



## research article

# Seeking a care–life balance: family carers' perspectives on how quality of life can improve when caring for an older person living with dementia

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Many family carers of older people living with dementia report reduced quality of life, but limited research has investigated what they believe could improve it. Our thematic analysis of in-depth interviews with 23 family carers questions the standardisation of carer support and the appropriateness of the current scope of services, and suggests strengthening carers' independent right to support. We propose the notion of a 'care–life balance', which also draws attention to the different logics inherent in informal and formal care that future service development should seek to reconcile to better support families affected by dementia.

**Key words** family caregiving • dementia care • quality of life • care–life balance

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## Introduction

The next decades will see a sharp worldwide increase in the number of people living with dementia (Cunningham et al, 2015). Dementia is a progressive illness, and those affected usually require extensive and progressive support from healthcare services and carers. In many countries, a mix of home-based or residential care is offered to those affected by dementia, and the demand for such services will increase. In many countries, the time spent by carers providing care to this population group matches that of services (Alzheimer's Disease International, 2013; White et al, 2018). Dementia care can therefore be perceived as the combined product of 'formal' care, provided by

professional care workers, and ‘informal’ care, provided by family members or close friends (carers). Health policy increasingly relies on informal care (WHO, 2018), and carers are often portrayed as ‘co-producers’ (Jenhaug, 2018) or ‘partners’ in care (Rugkåsa, 2015). Their contribution is particularly important where governments express an ambition for people to live at home for as long as possible.

Providing care to someone living with dementia can be meaningful and rewarding (Stansfeld et al, 2017). For some, it contributes to personal growth or family cohesion (Yu et al, 2018). Considerable negative impacts on dementia carers are also documented, however. These include poorer physical (Schulz and Martire, 2004) and mental health (Liu et al, 2017), while the often exhausting and time-consuming nature of caring can leave limited opportunities for engaging in other parts of life (Cès et al, 2017; Häikiö et al, 2020a). The combination of such negative impacts is often conceptualised as ‘carer burden’. Policymakers in a number of countries are aware of such burden (for the UK, see Department of Health, 2010) and seek to redress it in different ways. Like in other countries, Norwegian policy expresses an ambition to protect carers’ health, prevent stress and strain, provide them with opportunities to remain in employment, and give them necessary and regular leisure time to partake in ordinary everyday activities (Norwegian Directorate of Health, 2017). In Norway, local authorities hold responsibility for primary health and social care, and it is their duty to implement policies for carer support. In practice, however, it is usually the care recipient’s condition, and not the carer’s situation, that triggers support (Jessen, 2014), usually in the form of day-centre activities or short-term institutional stays. In some local areas, carer academies and support groups are available. Respite care is also on offer in many places, often in standardised periods, for example, one or two weeks at regular intervals. Carer allowances, which provide financial compensation to carers with particularly heavy carer loads, are available (but not a statutory right). These are modest and rarely used, especially for those over the age of 65 (Mørk et al, 2017).

Other public agendas also concern the situation of carers. Like in many other countries, Norwegian authorities perceive the population’s quality of life – in which they include such dimensions as autonomy and sentiments of security, trust and community – to constitute a considerable national resource (Barstad, 2016). Maintaining a good quality of life for all has become a policy goal in Norway (Nes et al, 2018) and elsewhere (for the UK, see Department of Health, 2010), and is commonly used as a care-quality indicator (Møller et al, 2020). Quality of life is perceived broadly, with clear subjective dimensions (van den Berg et al, 2004). This is in line with how the World Health Organization (1997: 1) describes it: ‘an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’, which is understood to be ‘affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment’.

A number of studies measuring quality of life have found that caring for a person living with dementia is associated with reduced quality of life compared to other types of caregiving (Karg et al, 2018). Factors found to be associated with reduced quality of life include heavy subjective carer burden, depression, higher age, poorer levels of health literacy, as well as co-residency with and the health status of the care recipient (Farina et al, 2017; Alltag et al, 2019; Häikiö et al, 2020b). On the other hand, better health and greater independence are associated with a higher quality of life (Farina

et al, 2017). Qualitative studies concur and show that dementia carers see their quality of life impacted by: the health and functioning of the care recipient; their opportunities to take breaks from the situation, including time to themselves; and support from family and services (Carlozzi et al, 2018; Lindeza et al, 2020; Oliveira et al, 2020). A systematic review of interventions to improve the health-related quality of life of dementia carers found that interventions that combine different components (for instance, counselling, support groups and stress management) and thereby address a heterogeneity of needs show most promise (Lee et al, 2020). Overall, however, the small body of existing research demonstrates that the quality of life of dementia carers is a complex construct that needs further exploration across cultural contexts in order to better understand its dynamics and how it can be improved (Oliveira et al, 2015). To address this gap, we present an analysis of how carers of people living with dementia in Norway perceive their quality of life and what could improve it. Based on our results and existing literature, we propose the notion ‘care–life balance’ to help us understand dementia carers’ situation and to derive implications from their perspectives for future service development.

