

“We’re kind of forgotten about really”

**An exploration into the impact of Covid-19 lockdown
restrictions on unpaid carers of individuals with
disabilities**

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Declaration

This thesis is a product of my own work and is not the result of anything done in collaboration.

I agree that this thesis may be made available for reference at the discretion of the University of Gloucestershire.

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Abstract

This research project aimed to identify how the Covid-19 lockdown restrictions in the UK impacted unpaid carers of individuals with disabilities. This was achieved through the application of a social constructionism methodological framework aided by the adoption of standpoint epistemology to prioritise the voices of the oppressed- the unpaid carers.

The data was collected using an embedded mixed-method approach employing semi-structured interviews and online questionnaires, with a total of 18 participants. The qualitative findings from both research methods were analysed using thematic analysis.

The findings from this research concluded that the lives and routines of unpaid carers have been negatively impacted by the Covid lockdown restrictions due to a variety of reasons such as changes in routines causing behavioural problems for the individual they care for. The restrictions also caused issues with activities such as shopping and attempting to adhere to the lockdown regulations whilst being a primary carer. The findings highlighted how issues already faced by unpaid carers were exacerbated in the pandemic, including their financial struggles. However, the findings of this research also concluded that there were positive outcomes of the lockdown which included more time to spend with family.

Furthermore, the findings helped examine carers' views on vulnerability and what it meant to be 'vulnerable'. It was concluded that the term is not inclusive and ignores the unpaid carers' inflicted vulnerabilities brought about due to their caring responsibilities. The debates surrounding vulnerability aided the discussion on carers views of inclusivity and it was apparent that more needs to be achieved in order to create a more inclusive society.

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1.0 Introduction

1.1 Context

This research project aimed to produce data to identify how Covid-19 lockdown restrictions within the UK have impacted unpaid carers of individuals with disabilities. On the 16th March 2020 it was announced by the UK Health Secretary that all unnecessary social contact must end and that the country will be going into full lockdown as of the 26th March 2020. Individuals were only allowed to leave their homes for essential activities and to exercise outside once per day (UK Government, 2020, cited in McKenzie et al, 2021:1). This is due to a strain of respiratory illness called 'Coronavirus' (Covid-19/Covid), which was officially classed as a 'global pandemic' on the 12th of March 2020 by the World Health Organisation (Baxter, 2020:765). Along with the national lockdown the government also advised all individuals who classed themselves as 'vulnerable' people, which included the elderly, disabled and individuals with underlying health conditions, to 'shield' by remaining at home at all costs (McKenzie et al, 2021:1). These measures were put in place with the intention to slow the spread of the virus and to save lives (Samboma, 2021:266). Those aged over 70 were advised to shield for 12 weeks by remaining at home and keeping social contact to a minimum (Baxter, 2020:765). The lockdown restrictions had significant impact on support services for older people, those with disabilities and those who have chronic conditions which led to an increased reliance on families to provide care at home for these individuals (Lafferty et al, 2021:2). The advice to physically isolate and remain at home to protect oneself and each other from the Covid-19 virus presented difficulties for disabled individuals (Kuper et al, 2020:3), which will be discussed throughout the thesis.

"Theoretical and empirical evidence has revealed that people living with disability are the most vulnerable yet [most] ignored" within societies (Samboma, 2021:265). Those with disabilities suffer from social exclusion as they lack equal opportunities and often have significantly more barriers preventing learning and participation in everyday life (Samboma, 2021:265). It is thus important to recognise the struggles that they faced during the pandemic to highlight these inequalities. Currently there is a paucity of research that explores disability and Covid-19. The research that has been conducted only represents a small margin of the disability population within the UK and does not accurately reflect the wider disability community. This is due to the current data primarily only being gathered from assisted living facilities meaning that many disabled individuals who live at home, alone or with families have not been included (Reed et al, 2020:423). The lack of data gathered about certain groups of disabled individuals "perpetuates the exclusion of disabled people from discussions of health equity and policies that are data driven" (Reeds et al, 2020:423).

Similarly, there is a significant lack of data relating to the experiences of carers within the pandemic and this therefore needed to be explored. An individual who cares for someone can often be referred to as a 'carer' and the exact definition of the term is often debated, for example some definitions state that a 'carer' is someone who

“provides unpaid support to a partner, relative or friend who could not manage to live independently...without this help” (RCGP, 2015 cited in Spencer and Swinglehurst, 2020:213). The reason a person needs to provide this care varies and can be due to issues related to “age, physical or mental health problems, addiction or disability” (Keeley and Clarke, 2003, cited in Knowles et al, 2016:204). The term ‘carer’ can be subjective due to the complexity and everchanging demands of the role (Spicer, 2007:30). Within this research project the participants cared for a range of people including, children, siblings, parents and grandparents. The reasons for providing the care also varied including physical disabilities, cognitive disabilities, learning disabilities and mental health problems.

Research into the topic of carers’ experiences is essential as “consistent evidence [has shown] that the burden on parents who have children with disabilities, or educational or social vulnerabilities, is greater than in the general population” (Coyne et al, 2020; Fontanesi et al, 2020; Masters et al, 2020 cited in Neece et al, 2020:747), and historically have been ignored from a large proportion of social research (Luckasson and Schalock, 2020:2). Furthermore, research has shown that individuals “with disabilities are frequently overlooked in crisis and emergency response [situations], leading to unequal outcomes” (Yates and Dickinson, 2021:1). This new situation that has arisen from the Covid-19 pandemic has been a great catalyst in enforcing change within the disability research community with the potential to become more inclusive within the data collection process (Luckasson and Schalock, 2020:3).

It is thus essential to carry out research that explores a wider range of experiences within the disability community in order to “create an inclusive pandemic response” (Reed et al, 2020:423), and to ensure that individuals living with disabilities are not forgotten in order to “avoid widening existing disparities” (Armitage and Nellums, 2020:257). Therefore, it is important to carry out comprehensive research using the pandemic as a rare opportunity to articulate and improve the lives of carers and the disabled individuals they care for, currently and in the future (Ebuenyi et al, 2020:2).

1.2 Why is the research being carried out?

In addition to the rationale provided above, this research has a personal connection to me, the researcher, as I have a 24 year old disabled brother. This is the main motivation for the research due to the personal interest and desire to raise awareness of the issues faced by disabled individuals and family members of those with some form of disability. This desire to raise awareness is something which has been a constant aspiration from a young age and was the influence behind my previous piece of research which looked at how being a Young Carer impacted people’s identity as they grew up. The situation that has been brought about due to the Covid-19 lockdown restrictions and regulations have further amplified this need to raise awareness of carers’ struggles. I witnessed first-hand how the restrictions negatively impacted my family. My autistic brother struggled with the change in routine and did not understand why the changes had been put in place. This caused his behaviour to become very challenging due to his frustration of not being able to

leave the house. The term vulnerability was something I noticed early on within the pandemic, the assumption that those are only vulnerable due to 'underlying health conditions' is not always the case. My brother was extremely vulnerable but not because of "health conditions" but rather due to a lack of understanding. If he became ill, he would not understand why and so our family lived in fear of the possibility of him becoming so ill from the virus he had to be hospitalised and put on a ventilator, which would be very difficult for my brother to understand. The uncertainty of the situation made life very stressful and fearful, which is why there is a need to carry out research that focuses on these experiences to give others in similar situations a voice to express the new struggles they have been facing and raise awareness of these battles.

1.3 Research objectives

The aim of this research project was to identify how the Covid-19 lockdown restrictions impacted unpaid carers of individuals with disabilities. In order to meet this aim, two objectives were formulated.

1. To explore how lockdown restrictions affected the lives and routines of unpaid carers and their cared for individual.
2. To critically examine unpaid carers' views of vulnerability and on achieving a transition towards inclusivity.

To meet these objectives a social constructionist methodological framework was used which aims to carry out research to discover information about the participants' own lived experiences (Nicholls, 2019:3). To be able to meet the aim of the research project it was important to apply a standpoint epistemology theory which "starts from the lives of the oppressed" (Cransnow, 2009:190). For this research project the 'oppressed' were the carers of the individuals with disabilities, due to society's medical discourse surrounding disability and caring. This is due to the medical gaze enforced by members of the able-bodied elite (Cameron, 2014:99), which create this stigmatised concept of a "a hierarchy of bodies" (Howe, 2008 cited in French et al, 2018:16). This prospect for carers to be involved within research prioritises their views and offers an opportunity for their experiences to become the forefront of knowledge.

The research was carried out using an embedded mixed methods design, where the findings of the semi-structured interviews and online questionnaire were combined within the analysis process (Bryman, 2016:639). A non-probability convenience sample was used to recruit participants for both research methods, with a total of 18 participants aged between 18-60+, caring for a variety of reasons. The criteria to participate required them to be aged 18+ and provide regular care for an individual with a disability/illness prior and during the Covid-19 lockdowns. The term carer was avoided within the recruitment process due to issues regarding the subjective meanings to the term (Hughes et al, 2013:79) and hence allowed a broad range of participants to be recruited.

The interviews and questionnaires contained similar questions and topics to allow for cross examination of findings. Topics that were focused on included a potential loss of support services, changes in routine, Carer's Allowance and discussions surrounding the term and implications connected to 'vulnerability'. The interviews were transcribed and analysed using thematic analysis to discover the core themes within the research (Babbie, 2016:313). The qualitative responses of the questionnaire were also integrated within the thematic analysis and the quantitative findings allowed for descriptive statistics to be explored. The thematic analysis provided an exploration of the data to meet the research objectives, establishing that the lives and routines of carers had been impacted in multiple ways due to the lockdown restrictions. They have been affected in various ways which includes issues related to exacerbated behavioural issues caused by a change in routine and challenges to adhere to government safety regulations. These findings were accompanied by experiences of isolation, fear and stigmatisation of carers and the individual they provide care for. Furthermore, the findings allowed a clear examination of carers views on the problems and benefits of using terms such as 'vulnerability' and allowed a discussion about achieving a transition towards inclusivity within society for unpaid carers, concluding their financial situation needs to be addressed.

1.4 Structure

This thesis is divided into seven main chapters, which will include discussing the current literature surrounding the topic of Covid-19 and disability along with how the lockdown restrictions worsened previous problems and struggles in chapter two. The theory and methodological approach applied to the research will be discussed in chapters three and four along with any issues that arose during the time of research. Additionally, the findings of both research methods will be discussed in relation to the current academic literature in chapters 5 and 6, which have been divided to focus on each objective. Chapter seven provides a conclusion and reflects on the aim and objectives of this research project to identify how Covid-19 lockdown restrictions have impacted unpaid carers of individuals with disabilities.

2.0 Literature Review

2.1 Introduction

This chapter will discuss the pre-existing literature on disability and carer related issues, Covid related research and how those with disabilities and their carers have been impacted by Covid. The literature selected will discuss topics such as how individuals' lives have been impacted by the Covid restrictions, individuals' opinions on terms such as 'vulnerability', and disability inequalities. Additionally, policy literature will be discussed around Carer's Allowance.

2.2 Disability and Covid-19

According to the Equality Act 2010, the UK government state that a person has a disability if they have "a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities" (Government Equalities Office, 2010:5). However, what it means to be 'disabled' is debated and explored through disability theory in chapter 3.

Individuals with disabilities are statistically more at risk of contracting Covid-19 due to many individuals being reliant upon the physical aid of carers meaning their exposure levels to the virus are increased (Sakellariou et al, 2020:2). Likewise, research has stated that disabled individuals are statistically more at risk because often those with disabilities live in close vicinity to others in care facilities, and individuals who have physical disabilities are reliant on the physical aid of caregivers to assist them on a daily basis meaning social distancing is not possible (Tummers et al, 2020:476). This therefore means that both the disabled individual and the caregiver are at higher risk of spreading and contracting the virus as physical contact is unavoidable due to the dependent care needs (Singh, 2020:2168). Furthermore, individuals who obtain a form of visual disability are often more dependent "on touch or tactile senses to perform their routine activities or outdoor movement which may further increase the chance of getting the infection from the virus" (Senjam, 2020:1368). Social distancing may also be made substantially harder for individuals with visual disabilities as guide dogs have not been trained to respect social distancing measures (Rizzo et al, 2021:416). Additionally, social distancing and shopping related restrictions may be difficult to adhere to due to the inability to leave the care recipient at home without their carer present, worsened by a reduction in support services which will be discussed later within this chapter (Belam, 2020).

Moreover, disabled individuals are statistically more likely to suffer from the virus due to potential underlying health conditions (Sakellariou et al, 2020:2). These health conditions could involve respiratory diseases and may result in an individual being unable to adhere to the government safety requirement of wearing a face covering while in public places, putting themselves and others at greater risk of spreading and catching the airborne virus (Masinter, 2020:3). Data gathered by the Office for

National Statistics (2021, cited in Boyle et al, 2021:1), concluded that “between January to November 2020 approximately two thirds of deaths as a result of coronavirus were disabled people and the risk of death was three times higher for those living with more severe levels of disability”. This statement alone shows the urgency and significance of researching disabled individuals’ experiences and the experiences of those that care for them during the pandemic.

At the beginning of the pandemic there were fears that disabled individuals would not be treated as equals. For example, disabled activist Alice Wong (2020 cited in Abrams and Abbott, 2020:169) stated that she feared that if she was hospitalised from the virus that they “might even take my ventilator for other patients who have a better shot at survival than me...[they] think I’m a waste of their efforts and precious resources”. The disability charity Mencap have also collected accounts of individuals with disabilities being discriminated against and stated that individuals with learning disabilities were told by hospital staff “they would not be resuscitated if they were taken ill with Covid-19” (Tapper, 2021). This fear of disabled lives not being as valuable links to the medical model of disability which examines social utility, basing “how valuable that person will be to society if they are saved” (Scully, 2020:24). The models of disability will be discussed within chapter 3, theoretical positioning.

Disability activists argue that triage frameworks of deciding who to prioritise will always favour “younger and healthier” people over individuals who are “old and sicker, including people with disabilities” (Chen and McNamara, 2020:513). This triage process links to economic productivity of a person within capitalist society. Individuals with disabilities are assumed to be “economically unproductive and therefore a net burden to society” (Scully, 2020:24), hence the fear that disabled lives will be ignored in favour of able-bodied individuals. This medical model approach of assessing people based on their physical capabilities highlights how society perceives disability and shows the necessity in challenging “the systemic discrimination and pervasive attitudes that are still held about people with disabilities across the medical” industry (Chen and McNamara, 2020:517).

2.3 Early Covid-19 disability research

A previous study that explored similar themes to this research was carried out in America by Neece et al (2020) between March and May 2020. It is noted that lockdown restrictions may have been slightly different, but the virtuous findings remain valuable to this research project. The research involved 77 parents of children with some form of learning disability who range from ages 3-5 years old, who were asked about their experiences during the early months of the Covid-19 pandemic. The research was completed via structured telephone interviews consisting of 5 questions covering topics such as the biggest challenges, the positives that arose, coping strategies and the feared long-term impacts.

The findings from these structured interviews were transcribed and analysed using thematic analysis. Parents were asked about the challenges they faced, and this research project concluded that the biggest challenge for parents with children who

have learning disabilities was the difficulty of being home constantly- 56% of parents stated this was the hardest part of the pandemic for their families (Neece et al, 2020:742). This may be due to the fact that 78% of parents also stated that due to Covid-19 access to their children services decreased (Neece et al, 2020:742) which would suggest a correlation to the increased time spent at home.

One parent stated that “the hardest thing has been for my children because they cannot go out, they are starting to go crazy and are bored of doing the same things” (Neece et al, 2020:742). Furthermore, the difficulties of being home constantly have been amplified by their children’s behavioural problems, which 32% of parents mentioned as the biggest challenge. For example, one parent stated her child’s behavioural issues have arisen “because she does not have her routine anymore and has moments where she does not want to do anything” (Neece et al, 2020:742). This study is a good example of previous work that this research project aims to replicate and build upon.

2.4 How has Covid-19 impacted the lives of carers and individuals with disabilities?

Research has shown that Covid-19 had negative impacts on carers and their cared for individuals. This included a loss of support services due to the lockdown restrictions, which worsened social isolation for carers and individuals with disabilities. Similarly, the lockdown caused a change in routine which has been evidenced to be very distressing for some individuals with disabilities and lead to an increase in challenging behaviour, resultant in caring responsibilities to be harder.

2.4.1 Social isolation and loss of support services

Many ‘able-bodied’ members of society experienced loneliness and isolation as a result of lockdown restrictions, this is a common occurrence for individuals with disabilities both prior to and during Covid-19 restrictions (Ebuenyi et al, 2020:2). This concept of social isolation is also a phenomenon experienced by the carers of these individuals prior to the lockdown restrictions and has been evidenced to be a significant issue for many carers (Greenwood et al, 2012:10). Isolation can be a result of many causes, such as the belief that family and friends of the carer are perceived to have “lack of understanding, empathy and support” which results in the carer isolating oneself from these people and cutting social ties (Broady et al, 2017:225). The nature of their caring role and individuals’ disability can often make carers feel stigmatised resulting in this self-isolation (Cormac and Tihanyi, 2006:163). The topic of stigmatisation is explored further within disability theory in chapter 3.

The feeling that carers are excluded and isolated from friends and family can result in carers feeling trapped, resentful, angry or upset and excluded from society (Cormac and Tihanyi, 2006:164). This isolation can often result in stress, anxiety and depression so it is important carers are offered support and services to reduce any of

these adverse impacts of caring (Greenwood et al, 2012:2). Services may be offered in the form of respite for the individual they provide care for, giving the carer “a sense of ‘freedom’ and ‘normality’” (Greenwood et al, 2012:3). Support services enable a proportion of the caring duties and responsibilities to be transferred elsewhere alleviating the care givers’ stress and providing time without their dependant (Giebel et al, 2020:6). The break from their caring responsibilities, even if this is only a short amount of time, can have significant positive effects upon a carer (Twigg and Atkin, 1995 cited in Lloyd, 2006:953).

However due to the lockdown restrictions many carers lost their services for themselves and their care recipient, whether these were formal or informal types of support, due to social distancing measures (Lafferty et al, 2021:2). Carers UK surveyed 8000 unpaid carers and more than half of those involved stated that they “have lost some or all of the support they need, since the pandemic” (Burns, 2021). The lack of support services results in damaging effects on carers with some stating the person they care for and themselves “both feel completely and utterly alone. We feel that nobody cares” (Burns, 2021). Support services which continued online may have been beneficial for some individuals but for others, such as unpaid carers, not having physical home visits from their support network meant losing the opportunity for a break from their dependant (Schariti and McWilliam, 2021:3).

Many carers who could continue to have paid home care were required to make the challenging decision of discounting this support or continuing to let multiple care workers enter their home, increasing the risk of contracting the Covid-19 virus for both themselves and their care recipient. Deciding not to seek external support inevitably led to an increased burden of sole caring responsibilities for unpaid carers (Giebel et al, 2020:6). Those that had to accept the potential risks by continuing with their support services were forced to do so due to being unable to cope otherwise (Giebel et al, 2020:7). Carers who lost their usual support services have reported amplified feelings of loneliness and isolation (Lafferty et al, 2021:6). The lack of help meant many carers had to perform what has been referred to as the “juggling act”, which involves accommodating for work demands and their dependant’s care needs, causing many carers to reach a “crisis point” (Lafferty et al, 2021:5).

2.4.2 Changes to routine

The pandemic response has been difficult for everyone, but for those with disabilities and their carers it has been extremely challenging. A common theme within current research is the difficulties associated with the changes in routines. This has been a significant issue for parents of children who are on the autistic spectrum as their children have found the disruption to their usual daily routine very distressing (Singh, 2020:2168). This is due to a reliance on “routine, structure and predictability” (McKenzie et al, 2021:2). This was a substantial finding within the Neece et al (2020) research discussed earlier. Individuals with intellectual disabilities found the lockdown significantly difficult due to “increased confusion and distress” as to why their usual routines have been disrupted (Grier et al, 2020 cited in McKenzie et al, 2021:2). The importance of these routines and regulations for individuals on the

autism spectrum cannot be underestimated as they can become very distressed by any alterations to their usual structure, which can be challenging for the individual themselves and for those that care for them (Alhuzimi, 2020:3). Not being able to attend schools has been noted by many parents within multiple research studies as a central issue impacting routine, for example one parent stated that “the biggest issue for me is schools closing. I have 3 children on the autism spectrum (with other learning needs) and am a sole parent” (Yates and Dickinson, 2021:3). This quote shows that the changes to their family’s routines have had a massive negative impact upon everyone with some families stating they have “struggled to cope” (Yates and Dickinson, 2021:3). This has been a common occurrence for parents, especially for mothers, who often were in charge of having to home school their children. Furthermore, the closing of schools resulted in a loss of childcare affecting parents’ ability to go to work (Cottam, 2021:4). The closing of schools and the transition to home schooling was significantly difficult for parents with children who have additional needs as they often require “more intensive services and support than children with typical development” (Neece et al, 2020:740). Research has evidenced the unequal divide of care during the pandemic and conclude that mothers were more likely than fathers to have been the parent forced to leave work since the pandemic began, plus mothers are also more likely to have to juggle work hours while simultaneously caring for their dependent child (Andrew et al, 2020)

Research carried out between 15th April to the 15th May 2020, focused on investigating participants’ emotional reactions to the Covid-19 response, as well as their concerns and expectations. The research was carried out through two structured surveys, one survey aimed at parents with disabled children aged 0-18+ and the other survey targeted at disabled adolescents aged 13+ (Silvia et al, 2021:2). There was a higher number of parents that took part in the survey with a total of 239 parents aged 33-55 with 81% being parents to a child with a motor disability. In the adolescent survey there were only 53 participants (Silvia et al, 2021:4). The survey aimed at the parents found that 41% of the participants “complained of the excessive burden of taking care of the family” (Silvia et al, 2021:5). It is not clear what these additional burdens are but evidence from other research suggests this could be linked to the struggles of a change in routine for their children or it could be due to schools closing and parents being solely responsible for their learning and care. Although the findings from this survey are useful and show clear similarities with other research carried out around the topic there are some weaknesses. For example, the research was carried out online which instantly discriminates against anyone who does not have access to an online device and further excludes anyone with reading or writing difficulties (Silvia et al, 2021:11). It is important when researching the lived experiences of people with disabilities and their carers that research is inclusive in how it recruits participants and collects data.

2.5 Emotional and material impacts of the pandemic on carers

Research has shown that there have been significant psychological effects on carers due to the requirement to quarantine, for example it has resulted in “post-traumatic

stress symptoms, confusion, anger, frustration, boredom, financial loss and stigma” (Brooks et al, 2020 cited in Neece et al, 2020:740). Parents of children with a form of disability compared to those caring for a “typically developing” child experience “higher rates of mental health issues, including stress, anxiety and depression” without including the impacts of a global pandemic (Green 2003, cited in Broady et al, 2017:225). Recent evidence concludes that the pandemic has amplified these issues for carers and has increased psychological distress on all individuals within society (Goldmann and Galea, 2020 cited in Samboma, 2021:266). Research carried out by Yates and Dickinson (2021:2) in Australia, found that 82% of 697 individuals stated that they felt there was a significant lack of information and help targeted towards disabled families which exacerbated the distress and uncertainty in an already stressful situation.

The unique experience that has been brought about by the pandemic has allowed members of the general population to experience first-hand some of the feelings and frustrations that individuals with disabilities have to experience on a daily basis (Armitage and Nellums, 2020 cited in Ebuanyi et al, 2020:1). For example, the nationwide feeling of confusion and frustration at the lack of accessible, clear information about the restrictions and guidelines that were put in place, was something that was experienced by many members of society from all backgrounds throughout the pandemic (Ebuanyi et al, 2020:2). Prior to the pandemic this lack of accessible information has often been a daily struggle for individuals with disabilities, such as not having accessible formats available like braille documents or sign language interpreters present (Senjam, 2020:1368). This lack of accessible information for those with disabilities has been constant across the lockdowns with public health information often not being provided within an accessible format (Yates and Dickinson, 2021:2). The information barriers of the pandemic response have amplified such inequalities (Armitage and Nellums, 2020 cited in Singh, 2020:2168) and has “exposed [the] persistent digital inequalities” within society (Samboma, 2021:267). The lack of information “left many families uncertain of what to do, particularly in the early days of the pandemic” (Yates and Dickinson, 2021:3). This now universal experience of trying to navigate inaccessible information is a frustration widely shared within society and could draw attention to the need for accessible information for all (Saurabh et al, 2020:260).

