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## article

# 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

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We investigated how carers of people with dementia evaluate their standing in their community and wider society, and if this is related to 'living well'. We used baseline data from the Improving the experience of Dementia and Enhancing Active Life programme and found that carers rated their standing in society higher than in their local community. Higher evaluations of both were associated with enhanced life satisfaction, well-being and quality of life. Initiatives that increase support or engagement in the community or wider society may help to increase carers' perceptions of their social status, enhancing their ability to 'live well'.

**Key words** informal caring • subjective social status • quality of life • well-being • life satisfaction

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## Background

There is an extensive literature focusing on caring and caregiving by family members. Previous research has examined the measurement of caring (Rutherford and Bu, 2018), the provision of caring within the general population, the future provision of caring (Pickard, 2015), caring among specific communities (such as minority groups) (Victor et al, 2019), caring for specific diagnostic groups (such as those with dementia) (Clare et al, 2019b) and the impact of caring (Lindeza et al, 2020). Research has consistently demonstrated that carers of people with dementia report poorer life satisfaction and well-being in comparison to carers supporting people with other long-term conditions and the wider adult population (Pinquart and Sörensen, 2003).

Explanations and interventions addressing the challenges of caring for people with dementia centre upon identifying and responding to stress/support at the individual or family level (see Gilhooley et al, 2016; Cunningham et al, 2019). However, the stress process model of caregiving, developed by Pearlin and colleagues (1990) with carers of people with Alzheimer's disease, suggests that carer outcomes can also be influenced by interactions of stress (or support) at the community as well as the individual and/or family level. Qualitative work by Daly et al, (2013) suggests that during informal social interactions, carers may draw social comparisons or make assessments of themselves in relation to others. When these evaluations are positive, Daly argues that carers experience a greater sense of belonging, connection and citizenship, and, potentially, enhanced well-being.

There has been relatively little attention given to the role of community-level support or stress in compromising the well-being of those caring for people with dementia. Recent policy developments in the UK, such as dementia- and carer-friendly community initiatives, suggest that there is a recognition that promoting greater awareness and understanding of dementia and the caring role in local areas may enhance the well-being of carers. The development of dementia- and carer-friendly communities provides the broad context for our work. The concept of dementia-friendly communities (DFCs) developed from the Age Friendly Cities movement and subsequently the Age-friendly World network. These global initiatives focus upon developing physical and social environments within which older people can age well. DFCs developed initially in Japan in recognition of the fact that most people with dementia live in the community and that we need to promote greater awareness and understanding of dementia to support their ability to 'live well'. The concept of DFCs has gained global appeal, with well over 30 countries adopting their own plans (Alzheimer's Disease International, 2016; Bartlett, 2016; Lin, 2017).

In the UK, in 2012, then Prime Minister David Cameron delivered his *Challenge on Dementia*, which championed DFCs as key to achieving the goal of living well for people with dementia and their carers (Department of Health, 2015). Within the UK, and in parallel with DFCs, the government's 'Carers action plan 2018–2020' included proposals to both raise awareness of the role and contribution of caring, and to build carer-friendly communities (Department of Health and Social Care, 2018). Implicitly, both DFCs and carer-friendly communities recognise that one potential means of enhancing carer well-being may be via enhanced recognition and support for carers in local communities and society more generally. Given the relative neglect of community/societal factors in work using the stress process model approach and a policy approach that includes area and societal factors, our study investigated if

carers' evaluations of their standing in the local community and wider society are associated with well-being.

We can evaluate how individuals perceive their standing in their local community and/or society more broadly using the concept of subjective social status, which is most often measured using a diagram of a ten-rung ladder. Respondents are asked to indicate their own place on this ladder, with those with the highest standing in their local community (as defined by the individual) or society (those with most wealth and the highest educated) at the top and those with the lowest standing at the bottom (Adler et al, 2000). Both community and society ladders have a range of 1–10, with higher scores reflecting higher ratings of individuals' community/societal evaluation. Studies using both the society and community ladders report that the ratings are correlated (Giatti et al, 2012) and that the effect sizes for the ladders are similar (Zell et al, 2018). Subjective social status is an established predictor of physical health outcomes (Adler et al, 2000; Singh-Manoux et al, 2003, 2005; Demakakos et al, 2008; Woo et al, 2010; Johnson et al, 2011; Tang et al, 2016; Cundiff and Matthews, 2017), increased stress response (Adler et al, 2000; Wright and Stepcoe, 2005), greater depressive symptoms (Singh-Manoux et al, 2005; Demakakos et al, 2008) and mortality (Woo et al, 2010; Demakakos et al, 2018), independent of objective measures of socio-economic status (SES), across a range of countries, including the US, Canada, UK, Brazil, Mexico, South Africa and Taiwan, as well as age and demographic groups (Hu et al, 2005; Nobles et al, 2013; Quon and McGrath, 2014; Präg et al, 2016). There is much less evidence, however, focused on how outcomes of living well, such as life satisfaction, well-being and quality of life (QoL), relate to ratings on the society and community ladders (Euteneuer, 2014).

A recent meta-analysis demonstrated that responses on the society and community ladders had small but statistically significant associations with health behaviours and mental and physical health indicators that were independent of objective social status and the inclusion of both ladders in the model (Zell et al, 2018). A study of 298 couples in the Utah Health and Aging Study reported mean scores on the society ladder of 6.1 for men and 5.8 for women aged between 40 and 50 years old, and 6.1 for both on the community ladder. For people aged between 60 and 70 years old, scores on both ladders were higher: 6.6 for men and 6.1 for women on the society ladder; and 6.8 for men and 6.3 for women on the community ladder (Cundiff et al, 2013).

