


## Original Research

# Dementia caregiving during the COVID-19 pandemic: an interpretative phenomenological analysis of caregivers' experiences

Marta Pinto-Grau<sup>1,2</sup> , Alberto Blanco-Campal<sup>2</sup> and Jessica Bramham<sup>1</sup>

<sup>1</sup>School of Psychology, University College Dublin, Dublin, Ireland and <sup>2</sup>Psychology Services, County Louth, Health Service Executive, Ireland

### Abstract

**Objective:** To explore the lived experience of informal dementia caregivers during the COVID-19 pandemic.

**Methods:** Interpretative Phenomenological Analysis (IPA) was employed. Eight primary informal caregivers were recruited from a community mental health service for older people when attending in their role as caregiver of a service-user. Semi-structured interviews were conducted at home or in the clinic based on the participants' convenience and preference. IPA was completed following Smith and colleagues framework for analysis.

**Results:** Six group experiential themes, each with a number of subthemes, emerged from the cross-case interpretative analysis: the ambivalent experience of caregiving (subtheme: *those complex emotional experiences*); navigating lockdown: lived challenges and opportunities (subthemes: *the pervasive fear, intensification of existing struggles, being prevented from caring for a loved one, and lockdown as a time for opportunity*); transitioning out of lockdown (subthemes: *regaining freedom, but restricted freedom after all and being in a lockdown of one's own*); the present with COVID-19, but mostly with dementia (subthemes: *dementia, a disease that does not pause, and 'takeaways' from the journey*); looking into the future (subthemes: *embracing COVID-19 and the true needs*); and a word on coping (subtheme: *managing it all as best one can*).

**Conclusion:** Findings demonstrate the significance of the meaning caregivers ascribed to their experiences on their wellbeing and ability to cope in times of COVID-19 and thereafter. Gaining an understanding of the caregivers' unique experiences is crucial to appreciate how to best support them.

**Keywords:** Dementia; caregiving; psychological wellbeing; COVID-19 pandemic; interpretative phenomenological analysis

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### Introduction

The Coronavirus Disease 2019 (COVID-19) has posed unique and unprecedented challenges to those caring for a loved one with dementia. Increasing evidence is emerging worldwide on how informal carers experienced such challenging times and the impact it had on their psychological wellbeing. The social distancing measures enforced during the lockdown phase precipitated feelings of loneliness and isolation, as well as fear and worry about the person with dementia becoming infected (Aledoh and Adam 2020; Cohen et al., 2020; Giebel et al., 2021; Hanna et al., 2022; Harris and Titler 2022; Hughes et al., 2021; Losada et al., 2022; Rising et al., 2022; Roach et al., 2021; Vaitheswaran et al., 2020). Evidence also showed increased strain and anxiety when witnessing the more rapid deterioration of the person with dementia due to loss of stimulation, and feeling pressure to compensate for it (Borges-Machado et al., 2020;

Canevelli et al., 2020; Hanna et al., 2022; Rainero et al., 2021; Rajagopalan et al., 2022; Tuijt, Frost, et al., 2021). Caregivers also described the personal repercussions of losing valuable formal and informal supports, and facing the uncertainty of the progression and long-term care needs of the care recipient (Baumbusch et al., 2022; Giebel et al., 2020; Harris and Titler 2022; Shrestha et al., 2023). Hanna et al. (2022) captured the ambivalence of caregiver's experiences following the easing of the public health measures, characterised by an immediate sense of relief and freedom to be able to reconnect with informal and formal supports while continuing to live in fear of the virus. Extant evidence also identify the perceived barriers and limitations of telemedicine and virtual care, and the difficult risk management decisions caregivers faced during the acute phase of the pandemic (Giebel et al., 2022; Giebel et al., 2021; Tuijt, Rait, et al., 2021).

Savla et al. (2021) assessed informal dementia carers' appraisals of lockdown stressors and of coping resources and supports available, and found that those caregivers that were able to identify positive aspects of the pandemic as well as those who felt that they received sufficient informal support experienced lower role

**Corresponding author:** Jessica Bramham; Email: [jessica.bramham@ucd.ie](mailto:jessica.bramham@ucd.ie)

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overload. Similarly, Tulloch et al. (2022) investigated the experiences of caregivers before, during and moving forward from the pandemic, and showed that in such times, participants focused more on their own needs and experiences and developed deeper connections and personal strengths that facilitated coping and adaptation.

The complexity of the lived experience of informal carers throughout this public health crisis is evident when reviewing extant research. Although research to date has investigated some aspects of the informal dementia caregivers' experiences during the COVID-19 pandemic, further understanding is needed of the processes by which they derived meaning from it. This study aimed to explore the lived experience of informal caregivers of persons with dementia during the COVID-19 pandemic, to make sense of appraised challenges and opportunities, perceptions of its psychological impact, and reflections on how they adjusted to the complexity of their realities.

