

**‘Caring beyond capacity’ during the coronavirus pandemic: resilience and family carers of people with dementia from the IDEAL cohort**

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**Abstract**

Family carers of people with dementia have reported increased caring demands during the COVID-19 pandemic. The aim of this qualitative study was to explore seven family carers’ accounts of dementia caregiving one year into the COVID-19 pandemic in England in relation to carer resilience. Themes described the complex challenges of caring during the pandemic, with interviewees burned out and ‘caring beyond capacity’ due to unmet needs within the caring role, therein highlighting the limitations of building individual resilience only. Timely practical support for carers is essential to protect their well-being and to ward against the potential consequences of carer burnout.

**Key words/short phrases**

Alzheimer’s; caregiving; COVID-19; qualitative

**Introduction**

There are an estimated 900,000 people living with dementia in the UK (Alzheimer’s Society, 2021; Nichols and Vos, 2021). People with dementia need care and support as the condition progresses (Prince et al, 2015), with much of this care provided by family carers (Lewis et al, 2014; Lindeza et al,

2020), and one in three people during their lifetime likely to care for someone with dementia (Parkin and Baker, 2021). Caring for someone with dementia can be a full-time role and may present unique challenges as people with dementia experience a range of behavioural, psychological and physical symptoms (Alzheimer's Society, 2022; Cohen-Mansfield, 2015; Feast et al, 2016). In 2018, 36% of carers of people with dementia devoted more than 100 hours a week to this role (Dementia Statistics Hub, 2018), with the UK's 700,000 unpaid carers of people with dementia providing care worth around £13.9 billion a year (Wittenberg et al, 2020). Care needs develop from the early stages of dementia and increase over time, although there will be variability across dementia subtypes and for individuals (Prince et al, 2013). In addition, most people with dementia also live with another health condition (Nelis et al, 2019), with a particularly high prevalence of other conditions such as cerebrovascular disease, stroke and diabetes compared with the general older population (Livingston et al, 2020).

Caring for a relative with dementia is a complex experience incorporating positive and negative aspects (Lindeza et al, 2020; Quinn & Toms, 2019), associated with both carer well-being and satisfaction with life (Quinn et al., 2019). This indicates that carers of people with dementia can adapt well and be resilient (Dias et al, 2015). Definitions of resilience vary, however, with resilience considered as a trait, outcome or process (Bekhet and Avery, 2018; Zhou et al, 2021). McKenna et al (2021) have contrasted trait and transactional approaches to carer resilience. In the former, carer resilience is considered to be an individual characteristic or inherent ability that remains stable across different situations; in the latter, carer resilience is regarded as an adaptive process that can fluctuate according to different challenges and life stages and hence as modifiable. Further expanding on a transactional approach, and informed by Ecological Systems Theory (Bronfenbrenner, 1994), Windle and Bennett (2012) emphasise the importance of assets and resources for carer resilience; how, in the face of potential adversity, individuals draw on a range of personal, social and community or societal resources (e.g. psychological and social support, and health and social services) which become "the resilience reserve" for positive adaptation (Windle, 2021). Nonetheless, others have argued that a "prevailing fixation on individual resilience" has persisted (McKenna et al, 2021:32). In addition, most resilience measures assess the individual level only (Windle, 2011), with resilience interventions poorly conducted (Petriwskyj et al, 2016) and largely aimed solely at fostering carers' psychological resources (Teahan et al, 2018).

