

# Living Alone with Mild-To-Moderate Dementia: Findings from the IDEAL Cohort

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## Abstract.

**Background:** A significant proportion of people with dementia live alone, but little is known about their specific needs.

**Objective:** To understand the profile of people living alone with mild-to-moderate dementia in the UK and identify any systematic differences associated with living situation.

**Methods:** We analyzed cross-sectional data from 1,541 people with mild-to-moderate dementia and 1,277 caregivers participating in the IDEAL cohort at the first wave of assessment.

**Results:** There were 1,256 (81.5%) people with dementia living with others and 285 (18.5%) living alone, of whom 51 (3% of whole sample) reported little or no informal support. There were relatively few differences associated with living situation and odds ratios were generally small. People living alone were older on average, and more likely to be female, than those living with others. Those living alone were more likely to have higher cognitive ability and self-reported functional ability, and more social contact with those from other households. They were also lonelier, expressed less satisfaction with life, and used home care services and equipment more. There were no differences in symptoms, mood, quality of life, or well-being.

**Conclusion:** The findings support the view that it is possible to 'live well' with mild-to-moderate dementia while living alone, given appropriate support, including home care and equipment. Nevertheless, it is important to consider how those living alone may be supported to have a more satisfactory experience, and how health and social care services can best respond to their needs.

Keywords: Aids and adaptations, Alzheimer's disease, service use, social capitals, assets and resources, vascular dementia

## INTRODUCTION

Social trends toward increasing numbers of people living alone in later life may point to future increases in the proportion of people with early-stage dementia living alone in the community [1]. People living alone with dementia may be at higher risk of adverse events and outcomes than those living with others, yet we

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know relatively little about their specific needs or how to provide care effectively [2].

Evidence from European and North American samples suggests that the proportion of people with dementia living alone lies somewhere between 28% and 51% [2–4]. As different recruitment strategies and inclusion criteria influence the proportion of people living alone who take part in research studies, figures from such studies may not be representative of the population as a whole. One early study based on medical records provided a lower estimate of 19% [5].

Living alone does not necessarily mean that people are unsupported through their informal social networks. Many of those living alone will still have access in varying degrees to help and support from family members or close friends, whether near at hand or further away. However, some have no such support. In a Canadian study, 31.5% lived alone and 4% said they had no-one they could count on for help [6]; in a more recent German study, 51% lived alone and 9% had no informal caregiver providing support [4]. These people constitute a particularly vulnerable group, and are likely to be admitted to residential care sooner than those who have at least some support from an available caregiver [7].

People with dementia living alone may sometimes have difficulty recognizing their own limitations or needs for help, and are at increased risk of numerous adverse outcomes, including social isolation, exploitation, accidental injury, malnutrition, and self-neglect [2]. A cross-sectional study in the UK found that people with dementia living alone were more likely to experience psychological distress, and more vulnerable to accidental self-harm, than those living with others [8]. A prospective study following 211 people with early-stage dementia living alone over one year in Canada found that 10% (22) experienced a significant harm during that period, such as significant injury, damage to property, or negative effects of self-neglect or disorientation [9].

The experience of living alone with the cognitive and functional impairments resulting from dementia has been explored in several qualitative studies and notably described as a ‘vague existence’ [10]. These reports suggest that the experience is characterized by difficulty managing the home, finances, and everyday tasks, difficulty getting out and about and navigating public spaces, and difficulty in keeping oneself entertained; the result is isolation, loneliness, boredom, and a lack of purpose and meaning in life [10–12]. In addition, some participants described

negative experiences with services and individual care workers [11, 12]. However, people with dementia in this situation draw on their personal resources, rich inner lives, and desire for meaningful connection to find ways of coping [13].

Living alone with early-stage dementia is likely to be a growing phenomenon, presents challenges for coping, and may result in higher levels of risk and unmet need and poor-quality experience in everyday life, especially for those with little or no support from family or friends. Understanding more about the profile and needs of people living alone with dementia is important to help shape future policy and practice in this area [2]. In the current study, we draw on data from the IDEAL cohort [14, 15] to better understand the profile of people living alone with mild-to-moderate dementia in the UK and to explore, across a range of indicators, whether there are systematic differences between those living alone and those living with others. In particular, we aim to identify any differences that might be amenable to, or point to new possibilities for, intervention at either individual or community levels.