## Method

### Study design

This study is concerned with the meaning-making experience of informal caregivers and a phenomenological stance is taken. In particular, Interpretative Phenomenological Analysis (IPA) is employed, a framework that draws from hermeneutic phenomenology and is concerned with description and interpretation (Smith and Osburn 2015). IPA involves a *double hermeneutic* process by which the researcher makes sense of the participant's sense-making, and does so through their own experience-informed lens (Smith et al., 2009). The researcher wrote a positionality statement and reflective commentary before the commencement of data collection (see Supplementary Material 1) to draw awareness into her beliefs, perceptions and processes in relation to the topic and ensure 'bracketing out' during analysis (Tufford and Newman 2012).

### Participants and sampling

Purposive sampling was employed to recruit individuals who fulfil the role of informal carer of a person with dementia. Inclusion criteria included: (1) being the primary caregiver; (2) that the caregiving duties began prior to the start of the pandemic; (3) that the care recipient lived in the community at the time and is still alive; (4) and that the caregiver is over 18 years old. No specific exclusion criteria were devised; anyone who met inclusion criteria and consented to participate was invited to do so as it was assumed that those who fulfil a caregiving role and consent to the research are able to share and reflect on their experience.

Rolling recruitment was employed in conformity with IPA. No specific sample size was aimed at; instead, the richness and depth of individual data was monitored throughout the data collection process. The final sample comprises eight primary informal caregivers of persons with dementia of different subtypes, severity and needs. Participant characteristics are presented in Table 1. All participants were assigned a pseudonym to ensure anonymity.

### Procedure

Participants were recruited from a community mental health service for the older person when attending in their role as carers of a service-user. Clinicians at the site identified potential participants and informed them of the study. Those who provided informed

**Table 1.** Participant characteristics

Participant	Pseudonym	Sex	Kinship	Care Recipient's Diagnosis
1	Mary	Female	Daughter	Vascular Dementia
2	John	Male	Husband	Dementia due to Alzheimer's Disease
3	Linda	Female	Daughter	Primary Progressive Aphasia
4	Susan	Female	Daughter	Dementia due to Alzheimer's Disease
5	Michael	Male	Husband	Dementia with Lewy Bodies
6	Teresa	Female	Wife	Parkinson's Disease Dementia
7	Ann	Female	Daughter	Mixed Dementia
8	Carol	Female	Daughter	Dementia due to Alzheimer's Disease

consent to partake were invited for interview. A semi-structured interview schedule informed by the research question was devised (see Supplementary Material 2), with open and expansive questions, starting with a descriptive account of their role as caregivers, followed by an invitation to take a more analytical approach when reflecting on their experience during the pandemic.

Interviews were carried out between September and December 2022. These were arranged at the participants' convenience and preference in the clinic ( $n = 4$ ) or in their home ( $n = 4$ ). Interview length ranged from 34 to 92 minutes ( $M = 59$ ,  $SD = 20$ ). All participants were debriefed at the end of the interview to address any distress they might have experienced in the process. The interviews were audio-recorded and transcribed verbatim using a fully GDPR-compliant automatic transcription software (Happy Scribe; Bastié and Assens 2017). These were manually checked thoroughly for accuracy.

### Data analysis

IPA was completed in accordance with the framework for analysis developed by Smith et al., (2009, 2021). This IPA model was chosen given its adequacy for studies involving a single small homogenous group of participants. The analytic process followed is outlined in Table 2. Any identifying information mentioned during the interviews was changed or omitted in the participant quotes presented to ensure privacy.

### Enhancing trustworthiness

The first author (MPG) conducted the entire analytical work as outlined in Table 2. To ensure rigour, transparency and plausibility of this analysis, a second researcher (JB) reviewed the coherence and consistency of the interpretation process from the initial raw data to this final report. The two researchers engaged in a joint reflective dialogue about the chain of arguments developed throughout the analytic process to ensure this was applied in a systematic, rigorous and dialogical manner, in accordance with the IPA's commitment to ensure trustworthiness of the interpretative account (Smith et al., 2021). This study was registered with Open Science Framework (registry link: [osf.io/sf34d](https://osf.io/sf34d)).

