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Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework

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Background: Dementia is a major global health and social care challenge, and family carers are a vital determinant of positive outcomes for people with dementia. This study's aim was to develop a conceptual framework for the Quality of Life (QOL) of family carers of people with dementia.

Methods: We studied family carers of people with dementia and staff working in dementia services iteratively using in-depth individual qualitative interviews and focus groups discussions. Analysis used constant comparison techniques underpinned by a collaborative approach with a study-specific advisory group of family carers.

Results: We completed 41 individual interviews with 32 family carers and nine staff and two focus groups with six family carers and five staff. From the analysis, we identified 12 themes that influenced carer QOL. These were organised into three categories focussing on person with dementia, carer, and external environment.

Conclusions: For carers of people with dementia, the QOL construct was found to include condition-specific domains which are not routinely considered in generic assessment of QOL. This has implications for researchers, policy makers, and service providers in addressing and measuring QOL in family carers of people with dementia.

KEYWORDS

Alzheimer's disease (AD), carers, dementia, family carers, informal carers, Quality of Life (QOL)

1 | INTRODUCTION

Dementia is a major global health and social care challenge. Forty-six million people have dementia worldwide, and it costs over \$600 billion per year with the numbers set to double and the costs at least to triple within 20 years.¹ Family carers provide £8 billion (\$11 billion) per annum of unpaid dementia care in the UK and an estimated \$522 billion annually in the USA.² Family carers are a vital determinant of positive

outcomes for people with dementia, for example, having a co-resident carer predicts lower hospital admission³ and lower transitions into care homes.⁴

Becoming a family carer for somebody with dementia is likely to impact upon valued aspects of life such as relationships, leisure, work, as well as plans and expectations. Whilst satisfaction can be derived from caring, the experience can be detrimental physically, psychologically, and financially demanding.⁵ Family carers of people with dementia

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have more anxiety, stress, and depression than those without such a role, and it has been suggested that caring for somebody with dementia is more impactful than with other disorders.⁶

Caring for somebody with dementia impacts upon all of the factors known to affect Quality of Life (QOL), including physical health, psychological state, independence, social relationships, personal beliefs, and environmental supports (World Health Organization, 1997). Whilst some of the factors influencing QOL of this group of carers are known, an overall conceptual framework that is specific to caring for a person with dementia is lacking. A recent systematic review identified good carer health, independence (from the person with dementia), self-efficacy, and health status of the person with dementia as factors which can ameliorate the negative impact of caregiving on the QOL of carers of people with dementia.⁷ Involvement in social networks and having time for oneself,⁸ concern about the future, need for support, and engagement in enjoyable activities^{9,10} have also been identified as factors influencing carers' QOL.

However, much of the existing literature is derived primarily from quantitative studies using generic measures of QOL.⁷ The complexity of caring for somebody with dementia is unlikely to be sufficiently captured by existing generic models of QOL, and it is suggested that a more nuanced understanding of family carers' QOL in dementia is required.¹¹ There are two existing measures of QOL for carers of people with dementia; however, there are limitations to each, and neither had a psychometrically robust development.¹²

Here, we report the results of a qualitative study undertaken to generate a conceptual understanding of QOL from the perspective of family carers of people with dementia building on existing stress process models.¹³ This study was conducted as part of the development of a new measure (C-DEMQOL) of QOL specifically for family carers of people with dementia.

2 | METHODS

2.1 | Sample and setting

We recruited family carers of people with a diagnosis of dementia from clinical services in the south of England. The study definition of family carers included married and unmarried partners, children, siblings, extended family, and close friends who were currently providing at least 4 hours of care each week for someone with dementia. We sampled for variation in characteristics of the family carers, in order to generate a framework for understanding QOL across the caregiving experience, including people with dementia in care homes. In addition, we recruited a smaller sample of clinical staff with dementia care experience. NHS Health Research Authority Ethics approval was granted.