## Method

The data reported here are from a wider qualitative interview study that explored experiences of carers of someone living with dementia, with a focus on their interactions with formal care. Two previous articles described participants’ views on patient safety in dementia care (Häikiö et al, 2019) and the strategies they use to involve themselves when they believe services are inadequate (Häikiö et al, 2020a). This article presents an analysis of a specific part of the interview concerning quality of life.

### *Recruitment and description of participants*

Eligible participants were all adults who cared for a person who experienced symptoms of dementia (any type or stage) and, as a result, received primary and/or specialist care. Given the focus in the wider study and the way in which Norwegian services are organised, we included carers of people over the age of 65. We sought a maximum variation sample to capture a wide range of experiences (Patton, 2015). Participants could be family, friends or neighbours of the care recipient. We sought variation in age, gender and duration of the carer experience. We also wanted participants with experience of interacting with a wide range of services, from different backgrounds, and from both rural and urban areas across Norway, as well as those born abroad.

We used a combination of convenience and purposive sampling. Eligible participants were approached by healthcare workers, who distributed study information on our behalf. Those interested could contact Kristin Häikiö (KH) or allow their contact information to be forwarded to her. After the first ten interviews, we sought to balance the sample by asking the care workers specifically to target male participants and those with migrant backgrounds. We also used snowball sampling to this effect. A total of 26 carers agreed to be interviewed, three of whom withdrew before the interview took place. A more detailed description of the recruitment is available elsewhere (Häikiö et al, 2019).

**Table 1: Characteristics of the sample**

Alias name	Age span	Relationship to care recipient	Care recipient's living situation at time of interview
Sepideh	41–50	Daughter	Nursing home
Meredith	41–50	Daughter	Nursing home
Lucy	41–50	Daughter	Independent
Thomas	41–50	Son	Independent
Lennert	41–50	Son	Independent senior housing
Christina	41–50	Daughter	Nursing home
Elisabeth	41–50	Daughter	Independent
Eva	51–60	Daughter	Independent senior housing
Angela	51–60	Daughter	Nursing home
Ahmed	51–60	Brother	Independent
Mary	61–70	Wife	With carer
Hannah	61–70	Wife	With carer
Theresa	61–70	Wife	With carer
Eric	71–80	Husband	With carer
Toril	71–80	Wife	With carer
Lucas	71–80	Husband	With carer
Helena	71–80	Wife	With carer
Stella	71–80	Wife	With carer
Linda	71–80	Wife	With carer
Sophie	71–80	Wife	With carer
Camilla	71–80	Wife	With carer
Gretha	71–80	Sister	Nursing home
Peter	81–90	Husband	Nursing home

Notes: With carer = living in the same household as the participant; independent = living alone or in a household separate from that of the participant; independent senior housing = living independently in housing tailored to, and reserved for, senior citizens.

Table 1 provides details about the participants. All 23 cared for someone in their close family, and 17 of them (74 per cent) cared for their spouse. While 17 carers (74 per cent) were female, care recipients were equally divided in terms of gender. Participants ranged in age from 44 to 83, with an average of 64 years, and care recipients' ages ranged from 65 to 88, with 78 being the average. A total of 11 respondents were retired and six were in full-time or part-time employment. One participant was on long-term sick leave, two were on disability benefit and three did not provide this information. Collectively, the carers in our sample had experience with the full range of services for people living with dementia at the primary and secondary level and in the voluntary sector.

### *Data generation and analysis*

Interviews were conducted between June and October 2017 at a time and place convenient to the participant. This was usually in their home or a local meeting venue

but, on occasion, in coffee shops or at the participant's workplace. The interviews were conducted by KH, who was a PhD student at that time and had received some training in qualitative interviewing. She introduced herself as a researcher with a nursing background, though with limited experience of dementia care.

