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ABSTRACT

Objectives: This study investigates factors associated with the person with dementia and the caregiver to identify those associated with an increased risk of transition to a care home.

Method: IDEAL data were collected at baseline and at 12- and 24-month follow-up for 1545 people with dementia and 1305 caregivers. Modified Poisson regressions with an offset for 'person years at risk' were used. Person with dementia factors explored were personal characteristics, cognition, health, self- and informant-rated functional ability, and neuropsychiatric symptoms. Caregiver factors explored were personal characteristics, stress, health, and quality of the dyadic relationship.

Results: A 5% people moved into care. Risk of moving into a care home was higher among people with dementia who were ≥80 years, among people with Parkinson's disease dementia or dementia with Lewy bodies, and among those without a spousal caregiver. Poorer cognition and more self-rated or informant-rated functional difficulties increased the risk of moving into care.

Conclusion: Factors related to increased dementia severity and greater disability are the primary influences that place people with dementia at greater risk of moving into a care home. Strategies that help to maintain everyday functional ability for people with dementia could help delay people with dementia moving into care.

Introduction

Globally there are 55 million people living with dementia (Alzheimer's Disease International, 2024), of which over 6.5 million live in the USA (Alzheimer's Association, 2023) and just under a million live in the UK (Alzheimer's Society, 2024). Both in the USA and the UK, at least two-thirds of people with dementia live in their own homes (Alzheimer's Association, 2024; Prince et al., 2014) while being supported by family members. In the USA it is estimated that 11 million caregivers provide unpaid care to people with dementia (Alzheimer's Association, 2024). There are around 700,000 caregivers of people with dementia in the UK (Lewis et al., 2014). In the UK, caregivers of people with mild-to-moderate dementia spend an average of 36 h per week providing care (Henderson et al., 2019). In 2022, in the USA caregivers of people with dementia provided an estimated 18 billion hours of unpaid assistance, equating to $339.5 billion (Alzheimer's Association, 2024). Most people with dementia and caregivers would prefer the person with dementia to continue living in their own homes for as long as possible (Lord et al., 2016), since remaining at home is important for maintaining social networks (Luppa et al., 2008), and quality of life (Martyr

et al., 2018). Depending on the country, health and social care funders either provide community based care as a lower-cost alternative to providing institutional care or encourage families to provide most of the care (Lee et al., 2020; Prince et al., 2014).

A number of factors may increase the risk of people with dementia moving into residential care. Providing care can increase caregiver burden and stress over time, and this may be one of the many reasons why people with dementia move into residential care (Afram et al., 2014; Cole et al., 2018; Ransmayr et al., 2018; Risco et al., 2015). As dementia involves a substantial and progressive increase in cognitive and functional difficulties (Martyr et al., 2024), as well as an increase in the number and severity of neuropsychiatric symptoms (e.g. hallucinations and delusions) (Aalten et al., 2005; Choi et al., 2022; Howard et al., 2015; Vik-Mo et al., 2018; Zahodne et al., 2015), the amount of support people with dementia require increases over time (Henderson et al., 2022). Consequently, as care needs increase dramatically with increasing functional difficulties and neuropsychiatric symptoms, the support provided by caregivers may not be sufficient (Gaugler et al., 2009; Okura et al., 2011; Risco et al., 2015), especially when caregivers are themselves in older age and may find it harder to provide sufficient care due to their own

concurrent health conditions (Afram et al., 2014). Characteristics of the person with dementia including being older, female, not having a partner, living alone, and/or being diagnosed with Parkinson-related dementia also increase the risk of moving into residential care (Clare et al., 2014, 2024; Dramé et al., 2012; Huyer et al., 2020; Knapp et al., 2016; Mjørud et al., 2020; Rongve et al., 2014). Poor dyadic relationship quality may also increase the likelihood of people with dementia moving into care (Afram et al., 2014; Knapp et al., 2016; Toot et al., 2017).

Large-scale studies investigating factors associated with people with dementia moving into care are needed to help identify strategies that may delay moving into residential care. This study uses two-year longitudinal data from a large cohort of people with mild-to-moderate dementia living in their own homes at the time of recruitment and focuses on those participants who were the first among the cohort to transition into residential or nursing care (hereafter collectively referred to as care homes) in order to examine which factors assessed at baseline predicted their admission into these settings.

