

RESEARCH ARTICLE

Initiating activities of daily living contributes to well-being in people with dementia and their carers

Clarissa M. Giebel^{1,2}  and Caroline Sutcliffe³¹School of Health Sciences, University of East Anglia, Norwich, UK²Division of Neuroscience and Experimental Psychology, University of Manchester, Manchester, UK³Personal Social Services Research Unit, The University of Manchester, Manchester, UKCorrespondence to: C. Giebel, E-mail: c.giebel@uea.ac.uk

Objective: Problems with everyday functioning are linked to reduced well-being in people with dementia (PwD) and their carers. However, previous research has almost solely investigated the performance of everyday activities, and global functioning without analysing individual activities. This study explored how deficits in initiating and performing individual activities were associated with carer burden and poorer quality of life of carers and PwD.

Methods: Carers of people with mild dementia were recruited via 10 National Health Service Trusts, as well as through attending six carer support groups. Carers were asked to complete the revised Interview for Deteriorations in Daily Living Activities in Dementia 2 (R-IDDD2), and measures on carer burden, well-being, and person with dementia well-being. Data were analysed using correlation analysis.

Results: Two hundred and seventy-two carers completed the R-IDDD2. Carers were grouped into those with low or high ratings of well-being based on the mean scores. All but three activities on the initiative and/or performance scale were significantly associated with carer burden and carer and PwD quality of life. Engaging in hobbies and maintaining an active social life were most strongly associated with carer and PwD well-being. Initiating computer use, driving, and medication management were not related to carer burden.

Conclusions: Findings from this study can have direct implications for improving care management early in the disease. Post-diagnostic support needs to provide more opportunities for PwD, and their carers, to engage in social groups, whilst interventions targeted at living well with dementia need to particularly improve the initiative of engaging in individual hobbies. © 2017 The Authors. *International Journal of Geriatric Psychiatry* published by John Wiley & Sons Ltd.

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Introduction

Living well with dementia is important once a diagnosis has been made. With an estimated 46 million cases worldwide (Alzheimer's Disease International, 2015), there is a much larger number of people who are affected by the condition: carers and other family members. Symptoms of dementia therefore not only affect the quality of life (QoL) of the person with dementia (PwD) (Beerens *et al.*, 2013; Orgeta *et al.*, 2015), including aspects of the person's physical, social, and psychological life (Birren *et al.*, 1991), but

also the QoL and stress that informal carers, and thus family members, might experience (Mioshi *et al.*, 2013; Sutcliffe *et al.*, 2016).

Unpaid family carers carry the greatest care burden in dementia (Prince *et al.*, 2014). As the disease progresses, carers have an increasing level of caring responsibilities, and depending on their coping strategies, this can have a negative impact on their burden and QoL (Mioshi *et al.*, 2013; Sutcliffe *et al.*, 2016). Depending on the symptom severity, family carers can become unable to cope with the symptoms on their own and need to engage paid carers, or decide

for the PwD to transition into a care home (Toot *et al.*, 2017). In order to delay care home placement and prolong living at home, carers' levels of well-being need to be maintained at high levels.

One primary symptom of dementia that is found to impact on the QoL is everyday functioning (Andersen *et al.*, 2004; Beerens *et al.*, 2016; Giebel *et al.*, 2016a). From the early stages of dementia onwards, people are found to struggle in performing complex instrumental activities of daily living (IADLs), such as using the telephone, and also maintaining more basic ADLs, such as continence (Monaci and Morris, 2012; Bier *et al.*, 2013; Giebel *et al.*, 2017a). In a large European analysis of community-dwelling PwD at the transition point into long-term care, deficits in ADLs were found to contribute to increased carer burden (Sutcliffe *et al.*, 2016) and to reduced PwD QoL (Beerens *et al.*, 2016), which is corroborated in other studies (Fauth *et al.*, 2016). However, how individual daily activities are related to well-being has received little attention to date. Difficulties in maintaining a social life and following current affairs were found to be linked to reduced well-being in both carers and PwD (Giebel *et al.*, 2016a). Exploring the overall association between everyday functioning and well-being offers little insights into this relationship. In order to help PwD and their carers on an individual basis, research needs to explore which individual activities have an effect on well-being.

