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Exploring the impact of perceptions of psychological therapy on access to and engagement with therapy

Lucy Harris

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(DPsych)

City, University of London

Department of Psychology

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Introduction to the Portfolio

This portfolio is compiled of three pieces of work that relate to different parts of my training in counselling psychology. First, I present a piece of original research which aimed to understand how carers of people with dementia perceive therapy when they have never accessed it before, and how these perceptions influence carers' decisions regarding therapy. Secondly, I present a combined case study and process report of my work with a client, Michelle (pseudonym used to protect confidentiality) who found therapy – particularly empathy and discussing emotions – a daunting space. Finally, I present a publishable paper which outlines the model emerging from the original research.

These three pieces of work are linked by two themes: firstly, the importance of listening to the subjective experiences of clients, and secondly the impact of the perceived safety and risk of therapy on client engagement and progress. The first theme fits with one of the core values of counselling psychology – valuing clients' subjective experiences. This value was one of the reasons I felt drawn to counselling psychology as a discipline, and is something I have come to see as increasingly crucial in my work. The second theme reflects perceptions reported by participants in my research and was a significant consideration in my work with Michelle. I had not originally intended to compile work around this theme, but the more I have engaged with it, the more it has benefitted my work.

My interest in the first theme – listening to the subjective experiences of clients – has been longstanding. As a Trainee Psychological Wellbeing Practitioner in 2011, I was fortunate to be training in an IAPT (Improving Access to Psychological Therapies) service that focused on user involvement from the early stages. I witnessed how regular focus groups with service users helped identify areas of improvement and, often, strategies to address these. This complemented a focus on individual performance and feedback, highlighting how clients' experiences could inform both my individual practice and the wider functioning of the service.

In the following years, I specialised in working with carers and began developing a CBT-based stress management group for carers. Carers who had previously accessed the service were involved in developing the key areas to address in sessions and developing the content and protocols for the group. This helped to ensure that the topics covered felt relevant to a range of carers, that case studies were realistic and that materials were accessible to carers attending the course. Additional feedback following the pilot and ongoing review of the materials further developed the course. I do not believe the course would have been as successful as it has been without the involvement of carers in its development; frequently, it has also benefitted from being facilitated by trained staff who also have lived experience of caregiving.

This approach of listening closely to my clients' experiences and feedback has supported both my clinical work with individuals and also my ongoing development as a counselling psychologist. The person-centred approach and collaborative approach of CBT both seemed a comfortable fit with this, and working pluralistically by bringing explicit conversations about different ways we can approach the same problem has been very enriching. I have witnessed how this can help clients start to listen to and trust themselves, because they see how their decisions impact our work and that together we can review this and make changes if needed.

As applied specifically to this portfolio, the importance of listening to clients' subjective perspectives informed both my choice of research topic and the case study being presented. While my research drew on the subjective perspectives of carers who have not accessed therapy (an area not previously researched), the presented case study reflects work with a client whose perceptions of therapy made it more challenging for her to engage with therapy. Working therapeutically with her required listening sensitively to her subjective experiences both in general and regarding the therapeutic work and therapy experience specifically. Taken together, these two pieces of work highlight that subjective experiences must be valued, given space and listened to, both in therapy and in research, in order to provide high-quality therapy that meets the needs of clients.

The second theme, regarding perceptions of therapy as threatening, I had considered less fully before starting my training as a counselling psychologist. I had thought about it in relation to the occasional client who seemed to find therapy particularly intimidating. For instance, I had thought about how some aspects of therapy may mirror threatening situations; two people behind a closed door discussing something private might mirror experiences of abuse, with the police or traumatic medical procedures. I had also thought about the stigma that can accompany having therapy or mental health struggles. But it was not until completing my research and beginning to think more about the potential threats of therapy that I moved from thinking not just about how can we make therapy safe, but also how do we attend to and sit with those parts of clients who are finding therapy threatening? How do we sit in that uncomfortable place, and seem comfortable enough there to help our clients move through it, or at least offer them a realistic alternative to retreat? How do we balance creating safety in therapy with not getting so stuck in safety that we risk preventing the very change clients wish to see?

There are no easy answers to these questions, although I have found that listening to my clients, my supervisor and myself have been crucial in navigating this balance. I tend to be cautious, and balancing this with feedback in supervision and from my clients has helped me to move from staying in safe waters with my clients to spending more time in territory that feels more challenging. At the same time, listening to myself and my clients has been helpful at times in remaining patient and not pushing clients too far, too fast. This has helped in building solid, trusting relationships that can withstand challenging work.

It is even more challenging to consider how to help clients feel safe enough to approach therapy in the first place, to make that a realistic option for them to make an informed decision about. Of course, not everyone will want or need psychological therapy, but my research highlights that there is still more to be done to ensure that those who may want therapy have accurate information about therapy and how to access it.

Within this portfolio, I explore this second theme in both my research and my case study. One of the categories to emerge from my research focuses on carers' perceptions of the threat level of therapy, and I present a model which considers how this and other factors seem to play a role in carers' decisions regarding accessing therapy. However, the perception of therapy as threatening is not unique to people who have not accessed therapy. My case study therefore explores my work with a client who found therapy threatening, and considers how my attempts to balance the relative safety and threat level of therapy both helped and hindered our work together. Although the client was not a carer, I noticed similar themes in working with her to those emerging from my research, and it was only by listening to her concerns and attempting to create safety in the therapy room that our work was able to progress. As such, the case study follows on from my research by extending the consideration of the impact of clients' perceptions of therapy from how these perceptions may prevent them from accessing therapy, to how such perceptions impacted on Michelle's engagement with therapy once she had begun to attend.

Section A: Doctoral Research

The first section of this portfolio comprises my doctoral research, entitled "Carers of people with dementia and psychological therapy: A grounded theory analysis of how perceptions influence decisions about having therapy." This research aimed to explore how carers of people with dementia perceive psychological therapy when they have not previously had therapy themselves; and how these perceptions influence carers' decision-making regarding therapy. A grounded theory approach underpinned by a critical realist theoretical position was chosen in order to prioritise carers' views and experiences and to support the development of a model indicating how carers' perceptions of therapy influence whether or not they wish to have therapy themselves. The core category identified was "Becoming Aware of Therapy," indicating that carers with greater awareness and more nuanced understanding of therapy were more confident in stating whether or not they wished to access therapy. The relative invisibility of therapy as an option for carers, the interrelatedness of their experiences with non-therapy services and their perceptions of therapy, and the difficulty of accessing therapy were also important categories to emerge from the study. These findings are considered against existing literature and help to extend existing models of help-seeking. The implications of these findings for counselling psychology and broader implications are also explored. I hope this research will help counselling psychologists to tailor their work more effectively to the needs of carers both before and during therapy. With appropriate dissemination, I hope my findings can also have a wider reach, particularly with carer support services and carers themselves.

Completing this research has highlighted to me the importance of demonstrating that we, as professionals, listen to the voices, needs and feedback of the people we work with in order to make our work accessible to them. This includes presenting both the potentially challenging aspects of therapy, which may feel threatening to clients, and the ways in which we strive to make therapy a sufficiently safe space for our work together, in a way that enables clients to make informed decisions about undertaking therapeutic work.

Section B: Combined Case Study and Process Report

In this section, I present my work with a client, Michelle, who presented with low mood and lethargy following a diagnosis of diabetes. Michelle found the idea of therapy and talking openly about her feelings very intimidating, struggled to trust her own judgement and was unsure if therapy would help her. By taking an explicitly pluralistic approach to our work together, I was able to demonstrate to Michelle that I trusted her judgement and valued her thoughts about how we should work together. It also helped prevent me from moving too far ahead of what Michelle was ready for, which may have made therapy feel too threatening at the time; and provided Michelle with evidence that she could make decisions that turned out well. Listening to what Michelle wanted to achieve from therapy but also how she wanted to achieve this facilitated her ability to engage through initially less threatening tasks (focusing on changes in behaviour, rather than making herself emotionally vulnerable). This provided the time for us to build a strong relationship and for me to demonstrate that I could safely maintain the boundaries of therapy and respect Michelle's boundaries when she was not ready to discuss something. Without this time, I am not sure we would have been able to explore Michelle's feelings about the death of her husband or her relationship with herself.

Section C: Publishable Paper

In the final section of this portfolio, I present a paper prepared with the aim of submitting to the journal Dementia. I chose this journal because they have published qualitative work considering the experiences of carers of people with dementia, both of which are relevant to my paper; and also because of their clear focus on using appropriate language regarding people with dementia. It feels particularly important to me that I share my findings because of the link carers drew between their experiences of feeling invalidated and not understood by non-therapy services and professionals and how they perceive therapy. It was therefore important not to limit my choice of journal to one targeting solely at therapists or psychologists.

I hope that by disseminating my findings, I can remind colleagues and peers of the need to discuss therapy as an option with carers where relevant and highlight the need to describe therapy in easily understood terms. I hope that my research can prompt further consideration of how to make therapy a visible, accessible option for those carers who may wish to access it. I have experienced colleagues who were concerned that carers may feel judged if they offered therapy as an option, and I hope that my findings can help to provide an alternative perspective: that carers who feel they need help may feel heard and valued through knowing that someone else has recognised their distress and is open to discussing options with them, one of which is therapy.

Section A: Doctoral Research

Carers of people with dementia and psychological therapy:

A grounded theory analysis of how perceptions influence decisions about having therapy

Lucy Harris

Supervised by: Professor George Berguno

Abstract

In the UK, approximately 850,000 people are living with dementia (Wittenberg et al., 2019) and 500,000 people are thought to be providing unpaid care for people with dementia in England (Department of Health, 2009). Caring for someone with dementia can have a significant negative impact on carers' physical and psychological well-being. Evidence suggests psychological therapy may be helpful in addressing this impact, but that carers do not always seek therapy despite significant distress. Previous research has suggested that carers who completed therapy appreciated the safe space to talk. This study focused on carers of people with dementia, who have not previously accessed therapy. It aimed to investigate how carers of people with dementia perceive therapy and how these perceptions influence carers' decisions regarding accessing therapy. Semi-structured interviews with carers were analysed using a grounded theory method. Findings included the apparent invisibility of therapy as an option for carers, varying levels of understanding regarding therapy, varying perceptions of the relative safety or threat-level of therapy (partly linked to carers' coping styles) and perceiving the process to access therapy as a battle. The resulting model provides insight into this process and indicates the importance of accurate, visible information about therapy being available to carers. Implications for clinical practice are discussed. These include considerations of information provided prior to psychological therapy by therapists and non-therapists, as well as considerations during therapy.

Chapter 1: Background: What do we Already Know about the Mental Health of Carers of People with Dementia?

Worldwide, estimates suggest that 44 million people are living with dementia and that this number could triple by 2050 (Prince et al., 2014). There are thought to be approximately 850,000 people with dementia living in the UK (Wittenberg et al., 2019), the majority of whom are supported at home by unpaid friend or family carers (Dodge & Kiecolt-Glaser, 2016; van der Lee et al., 2014). A working definition of carers as as “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support” (Carers Trust, n.d.) will be used in this paper. In England alone, there are thought to be 500,000 people providing unpaid care to people with dementia (Department of Health, 2009).

A literature review was carried out to ascertain what is already known about the mental health of carers of people with dementia. The approach taken to review the literature is outlined in Appendix A. Given the number of unpaid carers supporting people with dementia, a substantial body of work exists exploring the impact of caregiving and ways to address this. Caring has been associated with a range of negative impacts on mental and physical health (Colombo et al., 2011; Sorensen et al., 2002), with carers in general being at greater risk of anxiety and depression than the general population (HM Government, 2008), and carers of people with dementia being particularly negatively affected, as noted above. This is not to say that caring is a wholly negative experience. Positive aspects of caring have also been highlighted (Wang et al., 2018), although this has been less thoroughly researched.

However, carers of people with dementia were found to have experienced more negative impacts on their wellbeing than other carers (Bertrand et al., 2006; Mitchell et al., 2015). This suggests that different groups of carers are impacted differently by their caring role, and as carers of people with dementia seem to be more negatively affected, they may particularly benefit from support for their wellbeing, such as psychological therapy. It was therefore considered particularly important to understand how carers of people with dementia decided not to access therapy, in order to be able to promote therapy more appropriately to their needs or recognise if therapy may not be the most appropriate intervention.

In light of the impact caring can have on carers' wellbeing, a range of potential interventions have been evaluated. Many psychosocial interventions have been developed and studied, providing evidence that interventions combining psychoeducation and psychotherapy can effectively improve a range of outcomes, including carer burden, depression and anxiety (Gilhooly et al., 2016). This suggests that there is a role for psychological interventions in supporting carers; and there is a small amount of qualitative research suggesting that carers of people with dementia experienced psychological therapy as helpful (Elvish et al., 2014).

Yet despite increased access to psychological therapy forming part of England's National Dementia Strategy (Department of Health, 2012), it is unclear how many carers access or want to access this. Some work has been undertaken to identify barriers to accessing support (Stephan at al., 2018). It is also possible that carers prefer other types of support, such as support for the person they are caring for (Jegermalm & Sundström, 2013), rather than psychological therapies. It is not yet clear how carers of people with dementia perceive psychological therapies, or how relevant these approaches seem to them.

1.1 Definitions and Concepts

Throughout the literature on caregiving, definitions of the term 'carer' and of common concepts (such as 'carer burden') are variable and not always clearly explained. The Princess Royal Trust for Carers (PRTC) defined a carer as "someone who, without payment, looks after of provides help and support to somebody who could not manage otherwise due to age, physical or mental illness, addiction or disability" (PRTC, 2006, p. 1). Others have included an amount of time spent caring in their definitions (e.g. Lamura et al., 2008). Carers who provide more hours of care per week have been shown to experience higher rates of burden (Colombo, et al., 2011; Thomas et al., 2015), in which case it may make sense to focus resources on those carers at greatest risk.

Yet including the amount of time spent caring potentially also excludes significant groups of carers, such as those who may provide care less regularly, or those who are supporting another person who takes the lead caring role. While much research focuses on this primary carer, other studies are not explicit about whether only the primary carer is included (e.g. Chiu, et al., 2015). As Tatangelo et al. (2018) highlight, less attention has been given to the role of family dynamics in caring for someone with dementia. It is possible that those who are not the main carer may still experience negative effects, despite providing fewer hours of care, or that the complexities of negotiating care with multiple people involved may alter the experience of caregiving. Research to establish the extent to which non-primary carers provide care and the effects of this (both on the carer in question, and on the primary carer and care recipient) would be useful to clarify if this is the case.

As part of the Care Act 2014 (Department of Health, 2014), the UK government defined a carer as “someone who helps another person, usually a relative or friend, in their day-to-day life,” as long as they are not doing so as part of a voluntary or employment contract. This definition forms part of UK legislation and is more inclusive than those specifying an amount of time to be spent caring. However, it does not specify any particular circumstances in which the help is being provided, making it difficult to distinguish between someone taking on a caring role because the person they care for requires it and someone who provides help for other reasons.

As noted previously, The Carers Trust define a carer as “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support" (Carers Trust, n.d.). This definition is both more specific about the circumstances in which providing help becomes caring than the definition in the Care Act 2014, and also retains the inclusivity of not specifying how much time must be spent caring to count as a carer. As such, this is the definition which will be used throughout the remainder of this paper.

The concept of carer burden is frequently used in the literature but defined in different ways across studies. For example, Hunt (2003) highlights the differences between objective burden and subjective burden. Hunt (2003) focuses on objective burden as something which is tangible and can be observed (for example, caring tasks or time spent caring). By contrast, subjective burden refers more to carers' perceptions of the negative aspects of caring or the strains the caring role places upon them and their ability to manage or cope with this. Hunt (2003) notes that whether burden is subjective or objective, the concept refers to negative consequences as a result of caring, and the term will therefore be used here to encompass both aspects. Where studies make clear whether subjective or objective burden is being described, this will be noted.

1.2 Impact of Caring on Mental Health

Much research has highlighted a range of negative consequences of caring for psychological wellbeing and mental health. Carers UK reported that caring negatively impacted the mental health of 72% of carers (Carers UK, 2018); however, it is not clear from this self-report survey whether the degree of negative impact reached clinically significant levels. Carers and professionals may not have a shared understanding of the questions (for example, carers may have used lay rather than clinical definitions of terms such as 'anxiety'). Additionally, the measures used were not validated questionnaires with known psychometric properties. Finally, carers in contact with an organisation such as Carers UK may not be representative of carers as a whole; nor are the experiences of carers in general necessarily representative of the experiences of carers of people with dementia. Nonetheless, this finding suggests that carers perceive their mental health to have been detrimentally affected by their caring role.

This finding is supported by a multitude of other studies which specifically investigated the impact of caring for someone with dementia. A wide range of negative impacts have been reported, including higher rates of stress (eg. Gilhooly et al., 2016; van der Lee et al. , 2017), anxiety (eg. Li et al., 2012) and depression (eg. Clare et al., 2002; Cuijpers, 2005; Li et al., 2012) High levels of subjective and objective burden (eg. Adelman et al., 2014; van der Lee et al., 2017) and reduced quality of life (eg. Abdollahpour et al., 2015; Argimon et al., 2004; Cooper et al., 2007) have also been reported.

Given the high number of studies highlighting negative outcomes for carers of people with dementia, including several systematic reviews, Gilhooly et al. (2016) conducted a meta-review of systematic reviews from 1988-2014 which examined stress, coping and interventions for carers of people with dementia. Their meta-review supported the conclusion that caring for someone with dementia increases the risk of experiencing poor mental and physical health outcomes. This study has several strengths – it excluded one systematic review which was assessed as being of unacceptably poor quality, and covered a broad time period, such that the earliest systematic review identified by the authors was published 5 years into the inclusion dates for the study. Additionally, Gilhooly et al. (2016) addressed the potential concern that overlapping inclusion criteria for the systematic reviews included in their meta-review may mean that evidence from some studies is given greater weight due to being included in a greater number of systematic reviews. They used a corrected covered area index, based on 50% of their included studies, to check for overlap, and concluded that the degree of overlap was in the low-moderate range. Their findings therefore reinforced the conclusion that caring for someone with dementia is associated with increased levels of stress.

Of further concern regarding carers' wellbeing, O'Dwyer et al. (2016) found that one in six carers had contemplated suicide at least twice in the previous 12 months, one-fifth of whom said they were likely to attempt suicide in the future. They described their sample of 566 carers of people with dementia as similar to the broader population of carers of people with dementia in terms of gender, age, relationship to the person with dementia and length of the caring role, and used a larger sample than previous studies. However, the majority of their participants were North American or Australian, and further investigation to clarify if rates of suicidal ideation are similar amongst carers of people with dementia in the UK is warranted.

While many studies report negative outcomes for carers and this seems a sound finding, as Larkin et al. (2018) note, it could be argued that the type of effects being reported have also, at least to some extent, been driven by the way studies have been conducted. For example, the outcome measures chosen are commonly measures of burden, such as the Zarit Burden Inventory (ZBI), and depression. Larkin et al. (2018) highlight the need to also consider carers' lived experiences. Using qualitative or mixed-methods approaches may have illuminated a wider range of experiences (such as anxiety, guilt, or sense of obligation, as found by Tatangelo et al., 2018) which may also have helped inform the selection of outcome measures. Despite this, given the number of studies reporting similar findings, there is a clear association between caring for someone with dementia and poorer psychological wellbeing.

Ervin et al. (2015) assessed different aspects of subjective carer burden. Ervin et al. (2015) examined the levels of stress, anxiety and depression reported by carers of people with dementia, in relation to the emotional and behavioural symptoms which carers reported the person with dementia exhibited. They used validated outcome measures (the Depression, Anxiety and Stress Scales, DASS, and the Neuropsychiatric Inventory

Questionnaire, NPI-Q) and actively attempted to recruit a mix of participants who did or did not utilise services by recruiting through a range of avenues. This is a strength given than many studies primarily recruit via carer support services and therefore the findings may often be more representative of carers who access services than of carers as a whole.

In Ervin et al.'s (2015) sample, 48% of respondents scored in the moderate-extremely severe range on the stress subscale, 38% scored in the extremely severe range for symptoms of depression and 28% scored above the moderate range on the anxiety subscale, suggesting that many of the carers were experiencing high levels of distress, particularly with regards to depression. It is unclear how many carers scored highly on two or even all of the subscales; thus, it is not possible to determine whether the same carers who scored highly on some scales also scored highly on others, although this seems plausible. However, given the relatively small sample size (39), the findings may not be representative of the general population, particularly given that the study took place in a rural setting in December-January. It is unclear to what extent carers may have found the time of year more stressful than other periods. Despite this, the findings are consistent with numerous other studies in suggesting that carers of people with dementia experience high levels of stress, anxiety and depression.

Ervin et al. (2015) further break down their analysis by comparing carers who identified as the sole carer with those who reported they were not the sole carer using Mann-Whitney U tests. They found that being the sole carer was associated with significantly higher scores on the stress subscale, although there was no significant difference between the two groups in terms of depression or anxiety scores. This suggests that being the sole carer may be associated with higher levels of stress. This could be attributed to increased time spent caring as the sole carer. However, there was no significant difference in scores based on time spent caring, suggesting this factor was not creating this difference. The sample may have been too small to identify a statistically significant result for these variables, but it is also possible that other factors may play a role. For example, being the sole carer may be associated with greater sense of responsibility or duty as a carer, which may increase stress. Further research to attempt to replicate this finding with a larger sample would be beneficial.

Additionally, exploring carers' experiences of sharing caregiving responsibilities may help to deepen understanding of how carers approach sharing caring responsibilities or come to be sole carers. It is possible that care recipients who exhibit more apathy or aggression are experienced as more difficult to care for, and therefore those who have the opportunity to discontinue caring because another person will act as sole carer may be more likely to do so. Indeed, higher anxiety, apathy/indifference and agitation/aggression scores on the NPI-Q were associated with the highest levels of distress amongst carers in Ervin et al.'s (2015) study. Any of these factors may play a role in increasing carer burden, or there may be an interaction between them.

There is also evidence to suggest that carers of people with dementia may be at greater risk of negative outcomes than other carers. For example, Papastavrou et al. (2007) reported that carers of people with dementia experienced significantly higher levels of burden than other carers. Similarly, Bertrand et al. (2006) reported that carers of people with dementia experienced increased symptoms of depression and increased levels of burden compared to other carers. Collins and Kishita (2019) noted that carers of people with dementia may undertake a wider range of caring tasks than some other groups of carers and that a greater proportion of carers from this group may provide care for more than 40 hours per week. However, other factors may also play a role. For example, some people with dementia may also need care for additional health needs – while this is an exclusion criterion for some studies, many articles do not mention whether or not the care recipients also have additional diagnoses. If they do, this may create additional demands on the carer which in turn may contribute to increased levels of burden. It would be helpful for future studies to clarify whether care recipients have additional health or care needs to help clarify this.

Other factors which may play a role in carers' level of burden or distress have also been investigated. Kerpershoek et al. (2018) surveyed 451 carers of people with dementia and found that quality of life was negatively associated with higher ratings of needs of the care recipient. They also considered several additional variables, including carer age, gender, and relationship with the person with dementia. The only covariate that was found to be significant in linear backward regression analysis was whether the carer lived with the person being cared for. This suggests that living with the care recipient and caring for someone with more needs are associated with poorer quality of life for carers.

It is possible that having a poorer quality of life may mean that carers are more distressed and may therefore be more likely to perceive the person they care for as having a higher number of needs. However, this interpretation seems unlikely given that Kerpershoek et al. (2018) also included need ratings from the care recipient and from professionals, and reported that professionals tended to indicate higher levels of need than carers. However, this does not rule out the possibility that there may be a relationship between the need ratings given by carers and their living situation. For example, carers who live with the person they care for may be more aware of the range of needs of the person with dementia. Alternatively, carers may be more likely to choose to live with the care recipient if they perceive that the care recipient has too many needs to live alone (albeit this choice may be less available to spousal carers than to adult children of people with dementia). Kerpershoek et al. (2018) did not report on whether there was a relationship between living situation and level of care recipient need, and so it is not possible to clarify this based on their findings.

However, other studies have contributed to further exploration of factors which may influence carer burden.

One such study investigated whether the number of caring tasks undertaken – which might be expected to be higher when the care recipient has greater levels of need – is associated with carer burden. Kang et al. (2018) found a positive correlation between the number of caring tasks and carer burden. They also noted that carers who lived with the care recipient reported greater increases in carer burden as the number of caring tasks increased, compared to carers who did not live with the care recipient. The measures used in this study were reported to have strong psychometric properties, although it is unclear why the reported validity was often higher for the study sample than those reported elsewhere in the literature and noted by Kang et al. (2018). This suggests that there may be differences between the South Korean sample and other populations, and as such the findings may not generalise to the UK; however, several studies report that more time spent caring (which might be expected if there are a greater number of tasks required) is associated with higher levels of carer burden, including studies drawing on data from the UK (Colombo et al., 2011; Thomas et al., 2015). Time spent on caring tasks and the number of caring tasks undertaken therefore seem to play a role in carer burden.