**Table 2.** IPA analytic process as outlined by Smith et al (2021)

<b>Step 1</b>	Reading and re-reading the data, immersing oneself in it to ensure the participant becomes the focus of analysis.
<b>Step 2</b>	<p><i>Exploratory noting</i>, examining semantic content and language use on an exploratory level using three different processes of exploratory commenting:</p> <ol style="list-style-type: none"> <li>1. <i>Descriptive comments</i>: describing the content of what the participant said.</li> <li>2. <i>Linguistic comments</i>: exploring the participant's use of language.</li> <li>3. <i>Conceptual comments</i>: interpretative annotations, often interrogative at this stage.</li> </ol>
<b>Step 3</b>	Constructing <i>experiential statements</i> based on a more focused analysis of exploratory comments. This step reflects a synergetic process of description and interpretation.
<b>Step 4</b>	Searching for connections across experiential statements, charting how these fit together to produce a more structured account of the most relevant aspects of the participant's experience. Clusters of experiential statements become the participant's <i>personal experiential themes</i> (PETs), which reflect analytic entities of an individual's experiences or their experience of sense-making.
<b>Step 5</b>	Naming the PETs, and consolidating and organising them in a table. The table of PETs includes the highest level of organisation produced (i.e. PETs), any subthemes a specific PET is made up of, the set of experiential statements brought together to develop the cluster or sub-cluster, and a key quote for each. The table of PETs represents the analytic dialogue that has occurred between participant and researcher.
<b>Step 6</b>	Continuing the individual analysis of other cases, moving to the next participant and systematically repeating the process, appreciating each case's individuality and allowing new analytic entities to emerge.
<b>Step 7</b>	Working with PETs to develop <i>group experiential themes</i> (GETs) across cases, looking for patterns of similarities and differences across PETs. Cross-case analysis in IPA does not aim to present a 'group norm' but to understand and present commonality and individuality in the participants' experiences. Wider cross-case analyses move across different levels of comparison (i.e. PET, subtheme and experiential statement). The results of the phenomenological analysis across cases is presented as an interpretative narrative of findings, organised hierarchically as follows: GETs, group-level subthemes, synthesis of relevant experiential statements brought together to develop that subtheme, and quotes that represent the phenomenological essence from which the interpretation was developed. Where relevant, examples that bespeak breadth and variation are also presented.

Note. In line with IPA's idiographic commitment, Steps 1 to 6 focus on a particular individual and then analysis moves to more general claims in Step 7.

**Table 3.** Group experiential themes (GETs) and related subthemes

GETs	Subthemes
The ambivalent experience of caregiving	<i>Those complex emotional experiences</i>
Navigating lockdown: lived challenges and opportunities	<i>The pervasive fear</i> <i>Intensification of existing struggles</i> <i>Being prevented from caring for a loved one</i> <i>Lockdown as a time for opportunity</i>
Transitioning out of lockdown	<i>Regaining freedom, but restricted freedom after all</i> <i>Being in a lockdown of one's own</i>
The present with COVID-19, but mostly with dementia	<i>Dementia, a disease that does not pause</i> <i>'Takeaways' from the journey</i>
Looking into the future	<i>Embracing COVID-19</i> <i>The true needs</i>
A word on coping	<i>Managing it all as best one can</i>

**Results**

Six GETs emerged from the cross-case interpretative analysis, each with a number of related subthemes (Table 3). These are presented and discussed below in turn. Qualitative extracts from interview transcriptions for each GET and subtheme are presented in Supplementary Material 3, referenced in numerical order within brackets. Tables of PETs portraying idiographic analyses of each individual's experience are available upon request.

*The ambivalent experience of caregiving*

This experiential theme captures the ambivalent experience of caring for a loved one with dementia. Carers described the

challenges experienced in the role, in most cases already present before the onset of the COVID-19 pandemic, and the difficult emotions that arose because of the complex realities they faced. Regardless of the hardship experienced in the role, however, the caregivers' narratives conveyed an inherent sense of caring and concern for the care recipient.

*Those complex emotional experiences*

Caregivers highlighted the strain of the caregiving role by emphasising its demanding and stressful nature and by highlighting the constant emotional load it involves. Through the caregivers' descriptions, the emotional ambivalence, those conflicting feelings experienced towards the person with dementia and the situation they found themselves in transpired throughout. John, for instance, spoke about a sense of being captive in the caregiving role while he also spoke about the unreserved love he feels for his wife.

Loss and grief were also evident when caregivers spoke about the change endured since dementia entered their lives. That emotional chaos one experiences when a loved one is diagnosed with dementia is described in this fragment from Susan's interview. In it, Susan describes fear, anger, denial, helplessness, loneliness . . . but above all, admiration. This theme of ambivalence is a recurrent one, noticed throughout the caregivers' narratives surrounding meaning of their lived experience, during COVID-19 and beyond.

*Navigating lockdown: lived challenges and opportunities*

The lockdown was experienced by caregivers in very singular ways, and that individuality appeared to be influenced by each caregiver's specific personal and contextual circumstances, as well as by their unique appraisals of challenges and opportunities encountered

during lockdown and their emotional responses to this. Regardless, some convergence was captured across the individual experiences.

### *The pervasive fear*

A common theme that came up for most participants was fear. The most apparent fear reported was that of the person with dementia becoming infected with COVID-19. Caregivers spoke about the practical things they did to protect them, and also the need for all family members to be on the same page. Another common fear reported by caregivers was that of transmitting the virus to the person with dementia, and this fear was not only in themselves but also in others close to the person with dementia. Carol also spoke of the fear of any complications that could arise because of comorbidities, and Mary verbalised the fear of losing her mother to COVID-19.