One area of everyday functioning that has been little explored however, in itself and in relation to well-being, is initiating everyday activities. The majority of research solely focuses on the performance deficits experienced in dementia (Martyr *et al.*, 2012; Fauth *et al.*, 2013; Toots *et al.*, 2016). However, a burgeoning body of work is attending to steps that set up the performance of an activity. Some research discusses formulating an intention in the first place and planning the steps of the activity before its execution (Bier *et al.*, 2013), whilst other research discusses the initiative (Teunisse and Derix, 1997; Voigt-Radloff *et al.*, 2012; Giebel *et al.*, 2017b), which is similar to the aforementioned. It is important to distinguish between these different elements of an activity, as people might be impaired on one, but able to complete the other, as research has indicated (Voigt-Radloff *et al.*, 2012). In this case, it is valuable to take account of the element that the PwD is still able to complete, and continue engaging the PwD on this level. Particularly, in clinical practice, assessing both the initiative and performance of an activity is a frequent part of the general evaluation process, for which a specific tool, the Interview for Deteriorations

in Daily Living Activities in Dementia (IDDD) (Teunisse *et al.*, 1991), is used. In a pilot study employing a revised version of this tool, problems initiating some activities, such as engaging in hobbies, were linked to lower QoL in PwD (Giebel *et al.*, 2016a). In order to further explore comprehensively how initiating everyday activities contributes to well-being however, a larger sample size is required.

There can be different reasons why PwD might struggle at initiating and performing everyday activities. Whilst the performance is strongly linked to factors such as cognition (Moheb *et al.*, 2017), physical limitations (den Ouden *et al.*, 2012), or environmental limitations (Gitlin *et al.*, 2005), the reasons behind lacking the initiative to engage in an activity have been little explored. There might be other factors contributing to deficits in this area of functioning, which differ from those affecting their performance. Thus, distinguishing between the initiative and performance is important when exploring their effects on the well-being of those affected.

The aim of this cross-sectional study was to explore how deficits in the initiative and performance of IADLs in mild dementia were associated with PwD and carer well-being. Living well with dementia is a major objective of dementia care (DH, 2009), and understanding how initiative and performance deficits contribute to well-being in the early stages of the condition focuses on a so far mostly neglected aspect of everyday functioning. This knowledge could help target dementia care better and could help in the development of psychosocial interventions with the objective of improving and maintaining a good QoL early on. Therefore, only data from mild dementia cases were explored in this study, to provide information on possible support to people at the stage where most activities can still be performed. With a paucity of evidence on the relationship between individual activities and well-being and carer burden, for this exploratory study, it was hypothesised more generally that improved independence on activities was related to reduced carer burden and improved PwD and carer well-being (Beerens *et al.*, 2013; Fauth *et al.*, 2016; Reed *et al.*, 2016).

Method

Participants and recruitment

Informal carers of PwD living in the community were recruited to this study. They had to be aged 18 or above and have been caring for their family member

on a regular basis. The person they cared for had to have an official definitive diagnosis of dementia, the type of which was not considered an exclusion criterion. Carers were recruited via 10 National Health Service Trusts across England and via *JoinDementiaResearch*, a national research register for PwD, carers, and healthy volunteers wishing to participate in dementia research. Staff within the Trusts handed out or mailed out questionnaires to interested and eligible carers. Completed questionnaires were returned to the research team via freepost. Additionally, the research team attended six carer support groups in the North West of England, where carers completed questionnaires. Prior to completing the questionnaire, carers provided their written informed consent to participate in the study.

The Bristol NRES Committee South West approved the study.

Materials

The revised Interview for Deteriorations in Daily Living Activities in Dementia 2 (R-IDDD2) (Giebel *et al.*, 2017a) differentiates between the initiative and performance of 17 and 20 activities, respectively. Each activity can be rated from '0' (never lacking motivation/never any difficulties) to '4' (always lacking motivation/always difficulties). Each performance activity can be further explored if an activity is rated as impaired (so rated from '1' to '4'), by having three sub-activities for each of the 20 activities. The R-IDDD2 is a valid tool in assessing everyday functioning (Giebel *et al.*, 2017a).

