



Are profiles of social, cultural, and economic capital related to living well with dementia? Longitudinal findings from the IDEAL programme

Serena Sabatini^a, Anthony Martyr^a, Laura D. Gamble^b, Ian R. Jones^c, Rachel Collins^a, Fiona E. Matthews^b, Martin Knapp^d, Jeanette M. Thom^e, Catherine Henderson^f, Christina Victor^g, Claire Pentecost^a, Linda Clare^{a,h,*}, on behalf of the IDEAL programme team

^a College of Medicine and Health, University of Exeter, Exeter, UK

^b Population Health Sciences Institute, Newcastle University, Newcastle, UK

^c Wales Institute for Social and Economic Research and Data (WISERD), Cardiff University, Cardiff, UK

^d The Research Institute for the Care of Older People & Department for Health, Bath, UK

^e Faculty of Medicine and Health, University of New South Wales (UNSW), Sydney, Australia

^f Care Policy and Evaluation Centre, London School of Economics and Political Science (LSE), London, UK

^g College of Health, Medicine and Life Sciences, Department of Health Sciences, Brunel University London, London, UK

^h NIHR Applied Research Collaboration South-West Peninsula, UK

ARTICLE INFO

Keywords:

Capital
Assets
And resources
Quality of life
Satisfaction with life
Well-being
Longitudinal
Dementia
Latent profile analysis

ABSTRACT

Rationale: Research exploring social, cultural, and economic capital among people with dementia is scarce.

Objective: We describe levels of social, cultural, and economic capital in people with dementia at baseline and levels of social and cultural capital 12 and 24 months later. We identify groups of people with dementia having different combinations of capital and explore whether the identified groups differ in personal characteristics at baseline and in quality of life (QoL), satisfaction with life (SwL), and well-being over time.

Method: Baseline, 12-months, and 24-months data from 1537 people with dementia (age, mean = 76.4 years; SD = 8.5; Alzheimer's Disease = 55.4%) enrolled in the IDEAL cohort were analyzed. Social (interactions with friends, civic participation, social participation, neighborhood trust, social network), cultural (education, cultural participation) and economic (annual income) capital, QoL, SwL, well-being, and personal characteristics were assessed.

Results: Compared to people their age, people with dementia reported slightly lower frequency of interactions with friends, social networks and social support, civic and cultural participation, education, and annual income. However, social engagement, cultural participation, and annual income are low among British older adults. Latent profile analysis identified four groups that, based on their levels of social, cultural, and economic capital were named *socially and economically privileged* (18.0% of participants); *financially secure* (21.0% of participants); *low capital* (36.9% of participants); and *very low capital* (24.1% of participants). Latent growth curve models showed that over time QoL, SwL, and well-being remained largely stable for all groups. Compared to the *low capital* group, the *socially and economically privileged* and *financially secure* groups had higher QoL and well-being whereas the group with *very low capital* had poorer QoL, SwL, and well-being.

Conclusions: New policies and efforts from the government, philanthropic foundations, the voluntary and primary care sectors are needed to address social, cultural, and economic disadvantage among people with dementia.

1. Background

In the UK, 'living well' with dementia is a key policy objective (Department of Health, 2009) and aspiration for people with dementia

and those who support them (Quinn et al., 2021). 'Living well' has been described as the best attainable health state that encompasses elements of physical, mental, and social well-being (Institute of Medicine, 2012). 'Living well' may be more readily attainable for those with greater levels

* Corresponding author. Centre for Research in Ageing and Cognitive Health, College of Medicine and Health, South Cloisters, St Luke's Campus, University of Exeter, Exeter, EX1 2LU, UK

E-mail addresses: s.sabatini2@exeter.ac.uk (S. Sabatini), L.Clare@exeter.ac.uk (L. Clare).

<https://doi.org/10.1016/j.socscimed.2022.115603>

Received 13 February 2022; Received in revised form 19 November 2022; Accepted 6 December 2022

Available online 10 December 2022

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of the capitals, assets, and resources. The experience of 'living well' can be indexed for example by higher scores on measures of quality of life (QoL), satisfaction with life (SwL), and well-being (Clare et al., 2019).

This study focuses on QoL, SwL, and well-being in relation to three components of resources: social, cultural, and economic capital (Bourdieu, 1986). Social capital covers the resources individuals have due to their network of relationships. Elements of social capital include mutual relations with family members or other groups, political participation, and institutional trust. Social capital is a broad and disputed term as it has been conceptualized and operationalized in different ways that include measures of levels of trust, group norms, social networks, community support, civic engagement, and social cohesion. A tripartite approach breaks social capital into bonding (networks of individuals who connect with others in the same social group), bridging (enabling associational ties between members of different social groups) and linking (the capacity to connect with centers of power including leaders and institutions) (Folland and Nauenberg, 2018). Cultural capital includes behaviors and dispositions learned over the lifespan (e.g., norms) and educational achievement. Economic capital accounts for income, property, and other financial assets.

Different forms of capital are interrelated; Bourdieu (1986) emphasized the importance of the relative capacity to convert one form of capital into another; for example, economically privileged individuals have the financial resources to fund the development of cultural capital and this advantaged position can be utilized to create social capital. However, greater social capital may also compensate for poorer economic capital (Veenstra and Abel, 2019). Moreover, it is possible that while social capital, in some contexts, can be viewed in positive terms and related to benefits from stronger social ties and relations, there are also, in other contexts, potentially negative effects that arise from strong forms of bonding social capital leading to domination and oppression or exclusion of individuals and groups. Researchers have also separated structural social capital, which is related to activities such as volunteering, from cognitive social capital, which is related to feelings of trust and belonging, with a view to identifying the links between social capital and health outcomes (Rodgers et al., 2019). Reviews of the health literature have identified potential harmful effects of social capital and grouped them in relation to exclusion of outsiders, imposition of excess demands on group members, possible restrictions on individual autonomy, the downward levelling of norms of expectations, forms of social contagion that lead to harmful behaviors, and cross-level interactions whereby positive effects for some have negative effects for others (Vilalonga-Olives and Kawachi, 2017).

