



## Regular Research Article

# Living Alone With Mild-to-Moderate Dementia Over a Two-Year Period: Longitudinal Findings From the IDEAL Cohort

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## ARTICLE INFO

*Article history:*

Received October, 3 2023

Revised May, 15 2024

Accepted May, 29 2024

*Keywords:*

Alzheimer's disease

vascular dementia

social capitals

assets and resources

service use

aids and adaptations

## ABSTRACT

**Objectives:** To compare the experiences of people with dementia living alone or with others and how these may change over two years. **Design:** We analysed longitudinal data from three assessment waves, one year apart, in the British IDEAL cohort. **Setting:** Participants with mild-to-moderate dementia were recruited through National Health Service providers, where possible with a family caregiver, and interviewed at home. **Participants:** The current analyses include 281 people with dementia living alone and 1,244 living with others at baseline; follow-up data were available for 200 and 965 respectively at time 2 and 144 and 696 respectively at time 3. For those living alone, 140 nonresident caregivers contributed at baseline, 102 at time 2 and 81 at time 3. For those living with others, 1,127 family caregivers contributed at baseline, 876 at time 2 and 670 at time 3. **Measurements:** Assessments covered: cognitive and functional ability; self-reported perceptions of health, mood, social engagement, quality of life, satisfaction with life and well-being; use of in-home and community care; and transitions into residential care. **Results:** People living alone tended to have better cognitive and functional ability and were more frequent users of in-home care. However, they experienced poorer physical, social, and psychological health and reduced quality of life, satisfaction with life, and well-being. These differences persisted over time and rates of transition into

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<https://doi.org/10.1016/j.jagp.2024.05.012>

*residential care were higher. Conclusions: To facilitate continuing in place for people with dementia living alone, a dual focus on supporting functional ability and addressing psychosocial needs is essential in the context of an enabling policy framework.* (Am J Geriatr Psychiatry 2024; 32:1309–1321)

**Editorial accompaniment, please see page 1322.**

### Highlights

- **What is the primary question addressed by this study?**

How do people with dementia living alone differ from those living with others, both cross-sectionally and longitudinally over a two-year period?

- **What is the main finding of this study?**

People living alone had better cognitive and functional ability than those living with others but experienced poorer physical, social, and psychological health and reduced quality of life, satisfaction with life, and well-being. These differences persisted over time, and they were more likely to move into long-term care.

- **What is the meaning of the finding?**

To facilitate continuing in place for people with dementia living alone requires a dual focus on supporting functional ability and addressing psychosocial needs, in the context of an enabling policy framework.

### OBJECTIVES

Living alone is associated with increased risk of developing dementia<sup>1,2</sup> and lower likelihood of timely diagnosis.<sup>3</sup> Although people with a dementia diagnosis are less likely than others of their age to live alone, a significant proportion do live alone.<sup>4</sup> Estimates range from under one in five to half; the proportion was 18%–19% in Japanese and US samples drawn from medical insurance records<sup>5,6</sup> and 18.5% in the British Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort,<sup>7</sup> whereas in a German study 51% were living alone.<sup>8</sup> Other studies in the US and Europe report figures between these extremes.<sup>9–14</sup> These variations likely reflect different sampling methods and inclusion criteria, but even if the correct figure is at the lower end of the spectrum this still represents a large number of individuals managing life with dementia while living alone. It is important to understand how the needs of this group evolve over time and how they can best be supported.<sup>15</sup>

Available evidence suggests that, compared to those living with others, people living alone with dementia are more likely to be female and older, and to have lower incomes.<sup>7,12,16</sup> In terms of characteristics and symptoms, they do not differ markedly from

those living with others, but tend to have similar or better levels of cognitive and functional ability<sup>7,12,16</sup> and better physical health.<sup>16</sup> However, they are more likely to use in-home care services, aids and adaptations,<sup>7,12,16</sup> and to require formal home care sooner, than those living with others, and needs for care are more likely to increase over time.<sup>6</sup> Living alone predicts admission to residential or nursing home care,<sup>9,12,16–18</sup> especially for men,<sup>19</sup> and the duration of formal care is longer.<sup>20</sup> Greater impairment, or more rapid decline, in functional ability is a key factor influencing admission to residential/nursing home care among those living alone.<sup>12</sup> People with dementia living alone may not always recognize their limitations<sup>10</sup> and in a one-year follow-up were vulnerable to significant harms including injury, damage to property, self-neglect and disorientation.<sup>21</sup>

Less is known about the subjective experience of people living alone with dementia and how this differs from the experience of those living with others. In a cross-sectional study, people living alone were more lonely and less satisfied with life than those living with others.<sup>7</sup> This is consistent with qualitative data suggesting that difficulty in multiple domains, including managing everyday tasks, getting out and about, and keeping occupied, leads to isolation, loneliness, boredom and lack of purpose or meaning,<sup>22–24</sup> an experience characterized as a ‘vague existence’<sup>22</sup>

reflecting a state of precarity.<sup>25</sup> However, we do not know whether these differences persist over time.

To understand more about the experience of people living alone with dementia over time, we build on cross-sectional findings from the British IDEAL cohort<sup>7</sup> to explore differences in trajectories over a 24-month period according to living situation. We examine whether patterns of change over time differ between people living alone with dementia and those living with others in respect of cognitive and functional ability; self-reported subjective experience, including perceptions of health, mood, social engagement, quality of life, satisfaction with life, and well-being; use of in-home care and community care resources; and rates of transition into residential or nursing home settings.

