

Mixed-Methods Study on Caregiver Strain, Quality of Life, and Perceived Health

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Abstract.

Background: Caring for someone with dementia is associated with negative and positive experiences. There is little evidence based on large datasets.

Objective: To present data around the experience of caring for someone with dementia, to identify support (emotional and practical) needs, and inform future service provision.

Methods: A mixed-methods study embedded in the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) Randomized Controlled Trial. We administered questionnaires on strain, quality of life (QoL), and perceived health to 301 caregivers and assessment of cognitive performance, depression, anxiety, and disability in activities of daily living to 301 participants with dementia. Data were analyzed through descriptive and modelling statistics. A subsample of 20 patient-caregiver dyads were qualitatively interviewed. Data around caregivers' experience of providing care were extrapolated and analyzed through inductive thematic analysis.

Results: There were significant negative associations between caregiver strain and QoL ($p < 0.01$) and between caregiver age and QoL ($p < 0.01$), and significant positive associations between caregiver strain and disability ($p < 0.01$), cognitive impairment ($p < 0.01$), depression ($p < 0.05$), and anxiety of the person with dementia ($p < 0.05$). Older caregivers reported a lack of support, reinforced by their reluctance to seek help. All caregivers reported contradictory emotions associated with caring and accumulation of strain over time.

Conclusion: While there is recognition that it is essential to support caregivers, dedicated intervention programs, and support strategies to respond to the needs of older caregivers are still needed.

Keywords: Caregiver, caregiver exhaustion, dementia, quality of life, randomized controlled trial

INTRODUCTION

There are currently 700,000 families in the United Kingdom involved in the care of someone with dementia. Almost half of these families provide care 24 hours a day, seven days a week [1, 2]. In 66% of the

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cases, the caring role lasts more than one year and in 33% more than five years [3].

The term caregiver strain or burden denotes the negative impact of caring for someone with dementia on physical, mental, emotional, and social wellbeing [4]. Caring duties can heavily impact on the mental health of caregivers [5]. Several studies have linked caregiver's burden to negative effects on psychological health [6–8], including depression [9, 10], anxiety [7, 11–13], and psychiatric morbidity [14]. Caregiver burden has also been linked to physical ill-health, such as heart conditions, compromised immune system, and with higher risk of early mortality [3, 15–24]. Because of their caring duties, caregivers may also experience reduced social opportunities [25] and be at risk of social isolation [26], as well as reduced quality of life (QOL) [27].

The extent of effects on caregiver's health seems to be time-dependent (i.e., linked to the length of care that the caregiver provides). There are currently two opposing theories explaining the relationship between length of care and effects on caregiver's health. The so-called "Adaptation hypothesis" posits that the longer the care, the more the carer adapts to manage burden [28, 29]. The "wear and tear" hypothesis, instead, theorizes that longer periods of care are linked to increased carer burden [30, 31].

Although the scientific literature has traditionally focused on negative outcomes [32], caregivers can also experience positive reactions in caregiving situations [33–35]. Sources of satisfaction include experiencing a sense of togetherness, feelings of belongingness, personal reward and growth [36], altruism and reciprocity [37], protection from negative self-perceptions, repaying the cared-for for past services, honoring vows, and religious principles [38].

To date, there is little mixed-methods research around the experience of caring for someone with dementia based on large datasets [39]. This study aimed to present quantitative and qualitative data around the experience of caring for someone with dementia, to identify support (emotional and practical) needs and inform future service provision. The objectives were to:

- Determine the degree of caregivers' strain, QoL and perceived health;
- Test the association of caregivers' strain, QoL and perceived health with sociodemographic characteristics of caregivers and clinical outcomes of the person with dementia;

- Report on the caregivers' individual experience of caring for the person with dementia.

MATERIALS AND METHODS

Study design

This was a mixed-methods cross-sectional study comprising a quantitative and a qualitative element. It was based on data collected in the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) Randomized Controlled Trial, which tests the clinical and cost-effectiveness of a therapy intervention to promote activity and independence in people with early dementia or mild cognitive impairment [40]. The PrAISED therapy intervention lasts 12 months and consists of individually-tailored physical, dual-task exercises, and functional activities of daily living delivered in participants' homes by multidisciplinary teams of physiotherapists (PTs), occupational therapists (OTs), and rehabilitation support workers (RSWs).