A systematic review of factors that are associated with QoL, SwL, and well-being in people with dementia found correlations with numerous factors (Martyr et al., 2018), but there was insufficient evidence concerning associations with indicators of social, cultural, and economic capital, suggesting this relationship is not well-understood. Generally, cognitively healthy older people with greater social, cultural, and economic capital accumulate advantages over time (Dannefer, 2003; Savage et al., 2005), have better mental and physical health and well-being, and adapt better to age-related and environmental changes (Dahlberg and McKee, 2018; Hikichi et al., 2020; Jones and Williams, 2017). This may also apply to people with dementia.

Cross-sectional evidence links greater social (e.g., less social isolation), cultural (e.g., more cultural participation), and economic (e.g., living in more privileged areas) capital to SwL and well-being in people with dementia (Clare et al., 2019; Wu et al., 2018a, 2020). The few longitudinal studies available suggest that in people with dementia, better scores in some indicators of social (e.g., relationship with carers) and cultural (e.g., education) capital predict better QoL, whereas other indicators of social capital (e.g., contact with friends) do not (Hongisto et al., 2018; O'Shea et al., 2020). It may be that as the experience of dementia varies over time and place, individuals may need different levels of social and cultural capital as their dementia develops. For instance, in the late stages of the illness some individuals may privilege

social support whereas others may transition to focus more on things that transcend the social realm.

Overall, research exploring social, cultural, and economic capital among people with dementia is limited in several ways. First, relatively few indicators of capital, such as social networks, have been studied in relation to capability to 'live well', and other indicators, such as civic (political) participation, are largely unexplored. Second, although different profiles of individuals having different combinations of social, cultural, and economic capital have been reported in the general older population (Paccoud et al., 2020), a similar approach has, to our knowledge, never been undertaken in people with dementia. Third, most studies are cross-sectional and were therefore unable to link social, cultural, and economic capital to levels of QoL, SwL, and well-being over time in people with dementia.

To address the evidence gap in levels of social, cultural, and economic capital in people with dementia, as well as to shape policy and practice, studies investigating a range of indicators of social, cultural, and economic capital and how these relate to outcomes capturing capability to 'live well' with dementia are needed. The current study was based on Bourdieu's model (1986) of social, cultural, and economic capital and aimed to explore in a large cohort of people with dementia 1) the levels of social, cultural, and economic capital at baseline and levels of social and cultural capital at 12-month and 24-month follow-ups; 2) profiles of people with dementia having different combinations of social, cultural, and economic capital, and 3) whether the identified profiles are associated with differences in personal characteristics at baseline and QoL, SwL, and well-being over the three waves.

2. Methods

This study used longitudinal data collected in the first three waves (baseline: 2014–16; 12-month follow-up: 2015–17; and 24-month follow-up: 2016–18) of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) programme (Clare et al., 2014). Version 5 of the datasets were used for analyses. In IDEAL, people with dementia were recruited through a network of 29 National Health Service (NHS) sites in England, Scotland, and Wales, they were assessed at baseline and followed up 12 and 24 months later. Participants of any age could take part in the study if at baseline they lived in the community, had a diagnosis of any type of dementia, and a Mini-Mental State Examination (Folstein et al., 1975) score ≥ 15 , which corresponds to mild-to-moderate dementia. Exclusion criteria were at baseline inability to provide informed consent, living in residential care, having a co-morbid terminal illness, and at any timepoint any known potential for home visits to pose risk to research staff. Participants who moved into residential care during the study period remained in the study if willing. Participants with non-terminal chronic health conditions, such as heart conditions or chronic obstructive pulmonary disease, were eligible to enroll in the study; for further details of the co-morbidity profile of the sample see (Nelis et al., 2019).

Information about recruitment and assessments in IDEAL is reported in the study protocol (Clare et al., 2014). The IDEAL study 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). The IDEAL study is registered with the UK Clinical Research Network (registration number: 16593).

2.1. Procedure and measures

Based on Bourdieu's model (1986) of social, cultural, and economic capital, the following measures were selected for analyses in this study. Except where noted, all measures were self-rated by people with dementia. Indicators of social capital comprise interactions with friends, civic participation, social participation, neighborhood trust, and social network. Interactions with friends, civic participation, social participation, and neighborhood trust were assessed with questions taken from

the core question set of the Office for National Statistics Social Capital Scale (2008). As an indicator of social isolation the 6-item Lubben Social Network Scale (Lubben et al., 2006) was used. Indicators of cultural capital were educational attainment and 13 items from the Cultural Capital and Social Exclusion Survey (Thomson, 2004). Economic capital was assessed with a single-item question concerning annual income adapted from the Health Survey for England (Boniface et al., 2012). Income was judged as high or low based on the median income (before housing cost) for UK people aged ≥ 65 in 2014 and 2015; this was £24,492 for a couple and £12,740 for a single person (UK Government, 2016).

Measures of QoL, SwL, and well-being used in the analyses were the Quality of Life in Alzheimer's Disease scale (Logsdon et al., 2000); the Satisfaction with Life Scale (Diener et al., 1985); and the World Health Organization-Five Well-being Index (Bech, 2004), respectively.

Baseline personal characteristics used in the analyses were age, sex, marital status, dementia subtype, time since diagnosis, living situation, urban/rural location (Wu et al., 2018b), and social class (Office for National Statistics, 2010). The Addenbrooke's Cognitive Examination-III (ACE-III; Hsieh et al., 2013) was used to measure cognition.

A more detailed description of all measures used in the study at each wave can be found in [Supplementary Text 1](#).

2.2. Analyses

Descriptive statistics for study variables at all timepoints were reported.