## METHODS

### *Design*

We analyzed cross-sectional data from 1,541 people with mild-to-moderate dementia (of any type) and 1,137 caregivers participating in the IDEAL longitudinal cohort study [14, 15] at the first wave of assessment. The analyses are based on version 4 of the IDEAL T1 dataset. IDEAL was approved by Wales Research Ethics Committee 5 (reference 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 11684). IDEAL is registered with the UK Clinical Research Network (UKCRN), number 16593.

### *Participants*

IDEAL participants were recruited through memory services and other specialist clinics within the UK National Health Service (NHS), and via the online Join Dementia Research portal, between July 2014 and August 2016. Inclusion criteria were a clinical diagnosis of dementia, a Mini-Mental State Examination (MMSE) [16] score of 15 or above indicating mild-to-moderate severity, and residing in the community. Exclusion criteria were inability to provide informed consent, terminal illness, and

any known potential for home visits to pose a risk to researchers. Where possible a family member or close friend (here referred to as a 'caregiver') was recruited to participate alongside the person with dementia, and provided informant ratings on relevant measures. For the first wave of assessment in this longitudinal cohort study, participants were visited by researchers on 3 occasions; people with dementia completed the questionnaires in face-to-face interviews with the researcher, while caregivers were given their questionnaires to complete by themselves while the researcher was interviewing the person with dementia. The cohort at Time 1 comprised 1,547 people with dementia, of whom 1,283 also had a family member or close friend involved [17, 18]. Information about living situation was available for all but 6 of the participants with dementia.

### *Measures*

#### *Personal characteristics and demographic information*

We recorded age, sex, educational qualifications, and dementia diagnosis, and calculated socio-economic status on the basis of Office for National Statistics [19] classifications. The Charlson Comorbidity Index [20, 21] was used to identify number of co-morbid conditions in addition to dementia, which was excluded from the Index, and participants gave a subjective rating of their own health over the past 4 weeks on a 6 point scale from 'very poor' to 'excellent' [22].

#### *Cognitive and functional ability and other symptoms*

Cognitive function was assessed with the MMSE and the Addenbrooke's Cognitive Examination-III (ACE-III) [23]. Dependence was assessed with the Dependence Scale [24] and functional ability with the modified 11-item Functional Activities Questionnaire [25, 26], in both self-rated and where possible informant-rated versions. Depression was assessed through self-report on the 10-item Geriatric Depression Scale [27] recoded into a binary depressed (4–10)/not depressed (0–3) variable [28]. Neuropsychiatric symptoms were rated by caregivers where available using the Neuropsychiatric Inventory Questionnaire [29, 30].

#### *Psychological characteristics*

Self-esteem was assessed with the Rosenberg Self-Esteem Scale [31], self-efficacy with the Generalized

Self-Efficacy Scale [32], optimism with the six non-filler items from the Life Orientation Test-Revised [33], and loneliness with the 6-item version of the De Jong Gierveld Loneliness Scale [34, 35] recoded into a binary lonely (2–6)/not lonely (0–1) variable [35, 36]. We assessed perceived stigma with 4 questions from the Stigma Impact Scale for people with dementia [37]; these questions were only administered to participants showing awareness of having dementia based on responses to the screening items of the Representations and Adjustment to Dementia Index [38].

#### *Social capitals, assets, and resources*

Social network size was measured with self- and informant ratings on the 6-item Lubben Social Network Scale [39]. Access to social resources within these social networks was measured with the Resource Generator UK [40]; for the purposes of the present study, as questions about employment were not relevant for the majority of participants with dementia, some questions were removed when calculating the total score. Social capital was measured using the core social capital items from the Office for National Statistics [41]: neighborhood reciprocity and trust, neighborhood social problems, civic participation, social participation, and frequency of social contact with people not living in the same household. Civic and social participation were coded as 0 = no participation, 1 = some participation, and 2+ = extensive participation. Neighborhood reciprocity and trust (gauged by asking the participant to estimate the likelihood of a lost purse or wallet being returned with nothing missing) was recoded into a binary likely (4–5)/other (1–3) variable. Cultural capital was assessed with self- and informant ratings of frequency of engagement in 13 activities such as going to the opera, playing bingo, visiting stately homes, eating out, etc., taken from the Cultural Capital and Social Exclusion Survey [42].

