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

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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

Supplementary text 1.

Social Capital

      Interactions with friends and relatives were assessed with six items taken from Office for National Statistics (2008). A sample question is *"How often do you meet up with friends?"* (answer options: Never; Less often than once a month; Once or twice a month; Once or twice a week; On most days). The possible total scores for both interactions with friends and relatives range from 0 to 15; higher scores indicate more frequent interactions. "Don't know" responses were coded as missing. More frequent interactions with friends and relatives indicated higher social capital.

      Civic participation was assessed with a single-item question taken from Office for National Statistics (2008) listing seven civic actions (e.g., contacting a local councilor); see Supplementary Table 1. Participants reported whether in the last 12 months they had engaged in any of the seven listed activities. The possible total score (range: 0-7) was coded into a categorical variable (No participation=0; Participation=1; High participation ≥2) as described in Clare et al. (2020). Based on the distribution of scores no participation was considered an indicator of low social capital, whereas participation and high participation were considered indicators of high social capital.

      Social participation was assessed with a single-item question taken from Office for National Statistics (2008). This question asks individuals to report whether during the last 12 months they had provided any unpaid help to any of the 12 examples; these examples include various groups, clubs, and organizations as well as an "any other help" option, see Supplementary Table 2. The possible total score (range: 0-12) was coded into a categorical variable (No participation= 0; Participation= 1; High participation ≥ 2) as described in Clare et al. (2020). Based on the distribution of scores no participation was considered an indicator of low social capital, whereas participation and high participation were considered indicators of high social capital.

      Neighbourhood trust was assessed with a single-item question taken from Office for National Statistics (2008). This question asked participants to estimate the likelihood of a purse/wallet that they had lost in their local neighbourhood, and which contained their address, being returned to them with nothing missing. Responses were recoded into two

groups: "Likely" comprised the response options very likely and quite likely whereas "Not likely'" comprised the response options not very likely, not at all likely, and don't know. "Likely" was considered an indicator of high social capital, whereas "Not likely" was considered an indicator of low social capital.

Social network was assessed with the 6-item Lubben Social Network Scale (Lubben et al. 2006). Sample question is *"How many relatives do you see or hear from at least once a month?"* (answer options: None; One; Two; Three or four; Five thru eight; Nine or more). The possible total score (range: 0-30) was coded into a binary variable. Scores less than 12 were coded as indicating participants were "Isolated" whereas scores ≥12 were coded as indicating participants were "Not isolated" (Lubben et al. 2006). Isolated was considered an indicator of low social capital, whereas not isolated was considered an indicator of high social capital.

Cultural capital

Education was classified into four groups; no qualifications, school leaving certificate at age 16 (GCSE or equivalent), school leaving certificate at age 18 (A level or equivalent), and University level education.

Cultural participation was assessed with 13 items taken from the Cultural Capital and Social Exclusion Survey (Thomson 2004), see Supplementary Table 3 for the full list of cultural participation activities. Possible total scores ranged between 13 to 65; higher scores indicate more cultural participation. Scores were recoded into two groups: high cultural capital and low cultural capital. Scores were recoded into two groups: high cultural capital and low cultural capital. Scores between 40 and 65 were used to describe high cultural capital. Scores between 40-52 and 53-65 indicated that participants engage with several forms of cultural capital at least once a month or once a week, respectively. Scores <40 were used to describe low cultural capital. Scores between 14-26 and 27-39 indicated that participants engage in activities involving cultural capital only once or less a year or several times per year, respectively. Scores equal to 13 indicated that participants had not engaged in any of the listed cultural activities in the previous year. This scoring is consistent with previous research (Gayo-Cal 2006).

Economic capital

Annual income was used as an indicator of economic capital. To assess annual income a single-item question (*Do you think about your household income in weekly,*

monthly, or yearly terms? Here are incomes in [weekly/monthly/annually] amounts. Which of the figures represents your [and your husband's/wife's/partner's] combined income from all sources, before any deductions for income tax, National Insurance, etc.?) was adapted from the Health Survey for England (Boniface et al. 2012). The question was administered to the person with dementia and carer together in a joint interview; if a person with dementia had no participating carer the question was administered to the person with dementia only. If participants preferred to think of their household income in weekly or monthly instalments these were converted to corresponding annual equivalents in the analysis. Annual income was categorised based on quartiles of participants' scores (<£15600; £15600 to 23399; £23400 to 36399; £36400) as previously described in Clare et al. (2019). In 2014 and 2015 the Median Pensioner income (before housing cost) for people aged ≥65 and living in the United kingdom was £24,492 for pension couple and £12,740 for single pensioner (UK Government 2016).