Carer QoL was measured using the Adult Carer Quality of Life (AC-QoL) questionnaire (Elwick *et al.*, 2010). The measure includes 40 items which can be rated from 'never' to 'always' and has a maximum score of 120. Higher scores indicate better QoL. Carer distress was measured using the General Health Questionnaire 12 (GHQ-12) (Goldberg and Williams, 1988). Twelve items are rated on a four-point Likert scale comparing recent psychological distress to usual levels. A maximum score of 36 can be obtained, with higher scores indicating increased distress. People with dementia QoL was measured using the Quality of Life in Alzheimer's Disease (QoL-AD) (Logsdon *et al.*, 1999). Each of the 13 items, including family, financial situation, and life as a whole, can be rated from '0' (poor) to '4' (excellent). The R-IDDD2 also included one question about what carers consider to be the most distressing problem with everyday activities. This was entered into a free-text box.

Data analysis

Data were analysed using SPSS Version 22. PwD were categorised for their severity of dementia (mild, moderate, severe) based on a previous large European data set of community-dwelling PwD. The European data set on the *RightTimePlaceCare* programme (Verbeek *et al.*, 2012) contained global cognitive scores through the Standardised Mini-Mental State Examination (S-MMSE), as well as data on the length of symptom presentation and number of carer hours per day undertaking ADLs, IADLs, and general supervision. Thus, PwD in the European data set were categorised according to S-MMSE scores, into mild (24–20), moderate (19–10), and severe dementia (9–0). Next, the data were used to calculate average symptom duration, hours of ADL care and IADL care, and hours of supervision for each of the three stages. These means and approximate cutoffs were utilised in the present study in order to categorise the PwD into the three groups. Further details to the specific analyses are published elsewhere (Giebel *et al.*, 2017b). The overall study recruited 604 carers of PwD, of which 272 were categorised to care for someone with mild, 170 for someone with moderate, and 139 for someone with severe dementia. Twenty-three cases could not be categorised due to missing data. For this analysis, only data from carers of people with mild dementia were included.

Demographic characteristics and qualitative accounts of the most burdensome IADL were analysed using frequency analysis. Correlation analysis was employed to assess the relationships between individual IADLs on the initiative and performance scale with the GHQ-12, the AC-QoL, and the QoL-AD. To compare the proportion of PwD impaired for those with low and high distress and well-being, the median of the GHQ12, the AC-QoL, and the QoL-AD were calculated, and the groups were split based on the median. Chi² tests were used to compare the proportion of severely impaired PwD based on distress and well-being groupings.

Results

In total, data from 272 carers of people with mild dementia were included in this analysis (see Table 1). The majority of PwD had Alzheimer's disease, followed by vascular dementia and mixed dementia. Carers were on average 67 (+/–12) years old, primarily female, the spouses or child of the PwD and in the majority of cases lived with the PwD. Most

Table 1 Demographic characteristics and well-being scores

	Mild dementia N = 272
N (%)	
PwD gender	
Female	140 (51.5)
Carer gender	
Female	181 (66.5)
PwD ethnicity	
White Caucasian	162 (95.9)
Carer ethnicity	
White Caucasian	164 (96.5)
Relationship to PwD	
Spouse	183 (67.3)
Child	76 (27.9)
Grandchild	2 (0.7)
Other relative	5 (1.8)
Friend/Neighbour	6 (2.2)
Dementia type	
AD	152 (55.9)
VaD	38 (14.0)
Mixed	36 (13.2)
SD	1 (0.4)
FTD	6 (2.2)
DLB	9 (3.3)
PD	4 (1.5)
Unknown	26 (9.6)
Sole carer	214 (78.7)
Living with PwD	192 (70.6)
Mean (SD)	
PwD age	77 (9)
Carer age	67 (12)
Years of symptoms	3.1 (1.8)
Years of care	1.9 (1.4)
Hours/day ADL caring	0.7 (1.2)
Hours/day IADL caring	0.9 (0.8)
Hours/day spent supervising PwD	1.0 (0.9)
GHQ-12	13.8 (5.6)
AC-QoL	72.3 (18.7)
QoL-AD	31.2 (6.6)