Participants

Three-hundred and one dyads of participants with dementia and their caregivers ($n = 602$) were included in the quantitative element of this study. Inclusion criteria for the participant with dementia were: aged 65 years or over; having a diagnosis of mild cognitive impairment or dementia; scoring 13–25 (out of 30) in the Montreal Cognitive Assessment (MoCA) [41]; being able to walk without human help, communicate in English, see and hear, perform neuropsychological tests, and give consent to participate. Inclusion criteria for the caregiver were: being a family member, informal caregiver, or friend who knew the participant with dementia well (defined as having contact with them for at least one hour per week via internet, telephone, or in person); being willing and able to act as an informant and to be a research participant.

For the qualitative element of this study, the main researcher (CDL) accessed the PrAISED RCT database and purposively selected 20 participants with dementia receiving the PrAISED intervention at the time of recruitment and their respective 20 caregivers ($n = 40$) to be interviewed together (i.e., as a pair). Purposive sampling ensured that the selected participants were as representative as possible of the caregivers and participants with dementia involved in the PrAISED RCT in relation to residence status (i.e., living independently or together) and relationship of

the caregiver with the participant with dementia (e.g., spouse, child, or sibling).

The PrAISED RCT and process evaluation have received ethical approval by the Bradford Leeds Research Ethics Committee (Reference 18YH/0059). The ISRCTN Registration Number for PrAISED is 15320670.

Procedures

At baseline (i.e., month 0 of their involvement in the PrAISED RCT), for the quantitative element of this study, caregivers completed the following questionnaires:

- A socio-demographic questionnaire on age, gender, health, education, relationship to the participant with dementia, employment, residence status, and information related to caring;
- Caregiver strain index (CSI) [42], whose score range is 0–13, where 13 indicates highest CSI;
- Caregiver health related QoL (EQ5D-5L) [43], a standardized instrument investigating quality-of-life-related outcomes including mobility, self-care, main activity, social relationship, pain and mood. EQ5D-5L score range is 0–1, where 1 indicates highest caregiver QoL. The instrument was also used to investigate caregivers' perceived health through the item "your health today", whose score range is 0–100, where 100 indicates highest perceived health;

The participant with dementia completed the following questionnaires:

- A demographic questionnaire on gender, age, and ethnicity;
- The Montreal Cognitive Assessment (MoCA) [41]. Scores on the MoCA range from zero to 30, with a score of at least 26 generally considered normal.
- The Disability Assessment for Dementia (DAD) [44], whose score range is 0–100, where 100 indicates lowest disability.
- The Hospital Anxiety and Depression Scale (HADS) [45], a 14-item scale with seven items each for anxiety and depression subscales. Score range for each item is 0–3. A subscale score over 8 indicates anxiety or depression.

The qualitative element of this study aimed to add an individual dimension to the quantitative assessments by gathering in-depth narratives about the experience of caring for someone with dementia. The

selected participants took part in a semi-structured interview in their home at month 3 of their involvement in the PrAISED RCT. An interview topic guide (Supplementary Material) was developed through a collaboration of the research team with two Patient and Public Involvement (PPI) members (MG and MD) who had lived experience of caring for someone with dementia. While the topic guide mostly focused on the caregivers' experience of supporting the participant with dementia in the PrAISED RCT, a flexible approach was used in the interview to also explore and capture the experience of caring for the person with dementia more generally (i.e., out of the context of PrAISED). The qualitative interviews were digitally audio-recorded.

Data analysis

The quantitative data were fully anonymized and transferred in SPSS[®] 27.0 [46]. Pearson's correlation (for normally distributed continuous data), Spearman's correlation (for non-normally distributed data), *t*-test and Mann-Whitney U test were performed to compare the CSI and EQ5D-5L mean scores based on different caregivers' characteristics. Correlation was computed to test the relationship between CSI, and EQ5D-5L total scores, as well as between CSI and DAD, MoCA, and HADS scores. After checking for assumptions of normality, multi-collinearity, homoscedasticity, linearity and residual statistics, a hierarchical regression analysis was performed to estimate the effect of caregivers' age and gender and participants' MoCA, DAD, and HADS on CSI scores. A level of significance of $p < 0.05$ (two-sided) was used.