Materials and methods

Study design and participants

This study used data from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort collected at baseline (2014–2016) and at 12- and 24-month follow-up (Clare et al., 2014). Study analyses were conducted using Version 7 of the datasets. In IDEAL, people with dementia of any age were recruited through 29 National Health Service sites in England, Scotland, and Wales. Participants could take part if at baseline they lived in the community, had a diagnosis of any type of dementia, and scored ≥15 on the Mini-Mental State Examination (Folstein et al., 1975), indicating mild-to-moderate dementia. Potential participants were excluded from the study if at baseline they had a co-morbid terminal illness, were unable to provide informed consent, and/or there was potential for home visits to pose risk to research staff. When a person with dementia joined IDEAL a family member or a friend undertaking the caregiving role, where available, was invited to participate. Further details about recruitment and data collection are reported in the published study protocol (Clare et al., 2014) and in the results section of this paper. IDEAL was approved by the Wales 5 Research Ethics Committee (reference: 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference: 2014-11684), and is registered with the UK Clinical Research Network (registration number: 16593).

Measures

Moved into a care home. A dichotomous variable was created from follow-up data that indicated whether people with dementia were living in a care home at the given timepoint (yes, no).

Cognition of the person with dementia was assessed with the Addenbrooke's Cognitive Examination-III (Hsieh et al., 2013). Higher scores (range: 0–100) indicate better cognition.

Functional ability of the person with dementia was assessed with a slightly-modified 11-item version of the Functional Activities Questionnaire (Pfeffer et al., 1982) containing an additional question concerning telephone use (Martyr et al., 2012, 2019). Higher scores (range: 0–33) indicate poorer functional ability. Both self- and informant-rated versions were used.

Neuropsychiatric symptoms were assessed with the informant-rated Neuropsychiatric Inventory Questionnaire (Kaufer et al., 2000; Morris & National Alzheimer's Coordinating Center). The measure asks about the presence (yes/no) of 12 symptoms. Higher scores indicate more symptoms present.

Health conditions experienced by both the person with dementia and the caregiver were assessed using the Charlson Comorbidity Index (Charlson et al., 2008). For the person with dementia, when there was a caregiver taking part, the Charlson Comorbidity Index was administered as a joint interview between the person with dementia and the caregiver at baseline and at subsequent timepoints it was informant-rated by the caregiver only. Where there was no caregiver taking part the Charlson Comorbidity Index was self-completed by the person with dementia. The total score is the number of concurrent health conditions excluding dementia (range: 0–22). For caregiver health conditions, including dementia, it was self-completed by the caregiver at all timepoints (range: 0–23) (for more details see Sabatini et al., 2024a, 2024b). At baseline 238 (15.4%) people with dementia completed the Charlson Comorbidity Index alone. At 12-month follow-up 178 (15.4%) people with dementia completed the Charlson Comorbidity Index alone. At 24-month follow-up 130 (15.3%) people with dementia completed the Charlson Comorbidity Index alone.

Caregiver stress was assessed with the 15-item Relative Stress Scale (Greene et al., 1982). Higher scores (range: 0–60) indicate more stress.

Relationship quality within the dyad was assessed with a modified version of the Positive Affect Index (Bengtson & Schrader, 1982) comprising five questions addressing communication quality, closeness, similarity of views on life, engagement in joint activities, and overall relationship quality (Clare et al., 2012). Higher scores (range: 5–30) indicate better current informant-rated relationship quality.

Personal characteristics of the person with dementia were age, age group (<65, 65–69, 70–74, 75–79, 80+), sex, dementia type (Alzheimer's disease, vascular dementia, mixed-Alzheimer's disease, and vascular dementia, frontotemporal dementia, Parkinson's disease dementia or dementia with Lewy bodies, and unspecified/other), and time since diagnosis (<1, 1–2, and 3+ years). Information about dementia diagnosis was taken from medical records.

Personal characteristics of the caregiver were age, age group (<65, 65–69, 70–74, 75–79, and 80+), sex, and caregiver status (spouse/partner and family/friends).