To the best of our knowledge, no study has focused on subjective social status in carers of people with dementia or family carers more generally and well-being outcomes. We identified one study that examined the role of subjective social status using the community ladder for 122 staff working in a long-term care facility in Israel (Ayalon, 2008). This study reported a mean score of 6.3. Higher perceived community standing was associated with lower levels of carer burnout and experiencing more positive aspects of caring. This study focused only on paid carers and how they perceived their standing within the community, not within wider society, and did not measure well-being. However, these findings do hint that interventions focused on enhancing how paid carers feel they are perceived by their local community may have positive benefits for these staff in terms of reduced burnout and a more positive evaluation of their caregiving role.

Given the identified evidence gaps and the development of DFCs and community-based carer support initiatives (Department of Health, 2015; Department of Health and Social Care, 2018), we undertook a novel study with informal carers of people

with dementia to investigate the association between the evaluation of subjective community and societal status and 'living well'. We address two questions: (1) 'How do carers of people with dementia, predominantly family members or friends, perceive their standing in their communities and wider society?'; and (2) 'Are these evaluations related to their ability to 'live well', as measured by life satisfaction, well-being and QoL?' These measures reflect the multifaceted nature of what it means to 'live well' for family carers and older people more widely (Bowling, 2007; Clare et al, 2014), and follows the definition of 'living well' adopted by the Institute of Medicine (2012: 32): 'the best achievable state of health that encompasses all dimensions of physical, mental and social well-being'. These questions have clear policy relevance in terms of: (1) providing insights into the link between well-being and the perceptions that carers have of their place in society; and (2) the potential development of interventions to support the role of carers.

## Design and methods

### *Design and sample*

This study involved analysis of data from carers of people with dementia who took part in the first wave (2014–16) of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study (Clare et al, 2014; Silarova et al, 2018). Participants with dementia and their respective carers were recruited through 29 National Health Service (NHS) sites throughout England, Scotland and Wales. The inclusion criteria required participants to have a clinical diagnosis of dementia (of any subtype), to be in the mild to moderate stages (as indicated by an Minim Mental State Examination (MMSE) score of 15 or above [Folstein et al, 1975]) and to be living in the community at the time of study enrolment. People with dementia considered to meet the study inclusion criteria, as well as their carers if appropriate, were contacted by telephone/letter or spoken to in person during clinic appointments to establish their interest in participating in the study. Those who expressed interest were sent further information and visited at home, and, where appropriate, consent was taken from the people with dementia and carers who agreed to participate. In total 1,278 informal carers agreed to take part in the IDEAL study.

The assessments for the baseline wave of data collection involved the comprehensive collection of a significant range of items, measures and scales (see Clare et al, 2014). In recognition of participant burden, we allowed three visits to complete data collection and obtain consent and initiate data collection. The first visit consisted of an eligibility check and consent process; the second and third visits were research visits and were of two hours' duration. People with dementia were interviewed in person while carers self-completed the study questionnaires while the researcher was interviewing the person with dementia. This meant that any queries or needs for additional support with completion expressed by the carer could be addressed by the researcher. Participants were offered a shopping voucher (£10) as a token of appreciation for taking part in the study upon completion of the assessment. Data presented in this article are drawn from version 4.5 of the data set.

The IDEAL study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405) and the Ethics Committee of the School of Psychology,

Bangor University (reference 2014 – 11684). The IDEAL study is registered with UK Clinical Research Network (UKCRN) (registration number 16593).

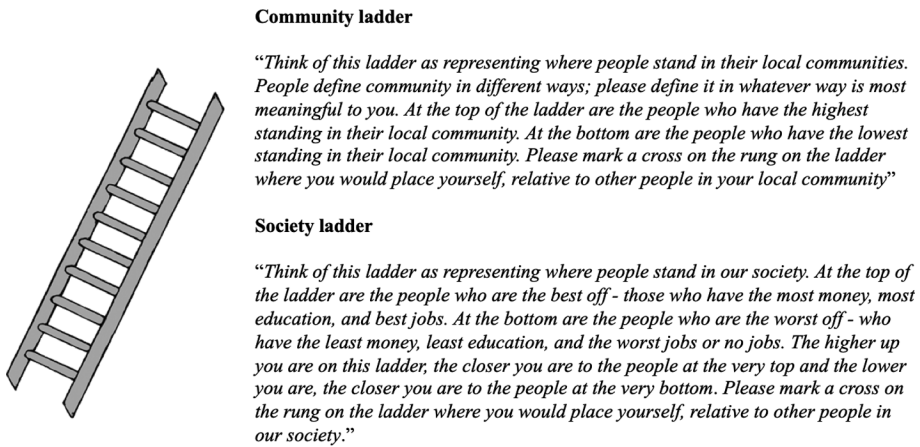
## Measures

### *Subjective social status*

Subjective social status was measured using the Macarthur Scale of Subjective Social Status (Adler et al, 2000). Participants were given two pictures of a ten-rung ladder and asked to place a cross on the rung on which they feel they stand, first, relative to other people in society based on an evaluation of financial status, education and employment (society ladder) and, second, relative to other people in their community (community ladder). The community ladder does not prescribe how social standing is conceptualised, nor does it specify a definition of the local community. These terms are interpreted by participants according to their own understandings (for full descriptors, see Figure 1). A recent article examining the psychometric properties of both subjective social status scales found strong construct validity for this measure (Cundiff et al, 2013).