AD, Alzheimer's disease; DLB, dementia with Lewy bodies; FTD, frontotemporal dementia; PD, Parkinson's dementia; SD, semantic dementia; VaD, vascular dementia.

carers were the sole carer for their relative with dementia. PwD were on average 77 (+/−9) years old, roughly equally gender distributed, and had presented symptoms of dementia on average for 3.1 (+/−1.8) years. A large proportion of carers and PwD was White Caucasian, with some people from ethnic minority backgrounds such as South Asian. Carers reported an average of 0.7 (+/−1.2) hours a day spent on ADLs, 0.9 (+/−0.8) hours a day on IADLs, and 1.0 (+/−0.9) hours a day supervising the PwD with everyday activities.

Table 2 shows the bivariate correlations between initiative and performance of IADLs and GHQ-12, AC-QoL, and the QoL-AD. Deficits in the initiative of daily activities were related to higher carer distress

(GHQ-12), and with lower carer QoL (AC-QoL) and PwD QoL (QoL-AD). Initiating *computer use, medication management, and driving* were not associated with carer distress. *Engaging in hobbies and maintaining an active social life, as well as cleaning and doing repair works*, showed the highest correlations with well-being for both PwD and carers.

Deficits in the performance of IADLs were significantly correlated with increased carer distress and lower carer and PwD QoL. *Driving* was the only activity not associated with carer burden and showed low correlations with carer QoL. *Engaging in hobbies and maintaining an active social life* showed the strongest associations with well-being.

Tables 3 and 4 show variations in the proportion of PwD severely impaired at initiating and performing everyday activities by splitting the sample into those with low (0–13) or high (13+) carer distress, low (0–72) or high (72+) carer QoL, or low (0–31) or high (32+) PwD QoL. For the majority of activities, significantly more PwD were impaired 'often' or 'always' on initiating or performing an activity in the group experiencing high carer distress, low carer QoL, and low PwD QoL. The greatest number of activities varied between low and high PwD QoL for their initiative and performance.

The qualitative evaluation of carer comments indicated that carers were mostly distressed by problems with *monitoring the day*, including keeping to appointments, (N = 24), followed by *dressing* (N = 17) and *preparing a meal* (N = 17). The vast majority of carers (N = 151) stated that they were not distressed by a specific activity or left the box blank.

Discussion

Difficulties with initiating and performing IADLs are significantly associated with reduced PwD and carer well-being and heightened levels of carer burden, thereby confirming the previously stated hypotheses. Focusing on individual activities offers a more comprehensive assessment that can detect variations in the relationship with well-being and consequently might aid in the targeted management of dementia. In particular, this study is amongst the first to highlight the importance of focusing on the initiative of everyday activities in order to live well with dementia.

Engaging in hobbies and maintaining an active social life were associated most strongly with both carer and PwD well-being. Data thus showed that not only difficulties in performing the activity, but also lacking the initiative to do so, are linked significantly to poorer

Table 2 Relationship between initiating and performing activities and well-being in mild dementia

	Initiating			Performing		
	GHQ12	AC-QoL	QoL-AD	GHQ12	AC-QoL	QoL-AD
Washing oneself	.261**	-.343**	-.394**	.291**	-.249**	-.347**
Making tea/coffee	.179**	-.239**	-.315**	.301**	-.183**	-.240**
Dressing	.271**	-.334**	-.373**	.301**	-.304**	-.363**
Brushing hair/teeth, shaving	.253**	-.316**	-.393**	.316**	-.283**	-.341**
Shopping	.191**	-.323**	-.364**	.220**	-.257**	-.399**
Using the telephone	.150*	-.312**	-.275**	.293**	-.361**	-.302**
Using the computer	.099	-.305**	-.380**	.175*	-.279**	-.306**
Preparing a cold meal	.199**	-.330**	-.358**	.259**	-.266**	-.309**
Preparing a hot meal	.233**	-.375**	-.363**	.257**	-.275**	-.221**
Cleaning house/doing repair work	.294**	-.431**	-.417**	.305**	-.354**	-.403**
Handling finances	.137*	-.283**	-.128*	.222**	-.276**	-.313**
Medication management	.038	-.204**	-.128*	.270**	-.317**	-.382**
Driving	.115	-.312**	-.371**	.121	-.235**	-.331**
Taking public transport	.195**	-.310**	-.413**	.317**	-.362**	-.389**
Maintaining active social life/ Engaging in hobbies	.230**	-.433**	-.527**	.250**	-.413**	-.477**
Following familiar routes	.280**	-.318**	-.314**	.239**	-.318**	-.358**
Following current affairs	.258**	-.360**	-.419**	.217**	-.315**	-.383**
Recognising familiar faces				.225**	-.255**	-.277**
Monitoring own day				.161**	-.257**	-.289**
Monitoring current activity				.277**	-.314**	-.341**
Total	.284**	-.451**	-.488**	.363**	-.398**	-.453**