Another worry that caregivers experienced during lockdown was that of the impact that the loss of social contact was having on the care recipient. A significant fear Mary reported was that of herself becoming sick with COVID-19 and the worry that nobody would be there to care for her mother. Mary's experience, characterised by significant unease because of the lack of family support, contrasted with Ann's experience, who felt reassured by that sibling togetherness.

A number of participants, despite recognising the seriousness of COVID-19, reflected on the impact the media had on this pervasive fear experienced by themselves and also by the person with dementia. Carol also expressed her perception of how society's sense of safety changed since COVID-19. Susan, differing from what most other carers experienced, denied experiencing fearfulness towards COVID-19. Her experience appeared to have been one of prioritising her pressing concern, which was the struggle her family was already going through because of dementia.

### *Intensification of existing struggles*

The caregiving experience was a complex one for a lot of the caregivers interviewed already before the enforced COVID-19 restrictions came into place. The lockdown, however, made that experience the more challenging for most. The efforts of providing care for their loved one were hindered by a number of barriers and hurdles, and the psychological wellbeing of caregivers suffered as a result.

A significant struggle a lot of carers encountered was that of the care recipient's lack of understanding and awareness of the situation due to amnesic difficulties. Carol, whose father returned home from a hospital admission following a COVID-19 infection that accelerated the progress of his dementia, described her struggle. Linda, whose father moved in with them just before lockdown, described a sense of role captivity and role conflict that was exacerbated by the lockdown.

Another significant challenge that appeared to intensify the struggle experienced by caregivers during lockdown was the loss of the usual outlets and supports. In most cases, these were the things that were taken for granted. Caregivers spoke about what they lost, but they also spoke about what their loved ones lost, appearing aware of the impact that was having on them. Mary, for instance, spoke about the significance of her mother losing the hug and the handshake when meeting others. The loss of social contact and peer support was another hurdle that caregivers had to embrace. Mary reflected on how COVID-19 stole that peer support that she felt would have been valuable, and John described the loneliness he experienced because of this.

Most carers also spoke about the struggle and impact of losing access to services and formal supports, and this was relevant for dementia-specific care but also to general healthcare. John reflected on the loss of emotional support he experienced when home care was discontinued, and Susan spoke about the loss of peer support services for informal dementia carers that resulted because of the lockdown.

Some caregivers also spoke about the loss of in-person formal care, which appeared to be mitigated, to some extent, through telemedicine. Many caregivers expressed a sense of gratitude that formal care could be continued remotely, but their reflexions were characterised by some ambivalence. In this regard, there appeared to be some barriers to the interaction with healthcare professionals online or by telephone.

### *Being prevented from caring for a loved one*

An experience many of the carers lived through was that of their loved one with dementia being admitted to hospital and them not being able to see them. While narrating these experiences, the distress and emotional pain experienced was apparent: the concern, anger, frustration, helplessness, loneliness, and foremost, fear.

### *Lockdown as a time for opportunity*

The individuality in the lived experiences of caregivers was particularly apparent when listening to carers speak about opportunities. Some caregivers, regardless of the hardship experienced during lockdown, also perceived it as a time for opportunity. For example, John and Linda spoke about the opportunity to plan new undertakings. Linda also spoke about opportunities the lockdown brought about for her family, the opportunity for family quality time and bonding, and also the opportunity for understanding and normalising dementia, and for acceptance of what might be down the line.

Teresa and Michael, both caring for their spouses, experienced lockdown as an opportunity to spend quality time with their loved ones, to slow down and to enjoy the little things. Both carers reflected on the fact that their spouses' symptoms of dementia were mild at the time, and that was what allowed for lockdown to be a more enjoyable experience.

### *Transitioning out of lockdown*

Most caregivers described the transition out from lockdown and into the "new normality" of COVID-19 as a freeing experience. Their narratives, however, described a regained sense of freedom that was not free from ambiguity due to the lingering concern that COVID-19 still represented a threat as well as a changed sense of safety and appraised need for wariness. Again here, the individual circumstances surrounding each carer's reality appear to determine how they appraised this point in time, but there was a general awareness of the need to balance safety and support necessity.

### *Regaining freedom, but restricted freedom after all*

Caregivers spoke about the contentment of being able to engage with the outside world when the lockdown restrictions lifted, but in their accounts there was a sense of wariness and concern that COVID-19 was still a threat, particularly for the person with dementia. When speaking about resuming home care, caregivers appeared aware of the risks, but the need to balance the concerns with the necessity of that extra support prevailed.

*Being in a lockdown of one's own*

For some carers, as the world opened up, the continued progression of their loved one's dementia prevented them from re-engaging with their lives outside of caregiving. This was particularly relevant for Michael and Teresa, who experienced lockdown as an opportunity and the reopening of society as a realisation that they were in a lockdown of their own.