With caring for someone with dementia already a potential stressor, how do understandings of carer resilience hold in relation to other potential adversities, such as the COVID-19 pandemic? Quinn et al. (2022) reported that carers of people with dementia coped well during the pandemic, whereas Hughes, Liu and Baumbach (2021) reported more depression and anxiety in carers than before the pandemic, with Geschke et al (2021) recommending enhancement of environmental and social resources to foster individual resilience (e.g. financial recompense for carers), arguing that the pandemic magnified pre-existing problems for carers. Certainly, worsening of behavioural and psychological symptoms in the person with dementia and increased carer stress have been reported (Cagnin et al, 2020; Pongan et al, 2021) as has additional carer burden (Budnick et al, 2021; Lorenz-Dant and Comas-Herrera, 2021), with poorer quality of life attributed to loss of support such as from paid carer workers (Masterson-Algar et al, 2022). Notably, carers with high resilience also reported higher levels of anxiety during the initial stages of the pandemic (Altieri and Santangelo, 2021), serving as a reminder that resilience is not the same as an absence of psychopathology (Bonanno, 2012; Southwick et al, 2014).

These studies suggest that there were additional challenges in caring for someone with dementia due to the social restrictions imposed during the early stages of the pandemic. The current study offers a contribution to this literature, focusing on the experiences of carers one year into the COVID-19 pandemic, by which time some may have adapted and devised new ways of coping, while others may have found continued restrictions increasingly difficult. Experiences during this later period may have additional implications for understanding and conceptualising carer resilience. The main aim of the study, part of the INCLUDE (Identifying and mitigating the individual and dyadic impact of COVID-19 and life under physical distancing on people with dementia and carers) component of the IDEAL cohort study (Clare et al., 2014), was to explore family carers' experiences of caring for someone with dementia in the UK one year into the COVID-19 pandemic, just after the vaccination programme had been introduced. A secondary aim was to consider the study findings in relation to resilience representations in dementia caregiving.

## **Methodological approach**

### ***Study design and ethics***

The INCLUDE 'post-vaccine' qualitative study with family carers of people with dementia presented here employed a subtle realist ontological approach (Blaikie, 2007; Hammersley, 1992). INCLUDE is a

pandemic-specific mixed-methods component of the UK IDEAL cohort study which recruited and followed people with mild-to-moderate dementia and their family carers. Running since 2014, 'Improving the experience of Dementia and Enhancing Active Life: living well with dementia. The IDEAL study' was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405), and the Ethics Committee of the School of Psychology, Bangor University (reference 2014-11684). The IDEAL-2 study was approved by Wales Research Ethics Committee 5 (reference 18/WA/0111) and Scotland A Research Ethics Committee (reference 18/SS/0037). INCLUDE was approved by Wales Research Ethics Committee 5 as an amendment to IDEAL-2 for England and Wales (18/WS/0111 AM12), comprising an online survey of IDEAL cohort participants with a sub-set approached for detailed interviews at three stages during the pandemic. IDEAL and IDEAL-2 were registered with the UK Clinical Research Network (UKCRN), numbers 16593 and 37955. Further details about INCLUDE can be found in Clare et al. (2022).

### ***Sampling and recruitment***

Family carers of people with mild-to-moderate dementia living in the community comprised a convenience sample of potential participants, drawn from INCLUDE survey respondents who had expressed willingness to participate in a qualitative interview. Initially approached either by telephone or email, eight family carers of people with dementia were contacted from an original pool of 22, among whom 10 had already been recruited to (or approached for) the INCLUDE qualitative interview study conducted with people with dementia and their family carers earlier in the pandemic and prior to introduction of the vaccination programme (Pentecost et al., 2022). Recruited participants had previously provided written informed consent to take part in the INCLUDE project (Clare et al., 2022) having been fully briefed about it and given time to consider if they wished to participate. Seven family carer interviewees were recruited to the study.

### ***Semi-structured interviews***

Semi-structured interviews based on a topic guide drawing on the pandemic timeline were conducted remotely, either by telephone or online via Zoom, in accordance with interviewee preference. Interview durations ranged from 39 minutes to 1 hour 14 minutes. All interviews were recorded and professionally transcribed. Interviews were conducted between January and April 2021, following introduction of the coronavirus vaccine programme in England in December 2020 (Institute for Government, 2022). One interview was conducted by CP, an experienced researcher

and member of the study team, during the first week of the third period of widespread nationwide mandatory 'lockdowns' (social restrictions) in England (January 2021). This was a joint interview with the carer and the person with dementia, but as the person with dementia did not engage with it, the interview was regarded as representing the carer's perspectives only. All other interviews were conducted by SS, a post-doctoral researcher and former family carer of a person with dementia, in April-May 2021.