Furthermore, the impact upon some parents of disabled children has been so severe that they have struggled to cope due to being “mentally drained, depressed and feel so alone” which has been exacerbated by having “no family or friends for support” (Yates and Dickinson, 2021:3). The lack of support for carers has been seen as a common occurrence especially when issues arise such as the carers themselves being ill or being required to self-isolate but lacking sufficient care agencies to find substitute support for their dependant (Kuper et al, 2020:3). This further puts the disabled individual at substantial risk of contracting the virus and intensifies the stress upon the carer.

The research carried out by Silvia et al (2021) found that 19% of parents reported experiencing significant financial difficulties since the beginning of the original lockdown in 2020, a phenomenon experienced by many parents of disabled and

non-disabled children across the country. Additionally, research has shown that parents experiencing financial stress are more likely to encounter feelings of reduced wellbeing which consequently may “exacerbate negative parenting practices, which in turn leads to increased behaviour and emotional problems for children with intellectual disabilities” (Totsika et al, 2020 cited in Bailey et al, 2021:398). This may add to the struggles relating the changes to their child’s routine.

There have, however, been benefits of the lockdown, for example Neece et al (2020:743) found that 49% of participants stated that they were glad to have more time at home to spend with their family. This increased time spent together provided an opportunity to bring families closer together (Lafferty et al, 2021:6). Similarly, the research carried out by Silvia et al (2021:5) with parents and their disabled adolescent children found that 64% of the children involved in the survey stated that they were “pleased to spend more time with their families” due to the lockdown situation. However only 27% of parents stated that they were happy about the increased amount of time spent together at home (Silvia et al, 2021:5). The lower percentage from the parents may be due to many causal factors such as the additional burden of care or the unprecedented financial struggles which parents have been faced with across the country due to the lockdown, therefore hindering their enthusiasm to spend excessive amount of time at home with their dependent children.

2.5.1 The financial struggles faced by carers

Financial struggles and poverty are two issues which go hand in hand and have been problems faced by carers for many years prior to the pandemic (Hughes, 2007:32). It is estimated that there are approximately 2.1 million unpaid carers across the UK living in poverty (Aldridge and Hughes, 2016:4).

Those with caring responsibilities are frequently required to reduce the number of hours they are available to participate in paid employment or often it is mandatory to stop paid employment all together, resulting in significant financial hardship (Spencer and Swinglehurst, 2020:216). A study carried out by Carers UK (2019, cited in Spencer and Swinglehurst, 2020:216), found that 38% of carers had been required to give up their paid employment and 18% needed to significantly reduce their working hours, only 4% of their participants stated their caring responsibilities had not affected their capacity to work. Research also states that even if a carer is able to access paid employment, they are less likely to be in a position that would pay for their poverty to be elevated (Lloyd, 2006:951) and are extremely unlikely to have access to disposable income Jesus et al, 2020:2). The inability to access significant financial employment opportunities for carers have been further amplified by the closing of schools, during the pandemic, resulting in a loss of childcare for their dependent children, ultimately meaning attending a job outside the home became more challenging or in some cases, impossible (Cottam, 2021:4).

The UK Government have acknowledged the financial impact caring has upon an individual and offers carers social welfare to try to tackle their problems (Alcock et al,

2016:21). This financial aid is provided in the form of a benefit called 'Carer's Allowance' however not every carer is eligible for this benefit and therefore to qualify must meet a set list of criteria (Spencer and Swinglehurst, 2020:216). The individual applying for the benefit must provide care for the individual they support for a minimum of 35 hours a week or more and will receive a sum of £67.60 a week (Carers UK, 2021). In order to be entitled to the financial support the individual they care for must be a recipient of certain benefits (Spencer and Swinglehurst, 2020:216), the person applying must be 16 years or older and must not be in full time education or earn over £128 a week (Carers UK, 2021). The UK Parliament Work and Pensions Committee criticise the eligibility criteria, specifically the weekly earnings limit, as they argue it is almost impossible for carers to combine both their caring responsibilities with paid employment, as they will lose their entitlement to Carer's Allowance if they earn a penny over the specified limit (UK Parliament, 2008 cited in Cantillon and Kirk, 2020:5). It could therefore be argued the earning allowance of £128 a week needs to be reviewed and potentially increased.

However despite the aim at financially supporting carers Coppola (2021:3) states that "carers' income is pitiful...[and is] far less than even universal credit" and therefore campaign organisations continue to advocate for an increased benefit level for carers to help avoid the poverty trap that exists with the current levels of benefits (Lloyd, 2006:950). Additionally, only one person is allowed to claim Carer's Allowance per individual cared for (Carers UK, 2021), for example only one parent would be entitled to the benefit for caring for their disabled child. If the care demands resulted in neither parent being able to access full time paid employment the family would struggle significant financial problems. Moreover, the benefit is to help with the additional living costs for individuals with disabilities which means if a carer cannot work alongside their role they are significantly financially impacted as the benefit payment exists in the aim to compensate for the additional costs, not provide the recipient with the finances to be "materially better off than someone without a disability" (Aldridge and Hughes, 2016:11). But evidence suggests that the current amount doesn't fully cover the costs of care and "more than two thirds (68%) of carers are using their own income or savings to cover the cost of care" (Cantillon and Kirk 2020:5). It can be argued that this pitiful amount also does not factor in the mental stress that carers and their families are under due to the nature of the caring and their difficult financial situation (Cottam, 2021:29).

Therefore, the financial issues affecting carers are a necessity to address within research in order for carers to be appropriately rewarded for their services and create an inclusive and equal society for all. This is crucial as Parker and Clarke (2002, cited in Lloyd, 2006:955) argue that their unpaid care services play "an essential role in maintaining low levels of social care service provision". It is estimated that these unpaid care services "save the UK economy approximately £119 billion per year" (Buckner and Yeandle, 2011 cited in Knowles et al, 2016:203) and therefore their services should be compensated and categorised as a core investment of essential infrastructure (Cottam, 2021:30). In order to save such a huge amount of money the government requires carers to be self-sacrificing and even small changes to income could have a large impact on a carers' financial

position (Lloyd, 2006:952). This “levelling up” of financial support will help carers gain the recognition for the care work they provide (Cottam, 2021:30).

This concept of “levelling up” or addressing the issues related with the benefit, is an idea suggested within research as the current system is argued to be “outdated”. In addition to the suggested “levelling up”, the idea of replacing the current method with a “two-tiered benefit for carers” covering not only carers support allowance but also a caring costs payment, in an attempt to increase carers finances and become more representative of the financial demands of caring (Cass and Yeandle, 2009:28).

Increasing financial aid for carers is a possible phenomenon and has been evidenced by the Scottish Government who announced in June 2021 that more than 91,000 carers in Scotland will receive an extra payment of Carer’s Allowance in December 2021 of £231.40. This additional investment is estimated to cost £21 million and will be the second time the Scottish Government have provided a doubled Carer’s Allowance supplement (Scottish Fiscal Commission, 2021). This shows that it is possible to increase financial help for carers. The UK government has stated that it “will take steps to ensure that unpaid carers have the support, advice and respite they need” (Burns, 2021), but as yet there has been no expansion upon these unfulfilled promises.

2.6 Negotiating ‘vulnerability’

Throughout the pandemic, the media, government reports and social commentators often used the terms ‘vulnerable’, ‘pre-existing’ and ‘underlying health conditions’ which “quickly became a shorthand for a significant othering of people affected by the virus” (Ktendis, 2020 cited in Abrams and Abbott, 2020:168). These connotations were often linked to individuals with disabilities and highlighted the ableist discourse associated with the medical model of disability, which is explored in chapter 3. However, policy makers often “conflate impairment that leads to disablement, with health status”, which is not always connected (Scully, 2020). ‘Othering’ is an important theme that will be explored and debated within this research project through discussing the term “vulnerability”. This is because research states that the term ‘vulnerable’ “does not include all people in need” (Kuper et al, 2020:3). This will be explored by identifying whether the participant and the person they care for were described as being vulnerable or if they felt vulnerable in relation to the virus, along with potential criticisms of the definitions and categories constructed due to the negative impacts the label of ‘vulnerable’ may have had.

Many individuals with some forms of ‘disability’ were not defined as “vulnerable enough” to be granted the temporary forms of government support offered to those termed as ‘vulnerable’. This resulted in 55% of disabled adults included in a survey carried out in May 2020, stating that they found it difficult to access “groceries, medication and essentials” (ONS, 2020 cited in Eskyte et al, 2020:332). The Guardian investigated the impact of being left off the coronavirus ‘vulnerable list’, with many individuals writing in explaining their disability has been ignored including individuals with motor neurone diseases, cancer, intellectual disabilities and many

more not making the 'vulnerable list' (Ryan, 2020). This resulted in many individuals not being able to access priority online shopping slots for their food deliveries (Eskyte, 2020:331). This forced a "huge number of disabled people... to put their health at risk by going to the supermarket" themselves, according to disability charity Scope (Ryan, 2020). Additionally, it was found that those who managed to obtain support from their friends, family or neighbours often felt they were "less independent and...[had] reduced choice" and would prefer the delivery slots if they could access them (Ryan, 2020 cited in Eskyte, 2020:331).

In addition, even disabled individuals who were defined as 'vulnerable' struggled to access the services provided by the government such as priority delivery slots from supermarkets (Jahshan, 2020; SCOPE, 2020 cited in Eskyte et al, 2020:332). Therefore, this link between the social construction of the terminology and definitions associated to the concept of being vulnerable, defined by elite members of society, must be discussed using a critical approach to assess the impact this had on the lives of carers and their disabled individuals.

Furthermore, concerns and fears arose for carers from not being labelled as being a member of the "highest risk groups for COVID-19" (Egan, 2020:2). This is due to fears of them becoming ill and becoming unable to provide the required support for the person they care for. Their responsibilities made them susceptible to vulnerability and forced them to 'shield' to protect themselves and their care dependant from the virus in order to remain healthy and to continue carrying out their responsibilities. The term "shielding by proxy" was used to describe this situation (Maitra, 2020:3106). The list of those who were "vulnerable" has been argued to have "completely missed the point" due to not including individuals on this list whose additional needs and responsibilities "would not go away because of a pandemic" (Turner, 2021:68), such as unpaid carers and the individuals they care for.

Previous disability studies evidence issues related to labelling disabled individuals. This rejection of labels is not a new phenomenon and research carried out by Stalker (2002, cited in Lloyd, 2006:954) states that their disabled participants found certain labels to be "intrusive or culturally inappropriate". For example, Liebowitz (2015) discusses how they do not "want to be identified solely on the basis of my disabilities" and it is therefore important to acknowledge the discriminatory language used as harmful labels can lead to long lasting damage that may result in social withdrawal (Broady et al, 2017:226). Preferences in relation to labels and terms varies from person to person, for example Liebowitz (2015) states that "instead of disabled person, we are urged to say person with a disability" (Liebowitz, 2015) and this has been adhered to where possible within this research project in order to avoid harmful or inappropriate terms.

These labels can be rejected for many reasons, for example previous literature states that mothers of children with a form of disability are victims of a form of disablism that emerges from the traditional medical model of disability which emphasises the burden of looking after a child with a disability (Ryan and Runswick-Cole 2008, cited in Broady et al, 2017:226). The medical model of disability is explored within the next chapter. This rejection of labels can also be due to an active

rejection of the idea the individual needs help, for example a carer stated, “the hardest part of my dad was him admitting, in himself, that he was ill” (Knowles et al, 2016:208). This denial of needing assistance can be applied to the situation brought about by the pandemic. For example, the above research by Ryan (2020, cited in Eskyte, 2020:331) demonstrates how individuals with disabilities would prefer to remain independent rather than having to be forced to rely upon someone else. Additionally, many individuals who provide care and assistance for dependant people actively chose to not identify as a ‘carer’ due the perception they are providing this help as part of normal life (Hughes et al, 2013:79). Individuals may solely view themselves as a parent or friend rather than a ‘carer’, perhaps due to the feminisation of care and/or resisting the formality of the label ‘carer’ (Spencer and Swinglehurst, 2020:214). This feminisation of care is said to be deep-rooted and the roles are often gendered with women’s care tasks taken for granted (Hochschild and Machung, 2012:54). This concept of gendered care is suggested to be located within the “normative framework of obligations and responsibility” (Cass and Yeandle, 2009:22). Furthermore, individuals who provide care may reject labels due to fear of being labelled as incapable of carrying out their role efficiently if they ask for help and can lead to feelings of judgement and shame (Knowles et al, 2016:210).

2.7 The future impact of the pandemic on the lives of individuals with disabilities and their carers

The majority of research carried out regarding future concerns about the pandemic has found many negative assumptions about the long-term impacts it will have upon people’s lives. For example, Silvia et al (2021:7), found that both parents and adolescents (60% and 74%) involved in their survey expressed concern about the uncertainty regarding when the pandemic and the lockdown measures would end. Similarly, Neece et al (2020:744) identified that 29% out of their 77 participants stated that their main concern for the future was connected to their economic position.

There have been concerns raised in the media by social care providers stating they are facing a staffing crisis due to “losing staff to better paid jobs in retail and hospitality” (Burns, 2021), and they are currently unable to recruit replacements. This staffing shortage has been further amplified by the threatened requirement of all NHS care workers to be vaccinated against Covid-19 (Allegretti, 2021). This has resulted in a “tsunami of unmet need[s]” and fears are expressed for this issue to persist throughout the winter of 2021 and potentially further (Burns, 2021). The lack of external care workers to assist unpaid carers may result in continued struggles that have already been discussed about the effects of losing support services.

However there have been some positives that have arisen from the pandemic response, for example the demand for remote working potentially “adds to a diverse workforce inclusive of people with varied disabilities” (Singh, 2020:2169). This new norm of working and socialising from one’s own home has potential long-term benefits (Abrams and Abbott, 2020:172) for not only the disabled individual but also

the caregiver who may now be able to be more active outside their family setting without having to leave their dependant. This has been aided by the widespread use of online programs such as Microsoft Teams or Zoom (Bubb and Jones, 2020:213). Furthermore, previous research has discovered the positive affect that the lockdown had by granting the opportunity for families to spend more time together at home ultimately creating a stronger family bond which holds positive future impacts (Lafferty et al, 2021:6). Likewise, communities have come together more to help each other out creating connections which may not have been made without the pandemic. These community bonds have been aided by the creation of community WhatsApp groups providing virtual support (Cottam, 2021:3).

2.8 Summary

While it has been reiterated by politicians frequently “that Covid-19 does not discriminate, [it is clear] our underlying social structures and systems mean some groups are more at risk in a pandemic context and are therefore more affected than others” (Yates and Dickinson, 2021:1). This can be seen in the evidence discussed in the above sections; for example, the fear that those with disabilities will be a victim to the medical triage process and not be prioritised for medical intervention due to underlying and often unspoken assumptions that disabled individuals are less worthy due to their potential lack of physical abilities. This societal discrimination can also be evidenced by the inability to gain access to accessible information regarding to the pandemic, for example the lack of sign language interpreters at major press conferences. It is therefore essential to establish the direct impact that Covid-19 has had upon disabled individuals and their carers in order to understand the struggles they have experienced due to the discrimination inbuilt within society’s structures. The “one size fits all approach...cannot effectively meet the needs and desires of the broad range of people with disability” (Dickinson, 2017 cited in Yates and Dickinson, 2021:3). It is thus vital to research disability related issues from the perspective of someone who has an understanding of disability with the aim of creating “a more equitable and healthier society” (Reed et al, 2020:423).

Therefore, this research project will focus on unpaid carers experiences of lockdown asking how it affected their lives, exploring the impact a loss of support services has upon routines and carers wellbeing. The challenges of adhering to regulations will also be discovered and carers views on terms such as vulnerability will be discussed along with suggestions on achieving a transition towards inclusivity.

The next chapter will be examining the relevant theory that will be applied to this research project including a discussion of the models of disability.

3.0 Theoretical Positioning

3.1 Introduction

The term “disability” is often contested and debated (Linton, 1998 cited in Vaccaro et al, 2015:28), it is therefore essential to explore the theory behind what the term means by examining the key models of disability. This chapter will outline the approach taken to disability in this research and how this is situated within dominant sociological literature around disability. Contemporary understandings arise from two key models of disability, the medical and the social model.

3.2 The medical model of disability

The medical model of disability emerged as a result of the late 19th century industrial revolution which created the importance of ‘productivity’ in relation to “the normal body” (Lucas et al, 2018:2). An individual is defined as disabled within this model if they lack the ability to carry out productive activities in the same way a person who is considered “normal” would, due to their impairment (Thomas, 2007 cited in French et al, 2018:16). This model primarily focuses on the medical diagnosis and treatment factors (Burke, 2008:13), which can be extremely damaging, leading to “stigmatization and alienation because it ultimately creates a hierarchy of bodies” (Howe, 2008 cited in French et al, 2018:16). The medical model enforces the medical ‘gaze’ which establishes disability as a problem for the individual themselves rather than an issue for society in general (Cameron, 2014:99).

This concept of disability being an individual’s “problem” results in resources being targeted at “disabled individuals” with a view to “fix” them enabling them to participate in society, however society and the environment around them is regarded as unproblematic, ignoring unequal access to opportunities (Cameron, 2014:99).

This results in the focus being on the individual’s impairment and differences (Bradshaw and Minogue, 2020:147), diverting attention away from the vital need for “collective political solutions” (Armstrong and Barton, 1999:223; Oliver, 1990 cited in Matthews, 2009:231).

The medical model is criticised by disability rights movements as it relies on cultural assumptions of what it means to be “normal” (French et al, 2018:16), defined by those with power, signifying that societal constructions are based on unequal power relationships (Burke, 2008:15). It is further criticised as it relies solely on medical diagnoses (Shakespeare, 2013; Siebers, 2013 cited in Lucas et al, 2018:3), created by those with the power to create ‘acceptable’ forms of knowledge. Therefore, the medical model will not be applied to this research project due to its incompatibility with social constructionism’s epistemological beliefs, which are outlined in chapter 4. Furthermore, the medical model will not be adopted within this research due to the potential negative impact this model may have upon participants if a researcher were to ask questions in a way that suggests that the disabled individual themselves ‘are

the problem'. However, it is important to acknowledge the existence of the model and to be able to criticise its approach to disability from a standpoint perspective.

3.3 The social model of disability

An alternative model of disability is the 'social model of disability', introduced in the late 1970s (Waldschmidt et al, 2017:20) from "political activism of disabled people's movement" (Brownlee and Cureton, 2009:89). It states that rather than oppression being caused solely by an individual's impairment, as suggested by the medical model, it is in fact the social barriers, both structural and societal that cause the social oppression that disabled individuals face (French et al, 2018:18). For example, an environment becomes disabling if the physical space is created without the thought or regard for the needs of individuals with disabilities (Rocco and Delgado, 2011:6), such as a building with only stair access and no ramp for wheelchair users.

Under this model, disability arises as an "outcome of an oppressive relationship between people with impairment and the rest of society" (Finkelstein, 1980:47 cited in Barnes, 2012:475), through the societal practices of 'disablement' that results in the disability becoming apparent (Waldschmidt et al, 2017:20). Society is constructed in a way that causes non-disabled individuals to be privileged and those with disabilities penalised (Brownlee and Cureton, 2009:21). This construction indicates that "for every oppressed group there is a group that is privileged in relation to that group" (Young, 1990:42, cited in Cameron, 2014:110). Disability is only viewed as a 'negative' thing because society has created and labelled it in that way (Liebowitz, 2015). The impact of labelling an individual with a disability as 'different' or even as 'deviant' from the norm has severe negative impacts on the individual, potentially resulting in isolation from other society members (Goffman, 1961; Susman, 1994 cited in Lucas et al, 2018:3) by creating "an unnecessary divide between disabled and non-disabled people" (Goodley, 2010 cited in Watson, 2012:198). This unequal status consequently results in stigmatisation (Burke, 2008:15) which may have a long-lasting damaging impact upon an individual's identity (Lucas et al, 2018:8) and self-esteem causing a constant battle of either fighting the stigmatisation or accepting societies negative image and opinions of themselves (Goffman, 2009:101). Stigma is a cause of "undesirable difference in a person's identity as perceived by others" (Goffman, 1963 cited in Burke and Parker, 2007:27) and results in marginalisation from society (Ali et al, 2012:2123). The stigmatisation not only impacts the individual with the disability who is being negatively labelled but also the family of this individual, which usually includes their carer (Burke, 2004, cited in Burke and Parker, 2007:12).

Unlike the medical model, the social model opposes the concept of "normality" (Brownlee and Cureton, 2009:90). The concept of what it means to be 'normal' and what it means to be 'disabled' exist in order to serve political purposes by creating oppression (Gleeson, 1999:9, cited in Rocco and Delgado, 2011:6) and power dynamics in order to gain control. The able bodied political dominant elite within society also gain and keep power through the use of ideology (Clegg, 1989 cited in Rocco and Delgado, 2011:7). For example, denying those with additional needs the

resources they need to be educated and knowledgeable, such as a lack of sign language interpreters for important news stories, resulting in further isolation and segregation. This concept of 'information marginalisation' is where certain groups of people have their needs "persistently ignored or overlooked" (Gibson and Martin, 2019:476). For example, a topic that will be explored in this research is whether the participants struggled to access appropriate information that applied to them about Covid-19 and the restrictions put in place or if they feel that they were socially excluded (Senjam, 2020:1368).

According to this model, the barriers faced by disabled individuals only exist to "uphold ableist attitudes" and values (Procknow et al, 2017:366), which aim to "normalise" those who are able-bodied (Waldschmidt et al, 2017:92), assuming that all bodies should be this way in order to participate "normally" (Singh, 2020:2168). This concept of ableism leads to a devaluation of disability and results in "segregation, social isolation and social policies that limit opportunities for full societal participation" (Brittain, 2010:57). This is because "it is the inaccessibility of society that actually disables" individuals not the physical disability itself (Liebowitz, 2015).

Therefore, if the correct changes are made to the social barriers which currently impair disabled members of society this would then allow them to fully participate in the community, encouraging social inclusion and challenging discrimination and marginalisation (French et al, 2018:18). Thus, the social model of disability is important as by removing barriers it creates "equality and offers disabled people more independence, choice and control" (Bradshaw and Minogue, 2020:147) and the chance to be involved in an integrated society (Burke, 2008:14) that is inclusive for all (Matthews, 2009:234). This is essential as all individuals regardless of their own abilities have "the right to a certain standard of living and to be treated with respect" (Vasey, 1992:44 cited in Barnes, 2007:207). Hence, it is therefore important to use the social model of disability within this research as it identifies the aspects where participants have struggled due to society's discrimination and disregard to their requirements and aims to suggest changes that can be made to improve and prevent these experiences happening again. Furthermore, the social model matches the epistemological beliefs of social constructionism as disability occurs due to the "function of the environment" (Burr, 2015:43). Social constructionism will be discussed in chapter 4.

Despite the social model influencing UK government policies and to help formulate "anti-discrimination legislation" (Prime Minister's Strategy Unit, 2005 cited in Watson, 2012:194) it has been criticised for being too simplistic as those with disabilities are not a "homogenous group...with a common identity" (Corker et al, 1999 cited in Watson, 2012:195) and many of their examples focus solely on physical disability. This is not an accurate representation of disabilities and needs to see each person individually rather than grouping their experience (Morris, 1991). To combat the social model criticisms, critical disability theory has emerged which is often called the cultural model.

3.4 Critical disability theory

Critical disability theory arose from an intertwining of “critical social theory, disability rights and disability studies” (Meekosha and Shuttleworth, 2009 cited in Arstein-Kerslake and Black, 2020:2). The theory provides a conceptual framework that helps understand disability and society (Lucas et al, 2018:4). The theory recognises that as a society we live “in a time of complex identity politics” and where definitions of identity change and become fluid (Waldschmidt et al, 2017:82). This notion of taking a critical stance aims to identify and focus on the aspects that are wrong within society focusing mainly on unequal power distributions, marginalised groups, and structural inequality (Walsham, 2005:112 cited in Adam and Kreps, 2006:203).

The cultural model states that disability is constructed differently compared to the previous models and is in fact solely due to the unchallenged concept of ‘normality’ that is “determined by hegemonic discourses” (Waldschmidt et al, 2017:24). This approach has a wider entrenched exploration of social inequalities. This “de-centering approach” aims to understand these dominant discourses that define normality, knowledge and the methods in which “forms of subjectivity are created and shaped” (Waldschmidt et al, 2017:25). This is important as the term “disability” is a result of “meaning-making” by a person in a position of power which has very real effects upon a disabled person’s sense of self (Titchkovsky, 2007 cited in Iannacci and Graham, 2010:53).

The conceptual framework provided by critical disability theory helps to inform all aspects of the research process, including the research questions, method selection and the analysis and interpretation of data (Vaccaro et al, 2015:26). The theory emphasises the importance of agency and aims to make positive transformations within politics (Devlin and Pothier, 2006:12 cited in Vaccaro et al, 2015:36) and “work towards the emancipation” of individuals with disabilities (Goodley, 2013; Stone and Priestley, 1996 cited in Arstein-Kerslake and Black, 2020:3). It is this element that is important to this research as the aim is to highlight voices and experiences of unpaid carers. It is hoped this will lead to a discussion around changes that can be made to help emancipate individuals with disabilities and their carers.