2.2 | Procedure

Study information was circulated across clinical and voluntary services in the local area. Written consent was obtained from participants before each interview or focus group. We developed draft topic guides (one for family carers and one for staff) from an initial review of the literature. For family carers, the topics included the

Key points

- This qualitative study identifies specific role-related factors that influence Quality of Life (QOL) from the perspective of family carers of people with dementia.
- These include perceptions of the relationship with and changes in the person with dementia, the caring situation, and external factors outside the dyad, which may be helpful or unhelpful.
- These findings will contribute towards the development of C-DEMQOL, a new measure of QOL for carers of people with dementia.

relationship with the person with dementia, the experience of caregiving, feelings towards caregiving, the perceived impact of caregiving on QOL, and factors influencing this assessment. The topic guide for staff explored their experiences of working with family carers including observations of factors influencing good or poor QOL in carers. The draft topic guides were reviewed by the authors and by a study specific Lived Experience Advisory (LEAP) group of family carers.

Interviews were carried out between November 2015 and March 2016 by SD. The majority of family carer interviews took place in participants' own homes, and staff were interviewed at their place of work. Interviews lasted between 45 and 60 minutes. We conducted two focus groups in order to explore preliminary themes in more depth, one with family carers (lasting 1 hour) and one with staff (lasting 1 ½ hours) in April 2016. All interviews and focus groups were audio-recorded, transcribed verbatim, and checked for accuracy.

2.3 | Qualitative analysis

Transcripts were analysed in three stages and are summarised in Figure 1 and discussed below.

The analysis started with descriptive coding, which involved giving descriptive codes to meaningful segments of text. S.D., N.F., and T.B. coded the content of three family carer transcripts independently. The researchers met to review their respective preliminary codes in order to identify areas of differences and to develop a draft coding framework. This was reviewed with an experienced qualitative researcher (J.M.) and the LEAP group, and an initial coding framework was agreed.

In the second phase, a further 18 interviews were completed and coded. Staff transcripts were also coded using the initial coding framework. The computer software package, NVivo 10 (QSR International, 2012), was used to enable the systematic collation and review of the data grouped within each code, which was reviewed on an ongoing basis using constant comparison techniques.¹⁴ A focussed coding framework was developed during this phase, and these codes were reviewed by S.D., N.F., and T.P. against the findings from a concurrent systematic review on the factors influencing QOL in family carers of people with dementia.¹⁵ The data were also reviewed with

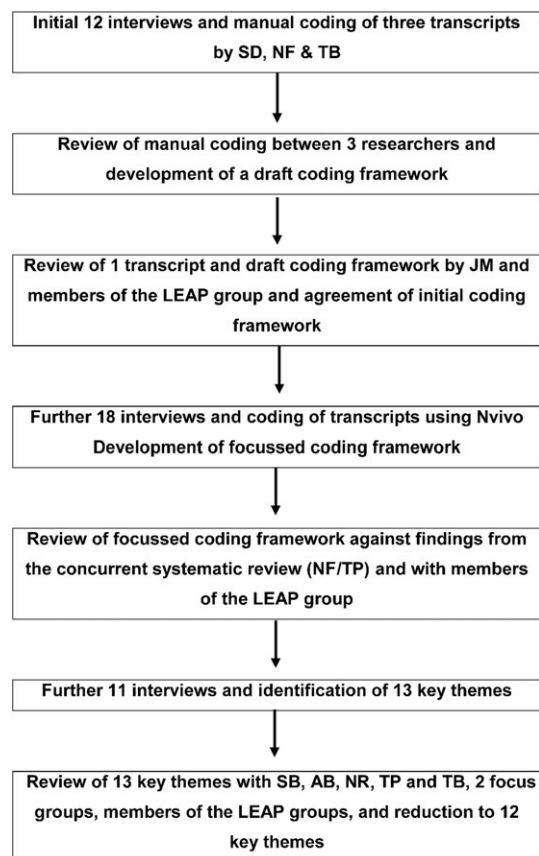


FIGURE 1 Process of analysis

the LEAP group. The final phase of the analysis included 11 final interviews, from which 13 overall themes were identified.