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## METHOD

### Design

We used longitudinal data from three waves of assessment with the IDEAL cohort<sup>26</sup> covering a 24-month period. Time 1 (T1) data were collected from August 2014 to July 2016, Time 2 (T2) from August 2015 to July 2017, and Time 3 (T3) from August 2016 to June 2018. The analyses are based on version 7 of the IDEAL datasets. The IDEAL study 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), and is registered with UKCRN (#16593). Cohort sample size was determined based on two previous studies<sup>27,28</sup> and to ensure reliability of coefficients in a proposed structural equation modelling analysis.<sup>29</sup>

### Participants

People with dementia were recruited through National Health Service research networks across England, Scotland, and Wales, and via the online Join Dementia Research portal. Inclusion criteria required a clinical diagnosis of dementia, a score of 15 or above on the Mini-Mental State Examination (MMSE)<sup>30</sup> indicating mild-to-moderate dementia, and the ability to communicate verbally in English. Exclusion criteria were co-morbid terminal illness, inability to provide

informed consent, and any known potential for home visits to pose significant risk to researchers. At T1, assessments lasted five hours and were split over three visits, and at T2 and T3 assessments lasted four hours and were split over two visits. Trained researchers administered questionnaires to people with dementia while caregivers completed questionnaires by themselves, usually in a separate room.

Data were provided by 1,525 people with dementia at T1, 1,165 at T2, and 840 at T3. Family caregivers, where available, provided informant ratings; there were 1,267 caregivers at T1, 978 at T2, and 751 at T3. Our previous cross-sectional analyses included 285 people with dementia living alone and 1,256 living with others.<sup>7</sup> A small number of these people were subsequently excluded from the IDEAL dataset due to change in diagnosis (3 living alone and 7 living with others) or because of inconsistent information about living situation (1 initially classified as living alone and 5 initially classified as living with others). Therefore, the current longitudinal analyses include 281 people living alone and 1,244 living with others. People living alone were no more likely to be lost to follow up than people living with others (Hazard Ratio 1.01, 95% CI: 0.83, 1.24,  $p=0.906$ ).

### Measures

Study measures are described briefly here; full details of all measures can be found in the [Supplemental Digital Content](#).

We collected details of age, sex, education, socioeconomic status, and marital status of the person with dementia. Dementia diagnosis was ascertained from medical records. Data on use of health and social care services in the previous three months, and current use of assistive technology, were collected with the Client Services Receipt Inventory. The presence of co-morbid conditions was determined based on self-report and/or informant report by the caregiver where available using the Charlson Comorbidity Index (see the [Supplemental Content](#) for further details). Cognition was assessed with the MMSE and the Addenbrooke's Cognitive Examination-III.

People with dementia completed the modified Functional Activities Questionnaire, Geriatric Depression Scale-10, De Jong-Gierveld Loneliness Scale, four items from the Stigma Impact Scale, Lubben Social Network Scale, Office for National Statistics core social

capital items, cultural capital items from the Cultural Capital and Social Exclusion Survey which assesses frequency of participation in a range of typically-available cultural activities, a single item assessing subjective health, Quality of Life in Alzheimer's Disease Scale, Satisfaction with Life Scale, and World Health Organization-Five Well-Being Index.

Caregivers provided informant ratings on the Functional Activities Questionnaire, Dependence Scale, Neuropsychiatric Inventory Questionnaire, and Lubben Social Network Scale.

### Statistical Analysis

Mixed effects models were used to investigate change in outcomes measured over the three timepoints (T1-T3). Random coefficient models, with a random intercept and a random slope, were fitted initially and tested against a random intercept model to see whether adding the random slope improved model fit. In cases where the model fit was not improved, a random intercept model was used. Missingness was handled using full information maximum likelihood estimation. Population-average predicted probabilities were estimated from models where the interaction effects were significant. The main analyses were conducted on people who lived alone or with others at baseline regardless of any subsequent change in living situation. However, living situation did change for several people, and a sensitivity analysis was conducted on study measures using data from only those people whose living situation remained the same across all timepoints in which they took part (248 of those living alone and 1,206 of those living with others). Cox regression models were used to investigate associations of living alone with loss to follow up or moving into care, adjusted for age, sex, and dementia diagnosis. See the [Supplemental Material](#) for further details of the statistical analyses.

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## RESULTS

Of the 281 people living alone with dementia, 140 had a nonresident caregiver taking part at T1, 102 at T2 and 81 at T3. Of the 1,244 who did not live alone, 1,127 had a caregiver, usually a spouse, taking part at T1, 876 at T2 and 670 at T3. Demographic and clinical characteristics are summarized by living situation in

[Table 1](#), and details of scores on study measures and statistical comparisons in [Tables 2 and 3](#). People living alone were more likely to be female and aged over 80, and a high proportion were widowed. Those living alone had more co-morbid conditions at baseline and rated their health less positively than those living with others. The number of co-morbid conditions increased over time for both groups, with no differences in trajectory, and subjective ratings of health did not change.

At baseline, people living alone scored higher on cognitive tests and on self- and informant-rated functional ability, and lower for informant-rated dependence, relative to those living with others. There were no differences in informant ratings of neuropsychiatric symptoms. Over time, cognition declined for both groups, but the decline was slower for those living alone (11% versus 14% per year for MMSE; rate ratio (RR) for interaction: 1.04 (95%CI 1.01, 1.08),  $p=0.002$ ; 4.9 versus 6.2 points per year for Addenbrooke's Cognitive Examination-III, estimate for interaction: 1.33 (95% CI 0.24, 2.41),  $p=0.017$ ; see [Table 3](#) and [Supplementary Figure 1](#)). Self- and informant-rated functional ability declined, and neuropsychiatric symptoms increased, for both groups over time with little difference. However, sensitivity analyses ([Supplementary Table 1](#)) suggested that self-ratings of functional ability declined at a lower rate in those living alone at all timepoints (12% versus 22% per year, RR for interaction: 0.92 (95% CI 0.85, 0.99),  $p=0.048$ ).

At baseline, people living alone reported more social contact than those living with others, although informant ratings suggested social networks were smaller, and levels of participation in cultural activities were lower. Over time, both groups showed reductions in social network size (self- and informant-rated), frequency of social contact, social engagement, participation in cultural activities, neighborhood reciprocity and trust, and neighborhood social problems, with no between-group differences. However, sensitivity analyses suggested that frequency of social contact declined less for those living alone (2% versus 6% per year, RR for interaction: 1.04 (95% CI 1.01, 1.08),  $p=0.014$ ). While rates of civic participation were low for both groups and did not differ at baseline, over time those living alone were more likely to participate while participation reduced for those living with others (+10% versus -38% per year, RR for interaction: 1.78 (95% CI 1.24, 2.55),  $p=0.002$ ).