The interview took the form of a conversation surrounding the themes in a topic guide. This was developed by the authors based on existing research, input from a user panel and a pilot interview (Häikiö et al, 2019), and included such topics as: how participants perceived the scope and coordination of services for the care recipient; their experiences of involvement with these services; and the scope and effect of the carer role. In the last section of each interview, participants were asked to mark their overall quality of life on a visual analogue scale (VAS), which was a picture of a thermometer where the lowest value (0) signified 'the worst possible quality of life' and the highest (100) 'the best possible quality of life'. No explanation of quality of life was provided to ensure that participants' answers reflected their subjective interpretations. Such single-item global instruments on quality of life have good reliability and validity (Douglas et al, 2020). Our rationale for using it was to frame the subsequent discussion about what the respondent believed could increase their quality of life considerably, and we specifically stated 20 points (for scores 80 or above, we simply asked what could help increase it).

We aimed to create a relaxed atmosphere that allowed the interviewee to elaborate on issues important to them. The interviews, which lasted around 90 minutes (range = 35–140 minutes), were audio-recorded and transcribed verbatim by KH. Given the context of the overall interview, much of the nuanced and detailed responses related to participants' quality of life and how it might improve revolved around formal services and interactions with care workers.

The analysis was conducted in five steps informed by systematic text condensation (Malterud, 2012). First, naive reading of all transcripts gave an overall impression of participants' views and experience. Both authors engaged in this step, which informed further analyses (that is, the present article and the two previous articles). Second, specifically for the analysis presented here, we identified 'meaning units' (Malterud, 2012) related to the quality-of-life questions. Third, each meaning unit was summarised (by KH) to capture the essence of what participants conveyed. Fourth, the summaries were then sorted into descriptive themes (by KH), which were then, in the fifth step, grouped to form higher-level themes. This involved an iterative process of gradual reconfiguration and refinement, in which both authors took part. Where needed, agreement was reached through discussion. This resulted in five interrelated higher-level themes (see later). KH then revisited the transcripts to ensure the themes reflected their content (re-contextualisation). When presenting results, we quote from the transcripts to illustrate and validate our interpretations, as suggested in the literature (Anderson, 2010).

### *Ethics*

The regional research ethics committee deemed the study outside the scope of the Norwegian Health Research Act (Ref: 2017/756 B). It was assessed and approved by the Privacy Ombudsman of Akershus University Hospital (Ref: 2017–128). All participants signed a consent form prior to interview. They were informed that all

data would be treated in confidence and that they had the right to withdraw from parts or the whole interview without giving a reason; none availed of this opportunity.

## Results

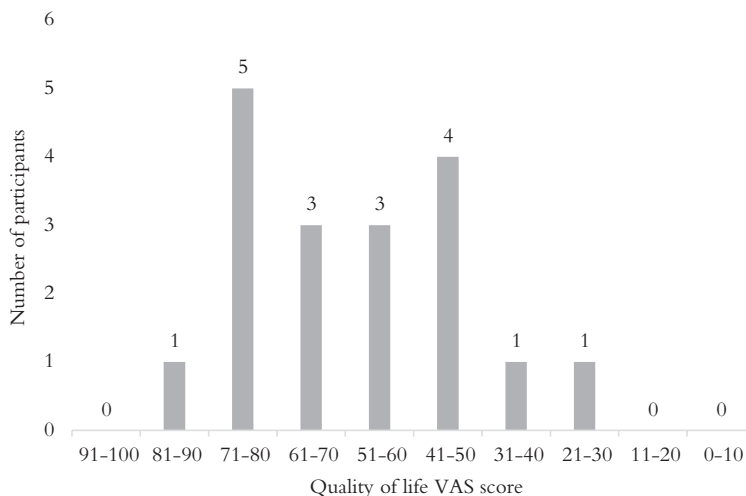
All 23 participants rated their current level of quality of life on ‘a normal day’ and discussed what could increase it. [Figure 1](#) shows the distribution of their scores, which ranged from 30–90 on the scale from 0–100, with a mean score of 62.5. The scores of five participants were unfortunately lost.

There was considerable variation in how participants rated their quality of life. Nonetheless, there were commonalities in their responses as to how it could increase, and these were captured in four themes: (1) getting assistance with the increasing number of tasks; (2) getting time off from care responsibilities; (3) knowing the person living with dementia is safe and well; and (4) altering caregiving responsibilities. A fifth theme (prioritising the carer’s quality of life could affect the care recipient negatively) included views that, in some situations, participants’ individual quality of life was secondary to other concerns. We interpreted this theme as modifying the opportunities identified in the other themes.