Analyses

Descriptive statistics for all study variables at baseline, and at 12-, and 24-month follow-up were reported for the overall study sample. Descriptive statistics were also reported separately for people with dementia who moved into care at 12- or 24-months and those who remained living at home at 12- or 24-months.

To identify factors related to moving into a care home a modified Poisson regression with an offset for 'person years at risk' was used. Separate analyses were conducted for person with dementia self-rated and caregiver self-rated and informant-rated predictors. Analyses for person with dementia self-rated predictors were conducted using the overall study sample of 1545 participants, whereas analyses for caregiver self-rated and informant-rated predictors were conducted using the reduced

sample (*n* = 1305) of people with dementia who had a caregiver enrolled in the study. Risk ratios (i.e. exponentiated coefficients) were reported in each case.

For person with dementia self-ratings three models were fitted. Model 1 was unadjusted using univariable regressions, in that we separately investigated whether age of the person with dementia, sex of the person with dementia, diagnosis, time since diagnosis, cognition, number of health conditions, and self-rated functional ability were related to moving into a care home. In model 2 each of these predictors of moving into a care home was separately investigated and adjusted for personal characteristics including age, sex, diagnosis, and time since diagnosis of the person with dementia. Model 3 included, in addition to personal characteristics (i.e. age, sex, diagnosis, and time since diagnosis of the person with dementia), all significant predictors from model 2 in a multivariable regression.

For caregiver self-rated and informant-rated analyses four models were fitted. Model 1 was unadjusted using univariable regressions in that we separately investigated whether age of the caregiver, sex of the caregiver, caregiver status, informant-rated functional ability, informant-rated neuropsychiatric symptoms, caregiver health conditions, caregiver-rated relationship quality, caregiver stress, and cognition in the person with dementia were related to moving into a care home. In model 2 each of these predictors of moving into a care home was separately investigated and adjusted for personal characteristics (age of the person with dementia, age of the caregiver, sex of caregiver, dementia diagnosis, time since diagnosis, and caregiver status). Model 3 comprised a multivariable regression that included in the same model all significant predictors from model 2. Model 4 comprised all the predictors included in model 3 and, in addition, cognition of the person with dementia. Cognition was included as an extra covariate in model 4 as the cognitive functioning of the person with dementia may affect levels of stress in caregivers and this may consequently affect how caregivers rate the number of neuropsychiatric symptoms present in the person with dementia. Caregiver self-rated and informant-rated analyses were based on the subsample of people with dementia who had a caregiver taking part in the study (*n* = 1305).

Missing values for predictive variables (see Table 1 for the proportion of missingness in the nine study variables that had missing data) were imputed using multiple imputation by chained equations; 25 imputed datasets were generated. Two separate imputations were conducted, one for the person with dementia self-rated predictors and one for caregiver self-rated and informant-rated predictors.

Analyses were conducted in Stata version 17 (StataCorp, 2021).

Results

Descriptive statistics

There were 1545 people with dementia at baseline, 1183 at 12-month follow-up, and 851 at 24-month follow-up; see Supplementary Figure 1 for reasons why people with dementia did not take part at later timepoints. Just over half were diagnosed with Alzheimer's disease and just over half were male. About 75% were married/partnered and living with their spouse/partner whereas 5% lived with others. At baseline they had on average two health conditions in addition to dementia. The median number of neuropsychiatric symptoms was three.

There were 1305 caregivers at baseline, 984 at 12-month follow-up, and 759 at 24-month follow-up. Caregivers were on average around seven years younger than people with dementia. The majority of caregivers were women and the spouse/partner of the person with dementia. On average caregivers reported low levels of stress and one to two health conditions. Generally, caregivers rated the quality of the relationship between themselves and the person with dementia positively. Characteristics of people with dementia and caregivers at follow-ups were similar to baseline; see Table 1.

Five percent of people with dementia (*n* = 77) moved into care over two years (*n* = 39 at 12-months, *n* = 38 at 24-months). Descriptive statistics for study variables at baseline for those who did and did not move into care at 12-month or 24-month follow-ups are reported in Supplementary Table 1.