To explore whether the population could be divided into groups of individuals characterized by different levels of social, cultural, and economic capital, latent profile analyses were conducted (Williams and Kibowski, 2016). The latent profile models were fitted based on manifest variables representing responses to each indicator of social, cultural, and economic capital assessed at baseline. To identify the model with the optimal number of groups, a two-group model was fitted and the number of groups systematically increased by one until adding more groups did not further improve the model fit. Criteria used to assess model fit were the Bayesian information criterion, sample-size adjusted Bayesian information criterion, Vuong-Lo-Mendell-Rubin, and Lo-Mendell-Rubin adjusted likelihood ratio tests (Nylund et al., 2007). Entropy was also reported. Having identified the best fitting model, the percentage of the population in each group was reported, alongside the mean or frequencies for each indicator of social, cultural, and economic capital. Groups were named based on comparison of their levels of social, cultural, and economic capital with the overall levels observed in this study sample.

Multinomial logistic regression models were conducted to look for associations between personal characteristics and the identified groups. Odds ratios and confidence intervals were reported. Misclassification error was taken into account using the BCH Method in Mplus (Asparouhov and Muthén, 2014).

Latent growth curve models were conducted to investigate whether group membership explained variability in baseline levels of QoL, SwL, and well-being, and in the trajectory of change in QoL, SwL, and well-being over the three waves. Each latent growth curve model estimated a mean intercept and slope, with random effects to account for variation across individuals. Models were adjusted for age, sex, dementia subtype, and time since diagnosis. Group membership was weighted by the posterior probabilities to account for uncertainty. Latent growth curve models for QoL, SwL, and well-being had good model fit indices (Comparative Fit Index/Tucker-Lewis Index >0.95 , Root Mean Square Error of Approximation <0.05). Latent growth curve models adjusted for age, sex, dementia subtype, and time since diagnosis were also conducted to investigate whether each indicator of social, cultural, and economic capital explained variability in baseline levels of QoL, SwL, and well-being, and in the trajectory of change over the three waves.

Analyses were conducted using Stata and Mplus (Muthén & Muthén, 1998–2017; StataCorp, 2017). For latent profile analyses and latent growth curve models, missing data were handled using Full Information Maximum Likelihood. For predictors, missing data were imputed using multiple imputation by chained equations, generating 25 imputed datasets.

3. Results

3.1. Participant characteristics

The sample comprised 1537 people with dementia at baseline, 1183 at 12-months, and 851 at 24-months. At baseline, just over half of the sample had Alzheimer's disease and just over half were male. Most were married and living with a spouse or partner. [Table 1](#) summarizes the characteristics of the sample at baseline and follow-ups.

3.2. Levels of social, cultural, and economic capital

Regarding social capital, most participants were not socially isolated, and most trusted their neighbors; however, on average participants reported interacting with friends in person or by phone less than once a month. At baseline, 13.9% of participants engaged in civic activities and 28.9% participated in social activities ([Table 1](#); see [Supplementary Tables 1 and 2](#) for frequency of engagement in civic and social activities, respectively). Among civic activities, those most frequently endorsed were attending a public meeting or neighborhood forum to discuss local issues, contacting an organization to deal with a problem, or contacting a member of the local council or national parliament. Among social activities, those most frequently endorsed were helping to run volunteering activities/events, visiting people, organizing activities/events, or raising money.

Regarding cultural capital, the sample comprised mostly people with a school leaving certificate at age 18 or no qualifications. People with dementia generally participated in cultural activities once a year or less. Among the cultural activities investigated, participants reported most often going to pubs and eating out, whereas very few reported ever going to the opera, concerts, musicals, rock concerts, bingo, or night clubs (see [Supplementary Table 3](#)). Regarding economic capital, annual household income was equal to or above the UK average for the equivalent age range for 30% of participants. Descriptive statistics show that, compared to baseline, there was a small decrease in levels of social and cultural capital at 12-months and 24-months; hence, levels of social and cultural capital remained relatively stable over 24 months. However, average level of capital was already low at baseline assessment.

3.3. Pattern of social, cultural, and economic capital profiles

Latent profile analyses were conducted to explore the number and characteristics of groups into which the sample can be divided based on levels of social, cultural, and economic capital. A four-group model was selected based on model fit and interpretability. This model showed better fit than either three-group or five-group models (see [Supplementary Table 4](#) for goodness of fit indices and entropy). In the selected model, Group 1 included 277 participants (18% of the sample); Group 2 included 323 participants (21% of the sample); Group 3 included 567 participants (36.9% of the sample); and Group 4 included 371 participants (24.1% of the sample). [Supplementary Table 5](#) shows the means/percentages for each of the indicators of social, cultural, and economic capital for each group.

Among participants in Group 1, 40.0% and 76.5% reported some civic and social participation, respectively; 86.7% exhibited neighborhood trust; on average participants interacted with friends once or twice a month (mean score = 8.1), and 5.2% felt socially isolated. Participants in Group 1 were well-educated; mean score for cultural capital (20.0) indicated that participants in this group engaged with cultural activities

Table 1
Descriptive statistics for study variables at baseline, 12-months, and 24-months.

