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Profiles of social, cultural, and economic capital as longitudinal predictors of stress, positive experiences of caring, and depression among carers of people with dementia

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Abstract (max 200 words):

Objective: We explored 1) social, cultural, and economic capital in [spousal](#) carers of people with dementia; 2) profiles of carers with different levels of capital; 3) whether the identified profiles differ in levels of stress and positive experiences of caring, and likelihood of depression over time.

Methods: Baseline (2014-2016), 12-month, and 24-month follow-up data were analyzed for 984 [coresident](#) spousal carers of people with dementia. We assessed social, cultural, and economic capital, stress, positive experiences of caring, depression.

Results: [On average carers](#) reported infrequent social and cultural participation. Most carers were not socially isolated, trusted their neighbours, had education at least to age 16, and had an income aligned with the 2014 UK average.

We identified four groups of carers with different levels of capital. Although on average stress was low, depression was infrequent, and positive experiences of caring were moderately frequent, the group of carers with lowest capital was the least stressed and reported the most positive experiences of caring over time. [Compared to the two groups with better capital](#), those with poorer capital were more likely to be depressed over time.

Conclusion: Social, cultural, and economic resources may decrease likelihood of depression, but not stress, in carers of people with dementia.

Keywords: resources; caregivers; caregiving role; mental health; mood; positive aspects of caregiving

Wordcount (max 7000 including abstract, text, references): [6920](#)

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Introduction

In the UK between 670,000 and 700,000 family members and friends (subsequently referred to as ‘carers’) provide unpaid help to people with dementia (Alzheimer’s Society n.d.; Lewis et al. 2014). One third provide care for more than 100 hours per week (Adult Social Care Statistics team & NHS Digital 2017). Carers can have both positive and negative experiences related to their role. Examples of positive feelings are personal growth, competence, emotional reward, reciprocity, and spiritual growth (Pradana et al. 2021; Quinn & Toms 2019). Nonetheless, caring for a person with dementia can also be particularly demanding and, depending on the stage of the condition, carers may help with multiple tasks including personal care, housekeeping, administration of medication, financial transactions, and other activities (Brodaty & Donkin 2009; Henderson et al. 2021). Carers often balance caring duties with other responsibilities as well as their own health problems (Adult Social Care Statistics team & NHS Digital 2017; Carers UK 2019). This study specifically focuses on [spousal](#) carers of people with dementia. This is because most carers are spouses of the care recipient (Alzheimer’s Research UK). Moreover, compared to non-spousal carers, [spousal](#) carers tend to receive less support from other family members, experience greater stress, and have poorer physical and mental health (Allen et al. 2017; Clare et al. 2019; de Oliveira et al. 2015; Farina et al. 2017; Hammar et al. 2021; Johansson et al. 2021; Kim et al. 2012; McAuliffe et al. 2020; Tatangelo et al. 2018).

Despite stress and depressive symptoms being more frequent among carers of people with dementia compared to the general population (Adult Social Care Statistics team & NHS Digital 2017; Collins & Kishita 2020), some carers cope better than others (Cherry et al. 2013; Donnellan et al. 2015). Many factors may contribute to the experience of stress and depression that carers have; these may include the social, cultural, and economic capital that carers have accumulated throughout their life (Bourdieu 1986). Social capital is generally accepted to include relationships with relatives, friends, or other groups, civic participation (e.g., contacting a local councillor or attending a protest meeting), and institutional trust. Cultural capital includes educational achievement and engagement in cultural activities such as visiting museums. Economic capital includes money, property, and other financial assets. Generally, for carers, greater social, cultural, and economic capital fosters mental and physical health maintenance (Cartwright et al. 2020; Clare et al. 2019; Clarke et al. 2020; Farina et al. 2017; George et al. 2020; Lindeza et al. 2020; Scheffler et al. ; Tay et al. 2016; Teahan et al. 2018; Victor et al. 2021a).

Due to the different experiences people have had in their lives, pre-existing levels of social, cultural, and economic capital, are likely to vary greatly among spousal carers of people with dementia. Those with stronger social, cultural, and economic capital may be better protected from high levels of stress and depression. Indeed, they report better well-being, quality of life, and more positive experiences of caring (Cartwright et al. 2020; Clare et al. 2019; Clarke et al. 2020; Clay et al. 2008; Farina et al. 2017; George et al. 2020; Lindeza et al. 2020; McLennon et al. 2011; Victor et al. 2021a). Finally, a higher level of education is related to better quality of life among carers (Teahan et al. 2018).

However, caring for someone with dementia may decrease levels of social, cultural, and economic capital for all carers. Indeed, social isolation is common among carers (Carers UK 2019; Victor et al. 2021b); for instance, in a survey conducted in the UK only 32% of carers of people with dementia reported having as much social contact as they would like (Alzheimer's Research UK n.d.). Moreover, due to their role and other responsibilities, carers often reduce their engagement in leisure activities (Adult Social Care Statistics team & NHS Digital 2017; Greenwood et al. 2018). Financial difficulties are also frequent among carers because of the additional costs associated with caring such as paying for care services and any assistive equipment (Carers UK 2019; Luscombe et al. 1998; Mayrhofer et al. 2021).