#### *Indices of 'living well'*

Quality of life was assessed with the Quality of Life in Alzheimer's Disease scale (QoL-AD) [43], life satisfaction with the Satisfaction with Life Scale [44], and well-being with the World Health Organization-Five Well-Being Index [45].

#### *Service use*

Methods of collecting and costing data on service use are described in detail in Henderson et al. [46]. Here we consider use of paid health

and care services, medications, and equipment and adaptations. A four-category variable describing the purpose of equipment and adaptations was created to explore whether their use differed by living arrangement: 1) memory aids (calendar clocks, medication dispenser reminders); 2) falls technology (pendant and falls alarms); 3) activities of daily living equipment (bath seats, bed rails, commodes, over bath showers, incontinence pads, walk-in showers, toilet seats, perching stools); and 4) mobility equipment (grab/stair rails, outdoor rails, sticks, frames).

Further details about the measures listed above can be found in the IDEAL study protocol and subsequent publications [14, 17].

### *Statistical analysis*

Participants with dementia were classified as living alone or living with others. Among those who were living alone, we identified a sub-group receiving little or no support from others (living alone with low support). These were individuals who 1) had no caregiver participating in the study, 2) said they received no help at all or less than one hour of help from family or friends in the past week, and 3) if the response to the previous question was missing, indicated in response to an earlier question that they had received no help from others for any of the following specific support needs in the past week: personal care; finances; housework or laundry; attending appointments; medication; safety; other.

Individuals living alone could have widely varying levels of support from others, and those who live alone with little or no support might be considered potentially most vulnerable. Therefore, in the analyses that follow, we considered 1) all those living alone, and 2) those living alone with low support. We used chi-square tests, ANOVA, and logistic regression to explore differences between these groups and the larger group of participants who lived with others, usually a spouse or partner. For analyses of service use, which only considered all those living alone, predictive margins and contrasts of predictive margins were also calculated. Holm-Bonferroni correction was applied to all analyses, and we report only findings that remained significant after correction.

## **RESULTS**

Of the 1,541 participants with dementia included in this analysis, 285 (18.5%) lived alone and 1,256 lived with others; 1,165 (75.6%) lived with a spouse

or partner and 91 (5.9%) lived with someone other than a spouse or partner. Of those living with others, 1,137 (90.5%) had a caregiver taking part in the study.

Just over half of the 285 individuals living alone had no caregiver participating in the study (145, 50.9%) while the remaining 140 had a caregiver contributing information. Of those with no caregiver contributing, 51 (35%) specifically indicated they had received no help or less than one hour of help during the past week. Information about the extent of help received was missing for 38 of those living alone. Among the rest, the majority received either 1–4 hours of help (42.6%) or 5–8 hours of help (29.6%).

### *Personal and demographic characteristics*

Personal and demographic characteristics, together with information about dementia diagnoses and health, are summarized in Supplementary Table 1. More than two-thirds of those living alone were female (67.7%) while nearly two-thirds of those living with others were male (61.8%);  $\chi^2(1)$ , 82.19,  $p < 0.001$ . The majority of those living alone were widowed (194, 68.1%); the remainder were divorced (62, 21.8%) or single (19, 6.7%). On average, those living alone were significantly older than those living with others (79.88 years versus 75.57 years;  $F(1,1539) = 61.49$ ,  $p < 0.001$ ). There was a significant difference in socio-economic status as the distribution across categories varied somewhat between the two groups with no clear pattern ( $\chi^2(1)$ , 18.64,  $p = 0.005$ ), but no significant difference in educational level ( $\chi^2(3)$ , 6.68,  $p = 0.083$ ). There was no clear pattern of differences due to dementia diagnosis, although the proportion of people with mixed Alzheimer's and vascular dementia was higher among those living alone (80, 28.1% versus 246, 19.6%) while the proportion of people with rare dementias (frontotemporal dementia, Parkinson's disease dementia, dementia with Lewy bodies, and other rare dementias) was lower ( $\chi^2(1)$ , 23.62,  $p = 0.001$ ). Neither number of co-morbid health conditions nor subjective ratings of health differed significantly between the groups after controlling for age, socio-economic status, and dementia diagnosis. Based on these initial analyses, age, sex, socio-economic status, and dementia diagnosis were included as covariates in subsequent analyses comparing all those living alone and all those living with others in the domains of cognitive and functional ability and other symptoms, psychological characteristics, social capitals, assets, and resources,