### *'Living well' indicators*

Given our adoption of the definition of 'living well' proposed by the Institute of Medicine (2012), we included life satisfaction, well-being and QoL in our study as, in combination, these encompass the meaning of 'living well' (Clare et al, 2019a; 2019b). Life satisfaction was measured using the Satisfaction with Life Scale (Diener et al, 1985). It includes five positively worded statements rated on a seven-point scale from 'strongly disagree' to 'strongly agree'. Possible scores range from 5 to 35, with higher scores indicating greater life satisfaction. Well-being was measured using the World Health Organization – Five Well-Being Index (WHO-5) (Bech, 2004). Participants were asked how much of the time over the past two weeks they 'have felt cheerful and in good spirits', 'calm and relaxed', 'active and vigorous', 'woke up feeling fresh and rested' and 'my daily life has been filled with things that interest me'. Each item is rated on a six-point Likert scale from 0 (at no time) to 5 (all the time). The raw score was transformed into a percentage score where 0 signifies the worst possible well-being and 100 represents the best possible well-being. QoL was measured using the World Health Organization Quality-of-Life Scale (WHOQOL-BREF) instrument (Skevington et al, 2004). It comprises 26 items that measure the broad domains of physical health, psychological health, social relationships and environment, plus two general questions, and are rated on a 1–5 scale. The mean score for items within each domain is used to calculate the domain score. The domain score is then multiplied by 4 to give a score out of 100. For the purposes of the present analysis, to derive a single QoL score, the four domains and two general questions were included in a factor analysis model and a predicted factor score was derived for those with complete information (Clare et al, 2019b). For convenience, the three measures together will be referred to as 'living well' measures.

**Figure 1: The Macarthur Scale of Subjective Social Status**

Source: [Adler and Stewart \(2007\)](#).

### **Covariates**

Our covariates were selected because they are well-established predictors of well-being outcomes in carers. Two indicators of objective social status were included: education, which was based on highest qualification achieved (categorised as: no qualifications; school leaving certificate at age 16; school leaving certificate at age 18; university); and SES, which was measured using the National Statistics Socio-economic Classification (NS-SEC) scheme, based on occupations and employment relationships ([Office for National Statistics, no date](#); [Rose and Pevalin, 2005](#)). For the purposes of analysis, the three-class version of the scale was used.

Additional demographic information was collected on age, sex, relationship to the person with dementia (spouse or partner, compared to other family member or friend; kin relationship), marital status (married or in civil partnership, compared to not married [single, widowed, divorced or separated]), the number of hours spent caring per day (less than one hour, one to ten hours and over ten hours) and the specific clinical diagnosis of the person with dementia recorded by researchers from recruitment sites when participants were enrolled into the study.

Our choice of covariates was informed by two factors: (1) previous literature using the subjective social status measure; and (2) carer-specific literature. In prior studies of subjective social status, socio-demographic indicators, such as age and sex, have been found to moderate the relationship between subjective social status and health ([Tang et al, 2016](#); [Cundiff and Matthews, 2017](#); [Zell et al, 2018](#)). In line with the wider literature on subjective social status, we included objective indicators of SES. In terms of the carer literature, age, sex and education may also influence how carers perceive their role (see, for example, [Brodaty and Donkin, 2009](#)). The stress process model ([Pearlin et al, 1990](#)) highlights that caring occurs in a social context and therefore key socio-demographic factors, such as age, sex, kin relationship, SES and education, may inform health and well-being outcomes and moderate the relationship between subjective social status and living well.



### Statistical analyses

Associations between subjective social status and key carer characteristics were assessed using univariate analysis of variance (ANOVA) for categorical variables. To investigate the influence of missing data, we imputed missing values using multivariate imputation by chained equations. Missing data ranged from 0.9 per cent (marital status) to 8.2 per cent (SES) and, overall, 22.7 per cent of participants had missing data on one or more variable of interest. We included all covariates from the analyses in the imputation model and 23 imputed data sets were generated. The number of complete data sets generated was determined following [White et al's \(2011\)](#) guidelines. We conducted a series of four multivariate regression models with both the community and society ladders serving as independent variables, and carers' life satisfaction, well-being and QoL as the outcome variables. Our models were built iteratively in order to establish the importance of subjective social status independent of established factors linked with our living well outcomes. In model 1, we included only the two measures of subjective social status to enable us to establish the relative strength of the two measures. In model 2, we adjusted for the key personal characteristics of the carers (age, sex, marital status and kin relationship). In model 3, the intensity of the role (measured by the number of hours spent caring per day) and the specific diagnosis of the person with dementia were added to the model. In model 4, we included the two indicators of objective social status – education and SES – in order to see whether any associations remained following their inclusion. Multivariate regression analyses were implemented in Stata's multiple imputation suite of commands ([StataCorp, 2015](#)). Results of analyses conducted on each complete data set generated by imputation were combined using Rubin's (1996) rules. Results are presented as unadjusted coefficients (B) with 95 per cent confidence intervals (CIs). All data were analysed using Stata 14.2 ([StataCorp, 2015](#)).