Evidence documenting levels of social, cultural, and economic capital in carers of people with dementia is scarce, however and to the best of our knowledge, no study has ever linked a range of indicators of social, cultural, and economic capital to longitudinal levels of stress, positive experiences of caring, and likelihood of depression in carers of people with dementia. Yet engagement in social and cultural activities may protect carers from stress and depression by providing a distraction from their caring role (Teahan et al. 2018). Economic capital may also protect carers from stress (Carers UK 2019; Luscombe et al. 1998; Mayrhofer et al. 2021).

This study aims to 1) describe levels of social, cultural, and economic capital among spousal carers of people with dementia living in Great Britain; 2) identify groups of carers with different levels of social, cultural, and economic capital; and 3) explore whether the identified groups differ in levels of stress, levels of positive experiences of caring, and likelihood of depression over time. We hypothesized that the study sample could be divided into groups of participants with different degrees of social, cultural, and economic capital and that the identified groups would have different levels of stress, positive experienced of caring, and likelihood of depression over time.

Methods

Study design and participants

This study used data for carers of people with dementia collected in the first three waves (baseline: 2014-16; 12-month follow-up: 2015-17; and 24-month follow-up: 2016-18) of the Blinded for review programme. Version 5 of the dataset was used for analyses. Blinded for review was approved by the Blinded for review (reference: Blinded for review) and the Blinded for review (reference: 2014-11684). Blinded for review is registered with the UK Clinical Research Network (registration number: Blinded for review). When a person with dementia joined the Blinded for review study, where available, an informal carer, defined as the primary person who provides practical or emotional unpaid support, was invited to take part as well. People with dementia were recruited through 29 National Health Service sites (NHS) and other specialist clinics, and via the online Join Dementia Research portal, between July 2014 and August 2016. Inclusion criteria were a clinical diagnosis of any subtype of dementia, a Mini-Mental State Examination (Folstein et al. 1975) score of 15 or above (indicating mild-to-moderate stages of dementia), and participants had to be residing in the community at the time of enrolment into the study. There were no specific exclusion criteria for carers other than people with dementia withdrawing from the study at baseline before sufficient information was collected. Further details about recruitment in Blinded for review are reported in the published protocol Blinded for review. At baseline the Blinded for review cohort comprised 1537 people with dementia and 1277 carers. Out of the 1277 carers enrolled in Blinded for review at baseline, the current study includes only those (n=984) who were spouses and consistently lived with the person with dementia in the community across all three assessment points.

Measures

Measures covered aspects of social (interactions with friends and relatives, civic participation, social participation, neighbourhood trust, social isolation), cultural (education, cultural participation), and economic (annual income) capital, stress, positive experiences of caring, and depression. Measures of social, cultural, and economic capital were selected from the wider Blinded for review dataset based on Bourdieu's model (1986) of social, cultural, and economic capital. [Among measures of social, cultural, and economic capital; the Lubben Social Network scale, education, and total household income were administered at all three timepoints whereas the remaining indicators of social, cultural, and economic capital were administered only at baseline due to less interview time at later timepoints.](#) Carers'

characteristics comprised age, sex, and co-morbid conditions. Characteristics of people with dementia were dementia subtype, and time since diagnosis at baseline. Study measures are described in Supplementary Text 1. Items assessing civic, social, and cultural participation are presented in Supplementary Tables 1-3.

Analyses

Descriptive statistics for study variables at baseline and follow-ups were reported.

To explore whether the population could be divided into groups of individuals characterised by different levels of social, cultural, and economic capital latent profile analyses were conducted (Williams & 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. To describe the profiles of each group attributions of “very high”, “high”, “low”, “very low” were assigned to refer to groups’ levels of social, cultural, and economic capital relative to the overall level observed in the current study sample. Each group was named based on levels of social, cultural, and economic capital.

Means or frequencies for demographic variables, stress, positive experiences of caring, depression, satisfaction with one’s personal relationships and with the support received from family and friends were also reported for each group. Satisfaction with one’s personal relationships and with the support received from family and friends across groups were examined as post-hoc analyses.

[Multinomial logistic regression models were conducted to examine whether the personal characteristics of the carer and of the person with dementia differed among the identified groups.](#) Odds ratios and 95% confidence intervals were reported. Misclassification error was taken into account using the BCH Method in Mplus (Asparouhov & Muthén 2014).