Table 1

Logistic regression analysis of the associations of cognition, functional ability, psychological characteristics, social resources, subjective health, and indices of living well, with living situation

Measure	Living alone ( $n = 285$ ) versus living with others ( $n = 1,256$ ) <sup>+</sup>	Living alone with low support ( $n = 51$ ) versus living with others ( $n = 1,256$ ) <sup>†</sup>
Mini-Mental State Examination	OR 1.08 (1.04, 1.13), $p < 0.001$	OR 1.18 (1.08, 1.28), $p < 0.001$
Addenbrooke's Cognitive Examination-III		
Attention	OR 1.14 (1.08, 1.20), $p < 0.001$	OR 1.22 (1.09, 1.37), $p < 0.001$
Fluency	OR 1.10 (1.04, 1.15), $p < 0.001$	OR 1.18 (1.07, 1.31), $p = 0.001$
Memory	OR 1.04 (1.01, 1.07), $p = 0.014$	
Visuospatial	OR 1.06 (1.01, 1.12), $p = 0.016$	
Total score	OR 1.03 (1.01, 1.04), $p < 0.001$	OR 1.04 (1.01, 1.06), $p = 0.002$
Dependence Scale-S	OR 0.86 (0.81, 0.92), $p < 0.001$	OR 0.64 (0.53, 0.76), $p < 0.001$
Dependence Scale-I	OR 0.90 (0.83, 0.98), $p = 0.011$	–
Functional Activities Questionnaire-S	OR 0.96 (0.94, 0.98), $p < 0.001$	OR 0.85 (0.80, 0.91), $p < 0.001$
Functional Activities Questionnaire-I	OR 0.97 (0.94, 0.99), $p = 0.007$	
Depressed	OR 1.38 (1.01, 1.89), $p = 0.042$	
Lonely	OR 2.11 (1.56, 2.84), $p < 0.001$	OR 2.11 (1.19, 3.75), $p = 0.011$
Lubben Social Network Scale-I	OR 0.93 (0.89, 0.97), $p = 0.001$	–
ONS Social participation		OR 1.40 (1.00, 1.96), $p = 0.048$
Frequency of social contact	OR 1.16 (1.11, 1.22), $p < 0.001$	
Cultural Capital-S	OR 0.97 (0.94, 1.00), $p = 0.020$	
Self-rated health	OR 0.84 (0.73, 0.95), $p = 0.007$	
Quality of Life in Alzheimer's Disease	OR 0.97 (0.94, 0.99), $p = 0.018$	
Satisfaction with Life Scale	OR 0.92 (0.90, 0.94), $p < 0.001$	OR 0.89 (0.86, 0.93), $p < 0.001$
World Health Organization-Five Well-Being Index	OR 0.99 (0.98, 1.00), $p = 0.009$	

Bold indicates significant at the 5% level after Holm-Bonferroni correction. – denotes analysis was not conducted as measures were informant-rated and there was no data. <sup>+</sup>Controlling for age, sex, socio-economic status, dementia diagnosis; <sup>†</sup>Controlling for sex. -S denotes self-rating and -I denotes informant rating. Living alone coded as 1 in logistic regressions.

and indices of 'living well'. We modelled the impact of living alone on service use controlling for age, sex, socio-economic status, and dementia diagnosis.