**TABLE 1. Participants' Demographic and Clinical Characteristics by Living Situation at Baseline**

	Living with Others at Baseline			Living Alone at Baseline		
	T1 (n=1,244)	T2 (n=965)	T3 (n=696)	T1 (n=281)	T2 (n=200)	T3 (n=144)
Age (mean, sd; N)	75.59 (8.16); 1,244 76.46 (7.95); 965 76.88 (7.99); 696 79.97 (9.10); 281 80.65 (9.39); 200 80.79 (9.71); 144					
Age group (N, %)						
<65	110 (8.8%)	84 (8.7%)	67 (9.6%)	23 (8.2%)	17 (8.5%)	13 (9.0%)
65–69	161 (12.9%)	131 (13.6%)	107 (15.4%)	15 (5.3%)	11 (5.5%)	18 (12.5%)
70–74	231 (18.6%)	183 (19.0%)	137 (19.7%)	24 (8.5%)	20 (10.0%)	17 (11.8%)
75–79	318 (25.6%)	253 (26.2%)	171 (24.6%)	45 (16.0%)	31 (15.5%)	27 (18.8%)
80+	424 (34.1%)	314 (32.5%)	214 (30.7%)	174 (61.9%)	121 (60.5%)	77 (53.5%)
Female (N, %)	473 (38.0%)	372 (38.5%)	271 (38.9%)	191 (68.0%)	130 (65.0%)	97 (67.4%)
Male (N, %)	771 (62.0%)	593 (61.5%)	425 (61.1%)	90 (32.0%)	70 (35.0%)	47 (32.6%)
Education (N, %)						
No qualifications	328 (26.5%)	247 (25.6%)	182 (26.1%)	95 (33.9%)	66 (33.0%)	47 (32.6%)
School certificate age 16	228 (18.4%)	169 (17.5%)	118 (17.0%)	44 (15.7%)	29 (14.5%)	18 (12.5%)
School certificate age 18	426 (34.4%)	345 (35.8%)	251 (36.1%)	88 (31.4%)	62 (31.0%)	43 (29.9%)
Higher education	257 (20.7%)	204 (21.1%)	145 (20.8%)	53 (18.9%)	43 (21.5%)	36 (25.0%)
Missing	5	-	-	1	-	-
Socio-economic status (N, %)						
1. Higher managerial, administrative, and professional occupations	525 (43.0%)	406 (43.1%)	289 (42.5%)	105 (38.2%)	83 (42.6%)	64 (45.7%)
2. Intermediate occupations	358 (29.3%)	271 (28.7%)	206 (30.3%)	86 (31.3%)	58 (29.7%)	37 (26.4%)
3. Routine and manual occupations	337 (27.6%)	266 (28.2%)	185 (27.2%)	84 (30.5%)	54 (27.7%)	39 (27.9%)
Missing/not applicable	24	22	16	6	5	4
Marital status (N, %)						
Single	7 (0.6%)	3 (0.3%)	3 (0.4%)	19 (6.8%)	12 (6.0%)	10 (6.9%)
Married/Partnership/Cohabiting	1,144 (92.0%)	885 (91.7%)	638 (91.7%)	7 (2.5%)	2 (1.0%)	1 (0.7%)
Divorced/Separated	25 (2.0%)	20 (2.1%)	13 (1.9%)	63 (22.4%)	52 (26.0%)	42 (29.2%)
Widowed	68 (5.5%)	57 (5.9%)	42 (6.0%)	192 (68.3%)	134 (67.0%)	91 (63.2%)
Dementia diagnosis (N, %)						
Alzheimer's disease (AD)	692 (55.6%)	543 (56.3%)	406 (58.3%)	153 (54.4%)	107 (53.5%)	77 (53.5%)
Vascular dementia	135 (10.9%)	92 (9.5%)	65 (9.3%)	32 (11.4%)	22 (11.0%)	16 (11.1%)
Mixed AD/vascular dementia	243 (19.5%)	204 (21.1%)	140 (20.1%)	80 (28.5%)	59 (29.5%)	44 (30.6%)
Frontotemporal dementia	50 (4.0%)	36 (3.7%)	29 (4.2%)	4 (1.4%)	3 (1.5%)	2 (1.4%)
Parkinson's disease dementia	43 (3.5%)	33 (3.4%)	16 (2.3%)	1 (0.4%)	1 (0.5%)	1 (0.7%)
Dementia with Lewy bodies	45 (3.6%)	34 (3.5%)	24 (3.4%)	8 (2.8%)	5 (2.5%)	3 (2.1%)
Other/Unspecified	36 (2.9%)	23 (2.4%)	16 (2.3%)	3 (1.1%)	3 (1.5%)	1 (0.7%)
Charlson Comorbidity Index <sup>^</sup> (mean, sd; N)	1.75 (1.60); 1,193 2.17 (1.78); 947 2.41 (1.87); 709 2.00 (1.74); 267 2.58 (1.90); 190 2.80 (1.86); 148					
Self-rated health (mean, sd; N)	3.83 (1.16); 1,240 3.83 (1.15); 954 3.86 (1.15); 683 3.69 (1.13); 280 3.82 (1.12); 199 3.81 (1.10); 141					

Note:

<sup>^</sup> Higher score indicates more co-morbidities (in addition to dementia).

At baseline, people living alone experienced lower mood and more loneliness than those living with others, and had lower scores for quality of life, satisfaction with life, and well-being. There were no differences in trajectories of mood or loneliness over time, and little evidence of differing trajectories for quality of life, satisfaction with life, and well-being over time apart from a slight decline in quality of life for those living alone relative to those living with others. Perceptions of stigma did not differ either at baseline or longitudinally.