### Results

[Table 1](#) sets out the descriptive characteristics of the sample. Just over two thirds (69 per cent) of the carers were female, 72 per cent were aged 65 and older, and the vast majority (81 per cent) were spouses or partners of the person with dementia. Almost half (44 per cent) of carers were in the highest SES classification, 26 per cent had a university degree and the sample is predominantly white British. A little over one third (39 per cent) of carers reported that they provided care for ten hours or more per week. In terms of the person with dementia, just over half (56 per cent) had a diagnosis of Alzheimer's disease, 21 per cent had mixed Alzheimer's and vascular dementia, and 11 per cent had vascular dementia only.

The mean score on the ten-rung community ladder was 6.2 (SD = 1.8) and on the society ladder was 6.6 (SD = 1.5), with a mode of 6 for both (see [Table 1](#)) (for the distribution of responses on each ladder, see [Figures 2](#) and [3](#)). The bivariate association between the two ladders was relatively large:  $r = 0.58$  ( $p < 0.001$ ) and is very similar to that reported by [Zell and colleagues \(2018\)](#) in their recent meta-analysis ( $r = 0.53$ ). There were significant differences within our sample for both community and society ladder rankings, with females rating their standing in society and the community lower than males; unmarried carers ranked themselves lower than married carers, and those without educational qualifications ranked themselves lower than those educated to at least degree level. On the society ladder only, those caring for over ten hours

**Table 1: Scores on the two ladders for the whole sample of carers and for specific subgroups, and analyses of between-group differences**

		Society ladder (N = 1,227)		Community ladder (N = 1,210)	
Variable	N (%)	Mean (SD)	p	Mean (SD)	p
Total	1,278	6.6 (1.5)		6.2 (1.8)	
Age group					
< 65	364 (28.5%)	6.3 (1.6)	< 0.001	5.9 (1.8)	0.002
65-9	209 (16.4%)	6.7 (1.5)		6.3 (1.8)	
70-4	267 (20.9%)	6.4 (1.4)		6.2 (1.8)	
75-9	223 (17.5%)	6.8 (1.4)		6.5 (1.6)	
80+	215 (16.8%)	6.9 (1.4)		6.5 (1.8)	
Sex					
Men	394 (30.8%)	6.7 (1.5)	0.006	6.4 (1.7)	0.006
Women	884 (69.2%)	6.5 (1.5)		6.1 (1.8)	
Marital status (missing = 11)					
Married	1,147 (90.5%)	6.6 (1.4)	< 0.001	6.3 (1.8)	0.004
Not married	120 (9.5%)	5.9 (1.7)		5.8 (1.8)	
Education (missing = 51)					
No qualifications	263 (21.4%)	5.9 (1.6)	< 0.001	5.7 (1.8)	< 0.001
School leaving certificate at age 16	272 (22.2%)	6.4 (1.4)		6.0 (1.8)	
School leaving certificate at age 18	374 (30.5%)	6.5 (1.5)		6.3 (1.7)	
University	318 (25.9%)	7.3 (1.2)		6.7 (1.6)	
NS-SEC (missing = 104)					
Level 1 (high)	511 (43.5%)	6.9 (1.4)	< 0.001	6.5 (1.7)	< 0.001
Level 2	390 (33.2%)	6.5 (1.4)		6.0 (1.7)	
Level 3 (low)	273 (23.2%)	6.1 (1.6)		5.9 (1.8)	
Kin relationship					
Spouse/partner	1,034 (80.9%)	6.6 (1.5)	0.140	6.3 (1.8)	0.423
Family/friend	244 (19.1%)	6.4 (1.5)		6.1 (1.8)	
Dementia subtype					
Alzheimer's disease	712 (55.7%)	6.7 (1.5)	< 0.001	6.3 (1.8)	0.257
Vascular dementia	141 (11.0%)	6.2 (1.5)		6.1 (1.8)	
Mixed Alzheimer's disease and vascular dementia	262 (20.5%)	6.4 (1.4)		6.2 (1.7)	
Frontotemporal dementia	45 (3.5%)	6.4 (1.6)		6.1 (1.4)	
Parkinson's disease dementia	43 (3.4%)	7.0 (1.5)		6.6 (1.8)	
Dementia with Lewy bodies	43 (3.4%)	6.4 (1.4)		5.7 (1.9)	
Unspecified/other dementia	32 (2.5%)	6.5 (1.7)		6.0 (1.8)	
Hours of care per day (missing = 15)					
Less than 1 hour	278 (22.0%)	6.8 (1.4)	0.001	6.4 (1.7)	0.134
1-10 hours	498 (39.4%)	6.6 (1.5)		6.3 (1.7)	
Over 10 hours	487 (38.6%)	6.4 (1.5)		6.1 (1.9)	



**Table 2: Results of multivariate regression between ratings of subjective social status and scores on living well measures**