Those living alone with low support ( $n = 51$ ) did not differ significantly from those living with others in age, socio-economic status, or dementia diagnosis. Gender composition followed the same pattern as seen in the wider group ( $\chi^2(1), 10.48, p = 0.001$ ). Therefore, when making further comparisons for this sub-group, we controlled for sex only.

Results of logistic regression analyses of the associations of cognition, functional ability, psychological characteristics, social resources, subjective health, and indices of living well with living situation are summarized in Table 1.

#### *Cognitive and functional ability and other symptoms*

Scores for cognitive and functional ability and other symptoms are summarized in Supplementary Table 2. People with higher MMSE and ACE-III scores, and those who by their own report were less dependent and had fewer functional difficulties, were more likely to live alone (see Table 1). However, for individuals with a caregiver participating,

informant ratings on these measures did not discriminate between those living alone and those living with others. The presence of depression or other neuropsychiatric symptoms was not associated with living situation. The pattern of results was the same where data were available for those living alone with low support ( $n = 51$ ); see Table 1.

#### *Psychological characteristics*

Scores on measures of psychological characteristics are shown in Supplementary Table 3. Overall, those with higher levels of loneliness were more likely to live alone (see Table 1), although levels of loneliness were low irrespective of living situation. Levels of self-esteem, self-efficacy, optimism, and perceived stigma were not associated with living situation. Considering just those living alone with low support ( $n = 51$ ), feelings of loneliness, self-esteem, self-efficacy, optimism, and perceived stigma were not associated with living situation.

#### *Social capitals, assets, and resources*

Scores on measures of social capitals, assets, and resources are summarized in Supplementary Table 4.

Overall, when social network size was rated by informants, people with smaller social networks were more likely to be living alone (see Table 1); however, as the mean difference in network size was small, this could simply reflect the fact that they were living alone rather than any difference in wider social networks. The difference in social network size did not emerge in self-ratings after correcting for multiple comparisons. In contrast, people reporting higher frequency of social contact with people not in the same household were more likely to be living alone. Neighborhood reciprocity and trust, social or civic participation, local problems, and self-rated or informant-rated cultural capital were not associated with living situation. Considering just those living alone with low support ( $n=51$ ), none of the measures of social capitals, assets and resources were associated with living situation.

#### Indices of 'living well'

Scores on measures of quality of life, satisfaction with life, and well-being are shown in Supplementary Table 6. Overall, people with lower scores for satisfaction with life were more likely to be living alone (see Table 1), but there were no differences in quality of life or well-being. This was the case both for all those living alone and for those living alone with low support.

#### Service use

The proportions of those living alone and those living with others using paid health and care services over the prior three months, and the proportions using equipment and adaptations, are given in Supplementary Tables 6 and 7.

In both groups, office visits to the general medical practitioner (GP) were the most commonly used service (66% living with others; 59% living alone). Use of GP home visits, home care, meals on wheels, and cleaners was higher in the living alone group, while use of practice nurses (who do not make home visits) was lower. Participants living alone in receipt of home care services had approximately seven times more visits on average than participants living with others. A greater proportion of participants living alone used equipment or adaptations of some kind than those living with others, and this was the case for all four specific categories: memory aids, falls technology, activities of daily living, and mobility equipment.

Table 2

Logistic regression analysis of the associations of service and equipment use over the previous 3 months with living situation

Service or equipment type	Living alone ( $n=285$ ) versus living with others ( $n=1,256$ )
General practitioner – home	OR 2.10 (1.19, 3.73), $p=0.011$
Home care	OR 4.44 (2.99, 6.61), $p<0.001$
Meals on wheels	OR 8.69 (3.04, 24.84), $p<0.001$
Cleaner	OR 1.68 (1.20, 2.35), $p=0.003$
Day center days	OR 1.53 (1.01, 2.31), $p=0.044$
Use of equipment	OR 2.05 (1.43, 2.96), $p<0.001$
Memory aids	OR 2.91 (2.01, 4.19), $p<0.001$
Fall prevention aids	OR 4.22 (2.96, 6.01), $p<0.001$
Activities of daily living aids	OR 1.63 (1.20, 2.21), $p=0.002$
Mobility aids	OR 1.47 (1.08, 2.00), $p=0.014$

Bold indicates significant at the 5% level after Holm-Bonferroni correction. Adjusted for age, sex, socio-economic status, dementia diagnosis.