However, critical disability theory has been criticised for being too “distanced from empirical evidence” and potentially risks becoming an “uncritical orthodoxy” (Waldschmidt et al, 2017:93). Therefore, in order to meet the research aims only certain aspects of critical disability theory will be applied, such as the importance of being critical of current societal structures and assumptions in order to identify aspects that are creating inequality, as well as the theory’s ambition to work towards positive changes within society. As this research engages with empirical evidence, it addresses the above weakness traditionally aimed at research that utilise a critical disability approach.

3.5 Intersectionality

This research project focuses on the experiences of unpaid carers during the pandemic and their views on how individuals with disabilities were treated and considered by government responses, thus one of the topics that may be discussed is discrimination faced by those with disabilities. However, it is important to acknowledge that different identity factors and potential discrimination strands cannot always be isolated, for example an individual may have a disability but also be oppressed or discriminated against due to their class, gender or ethnicity. In order to acknowledge this, it is important to use an intersectional theoretical framework to enable understanding of simultaneous multiple discrimination (Mercat-Bruns, 2017:47).

The theory of intersectionality emerged in the 1960s from black women's activism and the term was conceptualised by Kimberlé Crenshaw (Crenshaw, 1989 cited in Matthews, 2019:6) during her research of how patriarchy and other systems of oppression interrelate (Davis, 2008 cited in LaGory et al, 2001:10). The purpose of this framework is to understand how minority groups within society suffer from "interlocking systematic inequalities" (Mattsson, 2014:10) resulting in the complexity of discrimination (Hill Collins and Bilge, 2016:12). Intersectionality shares the common belief between the social model of disability and critical disability theory that the categories used to cause discrimination are in fact socially constructed and therefore it is society's labels and values that give the categories their "imagined" importance (Crenshaw, 1991:1254). Furthermore, these categories and labels often reflect the dominant hegemonic political views (Matthews, 2019:7), resulting in power differences due to elitism (Dorling, 2017), leading to injustice (Mattsson, 2014:15).

The importance of utilising an intersectional framework is due to the acknowledgement of the "additional burden" that those with disabilities face. As a group who may experience ableism, this can be further compounded by experiencing issues such as sexism, racism and classism (Crenshaw, 1991:1246). The framework acknowledges that the nature of social categories overlap and become "interdependent patterns of discrimination and disadvantage" (Lucas et al, 2018:8). Similarly, to critical disability theory, the framework aims to create positive outcomes and be used as a "tool for empowering people" (Hill Collins and Bilge, 2016:36).

As intersectionality theory highlights, it is important to acknowledge and explore different strands of oppression. Previous research into the areas of disability and carers of those with disabilities has found that there is a higher number of women who identify as "carers" (Chikhradze et al, 2017:13). It is therefore crucial "to our understanding of the effects of the structured disadvantage" (Ledwith, 2012:345) of disability that the sample of this study includes a large number of female participants.

However, just because research has discovered that there are more women who openly identify as carers does not mean that this is necessarily the case. The findings from previous research with Young Carers discovered that their participants believed, either consciously or subconsciously, that "caring is embedded within a normative framework of familial obligations" within the family, and so do not

recognise themselves as carers (Smyth et al, 2011:149). The same study, who used focus groups to research Young Carers' identities, concluded that the male participants were less likely than the female participants to actively identify as a Young Carer because of cultural expectations that are attached to gender and the notions of 'care work'. This meant that the male participants were more reluctant than the females to identify as a carer due to the fear of stigma from other members of society, in particular from their peer groups within school (Smyth et al, 2011:154). This trend has been identified in numerous research studies including, McDonald et al (2010:369) who found that one of the reasons that male participants are less likely to be actively involved in a care role within their family is because of the societal expectations that are associated and connected to the act of 'care'. This concept of men being less likely to identify with the caring role could potentially be the reason this research project had a higher number of female participants, although the reasoning behind this is not apparent within the research. The demographics of the research participants is discussed within chapter 4.4.

3.6 Feminist standpoint theory

As intersectionality theory highlights, it is not always possible to isolate different causal factors of inequality and thus in order to research the connection between carers, disability, oppression and gender it is important to adopt a feminist theoretical perspective. This arose due to many women observing how the majority of social science academia was "male mainstream" due to the research being completed by predominantly men and focusing mostly on male issues and problems (Kourany, 2009:211). The increased inclusion of women as social researchers has led to increased diversity within this community (Intemann, 2010:279) and has been significantly beneficial due to the subject gaining a "woman's epistemological standpoint" as research is completed by women who understand other women in a different way from that of men (Crotty, 1998:173). Feminists argue they have this vantage point to researching female related issues and topics as they have the ability to recognise concerns, raise issues and most importantly, can gain insights that are largely not articulated, raised or gained by men (Alby and Fatigante, 2014:174). This vantage point arises from female researchers' lived experiences in their own lives, potentially making their work more credible than researchers who may only have read about such experiences (Collins, 1989 cited in Swigonski, 1994:391). This is especially helpful when researching or asking participants about sensitive topics, such as domestic violence, as the rapport between a female participant and female researcher may be greater than if a male researcher asked the same questions.

The adoption of a feminist standpoint theory is especially important for this research project as numerous research studies have identified that over half (58%) of the carers within the UK are women (Carers UK, 2009, cited in Greenwood et al, 2012:1). As a female researcher who has experience of caring, this has benefits as I have epistemic advantage of understanding women's experiences, both social,

cultural and economic impacts and influences (Landau, 2008:1085). The researcher's positionality will be discussed within the methodology chapter 4.6.

Parallel to critical disability theory, feminists believe that the most oppressed groups within society have different experiences due to the oppression they face, compared to those who occupy positions of power within society (Swigonski, 1994:390). It is essential to identify and aim to understand these experiences of oppression and marginalisation in order for academia and society as a whole to work towards becoming more inclusive (Intemann, 2010:788). Furthermore, without including these experiences there are "missing voices" within data collection and the overall understanding of society dynamics (Grosser and Moon, 2019:322). It is necessary to employ a standpoint methodological approach to give a platform to women who are oppressed to express their issues and share their experiences in order to influence and hopefully bring about positive change.

This research project benefits from adopting a feminist standpoint methodological approach because standpoint theory puts the oppressed at the centre by focusing on their experiences. This meets the epistemological needs of the research project as it allows the participant to discuss how they personally construct meaning and how their lived experiences have influenced their own identities (Kitzinger and Barbour, 1999:69). The standpoint of the oppressed for this research project is the experience of carers of individuals with a form of disability. These carers' experiences need to be voiced to gain knowledge of their struggles, their ideas and have their stories heard to help reimagine and improve their situations. "It is about shifting the frame, starting from the perspective" of the oppressed who are currently suffering in the present societal structure and have their ideas about alternative futures heard (Cottam, 2021:24).

However, feminist standpoint methodological theory has been criticised. For example, as a result of focusing on the experiences of the oppressed at the centre of the research rather than at the cause of such discrimination may result in the true nature of the oppression not being discovered if the oppressor is not included within the research process (Pawson, 1992 cited in Haralambos and Holbern, 2000:990). Although for the purpose of this research, in order to meet the objectives that focus on the views and experiences of those caring for individuals with disabilities, this critique is not valid. This is firstly because the nature of the research specifically wants to focus on how people may be categorised as 'oppressed' or 'marginalised' and their experiences of this. For example, the research will explore whether the participant was defined as 'vulnerable' by the UK government during the Covid-19 pandemic and whether they agreed with the definition and were happy with either being labelled this or thus unhappy to not be given this label plus the impact that such label had upon them (Abrams and Abbott, 2020:168). The research findings may also be useful for those in positions of power to be able to question current practices and shape discussions around disability policy.

3.7 Summary

This chapter has examined the different theories and concepts that will be applied to this research project. In order to meet the research project objectives, which are to explore how lockdown restrictions have affected carers lives and critically examine their views of vulnerability and inclusivity, the social model of disability will be adopted. This disability model states that disability is a consequence of society's structural and societal barriers (French et al, 2018:18). The adoption of the framework provided by the critical disability perspective will further help to criticise these barriers and definitions. An effective way to achieve this is the application of feminist standpoint theory which priorities the voices and experiences of the oppressed. Equally, it is important to acknowledge that disability is not always the only determining factor of discrimination and it is not always possible to isolate forms of oppression due to them being overlapping and interlocking, occurring simultaneously (Mattsson, 2014:10). Hence an intersectional framework will be utilised and discussed within the research process.

The next chapter explores the research methodology in closer detail.

4.0 Methodology

4.1 Introduction

This chapter will explore the methodological framework and the impact this had upon choosing a research method. In order to address the research objectives a social constructionism methodological framework was adopted with the application of a standpoint epistemology. The research objectives are:

1. To explore how lockdown restrictions affected the lives and routines of unpaid carers and their cared for individual.
2. To critically examine unpaid carers' views of vulnerability and on achieving a transition towards inclusivity.

The sampling framework and researcher's positionality will also be discussed in this chapter, along with the issues faced during the time of the research and how these were addressed. The embedded mixed methods design will be explored to explain how the research methods were applied and analysed. Lastly the limitations of the research methods will be addressed, and ethical considerations stated.

4.2 Methodological framework

This section will explore the methodological framework which has been applied to the research project. This research project is based within the constructionist ontology, which states that the 'real world' is continually created and changed through the use of different interpretations and individual subjectivity (Neuman, 2014:94). Under constructionist ontology sits interpretivist epistemology that states there is no objective truth to be discovered as 'truth' and meanings solely exist because of continuous engagements and interactions in the social world, which results in meaning being constructed and applied to phenomena (Crotty, 1998:8). This is pertinent to this research as it explores how participants construct meaning in their lives, as well as the impact of wider societal constructions of 'care' and disability. The adoption of critical disability theory is essential in order to discuss knowledge and definitions, for this research the term 'vulnerability' will be explored critically.

Social constructionism takes a critical stance and believes that knowledge is generated through "daily interactions between people" (Gergen, 1985 cited in Burr, 2015:4). It is therefore accepted that there is "no such thing as an objective fact" due to all knowledge being derived from interactions from a person's individual perspective which influences how the phenomena is interpreted (Burr, 2015:9). In order to be able to interpret phenomena a framework of meaning is essential, this is supplied through the agreed principles within language, constructing a popular discourse (Burr, 2015:10). It is therefore suggested that terms such as disability or

vulnerability are only a function of the social context and are a product of this discourse (Burr, 2015:43). This is explored through the social model of disability which argues that what it means to be “disabled” is currently defined by those in positions of power, who construct the dominant discourse and shape society in a way that privileges certain discourse over others (Brownlee and Cureton, 2009:21). This highlights society’s construction of unequal power relationships (Burke, 2008:15) which emphasises the need to contest and counter dominant discourses, as participants in this study demonstrate. As discourse is ever inter-changing and debated, the meaning of these terms can be negotiated by participants, as they discuss their interpretation of relevant terms within the interviews. The interviews and questionnaires provided the space for participants to contest and counter popular discourses of terms such as disability, carer and vulnerability.

The epistemological beliefs of social constructionism mean that the aim of the research is to discover information about the participants’ own lived experiences (Nicholls, 2019:3) in order to interpret their social world (Walker and Dewar, 2000:714). This is best achieved through the adoption of standpoint epistemology. The standpoint theory arose from feminism and was created due to the belief that women obtain different knowledge to men due to their unique experiences and status (Babbie, 2016:40). This theory “starts from the lives of the oppressed” (Cransnow, 2009:190) prioritising their views and putting their experiences at the forefront of knowledge. For this research project the ‘oppressed’ are unpaid carers and by extension, the individuals they care for, as they are often ignored or marginalised within society. Furthermore, the voices of carers for individuals with disabilities are often unheard and their struggles overlooked. Thus, it is important to provide an opportunity to improve the recognition of carers’ stories (Lloyd, 2006:945), by providing an opportunity to discuss their experiences through this research project.

This concept of voicing the experiences of the socially oppressed is essential due to their unique and “special epistemological standpoint which makes possible a view of the world that is more reliable” (Janack, 1997:126), rather than someone who is an outsider to such group voicing the experiences of the oppressed. This is due to the fact that the lived experiences of the oppressed are usually “invisible or opaque to members of dominant groups” (Campbell, 2015:806). Through the use of prioritising the marginalised voices, it allows researchers to gain insights into experiences that are not only different but also “epistemically advantageous” (Janack, 1997:126). Furthermore, the theory gives respectful attention to those who belong to marginalised groups giving them the platform they deserve to have their voice and experiences heard (Janack, 1997:130).

The purpose of this research project’s epistemological stance is to “understand the world from the subject’s point of view; to unfold the meaning of their experiences [and] to uncover their lived world” (Kvale, 1996:1 cited in Alby and Fatigante, 2014:240), in a society that is socially constructed by human actors (Walsham, 1995:376). The meaning given to discourse is continually created and moulded through different interpretations of new encountered experiences (Hall, 2014:308) and it is therefore essential to adopt a framework that acknowledges the impact of

constructionism on the social world (Burnett and Lingham, 2012:225). To achieve this, the employment of a methodological approach that produces qualitative data was needed. This requires the adoption of a smaller sample size study to produce a large amount of rich in-depth data to be gathered and analysed (Walker and Dewar, 2000:714).

This research project also adopted elements of interpretivism, which similar to social constructionism, states that our knowledge of reality is a product of social construction created by human actors (Walsham, 1995:376). The knowledge of society is generated through new experiences encountered within our daily lives (Hall, 2014:308). Likewise, interpretivisms methodological belief matches that of social constructionism which favours small sample sized research projects, with minimalised importance of greater generalisations (Payne and Williams, 2005:295). Elements of the interpretivist framework were drawn upon within the research project which focused on the importance of developing a strong rapport between the research and the participants in order to gain their trust and honesty allowing the researcher to learn more about their lived experiences (Paton et al, 2004:178). This is important to the research as a strong rapport can lead to more in-depth data allowing a greater insight to the participants' experiences during the Covid-19 lockdown enabling the objectives of the research project to be met sufficiently.

Overall, the purpose of this research project is to uncover participants lived experiences achieved by taking an epistemological stance which prioritises the views of the 'oppressed'. In order to achieve this the employment of a methodological approach that produces qualitative data was needed. This required the research to obtain a small sample size to produce a large amount of detailed rich data to be gathered and analysed (Walker and Dewar, 2000:714) in accordance with the epistemological and ontological approaches of the research framework. The sampling framework is discussed in the next section.

4.3 Sampling

Within the research project it would not be possible to include all members of the carer population and therefore a sample of this population is needed instead (Babbie, 2016:117) through the use of a sampling frame. Originally contact was made with multiple charities who stated they would be happy to help find suitable participants for this research project, however once the time came to begin looking for participants it became apparent that this original connection and offer of help was no longer available for multiple reasons. Firstly, some charities simply did not respond to any contact made and secondly those who did respond expressed their own difficulty contacting similar participants for their own research purposes and suggested it was highly unlikely they would participate within this research process (appendix A). Therefore, an alternative sampling method was used. In order to gain participants for this study a non-probability convenience sample has been used, this is where the "sample that is selected [is] because of its availability to the researcher" (Bryman, 2016:689). The 'insider status' of the researcher allowed access to particular groups (Gómes et al, 2013 cited in Chen et al, 2017:4) due to contacts of

the researcher, for example carers of children with disabilities. The benefits and challenges to the researcher's positionality is discussed in section 4.6.

The sample of participants included some individuals the researcher already knew due to participating in previous research projects combined with relevant individuals who expressed interest in the research project when they heard about the nature of the topic. Furthermore, the majority of participants who completed the questionnaire were recruited through the use of the social media platform Facebook by posting the link to the questionnaire in various University of Gloucestershire's Facebook research pages and on the researcher's personal Facebook page where the link was shared among others, including individuals who work within disability related employment roles (appendix B). Those who completed the questionnaire were individuals who read the information provided about the nature of the research and felt they met the required criteria to participate within the research process. The criteria to participate was stated as: "If you are aged 18+ and provided regular care for someone with a form of disability / illness prior to the pandemic (March 2020) and continued to provide care for the same individual during the UK lockdown restriction" (appendix C). This approach was adopted due to issues related to the subjective definition of the term 'carer' (Hughes et al, 2013:79) and therefore avoiding this exact term within the recruitment process meant that people could still participate even if they did not identify with the label of 'carer'.

Four individuals were recruited to take part in a semi-structured interview and 14 individuals completed the online questionnaire. The demographics of all the participants involved within this research are shown in the next section. The relatively small sample size had practical benefits as by having a lower number of participants it made the research process much easier to manage and the data more manageable to analyse (Davies and Hughes, 2014:168) but was additionally due to strict time constraints to complete the research project (Babbie, 2016:105). Furthermore, the small sample size has theoretical benefits as it allows for the interviews to be longer and more in-depth gaining closer insight into the participants' reality, matching the epistemological demands (Davies and Hughes, 2014:168).

Due to the non-probability sample, it means that the sample selected is not representative of the whole population (Babbie, 2016:187). This is not a weakness, however, as a small sample meets the epistemological position of the research. The methodological framework selected is not concerned with the concept of generalisation and instead is exploring the meanings behind social constructions of experience. Therefore, the use of an in-depth qualitative method was chosen to gain analytical insight that could potentially inform future research or policy and help to develop theory. When considering validity, which is the "extent to which an empirical measure adequately reflects the real meaning of the concept under consideration", the sample size allows time to create in-depth data to be gathered from each participant aiding the researcher's understanding of the participants' experiences (Babbie, 2016:149). The next section introduces the participants who were involved in this research project.

4.4 Demographics of participants

The demographics of both the interview and questionnaire participants have been combined to produce a representation of all of the participants who contributed to this research project. The demographics of all 18 participants were gathered through the use of closed ended questions on an online.

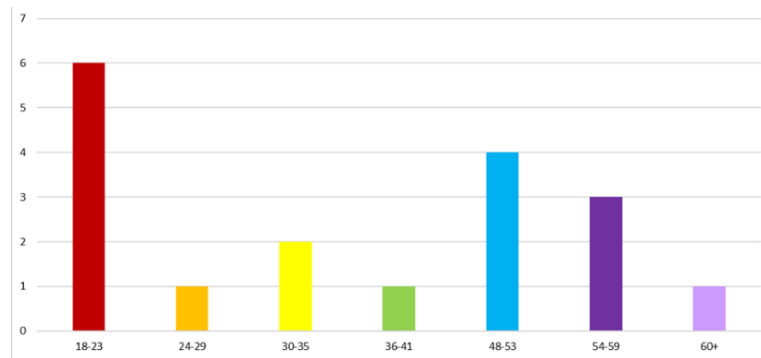


Figure 1 – Age of participants

The age of the participants for this research varied with a broad range of ages from 18-60+, with the highest proportion being aged 18-23 years old, which 6 participants selected (33%). The next most common age range for participants was 48-53 years old with 4 participants selecting this category (22%).

There was a disproportionate number of female participants with 13 out of 18 (72%) identifying as female and only 5 participants (28%) identifying as male (appendix D). The higher number of female participants may be due to gender bias explored among research surrounding carers and the carer role (Chikhradze et al, 2017:13). This was discussed within the chapter 3.

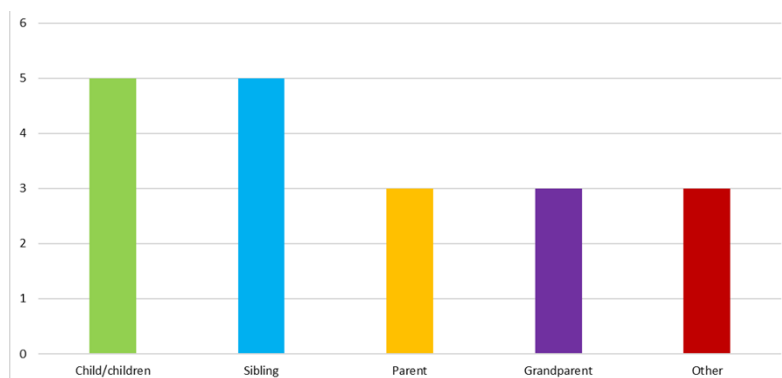


Figure 2 – Who the participant cares for

The individuals that the participants cared for varied including children, siblings, parents, grandparents and other, with one participant caring for more than one person. The most common individual participants cared for was both children (26%) and sibling (26%) with five participants for each of these options. Similarly parent (16%) and grandparent (16%) both had 3 responses. Furthermore, the category 'other' (16%) also had 3 responses, this could include the participants' partner which is suggested within one of the questionnaire responses.

Participants were asked if they lived with the individual they provide care for. There were 10 of the participants who stated that they lived with the individual they provide care for (56%) but 6 participant (33%) stated they do not live with the individual they provide care for (appendix E). Furthermore, 2 of the 18 participants stated they they live with the individual they provide care with sometimes (11%).

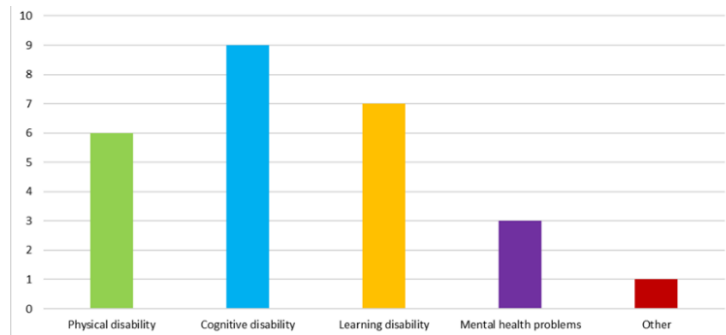


Figure 3 – Why the participant provides care

There was a range of reasons why the participants were required to provide care and assistance for the person they care for, with many stating more than one reason the care is needed. The most common response was due to a form of cognitive disability which was selected 9 times by participants (35%), meaning that the individuals with disabilities spoken about during the research was relating to a form of cogitive disability. Similary there was 7 (27%) responses for learning disability being the reason behind the care need and 6 (23%) responses for a form of physical disability. There was a total of 26 responses to the question asking why the participant provides care and this highlights that many carers were providing care for an individual with multiple disabilities and complex needs.

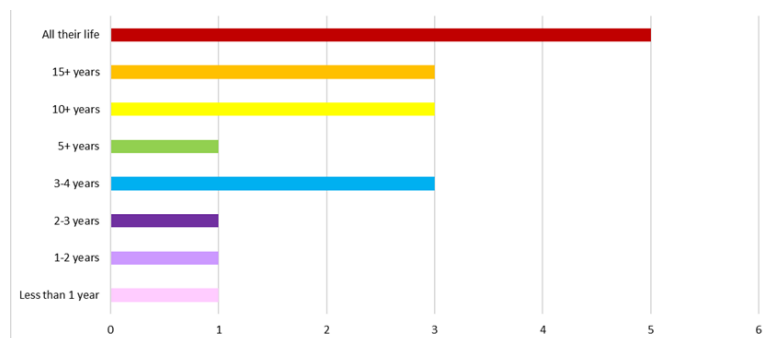


Figure 4 – How long the participant has provided care

Participants were asked approximately how long they have been carrying out their caring role. There was a variety of responses to this question which ranged from less than one year to 15+ years and 'all their life'. The highested response stated that participants had been providing care for their individual for 'all their life', which 5 (28%) participants indicated this was the case. However this cateogory is potentially not clear whether this means all the participants' life, for example an older sibling looking after their younger disabled sibling, or if this means all their life of the person the participants provides care for, for example a parent looking after their disabled child.

The demographics of all the research participants offer a wide diversity of ages, disabilities, relationships with the individual they care for and the amount of time they have cared for this individual. This is also the case with the 4 interview participants, whose names have been replaced with pseudonyms.

Sophie: 18-23, female, caring for a sibling with a cognitive disability for 15+ years

James: 30-35, male, caring for a grandparent with a cognitive disability for 2-3 years

Denise: 48-53, female, caring for a child with cognitive and learning disabilities for all their child's life

William: 54-59, male, caring for a child with a cognitive disability for 15+ years

The next section introduces the methods employed in the research and explains why these were best suited to meet the aim and objectives of the research.