	Life satisfaction	Well-being	QoL
	Coef (95% CI)	Coef (95% CI)	Coef (95% CI)
Model 1 – both ladders together			
Society ladder	0.86 (0.56, 1.16)***	2.43 (1.52, 3.33)***	0.39 (0.30, 0.49)***
Community ladder	0.36 (0.11, 0.60)**	1.56 (0.81, 2.31)***	0.11 (0.03, 0.18)**
Model 2 – model 1 ± carer age, sex, marital status and kin relationship			
Society ladder	0.75 (0.45, 1.05)***	2.41 (1.51, 3.31)***	0.39 (0.30, 0.48)***
Community ladder	0.31 (0.07, 0.56)*	1.43 (0.69, 2.16)***	0.10 (0.02, 0.18)*
Model 3 – model 2 ± hours of care and dementia diagnosis			
Society ladder	0.71 (0.41, 1.00)***	2.17 (1.28, 3.03)***	0.37 (0.28, 0.46)***
Community ladder	0.38 (0.06, 0.54)*	1.43 (0.71, 2.15)***	0.09 (0.02, 0.18)*
Model 4 – model 3 ± education and social class			
Society ladder	0.81 (0.51, 1.12)***	2.08 (1.16, 3.01)***	0.36 (0.26, 0.45)***
Community ladder	0.31 (0.07, 0.55)*	1.40 (0.68, 2.12)***	0.10 (0.02, 0.17)*
Education			
No qualifications	Ref	Ref	Ref
School leaving certificate at age 16	-1.98 (-3.07, -0.89)***	0.37 (-2.88, 3.63)	-0.15 (-0.50, 0.19)
School leaving certificate at age 18	-1.02 (-2.04, 0.01)	3.06 (-0.01, 6.14)	0.05 (-0.28, 0.37)
University	-1.48 (-2.72, -0.24)*	1.61 (-2.13, 5.35)	0.11 (-0.28, 0.51)
NS-SEC			
Level 1 (high)	Ref	Ref	Ref
Level 2	0.39 (-0.48, 1.27)	1.19 (-1.48, 3.85)	0.20 (-0.07, 0.48)
Level 3 (low)	0.52 (-0.55, 1.59)	-0.11 (-3.30, 3.07)	-0.02 (-0.37, 0.32)

Notes:  $N = 1,278$ . \*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$ .

a day had a significantly lower score than those caring for less than an hour a day, as did those caring for a person with Parkinson’s disease dementia compared with other diagnostic groups.

The results from the multivariate models indicate that subjective social status is associated with all three indicators of living well (see Table 2). Society ladder associations are linked with higher scores for ‘living well’ in comparison to the community ladder. In our baseline model 1, higher ratings on both ladders were linked with higher scores for all three of our ‘living well’ measures – life satisfaction (0.86; 95 per cent CI 0.56, 1.16; and 0.36, 95 per cent CI 0.11, 0.60), well-being (2.42, 95 per cent CI 1.52, 3.33; and 1.56, 95 per cent CI 0.81, 2.31) and QoL (0.39, 95 per cent CI 0.30, 0.49; and 0.11, 95 per cent CI 0.03, 0.18) – and remained following adjustment for age, sex, marital status and kin relationship (model 2), and caring hours and dementia diagnosis (model 3).