Linda also spoke about the increasing challenge she experienced to re-engage with life after lockdown given her father's progression. What was particularly relevant for her at this stage was the awareness that even though she was now able to reach out to family for support, there was no supportive family to reach out to. This brought up anger for Linda, but also guilt.

*The present with COVID-19, but mostly with dementia*

This overarching theme reflects the hardship lived throughout a journey of continued change and increased struggle brought up by the progressive nature of dementia, which was somewhat independent from COVID-19. Once more, that individuality came into it when speaking about the struggle, and some caregivers spoke about what they took away from the experience.

*Dementia, a disease that does not pause*

Something that became apparent from speaking to all of the caregivers was that, despite the fact that lives during the COVID-19 pandemic were put on hold, the progression of dementia was not. They therefore found themselves in a continued struggle that little has to do with COVID-19 anymore.

Carol described the uncertainty that accompanies dementia and the impact it had not only on the caregiver but also on the whole family. Teresa and Michael spoke about the loss of the person they married, their significant other. The two of them also talked about feeling unequipped and powerless to manage the symptoms of dementia, and Mary portrayed that helplessness and distress of watching your loved one suffer and not knowing how to help them. Carol and Mary also spoke about a sense of constantly being watched and judged by others, the self-doubt this causes, and the exhaustion of feeling that doing one's best is not good enough in other people's eyes.

An aspect of care that was brought up by most caregivers was that of having to make difficult decisions, in particular around long-term admission to a care facility. The caregivers interviewed were at different stages of their caregiving journey, and their perceptions and experiences around this were very much determined by that. For instance, Linda had gone through a difficult journey of coming to terms with this decision, characterised by a period of denial. Susan, who was in the process of applying for nursing home placement, described her realisation that with dementia, "home is never home". In both cases, that lingering guilt was very much appreciated in their narratives. Mary and John expressed different sentiments in relation to nursing home placement. Both opposed this idea but articulated different reasons. Mary described an anticipated sense of failure, while John highlighted his perceived value of the care he can provide at home.

*'Takeaways' from the journey*

Despite all the hardship encountered during their caregiving journey, some caregivers spoke about the positives they take away from the experience. The individuality in their lived experiences became apparent once again when hearing the carers reflect on this. Mary, for instance, spoke about the return of that expressed

affection between her and her mother that had been left behind years ago. John reflected on the opportunity to connect with others at a different level, and also to meet inspiring people and the invaluable support they offer. Carol also spoke about the opportunity it has offered her to spend more time with her father, and also the possibility for her father to develop a special bond with his granddaughter.

*Looking into the future*

This theme reflects the caregivers' thoughts on the future, which conveyed an awareness of a future where COVID-19 was still present, but also a future where their caregiving role continued and they had unfulfilled needs that prevailed.

*Embracing COVID-19*

At a time when most of the COVID-19 restrictions had been lifted and the virus continues to spread but at a relatively stable trend, it became apparent that COVID-19 was still at the back of some of the caregivers' minds. In particular, caregivers spoke about the uncertainty of how the COVID-19 situation might evolve, and the concern of how they would manage the caregiving situation were they to become infected. There was a sense, however, that the fear of COVID-19 infection lessened, which seemed to be determined by first person experience of COVID-19 infection and by witnessing the less severe effects it had in people over time. The concerns expressed were therefore mostly around the inconvenience of having to live through severe restrictions again or having to isolate from the care recipient. The importance of maintaining a balance between safety and freedom was also emphasised.

The individual circumstances each caregiver underwent during the height of the pandemic had an obvious influence in the way they appraised their lived experience, but also in the way they appraised the future to come. For instance, Michael, who lived lockdown as a pleasant and relaxing time, had since experienced COVID-19 infection first-hand and had also witnessed others close to him, including his wife with dementia, become infected with COVID-19 with no major complications. When speaking about the future having to live with COVID-19, Michael impressed as relaxed about the possibility of another infection and appeared reassured at the fact he had been vaccinated.

It was apparent, also, that the emotional impact of the hardship some caregivers endured because of COVID-19 still conditioned that anticipated fear of what might come, and the behaviours they engaged in to protect themselves and others. For example, Susan described a traumatic experience she sustained during COVID-19, and it became apparent that a fear of reliving that situation again was the only instance that made her fear COVID-19 in any way. Carol, whose father was severely afflicted by COVID-19 and the pandemic also caused significant loss and trauma in her family, recalled the pandemic as an emotionally painful and draining experience and reflected on how her decision to take the vaccine was conditioned by that fear that still remained in her.

*The true needs*

While reflecting on their caregiving journey and challenges encountered, a sense of incompetency and helplessness when looking into the past and uncertainty when looking into the future were evident in the caregivers' narratives surrounding meaning of their lived experience. Some caregivers spoke of their needs and what they felt would help them. Mary and Susan reflected on this in a very insightful manner and expressed their appraised need for

guidance but also for an understanding and compassionate ear to talk to. Both of them conceptualised this need as “a helpline” that informal dementia carers could avail of. Mary also spoke about the need for peer support; she reflected on the importance of the formal support and care offered by the healthcare professionals but also highlighted how certain understanding can only come from others who are living through a similar experience. Ann’s, contrasting with Mary and Susan’s experiences, spoke about the value it entailed for her and her family to receive prompt advice and guidance following her mother’s diagnosis. Susan spoke about the need to raise awareness, understanding and acceptance of dementia.