4.5 Method

Originally this research project was designed to have only one research method, however due to delays to the data collection stage that arose due to an unexpected lockdown across the UK which came into action on the 5th of January 2021 (Syal, 2021), the decision was made to delay the data collection stage. This was due to the nature of the participants' caring role and the potential additional burden they were already under due to the unforeseen lockdown situation. The introduction of this lockdown resulted in a shorter time frame for data collection than initially anticipated. The complications with data collection were further amplified by issues relating to access of interview participants due to being let down by contacts who previously agreed to participate. To continue the research project a decision had to be made which involved the adoption of a secondary research method (appendix F), a questionnaire containing similar questions to those asked within the interviews. This led to an embedded mixed methods design where the findings from both methods were "integrated to produce a more complete picture" (Bryman, 2016:639). Being adaptable in this way was crucial to the success of the research project.

4.5.1 Interviews

The first research method used within this research project was semi-structured interviews which involve the researcher working from a predetermined interview schedule that contains a list of questions (appendix G). The questions were formulated based on the key topics and issues faced by carers identified within the literature review. Unlike structured interviews, the researcher retains the flexibility to change the order of questions and to add questions, allowing the opportunity to explain the questions if needed and expand the questioning if the topic is relevant to gain further insight (Finch and Fafinski, 2016:326). This insight is generated in the form of qualitative data, which is "a good platform from which to make [individual

experiences] visible and open for more discussion and action” (Humphrey, 2014:63). The ability to be flexible with the research process allows the use of additional questions (O’Reilly et al, 2013:206), resulting in an increase of the knowledge gained (Babbie, 2016:269). The interviews varied in duration, with the longest interview lasting 33 minutes and the shortest being 13 minutes.

The use of open-ended questions further adds this essence of flexibility as gives the participant the freedom to express their views and experiences which may not have been obtained in more structured interviewing techniques (Sarantakos, 2013:256), ultimately leading to more insightful and valuable detailed data being produced (O’Reilly and Dogra, 2017:10). This is highly beneficial to the methodological stance, standpoint epistemology, as it puts the oppressed at the forefront of knowledge and this freedom allows more valid accounts of knowledge about their lived experiences to be obtained (Janack, 1997:130). In order for this to be successful it was essential to develop a strong rapport between the researcher and the participant, this is where an “open and trusting relationship” is established (Babbie, 2016:310). This aids the research process due to the hope that this dynamic will make the participant feel at ease to share their lived experiences (Paton et al, 2004:178). The discussion of how the rapport was developed is explained within the section 4.6.

Moreover, semi-structured interviews were epistemologically advantageous to the research project as they allowed the participant to openly discuss any phenomena that they regarded as relevant and important to the topic (Paton et al, 2004:178). In addition, the method allowed a critical stance to be applied by asking critical questions and giving the participant the opportunity to openly discuss their reasoning for their answers (Vaccaro et al, 2015:38). For example, within each interview there were discussions about the term ‘vulnerability’ around what this term meant to the participant and critically questioned the impacts the term has upon others.

Providing participants with a range of options for where the interviews would take place was also crucial in building rapport and meeting the research’s epistemological stance. The participants were asked where they would like their interview to take place. One interview was carried out online over Microsoft Teams, which was recorded and transcribed. The other three interviews commenced in person within an outside public area at a socially distanced spaced complying to all government safety guidelines at the time of the interviews (June 2021). Communicating with participants in this way meant they could choose to participate in a way that suited them and their circumstances.

4.5.2 Questionnaire

The second research method used within this research project was an online questionnaire which was completed by 14 different participants online via Google Forms. A questionnaire is a set of written questions which are to be answered by the participants (Bryman, 2016:695).

Due to the epistemological framework adopted within this research it was important that this additional research method continued to meet the desired generation of in-

depth knowledge that social constructionism requires (Walker and Dewar, 2000:714). Thus, the questionnaire design contained a mix of closed and open-ended questions which allowed the production of quantitative and qualitative data. (appendix H). The questionnaire was designed to be short and quick to complete due to the nature of the participants responsibilities and a potential lack of time. However, it is recognised that the questionnaire research design presents challenges for the social constructionist epistemology and hence forth the application of qualitative response options was essential in order to allow for the exploration of meaning to be examine and analysed from a critical disability and standpoint theory.

The questionnaire contained similar questions to those on the interview schedule, for example “Did you lose any help from friends/organisations that you previously received prior to the lockdowns?” was asked to both interview and questionnaire participants. Similarly, there was a section regarding the term “vulnerability” within the questionnaire which aimed to cover the same discussion topics that arose within the interviews. This was designed in a way to allow for cross-examination when it came to the analysis of the data gathered. This was helped by the adoption of the open-ended questions within the questionnaire as these provided the opportunity for the participant to provide a longer qualitative response to the question; permitting a deeper answer to the question (Cransnow, 2009:190). This method matches the standpoint epistemological positioning of this research as the qualitative responses provided a space for the participants to voice their views (Janack, 1997:126). These responses were then incorporated within the data corpus along with the interview participants’ responses.

Despite the opposition to structured research methods within the adopted methodological framework, the production of quantitative data in the questionnaire was essential due to the strict time constraints this research project was under. Although the quantitative responses may not allow such a deep insight into the participants’ lived experiences and explore the deeper meaning behind the responses, they still offer valuable data (Bryman, 2016:223) and help gain required knowledge in order to address the research objectives. Furthermore, the practical benefits were also important to consider, especially due to the nature of participants’ lives. Research has shown many carers are having to juggle their caring role and employment, along with other responsibilities (Lafferty et al, 2021:5) and this results in a lack of availability to participate in lengthy interviews. Online questionnaires can be completed at the participants’ own convenience and leads to a possibly higher uptake of completed questionnaires (Sarantakos, 2013:273). Additionally, for those that found the lockdown restrictions particularly difficult they may prefer to remain anonymous as there is no physical researcher present during an online questionnaire (Sarantakos, 2013:273).

The next section will discuss the researcher’s positionality and how this impacted the research process.

4.6 Research Positionality

This research topic was selected due to witnessing first-hand how the lockdown restrictions negatively impacted my family due to my autistic brother struggling to understand why the changes had been put in place. His frustration of being unable to leave the house affected all of us at home and I wanted to give carers of individuals with disabilities an opportunity to voice their struggles. My 'insider status', from growing up as a Young Carer and continuing to help care for my disabled brother means I understand the struggles carers face, both prior to and during Covid. This understanding potentially allowed a stronger rapport to be built between myself and the participants of this research.

My 'insider status' provided a benefit in terms of accessing research participants. For example, my positionality provided me with contacts to individuals who had been involved in my previous research project that focused on a reflection of how being a Young Carer impacted an individual's identity as they grew up. Furthermore, if it was not for the ingrained passion for the topic of carers and disability inclusivity, other participants would not have been discovered as conversations with strangers on similar topics would not have occurred.

My positionality as a female carer was further beneficial as previous research into areas surrounding disability and carers of those with disabilities have identified that there is a higher percentage of women who identify as "carers" (Chikhradze et al, 2017:13), this was apparent within this research as there was a higher proportion of women to men (13 compared to 5). Therefore, my gender may have impacted some of the responses in a positive way, so as a female identifying researcher this may aid the rapport gained with the participant due to potentially having similar status relationships and standpoint epistemologies (Babbie, 2016:296). Although it was not clear if this was the case within the research as the male identifying research participants also discussed similar topics as the female identifying participants, suggesting a similar rapport was gain with both males and females.

However, there may have been issues relating to power and status differences, including education differences as the participant may see someone who is in higher education as 'superior' and may not want to share certain aspects of their life due to fear of judgement (Babbie, 2016:294). Although it was clear that no questions or topics were compulsory, so it was at the participants own discretion as to what they chose to share.

The semi-structured interviews allowed space for an open discussion before, during and after the interview which provided me with the opportunity to explain my positionality and emphasise my understanding and passion for advocacy. This research method allowed me to discuss my own situation in lockdown and explain to participants how my brother struggled significantly with the changes which had an extensive negative impact upon his daily living support needs from his increased challenging behaviour. I feel this aided the research process and generated findings which potentially someone without this ability to provide a discussion element to the interviews would not have discovered. Additionally, by explaining my background and why the research was being carried out it is hoped this tackled any issues of

power difference as showed how we, as a family, equally struggled to cope with the changes.

Furthermore, my understanding meant I was consciously aware of the participants responsibilities and potential lack of availability. It was stated within the participant information sheet (appendix I) that I understood finding a quiet environment to carry out interviews is not always possible, and that interruptions and background noise were expected and not an issue. For myself, if I was a participant in this research, I would find this comforting to know that the person interviewing me understood my home situation and therefore I believe my positionality as a researcher benefited the research project.

For certain aspects of the research process the 'insider status' may act as a positive and aids the knowledge gathered, however this position may equally be criticised as implies that the research will not be "value-free". However, the interpretivist framework acknowledges that being "value-free" and being objective is not achievable due to the inability to detach oneself from the social world (Nicholls, 2019:3). This allows my own experiences to help guide the research process (Walsham, 1995:376). It is therefore important to acknowledge this intrinsic involvement within the research and to reflect on any influence this may have within the findings (Burr, 2015:171). This step of reflexivity is vital due to being unable to detach oneself from the social world and it is crucial to acknowledge the potential impacts this may have upon the research (Burr, 2015:177). This process of reflexivity is essential as my own characteristics may affect how findings are interpreted so this transparency ensures rigorous research. This acknowledgment is pertinent and allows the use of my insider discourse to gain understanding by placing the researchers background "at the centre of the production of knowledge" (Mannay, 2010:93).

The next section will discuss how the data from this embedded mixed methods design was analysed using thematic analysis and descriptive statistics.

4.7 Analysis of data

The analysis of the qualitative interview data was carried out by transcribing the recorded interviews (Robson, 2002:289), this is a process whereby the sound file is converted into a form of written text (Babbie, 2016:313). This process is a very important part of ensuring familiarity with the data (appendix J). Once this step has been completed it is possible to use these transcriptions to examine the data through a process called coding, which categorises the data set into core themes to be extracted (Babbie, 2016:387), these could be similarities, differences and repetitions between the interview transcriptions (Bryman, 2016:586) (appendix K).

The coding schedule for the themes was primarily informed by the literature around the current topic of Covid and disability along with the most important aspects of the issues and experiences of carers (Moore et al, 2011:166), but also included inductive themes that arose in the interviews. These themes included topics such as changes in routine, the effect of fear, and changes to financial support. The qualitative

responses from the questionnaires were also included within the thematic analysis and responses were categorised into appropriate themes, in order to address the research objectives (appendix L). The results from the thematic analysis were analysed by looking at the relation of the findings to the purpose of the study (Babbie, 2016:313). The thematic analysis results were additionally compared to previous findings mentioned within the literature review and the similarities and/or differences were discussed.

The quantitative responses to the questionnaire were displayed within graphs created in Microsoft Excel. The descriptive statistics from these questions are discussed within the findings and discussion chapter and offer visual representations of the outcomes of the questionnaire questions. Moreover, the descriptive statistics are included within the analysis of the data as comparisons are made between the findings in this research project and research within the literature review.

4.8 Limitations

A potential research limitation for this topic is that the qualitative semi-structured approach only has a small sample size, meaning it only includes the experiences of a few individuals (McDougall et al, 2018:578). This potentially leads to issues regarding the ability to identify if there are any clear and substantial patterns among the participants different experiences (Hamilton and Adamson, 2013:104). Furthermore, the small sample size means that generalisations to the wider population cannot be made as the study does not contain enough participants to be representative of the whole population (Babbie, 2016:187). However, due to the epistemological stance prioritising the need to understand and focus on the individual participant's experiences, this means that generalisability is an inappropriate criterion on research quality (Payne and Williams, 2005:295). Nevertheless, there is potential to explore the research topic further using a larger scale research method to collect sufficient data to allow for broader themes to be developed.

The constructionist epistemology acknowledges that objectivity is not achievable within any research as the researcher exists within the social world (Nicholls, 2019:3). Due to the lack of ability to detach themselves from the social world it may result in their own preconceptions affecting the process of the research enquiry (Walsham, 1995:376). This is recognised directly in this research as the researcher's positioning was crucial in shaping the research project and the research encounter with participants. This is not seen as a weakness of this research, despite what 'objective', quantitative approaches may suggest. Acknowledging our own position as researchers and stating this while analysing data is key to good quality, rigorous qualitative research.

There were challenges of having an 'insider status' as my own experiences of the lockdown situation meant I knew how it affected me and my family, but it was important to remember that not everyone involved within the research shared similar experiences. It was therefore essential to keep an open mind and avoid leading

questions in addition to ensuring the literature search involved topics that I had not experienced to create a diverse and inclusive piece of research. To achieve this inclusive research the adoption of a standpoint epistemology was essential in order to focus on the participants own experiences and highlight the issues they faced as someone who provides care for an individual with a form of disability during the Covid lockdown situations.

An additional limitation which arose included issues regarding gathering relevant participants. Prior to the third lockdown which came into action on the 5th of January 2021 (Syal, 2021), multiple charity members agreed to assist with locating interview participants, however the new restrictions were not anticipated and therefore a delay in the data gathering process occurred. This ultimately resulted in the original intended charities not being able to help and multiple others either could not help or simply did not respond to any form of contact. This therefore resulted in a change in approach and an additional research method was required in order to gain enough data to complete this project. This reflects the marginalised status of carers and the recipients of care as not only are they more 'at risk' of Covid-19, but they are also more likely to be difficult to access due to demands on carers' time. As a result, it means carers and recipients of care's voices are often unheard, which is something this research tried hard to address.

A new problem faced by social researchers has been brought about due to the Covid pandemic and lockdown restrictions, meaning that face-to-face interviews were not possible when the research first began. This therefore required an alternative adaptation of the interview data gathering process to be in place for them to be carried out online. This situation can bring limitations to research projects as interviews will ideally be carried out via Microsoft Teams, but this is only possible if the participant occupies a "suitable computer, with a webcam [ideally] and a relatively good internet connection" (Davies and Hughes, 2014:192). Issues may also arise if the participant has not used the program before and may not know how it works. These issues regarding technology and access to such devices may exclude some participants from the research process, whom otherwise would have been involved. However, the use of online interviews may be accompanied by some benefits as through the use of programs such as Microsoft Teams, visual cues can still be detected (Robson, 2002:282) and the interviews are still able to be recorded. The interview that was carried out online via Microsoft Teams was carried out equally as successful as those completed face-to-face.

The use of online interviews and the adoption of online questionnaires may be advantageous as there is no travel time or expense involved which result in them being cheaper to carry out (Babbie, 2016:272). A further benefit is there is potential to include a "significantly broader...range of people" (Davies and Hughes, 2014:28) in online interviews and questionnaires as geographic constraints no longer apply, but for this research project only UK based participants were recruited. Moreover, there are potential benefits with regard to ethical considerations. Firstly, a participant may be more comfortable taking part in an interview if it can be completed in their own home. In addition, if a participant feels they wish to withdraw once the interview has commenced it is considerably easier to do online as they can end the call,

whereas if the interview were in person they may not feel so comfortable withdrawing from a physical environment, thus may feel obliged to complete the interview (Babbie, 2016:272). And with questionnaires if they do not wish to respond to a question, they can simply leave it unanswered as none of the questions were compulsory.

The adoption of the online questionnaire enabled the collection of significant data in order to meet the research objectives however this method has significant limitations. The online questionnaires are self-completing without the presence of a researcher which means there is no opportunity for probing, prompting or clarification of a participant's response. This may result in valuable data not being collected due to the lack of supervision, impacting the overall validity of the questionnaire data (Sarantakos, 2013:273). The inability to develop the rapport between the participant and the interviewer has limitations for the social constructionist approach as the lack of rapport and in-depth communication potentially hinders the ability to gain insight into the participants' lived experiences (Paton et al, 2004:178). Nevertheless, without the mixed method approach this research project would not have been possible and it is therefore important to acknowledge the benefits that each research method provides. Despite the theoretical limitations of the questionnaire, it still holds a standpoint theoretical approach as "starts from the lives of the oppressed" (Cransnow, 2009:190). Constructionism states there is no objective truth and therefore the responses from the questionnaire participants can still provide accounts of experiences they are willing to share (Mayoh and Onwuegbuzie, 2014:10).

4.9 Ethical considerations

Before the research process began full ethical approval was gained from the University of Gloucestershire research ethics panel (appendix M), to ensure that all ethical principles were adhered to and to ensure that all measures were put in place to protect participants and the researcher from potential sources of harm (Ryan et al, 2007:741).

Participants who were being interviewed online were sent an information sheet (appendix I) which contained details about why the research was being carried out, along with what was expected of them and how the data will be used and stored. The interviews which commenced in person took place in an open public space adhering to all relevant Covid government guidelines and were handed a printed version of this information. It was made clear to all participants that they could ask questions before agreeing to participate.

Participants were also sent/given an informed consent form to sign before participating within the research (appendix N). This is where the participant is given enough detail surrounding the nature and purpose of the interview in addition to what can be expected from them, in order for them to agree to voluntarily participate within the research (Farrimond, 2013:109, cited in Davies and Hughes, 2014:43). This is essential as allows them to have access to all of the information required for them to

make an informed decision about whether they wish to participate (Finch and Fafinski, 2016:296) and to think of any questions they would like to ask about the process before research commences. Informed consent is an important step within the research process as provides clarity for the participant and allows an element of trust to be gained (Qu and Dumay, 2011:253), aided by the inclusion of information on the researcher's own position regarding disability and Covid-19. Additionally, verbal consent was gathered before the interviews started.

The participants were also assured that none of the questions were compulsory and that they could skip a question, in the interview or the questionnaire, with no requirement to justify their decision (Harcourt et al, 2011:46). Participants were equally assured that they obtain the ability to withdraw from the research process at any time during the interview, again without a required reasoning behind their choice (Warren, 2007:139) and they would also be able to withdraw their data up to two weeks after the interview commenced. This process of withdrawal was different for the questionnaire participants. The questionnaire participants were informed prior to them completing the questions; "please check you are happy with your answers before pressing submit as it would be difficult to withdraw your data from the research due to the anonymity aspect." Through submitting their answers, participants were consenting for their data being used in this research and were made aware that their responses could not be withdrawn once submitted.

The interviews were to be carried out with participants individually, unless the participant would like to have someone accompany them, this was to improve the reassurance of confidentiality as the identity of the participant will only be known to the researcher and those attending the individual interviews (Smyth and Michail, 2010:38). Moreover, individual interviews provided the participants a safe space to discuss their caring role without fear of others judgement. Confidentiality was also guaranteed as only the researcher who carried out the interview listened to the recording and completed the transcription. The data was stored on a private password protected laptop which only the researcher has access to, and audio files were deleted once transcribed (O'Reilly et al, 2013:48). Furthermore, any identifying information that was present within the interview transcripts was removed and any personal details mentioned, such as names, were anonymised with the use of pseudonyms or replaced with a non-identifiable status such as 'my wife' or 'my sister' (Barry, 2011:528).

The research topic may have been potentially upsetting for some participants and it was therefore important for the researcher to convey respect and empathy towards the participant where appropriate (Warren, 2007:139). At the end of the interview a debrief form was given or sent to participants via email. This form contained information on relevant charities, institutions, helplines and relevant websites which could offer support and advice on any of the topics discussed throughout the interview (appendix O). Similarly, at the end of the questionnaire participants were offered links to relevant websites which could potentially offer support (appendix P).

4.10 Summary

This chapter has explored the methodological approach which has influenced the research design and methods selected, in order to be able to best meet the research objectives. The application of standpoint epistemology allows the participant to express their views gaining knowledge and understanding of how the lockdown restrictions impacted on carers lives. The sampling frame used to select participants has been discussed along with the reasoning behind the chosen methods. The mixed method approach was selected due to unforeseen changes that occurred within the research approach. This allowed the development of an embedded mixed methods design with the thematic analysis drawing on data from semi-structured interviews and qualitative responses from the questionnaires. The limitations of the research process have been discussed and the choices made have been explained. The ethical considerations have been stated and adhered to throughout the research process.

The next chapter explores the research findings in relation to objective 1 which focuses on how unpaid carers lives and routines were affected due to lockdown restrictions.

5.0 Findings and discussion on the impact of lockdown restrictions on carers lives

5.1 Introduction

This chapter will be focusing on the findings from the interview and questionnaire data, discussed with reference to relevant academic literature and theory in order to address the first research objective:

To explore how lockdown restrictions affected the lives and routines of unpaid carers and their cared for individual.

In order to address the research objective an exploration into how the pandemic impacted carers is essential, along with discussions around issues such as isolation and fear.

5.2 The impact of the pandemic on the ability to provide care

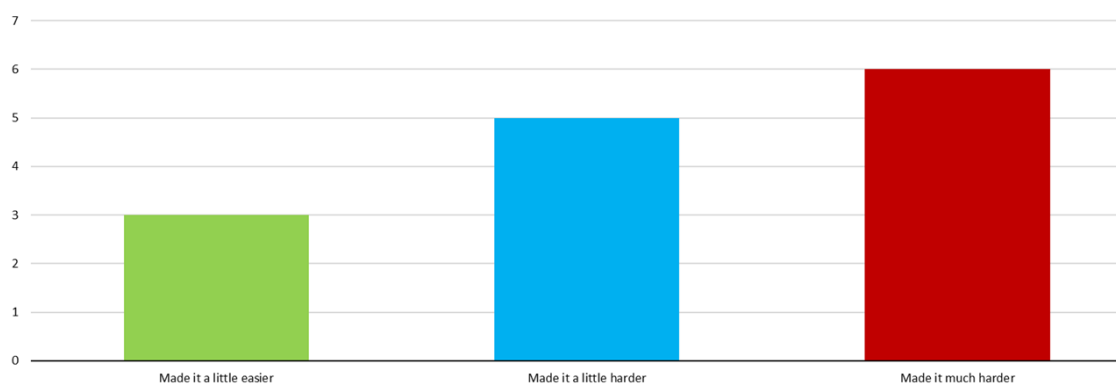


Figure 5 – How has Covid impacted the participants' ability to provide care?

The findings from the questionnaire show that 6 of the 14 participants felt that Covid-19 lockdown restrictions had a significant impact upon their caring, making it much harder than before the pandemic, with a further 5 stating it made caring a little harder. But only 3 participants stated that it made caring a little easier. The findings from this question correlate with some of the themes found within the literature stating that Covid has made caring harder, due to reasons such as changes in routine causing behavioural challenges (Singh, 2020:2168). This is a topic that was explored within the interviews and is discussed in the next section.

Similarly this theme of caring being harder due to the lockdown restrictions was uncovered in the interviews. For example, one of the interview participants stated that their caring had become more challenging due to “lots of more hours required, lots of more thinking about what we have to do” (William), whether this was thinking about how to keep everyone safe, thinking about what to do to keep the person they cared for busy and happy with the change in circumstances, or how to juggle work

and care. Additionally, another interview participant stated that their circumstances were worsened by the pandemic because it resulted in “more extreme caring because the challenges” (Denise) brought about by lockdown requirements affecting the cared for persons behaviour.

Furthermore, for some individuals the type of caring they had to provide changed. For example, one interview participant stated that their “physical side of caring was like impacted more than anything else really...I had to change his trousers and I had to start doing that and that was weird” (James). This was due to a loss of services for the person they provided care for, which is a topic that is discussed in more depth in section 5.2.2.

5.2.1 Changes in routine

One of the most challenging aspects for those who cared for someone in the pandemic has been issues surrounding changes to routines for the care giver and the care receiver. This concept has been explored in numerous pieces of research discussed within the literature and similarly was a very common theme discovered within this research project (Neece et al, 2020).

As the demographic breakdown in section 3.4 shows, around one third of the total number of participants within this research provide care for someone with a form of cognitive disability. Furthermore, 3 out of the 4 interview participants mentioned within their interviews that they care for an individual who is on the autism spectrum. Research on autism shows that these individuals in particular struggle with changes to their routines as they need structure. Routines and regulations for individuals on the autism spectrum are very important and alterations to these can become very distressing for the individuals, potentially resulting in behaviour ‘meltdowns’ which may make caring increasingly challenging (Alhuzimi, 2020:3). Having a need for structure was discussed within all the interviews with participants who stated that they care for an individual who is autistic. For example, to try to tackle the changes in routine it became essential for the caregiver to “think about and making a sort of structure” (William). Research states that this is important for those who struggle with changes and helps ease the transitions of routines (Alhuzimi, 2020).

The struggles surrounding changes in routine were discussed by one interview participant who spoke about the detrimental impact changes to routines have on individuals with autism. For example,

“when things changed he blamed me for the change of his daily routine being autistic he likes everything to be in routine...his behaviour changed towards me in particular and so it came quite challenging” (Denise).

The changes in routine were also found to be the biggest challenge for parents of children with learning difficulties in the Neece et al (2020:742) research. Children struggled while having to stay at home causing behavioural issues due to what one parent described as “not have[ing] her routine anymore”. The same issues of behavioural problems and changes due to the lack of routine were evidenced within

this research and caused the caring for one participant in particular, to become 'much harder' due to "extra pressures put on me because my pressures of daily life changed because my son's challenging behaviour increased" (Denise).

