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EXPLORING EXPERIENCES OF CARERS IN THE COVID 19 PANDEMIC

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Executive Summary

Background to the study

Carers are a vital, yet unrecognised, part of health and social care systems (Phillips et al., 2021). Their equivalent monetary input is estimated to amount to between €2.1 and €20 billion per year in Ireland (Hanley and Sheerin, 2017; Family Carers Ireland, 2021a). Oftentimes, carers have not had any relief from their caring role for years. COVID-19 created a health and social care crisis unprecedented in modern history. The mobilisation of responses focused heavily on infection protection, yet one of highest risk groups, carer recipients and carers, were subject to service suspension leading to the exacerbation of existing stresses and the creation of new challenges. It is important to understand the experience of carers and to identify what and how supports may be constituted to foster resilience and counteract negative impacts for carers, care recipients and their families.

Aim of the study

The aim of the study was to explore carers' experiences of providing care in the COVID-19 pandemic.

Research methodology

A qualitative research methodology using adapted photovoice methods was used to inform the conduct of the study. Data collection involved individual semi-structured interviews with participants during which photographs taken by participants were employed to facilitate exploration of experiences. Interview data were thematically analysed using the methods described by Braun and Clarke (2006; 2021; 2022) to produce an interpretation of the research phenomenon. Ethical approval and Data Protection Impact Assessment processes were submitted, reviewed and approved by Trinity College Dublin in advance of the study fieldwork beginning. Ethical elements of good research practice were adhered to during participant recruitment and consent, and the collection and confidential storage of data. General Data Protection Regulations (GDPR) (Government of Ireland, 2018) and the Health Research Regulations (under the GDPR Act, 2018) were adhered to, and the welfare of study participants was, at all times, prioritised.

Summary of findings

- The findings from the 15 qualitative interviews were organised with reference to three themes, which together provide an interpretation of participants' experiences of caring during COVID-19:
 - Theme 1: 'The nature of caring – becoming and being'
 - Theme 2: Navigating the COVID-19 tidal wave(s)'
 - Theme 3: 'Reflecting forward'
- **'The nature of caring'** was recounted by participants as a means to provide a background and context to their COVID-19 caring experiences. Related findings illuminate key facets of ongoing carer roles (including: advocacy, and service locator and navigator) and care-related impacts (including: the rewards of caring and experiences of restrictions to carer freedom, isolation and loneliness, fatigue and reduction or cessation of work lives outside of the caring role).
- Theme 2, **'Navigating the COVID-19 tidal wave(s)'**, contains five sub-themes which chart the experiences and life world of carers through the severest restrictions to the tentative emergence to pre-COVID-19 life in late 2021. The five themes are comprised of a) increases in the volume and intensity of work and b) life space reduction, c) impact of restrictions, d) mobilising resilience and e) reconnecting with services. These experiences could vary within the temporal context of COVID-19's impact.
- The final theme, **'Reflecting forward'**, encompasses carer identified means to address the challenges encountered during the pandemic based on reflections on the experience of living through COVID-19 as a carer. To this end, participants referred to the need: to recognise the place and role of carers; for points of contact and connection; care planning to include contingency and emergency planning consideration; provision of financial and material resources; and the need to prioritise the continuance and appropriateness of service provision for care recipients.

Study recommendations

1. Recognition of carers

- The place and role of carers is given official policy and service recognition.
- That carers be viewed as experts in care in light of their knowledge and experience.
- That the needs of carers arising from pandemic induced impacts on caring are elicited and addressed to support the caring role, and the health and welfare of carers and care recipients.
- That a formal means of carer identification is advanced to support carer recognition in the context of pandemic related restrictions.

2. Financial and material supports

- Similar to other groupings in society that received targeted financial supports in the pandemic, carers are provided with financial supports to meet the added costs of caring encountered during such times. These costs can include increased household bills, equipment purchase and household modifications. Such costs are faced by carers who frequently have to reduce working hours or withdraw from paid employment to undertake caring roles.
- That a system to support efficient and sufficient access to material resources including Personal Protective Equipment (PPE) is established for carers.

3. Building circles of support for carers

- Similar to proposals from Family Carers Ireland, this study advocates for the appointment of named Carer Advisers allocated to individual carers be considered to function as proactive points of contact to support information provision and connection to available services and supports.
- Family carers and care recipients are supported with a person-centred and needs driven care plan with in-built contingency or emergency care planning. Such care plans could be developed for completion concurrent to standardised care recipient assessments and should be subject to ongoing review in light of the dynamic and frequently progressive nature of care recipient needs. As the findings of the current study show, needs can be amplified in the context of circumstances which reduce or remove existing services and access to social and other outlets.
- That a relationship-centred approach to care be adopted incorporating consideration of the triad of care recipient, carer and service provider in the context of care planning and service delivery.

4. Enhanced service integration and reduction in fragmentation

- The landscape of service provision be reviewed to identify points of intersection and fragmentation to understand the potential to establish service/care pathways that support a more integrated and timelier caring journey for carers and care recipients.
- Carers need to be proactively included in planning and delivery of service provision with recognition in political, service and policy discourses.

Chapter 1 Introduction and Background to the Study

1.1 Introduction

Family carers are essential co-producers of care supporting individuals to live in community settings with societies often tacitly relying on such unpaid labour from an “invisible workforce” (UNECE, 2019: 1-2; Eurocarers, 2018). The work of such carers can delay or prevent the need to enter the residential care system (Centre for Disease Control and Prevention (CDC), 2019). As such, carers represent the “backbone of long-term care provided in people’s homes” (CDC, 2019: Webpage). With a continued ageing population and an increase in chronic conditions, there is a major impetus to comprehensively support carers as future numbers of people requiring assistance to live in the community will rise (Shilling et al., 2016). The support of carers is also necessary to well-being and quality of life.

So as to provide a background and context to the study conducted and reported on herein, this chapter will provide an overview of the background and context to the study by overviewing the nature and concept of family caring and current family carer statistics in Ireland before considering the impact that caring can have on carers. This chapter will also review recent research exploring how carers and those whom they provide care for have been impacted upon by the COVID-19 pandemic.

1.2 Family carers

Although there are diverse definitions of what constitutes a carer (UNECE, 2019), in Ireland a family carer is someone who provides “an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty” (Department of Health, 2012:8). A family carer can broadly refer to any relative, partner, friend or neighbour who has a significant personal relationship to the person for whom they provide care. The phenomenon of caring is dynamic and associated responsibilities may increase in level and breadth over time as the care recipient’s needs change (Heger, 2017; CDC, 2019). Equally, the quality of the relationship may transform as dependency rises (Orell et al., 2017).

Family carers often have no specific professional training and are therefore often referred to as informal carers. However, the term ‘informal carer’ is contested, and many would argue

that the caring service provided by family carers is formal in everything but the receipt of pay (Care Alliance Ireland, 2017). Given the amount and technical nature of the care provided by many carers, the term 'unpaid' carer is sometimes more apt (Beesley, 2006). Although informal care is usually unpaid, there is a growing number of paid informal carers who are replacing or complementing informal care provided by family members (UNECE, 2019). In Ireland, the work of carers is estimated to save the state €20 billion per year (FCI, 2020a), while in the United Kingdom, this is estimated to amount to £132 billion per year (Carers, UK, 2019). The economic cost of home-based informal care is greater than formal care and this should not only include replacement care hours but 'opportunity cost' of lost potential carer productivity in the general labour market (Sarris et al., 2020).

Caring is usually described in terms of assisting a care recipient with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs are basic self-care tasks such as dressing, grooming, toileting, and bathing. IADLs on the other hand are more complex organisational skills including managing finances, shopping and meal preparation, house cleaning, and managing medications (Family Caregiver Alliance, 2016). Carers also provide emotional support and help the care recipient cope with their dependency issues, for example, in relation to diagnosis and coping with a chronic condition (CDC, 2019). While the caring role is associated with certain benefits such as emotional rewards, personal growth, and a sense of accomplishment (CDC, 2019; Pysklywec et al., 2020), carers may also face many challenges masked by hidden costs (UNECE, 2019; AARP, 2021). Thus, caring is a multi-dimensional phenomenon. Financial difficulties, social isolation, physical, and mental health problems are just some of the issues experienced by many family carers. For those living in remote areas, social isolation can be intensified by physical isolation (Sarris et al., 2020).

The difficulties associated with caring have been significantly compounded by the COVID-19 pandemic. Research published since the global outbreak of COVID-19 has highlighted several challenges faced by carers. Some of these challenges are not new but have been intensified by the pandemic (Care Quality Commission, 2021). Before the COVID-19 pandemic, many family carers were already providing high and unsustainable levels of care (see Central Statistics Office, 2016). Three quarters of carers surveyed by Family Carers Ireland reported that prior to the coronavirus outbreak they had trouble accessing services for the people they care for. Since the pandemic, many carers have experienced the closure of day services, a

reduction or cancellation of homecare services, and the closure of respite services (Family Carers Ireland, 2020b, 2020c).

Estimating the prevalence of family carers is not an easy task. In the scientific and grey literature, there is no agreement on the definition of family carer. Available data is often not based on a uniform reference year nor common data source (Tur-Sinai et al., 2020). Carer-related figures have not yet been synthesised into a single report, nor have they been comprehensively reviewed in a coherent or robust way (Larkin et al., 2019). The World Health Organisation estimate that there are 349 million care-dependent individuals globally. The OECD (2017) reports that about 13% of people over 50 years provide care at least weekly with 60 % being female. The European Social Survey, based on data from 20 countries, showed that on average, one in three adults (34.3%) between 25 and 75 years provided informal care (Verbakel et al., 2017).

1.3. Family Carers in Ireland

Efforts to quantify the numbers of those providing unpaid care to a relative or friend have been included in the Irish national Census of Population since 2002 (Carers Alliance Ireland, 2019). The most recent Census (2016) has put that number at 195,263 carers. This represented 4.1% of the population, an increase of 31% from the figures reported in the 2002 Census. In 2019, the Central Statistics Office (CSO) published the findings of the Irish Health Survey which included a report entitled 'Carers and Social Supports'. This report provides more recent data and insights on carers in Ireland. According to the Irish Health Survey, 1 in 8 people in Ireland aged over 15 years are family carers. When this finding is extrapolated to the national population, the number of family carers is estimated at over 500,000 (Central Statistics Office, 2020). There are therefore serious discrepancies and inconsistencies between existing national data sources measuring carer prevalence. The wording of survey questions, for example, can lead to significant under-reporting of unpaid care and explains some of the discrepancies in data on carer prevalence (Family Carers Ireland 2021b). The low numbers of family carers enumerated through the census has led *Family Carers Ireland* and others in the sector, to rely predominantly on the CSO's Irish Health Survey as the most reliable source of data on carer prevalence because it uses a more broadly defined approach

to care in its wording. Figure 1 demonstrates the range of age groups who provide care in Ireland, using the Irish Health Survey 2019 data.

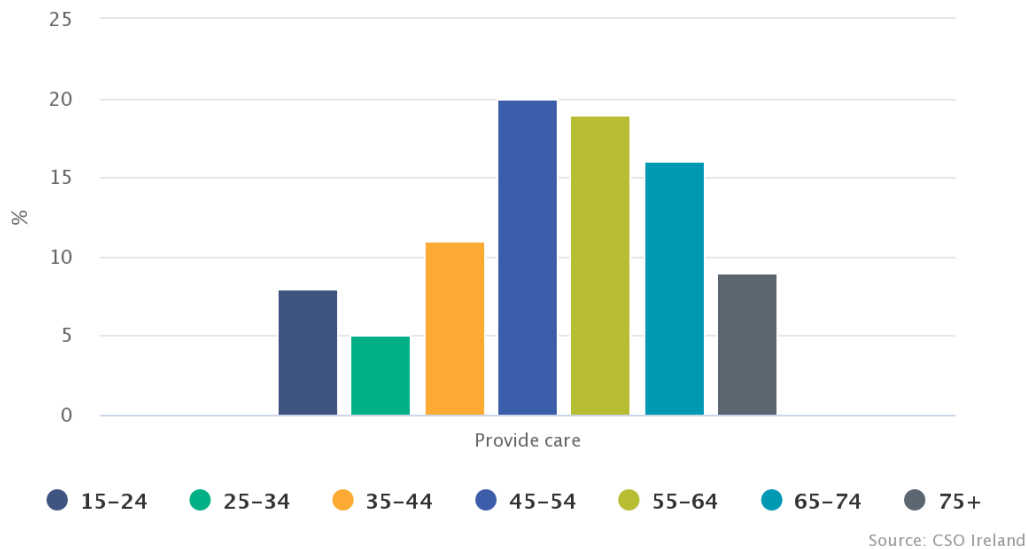
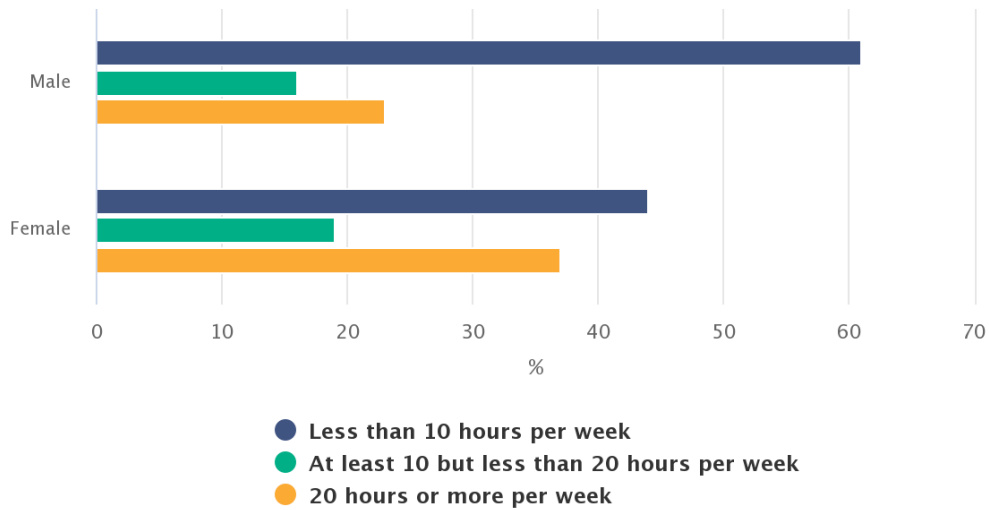


Figure 1.1 Care providers by age-group, 2019 (CSO, 2020)

An analysis of carer age groups (Figure 1) shows that the 45-54 years age group provides more care than another age group. A fifth of the national population of this age group provide care to another person at least once a week. The 25-34 years age group provides the least care, with 5% being identified as carers. For the 75 years and over age group, 9% provide care to another person at least once a week. The survey found that the care provided is mostly to another family member.

According to Census 2016, the carer gender breakdown was reported as 61% female and 39% male, showing no change in the relative number of males and females providing care since the 2002 Census. In terms of hours of care, it is estimated that carers provide 6,608,515 hours of care per week, an average of 38.7 hours per carer per week (Census, 2016). In the Irish Health Survey (CSO, 2020), of those who provide care (aged 15 years and over), 31% provide 20 or more hours of caring per week, with 37% of females providing this level of care compared to 23% of men (Figure 2).



Source: CSO Ireland

Figure 1.2 Care providers by sex and the number of hours they provide care per week (CSO, 2020)

For males who provide care, 61% provide less than 10 hours a week, compared to 44% of females. Over half (51%) of persons aged 75 years and over provide 20 hours or more of caring per week. Younger age groups are more likely to provide fewer hours (Central Statistics Office, 2020).

In October 2020b, Family Carers Ireland published the findings from Ireland’s first national *State of Caring* survey. The survey was completed by 1,250 family carers. Although it is not statistically representative of the wider Irish carer population, it provides a detailed insight into the profile and experiences of a large sample of family carers in Ireland. The *State of Caring* survey found, in terms of hours caring per week, 82% of respondents provided over 90 hours, 73% provided over 120 hours, and 57% provided between 140 and 168 hours per week. The survey also found that 26% of respondents care for more than one person and that 31% of respondents had been a carer for 15 years or more.

Among the key findings in the *State of Caring* (FCI, 2020b) survey were findings related to the financial impact of caring, reconciling caring and paid employment, as well as access to

supports and services. The key findings related to access to supports and services showed that 70% of carers felt they had missed out on support as a result of not getting the right information and advice. Three quarters of carers experienced difficulties accessing services for at least one of the people for whom they provide care. The following section will describe the various experiences of caring and how these impact on many aspects of carers' lives and well-being.

1.4 The Experience of being a family carer

Despite the heterogeneous nature of care recipients and carers, many caring experiences are common (Wang et al., 2020). However, it is important to acknowledge that experiences, coping mechanisms and resilience differ between carers. In addition, experiences can be mediated by the impact of socio-cultural contexts on meanings and perceptions of caring responsibilities and societal expectations. For example, the Chinese Confucian belief of filial piety (“xiao”(孝)) implies a moral obligation to respect and care for ageing parents. Equally, in Hindu religions, dharma implies a social responsibility to others (Banerjee and Dixit, 2012). However, there can be a dilution of traditional perspectives which can be impacted by acculturation of migrants to other countries with differing value systems (Yamaguchi et al., 2016; Qui et al., 2018; Guo et al., 2019). Similarly, in Ireland, a study by O’Riordan et al., (2010) points to caring as a love labour, founded on moral obligation, reciprocity and a sense of responsibility. Equally, Brinda et al. (2014) note the implications of the dependency of the care recipient differs between high income countries and middle and low-income countries. High income countries provide institutional, home care and social care services, while middle and low-income countries have generally less developed formal services, thus, rely more on relatives and community supports for caring activities at home (Brinda et al., 2014). In addition to socio-cultural and geographic location, intensity, timing and length of caring, living with the care recipient and the diversity of families impact the caring experience (Eurocarers, 2017). While caring activities can be shared among families and living with the care recipient is not necessary to be a family carer, Sarris et al. (2020) argues that the willingness to co-habit can mean the responsibility falls with that individual alone. The health status of the care recipient can also impact on decisions about who provides informal care (selection in), while also influencing the ability to continue care or cease care altogether (selection out) (Do et al.,

2015). For example, potential carers may be unable to care due to their own poor health status while those in good health may be expected to care.

Caring for a family member or loved one is associated with several benefits including emotional rewards, personal growth, improved self-worth and a sense of accomplishment (Cruz et al., 2017; Pysklywec et al., 2020). Reasons for engaging in caring include altruistic motivations such as paying back the person for past caring/kindnesses. Other reported positive benefits include closer relationships, a greater appreciation of life and increased empathy with others (Young and Snowden, 2017).

From the formal announcement of a global COVID-29 pandemic (WHO, 2020), non-essential services in most countries were suspended to prevent and control infection. People who were in the older age groups and those deemed medically at risk were advised to shield/cocoon. While many 'lockdown' measures impacted the general population, risk groups were expected to take additional precautions. It has further been reported that the lockdown has accelerated virtual inclusion and enabled a reassessment of priorities for some, but not all, family carers (FCI, 2021b).

Caring is also associated with significant physical and psychological challenges, social isolation, and financial difficulties (AARP Public Policy Institute and National Alliance for Caring, 2015; Carers UK, 2019; Family Carers Ireland et al., 2019). This is sometimes referred to as carer burden. Liu et al. (2020:442) undertook a review of what constitutes carer burden and propose it as a multi-dimensional concept described as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time." The negative responses which stem from carer strain may result in adverse objective and subjective outcomes. This encompasses antecedents (insufficient financial resources, multiple responsibility conflict, lack of social activities), attributes (self-perception, multifaceted strain, over time) and consequences (decreased care provision, decreased quality of life, physical and psychological health deterioration) (Liu et al., 2020). While the use of the word burden is common in the literature, it may position the care recipient in a negative way and can minimise the beneficial reward of being a family carer. Consequently, we will use the term challenges to review the domains of caring responsibly.

Challenges in caring were exacerbated in the COVID-19 pandemic (Maunder and McNicholas, 2021; Stubbs et al., 2021; Edge et al., 2021). In addition to those outlined above, access to care and caring routines such as day-care, social and health care and special needs education were decimated as public health restrictions prevented communal gatherings. Thus, familiar statutory, community and family supports were absent or reduced. One study using data from 26 countries identified that care delivered by carers aged 50 years and older to their parents increased in the pandemic (Bergmann and Wagner, 2021). Another study (Archer et al., 2021) observed that where there were adult carers of a parent, care responsibilities had increased. However, when examining differences between these adult carers, those carers with living siblings experienced less challenges than carers in sandwich generation situations or those giving care only for a parent (Archer et al., 2021). Budnick et al. (2021), in a German study of 1000 caregivers, found that the caring experience deteriorated for almost one third of carers due to the pandemic and that this was most impactful for carers of people living with dementia and those who received formal help. Equally, it was demonstrated that each year the carer aged equated to a slight increase in caring time delivered, although findings do not demonstrate if this is due to carer health decline or the care recipient's increased care needs (Budnick et al., 2021).