Stress was assessed with 15-item Relative Stress Scale (Greene et al. 1982). Sample question is *"Do you ever feel that you need a break?"* (answer options: Never, Rarely, Sometimes, Frequent, Always). Higher total score (range: 0-60) indicates greater stress.

Positive experiences of caring were assessed with the 9-item Positive Aspects of Caregiving scale (Tarlow et al. 2004). Sample question is *"Providing help to my relative/friend has made me feel more useful"* (answer options: Disagree a lot; Disagree a little; Neither agree not disagree; Agree a little; Agree a lot). Higher scores (range: 9-45) indicate the experience of a higher number of positive experiences of caring.

Depression was assessed with the 20-item screening tool Center for Epidemiologic Studies Depression Scale-Revised Short Form (Eaton et al. 2004). Total scores (range: 0-60) were dichotomized into Depressed (≥16); Not depressed (<16).

Personal characteristics – carers
Co-morbid conditions were assessed with the Charlson Comorbidity Index (Charlson et al. 2008; Charlson et al. 1987). For each of the 23 listed conditions participants indicated whether they had the condition or not. A higher score (range: 0-23) indicates a more severe level of co-morbidity.

Personal characteristics – People with dementia

Dementia subtype comprised seven diagnostic groups: Alzheimer's disease; vascular dementia; mixed-Alzheimer's disease and vascular dementia; frontotemporal dementia; Parkinson's disease dementia; dementia with Lewy bodies; unspecified/other.

Time since diagnosis comprised four groups (<1 year; 1-2 years; 3-5 years; 6+ years). This variable was calculated by subtracting date of diagnosis where available from date of the first IDEAL assessment and recoding into groups for analysis.

Supplementary Table 1. Frequency of engagement in 7 activities capturing civic participation at baseline

	Statistics n (%)
Contacted a local radio station, television station or newspaper	
Yes	23 (2.3)
No	911 (92.6)
Missing	50 (5.1)
Contacted the appropriate organization to deal with the problem, such as the council	
Yes	131 (13.3)
No	803 (81.6)
Missing	50 (5.1)
Contacted a local councilor or member of parliament	
Yes	72 (7.3)
No	862 (87.6)
Missing	50 (5.1)
Attended a public meeting or neighbourhood forum to discuss local issues	
Yes	115 (11.7)
No	819 (83.2)
Missing	50 (5.1)
Attended a tenants' or local residents' group	
Yes	66 (6.7)
No	868 (88.2)
Missing	50 (5.1)
Attended a protest meeting or joined and action group	
Yes	23 (2.3)
No	911 (92.6)
Missing	50 (5.1)
Helped organize a petition on a local issue	
Yes	16 (1.6)
No	918 (93.3)
Missing	50 (5.1)

Supplementary Table 2. Frequency of engagement in 11 activities capturing social participation at baseline

	Statistics n (%)
Raising or handling money/taking part in sponsored events	
Yes	134 (13.6)
No	797 (81.0)
Missing	53 (5.4)
Leading the group/member of a committee	
Yes	117 (11.9)
No	814 (82.7)
Missing	53 (5.4)
Organizing or helping to run an activity or event	
Yes	194 (19.7)
No	737 (74.9)
Missing	53 (5.4)
Visiting people	
Yes	125 (12.7)
No	806 (81.9)
Missing	53 (5.4)
Befriending or mentoring people	
Yes	39 (4.0)
No	892 (90.6)
Missing	53 (5.4)
Giving advice/information/counselling	
Yes	61 (6.2)
No	870 (88.4)
Missing	53 (5.4)
Secretarial, admin or clerical work	
Yes	77 (7.7)
No	854 (86.9)
Missing	53 (5.4)
Providing transport/driving	
Yes	84 (8.5)
No	847 (86.1)
Missing	53 (5.4)
Representing (e.g. addressing meetings, leading a delegation, talking to a council official)	
Yes	42 (4.3)
No	889 (90.3)
Missing	53 (5.4)
Campaigning	
Yes	17 (1.7)
No	914 (92.9)