Self-rated predictors of moving into care for people with dementia

Univariable analyses indicated that being younger than 80 years was related to decreased risk of moving into care compared to being 80 or over (Table 2). Compared to those with Alzheimer's disease, people with Parkinson's disease dementia or dementia with Lewy bodies had higher risk of moving into care. Those with poorer cognition and who reported more self-rated functional difficulties had greater risk of moving into care. Number of health conditions was not related to risk of moving into care. After adjusting for age, sex, diagnosis, and time since diagnosis (model 2) results remained similar, except that women were less at risk of moving into care than men. When including all significant predictors, in addition to the above covariates (model 3) the pattern of results remained similar, with cognition and functional ability independently associated with increased risk of moving into care.

Informant-rated and caregiver self-rated factors as predictors of moving into care

In univariable analyses (model 1, Table 3) people with dementia whose caregiver was aged 65 or over had lower risk of moving into care than those with a caregiver younger than 65. Compared to those with a spousal caregiver those with a different type of caregiver were more at risk of moving into care. More informant-rated functional difficulties and neuropsychiatric symptoms, greater caregiver stress, and more negative caregiver-rated dyadic relationship quality increased the risk of the person with dementia moving into care. The number of caregiver self-rated health conditions was unrelated to the person with dementia moving into care.

After adjusting for age of the person with dementia, age of the caregiver, sex of caregiver, diagnosis, time since diagnosis, and caregiver status as covariates (model 2), more informant-rated functional difficulties and neuropsychiatric symptoms, greater caregiver stress, and a more negative caregiver-rated dyadic relationship quality remained significant predictors of risk of people with dementia moving into care. In multivariable analyses (model 3), only greater informant-rated functional difficulties remained independently associated with greater risk of the person with dementia moving into care. The same pattern of results remained when including cognition of the person with dementia as an additional covariate (model 4).

Table 1. Descriptive statistics for study variables at baseline, 12-month, and 24-month follow-up.

Measures self-rated by the person with dementia	Baseline	12-month follow-up	24-month follow-up
N	1545	1183	851
Living in a care home	Not applicable	39	77
Age in years, M (SD; range)	76.40 (8.53; 43–98)	77.18 (8.39; 47–99)	77.52 (8.44; 48–97)
Age group, n (%)			
Aged <65	136 (8.8)	89 (7.5)	66 (7.8)
Aged 65–69	177 (11.4)	129 (10.9)	72 (8.5)
Aged 70–74	259 (16.8)	193 (16.3)	159 (18.7)
Aged 75–79	366 (23.7)	268 (22.7)	172 (20.2)
Aged ≥80	607 (39.3)	504 (42.6)	382 (44.8)
Sex, n (%)			
Women	676 (43.8)	514 (43.45)	375 (44.07)
Men	869 (56.2)	669 (56.55)	476 (55.93)
Diagnosis, n (%)			
Alzheimer's disease	857 (55.5)	661 (55.9)	488 (57.3)
Vascular dementia	170 (11.0)	116 (9.8)	82 (9.6)
Mixed (Alzheimer's and vascular	324 (21.0)	264 (22.3)	185 (21.7)
Frontotemporal dementia	55 (3.6)	40 (3.4)	32 (3.8)
Parkinson's disease dementia/ dementia with Lewy bodies	97 (6.3)	73 (6.2)	44 (5.1)
Unspecified/other dementia	42 (2.6)	29 (2.4)	20 (1.5)
Time since diagnosis, n (%)			
<1 year	810 (52.4)		
1–2 years	448 (29.0)		
3+ years	167 (10.8)		
Missing, n (%)	120 (7.8)		
Cognition, M (SD)	68.55 (13.52)	66.38 (15.90)	64.59 (17.92)
Missing, n (%)	46 (3.0)	100 (8.5)	110 (12.9)
Health conditions, M (SD)	1.80 (1.63)	2.24 (1.80)	2.49 (1.88)
Missing, n (%)	73 (4.7)	50 (4.3)	44 (5.2)
Functional ability, M (SD)	9.61 (7.69)	11.13 (8.39)	12.26 (9.01)
Missing, n (%)	61 (3.9)	181 (15.3)	113 (13.3)
Informant-rated measures	**Baseline**	**12-month follow-up**	**24-month follow-up**
N	**1305**	**984**	**759**
Functional ability, M (SD)	17.87 (8.59)	20.93 (8.57)	23.00 (8.68)
Missing, n (%)	122 (9.35)	43 (4.4)	25 (3.3)
Neuropsychiatric symptoms, M (SD)	3.57 (2.47)	3.77 (2.53)	4.16 (2.40)
Missing, n (%)	96 (7.4)	22 (2.24)	29 (3.8)
Measures self-rated by the caregiver	**Baseline**	**12-month follow-up**	**24-month follow-up**
N	**1305**	**984**	**759**
Age in years, M (SD; range)	69.01 (11.06; 26–92)	70.04 (10.73; 27–93)	70.61 (10.64; 28–94)
Age group, n (%)			
Aged <65	382 (29.3)	264 (26.8)	178 (23.5)
Aged 65–69	210 (16.1)	146 (14.8)	123 (16.2)
Aged 70–74	266 (20.4)	212 (21.5)	170 (22.4)
Aged 75–79	229 (17.6)	180 (18.3)	132 (17.4)
Aged ≥80	218 (16.6)	182 (18.6)	156 (20.5)
Sex, n (%)			
Women	902 (69.1)	681 (68.9)	521 (68.6)
Men	403 (30.9)	307 (31.1)	238 (31.4)
Caregiver status, n (%)			
Spouse/partner	1056 (80.9)	822 (83.5)	635 (83.7)
Family/friends	249 (19.1)	162 (16.5)	124 (16.3)
Caregivers living with the person with dementia, n (%)	1103 (84.5)	831 (84.5)	608 (80.11)
Stress, M (SD)	19.15 (9.82)	21.66 (10.06)	21.03 (9.82)
Missing, n (%)	113 (8.7)	68 (6.9)	56 (7.4)
Health conditions, M (SD)	1.35 (1.41)	1.70 (1.65)	1.88 (1.83)
Missing, n (%)	118 (9.04)	44 (4.5)	40 (5.3)
Caregiver-rated relationship quality, M (SD)	23.15 (4.71)	22.19 (4.86)	21.83 (4.81)
Missing, n (%)	62 (4.8)	55 (5.6)	39 (5.2)