Rates of service utilization in each group are described in [Supplementary Table 2](#), and statistical comparisons are shown in [Table 4](#). At baseline,

compared to those living with others, people living alone used in-home care more intensively, in terms of proportions using the service (30% versus 7%) and mean numbers of visits received (24.65 versus 3.77). They were also more frequent recipients of social worker visits, meal delivery and cleaning services. There was a greater proportion of missing data from people living alone than those living with others for contacts with general practitioners (T2 and T3), practice nurses (T1 and T2) and community nurses (T2). Over time, use of social work, in-home care and cleaning services increased in both groups. Increases in the use of in-home care and cleaning services were more marked in those living with others (increasing by

**TABLE 2. Scores on Study Measures by Living Situation**

**a) Cognitive Tests and Self-Rated Measures**

	Living With Others at Baseline			Living Alone at Baseline		
	T1 (n=1,244)	T2 (n=965)	T3 (n=696)	T1 (n=281)	T2 (n=200)	T3 (n=144)
Mini-Mental State Examination (mean, sd; N)	23.11 (3.67); 1,243	21.35 (5.19); 955	20.32 (6.30); 685	23.56 (3.29); 281	22.69 (4.25); 200	21.39 (5.84); 144
Addenbrooke's Cognitive Examination-III (mean, sd; N)						
Attention	13.75 (3.05); 1,217	12.84 (3.62); 895	12.50 (3.88); 606	14.25 (2.59); 277	13.85 (2.93); 185	12.91 (3.86); 128
Verbal fluency	6.71 (3.10); 1,217	6.32 (3.25); 892	6.13 (3.38); 605	7.17 (2.82); 276	6.57 (3.19); 185	6.71 (3.26); 128
Language	21.82 (3.79); 1,211	21.85 (4.36); 887	21.14 (5.16); 603	21.86 (3.36); 276	21.96 (4.09); 181	21.44 (4.67); 128
Memory	13.57 (5.53); 1,211	12.85 (6.04); 889	12.50 (6.33); 603	13.46 (4.81); 276	12.80 (5.62); 183	13.18 (6.08); 128
Visuospatial	12.42 (3.37); 1,211	12.11 (3.62); 887	11.68 (3.94); 603	12.81 (2.83); 276	12.64 (2.86); 181	12.55 (3.32); 128
Total score	68.30 (13.89); 1,211	66.01 (16.25); 887	64.00 (18.09); 603	69.55 (11.56); 276	67.92 (13.86); 181	66.79 (17.15); 128
Functional Activities Questionnaire <sup>^</sup> (mean, sd; N)	9.99 (7.85); 1,205	11.63 (8.46); 814	12.71 (8.89); 604	7.83 (6.44); 268	8.90 (7.61); 175	10.01 (9.22); 123
Geriatric Depression Scale-10 (mean, sd; N)	2.61 (2.29); 1,111	2.40 (2.25); 878	2.40 (2.13); 617	2.91 (2.28); 247	2.57 (2.29); 180	2.50 (2.16); 127
Loneliness (mean, sd; N)	1.25 (1.42); 1,164	-	1.35 (1.46); 625	1.85 (1.71); 259	-	1.75 (1.56); 128
Stigma (mean, sd; N)	7.61 (1.87); 1,060	7.74 (1.84); 796	7.54 (1.97); 538	7.71 (1.70); 233	7.58 (1.81); 169	7.69 (1.98); 117
Lubben Social Network Scale (mean, sd; N)	15.33 (6.26); 1,182	15.06 (6.24); 892	14.87 (6.30); 604	14.06 (5.65); 258	13.98 (6.23); 186	13.17 (5.96); 127
Frequency of social contact (mean, sd; N)	11.84 (3.62); 1,151	11.48 (3.79); 892	11.03 (3.87); 610	13.34 (3.33); 262	13.21 (3.67); 177	12.70 (3.53); 125
Neighborhood reciprocity and trust (N, %)						
Likely	919 (76.3%)	728 (79.9%)	496 (78.1%)	199 (73.4%)	142 (76.8%)	89 (68.5%)
Other	286 (23.7%)	183 (20.1%)	139 (21.9%)	72 (26.6%)	43 (23.2%)	41 (31.5%)
Missing	39	54	61	10	15	14
Social problems in neighborhood (N, %)						
No local problems	436 (38.4%)	374 (43.6%)	246 (41.8%)	121 (47.6%)	79 (47.9%)	52 (44.4%)
Some local problems	699 (61.6%)	483 (56.4%)	342 (58.2%)	133 (52.4%)	86 (52.1%)	65 (55.6%)
Missing	109	108	108	27	35	117
Civic participation (N, %)						
0	1,023 (84.5%)	814 (89.3%)	561 (89.3%)	248 (91.2%)	160 (86.5%)	112 (86.2%)
1	105 (8.7%)	68 (7.5%)	45 (7.2%)	13 (4.8%)	12 (6.5%)	10 (7.7%)
2+	83 (6.9%)	30 (3.3%)	22 (3.5%)	11 (4.0%)	13 (7.0%)	8 (6.2%)
Missing	33	53	68	9	15	14
Social participation (N, %)						
0	844 (69.8%)	684 (75.0%)	482 (76.8%)	195 (71.7%)	137 (74.1%)	91 (70.0%)
1	164 (13.6%)	107 (11.7%)	70 (11.1%)	33 (12.1%)	18 (9.7%)	15 (11.5%)
2+	201 (16.6%)	121 (13.3%)	76 (12.1%)	44 (16.2%)	30 (16.2%)	24 (18.5%)
Missing	35	53	68	9	15	14
Cultural Capital (mean, sd; N)	23.17 (5.63); 1,177	22.52 (5.51); 878	21.90 (5.49); 600	21.44 (5.19); 262	20.95 (5.38); 182	20.60 (5.13); 128
QoL-AD (mean, sd; N)	36.91 (5.99); 1,121	37.27 (5.77); 847	37.26 (5.65); 585	36.29 (5.70); 241	35.48 (6.19); 180	35.41 (5.40); 121
Satisfaction with Life Scale (mean, sd; N)	26.55 (5.97); 1,212	26.72 (5.94); 903	26.66 (6.22); 629	24.11 (6.13); 271	24.21 (6.34); 188	24.71 (6.36); 122
WHO-5 Well-Being Index (mean, sd; N)	61.57 (20.58); 1,222	61.50 (20.47); 919	62.14 (20.76); 642	58.56 (20.20); 277	57.46 (21.33); 192	57.26 (21.97); 130