### *A word on coping*

Interviewed caregivers also touched on what helped them during their caregiving journey to cope with the challenges encountered. They all approached the situation differently and described varied processes, approaches and strategies that helped them manage. It was apparent from the caregivers’ narratives that coping was individual, shifting, adapting, and that it determined and was determined by the carers’ unique experiences, circumstances, and appraisals of the future.

### *Managing it all as best one can*

Both John and Linda were perceived as “problem-solvers”, although the nature of their task-oriented coping approach impressed as being of a different nature. While John’s problem-solving approach was characterised by anticipatory anxiety but active coping, Linda’s task-oriented coping had a flavour of underlying emotion-avoidance coping that allowed her to function under stress. Linda also relied on humour to cope, humour and acceptance of their reality.

Most caregivers also relied on meaning-based coping. In particular, they sought a value-based deeper meaning to their caregiving role. For instance, Mary and Susan described a sense of giving back to their mothers, who had fulfilled the role of carer to them before. Susan also spoke about turning to her spiritual beliefs to find that deeper meaning of her role as caregiver. John spoke about altruism, about giving back to others, in particular to the person he loves and admires, and how fulfilling and rewarding this can be. He also spoke about the new world that caregiving had opened for him, and the possibility of new connections and learning. He also reflected on how the adversity that dementia and COVID-19 brought to his life built his strength and empowered him to believe in his confidence to overcome hardship. Susan also described a gained sense of perspective from previous adversity and the learning about her inner-strength that came from it. She also described an ability to remain present and compassionate towards herself. A different meaning-based coping approach that Susan described was reframing the situation in a more positive way, particularly when thinking about the uncertainty that COVID-19 and the lockdown brought into her life.

Finally, Carol, whose experience of COVID-19 was particularly challenging because of a family bereavement and the vicarious trauma of being a frontline healthcare worker at the height of the pandemic, described that sense of temporarily detaching herself from the situation to minimise its impact.

## **Discussion**

The COVID-19 pandemic posed unique and unprecedented challenges to those caring for a loved one living with dementia. The

aim of the present study was to explore the lived experience of informal dementia carers in the context of the COVID-19 pandemic to understand how they made sense of their experience. The interpretative phenomenological method was employed to this purpose. Semi-structured interviews were conducted with eight informal carers recruited through a community mental health service for the older person in their attendance as the primary carer of a service-user diagnosed with dementia. Fig. 1 depicts the sense-making process of the caregivers’ experience during COVID-19 conceptualised based on the overall integration of this study’s findings. This framework also considers the existence of personal and contextual predisposing factors that determined such experience (Gilsenan *et al.*, 2022; Martindale-Adams *et al.*, 2016; Vara-García *et al.*, 2021).

The experience of ambivalence in relation to dementia caregiving conveyed by the participants in this study is in line with existing evidence that those caring for a loved one with dementia experience conflicted feelings and cognitions towards the care recipient that can be quite intense and distressing (Caputo 2021; Losada *et al.*, 2018; Losada *et al.*, 2017; Shim *et al.*, 2012). Such ambivalent emotions characteristic of caregiving can arise as a result of different factors, for instance changes in the quality of the relationship or in the patterns of interdependence, competing care demands and role overload, a complex pre-caregiving relationship, or because of conflicting values, norms and expectations in relation to caregiving (Losada *et al.*, 2017). Evidence from quantitative research has shown that the experience of ambivalence contributes to an increase in depressive and anxiety symptoms as well as burden in informal dementia caregivers (Caputo 2021; Losada *et al.*, 2018; Losada *et al.*, 2017). A qualitative report also showed that the experience of ambivalent feelings towards the care recipient, brought about by loss in the relationship, intensified the caregivers’ distress (Shim *et al.*, 2012).

The sense of pervasive fear that most caregivers expressed when reflecting on their experience of caring for their loved one with dementia during lockdown is in keeping with reports from other studies exploring the impact of the pandemic on informal dementia carers (Cohen *et al.*, 2020; Giebel *et al.*, 2020; Hanna *et al.*, 2022). Conforming to existing evidence, the participants interviewed in this study reported fear that was general to many aspects of their reality with the virus but mostly around the safety and welfare of the person with dementia. Caregivers also spoke about those appraised hurdles that made their caregiving experience the more challenging during such severely restricted times, among which stood out the lack of understanding and awareness of the person with dementia, the loss of outlets and supports, and an exacerbated sense of entrapment. These are themes that are in consonance with the findings of Shrestha *et al.* (2023), who explored the experiences and perspectives of informal dementia caregivers on how the pandemic impacted them and reported, among other themes, difficulty with the care recipient’s inability to comprehend the need for safety measures, feelings of isolation and loneliness due to social distancing restrictions, and communication challenges with healthcare professionals.