The qualitative interviews were transcribed by a professional agency. Basic demographic data about participants and MoCA scores for the participants with dementia were extrapolated from the PrAISED database. The full interview transcripts were transferred to NVivo[®] 12.1 [47]. Interview quotes from the caregivers relating to the experience of caring for the participant with dementia were extrapolated from the transcripts, fully anonymized by the research team, by assigning each participant a unique code (e.g., C01, C02), and analyzed through inductive thematic analysis [48].

Two authors (MG and JL) familiarized themselves with the transcripts and identified preliminary 'emerging themes' independently of each other. These were reviewed by two different analysts (CDL and VvdW), who synthesized them (i.e., merging

themes by commonalities) independently of each other into “solidifying themes”. Discussions were held among these four analysts about how the themes would best reflect the data set. A codebook, featuring the “final themes” and their operational definitions was developed by CDL and fed back to the other three analysts (MG, JL, and VvdW) for consensus. CDL then recoded all transcripts based on the coding framework.

RESULTS

Quantitative data

Of the 301 caregivers included in the quantitative assessments, 198 (66%) were spouses or partners of the person with dementia. The majority of caregivers were female ($n=214$; 71.1%). Their mean age was 69 years ($SD=13$; range=21–95). The mean age of participants with dementia ($n=301$) was 80 years ($SD=7$; range=65–95). The majority were white ($n=294$; 97.7%) and male ($n=172$; 57.1%). Descriptive statistics of demographic information and outcome measures for caregivers and participants with dementia are presented in Table 1.

The mean CSI score was 4.69 ($SD=3.32$). Female caregivers recorded a mean CSI score of 4.97 ($SD=3.26$) and male caregivers of 4 ($SD=3.38$). The difference was statistically significant, $t(153)=-2.3$, $p<0.05$. Caregivers with pre-existing health conditions had significantly higher mean CSI scores than those without pre-existing health conditions ($U=7856$, $p<0.01$). The total mean EQ5D-5L score was 0.84, out of a possible total of 1.00 ($SD=0.19$). EQ-5D population norm mean for age range 65–74 in England is 0.78 [49]. We found statistically significantly lower mean EQ5D-5L for spouses compared to non-spouses ($U=4798$, $p<0.01$), for caregivers living with the person with dementia compared to those not living with them ($U=5578$, $p<0.01$), for retired caregivers compared to those actively working ($U=3899$, $p<0.01$), and for those with a long-term health condition compared to healthy ones ($U=3766$, $p<0.01$).

A linear regression analysis evidenced that younger age was associated with higher QoL, as measured by the EQ5D-5L [$F(1, 295)=30.5$, $r=0.35$; $p<0.01$]. The mean score for “your health today” was 81, out of a possible score of 100 ($SD=16$). We found statistically significant better health in children compared to spouses ($U=5123$, $p<0.01$), employed caregivers compared to retired ones ($U=4861$,

$p<0.01$), in caregivers with no long-term health conditions ($U=3703$, $p<0.01$), and in those not living with the person with dementia ($U=6020$, $p<0.01$).

We found a significant negative, but weak correlation between caregiver burden and caregivers’ QoL ($r=-0.21$, $p<0.01$, $n=292$). Pearson’s correlations between caregiver burden and outcomes of the person with dementia were significant (DAD: $r=-0.37$, $p<0.01$, $n=291$; MoCA: $r=-0.17$, $p<0.01$, $n=287$; HADS-anxiety: $r=0.13$, $p<0.05$, $n=294$; HADS-depression: $r=0.13$, $p<0.05$, $n=294$).

A hierarchical regression analysis controlling for age and sex showed that degree of disability and level of anxiety in the person with dementia was significantly associated with caregiver burden (see Table 2). Assumptions of normality, multi-collinearity, homoscedasticity, linearity, and residual statistics were met.