| | Baseline (N = 1537) | 12-month follow-up (N = 1183) | 24-month follow-up (N = 851) |
|--|---------------------|-------------------------------|------------------------------|
| | Statistics | | |
| Demographic variables | | | |
| Age in years, M(SD; range) | 76.4 (8.5; 43–98) | 77.2 (8.4; 47–99) | 77.5 (8.4; 48–97) |
| Age group, n(%) | | | |
| <65 years | 134 (8.7) | 89 (7.5) | 67 (7.9) |
| 65–69 | 177 (11.5) | 129 (10.9) | 71 (8.3) |
| 70–74 | 257 (16.7) | 193 (16.3) | 160 (18.8) |
| 75–79 | 367 (23.9) | 269 (22.7) | 171 (20.1) |
| ≥80 | 602 (39.2) | 503 (42.5) | 382 (44.9) |
| Sex, n(%) | | | |
| Women | 672 (43.7) | 514 (43.4) | 375 (44.1) |
| Men | 865 (56.3) | 669 (56.6) | 476 (55.9) |
| Marital status, n(%) | | | |
| Single | 27 (1.8) | 16 (1.4) | 13 (1.5) |
| Married/Civil partnership/Cohabiting | 1152 (75.1) | 884 (75.6) | 644 (75.7) |
| Divorced/Separated | 92 (6.0) | 77 (6.2) | 57 (6.7) |
| Widowed | 266 (17.3) | 199 (16.7) | 137 (16.1) |
| Living situation, n(%) | | | |
| Living alone | 288 (18.7) | 200 (16.9) | 134 (15.8) |
| Live with spouse/partner | 1161 (75.5) | 891 (75.3) | 642 (75.4) |
| Live with other | 86 (5.9) | 67 (5.7) | 45 (5.3) |
| Live in care | 0 (0.0) | 24 (2.0) | 29 (3.4) |
| Missing | 2 (0.1) | 1 (0.1) | 1 (0.1) |
| Urban/rural classification, n(%) | | | |
| Rural | 504 (32.8) | 401 (33.9) | 289 (34.0) |
| Urban | 1033 (67.2) | 774 (65.4) | 557 (65.5) |
| Missing | 0 (0.0) | 8 (0.7) | 5 (0.6) |
| Dementia subtype, n(%) | | | |
| Alzheimer's disease | 851 (55.4) | 661 (55.9) | 488 (57.3) |
| Vascular dementia | 170 (11.1) | 116 (9.8) | 82 (9.6) |
| Mixed (Alzheimer's and vascular) | 324 (21.1) | 264 (22.3) | 185 (21.7) |
| Frontotemporal dementia | 54 (3.5) | 40 (3.4) | 32 (3.8) |
| Parkinson's disease dementia | 44 (2.9) | 34 (2.9) | 17 (2.0) |
| Dementia with Lewy bodies | 53 (3.5) | 39 (3.3) | 27 (3.2) |
| Unspecified/other dementia | 41 (2.7) | 29 (2.5) | 20 (2.4) |
| Time since diagnosis, n(%) | | | |
| <1 year | 809 (52.6) | 624 (52.7) | 464 (54.5) |
| 1–2 years | 449 (29.2) | 351 (29.7) | 252 (29.6) |
| 3–5 years | 146 (9.5) | 110 (9.3) | 74 (8.7) |
| ≥6 years | 21 (1.4) | 17 (1.4) | 14 (1.6) |
| Missing | 112 (7.3) | 81 (6.8) | 47 (5.5) |
| Social class, n(%) | | | |
| Higher | 651 (42.4) | 518 (43.8) | 377 (44.3) |
| Intermediate | 603 (39.2) | 448 (37.9) | 317 (37.2) |
| Lower | 205 (13.4) | 150 (12.7) | 106 (12.5) |
| Not applicable | 59 (3.8) | 43 (3.6) | 34 (4.0) |
| Missing | 19 (1.2) | 24 (2.0) | 17 (2.0) |
| Addenbrooke's Cognitive Examination-III, M(SD) | 69.2 (13.1) | 66.4 (15.9) | 64.6 (17.9) |
| Missing, n(%) | 104 (6.8) | 107 (9.0) | 111 (13.0) |
| Social capital | | | |
| Interactions with friends, M (SD; range) | 5.0 (2.8; 0–15) | 4.9 (3.0; 0–16) | 4.8 (3.0; 0–14) |
| Missing | 98 (6.4) | 124 (10.5) | 128 (15.0) |
| Civic participation, n(%) | | | |
| No participation | 1275 (83.0) | 977 (82.6) | 673 (79.1) |
| Participation | 119 (7.7) | 82 (6.9) | 57 (6.7) |
| High participation | 96 (6.2) | 43 (3.6) | 30 (3.5) |
| Missing | 47 (3.1) | 181 (15.3) | 91 (10.7) |
| Social participation, n(%) | | | |
| No participation | 1033 (67.2) | 827 (69.9) | 567 (66.6) |
| Participation | 199 (12.9) | 127 (10.7) | 88 (10.3) |
| High participation | 246 (16.0) | 152 (12.8) | 101 (11.9) |
| Missing | 59 (3.8) | 77 (6.5) | 95 (11.2) |
| Neighborhood trust, n(%) | | | |
| Likely | 1126 (73.3) | 881 (74.5) | 589 (69.2) |

Table 1 (continued)

| | Baseline (N = 1537) | 12-month follow-up (N = 1183) | 24-month follow-up (N = 851) |
|---------------------------------------|---------------------|-------------------------------|------------------------------|
| | Statistics | | |
| Not likely/do not know | 362 (23.6) | 232 (19.6) | 186 (21.9) |
| Missing | 49 (3.2) | 70 (5.9) | 76 (8.9) |
| Social network, n(%) | | | |
| Non-isolated | 1022 (66.5) | 580 (49.0) | 386 (45.4) |
| Isolated | 425 (27.7) | 310 (26.2) | 227 (26.7) |
| Missing | 90 (5.9) | 293 (24.8) | 238 (28.0) |
| Cultural capital | | | |
| Education, n(%) | | | |
| No qualification | 429 (27.9) | 318 (27.1) | 232 (27.3) |
| School leaving certificate at age 16 | 271 (17.6) | 197 (16.8) | 136 (16.0) |
| School leaving certificate at age 18 | 518 (33.7) | 410 (35.0) | 295 (34.7) |
| University | 311 (20.2) | 248 (21.1) | 182 (21.4) |
| Missing | 8 (0.5) | 10 (0.8) | 6 (0.7) |
| Cultural participation, M (SD; range) | 22.8 (5.6; 13–42) | 22.2 (5.5; 13–39) | 21.6 (5.4; 13–42) |
| Missing, n(%) | 86 (5.6) | 107 (9.0) | 113 (13.3) |
| Economic capital | | | |
| Total household income, n(%) | | | |
| < £15600 | 277 (18.0) | 209 (17.7) | 141 (16.6) |
| £15600 to 23399 | 279 (18.2) | 224 (18.9) | 161 (18.9) |
| £23400 to 36399 | 250 (16.3) | 198 (16.7) | 147 (17.3) |
| ≥ £36400 | 210 (13.7) | 189 (16.0) | 147 (17.3) |
| Missing | 521 (33.9) | 363 (30.7) | 255 (30.0) |
| Living well | | | |
| Quality of life, M(SD; range) | 36.8 (5.9; 17–52) | 37.0 (5.9; 18–52) | 36.9 (5.6; 19–52) |
| Missing, n(%) | 152 (9.9) | 142 (12.0) | 136 (16.0) |
| Satisfaction with life, M (SD; range) | 26.1 (6.1; 6–35) | 26.3 (6.1; 5–35) | 26.3 (6.3; 5–35) |
| Missing, n(%) | 51 (3.3) | 76 (6.4) | 90 (10.6) |
| Well-being, M(SD; range) | 61.0 (20.5; 0–100) | 60.9 (20.6; 0–100) | 61.3 (21.0; 0–100) |
| Missing, n(%) | 34 (2.2) | 56 (4.7) | 90 (10.6) |

once a year or less. Just under 60% of participants in Group 1 reported an annual income in line with or above the UK national average for 2014.