Latent growth curve models were conducted to investigate whether group membership explained variability in baseline levels of stress and of experiences of caring,

and likelihood of depression across the identified groups, as well as in the trajectory of change of levels of stress, experiences of caring, and likelihood of depression across the identified groups over the three timepoints. For these analyses, depression was dichotomized into Depressed (≥ 16) and Not depressed (< 16) due to highly skewed data. Each latent growth curve model estimated a mean intercept and slope, with random effects to account for variation across individuals. Models were adjusted for carers' age, sex, and diagnosis subtype. Group membership was weighted by the posterior probabilities to account for uncertainty. Latent growth curve models for stress, positive experiences of caring, and depression had good model fit indices (Comparative Fit Index/ Tucker-Lewis Index > 0.95 , Root Mean Square Error of Approximation < 0.05).

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 independent variables, missing data were imputed using multiple imputation by chained equations, generating 25 imputed datasets.

Results

Carers' characteristics

This study included 984 spousal carers of people with dementia at baseline, 768 at 12-month follow-up, and 581 at 24-month follow-up. At baseline, carers' mean age was 72.4 (SD=8.3). The majority were women (66.6%). On average carers reported low stress and moderate positive experiences of caring; 10.9% were depressed. Characteristics of the sample at baseline, 12-months, and 24-months are reported in Table 1.

__Table 1__

Levels of social, cultural, and economic capital

Descriptive statistics for each indicator of social, cultural, and economic capital are reported in Table 1. Frequency of engagement in [each of the](#) examined civic, social, and cultural activities are reported in Supplementary Tables 1-3.

Regarding social capital, although on average participants reported interacting with friends and relatives less than monthly; most participants (81.7%) were not socially isolated as they had friends they could count on and with whom they felt at ease. Most carers trusted their neighbours (64.9%), while 28.6% and 42.7% participated in civic and social activities, respectively. Regarding cultural capital, educational achievements varied

greatly; one quarter of participants had no qualification, 22.5% had a school leaving certificate at age 16; 30% had a school leaving certificate at age 18; and 29.3% had a University level education. On average carers participated in cultural activities once a year or less. Finally, regarding economic capital participants had, on average, an annual household income aligned with the average UK household income in 2014 for people aged ≥ 65 years (Office for National Statistics).

Pattern of social, cultural, and economic capital across the identified groups

Latent profile analyses were conducted to explore the number and characteristics of groups into which the population could be divided based on baseline levels of social, cultural, and economic capital. A four-group model was selected based on model fit, entropy and interpretability (see Supplementary Table 4). Group 1 included 195 carers (20%); Group 2 included 338 carers (34%); Group 3 included 247 carers (25%); and Group 4 included 204 carers (21%). The means/percentages for each indicator of social, cultural, and economic capital for each group are shown in Table 2.

Among participants in Group 1, 17.7% and 16.0% reported some civic and social participation, respectively, 61.6% exhibited neighbourhood trust, on average participants interacted with friends (mean score=4.21) and relatives (mean score=5.56) less often than once a month, and 59.3% were not isolated. Half of participants had no educational qualifications; mean score for cultural capital (20.0) indicated cultural engagement once a year or less. In this group, 31.2% reported an annual income in line with or above the UK national average for people aged ≥ 65 in 2014.

Among participants in Group 2, 23.6% and 31.7% reported some civic and social participation, respectively, 54.0% exhibited neighbourhood trust, on average participants interacted with friends (mean score=7.9) and relatives (mean score=8.9) once or twice a month, and 89.5% were not isolated. About 40% had no educational qualifications; mean score for cultural capital (22.7) indicated cultural engagement once a year or less. In this group, 34.1% reported an annual income aligned with or above the UK national average for people aged ≥ 65 in 2014.

Among participants in Group 3, 42.4% and 69.4% reported some civic and social participation, respectively, 83.2% exhibited neighbourhood trust, on average participants interacted with friends (mean score=10.3) and relatives (mean score=10.1) once or twice a month, and no one was isolated. Only 4% had no educational qualifications. Mean score for cultural capital (29.3) indicated cultural engagement several times a year. Most (73%)

reported an annual income aligned with or above the UK national average for people aged ≥ 65 in 2014.

Among participants in Group 4, 38.2% and 65.2% reported some civic and social participation, respectively, 80.9% exhibited neighbourhood trust, on average participants interacted with friends (mean score=7.7) and relatives (mean score=7.4) once or twice a month, and 76.2% were not isolated. Only 1.8% had no educational qualifications. However, mean score for cultural capital (26.4) indicated cultural engagement once or less a year. Most (80.7%) reported an annual income aligned in line with or above the UK national average for people aged ≥ 65 in 2014.