Sutcliffe et al. (2016) report findings from interviews with 181 dyads of carers and people with dementia. They considered both objective measures of burden (such as hours spent on caring tasks) and subjective measures (such as scores on the ZBI). They also considered several care recipient factors, including neuropsychiatric symptoms, level of functioning in daily activities, cognitive functioning and use of services. Sutcliffe et al. (2016) selected their sample to reflect carers who might be expected to experience high levels of burden – those caring for someone expected to require residential care within the next year. Based on the outcomes of linear regression analysis, they identified 5 factors which explained 45% of the variance in carer burden scores on the ZBI: namely, higher levels of neuropsychiatric symptoms of the person with dementia, more time spent supervising the care recipient, being a female carer, being the adult child of the care recipient, and a lack of informal support for the carer. The severity and duration of dementia itself were not found to predict carer burden, and Sutcliffe et al. (2016) concluded that it may be psychological and behavioural symptoms rather than the stage of dementia which contributes to carer burden.

Other factors which Sutcliffe et al. (2016) reported had an impact on carer burden included the biological relationship with the care recipient and the amount of time spent on caring tasks. It seems possible that these factors may be interrelated; for example, adult carers may perceive tasks such as preparing meals as part of their caring role, where spousal carers may perceive this as part of their role as a spouse. This may contribute to spousal carers reporting that they spend less time on caring tasks, or moderate the extent to which spousal carers perceive these tasks as burdensome. This is important because carers were asked to self-identify the amount of time spent on caring tasks, but it is not clear how caring tasks are identified by carers.

It may be beneficial for future research to establish what kinds of task carers view as part of their caring role, rather than part of other roles (such as spouse). It would also be interesting to explore whether partner carers and adult-child carers identify the same tasks as caring-related. This may enhance understanding of the finding that adult-child carers experience higher levels of burden than spousal carers. It is also worth highlighting that focusing on spouses implies that non-married partners (which may include people in polyamorous relationships or queer platonic partnerships, but also other long-term partners who choose not to marry) were not identified in this study. As noted by Larkin et al. (2018), LGBT+ carers are underrepresented in the literature and it would be beneficial to explore their experiences in future research.

Potential reasons for the finding that adult-child carers experience higher levels of burden have been further examined. Tatangelo et al. (2018) explored the role of family dynamics through semi-structured interviews with 17 primary carers of people with dementia. Their thematic analysis identified four key themes: family expectations and carers feeling they had no choice in becoming the primary carer; differences between family members in their acceptance and understanding of dementia; differences in how family members approach and think about caring; and communication breakdown. They highlighted that juggling the caring role and managing aspects of family dynamics (such as negotiating caring responsibilities, dealing with communication breakdowns and managing the different perspectives of other family members) adds an additional layer of complexity to caring for a parent. Their interpretations are well supported by numerous quotations from participants. It would be interesting to explore the extent to which partner carers report similar or different experiences, but some differences seem likely. For example, partners may have fewer expectations for others to contribute to caring than siblings might have of each other, while childhood relationships between siblings may also impact on how siblings approach the shared task of caring (if, indeed, it is seen as a shared task). Thus, while further research is warranted and the authors acknowledge that their pre-selected questions may have influenced their findings, it seems plausible that family dynamics may play a role in the level of burden experienced by adult children caring for people with dementia.

Other factors which may influence carer burden were reported by Smith et al. (2018). Their factor analysis of the ZBI identified three key factors: the direct impact of caring, uncertainty regarding the future, and frustration/embarrassment. This perhaps reflects the different dimensions of carer burden, as noted earlier; it is likely that a number of variables impact this multifaceted concept. Smith et al. (2018) note that uncertainty about the future was a unique finding and was predicted by being an adult child providing care. This reinforces the idea that different groups of carers experience caring differently. Taken together with other findings, it is clear that several factors – such as hours spent caring, relationship to the care recipient, amount of caring tasks and family dynamics – play a role in carer burden. What is less clear from this research is how these factors may interact with each other or how to ameliorate carer burden.

It is important to note that caring is not only associated with negative impacts such as carer burden; there are also potential positive experiences. For example, Cohen et al. (2002) reported that 73% of their sample (289 carers of older adults) could identify at least one positive aspect of caring, with a sense of companionship and feelings of fulfilment being the most common positive aspects identified. However, given that carers of people with dementia report higher levels of burden than other carers and that only 6.9% of Cohen et al.'s (2002) sample could identify more than one positive aspect of caring, it is possible that being asked about positive aspects of caring prompted carers to consider this for the first time. It is not clear whether the carers in the study would have spontaneously identified such aspects if they had not been asked to do so. It may also be the case that this finding would not generalise to carers of people with dementia. This has been explored further, and consideration is now being given to factors which may affect the extent to which carers identify positive aspects of caring.

Several factors have been identified which may influence the perception of positive aspects of caring. These include what might be considered internal factors to the carer, such as self-efficacy (Semiatin & O'Connor, 2012), and factors that may be considered external to the carer, such as social support (Wang et al., 2018). Although there has been increasing interest in positive aspects of caring, this is a much less researched area than the negative impacts of caring, and Semiatin and O'Conner (2012) note that further research into aspects including optimism and self-esteem is warranted.

There is some evidence that identifying positive aspects of care may also impact on carers' response to interventions. For example, Hilgeman et al. (2007) found that carers who initially identified less positive aspects of care benefitted the most from intervention over 12 months, and that changes in reported positive aspects of care predicted a range of changes, including carer depression and daily care burden. However, they also noted that lower levels of daily care burden predicted levels of positive aspects of care. This makes it difficult to interpret how these findings may be related. For instance, decreasing daily care burden may increase positive aspects of caring. This may, in turn, improve other factors (such as depression or self-efficacy) and carers may therefore feel more able to actively problem-solve to reduce burden further. It is also possible that a cyclic or mutual relationship between daily care burden and positive aspects of care exists, such that improvements in one fuels improvements in the other and vice-versa, the mechanism of which is not known.

A key strength of Hilgeman et al.'s (2007) study was its longitudinal design, and while further research to confirm the impact of changes in perceived positive aspects of care with a larger sample would be beneficial, this also raises the question of whether psychological interventions can affect carers' experiences of positive aspects of caring. Indeed, this may be the reason that those carers initially reporting fewest positive aspects of caring benefitted most over the course of the study. Further exploration of what interventions may help increase positive aspects of care may therefore be useful. Caution is needed, however, as the potential implications of attempting to increase perceived positive aspects of care may be complex. For example, might this increase the sense of duty, obligation and feelings of guilt that some carers experience (Tatangelo et al., 2018) if it is perceived as implying that carers should be experiencing caring positively? Additionally, as Carbonneau et al. (2010) note, there is the risk that heavily emphasising positive aspects of care may contribute to carers continuing to provide care for longer than may be in the best interests of the carer or the person with dementia.

1.3 Psychological Interventions

Given that carers of people with dementia experience increased rates of stress, depression, anxiety and burden, increased access to psychological therapies was identified as part of the National Dementia Strategy (Department of Health, 2012). A substantial research effort has been put into investigating the effects of a range of interventions. Due to the nature of this paper, the focus here will be on psychosocial interventions which aim to improve the emotional wellbeing of carers, rather than interventions such as in-home or respite care or day centres. That is not to disregard these interventions as unimportant but instead is intended to allow a greater depth of consideration to psychological literature.

One psychological intervention which has been proposed as potentially useful is problem-solving. Chiu et al. (2015) allocated carers of people with dementia to either a group receiving problem-solving therapy or a control group. They reported that carers in the problem-solving therapy group showed significant improvements in task-oriented coping and competence, as well as reductions in burden and stress, while the control group showed no significant change. They concluded that problem-solving techniques can help improve carers levels of burden and stress.

However, Chiu et al. (2015) note that care coordinators providing the problem-solving therapy did so differently to how it may be used in therapeutic practice. In particular, the goal was not to train carers how to use these techniques but for care coordinators to use the techniques to help address the concerns of carers. It is therefore not clear whether carers would have gained the skills to use these techniques independently, following completion of the intervention. Additionally, although strengths included using intention-to-treat analysis and checking fidelity to the approach, as well as matching the intervention and control groups based on MAPLe scores (which assess the likelihood that a person will need care services), the method of checking fidelity to the model was limited. Worksheets were checked following sessions, but sessions were not recorded and therefore it is not clear if the model was fully adhered to in sessions.

An additional limitation of Chiu et al.'s (2015) study is that the control group did not receive any intervention. It is therefore possible that regular sessions with care coordinators produced the impact, rather than the problem-solving therapy itself or in isolation. Thus, while problem-solving may indeed be helpful for carers, further research would be needed to confirm this. It is also not clear to what extent problem-solving as part of CBT may have differential effects to problem-solving in isolation. It may therefore be helpful for future research to include an active control (for example, active listening sessions of the same duration as the problem-solving sessions), alongside problem-solving sessions and a third group undertaking CBT.

Several other interventions have also been investigated, and due to the substantial research in this area, many recent papers review the existing literature. One such review was carried out by Riddle et al. (2016), who systematically reviewed the literature regarding written emotional disclosure for carers. They found significant improvements in trauma and general psychological health, but not anxiety or depression, as a result of undertaking written emotional disclosure. This suggests that written emotional disclosure may be helpful for some outcomes, but not others.

It is not clear why Riddle et al. (2016) found a difference between outcomes for anxiety and depression compared to trauma and general psychological health. One possibility is that written emotional disclosure may bear similarities to treatments for trauma such as narrative exposure therapy (Schnyder & Cloitre, 2015). Riddle et al. (2016) suggest that the duration of carers' roles may have influenced the results, as the included studies which found positive effects for written emotional disclosure also had samples who had been caring for less time than the carers in other studies. It may therefore be important to consider how long carers have been caring for when evaluating the effectiveness of psychological interventions.

Although it is helpful that Riddle et al. (2016) investigated a specific psychological intervention (rather than multi-component or less clearly specified interventions), it is not clear how many services provide written emotional disclosure as an intervention for carers. Furthermore, it is unclear how many carers would value this kind of intervention. For example, it may be that carers would prefer interventions that are more interactive or that provide more human contact. Additionally, the authors noted that many of the studies were of poor quality and the findings may therefore be at risk of bias. Finally, in light of the current paper, it is important to note that the study was not specific to carers of people with dementia. There may be differences in how particular groups of carers respond to interventions or in how relevant interventions targeting trauma-related symptoms are to different groups of carers.

Most systematic reviews have been broader in focus. Sorensen et al. (2002) conducted a systematic review to update earlier findings from Knight et al. (1993), who reported small to moderate effects from interventions for carers, albeit with concerns that the results of included studies varied and were not always consistent with each other. Sorensen et al. (2002) aimed to investigate six different types of intervention and classified interventions as either psychoeducational, supportive, respite/adult daycare, psychotherapy, aimed at improving competence, or multicomponent. Although the study was not specific to carers of people with dementia, care recipients were required to be at least 60 years of age and many studies in the dementia literature cite this meta-analysis. This study was therefore considered relevant to the current paper.

Sorensen et al. (2002) reported that when taking all the interventions together, a significant improvement in levels of carer burden, depression, subjective well-being, carers’ sense of ability/knowledge in their roles, and the symptoms of care recipients was found. Psychoeducational interventions and psychotherapy were reported as having a significant effect on all outcome variables. However, these effects were less significant for carers of people with dementia and when studies included both dementia carers and other carers in the same sample. Sorensen et al. (2002) therefore recommended that multicomponent interventions may be most effective, and that combining respite/daycare with other components may be helpful for dementia carers. This suggests that multicomponent interventions incorporating psychotherapy could be helpful to carers of people with dementia.

There were some limitations to Sorensen et al.'s (2002) study, however. Classifying interventions based on the dominant approach unless multiple approaches seemed equally dominant presents challenges. Some aspects which seem to form a small part of an intervention may actually seem quite important to carers, and therefore some studies may have been experienced by participants as more similar to multicomponent interventions than they seemed to the authors. Additionally, it is unclear whether carers involved in the studies reported were equally invested in the different aspects of multicomponent interventions. Outcomes in some studies may have been mostly due to particular components, rather than the combination. Further research to clarify which components are most useful may be helpful, particularly given the tight constraints in terms of resources and finances on health and social care services. One option may be to investigate which components of interventions participants chose to engage with when they were invited to engage only with those components which seemed most relevant to them. Finally, it is worth noting that 9/10 psychotherapy studies included in the review were CBT focused. It is therefore not clear whether other types of psychotherapy may be beneficial.

Gilhooly et al. (2016) conducted a more recent meta-review of stress, coping and interventions amongst carers of people with dementia. They reviewed literature from 1988 to

2014, thus including the Knight et al. (1993) and Sorensen et al. (2002) papers. Gilhooly et al. (2016) identified 45 systematic reviews, of which 22 focused on evaluating interventions for carers. They highlight the very wide range of interventions reviewed in systematic reviews. While this may be a benefit in terms of considering the range of interventions which may be useful to carers, it also makes it more challenging to draw together the available evidence base. Gilhooly et al. (2016) reported that psychosocial and psychoeducational interventions were beneficial for carers; support groups and multicomponent interventions also generally seemed helpful. While this suggests that psychosocial interventions may be helpful, it does not help illuminate what is helpful about them, nor is the difference between psychosocial and psychoeducational interventions clear. For example, psychoeducational interventions may also have beneficial social effects when delivered in a group. Nonetheless, these findings support those of Sorensen et al. (2002) in suggesting that multicomponent interventions may be helpful for carers, including carers of people with dementia.

Within multicomponent interventions, research has also considered whether working with both the carer and the person with dementia is equally or more efficacious than working with the carer alone. Laver et al. (2017) systematically reviewed randomised controlled trials which involved carers of people with dementia (either by themselves or as a dyad with the care recipient) and compared multicomponent interventions with treatment as usual. They did not find a significant difference between those multicomponent interventions that supported the carer independently and those that worked with the dyad. However, they noted that none of the studies directly compared differences between carer-focused and dyadic interventions; a more noticeable difference may be observed for specific interventions. Therefore, studies directly investigating this for a particular intervention may be warranted. However, consideration should also be given to the most efficient use of resources, such as differences in cost between dyadic and carer-focused interventions, particularly where there is no evidence of differential outcomes. Equally, it would be useful to investigate carer and care recipient perceptions of these interventions, as it may be that subjectively they experience different levels of benefit, or benefit in different ways, from dyadic or individual interventions. These experiences may not be detected in quantitative studies investigating predetermined variables.

Thus, there is some evidence that multicomponent interventions may be helpful for carers, and limited evidence that there may be little difference between dyadic and carer focused interventions. One aspect which has been more thoroughly researched is technology-based support. This may include a wide range of types of intervention (including psychoeducational and psychotherapeutic interventions) delivered through a range of technology-based mediums, including telephone and Internet-based interventions. Jackson et al. (2016) conducted a systematic review to explore the effectiveness of telephone, internet and combined telephone-and-internet delivery of interventions for carers. They included 23 published studies and grey literature, with inclusion criteria including that the care recipient had some form of dementia and that telephone or online support was directly between individuals, even where this was not in real-time. They found that no existing studies addressed this question directly, but concluded that more studies utilising a combined internet and telephone approach reported successful outcomes. This suggests that technology-based interventions have the potential to be helpful, but with limited information about the specifics of the included interventions, it is difficult to know what made them helpful. Additionally, it is not clear whether they were also compared with traditional face-to-face interventions; it would be useful to explore whether carers have a preference between the two.

Of the technology-based studies that they reviewed, Jackson et al. (2016) identified two psychotherapy studies. One of the studies reported a significant reduction in carer burden and increases in self-efficacy; the other reported reductions in symptoms of depression and carer burden. Jackson et al. (2016) also noted that a CBT trial showed improved goal attainment, but it is not clear if this is associated with improvements in psychological well-being. In line with previous reviews, Jackson et al. (2016) reported that multicomponent interventions had positive effects on self-efficacy and mood. Furthermore, they identified that combining psychotherapy and psychoeducation appeared to be helpful and noted that all the multicomponent studies included both psychoeducation and psychotherapy. However, it is difficult to know how helpful psychotherapy specifically was from this review, given that only two studies were identified as pure psychotherapy and that the model of therapy used in these studies was not clarified. Additionally, and as noted by the authors, some of the included studies had very specific sample populations, with two being gender-specific and three which the authors considered “were limited to very distinct ethnic groups” (p. 226). Thus, while multicomponent technology-based interventions seem from this review to be helpful, further research with a wider variety of populations would be useful to verify this.

Further research has attempted to clarify whether the mode of delivery of technology-based interventions may affect outcomes. Steffen and Gant (2016) randomly allocated women living with somebody with a neurocognitive disorder to either a 14-week behavioural intervention delivered via telephone coaching, video instruction and a workbook; or to a basic education condition, with telephone support and a basic education guide. They reported that following the intervention, women in the behavioural coaching group were significantly more likely than participants in the education group to have reliably low scores on the BDI-II, which they interpreted as evidence that behaviour coaching delivered via telephone, video and workbook had a beneficial impact on depressive symptoms. However, it was not reported whether this represented a reduction in scores from before the intervention, and participants did not have to score clinically on the BDI-II at the start of the intervention. Furthermore, it was not noted whether a significant difference between the groups was present before the intervention. It is therefore difficult to determine the impact of the intervention itself. Additionally, it cannot necessarily be taken for granted that living with someone with a neurocognitive disorder equates to being a carer for them. A further limitation is a lack of clarity regarding exclusion criteria, particularly given that (despite excluding several conditions including Huntington's disease and muscular sclerosis) it was not clear from the report whether mild cognitive impairment was included or excluded from the study. It was also unclear why women under the age of 30 were excluded from participating. Thus, research more clearly evaluating whether technology-based interventions are effective for carers of people with dementia was still needed.

Scott et al. (2016) evaluated the effectiveness of technology-based cognitive behavioural therapy for carers of people with dementia. They conducted a systematic review and meta-analysis of full studies of pure technology-based CBT (that is, with no additional input from a therapist) for carers of people with dementia. Only randomised controlled trials and quasi-experimental studies were included. They noted that the evidence base was small, but tentatively indicated that pure self-help CBT appeared to reduce symptoms of depression amongst carers, with similar effect sizes to those noted for face-to-face CBT. While this is promising, it is important to note that the elements of CBT included in interventions varied, and some studies may have included relatively little CBT content. A substantially larger pool of studies would be needed in order to determine differential effects based on the CBT elements included in different interventions.

A further limitation is that one of the included studies involved a weekly telephone call to monitor engagement. While the intention of this was not to provide therapeutic input, it is not clear what monitoring was in place to ensure these calls did not include therapeutic aspects, nor was it clarified how these calls may be similar or different to computer-based guided self-help routinely provided in primary care. Given that this study reported the largest effect size of the studies included in the review, it may be that these telephone contacts were important in encouraging engagement with the programme; however, they may also have provided additional input over pure self-help, such as a sense of being listened to or additional therapeutic content. However, the authors noted that removing this study did not have a substantial impact on the findings, suggesting that technology-based CBT self-help may still be beneficial.

Further adding to the evidence base regarding technology-based psychosocial interventions, Duggleby et al. (2018) evaluated the effectiveness of a web-based intervention for carers of people with dementia and additional chronic conditions. This is one of few studies to specifically target carers of people with dementia and further needs. Carers were randomised to either complete a web-based intervention for three months or a control condition, in which carers received an education booklet. Following the intervention, carers in the intervention group scored more highly than those in the control group regarding hope for the future. There was no significant change in quality of life scores. As limited information was provided about the intervention, it is difficult to draw conclusions about why it specifically increased hope. However, it is notable that 27% of the treatment group did not use the intervention and that the median amount of time using any section of the site was 15 minutes; greater effects may have been found with a larger sample, higher levels of engagement with the programme or if participants were encouraged to use the program for a minimum amount of time.

One study which more clearly reported the intervention being delivered via technology compared telephone-based psychoeducation and general monitoring with telephone-based behavioural activation in a sample of 96 carers of people with dementia (Au et al., 2019). The participating carers reported experiencing mild to moderate levels of depression at the start of the study. Au et al. (2019) noted that participants in the behavioural activation group experienced significantly greater reductions in symptoms of depression than those in the control group, as well as reporting greater increases in relationship satisfaction.

This was a robust study, being both a double-blind randomised trial and also including a comparison group that received a similar amount of input as those in the intervention group. Au et al. (2019) also checked that the interventions received by both groups had high fidelity to the model using audiotapes of 10 sessions from each condition. Additionally, the sample was sufficiently large to adequately power the study. As such, the findings suggest that telephone-based behavioural activation may be beneficial to carers of people with dementia.

Despite the strengths of Au et al.'s (2019) study, it is unclear if the findings would generalise to the UK, given the Chinese setting, or to carers experiencing more severe symptoms of depression. Furthermore, the paraprofessionals delivering the interventions were all aged between 50 and 60 years; carers may have picked up on this and responded differently than they might have if they had perceived the paraprofessionals as significantly younger than them. This becomes more relevant in the context of the UK, where telephone-based behavioural activation might be most readily delivered by psychological wellbeing practitioners already delivering this type of intervention. As this is a common entry-level role into therapeutic work, there may be higher rates of younger paraprofessionals in this role compared to in this study. Research to clarify the impact of this would be beneficial.

There is, therefore, some evidence that technology-based interventions incorporating psychological techniques can be beneficial to carers of people with dementia; yet a much broader range of interventions have been investigated. Dickinson et al. (2017) systematically reviewed existing systematic reviews of psychosocial interventions for carers of people with dementia and provided a narrative summary. As they only included reviews rated of moderate or high quality, 13 reviews were included in their review. This included four studies evaluating psychotherapeutic interventions. Over these four reviews, one reported that cognitive reframing could have beneficial effects for anxiety, depression and stress, while another found that CBT was associated with improvements in carer burden and a third reported mixed results. The fourth identified only one study meeting the criteria, which reported that clinicians perceived a change in carer's attitudes following psychotherapy; in particular perceiving clients as more accepting, more optimistic and more non-judgemental. Dickinson et al. (2017) therefore concluded that there was evidence of a beneficial effect of cognitive reframing and CBT and reiterate that few studies investigate the effects of psychotherapy; this is particularly striking since inclusion criteria for Dickinson et al.'s (2017) review were quite broad, for example ensuring that non-English language reviews were included. An additional study, which Dickinson et al. (2017) classified as technology-based, investigated the effects of telephone counselling and reported a reduction in symptoms of depression, taking into account the findings from nine trials. It is not clear to what extent it is valid to separate technology-based interventions from interventions with similar content delivered face-to-face when evaluating the content of the interventions, rather than the effect of the mode of delivery. Thus, while it is notable that counselling in this study was delivered by telephone rather than face-to-face, the findings provide further evidence to suggest that psychological therapies can be of benefit to carers of people with dementia.

Given that psychoeducation and psychotherapy appeared to be beneficial for carers of people with dementia, Kishita et al. (2018) focused a systematic review around the evidence concerning psychoeducational and psychotherapeutic interventions for these carers. They specified that psychoeducation interventions must focus on increasing carers' knowledge of dementia and teaching specific coping skills, while CBT based interventions must utilise CBT techniques within the framework of the cognitive model. They reported that psychoeducation interventions had no significant effect on depression or quality-of-life but a small overall effect on burden (particularly when delivered face-to-face) and that CBT-based psychotherapy had a significant effect on symptoms of anxiety and depression. Additionally, one study used acceptance and commitment therapy, with good effect on symptoms of anxiety. They concluded that there is therefore strong empirical support for using CBT to treat symptoms of anxiety and depression in carers of people with dementia. They noted a need for future research to explore the efficacy of different components of CBT with these clients. One difference in this review is that it did not remove studies from content-based categories based on the mode of delivery, instead using mode of delivery as a covariate within each classification. This is a strength, as it did not arbitrarily remove therapeutic interventions from the psychotherapy group based on how they were delivered, as mentioned above.