Note: Grey-shaded areas are not part of the initiative scale.

GHQ12, General Health Questionnaire 12 (carer distress); AC-QoL, Adult Carer Quality of Life scale (carer); QoL-AD, Quality of Life in Alzheimer's Disease (PwD).

* $p < 0.05$;

** $p < 0.01$

Table 3 Association between initiative impairment and carer distress and quality of life (carer and PwD)

	^a GHQ12		Sig*	^b AC-QoL		Sig	^c QoL-AD		Sig
	low N = 150	GHQ12 high N = 118		low N = 119	AC-QoL high N = 117		low N = 136	QoL-AD high N = 128	
Washing oneself	14 (9.3)	28 (23.9)	$p \leq .001$	52 (43.7)	10 (8.5)	$p \leq .001$	32 (23.5)	8 (6.3)	$p < .001$
Making tea/coffee	26 (17.6)	29 (24.8)	—	27 (23.1)	22 (18.8)	—	36 (26.8)	18 (14.1)	$p < .01$
Dressing	10 (6.8)	16 (13.9)	$p < .05$	14 (11.8)	9 (7.9)	—	19 (14.4)	6 (4.8)	$p < .01$
Brushing hair/teeth, shaving	18 (12.0)	21 (18.4)	—	25 (21.2)	10 (8.6)	$p < .01$	31 (23.2)	8 (6.3)	$p < .001$
Shopping	53 (36.3)	55 (47.5)	$p < .05$	58 (49.6)	35 (30.5)	$p < .01$	69 (51.8)	37 (29.4)	$p < .001$
Using the telephone	59 (39.6)	63 (53.9)	$p < .05$	66 (55.5)	39 (33.7)	$p \leq .001$	77 (57.0)	43 (33.6)	$p < .001$
Using the computer	76 (69.1)	69 (76.7)	—	74 (81.3)	51 (61.4)	$p < .01$	86 (86.8)	55 (56.7)	$p < .001$
Preparing a cold meal	46 (31.5)	47 (41.6)	—	51 (44.0)	30 (26.6)	$p < .01$	62 (48.0)	30 (23.6)	$p < .001$
Preparing a hot meal	82 (56.2)	74 (66.6)	$p < .05$	80 (69.6)	57 (50.0)	$p < .01$	92 (71.3)	61 (48.4)	$p < .001$
Cleaning house/doing repair work	62 (41.9)	67 (59.3)	$p < .01$	72 (62.1)	42 (36.2)	$p < .001$	83 (63.4)	43 (33.9)	$p < .001$
Handling finances	105 (72.9)	90 (79.6)	—	94 (82.5)	76 (67.3)	$p < .01$	110 (84.0)	83 (67.5)	$p < .01$
Medication management	65 (43.6)	67 (59.3)	$p < .01$	66 (56.9)	48 (41.4)	$p < .05$	79 (59.9)	50 (39.4)	$p \leq .001$
Driving	63 (61.8)	53 (66.3)	—	63 (73.3)	42 (56.8)	$p < .05$	73 (80.2)	42 (47.7)	$p < .001$
Taking public transport	66 (50.0)	65 (63.1)	$p < .05$	71 (68.3)	46 (46.0)	$p \leq .001$	82 (70.1)	46 (40.7)	$p < .001$
Maintaining active social life/ Engaging in hobbies	64 (43.2)	62 (52.6)	—	69 (58.0)	41 (35.0)	$p < .001$	87 (64.0)	37 (29.1)	$p < .001$
Following familiar routes	31 (21.3)	46 (40.7)	$p \leq .001$	42 (36.2)	25 (22.0)	$p < .05$	53 (40.4)	21 (16.8)	$p < .001$
Following current affairs	56 (38.0)	66 (56.4)	$p < .01$	66 (55.5)	43 (37.1)	$p < .01$	80 (59.3)	41 (32.5)	$p < .001$