### ***Qualitative analysis***

Framework analysis was used to guide the thematic analysis of the transcripts (Ritchie and Spencer, 1994; Spencer and Ritchie, 2014). SS devised detailed transcript summaries to aid familiarisation with the data and notes to facilitate the analytic decision-making process and development of an inductively-derived thematic framework. To counter potential researcher bias and support reflexivity during the analytic process, SS remained cognisant of her former caring role; this was openly discussed in qualitative research team meetings on the analysis. SS also actively sought to challenge initial coding and theme development through negative case analysis, a strategy regarded as critical for quality in qualitative research (Morse, 2015), although debate on methodological rigour in qualitative research continues, in part due to the heterogeneity of qualitative approaches (Lester and O'Reilly, 2021). As well as regular discussion of the ongoing analysis by the three members of the qualitative research team SS, RC and CP, one (RC) reviewed the thematic framework against the complete interview set, providing additional notes and comments. NVivo (QSR International Pty Ltd, 2020) was used to index and chart the data. Final themes were derived using mapping and interpretation and discussed with INCLUDE co-investigators.

### **Findings**

The seven interviewees ranged in age from 53 to 89; five were female and all but one were caring for a spouse or partner (see Table 1). Four interviewees were caring for a relative with Alzheimer's disease (AD). Four carers reported 'shielding' their relative during the pandemic on Government advice to stay at home due to clinical vulnerability to COVID-19 resulting from other health conditions; other carers chose to adopt similar precautions even if their relative with dementia did not have additional health concerns. 'Years since dementia diagnosis' were calculated from the IDEAL dataset (version 5). Two interviewees were caring for a relative who had been diagnosed

between six and nine years ago, and three for a relative diagnosed between three and five years ago. Three interviewees also spoke about caring for other relatives with health problems.

<Table 1 here>

Three themes were derived from the analysis: 'Dimensions of caring'; 'Caring beyond capacity'; and 'Supporting carers and people with dementia: before COVID and beyond' (see Table 2). 'Dimensions of caring' relates to the nature and intensity of caring for someone with dementia, particularly during the pandemic, and how this is circumscribed by the context of normal family relationships. 'Caring beyond capacity' focuses on carer burnout during the pandemic due to ongoing caring demands in the post-vaccine period and the absence of appropriate service support and respite care. 'Supporting carers and people with dementia: before COVID and beyond' relates to supporting carers and people with dementia from diagnosis onwards, including funding care and providing individualised service support.

<Table 2 goes here>

### 1. Dimensions of caring

*Protecting the person with dementia: avoiding coronavirus risk* had dominated several interviewees' experiences during the pandemic. Some carers implemented their own measures to protect the person with dementia; for example, not allowing care workers in: "*we didn't want it brought into the house for us*" (Fran, aged 84, partner has AD) or delaying the move to residential care: "*there's no way I'm putting my mum [mother] into a care home. It's too dangerous*" (Joan, aged 53, mother has AD). Some interviewees said the person cared for did not understand coronavirus rules. One was concerned his wife would be berated for not socially distancing (Sam, aged 60, wife has young onset dementia). Another said her husband had forgotten there was a pandemic and thought social distancing meant something was wrong with him (Zoe, aged 63, husband has AD). Continually orienting the person with dementia to the pandemic was difficult for some carers who described the ongoing challenge of explaining why restrictions were needed and why the person with dementia had to stay at home. Interviewees were matter-of-fact about having had the vaccine, although some were cautious about COVID variants and taking "*small steps*" (Sam, aged 60, wife has young onset dementia) in going out more again. Thus even at a later stage in the pandemic, interviewees continued to focus on protecting the person with dementia.

