

# 'Caring beyond capacity' during the coronavirus pandemic: the experiences of family caregivers of people with dementia from the IDEAL cohort

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## Research Article

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## Abstract

Some carers of people with dementia have reported increased caring demands and carer stress during the COVID-19 pandemic. Carers' experiences during this time may also have implications for resilience. As part of the INCLUDE component of the IDEAL cohort study, the overall aim of this subtle realist qualitative study was to explore family carer experiences of caring for someone with dementia one year into the COVID-19 pandemic in England, and to consider the study findings in relation to resilience frameworks in dementia caregiving. Seven family carers of people living with mild-to-moderate dementia were interviewed, and themes derived using framework analysis. 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 and caring in isolation from family and professional support. Findings provide evidence that trait resilience approaches fail to account for important aspects of carers' experiences, highlighting the range of contextual factors which influence experiences of the caregiving role, lending support to transactional resilience frameworks. More importantly than building individual resilience, timely practical support for carers is essential to protect their well-being and to ward against the potential consequences of carer burnout.

## Introduction

There are an estimated 900,000 people living with dementia in the UK (Alzheimer's Society, 2021; Nichols & Vos, 2022). 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); one in three people during their lifetime is likely to care for someone with dementia (Parkin and Baker, 2021). Caring for a relative with dementia is a complex experience incorporating positive and negative aspects (Lindeza et al., 2020; Quinn & Toms, 2019), both associated with carer well-being and satisfaction with life (Quinn et al., 2019). Caring for someone with dementia can be a full-time role and may present unique challenges since people with dementia experience a range of behavioural, psychological and physical symptoms (Alzheimer's Society, 2022; Cohen-Mansfield, 2015; Feast et al., 2016). Care needs develop from the early stages onwards and increase over time, although there will be variability across dementia subtypes and for individuals (Prince et al., 2013). The majority of people with dementia are also living with another health condition (Nelis et al., 2019), with a particularly high prevalence of diabetes and stroke (Bunn et al., 2014). In addition, 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).

In spite of such potential challenges, research has suggested that family carers of people with dementia can adapt well and be resilient (Dias et al., 2015). Definitions of resilience vary, however, with resilience considered as trait, outcome or process (Bekhet and Avery, 2018; Zhou et al., 2021). Informed by Ecological Systems Theory (Bronfenbrenner, 1994), a transactional process approach to caregiver resilience has been discussed (Windle & Bennett, 2012) where, in face of potential adversity, individuals are situated in interaction with a range of personal, social and community or societal resources (e.g. psychological, social support, and health and social services) which become "the resilience reserve" for positive adaptation (Windle, 2021). Nonetheless, McKenna et al. (2021) have argued that a "prevailing fixation on individual resilience" (pp.29) has persisted; i.e. trait approaches to resilience such as personality or resilient coping (Jones, Killett and Miosho, 2019). 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).

Therefore, with caregiving for someone with dementia already a potential stressor, how do understandings of carer resilience hold in relation to another potential adversity; i.e. the COVID-19 pandemic? Hughes, Liu and Baumbach (2021) have 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 has magnified pre-existing problems for caregivers. 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 well as additional caregiver burden (Budnick et al. 2021; Lorenz-Dant and Comas-Herrera, 2021) and worsened quality of life attributed to loss of service supports such as paid carers (Masterson-Algar et al., 2022). Notably, carers with high resilience also reported higher levels of anxiety during the lockdown (Altieri and Santiago, 2021), serving as a reminder that resilience is not the same as an absence of psychopathology (Bonanno et al., 2012; Southwick et al., 2014).

Certainly, these studies suggest there were additional challenges of caring for someone with dementia due to the social restrictions imposed during the early stages of the pandemic. The current study focused on the experiences of carers one year into the COVID-19 pandemic rather than at its onset, by which time individuals may have adapted and devised new ways of coping. Therefore, experiences during this later time period may have additional implications for considerations and conceptualisations of carer resilience. As 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), the overall aim was to explore family carer experiences of caring for someone with dementia one year into the COVID-19 pandemic, and 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 IDEAL cohort study. Running since 2014, IDEAL was approved by Wales Research Ethics Committee 5 (reference 13/WA/0405) and IDEAL-2 by Wales Research Ethics Committee 5 (reference 18/WS/0111) and Scotland A Research Ethics Committee (reference 18/SS/0037). INCLUDE was approved as an amendment to IDEAL-2 for England and Wales (18/WS/0111 AM12). IDEAL and IDEAL-2 are 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, from which 10 had already been recruited to or approached for the INCLUDE 'pre-vaccine' qualitative interview study conducted with people with dementia and their family carers earlier in the pandemic. Recruited participants had previously provided written informed consent to take part in the INCLUDE project (Clare et al., 2022) having been fully briefed about the project and given time to consider whether 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. Interviews ranged between 39 minutes and 1 hour 14 minutes in duration. All interviews were recorded and professionally transcribed. Interviews were conducted following commencement of the coronavirus vaccine programme in England (December 2020). One of the interviews was conducted by CP during the first week of Lockdown 3 in England (January 2021). This was a joint interview with the carer and the person with dementia. However, as the person with dementia did not engage with the interview, the interview was regarded as representing the carer's perspectives only. The remainder of the interviews were completed by SS, a post-doctoral researcher who is also a former family carer of a person with dementia, on joining the study team (April-May 2021). CP is an experienced researcher and member of the IDEAL study team.