Further supporting the potential for psychological interventions to be of benefit to carers, Collins and Kishita (2019) conducted a meta-analysis of articles comparing before and after effects of mindfulness or acceptance-based interventions for carers of people with dementia. They found that mindfulness and acceptance-based interventions improved symptoms of depression, with these improvements generally being maintained over time. While mindfulness and acceptance-based interventions is a narrower category than, for example, psychosocial interventions, this still included four distinct intervention types: mindfulness-based cognitive therapy, dialectical behaviour therapy, acceptance and commitment therapy and multicomponent therapies. The multicomponent category was only used if an intervention was deemed to draw equally on two or more of the other interventions; it is not clear to what extent this would accurately reflect the interventions received, making it hard to judge the appropriateness of the categorisation. However, this was generally a robust study. Compared to other studies, significant efforts were made to reduce the risk of publication bias, both by including studies obtained from sources other than peer-reviewed journals and by calculating how many studies with a non-effect would be required to disprove the findings; this number was particularly high in relation to depression (539). Thus, this study provides initial evidence that mindfulness and acceptance-based interventions can have beneficial impacts for carers of people with dementia.

To summarise, a substantial research effort has investigated the impact of caring for people with dementia and the effectiveness of interventions to support these carers. Caring has often been associated with negative outcomes, including higher rates of depression, anxiety and burden. There is evidence, which has been pulled together in a number of systematic reviews, to suggest that multicomponent interventions involving both psychoeducation and psychotherapy can be beneficial. There is also some indication that psychological therapies -particularly CBT, but also (more tentatively) mindfulness and acceptance-based approaches - can alleviate some of these outcomes. Larkin et al. (2018) recently conducted a scoping review of what is known about carers. While this is not specific to dementia carers, they reported similar findings. Additionally, Larkin et al. (2018) highlighted the fragmented nature of research in this field and the relative lack of the subjective experience of carers in the literature.

1.4 Carers’ Use of Services and Barriers to Access

One area in which carers’ subjective perspectives may be particularly useful is regarding access to and use of services. Stephan et al. (2018) conducted focus groups in eight European countries to explore barriers and facilitators to services for carers. Although they noted that carers expected services to be tailored to their needs and that service providers would be aware of respite and psychological needs, it was not always clear whether this referred to the needs of the carer or the person being cared for. Furthermore, quotations provided to support the interpretations were brief and it was not always possible to be confident that the interpretation was the best fit to the quote provided. For example, the quotation “…I feel a duty to take care of her (the person with dementia).” (Informal carer/IT; p. 7) was expanded upon with the interpretation that formal care may be experienced as an intrusion or that carers may feel a sense of failure if accepting formal care. While this interpretation may be supported by the fuller transcripts, it can also be argued that it goes far beyond the sense of duty reported by the carer. Thus, even when carers voices are considered in the literature, it is important to ensure that their perspectives are conveyed with an interpretation that is as close to what was meant as possible.

Ervin and Reid (2015) also investigated carers’ use of services. They utilised postal surveys to understand what services carers used and were aware of. Of the 17 services in the local area, carers used an average of 6.8 services. However, of those carers reporting moderate to severe symptoms of depression, anxiety or stress, fewer than half reported using potentially helpful services. Only nine carers (23% of the sample) had made use of personal therapy, with an additional 12% having been offered it but not taken this up. 7% of the sample were not aware of personal counselling being available in the area. It is difficult to interpret why counselling may have been underutilised as no attempts to gain information about this were made. Additionally, it is not clear if this rate of accessing therapy is reflective of the general population, or the broader population of carers. Finally, because the proportion of the sample experiencing stress, anxiety and depression are reported separately, it is not clear how many people were experiencing two or even all of these difficulties. This makes it difficult to interpret whether the rate of access to counselling is proportionate to the number of people experiencing psychological distress. However, it does suggest that there is a need to investigate this further and to consider the extent to which carers access psychological therapy when it may be useful to them, including considering whether this is similar to rates of uptake in the general population.

1.5 Carers’ Perceptions of Psychological Therapies

While there is evidence that carers may benefit from psychological therapy, in addition to being unclear whether they make use of it, it is also unclear how they perceive therapy, and relatively little research has been undertaken in this area. One study reported that 100% of their sample thought that counselling could be helpful to them (Waters et al. (2016). This study reported several potential benefits identified by carers, such as providing relief and opportunity to offload, a private, non-judgemental space to speak confidentially, signposting and practical problem-solving, a space to focus on themselves and contributing to changes such as seeing things differently. Where participants expressed reservations or doubts about counselling, these were reported as uncertainty about how counselling could help, given that it could not change the situation. This suggests that participants may not understand the process of change as it occurs in therapy.

However, these findings may overestimate how positively carers view psychological therapies for several reasons. As the authors note, participants’ responses may have been influenced by their awareness of the interviewer’s links with a counselling organisation, and as such, they may have been reluctant to express negative views towards counselling. As participants were recruited via carer co-researchers, it is possible that carers with more positive views towards counselling may have been more open to discussing participation in the study; additionally, they may have been concerned that their contact (the carer co-researcher) would become aware of their comments and so their relationship may have had an impact on what they felt able to say. It is not clear from the report what efforts were made to support participants to feel able to criticise counselling and speak openly and freely, or whether participants were aware that the interviewer was not a counsellor themselves.

Additionally, the report refers to participants saying “yes to the first question” regarding counselling potentially being helpful (Waters et al., 2016, p. 169). It is possible that by phrasing this as a yes/no question, and by asking it first in the interview, participants may not yet have felt comfortable enough to say no. Alternatively, they may not yet have felt sufficiently sure about what counselling is to rule it out. Stating that counselling might possibly be helpful is not the same as thinking that counselling would be helpful for yourself, and it is not clear to what extent this was explored. It is also noteworthy that one of the participants had ceased caring a year ago, and it is not clear what impact this may have had on that participant's perceptions of counselling in relation to their role as a carer. Finally, nearly half the participants were caring for somebody with a physical or learning disability. Given that carers of people with dementia have been shown to experience more negative impacts of caring than other groups of carers, it is also possible that they would have different perspectives on counselling.

Elvish et al. (2014) conducted semi-structured interviews with six carers of people with dementia to explore carers' experiences and perceptions of therapy. The carers who took part had completed psychological therapy. Based on their findings, Elvish et al. (2014) identified three themes: loss and growth, feeling connected and understood, and wanting to share information with someone neutral. The carers in this study reported that therapy had been beneficial and provided a safe space to discuss their difficulties.

However, people who enjoy talking about their difficulties or experiences may also be more likely to enjoy participating in interview-based research, potentially biasing the findings. Additionally, carers were recruited via therapists. While it is hoped that therapists gave due consideration to the potential implications for the client's therapy that might arise from inviting them to participate (for example, how clients might interpret the invitation), this is not mentioned in the report. Additionally, therapists may have felt more comfortable informing clients of the study if the client was well engaged with therapy and making progress, or had a good relationship with the therapist; and clients may have felt that commenting negatively on therapy may have reflected badly on their therapist. No mention was made in the report of whether therapists were aware of whether or not their clients were participating. It was additionally not clear whether participants knew what information about their participation might be shared with therapists or about any relationship between their therapist and the researchers. These are important aspects in order to help clients feel able to make informed choices about their participation, and also to create a space in which they can speak freely regarding their experiences of counselling. Thus, although there is some tentative evidence that carers may perceive therapy as potentially helpful, this research may be at risk of bias. Furthermore, it does not clarify whether carers perceive therapy as something they might actually want to pursue themselves; nor have the perspectives of those who would not choose to pursue psychological therapies been explored.

Some carers may not identify therapy as the optimal source of support. Jegermalm and Sundström (2013) report that carers typically reported a desire for support for the person they care for, rather than for themselves. Furthermore, when they did want support for themselves, they preferred practical support; psychological therapies was not something most carers in Sweden reported wanting. This potentially reflects the sample – only 1 in every 10 carers surveyed were living with the person they provide care for, and those who did were more likely to want support for themselves. In the UK, approximately 50% of carers live with the person they care for (GfK NOP & Information Centre for Health and Social Care, 2011) and it is therefore not clear that these findings can be generalised to a UK population. Further research is needed to clarify how carers perceive psychological therapy and whether it seems relevant to them.

1.6 Conclusion and Research Question

To conclude, there is much evidence suggesting that carers of people with dementia experience a range of negative health outcomes, including increased rates of depression, anxiety, stress and burden. Research has also indicated that carers of people with dementia experienced more negative impacts on their wellbeing than other carers (Bertrand et al., 2006; Mitchell et al., 2015). There is a substantial and growing body of evidence suggesting that interventions which combine psychoeducation and psychotherapy can be effective in improving carers' emotional wellbeing. A smaller body of evidence suggests that CBT and CBT-based interventions such as cognitive reframing can be beneficial. There is also some indication that carers of people with dementia who have accessed therapy found this to be a helpful experience and that carers in general may perceive therapy as potentially beneficial.

What is less clear is how carers of people with dementia perceive psychological therapy, and whether it seems relevant to them. Although a limited about of research has considered carers' perceptions of therapy, no studies were identified which specifically focused on exploring how carers decide whether or not to access therapy or which primarily focused on carers who have not yet accessed therapy. The current study therefore aimed to expand our understanding of how carers of people with dementia perceive therapy, specifically focusing on carers who have not had therapy themselves. It also aimed to add to existing knowledge by exploring how carers' perceptions of therapy influenced their decision not to access therapy to date.

The key research question driving this study was therefore "How do the perceptions carers of people with dementia have about therapy influence their decisions regarding accessing therapy, when they have not experienced therapy themselves?" This question can be broken down further into two sub-questions:

1. What are the ideas or perceptions that such carers hold about psychological therapy?
2. What is the process by which these ideas influence carers' decisions regarding accessing therapy?

The aim of the study was therefore not simply to describe how this group of carers view therapy, but also to offer a potential theory which may provide some insight into the process by which carers decide whether or not to access therapy. It was hoped that increasing our understanding of the ideas, expectations and concerns held by carers who have not previously accessed therapy would enhance our capacity to effectively promote therapy to carers, while also helping to clarify situations when it may be more appropriate to focus on other support options (such as practical support). Additionally, it was hoped that improving our understanding of the concerns and perceptions carers may bring to therapeutic sessions would potentially enable these to be explored and addressed, where it is relevant and useful to do so.

The following chapter will outline the approach taken to address the research question and study aims.

Chapter 2: Methodology

2.1 Overview

This chapter clarifies the research question and study aims arising from the literature review discussed in the previous chapter. The method used to address the research question is explored; this includes a discussion of the theoretical paradigm used in the study and a rationale for the chosen method (grounded theory). I then provide an account of the procedure followed in the study, including ethical considerations. Throughout the chapter, consideration is given to the importance of reflexivity.

2.2 Theoretical Position

Before selecting a method, it was important to consider and clarify the theoretical assumptions underlying the research, to help in the selection of an appropriate method (Ponterotto, 2005). This particularly involved considering the epistemology and ontology underpinning the study.

2.2.1 Ontology

Ontology considers what exists that it is possible for us to know (Willig, 2013). Willig (2013) described a range of possible ontological positions, from realist positions which assume there is an objective reality we can have knowledge of, to relativist positions which assume that there is no one single reality, and that 'reality' is the result of each person's interpretations of the world.

Given that this study was interested in carer's perceptions of therapy, and that perceptions are interpretations by nature, I initially believed a relativist ontology would be most useful to explore the research question. However, I was concerned about some of the potential implications of this. In light of arguments that carers are not sufficiently empowered within the current systems (Larkin & Milne, 2014), it seemed important not to position carer's perceptions only as interpretations, but instead to acknowledge that carer's perceptions represent their real feelings and beliefs about an external reality they are experiencing. To achieve this, a more realist ontological position was considered necessary, albeit with the recognition that each individual carer will have different experiences and will therefore hold different perceptions and interpretations of their real experiences. Additionally, as part of the rationale for the study was to potentially influence an assumed external reality (by providing the opportunity to adapt how therapy is promoted to carers, for example), it was felt that the rationale for the study itself pre-supposed a shared external reality.

2.2.2 Epistemology

Epistemology considers how it is possible to know something and what it is possible to know about that phenomenon (Willig, 2013). Again, Willig (2013) described a range of epistemological positions, from positivism – which assumes that we can accurately perceive and describe an external reality – to social constructionism, which assumes that our understandings of the world are influenced by a range of factors (such as the culture, language and time in which we are attempting to understand them) and therefore our understanding of the world will always be filtered through our own particular lens. As this study was interested in carer's perceptions, the question being posed assumes that carers will have a particular view of therapy which is coloured by their experiences and situation; similarly, the researcher is assumed to understand carer's perceptions through the lens of their own individual experience.

2.2.3 Combining ontology and epistemology: The Theoretical Lens

Given the ontological position that there is a shared, external reality available to be known, and the epistemological position that different people will have different perceptions of this reality (which can therefore never be known entirely accurately), a critical realist position was considered to underlie this research. Critical realism assumes that experiences are real but cannot be fully, factually known (Willig, 2013). This allowed for an understanding of carer's perceptions as a response to their experiences of an external reality, but also for the subjectivity involved in generating knowledge and understanding the experiences of others (Willig, 2013).

While relativism assumes that there is no shared external reality, and instead posits that there are multiple ‘realities’ which are shaped by and experienced through the lens of our individual subjective perceptions and ideas (Willig, 2013), the realist aspect of critical realism does assume an objective reality (Gorski, 2013). Unlike realism, however, critical realism does not assume that this external reality can be directly observed, nor that observations can be made independently of interpretation by the observer (Gorski, 2013). Thus, despite a shared ontological view of the world, critical realism differs from naïve realism in epistemology.

As applied to the current study, a critical realist lens had important implications which would have been missed or watered down by other philosophies. From a critical realist perspective, both individuals and systems are types of entity which exert influence over actions (Vincent & O’Mahoney, 2018). This was considered to be particularly significant for the current study, in order to avoid positioning carers as the sole bearers of responsibility for whether or not they (are able to) access therapy in the context of a society where carer’s perspectives are not always heard (Arksey & Hirst, 2005; Larkin et al., 2018). Additionally, taking a critical realist stance facilitated consideration of carer’s perceptions as entities in their own right, alongside consideration of context and carers’ actions (Vincent & O’Mahoney, 2018). This allowed for a richer exploration of multiple facets which may play a role in carers’ decision-making about therapy.

A critical realist theoretical position also had implications for the suitability of different research methods. An appropriate method needed to facilitate exploration of carers’ real experiences and stated views. It also needed to facilitate reflexivity, including consideration of:

- the researcher's impact on the study and findings (for example, through what was chosen for further exploration)
- how both participants and the researcher made sense of how participants' experiences had influenced their decisions regarding therapy
- how the researcher's experiences and ideas influenced the analysis and subsequent findings.

The following section outlines how grounded theory was chosen as the most suitable method.

2.3 Research Design

2.3.1 Rationale for a Qualitative Approach

A qualitative approach to addressing my research question was considered most appropriate for a number of reasons.

Firstly, qualitative approaches, which aim to "describe and possibly explain experiences" (Willig, 2013, p. 9), seemed suited to addressing my research question. This study aimed to illuminate a description of how carers of people with dementia perceive psychological therapy. Furthermore, it was considered that using a method which would enable consideration and development of a theory which attempts to consider potential relationships (without assuming such relationships to be causal) between carer's experience and their perceptions of therapy would provide an opportunity to optimise the utility of the findings in clinical practice. For example, such a theory could assist counselling psychologists – and indeed other relevant professionals – in considering how their clients' experiences may influence the client's relationship with therapy and incorporating this into their formulation and intervention, where appropriate.

The second reason for choosing a qualitative method to addressing the research question is that selecting a quantitative framework - with a hypothesis to be tested (Willig,

2013) - would have had particular drawbacks in this instance. Developing a hypothesis based on existing literature about perceptions of therapy would have limited the ability to uncover ideas which were not already present in the literature (Willig, 2013); thus, any aspects which may be specific to the particular population in question would likely be missed.

Additionally, attempting to fit the question to a quantitative framework would have created further challenges. For example, to gain a wide perspective of the relationship between carers’ experiences and their perceptions of therapy would have involved a large sample of carers with a range of different caring (and potentially non-caring) experiences, and a wide range of perceptions of therapy – potentially introducing a large number of confounding variables. This might be more appropriately investigated through a series of studies, where the possibility of isolating particular factors may be less complex. Alternatively, the focus of this study could have been narrowed to select a particular focus (such as choosing a particular aspect of carers’ experiences and investigating to what extent this variable predicts or moderates particular aspects of carers’ perceptions of therapy) but this would have sought an answer to a narrower question than the one posed here. It would also have involved making assumptions about potential variables which may predict carers’ perceptions. This was considered to be presumptuous given the relatively scarce consideration given in the literature to how carers perceive therapy, much less what factors might influence these perceptions.

This brings us to the final key reason for having selected a qualitative approach; the lack of existing data on which to base hypotheses about how the particular group of carers under consideration might perceive psychological therapy. It was therefore considered most appropriate that this study be exploratory in nature. This indicated that an inductive approach – as used in qualitative approaches – would be more suitable than a quantitative approach (Willig, 2013).

In light of the above considerations, a qualitative method was felt most appropriate to answer the research question.

2.3.2 Considerations of Mixed-Methods Approaches

Mixed-methods approaches which examine a research area from both qualitative and quantitative perspectives have the potential to provide a fuller examination than using either approach alone (Yardley & Bishop, 2008). Additionally, the strengths of one approach may compensate for the weaknesses of the other (Wisdom & Creswell, 2013). Mixed-methods approaches therefore have the potential to provide important insights and can be utilised in a variety of ways, such as using qualitative data to inform development of a quantitative questionnaire measure, using a qualitative approach to further explore findings from quantitative data, or using both approaches concurrently during research (Wisdom & Creswell, 2013).

While mixed-methods approaches offer a number of strengths, they are not without drawbacks. One challenge when utilising mixed-methods approaches relates to the different epistemologies and ontologies typically underpinning qualitative and quantitative research. However, as Wisdom and Creswell (2013) highlight, a critical realist perspective acknowledges the objective reality assumed by (typically positivist) quantitative approaches, while also acknowledging the influence of context and interpretation on what we can know. A mixed-methods approach would not, therefore, have been contraindicated by the theoretical lens underpinning this research.

Additional challenges of utilising mixed-methods approaches include the potential challenge of interpreting and integrating potentially conflicting findings (Yardley & Bishop, 2008) and increased demands on the time and skills of the researcher (Wisdom & Creswell, 2013). My position as a doctoral student therefore influenced my decision not to use a mixed-methods approach. I was conscious of the time required for other elements of my course, as well as the limited time available in which to complete this research. I also lacked confidence in my ability to conduct high quality mixed-methods research when I was planning the project. I therefore decided that it would be more appropriate to focus on designing and carrying out a qualitative approach to the best of my ability than to attempt to do too much at an early stage in my development as a researcher. This allowed me to focus on developing and carrying out high-quality qualitative research, which was deemed suitable to address my research question for the reasons outlined in the previous section.

2.3.3 Qualitative Methods Considered

A number of qualitative methods were considered in selecting which would be best suited to answering the research question: grounded theory and thematic analysis, in particular, were both considered potentially appropriate, and interpretive phenomenological analysis (IPA) was frequently suggested as an alternative approach. Thematic analysis and IPA will be discussed briefly, along with the reasons they were not chosen; grounded theory and the reasons for selecting it as the method for this study will then be considered in greater detail.

2.3.3.1 Thematic Analysis. Thematic analysis aims to provide a rich, detailed analysis of the patterns or themes found within a set of data, such as from a number of interviews or focus groups, although these are not the only available options for data collection (Braun & Clarke, 2006). Braun and Clarke (2006) describe thematic analysis as a flexible approach in that it can be used to analyse data from a range of epistemological and ontological perspectives, and can be used either to develop a broad overview of themes within a given data set or to focus specifically on themes related to a particular aspect being explored within that data set.

Thematic analysis was considered to have some potential in addressing the research question; it would allow for consideration of the key themes or ideas that carers expressed regarding psychological therapy and can be used appropriately within the theoretical framework of the study. However, it was considered that thematic analysis would be of more limited help in answering the second part of the research question, regarding the process by which carers reach decisions about accessing therapy. As Braun and Clarke (2006) note, thematic analysis can be limited in the extent to which it can go beyond a descriptive analysis without an appropriate theoretical framework to support this. Grounded theory incorporates many aspects of thematic analysis (such as coding and comparing codes across a set of data, and being suited to use underpinned by a range of theoretical positions) but also focuses on relationships between codes, concepts and categories, and it was therefore considered that grounded theory would have more potential to explore the process-focused part of the research question.

2.3.3.2 Interpretative Phenomenological Analysis (IPA). IPA aims to explore, in detail, participants' lived experience of a given phenomenon, and is underpinned by a phenomenological theoretical framework which considers that the researcher cannot directly understand the participants' experiences exactly as participants experience them (Smith et al., 2009). Researchers must therefore interpret what participants say in order to describe their experience.

Although this study could be considered as exploring participants' lived experience of not having accessed psychological therapy in the context of caring for someone with dementia, it was considered that IPA would not be the most suitable approach for several reasons. Firstly, this study is aiming to explore how participants perceive something they have not actually had lived experience of (ie psychological therapy), and it was not clear how this would fit within IPA. Secondly, the phenomenological underpinning of IPA sits at odds with the critical realist stance taken in this study (although this could potentially have been resolved by adopting a phenomenological stance if IPA otherwise seemed the more appropriate choice). Thirdly, while IPA supports developing rich description of participants' experiences (Smith et al., 2009), it was again considered that utilising the capacity of grounded theory to extend from description to consider relationships between ideas and develop a theory regarding the topic being explored would more readily translate into clinical practice, for example by suggesting hypotheses which counselling psychologists could consider with regard to specific client formulations or engaging clients in therapy.

2.3.4 Grounded Theory

Grounded theory was selected as the most appropriate approach for this study. Grounded theory was initially developed by Glaser and Strauss (1967) as a move away from only testing out existing theories. Grounded theory focuses instead on developing new theories based on the data collected, with the view that both quantitative and qualitative data have important insights to offer (Urquhart, 2013). Over time, differences in Glaser's use of grounded theory and Strauss's have become increasingly apparent. For example, Glaser held to positivist principles (such as objectivity and generalisability) whilst Strauss's approach to analysis within grounded theory retained elements of a positivist paradigm (such as researcher neutrality) but explicitly drew on a pragmatist framework (Charmaz & Henwood 2008; Corbin & Strauss, 2015). The method has further been developed in keeping with constructivist approaches, which see the resulting theory as having been constructed in the context of a particular setting, influenced by values and representing one of multiple possible views (Charmaz & Henwood, 2008).

Arguably, the range of ways in which grounded theory has been developed represents a strength of the approach, in that it holds the flexibility to be usefully applied in a range of contexts and research paradigms (Urquhart, 2013). Despite the varied ways in which the method has been used, a number of general, core principles remain (Urquhart, 2013):

1. Aiming to result in a theory

2. The importance of setting aside pre-existing ideas
3. A focus on the interaction between individuals and the phenomenon being explored
4. Positing credible relationships between ideas within the theory
5. Theory remaining grounded in the data
6. Analysis commencing as soon as data has been collected and not only identifying categories but also considering relationships between categories
7. Based on ongoing analysis and initial findings, further data collection is undertaken
8. Emerging codes, concepts and categories are constantly compared both within and between groups of codes, concepts and categories.
9. Data collection continuing until data adds to existing concepts and categories but does not introduce new ideas
10. Analysis comprising of initial open coding, subsequent selective coding, and proceeding to theoretical coding
11. Analysis resulting in a theory which can be stated.

Grounded theory can therefore be seen as a method for analysing qualitative data which aims to go beyond the data to develop a theory, but also aims to ensure that the resulting theory is closely linked to the data collected.

2.3.4.1 Rationale for Grounded Theory. Within this study, grounded theory was selected for four main reasons:

1. The research question focuses on understanding a process; how the perceptions carers of people with dementia have about psychological therapy influence their decisions about accessing therapy. Grounded theory focuses on process and development of a theory, which was considered to be a good fit with the research question.

2. The focus on remaining close to the data was considered important due to the previously unexplored nature of the research question
3. It was considered that developing a theory would enhance the applicability of the findings to practice; for example, if two ideas are considered to be related in the resulting theory, and a carer expresses one of these ideas in therapy, the psychologist would then be in a position to consider whether a related idea posited in this theory may also be relevant.
4. Grounded theory is suitable for use with a range of underpinning philosophies, and methods have been put forward which partially align with either the more ‘critical’ or the more ‘realist’ elements of critical realism.