*Intensity, hypervigilance and decline* refers to the intensity and diversity of the person with dementia's care needs; inevitably these varied across interview accounts. Five of the seven

interviewees reported the challenges of managing intense and varied caring demands: distress in the person with dementia, wandering at night, not being recognised by the person cared for, personality change, verbal aggression, 'sundowning' (increased agitation during the evening), incontinence, immobility, seizures, and daily challenges in managing meals and medication. Two mentioned mainly dealing with lack of communication or somnolence. Managing the person with dementia's differing and intense needs typified the daily experience of some carers, whose accounts suggested they were in a constant state of hypervigilance: "*I live at a high level of adrenalin much of the time ... Always on my toes, wondering where the next potential...potential difficulty is*" (Fran, aged 84, partner has AD). Some felt the person they cared for had declined during the pandemic, intensifying their care needs. Although some acknowledged this may have been due to natural disease progression, others speculated that it was due to a lack of routine and being "*housebound for so long*" (Joe, aged 56, wife has an unspecified dementia diagnosis); a confinement interviewees and their relatives were experiencing again, during the third national lockdown in England, at the time the interviews took place.

The varied care needs of the person with dementia highlight *the complex nature of caring* and the diversity of roles (carer, therapist, advocate) involved in facilitating the person with dementia's activities and social interactions. These roles had increased and continued as the pandemic progressed. Several interviewees had set up regular calls with family during the lockdowns or thought of activities for the person with dementia "*to keep ... the mind working*" (Zoe, aged 63, husband has AD); walks, tasks around the home, and in one case trying to replicate activities such as art therapy that the carer's wife would have done at a day centre (Joe, aged 56, wife has unspecified dementia diagnosis). These intensified caring roles during social restrictions were complicated by *the dual caring role and family relationships*; caring was perceived as a normal role within a partnership or family. One interviewee said he had "*been through hell and back*", yet emphasised the importance of his marriage: "*...when you take your vows, you take them until ... just as ... as you said, 'Death 'til do part'*" (Joe, aged 56, wife has unspecified dementia diagnosis). Some interviewees spoke about continuing shared interests, "*a major string of the bow of friendship*" (Fran, aged 84, partner has AD), although these had been limited by the lockdowns. Other family relationships and caring roles, in addition to caring for their relative with dementia, meant one interviewee was also supporting a daughter with mental health problems, while two were caring for a parent, one of whom had recently also been diagnosed with Alzheimer's.

*Bounded time: carers' time for themselves* reflects interviewees having little or no time for their own activities or paid employment, particularly without their usual social supports during the pandemic. Linking with hypervigilance, interviewees were reluctant to leave the person with dementia alone for long periods of time. One interviewee felt he could leave his wife on her own for an hour, but "*doesn't chance it*" so all such activities were restricted: "*it's a snatched 20 minutes*" (Sam, aged 60, wife has young onset dementia). Another got up early, before her husband, to get time to herself (Zoe, aged 63, husband has AD). She was one of two carers in paid employment who, with day centres closed, had found combining working from home with a caring role challenging during the pandemic (Joan, aged 53, mother has AD; Zoe, aged 63, husband has AD); she had already cut her working days due to increasing care demands. Prior to the pandemic, a third interviewee had taken early retirement to care for his wife. Although not pandemic-specific, he was also one of a few interviewees who seemed to position their own needs and interests in the past or at some future

point: “I’ve got things I want to do, but first and foremost, it’s ... I’ve got to care for my wife and ... everything else takes a back seat” (Sam, aged 60, wife has young onset dementia).