Overall, engagement in cultural activities was infrequent across all groups whereas civic and social participation, neighbourhood trust, social isolation, and educational achievements varied greatly between groups. Relative to this sample, interactions with relatives and friends were very low in Group 1, but higher in the remaining groups. Economic capital was lower in Groups 1 and 2 than in Groups 3 and 4. As, relative to overall levels of cultural, social, and economic capital in this study sample, carers in Group 1 reported very low social, cultural, and economic capital, this group was named *very low capital* (N=195; 20%). Group 2 included carers with low social, cultural, and economic capital and therefore this group was named *low capital* (N=338; 34%). Group 3 included carers with very high social and cultural capital and high economic capital and therefore this group was named *socially connected* (N=247; 25%). Group 4 included carers with very high economic capital and high social and cultural capital and therefore this group was named *financially secure* (N=204; 21%).

__Table 2__

The distribution of characteristics of the carer and care recipient and differences between groups are reported in Supplementary Tables 5 and 6. The *low capital* group had the fewest female carers. Compared with the *low capital* group, carers in the *socially connected* and *financially secure* groups had fewer co-morbid conditions and were more likely to have been caring the person with dementia for longer. Carers in the *socially connected* group were more likely to be younger and less likely to be caring for people with a diagnosis of mixed dementia whereas carers in the *financially secure* group were less likely to be caring for people with a diagnosis of vascular dementia, mixed dementia, or dementia with Lewy bodies.

Longitudinal differences in levels of stress and positive experiences of caring, and likelihood of depression among the identified groups

Results from unadjusted and adjusted latent growth curve models investigating whether group membership explained variability in the trajectory of change in stress, positive experiences of caring, and depression are reported in Table 3. Distributions of measures of stress, positive experiences of caring, and depression (T1-T3) for the 4 latent groups are reported in Supplementary Table 5.

At baseline, following adjustment for age, sex, and dementia diagnosis, compared with the *low capital* group, participants in the *very low capital* group reported slightly lower levels of stress (mean intercept; 95% CI= -1.25; -3.13, .62) and slightly higher levels of positive experiences of caring (mean intercept; 95% CI= .73; -.68, 2.13). Compared to the *low capital* group, the *socially connected* group experienced similar levels of stress (mean intercept; 95% CI= -1.30; -2.94, .33) and of positive experiences of caring (mean intercept; 95% CI= -1.21; -2.44, .02), but were less likely to be depressed (mean intercept; 95% CI= .64; .47, .88). Compared to the *low capital* group, those in the *financially secure* group reported the same levels of stress (mean intercept; 95% CI= .98; -.95, 2.92), but fewer positive experiences of caring (mean intercept; 95% CI= -4.55; -6.01, 3.10).

Over the study period levels of stress increased up to 4 points for all groups, the proportion of depressed participants increased by about one third for those in the *very low capital*, *low capital*, and *financially secure* groups and almost doubled among participants in the *socially connected* group. Levels of positive experiences of caring decreased by 1.8 points and of .60 points in the *very low capital* and *low capital* groups, respectively, but increased by about .60 points in the *socially connected* and *financially secure* groups. At two-year follow-up, carers in the *very low capital* group consistently experienced the lowest levels of stress and highest levels of positive experiences of caring, although the proportion of carers who were depressed continued to be higher in the *very low capital* and *low capital* groups (19.4% and 22.9%, respectively) compared to the *socially connected* and *financially secure* groups (15.3% and 11.8%, respectively). When comparing the trajectory of each group, the trajectories were similar over time, but the *financially secure* group had a slightly greater increase in levels of stress (mean intercept; 95% CI= 1.13; .19, 2.08).

__Table 3__

Descriptive statistics representing the distributions of satisfaction with personal relationships and with the help received from family and friends are reported in Supplementary Table 7. Compared to the *low capital* and *socially connected* groups (59.8% and 62.2%, respectively), the *very low capital* and *financially secure* groups (50.5% and 50.8%, respectively) included a lower proportion of carers being very satisfied with the support received from family. Similarly, compared to the *low capital* and *socially connected* groups (47.4% and 57.9%, respectively), the *very low capital* and *financially secure* groups (30.4% and 42.8%, respectively) included a lower proportion of carers who were very satisfied with the support received from friends.

Discussion

This was the first study to explore baseline levels of social, cultural, and economic capital among spousal carers of people with dementia, and to link them to carers' stress, positive experiences of caring, and likelihood of depression over time. Overall, some aspects of social and cultural capital, including having friends and relatives to count on and hearing from them via the phone (social isolation), neighbourhood trust, and education, were high among carers whereas others, including interactions with friends and relatives, engagement in some cultural and civic activities, were infrequent among carers. Economic capital was aligned with the 2014 UK average for people aged ≥ 65 years (UK Government 2016). Stress was low, positive experiences of caring were moderate, and depression was infrequent for the overall sample across all timepoints.