(continued on next page)

TABLE 2. (continued)

**b) Informant-Rated Measures (Only Recorded Where a Caregiver Took Part Alongside the Person With Dementia)**

Informant-Rated Measures	Living With Others at Baseline			Living Alone at Baseline		
	T1 (n=1,127)	T2 (n=876)	T3 (n=670)	T1 (n=140)	T2 (n=102)	T3 (n=81)
Dependence Scale <sup>^</sup> (mean, sd; N)	5.68 (2.63); 1,050	6.44 (2.89); 832	7.14 (3.09); 632	5.34 (2.48); 132	6.05 (2.86); 98	7.57 (3.19); 76
Functional Activities Questionnaire <sup>^</sup> (mean, sd; N)	17.98 (8.60); 1,046	21.03 (8.56); 837	22.92 (8.54); 647	17.25 (8.31); 127	20.18 (8.46); 99	24.62 (9.09); 79
Neuropsychiatric Inventory Questionnaire (mean, sd; N)	3.58 (2.47); 1,067	3.78 (2.54); 857	4.14 (2.50); 646	3.54 (2.49); 132	3.57 (2.49); 100	4.37 (2.90); 76
Symptoms Severity	5.79 (4.92); 1,028	6.26 (5.23); 823	6.88 (5.24); 620	5.71 (4.92); 132	5.64 (4.41); 98	7.65 (6.55); 74
Caregiver distress	6.25 (6.48); 930	6.95 (6.88); 759	6.73 (6.66); 572	5.91 (5.80); 120	5.80 (5.53); 95	6.00 (5.62); 70
Lubben Social Network Scale (mean, sd; N)	14.89 (5.75); 970	14.52 (5.84); 788	14.35 (5.90); 604	12.85 (4.82); 111	12.61 (4.90); 95	10.77 (3.94); 71

<sup>^</sup> Higher score indicates poorer functional ability.

3.7 times versus 1.6 times per year for in-home care, odds ratio (OR) for interaction: 0.44 (95% CI 0.26, 0.72),  $p=0.001$ ), although use by people living alone was higher at each timepoint (Supplementary Figure 2). Day center attendance increased among those living with others but decreased among those living alone (+58% versus -50% per year, OR for interaction: 0.32 (95% CI 0.16, 0.62),  $p=0.001$ ; Supplementary Figure 2). People living alone made more use of assistive technology at baseline, both overall and for each specific purpose, whether support for memory, activities of daily living, mobility, or falls prevention. Use of assistive technology increased in both groups over time overall and for these specific purposes, with no differences in trajectories.

The only difference in health service use between the groups at baseline was that people living alone were less likely to visit the nurse at their general practitioner’s office but more likely to have a community nurse visit them at home. Over time, home visits by general practitioners and community nurses increased while visits by psychiatrists decreased, attendance at outpatient appointments decreased while emergency department visits increased, and use of central nervous system medications increased; trajectories did not differ between the groups. Consultations with physiotherapists and occupational therapists increased for those living alone but declined slightly for those living with others (by 50% versus -3% per year; OR for interaction: 1.54 (95% CI 1.06, 2.24),  $p=0.023$ ; Supplementary Figure 2). There were no differences between groups or changes over time in general practitioner office or telephone appointments, community mental health nurse visits, use of dementia medications, or inpatient stays.

Seventy-six people moved into residential or nursing homes, 38 by T2 and another 38 by T3. Of these, 26 had lived alone and 50 with others. The risk of moving into these settings was higher for those living alone (Hazard Ratio: 1.86, 95% CI: 1.09, 3.18,  $p=0.023$ , adjusted for age, sex, and diagnosis).

## DISCUSSION

Given that a considerable proportion of people diagnosed with dementia are living alone, understanding the experience and specific needs of this group is an essential prerequisite for provision of

**TABLE 3. Mixed Effects Models Showing Associations Between Living Alone (Compared to Living With Others) at Baseline and the Intercept and Slope of Scores on Longitudinal Measures**