## 2. Caring Beyond Capacity

Although not all interviewees reported feeling stressed during the pandemic, the accounts of those managing intense and varied care needs suggested *burnout and abandonment*: “a tsunami coming” due to the ongoing intensity of caring and lack of support; “they’ve taken us for granted” (Sam, aged 60, wife has young onset dementia). One of the working carers had felt she was “losing it” before recruiting a paid care worker for her mother during the middle of the pandemic (July 2020); she also argued there was “a tsunami coming” of carers continuing to struggle with their mental health in the future because they had not been supported during the lockdowns (Joan, aged 53, mother has AD). Interviewees also reported a lack of support from statutory services; some voluntary sector organisations contacted people by telephone to check on their well-being, but later in the pandemic even these calls had decreased. Others wanted to know when dementia groups and other services would be restarting.

Because of the lockdowns, carers’ sense of abandonment was compounded by *caring in isolation* and without support from family and friends, who could only telephone or video-call, or provide practical support at a distance such as online shopping. One interviewee had cared alone for four months, without the usual support of paid care workers or her partner’s family staying to look after him while she had some respite (Fran, aged 84, partner has AD), while the interviewee who had recruited a paid care worker during the pandemic had delayed this until she could no longer cope, due to fear of exposing her mother to coronavirus (Joan, aged 53, mother has AD). Carers’ sense of social isolation continued as the pandemic progressed and, for those at home with only the person they cared for, some were also affected by increasingly limited communication with the person with dementia: “... that’s the biggest thing that affects me, obviously” (Sheila, aged 89, husband has mixed AD/vascular dementia). For one interviewee, her husband no longer seeming to recognise her compounded her sense of isolation during the lockdowns: “...(he) doesn’t want to go to bed because he’s wait .... He says to me, ‘I’m waiting for your mum [mother] to get home’. But the mum is me” (Zoe, aged 63, husband has AD).

Some, though not all, interviewees, reported an *absence of day and respite care* or difficulty accessing it, even at the later stage of the pandemic. Others had discussed trying to get their relative to return to local day care but found they had been (or remained) reluctant to go. Potentially accessing respite care elicited mixed feelings, of guilt but also of the urgent need for a break from caring: “...if I could, I would spare him the kind of abandonment, but on the other hand, I ... I would not trust myself to be ... to keep going forever” (Fran, aged 84, partner has AD). This resonated with concerns over *fitness to care and future transitions*. Some carers indicated they were coping, but thinking ahead to future care options. Two of them were in their 80s (Sheila, aged 89, husband has mixed AD/vascular dementia; Fran, aged 84, partner has AD) and finding caring tiring, despite trying to remain physically fit: “but even so, objects have the audacity of getting heavier” (Fran, aged 84, partner has AD). The other older carer said: “(I’m) quite old...to be doing this” (Sheila, aged 89, husband has mixed AD/vascular dementia).



### 3. Supporting carers and the person with dementia: before COVID and beyond

Some issues seemed to pre-date the pandemic but came into focus more as carers managed on their own. *Disinterest beyond the diagnosis: needing continued pro-active support and signposting* refers to interviewees who said their relative was not followed up after once a diagnosis was given: “they all signed her off when they realised she had Alzheimer’s” (Joan, aged 53, mother has AD). Although some interviewees sought out information themselves, one assumed she had not been contacted recently because it was felt she was coping (Fran, aged 84, partner has AD). Instead, support during the pandemic seemed to have been triggered only when events reached crisis point, for example in managing the person with dementia’s incontinence (Fran, aged 84, partner has AD) or when attending paramedics triggered an occupational therapy assessment, resulting in installation of handrails in the home (Sheila, aged 89, husband has mixed AD/vascular dementia). Carers indicated that managing on their own was nothing new, and several said they had experienced their caring role, prior to the pandemic and after the diagnosis, largely in isolation from service support.