Qualitative data

All 20 caregivers and 20 participants with dementia approached for the qualitative element of this study agreed to be interviewed (see Table 3 for sample characteristics). Seventeen caregivers (85%) were female and 17 (all spouses) (85%) lived with the participant with dementia. The average MoCA score for the participants with dementia was 20 (Range=15–26; $SD=3$). The qualitative interviews lasted 48 min on average (range=31–65). Four themes were developed: i) Social aspects of caring; ii) Practical aspects of caring; iii) Emotional aspects of caring; and iv) Physical health and caring (Table 4). Participants’ quotes are reported by identifying their ID (e.g., C01, C02), relationship to the person with dementia (i.e., S = sister, W = wife, D = daughter, H = husband) and age.

Practical aspects of caring

The practical aspects of caring were found to be tightly linked to the level of cognitive impairment of the participant with dementia (see Table 3). Caregivers of more cognitively-deteriorated participants reported that it was time consuming to provide care, as the person needed constant supervision:

I still go out with him myself because for a start, he wouldn’t know which bus to get and he would probably end up god knows where. C02, W, 86 years

The caring duties generated added stress to those caregivers who were still working. Some caregivers

Table 1
Descriptive statistics

			N*	%	Mean; standard deviation; range	
Caregivers	Gender	Male	87	28.9		
		Female	214	71.1		
	Age		301	100	69.2; 12.9; 21–95	
	Relationship to participant with dementia	Spouse	198	65.8		
		Child	84	27.9		
		Sibling	3	1.0		
		Other relative	6	2.0		
		Friend	6	2.0		
		Other	4	0.7		
		Years in education	Up to 10	62	20.6	
		11–15	157	52.1		
		16+	80	26.5		
	Employment status	Paid or self-employed	80	26.5		
		Voluntary work	14	4.7		
		Retired	173	57.5		
		Housewife/husband	13	4.3		
		Unemployed	5	1.7		
		Exempt through disability	2	0.7		
		Full-time caregiver	10	3.3		
		Other	4	1.3		
		Taking days off work to provide care for person	Yes	46	15.3	
			No	50	16.6	
	Having a long-term health condition	Yes	103	34.2		
		No	198	65.8		
	Living with person with dementia	Yes	210	69.8		
		No	91	30.2		
	Hours/day leaving the person at home alone	Never	21	7.0		
Up to 4		95	31.6			
4–8		44	14.6			
8–12		11	3.7			
12–16		38	12.6			
Hours/week spent visiting the person (for non-co-residents)		86	94	14.5; 13.7; 1–70		
Times/week travelled to visit		87	96	4.9; 5.5; 0–30		
Distance travelled to visit the person (miles)		87	96	26.5; 32.5; 0–140		
Received help from others	Yes	144	47.8			
	No	155	51.5			
Hours/week receiving help from others		143	47.5	10.1; 24.7; 1–168		
Participants with dementia	Gender	Male	172	57.1		
		Female	129	42.9		
	Age		300	99.7	79.6; 6.6; 65–95	
	Ethnicity	White	294	97.7		
		Black	3	1		
		Asian	4	1.3		
	MoCA ¹		293	97	20.0; 3.1; 13–26	
	DAD score ²		293	97	77.6; 20.6; 5–100	
	HADS - anxiety ³		293	97	4.0; 2.3; 0–13	
	HADS - depression ³		293	97	4.5; 2.8; 0–14	

*Data for some participants are missing. ¹Montreal Cognitive Assessment [41]. ²Disability Assessment for Dementia [44]. ³Hospital Anxiety and Depression Scale [45].

lamented the fact that while their spouse previously helped in the house, they were now the only ones doing house chores:

I mean he's retired but I haven't retired, I still have to do everything I always did. In years gone by, G. was good at cooking and he'd do the washing up.

Well now he just sits there and waits until it appears in front of him. C19, W, 86 years

The caring routine also involved numerous medical appointments, which had time implications, particularly for the caregivers who did not live with the person with dementia. Caregivers' responsibilities

Table 2
Hierarchical regression analysis predicting caregiver burden

	B	SE B	β
Step 1			
Constant	4.22	1.37	
Age	-0.02	0.02	-0.6
Sex	0.92	0.43	0.13
Step 2			
Constant	9.80	1.51	
Age	-0.03	0.01	-0.10 ($p=0.081$)
Sex	0.77	0.40	0.11 ($p=0.057$)
DAD ¹	-0.06	0.01	-0.38 ($p=0.00$)
Step 3			
Constant	9.14	1.52	
Age	-0.02	0.01	-0.09 ($p=0.098$)
Sex	0.77	0.40	0.11 ($p=0.055$)
DAD	-0.06	0.01	-0.38 ($p=0.00$)
HADS-Anxiety ²	0.14	0.06	0.13 ($p=0.022$)

$R^2=0.02$ for step 1; $\Delta R^2=0.14$ for step 2 ($p=0.00$); $\Delta R^2=0.02$ for step 3 ($p=0.02$). ¹Disability Assessment for Dementia [44].