Figure 2: The distribution of rankings on the society ladder

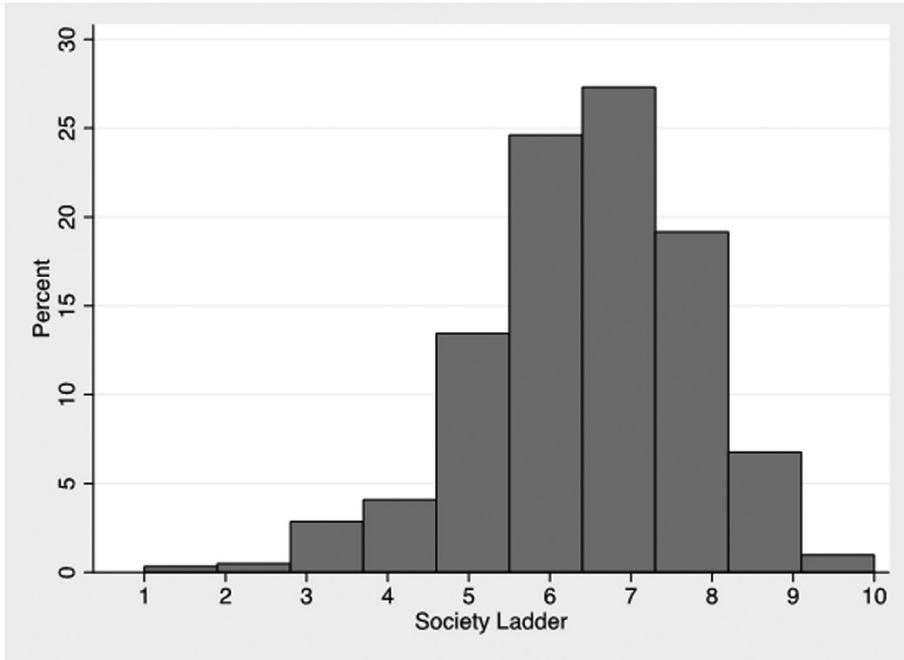


Figure 3: The distribution of rankings on the community ladder

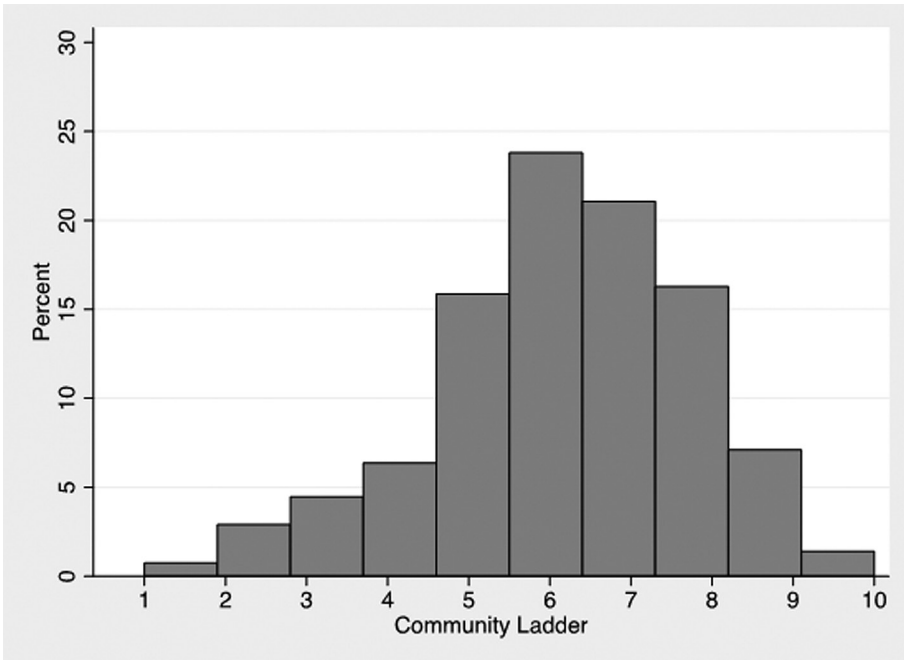


Table 3: Fully adjusted model of the association between subjective social status and living well

	Life satisfaction		Well-being		QoL	
	B (95% CI)	P	B (95% CI)	P	B (95% CI)	P
Society ladder	0.81 (0.51, 1.12)	< 0.001	2.08 (1.16, 3.00)	< 0.001	0.36 (0.26, 0.45)	< 0.001
Community ladder	0.31 (0.07, 0.55)	0.011	1.40 (0.680, 2.12)	< 0.001	0.10 (0.02, 0.17)	0.014
Sex						
Male	Ref		Ref		Ref	
Female	-1.97 (-2.73, -1.21)	< 0.001	-8.64 (-10.97, -6.31)	< 0.001	-0.54 (-0.79, -0.30)	< 0.001
Age group						
< 65	Ref		Ref		Ref	
65-9	0.87 (-0.34, 2.09)	0.157	4.08 (0.40, 7.76)	0.030	0.39 (0.01, 0.77)	0.047
70-4	1.05 (-0.11, 2.20)	0.075	3.91 (0.40, 7.42)	0.029	0.27 (-0.10, 0.63)	0.148
75-9	1.52 (0.30, 2.73)	0.014	2.65 (-1.04, 6.34)	0.159	0.28 (-0.10, 0.67)	0.149
80+	1.28 (0.11, 2.56)	0.048	0.26 (-3.56, 4.07)	0.895	-0.05 (-0.45, 0.35)	0.800
Marital status						
Married	Ref		Ref		Ref	
Not married	-1.85 (-3.16, -0.53)	0.006	3.30 (-0.62, 7.22)	0.099	-0.02 (-0.43, 0.39)	0.913
Kin relationship						
Spouse/partner	Ref		Ref		Ref	
Family/friend	1.83 (0.63, 3.03)	0.003	3.61 (-1.01, 6.23)	0.157	0.45 (0.07, 0.83)	0.020
Education						
No qualifications	Ref		Ref		Ref	
School leaving certificate at age 16	-1.98 (-3.07, -0.89)	< 0.001	0.37 (-2.88, 3.62)	0.823	-0.15 (-0.50, 0.19)	0.378

(Continued)

Table 3: (Continued)

	Life satisfaction		Well-being		QoL	
	B (95% CI)	P	B (95% CI)	P	B (95% CI)	P
School leaving certificate at age 18	-1.02 (-2.04, 0.01)	0.052	3.06 (-0.01, 6.14)	0.051	0.05 (-0.28, 0.37)	0.783
University	-1.48 (-2.72, -0.24)	0.019	1.61 (-2.13, 5.35)	0.398	0.11 (-0.28, 0.51)	0.570
NS-SEC						
Level 1 (high)	Ref		Ref		Ref	
Level 2	0.39 (-0.48, 1.26)	0.378	1.19 (-1.48, 3.85)	0.383	0.20 (-0.07, 0.48)	0.150
Level 3 (low)	0.52 (-0.56, 1.59)	0.345	-0.11 (-3.30, 3.07)	0.944	-0.02 (-0.37, 0.32)	0.898
Dementia subtype						
Alzheimer's disease	Ref		Ref		Ref	
Vascular dementia	-0.16 (-1.30, 0.97)	0.776	-0.73 (-4.10, 2.63)	0.669	0.03 (-0.33, 0.38)	0.880
Mixed Alzheimer's disease and vascular dementia	0.41 (-0.47, 1.28)	0.360	0.06 (-2.57, 2.69)	0.963	0.11 (-0.16, 0.39)	0.428
Frontotemporal dementia	-1.06 (-2.92, 0.80)	0.263	-1.63 (-7.27, 3.99)	0.568	-0.01 (-0.60, 0.58)	0.966
Parkinson's disease dementia	-2.18 (-4.06, -0.29)	0.023	-5.14 (-10.84, 0.57)	0.078	-0.53 (-1.13, 0.07)	0.085
Dementia with Lewy bodies	-2.34 (-4.24, -0.45)	0.015	-3.20 (-8.94, 2.54)	0.275	-0.27 (-0.86, 0.33)	0.380
Unspecified/other dementia	-0.86 (-3.06, 1.35)	0.445	1.29 (-5.29, 7.88)	0.700	-0.29 (-0.97, 0.40)	0.411
Hours of care per day						
Less than 1 hour	Ref		Ref		Ref	
1-10 hours	-1.62 (-2.53, -0.72)	0.001	-5.04 (-7.76, -2.32)	< 0.001	-0.45 (-0.73, -0.16)	0.002
Over 10 hours	-2.80 (-3.73, -1.87)	< 0.001	-9.14 (-11.95, -6.34)	< 0.001	-0.92 (-1.21, -0.62)	< 0.001

Note: N = 1,278.