However, due to the range of ways in which grounded theory has been applied, it was necessary to consider how to approach using the method within this particular study. None of the main approaches to grounded theory seemed a precise fit with my underlying theoretical position. Glaser’s positivist approach did not sit neatly with the importance of subjectivity and reflexivity in counselling psychology (Kasket & Gil-Rodriguez, 2011) or the relativist elements of the critical realist stance underpinning this study. Strauss and Corbin’s approach, underpinned by assumptions such as that the internal and external worlds are not separate but created through interaction (Corbin & Strauss, 2015), did not seem in keeping with the more realist ontological position taken; neither did Charmaz’s constructionist approach (Charmaz & Henwood, 2008). As a result, it was considered most appropriate to utilise the central features of classic or Glaserian grounded theory, but to draw also on influences from other sources, such as Charmaz (2006). It was hoped that this would enable the development of a theory that uncovered ideas which were generated by participants and considered to be based on an observable reality, while also recognising the ways the researcher influences the development of the theory. I believe this to be in keeping with the view that “there is no one way to do grounded theory” (Urquhart, 2013, p 1) and that, since research projects are rarely identical, so each project will require its own unique or adapted methodology (Crotty, 1998).

2.4 Ethical Considerations

This study was reviewed and approved by City, University of London Psychology Ethical Review Committee (Reference PSYETH (P/F) 16/17 77, see Appendix I) and Health Research Authority (London-Brighton and Sussex Research Ethics Committee, REC reference 17/LO/1515; see Appendix J). Where amendments were made (ie revising the interview schedule, extending the duration of the study to allow for further recruitment to be completed) and required ethical approval, the amendments were not implemented until ethical approval had been granted (see Appendix K for approval of amendment documents from the London-Brighton and Sussex Research Ethics Committee).

2.4.1 Informed Consent

Prior to their participation, the researcher discussed with participants what was involved in the study. It was explained that the researcher was interested in their ideas and preconceptions and that they did not need to know what therapy is or looks like to take part. Participants were made aware that their participation was confidential unless the researcher and their supervisor had concerns about the safety of the participant or anyone else, and it was explained that this was rare but that in these instances confidentiality may need to be broken to ensure safety. They were asked to choose a pseudonym and it was explained that this would be used in writing up the research and in any publications, to protect their privacy.

Participants were also made aware that they had the right to withdraw their consent until analysis has started. At this point, their responses would have been pseudonymised and further ideas may have been generated from their responses which would in turn guide further steps in the research and therefore have made withdrawing their data challenging. It was made clear that this research is part of a doctoral thesis. This information was provided in written form (see Appendix E), together with the contact details for the researcher and supervisor. Participants were given the opportunity to ask any questions they may have and asked to sign a consent form (see Appendix F) before commencing the study.

2.4.1.1 Participants referred from a local IAPT service. One IAPT service supported recruitment to the study by providing identified carers with information about the study and the researcher's email address. As the researcher was on placement with the IAPT service and offering therapy within the counselling team, it was agreed that the researcher would not work therapeutically with anyone who had participated in this research. Should any participants be put forward as potential training cases, the researcher would explain to their clinical supervisor that they know the client in another capacity and that it would therefore not be appropriate to work with them therapeutically; the client would therefore be assigned to another member of the clinical team. The researcher would not access the participant's notes or discuss their involvement in the research project with anyone other than their research supervisor at City, University of London. Likewise, if the researcher had worked clinically with a potential participant (for example, during their assessment or as a result of having been consulted about the client's clinical presentation), the participant would not be invited to participate. The researcher did not receive any expressions of interest to participate in the study from any previous clients.

Additionally, staff members at the IAPT service were advised to make clear to potential participants that their decision whether or not to take part would not be communicated to their therapist, nor would any information they disclose during any interview be shared with their therapist. This was reiterated by the researcher prior to participants deciding whether to take part.

The above information was explicitly stated in the information sheet given to potential participants (see Appendices C, E and F) and discussed with them during screening.

Participants were invited to ask any questions they may have about this before deciding whether or not to take part.

2.4.2 Emotional Distress

2.4.2.1 Participants referred from therapy services. Participants referred from therapy services, such as a local IAPT service, were encouraged to prioritise their psychological wellbeing. To allow sufficient time for participants to complete their involvement in the study without delaying them commencing therapy, staff were asked only to provide information about the study to carers who would be waiting at least 3 weeks to commence treatment. The researcher checked during screening that participants were not delaying or currently accessing psychological therapy. This was for two reasons. Firstly, checking this information was important in minimising the likelihood of participants waiting longer than necessary to access the support they had sought. Secondly, knowing the answers to this question enabled the study to focus on the views of carers who have not previously accessed psychological therapy, views which may have changed once therapy had started.

2.4.2.2 Detected at Screening. It was planned that participants whose scores on the PHQ-9 indicated severe symptoms of depression would be advised of what their scores indicate, including that this does not constitute a diagnosis, and provided with information about possible sources of support. They would be asked if they still wished to continue with their participation and reminded of their right to withdraw. No participants scored in the severe range on the PHQ-9.

2.4.2.3 Detected during Interview. Should participants become overtly distressed during their participation, they were asked if they wish to stop the interview, and the interview did not proceed without their consent. Participants were also advised prior to the study that they could withdraw at any time until analysis had started, including during the interview itself.

Three participants became tearful during their interviews; all indicated that they wished to continue their participation and that they felt they had benefitted from feeling listened to during the interview.

2.4.2.4 Debriefing. Following the study, participants were asked how they found participating and how they were feeling following the interview. It was explained that the study was interested in understanding and explaining how carers of people with dementia perceive therapy so that we can better understand their views on this. Participants were asked if they have any questions or concerns following their participation and were provided with a copy of the debrief sheet (see Appendix L). They were provided with information on local carers' centres, therapy services and crisis helplines. It was anticipated that most participants will be local to the London Borough of [redacted] as this is where most advertising was focused. Two participants living outside London also took part; they were provided with information regarding similar services in their local areas.

2.4.3 Confidentiality

To ensure confidentiality, participants were asked to choose a pseudonym for use with any direct quotations used in the write-up of the study. They were also asked if they wished to choose a pseudonym for the person they cared for, or preferred this person to be referred to by either a pseudonym chosen by the researcher or by their relationship to the participant (eg as "my husband" or "my mother"). Other identifying information was changed or omitted.

Electronic data were stored in two separate files (one for pseudonymised information, the other for personal information), each protected by a separate password, on a password-protected computer. Hard data were stored in separate, locked filing cabinets, to which only the researcher had the keys.

Participants were made aware prior to their participation that in rare instances, confidentiality may need to be broken if they disclosed anything which suggested they or someone else may be at risk of significant harm. Participants were invited to ask any questions they had regarding this before deciding to take part.

Prior to individual interviews, the researcher checked whether the participant would be able to speak confidentially in their chosen location and whether there was any risk of the interview being interrupted. If the interview may be interrupted, the researcher advised arranging an alternative time or location. Where other people were present at the chosen location (for example, at a local carer's centre or other residents at the participant's home), the researcher did not disclose the nature of the study without the participant's consent, instead stating only that they had an appointment with the participant.

2.4.4 Incentives

Travel expenses were reimbursed up to the cost of a 1-day London Zones 1-6 Travelcard. This was to reduce the likelihood of carers not being able to participate for financial reasons, as many carers report financial concerns (Carers UK, 2015).

2.5 Participants

Adult carers of people with dementia were interviewed. A carer was defined as anyone aged 18 years or over "who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support." (Carers Trust, n.d.).

Carers were excluded from participating if any of the following criteria applied:

- They had previously attended 1 or more sessions of psychological therapy or were due to start therapy before their participation in the study would be concluded
- They provided care for less than 10 hours per week

- They were under the age of 18
- They reported experiencing thoughts of suicide or self-harm during screening

Carers were excluded if they provided care for less than 10 hours per week because existing literature suggests that carers in the UK are at increased risk of mental health difficulties when they provide care for at least 10-19 hours per week (Colombo et al., 2011). This was a tricky decision to make. On the one hand, excluding carers on the basis that they may be less likely to be experiencing difficulties determined by another person as meeting clinical thresholds did not seem in keeping with the ethos of counselling psychology, which values the subjective experience of the individual rather than prioritising the views of professionals (Cooper, 2009), and of course some individuals caring for fewer than 10 hours per week may still experience significant challenges to their psychological wellbeing. There was also the possibility that excluding carers who spent less time caring would particularly exclude carers of people with more recent onset or mild symptoms of dementia, or those who were not the primary carer, and it was not clear whether these factors may play a role in how carers of people with dementia perceive psychological therapy.

At the same time, it was considered important to focus primarily on carers experiencing greater levels of burden as a result of their caring role, particularly as Colombo et al.'s (2011) report seemed to suggest a link between burden in terms of time spent caring and burden in terms of impact on psychological wellbeing. Understanding how these carers perceive therapy might be considered to have most relevance. Such understanding could support improvements in communicating with these clients regarding therapy if this was found to be needed, but also strengthen arguments for other types of support if therapy was well understood but not seen as relevant to them by these carers. Finally, considering the process of grounded theory – which requires that different participant groups are recruited to further the development of the emerging theory (Glaser & Strauss, 1967) – it was concluded that this criterion could be removed if warranted during data collection and analysis. This consideration helped to resolve the tension between the values of counselling psychology and the need to focus research efforts where it may be argued to have the most potential benefit.

Carers under the age of 18 were also excluded, as there is a separate body of literature and research concerning young carers.

For ethical reasons, it was proposed that any participants who indicated during the telephone screening conversation that they were experiencing thoughts of suicide or self-harm would not be interviewed, in order to prioritise their wellbeing. Instead, they would be strongly encouraged to contact their GP and signposted to appropriate support. During the course of the study, no participants indicated experiencing such thoughts.

Six participants took part in the study. This included three adult children caring for parents with dementia and three people caring for partners with dementia. Four participants indicated that they lived with the person they were caring for. One participant maintained paid employment alongside their caring role, two had attempted to maintain employment but had to stop working due to their caring role, and three had retired. One participant was caring for more than one person (the second of whom did not have dementia) and three participants indicated that the person they cared for had other care needs in addition to those arising from dementia. Two participants indicated that they had attempted to access psychological therapies previously; one was on a waiting list for therapy while the other stated they had not been able to find a therapist that was both affordable and accessible around their caring commitments. Since grounded theory emphasises the importance of investigating the research area with different groups of people (Glaser & Strauss, 1967), this diversity is considered to have enhanced the resulting theory by enabling constant comparison of codes, concepts and categories as they apply to different subgroups of carers within the population being investigated.

2.6 Recruitment

Adult carers of people with dementia were recruited to participate in the study via several avenues, including:

- Placing an article in the newsletter for local carer support organizations and online forums for carers (See Appendix B).
- Via a local IAPT service where carers are routinely identified during the existing telephone triage. Staff at the IAPT service were asked to provide any carers of people with dementia with information about the study (see information sheet in Appendix C), provided they were either:
    - being placed on the waiting list for individual therapy and are not expected to commence therapy within the next 3 weeks, which was considered to be sufficient time for participants to complete their involvement in the study; or
    - choosing not to access therapy with the service at this time.
- Making use of snowball sampling by asking participants to pass the researcher's university e-mail address on to any other carers they believe would be interested in participating
- Placing posters in community venues and public spaces, such as libraries, supermarkets and coffee shops, with the approval of those responsible for maintaining those spaces (See Appendix D)
- Placing posters in venues supporting people with dementia and their carers (such as local dementia support hubs and venues hosting memory cafes).

It was estimated that approximately 8-12 participants would be recruited to take part in the study; however, in line with the grounded theory method, theoretical sampling was used to guide the number of participants (Birks & Mills, 2015). Theoretical sampling is discussed further in section 9.0. Unfortunately, the final number of participants was limited by the introduction of restrictions in the UK as a result of covid-19, following which it was decided not to continue recruiting to the study for a number of reasons:

1. It was considered that carers may not be able to participate with adequate privacy in their own homes and that it would be more difficult for the researcher to ensure sufficient confidentiality conducting interviews via videocall, as the researcher would not necessarily be aware if anyone else was in the room with the participant.
2. It was felt that carers may need to prioritise their own wellbeing and the needs of the person they care for, given the impact of the restrictions on service provision in the local area (such as the closure of day centres).
3. The closure of a number of venues where posters were placed to advertise the study also limited avenues for recruitment, although alternative avenues could have been identified if this was the only reason for discontinuing recruitment.
4. It could be difficult to establish the extent to which subsequent interviews and findings would be affected by covid-19 and accompanying restrictions. For example, the restrictions meant that much psychological therapy was harder to access or only provided remotely in the geographical area where the research was being undertaken. Given that the battle to access therapy was an important category, this category in particular may have been affected. While this could have provided useful insights into the impact of covid-19 on carers' perceptions of therapy as difficult to access, such insights would not necessarily be applicable once restrictions were lifted, nor would it necessarily be straightforward to identify what aspects of the battle

to access therapy were specific to or exacerbated by covid-19 and which had pre-dated the restrictions. Establishing this was considered to be likely to require increasing the number of participants, which posed the challenges mentioned above regarding continued recruitment.

Due to the combination of these concerns and the fact that the analysis of the sixth interview had not identified any new codes or concepts or modified the researcher's understanding of the existing categories, the decision was made to end recruitment to the study at this point. This had implications for the extent to which theoretical saturation was achieved, which will be considered further in the Discussion chapter.

2.7 Procedure

On contacting the researcher, participants were provided with the participant information sheet (Appendix E) and consent form (Appendix F) and asked to read these to help them decide whether to participate. To ensure compliance with the General Data Protection Regulations, participants involved in or commencing the study following the implementation of GDPR in the UK were also provided with the Health Research Authority's (2018) patient information wording and assured that the researcher would not access their medical records. Participants were encouraged to contact the researcher if they had any questions.

Should they decide to go ahead with their participation, they were asked to sign the consent form and return a copy to the researcher. They were given the opportunity to ask any further questions and an initial screening conversation was arranged by telephone. Participants were advised to arrange to be somewhere private where they felt able to speak confidentially for this telephone call.

One potential participant stated that they did not wish to participate at this stage, indicating that this was because they were not sure the person they were caring for had been diagnosed with dementia. Two further participants did not contact the researcher on receiving the information sheet; one further email was therefore sent to each of them after two weeks, inviting them to contact the researcher if they had any questions or wished to take part, and thanking them for their time if they had decided not to participate at this time.

2.7.1 Screening

Participants initially attended a 10-minute telephone meeting, during which they were given the opportunity to find out any further information they required regarding the study. The researcher briefly summarised what their participation would involve, outlined the confidentiality arrangements and asked participants if they had any questions, before checking that participants met the study inclusion criteria and not the exclusion criteria; all participants who took part in a screening call met the inclusion criteria and none were excluded at this stage.

The 9-item version of the Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001) was also completed during the screening call. Scores on the questionnaire ranged from 2 (indicating no clinically significant symptoms of depression) to 17 (indicating moderate symptoms of depression). At the end of the screening call, participants were asked if they wished to arrange a face-to-face interview and a time and place for this was arranged.

Two participants who arranged a face-to-face interview at this stage withdrew from the study before the interview took place. Both participants indicated without prompting that their withdrawal was due to the worsened health of the person they were caring for.

2.7.2 Interviews

Individual, semi-structured interviews took place at a location of the participant’s choosing, provided the location was safe and participants were able to speak confidentially and without interruption. Interviews were audio-recorded.

2.7.2.1 Rationale for Choosing Semi-Structured Interviews. Individual interviews were selected as the method of data collection for a number of reasons. It was considered that individual interviews would provide greater confidentiality than, for example, a focus group, and would also allow increased flexibility in arranging a meeting at a time convenient to the participant, whose availability may be restricted by the need to arrange for someone else to be with the person they care for.

Semi-structured interviews were chosen in order to allow participants the space to raise ideas not thought of by the researcher, and for the researcher to be able to follow up on these, whilst also allowing for some consistency in what is covered with different participants (Corbin & Strauss, 2015). Corbin and Strauss (2015) suggest that unstructured interviews are more in keeping with grounded theory as they see it, as unstructured interviews ensure that participants have the space to discuss the ideas which are most pertinent to them. This highlights the importance of ensuring that participants have space to direct the course and pace of the interview. However, I agree with Charmaz (2006), who argues that constructing an interview guide helps the researcher to clarify what they are wanting to learn from participants and further elaborate on their research question, which I believe provided an important opportunity for engaging in reflexivity. For example, considering the questions I wanted to ask during the interview provided the opportunity to check that questions were phrased openly enough for participants to bring whatever was important to them, rather than in ways which might prompt participants towards considering certain aspects that I thought might come up or be important. It also allowed me to consider how I would feel if clients raised perspectives that were quite negative towards therapy, prepare myself to sit with and explore any such perspectives, and consider how I could encourage them to feel able to express these freely (for instance, by encouraging participants that there are no right or wrong answers, and asking open questions such as “Could you say more about that?” to encourage them to elaborate).

In order to balance these two perspectives, the interview schedule was not followed rigidly – where participants raised ideas which were relevant to the research question and not covered by the interview schedule, these were followed up, and where participants provided information which partially answered a question on the interview schedule, the order of the questions was reshuffled to follow the participant's line of thinking. At the same time, before concluding each interview, the interview schedule was briefly checked to ensure that all areas on it had been covered, thus balancing the need to follow up on what participants indicated was important to them with having some consistency in what was covered across interviews.

2.7.2.2 Development and Refinement of the Interview Schedule. An initial draft interview schedule was developed (see Appendix G). During interviews, when participants raised ideas not covered in the schedule but relevant to the research question, these were pursued, in line with a grounded theory method (Urquhart, 2013). The interviews typically lasted approximately 60 minutes, with the shortest interview lasting 32 minutes and the longest lasting 77 minutes. The draft interview schedule was piloted with two people prior to being used with participants, and some questions and prompts were clarified as a result. For example, in the pilot one question was “Do you have any fears about what therapy might involve, if you ever were to have therapy?” and this proved challenging for those taking part in the pilot to answer; however, rephrasing the question to ask about worries, anxieties or concerns rather than fears resulted in richer, more detailed responses.

Following three interviews, the interview schedule was again reviewed and a revised schedule was developed (see Appendix H). There were two reasons for this. Firstly, Glaser and Strauss (1967) recommend that emerging ideas are investigated further to elaborate and clarify codes, concepts and categories and their relevance to the emerging theories. This required revising the interview schedule to include a greater focus on the impact carers felt caring had on their lives, which had been identified as a potentially important category from early interviews but was not fully explored within the original interview schedule. It was also hoped that asking more explicitly about whether carers had previously been aware of psychological therapy as an option for them would provide an opening into exploring the process by which carers became aware of psychological therapy at greater depth.

The second reason for revising the interview schedule was in keeping with Charmaz (2006), who points to the importance of listening back to interviews to identify questions which do not work and refining the interview guide in light of this. It was identified in the first few interviews that participants struggled with the question “what do you know about therapy?” and, while it was important to discover that they felt they knew very little about therapy, this also seemed to make it harder for them to feel able to share their ideas and preconceptions about therapy. It is possible that asking participants what they know about therapy may have implied that there was a right/wrong answer or inadvertently left them feeling judged or otherwise unable to share their ideas about therapy freely. This question was therefore removed and replaced with questions asking what words or ideas first came to mind when participants thought about therapy, which it was hoped would encourage them to answer more freely and increase the richness of their responses.

2.8 Analytical Procedure

The step-by-step aspects of the analytic procedure will be documented first, followed by an outline of aspects which apply to all steps of the procedure (such as constant comparison).

As soon as possible on completion of an interview, an initial analysis of the data began with writing a memo documenting the researcher’s initial thoughts and impressions following the interview (see Appendix M for an example), in keeping with Glaser and Strauss’s (2017) approach. This ensured that early impressions were captured and could be returned to later and that aspects of the interview which may otherwise have been forgotten (such as the impression of urgency noted in the memo in Appendix M) were recorded. I found that writing down my initial thoughts also made it easier for me to put them to one side whilst undertaking subsequent analysis. I didn’t have to try to remember what I had thought about or wondered and could focus my full attention on the data in front of me, knowing that I could review my initial impressions later to check their relevance (or lack thereof).

The interview was then transcribed and the transcription was reviewed while listening to the interview, to check for accuracy and encourage familiarity with the data (Glaser & Strauss, 2017). Line-by-line open coding then was used to identify important codes and ideas from the data, without foreclosing areas of possible interest (Urquhart, 2013). While Glaser (1992) suggested that line-by-line coding is not always necessary and moved towards incident-by-incident coding (Charmaz & Henwood, 2008), I considered that line-by-line coding was preferable in order to offer maximum opportunity to engage at depth with the data, as suggested by Charmaz (2006).

Open coding was then followed by selective coding, in which open codes were organised and considered in order to develop categories. Using Glaser’s (1978) approach, at this point the codes were organised into core variables – key categories around which open codes could be organised. These were loosely held, especially early on in the analytic process, and open to revision as a result of constantly comparing emerging codes, categories and concepts, to help avoid prematurely fixating on a particular hypothesis or theory (Glaser & Strauss, 2017). As categories became more well-defined and approached saturation (that is, ongoing analysis was not generating further ideas but rather refining existing ones, Glaser & Strauss, 2017), the categories could be held with greater confidence and a core category was identified. Glaser (1978) identified the core category as that with the greatest explanatory power within the emerging theory, and to which the other categories relate.

Theoretical coding was then used to identify relationships and links between codes, in order to build a theory grounded in the data. While Glaser (2005) identified a number of coding families which could be usefully considered to aid in identifying relationships between codes, Charmaz (2006) highlights the importance of not forcing data to fit pre-existing ideas, while Kelle (2007) argues that the coding families represent an attempt to bridge the gap between the purely inductive approach and the difficulty in developing a theory without some further framework to guide the development of theoretical codes. I agree that reliance on these coding families would risk seeking out codes from within the perspectives offered by the coding families, and so (while the families nudge the researcher to consider a broad range of possible ideas and relationships in the data), they were used cautiously, referred to following initial coding as an aid to prompt additional perspectives, rather than to provide too much direction to the analysis. I hoped that this would maximise my ability to spot potential relationships in the data.

Throughout the analytic process, constant comparison was used. Codes, concepts and categories were constantly compared with each other in order to remain focused on the data and to clarify and re-evaluate the codes and categories being developed (Willig, 2013). This supported questioning the data; was the particular incident truly best represented by the code given, or did it fit better with another (new or existing) code? How did this code fit within the category it had been placed under, and what did it add in terms of understanding the category? Did the code/category label accurately reflect my understanding of the concept in question? Constant comparison also aided in identifying when a category was approaching saturation (Glaser & Strauss, 2017), by illuminating the properties and boundaries of each category. This enabled subsequent data collection and analysis to focus on developing other categories (Glaser & Strauss, 2017). For example, constant comparison highlighted early in the research that there was a need to gather more data regarding the impact of being a carer for someone with dementia on a person’s life, and on how carers had become (or not become) aware of psychological therapy as an option that might exist for them. The changes in the interview schedule were therefore intended to support exploring these areas further.

Theoretical sampling was considered throughout data collection and analysis. Theoretical sampling refers to identifying what data to collect next, and where from (Glaser & Strauss, 2017) and was utilised to seek out additional, new or disconfirming data. This is in order to maintain an openness to as many theoretical possibilities as possible. Theoretical sampling drove how recruitment efforts were targeted and expanded throughout the study. For example, it was considered that early participants were predominantly those accessing some form of support in their caring role, for example from a local carers charity or a comprehensive package of support from social care. The researcher wondered how receiving different types of support, or less support, might influence how carers perceived therapy. Additional efforts were therefore made to target recruitment in places where carers might go even if they were not accessing specific support in their caring roles (such as by displaying posters on supermarket community boards). Ideally, theoretical sampling should continue until theoretical saturation has been achieved; that is, when new data lend further support to existing codes and categories but new codes or categories are not being generated (Charmaz, 2006). The extent to which this is considered to have been achieved in this study will be considered in the Discussion chapter.

Memos formed an important part of the analytic process (Urquhart, 2013). They were kept during the design of the study, as well as throughout data collection and analysis, to increase reflexivity, aid transparency regarding decision-making and encourage increasingly abstract analysis. Memos were written whenever thoughts or ideas regarding the study and analysis occurred, when the researcher felt stuck or overwhelmed by the data, and during coding. This is in keeping with Glaser and Strauss's (2017) recommendations. Memos became particularly helpful later to aid in spotting patterns in the data and as space to think through potential relationships between concepts. They additionally helped in identifying gaps in the data by highlighting what questions needed answering to make sense of how emerging concepts were related (Glaser, 2013). Thus, memoing formed an essential part of the process. Some memos have been included in this and subsequent chapters to aid in transparency regarding the analytic process and decision making (see Appendices M, N, O and R).