In order to test out preliminary findings, the 13 themes were fed back to co-researchers (N.F., T.P., S.B., and A.B.), the LEAP group and at the two focus groups. Subsequent amendments were made to the categorisation of some of the themes, and the overall number of themes was reduced from 13 to 12.

Rigour in the research process was supported in two ways. First, S.D. met frequently with J.M. for academic supervision to review coding, the development of themes and reflexivity. Second, three researchers (S.D., T.P., and T.B.) met with the LEAP group on five occasions throughout the data collection and analysis period, to review and revise emerging themes.

3 | RESULTS

We completed 41 individual interviews with 32 family carers and 9 clinical staff. Two focus groups took place, one with family carers ($n = 6$) and one with staff ($n = 5$). One family carer took part in both an individual interview and the focus group. The socio-demographic characteristics of the family carer participants are shown in Table 1.

Thirteen of the staff interviewed were female, and the majority (92%) had worked in dementia services for over 6 years. The sample included seven nurses, three occupational therapists, one psychologist, and two voluntary sector staff.

TABLE 1 Socio-demographic characteristics of carer participants ($n = 37$)

Characteristic	Range	Mean
Age	45.9–84.8 years	66.05 years
Gender	Female	24 (64.9)
Ethnicity	White British White Irish Indian Persian	32 (86.5) 1 (2.7) 3 (8.1) 1 (2.7)
Marital status	Married/partner Widowed Divorced Single	34 (91.9) 1 (2.7) 1 (2.7) 1 (2.7)
Relationship with the person with dementia	Spouse/partner Son/daughter Daughter-in-law	21 (56.8) 14 (37.8) 2 (5.4)
Education	No qualification O-level/GCSE A-level NVQ level 2 NVQ level 3 NVQ level 4 Degree Post-graduate Missing	2 (5.4) 9 (24.3) 2 (5.4) 3 (8.1) 5 (13.5) 5 (13.5) 8 (21.6) 2 (5.4) 1 (2.7)
Currently employed	Yes	13 (35.1)
Current/last occupation	Managers/directors/officials Professional Associate professional/technical Administrative/secretarial Skilled trades Caring/leisure/service Sales/customer service Process, plant operatives Elementary	7 (18.9) 7 (18.9) 7 (18.9) 4 (10.8) 2 (5.4) 3 (8.1) 2 (5.4) 1 (2.7) 2 (5.4)
Geographical location	Urban Rural	31 (83.8) 6 (16.2)
Person with dementia		
Type of dementia	Alzheimer's disease Vascular dementia Lewy body dementia Frontotemporal dementia Mixed	23 (62.2) 6 (16.2) 2 (5.4) 2 (5.4) 4 (10.8)
Residence	Co-resident with carer Non-resident	24 (64.9) 13 (35.1)
Person with dementia	Community dwelling Care home resident	30 (81.1) 7 (18.9)
Time since diagnosis	Less than 1 year Between 1 and 5 years Over 5 years Not known	3 (8.1) 15 (40.6) 14 (37.8) 5 (13.5)

3.1 | Key themes

From the analysis of the interviews and focus groups, we identified 12 themes which were used to develop a framework. These were organised into three categories: according to the primary source of the influences on QOL, from the *person with dementia*, from within the *carer*, and from the *external environment*. These are summarised in Table 2 and are discussed below:

3.2 | Category one: Person with dementia factors

1. Relationship with the person with dementia

Carers' perception of the relationship with and feelings towards the person with dementia influenced their assessment of their QOL. Assessment of the quality of the relationship was not static, with the majority of family carers believing that the nature of the relationship had changed, often through a reversal in roles. Some participants reported increased closeness following the onset of dementia, whereas others perceived no change in the relationship. For spousal carers, loss of reciprocity and recognition of support influenced their assessment of the relationship. The quality of pre-existing relationship was seen as a significant factor for QOL by all participants.