### **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. In addition to regular discussion of the ongoing analysis between SS, CP and RC, RC reviewed this 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 but by retaining verbatim quotations. Final themes were derived using mapping and interpretation.

## **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. Four carers reported 'shielding' their relative during the pandemic, either on Government advice to stay at home due to clinical vulnerability or because they had decided to 'self-shield' the person with dementia. 'Years since dementia diagnosis' was calculated from the IDEAL dataset (version 5). Two interviewees were caring for a relative who had been diagnosed between six and nine years ago, with three interviewees caring for a relative diagnosed between three and five years ago. Three interviewees spoke about also caring for other relatives with health problems.

Table 1  
 Characteristics of the carers and people with dementia, and COVID-19 restrictions in place at the time of interview

ID No	Age	Gender	Ethnic background	Education	Relationship to person with dementia	Person with dementia's diagnosis	Years since dementia diagnosis	'Shielding' the person with dementia?	Lockdown stage interviewed
06-0326-SP	53	Female	White British	University	Daughter	Alzheimer's disease	Between 6 and 9 years	Yes	Step 2 of the 3rd national lockdown in England
09-0017-SP	60	Male	White (Other)	University	Spouse	Frontotemporal dementia (young onset dementia)	Between 3 and 5 years	Yes	Step 2 of the 3rd national lockdown in England
10-1144-SP	89	Female	White British	University	Spouse	Mixed Alzheimer's disease and vascular dementia	Between 1 and 2 years	No	Step 2 of the 3rd national lockdown in England
15-1523-SP	84	Female	White (Other)	University	Partner	Alzheimer's disease	Between 3 and 5 years	Yes	Step 2 of the 3rd national lockdown in England
18-1842-SP	63	Female	White British	No qualifications	Spouse	Alzheimer's disease	Between 6 and 9 years	No	Step 1 of the 3rd national lockdown in England
23-0512-SP	64	Female	White British	University	Spouse	Alzheimer's disease (young onset dementia)	Unknown	No	One week into the 3rd national lockdown in England
23-0835-SP	56	Male	Other	Unknown	Spouse	Unspecified/other	Between 3 and 5 years	Yes	Step 2 of the 3rd national lockdown in England

## <Table 1 goes here>

Three key themes were derived from the analysis: 1. Dimensions of Caring, 2. Caring Beyond Capacity, and 3. Supporting Carers and People with Dementia: Before COVID and Beyond (see Table 2; also Expanded Table 2 in Supplementary Materials). Dimensions of Caring relates to the nature and intensity of caring for someone with dementia, particularly during the pandemic, but also 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 during the post-vaccine time period and the absence of appropriate service support and respite care. Finally, 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  
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><b>Protecting the person with dementia: avoiding coronavirus risk</b></p> <p><b>Intensity, hypervigilance and decline</b></p> <p><b>The complex nature of caring</b></p> <p><b>The dual caring role and family relationships</b></p> <p><b>Bounded time: carers' time for themselves</b></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><b>Burnout and abandonment: "a tsunamic coming"</b></p> <p><b>Caring in isolation</b></p> <p><b>The absence of day and respite care</b></p> <p><b>Fitness to care and future transitions</b></p>
<p><b>3. Supporting Carers and People with Dementia: Before COVID and Beyond</b></p> <p>Supporting carers and people with dementia from diagnosis onwards including funding care and providing individualised service support</p>	<p><b>Disinterest beyond the diagnosis: needing continued pro-active support and signposting</b></p> <p><b>Accessing support from statutory services</b></p> <p><b>Needing appropriate, individualised and dementia-aware service support and activities</b></p>

<Table 2 goes here>

## 1. Dimensions of Caring

Protecting the person with dementia: avoiding coronavirus risk had dominated the experiences of several of our interviewees during the pandemic. Some carers implemented their own measures to protect the person with dementia; for example, not allowing in paid carers, "we didn't want it brought into the house for us" (15-1523-SP) or delaying the move to residential care: "there's no way I'm putting my mum into a care home. It's too dangerous" (06-0326-SP). Interviewees' care-recipients also did not understand coronavirus rules, with one interviewee concerned that his wife would be berated for not socially distancing (09-0017-SP). Another said her husband thought that social distancing meant something was wrong with him, because he had forgotten there was a pandemic (18-1842-SP). 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, with some still cautious due to COVID variants and so taking "small steps" (09-0017-SP) in going out more again. Therefore, even at a later stage during the pandemic, interviewees remained cognisant of protecting the person with dementia.

Intensity, hypervigilance and decline refers to the intensity and diversity of the care needs of the person with dementia, although inevitably these varied greatly across interview accounts. Five of the seven interviewees reported the challenges of managing intense and varied caring demands; for example, distress in the person with dementia, wandering during the night, not being recognised by the person they were caring for, personality change, verbal aggression, 'sundowning', incontinence, immobility, seizures, and challenges in various activities of daily living including managing meals and medication. Two mentioned mainly dealing with lack of communication or somnolence. Managing a range of different and intense needs for the person with dementia typified the daily experience of some carers, with their accounts suggesting being 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" (15-1523-SP). Some also suggested that the person they cared for had declined during the pandemic, and therefore their care needs had intensified further. Although some acknowledged this may be due to natural disease progression, others speculated that this decline was due to lack of routine and being "housebound for so long" (23-0835-SP), a confinement interviewees and their relatives were experiencing again at the time of interview which took place during the third national lockdown in England.