Discussion

This study used two-year longitudinal data from a large cohort of people with mild-to-moderate dementia at baseline and their caregivers to examine factors potentially related to increased risk of admission into care among the first members of the cohort to make this transition. Factors examined included characteristics of the person with dementia and of the caregiver, cognitive and/or functional difficulties, neuropsychiatric symptoms, caregiver stress, and caregiver-rated dyadic relationship quality. We found that risk of moving into care was higher among people with Parkinson's disease dementia or dementia with Lewy bodies compared to people with Alzheimer's disease. There was an increased risk of moving into care when people with dementia were aged 80 or over. Having poorer cognition

and more self-rated and informant-rated functional difficulties also increased the likelihood of people with dementia moving into care. Overall, it was factors related to greater dementia severity, particularly in people aged 80 or over and those with Parkinson-related dementias, that increased the risk of people moving into care (Afram et al., 2014; Dramé et al., 2012; Knapp et al., 2016; Toot et al., 2017).

This study found that a decrease in self-rated functional abilities was related to moving into care. This suggests that people with dementia who rate their functional ability as being more impaired are aware of their increasing difficulty managing everyday tasks and their increasing difficulty with living independently (Martyr et al., 2019, 2024). Therefore, it is possible that self-awareness of functional difficulties in people with dementia may in some cases facilitate joint decisions about

Table 2. Associations of baseline personal characteristics and measures of cognition, self-rated health conditions, and self-rated functional ability with risk of transitioning into a care home over two years.