2. Change in the person with dementia

Change in the person with dementia influenced the perceived impact of caring upon QOL, with change in personality being the most commonly upsetting factor. There did not appear to be a clear relationship between illness severity and its impact on family carer QOL. However, some disease characteristics, such as repetitiveness and short-term memory loss were frequently experienced as frustrating, with anger, poor motivation, and hallucinations experienced as particularly challenging.

3. Demands of caregiving

Feeling burdened by the demands of caring for the person with dementia was identified as a factor affecting QOL. This included the provision of physical care, supervision, dealing with incontinence,

TABLE 2 Summary of categories (n = 3)

Category	Includes	Examples
Person with dementia factors	Family carer's perception of their relationship, impact of the illness on the person with dementia, and the delivery of care to the person with dementia	<p><i>'I think he's more like my child than my Dad now. He's like a big toddler' (C6)</i></p> <p><i>'The biggest thing that I found difficult to get my head around is the change of character, from being quite a gregarious, outgoing, confident manager ... to somebody now who cannot make a decision for herself and is very dependent on me now. It's the change of character that's affected me more than anything.'</i> (C18)</p> <p><i>'It's wearing ... because you're always trying to remember and prompt him to do things he needs to do, like getting to appointments and just doing basic little things to keep himself ticking over.'</i> (C12)</p>
Carer factors	The carer and her/his life situation. Includes carer's appraisal of the impact of caring on their personal freedom and health, their expectations about caring, meaning derived from the experience, expectations about the future	<p><i>'Now I can't do all the things I would like to do. I can't go off to (town) and go to a theatre, or do any of the cultural things I used to do. So it's changed me totally.'</i> (C8)</p> <p><i>You know, I say to him, "You'd have done it for me" and he would ... I just think of it as, of course I would.'</i> (C1)</p> <p><i>'And sometimes I say because of my caring he's still here.'</i> (C19)</p> <p><i>'I've aged terribly over this last ten years, I've got all sorts of things I never used to have before ... I've slowed down, as much as he has.'</i> (C6)</p> <p><i>'And there will be a stage when I'm going to have to make a decision and say, I can't do this anymore. And I'm sure that when that decision is going to be made it will be extremely difficult for me to make it.'</i> (C5)</p>
External factors	People, places, and roles outside the person with dementia/family carer dyad. In particular, appraisal and perceived value of support to the family carer, as well as role conflict	<p><i>'In general, or where I have been disappointed, is the, not having the support from the children.'</i> (C21)</p> <p><i>'I haven't got brothers or brothers-in-law, or anyone who can help. It's the sense of responsibility for his life.'</i> (C8)</p> <p><i>'We're trying to get some money from Social Services (to fund domiciliary support) and we're having a battle.'</i> (C6)</p> <p><i>'We are a big family and without the family support I do not know where we would be.'</i> (C1)</p> <p><i>'You're going to get a lot of people, I think, like me, where they are middle-aged men and women looking after an elderly parent on one side, and trying to get children through university on the other, and we're literally being pulled apart'</i> (C5)</p>

physical health needs, and worry about falls and safety by non-resident family carers.

3.3 | Category two: Carer factors

4. Personal freedom

Carers described good QOL as being associated with participation in enjoyable activities, and conversely, poor QOL was associated with restriction on activities, lack of choice, freedom, and spontaneity. Most carers experienced some degree of restriction on preferred activities. The sense of restriction was less problematic for participants who enjoyed undertaking joint activities with the person with dementia and those receiving support from others. Having a break from the person with dementia was seen as enhancing QOL.

5. Acceptance of the caring role

Family carer willingness to accept the caring role influenced their appraisal of the impact of caring upon their QOL. Some attributed willingness to a sense of reciprocity in the relationship over many years or a mutual commitment to each other. Other family carers expressed reluctance or resentment about having to take on a caring role. Due to the progression of dementia, some adult children carers described finding themselves committed to a significant caring role which they had not originally envisaged.