Hanna *et al.* (2022), in their exploration of caregivers’ experiences following the easing of the public health measures, reported that their sample continued to live in fear of the virus, which negatively impacted on their psychological state. This is in keeping with what the caregivers interviewed in this study experienced when they spoke about a restricted freedom and a changed sense of safety. Hanna *et al.* (2022) conducted their interviews during June and July 2020, over two years prior to this

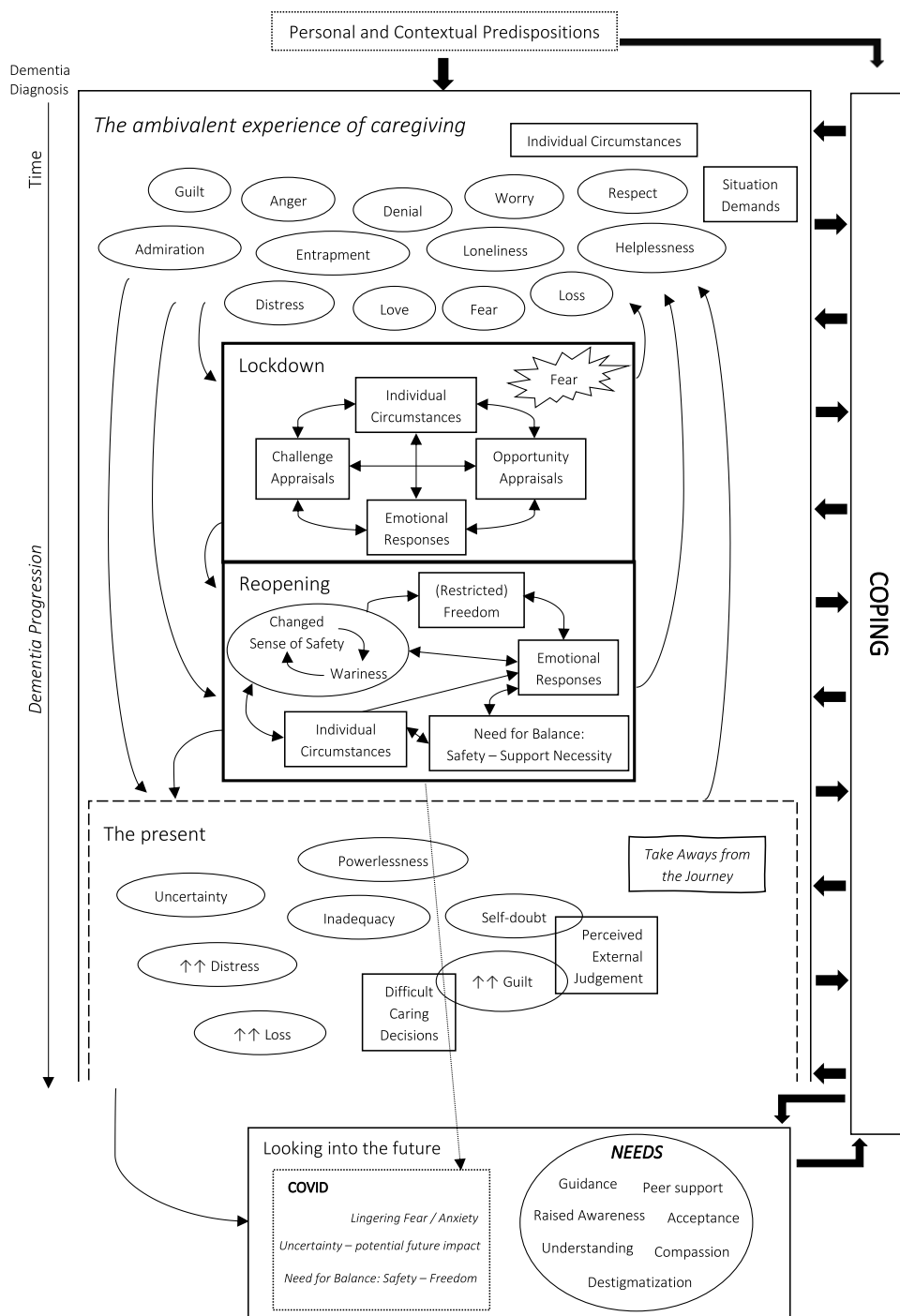


Figure 1. Sense-making of the experience of caring for a loved one with dementia in times of COVID-19.

study’s interviews. This suggests that the impact that lockdown had on caregivers and the fear that was developed because of the dangers of COVID-19 was enduring and significantly impacted on their sense of safety in the longer term.