	Model 1	Model 2	Model 3
	Univariable regressions	Adjusted for personal characteristics[a]	Adjusted for personal characteristics[a] and includes all significant study measures from Model 2
	Risk ratio (95% CI)	Risk ratio (95% CI)	Risk ratio (95% CI)
Personal characteristics			
Age of the person with dementia			
Aged <65	0.26 (0.08; 0.84)*	0.24 (0.07; 0.80)*	0.23 (0.07; 0.79)*
Aged 65–69	0.37 (0.16; 0.86)**	0.32 (0.14; 0.75)**	0.35 (0.15; 0.82)*
Aged 70–74	0.31 (0.14; 0.68)**	0.27 (0.12; 0.59)***	0.28 (0.13; 0.63)**
Aged 75–79	0.54 (0.31; 0.95)*	0.50 (0.29; 0.88)*	0.50 (0.29; 0.89)*
Aged ≥80 (reference)			
Sex of the person with dementia			
Women	0.70 (0.45; 1.11)	0.61 (0.39; 0.96)*	0.63 (0.39; 1.01)
Men (reference)			
Diagnosis			
Alzheimer's disease (reference)			
Vascular dementia	1.36 (0.66; 2.83)	1.38 (0.67; 2.83)	1.38 (0.65; 2.89)
Mixed (Alzheimer's and vascular	1.28 (0.73; 2.25)	1.26 (0.71; 2.23)	1.12 (0.63; 1.97)
Frontotemporal dementia)	0.84 (0.20; 3.56)	1.51 (0.34; 6.69)	1.60 (0.36; 7.24)
Parkinson's disease dementia/dementia with Lewy bodies	2.66 (1.28; 5.23)**	3.71 (1.75; 7.85)**	3.20 (1.43; 7.77)**
Unspecified/other dementia	1.09 (0.27; 4.53)	1.13 (0.26; 4.85)	1.08 (0.24; 4.76)
Time since diagnosis			
<1 year (reference)			
1–2 years	1.30 (0.77; 2.18)	1.31 (0.77; 2.25)	1.14 (0.66; 1.95)
3+ years	1.75 (0.89; 3.42)	1.99 (0.99; 3.97)	1.43 (0.70; 2.89)
Study measures			
Cognition	0.96 (0.95; 0.97)**	0.96 (0.94; 0.97)***	0.97 (0.95; 0.99)**
Health conditions	0.90 (0.77; 1.04)	0.87 (0.73; 1.03)	
Self-rated functional ability	1.07 (1.05; 1.11)***	1.07 (1.04; 1.11)***	1.05 (1.01; 1.08)**

[a]Personal characteristics include age, sex, diagnosis and time since diagnosis of the person with dementia. Model 1 comprises univariable regressions. In Model 2 each of the study measures are modelled separately, with adjustment for personal characteristics. Model 3 included all significant study measures, with adjustment for personal characteristics.
*p < 0.05; **p < 0.01; ***p < 0.001.

Table 3. Associations of baseline personal characteristics, cognition in the person with dementia, informant-rated and self-rated caregiver measures with risk of the person with dementia moving into a care home over two years.

	Model 1	Model 2	Model 3	Model 4
	Univariable regressions	Adjusted for personal characteristics[a]	Adjusted for personal characteristics[a] and includes all significant study measures from Model 2	Adjusted for personal characteristics[a] and includes all significant study measures from Model 2 in addition to cognition
	Risk ratio (95% CI)	Risk ratio (95% CI)	Risk ratio (95% CI)	Risk ratio (95% CI)
Personal characteristics of caregiver				
Age of the caregiver				
Aged <65 (reference)				
Aged 65–69	0.37 (0.17; 0.80)*	0.70 (0.27; 1.82)	0.79 (0.27; 2.32)	0.77 (0.26; 2.23)
Aged 70–74	0.46 (0.24; 0.88)*	0.72 (0.32; 1.63)	0.93 (0.36; 2.36)	0.87 (0.34; 2.23)
Aged 75–79	0.56 (0.29; 1.07)	0.64 (0.25; 1.65)	0.94 (0.31; 2.83)	0.86 (0.28; 2.64)
Aged ≥80	0.44 (0.20; 0.96)*	0.38 (0.13; 1.12)	0.64 (0.20; 2.12)	0.58 (0.18; 1.95)
Sex of the caregiver				
Women (reference)				
Men	1.09 (0.67; 1.80)	0.70 (0.41; 1.20)	0.62 (0.35; 1.11)	0.65 (0.34; 1.19)
Caregiver status:				
Spouse/partner (reference)				
Family/friends	3.71 (2.34; 5.81)***	2.23 (1.06; 4.71)*	2.64 (1.08; 6.49)*	2.41 (0.96; 6.05)
Study measures: informant-rated				
Informant-rated functional ability	1.12 (1.08; 1.16)***	1.11 (1.07; 1.14)***	1.09 (1.05; 1.13)***	1.07 (1.03; 1.12)***
Informant-rated neuropsychiatric symptoms	1.21 (1.12; 1.31)***	1.17 (1.07; 1.28)***	1.04 (0.93; 1.15)	1.03 (0.93; 1.14)
Study measures: caregiver self-rated				
Caregiver health conditions	0.94 (0.79; 1.12)	1.02 (0.86; 1.20)		
Caregiver-rated relationship quality	0.93 (0.90; 0.98)**	0.94 (0.90; 0.99)*	0.98 (0.92; 1.04)	0.98 (0.92; 1.04)
Caregiver stress	1.06 (1.03; 1.08)***	1.05 (1.03; 1.07)***	1.02 (0.99; 1.05)	1.02 (0.99; 1.05)
Person with dementia measures				
Cognition	0.96 (0.95; 0.98)***	0.98 (0.98; 1.00)		0.98 (0.96; 1.00)