These varied care needs of the person with dementia also highlight the complex nature of caring and the diversity of roles involved such as carer, therapist and advocate in facilitating the activities and social interactions of the person with dementia; roles which had increased and continued as the pandemic had progressed. Several interviewees discussed setting up regular calls with family during the lockdowns or thinking of activities for the person with dementia "to keep...the mind working" (18-1842-SP) such as going on walks or simply doing

tasks around the home, with one carer trying to replicate activities his wife would have done at a day centre, like art therapy (23-0835-SP). This intensified caring role during social restrictions was also complicated by the dual caring role and family relationships, in that caring was perceived as a normal role within a partnership or family. One interviewee said he had “been through hell and back” but reiterated the importance of his marriage: “...when you take your vows, you take them until...just as...as you said, ‘Death ‘til do part’” (23-0835-SP). Some interviewees spoke about continuing shared interests such as music, “a major string of the bow of friendship” (15-1523-SP), although these had been limited by the lockdowns. In the context of family relationships and other caring roles, in addition to caring for their relative with dementia, one interviewee was also supporting a daughter with mental health problems, and two were caring for a parent, one of whom had recently been diagnosed with Alzheimer’s.

Bounded time: carers’ time for themselves reflects interviewees having no or limited 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. 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” (09-0017-SP). Another got up early before her husband just to get time to herself (18-1842-SP). This interviewee was also 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 (06-0326-SP; 18-1842-SP) and who had already cut her working days due to increasing caring demands. A third interviewee had already taken early retirement to care for his wife. In addition, although not pandemic-specific, he was one of a few interviewees who seemed to position their own needs and interests in the past or at some future time 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” (09-0017-SP).

## 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” (09-0017-SP). One of the working carers had felt she was “losing it” before recruiting a paid carer 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 (06-0326-SP). In addition, interviewees also reported a lack of support by statutory services, with ‘checking in’ telephone calls only received from charities; even these had decreased later into the pandemic. 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 carers or her partner’s family staying to look after him while she had some respite (15-1523-SP), whilst the interviewee who had recruited a paid carer during the pandemic had delayed this until she could no longer cope due to fear of exposing her mother to coronavirus (06-0326-SP). Carers’ sense of social isolation continued as the pandemic progressed and, for those who were at home with only the person they were caring for, may also have been affected further where communication from the person with dementia had become limited: “...that’s the biggest thing that affects me, obviously” (10-1144-SP). For one interviewee, her husband also no longer seemed to recognise her, therefore compounding 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 to get home’. But the mum is me” (18-1842-SP).

Although not discussed by all interviewees, carers reported the absence of day and respite care or difficulty accessing it, even at this later stage of the pandemic. Other interviewees had discussed trying to get their relative to return to local day care but found that their partner had been or was still reluctant to go. The possibility of accessing respite care was also met with feelings of guilt but the need for a break from caring was urgent: “...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” (15-1523-SP). This also resonates with concerns over fitness to care and future transitions, with carers suggesting they were coping but still thinking ahead to future care options. Two of these interviewees were in their 80s (10-1144-SP; 15-1523-SP) and were finding caring tiring, although trying to remain physically fit: “but even so, objects have the audacity of getting heavier” (15-1523-SP). The other older carer said of herself: “(I’m) quite old...to be doing this” (10-1144-SP).

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

Certain issues seemed to pre-date the pandemic but were brought more into focus as carers managed on their own. Disinterest beyond the diagnosis: needing continued pro-active support and signposting refers to interviewees stating that their relatives were not followed up once a diagnosis had been given: “they all signed her off when they realised she had Alzheimer’s” (06-0326-SP). Although some interviewees sought out information themselves, one interviewee assumed she had not been contacted recently because it was felt she was coping (15-1523-SP). Instead, support during the pandemic only seemed to have been triggered when events reached crisis point such

as management of incontinence for the person with dementia (15-1523-SP) or when attending paramedics had triggered an occupational therapy assessment, resulting in provision of handrails for the home (10-1144-SP). Therefore, carers managing on their own was nothing new, with several experiencing their caring role prior to the pandemic, and after the diagnosis, largely in isolation from service support.

Where this had been needed, interviewees' experiences of accessing support from statutory services during the pandemic varied. Two interviewees suggested access to their GP had been good, although one was concerned that the absence of face-to-face appointments meant that her husband's symptoms might have been missed (23-052-SP). Some interviewees suggesting problems trying to get social care in place due to the pandemic; one said he had had to "fight the system" on his own (23-0835-SP) with others suggesting they could not get such support because they paid for their own carers. Another interviewee who had wanted to look into care options for his wife said he had been told that, due to the pandemic, Social Services would respond in six months (23-0835-SP). Other issues related to needing appropriate, individualised and dementia-aware service support and activities where the individual and inclusivity were considered; for example, allowing the family carer to go in an ambulance with the person with dementia during the pandemic rather than him travelling alone (23-052-SP). The husband of one person with young onset dementia also discussed not going back to a dementia group which involved much older members: "and with Glenn Miller in the back... background, it was... we didn't belong there. You know, we...we were quite obviously far, far too young for that" (09-0017-SP). Another made similar comments in relation to her husband, suggesting that it was important to get to know the person before recommending this sort of group (23-0512-SP). Therefore, as restrictions end and carers try to re-engage their relatives with the world, it is important that appropriate dementia support and other groups are 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 has further intensified these difficult aspects of caring including protecting the person with dementia and avoiding coronavirus risk, with interviewees also reporting observed decline in the person they care for. In the absence of social support from family and friends and formal respite care, and also at a time when dementia support groups and professional supports were still limited, some family carers had been caring beyond capacity, especially as the pandemic had continued. Also certain issues seemed to pre-date the pandemic but have been highlighted further by its onset; in particular, a lack of continued service support from diagnosis onwards and the need for appropriate, individualised service support and activities.