### *Getting assistance with the increasing number of tasks*

Participants described how they helped the person living with dementia with personal care, planning and the supervision of daily activities, and they often took charge of interactions with care workers. The scope of these tasks increased as the illness progressed. In addition, those living with dementia became gradually unable to do maintenance work, gardening, cooking or other household chores, and these tasks were often taken over by carers, particularly where they lived in the same household. This added significantly to their responsibilities, could drain energy levels

**Figure 1: Distribution of participants' quality-of-life VAS scores (0–100)**



and meant less time spent on simply being with the care recipient. Many expressed that if they got assistance with such additional practical tasks, they would have a more reasonable total load, have more balance between various responsibilities and be able to provide better care. Elisabeth, for example, worked full-time and lived with her husband and children in addition to caring for her mother. She regularly drove her parents to and from medical appointments and social activities. She also assisted with various chores, such as carrying firewood from her parents' barn to their house to make sure they kept warm during the cold Nordic winter. She often had to leave work to search for her mother, who frequently got disoriented and lost when leaving the house. Elisabeth (daughter, VAS 80) explained how assistance with practical tasks potentially could increase her quality of life, which fluctuated with the demands on her:

- Elisabeth: 'If I'm really, really tired, I'd be well below 50 [on the VAS]. At least once or twice a week I feel really low.'
- KH: 'And the other days?'
- Elisabeth: 'Then I'd place myself on 80.'
- KH: 'To maintain a quality of life of 80, what would that take, as regards your mother and the services?'
- Elisabeth: 'More help with the practical stuff.'

Many described it as a struggle to fulfil their full range of responsibilities. Lucy suggested that family carers in employment should have the option of reducing their hours while keeping their salary. She believed being able to manage her time more freely could alleviate stress and enable her to provide better support to her mother while also maintaining better quality of life herself.

### *Getting time off from care responsibilities*

Participants expressed how the nature of their care load was physically and emotionally draining, and exhausting at times, and that they needed time away from the situation to recover. Their need for respite varied considerably. Some said that they needed a few hours now and then, perhaps simply getting the time to sit down and read a book; others expressed the need for more long-term breaks to really benefit: "A week is nothing because you only get to rest for a few days and then he's back home again. So, that is far too little" (Camilla, wife, VAS missing).

The standard respite support on offer was too little for some, like Camilla, but unnecessary for others. A lack of flexibility and individual tailoring of support was a common concern. For some, regularity was key to allowing them to plan ahead. Mary (wife, VAS 40), who cared for her husband at home, expressed the need for support services that could offer her predictability:

'That I know there is predictability; that I know there is perhaps a weekend a month, or every other month when I can do stuff without having to think about what he'll do or if he's coming along or not. Or plan something with a friend, or say to someone: "Let's go for a long weekend away." Well, I suppose I can do those things, but not without feeling guilty.'

Several participants expressed the need for more immediate, responsive support at times when they felt particularly overwhelmed. Some also saw the benefit of support that allowed them to engage in 'normal', rewarding leisure activities that they had enjoyed in the past. Toril (wife, VAS 45) missed being able to enjoy a spontaneous round of golf rather than having to plan everything weeks ahead: "You know, it might be like, 'Oh my God, I so want to go for a round of golf, the weather is so nice.' But that doesn't work. They [the services] need one week's notice." Participants thus expressed different needs for respite but experienced that services usually had set allocations, systems or routines, which made it difficult to meet individual, sometimes fluctuating, needs.

### *Knowing the person living with dementia is safe and well*

Several participants said that it was difficult for them to take up offers of time off if they were unsure that the person they cared for was safe and well. Most participants described continuous worry when they were apart and, like Mary (wife, VAS 40), believed that life could improve if this worry could be lifted:

KH: "What would it take for you to feel that your quality of life increased by 20 points?"

Mary: "That I didn't need to worry, you know. Today, I was worried: I hadn't received any message yet when I was in town that he'd made it there [to the GP]."