6. Finding meaning

Some carers found meaning and value in the caring role by making the person with dementia as content as possible, maintaining their QOL and general health, or delaying progression of the illness. Some reported deriving satisfaction and pride from their own caring contribution, whereas others were unable to identify any positive impact.

7. Carer health

The perceived impact of caregiving on carers' health was also a factor in their QOL. Several family carers perceived that caring had impacted negatively or they had neglected their own health due to caring.

8. Expectations of the future

Worry about the future was a concern which led to significant anxiety for some. Most common was worry about progression of the illness, resulting in an uncomfortable tension between inevitable deterioration and not wanting the person with dementia to die. For older spousal carers, there was concern about what might happen to the person with dementia if the carer were to die first. For others, there was concern that due to their own ageing they might not be able to pick up their own lives again after the person with dementia had died. Where the person with dementia was still living at home, there was concern about possible care home transition, whereas for others, it was accepted as inevitable. Worry about the future was reduced if the person with dementia was in a care home. Some family carers

reported actively avoiding thinking about the future, focusing instead on the present. Many family carers described being unable to plan for the future, and for those who themselves were recently retired, there was distress about the loss of their preferred future.

3.4 | Category three: External environment

9. Evaluation of support

Whilst support from other family members, statutory services, or others was important to many family carers, the effects on QOL varied according to their perceived need for support. Of significance was the extent to which specific support offered or provided was valued by the family carer, and whether they perceived it met their requirements. In general, support from other family members was most highly valued, specifically practical help and shared decision-making. Lack of family support often led to distress and a sense of being let down, which has had a worsening effect on QOL. There was considerable variation in satisfaction with statutory services, with some carers reporting no difficulties or limited expectations, whilst for others frustration with services had become a source of extreme stress, which itself was perceived to worsen QOL.

10. Weight of responsibility

Some family carers, particularly those with limited family support, described feeling overwhelmed by the amount of responsibility they had for the person with dementia. Where family support enabled joint decision-making about the person with dementia, this was highly valued.

11. Family and social networks

Contact with family and social networks was highly valued by carers, allowing them to offload emotionally, overcome isolation, and for many carers, to discuss shared concerns. Tension in family relationships related to the caring situation was commonly identified as being related to poorer QOL. Whilst tension might exist for a number of reasons, it appeared heightened between siblings if caregiving responsibilities were not shared equally and unlike other factors, this did not appear to dissipate with care home transition. Family carers wanted recognition of the situation and their caring contribution by family members and others, leading to frustration if this was not given, downplayed or in some circumstances criticised.

12. Role conflict

Role conflict was primarily experienced by those looking after their parents, where other important roles such as employment or other family responsibilities (eg, looking after children) were in conflict with the caregiving role.

3.5 | Framework for understanding QOL of family carers of people with dementia

The framework generated is based within an existing stress process model¹³ but modified to enable a specific understanding of QOL for

family carers of people with dementia. In the model, the demands imposed by cognitive impairment, loss of functional abilities, and behaviour problems in the person with dementia are not the sole determinants of carer burden. The stress process model gives precedence to appraisal by the carer of their caring situation in relation to available resources, with stress occurring when there is perceived mismatch between demand and the carer's ability to respond. Our category of carer factors is consistent with this key element in the model of caregiver stress. Our final model is presented in Figure 2.

Within this framework, change in the person with dementia and the delivery of care can be seen as primary stressors, which in turn lead to the proliferation of secondary stressors in domains outside of caregiving such as loss of personal freedom, role conflict, and the emergence of family conflict. These in turn may lead to intrapsychic strains, such as worry, resentment, feeling trapped, or loss of identity. In the carer burden model of Pearlin and colleagues (1990), it is proposed that mediators (principally coping strategies and social support) explain outcome variability. However, in applying our findings to the model in order to understand QOL in this group of carers, we suggest that four of the factors identified in this study (personal freedom, finding meaning, evaluation of support, and

family/social networks) may each influence QOL either positively as mediators, or negatively as secondary stressors. A further development of the model is that acceptance of a caregiving role and its demands acts as a mediator. Carers may experience similar objective demands, but as differing secondary stressors or mediators may apply, outcomes for QOL will vary. This model captures the positive aspects of caregiving and extends the range of possible clinical interventions to enhance specific mediators, as well as the amelioration of secondary stressors.