Something that became apparent when making sense of the participants’ experiences through lockdown and the easing of restrictions was that the way they lived through lockdown shaped how they experienced the reopening of society. Thus, for those carers that experienced lockdown as a more stressful time, the reopening was perceived in more positive ways regardless of them still perceiving the threats and need for caution. In

contrast, for those caregivers that appraised lockdown as a more pleasant time, the reopening of society represented a reality shock. The individual experiences of caregivers when encountering COVID-19 in their lives also appeared to be a determinant of how they appraised the future threat of it. In line with this, for those caregivers that experienced traumatic events related to the pandemic, fear still lingered as well as anticipatory anxiety and the engagement in safety behaviours. This supports the idea that each individual’s circumstances and how these are appraised significantly influenced adaptation to their reality.

A similar phenomenon was observed when caregivers spoke about the opportunities that lockdown offered them, which included spending quality time with loved ones, bonding, slowing down, enjoying the little things, and planning new undertakings, and they also spoke about opportunity for understanding, normalising and accepting dementia. It became apparent from the caregivers' reflections that such more positive appraisals of their reality somewhat buffered the impact of the adversity lived through. This is largely in line with the findings by Savla et al. (2021) and Tulloch et al. (2022), who confirmed that those caregivers that were able to derive positive meaning and experiences from the COVID-19 pandemic were less likely to experience role overload and more likely to develop personal strengths that facilitated coping and adaptation.

Lastly, it is important to highlight that when looking into the future and irrespective of COVID-19, the caregivers interviewed in this study spoke about unfulfilled needs that are relevant to them in their continued journey of caring for a loved one with dementia. In particular, they spoke about the value of the support received from healthcare professionals, but also the need for further guidance on their understanding of dementia and how to address daily living challenges they might encounter in their caregiving role. They also highlighted the need for a compassionate ear to reach out to in moments of distress and the opportunity to exchange experiences with others in the caregiving role. Finally, at a societal level, the need for raised awareness, understanding and acceptance of dementia was also emphasised. The needs highlighted by the caregivers in this study are very much in line with those identified in the existing literature (Queluz et al., 2020).

#### Strengths and limitations

This study has employed an IPA model that is adequate for small homogeneous samples like this study's one and it has carefully followed its analytic process, ensuring the trustworthiness of the analysis and interpretation throughout. Employing an IPA approach has permitted an increased awareness and understanding of the participants' unique experiences by focusing on their deep and rich personal accounts. This study's sample, however, does not aim to be representative of the informal dementia caregiving population. The aim by employing IPA was to begin to develop an understanding of what it meant to be actively caring for a loved one with dementia in the community through such unprecedented times. Based on the researcher's understanding and interpretation of the caregivers' sense-making, a framework has been developed that intends to contextualise how the experience of caring for a loved one with dementia in times of COVID-19 was lived by this study's sample. Such meaning-making process of a small sample of participants offers a basis from which further research can be conducted. It must be considered, however, that this study was conducted with an Irish sample, characterised by particular cultural values and norms, and this has somewhat shaped their experiences and responses to the COVID-19 pandemic. Nevertheless, the fact that this study's findings are context specific might mean that these are somewhat more transferable to other individuals that provided informal care in the context of the pandemic.

This research appeared important given the unprecedented nature of the global health crisis that the COVID-19 pandemic represented, and the existing evidence that suggests that the impact it had on this population was significant and probably long-lasting (Aledeh and Adam 2020; Baumbusch et al., 2022; Hanna et al., 2022;

Hughes et al., 2021). In this interpretative account of the participants experiences, therefore, emphasis has been placed not only on the participants lived experience during the height of the pandemic, but also on their present reflections and future beliefs and expectations.

An acknowledgement must also be made of the active role this researcher has taken in the process of collecting and analysing the data of the study, and the potential impact that her personal preconceptions might have had on this process. An attempt for transparency has been made by stating the researcher's positionality, adopting a reflective and reflexive approach, and by having a second researcher review the rigour and plausibility of the interpretation process. Despite such efforts, complete 'bracketing out' of this researcher's beliefs and processes is implausible and this is something that must be taken into account when considering this particular interpretative account of the lived experience of informal dementia carers in COVID-19 times.

#### Conclusion

The findings of this study demonstrate the significance that the understanding and meaning caregivers ascribe to their experiences have on their psychological wellbeing and ability to cope with the challenges of their role. This study focused on a specific context, the COVID-19 pandemic, and although the circumstances that surrounded this global health crisis have mostly resolved, what each caregiver lived through and the impact it had on them is something that is and will continue to be relevant to their unique caregiving journey. The value of exploring their unique experience and the sense they make of it is therefore crucial to gain an understanding of how to best support them.

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**Competing interests.** All the authors declare that they have no conflict of interest to disclose.

**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. This study was granted full ethics approval from the HSE North East Area Research Ethics Committee (ethics approval reference number REC/21/031), and written consent was obtained from all participants.

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