Furthermore, 6 of the 14 questionnaire participants stated that caring was made much harder. This was echoed in another interview, where the participant stated that due to the pandemic lockdown restrictions and particularly the shift to online education, it became "a lot harder because they (sibling) struggle with change so we've had to obviously swap to completely onto online and this is all really overwhelming" (Sophie). The struggles of having to move to online schooling was also found within the literature review, where some families have "struggled to cope" (Yates and Dickinson, 2021:3), with the transition due to the loss of the vital role education plays in structuring their child's day and offering a form of respite to carers (Schariti and McWilliam, 2021:3). This loss of support is discussed in section 5.2.2.

'Online learning' was also touched upon in another interview, where the participant stated "the biggest struggle was routine especially with everybody working at home" (William). This quote makes reference to the established struggle of changes to routine but also mentions this was amplified due to the lockdown restrictions requiring those who could to work from home. Similarly, schools shut and required students to complete their education online, mostly through online technology such as Microsoft Teams or Zoom (Bubb and Jones, 2020:213). Both interview participants stated that this movement to online school and/or work made caring more challenging or "really overwhelming" (Sophie).

The impact the pandemic had on the ability to provide care highlights the amplified challenges carers faced due to the change in circumstances, especially the negative impact caused from a change in routine. Another aspect of lockdown that further made caring more challenging was the loss of services and support for carers, which is discussed in the section below.

5.2.2 Loss of services and support

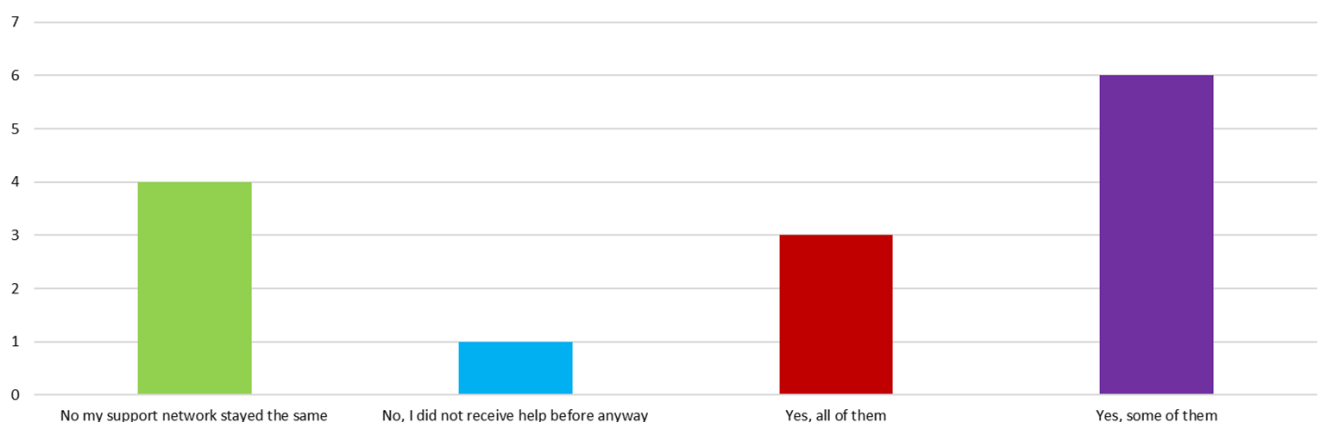


Figure 6 – Did the participant lose their support network during lockdown?

Having a support network of formal and informal support is vital for carers as it helps to alleviate the care giver's stress and provide time without their dependant, which is

crucial for the health of the carer (Giebel et al, 2020:6). However due to the lockdown restrictions many carers lost some or all of their support network. This was a topic which was discussed across both the interviews and questionnaires.

The findings from the questionnaire show that 6 out of 14 participants lost some of their support network, whether this was friends, family members or an organisation and a further 3 participants stated they lost all their support network during lockdown. This finding correlates with the findings shared earlier that caring has been made much harder (6 out of 14 participants), as where participants lost support this would have resulted in more care being put upon the main care giver. This concept of care becoming harder may be related to the loss of having the opportunity for a break from their care dependant due to the loss of their support network resulting in exhaustion (Schariti and McWilliam, 2021:3).

This was something evidenced in the interviews, for example one of the interview participants lost all their services as their “carer who use to come before when things were just like normal...stopped because [of the] first lockdown... [and] the restrictions” (William), which became quite challenging for them to adjust to. Similarly interview participant James, spoke about how the inability for carers to come into the home to assist required them to take on a much more physical caring role which they would not have needed to do prior to the pandemic restrictions, due to the lack of opportunity for the usual care duties to be transferred elsewhere (Giebel et al, 2020:6).

Additionally, within the qualitative questionnaire responses, a participant stated that for them “losing the additional family that used to help out” was very challenging for them and required them to “travel outside my local area [to provide care] which restrictions said I shouldn’t have done” (Questionnaire 14). Losing support from services provided by the government and/or family has been said to have significant negative impact on carers, leaving them feeling “mentally drained, depressed and...alone” (Yates and Dickinson, 2021:3). The negative impacts of a carer losing support services has been evidenced across multiple research projects both prior and during the pandemic, and can result in social isolation due a feeling of lacking a sense ‘normality’ (Burns, 2021; Giebel et al, 2020:6; Greenwood et al, 2012:2; Lafferty et al, 2021:2; Schariti and McWilliam, 2021:3). Social isolation is explored in more detail in section 5.3.1.

The questionnaire responses showed that 4 of the participants said that their support network stayed the same, this meant that they still had access to some help and additional assistance for those that they care for. Similarly within the interviews one participant spoke about how their support network adapted to the restrictions by moving events online. The participant’s carers support group “arranged like weekly zoom meetings” and “were doing like online quizzes...sessions every couple of weeks” (Sophie). This shows that although the in person support could no longer happen, the service was still available for people to continue to have other carers to speak to. Furthermore, this transition to online events meant there was no longer the requirement to physically travel to a destination to access these services, ultimately saving time and money. These alterations to a support network highlight that the

restrictions did affect the lives of carers but also resulted in adaptations that did not necessarily hinder all activities.

However, although the online events continued, this does not necessarily replace the importance of face to face interaction. Though face to face interaction does not count as a 'service', the loss of space and freedom for some could be detrimental. For instance, the same interview participant who spoke about their support group moving to online meetings emphasised the fact that they "couldn't wait to go back in person because that was my own little space that was my sort of free time, my place to just be me for that little bit" (Sophie). This impact of lockdown meant for this participant in particular they lost their sense of escapism, their "space to just breathe" (Sophie), having a negative impact on the individual and potentially leading to feelings of isolation (Greenwood et al, 2012:3). Similarly as evidenced within the literature, a loss of support network often exacerbated carers' sense of isolation and loneliness (Ebuenyi et al, 2020:2), which is a topic that will be discussed more in depth later within this chapter.

Figure 6 above also shows that in the questionnaire one participant stated they did not receive help or support from others prior to the pandemic. It is not clear if this is due to them not needing it or if this is due to them not being able to access support, however, not being able to access support was something discussed within interviews. For example, one of the interview participants spoke about the issues around not having outside support from the family which had been a struggle for them before and during the pandemic. Denise spoke about the reasons behind not having access to regular support, due to the financial struggles they face as a family- "it's all to do with the lack of money coming into the house basically as to what services we can actually have before lockdown and during lockdown". Despite not having regular government support she did mention a loss of services related to "two people that I used to pay privately" , on an infrequent occasion where support was vital and prioritised over the tight financial situation. The loss of this private service was due to the restrictions of social distancing and the need to "protect me and my son" . Needing to "protect" is discussed within the literature, where previous research has identified carers' struggles of having to make similar decisions about whether to continue the support for the person they provide care for at a heightened risk of contracting Covid-19, or the alternative option of stopping their services in order to protect but ultimately increasing the unpaid carers' workload (Giebel et al, 2020:6).

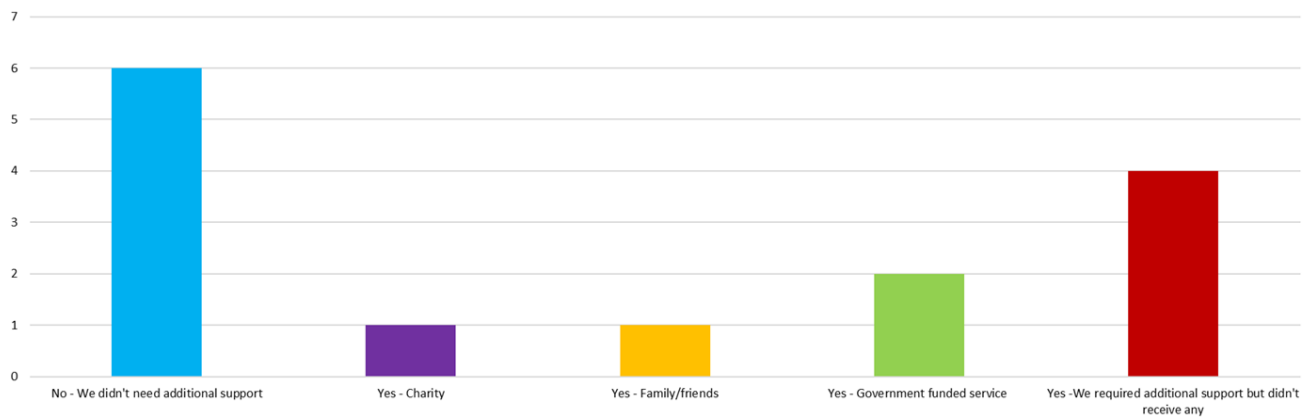


Figure 7 – Did the participant require additional support due to Covid restrictions?

Almost half of the questionnaire participants stated they did not need additional support during the pandemic (6 out of 14). However, this could potentially be due to the high proportion of 18-23 year old participants (33%) and around one quarter of care receivers being siblings (26%) within this research, suggesting that the person completing the questionnaire was not the sole carer. One potential improvement for the research would be to include an additional question in the questionnaire asking if the participants care alone or with the help of others, such as parents, which future research could build upon.

It is positive to see that some of those that did require additional assistance were able to find it in different places such as charities, family, friends and government funded services. However, 4 of questionnaire participants stated that they required additional assistance and support but they did not receive any. Not being able to access additional assistance and support may be due to many reasons which have not been made clear within the questionnaires, but it is still important to acknowledge this struggle faced by many of the respondents. Some of these struggles were highlighted by interview participants.

Within the interviews there were discussions surrounding why there were difficulties accessing help during the pandemic. For example, one participant stressed how they “couldn’t get external support whatsoever...[which] actually made care more difficult” (James). The reason for this lack of external support was explained as the person they cared for was regarded as someone who “wasn’t serious enough [disabled], supposedly” (James). This concept of not being labelled as “serious enough” was discussed by another interview participant who explained that their sibling for whom they provided care lacked the formal diagnosis needed to claim support services and financial assistance, such as Carer’s Allowance. This is because “formal diagnosis [are]...very difficult to get...[so] we haven’t got like important diagnosis, we haven’t ever got like any allowances” (Sophie). One of the reasons behind this lack of diagnosis may be because “a lot of girls can go undiagnosed [with autism] until the later age...which is the sort of situation that we’re in now” (Sophie). Research evidences that “girls on the autism spectrum are typically diagnosed later” or are likely to go undiagnosed due to a lack of symptoms (Carpenter et al, 2019:3). This constant need to achieve ‘approval’ through a medical diagnosis (Burke, 2008:13) reinforces the medical model of disability and leads to stigmatisation causing

dehumanisation of individuals through the “hierarchy of bodies”. The inability to obtain a diagnosis further reiterates the medical model’s ‘gaze’ that views disability as a problem for the individual rather than a collective issue for society and may be why these issues are not being addressed (Cameron, 2014:99).

Within the interviews, discussions around assumptions that others have around disability, care and access to services were touched upon. One interview participant said “I think everyone’s always assumed that just because you’ve got somebody disabled you get everything, you are entitled to everything” (Denise). This is evidently not the case, as shown by James and Sophie’s issues surrounding difficulties accessing services due to being unable to obtain a medical diagnosis. Likewise Denise explained how

“immediate neighbours didn’t help me, nobody knocked on my door but speaking to them afterwards I think they all assumed that because I had a disabled son that someone like social services etc would have actually helped me but they didn’t” (Denise).

Assumptions surrounding disability entitlement is potentially a big concern, with the potential to be isolating, as demonstrated in the quote above as no one offered to provide the additional support that was needed for this family. She went on to say “people that aren’t in that situation obviously don’t understand that or perhaps don’t even think about that, that won’t be the case because that’s just the assumed thing” (Denise). This lack of understanding could potentially lead to negative assumptions and labels which could be linked to disability discrimination (Goffman, 1961; Susman, 1994 cited in Lucas et al, 2018:3). An exploration of assumptions, labels and discrimination will be discussed more in depth within the vulnerability section in chapter 6.2.

This section explored how the pandemic impacted unpaid carers ability to provide care and has shown that a loss of services and restrictions increased carers responsibilities and negatively affected the individuals they cared by forcing a change in routine. The changes and loss also impacted carers wellbeing which is discussed in the next section.

5.3 The impact of the pandemic on unpaid carers wellbeing

The pandemic caused many changes to carers lives, including a loss of support services and changes to routines but it also impacted their sense of wellbeing. Carers social isolation was amplified and the burden of fear from catching the virus caused great anxiety for fear of their care dependants health along with the weight of their care responsibilities and the implications that contracting the virus would have. However this research project also found that some of the participants felt the lockdown restrictions of remaining at home and social distancing had a positive impact on improving their family relationships.

5.3.1 The effect of isolation

Previous research into the lives of carers concluded that the caring role can cause a strain on an individual and their family often leading to isolation (Yates and Dickinson, 2021:3) and the impacts of Covid have exacerbated these issues as carers are unable to “escape our carers’ responsibilities and then when something like the pandemic comes along you really are stuck” (Denise). This concept of caring often being a lonely and isolating experience is something that was discussed by several participants in this research.

The caring role can be particularly isolating for those that care alone, for instance, one participant who was a sole carer for their son said, “I have all the responsibilities myself, there is nobody else helping me” (Denise). Not only is this isolating but it also may suggest why there is a high proportion of questionnaire participants who stated their caring became harder. Furthermore, the same participant said,

“I actually don’t have any local support from family [and] I do quite keep myself quite distant from my friends because of the actual caring side of things normally so I don’t really mix with many people generally quite isolated to be honest” (Denise).

Previous research has concluded that a large proportion of carers isolate themselves from family and friends due to a perceived “lack of understanding, empathy and support” for them and their disabled individual (Broady et al, 2017:225). Thus, this participant’s experience of social isolation is a common occurrence for carers of individuals with disabilities.

Moreover, the questionnaires found that the issues surrounding isolation did not exclusively only affect the carers but also the care receivers. One participant said that the person they cared for “felt very isolated as time went on” (Participant 13). Similarly, from the questionnaires someone stated that the person they cared for “couldn’t go out so was feeling isolated” (Participant 14). This issue of the care recipient feeling the effects of loneliness has not been the only problem identified within the current literature. One research project has discovered that many of the participants involved within their research “reported observing a ‘decline’ in the care-recipient’s health” (Lafferty et al, 2021:6). This demonstrates that lockdown did not only negatively impact people’s mental health but also affected their physical health, highlighting the need to address these issues and offer support to these individuals, both carers and care recipients.

The findings within this research that relate to social isolation help address the objective as the responses highlight how carers lives prior to the pandemic were already affected due to their caring role and many of their experiences have been amplified following the impact of lockdown restrictions.

5.3.2 The burden of fear

The topic of fear was present within the interviews, including fear of catching the virus and the potential health implications for the person they care for and themselves. For example, one interview participant spoke about how a member of their household was a “key worker so he still had to like go out and stuff” which they found “a little bit frightening” due to them and the person they helped provide care for being medically “vulnerable” (Sophie). In order to combat this fear of catching the virus a routine had to be created where the key worker’s uniform “went straight into the washing and he was sent up for a shower...to try prevent contamination” (Sophie). This amplified psychological distress upon carers due to the fear of contracting the virus has been suggested to have a negative impact upon carers wellbeing (Goldmann and Galea, 2020 cited in Samboma, 2021:266).

Another interview participant spoke about a similar fear surrounding contracting the virus and decided to stop paid respite carers from visiting their home in order to lessen the risk of coming into contact with the virus. This was due to the support being provided by people who:

“worked at a school they were actually mixing with people and so I didn’t actually want anybody come to my house, so the services that I paid for privately I stopped because I literally didn’t have anyone through my front door just to protect me and my son” (Denise).

However, the loss of support network has been evidenced previously within this chapter to have negative impacts upon carers and may result in challenging care circumstances and further isolation. Equally, the same participant expressed their fear of having to take their vulnerable son out due to this forced loss in support services: “he’s a vulnerable person I really don’t want to take him out” (Denise). This similarly links back to the changes in routine discussed earlier which had negative impacts for this participant’s son and caused his behaviour to become more “challenging”, having a negative impact on both the carer and cared for individual.

Similarly, this concept of fear of passing on the virus was found within the questionnaire responses, with participants stating they were “scared to pass on the virus” (Participant 10) and another stating they feared “going out for shopping or exercise in case I caught the virus and became ill or worse passed it on to my son who was vulnerable” (Participant 13). This fear of catching the virus and passing it on to the person they care for was a common response with some participants even stating that “Covid caused me great anxiety as I knew I was vulnerable” (Participant 3). This was something discussed within the interviews where the carer was not necessarily medically vulnerable but due to their caring responsibilities it made them vulnerable as “going out meant I was actually a vulnerable person” (Denise), who was at risk of contracting the virus and passing it onto the person they cared for. This fear that arose from this enforced vulnerability was something discovered in other carers related research (Egan, 2020:2). The issues and fears of vulnerability are topics that are discussed within chapter 6.2.

This section shows how one participant spoke about their routine had to be altered in order to protect their medically vulnerable family and demonstrated the impacted fear had upon carers. The need to protect their family had negative consequences on some individuals behaviour, which as discussed earlier, resulted in caring becoming more challenging. Despite the many negative challenges, this research found that some participants experienced positive affects to their lives due to the pandemic, these are discussed in the next section.

5.3.3 Positive improvements in family relationships

One of the main positive outcomes for one of the interview participants was the ability to have more free available time to spend with their family which previously they may not have had time for. The lockdowns resulted in participants being able to complete “activities together as a family” (Sophie). For instance, Sophie explained how her family all took up one shared craft activity which they could all join in and enjoy together, giving them “like that sort of connection”. Feeling more connected to family was a shared notion across the questionnaire responses with participants stating how they were able to spend “more time with them and phoning more regularly to check up on them” (Participant 1). This opportunity meant it offered the chance for families to be brought closer together (Lafferty et al, 2021:6). Participants stated they were able to offer “family support” (James) and this ability to help increased due to the inability to “do anything else so had more time to offer to support” (Participant 7) and was further amplified by “working from home, so more available to provide care and supervision, so things were easier than normal” (Participant 6). This could potentially explain the findings discussed earlier in chapter 5.2 where 3 out of 14 questionnaire participants stated the lockdown restrictions made caring a little easier.

The ability to spend more time with family either physically or virtually had a positive effect on combating the “feeling [of being] isolated” (Participant 14) and was reported to have “positively impacted their mental health” (Participant 5). This positive outcome also featured in the literature where almost half of participants spoke about how they were glad to have more time with their family at home (Neece et al, 2020:743). However, as identified earlier in this chapter, one participant in particular emphasised the importance of contact with people outside of their immediate family in order to have “space to just breathe” (Sophie).

Another positive outcome for a different interview participant, was the impact it had upon the individual the participant provides care for. For one they explained how the pandemic brought about a unique experience which allowed their son to learn “a bit of self-responsibility and having to take care of himself” (William). He learnt new skills and was “cooking and doing house chores and things...he stepped up and you know did a really good job” (William). These skills may not have been learnt or improved to the level they are at now if it was not for the time made available due to the imposed lockdowns. The positive outcome from a change to routine was something only one participant mentioned but for them it has positively improved their care receiver’s life skills.

Similarly, an additional positive of lockdown restrictions was that for some, all social activities were transferred online. This meant that “there have been fewer events available where we must go to the place and they have instead been replaced by zoom meetings. This has saved time and money for us” (Participant 4). This positive outcome of saving money was spoken about by another questionnaire participant who said, “I could stop my mortgage payments for 6 months so it took financial pressure off me and not going out meant I saved some money, I was able to pay for items my carer’s allowance wouldn’t normally stretch to” (Participant 13). The financial pressures and struggles discussed by carers within this research project and in previous research show that having access to an adequate income can be difficult (Silvia et al, 2021) and so free, online events help to reduce this financial burden whilst ensuring social connectedness.

Despite the positive outcomes of the lockdowns identified above many participants struggled with adhering to regulations for various reasons which are discussed below.

5.4 Everyday challenges of adhering to regulations

The lockdown restrictions enforced numerous regulations that the public were legally bound to follow. One of these regulations were rules and restrictions affecting food shopping (Belam, 2020). This was something that particularly affected interview participant Denise; “the most challenging thing for me was shopping just getting food basically because the regulations and everything changed”. She then went on to speak about how as a family they “couldn’t actually afford to do online shopping...because we’re on a really really tight budget” (Denise). They explained how if their financial situation was different they could have been able to afford to shop at supermarkets that offered the delivery service. This issue surrounding carers’ “tight budget” due to suffering from financial hardship is an issue faced by many prior to the pandemic and the situation brought about by the lockdown restrictions have exacerbated these financial struggles (Spencer and Swinglehurst, 2020:216). The problems relating to financial struggles will be discussed further in chapter 6.5.

Several questionnaire participants made reference to the rules relating to the number of items one could buy, for example, one participant stated that “shopping was difficult too as unable to get many of the items required” (Participant 14). An issue relating to shopping that became apparent within the literature review was the access to online shopping slots (Eskyte, 2020:331), although this was not mentioned as an issue by any of the participants within this survey.

Another issue related to shopping regulations was the need to break the restrictions and government guidelines, for example “I had no choice but to take my son with me so there needed to be two of us together and then people were judging you on that...[because] I was breaking a rule” (Denise). This quote not only touches on the subject of people’s judgement but also suggests a lack of support due to there being no one else to look after the participant’s son while they went to do the shopping and

increases the risk of being exposed to the virus. Judgement was also something that arose within the questionnaires, for example:

“in the shops people would judge you for buying a lot because I was shopping for myself and my nan but people assumed you were being greedy and stock piling so I always felt the need to have to explain myself which I shouldn't of had to” (Participant 10).

This need to justify their actions can lead to feelings of shame and can make a carer feel disempowered and isolated within their role due to fear of judgement from others (Knowles et al, 2016:210).

In addition, in the questionnaires one of the participants found the restrictions challenging due to “not being able to go out and the restrictions in shops made it difficult as they (the person they care for) didn't understand why we couldn't go out” (Participant 9). This lack of understanding was a phenomena discovered within the literature where parents stated that their children struggled with “confusion and distress” to the changes in society and their usual habits and routines (McKenzie et al, 2021:2).

A further challenge to adhere to government restrictions was connected to the anxiety associated with personal protective equipment (PPE) requirements, specifically facial coverings such as masks and the inability to wear them (Masinter, 2020:3). For instance, one interview participant discussed the issues around how they believed that

“one of the things that did go quite unnoticed [was] learning disabilities, a lot of people sensory wise struggle wearing their masks...I know certainly one of my sisters did struggle with that” (Sophie).

This statement was further supported by another interview participant who explained her “son actually couldn't wear a mask cos he wouldn't understand it, he also wouldn't understand social distancing” (Denise). This inability to wear PPE is linked to carers' fears for the safety of their individual they provide care for and this worry had a negative impact on their lives.

In order to address the inability to adhere to the required regulations, the use of the wearing of a sunflower lanyard was adopted as a way to discreetly signify those that were unable to wear a mask due to hidden disabilities and indicate those who may also require additional help or support (Hayton, 2020). However, the issue surrounding people not being able to wear a mask was stated to be “a huge anxiety of mine” (Sophie) by one of the participants. This anxiety was potentially amplified due to what one participant described as people “that will abuse the system” (Denise), by wearing a lanyard as a way to avoid wearing a mask. This public knowledge of the possibility of such ‘abuse’ to the system may result in genuine users of the sunflower lanyard system being viewed with scepticism or mistrust by the general public and result in them being victims of judgement from others. This fear of anticipating the stigma forces individuals to feel the need to explain their situation and can have damaging lasting impacts often resulting in withdrawal from

social situations, leading to isolation (Woodgate et al, 2008 cited in Broady et al, 2017:226).