4 | DISCUSSION

This study adds to the literature on caring in dementia by identifying specific role-related factors that influence QOL from the perspective of family carers of people with dementia. Using an inductive approach to the analysis of carers' experiences, 12 themes were identified as being influential in carers' appraisal of their QOL. These included their perceptions of their relationship with and changes in the person with dementia, the caring situation, and the extent to which external factors outside the dyad were helpful or unhelpful. The framework

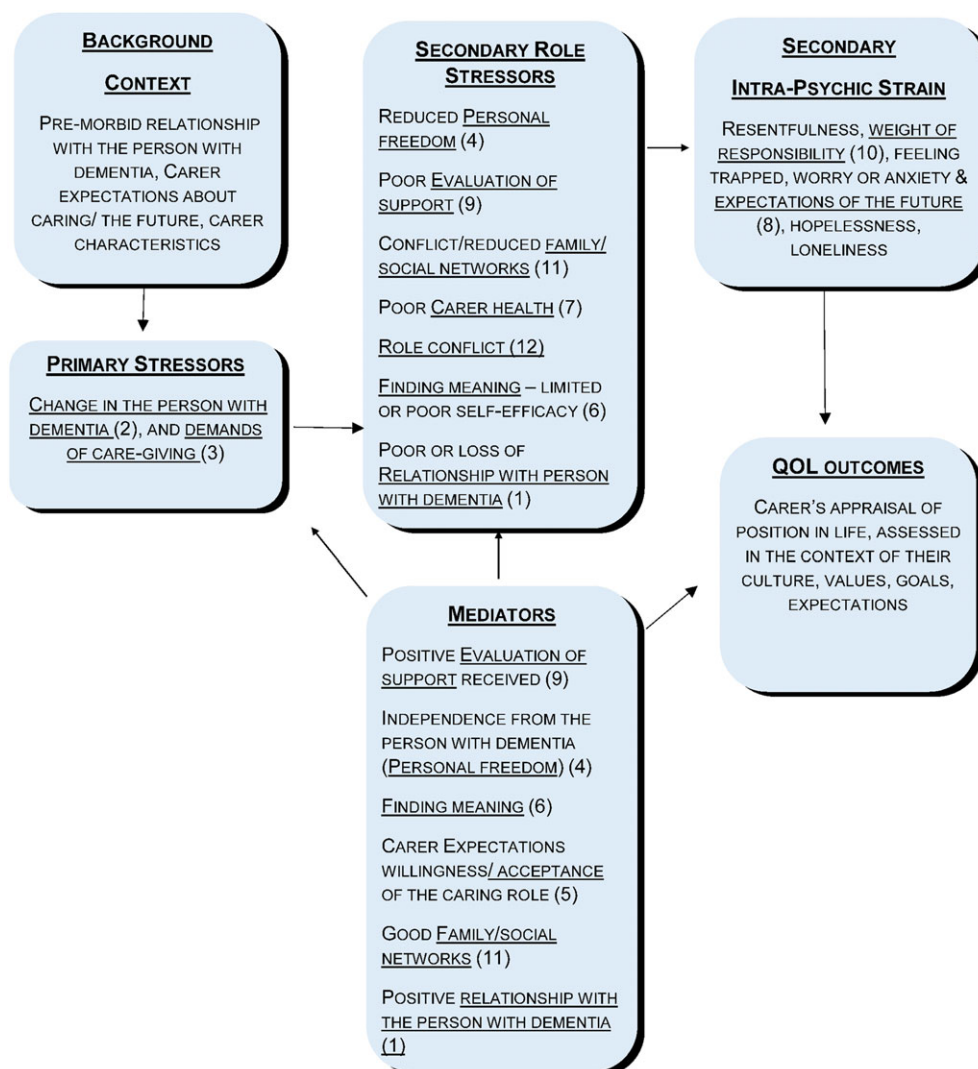


FIGURE 2 Factors influencing QOL in family in carers of people with dementia [Colour figure can be viewed at wileyonlinelibrary.com]