Relative to the levels of capital found in the sample as a whole, we identified four groups of carers having very low social, cultural, and economic capital (*very low capital*); low social, cultural, and economic capital (*low capital*); very good social and cultural capital and good economic capital (*socially connected*); very good economic capital and good social and cultural capital (*financially secure*). Although carers in the *socially connected* and *financially secure* groups had higher levels of social, cultural, and economic capital compared to carers in the remaining groups and only a small proportion in the *financially secure* group was socially isolated, no one in the *socially connected* group was socially isolated. Even though differences between groups were small, carers in the *very low capital* group were less stressed than carers in the *low capital*, *socially connected*, and *financially secure* groups, and carers in the *very low capital* and *low capital* groups were more likely to be depressed and reported slightly more positive experiences of caring than carers in the *socially connected* and *financially secure* groups.

The degree of engagement in social interactions and social, civic, and cultural activities found among carers in this study is consistent with previous research with carers, the general adult population, and older people (Adult Social Care Statistics team & NHS Digital 2017; Davidson & Rossall ; Gayo-Cal 2006; Greenwood et al. 2018; Lubben et al. 2006). For instance, frequency of engagement in cultural activities among carers was similar to that reported by the general population of adults living in England (Gayo-Cal 2006). Comparing our findings and those obtained for the general population of older adults suggest that some activities, such as eating out, are slightly more frequent among carers, whereas others, such as going to pubs, are more frequent among the general population (Gayo-Cal 2006). [Research studies suggest that while transitioning to the caregiving role carers' social networks change \(Carpentier & Ducharme 2005; Roth 2020\)](#). Importantly, as previous surveys conducted with English older adults have found, the main reason for disengagement with cultural activities among carers may be lack of interest in these kinds of activities (Gayo-Cal 2006).

The low levels of civic participation reported by carers may suggest they did not have many concerns or did not know, or were not motivated, to address these. However, it has been noted that local government in England neither supports nor encourages active citizenship (Andrews et al. 2008). Moreover, some of the civic activities investigated, such as contacting a local councillor, may be easier to engage with compared to other activities, such as taking part in a demonstration. National data for the UK using the same measure of civic participation used in the current study (Office for National Statistics 2008) shows that 40% of people aged 25 and over are engaged in civic participation (Office for National Statistics 2018); this proportion is slightly higher than that found among carers in this study (28.6%). The proportion of carers who were socially isolated was similar to that found in the older population in England (Lubben et al. 2006). However, in this study a smaller proportion of carers (64.9%) trusted their neighbours compared to UK adults aged 25 and over (97%) (Office for National Statistics 2018).

Despite effects being small, carers in the *very low capital* group consistently reported less stress than carers in the *low capital*, *socially connected*, and *financially secure* groups. What distinguished the carers in the *very low capital* group most from the remaining groups were the less frequent interactions with friends and relatives and the higher proportion of carers being socially isolated. Hence, contrary to our hypothesis and to literature from the wider population that links higher social capital to lower stress (Song 2011), results suggest that among carers of people with dementia, those who are less involved in social and cultural

activities are slightly less stressed than those who are more involved in these activities. The lack of an association between fewer social interactions and more stress may be due to the quality of social interactions being more important than the quantity of interactions carers have (Donnellan et al. 2017; Wilks & Croom 2008). Generally, meeting other people reduces carers' stress and depressive symptoms, that are two overlapping and often related constructs (George et al. 2020), only when carers talk with people who understand them, such as other carers facing similar difficulties (Donnellan et al. 2017). Post hoc analyses showed that carers in the *very low capital* group reported both the least frequent and least satisfying interactions with family and friends. It may be that people with very low social, cultural, and economic capital have low expectations in life and, as a consequence, experience less stress when undertaking caring responsibilities.

Another possible explanation for the counterintuitive association between lower social and cultural participation and less stress is that carers who engage in social and cultural activities may feel guilty for taking time off from their role (Gallego-Alberto et al. 2020). An explanation may also be that carers who have frequent social interactions are often immersed in situations in which their everyday life is compared with that of non-carers. In this regard, meeting other people may be a stressful reminder of all the activities they are missing due to their caring role. It may also be that carers who engage in social and cultural activities they value and enjoy find it hard to return to their caring role. Moreover, it may be that, compared to carers who have more frequent social interactions, those who engage less frequently in social interactions have more time to dedicate to the person they are caring for and, due to having fewer competing activities and tasks, feel less stressed. Finally, it may simply be that some carers do not feel the need for much social interaction or participation in social activities and, therefore, manage better than carers who need but feel deprived of social interactions.

However, although participants in the *very low capital* group reported the lowest levels of stress, they were more likely to be depressed compared to those in the *socially connected* and *financially secure* groups. The *low capital* group also included a greater proportion of carers who were depressed than the *socially connected* and *financially secure* groups. In the *very low capital* and *low capital* groups, slightly more than two-thirds of carers had an income below the UK average in 2014 and economic deprivation is a risk factor for depression (Charlton et al. 2013).