These examples of anxiety and struggles related to adhering to regulations in lockdown highlight the additional stress and challenges which carers had to face in addition to their pre-existing caring duties.

5.5 Summary

This chapter has discussed the findings of this research project in relation to objective one which aims to establish the extent to which lockdown restrictions have affected the lives and routines of unpaid carers and, by extension, their cared for individual. The findings highlight the affect the lockdown restrictions had by bringing new struggles and amplifying challenges carers faced prior to the pandemic.

The loss of support services for many participants appeared difficult and the daily task of caring was made tougher by having to adhere to the restrictions and guidelines put in place by the UK government. For example, shopping was said to be a struggle for many participants whether this was having to take their vulnerable care receiver into the shops with them or the difficulty trying to purchase enough products for all those they were buying for. This need to take their cared for individual with a disability into shops was discussed by some participants as necessary due to a loss of their support network which had drastic effects on their usual routine and carers' wellbeing. Another guideline that was found to be a challenge was the advice to wear a face covering and keep a socially distanced space between people. This was difficult for some individuals that the participants provide care for and also caused a lot of distress and anxiety intensifying their already troubling fears of catching the virus and infecting those most vulnerable.

The next chapter will explore the further findings of the research and discuss them in relation to objective 2, focusing on vulnerability and inclusivity.

6.0 Findings and discussion on carers views of vulnerability and inclusivity

6.1 Introduction

This chapter will be focusing on the findings from the interview and questionnaire data, discussed with reference to relevant academic literature and theory in order to address the second research objective:

To critically examine unpaid carers' views of vulnerability and on achieving a transition towards inclusivity.

In order to address the research objective, an exploration into the participants' views on terms such as 'vulnerability' was essential, along with discussions about the positive outcomes of the lockdown restrictions alongside their future concerns and any recommended changes towards inclusivity.

6.2 Understandings of vulnerability

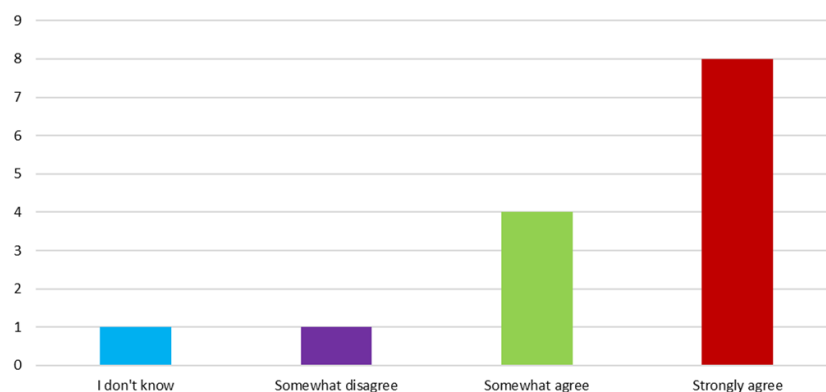


Figure 8 – Did they agree with the term 'vulnerable' for the person they care for?

Discussion around the topic vulnerability was something that the literature highlighted as important due to many previous disability studies indicating that their disabled participants considered certain labels, such as 'vulnerable', to be "intrusive or culturally inappropriate" (Lloyd, 2006: 954). It was therefore important to ask all participants within the research project their thoughts on the term 'vulnerability'.

Figure 8 above shows that 8 out of 14 of the questionnaire participants agreed that the individual they provide care for is vulnerable, with a further 4 participants stating that they somewhat agree that they care for someone vulnerable. There was clear consensus that almost all of the questionnaire participants provided care for someone who is vulnerable in some way. Similarly, 3 out of 4 of the interview participants agreed they provided care for someone vulnerable, with one participant responding when asked, "oh absolutely, yes indeed" (William).

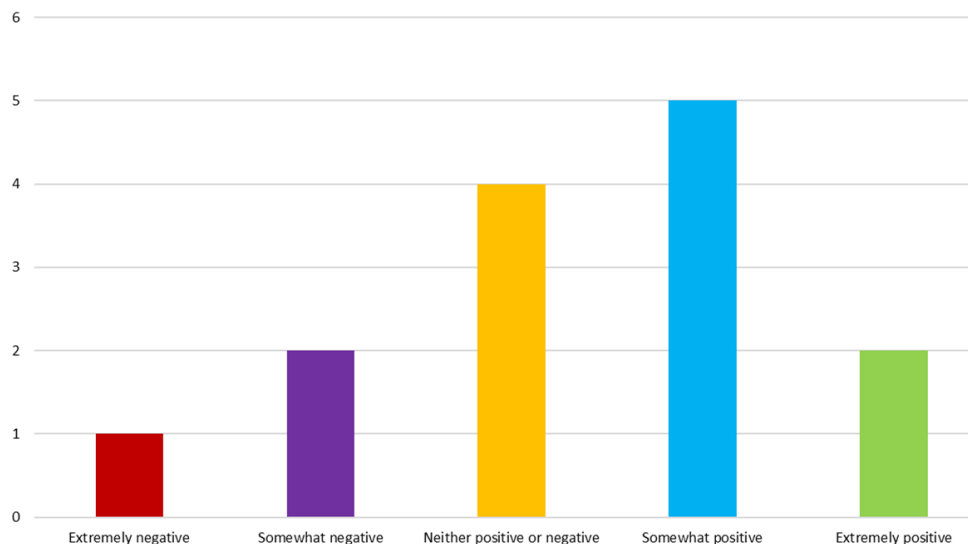


Figure 9 – Do they think this label is positive or negative for the person they care for?

The questionnaire participants were then asked if they thought that the label 'vulnerable' was positive or negative for the person that they provide care for. Unlike the previous question there was a much less distinctive conclusion with 4 participants selecting 'neither positive or negative' suggesting that they think the label either does not hold any value or rather it does not change their circumstances so does not affect them. However, 7 of questionnaire participants selected either 'extremely positive' or 'somewhat positive' as their response which shows that many of the participants think that the label is beneficial, perhaps due to the support they can receive when a label of 'vulnerable' is applied such as, such as being entitled to certain benefits or social care services.

These past two questions asked the participants their opinion of the vulnerability of the person they provide care for but an interesting counter-response from one interviewee was that "actually I don't feel it's up to me to choose" (James). The questions asking about another person's vulnerability requires the participant to make that decision for them on their behalf, imposing their position over the care receiver's. The same participant continued to explain their opinion on this topic saying,

"if we inferred anything to my granddad if anything he wouldn't have liked whatever he was called...because he would have really cared because he did not want to be seen as unable to do anything or needing care or needing to be looked after...he didn't want any label" (James).

This hesitation of labelling individuals or oneself is something that has been evidenced across disability and carer research, with individuals stating they are reluctant to adopt labels "due to the cared-for persons' struggle to accept their need for support from others" often being in denial about their situation of dependency (Knowles et al, 2016:208). This implies that the term 'vulnerability' is potentially seen as a negative label and the process of attributing labels to others can have negative consequences and connotations for the individual being labelled.

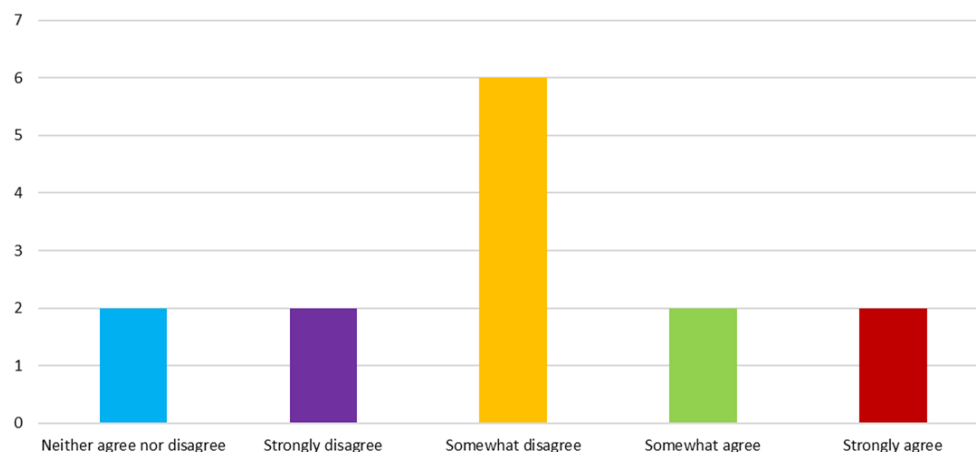


Figure 10 – Did they agree with the term 'vulnerable' for themselves?

Unlike the question which asked about the person they provide care for and the label of vulnerability, when asked about themselves and if they believed they matched this label of vulnerability, 6 of the 14 questionnaire participants selected 'somewhat disagree' with a further 2 participants selecting 'strongly disagree' meaning the dominant response was that the carers themselves believed they did not match a label of vulnerability. There were several reasons identified by interviewees for viewing themselves as vulnerable as a result of Covid-19. For example, one participant stated that that they were "vulnerable myself, me and my sister both have asthma it was a little bit frightening" (Sophie).

On the other hand, interview participant Denise explained how she had never seen herself as vulnerable before so would have previously answered no to the question but due to the negative impacts of the pandemic it required her to think and reflect on her situation:

"I actually didn't consider myself to be vulnerable at all before the pandemic but when I was started to realise that if I became ill I had no one to look after my son so therefore me going out meant I was actually a vulnerable person nobody was labelling me as a vulnerable because nobody was necessarily thinking she's a carer and if she can't care then what's going to happen to the person that you're caring for" (Denise).

This quote touches on the issues surrounding definitions of 'vulnerable' as this participant states how technically she would not be described as necessarily vulnerable but due to her responsibilities, she suggests this creates a sense of vulnerability for her. This concept of induced vulnerability and "shielding by proxy" (Maitra, 2020:3106) was identified within the recent literature which identified how carers of vulnerable children or family members were forced to 'shield' to protect themselves from becoming ill to protect the health of the person they care for and to remain healthy to continue their essential caring role.

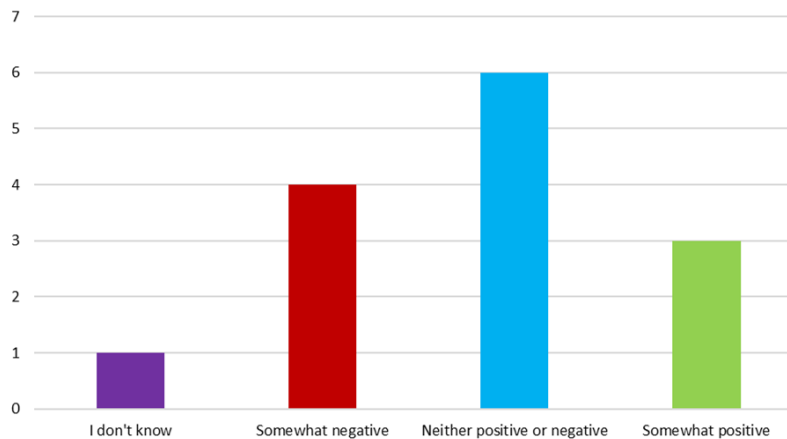


Figure 11 – Do they think this label is positive or negative for themselves?

Questionnaire respondents were more ambivalent about whether being potentially labelled as vulnerable was a positive or negative experience. The most commonly answered response was ‘neither positive or negative’ (6 out of 14), which correlates with the previous answers as most participants did not see themselves as matching the label ‘vulnerable’.

Those that believe the label of being vulnerable has been ‘somewhat negative’, (4 out of 14), may be due to similar reasons discovered within the interviews. For instance, the term vulnerable may have caused someone distress. This was the case for some of the interview participants with one saying, “myself knowing that I was sort of in that vulnerable category kind of made it quite nerve wracking” (Sophie). This worry for their own health is amplified due to their continued responsibility pressures (Turner, 2021:68) which left many carers feeling like “we’re kind of forgotten about really” (Denise). Thus, the problems with the term are discussed in the next section.

6.2.1 Problems with the term ‘vulnerable’

All the interview participants discussed their concerns with the term vulnerability, which unfortunately was not as well articulated within the questionnaire. One of the significant issues surrounding the term was the lack of inclusivity of it. The descriptions of those who are classed as ‘vulnerable’ are mostly due to underlying health conditions (Ryan, 2020). However, as Denise notes:

“it's not that you know you're medically vulnerable to say but it's the fact that you're vulnerable because of your you know your responsibilities as a parent that you're vulnerable because you are the sole person looking after that person therefore you are vulnerable to that virus”

Within this quote, Denise mentions being “medically vulnerable” which can be reflected back to the medical model of disability discussed in chapter 3. This model sees those with disabilities as their medical diagnosis and views the individual on their lack of ability to carry out activities in the same way a person who is considered “normal” would, due to their impairment (Thomas, 2007 cited in French et al,

2018:16). In the case of the pandemic, definitions of vulnerability largely overlooked unpaid carers despite it being crucial that they avoid contracting Covid-19.

The term vulnerability was very much only aimed at the person who was being cared for which neglected the unpaid carers who support these 'vulnerable' people. This was something that arose within the questionnaires as one participant stated, "it was only the person with the disability who was "vulnerable" not much focus on the whole family" (Participant 9), which shows the narrow categorisation of what it means to be vulnerable.

Another main issue with the term vulnerability discussed was the concept of 'hidden disabilities'. This is where it is not necessarily visually obvious that someone has a form of disability (Hayton, 2020). This leads to potential problems as "someone who is in a wheelchair they have a vulnerability that's obvious so you know who looks and appears vulnerable" (William), whereas someone with a hidden disability may be overlooked and less likely to be acknowledged as vulnerable and potentially in need of support. For example, one interview participant stated that they care for someone they would consider vulnerable but they have concerns:

"because the vulnerability is not...necessarily visible especially in his case coz you know he's able bodied and but not able minded that he's not neuro-typical in any way shape or form, so he is very vulnerable from that point of view"
(William).

Many with a form of hidden disability are often overlooked and not categorised as 'vulnerable'. This was an issue that became apparent within the literature review where those with different forms of disabilities were left off the 'vulnerable list', including motor neurone diseases and individuals with cancer (Ryan, 2020). There is a need for notions of vulnerability to be widened to include those who may be vulnerable for a wider variety of reasons.

6.2.2 Negotiating the term 'vulnerability'

The term 'vulnerability' can be argued to be exclusionary and as ignoring or overlooking those with hidden disabilities, alongside disregarding carers. Therefore, a different term may to be more inclusive may have been needed to cover a wider range of people and situations. One interview participant explained that their belief that "vulnerable might not have necessarily been the best word to use" (Sophie), instead government officials should have looked at those who needed "to be a bit more protected" (Sophie). This participant's suggestion of using a more inclusive term can once again be linked back to the medical model of labelling and critical disability theory which questions the language around disability. For example, as Sophie explains, the term vulnerability implies that those individuals "can't do nothing". The narrow scope of vulnerability built upon medical assumptions was also raised by Denise as she states, "vulnerable makes it sound like you have a disability um but I don't personally think that vulnerable just means medical" (Denise). Those in power, such as government ministers who defined the term are, due to pre-existing power structures, less like to fit the definition of 'vulnerable' but imposed

their definition upon others. This can be linked back to the medical model of disability which was used to label those who were considered 'vulnerable' under an enforced medical gaze (Cameron, 2014:99), defined by those who hold positions of power within society. This highlights the unequal power dynamics that construct society (Burke, 2008:15). This term 'vulnerability' then has stigma attached due to a construction of normality and those who are disabled and/or vulnerable deviate from the assumed stereotype of what it means to be "normal" (Goffman, 1963). Widening our understandings of vulnerability could perhaps alleviate stigma as the term becomes more inclusive to a range of circumstances.

Overall, from the questionnaire and the interviews the conclusion can be characterised as "vulnerability is good but needs to include more within it" (Participant 10), especially in terms of those who provide the care for others. Carers needed to be included within the category 'vulnerable' because of their duty of care and responsibility, as well as the detrimental impact it would have upon those they provide care for if they could no longer facilitate this role.

6.3 Increased public awareness of disabilities

Despite the abundant examples discussed above surrounding the negative experiences and the struggles faced by carers throughout the pandemic, this research found numerous examples of positives that arose due to the lockdown restrictions. These were discussed in the previous chapter and mostly evolved around time that could be spent with family. Similarly, another positive outcome was the increased public awareness of disabilities.

A positive outcome of the pandemic which mainly arose from the interviews was the increased awareness of individuals with disabilities. The pandemic has "made some people aware that there are people out there that sort of more vulnerable and need support" (Denise). This quote links to the topic of 'vulnerability', which was discussed earlier within this chapter, suggesting the use of the term 'vulnerable' has been positive in terms of raising awareness "that society was made up of different types of people" and "as the time went on it became obvious that there were more people that needed support" (Denise). The pandemic allowed the rest of society who are outsiders to try to gain an understanding of "our reality" as carers (Sophie). Once this understanding has been achieved it is hoped that "caring has become more noticed than before so hopefully it will make it more of a government priority to address how little money is available to full-time carers in future" (Participant 12). Initiatives such as the 'Clap for Carers' were demonstrative of this increased awareness of carers and health workers. This is where people stood on their doorsteps and clapped which showed that as a nation people can come together to show appreciation (Brooks and Morris, 2020).

In addition, in order to increase awareness of individuals with hidden disabilities the widespread adoption of the sunflower lanyard was used to "show why people weren't wearing masks etc...because before people wouldn't have known coz that's the whole point they were hidden disabilities" (Denise). The use of the lanyard as a

visual representation of a hidden reason for not wearing a mask may have been significant progress in raising awareness and aiding the process of “people understanding each other a bit more” (William). However, issues around drawing attention to hidden disabilities was stated by one participant as a potential negative for those who did not want attention drawn to their disability. This is discussed in the next section.

One interview participant hoped this increased awareness may continue to have future positive impacts for inclusivity, particularly for individuals who struggle to leave their homes for education. This could be due to mental health reasons or a form of disability or illness. The movement to online learning and being more accommodating by recording lessons in order for students to “catch up at a later time” (Sophie) is seen as a positive move. This was a similar positive identified within the literature review as the pandemic has brought about a situation which required a remote workforce and may diversify the future of work becoming more “inclusive of people with varied disabilities” (Singh, 2020:2169). This may open up more opportunities for individuals with disabilities, perhaps leading to more personal independence.

This section presented the views of unpaid carers on the positive outcomes of the lockdown in terms of increasing the public’s awareness of disabilities and carers circumstances. The findings hint at the possibility to achieve a step in the right direction for a transition towards inclusivity, even if it is simply just more people being made aware of carers situation. The next section discusses the future concerns participants have about a post-pandemic society.

6.4 Future concerns and changes towards inclusivity

Participants were asked about their future concerns in a post-pandemic society and there were a range of responses, including the concerns relating to the future impact the pandemic may have upon the social care system due to financial struggles. Thus, emphasis was placed on the need to “reflect on...how things can be addressed better” (William), in order to minimise the consequences from the mistakes made to tackle the pandemic response.

There were concerns surrounding the potential lack of face to face interaction and a permanent move to online life. This was an issue for one participant in particular who said they “definitely don’t wanna see everything go online”, this is because by moving online they lost their feeling of “having that space that’s yours you know” (Sophie), which could potentially lead to issues around social and physical isolation. The problem of social isolation for carers was discussed within chapter 5.3.1, which highlighted how carers’ isolation was amplified by lockdown restrictions.

Earlier within this chapter there was a discussion about hidden disabilities and the potential benefits that have arose out of the pandemic in highlighting differences between people, helping others to appreciate that not everybody is the same with equal abilities. One interview participant, however, discussed their concerns around drawing attention to these hidden disabilities through things such as “lanyard

wearing”, because potentially “those people [are] now going to be discriminated against as well so I could kind of see that there could be some hidden discrimination towards hidden disability” (Denise). This discrimination is due to their hidden disability being highlighted and attention drawn to them in the form of the sunflower lanyard, “the people that didn’t want those disabilities visible have now had to be visible” (Denise). The issues also arise when people “abuse the system...[which] will decrease the efficiency of it...so people are going to discriminate and not believe them which means people that wearing them genuinely for anxiety are going to feel more discriminated against” (Denise). Therefore, this participant thinks that although the implementation of the sunflower lanyards has its benefits of raising awareness and helping aid inclusivity, the lanyard is also a visual representation which could lead to further discrimination, amplified by people using the resource as a way of escaping government guidelines, reducing the effectiveness of the idea. It acts as a physical ‘marker’ of difference that may work to further marginalised and alienate already ‘vulnerable’ people. This visual representation and the participants concern for disability discrimination can be linked back to issues surrounding disability theory and stigma. The visual aspect of highlighting a previously hidden disability presents an opportunity to allow negative labelling to occur as an individual can be labelled as “different” (Lucas et al, 2018:3). This negative label can impact an individual’s self-esteem (Goffman, 2009:101), which ultimately could result in marginalisation and social withdrawal increasing issues of isolation (Ali et al, 2012:2123). It is therefore essential that society is educated on differences in a positive way to achieve an inclusive safe environment for everyone.

Correspondingly, all participants were asked what a meaningful and permanent improvement in their circumstances would look like to them. There was a variety of responses, including the need for “accessibility to support if and when needed at short notice” (James), the importance of being able to gain the required diagnosis, and an increase in “professional help...from outside organisations” (Participant 8). Nevertheless, ultimately the majority of responses to this question referred back to the financial dimension of the participants’ lives, with the stressed importance of “increased carer’s allowance to cover the true costs of not receiving any other support” (Participant 11). There also needs to be “priority to address how little money is available to full-time carers” in order for them to have “better living conditions” (Participant 12) in the near future and reduce the “financial strain” (Denise) they are currently under.

These findings demonstrate that there is an element of concern for increased marginalisation and stigma against individuals with disabilities in the future and precautions must be taken to alleviate this discrimination in order to achieve a safe inclusive society. The predominately identified improvement in the participants lives within this research was positive changes to their financial situation. The next section explores the changes to carers financial support. This improvement in carers situations will aid towards achieving the transition towards inclusivity for all.

6.5 Change to financial support

As the previous section states, the majority of interview participants stated an improvement in their circumstances could be achieved through improvements to their financial situation. The main financial support offered to carers is Carer's Allowance, as discussed within the literature (Spencer and Swinglehurst, 2020:216). Questionnaire participants were asked if they claimed Carer's Allowance, 11 out of the 14 participants answered 'no', they do not currently claim financial support in the form of Carer's Allowance (appendix Q). This was not the expected result when researching carers and it would be interesting to identify the reasoning behind such a high proportion of participants not claiming this government benefit. Potentially it could be due to the participants who were involved within this research not being the primary care giver and as discussed within the literature only one person can claim for the care recipient (Carers UK, 2021). In one of the interviews, a participant discussed the problems gaining the essential "formal diagnosis" (Sophie) needed to qualify for the benefit. This has resulted in a constant battle to obtain the diagnosis, in order to meet the requirements of the desired medical diagnosis. This again works to reinforce the medical model that focuses on individuals' differences and impairments (Bradshaw and Minogue, 2020:147).

Likewise, within the qualitative response options in the questionnaire some participants stated an explanation for their answer, with one explaining a similar reason due to a lack of having "nothing diagnosed" (Participant 9). Additionally, another explanation for their inability to claim the benefit was due to a participant who does "not qualify for Carer's allowance as I do not care for 35 hours" (Participant 1) and another stating they are unable to claim it because "my mum claims carer's allowance not me" (Participant 7). This last response highlights the requirement for an additional question which needed to have been included asking participants if anyone in their family claims Carer's Allowance for the individual they provide care for. This is especially important due to the high percentage of participants who help provide care for their sibling (26%), which would presumably mean they are less likely to care for this individual alone. Thus, the question needed to ask more broadly about claiming the allowance. Similarly, an additional question asking why the participant does not claim the allowance may have brought to light other struggles with access issues which could have been discussed.

6.5.1 The need to review Carer's Allowance

One of the last questions within the questionnaire asked participants their views on reviewing Carer's Allowance in order to support carers more during the challenging times brought about by Covid. Out of the 14 questionnaire participants 12 answered 'yes' they believe it should be reviewed (appendix R). None of the participants answered 'no' and only 2 participants stated that they 'didn't know', which suggested that the general consensus is that Carer's Allowance needs to be reviewed. All 4 of the interview participants stated that they believe that financial assistance for carers should be reviewed. Both the questionnaire and interview participants suggested their ideas on how this needed to be achieved.

The foremost response across both interviews and the questionnaire was that Carer's Allowance is currently not financially adequate and there is a need to "make it more of a government priority to address how little money is available to full-time carers" (Participant 12). This concept of the financial assistance not being sufficient was something evidenced within the literature (Lloyd, 2006:950).

