)	.176	5.01 (1.65-15.28)	.005
Dementia sub-type				
Alzheimer's disease	Ref.		Ref.	
Vascular dementia	0.75 (0.48-1.16)	.192	1.10 (0.47-2.59)	.822
Mixed Alzheimer's disease and Vascular dementia	1.02 (0.74-1.41)	.917	0.85 (0.40-1.78)	.660
Frontotemporal dementia	0.91 (0.46-1.83)	.795	1.79 (0.42-7.62)	.431
Parkinson's disease dementia	0.96 (0.45-2.06)	.922	1.30 (0.25-5.61)	.728
Dementia with Lewy bodies	0.91 (0.45-1.85)	.798	0.88 (0.25-3.07)	.841
Unspecified/other	1.23 (0.54-2.79)	.629	0.85 (0.16-4.44)	.844
Marital status				
Married	Ref.		Ref.	
Single/divorced	0.75 (0.43-1.31)	.310	0.72 (0.23-2.28)	.577
Widowed	1.43 (0.86-2.38)	.165	1.40 (0.42-4.66)	.585
GDS-10	1.18 (1.08-1.28)	<.001	1.34 (1.14-1.58)	<.001
Social isolation	0.93 (0.91-0.95)	<.001	0.86 (0.81-0.91)	<.001
Comorbid conditions				
No comorbidity	Ref.		Ref.	
Mild (1-2)	0.85 (0.61-1.19)	.350	0.74 (0.30-1.80)	.502
Moderate (3-4)	0.94 (0.63-1.41)	.771	0.76 (0.29-1.98)	.568
Severe (five or more)	0.61 (0.29-1.10)	.099	0.65 (0.21-2.03)	.455
Life satisfaction	0.96 (0.93-0.99)	.004	0.97 (0.92-1.02)	.222
Well-being	0.99 (0.99-1.00)	.208	0.99 (0.97-1.01)	.380
QoL-AD	0.98 (0.94-1.01)	.171	0.87 (0.81-0.94)	<.001
Cognition (MMSE)	1.01 (0.98-1.05)	.338	1.04 (0.96-1.13)	.360

Abbreviations: CI, confidence interval; GDS-10, Geriatric Depression Scale; MMSE, Mini-Mental State Examination; RRR, relative risk ratio; QoL-AD, quality of life in Alzheimer's disease scale.

dementia diagnosis, comorbidity and cognition were not significantly associated with loneliness.

4 | DISCUSSION

In this large scale study, we examined the prevalence and established and dementia-specific determinants of loneliness in people with mild-to-moderate dementia. Approximately a third of respondents, 30%, reported being moderately lonely and a further 5% were severely lonely. Around 19% of respondents in our sample lived alone, with the proportion living alone increasing with severity of loneliness. Increased depressive symptoms and greater social isolation were predictive of both moderate and severe loneliness in comparison with no loneliness in this cohort of people with dementia. Loneliness was associated with poorer life satisfaction, well-being and QoL. In addition, living alone and poorer QoL were related to an increased risk of severe loneliness.

Precise comparisons of our loneliness prevalence data with estimates obtained in other studies are problematic because prior studies of loneliness in people living with dementia have used different measures to assess loneliness,¹⁶⁻¹⁸ have used a range of methods of reporting data (eg, mean scores or categories of loneliness severity) and have largely focused on people with a diagnosis of Alzheimer's disease and not the full range of dementia diagnoses, or have used MMSE scores rather than diagnosis to indicate the presence of dementia. Overall 35% of our participants experienced loneliness which is less than the level reported in a Swedish study (46% reported social loneliness and 53% emotional loneliness using two single item questions).¹⁶ Our loneliness prevalence estimates are broadly comparable with those reported by older people in the general population in Europe and the United States which range from approximately 19% to 34%.³⁵ We can make a comparison with a general population survey of adults aged 65+ in Norway that used the same measure and same loneliness definition, a score of 2+ on the six-item DJG.³⁶ This study reported a loneliness prevalence of 30% compared with our 35% for people with dementia. There is, therefore, clear potential for further research using consistent definitions of dementia and measures of loneliness to establish whether loneliness is especially problematic in this population.

We investigated two specific types of loneliness determinants: dementia-specific factors and those reported for the general population of older people. In terms of dementia-specific factors, we did not observe a relationship between loneliness and dementia sub-type nor between loneliness and cognition as defined by the MMSE. Given that our population were all in the mild to moderate category on this scale, it is likely that the lack of variation in scores accounts for this difference in findings compared to other studies. The failure of dementia-specific factors to emerge as loneliness determinants is also intriguing and one that we can investigate in our longitudinal follow-up of the IDEAL cohort.