This study has several limitations. First, approximately one third of participants refused to report their annual income; however, non-response for income is frequent in surveys (Yan et

al. 2010). Second, as annual income was self-reported by study participants, it is possible that they over-estimated their annual income (Angel et al. 2018). Third, the measures used to assess social and cultural participation may not cover all social and cultural activities undertaken by participants. Moreover, these measures do not take into account proximity to or availability of sources of social and cultural participation, such as museums and theatres, in local areas. Fourth, as this study was conducted only on coresident spousal carers, study results may not apply to non-spousal carers nor to spousal carers whose husbands have transitioned into residential care. Fifth, the relationship we found between less involvement of spousal carers in social and cultural activities and less stress may be due to these carers having less to lose compared to those carers who were more engaged in social and cultural activities. Sixth, the exploration of indicators of social and cultural capital as baseline predictors of stress may have prevented us from testing whether decline in social and cultural capital is associated with increase in stress over time. Even though those measures of social, cultural, and economic capital did not change over time, it is however possible that lack of change is due to selective attrition as those caregivers who were struggling more would be more likely to withdraw from the study.

Conclusions

This study identified four profiles of social, cultural, and economic capital among coresident spousal carers of people with dementia. We found that those with stronger social, cultural, and economic capital have less likelihood of depression. However, results do not support the protective role of greater social, cultural, and economic capital in relation to the experience of stress nor the link between greater social, cultural, and economic capital and more positive experiences of caring. Nonetheless, findings highlight the need for policies promoting higher social and cultural capital among carers of people with dementia. New policies and initiatives are also needed to address financial difficulties among carers of people with dementia, as well as to increase awareness of the economic benefits to which carers are entitled.

References

- Adult Social Care Statistics team, & NHS Digital. (2017). *Personal Social Services Survey of Adult Carers in England, 2016-17* (Personal Social Services Survey of Adult Carers, Issue).
- Allen, A. P., Curran, E. A., Duggan, Á., Cryan, J. F., Chorcóráin, A. N., Dinan, T. G., Molloy, D. W., Kearney, P. M., & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neuroscience & Biobehavioral Reviews*, *73*, 123-164. <https://doi.org/10.1016/j.neubiorev.2016.12.006>
- Alzheimer's Research UK. <https://www.dementiastatistics.org/statistics/impact-on-carers/>
- Alzheimer's Society. Retrieved 09-12-2021 from <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/carer-support>
- Andrews, R., Cowell, R., Downe, J., Martin, S., & Turner, D. (2008, 2008/08/01). Supporting effective citizenship in local government: Engaging, educating and empowering local citizens. *Local Government Studies*, *34*(4), 489-507. <https://doi.org/10.1080/03003930802217462>
- Angel, S., Heuberger, R., & Lamei, N. (2018, 2018/07/01). Differences between household income from surveys and registers and how these affect the poverty headcount: evidence from the Austrian SILC. *Social Indicators Research*, *138*(2), 575-603. <https://doi.org/10.1007/s11205-017-1672-7>
- Asparouhov, T., & Muthén, B. O. (2014). Auxiliary variables in mixture modeling: Using the BCH method in Mplus to estimate a distal outcome model and an arbitrary secondary model. *Mplus web notes*, *21*(2), 1-22.
- Bourdieu, P. (1986). The forms of capital. In J. G. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (Vol. 241-258, pp. 258). Greenwood Press.
- Brodsky, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217-228. <https://doi.org/10.31887/DCNS.2009.11.2/hbrodsky>
- Carers UK. (2019). *Facts about carers*.
- Carpentier, N., & Ducharme, F. (2005). Support network transformations in the first stages of the caregiver's career. *Qualitative Health Research*, *15*(3), 289-311. <https://doi.org/10.1177/1049732304270813>
- Cartwright, A. V., Pione, R. D., Stoner, C. R., & Spector, A. (2020). Validation of the multidimensional scale of perceived social support (MSPSS) for family caregivers of people with dementia. *Aging & Mental Health*, 1-8. <https://doi.org/10.1080/13607863.2020.1857699>
- Charlton, J., Rudisill, C., Bhattarai, N., & Gulliford, M. (2013, 2013/10/01). Impact of deprivation on occurrence, outcomes and health care costs of people with multiple morbidity. *Journal of Health Services Research & Policy*, *18*(4), 215-223. <https://doi.org/10.1177/1355819613493772>
- Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology*, *23*(4), 251-266. <https://doi.org/10.1017/S0959259813000130>
- Clare, L., Wu, Y.-T., Quinn, C., Jones, I. R., Victor, C. R., Nelis, S. M., Martyr, A., Litherland, R., Pickett, J. A., Hindle, J. V., Jones, R. W., Knapp, M., Kopelman, M. D., Morris, R. G., Rusted, J. M., Thom, J. M., Lamont, R. A., Henderson, C., Rippon, I., Hillman, A., Matthews, F. E., & On behalf of the IDEAL study team. (2019). A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: Findings from the