²Hospital Anxiety and Depression Scale [45].

also had a negative impact on respite opportunities:

I can still go out and do, I don't go to everything that comes my way, but I still go to my meetings and I can leave him, but I don't stay out as long as I maybe would in the past. C02, W, 86 years

Several other caregivers reported that although they recognized a need to have "me time", they still prioritized the needs of the person they cared for. One caregiver reported having to give up respite time, because of the costs of having the person she cared for attend a day center:

I need to be doing something to, protect myself. I was probably going to go to Pilates, but I haven't got there. Well, I have to see if there is anything for P. on that night. C15, W, 67 years

I used to drop him off and it was two hours and I could do what I wanted. But it was costing €60, which is a lot every week, so he stopped going there. C12, W, 65 years

Overall, the qualitative interviews highlighted an association between caregiver's time spent visiting or caring for the person, consequent reduction of respite and strain. They also validated the quantitative findings linking higher caregiver strain to increased functional impairment (DAD: $r=-0.37$, $p<0.01$, $n=291$) and cognitive deterioration (MoCA: $r=-0.17$, $p<0.01$) of the person with dementia.

Physical health and caring

The caregivers discussed at length about how caring for the person with dementia was linked to

their own physical health, particularly the caregiver-spouses, who were often dealing with their own challenges related to the process of aging. A caregiver reported how, because of age-related frailty, she had experienced difficulties helping her husband after a fall:

There was suddenly this great big thump upstairs. I dashed upstairs and he was trapped between the wardrobe and the chair at the side of it and he couldn't move. I managed to get the chair out of the way but I can't lift him up because I have got rheumatoid arthritis. C09, W, 81 years

At the same time, physical ailments could occur as a result of caring for the person with dementia. For example, some caregivers reported physical fatigue as a result of carrying out caring duties:

It's difficult to get out, because you are so tired at the end of the day that all you feel like doing is sitting down! C13, W, 73 years

Overall, the qualitative interviews supported the quantitative findings linking health conditions to higher strain ($U=7856$, $p<0.01$) and lower QoL ($U=3766$, $p<0.01$).

Social needs of caregivers

Caregivers reported that they actively sought support in the community to combat feelings of social isolation and gather useful information on dementia care. The dementia-friendly activities that caregivers attended in the community as a result of their involvement in PrAISED gave them an opportunity to establish an empathetic connection and share their experience with other caregivers on a similar journey:

By me going... I chat to other people that have got similar problems. And so in a way I quite look forward to going because rather than the little circle I've already got, I see a little bit bigger circle. I mean we're all in the same boat. C02, W, 86 years

Many were also the benefits that the caregivers obtained from interacting with the therapists delivering the PrAISED intervention. Some caregivers stated that the therapists offered valuable advice on how to better take care of the person with dementia:

(The support worker) has helped me handling M., you know, giving me advice and this sort of thing. C11, H, 74 years

Counting on the help of others also presented opportunities for the caregiver to have respite from caring duties. One caregiver reported that she could leave her husband at home with neighbors, so she could safely attend to other engagements:

Table 3
 Characteristics of sample of qualitative interviews

ID	Caregiver					Participant with dementia			
	Gender	Age	Ethnicity	Living with person with dementia?	Relationship to person with dementia	Gender	Age	Ethnicity	MoCA ¹ score of participant with dementia
C01	F	73	White	No	Sister	M	70	White	18
C02	F	86	White	Yes	Wife	M	88	White	21
C03	F	67	White	Yes	Wife	M	65	White	21
C04	F	47	Black	No	Daughter	F	72	Black	18
C05	F	58	White	No	Daughter	F	90	White	20
C06	M	78	White	Yes	Husband	F	75	White	18
C07	F	72	White	Yes	Husband	F	72	White	26
C08	F	73	White	Yes	Wife	M	78	White	15
C09	F	81	White	Yes	Wife	M	87	White	18
C10	M	79	White	Yes	Husband	F	71	White	20
C11	M	74	White	Yes	Husband	F	74	White	23
C12	F	65	White	Yes	Wife	M	88	White	18
C13	F	73	White	Yes	Wife	M	77	White	23
C14	F	75	White	Yes	Wife	M	78	White	24
C15	F	67	White	Yes	Wife	M	78	White	19
C16	F	70	White	Yes	Wife	M	69	White	20
C17	F	79	White	Yes	Wife	M	80	White	19
C18	M	81	White	Yes	Husband	F	77	White	22
C19	M	86	White	Yes	Wife	M	91	White	15
C20	F	89	White	Yes	Wife	M	92	White	Not available

¹Montreal Cognitive Assessment [41].

Table 4
Themes identified through thematic analysis and operational definitions

Emerging themes		Solidifying themes*		Final themes** and operational definitions
Identified by academic researcher (JL)	Identified by PPI contributor (MG)	Identified by first academic analyst (CDL)	Identified by second academic analyst (VvdW)	Developed by CDL and fed back to JL, MG and VvdW for consensus
1. Support (or lack thereof) (i.e., from family, community, friends, paid caregivers, the PrAISED team)	6. Support from others (i.e., Support and advice given to person with dementia and caregiver by other family and friends)	Support (1 and 6)	Support network (1 and 6)	<i>Social needs of caregivers:</i> Positive or negative social aspects of caring, such as expanding social contacts, social isolation and support from others
2. Challenges (i.e., lack of respite, increased dependency of person with dementia, adjustments, isolation, decrease in previous skills)	7. Additional demands (i.e., additional demands made on caregivers own time and space)	Challenges (2, 7, and 8)	New limitations (2, 3, 7, and 8)	<i>Practical aspects of caring:</i> Positive or negative practical aspects of caring, such as improving caring skills, demands on time and space, and change of life plans
3. Independence (i.e., travel and transport, change of holidays plans)	8. Restrictions (i.e., restrictions of life and interests placed on the caregiver)	Synthesis Independence (3)	Synthesis	
4. Benefits (i.e., expanding activities, groups, physical or social interactions, increased motivation to be physically active, physical and practical improvements)	9. Physical health (impact of ageing and care burden on physical health)	Benefits (4)	Activities of daily living (4)	<i>Emotional impact of the caring role:</i> Positive or negative feelings, including adjusting and accepting change, worry, stress, depression, anger, tension, desperation, fear, guilt, and sense of purpose
5. Emotions (i.e., loyalty, duty, acceptance of change, anxiety, worry, depression, guilt, anger and frustration)	10. Mental impact (i.e., worry, stress, depression, anger, tension, loneliness, desperation, fear, guilt, feeling overwhelmed, loss of purpose)	Emotions (5 and 10)	Psychological factors (5 and 10)	
		Physical health (9)	Physical health (9)	<i>Physical health and caring:</i> Positive or negative impact of caring on physical health, such as physical illness, exhaustion, tiredness and fatigue

*Obtained by synthesizing the academic and PPI raters' themes. In parentheses which emerging themes were synthesized to obtain the solidifying themes. **Obtained by synthesizing the academic raters' themes.

We've got all the neighbours and friends and they've all rallied round. And you know, they come in and they say, you go off for a couple of hours and I go off and they sit with her. C11, H, 74 years

While extra support was frequently available for sibling and child-caregivers, in line with the quantitative findings, several spouse-caregivers reported that they did not receive any extra support from others. This could depend on a number of factors. For example, they might have children who lived far away. Another frequently reported factor was that caregivers preferred not to burden other family members and try, as much as possible, to make it on their own:

We're trying to be independent and all that, we don't want to bother our children. We'd rather soldier on. C10, H, 79 years

Another factor causing a lack of support was limited social opportunities. Several spouse-caregivers reported that, as a result of dementia progression, they had lost all social contacts. Because of the lack of social opportunities, these caregivers manifested a need to actively seek social opportunities outside the home, in order to safeguard their wellbeing:

Since G. has given up exercise, he's become less sociable. As a result, I've become less sociable. I often don't see other people. There's two things I go out to during the week and I really find now that I need those things to go to just to be with other people. C03, W, 67 years

Overall, the interviews confirmed the quantitative findings linking lower QoL and perceived health to being married to ($U=4798$, $p<0.01$) and living with the person with dementia ($U=5578$, $p<0.01$), with spouses-caregivers reporting greater reduction in social opportunities and increased risk of social isolation as a result of dementia progression and caring duties.