[a]Personal characteristics include both caregiver and person with dementia measures; age of the person with dementia, age of the caregiver, sex of caregiver, diagnosis, time since diagnosis, and caregiver status. Model 1 comprises univariable regressions. In Model 2 each of the study measures was separately investigated and adjusted for personal characteristics. Model 3 included all significant predictors from Model 2, with adjustment for personal characteristics. Model 4 included all significant predictors from Model 2 and additionally included cognition of the person with dementia, with adjustment for personal characteristics. Cognition was included as an extra covariate in Model 4 because people with dementia' cognitive functioning may affect caregivers' levels of stress and caregivers rate the cognitive difficulties and neuropsychiatric symptoms of the person with dementia. Study measures that were not associated with risk of moving into a care home in Model 2 were not included in Models 3 and 4.
The shaded areas indicate where measures were not included in the multiple regression analysis due to not being statistically significant.
These analyses are based on the subsample of participants who had a caregiver enrolled in the study (N = 1305).
*p < 0.05; **p < 0.01; ***p < 0.001.

moving into care, as well as other decisions related to advanced care planning (Song et al., 2024). This could help to reduce the distress often associated with a person with dementia moving into care (Gill et al., 2010). The finding that both decreased cognitive ability and increased self-rated functional difficulties increase the risk of moving into care is not surprising as cognitive difficulty has previously been identified as increasing the risk of moving into care (Toot et al., 2017) and cognition and functional abilities are intertwined in complex ways (Martyr et al., 2024). Our findings suggest the importance of early intervention to address functional difficulties in people with dementia as this could delay moving into care. Cognitive rehabilitation that addresses functional difficulties has been shown to delay admission to a care home by six months (Amieva et al., 2016). Adaptations to the home and use of assistive technologies that can mitigate cognitive and functional difficulties can also help people with dementia to remain living at home independently for longer (Gibson et al., 2015; Newton et al., 2023).

In this study people with Parkinson's disease dementia or dementia with Lewy bodies had a higher risk of early moving into care. This may be due to people with Parkinson-related dementias typically having a complex set of symptoms including hallucinations, sleep disorders, apathy, and low mood (Moylett et al., 2019). This is important as not all care homes have staff that are trained to deal with both dementia and Parkinson-related symptoms (Jackson et al., 2017). Consequently, finding appropriate care facilities that can manage the unique challenges of these conditions becomes crucial for maintaining quality of life for people with Parkinson's disease dementia or dementia with Lewy bodies, especially as people with these diagnoses have lower quality of life scores than people with the other types of dementia included in the present study (Clare et al., 2022; Wu et al., 2018).

In contrast to previous research we found that while univariable analysis suggested that higher carer stress, informant-rated neuropsychiatric symptoms, and poorer relationship quality were associated with people with dementia moving into care (Afram et al., 2014; Knapp et al., 2016; Risco et al., 2015; Toot et al., 2017) these were not associated in multivariable analysis. Indeed, in multivariable analysis only informant-rated functional difficulties and having a non-spousal primary caregiver remained associated with moving into care. This suggests that functional difficulties may be one of those factors influencing whether people with dementia move into care. This is possibly due to functional difficulties being present more frequently than neuropsychiatric symptoms: the overall mean scores for number of neuropsychiatric symptoms remained relatively low in the present study whereas functional difficulties increased over the two years (Martyr et al., 2024). Similarly, relationship quality also remained relatively stable over the study as did caregiver stress which increased by around 2.5 points per year (Quinn et al., 2024).