These findings have implications for resilience in family carers of people with dementia, in relation to unmet needs within and outside of the caring role. Prior to the pandemic, it has been reported that carers of people with dementia have a higher level of 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 with the person with dementia they care for (Mazurek et al., 2019). Our study suggests unmet needs have been compounded during the pandemic, with carers often managing a range of intense care needs for the person with dementia but without their usual social supports and day or respite care and with no checking in by statutory services. Consequently, carers' accounts suggested they were or had been at breaking point, burned out and caring beyond capacity due to intensified caring demands which had continued as the pandemic progressed. Hanna et al. (2022) have also considered resilience and the experiences of people with dementia and their family carers during the pandemic, reporting greater emphasis on individual coping in the absence of system level 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 research and interventions discussed previously (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 in the absence of practical support (Henwood, Larkin and Milne, 2017) nor should it exclude a focus on health and political macro-systems (Teahan et al., 2018), particularly as the COVID-19 pandemic has further highlighted the problems for carers when such systems are eroded. However, individual approaches to resilience may persist under the guise of personal responsibility and active citizenship to divert attention from underfunding of services (Windle, 2021) such as social care and day care; although, as our study has suggested, it is uncertain how carers can be expected to go on indefinitely without such supports in place. Consequently, there may be a subtext to resilience approaches, not dissimilar to the 'positive thinking' in cancer rhetoric during the 1990s (De Raeve, 2003; Wilkinson and Kitzinger, 2000), wherein resilience may be forced as a moral imperative or "expected norm" (Windle, 2021, pp.42). Such an imperative is also suggestive of another problem with the resilience rhetoric in general, in that meeting carers' own needs outside of the caring role are not represented within transactional models of resilience. Focus of support for carers in general is not on individuals themselves but rather to facilitate their caring role (Henwood, Larkin and Milne, 2018), with sparse attention afforded the unmet needs of carers of people with dementia outside of the caring role (Holt Clemmensen et al., 2020). Notably, maintaining carers within the caring role only is explicitly stated as the impetus behind delineation of the carer resilience model by Parkinson et al. (2017) and

is arguably the subtext of other discussions. Therefore, almost 30 years on from the typology of caring (Twigg and Atkin, 1994), the resilience rhetoric may further position carers of people with dementia as 'resources'. From our study findings, this appears to have been the case during the pandemic.

In our study, as well as carers' unmet needs in relation to the caring role, findings suggested unmet needs separate from this role, although this was complex to determine. Quinn, Clare and Woods (2015) have reported the continual dilemma carers may have in balancing their own needs against those of the person they care for, although carers can benefit from a needs-based approach to consider the impact of caring on their lives (Pini et al., 2018). Our carers' accounts resonated with 'boundarying' 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). For our interviewees, however, considering their needs in isolation from the caring role was sometimes difficult, although absence of discussion does not mean absence of need. Carers' reluctance to discuss their own needs is not uncommon, and in dementia caregiving, where motivations to care are embedded within spousal and family relationships, the term 'carer' may be rejected entirely (Greenwood, McKeivitt and Milne, 2018; Greenwood and Smith, 2019). However, also not uncommon, our study suggested that the caring role itself may be difficult to separate from other roles within family relationships (e.g. wife; partner; daughter). Therefore, it can be argued that, existing within this liminal space, family members who care for a relative with dementia are at risk of being overlooked by services.

Our findings also show aspects of the caring role not overtly represented in transactional frameworks of resilience. Only one framework includes unmet needs outside of the caring role in relation to carers' quality of life as well as carers' own health needs (Parkinson et al., 2017). Responsibilities outside the caring role (e.g. paid work roles; caring for other relatives) are not represented, although these are depicted as secondary role strains in the stress-process model of caring (Pearlin et al., 1990). Carer-care recipient relationships have been represented within some transactional frameworks (Parkinson et al., 2017; Windle and Bennett, 2012) but not all (Donnellan, Bennett and Soulsby, 2017), although relationship quality may be important for life satisfaction and well-being (Rippon et al., 2020). The range and intensity of daily care demands was also suggested by our interviews, yet surprisingly are not represented in resilience models, when resilience has been shown to vary depending on the need for high levels of care (Joling et al., 2016). In addition, duration of the caring role may have implications for studying resilience but caregiving research in general is seldom longitudinal (Greenwood, McKeivitt and Milne, 2018), therein overlooking caregiving trajectories over time and in context.