1.4.1 Explaining carer stress

Caring can create physical and psychological strain over extended periods of time, similar to the experience of chronic stress (Sit et al., 2020). It is often accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance (Schulz and Sherwood, 2008). Caring fits the formula for chronic stress so well that it is used as the dominant model for studying the health effects of chronic stress (Vitaliano et al., 2003). Chronic stress in caring can lead to burnout and involve emotional exhaustion, depersonalisation of the care recipient and engender a reduced sense of personal achievement (Gérain and Zech, 2019).

According to Lafferty et al. (2021), a number of theories have been used to frame the stress of caring such as work-family conflict theory (Greenhaus and Beutell, 1985), role strain theory (Goode, 1960), role conflict theory (Kahn et al., 1964), and spill over theory (Wilensky, 1960).

The stress process model designed by Pearlin and Colleagues (Pearlin et al., 1990) has been widely used in the study of the impact of caring on carers. This model has been suggested as an appropriate framework to better understand the impact that the current COVID-19 pandemic has had on carers' health and behaviour (Budnick et al., 2021).

The stress process model proposes that there are multiple stressors specifically associated with caring which push a carers' ability to cope or adapt to the limit (Pearlin et al., 1990). The model views stress a dynamic process involving three main components: stressors (primary and secondary), resources, and outcomes. Stressors, according to the model, are influenced by a variety of background and contextual factors and may be primary or secondary in nature. Primary stressors are those emanating directly from the demands of care. Secondary stressors then are indirect consequences of primary stressors. Resources may include social support and the carer's own personal sense of coping resources (e.g. self-efficacy). The stress process model is based on the concept that there are close interrelationships among stressors and resources that contribute to health outcomes. These health outcomes may be detrimental in nature and include physical and mental health consequences (Skaff et al., 1996). Studies which have used the stress process model point to the need for early intervention for carers to avoid poor quality of health such as depression and anxiety (Segrin et al., 2018; Reblin et al., 2018) with hope, sense of achievement and purpose being identified as important mediators for stress (García-Castro et al., 2021).

1.4.2 Physical and mental impacts

In terms of physical and psychological health, the impact of family caring is well established (Schulz and Sherwood, 2008; Aldeman et al., 2014; Roth et al., 2015; Bom et al., 2019). Caring has serious implications for both physical and mental health of carers (Kiecolt-Glaser et al., 2002). In 2019, Family Carers Ireland, in collaboration with the College of Psychiatrists and the UCD School of Nursing, Midwifery and Health Systems, published the findings from the national Family Carer Health Survey. The survey was completed by 1,102 family carers and was a repeat of a similar survey undertaken in 2009. The survey gives an insight into how the health, wellbeing, and burden of carers in Ireland has changed over a ten-year period. Findings demonstrated that family carers were less likely to report themselves as being in good health compared to the general population (64% and 83%, respectively). This figure

represents a 24% increase in carers reporting poorer overall health since 2009. Further comparisons between the findings from the 2009 and 2019 surveys illustrate that the physical and mental health of the carers surveyed has deteriorated in the ten-year period. In 2009, 29% of carers reported poor health. This increased to 36% of respondents in 2019.

In data from the Central Statistics Office (2020), over two thirds of carers reported that they experienced physical ill-health. For instance, in a Family Carers Ireland et al (2019) study, four in ten carers (40%) reported back injuries and two thirds (67%) of these felt their injury was caused or exacerbated by their caring role. This figure is substantially higher than the 18% of the public who report back pain (Central Statistics Office, 2020). Other studies have also noted the physical impact of caring. Caring activities can lead to an increase in pain which impacts carer's ADLs as in many instances, physical effort is needed in the caring role (Do et al., 2015). Research also demonstrates that there may be an increase in alcohol or drug use by carers as a method of coping (de Zwart et al., 2017; Chivukula et al., 2018; Walke et al., 2018). Moreover, in a study on cancer carers, it was suggested that the experienced stress and autonomic imbalance could contribute to health decline through infectious diseases, cardiovascular ill health or even death (Teixeira et al., 2019).

Carers can further report a negative mental health status higher than the prevalence in the general population (CDC, 2019; CSO, 2020). Almost half (48%) of the respondents to the Family Carer Health Survey reported being diagnosed with depression and/or anxiety. Two thirds of respondents indicated that their mental ill-health was caused or exacerbated by their caring role. This finding is substantially higher than 12% of the general population who report mild to moderate depression (Central Statistics Office, 2020). Family Carers Ireland et al. (2019) also found that the number of surveyed carers diagnosed with depression has increased from 20% in 2009 to 35% in 2019. In addition, the prevalence of anxiety amongst these family carers had increased from 31% to 39% (Family Carers Ireland et al., 2019).

The type of caregiver can also impact on issues related to stress. For example, in a review of issues in caring for people with intellectual disabilities and their ageing family carers, Ryan et al. (2014) identified that family carers, who were predominantly mothers, were likely to experience health problems related to their own ageing experience and be concerned about the future planning for their child. In addition, it is suggested that spouses of people living with dementia have to reposition themselves in their relationship (O'Shaughnessy et al.,

2010), while the amount and intensity of care delivery, support received, level of restrictions on social life and negative psychological impact can differ from non-spousal carers (Johansson et al., 2021).

Some studies have pointed to the stress related to witnessing the decline of a loved one, anticipatory grief and bereavement (including complicated grief) after the care recipient's death (Bobinac et al., 2010; Hamilton, 2016). Caregiver stress may be particularly high in the context of caring for an individual with mental health difficulties (Walke et al., 2018) while some studies have pointed to a higher stress level in carers who care for people living with dementia particularly as responsive behaviours can impact both the relationship between the carer and the care recipient as well as create challenges in delivering care (Cheng, 2017). Stress can also be compounded by trying to negotiate various interfaces with formal healthcare services, such as out-patients' appointments, treatment visits or accessing appropriate services (Witham et al., 2018).

Prolonged isolation is a known risk factor for premature morbidity and mortality and can profoundly affect one's mood and mental health (Cacioppo and Hawkley, 2003) and increase stress levels (AARP, 2021a). The COVID-19 pandemic has necessitated quarantine and stay-at-home orders in an effort to curb the spread of infection. Carers have thus been required to spend more time than usual at home, in some cases working and supervising home schooling. The restrictions were seen to render carers forgotten (FCI, 2022). This has also removed them from other more pleasurable and mood elevating experiences. These requirements have contributed to stress amongst parents and are likely to be intensified when a parent is also required to assume an increasing volume of time caring without services' support (Maunder and McNicholas, 2021). Equally, homecare services have also been impacted. As highlighted previously, carers, such as those caring for people living with dementia, may have lost professional help care hours and this has created a higher risk of burnout and depression (Budnick et al., 2021). Bergmann and Wagner's (2021) study also points to significantly more mental strain in adult carers of their parents during the pandemic which concurs with findings from the CDC in the United States (Czeisler et al., 2021).

In their review, Maunder and McNicholas (2021) explore the negative impact of caring amongst carers of a child or adolescent with an eating disorder during COVID-19. Among their findings are factors specific to the social impact of the pandemic on carers such as reduced

access to support services, and social isolation (decreased social support). The authors suggest that prior to the COVID-19 pandemic, carers may have relied on friends or external family members as a source of psychosocial support. Loss of employment, or a decision to work from home, given their child's physical vulnerability, may further reduce the amount of contact carers have with others outside the home. Carers may then feel imprisoned and isolated within their home trying to balance the needs of their family, while their usual outlets to manage stress and psychosocial support have been curtailed due to the pandemic.

Fear of decline in the care recipient's health and wellbeing or of catching COVID-19 and not being able to provide care was an issue for Irish carers (FCI, 2020b). In addition, Family Carers Ireland (2021) report that carers fear attending hospital during the pandemic as it may lead to catching COVID-19 and there could be pressure from medical staff to attend. Even in the event of bringing the care recipient to hospital, they could be refused permission to remain or visit with the care recipient, even if the person was frail. Research undertaken by the Alzheimer's Society of Ireland (ASI) (2021a) explores the impact of the COVID-19 pandemic on people with dementia and their carers. The ASI (2021a:43) found that the pandemic has led to a "significant and largely irreversible deterioration in people living with dementia." The survey found that 40% of family carers reported a decline in their physical health, while 54% reported a decline in their mental health due to the impact of the COVID-19 pandemic. The report also found that people with dementia and their carers continue to experience pervasive loneliness and social isolation both parties cited loneliness as one of their greatest challenges of the COVID-19 pandemic. Equally as study by West et al. (2021) has pointed to fear and anxiety as overarching experiences in both people living with dementia and their carers during the pandemic.

1.4.3 Social and financial impacts

Assuming a carer role means a transformation of familiar life activities to a focus on caring for another person (Committee on Family Caring for Older Adults, 2016). This can result in a changed relationship with the care recipient and deviations in social activities. Limited social interaction may be due to reduced time to physically engage with friends and acquaintances as well as reduced personal time. Carer UK (nd) identified that the changes in relationships due to caring can lead to social isolation with the experience of being disconnected from

family and friends as well as a dissatisfaction with limitations in leisure time (Hajek and König, 2019). In addition, loneliness is common for caregivers (Victor et al., 2021) and contributes to poor mental and physical well-being as indicated in the previous section, mostly at the beginning of the caring role (Gray et al., 2020). Issues related to social exclusion are particularly associated with caring for people living with dementia or those with mental health problems as stigma and social isolation can be common experiences (Greenwood et al., 2017; Bramboeck et al., 2020). Carers of people with mental health challenges may have multiple dimensions of exclusion due to coping with the taboo of mental health, isolation, lower levels of hope, reduced networks, restricted time availability, or time to engage in work, college or training (Gray et al., 2010; Stanely and Balakrishnan, 2021; Paradis-Gagné et al., 2020). In Ireland, caring in lockdown also increased concerns about becoming socially isolated with concern about home care service staff carrying COVID-19 leading to 14% of carers cancelling supports (FCI, 2020c). Thus, mainlining connections is central to positive carer health, with activities such as phone calls, virtual platforms and attending dementia cafes identified as useful supports (Greenwood et al., 2017; Han et al., 2020).

A study conducted by Tuijt et al. (2021) explored the experiences of lockdown and social restrictions from the perspective of people living with dementia and their family carers living in England. A thematic analysis was conducted from qualitative data from 31 carers and 30 people living with dementia. Much of the study's findings refer to the impact of the pandemic and the restrictions that were subsequently imposed on the care recipients. In particular, difficulties with understanding the implications of restrictions, changes to living arrangements, increased cognitive and psychological difficulties, and a lack of social engagement. However, the authors also refer to the stress and frustration cited by the carers. For example, some carers highlighted how people living with dementia struggled to understand the restrictions and their reasons for them, notably during the height of the lockdown when people were only allowed outside their home for a limited amount of time. These carers felt frustration at having to continuously respond to the person living with dementia by explaining the lockdown restrictions or reminding them about the current pandemic. The study highlights that supporting carers of people living with dementia requires particular attention for those who have experienced fluctuations to their caring role, due, for example, to changes in living situations as well as social restrictions affecting carer roles

within a larger family. The authors also recommend further research to explore in greater depth the impact of the COVID-19 pandemic on carers specifically. Similar findings were found in carers of people with intellectual disability as care recipients found it difficult to understand care restrictions (Doody and Keenan, 2021).

For many families, taking on caring responsibilities results in long-term financial hardship. Gardiner et al. (2020) categorises carer financial costs into three areas namely work-related costs (change of employment/withdrawal from employment), carer time costs (time for caring) and out-of-pocket costs associated with caring. Carers have a lower-than-average rate of employment and have lower than average gross incomes (Sarris et al., 2020). This may be due to giving up employment to provide caring or having out of pocket expenses due to meeting the needs of both their care recipient and their own health needs (Do et al., 2015; FCI, 2020b). The American Association of Retired Pensioners (2021b) estimates that 78% of carers have out of pocket expenses due to caring, with an average expenditure of \$7,242, and constituting approximately 26% of their income. Expenses are due to home modifications, medical bills, equipment and general care related costs (AARP, 2021b). In a study of carers of people with cancer, de Moor et al. (2017) identified that many carers make changes in their employment patterns or suspend employment to provide care. Family Carers Ireland (2020b) state that, in the context of the financial impact of caring, 70% of carers surveyed reported struggling to make ends meet. Over one fifth (21%) reported having to cut back on essentials such as groceries and heating. Many respondents reported having incurred debt, while one third have used all or most of their savings. In terms of reconciling caring and paid employment, it was found that 75% of carers who juggle caring with full-time employment provide over 50 hours of care per week (FCI, 2020b). Caring in lockdown also caused financial concern with 39% of carers in a FCI (2020c) worried about costs related to pandemic.

Studies have also pointed to both direct and indirect costs due to having to take a loan out, medication costs, travel time, waiting time, and having to take time off work (Addo et al., 2013; Addo et al., 2018). In a 2012, Eurobarometer, financial remuneration was ranked by carers as the highest support need. Yet, the financial burden may be disproportionate between carers. For example, Gardiner et al. (2020) argues that carers of people with palliative care needs can experience inequity based on issues such as access to specialist care, socio-economic status and gender. Moreover, carers in rural areas have more financial

barriers (low-income level or not able to access healthcare when needed due to cost) (Bouldin et al., 2018) and in COVID-19, heighten the risk of mental health difficulties (Carers Alliance Ireland, 2020). Ethnicity has also been shown to influence fiscal outlay related to caring in the US (AARP, 2021b). This is supported by research from Smith et al. (2019), who identified geographical patterns of inequity in service supply. It is also noted that there is a health systems financial price related to managing any health deterioration of carers, loss to the labour market and an increased risk of social exclusion and loneliness (UNECE, 2019).

The impact of the pandemic on carer employment and carer experiences has also been identified. In their open letter, Phillips et al., (2020) describe how, in response to the COVID-19 pandemic, the worlds of both employment and caring have been dramatically altered. In Ireland, 57% of carers are in the paid labour force (FCI, 2020b). The challenge of managing the responsibilities of care provision and paid employment has been greatly exacerbated by school and creche closures and the suspension of respite services and home care. This challenge may be made harder for some because of significant loss of income for some family carers. Carers who are employers or business owners may find their multiple roles incompatible at this time or experience increased stress and uncertainty (Phillips et al., 2020).

In a recent study, Lafferty et al. (2021) examined the impact of the COVID-19 pandemic on family carers on their employment and caring responsibilities. The study found that the boundaries between work and caring became increasingly blurred, presenting challenges for family carers. The authors also found that attempting to reconcile work and care with depleted coping resources generated considerable stress for family carers. Another study by the American Association of Retired Persons (2021a) demonstrated that 75% of carers are concerned about balancing work and juggling carer responsibilities as more employment settings are reopening.

1.5 Gender

The context of informal caring was relatively invisible up until the 1970s. However, a growing feminist and economic lens pointed to the fact women were providing unpaid work which included caring (Yeandle et al., 2017). Caregiver research literature has consistently found that the majority of family carers are women (Pinquart and Sörensen, 2006; Penning and Wu,

2016; Swinkels et al., 2017). According to the National Institute on Aging (2016), upwards of 75% of all carers in the United States are female and they may spend as much as 50% more time providing care than males. On average, across Organisation for Economic Co-operation and Development (OECD) countries, 60% of those providing daily informal care are women (OECD, 2017). This figure is consistent with carer data in Ireland, with 60.5% of carers being female (Central Statistics Office, 2017). Of the total number of care hours provided, women provide almost two thirds (65.9%).

According to Swinkels et al. (2017), explanations of gender differences related to the negative impact of caring may follow two lines of reasoning. The first is down to the unequal distribution of opportunities and responsibilities that may push women into carer roles more often than men. This is contingent on the argument that women and men live on different structural contexts and the unequal distributions of rewards, privileges, opportunities, and responsibilities exposes individuals to different kinds and intensities of stressors (Pearlin et al., 1990). The fact that women provide more care hours than men may explain the greater negative impact. The second line of reasoning pivots on the argument that women and men experience caring differently (Calasanti, 2010; Mc Donnell and Ryan, 2013), even if the conditions are similar (Hong and Coogle, 2016). This line of reasoning is based on the masculinity theory of Calasanti (2010) and suggests that women may feel more responsible and obliged to care and men are more likely to step away from the care work due to gender roles. Because of this, the conditions of caregiver burden (e.g. intensity of caring) may play out differently for women and men.

There is also a specific body of literature addressing male caring, which is an increasing focus of research agendas. For example, in their review Mott et al. (2019) explore the literature to define characteristics of male carers. The authors found the most common trait of male carers was that they bring a unique set of masculine behaviours to the care they provide. Male carers demonstrate caring by highlighting the practical tasks they perform, the technical skills they possess, and their ability to take control of the situation. Other studies have emphasised the need to have a nuanced approach in supporting carers which includes a gender lens. However, careful assessment of support needs is required on a case-by-case basis; for example, in one study, network size was seen to be increased for male carers and issues such as traditional gender roles were played out (i.e., women not needing as much practical

support) (Zwar et al., 2020). Yet, other research has suggested that men may become more socially isolated and reluctant to seek help when undertaking caring roles (Fee et al., 2020).

1.6 Supports for carers

Assuming a carer role can transform people's lives in many domains. It is therefore recognised that carers require a great amount of support in a myriad of areas as studies have demonstrated that supportive strategies can mitigate against the challenges of caring. For example, mobilising one's own internal resources (i.e. optimism) and coping strategies can limit the impact of depression, anxiety and stress (Sit et al., 2020). This is linked to an individual's resilience which translates to overcoming adversity and recovering and growing from such adversities (Zhou et al., 2020; Palacio et al., 2020). Consequently, helping mechanisms can include support groups and counselling, and carers may draw on spirituality for strength and build on previous coping ability (Walke et al., 2018). In addition to increasing the resilience of carers, Bom et al. (2019), in a systematic review, also pointed to supports which reduce the amount of care to be provided by the carer. Thus, having a system of care that fosters family mutuality in caring is important while access to community and statutory supports is key. This includes creating a health and social care system that is responsive to individual need, employing the concept of person-centredness not only in relation to the care recipient but to the carer also.

Carers are recognised as a major societal asset, however, as illustrated earlier, there are issues related to definition, recognition and caring for carers. Moreover, it is recognised that there is a need for caring interventions to map to individual need (Bom et al., 2019). In this context, there have been calls for a system realignment with the recognition and integration of carers as key stakeholders being fundamental in supporting the role. Recommendations point to the imperative of enabling:

- a clear definition of informal care and informal carers at a national level,
- raised awareness regarding challenges of informal long-term care and the need to maintain carers' health and wellbeing,
- public awareness of the responsibilities of and available support in caring,
- a requirement to assess carers' needs and have a spectrum of supports which give options for alternative care provision. This includes community-based support services (home care, day care, respite),

- a recognition of carers as equal stakeholders with input into decision making in care delivery as co-clients,
- that administrative processes are user friendly and improve access to services and benefits
- an improvement in access to information on supports related to services, own health and welfare (psychological, financial social and physical),
- a robust health care and social protection system to support carers,
- professionals focus on a perspective of carers as co-producers of care while concurrently being a co-client (i.e. being responsive to the carer's health and wellbeing needs),
- an assessment of the efficacy of current programmes of carer support and revise according to identified need, ensuring access to programmes is available when required,
- a system level evaluation of the gap between carer and care recipient demands and service supply and development of strategies to meet need,
- input of carers into design delivery and evaluation of policies about health, social care, long term care and disability and
- support for the voice of carers as a collective, for example, through carer representative organisations.

(Eurocarers, 2018; CDC, 2019; UNECE 2019).

The deficits in supports for carers have also been subject to debate in the Oireachtas. In 2020, a private members motion, entitled *Caring for Carers* highlighted shortfalls. These include income support in line with inflation, eligibility for the Carer's Benefit and Carer's Allowance, increasing the Annual Carer's Support Grant, free General Practitioner care, counselling support, updating the National Carer's Strategy as well as prioritising carers in pandemic times (Cullinane, 2021). Following the budget of 2021, a commitment was made to increase supports for home care with 5 million hours of home care announced, while the Annual Carer's Support Grant increased by €150 to €1850 alongside an increase in the dependent tax credit to €245 (Alzheimer Society of Ireland, 2021b). However, whilst Family Carers Ireland (2022) welcomed the social welfare measures announced in Budget 2022, saying they are a significant step in the right direction, the organisation warns that a lot more work needs to be done to recognise and support family carers across all Government sectors. The 'Family Carer Scorecard' reviews the Government's progress in implementing the commitments made to family carers contained in the 2020 Programme for Government (FCI, 2022). The scorecard shows that progress on the Government's commitments is slow, with the situation of family carers getting worse in relation to some key commitments, such as the provision of

additional residential places and respite nights for people with a disability and the delivery of an updated National Carer's Strategy.