Our univariable regression findings suggest that people with dementia with a non-spousal caregiver and those whose caregiver was younger than 65 may be at elevated risk of moving into care. In the present study this group was primarily adult children and it may be that work commitments and their own child care responsibilities might make it harder for adult child caregivers to provide sufficient support for their parent with dementia. Many adult children do not live with their parent with dementia, which might also make it more challenging for them to provide sufficient care; however, small numbers prevented

this being investigated in the present study though previously we found that there was no difference between spouse/partner and family/friend caregivers and their levels of resilience regarding providing care (Martyr et al., 2023). Findings from others studies suggest that people with dementia living with a spouse have less risk of moving into care compared to those living with other caregiver types (Cepoiu-Martin et al., 2016). Future research focused on the specific challenges faced by adult child caregivers and the support needs of their parents with dementia might help to identify ways of delaying the need to move into care.

This study has several limitations. Despite the study involving 1545 people with dementia only 5% of participants moved into care within two years. As people with dementia were in the mild-to-moderate stages at baseline, a two-year follow-up period was too short to capture a higher proportion moving into care. There may also have been insufficient statistical power to detect other factors that contributed to moving into care due to the relatively small number of people who moved into care. Moreover, caregivers usually notified the research team about when people with dementia moved into care when they completed their questionnaires, but as people could withdraw from the study without giving a reason, some of those who did not participate at later timepoints may have moved into a care home without this information being available to the research team. Consequently, this limited recording may have led to an underestimation of the number of people with dementia who moved into care. As a consequence, this may have biased the investigated associations. In addition, as exploring transitions to a care home was not a primary aim of the cohort study from which the data were drawn, there was no detailed information about the circumstances surrounding the transition into care, whether this was planned or resulted from a crisis situation, and how this related to changes in cognitive and functional ability. Moreover, as data were not collected on death and there was incomplete information about time in hospital settings, it was not possible to consider the effects of these variables in the analyses. Another potential limitation is relying on self- and informant reports for the Charlson Comorbidity Index. As the study does not have access to an objective record of chronic conditions of people taking part in the study, it was not possible to check whether self-reports or informant reports accord with conditions recorded in medical records. Indeed, whereas there is some evidence suggesting that people with dementia are accurate in reporting conditions such as depression (Snow et al., 2005), there is also evidence for the general population of older adults indicating a degree of discrepancy between health conditions from self-reports vs objective sources (Hansen et al., 2014). Finally, as study analyses were based on a sample of people with mild-to-moderate dementia at baseline, study results cannot be generalized to people with more advanced dementia. This study, however, has several strengths including the exploration of a range of both self-rated and informant-rated variables including caregiver health, that have not hitherto been explored in relation to people with dementia moving into a care home.

Conclusions and implications

Overall, among all the possible risk factors for people with dementia moving into care, increasing functional difficulties appeared to be the most crucial factor. Indeed, this study found

for the first time that, in addition to informant-rated functional ability, self-ratings of functional difficulty by people with dementia predicts their risk of moving into a care home. When a person with dementia is aware of increasing functional difficulties this may potentially facilitate discussions around moving into care. The findings also suggest that strategies that promote functional ability in people with dementia may increase their likelihood of living at home for longer. Strategies aimed at maintaining cognitive and everyday functioning, such as cognitive rehabilitation and the implementation of assistive technologies, may help support people with dementia to remain living at home for longer, if they so wish.

Authors' contributions

IDEAL investigators AM, FEM, JMT, CQ, and LC contributed to all aspects of the IDEAL project including design, supporting the conduct of field work, and data acquisition. SS drafted the manuscript. AM co-edited the draft of the manuscript. SS and LDG analyzed the data under the supervision of FEM. AM, LDG, and AH curated the IDEAL datasets. All authors provided comments on the draft of the manuscript and approved the version to be published.

Disclosure statement

The authors declare that they have no competing interests.

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