People receiving home care and meals on wheels services, people using equipment of any kind, and people specifically using aids for memory, falls prevention, and activities of daily living were more likely to be living alone (Table 2). The odds of having home care and the odds of using aids for falls prevention were both about 4 times greater for people living alone than for people living with others.

Predicted probabilities of use, controlling for age, sex, socio-economic status, and diagnosis, were low for many services (Supplementary Figure 1). Contrasts of predictive margins suggested that people using a home care service had a 25% higher likelihood of living alone (contrast 0.25; 95% CI: 0.17, 0.32) and users of aids for falls prevention had a 23% higher likelihood of living alone (contrast 0.23; 95% CI 0.17, 0.23), than non-users.

## DISCUSSION

Understanding more about the profile and needs of people living alone with dementia is important, but relatively little evidence is available to help shape policy and practice. This study contributes new evidence by drawing on data from a large cohort of people with a diagnosis of mild-to-moderate dementia recruited through NHS memory services in Great Britain to examine the characteristics of those living alone and identify any systematic differences between those living alone and those living with others. Comparison of personal and demographic characteristics, cognitive and functional ability, symptoms, psychological characteristics, social capitals, assets and resources, and perceptions of 'living well' yielded few differences. Overall, people living alone were older on

average, and more likely to be female, than those living with others. Those with higher cognitive ability and self-reported functional ability, who reported more loneliness, more social contact with those from other households, and less satisfaction with life, and who used home care services and equipment such as falls prevention aids, were more likely to live alone. The only characteristics associated with greater likelihood of living alone with low support were higher cognitive and self-rated functional ability and lower satisfaction with life.

The proportion of people with dementia in the IDEAL cohort who were living alone was 18.5%. This is lower than the range identified in the majority of studies [2], which is closer to one-third. Variations in sampling procedure and inclusion criteria may, to some extent, account for the differing proportions identified in different studies and it is noteworthy that an earlier US study based on a large sample of medical records rather than direct recruitment from clinical services [5] gave a similar proportion to our estimate which is based on participants recruited in 29 areas of Great Britain through the comprehensive publicly-funded health care system. The finding that around one-fifth of individuals with a diagnosis of mild-to-moderate dementia are living alone nonetheless demonstrates that this is a sizeable group of people whose needs require consideration.

In terms of personal and demographic characteristics, previous studies have found that people living alone with dementia include a preponderance of widowed women [3–6], and our findings were in line with this. Most studies have found that those living alone tend to be older than those living with others [3–5] although this is not a universal finding [6]. Our overall group of people living alone did tend to be older than those living with others, but this was not the case for the sub-group that were living alone with low support. This emphasizes the point that people living alone with dementia are not a single homogeneous group; rather, the reasons why people are living alone, and the viability of continuing to live alone, will differ for different individuals and groups, and a more fine-grained approach is indicated when considering the support needs of those living alone.

Similarly, our findings indicate that in terms of cognition, functional ability, mood and neuropsychiatric symptoms there is no distinct profile that characterizes people living alone with mild-to-moderate dementia. We found few significant differences, and for those differences that remained significant after correction for multiple comparisons, the odds ratios

were small. Findings from other studies are mixed. Some report differences in cognition [5, 6] while others do not [3, 4]. Some report differences in functional ability [6, 47] and others do not [3, 4]. No other studies have reported differences in depression [4, 47]. Thus, people living alone with mild-to-moderate dementia can in general be considered not much different to those living with others in these domains; however, as dementia progresses, those who do not have an available caregiver may require more support to manage the impact of their symptoms on daily life.