1.7 Summary

- While there is no single universal definition of caring and indeed controversy about what the most acceptable term for the concept should be, the centrality of the caring role, its place within society and the magnitude of the contribution of carers are clear.
- Further, the evidence on caring identifies the multi-dimensional nature of the phenomenon of caring as a lived experience and the reach of its impacts in terms of its positives and challenges.
- As overviewed in this chapter, such challenges can involve physical and mental health consequences, as well as social and financial impacts.
- With the unfolding of the COVID-19 pandemic, international evidence suggests that there have been particular and, in some cases, significant impacts on caring arrangements for those in receipt of and providing care at home in the community.
- Therefore, the purpose of this study was to explore carer experiences of providing care in the COVID-19 pandemic to understand the lived experience of the phenomenon in an Irish context.
- Having presented an overview of the landscape of caring in the current chapter, the chapters following this one will overview the methodology used to implement the study (Chapter 2), present the study findings (Chapter 3) and conclude the report and outline the resultant recommendations (Chapter 4).

Chapter 2 Methodology

2.1 Introduction

This research study involved an in-depth exploration of Irish carers' experiences of providing care in the context of the COVID-19 pandemic to provide important insights into the realities experienced by participants. This chapter will provide an overview of the research methodology employed to underpin the conduct of the study.

2.2 Research aim

The aim of the study was to explore carer experiences of providing care in the COVID-19 pandemic.

2.3 Research methodology

A qualitative research methodology using adapted photovoice methods was used in the conduct of the study. A qualitative research approach was deemed most suitable to achieve the aim of the study as it facilitates exploration of the experience of people and their social worlds by seeking participants' understanding "of their own and others behaviour and its social context" (Richards 2021, p.2).

2.4 Inclusion criteria

The following inclusion criteria were used to facilitate carer participant recruitment:

- Adults over 18 years
- Family Carers Ireland (FCI) members
- Those who had registered their interest in taking part in research with FCI

Those who did not have functional decision-making capacity were not eligible to participate in the study.

The following criteria were used to facilitate care recipient recruitment where relevant:

- Be a care recipient
- Consent to the inclusion (unless a child with an Intellectual Disability or a child under 12 years where parental/guardian consent was needed)
- Assent was required for those aged between 12 and 17 years.

Those adults without functional decision-making capacity (e.g. due to dementia or profound Intellectual Disability) and those care recipients who were severely ill were not eligible to participate in the study.

2.5 Sampling

The approach to sampling was both purposive and voluntary so as to ensure that those with knowledge and experience of the research phenomenon and could speak to the research aim were included in the study (Ritchie *et al.* 2014). Family Carers Ireland, as co-applicant in the study, agreed to assist in recruitment via distribution of study information through gatekeepers. As an organisation, FCI have a membership of 7,760 with 5,762 persons interested in being contacted in relation to research. The intent at the outset of the study was to recruit a sample of 20 carers via purposive sampling and self-selection. Invitations to participate were distributed to five potential participants by nine FCI support managers. Potential participants received a letter of invitation, participant information leaflet, guidelines for taking photographs and a copy of the consent form. Invitees were given two weeks to consider the information provided. Following this time-period, invitations continued to be distributed depending on the recruitment numbers at the time. If a potential participant self-selected to consider participation, they contacted the Research Assistant or Principal Investigator on the study who then answered any queries the individual might have had and confirmed whether the person wished to proceed with participation.

At this point also, the photograph guidelines were explained to participants. If a carer wished to include a care recipient's photograph, the guidelines for this process were explained and a care recipient information pack was forwarded to the care recipient participant via the carer who invited the care recipient to participate. After seven days, the research team member from TCD allocated to the participant followed up to discuss the photograph participation with the care recipient. The TCD research team member followed the process for oral

consent/or assent as appropriate. The bespoke documentation in the information packs was developed for each of the target groups identified in table 2.1. For those with cognitive challenges, documentation was broken down and pictures assisted in providing information to support informed consent. Most carers provided four photos which included objects or images that did not identify their care recipient.

Table 2.1: Information packs for carer and carer recipient

Participant	Information pack
<i>Carer</i>	Letter of invitation, participant information sheet, consent form, guidance for photographs Could consent for a child under 12 years or a child under 18 with intellectual disability.
Care recipient	
<i>Adult with decision making capacity challenges (but could demonstrate function decision making)</i>	Letter of invitation, participant information sheet, consent form, guidance on photographs
<i>Adults with Intellectual Disability</i>	Letter of invitation, participant information sheet, consent form, guidance on photographs
<i>Child (12-17 years)</i>	Letter of invitation, participant information sheet, assent form, guidance on photographs

2.6 Data collection

The Principal Investigator, Prof Amanda Phelan allocated participants to one of the three Trinity College Dublin members of the research team. The nominated research team member then supported the participants in the photovoice methods aspect of the study and conducted the semi-structured interview with the participant.

2.6.1 Photovoice methods

Photovoice is an empowering research approach with the aim 1) to enable people to record and reflect their communities' strengths and concerns, 2) to promote critical dialogue and knowledge about important issues based on photographs, and 3) to reach policy makers

(Wang and Burris 1997). Use of photovoice is an approach that supports the enablement of research participants in being active within the research process by exercising choice and control in terms of what they wish to share about their lives and experiences (Levin et al. 2007; Wiersma 2011; Dooley et al. 2020). In the current study, the traditional photovoice methods were adapted to meet the needs of achieving the study aim and with due regard to the impacts of the COVID-19 pandemic on, for example, in-person meetings. To this end, and with due regard to balancing the demands of the study on participants with supporting the opportunity to be in the study, participants were provided with clear guidelines on the nature of photographs to be taken (conceptualised as objects which have meaning) and the parameters for taking photographs and their purpose in the context of the study and potentially dissemination activities (i.e. inclusion of photograph in report, exclusion of intimate photos etc). Each carer was asked to take 4 photographs over a 24-hour period on their smartphone to represent caring in Covid 19. Up to 2 photographic images of the carer and the care recipient could be included, however, explicit consent must have been given by the carer and the care recipient in such cases. For children 12-17 years, assent could be obtained, while for children below 12 years and children with an Intellectual Disability, consent could be by a parent/guardian. Photographs were emailed/What's App'd to the research team member linked to each participant in the study. For carers without access to e-technology, disposable cameras could be provided and returned (via a stamped addressed envelope) to the linked person in the research team, sent for development (via post), scanned with the hard copy photos posted back to the carer. However, this option was not needed as all participant has access to mobile phones or technology which facilitated e-communication of photos. Photographs were given a code linked to the connected interview on receipt and then imported securely into NVIVO (QSR International ©1990-2021) for analysis.

2.6.2 Semi-structured interviews

Following receipt of the photographs, the research team member allocated to conduct the interview with an individual participant reviewed the images for concordance¹ with the guidelines provided and then proceeded to conduct the semi-structured interview with each

¹ Some photos were cropped, blurred or had parts redacted.

carer participant. Semi-structured interviews allow for a depth exploration of the experience of the research phenomenon. A bespoke interview schedule based on a general exploration of the carer's experiences of COVID-19 was devised for the purposes of the study. The interview guide used alongside each participant's photographs enabled a focus on exploring meaning and significance in relation to each participant's experiences. Consistent with the perspective on semi-structured qualitative interviews overviewed by Adhabi and Anozzi (2017), the interview schedule was used in a flexible manner in response to the individual circumstances of each interview and interviewee responses. The approach was apt given the qualitative research methodology employed and supports a view of the researcher(s) as part of the data, given that qualitative data result from interaction between interviewer and interviewee and such data is both "complex and contexted" (Richards 2021: 2). Interviews were recorded with participant consent and matched via codes to each participant's photograph code.

2.7 Data analysis

Interview audio recordings were securely forwarded to a professional transcription service with a confidentiality contract with the School of Nursing and Midwifery. On confirmed return of the interview transcripts to Professor Amanda Phelan, Audiotrans destroyed both audio recordings and transcripts. The interview transcripts were cross checked with the original audio recordings by a TCD member of the research team and allocated a code linked to the connected photographs. The transcript content was then anonymised and any identifiers removed. Checked and cleaned transcripts were then imported into NVIVO 12 (QSR International ©1990-2021) for analysis. Original audio and transcripts were then destroyed.

The reflexive thematic analysis approach of Braun and Clarke (2006; 2018; 2022) was utilised to facilitate data analysis. This research approach is a means to capture patterns across a qualitative data set. Thematic analysis is an inherently flexible analysis approach meaning that it can be used in conjunction with a range of traditional and contemporary data collection methods such as those employed in the current study (Terry et al. 2017). Using Braun and Clarke's (2006; 2021; 2022) approach to reflexive thematic analysis, a theme is understood to relate to a central organising concept that enables the conceptualisation of shared and contrasting meanings rather than descriptive summaries outlining differing perspectives. As

such, this approach to data analysis supports interpretation of the ‘so what’ of the data and the “situated and contextual nature of meaning” (Clarke and Braun, 2018:107). Applied to the current study, the six recursive phases from Braun and Clarke (2006; 2022) overviewed in Table 2.2 were employed in the data analysis process.

Table 2.2: Phases of reflexive thematic analysis (Braun and Clarke, 2022)

Phase number and name:	Focus of analysis in the phase:
Phase 1: Familiarising yourself with the dataset	The focus here is on closeness to and familiarity (immersion) with the data coupled with distance or critical engagement.
Phase 2: Coding	The smallest unit of analysis involving the systematic labelling of data with codes that form the building blocks to develop themes.
Phase 3: Generating initial themes	Involves the initial clustering of codes to form potential or tentative themes that will require further exploration and refinement.
Phase 4: Developing and reviewing themes	Review of the viability of tentative themes via the review of initial clustering and examination of scope for better patterning. Involves movement back and forth between data and analysis.
Phase 5: Refining, defining and naming themes	Onward process of fine tuning of analysis with clear thematic demarcation around centralised concepts and mapping out the structure and flow for write-up.
Phase 6: Writing up	Deep analytic refinement continues in this phase to sharpen detail and flow to produce the formal write-up.

2.8 Ethical considerations

Ethical permission to complete the study was granted by the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin (TCD). The ethics application was also subject to a Data Protection Impact Assessment by the Data Protection Officer in TCD. The processing and storage of data in the study was in line with best practice as required by the General Data Protection Regulations (GDPR) (2018) and the Health Research Regulations

(2018). All data were securely stored in electronic format in the designated research project folder on a secure project server in the School of Nursing and Midwifery. Only TCD members of the research team had access to the data. Following completion of the study, data will be destroyed after 7 years by the Principal Investigator Prof Amanda Phelan. Personal data obtained in the course of the study was the minimum required to conduct the research. Such data related specifically to facilitating contact with the carer participants and any care recipient participants who consented to be in pictures and to recording explicit informed consent to participate. In addition, demographic data relating to the carer participant and care recipients was collected. This was recorded for the purposes of describing the study sample.

In accordance with adherence to ethical standards in research (Nursing and Midwifery Board of Ireland, 2021), the welfare of participants was at all times prioritised over the needs of the study. Family carer participants and care recipients involved in the study did so voluntarily. A copy of the informed consent form and participant information sheet was forwarded to each participant. A seven-day period was then provided to enable potential participants to review the information and make an informed and voluntary decision whether or not to participate. A process approach to ensure ongoing consent was also employed during each interview to assess each participant's willingness to continue as each interview unfolded. In addition, a protocol was agreed within the research team to ensure the welfare of a participant should an individual become upset during an interview. This protocol did not require enactment. However, the participant information leaflets also contained information on relevant support services in the case that a participant wished to avail of such support.

2.9 Trustworthiness

It is important to establish the trustworthiness of research studies in relation to the overall research process and components of the data analysis phase to include the preparation, organisation, and reporting of results (Elo et al. 2014). According to Nowell (2017:1) "to be accepted as trustworthy, qualitative researchers must demonstrate that data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible". The widely used and well-regarded criteria of

credibility, transferability, dependability, confirmability and authenticity outlined by Lincoln and Guba (1986) were used to establish and demonstrate the trustworthiness of the research process employed in this study. For example, a prolonged engagement with the data occurred to ensure research familiarity. As part of this process, each transcript was initially reviewed by one researcher and regular research team meetings and peer debriefing served to support the development of coding followed by the formulation of themes. A constant cross checking of the emergent thematic structure with the participant data also occurred. Themes were therefore reviewed and refined by the research team throughout the process of analysis to ensure that an analytical level of coding was achieved via an iterative process of interpretation and reflection on meanings (Richards 2021; Braun and Clarke 2022). The description of the approach to data collection and analysis provided in sections 2.6 and 2.7 above support the criteria of dependability, confirmability and provide an audit trail of the processes employed.

2.10 Summary

- The aim of the study was to explore carer experiences of providing care in the COVID-19 pandemic.
- A qualitative research methodology using adapted photovoice methods was used to inform the conduct of the study.
- Data collection involved individual semi-structured interviews with participants during which photographs taken by participants were employed to facilitate exploration of experiences.
- Interview data were transcribed and thematically analysed using the methods described by Braun and Clarke (2006; 2021) to produce an interpretation of the research phenomenon.
- Ethical approval and Data Protection Impact Assessment processes were submitted, reviewed and approved in advance of the study fieldwork beginning.
- Ethical elements of good research practice were adhered to during participant recruitment and consent, the collection and confidential storage of data.
- GDPR (2018) and the Health Research Regulations (2018) were adhered to, and the welfare of study participants was at all times prioritised.
- The following chapter will present the study findings.

Chapter 3 Findings

3.1 Introduction

This chapter presents the qualitative thematic findings identified in the current study. As overviewed in Chapter 2, interviews focused on carer experiences of providing care in the COVID-19 pandemic.

3.2 Interview sample overview

Fifteen interviews were undertaken from September 20th 2021 to November 17th 2021. Interviews ranged from 32.28-81.51 minutes in length. Table 3.1 provides a summary of the characteristics of the study sample.

Table 3.1 Summary of participant characteristics

Characteristics	Range
Gender	1 male, 14 females
Carers' age	39-68 years
Length of time caring	4-37 years
Relationship to care recipient	1 son, 14 mothers
Total number of care recipients	19 (12 delivering care to 1 care recipients, 2 delivering care to 2 care recipients, 1 delivering care to 3 care recipients)
Care recipient gender	9 females, 10 Males
Care recipients' age	8.5–82 years
Range of caring reasons	Frailty, genetic disorders, physical disability, intellectual disability, ADHD, dementia, dyspraxia, hip dysplasia, cerebral palsy, mental health issues, Down's Syndrome and developmental disorders, heart condition and diabetes

3.3 Thematic findings

As described in Chapter 2 (section 2.7), a reflexive thematic analysis was conducted to support the interpretation of the data from the qualitative interviews. This resulted in the

identification of three themes which inter-articulate with each other to together encapsulate participants' experiences. The research findings will now be presented with reference to the themes identified, which were:

- Theme 1: The nature of caring
- Theme 2: Navigating the COVID-19 tidal wave(s)
- Theme 3: Reflecting forward

3.3.1 Theme 1: The nature of caring

While the focus of the current study related to participants' experiences during COVID-19, the embedded and encompassing nature of the research phenomenon in the overall context of participants' caring roles was recounted by the majority of participants as a means to contextualise the background to their experiences during the pandemic. As such, participants reported on their experiences of becoming and being a carer and a number of those interviewed referred over and back between pre- and intra-COVID-19 circumstances and activities when discussing the particulars of their pandemic-related caring experiences. All participants provided descriptions of how they came to be carers. The majority of those interviewed were carers for their children, some of whom were adults at the time of the study. Therefore, the majority of participants had been in the caring role for many years as shown in table 3.1 above. For the majority of carers, the realities of becoming a carer unfolded over time from the point of recognition of a potential care-recipient related issue, through diagnosis and beyond and this continuum of caring was frequently portrayed as an involved and time intensive process:

Fast forward a number of years, he was finally diagnosed with [name of condition].
(Participant 12)

From six weeks old we discovered this and from 6 months old then, she [child] was ongoing operations. She's [age] now and she's had multiple operations most of her life. (Participant 15)

Where carers were providing care for multiple care-recipients and/or where care-recipients were living with more than one diagnosis, additional or cumulative caring activities were referred to:

But as the years progressed, he is moderate to severe and relies on us for all his care. He's non-verbal and all his daily tasks will need help and supervision. (Participant 6)

So she would have over..., quite a lot of different conditions (Participant 9)

Participants further highlighted that the nature of caring was dynamic in that it could change in terms of the time involved and/or the nature and intensity of caring activities in response to evolving care-recipient needs:

So I suppose from the outset from his birth there was just a lot more care involved than would be sort of the norm. And I suppose that has continued really quite throughout his life, there hasn't really been a complete let up in the intensity of the care... So it really has compounded, it's almost like he went from intense care to sort of extreme care and yeah, so that's really been it you know for the last twenty years. (Participant 7)

Thus, in recounting experiences of being a carer, participants described the multicomponent nature of the caring role in terms of its rewards and positives, and its component activities, challenges and impacts as will be illustrated in the sub-themes of this theme which are outlined in figure 3.1.

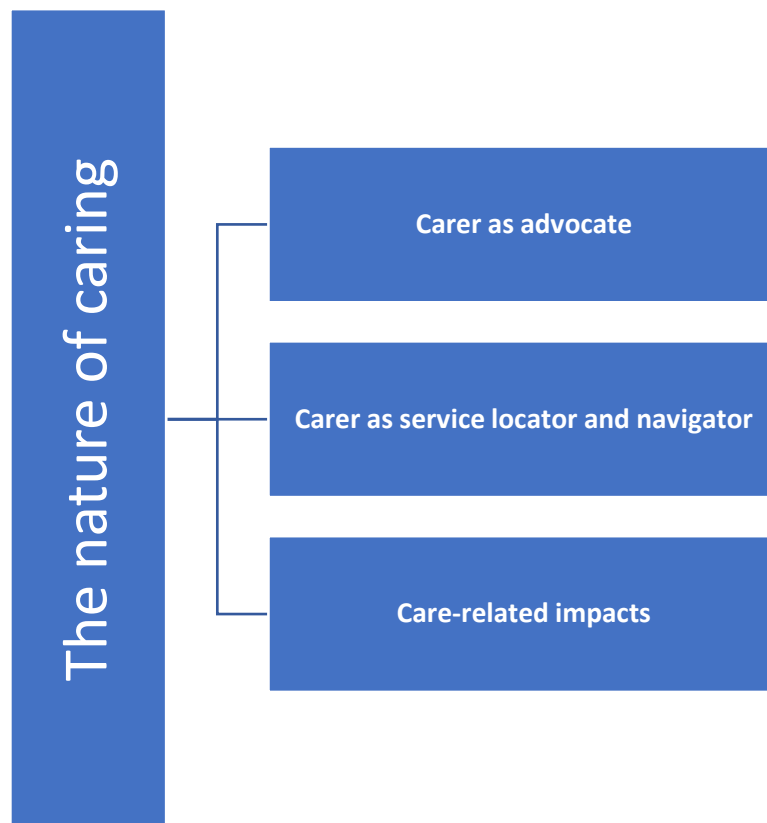


Figure 3.1 Theme 1: The nature of caring

3.3.1.1 Carer as advocate

Advocacy was identified as a key feature of the carer experience with data suggesting that engagement in advocacy was a significant and ongoing aspect of caring. The constancy of advocating did not tend to abate over the course of the caring role and for carers, related activities on behalf of care-recipients frequently involved engagement with multiple services or agencies simultaneously and over time:

I think from the get-go I suppose the big one was sort of constant advocacy and the stress of being your child's advocate all the time. Dealing with basically dealing with services from early intervention, and then trying to get an appropriate school placement... (Participant 1)

I was, you know caring for her and advocating for her on her needs. I suppose the word I would use is advocate. That really you're an advocate for your child. And the fact that [name of daughter]'s condition is so rare means that for me that's probably part of why it's so complicated because she, nobody really knows about her syndrome or her.