**a) Measures Rated by the Person With Dementia**

Outcome	Baseline: Lives Alone	Slope: Lives With Others	Interaction: Lives Alone x Slope
Linear model	Estimate (95% CI)	Estimate (95% CI)	Estimate (95% CI)
Quality of Life in Alzheimer's Disease Scale	-1.15 (-1.94, -0.35)*	0.07 (-0.31, 0.46)	-0.53 (-0.99, -0.08)*
Satisfaction with Life Scale	-2.94 (-3.72, -2.15)*	0.03 (-0.40, 0.46)	0.26 (-0.24, 0.76)
World Health Organization-Five Well-Being Index	-4.26 (-6.92, -1.60)*	-1.16 (2.62, 0.29)	-0.71 (-2.39, 0.98)
Addenbrooke's Cognitive Examination-III	3.28 (1.44, 5.12)*	-6.20 (-7.14, -5.26)*	1.33 (0.24, 2.41)*
Lubben Social Network Scale	-0.71 (-1.55, 0.14)	-0.47 (-0.90, -0.04)*	-0.14 (-0.64, 0.36)
Self-rated health	-0.18 (-0.33, -0.03)*	-0.02 (-0.10, 0.07)	0.10 (-0.01, 0.20)
Nonlinear model: continuous	RR (95% CI)	RR (95% CI)	RR (95% CI)
Mini-Mental State Examination	1.04 (1.02, 1.06)*	0.86 (0.84, 0.88)*	1.04 (1.01, 1.08)*
Functional Activities Questionnaire	0.75 (0.67, 0.85)*	1.23 (1.15, 1.31)*	0.95 (0.88, 1.02)
Frequency of social contact	1.15 (1.09, 1.20)*	0.93 (0.91, 0.96)*	1.03 (0.996, 1.06)
Cultural capital	0.96 (0.93, 0.99)*	0.96 (0.95, 0.98)*	1.01 (0.995, 1.03)
Depression	1.12 (1.03, 1.22)*	1.00 (0.95, 1.05)	0.96 (0.91, 1.02)
Loneliness	1.30 (1.20, 1.41)*	1.00 (0.95, 1.05)	0.97 (0.92, 1.03)
Nonlinear model: binomial	OR (95% CI)	OR (95% CI)	OR (95% CI)
Neighborhood reciprocity and trust	1.39 (0.84, 2.30)	0.98 (0.69, 1.38)	1.24 (0.86, 1.79)
Neighborhood social problems	0.74 (0.47, 1.16)	0.74 (0.54, 1.00)	1.30 (0.92, 1.84)
Nonlinear model: count	RR (95% CI)	RR (95% CI)	RR (95% CI)
Social participation	1.32 (0.93, 1.89)	0.77 (0.63, 0.93)*	1.14 (0.94, 1.37)
Civic participation	0.83 (0.51, 1.38)	0.62 (0.43, 0.89)*	1.78 (1.24, 2.55)*
Number of health conditions	1.15 (1.00, 1.31)*	1.21 (1.12, 1.30)*	0.99 (0.91, 1.07)
Two-part model	RR (95% CI)	RR (95% CI)	RR (95% CI)
Stigma: conditional on awareness of condition	1.03 (0.99, 1.08)	1.01 (0.98, 1.04)	0.98 (0.95, 1.01)

**b) Measures Rated by Informants**

Outcome	Baseline: Lives Alone	Slope: Lives With Others	Interaction: Lives Alone x Slope
Linear model	Estimate (95% CI)	Estimate (95% CI)	Estimate (95% CI)
Dependence scale	-0.68 (-1.16, -0.20)*	1.00 (0.80, 1.20)	0.28 (-0.01, 0.58)
Lubben Social Network Scale	-1.83 (-2.94, -0.72)*	-0.69 (-1.09, -0.30)*	-0.18 (-0.75, 0.39)
Nonlinear model: continuous	RR (95% CI)	RR (95% CI)	RR (95% CI)
Functional Activities Questionnaire	0.88 (0.78, 0.99)*	1.19 (1.14, 1.23)*	1.04 (0.99, 1.10)
Nonlinear model: Count	RR (95% CI)	RR (95% CI)	RR (95% CI)
NPI-Q symptoms	1.08 (0.93, 1.24)	1.10 (1.03, 1.17)*	1.03 (0.94, 1.12)
Two-part model	RR (95% CI)	RR (95% CI)	RR (95% CI)
NPI-Q severity: conditional on having symptoms	1.10 (0.93, 1.30)	1.07 (0.99, 1.31)	1.04 (0.94, 1.14)
NPI-Q distress: conditional on having symptoms	1.11 (0.91, 1.36)	1.08 (0.98, 1.18)	1.05 (0.94, 1.18)

\* Indicates that, for linear models, 95% CI do not cross 0 and for nonlinear models, 95% CI do not cross 1. The interaction is the difference in slope compared to the slope for 'Lives with others'. Models were adjusted for age, sex, and dementia diagnosis. OR, odds ratio; RR, rate ratio; CI, confidence intervals, NPI-Q, Neuropsychiatric Inventory Questionnaire.

appropriate personalized care. The present findings provide novel evidence about how the experience and needs of this group differ from those of the majority who live with others, and how these differences evolve over a 24-month period. The 18% of participants with mild-to-moderate dementia in the current sample who were living alone at baseline, compared to those living with others, had better cognitive test scores and functional ability, were more independent, and reported more social contacts. However, they had poorer health, smaller informant-rated social networks, lower cultural capital, higher levels of depression and loneliness, and poorer scores

for quality of life, satisfaction with life, and well-being. They were also more frequent users of in-home care and assistive technology. Over a 24-month period, those living with others experienced declines in health, cognition, functional ability, social networks, social capital including civic participation, and participation in cultural activities, while use of in-home care and assistive technology increased. Change over time for people living alone followed a broadly similar pattern with the initial differences remaining evident, but there were some key variations: cognition declined at a slower rate but decline in quality of life was more likely, use of in-home care



**TABLE 4. Mixed Effects Logistic Regression Estimates of Service Use Over the Prior Three Months and Current Use of Assistive Technology**