Our study has provided some insights into the experiences of family carers of people with dementia one year into the COVID-19 pandemic as well as suggesting potential implications of these in relation to carer resilience. Nonetheless, the study is not without its limitations. Convenience sampling was employed which was necessary to facilitate the INCLUDE 'rapid response' to the COVID-19 pandemic but is not an optimal approach within qualitative research (Patton, 2014). Although reflecting the socio-demographic characteristics of the INCLUDE cohort from which the sample was drawn, we did not attempt to contrast experiences across gender, ethnic background, different ages and in different circumstances, for example spousal and filial carers, older carers, working carers, and those caring for someone with young onset dementia. In addition, resilience was not devised as the theoretical frame for the study at the design stage which would have informed the topic guide and interviews accordingly, although the conceptual framework for IDEAL includes the multiple psychosocial resources necessary to make it possible to adapt and live well as a carer for someone with dementia (Clare et al., 2019). Nonetheless, the experiences of our interviewees during the COVID-19 pandemic have highlighted some of the challenges in conceptualising carer resilience in dementia and how certain theoretical resilience frameworks may have overlooked key facets.

## Conclusions

Our findings suggest that the ongoing COVID-19 pandemic has increased and intensified the complex challenges of caring for someone with dementia, whereby without access to social and service support, carers have become burned out and caring beyond capacity. Without timely support and provision of services, their well-being may be at risk and their caring role unsustainable. This further highlights the importance of transactional models of carer resilience and interventions which focus on building resilience at individual, 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 only rendered visible as a resource for caregiving.

## Declarations

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## Declaration of Interest Statement

No potential competing interests are reported by the authors in relation to this published work.

## References

1. Altieri, M., & Santangelo, G. (2021). The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. *American Journal of Geriatric Psychiatry*, *29*(1), 27–34. <https://doi:10.1016/j.jagp.2020.10.009>
2. Alzheimer's Society (2021, December 13). *How many people have dementia in the UK?* Alzheimer's Society. Retrieved December 16th, 2021, from <https://www.alzheimers.org.uk/blog/how-many-people-have-dementia-uk>
3. Alzheimer's Society (2022, n.d.). *Dementia symptoms and diagnosis*. Alzheimer's Society. Retrieved December 16th, 2021, from <https://www.alzheimers.org.uk/about-dementia/dementia-symptoms-and-diagnosis>
4. Bekhet, A. K., & Avery, J. S. (2018). Resilience from the perspectives of caregivers of persons with dementia. *Archives of Psychiatric Nursing*, *32*(1), 19–23. <https://doi:10.1016/j.apnu.2017.09.008>
5. Blaikie, N. (2007). *Approaches to social enquiry: Advancing knowledge* (2nd edition). Polity Press.
6. Bonanno, G. A. (2012). Uses and abuses of the resilience construct: Loss, trauma, and health-related adversities. *Social Science & Medicine*, *74*(5), 753–756. <https://doi:10.1016/j.socscimed.2011.11.022>
7. Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & social care in the community*, *28*(6), 1942–1960. <https://doi.org/10.1111/hsc.13048>
8. Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husen & T. N. Postlethwaite (Eds.), *International Encyclopedia of Education* (Vol. 3, 2nd edition) (pp. 1643–1647). Elsevier:New York
9. Budnick, A., Hering, C., Eggert, S., Teubner, C., Suhr, R., Kuhlmeier, A. & Gellert, P. (2021). Informal caregivers during the COVID-19 pandemic perceive additional burden: Findings from an ad-hoc survey in Germany. *BMC Health Services Research*, *21*(1), 353. <https://doi:10.1186/s12913-021-06359-7>
10. Bunn, F, Burn, A.-M, Goodman, C, Rait, G, Norton, S, Robinson, L, Schoeman, J. & Brayne, C. (2014). Healthcare organisation and delivery for people with dementia and comorbidity: a qualitative study exploring the views of patients, carers and professionals. *BMJ Open*, *7*(1), e013067. <https://doi:10.1136/bmjopen-2016-013067>
11. Cagnin, A., Di Lorenzo, R., Marra, C., Bonanni, L., Cupidi, C., Laganà, V., Rubino, E., Vacca, A., Provero, P., Isella, V., Vanacore, N., Agosta, F., Appollonio, I., Caffarra, P., Pettenuzzo, I., Sambati, R., Quaranta, D., Guglielmi, V., Logroscino, G., Filippi, M., ... SINDem COVID-19 Study Group (2020). Behavioral and psychological effects of coronavirus disease-19 quarantine in patients with dementia. *Frontiers in Psychiatry*, *11*, 578015. <https://doi.org/10.3389/fpsy.2020.578015>
12. Cherry, M., Ablett, J., Dickson, J. M., Powell, D., Sikdar, S. & Salmon, P. (2019). A qualitative study of the processes by which carers of people with dementia derive meaning from caring. *Aging & Mental Health*, *23*(1), 69–76. <https://doi.org/10.1080/13607863.2017.1393792>
13. Clare, L., Wu, Y. T., Quinn, C., Jones, I. R., Victor, C. R., Nelis, S. M., Martyr, A., Litherland, R., Pickett, J. A., Hindle, J. V., Jones, R. W., Knapp, M., Kopelman, M. D., Morris, R. G., Rusted, J. M., Thom, J. M., Lamont, R. A., Henderson, C., Rippon, I., Hillman, A., ... IDEAL Study Team (2019). A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: Findings from the IDEAL Study. *Alzheimer Disease and Associated Disorders*, *33*(1), 29–35. <https://doi.org/10.1097/WAD.0000000000000285>
14. Clare, L., Martyr, A., Henderson, C., Gamble, L., Matthews, F. E., Quinn, C., Nelis, S.M, Rusted, J, Thom, J, Knapp, M, Hart, N. & Victor, C. (2020). Living alone with mild-to-moderate dementia: findings from the IDEAL Cohort. *Journal of Alzheimer's Disease*, *78*(3), 1207–1216. <https://doi: 10.3233/jad-200638>
15. Clare, L., Martyr, A., Gamble, L. D., Pentecost, C., Collins, R., Dawson, E., Hunt, A., Parker, S., Allan, L., Burns, A., Hillman, A., Litherland, R., Quinn, C., Matthews, F.E. & Victor, C. (2021). Impact of COVID-19 on 'living well' with mild-to-moderate dementia in the community: Findings from the IDEAL cohort. *Journal of Alzheimer's Disease*, (Preprint), 1–16.
16. Clare, L., Martyr, A., Gamble, L.D., Pentecost, C., Collins, R., Dawson, E., Hunt, A., Parker, S., Allan, L., Burns, A., Hillman, A., Litherland, R., Quinn, C., Mathews, F.E. & Victor, C. (2022). Impact of COVID-19 on 'living well' with mild-to-moderate dementia in the community: Findings from the IDEAL cohort. *Journal of Alzheimer's Disease*, *85*, 925–940. <https://doi: 10.3233/JAD-215095>
17. Clare, L., Nelis, S.M., Quinn, C., Martyr, A., Henderson, C., Hindle, J.V., Jones, I.R., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Savitch, N.M., Thom, J.M., & Victor, C.R. (2014). Improving the experience of dementia and enhancing active