Once a theory was developed, it was considered in light of a further literature review. In keeping with the view that a preliminary literature review is needed to identify a research problem, as outlined by Urquhart (2013), an initial literature review was completed, as outlined in the previous chapter. This was also considered to be in keeping with both Glaser's (1992) and Charmaz's (2006) assertion that reading around issues related to – but not too closely overlapping with – the research area would encourage the development of theoretical sensitivity, thereby enabling the researcher to identify codes and ideas which may have relevance in the emerging theory whilst minimising the impact of pre-existing knowledge on the specific topic being investigated. In an effort to achieve this, reading specifically regarding perceptions of therapy was limited until after a theory began to be developed and the core category was considered to be approaching saturation. However, Glaser and Strauss (2017) also note that existing literature can be considered further data for refining a theory emerging from grounded theory. The theory resulting from this study will therefore be considered in light of a further literature review and Glaser and Strauss's (2017) criteria for the properties a theory should have in the Discussion chapter, after the theory itself has been presented.

2.9 Reflexivity

As noted previously, memos were used to aid methodological reflexivity and to increase transparency about my thoughts and decision-making process throughout the study design, data collection, analysis and write-up (Urquhart, 2013). While I found memoing to be very useful for considering the implications of my decisions and spotting patterns in the data, I also found memoing constrictive at times. This was particularly the case with regard to personal reflexivity. I noticed I had a tendency to curtail consideration of personal reflexivity when memoing in favour of focusing on coming back to the data. For this reason, I also kept a research journal (Ortlipp, 2008), as I found this provided a more natural space for deeper consideration of personal reflexivity. To ensure that personal and methodological reflexivity did not become too separated, I followed up entries in my research journal with a memo summarising any conclusions I had reached or ongoing dilemmas, and relating these to the current stage of the research. I found that this helped me to stay focused on considering how my position influenced how I carried out the research (Ortlipp, 2008), while also highlighting instances in which my personal ideas and preconceptions aligned with or differed from my findings. I was then more able to review the data, analysis and findings in light of my own influence and ideas, to check that my findings remained grounded in the data as far as possible.

As I have noted throughout this chapter, grounded theory offered a number of benefits to my research, including emphasising the importance of rich data, prioritising staying grounded in the data to prioritise participants' views, and the ability to develop an explanatory model (Glaser & Strauss, 2017). I have previously outlined a number of other approaches which could have been taken, and how decisions were made regarding aspects of the study design such as data collection, and reflexivity regarding the analytic process is considered in the Discussion chapter. This reflexivity section will therefore focus on personal and ontological reflexivity.

2.9.1 Personal Reflexivity

I am conscious that the reason I became interested in this topic also had the potential to influence how the research was conducted and the resulting findings (Willig, 2013). It seemed particularly important to be aware of this given the focus in grounded theory on remaining close to the data. It was crucial to identify the impact of my own position and beliefs to help in recognising their influence and attempting to put them to one side so that the experiences of my participants, as reflected in my data, could be prioritised. This helped me to remain as objective as possible, in line with Glaser's (2005) stance, while also recognising that my interpretations would inevitably be coloured by my own ideas and experiences. This was felt to be in keeping with the critical realist position underpinning this study.

I was drawn to this topic as a result of both personal and professional experiences. From a personal perspective, having been a carer myself (albeit not for someone with dementia), I was aware of the stresses that can result from such a situation. My own perception has been that little support is truly offered to carers, with the focus remaining on the person being cared for. In developing this study, I thought a lot about how I would answer the question(s) I posed, and also about how my participants' experiences may be different from mine.

Reflecting on this helped me to consider how it may be impacting some aspects of the study. For example, such reflections prompted me to consider whether questions on my interview schedule might lead participants towards considering the aspects that I, myself, would consider, or were they phrased openly enough to allow participants to bring whatever was important to them? As part of my memoing throughout the study, I reflected on how I had followed up on participants' responses during interviews, to help in refining my sensitivity to picking up on what participants seemed to find important and follow this during the interview, whether or not it seemed to fit with my own ideas. An example of such a memo can be viewed in Appendix N. This helped me to realise the importance of remaining open to following up on ideas which were similar to my own, and those which were not. In my efforts to avoid simply replicating my own views, there was a risk (in early interviews) that I moved on too swiftly when participants echoed thoughts I had also had. Memoing therefore helped me to realise the importance of sitting with and following up on participants' responses as much as possible without reference to my own pre-existing ideas, as well as reflect on and continue to develop my ability to achieve this.

My personal experiences of caring were also relevant to the concept of theoretical sensitivity. On one hand, they may be seen as a challenge to Glaser's (2005) perspective that it is important to minimise the impact of pre-existing knowledge on the emerging theory. At the same time, my experience had left me with lots of questions. For example, I wondered if the level of care needed by the person with dementia might influence how carers perceived therapy, and what might lead a carer for someone with dementia to decide to access therapy or not. This curiosity and questioning stance helped bridge the gap between descriptive codes and the more abstract ideas required to develop a theory (Glaser, 2013), when balanced with a constant comparison of categories and the focus on staying grounded in the data. I found memos helpful here, in providing a space to consider and clarify the extent to which my ideas were grounded in the data from my participants; an example is provided in Appendix O for transparency.

My professional experience is relevant to the study in different ways. My interest in the research question was fuelled not just by my personal experiences but also by experiences in my professional life. For example, when developing a CBT-based stress management group for carers, I frequently encountered other professionals (such as nurses and support workers, but not only professionals from those groups) who responded enthusiastically that carers were very stressed and needed CBT. Of course, this was not the only response, but it left me wondering what the carers thought. Did they agree that they needed CBT? I was reminded of these responses when I received similar responses to this study – responses indicating that carers need therapy because of the stresses and demands of caring. Again I wondered, what do carers think about this? Indeed, I was surprised during my review of the literature that this question did not seem to have been asked in previously published research.

In addition to contributing to my interest in the research question, these responses also contributed to my ontological and epistemological stance. As a trainee counselling psychologist, I had become familiar with a range of diverse experiences clients who were carers had reported. I could not deny that I had worked with clients who were carers and reported that therapy had been very helpful to them, but I had also worked with clients who had not found therapy so helpful. To hear other professionals assume all carers needed therapy sat uncomfortably (perhaps especially because I would have disagreed with them for much of my time as a carer). Where was the voice of the carer in this? What would the response be to a carer saying they did not think therapy was the thing that would be most helpful? I thought of clients who had made little progress until the care plan of the person they cared for was changed, or they were able to arrange respite care. I have wondered whether the perspective that carers need therapy shifts the focus from a systemic difficulty – how, as a society, support is provided to those who need care and those who support them – to an individual one. It therefore seemed crucial that the experiences of carers participating in the study were taken as reflecting an external reality, and to take their perceptions of therapy and decisions whether or not to access therapy as individual ways of responding to and experiencing caring. As such, a critical realist stance seemed warranted. This was also felt to be in keeping with values such as social justice within the field of counselling psychology (Cutts, 2013; Kennedy & Arthur, 2014).

2.9.2 Reflexivity: Epistemology and Ontology

While I have focused above on how personal reflexivity helped illuminate some of my reasons for choosing a critical realist approach, I am also conscious that selecting this approach impacted the method chosen for the study, how I approached completing the interviews and analysis, and how the findings are presented. I have noted previously some of the ways taking a critical realist lens influenced my decision to use grounded theory and my decision to take a predominantly Glaserian approach while drawing on influences from

Charmaz, in particular. However, in completing the study and through the use of both memos and a research journal, other implications were also apparent.

At the outset of the study, I had been concerned about whether underpinning my study with a critical realist position would create additional challenges, given that none of the three main approaches to grounded theory were underpinned by critical realism. Although this required me to consider which elements to draw from which approach and my reasons for doing so, I found that critical realism felt a natural fit with grounded theory. In particular, I felt that the critical realist focus on remaining aware that there may be other, deeper relationships between entities than was immediately apparent (Vincent & O'Mahoney, 2018) supported the emphasis in grounded theory on holding ideas loosely and continuing to ask questions of the data (Glaser & Strauss, 2017). I therefore found that my critical realist stance and my grounded theory method supported each other.

I also considered how my critical realist stance might impact the outcomes of the study. Since critical realism is often used in studies aiming to move beyond description to explanation (Clark, 2008), it was sometimes difficult to disentangle the influences of my choice of method from the influences of my philosophical position. From a critical realist perspective, it is necessary to have a deep and rich explanation for patterns before actions can be taken to address such patterns (Clark, 2008). This nuance positions the explanation as providing options for intervention. Since I aimed for the findings to influence how therapy is promoted to carers, this aspect of critical realism was important, and again fit well with the aims of grounded theory.

2.10 Summary

Grounded theory was selected to address the research question "How do carers of people with dementia perceive psychological therapy when they have not had such therapy themselves?" Glaserian grounded theory was taken as the main approach underpinning the study, but aspects of Charmaz’s (2006) approach (particularly the development of an interview schedule and regarding reflexivity) were also incorporated to reflect the critical realist theoretical lens. It was considered that this methodological approach would best support an exploration of this question, given that no literature was identified which has considered it previously. It was felt that aiming to develop a theory from which ideas and hypotheses could be developed would increase the practical utility of the findings for counselling psychologists by making it clearer how the findings may relate to individual client formulations or to how therapy is promoted to carers. Six semi-structured interviews were conducted and analysed using line-by-line open, selective and theoretical coding. Constant comparison, use of memos and theoretical sampling were important throughout the analysis and data collection, which took place concurrently. A theory was developed based on the findings, which will be presented in the following chapters.

Chapter 3: Analysis

3.1 Overview

This chapter will outline the key findings from the research. First, the main categories emerging from the research will be outlined. The core category will then be discussed in relation to other categories.

For transparency, a coded transcript excerpt can be found in Appendix P. Memos will be used to illustrate my thought process during the analysis, and excerpts from participant interviews will be used throughout to illustrate the codes which formed the basis for the emerging categories. The role of reflexivity will also be considered, in line with the critical realist theoretical position underpinning this study.

3.2 Identifying the Important Categories

Throughout the analysis process, constant comparative analysis was used to compare codes and categories both within and between individual interviews. This aimed to ensure that all categories were developed as fully as possible. Categories were considered well saturated when a number of different properties of that category had emerged as a result of this constant comparison (Glaser & Strauss, 2017). The categories reported here are those which were considered to be both most well-saturated following analysis and most relevant to answering the research question. The core category was identified as that which was considered to have the greatest explanatory power within the model (Glaser & Strauss, 2017). A summary table of the presented categories and subcategories is provided in Appendix Q.

3.3 Overview of Findings

The following categories were identified as well-saturated and meaningful in explaining how carers' perceive therapy and how this influences their decisions about accessing therapy:

- Visibility of Therapy
- Understanding of Therapy
- Self-perceived Coping
- Threat Level of Therapy
- Battling for Access

The core category was identified as “Becoming Aware of Therapy.” This was considered to relate to each of the above categories, such that participants who had already gained greater awareness and understanding of what therapy is, what it might involve and how to access it also tended to have made more definitive decisions about whether or not they wished to have therapy. Conversely, participants who had decided they definitely did not want therapy also tended to be uninterested in becoming more aware of therapy. The relationship between “Becoming Aware of Therapy” and each of the other categories will be explored further after each of the other categories has been outlined.

While each category will be outlined in turn and considered with reference to the subcategories and codes arising from the analysis, it is important to remember that each category is presented as part of a process by which carers decide whether or not to access therapy. As such, relationships between categories will be considered throughout and drawn together in the presented model.

3.4 Visibility of Therapy

There was a general consensus among participants that therapy was not easily visible, and that they had not been aware of therapy as an option for carers. A number of subcategories were identified which relate to this. These will be explored in turn and elaborated upon with reference to examples from participant interviews.

This category is broken down into the following subcategories:

- Therapy for carers as invisible
- Therapy as not discussed much
- Therapy as hard to picture
- Absent therapy as a gap in support
- Awareness is a prerequisite for access

3.4.1 Therapy for carers as Invisible

Participants reported a general lack of awareness or visibility regarding therapy, with an assumption that it doesn't exist as an option for them. For example:

> "*I didn't know that, that therapy for dementia carers existed"* and "*All the information I've had, that people have sent or I've asked for, the nothing, there's never been anything about therapy for dementia carers, I've never seen it, I've looked through for ages* ". – Barbara, lines 391 and 420-422.
>
> "*I'd never heard of any therapy available for carers before this project, no. And I think it would be very relevant*." – Katherine, lines 156-157
>
> *"I guess if it's not occurred to me [that therapy might be available], it's probably not occurred to your average layperson. Um. It's obviously not* ***out there***." – Gina, lines 292-293, Gina's emphasis

This indicates that carers in this study were not aware of therapy as an option for them and did not feel that therapy was visible in the information and support options provided to them. While this may reflect their focus on therapy targeted specifically at carers of people with dementia, when Barbara was asked if she was aware of therapy more generally, and not with a specific focus for carers, she responded, "*No.*" (line 146). Notably, even Gina and Katherine, who have worked in the healthcare sector, did not report being aware of therapy as an option for them. This suggests that there is a lack of visibility of therapy, and as such this option becomes seemingly invisible to carers.

3.4.2 Therapy as Not Discussed Much

Another form of invisibility seemed to come from a general lack of discussion about therapy. For example, William and Ruth both said that they had not heard any anecdotes about therapy:

> "*Researcher: So have you heard any anecdotes about therapy or heard about any ideas or experiences of therapy?*
> *Ruth: No."*-Ruth, lines 508-511.

> and

> "*Researcher: Have you ever heard anything about therapy or any kind of stories or anecdotes about it?*
> *William: No… No, I don't think so."* -William, lines 240-243.

This suggests that, for at least some carers, therapy may be something that is not much talked about. Furthermore, responses from other participants suggest that when therapy *is* talked about, this is in a limited way. For example, Gina said, *"We're going back a, a good number of years"* (lines 537-538) to identify anyone having spoken with her about their experience of therapy, while Mary noted that *"A lot of them used to go for therapy but equally they didn't talk too, too [sic] much about it"* (lines 286-297). This may reflect the private nature of what is discussed in therapy, as indicated by Katherine:

> "*She, she hasn't talked about it, but she's just said she found it very helpful. She is quite private about her, erm, which is talked about. So none of them have been into any great detail, erm, about what was said or talked about*." – Katherine, lines 589-592

Taken together, these excerpts may indicate that therapy is invisible, or only visible in a limited way, in the conversations that carers have. This may make it more challenging for carers to become aware of therapy as an option for them, particularly in conjunction with the apparent invisibility of therapy in service literature, as noted above. It would have been interesting to have also explored whether carers themselves have ever initiated conversations about therapy, or whether the limited conversations about therapy were initiated by others. Understanding this may have helped to clarify whether the lack of discussion is a result of stigma regarding therapy or may be more tied to the relative invisibility of therapy as an option.

3.4.3 Therapy as Hard to Picture

Another example of the apparent invisibility of therapy to carers is evident in the way participants struggled to describe or imagine therapy when first asked. Katherine and William both explicitly stated their struggle with this:

> *"… To find a way to… What's the next bit… To help them… [Long pause] I'm struggling here aren't I…*" – Katherine, trying to put into words her ideas about what therapy is, lines 505-507.
>
> "*Oh gosh… [Long pause] I don't know, erm… I mean, the first vision that comes to mind is laying on a couch with a psychiatrist you know, erm… And, erm… That wouldn't worry me I think. Erm… I erm, I, I can't think of any other images really, to be honest*." – William, lines 163-166

Although these struggles represent Katherine's and William's first attempts to put words to their ideas about therapy, they suggest that therapy may be invisible, not just in terms of information from others, but also in terms of being able to form an internal sense of therapy. All participants were able to identify some ideas or images that they had of therapy, which will be discussed in more detail later. However, it is notable that at least some participants seemed to have a limited impression of therapy until they were prompted to consider their ideas. This suggests that external prompting or visibility of therapy may be necessary for carers to consider their own ideas about therapy, as well as to bridge the gap in carers' understanding of therapy.

3.4.4 Absent Therapy as a Gap in Support

The apparent invisibility of therapy was so complete as to be experienced by carers as a gap in the support available to them, at least amongst those carers who identified therapy as potentially of use to them, such as Katherine, Gina and Ruth. For example:

> "*There is a gap there. Maybe it [therapy] should... be on offer. Um. But as far as I'm aware it's not, certainly not routinely..*" – Gina, lines 294-295

> "*You just need to be able to express what it is that you're feeling, because there aren't any easy answers, I mean there's different sorts of support that carers need, they need obviously the practical support, erm, but you also need the emotional support. I think probably that's what's lacking*." – Katherine, lines 187-191

> "*I mean that would be absolutely. So that [therapy], that's around is it?"* and *"I would think it [my experience] probably confirms that it's [therapy's] the sort of thing that's needed for carers. Absolutely*." – Ruth, lines 801-802 and 811-812

This suggests that Gina, Katherine and Ruth viewed therapy as an absent support option; one they just did not know might be available but that they experienced as a gap in their support. Although Mary and William did not make any reference to there being a gap in support/ provision of therapy, they also both indicated that they did not think therapy was something they needed:

> "*I don't need it. I don't need therapy*." – Mary, line 111
>
> And
>
> "*But I hadn't bothered to look into it because, I didn't think I needed it*". – William, 124-125.

This suggests that carers who see therapy as relevant to their needs, either now or in the future, also identify a lack of visible information about and access to therapy as problematic. It is perhaps unsurprising that carers who feel they might benefit from therapy highlight a lack of visible therapy provision as a gap in services, while those who do not feel a need for therapy may not perceive a gap.

3.4.5 Awareness as a Pre-Requisite for Access

Among participants who felt that therapy might be relevant to them, either now or in the future, there was a sense that they had not previously considered therapy simply because it had not been visible as an option for them. For example:

> "*It just has not occurred to me that therapy would… be available to help. It's as simple as that [laughs]" and "Erm. I think it, it is something that I think I would consider, p'raps not at the moment, but it may be something that, might be needed, further, further down the line. Depending on how long mum goes on with this and, it it is only gonna get worse, um… So it, knowing it-it's potentially available, I think yes, I think I probably would. Erm. Utilise it*." – Gina, 404-405 and 410-415

> *"If there was more… Knowledge, if people have more knowledge about it [therapy], that it's there, and then you would keep that number, or I would keep that number for, if I did, I knew there was someone there that I could talk to about it*." – Barbara, 191-192 and 424-428

This suggests that Gina and Barbara felt that they had needed to be made aware of therapy as an option so that they could consider it for themselves. Although Katherine had done some research into therapy herself prior to her participation, she also advocated for the importance of information and being aware of therapy in order to access it:

> "*I mean I certainly think the GP should be able, should have that information, maybe they do, erm, but I, at that point, it would have been nice if they could have then said, well look, here's what you can get, this is what is available locally to you*." – Katherine, lines 436-439.

Katherine therefore seems to have felt that her GP could have helped increase her awareness of therapy or made therapy a visible option. This suggests the need to increase awareness of therapy as an option not just amongst carers, but also amongst the professionals to whom carers may turn for support.

In addition to carers expressing that they had not been aware of therapy in order to consider whether it would be useful to them, Gina described her concerns that not having told her siblings about support options had prevented them from accessing the support they might need:

> "*B-But I don't know if I'm… preventing the others getting support, because I've not shared my thoughts with them. Um, I, I'm, this is kind of occurring to me now so it's, it's kind of happening in real-time because somebody's actually asking me about it, erm. So I, I'm now questioning myself as to whether I'm preventing them getting support that they might need*." – Gina, 324-329

This highlights that carers cannot make decisions about whether or not to access services that they do not know exist. Being aware of those services can therefore be seen as a pre-requisite for them to access or consider accessing them.

On reflection, I am surprised by how shocked I was at first when carers told me that they were not aware of therapy. I considered that this may be down to how my project was framed – perhaps carers meant they were not aware of therapy specifically for carers of people with dementia – and it would have been useful to clarify this earlier in the project. However, when I did clarify this, the response remained that therapy was not visible. Additionally, Katherine described her GP as prescribing antidepressants but not discussing therapy, suggesting that lack of information about therapy is important more generally.

I was also conscious in coding for "awareness as a pre-requisite for access" that, although I had been surprised by how little awareness carers had of therapy, I was very unsurprised by the implication that such awareness is necessary for carers to consider having therapy. As such, I was careful to check this was actually borne out in the data through revisiting the instances I had coded in this way and comparing them with other instances. It would have been useful to also have asked William and Mary whether becoming aware of therapy through this project had influenced how much they considered it; their confidence that they would not need it may have meant they did not give it much consideration despite increased awareness.

3.5 Understanding of Therapy

The carers who took part in the study described varying levels of knowledge about therapy, with Gina and Katherine indicating that they had some knowledge from their work in healthcare and Ruth indicating that she had learned some information from a relative who works in the field. William, Barbara and Mary described themselves as having little to no confident knowledge of therapy.

In exploring participants’ understanding of therapy, the following subcategories emerged:

- Therapy as Talking
- Potential Therapy Aims
- Problems People Take to Therapy
- Therapy as a Last Resort

Self-perceived level of knowledge about therapy was also considered as a possible subcategory. However, it was concluded that comparing responses from those who consider themselves as more knowledgeable with those who consider themselves less knowledgeable would provide the opportunity to elaborate on the properties of the above subcategories. This is in keeping with the constant comparative method outlined by Glaser and Strauss (2017). A memo documenting my thought process in reaching this decision can be found in Appendix R.

3.5.1 Therapy as Talking

All participants identified that therapy involves talking, although the purpose and nature of talking were perceived differently by those with more self-perceived knowledge of therapy.

William and Mary indicated that talking is part of therapy, and did not comment on the purpose or nature of talking in therapy, beyond an expectation that it would be led by the therapist:

> "*Just discuss things. That discussion obviously being led by the therapist, erm… That's how I imagine it would work…*" - William, 284-286

> "*Well, I'd assume somebody talking to me, sitting down talking to me and… should I need help, helping me! [laughs]"* – Mary, 81-81.

Mary and William both indicated that they see themselves as knowing relatively little about therapy, and also indicated that they do not feel therapy is something they need. It is therefore difficult to draw conclusions regarding whether participants who felt less knowledgeable about therapy were also less aware of how talking in therapy might be helpful. Indeed, this could be seen as two different ways of saying the same thing. However, Barbara identified that therapy may be helpful to her and also as feeling that she knew relatively little about therapy. She elaborated a little more than Mary and William on a possible purpose for talking in therapy:

> *"I think, if you, if I, me, personally, if I go to therapy, erm… I think maybe, it would, take [away] a burden if I was talking to someone about it*." – Barbara, 249-251

This suggests that Barbara considers one purpose for talking in therapy is to unburden oneself or offload. This perception was shared by Gina, Katherine and Ruth:

> "*Kind of opportunity to, to offload stuff, talk through stuff, process stuff*" – Gina, 523-524

> "*So you're allowed to dump [laughs]. It gives you the luxury of being able to dump your own thoughts on somebody who is there, trained to help you with those thoughts*." – Katherine, 544-547

> "*I think for somebody like me… it would be very useful because I do just go. And 'specially at the moment [mimes words spilling out of mouth]*" – Ruth, 819-821

This suggests that talking to offload may be a perception that is shared between those who feel more and less well-informed about therapy. It also raises the possibility that a perception of therapy as talking may be widely shared amongst carers, but that a perception of talking in therapy having a particular purpose may be more commonly held by carers who see therapy as potentially relevant to them. This must be a tentative conclusion given the small sample, and of course, does not indicate a causal direction for such a relationship.

Carers who both felt that therapy was relevant to them and who felt more knowledgeable about therapy also identified additional purposes for talking in therapy:

> "*so I do miss that so, to come back round to the, the therapy, talking that through might actually help*." – Gina, 493-494 (in addition to seeing therapy as an opportunity to "process stuff" (line, 524), as mentioned above).

> "*This one person I was recommended, and I can't remember the type of therapy it was called, but part of it, what she does is, is look back on how, you know, things that might have happened to you in the past and then how, how this affects the way you,*

> *you know, you behave in different situations now, I think that's, well that might be quite helpful*." – Katherine, 313-318
>
> "*I want to know why you know, that handkerchief business, why it's that and not that, you know, and things like that*." – Ruth, 707-708

Gina, Katherine and Ruth's responses seem to suggest an understanding of talking in therapy as being about processing, working through or making sense of things, in addition to offloading. Given that Gina, Ruth and Katherine all identified as having a reasonable amount of knowledge about therapy in general, and also all indicated that therapy may be helpful for them, it is difficult to draw clear conclusions about whether increased understanding of the nature and potential purposes of talking in therapy relates to an increased sense of therapy as potentially useful. It is of course also possible that increased understanding may help some carers clarify that therapy does not seem useful to them, and this would benefit from clarification and further study in future research.

In summary, while therapy as talking was a commonly held perception of therapy, carers who felt more knowledgeable about therapy and that therapy is more relevant to them tended to have a more nuanced understanding of the role of talking in therapy.