So everything that's done is unusual and requires a lot of effort and research and work. And in the end as an advocate and most people find this, they become the carer and advocate for your child, that you're almost the expert on the child. (Participant 9)

The data suggested that the advocacy role of carers was a pro-active one involving problem solving, negotiation and a need for staying power in the light of the time it could take to accomplish related activities:

So it took me ten years to get that primary medical certificate. We started when she was five, and the assessment procedure and everything you go through, it's just, there is no need for it. There is absolutely no need for it. (Participant 15)

However, counterbalanced with the role of the carer as advocate was some suggestion of the vulnerability of the carer position when working to advocate on behalf of the care-recipient to access or make a change to a service, as shown here:

...you're too afraid to say in case they take it [service] (Participant 13)

Thus, the responsibility involved in being a carer was identified. The weight of carrying such responsibility was indicated by some as burdensome and something that carers were conscious of even where service provision was in place and working well:

...I think it's the state and very widely speaking about the health service, the social welfare, the education system, everything over burdens somebody like me because the weight of responsibility is all, not all mine but I would feel 2 thirds of it is mine... (Participant 3)

So, it's, it's tough, it's tough to have to make decisions for another person and be responsible for another person when in reality they should be heading off into the world now and making their own life choices. (Participant 11)

3.3.1.2 Carer as service locator and navigator

Inter-articulating with advocacy, the work related to locating and navigating services was referred to by a majority of those interviewed. This was identified as a significant activity and critical to meeting the needs of care-recipients:

I believe in solving problems, I don't believe in kind of just wondering will they go away, I look at all aspects of a problem and that would have been in my training so therefore when I knew he was having problems I was all the time trying to source out information around it and, you know, making appointments to go places and you're continuously searching and definitely you would not be told. (Participant 12)

The need for related work was highlighted by a number of carers as being linked to the lack of information provision to them such that sourcing and navigating services were for many carer-led in systems that in the beginning at least were unknown and experienced as fragmented by those interviewed:

So my experience overall is that you spend an awful lot of your time just trying to work out how to get the best care in the different health system and education system... (Participant 9)

... you have to go to such and such a place to go for a primary medical cert, then you have to go down to another place to get something else with OT. Then you have to go to... like, there's no just one door that you can knock on and that everything is there at your accessibility. (Participant 15)

The related work was referred to by some participants in terms of being a 'fight' to ensure inclusion for and that the rights of care-recipients would be respected:

everything is a fight, to get equipment, to get services, to get education, to get medication, to see a doctor, to see a specialist, to get physio, to get OT, to see a psychologist, to see a social worker, to see basically anybody, to get any service is a fight, there's nothing just given to you and it's really terrible and the most important help you get is from other parents and the biggest supports are from other parents and the people who tell you what you're entitlements are other parents ... (laughs). (Participant 13)

What I found was a lot of fight on your hands as a carer or a child or as a carer with a person with a disability. I think most carers find that... So yeah, fighting, which I think is terrible but that's what carers do. They fight for the rights of the person they're

caring for, you know, so they can be inclusive of everything, you know so. (Participant 15)

3.3.1.4 Care-related impacts

A number of participants referred to the mixed experience of caring including references to the rewards of caring, which could co-exist alongside the challenges and impacts of caring that will be outlined below. To this end, participants recounted the following:

My overall experience as a care giver – there's some joy there as well, [Name of researcher], you know, there's some good times that we've had. (Participant 10)

And you know just being his carer I find it, I love being his carer. It's great. (Participant 14)

The impact of caring in terms of restrictions to the participant's freedom was frequently referenced in interview. Restrictions to freedom were in turn linked to experiences of isolation and loneliness for some carers. This was identified in two regards, firstly in terms of carer ability to socially connect to others due to caring role commitments:

Up until she was about three, I was very isolated. (Participant 2)

I suppose it's very restricting, you have, you know, I can't come and go as I please, I have to plan everything and ensure that there's always someone here. It can be quite a lonely place to be and, yeah, you know, sometimes you do feel like you're missing out on life. It does have an effect on the whole family really and what we can and can't do. (Participant 11)

Secondly, there was some reference to a melting away of friends due to lack of understanding of the caring role:

And because none of my friends understood what it was like to have a child with special needs or me being a carer, it's just like everybody just kind of disappeared. (Participant 1)

Where loneliness was a reality, participants identified the importance of making connections with understanding others, including support groups and organisations:

I think the loneliness as well actually. You know, you find, now not that it's happened to me but it has happened to other carers that I am familiar with and I do speak with and you know, regularly try and keep in contact with, a support group here in our local area, Family Carers Ireland. Like you know, and you do listen to their stories and that but I think loneliness, it can happen up and down. (Participant 15)

The experience of fatigue was also highlighted by numerous carers a number of whom referred to the associated tiredness and draining nature of caring. Unlike more formal caring service-related roles, participants could not cease caring activities at the end of a working day:

And it's not like, I suppose if I was a support staff or a health care worker, if I was doing the waking nights and then you can go home and you can go to bed. But when you're a family carer, even if you've had no sleep, you still have to function... So you're the whole time pushing, pushing, pushing yourself beyond limits, beyond you know human capacity to be honest or capability. And you know you just keep digging deeper and deeper and deeper and somehow you know thankfully and touch wood I've managed to always find the strength to keep going and the energy to keep going. (Participant 3)

Yeah, (yawns) exhausting, I'm exhausted today because it's full on and it's relentless I suppose... So there is nobody else to stand in for me if something happens to me and it's just a fact, you know, and that's the thing with a lot of families. (Participant 13)

The impacts of the time and the activity intensive nature of caring on the participant's work life was further identified as a significant factor with a number of participants referring to having had to cease working outside of the caring role due to the demands of caring and their wish to ensure they were available to meet care-recipient needs, juggle multiple appointments and so as to support care-recipient and family wellbeing. For some, this was a process that happened over time with a gradual reduction in work life to the eventual point of cessation. Additionally, for some participants, the wish and intent to return to work persisted but this had not yet been possible:

...I never got back to work. (Participant 3)

In the meantime, I had given up full-time [name of profession]. I was doing part-time [name of profession] so that I, and I worked in near the city where I was on call to him because we found that was the best thing, was that if anything was happening, he needed intervention in school, that I was available to come to him. (Participant 12)

Caring pre-pandemic demanded that carers met the wide range of responsibilities and this meant juggling a wide variety of caring related tasks:

Now, when he was not developing in the developmental delay clinics, he was being put forward to psychologists for six or seven years and they were telling me what to do and I was doing it. Going to speech language therapy - you'd get the homework, I was the person doing it. Occupational therapy – I was doing it. Physiotherapy – I was doing it. (Participant 12)

3.3.2 Theme 2: Navigating the COVID-19 tidal wave(s)

As news of a new epidemic, COVID-19 in China reached Ireland, with its subsequent pandemic (WHO 2020), carers braced themselves for the potential impact. Like the effect of a tidal wave, this caused displacement in the daily lives of the carer, the care recipient and families as they sought to compensate for gaps in familiar supportive care services (health, social care and education), ensure protection from infection for the care recipient and develop resilience and coping mechanisms. When public health restrictions were introduced, carers described a multitude of domains which increased their caring responsibilities. Navigating the COVID-19 tidal wave(s) contains the five sub-themes shown in figure 3.2, which chart the experiences and life world of carers through the severest restrictions to the tentative re-emergence to pre-COVID-19 life in late 2021. These experiences could vary within the temporal context of COVID-19's impact. In addition, bereavement was experienced by three carers (two who described losing their care recipient and one a spouse) during COVID-19 and they communicated how that experience was endured both at the time of death and following death. In navigating the pandemic experiences of the carers, we have included two photographs from each participant which are presented either within the context of the findings or in appendix one with a brief description to convey meaning.

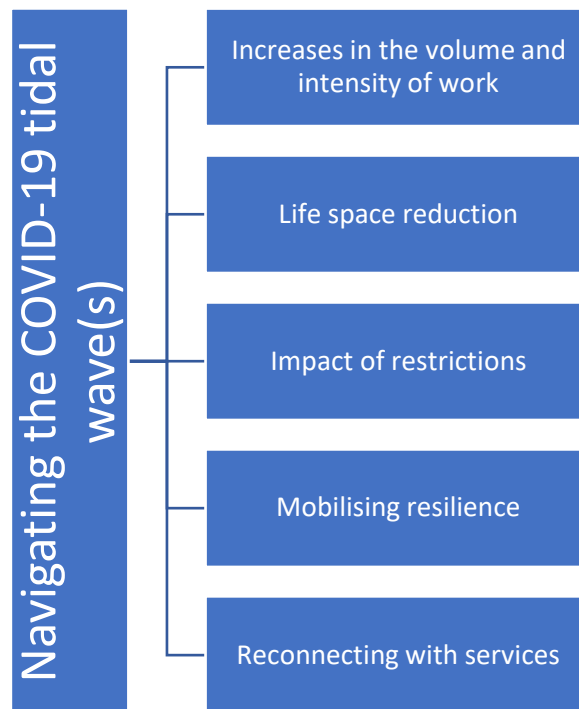


Figure 3.2 Theme 2: Navigating the COVID-19 tidal waves

3.3.2.1 Increased volume and intensity of work

Within society’s orientation to public health restrictions, most carers experienced an abrupt withdrawal of care supports. This translated to assuming a larger volume of caring responsibilities within the spheres of health care, social care and education support. The reality of COVID-19 caring was not without consequences and impacted on the carer, the care recipient and the family. Managing the volume and intensity of this increased work was contrasted to the common rhetoric of unity in response to the pandemic, which belied the experience of carers:

“And it just kind of upsets me a bit when they said oh during COVID that we’re all in this and the line they use, the government used, “oh we’re all in this together”. I felt there was a great disparity in the different groups during COVID, a lot of people really suffered losing jobs, services etc while others’ workloads lessened but still received their full pay and could take time off and enjoy being at home.” (Participant 6)

The reality of COVID-19 was acutely realised as the restrictions were announced:

I remember actually putting away laundry upstairs and having the radio on and the Taoiseach's speech about the schools closing and then just sitting at the bed and just getting very upset and just burst into tears and just very [upset]. (Participant 3)

To this end, carers detailed the sudden removal and the types of supports which were withdrawn or delayed:

Oh it [change in caring] did because it was like everything just stopped. I mean we had just had respite just before the first close down, and we came home, sort of. Nobody thought this was going to be much, and the next thing it was announced that everything was closed, that all her day services, yeah, her day services, her transport, everything stopped and she was left at home. (Participant 4)

But in some areas it's, you know there were a lot of delays, like [name of daughter]'s surgery was delayed and other things like that. And a lot of the appointments were turned into phone calls which really weren't helpful. (Participant 9)

In the main, participants comprehended this as difficult, rendering them effectively isolated. Carers were left to manage the totality of caring responsibilities. For example, the perception of the additional caring described in the excerpt below portrays how lonely the impact of removal of services was experienced:

I'm looking out of my window at that field because again we're in, well that's a wood above us, but when the maze cutters came and they cut all that field one stalk was standing up and every time I looked at that stalk it reminded me more and more of myself. And I resonated with that stalk because it was like everything was normal and everything was manageable up until the time that when COVID came and everything was taken from us and all of a sudden you were totally on your own, looking around, everything gone. Everything that you knew, everything that was, you considered normal, everything that was with you was gone, wiped, gone. And that's what that stalk looks to be, as if it is me. (Participant 12)



Participant 12

For one mother who cared for two children with intellectual disability, the increase in the intensity of work was demonstrated through efforts to try to keep up with allocated schoolwork which was overwhelming and went beyond her skillset:

Yeah, yeah, like I was supposed to be mam and teacher. I'm not a teacher, nor would I want to be either. I wouldn't have the patience for it. But they just uploaded their stuff onto their SeeSaw and go ahead, do it. Nothing was offered, no help, no nothing.

(Participant 2)



Participant 2

Another participant described the detail of physical care which extended over a 24-hour period:

Recently his pads [continence wear] are leaking through so I would say 5 days out of 7 last week I had to strip him during the day and then also strip his whole chair. So that's, it's a big rigmarole, he's got a big power chair and stripping all the covers off that is quite a rigmarole. And then they have to be constantly washed. You only get 2 sets so you constantly have to make sure you've one ready to go. So then in the evening times it would usually be an hour medicines again, he gets his meds in the evening. And getting him ready for bed, [Name] then sleeps with us because he has to be turned, I turn him on a good night about 10 times a night. (Participant 5)

Conversely, a small number of carers reported that services were initiated, out of necessity, or continued in some form due to absolute need:

I threw everything at the HSE before Christmas and I got a reply on Christmas Eve and it did kick in straight after Christmas because the IWA were subcontracted to deliver care. (Participant 1)

I suppose following that crisis [increased agitation], about 2 weeks into the first lockdown in March 2020 [Name A] maintained a little bit of support from there on in now right back in the early days, it might have been, I think it was 6 hours a week, you know that he got out on the bus for 2 hours. Now they didn't even get out of the bus, they just drove him around for 2 hours. (Participant 2)

For some participants, trying to access supports proved impossible and even when some support was given, this could have a minimum impact, or the expected tasks were too overwhelming:

But, yeah, coping was difficult and it was a case of just ringing every professional that we could just asking, please, could you help us, which, you know, yeah, that was, that was really it...Now they rang up every single day but that was the only service and I think we spoke to psychology, I remember we did a Zoom call, I think, once but everything else, everything else that we'd ever accessed was gone. (Participant 11)

That's [Name A]'s runner, my son's runner. Well I suppose, look it [photo] symbolises the hospital visits and [care recipient] and I go, for the amount of work that goes to getting the appointment and it can be weeks and weeks of phone calls and emails to try and secure an appointment and to really try and sell the fact that you really need this appointment. (Participant 3)



Participant 3

Another concern for carers was, in some cases, trying to also ensure other children were supported during the general stress of the pandemic. Here, one mother describes the impact of life during COVID-19 on her other children:

And my 2 other children as well, they had their own problems as well because they actually found it very strange and their stress levels actually were heightened as well because they didn't really know like what was happening. And even though they could understand like what was happening and the news and the radio but they found sometimes it was very overwhelming with all these facts and figures and often they'd say to me like at the start if I was listening to the radio in the morning, just take it off, they've actually found it very overwhelming as well. (Participant 6)

The same carer indicated how she had received respite during the pandemic and explicitly articulated that this was structured to give time to the other family members, to compensate for her additional volume of work during the week with the care recipient:

You know we may get respite on a Saturday for a few hours and I did choose a Saturday because with the other 2 children and my husband, then being off it gives us quality time for ourselves to do something as a family. Because I feel you know all the important and what do you call it, focus can go on the child with the special needs. And then the other siblings are kind of, you know forgotten about. (Participant 6)

Thus, carers who were parents could also reflect on the need to have time for the care recipients' siblings, so this added to their responsibilities:

Because we just needed you know we needed some other space and for our [age] year old daughter you know as well. It wasn't fair on her, you know that he was here because we were all here all the time. She wasn't going to school either. You know, she wasn't doing anything either we were all here. So we really felt that we had to do something so that's what we did. (Participant 14)

...give my other daughters a bit of time as well. So they missed out on time with me, just me doing things for them, they actually had to do things for me. (Participant 5)

There was a temporal aspect to the experience of caring in COVID-19. In the early stages of the first wave of COVID-19, some participants spoke of the novelty of lockdown and how this

eclipsed, temporarily, the full realisation of greater caring responsibilities. Two participants used clocks as symbolic of their experiences. One participant described this using a photo of a clock and articulated how the initial lockdown experience of time moved from a novel period to stressful time:

And I suppose for us as well it's the difference is, it was lovely when lockdown first come and I think we all felt it, that all of a sudden we were kind of free of time, you know, that we didn't have to worry about what the time was 'cause there was nowhere to go, we didn't have to be anywhere at a certain time, you know, you really kind of stopped in the end looking at the clock and I guess the meaning for the clock for me now is I spend my life looking at the clock because it's all based around, you know, I get up in the morning and you're kind of thinking I hope, you know, what time is she gonna get up on the days that she's home, God I hope she has a lie-in, that she doesn't get up too early because some mornings she could be up at the crack of dawn and then you're gonna have a really long day. (Participant 11)



Participant 11

The second used the clock to symbolise getting through the day. Each hour reflected an achieved in managing care:

I used to look up and that's the picture of the clock again, if I can get through the next hour we're going to be ok. If I can get everybody through the next hour we're going to be ok, if I can get everybody through the day. It was very hard to think any further than that, you know. (Participant 3)



Participant 3

Another component of the volume and intensity of work related to the constant effort to ensure the care recipient was protected from contracting COVID-19. This encompassed close adherence to the public health guidelines and ensuring that participants, as responsible carers, took personal and family precautions, including shielding. Thus, there was a constant reference to protecting the care recipient and how this added to caring responsibilities:

Well I suppose it [caring] has been more intense because you are here, you are making sure that he's safe. (Participant 8)

I just took a quick snap [photo] of sanitizing equipment and cleaning equipment, gloves and that, [Name of researcher], because it has become stringent in our house, that everyone had to really, you know, mind themselves and be very protected, you know, when they leave the house (Participant 10)



Participant 10

One carer described her increasing concerns as COVID-19 moved from an epidemic to a pandemic. These concerns led to attempts to prepare and ensure a proactive role to protect her care recipients by contacting support services, particularly as it was identified that being admitted to an unfamiliar environment, such as a hospital, could be detrimental:

But even up to a couple of weeks before it came to Ireland, I had emailed the HSE Disability Manager to say how concerned I was and I suppose my concerns were two-fold in that I was concerned obviously of COVID, of this devil at the door getting into the house and us getting sick. The implications say if somebody needed to go to hospital, neither of those boys would be able to manage without me in hospital. (Participant 3)

Often, there was an explicit description of the additional risk for a care recipient:

Yeah so we did, we were really worried because [Name] would have chest problems. And that's why he's peg fed because he used to aspirate. And his lungs weren't great. So yeah that's why we didn't even have family members or anything, anywhere near us. So it was literally just us. (Participant 5)

Yeah, because we knew she was, I mean she was very good in general physically but we knew. I mean like she was very small, we knew it wouldn't take much [if she caught COVID-19], you know that sort of thing. (Participant 4)

Consequently, all carers demonstrated similar awareness of heightened risk, due to age of the care recipient or the care recipients' health. This impacted on decisions to also engage in additional precautions, such as carer shielding, to limit their own exposure to infection which could lead to passing on COVID-19 which could be devastating for the care recipient. Engaging in shielding translated to changing usual familiar daily activities to reduce risk:

We were shielding and thank God it worked out. Like we know we did it, we did it for his [care recipient's] sake and we don't regret it. I'll be straight with you but it was tough. (Participant 8)

Like we avoid going places, [Name of researcher], we avoid being around too many people. We avoid, even when we're shopping, we're online shopping, we're not shopping in shops, do you know. (Participant 10)

Although carers made huge efforts to protect, they recognised unavoidable risks:

And my son [not the care recipient] then who was working in the supermarket, you know, I was still a bit worried about him having to go and face, you know the public and just in case he would bring COVID home. (Participant 6)

Although many services were discontinued during the pandemic, some remained open. However, this could provide a dilemma for the carers in terms of safety considerations. Consequently, some made the difficult choice to withdraw from services such as school and to decline homecare services:

So, if I sent him [care recipient] in [to school], I just feel I'm sending him in to get COVID so like for me the only thing to do is keep him home and, experience I suppose, because like for the first year I didn't get nurses at all because I didn't want any nurses in the house because I was too afraid. (Participant 13)

I myself took the decision to stop that [a service] for a while. Just to not have people coming into the house. So I would have, I think it would be fair to say that actually those services were still available to us and there was a period of time when we just made the choice to not have them if that makes sense to you. (Participant 7)

Even if services were available, the environment changed to reduce risk as far as possible:

And then we had meetings about risk assessment [to attend day centres] and will we have paper plates and plastic utensils. (Participant 1)

3.3.2.2 Life space reduction

Life space reduction relates to both physical space reduction and social space reduction in the context of caring responsibilities. There was a high degree of compliance with public health guidance as carers were very aware of the safety risk for the care recipient(s) if non-compliant. This section considers issues related to the physical and social life space reduction during the pandemic, while safety issues were presented in section 3.3.2.1 above.