- life-living well with dementia: study protocol for the IDEAL study. *Health and Quality of Life Outcomes*, 12, 164. [https://doi:10.1186/s12955-014-0164-6](https://doi.org/10.1186/s12955-014-0164-6)
18. Cohen-Mansfield, J. (2015) Behavioral and psychological symptoms of dementia. In P.A. Lichtenberg, B.T. Mast, B.D. Carpenter, & J. Loebach Wetherell (Eds.), *APA Handbook of clinical geropsychology, Vol. 2: Assessment, treatment, and issues of later life* (pp. 271–317). APA Handbooks in Psychology, American Psychological Association, Washington DC.
  19. De Raeve, L. (1997). Positive thinking and moral oppression in cancer care. *European Journal of Cancer Care*, 6(4), 249–256. <https://doi.org/10.1046/j.1365-2354.1997.00043.x>
  20. Dementia Statistics Hub (2018, n.d.). *Impact on carers*. <https://www.dementiastatistics.org/statistics/impact-on-carers/>
  21. Dias, R., Santos, R. L., Sousa, M. F., Nogueira, M. M., Torres, B., Belfort, T. & Dourado, M. C. (2015). Resilience of caregivers of people with dementia: A systematic review of biological and psychosocial determinants. *Trends in Psychiatry & Psychotherapy*, 37(1), 12–19. <https://doi:10.1590/2237-6089-2014-0032>
  22. Donnellan, W. J., Bennett, K. M. & Soulsby, L. K. (2017). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging and Mental Health*, 19(10), 932–939. <https://doi:10.1080/13607863.2014.977771>
  23. Feast, A, Orrell, M, Charlesworth, G, Melunsky, N, Poland, F & Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *British Journal of Psychiatry*, 208(5), 429–434. <https://doi:10.1192/bjp.bp.114.153684>
  24. Geschke, K., Palm, S., Fellgiebel, A. & Wuttke-Linnemann, A. (2021). Resilience in informal caregivers of people living with dementia in the face of COVID-19 pandemic-related changes to daily life: A narrative review. *Journal of Gerontopsychology & Geriatric Psychiatry*, (Sep 8, 2021). <https://doi:10.1024/1662-9647/a000273>
  25. Greenwood, N., McKeivitt, C., & Milne, A. (2018). Time to rebalance and reconsider: Are we pathologising informal, family carers? *Journal of the Royal Society of Medicine*, 111(7), 253–254. <https://doi:10.1177/0141076818779204>
  26. Greenwood, N. & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, 19(1), 1–18. <https://doi.org/10.1186/s12877-019-1185-0>
  27. Hammersley, M. (1992). *What's wrong with ethnography?* London: Routledge
  28. Hanna, K., Giebel, C., Butchard, S., Tetlow, H., Ward, K., Shenton, J., Cannon, J., Komuravelli, A., Gaughan, A., Eley, R., Rogers, C., Rajagopal, M., Limbert, S., Callaghan, S., Whittington, R., Shaw, L., Donnellan, W. & Gabbay, M. (2022). Resilience and supporting people living with dementia during the time of COVID-19; A qualitative study. *Dementia*, 21(1), 250–269. <https://doi.org/10.1177/14713012211036601>
  29. Henwood, M., Larkin, M. & Milne, A. (2017). *Seeing the wood for the trees. Carer related research and knowledge: A scoping review*. Melanie Henwood Associates. <http://docs.scie-socialcareonline.org.uk/fulltext/058517.pdf>
  30. Henwood, M., Larkin, M. & Milne, A. (2018, November 8). To meaningfully support carers, we must rethink their purpose and contribution, *British Politics and Policy at The London School of Economics and Political Science*. <https://blogs.lse.ac.uk/politicsandpolicy/supporting-carers/>
  31. Holt Clemmensen, T., Hein Lauridsen, H., Andersen-Ranberg, K. & Kaae Kristensen, H. (2021). Informal carers' support needs when caring for a person with dementia: A scoping literature review. *Scandinavian Journal of Caring Sciences*, 35(3), 685–700. <https://doi.org/10.1111/scs.12898>
  32. Hughes, M. C., Liu, Y. & Baumbach, A. (2021). Impact of COVID-19 on the health and well-being of informal caregivers of people with dementia: A rapid systematic review. *Gerontology and Geriatric Medicine*, 7, 23337214211020164. <https://doi:10.1177/23337214211020164>
  33. Joling, K. J., Windle, G., Dröes, R. M., Meiland, F., van Hout, H. P., MacNeil Vroomen, J., van de Ven, P. M., Moniz-Cook, E. & Woods, B. (2016). Factors of resilience in informal caregivers of people with dementia from integrative international data analysis. *Dementia and Geriatric Cognitive Disorders*, 42(3–4), 198–214. <https://doi.org/10.1159/000449131>
  34. Jones, S. M., Killlett, A. & Mioshi, E. (2019). The role of resilient coping in dementia carers' wellbeing. *British Journal of Neuroscience Nursing*, 15(1), 6–12. <https://doi:10.12968/bjnn.2019.15.1.6>
  35. Lewis, F., Karlsberg Schaffer, S., Sussex, J., O'Neill, P. & Cockcroft, L. (2014). The trajectory of dementia in the UK: Making a difference. Office of Health Economics Consulting Report. <https://www.ohe.org/publications/trajectory-dementia-uk-making-difference>
  36. Lindeza, P, Rodrigues, M, Costa J, Guerreiro, M. & Rosa, M, M. (2020). Impact of dementia on informal care: a systematic review of family caregivers' perceptions, *BMJ Supportive & Palliative Care*, Published online first: 14 October 2020. doi: 10.1136/bmjspcare-2020-002242