There were numerous responses within the questionnaire which simply stated the need to have "increased carer's allowance" (Participant 14), however, there were also several suggestions for how these much-needed changes could be implemented. For example, as discussed previously one of the reasons a questionnaire participant could not claim Carer's Allowance was due to not caring for the required "35 hours" (Participant 1) in order to qualify. It was suggested that "maybe a lower payment for fewer hours would be an option" (Participant 1), meaning that there could be financial support made available even for those who do not meet the current 35 hour a week care minimum (Carers UK, 2021). Similarly, on the other end of the scale it was suggested by another participant that they believe that "the hours worked maximum should be upped" (Participant 3), therefore implying that those who care for more than the 35 hours a week should be entitled to a larger payment. This would be beneficial to one participant as they would "be less stressed during those caring times and we could on good days go out and enjoy ourselves together" (Participant 4). This quote shows the importance of increased financial support because as a result the quality of life for both care receiver and giver would be improved and reduce and adverse effects that come with caring for someone, such as anxiety, depression and isolation (Greenwood et al, 2012:2).

This idea of making Carer's Allowance more than "just a one level payment" (Denise) would improve the lives of carers involved within this research, whether that is the carers who provide care under the 35 hour criteria by doing tasks such as "shopping and personal care" (Participant 2) or the carers who provide "caring around the clock for 24 hours a day 7 days a week" (Denise). This increase in financial support will help carers gain the recognition for the care work they provide (Cottam, 2021:30) and hopefully help towards achieving a transition towards inclusivity.

In addition, the way the money is given to access paid services was discussed in the interviews. For example, one participant discussed their idea of how they could become "the employers" (William), of the carers they pay for using their Carer's Allowance budget. This is important to them as a family as it would allow them to "make that decision" (William) about which paid carer would be in charge of their son. A similar suggestion was made by another participant who explained the difficulty about matching the level of payment to the level of care provided and proposed the idea of "rather than paying an individual...why not pay that effective salary that someone would actually be earning to the family member who was caring for that person" (James). This idea is in order to make the level of care in terms of hours match to the amount of financial support received. For instance, it was explained further by saying:

"easy numbers £10, if you pay someone £10 an hour as an NHS employee pension costs going to be 22% national insurance is going to 12 so you're

looking at properly, that will cost the NHS £14.00 an hour if they were just giving somebody £10 an hour...it's saving £4.00 an hour...it's cost effective” (James).

This suggestion potentially saves the government money and may result in the family carer receiving a larger financial payment as if it were an income salary. This concept of making the caring role become a form of salaried labour would highly benefit carers as many are unable to access paid employment due to their caring responsibilities and this increase in financial assistance may alleviate their financial situation (Spencer and Swinglehurst, 2020:216). This would be extremely beneficial for female carers as research has evidenced that the feminisation of care means that women are more likely to adopt a caring role (Hochschild and Machung, 2012:54) and recent research has shown women were more likely than men to be forced to leave paid employment in lockdown due to their caring responsibilities (Andrew et al, 2020). If a carer received the equivalent to a job salary for their currently unpaid caring role they would be in a better financial position and alleviate additional financial stress associated with forced unemployment.

This section explains the suggestions made by several of the participants on how to improve their financial situation. This improvement would increase their quality of life and provide them and their dependant with better opportunities. This would help towards increasing the inclusivity of carers within society by providing them with equal financial rights as other non-carers.

6.6 Summary

This chapter has discussed the findings of this research project in relation to objective two which aims to examine unpaid carers' views of vulnerability and on achieving a transition towards inclusivity.

This research found a mixed response in relations of the term 'vulnerability' although it suggests that it is overall a positive term that has helped raised awareness of those who need extra support, such as those with hidden disabilities and provides positive outcomes towards a movement of societal inclusivity. However, there are negative connotations with the term vulnerable and there are suggested risks and examples of discrimination and judgement. The term therefore needs to be reviewed to become more inclusive, positive and beneficial for those who are termed 'vulnerable'.

In order to help unpaid carers further, changes need to be made to how care 'work' is remunerated. One of the main concerns raised by participants was connected to financial struggles with participants in agreement with the need to review Carer's Allowance to sufficiently match their caring role and allow them to be equal inclusive members of society financially.

The next chapter will conclude the findings of both objectives and reflect upon the research process.

7.0 Conclusion

7.1 Summary of findings

The aim of this research was to identify how the Covid-19 lockdown restrictions impacted unpaid carers of individuals with disabilities. The application of a social constructionist framework was pertinent to this research as it allowed information to be gathered about the participants' own lived experiences (Nicholls, 2019:3). The adoption of standpoint theory permitted the research to start "from the lives of the oppressed" (Cransnow, 2009:190), which was the unpaid carers of individuals with disabilities.

An embedded mixed methods research approach was utilised, which consisted of two research methods; semi-structured interviews which contained 4 participants and an online questionnaire which had 14 responses. The questions and topics of discussion within both research methods were similar, to allow for cross examination of the data. The qualitative responses of the questionnaires were included in the thematic analysis process, in order to address the aim and objectives of this research project. And the quantitative responses were displayed in the form of descriptive statistics and mentioned in connection to relevant literature.

Objective 1: To explore how lockdown restrictions affected the lives and routines of unpaid carers and their cared for individual.

The findings from this research demonstrate that the lives and routines of unpaid carers and their cared for individual have been affected in many ways due to the lockdown restrictions.

Primarily, the act of caring became more challenging for care givers with "lots of more hours required" and "more extreme caring because the challenges" that arose due to the lockdown restrictions. One of the main challenges discussed and evidenced within previous research are the problems related to the changes in routine for their cared for individual. The change in routine, for example the inability to access normal life activities or attend education, resulted in behavioural problems from finding it "really overwhelming", causing additional pressures on unpaid carers. However, it is important to note the demographics of the participants involved within this research as the majority of participants were talking about their experiences of caring for an individual with a cognitive disability. As literature states individuals with a form of cognitive disability, such as autism, they are more likely to struggle with a change in routine (Alhuzimi, 2020:3), so this may explain the reason behind this finding.

An activity which was impacted by the lockdown restrictions was the ability to do essential activities such as food shopping. This raised many issues for carers, with one participant describing this to be the "most challenging thing" they had to face during the lockdowns. The issues mostly arose due to the inability to leave their care

recipient at home resulting in them having to attend the shopping trip, breaking the government guidelines of one person per household to attend (Belam, 2020). This affected the lives of carers by amplifying their fears and stress of their care recipient catching the virus. Furthermore, many carers feared catching the virus themselves and worried about the implications this would have for the person they care for due to a lack of alternative care assistance. This resulted in carers becoming vulnerable by proxy and 'shielding' to protect themselves in order to remain healthy to continue their caring role.

Another sizeable problem for unpaid carers was the loss of services and support networks due to the lockdown restrictions, with 9 out of 14 (64%) of questionnaire participants stating they lost all or some of their support services. There was an expression of worry that these support networks would remain a virtual service in the future, which one participant stated made them feel like they would lose their "space to just breathe", their sense of escapism and could ultimately result in isolation. Furthermore, an issue which was discussed was the inability to access support services even prior to the pandemic due to the lack of formal diagnosis required in order to be entitled to this support. This issue relates back to the medical model of disability which views disability from a "medical gaze" and as a problem which needs to be fixed (Cameron, 2014:99). The idea that society views disability as a "problem" often results in stigmatisation (Broady et al, 2017:226) and causes feelings of fear from judgement from others. Judgement was experienced in relation to carers' shopping practices and the inability for their care recipient to wear facial coverings.

The lack of a desired medical diagnosis also had implications for access to financial aid for unpaid carers. A lack of financial assistance for carers was a significant issue that was raised in the interviews and questionnaires. Although this problem existed prior to the covid lockdowns, this research highlighted and raised awareness of the financial situations for carers, exacerbated by the pandemic, and provided an opportunity for carers to voice these matters. For example, one participant stated how they lacked the income to access online shopping due to this only being available at the more expensive supermarkets. The issue of financial struggles for many unpaid carers resulted in discussions on the need to review the Carer's Allowance benefit, in order to improve the quality of life for carers and the individual they provide care for.

It is additionally important to acknowledge how carers' lives were impacted positively by the pandemic with many expressing happiness to be gifted the opportunity to spend additional time at home with their family providing the chance to participate in activities and generate a stronger family bond.

Objective 2: To critically examine unpaid carers' views of vulnerability and on achieving a transition towards inclusivity.

In order to examine unpaid carers' views on the inclusivity of the pandemic response, it was crucial to discuss their thoughts on the terms used to describe people during the pandemic, such as vulnerability. Previous research demonstrates a hesitance to accept labels given to individuals, this could be for many reasons such as not agreeing with them due to believing they are inappropriate (Lloyd, 2006:954). Thus, in order to address the objective, it was essential to ask the participants if they agreed with the terms used for themselves and for the individual they care for.

Almost all participants were in agreement that they provide care for someone who is vulnerable in some way, but there was no clear consensus if this label of vulnerability had a positive effect. Concerns were raised about the problematic consequences of imposing a label on somebody else, as the research asked the unpaid carer to assert their opinions on behalf of the individual they care for. There was some resistance to this by one participant which relates to the wider literature around the difficulties of applying labels to individuals with disabilities (Knowles et al, 2016:208).

In contrast, when questionnaire participants were asked about their own vulnerability there was a very different response with just over half (57%) the participants stating they somewhat or strongly disagree for this label of vulnerability for themselves. Despite this, it became apparent that some of the participants realised an element of vulnerability for themselves. A potential reason behind the response to this question may be because "nobody was labelling me as a vulnerable" person but upon reflection they "started to realise that if I became ill I had no one to look after my son". This meant that their caring responsibilities inflicted this vulnerability upon them.

There were discussions about inclusivity of labelling individuals as vulnerable with the agreement that many people who should have been described as vulnerable were not. For example, this inflicted vulnerability was not because "you're medically vulnerable to say but it's the fact that you're vulnerable because of your you know your responsibilities". This view of narrow categorisation arose from many participants stating how the focus was solely on the individual with the disability. This lack of listing the unpaid carers as 'vulnerable' highlighted the lack of inclusivity of the term and demonstrated how the term was very much only aimed at the person who was being cared for, neglecting the unpaid carers' 'vulnerability'. Furthermore, another issue with the term was the problem of hidden disabilities being overlooked and left off the 'vulnerable list' (Ryan, 2020).

Within the findings it was recognised that there were some positives that arose from using such terms as 'vulnerable'. For instance, it helped raise awareness "that society was made up of different types of people" and "as the time went on it became obvious that there were more people that needed support". This awareness was amplified by the widespread use of the 'sunflower lanyard' highlighting hidden disabilities. The pandemic offered a unique experience to raise awareness that there are people within society that have additional needs and can hopefully lead to

positive changes to “tackling dominant ableist norms” (Eskytė et al, 2020:333) and achieve a transition towards inclusivity within society. However, concerns were raised about highlighting hidden disabilities as this could result in issues around stigma and labelling of individuals (Ali et al, 2012:2123). Therefore, the transition to full inclusivity is not achievable until all negative labels and imposed discrimination is eradicated.

Furthermore, the literature suggests that pandemic potentially has helped create a more inclusive and diverse workforce due to the requirement of remote employment resulting in work being diversified and accommodating for “people with varied disabilities” (Singh, 2020:2169) offering them the opportunity to work from home and participate within the labour market. This would help the transition towards an inclusive society that offers equal opportunities for all.

The main suggested improvement for unpaid carers, for the participants within this research was stated to be increased governmental financial assistance with many suggestions on how this should be altered. The concept of the current governmental financial support not being sufficient for carers of individuals with disabilities is evidenced within literature (Lloyd, 2006:950) and similarly was identified within this research. To improve the lives of carers and the individuals they provide care for, Carer’s Allowance needs to be reviewed and changed from “just a one level payment” to provide carers with adequate financial assistance sufficiently reflecting the hours of care they provide. This increase in financial support will help carers gain the recognition for the care work they provide (Cottam, 2021:30) and hopefully assist a transition towards achieving inclusivity within society by helping alleviate carers poverty and providing them and their cared for individual with equal life chances as those without caring responsibilities or disabilities.

7.2 Reflection and future research

Although this research successfully addresses the aim and objectives it is important to reflect on the research process. Firstly, it is important to note the change of wording of the original objectives which are stated on the ethics form and participant information sheet. This is because as the research progressed it became apparent that the objectives had to become more refined. This reflects the cyclical nature of the research process.

Secondly, reflexivity must be acknowledged due to the researcher’s ‘insider status’. The literature searches for relevant research have been broad and included a variety of different subjects which were not discovered within the data. It is also important to note that the researcher explained their positionality throughout the research process, including within the participant information sheet for the interviews and for the questionnaires, along with openly discussing their positionality within the interviews with the participants. All the findings of the interviews and questionnaires were included within the data analysis stage and the selection of information chosen was due to the value it brought to the research.

Despite the abundant findings of the research, it is crucial to recognise that there would be changes that would be made in future if this research is to be built upon. This is especially the case for the questionnaire. The usage of a questionnaire was a decision made later on in the research process due to unforeseen circumstances. The wording of some of the questions and the quantitative responses meant that for some findings the 'full picture' could not be seen. For example, there should have been an additional question that asked the participants if they cared for the individual alone or with the help of others, such as parents. This could have potentially shown a different outcome to the questions which focused on additional support. Furthermore, an additional question needed to be included around any carers claiming Carer's Allowance. Upon reflection this is an important question as only one person can claim the benefit for individual with a disability (Carers UK, 2021) and 85% of questionnaire participants answered 'no' when asked if they claim this allowance. It would have been beneficial to discover why such a high percentage do not claim this amount, which may have brought to light struggles related to accessibility issues or it may have shown that there is another additional carer who is the person claiming the allowance.

In the future, if this research was to be continued, it would benefit from a greater number of interviews and a transition away from the quantitative questionnaire method in order to adhere more closely to the epistemological preferences of social constructionism. Furthermore, the research would benefit from a wider diversity of participants to identify the intersectional impacts on carers' lived experiences.

7.3 To conclude

This research has identified how the Covid-19 lockdown restrictions have impacted unpaid carers of individuals with disabilities. This has been achieved through the application of two key objectives. The first objective was to explore how the lockdown restrictions affected the lives and routines of unpaid carers. The findings have discovered that the lives of carers have been affected in many ways including the burden of additional stress caused by the fear of contracting the virus and the consequences this would have on themselves and most importantly their dependant. The routines of carers have changed as they have learnt to adapt to a life with a loss of their support services and the struggles of adhering to government guidelines. The second objective aimed to critically examine carers' views of vulnerability and on achieving a transition towards inclusivity. The findings highlight the issues surrounding the lack of inclusivity, not only for individuals with disabilities or hidden disabilities, but also for the carers of these individuals who were not considered to be 'vulnerable'.

Additionally, the research unearthed pre-existing problems for carers especially related to their financial struggles and suggestions were made on how to create more inclusivity. It was suggested that there needs to be a priority in addressing "how little money is available to full-time carers". Potential solutions were proposed with the idea of making Carer's Allowance more than "just a one level payment". This could be achieved by providing financial support to carers who provide care for less

than the current required 35 hours a week and providing carers who provide care for more than 35 hours a week an additional sum of money to adequately fit the care they provide. The findings from this research suggest these unpaid carers would benefit from this change in financial assistance and would ultimately increase their quality of life by reducing financial strain and providing them with wider prospects. This ultimately would increase the inclusivity of society by reducing the exclusion carers face from financial hardship.

To conclude, the situation brought about due to Covid-19 have offered an opportunity for carers to voice their pre-existing struggles and express how the restrictions exacerbated these. The findings from this research evidence that all the unpaid carers within this research suffered from some form of negative experience or problem that was influenced by the Covid-19 lockdown restrictions. It is essential to take the virtuous findings from this research and acknowledge the suggestions that have been made about the changes and improvements that would increase the inclusivity of society and importantly make positive changes to the lives of unpaid carers and the individual they provide care for. It is hoped that the awareness raised through this research transcends into society emphasising the need for reform by tackling ableist norms and prioritises inclusion, collaboration and diversity beyond the Covid-19 pandemic.

8.0 Bibliography

- Abrams, T. and Abbott, D. (2020) "Disability, Deadly Discourse, and Collectivity Amid Coronavirus (COVID-19)," *Scandinavian Journal of Disability Research*, 22(1), pp.
- Alby, F. and Fatigante, M. (2014) "Preserving the Respondent's Standpoint in a Research Interview: Different Strategies of 'doing' the Interviewer," *Human Studies: A Journal for Philosophy and the Social Sciences*, 37(2), pp. 239–256. doi: 10.1007/s10746-013-9292-y.
- Alcock, P., Haux, T., May, M., and Wright, S. (2016) *The student's companion to social policy*. Fifth edn. Chichester, UK: John Wiley & Sons. Available at: <https://ebookcentral.proquest.com/lib/uniofglos/reader.action?docID=4567441&ppg=39> (Accessed: December 16, 2021).
- Alhuzimi, T. (2020) "Stress and Emotional Wellbeing of Parents Due to Change in Routine for Children with Autism Spectrum Disorder (ASD) at Home during COVID-19 Pandemic in Saudi Arabia," *Research in developmental disabilities*, 108, pp. 103822–103822. doi: 10.1016/j.ridd.2020.103822.
- Ali, A., Hassiotis, A., Strydom, A., and King, M. (2012) "Self Stigma in People with Intellectual Disabilities and Courtesy Stigma in Family Carers: A Systematic Review," *Research in developmental disabilities*, 33(6), pp. 2122–40. doi: 10.1016/j.ridd.2012.06.013.
- Anderson, C. (2010) "Presenting and Evaluating Qualitative Research," *American Journal of Pharmaceutical Education*, 74(8), pp. 141–141. doi: 10.5688/aj7408141.
- Andrew, A., Cattani, S., Costa Dias, M., Farquharson, C., Kraftman, L., Krutikova, S., Phimister, A., and Sevilla, S. (2020) "Parents, especially mothers, paying heavy price for lockdown" [online] Institute for fiscal studies. Available at: <https://ifs.org.uk/publications/14861> (Accessed: December 12, 2021).
- Barnes, C. (2012) "Re-Thinking Disability, Work and Welfare," *Sociology Compass*, 6(6), pp. 472–484. doi: 10.1111/j.1751-9020.2012.00464.x.
- Baxter, L. F. (2020) "A hitchhiker's Guide to Caring for an Older Person Before and during Coronavirus-19," *Gender, Work & Organization*, 27(5), pp. 763–773. doi: 10.1111/gwao.12470.
- Broady, T. R., Stoyles, G. J. and Morse, C. (2017) "Understanding Carers' Lived Experience of Stigma: The Voice of Families with a Child on the Autism Spectrum," *Health & Social Care in the Community*, 25(1), pp. 224–233. doi: 10.1111/hsc.12297.
- Bryman, A. (2016) *Social research methods*. Fifth edition. Oxford: Oxford University Press.
- Bubb, S. and Jones, M.A. (2020) "Learning from the COVID-19 Home-Schooling Experience: Listening to Pupils, Parents/carers and Teachers," *Improving Schools*, 23(3), pp. 209–222.
- Burke, P. and Parker, J. (2007) *Social work and disadvantage: addressing the roots of stigma through association*. London: Jessica Kingsley. Available at: <https://ebookcentral.proquest.com/lib/uniofglos/reader.action?docID=296039&ppg=14> (Accessed: December 16, 2021).
- Burnett, G. and Lingam, G. I. (2012) "Postgraduate Research in Pacific Education: Interpretivism and Other Trends," *PROSPECTS: Quarterly Review of Comparative Education*, 42(2), pp. 221–233. doi: 10.1007/s11125-012-9230-1.

Cameron, C. (2014) *Disability studies : a student's guide*. Los Angeles: SAGE.

Cantillon, S. and Kirk, E. (2020) Scotland's progressive rhetoric: devolution and carer's allowance. *Social Policy and Society*, 19(3), pp. 396- 413. (doi: 10.1017/S1474746419000502).

Carpenter, B., Happé, F. and Egerton, J. (2019) *Girls and autism : educational, family and personal perspectives*. Abingdon, Oxon: Routledge. doi: 10.4324/9781351234429.

Chikhradze, N., Knecht, C. and Metzger, S. (2017) "Young Carers: Growing Up with Chronic Illness in the Family - a Systematic Review 2007-2017," *Journal of Compassionate Health Care*, 4(1), pp. 1–16. doi: 10.1186/s40639-017-0041-3.

Coppola, F. (2021) "Carers Are Due a Decent Wage and Pension Too," *Financial Times*, 23, pp. 23–23.

Crenshaw, K. (1991) "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color". *Stanford Law Review*, 43(6), pp 1241-1299.

Crotty, M. (1998) *The foundations of social research : meaning and perspective in the research process*. London: Sage Publications.

Ebuenyi, ID., Smith, EM., Holloway, C., Jensen, R., D'Arino, L. and MacLachlan, M.

Egan, K. (2020) "Digital Technology, Health and Well-Being and the Covid-19 Pandemic: It's Time to Call Forward Informal Carers from the Back of the Queue," *Seminars in Oncology Nursing*, 36(6). doi: 10.1016/j.soncn.2020.151088.

Finch, E. and Fafinski, S. (2016) *Criminology skills*. Second edn. Oxford: Oxford University Press.

French, L., Le Clair, J. M. and Brittain, I (2018) "The Palgrave Handbook of Paralympic Studies," in *Game Changer? Social Media, Representations of Disability and the Paralympic Games*. London : Palgrave Macmillan UK : Palgrave Macmillan, pp. 99–121. doi: 10.1057/978-1-137-47901-3_6.

Critical and Radical Social Work

Giebel, C., Hanna, K., Cannon, J., Eley, R., Tetlow, H., Gaughan, A., Komuravelli, A., Shenton, J., Rogers, C., Butchard, S., Callaghan, S., Limbert, S., Rajagopal, M., Ward, K., Shaw, L., Whittington, R., Hughes, M. and Gabbay, M. (2020) "Decision-Making for Receiving Paid Home Care for Dementia in the Time of Covid-19: A Qualitative Study," *BMC geriatrics*, 20(1), pp. 333–333. doi: 10.1186/s12877-020-01719-0.

Goffman, E. (2009) *Stigma : notes on the management of spoiled identity*. New York: Touchstone. Available at: <https://ebookcentral.proquest.com/lib/uniofglos/reader.action?docID=5663894&ppg=101> (Accessed: December 12, 2021).

Greenwood, N., Habibi, R. and Mackenzie, A. (2012) "Respite: Carers' Experiences and Perceptions of Respite at Home," *BMC Geriatrics*, 12(1), pp. 42–42. doi: 10.1186/1471-2318-12-42.

Greig, A., Taylor, J. and MacKay, T. (2012) *Doing research with children : a practical guide*. 3rd edn. London: SAGE.

Hall, I. (2014) "The Promise and Perils of Interpretivism in Australian International Relations," *Australian Journal of Public Administration*, 73(3), pp. 307–316. doi: 10.1111/1467-8500.12084.

Hamilton, M. G. and Adamson, E. (2013) "Bounded Agency in Young Carers' Lifecourse-Stage Domains and Transitions," *Journal of Youth Studies*, 16(1), pp. 101–117.

Haralambos, M. and Holbert, M. (2000) *Sociology : themes and perspectives*. 5th edn. London: HarperCollins.

Harcourt, D., Perry, B. and Waller, T. (2011) *Researching young children's perspectives : debating the ethics and dilemmas of educational research with children*. 1st edn. London: Routledge.

Harding, S. (2009) "Standpoint Theories: Productively Controversial," *Hypatia*, 24(4), pp. 192–200. doi: 10.1111/j.1527-2001.2009.01067.x.

Hayton, W. (2020) *We wear the sunflower lanyard - HM Land Registry*. [online] Hmlandregistry.blog.gov.uk. Available at: <https://hmlandregistry.blog.gov.uk/2020/09/29/we-wear-the-sunflower-lanyard/> (Accessed: October 4, 2021).

Intersectionality

Hochschild, A. R. and Machung, A. (2012) *The second shift : working families and the revolution at home*. New York, N.Y.: Penguin Books.

Hughes, N., Locock, L. and Ziebland, S. (2013) "Personal Identity and the Role of 'carer' among Relatives and Friends of People with Multiple Sclerosis," *Social Science & Medicine*, 96, pp. 78–85. doi: 10.1016/j.socscimed.2013.07.023.

Humphrey, C. (2014) "Qualitative Research – Mixed Emotions," *Qualitative Research in Accounting & Management*, 11(1), pp. 51–70. doi: 10.1108/QRAM-03-2014-0024.

Kitzinger, J. and Barbour, R. S. (1999) *Developing focus group research : politics, theory, and practice*. London: SAGE Publications.