3.5.2 Potential Therapy Aims

Participants identified therapy as something people tend to do with a particular aim in mind. They identified a range of potential aims people might have in undertaking therapy. Aims around coping day-to-day were the most commonly identified:

> "*Every time I have something very stressful, I really need some strategies, how to, to deal with it. An ongoing stress, because it's always something going on and if I'm busy, I just need to find a way of calming my anxiety*."- Katherine, 655-658

> *“[I’d hope it would give me] Peace of mind. Settle me down so I can carry on again tomorrow*.” – Mary, 183.

> “*And I suppose, erm. Methods to…. Stop me in my tracks before I flip. Mainly. I think is what I need*.” – Ruth, 523-524

This suggests that carers of people with dementia can find this role challenging to cope with and feel they need support with this. Furthermore, therapy seems to be seen as a way to gain coping strategies or feel more able to continue to manage. Mary, who did not see herself as knowing much about therapy, also shared this perception. This suggests that it may be a more widely held perception, and not limited to those who know more about therapy.

Day-to-day coping was an aim identified by several participants, but by no means the only aim identified. In addition to learning current coping skills, Katherine also identified longer-term resilience and learning from her past as an aim:

> “*I think I’d just need to use that, use some of the things that happened and the way I’ve dealt with life, I want to learn from that and see how I can, erm, be a little bit more resilient, erm, life is full of stresses and always will be and things will happen*.” – Katherine, 401-404

This suggests that some carers perceive therapy as helpful for longer-term change, rather than focusing solely on current coping. It is unclear from this study what factors might influence such perceptions, and this is an area which could benefit from further research.

While most carers identified direct aims of therapy, William took a slightly different perspective from other participants:

> “*I, it would be nice if, er, such therapy did give me information… That would help me go and do something, more, get some treatment or something*.” – William, 371-373.

William’s response seems to suggest that he sees therapy as providing information and signposting for further treatment, rather than (to use medical terminology) treatment in its own right. Some CBT-based approaches might be in keeping with this to a certain extent, in terms of providing psychoeducation and using active tools to generate change (Beck, 2011). It is possible that William might find such an approach in keeping with his perceptions of therapy. However, William is also one of the participants who felt less knowledgeable about therapy, and this may be reflected in his perceptions of the aims of therapy. This reinforces the importance of visible, accurate information about therapy being available to carers. Understanding that therapy can provide direct benefits and is not typically primarily focused on providing information and signposting might alter or reinforce William’s perception of therapy as not useful to him.

3.5.3 Problems People Take to Therapy

Participants indicated that they perceive therapy as for support with chronic, severe or diagnosable distress:

> “*I have a lot of friends who are stuck, over and over and over and over, the same issues, and so I hope, I hope that counselling would get you over that…*” – Katherine, 548-551

> “*With therapy, I always think it’s for someone who is depressed rather than… You always think of, you’re depressed*.” – Barbara, 188-189

> “*I imagine that one would only think about it when, if I did start to get depressed*.” – William, 199-200

Mary also described clients she had worked with who she believed had been hospitalised to have therapy: “*Some of them were really bad. And that and they would disappear for a few weeks they wouldn’t be coming*.” (Lines 300-302)

This suggests that carers view therapy as something that people only seek or have when they are feeling extremely distressed, such as when a problem has been long-standing or has reached clinically diagnosable severity. This may prevent carers from accessing support when they experience lower levels of distress or are beginning to struggle. Furthermore, Katherine and Barbara indicated that they would not have considered therapy to discuss difficulties coping with caring:

> "*I wouldn't think of going to counselling in my normal day-to-day, caring for my father and all of the stuff that I'm doing… To me that's just… Stuff that has to be done, and I have to get on with it*." – Katherine, 687-690

> "*Because it is, it's part of your life isn't it, so putting it that way I've never thought therapy for carers*." – Barbara, 192-194

This suggests that carers view therapy as not suited to addressing stresses arising from daily life. As such, concerns that struggling with caring is not a valid reason for having therapy may play a role in whether carers do seek such support. This perhaps makes it doubly important that information about caring is available to carers, ideally targeted to address this concern. It may not be sufficient for therapy to be visible; it also needs to be visible specifically as an option for carers who may not consider themselves to be severely distressed.

3.5.4 Therapy as Last Resort

In addition to being seen as only for those experiencing severe distress, some participants also seemed to view therapy as a last resort, to access at a crisis point or when other support options were no longer possible.

For example, Barbara described considering therapy as potentially useful if family aren't available:

> "*Maybe there is a time where you can't meet up and discuss it, and that's the time when you think, well, I can make an appointment and that person's there when somebody else isn't because obviously it's, family's not there all the time*." – Barbara, 253-256.

This suggests that Barbara did not see therapy as something she would pursue unless family support was unavailable or had failed. This suggests that therapy was seen as a secondary or back-up option, and not the first choice for support.

Similarly, Katherine described seeking therapy because she could no longer take antidepressants, which had helped her in the past:

> "*So I was on antidepressants then which were great, they, they made me feel brilliant, erm, but I suffer from a longer-term condition called restless leg syndrome which is, quite severely, which affects my sleep and erm, antidepressants such as fluoxetine… Absolutely can't be taken with it and make it worse. So I knew, which is a good thing, that it, for me, … It stopped me taking them this time, but however I still felt absolutely awful, very, very anxious, erm, and low. And so, you know it was. And then this friend, who I've worked with, really good friend at work, just said all have you thought about, she-and she's actually lovely, she's phoned me, every week and she said will have you thought about, you know, have you made any more contact with anybody? And… So she's generally pushing me. Erm. So it was this time, it was because, yeah, I just thought, erm… I really have got to find a way through*." – Katherine, 639-654

This suggests that not being able to take antidepressants and needing to find an alternative way to address her anxiety and low mood prompted Katherine to consider therapy, where she might otherwise have taken antidepressants again. As such, this is another example of therapy being considered only when preferred options were not suitable or available.

Other participants described therapy as a last resort in an attempt to cope with crisis (which may or may not be when other support options are unavailable):

> "*Yes I think people should talk to people if they're desperate*." – Mary, 154

> "*No, if I had to go. Mind you I dread… Getting to a stage where I need that getting so depressed…erm… I hope I can avoid that*." – William, 173-176

> "*If it's affecting your, well it does affect my life actually. erm… Maybe there's a point where you get, like dark thoughts about ending it, something maybe. Like when you're at crisis*." – Barbara, 201-204 [Ethics note: Barbara stated that she herself was not in crisis or having thoughts of suicide, and that she would contact her GP if she did experience such thoughts in future.]

This suggests that therapy is seen as something one only does if one has to because they are desperate or in crisis, or because their preferred support is not available. Of course, if other support is helpful and reduces the challenge for which therapy may be helpful, then the perception of therapy as a last resort to try after other options may be less problematic. However, as Gina outlines, the perception of therapy as a last resort can also mean that people are struggling much more when they do come to access therapy:

> "*Y'know maybe it, it would be better at a lower level, rather than having to go through all the, the different stages 'cause usually when you get to this level you, you're pretty messed up aren't you, y'know, and if you tip the balance that. Help people sooner to, to kind of deal with it, that would really make a difference*." – Gina, 878-882

This suggests that the perception of therapy as a last resort may mean carers delay accessing therapy, and may experience greater distress as a result of this delay. As such, even when other support options are available, it may be important for carers to be made aware that they do not need to be in crisis or have exhausted other options to access therapy. One implication of trying other options first before accessing therapy is also that therapy cannot be used alongside other options. It may therefore also be beneficial to explicitly indicate to carers that therapy can be additional support to that provided in other ways (such as support from friends or medication from GPs).

3.6 Self-Perceived Coping

Carers described different perceptions of their own current coping, including a range of coping styles. Their perceptions of the relevance of therapy to them seemed to be linked to how well they felt they were coping.

The following subcategories were identified relating to self-perceived coping:

- Coping Styles
- I'm Coping
- Managing at the Moment
- Maybe Later

3.6.1 Coping Styles

Participants described a range of coping styles, including coping through suppressing and coping through connection. Some coping styles were more common amongst participants who were uncomfortable with the idea of therapy or did not see therapy as relevant to them.

William and Gina both described coping through connection with others:

> "*Yes [it helps], talking to other people, and of course they have people at those places [dementia cafes], as you will know, erm… Who can provide us with*

> *information and so on. Yes. That's very helpful, particularly the, the talking to other people*." – William, 47-50

> "*But I, I suppose when I talk about that level of care I think of y'know sort of low grade, what we're doing now, supporting each other erm. And we do laugh about it and I know that, it prob'ly seems cruel but some of the comments on the WhatsApp group have, erm, have like, been really funny but you'd, you'd only think they were funny if you were part of the group*." – Gina, 603-608

This suggests that social support and connection can be a helpful coping strategy for carers. For William, the support he got from family, friends and other opportunities for social support seemed sufficient; he described himself as coping and did not feel therapy was relevant to him "*because I didn't think I needed it*" (line 125). Gina, on the other hand, was not sure if she felt therapy would be helpful now but did think it might be useful in the future. Unlike William, Gina also described using a second coping style, coping through suppressing:

> "*Mum's got this diagnosis erm, some days...let's, it's just a word, let's treat it as a word, let's, forget, forget all the connotations around it*." – Gina, 580-582

This suggests that Gina did not find the social support available to her sufficient and additionally made use of a second approach to cope; trying not to think about the implications of her mother's diagnosis. Barbara, Katherine and Mary also described coping in this way:

> "*If it's back in your mind, then you try and keep it there*." – Barbara, 174-175

> "*Everything else, I'm just so busy and just put pushing everything down*." – Katherine, 694-695

> "*I'd get over it or, that's it, or I'll just ignore it, it'll go away [laughs]*." – Mary, 285-287

This suggests that suppression may be quite a common coping style for carers. The extent to which this varied alongside carers' perceptions of the relevance of therapy to them was considered. Like Gina, Barbara was unsure if therapy was currently relevant to her but felt it might be in the future. Mary did not consider therapy as relevant to her. And although Katherine was seeking therapy, she expressed some anxiety about doing so (which will be explored further in the following category, threat level of therapy). However, this does not explain why Mary does not feel therapy is relevant to her while Gina and Barbara feel therapy may be relevant to them, despite using the same coping style. This will be considered further with regard to the extent to which carers seemed to feel they were coping while using suppression as a strategy.

3.6.2 I'm Coping

Perhaps the key difference between Mary, Gina and Barbara is that Mary seems to find suppression an effective coping style: as she put it, "*And in fairness I cope with my husband… very well"* (line 265). Mary seems to link this with a perception of herself as resilient:

> "*The life we've led with the hairdressing, coping. I've coped with, working in beauty and personal care, very young and very old since I was 19 and I'll be 81 next week. So. [laughs]."* – Mary, 111-113
>
> And
>
> "*When it does [get worse] I'll cope with that part when I get to it*." – Mary, 138-139

This suggests that a perception of herself as coping and resilient may be helping Mary to feel more able to manage the struggles of being a carer, both now and in the future. While William did not explicitly describe himself as resilient, he described having grown up in a very working-class environment and having worked hard to own his own home. It therefore seems possible that he, like Mary, sees himself as resilient. It would have been useful to have explored this further during William’s interview. Unfortunately, as Mary was interviewed after William, “I’m Coping” had not yet been identified as a code.

3.6.3 Managing at the Moment

While Mary expressed confidence in her continued ability to cope, Ruth and Gina were less sure:

> “*We’re at the very early stages of this and we’re managing things at the moment even though we have our frustrations”* but, *“I think about dementia and I think about what we’ve got to come, erm if she, if she y’know lives that long. Erm. It is only gonna get worse and I suppose that does, it does scare me. For her. Er, it scares me for all of us.”* - Gina, 330-332 and 584-588
>
> “*It’s… working but, not very efficiently I have to say.”* – Ruth, 151

This suggests that Ruth and Gina felt they were managing at the moment, but were not sure this will stay the same in the future. This is in contrast with Mary’s confidence that she would continue to cope, and Katherine’s having sought therapy due to anxiety and depression. Each of these carers described using suppression as a coping style, but while Mary seemed to find this effective, Ruth, Gina and Katherine seemed to find it less so. It therefore seems plausible that carers’ perceptions of whether they are currently coping (including whether their current support options and coping styles are effective) and whether they will continue to cope in the future may influence the extent to which they perceive therapy as potentially useful to them. It is possible that perceiving therapy as a last resort also prevented those carers who felt they were managing for now from feeling able to access therapy at this point, when they predicted a need for future support but did not yet feel in crisis.

3.6.4 Maybe Later

Perhaps connected with a sense of managing at the moment and viewing therapy as a last resort, some participants also described feeling that they may need therapy later:

> "*It is something that I think I would consider, p'raps not at the moment but it may be something that, might be needed, further, further down the line*." – Gina, 410-412

> "*Maybe, later on the line I think maybe I do need therapy*." – Barbara, 156-157

However, while Gina described managing at the moment, Barbara did not feel she was coping (although she had also stated that she did not feel at crisis point):

> "*Well I'm not coping really, I said I find it very hard and I got emotional talking about it*."– Barbara, 30-31.

Given that Barbara sees herself as not coping currently while Gina sees herself as coping for now, current self-perceptions of coping do not seem to explain their shared perception of therapy as something they may find useful later. However, one other similarity Gina and Barbara share is that they both cope through suppression. It is therefore possible that there may be a link between this coping style and placing therapy as something for 'maybe later.' Positioning therapy as an option for the future may be a way of suppressing any emotions attached to considering therapy or of continuing to put off experiencing the feelings carers were trying to suppress. This cannot be confirmed in such a small study and as such can only be a tentative suggestion, offered as part of a broader category regarding self-perceived coping.

3.7 Threat Level of Therapy

Participants described a number of factors which seemed to influence the extent to which therapy was perceived as threatening. These factors seemed to also be linked to carers' understanding of therapy and their self-perceived coping.

The following subcategories were identified as part of this category:

- Therapy as Risky
- Safety Features of Therapy
- Validation and Feeling Heard

3.7.1 Therapy as Risky

Participants described a number of ways in which therapy was quite intimidating. William, in response to being asked if he had any concerns about what therapy might be like, described his concern about what the therapist might be like:

> *“[I would hope they wouldn’t be], I don’t mean quite aggressive but… Sort of overbearing or… Something, erm… That wouldn’t happen, because I, I wouldn’t want that, er, because I would, to an extent I would succumb to it, I’m an easy-going person, I don’t, erm… I don’t fight battles [laugh]. I try, try not to. Erm, erm, with people*.” – William, 309-314

This suggests that William is concerned that there is a risk the therapist might be intimidating, that they might dominate the session and that William might not be able to challenge this. Ruth identified another way in which the relationship with the therapist might be intimidating:

> “*Sorry I’m not looking at you, it’s not because, I can, if there’s just two of us it’s hard to hold your, that’s all, or for you to hold my gaze all the time*.” – Ruth, 78-80

Although this was about her experience of the interview, it was about an aspect of the interview that would also be present in therapy. Ruth’s comment suggests that there is something about the intimacy of two people talking that can be intimidating. This adds another way in which therapy may be seen as intimidating.

Furthermore, Katherine highlighted that the nature of what might be discussed in therapy was also daunting in itself:

> "*I feel quite daunted at the fact of doing, erm, doing counselling… erm… And I think it's going to be, probably, I'm almost getting emotional saying that to you, erm, bring up a lot of feelings about my mum, losing my mum very suddenly when I was 23, so erm… And that has been real buried, right down, because I had to get on with life really, so I think I'm very, I'm quite erm… Nervous about revisiting that time. And my childhood, erm. Some, some difficult things*." – Katherine, 390-397

Taken together, these responses come from participants with varying opinions regarding how relevant therapy is to them, who use different coping styles and have varying levels of knowledge about therapy. This suggests that the perception of therapy as intimidating may be held by many carers, independently of these factors.

In addition to the risk of feeling intimidated by therapy, participants also identified that therapy might feel quite intrusive:

> "*Whether they might… because they, they might not necessarily have the same, erm. Knowledge of the potential support or, or help it could give whether they might see it as intrusive. Erm. Challenging*." – Gina, 524-527

> "*Some, some people I know, want to keep the thing confidential to themselves and don't like other people knowing*." – William, 383-385, in response to being asked what might put him or others off accessing therapy.

This suggests that carers may be concerned about having to share information with the therapist that they might not wish to, or that they might prefer to keep private. Notably, Gina and William spoke about this in reference to how other people might feel. This might indicate that it perhaps felt too difficult to tell the researcher, as a therapist, that they were concerned therapy might feel intrusive. It could also mean that they were trying to imagine others' perspectives, to add to their own. While it would have been useful to explore further how therapy might feel intrusive and what might help mitigate this, I was also conscious of not wanting to probe too much and reinforce William and Gina's perception. Additionally, I wondered if they were perhaps experiencing the interview itself as intrusive already. As a result, I chose not to ask further questions around this, as I was concerned that if I did so and this was experienced as intrusive, this might make it harder for William or Gina to access therapy in the future (should they wish to do so).

In addition to the perception that therapy may be intrusive, participants also expressed concerns that therapy might be emotionally overwhelming:

> "*Researcher: Would you have any concerns about having therapy?*
> *Gina: Yeah I do! Sort of, being overwhelmed. Nobody likes to cry in front of strangers do they?"*– Gina, 497-499

> "*I know with the social worker, once you're talking about, you know, she was asking me questions, and it makes you emotional… And you try and hold it back… So maybe, there is things which I'm holding back which would be best… Out in the open. So quite… Mixed, ambivalent, I guess. I mean she rang me up the other day and straight away I was on guard, because she… Made me emotional."* – Barbara, 257-263

This suggests that Barbara and Gina, who both used suppression as a coping style, were concerned about opening up in therapy. Given that this would involve doing the opposite of their usual coping style, it is perhaps unsurprising that they are anxious about this:

> "*My view is, I'd rather it be… Back in my mind somewhere and not bring it out, because I think to me… To me personally that, if it comes out, then it upsets you*

> *more. If it's back in your mind, then you try and keep it there. Erm… But that's not saying it's right, maybe you should get out. But what's important for me is just carrying on, getting through the day*." – Barbara, 172-177

This suggests that Barbara was concerned not only about being upset in therapy, but also that having therapy would interfere with her ability to cope and get through each day. Gina did not mention such a concern, but it was also not explicitly asked about because it had not yet been identified as a code at the time of Gina's interview. It would have been useful to gather further information to explore the extent to which a perception of therapy as interfering with day-to-day coping might be held by carers.

Overall, carers described a range of ways in which therapy seemed to be perceived as threatening. These included concerns about feeling intimidated by the therapist, feeling daunted by the nature of the discussion and fears of being overwhelmed and less able to cope day-to-day.

3.7.2 Safety Features of Therapy

Although most participants expressed potential risks in having therapy, they also described aspects of therapy which might help therapy feel safer or help mitigate these risks. These included trust in the therapist's skill, viewing therapy as protected time and space, and confidentiality.

Several participants described trusting that the therapist would use their training, skills and experience to direct the session to be helpful and avoid harm:

> "*They're the ones, the experts and possibly they would know er. What I need." –* Ruth, 428-429

> "*I was looking for somebody fairly experienced" and "I mean it's obviously a bit more guided, erm, again, I guess that depends on the type of counsellor but erm… A little*

> *bit more guided and, and hopefully also, you know, somebody here to help you, bring you on a bit of a journey*." – Katherine, 312-313 and 535-538

> "*But, she copes with problems differently… After seeing the therapist she used to see, she [the therapist] was very good*." – Barbara, 347-349

> "*I mean, the therapist, obviously being fully trained would not be, erm, aggressive*." – William, 308-309

This suggests that carers view therapists as experts and believe that seeing a skilled, experienced therapist provides some protection against the potential risks of therapy. Katherine, who had started the process of seeking therapy, additionally indicated that this perception had influenced her search. Not only was she seeking an experienced therapist, she also considered other ways in which her choices would influence the perceived safety of therapy:

> "*I feel I want to see a female counsellor, that's important for me I think I feel, safer and more comfortable, then a male, but, that may all be complete nonsense but that's how I feel."* – Katherine, 233-235

> "*I don't think I would like to go for an evening appointment because I think it would be quite difficult to explore maybe, some difficult, erm… Some difficult feelings and situations and then come back and try and relax and go to bed*." – Katherine, 352-356

This suggests that having a choice of therapist – including gender in addition to the skills and experience noted previously – could be an important aspect of creating a sense of safety in therapy. However, factors relating to the therapist were not the only things that could influence the perceived safety of therapy, as the appointment time was also important to Katherine. Katherine seemed to feel that choosing an appointment time to suit her might increase her ability to take risks in therapy by discussing difficult experiences. Having choices regarding a range of aspects of therapy therefore seemed to help increase the perceived safety of therapy. Katherine may have had increased awareness of the potential choices involved in accessing therapy compared to other participants, as she was the only participant who had started pursuing therapy. Katherine also seems to have been aware that she may have some capacity to shape her therapy experience, in this case by choosing an experienced, female therapist and evening appointment time. Ruth also seemed to feel that she had some agency to shape her experience of therapy:

> "*And I'm quite capable of saying I don't want to go down that line if I don't want to*." – Ruth, 773-774

Katherine and Ruth both also expressed wanting to access therapy. This suggests that carers' awareness of their choices and right to express and maintain their own boundaries may be important in influencing the extent to which therapy feels sufficiently safe to access.

Participants additionally described the boundaries of therapy as contributing to a perception of safety:

> "*I s'pose that's, that space would be, kind of protected time for, things like that*." – Gina, 499-501

> "*It is about having a safe space, which I did talk to you about earlier. Which people don't normally have., And, and the time, erm in a protected environment, to just… Work things through*." – Katherine, 530-532

> "*It's someone that doesn't know you as a person, so, maybe you would, you speak to them more… Confidential stuff that you wouldn't probably… Or some people, because I know I, I speak to my family…*" – Barbara, 323-326

> "*I think there again talking to somebody that's not involved with them and it's private, it doesn't go any further, is a massive help to them*." – Mary, 360-362

This suggests that carers have some awareness of therapy in general as confidential and as a protected time/space, despite its lack of visibility as something potentially available to them. This awareness seems to be identified as helping therapy feel safe for those who need it, with even Mary (who did not feel she needed therapy) identifying confidentiality as one of the aspects which makes therapy helpful. Given that even carers who felt they had little knowledge of therapy identified such boundaries as increasing the perceived safety of therapy, it seems likely that aspects such as confidentiality and a safe space are relatively well-known. Ensuring that carers are aware of these aspects of therapy and of their own choices when accessing therapy may help increase perceptions of therapy as sufficiently safe to be worth the risk.

3.7.3 Validation and Feeling Heard

Some participants expressed feeling that their feelings or needs were dismissed, ignored or invalidated by professionals:

> "*I asked them about, help, and they gave me a number I can ring, erm… Which I did a couple of weeks ago, and… Virtually, I didn't think it was a lot of help, it was basically saying, oh you're coping, that's fine, sort of thing. So, erm, she rang me today, I said well I'm not coping really, I said I find it very hard and I got emotional talking about it. Erm, and I think their view is if you… Managing, you're coping, erm. So, she's sending me through all information, erm… She's got savings as well of 20,000, and they said, oh that's too much. Erm, you'd have to self-fund, and it's basically saying go away until… Such time as it's even worse or all your savings are gone*." – Barbara, 26-36

> "*GPs are looking at the screen. And I said to to the male doctor, the only male doctor we've got, y'know y-you're not listening. Oh yes yesyesyesyes. I said no. You're hearing. But what you're hearing is symptoms so that you can give me a tablet. I don't need a tablet. I need help*." – Ruth, 371-375

This suggests that, for Ruth and Barbara at least, they had experienced a system in which they did not feel their needs had been heard and validated, much less addressed. Instead, they seem to have felt dismissed. This may have reinforced perceptions that therapy is not available (since it was not discussed as an option) or their difficulties were not sufficient to warrant therapy.

Additionally, feeling dismissed may have contributed to carers' views of professionals, including therapists. There was some indication that participants' experiences of support from non-therapy sources influenced how they perceived therapy:

> "*I'm just thinking… Whether or not I would I would appreciate or… Dislike… Group therapy. And I… And I, er, I don't really know, it, it might be, because I, I'm linking it almost to the memory café where we all sit round, and to a certain extent…*" – William, 324-327

> "*I know with the social worker, once you're talking about, you know, she was asking me questions, and it makes you emotional… And you try and hold it back… So maybe, there is things which I'm holding back which would be best… Out in the open. So quite… Mixed, ambivalent, I guess*." – Barbara, 257-262, in response to being asked about whether her experiences with the services she has accessed have influenced how she feels about therapy.