- IDEAL study. *Alzheimer Disease and Associated Disorders*, 33(1), 29-35.
<https://doi.org/10.1097/WAD.0000000000000285>
- Clarke, R., Farina, N., Chen, H. L., Rusted, J. M., & in collaboration with the IDEAL programme team. (2020). Quality of life and wellbeing of carers of people with dementia: are there differences between working and non-working carers? Results from the IDEAL Programme. *Journal of Applied Gerontology*.
<https://doi.org/10.1177/0733464820917861>
- Clay, O. J., Roth, D. L., Wadley, V. G., & Haley, W. E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *International Journal of Geriatric Psychiatry*, 23(8), 857-862. <https://doi.org/10.1002/gps.1996>
- Collins, R. N., & Kishita, N. (2020). Prevalence of depression and burden among informal care-givers of people with dementia: A meta-analysis. *Ageing and Society*, 40(11), 2355-2392. <https://doi.org/10.1017/S0144686X19000527>
- Davidson, S., & Rossall, P. *Age UK. Evidence review: Loneliness in later life*.
https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_june15_loneliness_in_later_life_evidence_review.pdf
- de Oliveira, D. C., Vass, C., & Aubeeluck, A. (2015). Ageing and quality of life in family carers of people with dementia being cared for at home. *Quality in Primary Care*, 23(1), 18-30. <https://doi.org/10.1177/1471301217700741>
- Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health*, 19(10), 932-939. <https://doi.org/10.1080/13607863.2014.977771>
- Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2017). Family close but friends closer: Exploring social support and resilience in older spousal dementia carers. *Aging & Mental Health*, 21(11), 1222-1228. <https://doi.org/10.1080/13607863.2016.1209734>
- Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, 13(5), 572-581. <https://doi.org/10.1016/j.jalz.2016.12.010>
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189-198. [https://doi.org/10.1016/0022-3956\(75\)90026-6](https://doi.org/10.1016/0022-3956(75)90026-6)
- Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro Del Sequeros, M., & Márquez-González, M. (2020). "I feel guilty". Exploring guilt-related dynamics in family caregivers of people with dementia. *Clinical Gerontologist*, 1-10. <https://doi.org/10.1080/07317115.2020.1769244>
- Gayo-Cal, M. (2006). Leisure and participation in Britain. *Cultural Trends*, 15(2-3), 175-192. <https://doi.org/10.1080/09548960600713015>
- George, E. S., Kecmanovic, M., Meade, T., & Kolt, G. S. (2020). Psychological distress among carers and the moderating effects of social support. *BMC Psychiatry*, 20(1), 154. <https://doi.org/10.1186/s12888-020-02571-7>
- Greenwood, N., Mezey, G., & Smith, R. (2018). Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas*, 112, 39-45.
<https://doi.org/10.1016/j.maturitas.2018.03.011>
- Hammar, L. M., Williams, C. L., Meranius, M. S., & McKee, K. J. (2021). Being 'alone' striving for belonging and adaption in a new reality—The experiences of spouse carers

- of persons with dementia. *Dementia*, 20(1), 273-290.
<https://doi.org/10.1177/1471301219879343>
- Henderson, C., Knapp, M., Martyr, A., Gamble, L. D., Nelis, S. M., Quinn, C., Pentecost, C., Collins, R., Wu, Y.-T., Jones, I. R., Victor, C. R., Pickett, J. A., Jones, R. W., Matthews, F. E., Morris, R. G., Rusted, J., Thom, J. M., Clare, L., & on behalf of the Ideal programme team. (2021). The use and costs of paid and unpaid care for People with dementia: Longitudinal findings from the IDEAL cohort. *Journal of Alzheimer's Disease, Preprint*, 1-18. <https://doi.org/10.3233/JAD-215117>
- Johansson, M. F., McKee, K. J., Dahlberg, L., Williams, C. L., Summer Meranius, M., Hanson, E., Magnusson, L., Ekman, B., & Marmstål Hammar, L. (2021). A comparison of spouse and non-spouse carers of people with dementia: A descriptive analysis of Swedish national survey data. *BMC Geriatrics*, 21(1), 338.
<https://doi.org/10.1186/s12877-021-02264-0>
- Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846-855.
<https://doi.org/10.1111/j.1365-2648.2011.05787.x>
- Lewis, F., Karlsberg Schaffer, S., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). *The Trajectory of Dementia in the UK - Making a Difference*.
- Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*, bmjpcare-2020-002242.
<https://doi.org/10.1136/bmjpcare-2020-002242>
- Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *Gerontologist*, 46(4), 503-513. <https://doi.org/10.1093/geront/46.4.503>
- Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: Diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*, 13(5), 323-330. [https://doi.org/10.1002/\(SICI\)1099-1166\(199805\)13:5<323::AID-GPS768>3.0.CO;2-O](https://doi.org/10.1002/(SICI)1099-1166(199805)13:5<323::AID-GPS768>3.0.CO;2-O)
- Mayrhofer, A. M., Greenwood, N., Smeeton, N., Almack, K., Buckingham, L., Shora, S., & Goodman, C. (2021). Understanding the financial impact of a diagnosis of young onset dementia on individuals and families in the United Kingdom: Results of an online survey. *Health & Social Care in the Community*, 29(3), 664-671.
<https://doi.org/10.1111/hsc.13334>
- McAuliffe, L., Ong, B., & Kinsella, G. (2020, Oct). Mediators of burden and depression in dementia family caregivers: Kinship differences. *Dementia*, 19(7), 2234-2250.
<https://doi.org/10.1177/1471301218819345>
- McLennon, S. M., Habermann, B., & Rice, M. (2011, May). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health*, 15(4), 522-530. <https://doi.org/10.1080/13607863.2010.543656>
- Muthén, L. K., & Muthén, B. O. (1998-2017). *Mplus User's Guide. Eighth Edition*.
- Nylund, K. L., Asparouhov, T., & Muthén, B. O. (2007). Deciding on the number of classes in latent class analysis and growth mixture modeling: A Monte Carlo simulation study. *Structural Equation Modeling*, 14(4), 535-569.
<https://doi.org/10.1080/10705510701575396>
- Office for National Statistics. Retrieved 23-06-2021 from
<https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/bulletins/householddisposableincomeandinequality/financialyear2020>