Physical space reduction

Physical space reduction was spoken about in the context of the greatly reduced space experienced while being limited to staying within the home and the very difficult challenge in caring in a more confined world. As indicated in section 3.3.2.1, the impact of the restrictions was felt by the carer, the care recipient and their families. Here we observe the practical manifestation of how physical space restrictions were experienced:

So we couldn't move, he [care recipient] couldn't go anywhere. And literally for two months he did not leave this house at all, he didn't go outside the door. And it was just, it was the most challenging time of my entire life. It was so, so difficult. (Participant 14)

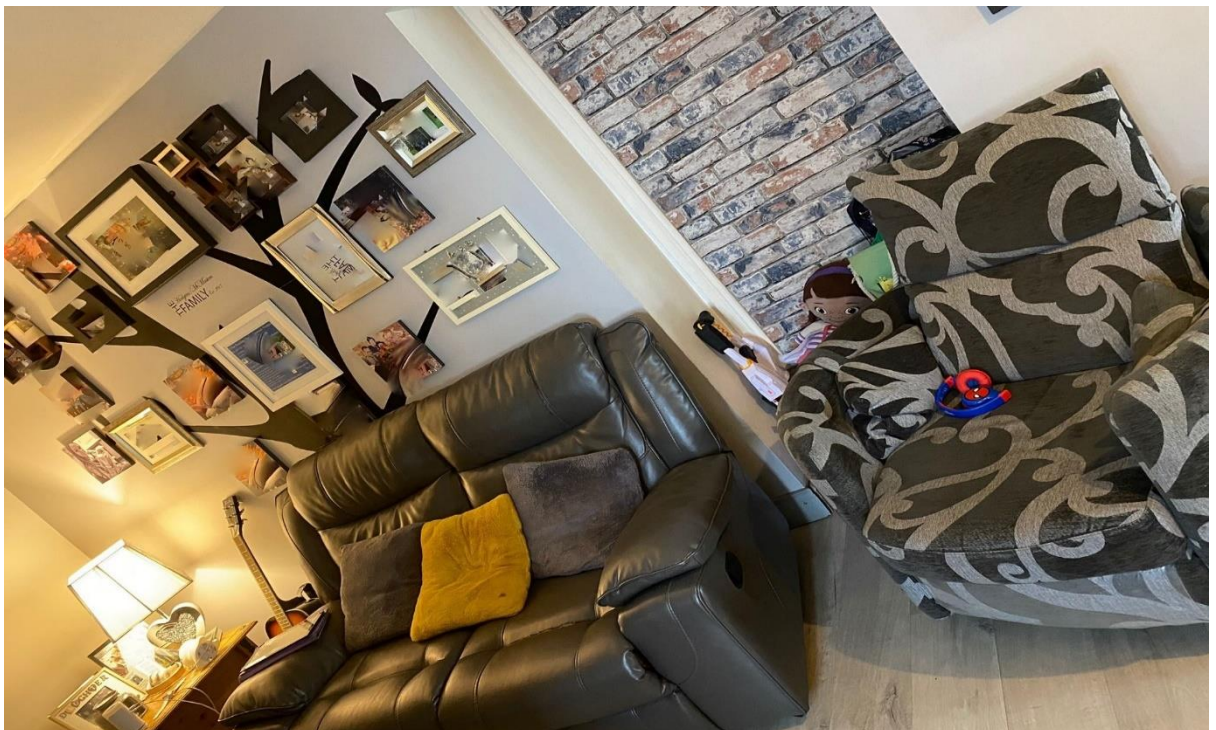
Consequently, the world of the carer and care recipient revolved around the home. The home, for some participants, became a prison and there was no escape. This contrasted with the previous familiar world of relative freedom as opposed to being/feeling trapped, as described below:

And again, you know, when they're [care recipient] not out on those little breaks, [Name of researcher], everyone suffers here in the home, you know, because there's a knock-on effect, they're used to being out, then they're at home, they're kind of, it feels like a prison sometimes, you know, the house. (Participant 10)

Because if you're a single parent of younger children or like me with a child who can't be left on her own, you really are trapped. (Participant 9)

Using a photo to illustrate the difficulties in space, Participant 2 showed how the confines of living space exacerbated stress. This was in the context of a small open plan space, where the carer, a mother, has made huge efforts to support home schooling, but found trying to support two children with intellectual disabilities impossible:

Around the corner is a small kitchen and that's it. So for me, not being able to get out and do anything. And for me and the three kids, because my husband was working, was just, I never experienced anything like that in my life. The kids didn't understand what was going on. That room was just, for the first six months that was where we were. (Participant 2)



Participant 2

One participant described how even the space within the house was limited as it was necessary to sit in with the care recipient for long periods of time:

I mean as I say, it was just there was nothing to do. You didn't feel... well I was depressed, I knew that. So, I think I spent about four of five hours sitting in the chair with [Name] every day. (Participant 4)

Another experience in internal house space limitations pertained to being mindful of other family members working from home. In this context, an additional challenge was not to disturb their work:

People had to stay at home and the changing in the working conditions as I said for everyone in the household such as my husband and my daughter having to work from home in their bedrooms. (Participant 6)

The participants recalled various conscious efforts to mitigate against the confines of the home. Some participants maximised the garden and remained in the proximity of the home:

...you just kind of walk out your garden or walk round the street and come back in again, like you know, for a bit of fresh air and that, you know. So that was mainly it. (Participant 15)

The garden and the green space. Ok I just said, I have little notes here as well, so just having a back garden was a god send to us being stuck at home. (Participant 6)



Participant 6

It was noted that the experience of caring was impacted by the weather as the garden could be used to increase the geographical space for the family. It seemed the good weather enabled relief:

Yeah, it was the only thing that saved us [garden table]. Like if the weather had have been bad like we usually have it, I think I would have went off my rocker. But we were able to have barbecues, they had a ball out the back. Only for it. (Participant 2)

While the COVID-19 restrictions related to the closure of many services and the confinement to home to shield, government restrictions also limited travel within a geographic distance of 2 or 5 kilometres (different limitations at different times). A number of participants acknowledged derogation for some people, including those who had caring responsibilities, which was much appreciated to alleviate the ennui of being confined to the home:

And then you know we would, sorry another strategy was I asked her OT for a letter that if we were stopped by police that we can go for a drive because just to get out of the house was really important. (Participant 9)

Our saviour and one of the pictures I took a picture of was the car. I got a letter from services that deal with [Name of daughter B] and with my other kids and it was to travel, you know, that we could drive. So we were still shielding, we were shielding within our car but we were driving, we could drive down the coast and just look out at the sea and things like that. (Participant 10)



Participant 10

However, it seems knowledge about this was not universal with one participant reflecting on what way this may have helped in being able to move outside, if this access was known:

...but had we known [pass to travel beyond restrictions] that like we could have gone a bit further, gone up the country. Not up the country but sure to another area in [county], where the shops were open we could have got his ice cream and that.
(Participant 8)

Many participants described their car as a method of relief as this afforded a method of getting out of the house but not increasing risk of exposure:

I was able to even just take the kids, put them in and go for a spin for different scenery. And if we found, like if we found a beach or a park when there was nobody in it, I let them out, yeah. (Participant 2)

Car a lifeline (P10)

The national travel restrictions also impacted on one participant's potential receipt of help as they tried to avoid any difficulties with gardai if stopped outside the permitted travel kilometre range:

...my [family member] came down to me after a month and like he rang the police in [name of place] and said "look I'm going up to my [carer], I'm doing the shopping and I'm going to the chemist for her" and the guy said to him "oh well if you get stopped it's on your own head". Like my [family member] said to him she's a single parent and she's a carer and she's totally on her own, so you know. (Participant 9)

Engaging in safe outdoor pursuits was identified by several participants as being a way to relieve the pressure of the physical space limitations of the home:

...the only thing we really do is go for a walk on the canal, now I live near the canals but I'm in the country so I have to go down a country road so, you know, like it has to be obviously during daytime. (Participant 13)

So around here there's a lot of playgrounds, they're not suitable for [Name] so why I kind of chose this picture is because this playground, it's not one that's suitable for [Name] but my daughter said we can fit him on this, it's like a trampoline but it's in the ground and the kids jump on it. And she said mam I'll put him on that and bounce him up and down. So it's just little things that he absolutely loves that. So he likes to go there just to do this, we put his chair on it and she bounces him up and down. (Participant 5)

Social space reduction

In tandem with, but closely aligned to, physical space confines, there were limitations in relation to the social space of the carers and care recipients. Many pleasurable social activities ceased. For example, the participants below identified the lack of ability to attend the cinema, go to dinner or catch up with friends:

But, yeah, basically I have no outlet now at all and of course because of the pandemic it means I can't even go out at night (laughs) whereas before I'd go out for dinner or to the cinema with my partner. (Participant 13)

...sometimes I used to meet them [friends] for a coffee but sure all that was gone and we were so wrecked by come evening, a lot of it like we used to ring each other. But we were so tired and then we felt like, you know we were so overburdened, I don't think we wanted to be listening to their stories as well because we were so overburdened. I felt there was kind of a loss of contact between us. (Participant 6)

Social space was also impacted by the disruption to visitors coming into the home:

You are not going out, not getting out of the house. You are not getting an outlet. You are here sitting in the back garden or sitting at the kitchen table or doing the work, keeping the house warm, you know that was difficult all right. There was no one coming in, the gate was closed. (laughing) the doors were closed unfortunately you know. (Participant 8)

Yeah, it was, it's been very difficult, you know, the not being able to visit people I think has been a huge problem area and people not being allowed to visit us would have really affected, affected things. (Participant 11)

The dual impact of having to safeguard and manage in COVID-19 was considered a challenge, but this was also aggravated by limitations in family connectivity:

Also, then what, I suppose, one of my sisters said afterwards that, it was something that I kind of hadn't clicked into, but when she went "not alone did COVID come but he lost all the links with all the family members". (Participant 12)

There were also references to the impacts on the social space of care recipients specifically. For example, one participant described how her son attempted to compensate for his lack of social activities as he tried to make that connection virtually via his iPad or call a familiar friend' name from the education support service:

There was a lot more interaction with other classes and other children [pre-COVID] and he actually misses that because he can see, sometimes he might say someone's name or he might go on to his iPad and look for that child. (Participant 6)

3.3.2.3 Impact of restrictions on the carers' world

The impact of restrictions on support services could be considered in three ways: impact on the carer, impact on the care recipient and impact on family life. The additional caring responsibilities took a toll on the psychological health of carers. The removal of supports was spoken of as leading to burnout and experienced as traumatic:

...you just go into a survival mode, you just kind of, if we had known what had been coming, I feel like the anxiety levels would have been much higher because we wouldn't have known how we would have coped. But because we were thrown into it and we had to face it head on, we actually did but I feel like then there might be an aftermath, you know because the trauma, you know that kind of comes maybe after you realise like what you've been through. (Participant 6)

And that fear then, because I was so drained which I didn't realize, I'm only learning about it now really, well like, you know, you know it but you haven't time to give in to it, that's basically it, you just don't listen to your body, you don't listen to the flag signs, you just say, no, no, I have to keep going, keep going. And then I started to kind of, about six months into it I started to get panic attacks, depression, scared out of my life. I think kind of before that I was having little bits of them but I suppose I acknowledged them, would be the way to put it. (Participant 12)

This also manifested to a sense of some carers wanting to escape the huge toils demanded of them. The participant below expresses this as coming to a point where even trying to articulate their reality became difficult. This carer also, reflecting on the experience of her caring in COVID-19, considered this so overwhelming that she felt that the stress of contracting the infection would have a less impact than the continued additional responsibilities she had assumed during the pandemic:

I was literally on the phone daily [to support services], you know, and some days I would just, I couldn't even, I'd ring people and I couldn't even speak to them because I couldn't stop crying, you know, and you were kind of saying "I'm on my knees, like the next time I get in the car I'm taking her to hospital and I'm leaving her there because I'm done, I can't do it anymore" (Participant 11)

You know, because in the end for me, I would take the risk of COVID rather than live like this because COVID was, you know, nothing compared to what we've gone through, the mental health that's been affected by it far outweighs what COVID could have done, in my mind anyway, yeah. (Participant 11)

Not only did the volume and intensity of work impact on the carer's psychological health, carers also described physical health deterioration due to the increased work of caring:

Because physically I'm definitely not the same now as I was before the pandemic. I have a lot more aches and pains. I've a lot more, I've back trouble, I have shoulder trouble. And this is all due to the 24/7 care. So the 24/7 care could never be looked at us doing it again, we could never be asked to do 24/7 care again I feel. (Participant 5)

Equally, the care recipient's physical health could be impacted by the cancelling of services:

Yeah the day services were, well you see medical... because my son is medical here [hospital named previously], he was supposed to be seen every five or six weeks in hospital in 2020 and then they just stopped seeing him... (Participant 7)

Or the longer-term impact of COVID-19 was described by one carer:

It is, it's a nebulizer and the bag of medicine represents what's in there would be [Name of daughter B]'s, between nebulizer tabs, medication that she has to take and this will be for the foreseeable, [Name of researcher], you know, she's on quite a lot of medication, you know, and a lot of that came from within she was in hospital with COVID. (Participant 10)

Carers described how the lack of familiar routines and structure to the day had a range of impacts on the coping mechanisms of the care recipient. This was observed in the behaviours experienced in some cases, which were borne out of frustration due to service withdrawal:

Yeah, her challenging behaviour, that just went from 0 to a hundred. She would hit out, only at me, she would hit out at me, throw herself on the ground, hit her siblings. She just was so frustrated... (Participant 2)

So he just, I got him up one morning and he just became totally and utterly overwhelmed and he just lost control, you know the poor fella. So look it he hurt me,

he hurt himself and [Name B] could hear it going on, [Name B] got really anxious so [Name B] was banging his head off against the wall at the same time. So I was running up and down the stairs, in between the two of them trying to keep them safe. And trying to, you know what I mean. See if we can just get over these waves, you know without anybody getting hurt. But look it eventually [Name A] did calm down, over an hour I'd say and he was complete, I said look it the last thing he'd want to do is hurt anybody, you know what I mean. (Participant 3)

The impact of COVID-19 on the care recipient's mental health was observed by the participants. This included a general decline as well as describing increases in stress and anxiety as well as depression manifesting in the care recipient:

Yeah, no her mental health could have gone down because of the pandemic but her physical health, no, I don't think so. (Participant 4)

Well, her day service closed, so that would have been a huge, a huge part. We then, because she was suffering, she was kind of, you could see the stress and anxiety so we weren't able to access psychology. (Participant 11)

Other impacts on mental health were portrayed as an increase in obsessive compulsive behaviours and was linked to the lack of familiar structure to daily life:

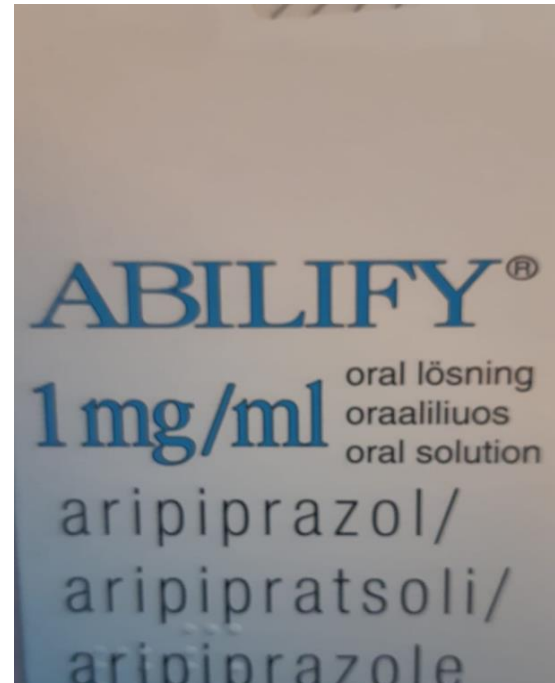
And so you know he wasn't out because at least from the age of four he was going somewhere every day you know what I mean. And suddenly he was at home and definitely I suppose that intensified you know the care giving experience obviously and also he has got quite OCD so there are behaviours. (Participant 7)

For participant 14, lockdown increased anxiety and aggression from the care recipient, an adult child. This led to commencing new medication, which was a last resort, due to side effects:

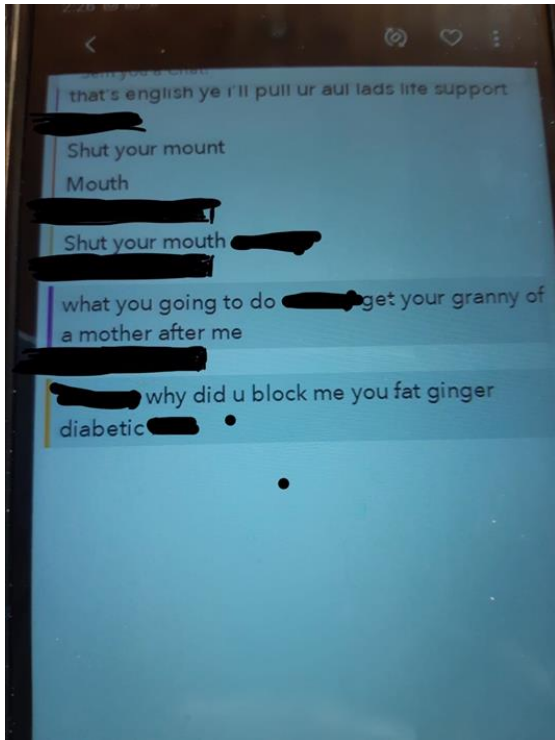
there were other ones [medications] that he kind of had been on before which you know didn't have, were maybe milder but didn't have the weight gain. But I felt that you know these weren't working, once lockdown hit what he was on wasn't working. So I had to ring the psychiatrist and then he said we are going to have to go with this. Then he didn't have a choice. You know because he had been tried on so many of the

other ones and that you know we were actually really in a dangerous situation.
(Participant 14)

Participant 14



Participant 14 also described how the lack of social interaction led to the care recipient's upset at not seeing friends. As a relief, access to online gaming (Playstation) was allowed, however, this had a devastating repercussion as the care recipient was bullied as demonstrated (in one of many incidences) in the photo below:



Participant 14

Trying to negotiate the mental health impacts translated to trying to manage treatment and ensure sleep, be mindful of depression risk and reduce associated agitation. This could mean a remarkable increase in medication as detailed below by one mother:

And was always a little soldier, always got up and kept going and now it was another thing, do you know and I just felt like it all accumulated and just really badly affected his health. And him not having that routine you know was hugely, hugely damaging to his health as well. So now he's gone from 2 medications per day to 14. So look it I suppose he's on medication for depression, he's on medication for sleep, he's on a few medications for sleep. (Participant 3)

The public health restrictions could also mean that the care recipient demonstrated new fears in terms of adhering to the restrictions. As mentioned previously, travel letters were provided to some carers as exceptions to the geographical restrictions. Yet, there could be a fear of breaking the “rules”:

So I guess we spoke about that before and not being able to go anywhere and how the effects that had and then also when we were given the letters to go somewhere that you, that fear was still there, do you know, with the Guards are gonna be on the road

and, you know, gonna be asking us questions so this is all things she [care recipient] would be fearful of, you know, “are we allowed to go?” (P11)

In addition, some carers spoke of impacts on care recipients’ pre-Covid 19 status, as they had observed deterioration or plateauing in their child’s abilities. In the excerpt below, the carer notes that an unintended consequence of the public health restrictions, mask wearing, had impacted on her son’s language skills:

So I feel like, you know because we’ve been wearing them [masks] for months and they’re still wearing them in school like, his language is affected. (Participant 6)

While some carers spoke of how the care recipient adapted well to mask wearing, another mother spoke of the difficulties her son experienced due to sensory-based sensitivities:

He won’t wear a mask and he has lots of sensory issues like he doesn’t like hats, he doesn’t like certain materials. So he actually finds the mask a bit intimidating and he just doesn’t like it. When I actually have to go to the bus now to pick him off the bus, to take him off the bus, the minute he sees me with the mask he tries to pull it off me. (Participant 6)

3.3.2.4 Mobilising resilience

All carers described how they mobilised resilience to cope with the increased caring responsibilities coupled with protecting against COVID-19. It was observed that where professionals and others’ orientation demonstrated a person-centred focus imbued with empathy and engaging in supporting the carer, this provided a key element of coping with the impacts of increased caring:

I think looking back on it, just to know however bad things were, there were still people that felt that humanitarian feeling for you, you know that sort of understood what you went through and wanted to help you. (Participant 4)

From a personal perspective, carers articulated mechanisms of stress relief in various ways such as getting out of the house, with many referencing going for a walk as contributing to coping:

...how do you eat an elephant, you know you take the first bite. And I suppose that's been my kind of way of coping, (laugh) over the last, yeah during the lockdown you know just get through the day. And I think actually walks, I'm going to say to you actually my walks were the biggest thing. (Participant 7)

because I was stressed with it all, generally if you walk 10,000 steps you're ok but some days I'd walk nearly 20... (Participant 1)

Other family members were also cited as helping carers and fostering resilience. This was particularly related to sharing the responsibilities of caring:

At its worst, just the thing that we needed, [Name of researcher], was sleep and the biggest area of what we did for coping, we put a daily planner in place in the house where it came to, we had activities within the house, cooking, painting, we would have game time on the TV, we did a lot of family stuff. We kind of tried to make it not about one child but about all, that everyone had a part to play in things and, do you know, even where it came to cleaning and sanitizing, everyone had a responsibility, we tried to, we tried to bond really tight as a family, you know. (Participant 10)

Because my family give us a lot of support you know. Like more than anyone I know, they're brilliant, they're here with me every morning. My mam is out with me every morning, my dad is around the corner, it's a constant support that I know I have. (Participant 5)

Participants spoke of how their other children (siblings) helped. This assistance could relate to practical tasks such as shopping or provide help with home educational activities for the care recipient. Siblings' assistance in the home environment enabled the carer to catch up on other household tasks:

And I was really lucky because my elder daughter was living at home ... so because she was there I was able to go out and go to the supermarket at times or go to the chemist, you know things like that, the essentials. (Participant 9)

And my daughters would actually, if they were finished doing their schoolwork they'd help and sit and do a Zoom class with [Name]. So that I could get the dinner on or do some work in the house, you know because while we were in the middle of trying to

care for him, home school [other children], I also had to keep a house going, do dinners, washing and, where normally I'd have the time to do that, they're all in school and [Name] gets his care during the week, you know we get the few hours so it gives us time to get things done. You know so the girls did play, my daughters played, they did play a role in helping out. (Participant 5)

Resilience helps to overcome adversity. In that context, some participants developed strategies or had supports to adapt to their new circumstances. Coping could also involve initiating novel, fun activities:

So one of the things I did was I started, you know it was like every day we would do these shows, plays, she'd do a play for me or I'd do a play for her and then we'd play with the dolls together. And then I would, you know even though I mightn't have that much money, I would order things on-line, that was another thing in my, just where some of my friends were really helpful in sending presents. So that was actually another coping mechanism was the An Post postcards. And the people who sent them to [name of daughter], you know something coming in the post every day was an amazing help. (Participant 9)

Participant 9 also detailed that she would make a point of stopping for a picnic when travelling for a regular hospital appointment with her care recipient. The lockdown restrictions meant that the beach was deserted. They were given a travel exemption. For this participant, it was a way of coping.