Item	Baseline: Lives Alone OR (95% CI)	Slope: Lives With Others OR (95% CI)	Interaction: Lives Alone x Slope OR (95% CI)
General practitioner – office visits	0.74 (0.53, 1.03)	1.07 (0.91, 1.26)	0.85 (0.62, 1.16)
General practitioner – home visits	1.82 (0.99, 3.35)	1.77 (1.41, 2.22)*	1.15 (0.76, 1.76)
General practitioner – telephone calls	1.27 (0.81, 1.99)	0.85 (0.60, 1.20)	0.93 (0.63, 1.38)
Practice nurse office visits	0.60 (0.42, 0.84)*	0.98 (0.88, 1.09)	1.02 (0.78, 1.34)
Community nurse visits	2.08 (1.19, 3.63)*	1.88 (1.55, 2.29)*	0.84 (0.57, 1.24)
Physio/Occupational therapy visits	0.70 (0.43, 1.16)	0.97 (0.83, 1.14)	1.54 (1.06, 2.24)*
Community mental health nurse visits	1.18 (0.8, 1.74)	0.21 (0.02, 2.00)	0.74 (0.39, 1.38)
Psychiatrist visits	0.87 (0.47, 1.62)	0.18 (0.08, 0.40)*	1.21 (0.60, 2.43)
Social work visits	1.83 (1.03, 3.27)*	1.49 (1.20, 1.84)*	0.94 (0.61, 1.45)
In-home care visits	19.50 (7.72, 49.29)*	3.67 (2.41, 5.58)*	0.44 (0.26, 0.72)*
Meals on wheels visits	10.91 (3.8, 31.30)*	0.98 (0.24, 3.94)	1.13 (0.49, 2.63)
Cleaner visits	4.25 (2.04, 8.86)*	1.88 (1.53, 2.30)*	0.47 (0.30, 0.72)*
Caregiver support visits	0.79 (0.34, 1.81)	1.19 (0.91, 1.55)	1.28 (0.69, 2.37)
Day center days	1.90 (0.89, 4.09)	1.58 (0.98, 2.54)	0.32 (0.16, 0.62)*
Lunch club visits	1.29 (0.66, 2.51)	1.00 (0.81, 1.24)	0.93 (0.58, 1.50)
Emergency department visits	1.14 (0.63, 2.07)	1.27 (1.03, 1.57)*	1.26 (0.82, 1.94)
Inpatient days	1.20 (0.67, 2.15)	1.16 (0.96, 1.41)	1.11 (0.72, 1.73)
Outpatient appointments	0.90 (0.63, 1.28)	0.40 (0.33, 0.48)*	1.12 (0.78, 1.61)
Central nervous system medications	1.61 (0.69, 3.78)	1.95 (1.39, 2.73)*	1.00 (0.56, 1.77)
Dementia medications	0.67 (0.28, 1.59)	1.21 (0.96, 1.52)	0.87 (0.52, 1.45)
Any use of assistive technology	3.41 (1.99, 5.84)*	1.38 (1.20, 1.59)*	0.91 (0.62, 1.33)
Memory <sup>a</sup>	2.33 (1.36, 4.00)*	1.27 (1.07, 1.50)*	0.77 (0.50, 1.16)
Falls prevention <sup>b</sup>	144.02 (16.44, 1,261.28)*	2.59 (1.02, 6.57)*	0.81 (0.31, 2.08)
Activities of daily living <sup>c</sup>	16.6 (4.70, 58.65)*	1.87 (0.90, 3.88)	0.76 (0.33, 1.78)
Mobility <sup>d</sup>	2.49 (1.39, 4.44)*	1.44 (1.23, 1.68)*	0.98 (0.67, 1.41)

\* Indicates that 95% CI do not cross 1. OR, odds ratio; CI, confidence interval.

Notes: Models were not fitted to service use data when there were 5 or fewer instances of use by either living arrangement group. The interaction is the difference in slope compared to the slope for 'Lives with others'. Models were adjusted for age, sex, and dementia diagnosis.

<sup>a</sup> Calendar clocks, medication dispenser reminders.

<sup>b</sup> Falls detectors, pendant alarms.

<sup>c</sup> Bath seats, bed rails, commodes, over bath showers, incontinence pads, walk-in showers, toilet seats, perching stools.

<sup>d</sup> Grab/stair rails, outdoor rails, sticks, frames.

increased at a slower rate but remained higher, and rates of transition to residential or nursing home care were higher.

The pattern we identified whereby differences evident at baseline tended to remain the same over 24 months as dementia progressed cannot be attributed to variation in withdrawal rates, as people living alone were no more likely than others to be lost to follow up. Rather, it suggests that many features of the experience of living alone with dementia are evident at an early stage and that timely intervention offers the best chance to ameliorate those aspects of the person's situation that can potentially be changed.<sup>18</sup> There are many reasons why people with dementia may be living alone and these are likely to influence how they feel about their situation. For example, some may have always lived alone and may live alone through choice, while others may be living alone unwillingly due to recent bereavement or

divorce. There are also many factors which can affect how well-equipped they are to manage, both extrinsic such as variations in family support and social networks, and intrinsic, such as functional ability or sociability. Although we cannot determine this from our data, the finding that people living alone with dementia have better cognitive and functional ability, and are more independent, probably arises not because living alone improves these abilities but because these abilities are necessary for continuing to manage alone. Poorer health may result from difficulty recognising and attending to other health problems or challenges in navigating health services, while low mood may result from loneliness and limited social contact and participation, and these issues could potentially be addressed with appropriate support.

People living alone have relative advantages in cognition and functional ability and continue to

## *Living Alone with Dementia Over Two Years*

manage at home by using in-home care services and assistive technology at an earlier stage. The importance of maintaining functional independence and mobility may account for higher rates of occupational therapy and physiotherapy involvement. These protective factors can prolong the ability to live independently at home,<sup>17</sup> especially if combined with adequate financial resources and availability of practical support from family or friends,<sup>31</sup> and suggest avenues for developing interventions to promote continuing in place. For example, although not directed at people living alone, the ETNA3 (Évaluation de 3 Thérapies Non médicamenteuses dans la maladie d'Alzheimer) trial showed that an individual, personalized cognitive rehabilitation intervention addressing the impact of cognitive impairment on functional ability, delivered weekly for three months and then six-weekly for 21 months, delayed admission to residential or nursing homes by six months relative to usual care.<sup>32</sup> This kind of approach could be particularly beneficial for people living alone.

People living alone are disadvantaged in relation to their physical, social, and psychological health and this pattern persists over time. Other studies report similar findings; for example, very old people with dementia living alone are more likely to experience loneliness and depression than those living with others.<sup>33</sup> These domains are all important predictors of quality of life, with psychological health dominating when all three are modelled together.<sup>34</sup> As expected, therefore, people living alone in our cohort are also disadvantaged in relation to capability to 'live well' with the condition, again a pattern that persists over time. In contrast, one study<sup>13</sup> reported better quality of life among people with dementia living alone; however, these were people in the very early stages who had regular contact with relatives, and the authors emphasize that in other circumstances living alone is likely to increase the risk of social isolation and depression. Therefore, alongside practical support to manage everyday activities, and active management of co-morbid health conditions, it is vital that professionals are aware of the risks linked to living alone, and able to attend to the psychological and social needs of people with dementia living alone.<sup>18</sup> The COVID-19 pandemic highlighted the importance of social contact and social support for everyone living with dementia, and especially for those living alone.<sup>35</sup> Pandemic restrictions led to withdrawal of

many community-based services and support options, some of which remain closed permanently. This could have a disproportionate impact on people with dementia who are living alone.