Missing	53 (5.4)
Other practical help (e.g. helping out at school, religious group, shopping)	
Yes	132 (13.4)
No	799 (81.2)
Missing	53 (5.4)
Any other help (e.g. helping out at school, religious group, shopping)	
Yes	82 (8.3)
No	849 (86.3)
Missing	53 (5.4)

Supplementary Table 3. Frequency of engagement in 13 activities capturing cultural participation at baseline

	Statistics n (%)
How often do you go to the cinema?	
At least once a week	9 (0.9)
Less often but at least once a month	76 (7.7)
Less often but at least several times a year	241 (24.5)
Once a year or less	305 (31.0)
Never	304 (30.9)
Missing	49 (5.0)
How often do you go to museums?	
At least once a week	6 (0.7)
Less often but at least once a month	28 (2.9)
Less often but at least several times a year	226 (23.2)
Once a year or less	362 (36.1)
Never	313 (31.9)
Missing	49 (5.2)
How often do you go to pubs?	
At least once a week	128 (13.0)
Less often but at least once a month	183 (18.6)
Less often but at least several times a year	296 (30.1)
Once a year or less	90 (9.1)
Never	236 (24.0)
Missing	51 (51.2)
How often do you go to rock concerts?	
At least once a week	1 (0.1)
Less often but at least once a month	2 (0.2)
Less often but at least several times a year	22 (2.2)
Once a year or less	74 (7.5)
Never	836 (85.0)
Missing	49 (5.0)
How often do you go to the opera?	
At least once a week	0 (0.0)
Less often but at least once a month	2 (0.2)
Less often but at least several times a year	32 (3.3)
Once a year or less	135 (13.7)
Never	765 (77.7)
Missing	50 (5.1)
How often do you to bingo?	
At least once a week	17 (1.7)
Less often but at least once a month	9 (0.9)
Less often but at least several times a year	19 (1.9)
Once a year or less	25 (2.5)

Never	864 (87.9)
Missing	50 (5.1)
How often do you go to orchestral to choral concerts?	
At least once a week	0 (0.0)
Less often but at least once a month	17 (1.7)
Less often but at least several times a year	162 (16.5)
Once a year or less	239 (24.3)
Never	513 (52.1)
Missing	53 (5.4)
How often do you go to stately homes or historic sites?	
At least once a week	2 (0.2)
Less often but at least once a month	38 (3.9)
Less often but at least several times a year	331 (33.6)
Once a year or less	321 (32.6)
Never	242 (24.6)
Missing	50 (5.1)
How often do you go to musicals?	
At least once a week	0 (0.0)
Less often but at least once a month	2 (0.2)
Less often but at least several times a year	153 (15.5)
Once a year or less	345 (35.1)
Never	432 (43.9)
Missing	52 (5.3)
How often do you go to the theatre?	
At least once a week	0 (0.0)
Less often but at least once a month	16 (1.6)
Less often but at least several times a year	250 (25.4)
Once a year or less	346 (35.2)
Never	321 (32.6)
Missing	51 (5.2)
How often do you go to art galleries?	
At least once a week	5 (0.5)
Less often but at least once a month	18 (1.8)
Less often but at least several times a year	154 (15.7)
Once a year or less	290 (29.5)
Never	465 (47.2)
Missing	52 (5.3)
How often do you go to night clubs?	
At least once a week	0 (0.0)
Less often but at least once a month	0 (0.0)
Less often but at least several times a year	5 (0.5)
Once a year or less	9 (0.9)
Never	920 (93.5)

Missing	50 (5.1)
How often do you go somewhere to eat out?	
At least once a week	263 (26.7)
Less often but at least once a month	350 (35.6)
Less often but at least several times a year	265 (26.9)
Once a year or less	34 (3.5)
Never	21 (2.1)
Missing	51 (5.2)

Supplementary Table 4. Goodness of fit indices and entropy for the latent profile models

Model	Bayesian information criterion (BIC)	Sample-size adjusted Bayesian information criterion (BIC)	Likelihood ratio test p-value		Entropy
			Vuong-Lo-Mendell-Rubin	Lo-Mendell-Rubin adjusted	
Two-group model	24003.33	23904.87	< .001	< .001	.65
Three-group model	23934.12	23784.84	< .001	< .001	.72
Four-group model	23988.07	23787.98	.01	.013	.78
Five-group model	24060.41	23809.51	.79	.79	.65

The Vuong-Lo-Mendell-Rubin test compares a model with K group to a model with (K-1) group. Significant *p* values indicate that the model with K groups is a better model than the model with K-1 groups.