Participant 9

As discussed in previous sections, the public health restrictions of COVID-19 could render carers in a lonely position. To counter this, carers could make efforts to maintain contact with distant family:

I'd ring maybe my daughter and a cousin in [country] and a few things and just have a drink and just talk for a few hours on the phone. (Participant 1)

Careful meeting up with friends and drawing on the security of their support was also seen as a method of maintaining resilience:

I've two very good friends who are also neighbours and very supportive of us but even if I need them and I didn't see them for a long time but we kept in touch via Facetime and WhatsApp and you know. And they were very good if I needed something and couldn't go out, they would have got it for me, landed at the front door and stuff like that. But if I see them now, we always meet outside still, you know. (Participant 3)

Having some connection with external people, outside family, was also seen to help the care recipient:

got somebody to come privately to help me with outside in the garden and that person would help [name of son] as well. So, that helped [name of son] when I could afford, this guy was very good...he'd come when I had some money and I would give, you know, ask him to stay (laughs), I'm not paying you for the counselling hours now, he used to be roaring laughing, and they would do stuff outside and [name of son] loved that because it was like kind of having somebody to talk to. (Participant 12)

One participant detailed her desire to have some part of her life separate to the caring role and cited pre-pandemic and pandemic modes to achieving this:

Yeah, [before pandemic] which was great because nobody knew me as anything else like in bridge playing. Nobody knew I was a carer. So, it was me being me and not being [Name]'s mother which was what my normal here was, you know. (Participant 4)

And also that I had the internet [during the pandemic]. I could go on the internet and look at something and read something and do something that wasn't involving being a carer. I could just switch off and be any idiot, you know that sort of thing. (Participant 4)

Similarly, another participant spoke of the importance of time out:

I get to sit down after cleaning up after they're gone to bed, you're kind of just either having a bath or picking a show on tv to watch in bed to ...yeah... (Participant 2)

Several carers spoke of how they were able to maintain resilience due to the support of Family Carers Ireland. In many accounts, this was a lifeline and helped to combat the struggle of caring in COVID-19:

So I was left kind of isolated and alone, only the fact that we had Family Carers [Ireland], as I said, you know, to support. (Participant 10)

Such support by Family Carers Ireland and others extended to the provision of services beyond social connection to areas such as counselling, assisting the negotiation for support from services and bereavement support for a family member (not the care recipient):

Family Carers Ireland came on board and for me they gave me three things. One was that they took the huge burden of fear by knowing that in the event of something happening that somebody would, as the fella says, chase up, sort out and then get something sorted for [name of son], so that was one of the things. The second thing was that they gave me, over the months when we were really into the thick of everything, as I say the start of the year and coming up to my mother's first anniversary, that I had counselling and that was a guaranteed fifty minutes any time I needed it, I had it booked and that person was there for me at the end of the phone and that person listened to me. I was in contact with family, everything, but that person was there for me and I was able, again I refer back to the aloneness, I was alone, I wasn't so much lonely as I was alone and to know that you have somebody that would listen to you, no matter what it was, you could say it. (Participant 12)

The participant who contributed the photo below said that this represented her experience with Family Carers Ireland. The participant likened the help that she received from Family Carers Ireland to a tea break and a nice chat on a busy day.



Participant 12

Coping could involve proactively seeking professional help to navigate pandemic related stress. This assisted in alleviating the anxiety of the challenges of caring in COVID-19:

the coping was, it's been difficult. I mean I've been probably talking to a psychotherapist for about four or five weeks now, on a weekly session, to try and cope with how I feel about things. We've, there a couple of weeks ago we was in with a fella who does like Tai Chi and things, he was teaching us breathing exercises and just little exercises that, you know, we could both do together to help calm us down. (Participant 11)

The final aspect of this subtheme relates to coping and resilience in bereavement. Two participants experienced the death of a care recipient during the pandemic, while one spoke of bereavement of a spouse. This is an important aspect of the carers' experience as death in COVID-19 was difficult due to restrictions and traditional cultural supports were impacted. Bereavement also includes experiences after the death as carers came to terms with the loss of a loved one. This was evidenced in some of the photos which portrayed spaces representing their memories and recollections.

Negotiating end of life care in hospital was challenging for one participant in the context of ensuring the presence (and mutual support) of two parents. One participant described how she insisted on such access:

*Well it didn't happen [services restricting spouse to visit when daughter at end of life]. I just said "listen, he's coming in because I can't cope without him" and they said "well you shouldn't even be in here". So I said "f*** off, go and get somebody who knows what they're talking about because I'm staying here and he's coming in too...Yeah, I mean, it just wasn't going to happen [carer being alone]. It wasn't going to be, and in all fairness like the nurses and the doctors and that were fine, you know, they sort of said okay. (Participant 4)*

The relief of human touch was also missed as familiar and comforting gestures between family and friends in grief situations were also impacted:

... but you miss it when you don't have it is someone to hold you and not having somebody, especially through COVID, you know, you weren't hugged, oh you couldn't get somebody by the hand, you couldn't, somebody couldn't pat you on the shoulder, things you take no notice of normally. (Participant 12)

There were restrictions but it was, most people that came stayed outside in the church and didn't come in. (Participant 4)

One participant spoke of finding his mother, on the morning of her death, in the bedroom and noted her lifetime habit of neatness:

She was very house proud and very neat but her room was always like that you know. But that's the bed [picture above] where I found her, myself that morning, so that for me is, yeah. (Participant 1)



Participant 1

Another participant expressed gratitude that she was comforted by her community. This rendered her a feeling of being supported, particularly as the caring experience extended over 35 years:

I guess, yeah, again as I said, I had contact with people, you know that... people were, especially with the funeral and [Name] dying and all that, I got a lot of letters and cards from people that knew me from other places, and I had people ring me up. And it was lovely to get that support from people. (Participant 4)

For this participant, there were symbolic artefacts to remember her loved one which were represented in two photographs. Firstly, a bedroom which housed things that held good memories:

You just, you know, actually what it is in a way, they're all memories to me. The pictures on the wall I have bought, there's a couple of soft toys there that she got from my brother and sister I think it was. There is a couple of pictures up and they're from her friend, her first cousin that doted on her, you know that sort of thing. That's really what it means to me, is memories, and it's good memories. (Participant 4)



Participant 4

For this participant, the garden provided a space of closeness, despite her daughter not having a particular affinity with plants:

And we said why don't we make a little corner out of it [garden] and we did, and it makes me feel really close to her when I'm down there. I don't know why because again she had no interest in flowers herself, she'd tear them up. But to me, it's that sort of bright and cheerful.
(Participant 4)



Participant 4

Similarly, the garden held memories for Participant 1, whose mother loved gardening:

...the roses [picture above], I mean she used to keep her garden so well. (Participant 1)



Participant 1

For the third participant, the death of her spouse lead to an access to counselling for her but she noted the lack of grief counselling for her care recipient:

But he [son] got nothing because he's a vulnerable adult, there's nobody specialized in his grief. (Participant 12)

3.3.2.5 Reconnecting with services

Some services continued during the public health restrictions as they provided life sustaining supports (i.e., kidney dialysis). However, for most carers, services were disrupted. In one account, when the carer withdrew their child's homecare supports to limit risk, their General Practitioner advised resumption based on the anticipated duration of the pandemic:

But then our own doctor when I went to him June or July he said to me look it, I wish I could tell you this was going to over in a short time but it's not." And you get your carers back he said because they will be very well, they will look after themselves, they are good so you get them back" (Participant 8)

At the time of data collection in September-November 2021, many services were cautiously reconnecting with carers and care recipients, albeit at a reduced capacity:

I suppose over time it [support] increased. So [Name A] would have gone back to day service, then 1 day a week, 2 days a week and then there was 3 days a week for a long time, for the best part of a year I suppose. And then of course the special schools, you know where [Name B] goes it's a special school in [Town], so that was closed for a long time that year. Now he went into July provision, they put on, the Department of Education put on the July provision. (Participant 3)

Yeah, my oldest had her first night at respite last night and everything went really, really well. So that's a huge thing for us now that she has that. (Participant 2)

Yet, the take up of services could remain burdensome for the carer. In the examples below, the participants detail their efforts to ensure services could be availed of:

...and when they started to open up then they would give three hours, twice a week. For his assigned time, I would drive him in, I would wait the three hours and bring him home because it wasn't feasible, he had no bus, he had no way in and out and for his mental health and everything and because the shops were closed, so it was, you know. So that came in all the way through the Summer and things like that but still the huge fear factor was, because the health service had nothing for us and the service provider had absolutely nothing for us. (Participant 12)

So how am I going to get him, its 40 miles away, do you know, or 40 minutes away. How am I going to get there, how am I, I can't leave [Name A] on his own. So look it thankfully one of the Special Needs Assistants who lives near us, who worked with [Name B] years and years ago, who doesn't even work in that school, he said I'll bring him up. (Participant 3)

Despite such difficulties, other carers spoke of the relief of accessing some supports:

When it did open like I did send him straightaway and it's the only thing I sent him to is [name of service provider] for respite but it has been amazing and even, even if I am doing nothing because there's nothing to do because of the pandemic, it's still been great to just have that. (Participant 13)

Yeah, like as I said, at least the kids are at school. If I need to get stuff done during the day before they come home, it's done. (Participant 2)

Some efforts could be made by services to reconnect via virtual means, however, this support resulted in mixed impact:

We did have, I think it was the second lockdown we were given Zoom calls which I did think in the beginning would be more of a hindrance than a help but they weren't too bad to be fair. And my daughters would actually, if they were finished doing their schoolwork they'd help and sit and do a Zoom class with [Name] (Participant 5)

And for one participant, the resumption in services was welcome, yet reassurance was needed that their child had settled well:

Oh I didn't go to bed until I got that text. I had asked the girls that was looking after her, "look, don't get her to ring me because in case she gets upset". I just want to know if she settles in bed and when she gets off to school in the morning. So yeah, they text. (Participant 2)

3.3.3 Theme 3: Reflecting forward

This theme presents the participant suggested means to address the challenges encountered by carers and care recipients based on their reflections on the experience of living through COVID-19 as a carer. The identified actions are shown as subthemes of 'Reflecting forward' in

Figure 3.3. As can be seen, these were multi-dimensional reflecting the reach of caring and the domains within which caring roles are experienced. It is important to note the constituents of *'Reflecting forward'* were presented by participants through their in-depth reflection on the realities of life for themselves, for society and its governance during the pandemic. These included the fear of virus and ensuring safety through adhering to public health actions to protect each other balanced with the need to ensure the ability to sustain caring and meet the needs of care-recipients.

Participants consequently recognised the particular challenges encountered by government, service providers and society during the pandemic, given that it was a new virus and therefore information and understanding were emergent. They were also realistic in terms of acknowledging the ongoing challenges they experienced as carers prior to the onset of the pandemic as demonstrated in 3.3.1 *'The nature of caring'*. However, as shown in 3.3.2 *'Navigating the COVID-19 tidal wave(s)'*, the onset and lived experience of the pandemic brought new and amplified existing challenges. Thus, the actions suggested by participants were referred to as being essential to support continuance in the caring role in future similar situations and, of central concern to those interviewed, the safety, health and wellbeing of care recipients, carers and in some instances significant others. This noted, many of the constituent sub-themes of *'Reflecting forward'* cannot be perceived as isolated from the experiences of caring pre-COVID-19, as pre-existing caring-related challenges did not abate and in many instances were exacerbated.

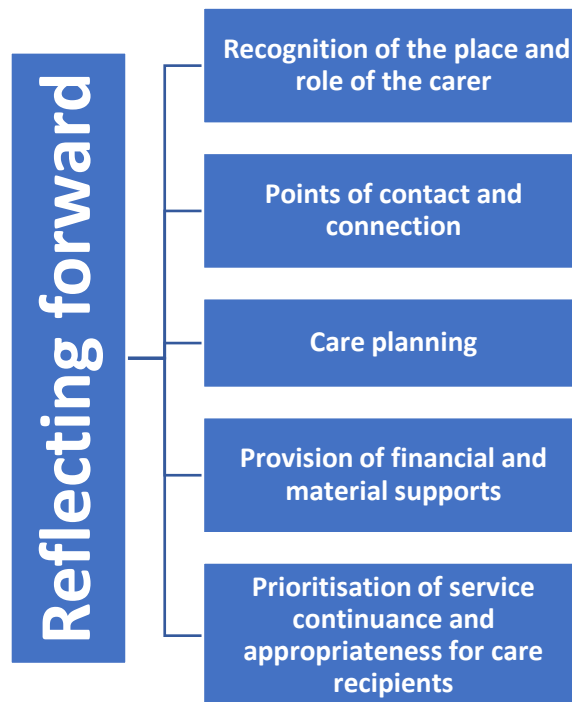


Figure 3.3 Theme 3: Reflecting forward

3.3.3.1 Recognition of the place and role of the carer

Participants referred to the absence of the visibility and valuing of carers in societal, political and service discourses during COVID-19. While other narratives were perceived to be more widely recognised such as frontline workers, the experience and challenges of caring at home during this time were felt to be less visible, if not hidden and unacknowledged. Despite this, carers felt they were expected to keep going and there were references to this expectation in the light of the savings to government and society provided by carers:

“I felt in the lockdown is that carers were not considered, not talked about, not cared about.” (Participant 5)

“We’re saving the government millions every year in caring for the people at home. If we all gave up caring, how much would it cost the government each year to care for those people in facilities, in respite centres, in care homes? ... So the government be willing to pay for that [formal services] but yet give carers an awful less money, and means tested as well. I think that should be changed.” (Participant 15)

Thus, the need for consideration of the impact of the pandemic on carers and acknowledgement and valuing of the place of carers in society and the fabric of provision of care to care-recipients was identified. This was referred to both in terms of cost savings to government as shown above and in relation to the increased volume and intensity of caring tasks undertaken by carers during the pandemic as reported in 3.3.2. As such, the need to listen and respond to the voice and perspectives of carers was emphasised:

“They [government] didn’t listen to us but at least, for me anyway and I know people will feel differently, it’s really important to have your say anyway you know”
(Participant 3)

“And again, you know, I’d like to see the carer being recognized not as a social welfare payment, I would like to see a carer being recognized as frontline staff and that they’re receiving a wage, they’re receiving a holiday break like every other person in the country.” (Participant 10)

There was also specific reference to the need for meaningful and practical recognition of the place of carers across the continuum of the pandemic as pandemic-related policy and practice changes occurred. Examples cited included consideration of the impact of service cessation or reduction on family carers, considerations pertinent to the opening up of services and supports (e.g. concerns around safety and care-recipient return) and highlighting the importance of carers being considered for inclusion in relation to early vaccination due to the inherent nature of and tasks associated with their role:

“Yeah, well just when I talked about the vaccine situation there. I mean when the flu comes round every year, the carer usually gets the flu vaccine along with the person they’re caring for, you know, so that they’re not transmitting anything to them. You know, so I just think, God forbid, if ever a pandemic comes around again, that there should be none of this kind of, what’s the way it’s put... yes, frontline staff are very important because they’re dealing with a person coming into the hospital who has this infectious viral infection, disease, whatever you want to call it, and can pass it along. Yes, they should be given a vaccine but so should the carers because they’re dealing with most vulnerable people.” (Participant 15)

3.3.3.2 Points of contact and connection

The need for a point or points of contact and connection were identified as a potential lifeline for carers. Responses from some participants in their interview demonstrated the frustrations of not knowing where to go or how to access help or advice. This was referenced in the light of a number of participants not having received contact from formal services during the pandemic:

“Maybe if our own health service like our public health nurse or someone like that had contacted us, nobody contacted us.” (Participant 8)

“Because it would have been, it was just, we just had nowhere to turn to, we didn’t know who to turn to ...” (Participant 11)

Where services had ceased, usual channels of communication and available supports were in some cases no longer available or for some, there was a need to locate and access services previously not required. Thus, the need for provision of clear points of contact and facilitation of connection were identified. Such contacts should be readily known and accessible to carers and should be fit for purpose so as to offer the types of assistance that might be required when needed:

“... identifying somebody within the services who contacts them and is in touch with them regularly to make sure they’re ok. And what needs do they have, how can they be met.” (Participant 9)

The data suggested that such assistance could relate to care recipient needs or those pertinent to carers themselves. The importance of points of contact meeting extant needs was evident where interviewees referred to seeking information and supports both to avert a build-up to, or potentially more urgently in, times of crises:

“Yeah well I didn’t know what was possible. I didn’t know what anybody could, I didn’t know what people could do like COVID wise. You know like what was allowed because you know as far as we were concerned nothing was allowed which I don’t know probably in the beginning it wasn’t.” (Participant 14)

In terms of the types of assistance required from points of contact, this was referred to in two regards. Firstly, in terms of information provision with the type of information needed

according to one participant relating to information that is of “*practical help*” (Participant 14). Secondly, in relation to psychosocial support, Theme 2: ‘*Navigating the COVID-19 tidal wave(s)*’ demonstrated the isolation, loneliness, grief and exhaustion experienced by some carers during the pandemic and the circumstances that led to these. Based on such experiences, some participants referred to the need for social support, human connection and the importance of the need for pre-emptive and pro-active out-reach connection to carers by services. This could take a number of forms along a continuum of support from check-in phone calls to counselling and psychological supports. In addition, where carers were enabled to access formal supports, there was some inference that these would need to be accessible:

“Like I never got a call from a social worker, ever to see how I was doing or did I need any extra help and I know there’s community help but you know there was no proactive help” (Participant 9)

The final participant recommendation in relation to points of contact and connection to supports related to the need for such access points to be co-ordinated and integrated, as opposed to fragmented:

“And I suppose look it I think there would be room for maybe the disability services and the hospital system to work together a little bit...” (Participant 3)

“So there should be a one for all or a go to one area where you just connect with and then all the services are linked together to say, yes you can get this, you can get that.” (Participant 15)

3.3.3.3 Care planning

A number of participants referred to the absence of a formal care plan to support caring during the pandemic and identified the need to have such a plan in place in the future:

“They’re getting older, I’m getting older. There is no plan for us, you know, there’s no plan for the boys. I worry about what would happen if I had an accident in the car, I worry about if I get COVID, there was no plans to look after the boys, apart from emergency intervention.” (Participant 3)

“There was no actual plan for families like ourselves and I found that very difficult to digest, you know, that, you know, when I look back things could have went a lot worse, which they didn’t and we were lucky, you know?” (Participant 10)

The importance of having a care plan that was not just person-centred but inclusive of the care recipient and carer was pivotal. Thus, the need for recognition of caring as involving both individual (care-recipient and carer) and combined needs was evident. This was considered important as for many interviewed, there were no, or limited, safety nets should unforeseen or indeed foreseen circumstances arise for which supports were not available during the pandemic. A number of carers lived in fear of what would happen should they become unwell for example. This was a particular concern where carers had limited or no supports to call on during the pandemic. Therefore, in terms of living through the pandemic within the context of caring, the need for a care plan inclusive of in-built contingency and emergency care planning was identified:

“I would say first of all plan, you know have a plan and the plan not to be we’ll wait for it all, you know to arrive at a crisis point and then we’ll intervene. That’s not a plan and its actually very powerful to people like my sons and myself, the carer, you know life is hard enough, it’s causing so much additional stress and upset and you know coming very close to that crisis point is really, really scary. And I think that could be mitigated for, by contingency plans. I mean it’s something that we as carers do all the time, I’m always planning for well the what ifs, what if this happens you know. I know we’d had plan B and you know I would say that is part of my job, I suppose I need the system to have a plan B too.” (Participant 3)

“And again, you know, in around emergency care plans should have been set up for each family.” (Participant 10)

The value of having a care plan that translated into practical assistance and could facilitate breaks to support carer coping was particularly emphasised by the following participant:

“I feel like our lives could be enriched so much more if we got the help and got the breaks and they would help us cope a lot more with the daily tasks and issues that we face.” (Participant 6)

3.3.3.4 Provision of financial and material supports

Financial and material costs and consideration of supports in relation these were referred to by some. Coinciding with the continuance of the pandemic, one participant highlighted increases in costs of living for example, costs in relation to staples such as food and heating as being critical considerations in terms of their available funds:

“...you could go over a do a shop in [name of store] and take it for granted that you’d spend €200 during the early, before the pandemic, now it’s costing you €3/350 for the same shop so the inflation has been massive, even for just groceries alone and now we’re looking at rising gas bills, electricity bills and all the rest. There has never been a change in the payment of family, in the Carer’s Allowance, you know, to say that it meets the need, do you know, that you can match the needs of the household, you know. So I think there’s a big gap missing there where it comes to how, how a family carer was treated, you know.” (Participant 10)

The costs associated with caring also increased for carers during COVID-19. The nature of such costs varied amongst carers, but examples cited included purchasing of materials to support meaningful engagement of care-recipients in occupation and enjoyable activities. This was necessary as many care recipients were spending more if not all of their time at home with limited or no access to usual educational, social or occupational opportunities. There was also reference to home modifications to support caring in a few instances as well as challenges in sourcing and costs associated with personal protection equipment (PPE) provision or antigen tests cited as examples. Thus, the need for financial recognition and support was highlighted and for one participant this was expressed in terms of the need for equity across sectors, where there was provision for financial assistance for some groups in society but not increased costs of caring for carers as shown here:

“And the government need us. Society needs us you know. If we were all family carers in Ireland, every family carer in Ireland was to get up tomorrow morning and say look it I can’t do this anymore, you know. The health service would collapse without us, you know. And look its equality I suppose is a big thing in that, that I suppose I feel that, and quite rightly and I certainly wouldn’t begrudge you know that every other sector of society was supported from businesses to the employed people to PUPs to you know and the people needed that and absolutely but you know I believe that they should

have and continue to do it for as long as they need to. But there was nothing for us at all, do you know what I mean.” (Participant 3)

3.3.3.5 Prioritisation of service continuance and appropriateness for care recipients

As identified in ‘*Navigating the COVID-19 wave(s)*’, for the majority of participants, service reduction or service cessation was experienced. Participants identified a need to prioritise the continuance of services for care recipients in light of the impacts of reduction and cessation of these on the care recipient and carer highlighted in 3.3.2. The importance of this to the wellbeing of everyone concerned was identified, as was a need to consider service and support contribution in terms of the importance of routine and consistency, the critical value of services and supports to health (physical and mental), social engagement, education of care recipients (where this was applicable) and the continuance of the caring role:

“I guess if services for those with special needs could have been kept going in some shape or form, you know, I guess because for me, because we hadn’t really had any difficulties before, you know, I didn’t really see that the pandemic was gonna be a problem until I actually experienced it and the lack of services ...” (Participant 11).

“And it’s very difficult to balance that in people who have special needs or you know who have additional needs. It’s a very hard balance, but you know to me I think the essential services for people with disabilities if at all possible should never be closed. They should be on a par with nursing homes and you know like they just have to be open.” (Participant 14)

If services were to have no choice but to close again in the future for reasons similar to those encountered in the pandemic, there was some suggestion in the data of the need to consider a pivot to a different mode of service delivery as shown here:

“...also if somebody you know if we could get some help at the house as well, if it were to happen again and he couldn’t go somewhere if somebody could come here. I think that would be really useful. You know it would be an absolute disaster for him now if things had to close down again. And he had to go back to square one, I don’t know if he would cope with it. I don’t know if we could cope with it.” (Participant 14)

This was, however, counterbalanced in the data with a need to consider the suitability of particular modes of service engagement for individual care recipients. For example, in some instances services had some online engagement. However, this was found to not be suitable to meet the needs or abilities of some care recipients:

“But it [Zoom] really wasn’t beneficial for him. And I felt a lot more could been done. Like the special schools, especially the ones catering for the children with the higher needs and severe disabilities, should have been classed as front-line services and should have stayed open.” (Participant 6)

Even where approval for services was in place, a particular issue indicated by a few participants was that while they had such approval, they could not access or source personnel to deliver the service in the home in the way that was needed, or for example access to an external service that they had a place in was challenging. Thus, where resumption of services was occurring, the need to review how and when particular services were introduced, their accessibility in terms of actual availability was also commented upon:

“I do find that its, the one thing that really bothered me is when the special needs schools should have gone back and didn’t go back sooner than regular schools. I was really angry when they didn’t go back. I think they were kept out too long. The kids like [Name], they needed to be back in school... And we had to fight for everything to come back, it wasn’t just automatic, this is what you deserve back and we’re sorry that it had to be taken off you. We understood the reasons but get it back quicker. We should have had the schooling back quicker. And definitely his respite back quicker.” (Participant 5)

3.4 Summary

- The findings from the 15 qualitative interviews were organised with reference to three themes, which together provide an interpretation of participants’ experiences of caring during COVID-19:
 - Theme 1: ‘The nature of caring – becoming and being’
 - Theme 2: Navigating the COVID-19 tidal wave(s)’
 - Theme 3: ‘Reflecting forward’

- **'The nature of caring'** was recounted by participants as a means to provide a background and context to their COVID-19 caring experiences. Related findings illuminate key facets of ongoing carer roles (including: advocacy, and service locator and navigator) and care-related impacts (including: the rewards of caring and experiences of restrictions to carer freedom, isolation and loneliness, fatigue and reduction or cessation of work lives outside of the caring role).
- Theme 2, **'Navigating the COVID-19 tidal wave(s)'** contains five sub-themes which chart the experiences and life world of carers through the severest restrictions to the tentative emergence to pre-COVID-19 life in late 2021. The five themes are comprised of a) increases in the volume and intensity of work and b) life space reduction, c) impact of restrictions, d) mobilising resilience and e) reconnecting with services. These experiences could vary within the temporal context of COVID-19's impact.
- The final theme, **'Reflecting forward'**, encompasses carer identified means to address the challenges encountered during the pandemic based on reflections on the experience of living through COVID-19 as a carer. To this end, participants referred to the need: to recognise the place and role of carers; for points of contact and connection; care planning to include contingency and emergency planning consideration; provision of financial and material resources; and the need to prioritise the continuance and appropriateness of service provision for care recipients.
- The following chapter will discuss the overall study findings and its strengths and limitations.

Chapter 4 Discussion

4.1 Introduction

Having presented the thematic findings of the study, this chapter will discuss these findings in light of relevant national and international empirical and policy literature. Following this discussion, the strength and limitations of the study will be outlined.

The aim of the study was to explore the experience of carers during the COVID-19 pandemic. The findings in this study echo the extant research and commentary related to informal carers' experiences within the pandemic (Mortazavi et al., 2020; FCI, 2020c; Cohen et al., 2021; Giebel et al., 2021; Muldrew et al., 2021). The interviews in this study occurred approximately eighteen months into the pandemic, with 15 carers who provide care to 19 care recipients. Three main themes were identified, namely, *'the nature of caring'*, *'navigating the COVID-19 tidal wave(s)'* and *'reflecting forward'*. All carers submitted meaningful photographs, which served as touchpoints to support discussions of their lives in COVID-19. The photographs were symbolic of their personal experiences of caring and provided powerful imagery from which meaningful discussions occurred. As such, the themes in this study drew upon these pictures as they framed part of the interpretation of carers' experiences of the pandemic within their social context (Richards, 2021).

Carers are a vital, yet broadly unrecognised, part of health and social care systems (Phillips et al., 2021). Their equivalent monetary input is estimated to amount to between €2.1 and €20 billion per year in Ireland (Hanley and Sheerin, 2017; FCI, 2020a). Oftentimes, carers have not had any relief from their caring role for years. For example, Carers UK (2021) found almost half of carers had not had a break from caring responsibilities within the previous five years. Carers undertake multiple and diverse activities and many report rewarding aspects of their role (Pysklywec et al., 2020; Hovland and Mallett, 2021). However, challenges in caring have also been identified. Particular discrete difficulties may be more prominent for carers of various groups such as older people living with dementia (Greenwood et al., 2018; Dementia UK; Xu et al., 2021), care recipients with chronic illness (Sharma et al., 2021; Carleton-Eagleton et al., 2021), children with cerebral palsy or intellectual disability (Barchu et al. 2021; Vaz et

al., 2021) or carers of people with a mental health illness (Sun et al., 2019; Sin et al., 2021). Challenges pertain to issues such as negative carer physical and mental health, social support gaps, loneliness and financial hardship (FCI, 2020c).

When COVID-19 emerged in late 2019, this represented a major additional challenge for carers globally as they subsequently struggled to adapt to pandemic life which was dominated by public health restrictions and ultimately, the dwindling of familiar supports (Russell et al, 2020; Giebel et al., 2020; Carers UK, 2021; FCI, 2021b). Similar to other observations in the literature, this translated to what Kent et al. (2020: e 66) describe as “the family caring crisis meets an actual pandemic.” Such challenges were a result of the increased impact of existing difficulties in caring or the emergence of new issues (Care Quality Commission, 2021; Muldrew et al., 2021).

Carers’ experiences before COVID-19

All participants in this study co-habited with the care recipients and described how they had come to the caring role. The majority of participants were mothers who had delivered care since the birth of their child(ren), some of whom were now in adulthood. Only one male volunteered in the study and the context of caring differed in that the caring role was due to increasing dependency, due to advancing dementia and frailty, of a parent. While many statistics globally demonstrate that there is a gender divide in informal caring roles (Glauber, 2017; Akpinar et al, 2011; Cohen et al., 2021), the ratio is less than the proportion of male/females in this study. For example, statistics on caring point to approximately 60% of carers being female (CSO, 2017; OECD, 2017; Barry, 2021). Reasons purported for the higher number of females caring point to role socialisation, different structural contexts, unequal opportunities and role expectations (Hong and Coogle, 2016). Swinkels et al. (2019) also propose that females have a greater challenge due to secondary stressors, such as relational and financial problems and issues connected to combining tasks, however, in that study, more hours of caring did not impact females as opposed to males, suggesting the act of caring is experienced differently by genders. All of the participants spoke of their caring responsibilities and some mothers detailed how they withdrew from employment to care for their child(ren) representing the ‘opportunity cost’ to the labour market as noted in the literature (Moussa,

2019; Sarris et al., 2020). Withdrawing from employment to look after a child with dependent needs is not an uncommon finding for mothers who have assumed a carer role (Spindler et al., 2017; Fernández-Ávalos et al., 2020).

The age range of carers in this study reflects the most common age groups of carers nationally (CSO, 2020) and the length of caring spanned periods of up to 37 years. The longer length of caring activities for children born with intellectual disabilities concurs with evidence that life expectancy has increased in the last 50 years, with McCarron (2015) noting that children born with Down's Syndrome in the 1930s had a life expectancy of just 9 years while currently life expectancy with a 50% survival rate is up to the late 60s in age (Dolan et al., 2019). Thus, for this cohort of care recipients, 'two generation elderly families' are increasing with concurrent longer years of caring (McCallion et al., 2005). Compound caring was also evident in three families as the carer provided care to more than one care recipient. This is not uncommon. For example, in an Irish study by Lafferty et al. (2016), compound caring was a feature in just over a quarter of the carer respondents (26.3%) (n=249) caring for people with an intellectual disability.

The findings demonstrated that carers' lives before COVID-19 demonstrated a wide variety of roles in navigating the complexities of care. As discussed in the literature review, the caring role can include assistance with activities of daily living, management of health, education and social activities and advocacy (Beesley, 2006; Family Caregiver Alliance, 2016) and the experience and responsibilities of care could change over time (Kajiwara et al., 2018; Lacey et al., 2019). All participants described the various activities they engaged in, and all recounted moderate to high dependency levels with many reporting the multi-morbidities experienced by the care recipients. For the fourteen mothers, caring was a long-term role. The theme '*The nature of caring*' presented important positives and recognised the participants' essential role of being an advocate for the care recipient(s). Yet, the participants' narratives demonstrated a recognition of their own situated vulnerability related to service provision and holding the responsibility of negotiating care. The nature of caring also demonstrated the depth of knowledge related to the individuality of care recipients and advocacy on their behalf. This is apparent in the context of descriptions of the close knowledge of the carer regarding the behaviours and responses of care recipients, and the accounts related to their depth knowledge of the dependence levels and comfort of the care recipient, constituting emotional

care provided (George et al., 2020). Similarly, in an integrative review of the literature, Finucane et al. (2017) explored carers of patients receiving palliative care who had delirium, and found advocacy was manifested in interpreting the care recipient's behaviours and providing information to healthcare professionals, particularly when communication was difficult for the care recipients. In a study of youth and young adults with special healthcare needs, advocacy was deemed important to support healthcare transitions and in navigating the complexities of health services (Okumura et al., 2015). While the role of advocacy is important, its application could also be frustrating for the carers in this study due to multiple attempts to have their concerns recognised or their requests actioned on. This frustration is echoed in the literature. For example, in a 2016 Irish study examining person centred coordinated care, Phelan et al, (2017), in focus groups with service users, carers and patient lobby groups, found a major issue for carers was the challenge in care integration. Similarly, Family Carers Ireland (2020b) report that accessing services proved challenging for 75% of carers. Such issues are embedded in factors such as care fragmentation, and poor care coordination (Lloyd et al., 2017).

Descriptions of the carer role pre-pandemic also constituted a picture of the loneliness of the role as previous work engagements were withdrawn from, meeting with friends diminished and indeed spontaneity in daily life was countered by both caring responsibilities and the fatigue from caring activities, which could be round the clock. The experience of carer loneliness and fatigue is well documented in the literature (Vasileiou et al., 2017; Victor et al, 2021; Hajek et al., 2021). Moreover, caregiver loneliness is linked to health problems such as emotional eating and hypertension (Family Caregiver Alliance, nd), and depression (Victor et al., 2021). In a concept analysis, caregiver fatigue is described as:

“...the extreme physical experience of fatigue by carer(s) or caregivers of chronically ill or disabled family member as a result of performing caring tasks. The caregiver assumes these caring tasks out of a sense of personal duty or responsibility for the ill or disabled family member, and this may be for a prolonged or indeterminate period. The care provided is considered outside the norm of role expectations. Physical fatigue, rather than mental, social, or emotional fatigue, is more pronounced due to the excess physical demand of caring. Eventually, caregivers may exhibit physiopsychological symptoms of fatigue, including but not limited to irritability, drowsiness, sleepiness, lack of energy, social isolation, palpitation, tachycardia, and/or extreme exhaustion, which do not easily resolve.”

(Beydoun, 2019:304)

Such symptoms were identified in the interviews in this study as carers illuminated their roles. Like loneliness, the consequences of fatigue are potentially serious and can lead to burnout as well as physical and mental health deterioration (Gérain and Zech, 2019). The participants' accounts demonstrate the pre-existing realities before COVID-19, however, once COVID-19 reached Ireland, these pre-existing difficulties were magnified as carers attempted to provide care and compensate in the context of service reduction or service withdrawal.

The first known case of COVID-19 in Ireland was confirmed at the end of February 2020. Given its high infection rate, consequences which were more severe for those with at risk conditions and the lack of a vaccine at that point, severe public health measures were mandated by government. This translated to education facilities being closed and in the anticipation of a tsunami of COVID-19 admissions to hospital and to limit infection spread, many routine non-essential health and social care services were suspended indefinitely. In addition, those deemed at high risk of infection were advised to shield, further decreasing the physical and social milieu of carers, the care recipients and their families. In reality, the public health restrictions exacerbated existing challenges carers faced while also presented new concerns through the withdrawal of services, health deterioration in both the carer and the care recipient and challenges in managing care in the context of a pandemic (Muldrew et al., 2021).

The findings of the current study demonstrate the extent to which the daily lives of carers were transformed as the majority assumed the responsibilities of previous education facilities, health and social care support services. Similarly, many studies demonstrate that within the pandemic, the hours of caring and the intensity of work increased for carers (Carers UK, 2021; FCI, 2021b; D'herde et al., 2021; Giebel et al., 2021). Pearlin et al. (1990) points to caregiver stress as stemming from primary factors (due to challenges in direct caring) and secondary factors (due to the strain of roles outside caring and a diminishing of self-intrapsychic strains). Both forms were evident in the data in our study and such impacts can be aggravating factors in levels of carer depression and anxiety (Segrin et al., 2018; Reblin et al., 2018). In an examination of the literature on carer stress, there is also no unity with regard to defining the phenomenon. It has been constituted as:

“...a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers' health and behavior.”

(Pearlin et al., 1990:591),

Service withdrawal or reduction is linked to increasing challenges for carers within the pandemic (Prasad, 2020) as service supports are key in reducing carer stress (Sun et al., 2019; Sin et al., 2021; Carleton-Eagleton et al., 2021). The abruptness of service withdrawal translated to limited time to create back up plans, and carers in this study provided depth accounts of how their daily lives had altered. Equally, previous contingency supports (family, friends) were not generally accessible due to the risk of infection. Carers also echoed their perception of the invisibility of carers as a workforce and the reality that they were tasked with shouldering care without effective alternative supports (FCI, 2021b; Phillips et al., 2020). This translated to a higher need in the context of physical and psychological demands and impacted the wellbeing of the carers, who often spoke of reaching breaking point. Similarly, a survey of carers in the United Kingdom reports 70% of carers indicated their work in caring had increased during COVID-19 (Carers UK, 2021). For 35%, this was attributed to the closure of services, while another 10% indicated that allocated care hours had reduced. A further 22% stated they assumed care to reduce exposure to service providers due to fear of infection exposure, while 69% indicated that they were providing more support in the context of care recipient motivation, promoting positive mental health and supervision. Similarly, Family Carers Ireland (2020c) observed an increase in carers' work with 36% having day care services cancelled and a further 36% having reduced homecare hours while 28% had respite withdrawn. In the same study, fourteen percent cancelled services during the pandemic to reduce infection risk (FCI, 2020c). In our study, the majority of participants reported the suspension of usual services, with two reporting that they had made a decision to stop services to limit the care recipient's risk of exposure to COVID-19. Many of the accounts, mostly from mothers, detail the continuous supervision and responsibility on a 24/7 basis where care needs and dependency were high. Studies have also indicated that hours of caring are greater when there is cohabitation with the care recipient (Gbiri et al., 2015), particularly in those delivering care to a child (Viñas-Diez et al., 2017). As indicated previously, all study participants co-habited with their care recipient(s), with 14 being mothers of dependent children

In the context of life space reduction, the world of carers generally became confined to the home. While the public health restrictions were population based, for those who were medically at risk, there was a greater impact. For all participants, there was an acute awareness of the heightened risk. The literature demonstrates that shielding, which targets those with high risk of severe infection impact by minimising interactions between themselves and others (Clarke Bryan et al., 2020), has had a lasting negative impact on carer mental health (Brooks et al., 2020; Cohen et al., 2020; FCI, 2020c). For some participants, the space was further reduced as they delicately negotiated their movement in the house and sound in the house due to other family members working from home. One participant described the impossibility of caring in a small open plan space and trying to support the education of two care recipient children as impossible. This concurs with literature which found remote learning for children with special needs in COVID-19 very challenging for parents and concluded that this could have emotional toll for carers (Garbe et al., 2020), particularly in relation to caring for children with autism (Ameis et al., 2020; Asbury et al., 2021) or younger children. Some reasons for such difficulties could be due to missing the routine of face-to-face education, a high level of distractions, or parents feeling ill-equipped for this educational role. While the intensity of responsibility to provide care had increased, some participants spoke of trying to support their child(ren) in activities which were new, such as education via virtual means (i.e. Zoom). Again, this proved particularly challenging as participants were more familiar with the general care of their care recipient rather than providing specialist education (Henley-Averett, 2021). Although not discussed by participants in this study, another potential barrier in remote education or technology use could be problems in access and use for low-income families (Valicenti-McDermott et al, 2022) and in Ireland poor connection to broadband (NBI, 2020).