The domain of social contact and social inclusion is a particular focus of the IDEAL program from which our data were drawn. We found few differences between those living alone and those living with others in this domain, and those differences identified were small. However, one important finding is that people living alone were significantly more likely to feel lonely than those living with others, despite being significantly more likely to have higher levels of social contact with people from outside the household. While it appears that people living alone with mild-to-moderate dementia are not particularly different to those living with others, it is probable that due to their circumstances they may benefit from support to reduce feelings of loneliness and ensure continued social inclusion.

While those living alone rated quality of life and well-being lower than those living with others, the differences were small, and not statistically significant [48]. However, satisfaction with life was significantly lower for all those living alone and for those living alone with low support, reflecting a small but consistent effect. This highlights the value of considering a range of indices that reflect aspects of 'living well'; although there is measurement overlap between the different constructs of quality of life, well-being, and satisfaction with life, they are not equivalent [17, 48]. The finding of differences in satisfaction with life may reflect the experience of a 'vague existence' [10] described in qualitative studies, with practical difficulties leading to a lack of meaning and purpose in life [10–12]. Consideration could be given to ways of enabling those living alone with dementia to have a more satisfying experience. Given the heterogeneity among this group, a personalized approach seems most likely to be effective.

Regarding service use, the findings in the current study suggest a general pattern of higher use of home-based services. As might be expected, those living alone with dementia were more likely to use domestic help and equipment than those living with others

because there was no-one else in the household to assist with activities of daily living.

A limitation of the study may be the sampling strategy whereby participants were recruited mainly from among those attending NHS services. It was not possible to include people living with dementia who have not been formally diagnosed. Caregivers, especially spouses, might encourage participation, while people with no caregiver may be less likely either to be approached or to join the study. However, we did explicitly encourage recruitment of those with no caregiver, including those living alone, as we did not want to exclude this group. The IDEAL cohort participants were 96% white British, and therefore our study does not address the situation of people from black and minority ethnic groups. Nevertheless, the findings are based on a large sample which is considered to represent the population attending NHS memory clinics in the UK reasonably well, and provides information about the broad range of social and psychological resources that influence ability to 'live well' with dementia. Although this was a large sample, making it feasible to compare those living alone and those living with others, the sub-group of individuals living alone with low support was small, and the limited range of statistically-significant effects may be attributable at least in part to the small numbers in this sub-group. This may be the case both for variables such as loneliness which did emerge as relevant for the whole group of people living alone and for variables such as social participation that did not show significant differences for the whole group of people living alone. It seems reasonable to assume that the psychological and social impact of dementia is extensive for all or at least the majority of participants irrespective of living situation, and additional differences relating to living situation may be relatively smaller and hard to detect. Further research with a larger sample of individuals living alone with limited support could yield more fine-grained analyses. Additionally, as IDEAL was an extensive survey, short versions of measures were used where possible to avoid over-burdening participants; it is possible that a more in-depth focus on specific areas of experience with more extensive measures might identify differences not found in our analyses. However, as the finding of no or only small differences is consistent across a range of measures, and the full score range was typically used, there is no particular reason to think that any individual measures are especially insensitive. Our findings are based on cross-sectional data and as IDEAL is a longitudinal study it will

be possible in future to explore whether and at what point the experiences and needs of people living alone diverge from those living with others, and the influences on these trajectories over time.

### *Conclusions*

People living alone with mild-to-moderate dementia constitute a sizeable group, and it is important to establish how their needs may best be met and how they may be supported to have a more satisfactory experience. The findings are consistent with the view that it is possible to 'live well' with mild-to-moderate dementia while living alone, given appropriate support. This may include support to reduce loneliness, maintain social engagement, and manage the impact of dementia symptoms on everyday life, including availability of home care and access to equipment such as memory and falls prevention aids. Consideration should be given to the best ways of ensuring that this kind of support is available. As patterns of service use differ according to living situation, consideration should also be given to ensuring that health and social care services are responsive to the particular needs of those living alone. It will be important to establish how the needs of this group change as dementia progresses and what additional support is required over time.

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## DATA AVAILABILITY

IDEAL data were deposited with the UK data archive in April 2020 and will be available for access from April 2023. Details of how the data can be accessed after that date can be found here: <https://reshare.ukdataservice.ac.uk/854293/>.

## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/JAD200638>.

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