Among participants in Group 2, 9.5% and 27.0% reported some civic and social participation, respectively; 84.2% had neighborhood trust; on average participants interacted with friends less often than once a month (mean score = 4.8); and 29.0% felt socially isolated. Participants were well-educated. Although cultural participation was the highest across the groups (mean score on the Cultural Capital Survey = 25.3), participants in this group engaged with cultural activities once a year or less. Participants in Group 2 had the highest levels of economic capital; 89.0% had an annual household income above the 2014 UK average and no-one reported an annual income far below the 2014 UK average.

Among participants in Group 3, most reported not participating in civic (89.7%) or social (72.8%) activities, 78.1% trusted their neighbors, on average participants interacted with friends less often than once a month (mean score = 5.4); and 15.7% felt socially isolated. A third of participants in Group 3 had no educational qualifications (34.8%) and participants took part in cultural activities only once per year or less (mean score; 21.4). Most participants in Group 3 (74.6%) had an annual income below the 2014 UK average.

In Group 4, participants reported no civic (94.2%) or social (97.4%) participation; 60.9% trusted their neighbors; saw friends infrequently (mean score = 1.9); and most (68.7%) felt socially isolated. Just over half had no educational qualifications and, relative to the rest of the sample, participants in Group 4 had the lowest levels of cultural participation (mean score; 18.4) and the lowest economic capital. Indeed, 76.2% of participants had an annual income below the 2014 UK average.

The total sample reported generally low cultural participation and

there was a small mean difference of 6.9 points between the four groups. Relative to overall levels of social, cultural, and economic capital in this sample, Group 1 included the highest proportion of people with dementia participating in social activities and two-thirds of participants in this group reported average or above average economic capital; this group was therefore named *socially and economically privileged*. Group 2 included participants with the highest economic capital but with low social and cultural capital and therefore this group was named *financially secure*. Group 3 included participants with low social, cultural, and economic capital and therefore this group was named *low capital*. Group 4 included participants with the lowest levels of social, cultural, and economic capital and hence this group was named *very low capital*.

3.4. Differences in characteristics among the identified groups

The distribution of personal and clinical characteristics and differences between groups were investigated using multinomial regression (see Table 2 and Supplementary Table 6); the *low capital* group was the largest group and was used as the reference group.

Compared to the *low capital* group, and people with Alzheimer's disease at baseline, those with frontotemporal dementia or Parkinson's disease dementia were more likely to be in the *socially and economically privileged* group whereas those with mixed Alzheimer's disease and vascular dementia were less likely to be in the *socially and economically privileged* group. Those in the *socially and economically privileged* group were less likely to be women, and more likely to be younger, married, and living with their spouse/partner. People with dementia in the *socially and economically privileged* group were more likely to be of higher social class and to have better cognition.

Compared to the *low capital* group, and people with Alzheimer's disease at baseline, those with frontotemporal dementia or dementia with Lewy bodies were more likely to be in the *financially secure* group whereas those with mixed Alzheimer's disease and vascular dementia were less likely to be in the *financially secure* group. Participants in the *financially secure* group were more likely to have received their dementia diagnosis within the 1–2 years prior to the baseline assessment. Those in the *financially secure* group were less likely to be women, and more likely to be married and to live with a spouse/partner. Participants in the *financially secure* group were more likely to be of higher social class.

Compared to the *low capital* group, and people with Alzheimer's disease at baseline, those with vascular dementia were more likely to be in the *very low capital* group. Those in the *very low capital* group were much less likely to live with a spouse/partner, less likely to have higher social class, and more likely to have impaired cognition.

3.5. Associations for each indicator of social, cultural, and economic capital with QoL, SwL, and well-being at baseline and over time

Latent growth curve models investigated whether each indicator of social, cultural, and economic capital explained variability in baseline levels of QoL, SwL, and well-being, and in the trajectory of change over the three timepoints. Analysis showed that indicators of social, cultural, and economic capital were associated more strongly with baseline QoL, SwL, and well-being than with change in QoL, SwL, and well-being over time. More specifically, the indicators of social capital associated with higher baseline QoL scores (see Supplementary Table 7) were having more frequent interactions with friends, participating in social activities, greater neighborhood trust, and not being socially isolated. Participation in civic activities was not associated with baseline QoL. Regarding cultural capital, lower educational achievements and/or attending fewer cultural activities were associated with poorer baseline QoL. Higher economic capital was associated with better baseline QoL. Findings at baseline were similar for SwL and well-being (see Supplementary Table 7).