This suggests that the wider context in which therapy takes place, and the experiences carers have had with other support, may influence their perceptions of therapy. While exploring this potential interaction in more detail is beyond the scope of this project, it is notable that there was also a strong sense in the data of carers needing to feel heard and understood:

> "*I need someone who would sympathise that it's not easy, not like, and coping is, isn't easy sort of thing, and then not having a three-hour, I think they do a three-hour sitting or something, when someone sits with her for three hours, she said, well then you'll have three hours a week, it sort of, you know… Not someone who, I don't suppose she's ever… Being a carer for someone with dementia, I think you've got, not, not, you haven't got to be someone who cares for someone with dementia, but understands like… What it's like to have to put your life on hold when you're looking after someone*." – Barbara, 281-290

> "*Because it's a bit like walking through a quagmire. And erm [crying] I find that, as I say I find the GPs… all they can do. And now you see, you're listening because you're looking at me all the time*." And "*Yes. But actually listening and, well y'know, body language. Is so important.*" – Ruth, 368-371 and 399-400

This suggests that feeling heard and understood was an important need for carers, although it was rarely identified explicitly as a potential benefit of therapy. It is possible that feeling dismissed by other professionals had contributed to carers not being confident that a therapist would facilitate a different experience. Mary expressed concern about the possibility of carers' needs being invalidated:

> "*It's not easy. I can't imagine being um. In that… unhappy place, with people telling you 'pull yourself together!' [laughs] Please don't do that*!" – Mary, 322-327

This suggests that many carers may have a need to feel heard which may not be being met by the services they are currently using and which they may not realise therapy might provide. Highlighting this as an aspect of therapy may be important in ensuring that carers have accurate information on which to base decisions about accessing therapy.

Additionally, experiencing invalidation or feeling dismissed by services may contribute to a perception of therapy as risky. It may therefore be important, when carers access therapy, to explore their experiences of support from other services and any concerns they may have about therapy as a result of these experiences.

3.8 Battle for Access

Although Katherine was the only carer in this study who had already begun attempting to access therapy when they took part, some of her concerns about accessing therapy were shared by other participants. Additionally, these concerns built upon ideas raised in the categories previously discussed. Although other factors may also be important, it was therefore considered that omitting this category would be to the detriment of the overall theory to emerge from this study.

A number of factors were highlighted as contributing to a perception that accessing therapy was a battle. These contributed to the following subcategories:

- Scarcity of Support Resources
- Navigating the System
- Lost in Jargon
- Role Juggling

3.8.1 Scarcity of Support Resources

Several participants highlighted a general lack of support available for carers:

> "*I think the government are quite happy all the time people are coping so you're not gonna get anything more as a carer*." – Barbara, 379-380

> "*And at the end of the day, I don't think there is much help out there. Erm, you know, there's lots of words, but, the only one that has absolutely come up trumps is this [local service name] centre*." – Katherine, 794-797

> "*The professional help sometimes is lacking*." – Mary, 445

> "*Well, erm… I don't get actual sup-, I've now engaged a cleaner to clean the house, erm… Once a fortnight…"* – William, 32-33

This suggests that carers did not feel there was much support available, with William in particular only identifying support he had paid for himself. Carers seemed to link this lack of support with a lack of resources from the government. Gina most clearly linked this with a scarcity of resources to support carers:

> "*And further down the line we will need support and those resources are scarce. So let others use them now and we'll use them when we need them*." – Gina, 333-335

This suggests that Gina, at least, was putting off accessing services as a result of a perception that there are a lack of resources to go around and that they must be prioritised for those most in need. This may also reinforce perceptions that resources such as therapy should only be used as a last resort.

Other carers indicated that the consequences of a lack of support resources either put them off accessing therapy or limit their ability to do so. For example, Ruth and Katherine indicated that limited appointment times were a factor:

> "*Because I haven't been able to get to any [courses of coping with caring] because I get [a sitting service] 10:30 as I say to two thirty so. By the time I've got anywhere it'll be gone 11 and they start at 10 and it'll be two hours so it finishes at twelve so it's pointless, or they start at two. And I have to be home by two thirty. So I've never been to any of these*." – Ruth, 186-190

> "*And again, time, you know, and a lot of the counsellors only work at certain times.*" – Katherine, 341-342

This suggests that one consequence of limited resources – limited appointment availability – can make accessing therapy challenging for carers. It also highlights that limited support from other avenues – such as sitting services – can compound the difficulties of limited appointment times. Therefore, scarcity of resources refers not only to therapy appointments themselves but also to other services that may be needed to enable carers to attend therapy. This poses a significant challenge in the current health and social care system in the UK and reinforces the idea that experiences with non-therapy services impact on carers' access to therapy.

Another way in which carers noted the impact of scarce resources was in relation to long waiting lists to access therapy:

> "*I was also trying to get some individual counselling but they've got unbelievably long waiting lists [laugh] for everything. Even privately. So, erm, that sort of been put on the backburner*." – Katherine, 52-53

> "*They get a triage and then they get a well we'll put you on the waiting list and then they have to wait 6 months and. Its gotta be timely, if somebody decides that they need that service it's got to be timely. And waiting 6, 12, 18 months however long is it's just not satisfactory. So… the harder it is for a person to access a service the less likely they are to push to get that help that they've identified 'cause when somebody identifies that they need help they need it there and then*." – Gina, 783-790

This suggests that carers find the long wait off-putting and a barrier to accessing therapy. It seems unlikely that this barrier is unique to carers, and although it could be argued that carers' situations and coping may worsen while they are waiting, this also applies to many people waiting for therapy. Nonetheless, long waiting times were highlighted as one way therapy can be challenging to access, even once it has been made visible as an option and carers have decided to pursue it.

3.8.2 Navigating the System

Finding out how to access therapy was another obstacle described by carers:

> "*So how would one find it [therapy]?"* – Ruth, 804

> "*And getting information, it's, it is, it's mainly, knowing where to get help*." – Katherine, 343-344

This suggests that increased visibility and awareness of therapy is not enough unless it is accompanied by clarity about how to access therapy, as the carers in this study were not sure how to do so. William was also unsure how to access therapy but indicated that he would ask his GP if he needed to:

> "*What would happen is, I'd go straight to my GP… And let her tell me, where I should go for…*" – William, 273-274

This highlights that learning how to access therapy may be reliant on carers identifying how to find this information. However, as Katherine noted, going to the GP was not a guarantee of being offered therapy:

> "*When you go to your GP for example I mean, I've had very mixed er experiences with my GP. The first time I went I was just handed a prescription for antidepressants that was, that was it. I was not impressed with them and which I haven't taken, erm. The second time… I asked about IAPT and erm… And I self-referred*." – Katherine, 429-434

This suggests that even if carers approach their GP, they may not be offered therapy unless they are aware that therapy is a potential option for them and perceive it as sufficiently relevant to their needs to ask for it. Given that most carers in this study were not aware of therapy as an option, it seems unlikely that they would have requested it from their GP. Even if carers did ask their GP about therapy, both Katherine and Barbara seemed to perceive the next step – actually being referred or contacting a therapy service – as another obstacle:

> "*I know how hard it is to be referred for counselling*." – Barbara, 343-344
>
> "*It's very, very difficult I think. Very difficult*." – Katherine, 290-291, regarding the process to obtain a referral for therapy.

This suggests that both knowing where to go to access therapy and obtaining a referral for therapy are both perceived as barriers to therapy. Carers did not seem to know how to navigate the health system in order to access therapy on the NHS. Katherine had also investigated private therapy as an alternative:

> "*A friend recommended someone locally, who I then contacted, and she had a waiting list [laugh] and you look at the just lists and lists of therapists. How do you even begin to know, you know, what to do or who to go to, to go with, so in the end I haven't*." – Katherine, 197-201

This suggests that it is not only in the NHS that lack of knowledge about how to navigate the system is a barrier to accessing therapy. Katherine seemed to find the process of choosing a therapist sufficiently challenging as to prevent her from accessing therapy. This seems to have been partly due to a repetition of a scarcity of resources (ie the therapist needing to operate a waiting list) and partly due to an overabundance of therapists to choose from and not knowing how to make such a choice. This suggests that both too many and too few choices present an obstacle to arranging a therapy appointment. Thus, challenges in navigating the system both in terms of NHS and private therapy provision and knowing where to look for therapy appear to contribute to a sense that accessing therapy is a battle.

3.8.3. Lost in Jargon

In her attempt to access therapy, Katherine described struggling with the range of specific, technical terms used by therapists:

> *"… I sort of understand some of the terms, but not all of them. You know that's the other thing, there's lots of different sorts of therapies available and what does that mean, what does that mean… And I have, I mean you know, I have heard of CBT, erm, although never, never tried it before. So yeah, completely overwhelming, didn't know where to start. And I still don't."* – Katherine, 214-220
>
> "*And they don't even explain what they mean in most of their, the sort of blurb, erm… I had to Google it, literally went and Googled it. To say okay, what does that word mean?"* – Katherine, 224-226
>
> "*You need to know that the person that, that that obviously erm… Is a professional and is accredited, but you need to know what the accreditation actually means, because anybody could call themselves anything, anybody can have names after, letters after their name*." – Katherine, 304-309

Katherine therefore seems to have been prevented from accessing therapy by the range of technical terms, therapy models and accreditations that she encountered. Furthermore, attempting to understand them added an additional task to her search for therapy, as she looked up terms to understand them. Again, this suggests that accessing therapy was perceived as a battle requiring a lot of effort on Katherine's part. Of course, this may not be unique to carers and as it was only reported by one participant it must be considered with caution. However, it seems likely that the use of jargon may prevent carers from accessing therapy. Given that carers also reported feeling professionals did not understand their needs, it is possible that by using such technical language, therapists inadvertently reinforce a perception that they may not understand carers' needs or perspectives. This may, in turn, have an impact on the extent to which therapy is perceived as risky or safe. The usability of therapists' websites and their impact on clients' perceptions of therapy may be a useful avenue for further research.

3.8.4 Role Juggling

In addition to describing challenges in knowing where to go, how to access therapy, and how to choose a therapist, carers also described juggling a multitude of roles (such as carer, parent, grandparent, employee and partner) alongside these tasks. While a detailed consideration of these different roles is outside the scope of this project, the impact of juggling multiple roles on carers' ability to access therapy was apparent:

> "*But again it's difficult to go somewhere [for therapy]. Because I'm, I need somebody to look after Mark. So anything, ideally if I, if somebody could come here or or if I, or if this Friday thing worked I'd get Friday and I could always use a Tuesday*." – Ruth, 767-771
>
> "*Whereas when I'm back at work it's [sucks in breath through teeth]… Yeah I've got to fit this in, got a do dad's shopping, gotta go and see dad…" and "I'm going to have to negotiate, with my employer to see if I can, if I do want to pursue some counselling, whether I'll be allowed some time off*." – Katherine, 144-146 and 358-360
>
> "*The other thing, you think, how could I fit in time to see therapy*." – Barbara, 212-214
>
> *"It wasn't so easy to get over there with working and looking after grandchildren. Um. And, and trying to live* ***a life*** *as well."* – Gina, 36-38, Gina's emphasis.

This suggests that therapy might be experienced as another ball for carers to juggle, alongside existing roles. The battle may therefore not just be in accessing therapy in the first place, but also in creating and maintaining time in which to attend therapy. This role juggling and the limitations it places on carers' time may also affect their willingness or ability to research how to access therapy or what particular terms mean, compounding the impact of these barriers on carers' access to therapy.

3.9 Core Category: Becoming Aware of Therapy

The core category identified in this study is 'Becoming Aware of Therapy.' It is proposed that carers' changing awareness and understanding of therapy influences their perceptions of therapy and how they decide whether or not to access therapy. The relationship between 'Becoming Aware of Therapy' and the other categories identified in this study will now be outlined.

Carers' awareness of therapy seems to influence each of the categories already presented, such that:

1. Carers must become aware that therapy is an option that is available to them before they can consider whether or not they wish to access it. The visibility of therapy is vital in carers coming to this awareness.

2. Becoming aware of therapy and learning more about therapy influences carers' understanding of therapy and whether it is relevant to them.

3. Being aware of therapy is necessary for carers who perceive themselves as not coping to be able to access it. Becoming aware that you do not need to be in crisis to access therapy and that therapy does not have to be the last resort may also facilitate carers accessing support when they are less intensely distressed.

4. Those carers with greater self-perceived awareness of therapy tended to identify more safety features of therapy. Becoming more aware of these aspects of therapy may also change the degree to which carers perceive therapy as threatening or relatively safe.

5. If, after becoming aware of therapy, carers wish to access it, they may experience the process to do so as a battle. Awareness of how to access therapy and understanding of the terms used to refer to therapy may help decrease the perception of accessing therapy as a battle.

3.11 Summary

This chapter has presented the main findings from this study, illustrated with examples from interview transcripts. The next chapter presents a proposed model of how carers' perceptions of therapy influence their decisions about whether or not to access therapy. This theory will be discussed in the context of wider literature and the strengths and limitations of the study will be considered.

Chapter 4: Discussion

4.1 Overview

This chapter will present the model developed as a result of the study and consider the findings in the context of existing literature. Connections with existing literature regarding help-seeking and regarding other populations of carers will be drawn. The overall quality of the presented theory will be considered in the light of Glaser and Strauss's (2017) criteria for a good grounded theory. The strengths and limitations of the study will then be considered, along with how limitations could be addressed. Consideration will be given to the relevance of this study to counselling psychology and the wider implications of the findings. Reflexivity will be addressed from both a personal and a methodological perspective. Finally, further research suggestions arising from the project will be considered.

4.2 Restating the Study Aims

Carers, and particularly carers of people with dementia, experience higher levels of burden and psychological distress (eg Clare et al., 2002; Cuijpers, 2005; Gilhooly et al., 2016; Li et al., 2012). There is some evidence carers may benefit from psychological therapies (eg Dickinson et al., 2017; Kishita et al., 2018). However, there is also evidence that carers make less use of psychological therapy than may be expected (Ervin & Reid, 2015).

While there is some evidence that those carers who have accessed therapy reported finding it helpful (eg Elvish et al., 2014), and a limited amount of evidence regarding carers' perceptions of therapy, it is less clear how carers who have not previously accessed therapy perceive it. Furthermore, it is unclear how such perceptions influence carers' decisions about whether to access therapy. This study therefore aimed to explore carers' perceptions of therapy and to develop a model of the role their perceptions may play in how carers of people with dementia decide whether or not to access therapy.

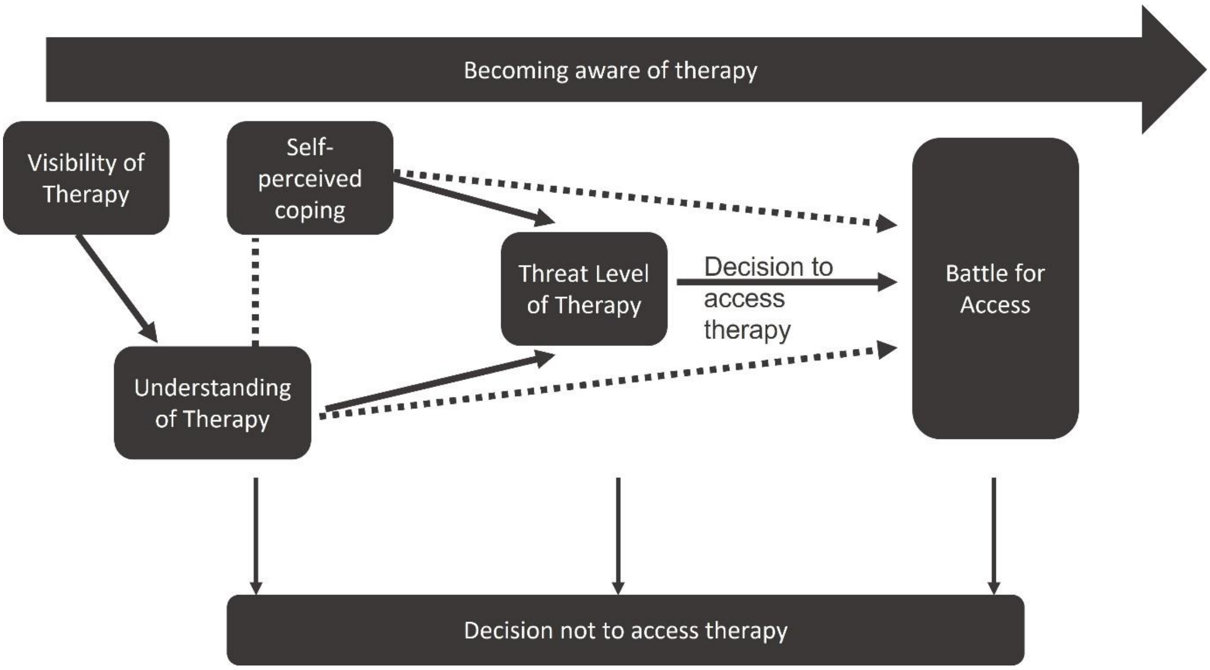
Findings suggest that carers perceive therapy as invisible and not available or regularly discussed. Additionally, carers described a range of understandings of therapy. All carers in the sample described therapy as a place to talk or offload. Only those carers who reported a greater understanding of therapy were able to elaborate on the potential purposes of and outcomes from talking in therapy. Carers perceived therapy as undertaken with a particular aim in mind. Additionally, the problems carers described as potentially suitable for therapy tended to be chronic, clinically significant or severe, and taken to therapy only as a last resort. Carers varied in the strategies they used to cope with caring and the extent to which they felt able to cope. Equally, carers varied in the extent to which they perceive therapy as potentially threatening and how able they were to identify features of therapy which helped it feel safe. Those carers who did feel that therapy was relevant to them and wished to access it appeared to perceive the process to do so as a battle. Overall, becoming aware of therapy was an important factor in carers' perceptions of the relevance of therapy to them.

4.3 Presentation of the Model

Based on the findings of this study, the following model of how carers' perceptions of therapy influence their decisions whether or not to access therapy is proposed, as illustrated in Figure 1.

Figure 1

How Carers' Perceptions Influence Decisions about Accessing Therapy



Carers' perceptions of therapy and its potential relevance to them changes as their awareness of therapy increases. While therapy remains an invisible option for carers, they are unlikely to consider whether or not they wish to access it. Carers for whom therapy is visible can draw on their understanding of therapy and their perception of how they are coping to begin weighing up whether or not to access therapy. The extent to which they are accurately aware of therapy informs their understanding of therapy and their perception of whether their current coping warrants therapy, such that carers who consider they are currently coping well enough and perceive therapy as only for more severe problems are likely at this point to decide not to access therapy. Carers who feel they are struggling to cope but also perceive therapy as only for the most severe problems or as a last resort are also likely to decide not to access therapy. However, if they become more aware of therapy as for a wide range of problems and not necessarily a last resort, they may continue to weigh up whether or not to access therapy. Carers who feel their current coping matches with their understanding of therapy – particularly who and what it can be for – are most likely to continue considering therapy as an option.

For carers who continue to consider therapy, their understanding of therapy and self-perceived coping influence how threatening therapy seems. For example, carers who cope by avoiding talking about their emotions are likely to perceive therapy as more threatening than carers who are comfortable talking about their feelings. Carers with a greater awareness of therapy also tend to be more aware of safety features such as confidentiality, which may reduce their perceptions of therapy as threatening. If the threat level of therapy feels too high, carers are likely to decide not to access therapy. Developing a more sophisticated awareness of therapy may change the extent to which therapy is perceived as threatening.

Carers who are not satisfied with their current coping with caring and perceive therapy as suited to addressing their needs and not too threatening may then decide to access therapy. They may experience the process to do so as a battle in which they must learn how to access therapy and navigate the systems required to arrange a first therapy appointment. The extent to which this battle feels like one they can win is influenced by their awareness of therapy, such that carers with a greater awareness of therapy are more likely to know or be able to find out how to access it. It can also be influenced by their current coping, as carers who are struggling the most to cope may not feel they have the resources to overcome the hurdles in order to access therapy. As carers become more aware of therapy, they are more likely to become aware of various routes to access and to begin to understand the jargon and processes involved. Carers who find the battle to access therapy overwhelming are likely to decide not to access therapy.

It should be noted that although 3 key points at which carers are most likely to decide not to access therapy have been highlighted, carers may make this decision at any point during the process. Additionally, it is likely that carers who later revisit their decision not to access therapy can re-enter the model at any stage, except perhaps visibility of therapy. This was beyond the scope of the current study to determine, as participants did not describe experiences of reviewing a previous decision not to pursue therapy, and would benefit from consideration in future research.

4.4 Contextualising the Findings

Each category will be briefly considered in the context of relevant existing literature before similar consideration is given to the presented theory. As there is, to my knowledge, no other research specifically exploring how carers' perceptions of therapy influence their decisions about whether to access therapy for the first time, this consideration is predominantly based upon research in two main areas. This includes research with other groups of carers and research that did not focus on carers specifically but considered the help-seeking process or expectations of therapy.

4.4.1 Visibility of Therapy in Context

Findings related to this category suggested that carers of people with dementia experienced therapy as largely invisible, instead perceiving a gap in support. Additionally, findings suggested that the carers experienced therapy as rarely discussed and difficult to imagine. Finally, carers seemed to perceive awareness that therapy is an option as a pre-requisite for considering whether they wished to access it.

The perception of therapy as invisible or absent was challenging to hear as a researcher also working therapeutically with carers in my placements. It was a sharp contrast to my awareness that there is some therapy provision, albeit not necessarily specifically adapted to the needs of carers of people with dementia. I was struck that for Ruth and Katherine in particular, their participation in the study appeared to have been motivated by an interest in learning more about therapy. It is therefore possible that the study advert in some ways acted to alert participants to the possibility of therapy as an option. Indeed, most participants reported that they had not been aware that therapy may be available to support them in their caring role until they had seen the study advert.

Given that carers did report some understanding of what therapy involved, they may have been aware of the availability of therapy in general but assumed the research was only interested in therapy specifically targeted at carers of people with dementia. However, this was checked with participants in a number of the interviews. Barbara and Ruth both indicated that they were not aware of therapy being available either in general or specifically aimed at carers, and William was unsure if it was available in either context. This supports the interpretation that some carers do not access therapy simply because they are not aware that it is an available option in general.

This is supported by the findings of Lim, et al. (2012), who reported that knowledge of available services and carer employment status were the only variables to significantly predict services used. They took several variables into account, including age, gender, marital status, whether or not the carer was living in the same household as the person being cared for, and the age of the person with dementia. It therefore seems important to ensure that carers are provided with accurate information about therapy provision in their area.

Although becoming aware of therapy as an available option appears to play an important role in carers considering accessing therapy, it is not clear how widespread the apparent invisibility of therapy might be. Ervin and Reid (2015) reported that 7% of their sample were not aware of counselling being available in the area. This study took place in a rural location in Australia, and therefore may not generalise to a UK population. Nonetheless, the finding does indicate that therapy may be an invisible option for a notable proportion of people. This highlights the need to increase the visibility of therapy.

There is some evidence to suggest that carers expect information about available services, such as therapy, to be provided by healthcare professionals (Stephan et al., 2018). There is also evidence that carers prefer to be asked about their mental health by GPs, rather than being expected to initiate this discussion themselves (Hannaford, Shaw & Walker, 2018). This suggests that GPs may have an important role in increasing the visibility of therapy for carers. Dow and Robinson (2014) highlight NICE guidance stating that carers experiencing psychological distress should be offered psychological therapy (a recommendation which remains in updated NICE guidance, 2018). They also note that GPs are advised to consider annual depression screening for carers. Such annual screenings may be an opportunity for GPs to discuss therapy with carers. Alternatively, leaflets about coping with caring may be provided in GP surgeries and mention therapy as an option.

Carers in the present study further indicated that they felt therapy would be beneficial to carers, but were not sure difficulty coping with caring was a sufficient reason to seek therapy. It is therefore important that therapy is promoted specifically with carers in mind. This may include ensuring that information leaflets about therapy are provided to carer support organisations, perhaps with tailored content to address some of the concerns highlighted in this study. For instance, leaflets could note that caring can be stressful and that therapy may be helpful for carers who feel stressed. Therapy services could also arrange for representatives to visit carer support organisations to clarify when therapy may be helpful.

4.4.2 Understanding of Therapy in Context

Findings in this category suggested that carers have good awareness that therapy involves talking. Carers with greater knowledge about therapy also seemed able to express a more nuanced understanding of the purpose of talking with a therapist and the potential outcomes of this. Carers also seemed to perceive therapy as being aimed at addressing a particular problem, and often viewed therapy as a last resort to tackle particularly distressing problems.