In considering the precariousness of living alone with dementia, the dearth of suitable services and programmes designed to meet the needs of this group and enable them to remain in their own homes has been identified as an important contributor, and the need to develop suitable services emphasized.<sup>25</sup> In practice, it is rare to find services that are specifically directed at people with dementia living alone, or that offer dedicated pathways or options for this group. Community-based provision often excludes people who do not have a caregiver to accompany them and provide personal care if needed. The extent to which people living alone with dementia are willing to engage with formal support services depends not just on perceived need but also on the way in which these services are viewed.<sup>31</sup> As a group that places high value on independence, they may be more ready to engage with services that attend to psychosocial rather than simply functional needs, that are based on self-determination and integrate elements of self-help, and that put the preferences of people with dementia first. Furthermore, services must take account of, and respond to, age- and gender-based variations in experiences, needs and preferences.

Our findings must be considered in the context of several limitations. Despite having a large cohort at baseline, as might be expected in a study of people with dementia, there was considerable attrition at subsequent timepoints. Using mixed effects models with maximum likelihood estimation, which have a missing at random assumption, helps to mitigate this issue to some extent as people with missing scores at any timepoint are still included in the study and calculation of the slope for each individual is based on all data available. However, there may be some selective attrition meaning that certain trajectories are missed. Factors we found to be associated with drop-out included cognitive or functional impairment, more or more severe neuropsychiatric symptoms, depression, and less social contact. The problem of missing data was particularly relevant in relation to data on service use. While level of missingness at baseline was similar for both groups except in the case of practice nurse visits, at follow-up the level of missingness remained stable for those living with

others but became more variable for those living alone. Relatively small numbers living alone at Time 3 precluded more detailed subgroup analyses, for example according to type of dementia. While our analyses controlled for age and sex, further exploration of how the needs of those living alone differ according to age and sex would be informative. For the modeling, given that data were only collected at three timepoints, a linear trend had to be assumed to calculate a slope, whereas in reality, patterns might be more complex. A minimum of four timepoints is needed to add terms to test for nonlinearity. To address this, we explored models that treated time as categorical, and conclusions remained the same.

The data are based on self- and informant reports and may have been subject to limitations in recall on the part of both people with dementia and caregivers. Participants were recruited mainly from National Health Service memory services which may have led to greater inclusion of people receiving a timely diagnosis, and our sample was 96% white British, reflecting the current small proportion of older people with dementia from other ethnic groups,<sup>36</sup> which precluded consideration of differences according to ethnicity. Recent work has identified the key challenges to recruiting ethnically diverse samples in the UK context and possible solutions, including community and patient education, changes in health service delivery, and researcher training to improve cultural competence.<sup>37–39</sup> To facilitate the latter, the UK National Institute for Health and Care Research<sup>40</sup> has developed guidance to enhance inclusion of under-served groups in future research. Despite these limitations, the IDEAL cohort is a large and well-characterized sample that reasonably reflects the characteristics of the population attending memory services in the UK,<sup>41</sup> with data collected and managed to rigorous standards, providing a basis for robust and reliable analyses.

The information presented here about service use reflects the UK context—a welfare state under considerable economic and political pressure—which provides worse support for older people than some other European countries,<sup>42</sup> but compares well with, for example, support for many older people in the US.<sup>43</sup> Organizational, cultural, and economic contexts substantially shape the experiences of older people living alone. In the US, attention has been drawn to the lack of long-term services and support for people living alone with dementia, the extent of unmet needs, and the kinds of

innovative practices that could make a difference.<sup>15,44–46</sup> There is a pressing need for policies, systems and practices that ensure appropriate services and equitable access for people living alone with dementia.

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## CONCLUSIONS

This study based on data from the British IDEAL cohort has provided novel longitudinal evidence about the experiences and needs of people with dementia who are living alone. People living alone tend to have better cognitive and functional ability than people living with others, but experience poorer physical, social, and psychological health, and reduced quality of life, satisfaction with life, and well-being. These differences persist over time. To facilitate continuing in place for people with dementia living alone, a dual focus on supporting functional ability and addressing psychosocial needs is essential and should be introduced at an early stage. Policies, systems, and practices are needed that ensure people living alone with dementia receive the services and support they require.

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## DISCLOSURES

*The authors declare no conflicts of interest.*

*'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 and Care 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.E. Matthews, R.G. Morris, S.M. Nelis, J.A. 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.E. Matthews, R.G. Morris, S.M. Nelis, C. Quinn, J. Rusted. This report is independent research supported by the National Institute for Health and Care Research Applied Research Collaboration South-West Peninsula. The views expressed in this publication are those of the authors 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.

### AUTHOR CONTRIBUTIONS

Authors LC, AM, MK, and FEM were involved in the original conception and design of the IDEAL programme and acquisition of funding. All authors were involved in the conception and design of the study reported here. CH analysed data on use of in-home and community care with input from MK. LDG conducted all other analyses with input from FEM. LC drafted the article. All authors contributed to interpretation of results and critical review of the manuscript.

### DATA STATEMENT

IDEAL data were deposited with the UK data archive in April 2020. Details of how to access the data can be found here: <https://reshare.ukdataservice.ac.uk/854293/>.

### ACKNOWLEDGMENTS

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 gratefully acknowledge the local principal investigators and researchers involved in participant recruitment and assessment within these networks. We are grateful to the IDEAL study participants for their participation in the study and to members of the ALWAYSs group and the Project Advisory Group for their support throughout the study. Linda Clare acknowledges support from the NIHR Applied Research Collaboration South-West Peninsula. For the purposes of open access, the authors have applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising.

### SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.jagp.2024.05.012>.

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