Where *accessing support from statutory services* was needed, interviewees’ experiences during the pandemic varied. Two said accessing their GP had been good, although one was concerned that the absence of face-to-face appointments meant her husband’s symptoms might have been missed (Claire, aged 64, husband has young onset dementia). Some described problems getting care support in place during the pandemic; one said he had needed to “fight the system” on his own (Joe, aged 56, wife has an unspecified dementia diagnosis), while others felt it was harder to access support and information from the local authority because they were already paying for their own care worker(s). Another interviewee, wanting to learn about care and support options for his wife, said he had been told that, due to the pandemic, the local authority Social Services department would respond in six months (Joe, aged 56, wife has an unspecified dementia diagnosis). Other issues related to *needing appropriate, individualised and dementia-aware service support and activities*. Individual needs and inclusivity were discussed; for example, not allowing the family carer to travel with the person with dementia in an ambulance rather than alone (Claire, aged 64, husband has young onset dementia). One carer (Sam, aged 60, wife has young onset dementia) spoke about not returning to the dementia group his wife had attended, where most members were older: “and with Glenn Miller in the ... background, it was ... we didn’t belong there. You know, we ... we were quite obviously far, far too young for that”. Another made similar comments, saying it was important to get to know the person before recommending this sort of group (Claire, aged 64, husband has young onset dementia). Carers thus pointed out that as restrictions end and carers try to help their relatives re-engage with the world, it is important for appropriate dementia support and other groups to be available.

## Discussion

Interviews with seven carers one year into the pandemic in England have highlighted different dimensions of caring, including the range and intensity of everyday challenges of caring for someone with dementia. The COVID-19 pandemic had intensified already difficult aspects of caring, including protecting the person with dementia and avoiding coronavirus risk, and some interviewees reported a decline in the person they cared for. Without social support from family and friends and formal

respite care, and with dementia support groups and professional support limited, some carers had been caring beyond capacity, especially as the pandemic had continued. Some concerns pre-dated the pandemic but were exacerbated by it, including a lack of continuing service support following initial diagnosis and the need for appropriate, individualised service support and activities.

These findings have implications for carer resilience approaches and the planning of support for family carers of people with dementia, including in relation to unmet needs, within and outside the caring role. Before the pandemic, studies had shown that compared with those caring for people with other conditions, carers of people with dementia had more unmet needs and less use of services compared with those caring for people with other conditions (Bressnan, Vistintini and Palese, 2020; McCabe, You and Tatangelo, 2016) and compared with people with dementia themselves (Mazurek et al, 2019). Our study suggests unmet needs had been compounded during the pandemic. Carers had needed to manage a range of intense care needs for the person with dementia, without usual social supports or day or respite care, and with no 'checking in' by statutory services. Carers' accounts indicated some were, or had been, at breaking point, burned out and caring beyond capacity due to the intensification of caring demands as the pandemic progressed. Hanna et al (2022), who also explored resilience and the experiences of people with dementia and their carers during the pandemic, report more individual coping in the absence of system supports such as dementia groups and paid care. Therefore, particularly within the context of the pandemic, it seems difficult to justify the focus on trait-based approaches to carer resilience discussed elsewhere (McKenna et al, 2021; Teahan et al, 2018) in which the family carer is divorced from the socio-ecological context in which they are providing the care.

Building carers' individual resilience cannot be achieved without practical support (Henwood et al, 2017) and should include a focus on healthcare and political macro-systems (Teahan et al, 2018), particularly as the COVID-19 pandemic has highlighted the problems carers experience when support systems are eroded. It seems likely, however, that individual approaches to resilience may persist, under the guise of personal responsibility and active citizenship, diverting attention from underfunding of social care and day care services (Windle, 2021). Our study suggests that carers may be unable to continue indefinitely without such supports in place. Also a subtext to resilience approaches, not dissimilar to the 1990s 'positive thinking' in cancer rhetoric (De Raeve, 1997; Wilkinson and Kitzinger, 2000) that positioned resilience as a moral imperative or "expected norm" (Windle, 2021, pp.42), may be suggestive of a broader problem, as meeting carers' own needs