generated will be used to underpin the development of a new measure of QOL that is specific to carers of people with dementia. But it is also potentially of value in itself in terms of understanding what drives QOL for family carers of those with dementia and how we might generate better ways of supporting them.

Four themes identified in this study are consistent with findings from the wider literature, including the importance of the relationship with the person with dementia,^{8,16,17} the demands of caregiving,^{18,19} and carer health.^{17,20} Loss of personal freedom has also been identified as a factor in family carer QOL in dementia in two Italian studies.^{9,10} Related to this is the positive impact of time away from the person with dementia through either time for oneself⁸ or through the pursuit of leisure activities.^{17,21}

The study findings contribute to three areas where the existing literature is limited. First, we found that family carers can find meaning in their role. There is limited research in this area, but a previous study has also identified finding meaning as a factor influencing carer burden.²² Second, our findings on expectations about the future are consonant with the data from the two studies by Vellone and colleagues. Third, the value of family and social networks adds to similar observations from two qualitative studies.^{8,10} These three areas warrant further investigation in quantitative studies.

We found five new themes which are not represented in generic QOL models: change in the person with dementia, acceptance of the caring role, evaluation of support, weight of responsibility, and role conflict. Our findings suggest that perceived change in the person with dementia has an impact on family carer QOL. The impact of change on carers appears to be particularly relevant given the progressive and pervasive nature of dementia.

Carer evaluation of support offered and received was identified as a significant factor in QOL. Although interaction with agencies has been identified as a factor influencing carer QOL,⁸ evidence on the relationship between the amount of support received and family carer QOL is mixed.^{9,10,18,23} Our data extend this evidence base by exploring the impact of satisfaction with services. Our study also highlights both the value of family support in improving QOL by reducing care delivery demands and weight of responsibility, as well as the converse negative impact of lack of family support and conflict on QOL. Overall, our findings add to the understanding of the contribution of support, and the significance of carer evaluation of this on their QOL.

The impact of acceptance of the caring role, weight of responsibility, and role conflict on family carer QOL is under researched and needs further investigation.

There are two main limitations to this study. First, there was limited ethnic diversity in the family carers interviewed despite attempts to increase this, and the economic status of carer participants was not directly identified. The ethnic mix does reflect the population proportion for black and minority ethnic group carers (10% in the 2011 UK Census), but it limits the extent to which conclusions might be drawn about how ethnicity, social and economic characteristics of family carers of people with dementia might impact upon QOL. Further research is needed in this area. Second, participants were exclusively either spouses/partners or son/daughters of the person with dementia. As a result, we are unable to comment on whether the findings

reported here apply to other carer relationships such as siblings or friends or to paid carers.

There are, however, three strengths to the study. First, we used an inductive rather than deductive approach to data collection and analysis in order to make the experiences of family carers central to the development of a framework for understanding of QOL. This enhances the validity of our results. Second, emerging findings were repeatedly checked with members of the LEAP advisory group. This has allowed findings to be validated and grounded in lived experience and has allowed for amendments to be made iteratively. Third, preliminary findings were also validated with two focus groups, one with family carers and one with staff, which aided interpretation.

Our study offers rich new evidence to help understand the QOL of family carers of people with dementia. The revised framework generated in our study and the new empirical evidence will, we believe, prove useful both in developing a condition specific measure of QOL and to support policy discussion and practice development in this increasingly important field.

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CONFLICT OF INTEREST

None declared.

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