Supplementary Table 5. Distributions of stress, positive experiences of caring, depression, and personal characteristics for the four latent groups

	Group 1 (n= 195; 20%) *Very low capital*	Group 2 (n= 338; 34%) *Low capital*	Group 3 (n= 247; 25%) *Socially connected*	Group 4 (n= 204; 21%) *Financially secure*
Variables		Mean scores (SD) / n (%)		
Indicators of stress and depression				
Stress at baseline	17.93 (10.04)	19.48 (10.0)	19.12 (9.29)	19.53 (9.50)
Stress at 1-year follow-up	20.98 (10.30)	22.0 (10.40)	21.72 (9.87)	22.09 (9.56)
Stress at 2-year follow-up	22.04 (10.42)	23.80 (11.10)	23.04 (9.72)	24.09 (9.30)
Positive experiences of caring at baseline	30.0 (7.28)	28.60 (7.46)	27.27 (7.25)	26 (7.34)
Positive experiences of caring at 1-year follow-up	28.42 (8.54)	28.20 (7.70)	27.30 (7.16)	26.5 (7.43)
Positive experiences of caring at 2-year follow-up	28.83 (8.43)	28.0 (8.10)	28.04 (7.31)	26.56 (7.58)
Depression at baseline				
Depressed	25 (13.4)	44 (13.6)	20 (8.3)	18 (8.8)
Not depressed	161 (86.6)	281 (86.4)	222 (91.7)	180 (88.2)
Depression at 1-year follow-up				
Depressed	27 (20.1)	50 (20.8)	26 (13.7)	18 (12.2)
Not depressed	104 (79.9)	189 (79.2)	163 (86.3)	129 (87.8)
Depression at 2-year follow-up				
Depressed	18 (19.4)	40 (22.9)	23 (15.3)	14 (11.8)
Not depressed	75 (80.6)	135 (77.1)	127 (84.7)	104 (88.2)
Personal characteristics - carers				
Age in years (Carer), M (SD; range)	74.0 (8.08)	72.5 (8.7)	70.72 (7.34)	72.84 (8.42)
Age group, n (%)				
Aged < 65	23 (11.7)	52 (15.3)	44 (17.6)	30 (14.6)

Aged 65-69	29 (14.9)	60 (17.7)	57 (23.0)	44 (21.3)
Aged 70-74	54 (27.6)	76 (22.6)	69 (28.1)	44 (21.3)
Aged 75-79	36 (18.2)	76 (22.5)	51 (20.7)	41 (20.2)
Aged ≥80	54 (27.6)	74 (21.9)	26 (10.6)	46 (22.6)
Sex, n (%)				
Women	101 (52.1)	92 (27.1)	182 (73.9)	125 (61.0)
Men	93 (47.9)	247 (72.9)	65 (26.1)	80 (39.0)
Personal characteristics – person with dementia				
Diagnosis subtype, n (%)				
Alzheimer's disease	108 (55.4)	173 (51.2)	148 (60.1)	130 (63.6)
Vascular dementia	21 (10.8)	39 (11.5)	24 (9.8)	15 (7.6)
Mixed (Alzheimer's and vascular	40 (20.6)	79 (23.4)	38 (15.5)	33 (16.4)
Frontotemporal dementia	4 (2.2)	14 (4.0)	14 (5.8)	8 (4.1)
Parkinson's disease dementia	8 (4.2)	9 (2.6)	10 (3.9)	5 (2.6)
Dementia with Lewy bodies	7 (3.4)	15 (4.3)	7 (2.9)	6 (2.7)
Unspecified/other dementia	7 (3.4)	10 (3.0)	5 (2.0)	6 (3.0)
Time since diagnosis, n (%)				
< 1 year	95 (53.1)	177 (55.8)	121 (52.4)	92 (50.0)
1-2 years	62 (34.7)	93 (28.9)	82 (35.6)	63 (33.6)
3-5 years	19 (10.5)	44 (13.8)	26 (11.2)	29 (15.2)
≥6 years	3 (1.7)	5 (1.5)	2 (0.8)	2 (1.2)

Supplementary Table 6. Unadjusted multinomial logistic regression models with group membership as the outcome and baseline characteristics of the carer and person with dementia as the predictors