A number of participants worried about the quality of formal care. Many described risky situations, such as risks of falls or insufficient nutrition or hydration, in long-term care, respite care and home-based services. Christina (daughter, VAS 80) explained how her mother, who lived in a nursing home, suffered repeated urinary tract infections (UTIs) because her incontinence pad was not changed frequently enough:

"In one week, I was there three times, and every time I come, I first think she's spilled something on the floor. But when I lift her up, she's peed out. But when this happens every other day for a week, that's not OK. And they get so many UTIs because they are sitting in that wet incontinence pad."

Participants also worried about the mental and emotional well-being of the person living with dementia, and the negative effect of a lack of meaningful activities in nursing homes or day centres. Mary (wife, VAS 40) was reluctant to leave her husband in such a place:

KH: "So, you want for him to have shorter or longer periods with respite every so often but in a place that suits his needs?"

Mary: "Yes! A place where they don't sit next to the lift "waiting for the train" [waiting to die], you know."



Perceptions of poor quality of formal care could therefore make participants worry about the safety and well-being of their relative, which impacted both their own quality of life and the uptake of services.

### *Altering caregiving responsibilities*

While participants showed commitment to their carer role and accepted a degree of burden to do what was best for their relative, a few elaborated that if they were to prioritise their own quality of life, this would require a change in overall responsibilities. Linda (wife, VAS 45) expressed that if she could trust that services were of good quality, she could envisage a situation where the time her husband was with her was reduced and believed that this would significantly increase her quality of life:

‘If he could go into one of those [dementia] villages, or what you call it, and be there for periods of time, so that he and I could have [sighs] let’s say half the time together then and half the time for other things – because I still want to be with him because I believe that it still means something to him.... then I would shoot high up on the [VAS] thermometer.’

Some expressed that services seemed unwilling to negotiate changes in responsibilities or did not communicate with the carer about such change. As a result, carers’ situations were often not taken into consideration when care decisions were made. One example was provided by Mary (wife, VAS 40), who explained how a hospital doctor had decided, without discussing with her, that her husband should be discharged directly to their home after surgery, as there was no need for him to recover in the short-term unit because “he had a stay-at-home, competent wife”.

Some participants who reported very poor quality of life expressed that for this to improve, they would need to withdraw from the carer role altogether. Eric (husband, VAS 30) explained that he had applied for a place at a nursing home for his wife several months ago, but she had not yet been prioritised. His wife no longer recognised him or their home, and his wish was that the service should take over responsibility for her:

‘What is needed for a 20-point increase is for her to be taken care of by others, quite simply, that I get my freedom back. Then, I could go to the cabin and do what I wanted there, both in the mountains and [place name]. I can’t do that now.’

On the whole, participants did not experience that carers’ quality of life was something that services considered when prioritising care for those living with dementia.

### *Prioritising the carer's quality of life could affect the care recipient negatively*

Despite its negative effects on their quality of life, most expressed that caring for someone they loved and cherished was not only necessary but also rewarding and gave them a feeling of gratitude. It was described as an integral part of life, a continuation

of lifelong, reciprocal relationships and a natural consequence of their overall value systems:

‘I have to say it brings me satisfaction to be able to help her because it’s a person you love and who has done everything for you throughout your life, you know. So, in the period after my father passed away, she [the mother] did *everything* to make my life as good as possible. So, I feel that now is time to give back. So, of course it gives me pleasure to be able to help her, you know.’ (Lucy, daughter, VAS 75)

Such sentiments of mutuality, obligation and commitment might explain why some participants were unwilling to prioritise their own need for respite when they experienced that services did not reach an acceptable standard. Some chose not to go on vacations or take time to themselves, or they reduced time spent on social activities or other relationships, all of which affected their quality of life. For some, these mechanisms impacted significant life choices. Eva (daughter, VAS 55), who described her quality of life as low, expressed that it was nevertheless more important to her to continue to care for her mother than to prioritise herself:

- Eva: ‘Increasing by 20 points would be as simple as moving abroad. Norway is not the place for me.... But I’ve promised not to leave as long as my mother needs me.... So, I know exactly what I have to do to get there [20 points up], but it doesn’t fit in now, or where I am now in life.’
- KH: ‘Well, so it’s an active choice, but at the same time, it’s kind of a price you pay, you pay with your own quality of life?’
- Eva: ‘Yes, I do.’