Following the addition of SES and education (model 4), the society ladder remained a predictor of living well in carers of people with dementia, and a small but significant association remained between the community ladder and the three living well indicators. In this fully adjusted model, a higher ranking on the society ladder was associated with an increase of 0.81 points in life satisfaction (95 per cent CI 0.51, 1.12,  $p < 0.001$ ), 2.08 points in well-being (95 per cent CI 1.16, 3.00,  $p < 0.001$ ) and 0.36 in QoL (95 per cent CI, 0.26, 0.45,  $p < 0.001$ ), and a higher ranking on the community ladder was associated with an increase of 0.31 points in life satisfaction (95 per cent CI 0.07, 0.55,  $p = 0.011$ ), 1.40 in well-being (95 per cent CI 0.68, 2.12,  $p < 0.001$ ) and 0.10 in QoL (95 per cent CI, 0.02, 0.17,  $p = 0.014$ ). Neither SES nor education was significantly associated with the living well indicators when other factors were taken into account. Full details of the fully adjusted model are provided in Table 3.

## Discussion

The global development of DFCs and country-specific initiatives such as the UK 'Carers action plan' and carer-friendly communities raises the question of whether such initiatives change perceptions of the value of caring, both locally and nationally, and whether this enhance carers' well-being. We believe that this is an important evidence gap to address and, to the best of our knowledge, this is the first study we are aware of that has examined the associations between subjective social status and indicators of 'living well' in informal carers.

This study is one of the few that has included both society and community ladders in the analysis. Zell et al (2018) report that of the 374 articles examining the relationship between subjective social status and health that they identified, 231 used the society ladder only and 86 used both. We contextualise our findings by discussing three elements of our results: the relationship between the community and society ladder scores; the comparative values of scores; and the relationship between scores and socio-demographic factors. Our carers rated their perceived standing in society higher than their perceived standing in the community, with mean ladder scores of 6.6 and 6.2, respectively. This is consistent with the study by Garbarski (2010), who used the Wisconsin Longitudinal Study (mean ladder scores of 6.6 and 6.5, respectively), and the study by Wolff et al (2010), who did not use the ladder, but asked a similar set of subjective status evaluation questions; however, it is inconsistent with others (Cundiff et al, 2013; Euteneuer, 2014; Zell et al, 2018). Our finding may reflect the fact that our sample of carers feels less supported or valued in their local community, perceiving their standing in their local community to be lower than their standing in society, which encompasses their educational level, income and occupation. This latter explanation may be plausible given that our sample contained a very high proportion with a degree (25.9 per cent) and post-compulsory education (30 per cent). The inconsistency of findings across studies may reflect age and health status differences in samples or the cultural context of society within which research is being conducted. It may also potentially reflect the specific nature of our sample, where the experience of difficult local interactions may perhaps generate a lack of perceived standing in their locality and hence a lower community score.

Population norms for these two measures of subjective social status vary considerably between and within populations, and there is more data published for the society than

community ladder. Using the English Longitudinal Study of Ageing, Demakakos et al (2008) report a mean society ladder score of 5.9. Using the Health and Retirement Survey for the US, Zahodne et al (2018) report a mean society ladder score of 6.7, which is very similar to our 6.6 score. Responses to these types of questions are culturally sensitive, making cross-national research problematic. Mean scores reported for the society ladder using data for 29 countries in the International Social Survey Programme were lowest in Bulgaria (approximately 4.2) and highest in Denmark (approximately 6.7) (Präg et al, 2016). Goldman et al (2006), in their study of Taiwan, report mean community and society ladder scores of 4.3 and 3.9, respectively. Hu et al's (2005) study of older people in Taiwan also reported lower figures on the society ladder, with a mean score of 3.9. They argue that the lower score in comparison to other studies may be related to cultural factors, where a higher value may be placed on modesty and humility, especially in older age groups.

How do our findings fit with existing evidence? Our finding that male carers rated their social and community standing higher than female carers is in accordance with previous studies (Demakakos et al, 2008; Woo et al, 2008). We also observed an increase in mean scores with age. This is in line with the study from Utah, which reported mean scores on the society ladder of 6.1 for men and 5.8 for women aged between 40 and 50 years old, and 6.1 for both on the community ladder. For those aged 60 to 70, scores increased to 6.6 on the society ladder and 6.8 on the community ladder for men, and 6.1 and 6.3, respectively, for women (Cundiff et al, 2013).

Overall, for carers of people with dementia, subjective ratings of relative standing in the local community and wider society are positively related to life satisfaction, well-being and QoL (Euteneuer, 2014). The small but significant associations between subjective social status and living well are consistent with findings from the recent meta-analyses examining the relationship between both ladders and mental and physical health outcomes (Zell et al, 2018). Although our findings suggest that this relationship was weaker using the community ladder, there was still a positive link with our well-being outcomes. The observed relationships were independent of education and SES, and our results suggest that these two indicators of objective social status have limited association with 'living well'. This supports previous research, where subjective social status was more consistently and strongly related to health outcomes than more objective measures of SES (Singh-Manoux et al, 2005; Euteneuer, 2014). Females also reported lower levels of all three indices of 'living well' in comparison with male carers, and this is supported by prior research on gender differences in caring (Pinquart and Sörensen, 2006).