beyond their caring role, is not represented within transactional models of resilience. Too often the focus of support for carers is not on them as individuals but on facilitating their caring role (Henwood et al, 2018), with scant attention paid to the unmet needs of carers of people with dementia outside of the caring role (Holt Clemmensen et al, 2021). Indeed, maintaining carers in their caring role is explicitly the impetus behind the carer resilience model (Parkinson et al, 2017) and arguably a subtext in other discussions. Almost 30 years on from the typology of caring set out by Twigg and Atkin (1994), the resilience rhetoric may further position carers of people with dementia as 'resources'. Our findings suggest this has been the case during the pandemic.

Beyond carers' unmet needs in relation to their caring roles, our findings indicate they have other unmet needs, separate from this role, although their perceptions of these may be complex. Quinn, Clare and Woods (2015) identified the dilemma carers may face in balancing their own needs with those of the person they care for, and some may benefit from a needs-based approach to the impact of caring on their lives (Pini et al, 2018). In our study, carers' accounts resonated with the 'boundarying' reported in other studies, where carers pursue their own meaningful activities to compartmentalise the caring role and maintain a sense of self-identity (Cherry et al, 2019). Our interviewees sometimes found considering their own needs, separate from the caring role, difficult; however, absence of discussion does not mean absence of need. Carers' reluctance to discuss their own needs is not uncommon, and in dementia caring, where motivation to care is embedded in spousal and family relationships (Quinn et al., 2015), the term 'carer' may be rejected entirely (Greenwood et al, 2018; Greenwood and Smith, 2019). Our study also indicates that the caring role itself may be difficult to separate from other family relationship roles (e.g. wife, partner, daughter), with the result that, family members who care for a relative with dementia risk being overlooked by services.

Our findings also show aspects of the caring role often missing from transactional frameworks of resilience, although Parkinson et al's framework (2017) includes unmet needs outside the caring role in relation to both carers' quality of life and health needs. Often, responsibilities outside caring (e.g. paid work, caring for other relatives) are not represented, although in the stress-process model of caring (Pearlin et al, 1990), they may be viewed as secondary role strains. Carer-care recipient relationships are represented within some transactional frameworks (Parkinson et al, 2017; Windle and Bennett, 2012), although not all (Donnellan et al, 2017), even though relationship quality may be important for life satisfaction and well-being (Rippon et al, 2020). The range and intensity of daily

care demands evident in our interviews is surprisingly not represented in resilience models, although resilience varies according to intensity of care needs (Joling et al, 2016). Further, although the duration of caring may have implications for resilience, research on caring is seldom longitudinal (Greenword et al, 2018) and thus overlooks caring trajectories over time and in context.

Our study of course has limitations. Convenience sampling was used to facilitate the INCLUDE 'rapid response' to the COVID-19 pandemic but may not be the optimal approach for qualitative research (Patton, 2014). Also, while our sample reflected the socio-demographic characteristics of the INCLUDE cohort, we did not attempt to contrast experiences of carers in different circumstances (such as spousal and filial carers). Furthermore, resilience was not selected as the study's theoretical frame at the design stage. It thus did not inform our topic guide and interviews, although the conceptual framework for IDEAL included the multiple psychosocial resources necessary to enable carers of a person with dementia to adapt and live well (Clare et al., 2019). The experiences of our interviewees during the COVID-19 pandemic nonetheless highlight important challenges in conceptualising carer resilience in dementia and that some theoretical resilience frameworks may have overlooked key facets of caring contexts.

## **Conclusions**

Our findings suggest that the ongoing COVID-19 pandemic increased and intensified the complex challenges of caring for someone with dementia. Without access to social and service support, carers in our study reported experiencing burnout and caring beyond capacity. With timely support and provision of services absent, carers' well-being is likely to be at risk, and their caring role may become unsustainable. This suggests the importance of transactional models of carer resilience and interventions which focus on building resilience at social and societal levels as well as addressing health policy. Carers' needs outside of the caring role must also be recognised to avoid perpetuating a resilience rhetoric where carers are rendered visible only as a resource for caregiving.