When Peter (husband, VAS 50) was asked about what it would take for his quality of life to increase, his answer shows how it was difficult for him to disentangle his quality of life from his relationship with his wife:

‘It maybe pains to say, but if [name of wife] passed away [weeps; pauses], then I didn’t have to worry. [Weeps.] But she is part of my quality of life, so it’s wrong to say it like that, but on the other hand, I don’t know, but in a situation like that.... It’s not exactly quality of life, but it is what characterises everyday life. It is not a desirable situation [that she should die], but then I would have less worry.’

Peter’s expression of his wife being “part of my quality of life” yet that he simultaneously expected his quality of life to increase when she died illustrates the complexities of the relationships and emotions involved in caring for someone whose life is fundamentally changed due to dementia.

## Interpretation

From the international literature, we know that carers of people living with dementia experience poorer quality of life than others. Given the reliance of health services

across countries on the contribution from carers, it is important to explore how this group perceive their quality of life and how it might improve in order to sustain their caregiving abilities. We have explored the experiences of a diverse group of carers of older people living with dementia in Norway. There was considerable variation in how participants rated their current quality of life (30–90 on a scale from 0 to 100). Although the sample was small and not representative, the median of 62.5 is below the score of 80 (measured with a similar VAS) in the general Norwegian population (Stavem et al, 2018). Self-rated quality of life tends to reduce with age (Stavem et al, 2018), and this is also found among dementia carers internationally (Oliveira et al, 2015), the majority of whom are in late middle age or old age (Xiong et al, 2020).

Despite the variation, there were common themes in participants' discussions – grounded in their specific care situation – of how they believed their quality of life could improve if various imbalances were redressed. These included: having someone take on practical tasks in order to get a more manageable load of responsibilities; having some 'time off' to regain energy and maintain social activities and interests; and to reconsider the balance between informal and formal care responsibilities. To enable them to take up available support, participants needed to know that their relative was safe and well. Also impacting their perceived opportunities for redressing imbalanced situations were concerns that this might have negative effects on the care recipient, to whom they expressed profound commitment.

Our analysis suggests that two fundamental dynamics must be taken into account when designing services that can meet the needs of the person with dementia *and* their carers: first, that caring is embedded in long-lasting reciprocal relationships of mutuality and obligation; and, second, that this perspective might not align with the logic of services, within which formal care workers hold power to define needs and how to meet them. We discuss these two dynamics in turn before we elaborate on how our interpretation of participants' views might be summed up in a notion of a 'care–life balance'. This notion, we argue, might help to disentangle some issues that result from this lack of alignment and, through that, aid the policy ambitions of improving subjective quality of life while simultaneously maintaining a sustainable source of informal care. Given the correspondence between our results and those reported in other contexts (Oliveira et al, 2015), we believe that this perspective has applicability beyond the Norwegian context.

### *Family caregiving as part of long-term reciprocal relationships*

The considerable physical and emotional strain resulting from caring that is reported in the international literature (Schulz and Martire, 2004; Chiao et al, 2015; Cès et al, 2017; Liu et al, 2017) was also evident in our data. The impact of being a carer on quality of life stemmed not only from the (progressive) need to attend to personal care, nutrition or interactions with services but also from a gradual redistribution of everyday, practical chores. This increased carers' overall responsibilities exponentially and came on top of those associated with other parts of their lives. This was one factor that contributed to their struggle to find the time and energy for the activities that, in combination, reflected their 'goals, expectations, standards and concerns', which form part of the government's ambitions for everyone's quality of life (Barstad, 2016).

Caring often happens in the context of long-term reciprocal relationships. Our participants expressed how caring, including taking on new tasks, was enveloped in emotional ties to close family members. Some expressed sentiments of duty and reciprocity as reasons why it would not be right to prioritise their own quality of life at a time when the care recipient was vulnerable and dependent on them. Eva did not think that it was right to move abroad, and Peter could not see how his individual quality of life could increase until his wife died. As such, their care responsibilities seemed embedded in their personal value systems and within relationships and their histories (Rugkåsa, 2015). These attitudes can be understood as poignant expressions of commitment and love, as well as an acknowledgement of an interdependency between their and their relative's quality of life. Such long-term interdependency informs the viewpoint from which many carers perceive their role and their interactions with, and support from, care workers. It has been suggested that considering quality of life at the level of the family affected by dementia when identifying needs is a way forward (Ducharme and Geldmacher, 2011), and our results support such a position.