In terms of the identification of the general determinants of loneliness, our findings showing that depressive symptoms, isolation, living alone and quality of life are associated with loneliness are consistent with the existing literature.^{9,18} The lack of a relationship between

loneliness and increased age and gender is also consistent with existing research, although findings across studies can be inconsistent. Studies in the general population show a relationship between poor physical health and loneliness which we did not observe, but this may reflect high levels of co-morbidity. The lack of a relationship with marital status is, however, intriguing as this is one of the most consistently reported determinants of loneliness in the general population. Further research to investigate this counterfactual finding is merited.

4.1 | Strengths and limitations

To the best of our knowledge, this study has used a larger cohort of people with dementia than previous studies investigating the prevalence and determinants of loneliness in this population. As well as numerical size, which enables us to undertake analyses that can look at a broader range of determinants than previous studies,¹⁶⁻¹⁹ we included the full range of dementia sub-types and all participants had a clinical diagnosis. We included an established measure of loneliness that was completed by 93% of our total cohort, confirming that it is appropriate and acceptable for people with mild to moderate dementia. Additionally, we included in our analysis both dementia-specific and generally established loneliness determinants. However, we fully acknowledge the main limitation of our study which is the cross-sectional design. This does not compromise our prevalence estimates, it does, however, mean that it is not possible to establish causal relationships or the direction of the observed associations. For some determinants, this is not problematic. For example, based upon previous studies, it is highly likely that loneliness is, in part, a consequence of living alone rather than vice versa. For some other observed relationships, such as depression or quality of life, these could be either a cause or consequence of loneliness. However, the IDEAL cohort study is longitudinal which will enable us to investigate the robustness of our observations and directionality of relationships when data from further time-points become available.

5 | CONCLUSION

This is one of only a few studies to explore the prevalence and predictors of loneliness in people living with dementia. We found that people with dementia had a loneliness prevalence which was broadly comparable with that of their peers who did not have dementia. We demonstrated that established loneliness predictors such as living alone were also important for people with dementia and that there was a relationship between loneliness and depression. Whilst we cannot establish directionality at this stage, it seems likely that addressing depressive symptoms will offer benefits in terms of reduced loneliness. It is important that interventions designed to help alleviate loneliness should be person-centred and focused on the specific needs of people living with dementia.³⁷ Our study produced the unique and counterfactual finding of no relationship between loneliness and marital status. This highlights an important area for further research in the

field of loneliness and dementia, but also with regard to wellbeing more generally. It further suggests that we need to look not just at marital status but also at relationship quality³⁸ when trying to understand these associations, and focus more on the dyad rather than simply looking at individual wellbeing in isolation.

ACKNOWLEDGEMENTS

We would like to acknowledge the support of the following research networks: NIHR Dementias and Neurodegeneration Specialty (DeNDRoN) in England, the Scottish Dementia Clinical Research Network (SDCRN) and Health and Care Research Wales. We are grateful to the IDEAL study participants for their participation in the study and to members of the ALWAYS group and the Project Advisory Group for their support throughout the study. We would also like to thank Fiona Matthews for her statistical advice. 'Improving the experience of Dementia and Enhancing Active Life: living well with dementia. The IDEAL study' was funded jointly by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR) through grant ES/L001853/2. Investigators: L. Clare, I. R. Jones, C. Victor, J. V. Hindle, R. W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F. Matthews, R. G. Morris, S. M. Nelis, J. Pickett, C. Quinn, J. Rusted, J. Thom. ESRC is part of UK Research and Innovation (UKRI). 'Improving the experience of Dementia and Enhancing Active Life: a longitudinal perspective on living well with dementia. The IDEAL-2 study' is funded by Alzheimer's Society, grant number 348, AS-PR2-16-001. Investigators: L. Clare, I. R. Jones, C. Victor, C. Ballard, A. Hillman, J. V. Hindle, J. Hughes, R. W. Jones, M. Knapp, R. Litherland, A. Martyr, F. Matthews, R. G. Morris, S. M. Nelis, C. Quinn, J. Rusted. The views expressed are those of the author(s) and not necessarily those of the ESRC, UKRI, NIHR, the Department of Health and Social Care, the National Health Service, or Alzheimer's Society. The support of ESRC, NIHR and Alzheimer's Society is gratefully acknowledged.

CONFLICT OF INTEREST

None declared.

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

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: Victor CR, Rippon I, Nelis SM, et al. Prevalence and determinants of loneliness in people living with dementia: Findings from the IDEAL programme. *Int J Geriatr Psychiatry.* 2020;35:851-858. <https://doi.org/10.1002/gps.5305>