Among indicators of social capital, only greater neighborhood trust was associated with a small improvement in QoL or well-being over

Table 2

Unadjusted multinomial logistic regression models with group membership as the outcome and baseline personal characteristics as the predictors.

| | <i>Socially and economically privileged</i> (N = 277; 18.0%) | <i>Financially secure</i> (N = 323; 21.0%) | <i>Low capital</i> (N = 566; 36.9%) | <i>Very low capital</i> (N = 371; 24.1%) |
|--|--|--|-------------------------------------|--|
| Odds ratio (95% CI) | | | Reference | |
| Addenbrooke's Cognitive Examination-III | 1.04 (1.03, 1.05) ^a | 1.01 (1.00, 1.01) | | .98 (.98, .99) ^a |
| Age | .96 (.95, .97) ^a | .99 (.98, 1.00) | | 1.01 (1.00, 1.02) |
| Dementia subtype (ref: Alzheimer's Disease) | | | | |
| Vascular dementia | .90 (.66, 1.23) | .77 (.59, 1.01) | | 1.35 (1.04, 1.76) ^a |
| Mixed (Alzheimer's and vascular) | .67 (.52, .86) ^a | .76 (.63, .93) ^a | | 1.16 (.95, 1.41) |
| Frontotemporal dementia | 1.73 (1.07, 2.80) ^a | 1.59 (1.04, 2.43) | | 1.21 (.76, 1.92) |
| Parkinson's disease dementia | 2.13 (1.23, 3.66) ^a | 1.20 (.72, 1.98) | | 1.09 (.65, 1.84) |
| Dementia with Lewy bodies | .60 (.33, 1.11) | 1.74 (1.14, 2.64) ^a | | 2.05 (1.35, 3.11) ^a |
| Unspecified/other dementia | .76 (.43, 1.34) | 1.15 (.75, 1.76) | | 1.17 (.67, 2.04) |
| Time since diagnosis (ref: <1 year) | | | | |
| 1–2 years | 1.15 (.92, 1.42) | 1.26 (1.05, 1.50) ^a | | 1.01 (.84, 1.22) |
| 3–5 years | .72 (.51, 1.00) | 1.15 (.89, 1.49) | | .93 (.70, 1.23) |
| ≥6 years | 1.10 (.44, 2.76) | 1.22 (.59, 2.54) | | 1.70 (.91, 3.10) |
| Sex (ref: Men) | | | | |
| Women | .76 (.63, .93) ^a | .67 (.58, .78) ^a | | .97 (.82, 1.14) |
| Marital status (ref: Married/Civil partnership/Cohabiting) | | | | |
| Single | .71 (.38, 1.32) | .59 (.33, 1.08) | | 1.05 (.59, 1.86) |
| Divorced/Separated | .86 (.59, 1.27) | .50 (.34, .72) ^a | | .81 (.58, 1.15) |
| Widowed | .46 (.35, .61) ^a | .38 (.31, .47) ^a | | 1.10 (.90, 1.34) |
| Living situation (ref: Live with spouse/partner) | | | | |
| Living alone | .66 (.51, .85) ^a | .45 (.36, .55) ^a | | .98 (.80, 1.20) |
| Live with other | .35 (.20, .61) ^a | .34 (.23, .50) ^a | | 1.41 (1.04, 1.92) ^a |
| Urban/rural classification (ref: Urban) | | | | |
| Rural | 1.21 (.99, 1.48) | 1.11 (.94, 1.31) | | .86 (.73, 1.03) |
| Social class (ref: Higher) | | | | |
| Intermediate | .32 (.26, .39) ^a | .35 (.29, .41) ^a | | 1.16 (.96, 1.39) |
| Lower | .16 (.11, .25) ^a | .27 (.21, .35) ^a | | 1.70 (1.34, 2.15) ^a |

^a Confidence intervals do not include one.

time. Civic participation was associated with a small decline in SwL whereas social participation was associated with a small improvement in SwL. Other indicators of cultural and economic capital were not associated with change in QoL, SwL, or well-being over time.

3.6. Differences in levels of QoL, SwL, and well-being at baseline and over time among the identified groups

Table 3 reports results from latent growth curve models investigating whether group membership explained variability in baseline levels of QoL, SwL, and well-being and in the trajectory of change of QoL, SwL, and well-being. Supplementary Table 6 reports distributions of QoL, SwL, and well-being (T1-T3) for the four latent groups. Compared to the *low capital* group, at baseline both the *socially and economically privileged* group and the *financially secure* group had higher QoL and well-being but not SwL. The *low capital* group had lower QoL, SwL, and well-being. Scores for all groups were largely stable for QoL, SwL, and well-being over the course of the study, although there was a small decline in well-being for the *socially and economically privileged* group compared to the *low capital* group. Scores for QoL, SwL, and well-being were consistently lower in *low capital* group than all other Groups.

4. Discussion

This study used indicators of social, cultural, and economic capital, as defined in Bourdieu's model of capital (1986), to provide in a large sample of people with dementia descriptive levels of social and cultural capital over two years and of economic capital at baseline. Overall,

Table 3

Latent growth curve modelling of quality of life, satisfaction with life, and well-being over time and the effect of group membership.

| Latent growth curve modelling of quality of life over time and the effect of group membership | | |
|--|-----------------------------------|----------------------------------|
| | (Mean intercept, 95% CI) | (Mean slope, 95% CI) |
| Quality of life | 37.39 (36.72, 38.06) ^a | -.04 (-.42, .34) |
| Groups (ref: <i>Low capital</i>) | | |
| <i>Socially and economically privileged</i> | 1.82 (.93, 2.73) | -.17 (-.66, .33) |
| <i>Financially secure</i> | 1.16 (.13, 2.18) | -.47 (-1.05, .12) |
| <i>Very low capital</i> | -3.53 (-4.42, -2.64) ^a | .26 (-.28, .79) |
| Latent growth curve modelling of satisfaction with life over time and the effect of group membership | | |
| | (Mean intercept, 95% CI) | (Mean slope, 95% CI) |
| Satisfaction with life | 27.13 (26.44, 27.83) ^a | .06 (-.36, .47) |
| Groups (ref: <i>Low capital</i>) | | |
| <i>Socially and economically privileged</i> | .13 (-.79, 1.06) | -.20 (-.74, .34) |
| <i>Financially secure</i> | .46 (-.60, 1.51) | -.02 (-.65, .62) |
| <i>Very low capital</i> | -2.97 (-3.88, -2.06) ^a | -.03 (-.61, .54) |
| Latent growth curve modelling of well-being over time and the effect of group membership | | |
| | (Mean intercept, 95% CI) | (Mean slope, 95% CI) |
| Well-being | 63.49 (61.15, 65.84) ^a | .37 (-1.07, 1.82) |
| Groups (ref: <i>Low capital</i>) | | |
| <i>Socially and economically privileged</i> | 3.51 (-.07, 7.08) | -2.35 (-4.57, -.13) ^a |
| <i>Financially secure</i> | 4.55 (1.42, 7.69) ^a | -.74 (-2.62, 1.14) |
| <i>Very low capital</i> | -6.88 (-9.96, -3.80) ^a | -.47 (-2.47, 1.52) |

Models were adjusted for age, sex, dementia subtype, and time since diagnosis. CI = confidence intervals.