- Office for National Statistics. (2008). *Harmonised concepts and questions for social data sources, secondary standards: Social capital*.
- Office for National Statistics. (2018). *Neighbourhood belonging and community engagement by age group*.
<https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/youngpeopleandtheirneighbourhoods>
- Pradana, A. A., Sahar, J., & Permatasari, H. (2021). Dementia: How does spouse perceive it? *Enfermería Clínica*, 31, S16-S19. <https://doi.org/10.1016%j.enfcli.2020.10.007>
- Quinn, C., & Toms, G. (2019). Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *Gerontologist*, 59(5), e584-e596. <https://doi.org/10.1093/geront/gny168>
- Roth, A. R. (2020). Informal caregiving and network turnover among older adults. *The Journals of Gerontology: Series B*, 75(7), 1538-1547.
- Scheffler, R. M., Petris, N. C., Borgonovi, F., Brown, T. T., Sassi, F., Dourgnon, P., & Sirven, N. *Social capital, human capital and health. What is the evidence?*
<https://www.oecd.org/innovation/research/45760738.pdf>
- Song, L. (2011). Social capital and psychological distress. *Journal of Health and Social Behavior*, 52(4), 478-492. <https://doi.org/10.1177/0022146511411921>
- StataCorp. (2017). Stata Statistical Software: Release 16. *College Station, TX*2016.
- Tatangelo, G., McCabe, M., Macleod, A., & You, E. (2018). "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. *International Journal of Nursing Studies*, 77, 8-14. <https://doi.org/10.1016/j.ijnurstu.2017.09.011>
- Tay, K. C., Seow, C. C., Xiao, C., Lee, H. M., Chiu, H. F., & Chan, S. W. (2016). Structured interviews examining the burden, coping, self-efficacy, and quality of life among family caregivers of persons with dementia in Singapore. *Dementia*, 15(2), 204-220. <https://doi.org/10.1177/1471301214522047>
- Teahan, Á., Lafferty, A., McAuliffe, E., Phelan, A., O'Sullivan, L., O'Shea, D., & Fealy, G. (2018). Resilience in family caregiving for people with dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 33(12), 1582-1595. <https://doi.org/10.1002/gps.4972>
- UK Government. (2016). *Data tables: Pensioners' incomes series 2015/16 - GOV.UK*.
<https://www.gov.uk/government/statistics/pensioners-incomes-series-financial-year-201516>
- Victor, C. R., Rippon, I., Quinn, C., Martyr, A., & Clare, L. (2021a). The role of subjective social status in living well for carers of people with dementia: Findings from the Improving the experience of Dementia and Enhancing Active Life programme. *International Journal of Care and Caring*.
<https://doi.org/10.1332/239788221X16104266615749>
- Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr, A., Hart, N., Lamont, R. A., & Clare, L. (2021b). The prevalence and predictors of loneliness in caregivers of people with dementia: Findings from the IDEAL programme. *Aging & Mental Health*, 25(7), 1232-1238. <https://doi.org/10.1080/13607863.2020.1753014>
- Wilks, S. E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging & Mental Health*, 12(3), 357-365. <https://doi.org/10.1080/13607860801933323>
- Williams, G. A., & Kibowski, F. (2016). *Latent class analysis and latent profile analysis*.
- Yan, T., Curtin, R., & Jans, M. (2010). Trends in income nonresponse over two decades. *Journal of Official Statistics*, 26(1), 145.