Emotional impact of the caring role

Caregivers expressed a great sense of commitment to the wellbeing of the person they cared for. Most were happy to offer support and help at any time of the day and night:

I love M. dearly and I will do whatever I can to support him and to keep his independence as long as possible. He can pick up the phone any time day or night. C01, S, 73 years

Because of their investment in the person's wellbeing, some caregivers manifested worries and anxiety about safety, particularly when having to leave the person unattended. Safety concerns were often also

accompanied by a sense of guilt, when the caregiver had to leave the person with dementia at home alone:

I'm on the phone every half hour or so while I'm away, just to check that she's all right. C06, H, 68 years

I feel guilty about going out and leaving him to do the shopping. C09, W, 81 years

Caring was often driven by a sense of duty and responsibility, particularly among spouses. At times, caregivers' words implied a sense of being trapped in the role of caregiver. In fact, mixed feelings were quite common:

As a caregiver I'm just, well, I've got to be here anyway, because I'm married to the lady. C06, H, 68 years

Although not necessarily openly manifested, it seemed that frustration often derived from the difficulty of accepting the inevitable changes that dementia caused. The changes and adjustment that the progression of dementia required also caused feelings of helplessness and hopelessness:

The only worry I've got is the loss of short-term memory, but there's nothing I can do about it. It's sometimes very frustrating; you have to repeat yourself three or four times. C06, H, 68 years

I get down about it sometimes. I get a bit depressed. It's not very often I'm like that, but if I get it, I'm really down! C08, W, 73 years

Others were more accepting of change and this seemed to safeguard their own emotional wellbeing. These cares appreciated the possibility that change was not necessarily negative and that the person could, for example, take up new activities and learn new skills:

He goes to this chair yoga on a Tuesday morning round at the community centre. For me to see him doing something that he couldn't do before is a bonus. C02, W, 86 years

Overall, the qualitative interviews found that the caregivers exhibited co-existing positive and negative feelings associated with caring, with stresses and rewards that were often not easy to reconcile.

DISCUSSION

This mixed-methods study based on data from the PrAISED RCT investigated caregivers' strain, QoL and perceived health, and reported on the experience of caring for someone with dementia.

The study revealed how caring is characterized by a complex interaction of contradictory emotions. Our findings appear in contrast to the clear-cut

division operated in the previous literature between the negative emotions exhibited by those who become caregivers not by personal choice and the positive ones experienced by those who do [50]. In the interviews, participants disclosed a range of negative feelings and emotions including frustration, anger, and depression. These qualitative findings were compounded by the significant association we found between caregivers' burden and QoL, especially in the presence of high levels of anxiety and disability of the person with dementia. Although to a lesser extent, participants also reported positive emotions linked to their caring role, including a sense of fulfilling one's responsibilities, pleasure and pride in seeing the person can still do some activities or take up new ones, and reassurance in the availability of support from the family and the community.

Another important finding was that the experience of caring varied quite markedly because of the diverse range of caregivers' characteristics. Older spouse-caregivers faced disadvantaged circumstances that greatly affected their overall experience of caring. While some research found higher life satisfaction in older caregivers compared with younger ones [51–54], this study found that caregiver's age was significantly associated with strain, supporting evidence on the greater challenges of aging while undertaking a caregiver's role [55].

As in previous studies [56, 57], residing with the person with dementia was also associated with higher caregiver burden in the quantitative findings, and reduced contact with others in the qualitative ones. In line with previous research [25, 26], we found that older spouse caregivers in particular had a limited support network and experienced an overall sense of isolation and loneliness, both without and within the relationship with the person with dementia [55]. On the other hand, the younger caregivers might be more likely to have work and (other) family commitments outside the caregiving role, which could provide them with increased social opportunities and respite.