^a Confidence intervals do not include zero.

people with dementia interacted with friends less often than once a month and did not engage in most civic, social, or cultural activities. Economic capital was in line with or above the UK average for the equivalent age range for slightly less than one-third of participants. Their social and cultural capital remained largely stable over 12-months and 24-months. Relative to the levels of capital found in the sample as a whole, four groups of people with dementia were identified. The first two groups were *socially and financially privileged* and *financially secure*, respectively. The last two groups had *low capital* and *very low capital*, respectively. Compared to the *low capital* and *very low capital* groups, participants in the *socially and financially privileged* and *financially secure* groups reported better concurrent levels of QoL and well-being, but similar SwL. The *low capital* and *very low capital* groups represent nearly two-thirds of the sample and reflect the wider social disadvantage among older people in the UK. The *very low capital* group represented people with dementia who were older, the most disadvantaged in terms of social, cultural, and economic capital, and who had poorer QoL, SwL, and well-being over time.

Regarding social capital, engagement in civic and social activities was low across the study sample. UK estimates indicate that 40% of people aged ≥ 25 years are engaged in civic participation (Office for National Statistics, 2018); this proportion is three times higher than that found among people with dementia (13.9%) in this study. The low levels of civic participation reported by people with dementia may suggest they did not have anything negative to address. However, it may well be that people with dementia neither knew how, were not motivated, nor were allowed to report their concerns to authorities. This study found that a larger proportion of people with dementia were socially isolated (27%) compared to people their age in England (15%) (Lubben et al., 2006). Finally, a smaller proportion of people with dementia (73.3%) trusted their neighbors compared to that estimated for UK adults (97%) (Office for National Statistics, 2018). Overall, results from this study suggest that social capital is slightly lower among people with dementia compared to older people without dementia.

Cultural capital was also consistently low across the study sample. However, evidence suggests that adults in England very rarely or never engage in the classic forms of cultural capital examined in this study (e. g., going to the theatre); instead, people prefer spending their time with friends, their partners, and/or engaging in other forms of entertainment such as playing video games (Miles and Sullivan, 2012). Nonetheless, results of a study by Gayo-Cal (2006), using the same measure of cultural capital that was used in the current study, suggest that, although older people in the UK engage rarely with cultural capital activities, cultural participation may be slightly lower among people with dementia compared to older people without dementia. For instance, comparing the current studies' results with those of Gayo-Cal (2006) shows that whereas 16% of older people never go to pubs, 39.2% people with dementia never go to pubs. Similarly, whereas 25.4% of older people never go to the cinema, 47.4% people with dementia never go to the cinema. In the study by Gayo-Cal (2006) a large proportion of older people reported lack of interest in cultural activities as the main cause of their disengagement from cultural activities. It is therefore probable that some of the items used to assess cultural capital, such as attending rock concerts or night clubs -the two least endorsed of the 13 cultural activities-may not be relevant for most people with dementia, especially those who are older. To our knowledge, however, there is not a measure assessing cultural activities that is specifically tailored to people with dementia and/or older people in general.

The lower social and cultural capital reported by the majority of people with dementia compared to the older population may be due to several factors, such as people with dementia avoiding social interaction and social and cultural activities due to fear of stigma and/or not being able to engage in activities at their previous ability level (Clare et al., 2020; Pinkert et al., 2021). Therefore, encouraging people with dementia to engage with social groups who have certain expectations regarding the abilities and behavior of people with dementia may

potentially lead to unpleasant consequences (Villalonga-Olives and Kawachi, 2017). However, social networks, such as close neighborhood networks, may support maintenance of cognition among women with dementia (Murayama et al., 2019). The lower social and cultural capital reported by the majority of people with dementia may also arise because receiving a diagnosis of dementia, which involves cognitive and functional limitations (World Health Organization, 2018), leads to significant disruption of social interactions (McGettrick and Williamson, 2015; Sawyer et al., 2019). It may also be that people with dementia do not want to take part in those activities that involve high sensory stimulation. Indeed, due to cognitive decline people with dementia find it hard to accurately interpret what they hear and can therefore experience confusion and frustration in noisy environments (Joosse, 2012).

Levels of social and cultural capital (e.g., social and/or civic participation) were similar at all three timepoints in this study; other studies in healthy older people suggest that many aspects of social and cultural capital, such as contact with family members and friends, stay relatively stable (Gjonca et al., 2010; Ward et al., 2019). For instance, Hackett et al. (2019), using data from the English Longitudinal Study of Ageing, compared levels of social engagement at three timepoints -prior to a self-reported diagnosis of dementia, contemporaneous with receiving a diagnosis of dementia, and two years post-diagnosis- and found that social engagement declined slightly in the two years prior to a dementia diagnosis and in the two years following diagnosis. The current study lasted two years and included people who had mild-to-moderate dementia at baseline. Therefore, the timeframe may have been insufficient to detect the likely changes in social and cultural engagement that occur in the later stages of dementia. It may be that, similar to earlier stages, in the more advanced stages of the illness the level of capital needed may differ based on individual preferences and needs. Policy initiatives that assume that greater social capital should be promoted for everyone without taking individual differences into account at each stage of the illness may have unintended negative effects.