Although we observed a positive relationship between subjective social status and 'living well', the effect sizes observed were small. Recent analyses by Clare and colleagues (2019b) demonstrated that when considering a number of life domains together, psychological health had the biggest impact on 'living well' for carers, with socio-demographic indicators, such as social class and subjective social status, having a limited but meaningful effect. Similarly, a systematic review by Farina and colleagues (2017) found no strong evidence regarding associations between demographic characteristics of the carer, such as educational level, and carer QoL.

Focusing on factors that are amenable to intervention, such as psychological (ill) health may potentially enable us to improve the well-being of carers. Our results indicated that carers who provided more than ten hours of care per day ranked themselves lower on both the society and community ladders in comparison with

those providing fewer hours of care per day. Providing fewer hours of care was also associated with better life satisfaction, well-being and QoL, suggesting that providing support for carers may offer the potential for enhanced well-being.

It is feasible that caring itself may change how carers perceive their standing in their local community and in society (Daly et al, 2013; Keating and Eales, 2017). Often, caring duties mean that individuals are not as able to actively contribute to society as they have done in the past, for example, they might have to give up community roles or full-time employment. As our study is cross-sectional, we do not have information about previous perceived standing in the community; however, we will be able to investigate the associations longitudinally in the future as the IDEAL programme is a longitudinal cohort study. In addition, both people with dementia and their carers may experience stigma following a diagnosis of dementia; therefore, carers may also find themselves excluded from their local community and society (Daly et al, 2013). In their theory of 'sustaining place', Daly and colleagues (2013) outline how carers' sense of place may be linked to factors such as their social identity and place within society and organisational structures. At times, carers reported a sense of 'living on the fringes' due to stigma and a change in how they contributed to or engaged with the local community and their social networks. This may, in part, explain why carers reported lower standing within their local community. Similarly, negative interactions with health and social care services were also highlighted by some carers as leading to a sense of marginalisation (Daly et al, 2013). Support for carers via dementia and carer-friendly initiatives may offer a potential route to enhanced carer well-being, both directly and indirectly by changing knowledge and attitudes towards carer roles.

As far as we are aware, there are few, if any, studies from Great Britain that have investigated both ladders, or that have investigated carers of people with dementia or other long-standing illnesses or disabilities. As such, the inferences we can draw are limited. However, the lower ratings on the subjective social status community ladder in comparison with the society ladder could suggest that interventions aimed at enhancing social engagement in local communities may help to improve ability to 'live well' and may help individuals feel more part of their local communities. The provision of services within the local community may also be of importance. Initiatives that enable carers to maintain engagement in the community may help to increase carers' perceptions of their status in the local community. While it is still unclear as to the impact of initiatives such as DFCs on carers of people with dementia, the recent proposals to raise awareness of caring and to build carer-friendly communities included in the UK government 'Carers action plan 2018–2020' (Department of Health and Social Care, 2018) could also have an important role here. The action plan recognises that carers need better community support and plans to ensure that there is better support for carers in their local communities and in areas such as employment. Continuing to be employed while an informal carer of people with dementia has recently been found to positively affect health-related QoL in carers in the IDEAL programme (Clarke et al, 2020), suggesting that employment may protect against the responsibilities of care and caregiving stress. A recent qualitative study found that dementia cafes offered valuable support for carers and provided an opportunity for respite from their caring role (Greenwood et al, 2017). Initiatives such as these may go some way to enhance perceptions of support and standing within the local community, as well as helping to improve the well-being of carers.



### ***Strengths and limitations***

To the best of our knowledge, this is one of the first studies to examine how informal carers perceive their standing in society and in their local community. Further, it has added to the existing literature examining the role of both ladders rather than focusing on the society one. However, there are several limitations and caution is needed in interpreting our findings. First, it is not possible to establish causal relationships in this cross-sectional study. Longitudinal data would enable us to see whether the subjective social status rankings change over time, along with their impact on ‘living well’ indicators. As IDEAL is a longitudinal study, we will be able to examine these associations prospectively. We were unable to consider cultural and ethnic differences as the sample consisted almost entirely of white carers. Prior studies have indicated that respondents from black, Asian and minority ethnic (BAME) groups may report higher scores on the community ladder in comparison with white respondents (Cené et al, 2016), and may rate their standing within their local community higher in comparison to their standing in society. It has recently been argued that the community status ladder may reflect subjective social status in BAME groups more accurately than the social ladder as it does not make explicit reference to objective indicators of SES (Tang et al, 2016). Therefore, it will be important to consider carers from BAME groups in future studies.

### **Conclusions**

The way in which informal carers of people with dementia evaluated their subjective social status was positively related to their ratings of life satisfaction, well-being and QoL. The rankings on both the society and community ladders were linked with indicators of living well, whereas educational level and occupational SES were not. Carers reported lower subjective standing in their communities than in society. Interventions aimed at enhancing support in local communities may help to improve carers’ perceptions of their standing within their communities and enhance ability to ‘live well’.

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## 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: <http://reshare.ukdataservice.ac.uk/854293/>.

## Conflict of interest

The authors declare that there are no conflicts of interest.

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