	Group 1 (n= 195; 20%) *Very low capital*	Group 2 (n= 338; 34%) *Low capital*	Group 3 (n= 247; 25%) *Socially connected*	Group 4 (n= 204; 21%) *Financially secure*
		Odds ratios (95% CI)		
Variables				
Carer's age	1.02 (1.01, 1.04)	Reference group	.98 (.96, .99)*	1.01 (.99, 1.02)
Carers' comorbidity	1.01 (.97, 1.06)		.88 (.82, .94)*	.91 (.86, .96)*
Carers' sex (ref: Men)				
Women	2.47 (1.96, 3.14)*		.95 (.74, 1.22)	1.72 (1.37, 2.16)*
Diagnosis subtype (ref: Alzheimer's disease)				
Vascular dementia	.85 (.59, 1.23)		.72 (.49, 1.04)	.52 (.36, .75)*
Mixed (Alzheimer's and vascular)	.81 (.61, 1.08)		.56 (.42, .76)*	.56 (.43, .74)*
Frontotemporal dementia	.49 (.24, 1.01)		1.20 (.69, 2.10)	.80 (.46, 1.39)
Parkinson's disease dementia	1.56 (.84, 2.89)		1.29 (.68, 2.44)	.80 (.40, 1.61)
Dementia with Lewy bodies	.73 (.40, 1.33)		.58 (.30, 1.10)	.52 (.28, .98)*
Unspecified/Other dementias	1.12 (.53, 2.34)		.59 (.29, 1.19)	.86 (.47, 1.57)
Time since diagnosis (ref: < 1 year)				
1-2 years	1.26 (.97, 1.65)		1.31 (1.02, 1.70)*	1.30 (1.01, 1.67)*
3-5 years	.79 (.53, 1.18)		.89 (.60, 1.24)	1.22 (.87, 1.71)
≥6 years	1.24 (.48, 3.19)		.57 (.20, 1.58)	.90 (.33, 2.48)

* Confidence intervals not encompassing 1.

Group 2 was used as reference as it contained the most people and therefore it is the group that may best represent the population of carers.

Supplementary Table 7. Distributions of satisfaction with personal relationships and with the help received from family and friends at baseline for the four latent groups

Variables	Group 1 (n= 195; 20%) *Very low capital*	Group 2 (n= 338; 34%) *Low capital*	Group 3 (n= 247; 25%) *Socially connected*	Group 4 (n= 204; 21%) *Financially secure*
		n (%)		
How satisfied are you with your personal relationships?				
Very dissatisfied	1 (0.6)	3 (1.0)	0 (0.1)	1 (0.7)
Dissatisfied	10 (5.1)	11 (3.4)	12 (4.9)	12 (6.2)
Neither satisfied nor dissatisfied	28 (14.5)	41 (12.4)	32 (13.2)	28 (13.9)
Satisfied	98 (51.8)	178 (53.7)	129 (53.3)	110 (55.5)
Very satisfied	53 (28.0)	99 (29.5)	69 (28.59)	47 (23.7)
How satisfied are you with the support you receive from family?				
Very dissatisfied	21 (11.1)	21 (6.4)	6 (2.32)	6 (3.0)
Slightly dissatisfied	12 (6.4)	16 (4.7)	15 (6.11)	16 (8.3)
Neither satisfied nor dissatisfied	32 (16.6)	58 (17.4)	38 (15.7)	45 (22.9)
Slightly satisfied	24 (12.7)	35 (10.5)	31 (12.9)	27 (13.4)
Very satisfied	96 (50.5)	199 (59.8)	149.7 (62.2)	100 (50.8)
Don't know	5 (2.7)	4 (1.2)	2 (0.8)	3 (1.5)
How satisfied are you with the support you receive from friends?				
Very dissatisfied	12 (6.1)	13 (3.9)	3 (1.1)	3 (1.3)
Slightly dissatisfied	5 (2.4)	10 (3.0)	3 (1.4)	6 (3.0)
Neither satisfied nor dissatisfied	55 (29.0)	80 (23.9)	50 (20.6)	60 (30.2)

Slightly satisfied	38 (20.1)	61 (18.4)	42 (17.4)	39 (19.7)
Very satisfied	58 (30.4)	158 (47.4)	140 (57.9)	86 (42.8)
Don't know	22.8 (12.0)	11 (3.4)	4 (1.6)	6 (3.0)

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