The participants in this study all described how they and their families engaged in safety measures as they recognised the potential impact of their care recipient(s) being infected with COVID-19. As discussed, this encompassed adherence to the general public health restrictions, including making decisions to shield themselves to protect the care recipient. The potential impact of infection was illustrated by one participant who described a care recipient having caught COVID-19 and observed that there were long term impacts in terms of the care recipient's health. Other participants described their own fear of being infected and having

to be admitted to hospital. These accounts focused on the potential impact this could have on both themselves and the care recipients. In 2021, Family Carers Ireland detailed the challenges in interfacing with hospitals; issues identified included a general fear of going to hospital with their care recipients (as this heightened potential infection exposure) or restrictions on visiting if the care recipient was admitted.

Two participants had lost their care recipients during the pandemic in the current study, although neither death was related to COVID-19. However, one care recipient, described the challenges of being in hospital during the pandemic in terms of family accessing visitation at end of life. Moreover, the familiar rituals of funerals were impacted, although, participants did speak of support received from their community. Compounding the stresses identified for carers, the literature has indicated that changes in face-to-face funeral rituals in COVID-19 could impact mental health (Chew et al., 2020), and contribute to a risk of complicated grief and prolonged bereavement disorder (Age UK, 2020; Mortazavi et al., 2020).

Despite efforts, some mothers described pandemic related deterioration in the mental and physical well-being of their children, particularly those who had an intellectual disability. Several participants detailed how responsive behaviours of their care recipients had worsened as social isolation impacted the care recipient's psychological health and, in some cases, this was to the point of a crisis where additional medications were required to assist with the stress or emergency calls to services to obtain support were required. It is recognised that people with intellectual disability can have multi-morbidity and coping with public health measures can be more stressful for them (Alexander et al., 2020; Willner et al., 2020; Courtenay and Perera, 2020). For example, Courtenay and Perera (2020) and the College of Psychiatrists of Ireland (2020) note that individuals who have autism and attention deficit hyperactive disorder find it particularly difficult to cope with changes in routines and can experience the restrictions, such as the lack of school structure and their access to familiar networks, anxiously and stressfully. Staying at home could also render the care recipient lonely as they missed their social network both within their support services, but also within their wider family. This is particularly significant when the fact that, pre-pandemic, loneliness was found to be experienced by up to 50% of people within intellectual disability (Gilmore and McCuskelly, 2014), thus it is likely that restrictions exacerbated a sense of social isolation and the prevalence of loneliness increased. In addition, the experience of loneliness is linked

to a higher risk of physical health decline in the context of coronary artery disease, an increased likelihood of mortality, stroke, high blood pressure, and mental health issues (Vasileiou et al., 2017; Holt-Lunstad et al., 2010; 2015). Physical health deterioration was not as common in the participants' narratives; however, it is noted that the impact of the pandemic can lead to physical decline (Bergman and Wagner, 2021), while some studies on older people living with dementia have demonstrated general health and wellbeing deterioration during COVID-19 with an acceleration of dementia symptoms (Alzheimer's Society UK, 2020; O'Shea et al., 2020; Sriram et al., 2021; Smaling et al., 2022).

Carer wellbeing and depression also deteriorated further in COVID-19. Budnick et al., (2021). Details carers' reflections on the personal psychological impact of the pandemic. Participants' descriptions demonstrated fear and anxiety related to contracting COVID-19 infection in relation to themselves, care recipients, or another family member, which could have devastating impact on the care recipient. Consequently, in this study, all participants described how their lives changed in efforts to protect the care recipient(s). Carers' fear of infection has also been highlighted as a major concern in other studies (Brooks et al., 2020; Muldrew et al., 2020; FCI, 2020c).

In tandem with the impact on self, participants spoke of other family members who were also engaging in careful social interactions. However, adding to the stress of some was the concern regarding the effect of restrictions on their other children who were not care recipients. Many spoke of a self-mandated exclusion of family members from usual social activities, (meeting friends, family or shopping) including restricting or discontinuing family help or visitation. This resulted in some reflecting on their own experience of loneliness and social isolation, a common finding in the literature on the impact of the pandemic on carers. For example, in the Family Carers Ireland study, *Caring through COVID: Life in lockdown* (2020c), being socially isolated was identified by 37% of carers. Similarly, in the United Kingdom, loneliness was highlighted by carers and was interlinked with their experience of increased social isolation (Bristol et al., 2021). Although familiar support systems were compromised for participants, some did describe support from services via virtual means and continuity for essential healthcare, such as kidney dialysis. Other forms of support were highlighted, particularly those from Family Carers Ireland, where participants described accessing personal and protective equipment, participating in a discussion forum or being able to access counselling.

The participants described their mental stress and anxiety associated with caring in COVID-19. While social isolation and loneliness were a feature in this study's carers' experiences, the literature also evidences an increase in mental health issues such as depression, anxiety and stress due to COVID-19, while increased levels of uncertainty, a sense of loss of control, sleep disturbance and frustrations have also been observed (FCI, 2020c; Muldrew et al., 2020; Brooks et al., 2020; Russell et al., 2020; Giebe et al., 2020; Bergman and Wagner, 2021; Bristol et al., 2021). For mothers of children with intellectual disability, research by Willner et al. (2020) has identified that mental health problems have significantly increased in comparison to the study's comparison group (8% for severe anxiety and 3%–11% for major depression). Using data from 26 countries, Bergman and Wagner (2021) examined the impact of the pandemic on 51,983 carers and care recipients over 50 years of age data extracted from the Survey of Health, Aging and Retirement (8th wave). Findings demonstrated that carers expressed more depression due to the pandemic measures when compared with non-carers. The impact was particularly seen in carers who were parents, with 30% expressing depression more frequently, while 40% experienced higher levels of anxiety. In the Carers UK study undertaken in April 2020, 55% of respondents were fearful of burnout. This was also a feature of our study as the participants described their struggle to cope with reduced support and public health restrictions and demonstrated some of the factors described earlier as contributing to caregiver fatigue.

Despite the huge challenges experienced by carers, there were accounts of resilience. The American Psychological Association (2020: online) describes resilience as:

“...as the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress...bouncing back from these difficult experiences. It involves personal growth”

Carers in this study continued to care, despite the major and diverse challenges, both in the exacerbation of existing issues and the emergence of pandemic related difficulties. As discussed, carers described fostering resilience as they tried to relieve the pressure for both themselves and the care recipient(s), by making the most of their garden space, or initiating outings in the car or outdoor walks. Resilience was also facilitated in sharing the caring activities and interactions with family, accessing some support systems such as Family Carers

Ireland and virtual connections. Resilience has also been noted as a coping mechanism in carers in other studies. Hanna et al.'s (2022) study examined resilience in people living with dementia and their carers and identified resilience being enhanced by COVID-19 successful adaptations, good communication and support networks and robust individual coping mechanisms. However, having a good range of supports being in place is crucial to enhance resilience (Sun et al., 2019; Muldrew et al., 2020). For carers of children, one study found that carers' mental health was predicted by the level of the child's psychosocial stress (Davidson et al., 2021), thus support to address strain experienced by a distressed child, who is a care recipient, is required to mediate the carer's coping and enhance resilience. Equally, the literature also suggests that carers of people with intellectual disability can foster resilience when external supports are available when necessary (Courtenay and Perera, 2020; Ameis et al., 2020) and emotional, cognitive, and sociocultural interventions are key (Ramos et al., 2020). In this study, there was a common discussion focus on the need to provide additional support to carers and that an authentic understanding of the challenges experienced was fundamental for future similar public health crises.

Carers have expressed concern related to the uncertainty of services' recommencement (Giebel et al., 2020; FCI, 2020c). When our interviews were conducted, many carers spoke (with relief) that support services were starting to re-engage, although, not always at the level of pre-pandemic times. Up until 22nd of January 2022, many restrictions in Irish society remained, reflecting the cautious approach of Government to protect public health, particularly in the context of the most recent COVID-19 variant at the time, Omicron. As the pandemic has persisted, carers may also describe concerns at service reconnection, as the fear of exposure to COVID-19 persists (Muldrew et al., 2021). Thus, emergence from pandemic related restrictions can bring additional concerns and challenging decision-making processes regarding service resumption for care recipients.

In this study, carers were also asked to reflect on their own experience and consider what would have helped them in fostering resilience and coping in the pandemic. Carers spoke of the need to be recognised, heard and valued in society with their inclusion in services, political and care planning discourses. The invisibility of carers in society is noted in the literature, within carer representative groups and has been highlighted in the media. For example, Egan (2020) points to carers being champions of the pandemic and yet, paradoxically, are not

recognised. Chan et al. (2020) suggests that the shut down and lack of comprehensive support for carers is premised on the dubious assumption that carers were able and prepared for the additional responsibilities stemming from the withdrawal or restriction of services. Moreover, some carers in this study spoke of the lack of access to personal protective equipment required to safeguard high risk groups. A lack of availability was also noted by Family Carers Ireland (2020c) who found 47% of carers reported difficulty in accessing personal protective equipment. Similar to other sections of society, such as private and voluntary nursing homes initially, this target group was eclipsed in policy guidance in the context of operationalising the required equipment to safeguarding risk groups (Phelan et al., 2021). Equally, carers in this study voiced a concern that they were not prioritised for vaccination, and this should be a key objective for further vaccination roll outs. This echoes calls by carer representative groups who argue that carers should be considered equivalent to formal caregivers in prioritisation and that vaccinating carers can reduce hospital admissions and, from an ethical stance, protect those at highest risk (FCI, 2021a; Care Alliance Ireland, 2021; Eurocarers, 2021). Participants also expressed frustration at a lack of points of contact, both in terms of services reaching out and carers sourcing assistance. Having a coordinated system and being able to obtain information and sourcing assistance in COVID-19 was considered important in relation to both issues concerning the care recipient and the carer. Future actions should, consequently, reflect the fundamental facilitators of resilience and coping with appropriate support services provided. Of particular concern was the need for person centred care planning in the context of the carers' fears of contracting COVID-19 or in terms of supporting carers with practical assistance to avoid caregiver fatigue and burnout. This concurs with other studies which illustrate the uncertainty and lack of information for carers (FCI, 2020c; Muldrew et al., 2020; Carer Alliance Ireland, 2020).

Financial challenges were also a concern for carers in this study. The provision of care and withdrawal of support services translated to additional fiscal costs. Family Carers Ireland (2020c) note that increased financial concerns were important considerations for over one third of carers. In our study, for example, one participant noted the value of the pandemic unemployment payment (PUP) but identified that no similar support was provided for carers, even though their economic costs could rise due to the public health restrictions' impact on service withdrawal. Concerns on economic hardship in caring can also contribute to mental

health issues and financial strain has direct implications on meeting basic needs such as food and shelter in COVID-19 (Hosking et al. 2020; Lorenz-Dant and Comas-Herrera, 2021; AARP, 2021b).

On reflecting on helping mechanisms, carers emphasised that some form of support should continue, rather than a complete suspension of services, but this needed to be in a format that was acceptable and helpful. As service withdrawal or reduction is linked to increasing challenges for carers (Prasad, 2020), having some form of continued and guaranteed support is, therefore, crucial. Consequentially, a determined focus is needed in policy, political and service responses which transcends protectionism to balancing unintended consequences which negatively impact on the carer, the care recipient and the family (Masterson-Algar et al. 2021).

4.3 Strengths and limitations of the study

As with all research, the findings of the current study need to be considered in light of considerations pertinent to its strengths and limitations as shown in table 4.1.

Table 4.1 Strengths and limitations of the study

Study strengths	Study limitations
The study methodology enabled an in-depth exploration of participants' caring experiences during the COVID-19 pandemic.	Consistent with qualitative research, the study sample is small. Therefore, findings are not representative of all carers during the COVID-19 pandemic.
Inclusion of adapted photovoice methodology supported access to and enhanced understanding of the everyday worlds of those carers interviewed.	Data collection occurred during the COVID-19 pandemic and the accompanying challenges encountered by carers. The impact of this on potential participants' ability to participate in the study is unknown.
The use of an adapted photovoice methodology further supported participant control over what they wished to share in interview and provided a visual methodological opportunity for researchers to enhance meaningful and shared engagement with those interviewed.	Interviews were conducted via telephone due to pandemic related considerations. While this supported participant inclusion, the conduct of face-to-face interviews might have supported variance in responses. However, a tenet of qualitative research is that data is produced within the moment of

	interview as a co-production between participant and researcher and is therefore understood to not be replicable.
Participants in the study were all experienced carers. This added a richness and depth to the data including comparing and contrasting pre and intra pandemic caring perspectives to demonstrate the impact of COVID-19 on caring.	Due to the characteristics of the participant sample, the study findings do not include the perspectives of less experienced carers who may have had complementary or contrasting experiences to add.
	Almost all participants were female and mothers. This may have contributed to a gender bias in the findings of the study, particularly as research has demonstrated perceptions of caring are influenced by gender.

4.4 Summary

- The experience of carers in this study concurs with the extant literature on how carers had managed caring activities before COVID-19 and during COVID-19.
- Carers demonstrated an exacerbation of existing challenges while other challenges arose due to the additional responsibilities of keeping their care recipients safe and adhering to public health restrictions.
- Similar to the extant literature on carers' experiences in the pandemic, participants demonstrated high stress levels impacting psychological and physical health.
- Carers found themselves in a position of uncertainty as services were suspended or reduced with little idea of when these would revert to pre-pandemic levels.
- Strengths and limitations of the study have been identified.
- The final chapter will conclude the report and present the recommendations identified following the interpretation of participant experiences in Chapter 4 and their consideration in the light of national and international empirical and policy literature.

Chapter 5 Conclusion and Recommendations

5.1 In conclusion

COVID-19 created a health and social care crisis unprecedented in modern history. The mobilisation of responses focused heavily on protection, yet one of highest risk groups, care recipients and carers, were subject to service suspension leading to the exacerbation of existing stresses and creation of new challenges. This compounds the reality of a taken for granted valuable workforce, who are already invisible in health and social care systems. Barry (2021) argues for the urgent prioritisation of this care economy. There is a fundamental need to support carers and reduce the impact of the additional responsibilities they experience everyday but particularly those assumed in COVID-19. In particular, this means addressing mental and physical health (Bergman and Wagner, 2021) and supporting carers comprehensively (Brooks et al., 2020). This should involve a co-production of acceptable interventions and supports that are fit for purpose and flexible to provide person centred coordinated care. In conclusion, our study adds to the body of literature describing the life world of carers in COVID-19. Given the projected increase of the prevalence of carers in the future, the fact that this may not be the last pandemic (Craven et al., 2020) and due to issues such as better healthcare and longer life expectancies, it is imperative that the eclipsing of carers is addressed and that they are framed as equal and valued stakeholders in people centred healthcare systems (WHO, 2007; 2013; 2015), underpinned by appropriate structural supports (Budnick et al., 2021).

5.2 Recommendations

The following recommendations are advanced further to consideration of the findings identified in the study.

Recommendation focus:	It is recommended that:
1. Recognition of carers	<ul style="list-style-type: none">• The place and role of carers is given official policy and service recognition.• That carers be viewed as experts in care in light of their knowledge and experience.

	<ul style="list-style-type: none"> • That the needs of carers arising from pandemic induced impacts on caring are elicited and addressed to support the caring role, and the health and welfare of carers and care recipients. • That a formal means of carer identification is advanced to support carer recognition in the context of pandemic related restrictions.
<p>2. Financial and material supports</p>	<ul style="list-style-type: none"> • Similar to other groupings in society that received targeted financial supports in the pandemic, carers are provided with financial supports to meet the added costs of caring encountered during such times. These costs can include increased household bills, equipment purchase and household modifications. Such costs are faced by carers who frequently have to reduce working hours or withdraw from paid employment to undertake caring roles. • That a system to support efficient and sufficient access to material resources including Personal Protective Equipment (PPE) is established for carers.
<p>3. Building circles of support for carers</p>	<ul style="list-style-type: none"> • Similar to proposals from Family Carers Ireland, this study advocates for the appointment of named Carer Advisers allocated to individual carers be considered to function as proactive points of contact to support information provision and connection to available services and supports. • Family carers and care recipients are supported with a person-centred and needs driven care plan with in-built contingency or emergency care planning. Such care plans could be developed concurrent to standardised care recipient assessments and should be subject to ongoing review in light of the dynamic and frequently

	<p>progressive nature of care recipient needs. As the findings of the current study show, needs can be amplified in the context of circumstances which reduce or remove existing services and access to social and other outlets.</p> <ul style="list-style-type: none"> • That a relationship-centred approach to care be adopted incorporating consideration of the triad of care recipient, carer and service provider in the context of care planning and service delivery.
<p>4. Enhanced service integration and reduction in fragmentation</p>	<ul style="list-style-type: none"> • The landscape of service provision be reviewed to identify points of intersection and fragmentation to understand the potential to establish service/care pathways that support a more integrated and timelier caring journey for carers and care recipients. • Carers need to be proactively included in planning and delivery of service provision with recognition in political, service and policy discourses.

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Appendix 1

Photos

The report contains 2 photos from each participant. Some are contained in the findings section. Here we present the other photographs.



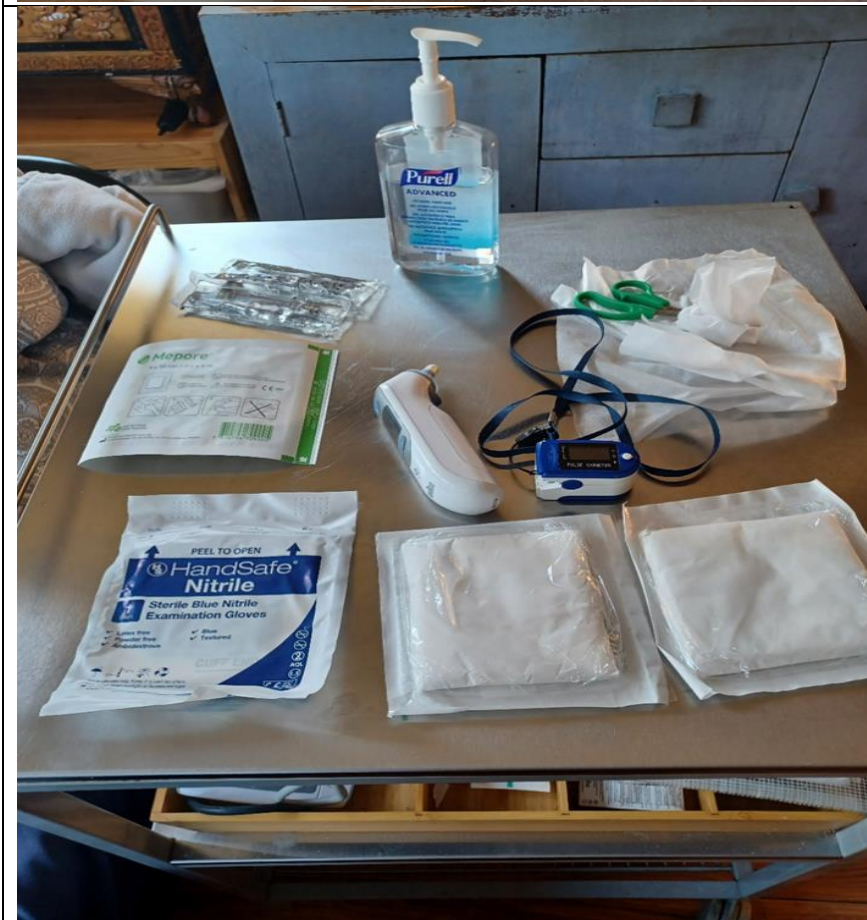
Getting the bumbalance (children's ambulance) to help with transport to a hospital appointment (Participant 9)



Care recipient sleeping beside the carer as needs multiple turns (Participant 5)



Caring at home
(Participant 5)



Changing the
dressing every 2 days
and monitoring
oxygen (Participant
7)



Closed door-
everything closed at
once (Participant 6)



Sign put up early to
warn the postman
of care recipient's
risk (Participant 13)



Art therapy helped keep the care recipient occupied (Participant 11)



Some of the medications administered during the day (Participant 13)



Coping in a house where the wheelchair won't fit through the door (Participant 15)



Keeping the room nice and warm with a new fire for the care recipient (Participant 15)



Fun outside in the garden enjoying the famous banana bread! (Participant 8)



The first time out in the lockdown-a return to Sunday treats (Participant 8)



Having treatment in
COVID-19
(Participant 7)