### *Informal and formal care: unequal abilities to define and prioritise needs*

The perspective just described might contrast with the 'logic' of service organisation. As with other public services, support for those living with dementia and their carers is carefully prioritised against tight budgets and expected to reflect effective and fair use of resources (Aasen et al, 2018). This makes it difficult to take subjectively defined carer needs into account. A notion of limited resources thus shapes care workers' roles and interactions vis-a-vis carers, and contributes to cementing an unevenness in the relationship between formal and informal care, with decision-making power firmly placed in the formal sector (Anker-Hansen et al, 2020). This unevenness was manifest in the experiences of those participants who believed a shift in responsibilities from informal to formal care could improve their quality of life: they did not experience that their personal needs were given much weight in decision making. This has also been reported among family carers of people with mental health problems (Anker-Hansen et al, 2020).

In different ways, our participants expressed that for their quality of life to improve, they would need some 'time off', which has been found to improve carers' situation internationally (Neville et al, 2015) and is incorporated into public policy. The need for respite varied across time and care situations, however. Some recuperated by sitting down to read a book, sleep, meet friends or participate in recreational activities, while others needed several weeks away from caring responsibilities. While long-term planning was paramount for some, for others, more immediate, responsive approaches were the most helpful. Often, however, the respite offered to our participants seemed to lack the flexibility needed to meet heterogeneous and fluctuating needs, as defined by carers themselves. This is reflected in systematic reviews of the international literature, which also report, perhaps unsurprisingly, that uptake of support services in general is low (Neville et al, 2015).

The unequal power to define and address needs was also evident when participants explained how they often simply did not trust the quality of formal care provided in their absence. Constant mistrust in care quality and worry over safety risks can affect quality of life negatively (Oliveira et al, 2019). This is (indirectly) recognised in the

current Norwegian carer strategy, which states that ‘knowing that one’s relative is looked after by caring and competent health professionals is of great importance to family carers’ sense of security, health and quality of life’ (Ministry of Health and Care, 2020: 39). From our data, it seems clear that despite this recognition, current services are not putting all carers at ease in this regard: taking time off to recover might seem useless if that time is spent worrying whether their loved one is safe and well. As a consequence, many chose not to avail of short-term respite, go on holiday or take time to themselves. That services de-prioritise carers’ appraisals of need paradoxically leads to a situation where carers themselves also cannot prioritise their needs due to their commitment to the person living with dementia, which is embedded in long-term, reciprocal relationships. The inability of services to meet subjectively defined needs thus becomes a driver for public policy to ‘piggyback’ on the personal value systems of family carers. Public policy has long taken family obligations to care for granted (Sevenhuijsen, 2000), and our participants’ experiences suggest this is still the case.

### *Seeking a ‘care–life balance’ and implications for policy*

Our participants described how caring is part of complex and unique care situations that include a wide range of responsibilities, stresses and strains, with negative – and positive – impacts on quality of life. As mentioned, current policy seeks both to support carers to remain a sustainable source of informal care and to maintain good quality of life. Participants had clear ideas of how this could be achieved in some situations by altering the balance of responsibilities between informal and formal care. Yet, like carers in other contexts (Raivio et al, 2007), they experienced limited opportunity to make this happen.

To better understand the implications of these findings for the policy and service agenda, we propose that a notion of ‘care–life balance’ might be helpful. The concept of a ‘work–life balance’ is commonly used to describe the sometimes difficult relationship between work commitments and personal lives (Kelliher et al, 2018), which does affect quality of life (Greenhaus et al, 2003). This notion has also been applied to highlight the competing demands on family carers (Bouget et al, 2017). We would argue, however, that for family caregivers who are in or approaching old age with substantial care loads, there are additional layers of complexity involved. First, a substantial number of dementia carers are not in employment (Xiong et al, 2020) but nonetheless experience a constant increase in responsibilities as they grow older (often with depleting energy levels). This makes it gradually more difficult to find a healthy balance between their daily responsibilities. Second, the notion of ‘work–life balance’ often focuses on the individuals’ choices to prioritise what this balance should look like in their situation. While informal care is often described as ‘voluntary’ (Ministry of Health and Care, 2020), both its embeddedness in long-term obliging relationships and the explicit expectations in policy make this description problematic: many do not experience much choice but to take on (increasing) care loads (Rugkåsa, 2015; Pertl et al, 2019). Third, their role involves interactions with formal services, which, as suggested, hold key defining powers. As a result, it might seem almost impossible for many individual carers to try to address unhealthy imbalances between competing demands because the factors that could redress them appear unnegotiable or outside their control.