Table shows N (%) of PwD impaired 'often' or 'always'.

*Chi-square test of association.

a = General Health Questionnaire 12 (carer distress); b = Adult Carer Quality of Life scale (carer); c = Quality of Life in Alzheimer's Disease (PwD).

well-being, thereby confirming and further elaborating on evidence reporting the relationship between activities of daily living and QoL (Farina *et al.*, 2017; Miguel *et al.*, 2016). A previous pilot investigation into

the relationship between initiative and well-being with 20 carers of people with mild dementia corroborates this finding now on a much larger scale (Giebel *et al.*, 2016a). Indeed, the present study provides strong

Table 4 Variations in performance impairment based on high or low carer distress, QoL, and person with dementia QoL

	^a GHQ12 low N = 147	GHQ12 high N = 116	Sig*	^b AC-QoL low N = 118	AC-QoL high N = 115	Sig*	^c QoL- AD low N = 132	QoL-AD high N = 128	Sig*
Washing oneself	19 (13.3)	29 (25.4)	$p < .01$	28 (24.1)	15 (13.1)	$p < .05$	34 (26.1)	13 (10.4)	$p < .001$
Making tea/coffee	19 (13.1)	35 (30.9)	$p < .001$	30 (25.8)	20 (17.3)	—	36 (28.3)	17 (13.3)	$p < .01$
Dressing	18 (12.5)	31 (26.7)	$p < .01$	31 (25.5)	14 (12.4)	$p < .01$	35 (26.7)	13 (10.4)	$p < .001$
Brushing hair/teeth, shaving	13 (9.3)	25 (21.9)	$p < .01$	25 (21.6)	10 (9.0)	$p < .01$	26 (20.2)	12 (9.6)	$p < .05$
Shopping	43 (32.3)	42 (42.8)	—	46 (45.6)	33 (30.0)	$p < .05$	55 (48.3)	29 (25.0)	$p < .001$
Using the telephone	41 (28.7)	59 (50.9)	$p < .001$	56 (48.7)	34 (29.6)	$p < .01$	64 (48.9)	35 (28.0)	$p < .001$
Using the computer	58 (63.1)	59 (73.8)	—	57 (76.0)	48 (60.1)	$p < .05$	66 (80.5)	48 (55.2)	$p < .001$
Preparing a cold meal	24 (17.3)	31 (28.5)	$p < .05$	30 (27.3)	20 (18.1)	—	34 (28.1)	19 (15.3)	$p < .05$
Preparing a hot meal	43 (33.3)	44 (54.6)	$p < .001$	51 (50.5)	27 (35.2)	$p < .05$	56 (49.6)	39 (25.5)	$p < .05$
Cleaning house/doing repair work	39 (27.9)	52 (48.6)	$p < .001$	52 (47.3)	31 (28.2)	$p < .01$	61 (50.0)	29 (23.4)	$p < .001$
Handling finances	73 (51.8)	74 (65.5)	$p < .05$	77 (67.0)	58 (52.2)	$p < .05$	88 (69.3)	59 (47.6)	$p < .01$
Medication management	54 (39.4)	69 (61.6)	$p < .001$	68 (61.2)	44 (38.0)	$p < .001$	77 (61.2)	44 (36.3)	$p < .001$
Driving	52 (59.8)	44 (60.2)	—	47 (64.4)	43 (61.40)	—	52 (71.2)	45 (52.3)	$p < .05$
Taking public transport	46 (42.2)	48 (54.0)	—	56 (63.0)	35 (39.7)	$p < .01$	65 (63.7)	30 (31.9)	$p < .001$
Maintaining active social life/Engaging in hobbies	65 (45.7)	72 (62.6)	$p < .01$	78 (67.8)	44 (38.9)	$p < .001$	88 (68.8)	47 (37.4)	$p < .001$
Following familiar routes	36 (25.2)	46 (41.1)	$p < .01$	48 (42.1)	26 (23.0)	$p < .01$	54 (42.6)	28 (22.4)	$p < .001$
Following current affairs	67 (45.8)	74 (64.3)	$p < .01$	73 (62.4)	51 (45.2)	$p < .01$	86 (65.1)	53 (42.0)	$p < .001$
Recognising familiar faces	18 (12.2)	17 (15.0)	—	18 (15.60)	15 (13.0)	—	22 (16.8)	13 (10.3)	—
Monitoring own day	56 (38.4)	61 (53.1)	$p < .05$	60 (50.9)	47 (41.3)	—	72 (54.4)	43 (34.1)	$p < .001$
Monitoring current activity	59 (41.0)	63 (54.8)	$p < .05$	65 (55.5)	43 (37.7)	$p < .01$	74 (56.5)	46 (36.8)	$p < .001$