37. Lorenz-Dant, K. and Comas-Herrera, A. (2021). The impacts of COVID-19 on unpaid carers of adults with long-term care needs and measures to address these impacts: A rapid review of evidence up to November 2020. *Journal of Long-term Care*, (2021), 124–153. <https://doi.org/10.31389/jltc.76>
38. Masterson-Algar, P., Allen, M. C., Hyde, M., Keating, N. & Windle, G. (2022). Exploring the impact of Covid-19 on the care and quality of life of people with dementia and their carers: A scoping review. *Dementia*, 21(2), 648–676. <https://doi.org/10.1177/14713012211053971>
39. Mazurek, J., Szczeñiak, D., Urbańska, K., Dröes, R. M. & Rymaszewska, J. (2019). Met and unmet care needs of older people with dementia living at home: Personal and informal carers' perspectives. *Dementia*, 18(6), 1963–1975. <https://doi.org/10.1177/1471301217733233>
40. McCabe, M, You, E. & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *The Gerontologist*, 56(5), e70–e88. <https://doi.org/10.1093/geront/gnw078>
41. McKenna, O., Fakolade, A., Cardwell, K., Langlois, N., Jiang, K., & Pilutti, L. A. (2021). Towards conceptual convergence: A systematic review of psychological resilience in family caregivers of persons living with chronic neurological conditions. *Health Expectations*, Feb; 25(1), 4–37. <https://doi.org/10.1111/hex.13374>
42. Nelis SM, Wu Y-T, Matthews FE, Martyr, A. Quinn, C, Rippon, I, Rusted, J, Thom, J.M, Kopelman, M.D, Hindle, J.V, Jones, R.W. & Clare, L. (2019). The impact of comorbidity on the quality of life of people with dementia: Findings from the IDEAL study. *Age and Ageing*, 48(3): 361–367. <https://doi.org/10.1093/ageing/afy155>
43. Nichols, E. & Vos, T. (2021). The estimation of the global prevalence of dementia from 1990–2019 and forecasted prevalence through 2050: An analysis for the Global Burden of Disease (GBD) study 2019. *Alzheimer's and Dementia*, 17: e051496. <https://doi.org/10.1002/alz.051496>
44. Parkin, E. & Baker, C. (2021) Dementia: policy, services and statistics, House of Commons Briefing Paper, Number 07007, 14 May 2021, <https://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf>
45. Parkinson, M., Carr, S. M., Rushmer, R. & Abley, C. (2017). Investigating what works to support family carers of people with dementia: A rapid realist review. *Journal of Public Health*, 39(4), e290–e301. <https://doi.org/10.1093/pubmed/fdw100>
46. Patton, M. Q. (2014). *Qualitative research & evaluation methods: Integrating theory and practice (4th edition)*. Sage Publications
47. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583–594. <https://doi.org/10.1093/geront/30.5.583>
48. Petriwskyj, A., Parker, D., O'Dwyer, S., Moyle, W. & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: A comprehensive systematic review. *JBIC Evidence Synthesis*, 14(6), 238–273. <https://doi.org/10.11124/JBISRIR-2016-002555>
49. Pini, S., Ingleson, E., Megson, M., Clare, L., Wright, P., & Oyeboode, J. R. (2018). A Needs-led framework for understanding the impact of caring for a family member with dementia. *The Gerontologist*, 58(2), e68–e77. <https://doi.org/10.1093/geront/gnx148>
50. Pongan, E., Dorey, J. M., Borg, C., Getenet, J. C., Bachelet, R., Lourioux, C., Laurent, B., COVCARE Group, Rey, R., & Rouch, I. (2021). COVID-19: Association between increase of behavioral and psychological symptoms of dementia during lockdown and caregivers' poor mental health. *Journal of Alzheimer's Disease*, 80(4), 1713–1721. <https://doi.org/10.3233/jad-201396>
51. Prince, M, Prina, M. and Guerchet, M. (2013). *World Alzheimer Report 2013. Journey of caring: an analysis of long-term care for dementia*. Alzheimer's Disease International. <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>
52. Prince, M. J., Wimo, A., Guerchet, M. M., Ali, G. C., Wu, Y-T., & Prina, M. (2015). *World Alzheimer Report 2015 – The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International. <http://www.alz.co.uk/research/world-report-2015>
53. QSR International Pty Ltd (2020). NVivo (released in March 2020), <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
54. Quinn, C., Clare, L. & Woods, R. T. (2015). Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London)*, 14(2), 220–237. <https://doi.org/10.1177/1471301213495863>
55. Quinn, C, Nelis, S. M, Martyr, A, Victor, C, Morris, R. G. & Clare, L. (2019). Influence of positive and negative dimensions of dementia caregiving on caregiver well-being and satisfaction with life: Findings from the IDEAL Study. *American Journal of Geriatric Psychiatry*, 27(8), 838–848. <https://doi.org/10.1016/j.jagp.2019.02.005>
56. Quinn, C. & Toms, G. (2019) Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *The Gerontologist*, 59(5), e584–e596. <https://doi.org/10.1093/geront/gny168>

57. Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology*, *58*(3), 307–321. <https://doi.org/10.1002/jclp.10020>
58. Rippon, I., Quinn, C., Martyr, A., Morris, R., Nelis, S. M., Jones, I. R., Victor, C. R., & Clare, L. (2020). The impact of relationship quality on life satisfaction and well-being in dementia caregiving dyads: Findings from the IDEAL study. *Aging & mental health*, *24*(9), 1411–1420. <https://doi.org/10.1080/13607863.2019.1617238>
59. Ritchie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman and R.G. Burgess (Eds.). *Analyzing Qualitative Data*, (pp. 173–194). Routledge.
60. Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C. & Yehuda, R. (2014). Resilience definitions, theory, and challenges: interdisciplinary perspectives. *European Journal of Psychotraumatology*, *5*. <https://10.3402/ejpt.v5.25338>
61. Spencer, L. & Ritchie, C. (2014) Analysis in practice. In L. Spencer, J. Ritchie, C. McNaughton Nicholls, & R. Ormston (Eds.), (2014) *Qualitative research practice: A guide for social science students and researchers*. 2nd edition (pp. 269–345). Sage.
62. Teahan, Á., Lafferty, A., McAuliffe, E., Phelan, A., O'Sullivan, L., O'Shea, D. & Fealy, G. (2018). Resilience in family caregiving for people with dementia: A systematic review. *International Journal of Geriatric Psychiatry*, *33*(12), 1582–1595. <https://doi:10.1002/gps.4972>
63. Twigg, J. & Atkin, K. (1994). *Carers perceived: policy and practice in informal care*. McGraw-Hill Education (UK).
64. Wilkinson, S. & Kitzinger, C. (2000). Thinking differently about thinking positive: a discursive approach to cancer patients' talk. *Social Science & Medicine*, *50*(6), 797–811. [https://doi.org/10.1016/S0277-9536\(99\)00337-8](https://doi.org/10.1016/S0277-9536(99)00337-8)
65. Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, *27*(2), 151–169. <https://doi:10.1017/s0959259810000420>
66. Windle, G. (2021) Resilience in Later Life: Responding to Criticisms and Applying New Knowledge to the Experience of Dementia. In A. Wister, & T. D. Cosco (Eds.), *Resilience and Aging. Emerging Science and Future Possibilities*. (1st edition, Vol. 1, pp. 31–49). Springer International Publishing.
67. Windle, G. & Bennett, K. M. (2012). Caring relationships: How to promote resilience in challenging times. In M. Ungar (Ed.), *The social ecology of resilience: A handbook of theory and practice* (pp. 219–231). Springer Science + Business Media. [https://doi.org/10.1007/978-1-4614-0586-3\\_18](https://doi.org/10.1007/978-1-4614-0586-3_18)
68. Wittenberg, R, Hu, B, Jagger, C, Kingston, A, Knapp, M, Comas-Herrera, A, King, D, Rehill, A. & Banerjee, S. (2020) Projections of care for older people with dementia in England: 2015 to 2040, *Age and Ageing*, *49*(2), March 2020, 264–269. <https://doi.org/10.1093/ageing/afz154>
69. Zhou, Y., Ishado, E., O'Hara, A., Borson, S. & Sadak, T. (2021). Developing a unifying model of resilience in dementia caregiving: A scoping review and content analysis. *Journal of Applied Gerontology*, *40*(10), 1377–1388. <https://doi:10.1177/0733464820923549>

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