We believe the complexities of these dynamics might be better accounted for by the notion of ‘care–life balance’, by which we mean the relative weight of a carer’s different responsibilities in terms of their caregiving, their employment, domestic and social commitments, and their personal needs. Striking an optimal care–life balance would require taking into account: the carer’s unique, extensive and accumulating care responsibilities (including internal and external expectations to take them on); their abilities and resources to carry these out; and their need for social and recreational activities. Achieving such a balance is likely to require the input of public services, and we think the notion provides a lens through which to view implications for carer support in at least three ways.

First, it draws attention to the need for an increased tailoring of support offered to families affected by dementia so that the needs of carers and care recipients are met simultaneously. As argued, carers’ needs are complex and heterogeneous, and while tailored services are frequently advocated in policy, in practice, service organisation makes this difficult to achieve (Jessen, 2014; Anker-Hansen et al, 2020). Offering standardised support might meet organisational demands for efficiency savings, but it limits services’ abilities to maintain or improve carers’ subjective quality of life, for which the services also hold responsibility.

Second, a ‘care–life balance’ draws attention to the differing perspectives of those providing informal and formal care, which, in turn, problematises what the remit of formal services is and ought to be. We have previously shown that our participants perceive patient safety in much broader terms than they believe care workers do and, as a result, absorb needs and fill what they perceive as gaps in care to keep the care recipient safe (Häikiö et al, 2019; 2020a). What we have shown in this article is how participants identify types of support that could both help them to sustain their carer role and improve their quality of life. These included help with non-dementia-related household chores, which is currently beyond the scope of carer support. A focus on ‘care–life balance’, which includes subjective perspectives on quality of life, might thus challenge how needs are defined and what kinds of support should be available.

This leads us to the third aspect of how the notion can contribute, namely, by drawing attention to carers’ independent right to adequate support as a separate issue from the rights of care recipients. Despite what is promised in policy, support to families affected by dementia is usually based on patients’ conditions (Jessen, 2014). However, if societies organise welfare in ways that rely on family caregiving, knowing full well the impact this might have on them, it seems reasonable to make sure they are afforded rights to adequate support.

### *Strength and limitations*

Our sample had a good spread of age, location, gender, duration of being a family carer and experiences with different services. It consisted of carers who volunteered to take part and who were in contact with services. The majority of respondents were spouses to someone living with dementia. We had good representation from the indigenous Sami population but only two participants with migrant backgrounds. It is possible that results would have differed if the sample had included, for example, more siblings, more migrants, people with other connections to the care recipient than kinship, those

not in contact with services and those caring for someone under the age of 65 living with early-onset dementia. The study was conducted in Norway, which might limit its applicability in other settings. Our findings are, however, in line with those from other countries (Chiao et al, 2015; Oliveira et al, 2015; Farina et al, 2017; Alltag et al, 2019). Our data might be open to additional interpretations. The interviews took place around five years ago and prior to the COVID-19 pandemic. It is possible that participants would have offered different perspectives had we interviewed them now, though the service context remains largely unchanged.

## Conclusion

Caring for older people living with dementia is associated with reduced quality of life (Oliveira et al, 2015; 2020; Farina et al, 2017). The carers we interviewed identified a number of ways in which their quality of life could improve and how services could contribute to that. This included getting time and support to meet ongoing and fluctuating needs by reducing the level of practical chores or shifting the distribution of responsibilities between formal and informal care. As they did not experience flexibility in what was on offer or that their individual appraisals of needs were considered in care decisions, their opportunities to negotiate responsibilities were limited. Combined with concern that the care recipient was unsafe in formal services, this prevented some from using available support. Caring was described as value driven and embedded in enduring reciprocal family relationships, sometimes making a focus on individual quality of life problematic. Carers' commitment to look after their relatives despite costs to themselves allows public policy to take advantage of personal value systems.

We propose the notion of 'care–life balance' to enhance our understanding of the complexities of needs in individual care situations, which may support the dual policy aim of enabling carers to remain a sustainable source of informal care while also maintaining their subjective quality of life. The notion problematises the standardisation of carer support, questions the appropriateness of the current scope of formal care and indicates the potential of strengthening carers' independent rights to support. It also draws attention to the different logics inherent in informal and formal care as a topic for further research, with the aim to find ways to reconcile these in the development of good-quality services for families affected by dementia.

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## Conflict of interest

The authors declare that there is no conflict of interest.

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