Table shows proportion of PwD impaired 'often' or 'always'.

*Chi-square test of association.

a = General Health Questionnaire 12 (carer distress); b = Adult Carer Quality of Life scale (carer); c = Quality of Life in Alzheimer's Disease (PwD).

additional evidence that engaging in hobbies/maintaining an active social life is a vital element to well-being. Whilst the pilot investigation showed that initiative deficits in this activity were associated only with PwD QoL, the present analysis demonstrates that this activity is the most strongly related to QoL of PwD and carers, and well-being. Whilst causation has not been shown within this study, in order to improve well-being for both the PwD and the carer, there could be two possible options that integrate social activities. On the one hand, psychosocial interventions might need to specifically target the individual hobbies of a PwD, both in their initiative by raising levels of motivation and in their performance, by providing structured training and support to perform the activity. An alternative or additional option might be for the PwD, and carer, to participate in dementia-specific social groups or activities. One such example is 'Coffee, Cake, & Culture', an art initiative by the Whitworth Art Gallery in Manchester to appreciate art and engage with peers in a friendly environment (Roe *et al.*, 2014). Other options are singing groups (Osman *et al.*, 2014) or community-based football groups specifically for PwD (Carone *et al.*, 2016), all of which have been found to improve well-being. Hence, encouraging participation in previously enjoyed hobbies and other social activities appears to be a vital contributor to well-being, which might require a greater level of attention than other IADLs, especially because

engaging in social activities and maintaining social relationships contributes to a reduced risk of developing dementia, amongst others (Marioni *et al.*, 2015).

It is unclear why carer distress as measured on the GHQ-12 was not found to be significantly associated with engaging in hobbies and maintaining an active social life. However, there are other activities which were only found to be significantly associated with carer and PwD well-being, but not carer distress, e.g. driving and handling finances. One possible reason could be that lacking the initiative to engage in an active social life only affects the well-being of a carer, whilst it is not linked to being distressed or burdened. Findings suggest that needing reminders to initiate tasks such as preparing a hot meal or getting dressed are related to carer burden, as they presumably cause a carer to provide many prompts on a daily/weekly basis. In addition, lacking the initiative to adhere to medication is equally associated with carer burden, an important everyday task which PwD often not adhere to (Arlt *et al.*, 2008). In contrast, engaging in hobbies is not a necessary part of a person's everyday life and might therefore require fewer reminders, or hobbies might get neglected altogether so that no reminders might be required. This suggests that care interventions focusing on maintaining or improving social functions should weigh up the benefits for patient and carer well-being and carer distress.