Relative to this sample, participants in the *very low capital* group were particularly disadvantaged in terms of social capital as two-thirds were socially isolated. This proportion of socially isolated individuals is considerably higher compared to the remaining groups and the older population (Ward et al., 2019). Increasing wider understanding of dementia may help to change societal attitudes and reduce stigma toward dementia and, consequently, to foster inclusion of people with dementia within society through reciprocal relationships and in social activities at community level (Gronholm et al., 2017). Social isolation among older people, including people with dementia, could be decreased through the provision of social activities through the voluntary and primary care sectors. An example is the Golden Ticket model implemented in Sussex (The Health Foundation, 2016). The Golden Ticket is given to people with a diagnosis of dementia and includes free and subsidised access to a range of community-based interventions, as well as to pro-active primary care interventions. Services designed for and offered to broader society could also become more inclusive towards more groups of older people, including those with dementia (World Health Organization, 2021).

Regarding economic capital, slightly more than one-third of participants reported an annual household income below the UK average for equivalent age range. These participants also reported the lowest levels of social and cultural capital suggesting that, social and cultural capital may be even lower among those with poor economic resources. Moreover, participants with lower social, cultural, and economic capital, such as those in the groups with *low capital* and *very low capital*, reported lower levels of QoL and well-being compared to the remaining groups; reflecting the disadvantage that people with lower social, cultural, and economic capital generally have.

The association between lower social, cultural, and economic capital and poorer QoL and well-being is consistent with research linking greater well-being in older people, including the oldest-old (≥ 80 years) or those living with illness, to engagement in social and cultural

activities, such as visiting museums or historical sites and eating out (Gjonca et al., 2010; Schall et al., 2018). The beneficial effect of greater social capital for QoL and well-being may be due to family and/or peers helping people with dementia to come to terms with a diagnosis of dementia in a less stressful way (Sawyer et al., 2019). In this study, exploration of associations between social, cultural, and economic capital and QoL, SwL, and well-being suggests that social network and cultural participation may exert the greatest influence, whereas most other indicators of social, cultural, and economic capital have a smaller influence. Although levels of QoL, SwL, and well-being across groups remained relatively stable, QoL, SwL, and well-being were consistently lower among people with dementia in the *low capital* and *very low capital* groups.

Overall, results suggest that those with low social, cultural, and economic capital are a doubly disadvantaged group as they have higher risk of dementia and when they do get dementia have fewer resources to manage dementia and maintain their QoL, SwL, and well-being. The findings have immediate policy implications for those who are living with dementia now or will be soon, and distal policy implications for future generations. Policies with an immediate impact are needed to compensate for the social, cultural, and economic disadvantage of older people, especially those living with dementia. New strategies are needed to ensure that people get the benefits they are entitled to, that advice is available, and that staff are trained to engage with people with dementia and inform them about their entitlements. There is also the need to direct effort to more disadvantaged areas, since more resources tend to be available in areas that have greater social advantages (Bock, 2016). Policies with a distal impact are also needed to reduce inequalities throughout the life-course starting with early years and education. Examples of recommendations to promote cognitive reserve and to reduce social and economic inequalities include those developed by the International Federation on Aging (Valenzuela and Barratt, 2019).

4.1. Limitations

Study results need to be interpreted while acknowledging the following limitations. First, approximately one-third of participants either did not know or declined to provide their annual income at baseline, however, this is consistent with previous research (Yan et al., 2010). Moreover, as people tend to slightly overestimate their income (Angel et al., 2018) and in this study information of annual income was self-reported, it is possible that annual income was slightly overestimated. Second, a reduced number of participants took part at 12-months and 24-months, although this is not uncommon in longitudinal studies of people with dementia. Third, information concerning levels of social and cultural capital prior to receiving a diagnosis of dementia was not available; this is a limitation as it was not possible to investigate whether the low levels of social and cultural participation reported were due to lack of interest in these activities. However, it is unlikely that other indicators of capital such as education and income changed prior to receiving a diagnosis for most people. The large sample may have attenuated some of these concerns. Fourth, data for 13 cultural activities were collected; these activities may not have been extensive enough to adequately encompass cultural capital, and consequently cultural activities may have been underreported. This could be rectified in future studies by developing a more comprehensive list of cultural activities relevant to older people, including people with dementia, or offering space for additional activities to be recorded that are not otherwise included. This latter approach could provide a more personalized understanding of the relationship between individually relevant cultural participation and QoL, SwL, and well-being in people with dementia.

Nonetheless, to the best of our knowledge, this is the first study utilizing information from a large sample of people with dementia and using latent profile analyses to identify groups of individuals with different combinations of social, cultural, and economic capital and to

examine how these groups differ in their ability to live well. Moreover, the study assessed an extensive range of indicators of social, cultural, and economic capital.

5. Conclusions

This study contributes new evidence by drawing on longitudinal data from a large cohort of people with dementia and identifying people with distinct combinations of social, cultural, and economic capital. Social capital and cultural capital were low across the whole sample whereas cultural capital was low for slightly more than one-third of participants. Levels of social, cultural, and economic capital in people with dementia were slightly lower than those of cognitively healthy older people living in Britain. People with dementia with lower social, cultural, and economic capital may constitute a highly disadvantaged group with slightly poorer QoL and well-being over time. New policies and efforts from government, philanthropic foundations, and the voluntary and primary care sectors, are needed to compensate for the social, cultural, and economic disadvantage of older people, and particularly those living with dementia.

Credit author statement

SS ideated the research questions, conducted study analyses, and drafted the manuscript. LDG identified the appropriate data analyses techniques and supervised study analyses. FEM co-supervised study analyses. AM, LDG, IRJ, RC, FEM, MK, JMT, CH, CV, CP, and LC contributed to design of the work, interpretation of data, and provided comments on the draft of the manuscript.

Funding statement

'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 author(s) and not necessarily those of the ESRC, UKRI, NIHR, the Department of Health and Social Care, the National Health Service, or Alzheimer's Society. The support of ESRC, NIHR and Alzheimer's Society is gratefully acknowledged. Linda Clare acknowledges support from the NIHR Applied Research Collaboration South-West Peninsula.

Data availability

IDEAL data were deposited with the UK data archive in April 2020 and will be available to 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/>.

Acknowledgment

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 ALWAYS group and the Project Advisory Group for their support throughout the study. For the purpose of open access, the authors have applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2022.115603>.

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