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INCLUDE data were deposited with the UK data archive in June 2022 and will be available to access from July 2023. Details of how the data can be accessed after that date can be found here:

<https://reshare.ukdataservice.ac.uk/855800/>.

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### **Conflict of interest statement**

The Authors declare that there is no conflict of interest.

### **Author contributions**

SS conducted interviews, carried out the analysis, devised and wrote the draft paper. CP contributed to the study's concept and design, conducted interviews, took part in ongoing discussions about and agreed the final analysis, provided edits and comments on drafts, and agreed the final version to be published. RC contributed to the study's concept and design, took part in ongoing discussions about and agreed the final analysis, provided edits and comments on drafts, and agreed the final version to be published. CQ contributed to the study's concept and design, provided edits and comments on drafts, and agreed the final version to be published. ED identified potential participants, provided edits and comments on drafts, and agreed the final version to be published. JT provided edits and comments on drafts and agreed the final version to be published. LC devised the study, provided edits and comments on drafts, and agreed the final version to be published.

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**Table 1.** Characteristics of the carers and people with dementia

<b>Pseudonym</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnic background</b>	<b>Education</b>	<b>Relationship to person with dementia</b>	<b>Person with dementia's diagnosis</b>	<b>Years since dementia diagnosis</b>	<b>'Shielding' the person with dementia?<sup>2</sup></b>
Joan	53	Female	White British	University	Daughter	Alzheimer's disease	Between 6 and 9 years	Yes
Sam	60	Male	White (Other)	University	Spouse	Frontotemporal dementia <sup>1</sup>	Between 3 and 5 years	Yes
Sheila	89	Female	White British	University	Spouse	Mixed Alzheimer's disease and vascular dementia	Between 1 and 2 years	No
Fran	84	Female	White (Other)	University	Partner	Alzheimer's disease	Between 3 and 5 years	Yes

Zoe	63	Female	White British	No qualifications	Spouse	Alzheimer's disease	Between 6 and 9 years	No
Claire	64	Female	White British	University	Spouse	Alzheimer's disease <sup>1</sup>	Unknown	No
Joe	56	Male	Other	School leaving certificate at 16	Spouse	Unspecified/other	Between 3 and 5 years	Yes

<sup>1</sup>Young-onset dementia refers to a diagnosis made before the age of 65 (Dementia UK, 2021)

<sup>2</sup>'Shielding' on Government advice to stay at home due to clinical vulnerability to COVID-19 in relation to other health conditions



**Table 2. Overview of the Main Themes and Associated Sub-Themes**

Main Theme	Subthemes
<p><b>1. Dimensions of Caring</b></p> <p>The nature and intensity of caring for someone with dementia, particularly during the pandemic, within the context of normal family relationships</p>	<p>Protecting the person with dementia: avoiding coronavirus risk</p> <p>Intensity, hypervigilance and decline</p> <p>The complex nature of caring</p> <p>The dual caring role and family relationships</p> <p>Bounded time: carers' time for themselves</p>
<p><b>2. Caring Beyond Capacity</b></p> <p>Carer burnout during the pandemic due to caring demands and the absence of appropriate service support/respite care</p>	<p>Burnout and abandonment: "a tsunamic coming"</p> <p>Caring in isolation</p> <p>The absence of day and respite care</p> <p>Fitness to care and future transitions</p>
<p><b>3. Supporting Carers and People with Dementia: Before COVID and Beyond</b></p>	<p>Disinterest beyond the diagnosis: needing continued proactive support and signposting</p>

Supporting carers and people with dementia from diagnosis onwards including funding care and providing individualised service support	Accessing support from statutory services  Needing appropriate, individualised and dementia-aware service support and activities
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