When asked directly about the most distressing everyday activity, the majority of carers were either not distressed by one, or stated a behavioural problem, such as aggression or repetition as the most disturbing symptom, rather than an IADL or ADL. Specifically, *monitoring the day*, followed by *dressing*, were regarded as the most distressing activities. Contrary to the quantitative findings, few carers ($N = 13$) stated that difficulties with initiating or performing *hobbies or engaging in social activities* were most distressing. All carers were aware of the spectrum of IADLs, which could therefore not explain why carers' qualitative responses varied from the quantitative results. This suggests that some carers might not realise that one or more activities affect their well-being, as is supported by the large number of carers who did not provide an answer to this question.

The initiative of some activities was not related to well-being. *Computer use* and *driving* were amongst these and, indeed, were also the two activities which carers frequently left blank and noted as not applicable, as the PwD was never able to do these. Considering that these two, very technical, daily activities were managed by the smallest number of participants in the first place, it might not be surprising to see that lacking the initiative for either has no statistical impact on carer burden. Problems initiating *medication management* on the other hand might not affect carer burden because of the ready availability of assistive technology (AT) for this IADL. Medication dispensers with alarms are frequently used in dementia care (Gibson *et al.*, 2016), with AT in general being found to be of greater benefit to carers (Gibson *et al.*, 2015). This suggests that deficits in the initiative of some IADLs could be relatively easily addressed with the use of AT, in providing reminders and thus effective triggers (Giebel *et al.*, 2017a), which would reduce the responsibilities and burden placed on the carer.

Overall, the associations between initiative and performance and PwD QoL were stronger than those with carer well-being. Considering that carers rated all types of well-being, it might be the case that carers rated PwD well-being to be more severely affected than their own well-being. Indeed, previous research corroborates variations in ratings between proxies and PwD (Sands *et al.*, 2004). There are also other factors that might have influenced proxy ratings of the PwD' QoL, including levels of carer burden, carer health, and age of the PwD (Orgeta *et al.*, 2015). Depressive symptomatology might also have contributed to low initiative ratings in PwD, as depression is found to be linked to everyday functioning in general (Payne *et al.*, 1998). Future

research should explore how PwD would rate their own levels of initiative and performance, and how this is associated with well-being.

Findings can have important implications for effective care management and the design of non-pharmaceutical interventions. As outlined in the Medical Research Council guidelines (2005), developing effective interventions involves focusing on theory as well as evidence, which can then be translated preferably with the input of patients, carers, and clinicians into an intervention. Findings suggest that addressing individual activities might have a greater impact on improving PwD QoL, whilst still providing benefits to carers by potentially improving well-being and reducing carer burden. In the intervention design process, it is therefore important to clarify the motivations behind participating in an intervention (Giebel *et al.*, 2016b), whether this is targeted at improving PwD QoL or carer burden for example.

There are some limitations to this study. One potential limitation is the categorisation of people into mild dementia. However, this categorisation was based on an extensive statistical procedure involving a large European data set, of which findings from the overall sample, including people in the mild, moderate, and severe stages of dementia, have been published elsewhere (Giebel *et al.*, 2017b). Furthermore, statistically we performed a large number of Chi-square tests and correlation analyses. We did not adjust for this with a Bonferroni correction, because the significance cut-off value would decrease to such a degree that the Type I error would be reduced, but the Type II error would be increased by a large amount.

Conclusions

In conclusion, living well with dementia involves being aware of how individual daily activities affect the well-being of PwD and their carers, and how these can be addressed more directly. Social activities were found to be particularly strongly linked to well-being in mild dementia, suggesting the need for greater accessibility to dementia-based social groups. From the data, it could be further implied that AT might be a feasible way to reduce carer distress, as evidenced for medication management. Findings could thus have direct implications for dementia care practice, by providing more social opportunities for PwD or dyads, and possibly by integrating AT to a greater extent in everyday life. Future research ought to explore whether AT can indeed result in reduced carer distress for a variety of IADLs.

Description of authors' roles

C.G. designed the study, collected and analysed the data, and drafted the article. C.G. and C.S. rated the dementia cases for their severity. C.S. commented on versions of the paper and approved the final draft.

Conflict of interest

None.

Key points

- Lacking the initiative to engage in everyday activities is associated with poor carer and people with dementia quality of life and increased carer burden.
- Quality of life, as opposed to carer burden, is strongly associated with initiation.
- Carer management should consider the associations with well-being when addressing individual activities.

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