Despite the recognition of the benefits of social contacts [58], this lack of a support network was at times compounded and reinforced by the caregivers' reluctance to seek help from others. A potential explanation can be traced back to cultural factors, making older generations feeling less entitled to ask for help and caring duties seen as a responsibility within long-term relationship and marital vows [55]. Deeply rooted cultural imperatives to functional independence as a prerequisite for adult status and competence might also be at play.

While caregiver strain has been long-established as a potential factor in the development of ill-health [3, 15–23, 58], this study found that health conditions may not only develop as a result of strain, but actually be the cause of it. The quantitative element of this study showed that having a health condition was associated with decreased QoL and increased caregiver strain. The qualitative data provided some further insight into this interaction, showing that presenting with health conditions (i.e., more frequent age-related ailments such as arthritis), generated strain because of the reduced opportunities to access community support (e.g., because of reduced mobility) or because the caregiver could not provide adequate care to the person (e.g., because of physical limitations) [59].

Overall, findings from the experience of older caregivers rebutted the "adaptation hypothesis" [28, 29], suggesting that caregivers successfully adapt to coping with burden over time. Instead, because of the unique combination of circumstances in which the older caregivers found themselves, their experience seems to validate the "wear and tear" theory [30, 31], suggesting the accumulation of burden over time.

This work was characterized by certain strengths and limitations. It is among the few studies exploring caregivers' experience of caring for someone with dementia through a mixed-methods design based on large samples. However, certain demographic characteristics (e.g., ethnicity) were under-represented, requiring future research to include harder-to-reach groups, in order to gather more culturally-diverse evidence.

Some biased results may have been caused by the self-reporting measures in the quantitative assessments, as well as during the qualitative interviews with participants. It was observed that some caregivers were reserved in discussing sensitive subjects in the presence of the person with dementia, a challenge which has been previously reported [55, 60]. Therefore, efforts should be made to ensure that caregivers feel comfortable to open up during the research process, by for example, provision of alternative arrangements (e.g., two researchers attending the interview session, so that one can supervise the person with dementia during data collection). Another study limitation was the lack of longitudinal data to look at stability/trajectory of caregiver responses.

This study has identified certain support (emotional and practical) needs that present important implications for practice. There is a need to provide support services that better respond to the complexity

of caregivers' life situations. Because of the blurred boundary between being a care-provider and a care-receiver, caregivers may find enormous difficulties in finding support for themselves [61]. In addition, given the emphasis on person-with-dementia-centered approaches to care delivery, professionals may struggle to include caregivers as the recipients of care [62]. In line with Oliveira, Sousa, and Aubeeluck [63], we advocate that dedicated strategies for caregivers should be in place to address their unique challenges [61].

Building on the positive outcomes associated with caring, activities that are enjoyed by both people with dementia and their spouses may represent an inclusive strategy to promote positive relationship between the caregiver and the person, and in turn reduce caregiver burden [64]. Initiatives of this sort might be particularly appropriate for older spouse caregivers, who share similar demographics (and potential interests) with the person they care for. A recent impact evaluation of a dementia-friendly exercise class [65], as well as established evidence around dementia cafés [66] and Singing for the Brain [67] identified numerous benefits for caregivers, including networking opportunities to share and learn from peers.

Caregiver peer-support groups could also represent a helpful resource. These groups are usually based on a psychoeducational model, which encourages group members to gather information and share support with peers [61]. Integrating IT peer-support platforms might be able to address isolation/barriers of access to community support experienced by caregivers who live in remote geographical locations [61]. Telemedicine is becoming increasingly used in assisting caregivers by offering support (e.g., opportunity to be in contact with other caregivers and clinicians) and services (e.g., health and social care or third sector organizations providing educational material about dementia).

In conclusion, this study found that while caring for someone with dementia can present with both positive and negative experiences, older spouse caregivers living with the person with dementia present with a high risk of ill-health, social isolation, and lower QoL. We advocate for the provision of dedicated intervention programs and support strategies in the community, which are age-friendly and adequately respond to the needs of older caregivers at different stages of their caregiving journey. While there is recognition that it is essential to support caregivers because they are key to supporting people with dementia and because they struggle in a number of

ways, the current policy rhetoric should be matched by (successful) commensurate efforts.

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SUPPLEMENTARY MATERIAL

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