Kourany, J. (2009) "The Place of Standpoint Theory in Feminist Science Studies," *Hypatia*, 24(4), pp. 209–218. doi: 10.1111/j.1527-2001.2009.01069.x.

(2020) "Disability-Inclusive Covid-19 Response: What It Is, Why It Is Important and What We Can Learn from the United Kingdom's Response," *Wellcome open research*, 5, pp. 79–79. doi: 10.12688/wellcomeopenres.15833.1.

Lafferty, A., Phillips, D., Dowling, L., Majella, H., Fahy, M., Clare, M., Gillian, D., Gerard, P. and Kroll, F. (2021) "Colliding Worlds: Family Carers' Experiences of Balancing Work and Care in Ireland during the Covid-19 Pandemic," *Health & social care in the community*, (202123). doi: 10.1111/hsc.13365.

Landau, I. (2008) "Problems with Feminist Standpoint Theory in Science Education," *Science & Education : Contributions from History, Philosophy and Sociology of Science and Mathematics*, 17(10), pp. 1081–1088. doi: 10.1007/s11191-007-9131-5.

Ledwith, S. (2012) "Outside, Inside: Gender Work in Industrial Relations," *Equality, Diversity and Inclusion: An International Journal*, 31(4), pp. 340–358. doi: 10.1108/02610151211223030.

Lloyd, L. (2006) "Call Us Carers: Limitations and Risks in Campaigning for Recognition and Exclusivity," *Critical Social Policy*, 26(4), pp. 945–960.

Maitra, R. (2020) "Making the Most of Shielding: Covid-19 Is Exposing the Unpaid Carers in Nhs Workforce," *BMJ (Clinical research ed.)*, 370, p. 3106. doi: 10.1136/bmj.m3106.

Mannay, D. (2010) "Making the Familiar Strange: Can Visual Research Methods Render the Familiar Setting More Perceptible?," *Qualitative Research*, 10(1), pp. 91–111.

Mattsson, T. (2014) "Intersectionality As a Useful Tool: Anti-Oppressive Social Work and Critical Reflection," *Affilia - Journal of Women and Social Work*, 29(1), pp. 8–17.

Mayoh, J. and Onwuegbuzie, A. J. (2014) "Surveying the Landscape of Mixed Methods Phenomenological Research," *International Journal of Multiple Research Approaches*, 8(1), pp. 2–14.

McDonald, J., Dew, K. and Cumming, J. (2010) "Change and Adaptation in Families with Young Carers," *Australian Journal of Social Issues*, 45(4), pp. 459–475.

Moore, T., McArthur, M. and Noble-Carr, D. (2011) "Different but the Same? Exploring the Experiences of Young People Caring for a Parent with an Alcohol or Other Drug Issue," *Journal of Youth Studies* 14 n2 pp. 161–177. doi: 10.1080/13676261.2010.522561.

Mosedale, S. (2014) "Women's Empowerment As a Development Goal: Taking a Feminist Standpoint," *Journal of International Development*, 26(8), pp. 1115–1125. doi: 10.1002/jid.3050.

Neuman, W. L. (2014) *Social research methods : qualitative and quantitative approaches*. Seventh edition. Pearson new international edn. Harlow, Essex: Pearson.

The new politics of disablement

O'Reilly, M. and Dogra, N. (2017) *Interviewing children and young people for research*. Los Angeles: SAGE.

O'Reilly, M., Ronzoni, P. and Dogra, N. (2013) *Research with children: theory and practice*. Los Angeles: SAGE

Qu, S.Q. and Dumay, J. (2011) "The Qualitative Research Interview," *Qualitative Research in Accounting & Management*, 8(3), pp. 238–264. doi: 10.1108/11766091111162070.

Rizzo, JR., Beheshti, M., Fang, Y., Flanagan, S. and Giudice, NA.

Robson, C. (2002) *Real World Research*. Second edition. Blackwell Publishing Ltd.

Ryan, F., Coughlan, M. and Cronin, P. (2007) "Step-By-Step Guide to Critiquing Research. Part 2: Qualitative Research," *British Journal of Nursing*, 16(12), pp. 738–744. doi: 10.12968/bjon.2007.16.12.23726.

Sarantakos, S. (2013) *Social research*. 4th edn. New York, NY: Palgrave Macmillan.

Saurabh, R., Bihari, L.S. and Prateek, S.S. (2020) "Extending an Equitable Covid-19 Response to the Disabled Individuals," *Indian Journal of Health Sciences and Biomedical Research KLEU*, 13(3), pp. 260–261. doi: 10.4103/kleuhsj.kleuhsj_168_20.

Schiariti, V. and McWilliam, R. A. (2021) "Crisis Brings Innovative Strategies: Collaborative Empathic Teleintervention for Children with Disabilities during the Covid-19 Lockdown," *International journal of environmental research and public health*, 18(4). doi: 10.3390/ijerph18041749.

Smyth, C. and Michail, S. (2010) "Exploring Young Carers' Agency," *Qualitative Research Journal*, 10(2), pp. 36–50.

Smyth, C., Blaxland, M. and Cass, B. (2011) "'so That's How I Found Out I Was a Young Carer and That I Actually Had Been a Carer Most of My Life'. Identifying and Supporting Hidden Young Carers," *Journal of Youth Studies*, 14(2), pp. 145–160. doi: 10.1080/13676261.2010.506524.

Spencer, S. and Swinglehurst, D. (2020) "Supporting Carers," *InnovAiT*, 13(4), pp. 213–217. doi: 10.1177/1755738019898499.

Spicer, I. (2007) "Disability and Family Carers," *Family Matters*, 76(76), pp. 30–31.

Swigonski, M. E. (1994) "The Logic of Feminist Standpoint Theory for Social Work Research," *Social Work*, 39(4), pp. 387–393.

Tummers, J., Catal, C., Tobi, H., Tekinerdogan, B. and Leusink, G. (2020)

Turner, D. (2021) *Social work and covid-19 : lessons for education and practice*. St Albans: Critical Publishing. Available at: <https://ebookcentral.proquest.com/lib/uniofglos/reader.action?docID=6468572> (Accessed: September 5, 2021).

Walker, E. and Dewar, B. J. (2000) "Moving on from Interpretivism: An Argument for Constructivist Evaluation," *Journal of Advanced Nursing*, 32(3), pp. 713–720. doi: 10.1046/j.1365-2648.2000.01532.x.

Walsham, G. (1995) "The Emergence of Interpretivism in IS Research," *Information Systems Research*, 6(4), pp. 376–394. doi: 10.1287/isre.6.4.376.

9.0 Appendices

Appendix A – Email demonstrating the difficulty accessing participants

Hi Amy and all,

To be honest, I couldn't even get parents/carers to do a 2 minute questionnaire on their GP access. I am happy to ask around but would be surprised to get any positive response!

I will talk to people next week and let you know if anyone is interested.

Good luck on your research,

Appendix B – Online recruitment post for questionnaire participants

25 May · 🌐

I'm currently completing my masters by research in social science.

I'm looking for people who provided care for someone (with some form of disability) prior to the pandemic who continued to care for this individual throughout lockdown to identify how COVID-19 impacted their circumstances.

If this applies to you or anyone you know I would very much appreciate it if you could complete this very short survey that is completely anonymous.

Please feel free to share the link with anyone who this may be relevant to.

Thank you!!

FORMS.OFFICE.COM
Microsoft Forms

About This Website

Appendix C – Questionnaire informed consent information

Changes in daily living support needs for those with disabilities during COVID-19

If you are aged 18+ and provided regular care for someone with a form of disability / illness prior to the pandemic (March 2020) and continued to provide care for the same individual during the UK lockdown restrictions, please complete the below questions about your situation.

I am researching this topic due to personally growing up as a young carer for my disabled brother and over the course of the last year during the lockdown restrictions I experienced first hand the changes in support needs and witnessed the struggles faced by my family. Therefore I am completing this research as part of a Social Science Master's by Research Degree at the University of Gloucestershire, in order to give others in similar situations a voice and raise awareness.

This research has gained full ethical approval via the University of Gloucestershire ethics committee. None of the questions are compulsory and all data will be anonymous. Please check you are happy with your answers before pressing submit as it would be difficult to withdraw your data from the research due to the anonymity aspect.

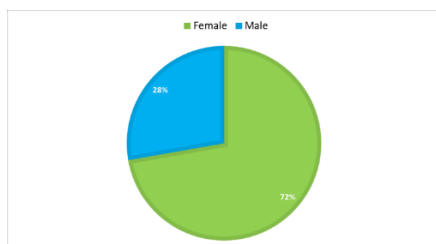
This survey should take approximately 5 minutes.

Thank you for your time. Your help is very much appreciated.

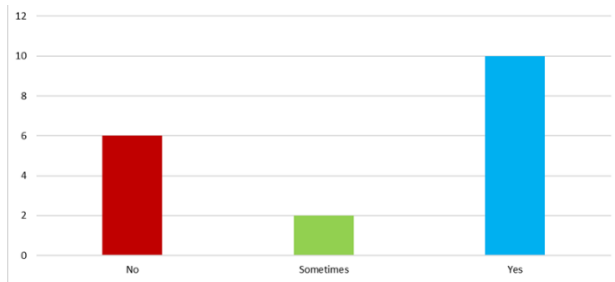
If you know anyone else who would be happy to complete this survey, please forward it on. Thank you

Amy Gass
amygass@glos.ac.uk

Appendix D – Participant's gender



Appendix E - Does the participant live with the person they care for?



Appendix F – Approved changes

Hi,

I received ethical approval for my masters research project, REC-21.34.1ab in April. Since then, I've decided due to time constraints and difficulty accessing participants I would like to do less interviews and add a short survey to my research.

I came to this decision after speaking with multiple organisations who stressed the issue with trying to access carers due to the time interviews would take and that the organisations themselves have faced the same issue of access.

The survey contains the same questions as the interview but has been condensed and mostly contains closed responses. Therefore, in theory the survey has less ethical implications than the original research method. The link for the survey is at the bottom of this email.

I am emailing just to double check that this is okay and is covered in my ethical approval as the question content is the same the only difference is the format.

Hi Steph, yes that's fine although I would suggest for Amy to provide a debrief at the end of the survey with signposts to support services.

If you can just add Amy's email to the rest of the documentation to keep a record of these changes.

Regards,

Appendix G – Interview schedule

Introduction:

1. Please can you tell me your relationship to the person you care for and how long you've cared for them?
2. Do you live with the person you care for?
3. Do you care for this person alone or with the help of others? – Who? Family? Paid carers? Charity/organisation?

How has COVID-19 changed their circumstances?

4. Did the lockdown restrictions impact your caring responsibilities?
5. Did the number of hours a week you care for increase, decrease or stay the same?
6. How did the restrictions affect your daily living support responsibilities?
7. Did you experience a loss of services which you would have received prior to the pandemic?
8. Due to the restrictions did this cause a need for additional assistance and support from outside your home? Where did you find this support? – Family? Friends? An organisation?
9. If an organisation – Who? How did you find out about them? Did you use them prior to the pandemic? What did they provide? Was this helpful?
10. Were there any significant additional struggles that arose?
11. Were there any positive changes that arose during lockdown?
12. How did you cope with the restrictions put in place – for example the 'one person per household' shopping rule?
13. Do you feel that there was a difference in your personal circumstances as the year went on? For example, if at the beginning you experienced a loss of services, have this been replaced or reinstated?
14. Would you say there was any differences in circumstances between the three lockdowns?
15. If you had additional support required during the lockdowns, did you also require this during the non-lockdown periods of the pandemic? Why?

Their feelings towards the pandemic situation:

16. How do you feel about the way that unpaid carers have been treated during the pandemic?
17. Do you feel this representation personally reflects you and your situation?
18. Are the representations accurate? How would you change them? What's missing?
19. How do you feel about the way those with disabilities were described/treated?
20. Was the person you care for described as vulnerable? Are you happy and within agreement with this? Why?
21. Do you agree with the label of being 'vulnerable'? Do you think this is helpful and something that represents the individual you care for?
22. Do you wish that more people were included within that category?
23. What do you wish was different about the representations?
24. Are you aware of anyone that became involved within activism in response to this potential representation issue?
25. Did you address any concerns about the way you and/or your care receiver were treated? – petitions, social media, council letters etc
26. Do you claim Carers Allowance?
27. Do you think this needs to be reviewed? How?

Looking forward:

28. Do you worry about future support impacts due to the pandemic?
29. Are you concerned that the additional care implications will continue?
30. What would a meaningful, permanent improvement in your circumstances look like to you?

Appendix H – Questionnaire questions example

10. Please explain the main negative impact the lockdown restrictions had on your caring role (if applicable).

11. Please explain the main positive impact the lockdown restrictions had on your caring role (if applicable).

12. The term "vulnerability" was used within the media frequently to describe individuals.

Would you personally agree with this label of 'being vulnerable' for the individual you care for?

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- I don't know

13. Do you think that this label of being "vulnerable" has been positive or negative for the individual you provide care for?

17. Many full-time unpaid carers are currently receiving £67.60 in Carer's Allowance from the UK government.

Do you currently claim this?

- Yes
- No
- Prefer not to say
- I don't know

18. Do you think the Carer's Allowance amount should be reviewed to support carers accordingly during these challenging times?

- Yes
- No
- I don't know

19. What would a meaningful, permanent improvement in your overall circumstances look like to you?

20. Is there anything else you would like to add about this topic?

Appendix I – Participant Information Sheet example sections

Why have I been invited?

You have been invited to take part in this study due to being identified as someone who provides significant care for someone else and therefore may identify as a 'carer'. Due to your care responsibilities, there is a possibility that you and/or the individual you provide care for may have experienced a different demand/change to daily care needs because of the pandemic. This study is an opportunity for you to discuss these changes and the potential issues that may have arisen.

Will my taking part in the study be kept confidential?

The information provided will be sanitised in the research. Direct quotations may be used, but not attributed to a named individual, as participants will be allocated a pseudonym.

If you join the study, it is possible that some of the data collected will be looked at by authorised persons from the University of Gloucestershire. Data may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and will abide by this duty.

- The data will be collected by audio recording the interview or recorded using the record function on Microsoft Teams and then destroyed after being transcribed.
- Audio recordings will be transcribed and anonymised and will be stored securely on University of Gloucestershire secure servers.
- The transcribed anonymous data used for this particular research but may be retained for use in future studies.
- The researcher, supervisor and other relevant persons from the University of Gloucestershire will have access to the transcribed anonymous data.
- The transcribed data will be retained until such time it isn't required and it will be disposed of securely after 10 years.
- Participants have the right to check the accuracy of data held about them and correct any errors.

What are the possible disadvantages and risks of taking part?

There should be no possible disadvantages of participating however it does require approximately 30 minutes of your time to have a detailed in-depth discussion about your experiences. I appreciate this may be potentially difficult due to caring responsibilities and would therefore be extremely grateful for any time you may be able to dedicate to my study, even if you're unable to complete the full interview. As someone who has a special needs brother who makes lots of noise I fully understand how difficult completing things online may be and am therefore extremely understanding to interruptions, so this is not something to worry about.

What will happen if I don't want to carry on with the study?

You do not have to continue to participate in the study once it has started and may leave at any time, without the need to justify your reasoning behind your decision. There is also no obligation to answer all questions if you do not wish to. You also have the right to withdraw your data up to 2 weeks after the interview has commenced.

Appendix J - Interview transcript extract

P: yeah so in terms of caring I don't like physically, I don't necessarily like take on the roles like you might someone who's got a physical disability like dressing them, clothing them

I: yeah

P: it's more like being out and about emotionally what you've got from sort of the meltdowns that they might and the stress from that and stuff. And especially with lockdown that has been a lot harder because they struggle with change so we've had to obviously swap to completely onto online and this is all really overwhelming and you've not had as much support and then you've obviously then had to try and do your work on top of that it's all a lot, it seems like there's a lot going on yet you're completely confined into this one place

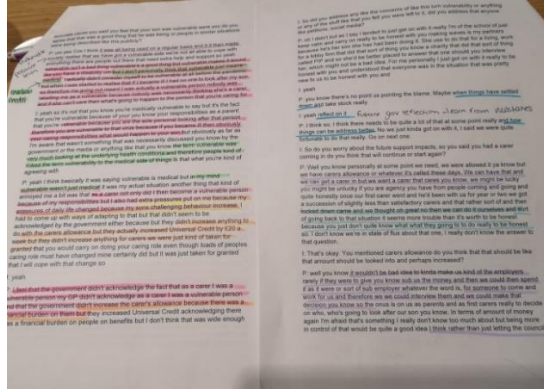
I: yeah so we you say that because everything is obviously gone online would you say that's had the most negative impact because of the change in the routine you're not there is out as much and it's just that extra

P: yeah I'd definitely say it had a negative impact because definitely my twin sister she loves going out and about like she likes to go out about once a day so you know without having college and stuff it's been really hard to like plan trips out or sort of think of all where can we go for a walk with my mum having restricted mobility and stuff we've had to try and think like well where's safe covid's obviously been dangerous so it's

I: yeah

P: we've had to try and balance it so she's had her outing but it caters for everyone else's needs in the house as well

Appendix K – Highlighted transcripts



Appendix L – Thematic analysis simplified tables

Theme	Summary	Example quote
Changes in routine	<ul style="list-style-type: none"> Behavioural issues The need to make a new routine with structure Overwhelming moving online 	▷ "extra pressures put on me because my pressures of daily life changed because my son's challenging behaviour increased" (Denise)
Loss of services and support	<ul style="list-style-type: none"> Lost help from paid carers and family Services adapted (online) – not as affective Financial issues mentioned Medical model referenced in terms of lack of diagnosis 	▷ "space to just breathe" (Sophie)
The challenges to adhere to regulations	<ul style="list-style-type: none"> Difficult to buy enough items Loss services mean taking their cared for individual with them – links to fear of catching the virus Sensory issues around mask wearing Anxiety and stigma of peoples judgement and lack of understanding 	▷ "son actually couldn't wear a mask cos he wouldn't understand it, he also wouldn't understand social distancing" (Denise)
The effect of isolation	<ul style="list-style-type: none"> Amplified pre-existing problem No services – lack escapism Lack understanding – isolate from friends Isolating for cared for individual 	▷ "couldn't go out so was feeling isolated" (Participant 14)
The effect of fear	<ul style="list-style-type: none"> Fear of catching virus for them and the person they care for Fear caused further loss services Forced vulnerability 	▷ going out meant I was actually a vulnerable person" (Denise)

Theme	Summary	Example quote
Vulnerability	<ul style="list-style-type: none"> Hesitation to label Enforced vulnerability due to their caring responsibilities 	▷ "actually I don't feel it's up to me to choose" (James)
Problems with vulnerability	<ul style="list-style-type: none"> Medical model issue of labelling people as 'vulnerable' – critical disability theory Ignored hidden disabilities and carers 	▷ "you're vulnerable because of your you know your responsibilities as a parent that you're vulnerable because you are the sole personal looking after that person therefore you are vulnerable to that virus" (Denise)
Negotiating the term	<ul style="list-style-type: none"> Needs to be inclusive Reject medical gaze 	▷ "vulnerable might not have necessarily been the best word to use" (Sophie)
Positive outcomes	<ul style="list-style-type: none"> Time with family – helped combat sense of loneliness Movement to online events – saved money 	▷ "activities together as a family" (Sophie)
Awareness	<ul style="list-style-type: none"> Shown there are people who need extra help Highlighted hidden disabilities 	▷ "that society was made up of different types of people" (Denise)
Future concerns and changes towards inclusivity	<ul style="list-style-type: none"> Loss of face to face interaction – isolation Highlighting hidden disabilities may cause discrimination Need to make changes 	▷ "priority to address how little money is available to full-time carers" (Participant 12)

Changes to financial support	<ul style="list-style-type: none"> ▪ Problems accessing – issues with gaining diagnosis, don't meet hour criteria ▪ Change the way the money is distributed 	▷ "increased carer's allowance"(Participant 11)
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Appendix M – Ethical approval letter


UNIVERSITY OF GLOUCESTERSHIRE
 Dr Emily Ryall
 Research Ethics Committee Chair
 Reader in Applied Philosophy
 Oxstalls Campus,
 Longlevens, Gloucester, GL2 9HW

Via email
 Amy Gass
amygass@connect.glos.ac.uk

28 April 2021

Dear Amy

Thank you for your application for ethical approval.

I am pleased to confirm ethical clearance for your research following ethical review by the University of Gloucestershire's Research Ethics Committee (REC) fast track panel.

Please keep a record of this letter as a confirmation of your ethical approval.

Project Title: 'An examination of the changes in daily living support needs for those with disabilities during the COVID-19 pandemic.'

Start Date: 31 March 2021

Projected Completion Date: 30 September 2021

REC Approval Code: REC.21.34.1ab

If you have any questions about ethical clearance please feel free to contact me. Please use your REC Approval Code in any future correspondence regarding this study.

Good luck with your research project.

Regards,

Dr Emily Ryall
 Chair of Research Ethics Committee



University of Gloucestershire, The Park, Cheltenham, GL50 2PH. The University of Gloucestershire is a company limited by guarantee registered in England & Wales. Registered number: 06022343. Registered office: The Park, Cheltenham, GL50 2PH. Tel: 01454 601 601 www.glos.ac.uk

Appendix N – Consent form

		Please tick box
1.	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time during the interview and up to 2 weeks after it concludes, without giving any reason, and that if I choose to do this any contribution made won't be used in the final report.	
3.	I understand that data collected during the study, may be looked at by relevant individuals, such as the researcher's supervisors, as the University of Gloucestershire or from regulatory authorities.	
4.	I give permission for the relevant individuals to have access to my data. This will include the researcher, the researchers supervisors and any regulatory authorities within the University of Gloucestershire.	
5.	I agree to my interview / focus group being audio recorded.	
6.	I agree to being quoted verbatim	
7.	I agree to my transcribed anonymous data I contribute being retained for future research purposes, this will be held for up to 10 years.	
8.	I agree to participate in the study.	
9.	I understand that I have the right to withdraw all my data up to 2 weeks after my interview date by contacting the researcher directly via email amygass@glos.ac.uk	

If you have any questions or queries around the ethics of the project please feel free to contact the University of Gloucestershire's Research Ethics Committee Chair Dr Emily Rydall eryall@glos.ac.uk

Name of Participant:

Date:

Signature:

Name of Person taking consent:

Date:

Signature:

Appendix O – Interview debrief form

Support services

Below are the contact details for local support services that you may wish to access should you require further support.

Local council – Cheltenham

Coronavirus support available at

<https://www.gloucestershire.gov.uk/gloucestershires-community-help-hub/> and by telephone: 01452583519.

Carers UK

Can help if you need advice regarding your current situation. The website is <https://www.carersuk.org/> or you can phone them on 02073784999.

Cheltenham Foodbank

May be able to assist you if you require emergency food parcels and have received a referral for a Foodbank voucher. The website is <https://cheltenham.foodbank.org.uk/> and contact telephone number is 01452527202.


The Samaritans

If you are struggling with mental health concerns and need someone to talk to you can access The Samaritans by emailing jo@samaritans.org or by calling 116123 for free at any time.

Mencap

Can help if you need advice for yourself or the person you care for. The website is <https://www.mencap.org.uk/> and contact telephone number is 08088081111 or you can email them at helpline@mencap.org.uk

Appendix P – Questionnaire debrief example

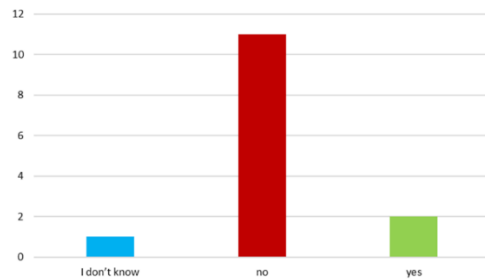
 Thanks!

Thank you for completing this survey.
Your help is very much appreciated.

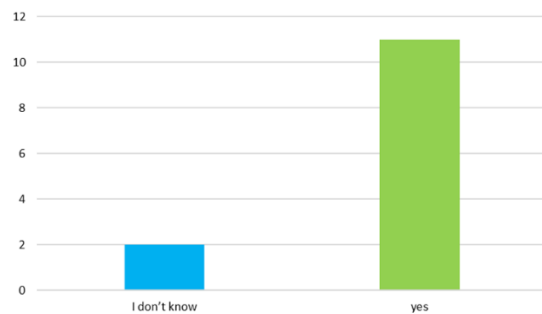
If you would like to discuss any of the topics covered please feel free to contact the following support services:

<https://www.carersuk.org/>
<https://www.mencap.org.uk/>

Appendix Q - Does the participant claim Carer's Allowance?



Appendix R - Does the participant think that Carer's Allowance should be reviewed?





There's no such thing as "normal"