Within the present study, those carers who reported greater knowledge of therapy were also the carers who perceive therapy as potentially beneficial to them. There are a number of possible ways this finding could be interpreted. For example, carers who view therapy as most relevant to their needs may be more likely to take steps to increase their knowledge about therapy. This may be seen in Katherine’s efforts to research models of therapy and private therapists online. An alternative explanation is that as carers become more aware of therapy, this increased knowledge also helps them to consider the ways in which therapy may be relevant to them. It is also possible that a combination of both these explanations may be important.

Waters et al. (2018) investigated the perceptions held by a broader range of carers (including carers of people with physical health conditions, learning disabilities and mental health problems, in addition to carers of people with dementia). They found that knowledge of therapy appeared to be related to experience of therapy. Similarly to the present study, they found that carers were aware of therapy as a place to talk and offload negative feelings in a private, non-judgemental space. However, only those carers who had actually had therapy identified the potential for therapy to bring about change and the opportunity for therapy to provide a space to focus on themselves, rather than the person they were caring for. This suggests that increased understanding of, or at least familiarity with, therapy may be associated with an enhanced understanding of the potential benefits of therapy for carers. However, larger studies would be needed to replicate this finding. Such studies could investigate carers’ knowledge and perceptions of therapy before providing information about therapy, to see if this alters carers’ perceptions of the potential benefits of therapy. Ideally, this would be a longitudinal study which followed carers over time to explore how such perceptions may interact with carers’ actual therapy seeking behaviour.

In addition to perceptions of therapy as involving talking and an opportunity to offload, carers in the present study seemed to perceive therapy as suitable for certain types of difficulties. These included chronic, severe or diagnosable distress. Depression, anxiety and mental illness were particularly mentioned. Furthermore, carers indicated that they did not see therapy as suitable for discussing day-to-day difficulties, including difficulties associated with coping with caring. Carers may have been primed to consider depression as a result of completing the PHQ9 during the screening process for the study. On completing this questionnaire, some carers commented that they were not depressed, indicating they had ascertained the purpose of the questionnaire. This may have prompted them to consider depression as a potential reason to seek therapy. However, Hannaford et al. (2018) similarly reported that older adults identified depression as a reason for accessing psychological help, suggesting that this finding is not merely an artefact of the design of the present study.

The finding that carers did not feel difficulties in coping with caring were sufficient to warrant therapy may prevent carers accessing therapy, or leave carers concerned about being judged by the therapist if they do seek sessions. The finding that perceiving their difficulties as normal in the circumstances is a barrier to accessing therapy has also been reported in other samples. For example, Wuthrich and Frei (2015) found that adults aged 60-79 experiencing clinically significant symptoms of anxiety and/or depression did not feel their symptoms were severe enough to require therapy; they viewed their symptoms as normal for their age. As some participants in the present study also fall into the 60-79 age bracket, this may also be a factor for some of the carers in the sample. However, younger participants also indicated that caring-related difficulties were not sufficient to justify therapy.

It is not fully clear what underlies William and Mary’s perceptions that their experiences were not sufficiently distressing to warrant therapy. These perceptions may have been based on assumptions that any difficulties they experienced were normal either due to their caring role or to their age (both over 60), or a combination. Equally, it is possible that William and Mary were not experiencing significant distress. This seems the most likely explanation, as their scores on the PHQ9 were below the clinical cut-off for the measure. Nonetheless, given that carers in this study did not think difficulties in coping with caring was a sufficient reason to access therapy, it seems important that information aimed at carers explicitly states that therapy can help with negative emotional and psychological consequences of being a carer.

In addition to perceiving therapy as suitable for more severe difficulties, participants also described viewing therapy as a last resort, to be tried after other options. This finding has also been reported in the general population (Vogel et al., 2007) and therefore may not be specific to carers. However, given that successful intervention to support carers can also be beneficial in delaying the need for the person with dementia to enter residential care (Luppa et al., 2008), it is perhaps even more important for carers to access support early. Therefore, it is likely to be important that as soon as a carer’s distress is identified, the option of therapy is sensitively discussed. Additionally, carers should be actively encouraged to seek help early.

4.4.3 Self-Perceived Coping in Context

Findings related to this category suggested that both the degree to which carers felt they were coping and the type of strategies they used to cope influenced how relevant therapy seemed to them. Carers who reported suppressing their emotions to cope with caring tended to also report concerns about finding therapy overwhelming, with the exception of Mary, who was the only carer who both used suppression to cope and predicted that she would continue to cope in the future. William, who used connection with others to help him cope, also seemed confident that he would continue to cope without the need for therapy.

The impact of coping style on carer distress has been more thoroughly investigated than many of the other categories to emerge from this study. A consistent finding has been that carers who use problem-focused coping, acceptance and social-emotional support tend to have relatively better mental health, while denial and avoidance have been linked with poorer outcomes (Gilhooly et al, 2016; Li et al., 2012). The current findings suggest that coping strategies may not only affect carer distress, but also the extent to which carers perceive therapy as daunting. Additionally, certain interventions, such as problem-solving, may reduce unhelpful coping strategies by helping carers identify alternatives (Chiu et al., 2015). Coping style therefore seems an important factor to consider.

Some of the ways in which coping style acts as a barrier to therapy may be mitigated with appropriate information. For example, leaflets about therapy or informational websites may explicitly state that the therapist will not force clients to talk about things they do not wish to discuss. Additionally, carers may find it helpful to know that some types of therapy focus on finding practical strategies to overcome challenges, and that while therapy involves discussing difficulties, there are different approaches to therapy which differ in the extent to which they focus on exploring and sitting with difficult emotions. A downside of such information is that it may confuse carers or further contribute to carers feeling overwhelmed by the amount of information and jargon. An alternative may be for literature to reference that therapists understand that therapy can feel daunting, appreciate the courage clients show in making and attending therapy appointments, and tailor their approach to the needs of individual clients.

4.4.4 Threat Level of Therapy in Context

Findings in this category suggested varying perceptions of how safe or risky therapy might be. Carers who reported greater awareness of therapy tended to also describe ways in which therapy could feel safe to them and to identify therapy as potentially useful. By contrast, carers who described trying to suppress their feelings seemed to perceive therapy as more threatening and were less able to identify aspects of therapy which might mitigate the risk. Additionally, carers' ideas about therapy seemed to be influenced by their experiences of non-therapy support. In particular, carers described experiences of not feeling understood by services or professionals. This may be both an unmet need that therapy might help to address and a barrier to accessing therapy (if carers are concerned that the therapist may not understand, either, for example).

This balancing of risky and safe features of therapy is echoed in the findings of Vogel et al. (2007), who summarised existing literature regarding psychological barriers to seeking counselling in the general population. Vogel et al. (2007) framed their findings in terms of Kusher and Sher's (1989) avoidance/approach perspective, but focused on barriers to counselling. They noted a number of avoidance factors, some of which are similar to those found in the present study.

In particular, Vogel et al. (2007) reported fear of emotion, discomfort with opening up to others and disclosing personal information as potential barriers to accessing therapy. These concepts bear similarity to concerns reported in the present study, particularly carers' concerns about feeling overwhelmed by their emotions. It seems plausible that people who dislike opening up to others may also use suppression as a coping strategy. These findings suggest that weighing up threatening and safety-supporting aspects of therapy is not unique to carers of people with dementia.

An additional finding reported by Vogel et al. (2007) related to treatment fears. This concept particularly related to participants' concerns about how they would be treated and viewed by professionals and about coercive practice. Although this did not emerge as a significant finding in the present study, it was not entirely absent; William expressed the importance of therapists not being aggressive or dominating. It is unclear why William was the only participant to raise this. It is possible that other participants experienced similar concerns, but did not feel able to say so due to the researcher's dual role as a therapist. It is also possible that participants' experiences during the interview may have influenced their perceptions regarding this. For example, following up on participants' concerns, listening to what they had to say and approaching the interview calmly and without aggression may have reassured participants in this respect. This interpretation may be supported by Ruth's comments that the researcher was really listening to her and by Katherine's comment at the end of the interview that she had found it a helpful opportunity to consider and express her perspective.

Not all of Vogel et al.'s (2007) findings were replicated in the present study. For example, social norms and stigma were mentioned relatively little by carers, with the exception of Mary's references to people being hospitalised to have therapy. It could also be argued that the general lack of discussion about therapy may reflect underlying social stigma, although this cannot be separated out from the potential that therapy was not discussed simply because it was not visible.

The lack of emphasis on stigma was surprising, as stigma has frequently been reported to be the main barrier to accessing psychological therapies (Vogel et al., 2007). It is possible that asking directly about stigma would have elicited greater concerns regarding stigma from participants. However, it was considered that this would go against the ethos in grounded theory of being led by participants rather than the researcher's preconceptions (Glaser & Strauss, 2017). Additionally, if stigma had then emerged as an important theme, it would not be possible to rule out that the role of stigma may be exaggerated in the findings, as a result of being prompted by the researcher rather than arising from participants' spontaneous concerns.

An alternative explanation for the relative lack of emphasis on stigma as a barrier to therapy may be that stigma has reduced in recent years. Hannaford et al. (2018) found that older adults reported stigma had been reduced (albeit, not extinguished) and that this reduction in stigma had altered their attitude to seeking therapy. It is therefore possible that stigma was mentioned relatively little because the importance of stigma has reduced since earlier studies. Further supporting this, it is perhaps worth mentioning that Mary was one of the older participants in the sample. Like participants in Hannaford et al.'s (2018) sample, Mary described growing up in a culture which placed a premium on stoicism and relying on oneself, and did not look favourably on seeking help. This may help to explain why stigma may have been more significant to Mary than to other participants in the present study.

An additional finding of the present study was that carers' experiences with non-therapy professionals and of seeking help both for themselves and the person with dementia influenced their perceptions of how therapy might be. I have not been able to locate previous studies reporting the same finding. One study by Chaturvedi (2016) did note that poor past experiences of help-seeking were experienced as a barrier to future help-seeking for homeless young people. However, this was not focused on help-seeking from professionals and included young people's negative experiences of seeking help from friends and family. Additionally, young people might be considered a very different demographic from the carers in this study.

Given that carers in the present study reported a need to feel heard and validated, and that Barbara in particular described feeling uncontained by her social worker, it is possible that carers felt their needs were not a priority for services or were not understood. It is plausible that this perception was reinforced by the apparent invisibility of therapy, or that the apparent lack of concern for carers' needs reinforced carers' perceptions that their needs were not significant enough to warrant therapy. Additionally, carers may find it more challenging to overcome concerns about therapy being overwhelming if their experiences of becoming emotional when speaking with other professionals are not supported and contained. Therefore, carers' experiences of the support systems external to therapy may influence their expectations regarding therapy itself.

Given this, it may be particularly important to emphasise differences between therapy and other types of support. Additionally, it may be important that the wider range of professionals working with carers have the time, training and support they need to be able to demonstrate to carers that their concerns are heard and valid. Such professionals may also benefit from training about therapy, and/or therapists may wish to highlight the existence of therapy services and appropriate referral pathways to such professionals.

4.4.5 Battle for Access in Context

Findings suggested that those carers who did wish to access therapy perceived the process as a battle to learn how to access therapy. This included overcoming obstacles such as long waiting times and limited appointments, learning technical terms related to therapy, and juggling therapy alongside their many other roles.

Lack of information about how to access support is a well-established finding amongst carers of people with dementia (Sutcliffe et al., 2016), carers of older adults with severe and enduring mental illness (Berry et al., 2020) and more mixed samples including participants caring for people with a range of conditions (Arksey & Hirst, 2005). Similar findings have also been reported amongst older adults experiencing anxiety and depression (Wuthrich & Frei, 2015). This suggests lack of information is a particularly important barrier to address. Indeed, Katherine described the combination of not knowing how to access therapy and being overwhelmed by choice when attempting to access private therapy as sufficient to have prevented her accessing therapy. That this has been a consistent finding suggests not only the importance of improving knowledge about how to access therapy, but also that this may be a particularly challenging barrier to overcome.

Meyer (2018) highlighted that how services are organised and the way they disseminate information is currently passive, relying on carers to actively seek out information. This is problematic given that carers are not necessarily aware that the information is available or what questions to ask. It might also explain the finding in the current study that therapy was relatively invisible to carers; perhaps this invisibility is a result of therapy services waiting for people to search for them. Sutcliffe et al. (2016) noted that carers wanted all information to be provided by a single source. While this may make it easier for carers to know where to find information, it does not necessarily change the reliance of services on carers actively seeking information. It seems unlikely that carers would seek information regarding a service such as therapy if they are not aware that such a service might be available to them.

Another option is to increase the role of services and professionals in actively highlighting therapy as an available option. It seems unrealistic to expect any single professional to be aware of all the support options available to carers, and services may need to consider how to ensure their staff are as aware of these options as possible. However, GPs, carer support workers and social care staff may be particularly well-placed to spot emotional distress in carers and potentially discuss therapy as an option. This may need to be supported by written information such as leaflets and business cards with links to therapy services' websites. Such information may reinforce conversations about therapy but may also be noticed by carers even if therapy is not explicitly discussed, and should indicate how carers can access therapy.

Carers in the present study also highlighted the importance of the language used regarding therapy. The need to avoid jargon was emphasised. Hannaford et al. (2018) similarly noted that their participants were unfamiliar with the term psychotherapy, expressed concern about psychological terminology due to unfamiliarity, and were more comfortable with the term counselling. Katherine also highlighted her difficulty in understanding the terms used to describe therapists' theoretical orientation and accreditation.

Using language that carers find hard to understand not only has the potential to increase their experience of therapy as a battle to access, but may also reinforce concerns that therapists may not understand carers' perspectives or needs. It is therefore important that therapy services and private therapists pay close attention to the language used in their written materials. This may include explaining what therapy is, finding alternative ways to express how therapists work (such as briefly outlining core features of the model, rather than simply naming it) and explaining the meaning of their accreditations. It is not clear to what extent the term 'Counselling Psychologist' is easier or harder for carers to understand than other titles, and so it may also be useful for counselling psychologists to provide information about the title.

Finally, with respect to the battle to access therapy, carers reported concern about juggling therapy alongside the many roles in their lives. Such concerns are unlikely to be unique to carers. For example, parents have reported similar concerns (Tapp et al., 2018). This does not mean that the challenges of juggling multiple roles while attempting to navigate the process of accessing therapy should be overlooked amongst carers. Lim et al. (2012) identified lack of time as the most reported barrier to service use amongst carers of people with dementia, and it therefore seems an important aspect to consider. Of course, therapists cannot prevent carers (or anyone else juggling multiple roles) from being busy. However, it may be important for therapists to acknowledge the time and effort taken to investigate how to access therapy, what many of the terms used when describing therapy mean, and then actually arrange a session. This would contribute to helping carers to feel heard in therapy and demonstrate that therapy is a different experience from other types of support.

In addition, while the difficulty of juggling multiple roles was raised by most participants in reference to making time to attend therapy, being very busy would likely also reduce carers’ capacity to undertake the kind of research needed to learn about therapy. This reinforces the importance of information about therapy being visible and available in the course of carers’ daily lives. Relying on carers to identify and search out information about therapy may in itself imply a lack of understanding of the challenges carers face.

4.4.6 Becoming Aware of Therapy in Context

There seem to have been relatively few studies, if any, investigating how awareness of therapy influences the way that therapy is perceived or how relevant therapy seems to carers. As previously mentioned, Lim et al. (2012) reported that awareness of services significantly predicted service use for carers, alongside the carer’s employment status. Although their findings related to the use of a range of different services and were not specific to therapy, this nonetheless supports the suggestion that awareness of service availability is important in facilitating access. The present study highlighted that becoming aware that therapy was available, of what therapy is and of how to access it were important in carers considering whether they wished to have therapy, and this seems in keeping with Lim et al.’s (2012) findings.

Additionally, the present study suggests that becoming more aware of therapy may help carers reach more informed decisions about whether to access therapy. Greater awareness may also help in overcoming some barriers to access. For instance, increasing awareness may support carers to identify aspects of therapy which may help reduce the perceived threat level of therapy. They might realise that they are in control of how much they disclose, for example, or that although therapy may involve experiencing distressing emotions, this is with the aim of reducing distress in the longer term. Greater awareness of therapy may also help carers identify how to access therapy if they wish to.

4.5 The Model in Context

The model presented in this paper bears some similarities to, and further elaborates on, two existing models of how people in the general population decided to seek therapy. Each of these models will be considered in turn.

4.5.1 Cramer's Model of Help-Seeking

Liao et al. (2005) investigated Cramer's (1999) help-seeking model, seeking to confirm that it explained how white American college students made decisions about seeking therapy, and to check if the model was also a fit for Asian and Asian American students. Cramer (1999) proposed that students were more likely to seek counselling if they were highly distressed and had positive attitudes regarding counselling; and that students' tendency to conceal their difficulties was related to limited social support, greater distress and less positive attitudes about counselling. Liao et al. (2000) found this model was a good fit for the intentions of white American college students to seek counselling and an adequate fit for the intentions of Asian and Asian American students.

There is some overlap between this model and the model proposed as a result of the present study. In particular, carers reported perceiving therapy as suited to addressing severe distress. Additionally, those carers who perceived therapy in arguably more positive ways (for example, those who perceived therapy as relatively safe) tended to be those who identified therapy as potentially useful to them. Furthermore, carers who preferred to suppress their emotions – and therefore might be more likely to conceal their difficulties from others – tended to be more daunted by the idea of having therapy. While social support did not emerge as a category in relation to the present study, it may have influenced carers' knowledge of therapy. For example, Katherine reported that a friend had suggested therapy and recommended a particular therapist. It is possible that the focus on how carers' perceptions influence how relevant therapy seems to them, rather than on what influences carers' perceptions of therapy in the first place, may have contributed to the role of social support being less fully considered.

In addition to having similarities with Cramer's (1999) help-seeking model, the current findings also extend the model. The present findings add consideration of the need for therapy to be a visible option for carers to consider accessing it. They also highlight the battle carers face in moving from wanting therapy to arranging an appointment. Furthermore, the present findings begin to offer a potential explanation for the relationship between distress, attitudes to therapy and (tentatively) self-concealment. The present findings suggest that Cramer's concepts may be mediated by and contribute to the extent to which therapy is perceived as threatening, such that carers who are highly distressed, view therapy as relatively safe and potentially helpful, and are more comfortable with discussing their difficulties may be more likely to go on to access therapy in future.

However, the findings of the present study are drawn from a specific group of carers who have not previously accessed therapy and may not translate to a more general population sample. Additionally, the present study did not follow up participants to investigate whether those carers who indicated an interest in having therapy attended an appointment. Further longitudinal research to investigate this with a larger sample would be beneficial. That said, it is notable that 2 participants (Katherine and Ruth) who expressed interest in having therapy during the study later contacted the researcher to thank them for the information about therapy. Both indicated that they had arranged an initial therapy appointment.

4.5.2 Saunders' Model of Help-Seeking

Saunders (1993) identified 4 stages in deciding to seek therapy: identifying a problem, deciding therapy might be a helpful option, making the decision to access therapy, and making contact with a therapy provider. Social support was found to be important at all stages of the help-seeking process (Saunders, 1996). Elliott et al. (2015) replicated Saunders' findings, although they omitted the first stage (identifying a problem) for reasons that were not made clear. Elliott et al. (2015) also found that deciding therapy might be helpful was the most difficult stage of the process, and that participants who took longer to make decisions at each stage anticipated finding therapy more difficult but were no less committed to therapy than participants who made decisions more quickly.

Saunders' (1993) model has some similarities with both Cramer's (1999) model and the model presented in this study. Both Saunders and Cramer suggest that distress plays a role, as identifying a problem implies some degree of distress, and the present study suggests that distress must be perceived as sufficiently severe as to warrant therapy. Although Cramer (1999) indicated that greater distress was associated with increased intention to seek counselling, Elliott et al. (2015) found that greater distress was associated with greater difficulty in making decisions at each stage in the process.

The findings of the present study may provide a way to make sense of how these findings fit together. Carers who did not feel they were coping with their role (and might therefore be considered to be subjectively more distressed) and who preferred to cope by suppressing their emotions also described therapy as more daunting. They also identified fewer aspects of therapy which might help it feel safer. This may contribute to making it harder for them to decide to have therapy than carers who perceived therapy as less threatening. Furthermore, their higher levels of distress may have increased the perceived risk of therapy (for example, by increasing the anticipation of therapy as overwhelming) as well as making decision-making more challenging, such as by impacting on concentration. This might be one potential mechanism by which higher levels of distress may contribute to taking longer to decide to access therapy. This is a tentative suggestion at this stage, as it is unclear to what extent findings from the present study can be expected to generalise to the general population.

The order of the stages in Saunders' (1993) model and the present study also present a discrepancy. Saunders suggests that the first stage is identifying a problem before deciding therapy may help address this problem. Carers in the present study reported needing therapy to be visible before they could consider it; this could conceivably happen between the first and second stages of Saunders' model. However, carers also reported needing to become aware of therapy as potentially helpful to them in relation to difficulties coping with caring; otherwise, they perceived therapy as suited to more severe difficulties. This suggests that a certain degree of knowledge and understanding about therapy, as well as an awareness that it is an available option, may be important before some carers are able to decide that they have a problem that therapy may help them address. Identifying a problem and deciding therapy might help may therefore oversimplify the process. It is possible that identifying the problem is followed at a later stage by identifying that the problem is significant enough to warrant therapy, supported by information that therapy can be helpful for this type of problem.

Of course, it is also possible that the importance of the visibility of therapy emerged in the present study due to the focus on carers who have not previously accessed therapy. Carers who have accessed therapy may have experienced therapy as more visible, enabling them to consider it as an option. This would benefit from being considered in future research.

Taken together, the present model is not inconsistent with Saunders' or Cramer's models, and elaborates on the processes by which the perceptions of carers in the study influenced how they negotiated each stage in deciding whether to access therapy. Additionally, the present model highlights the importance of visibility and awareness of therapy as playing a role in this process, and extends these models by considering the process by which a person might move from intending to access therapy to arranging an appointment. This extends on Cramer's and Saunders' models by considering the interaction between system-based factors (such information being lacking or hard to find) and individual perceptions (such as perceiving therapy as unavailable because it is invisible to the individual). Further research to explore how carers make this transition would be beneficial to increase understanding of how to make this process feel less like a battle for carers.

4.6 Quality of the Emergent Theory

Glaser and Strauss (2017) highlight a number of properties that a theory must have to be usefully applied. They state the theory must:

- be a good fit with the area in which it is to be utilised
- be clear and easily understood by relevant laypeople
- be abstracted enough to be generalisable to a range of situations and experiences in the relevant area, and
- allow the person using the theory to identify ways in which they can influence or control the process to some extent.

Glaser and Strauss (2017) argue that constant comparative analysis, theoretical sampling and aiming for theoretical saturation all help to ensure that the emergent theory is a good fit with the area being explored; thus, following grounded theory protocols rigorously should ensure good fit. Constant comparative analysis, in particular, helped illuminate areas in need of further exploration and to highlight similarities and differences between how different carers in the study perceived therapy and the implications of this. The emergent theory from this study is considered to be a good fit with the area being considered (that is, carers of people with dementia where those carers have not previously accessed therapy). This is because the emergent theory:

- is consistent with existing theory regarding help-seeking
- elaborates on existing theories with reference to the particular area being considered

- highlights aspects of the process which may be specific to carers (such as the impact of other professionals' attitudes towards carers, and the role-juggling required for carers to make time for therapy).

Further research with other types of carers or other populations would help clarify the extent to which the theory presented may be specific to this group or can be generalised more broadly.

It is more difficult to determine the extent to which the model presented in this paper is easily understood by laypeople. A summary of the findings has been sent to those participants who requested it, but as none have responded with any questions or reactions to the findings, it is not possible to comment on how easy they found the model to understand. Feedback from participants was not incorporated into the original study design, and therefore while the researcher invited participants to ask any questions, feedback was not explicitly sought. It would have been beneficial to have planned to seek feedback from participants regarding the findings, as this would have enhanced the quality of the research further.

Glaser and Strauss (2017) also state that a theory must be sufficiently general to apply to a range of situations. The proposed model can arguably be applied in relation to carers at different stages in their awareness and consideration of therapy and with different experiences of coping with caring for someone with dementia. Participants reported a range of awareness of therapy and experiences of coping with caring, and so the model should be sufficiently flexible to cope with this range of experiences and perspectives. The sample included a diversity of carers who:

- were spouses or adult children of the person with dementia
- were working, retired or had given up work due to their caring role

- had been caring for different lengths of time (ranging from 1 - 10 years)
- lived with the person they were caring for only, with the person they were caring for and other relatives, or lived separately from the person they were caring for
- had different levels of familiarity with services for carers and for people with dementia
- were caring for someone whose only diagnosis was dementia or who had additional health considerations
- reported different degrees of distress and of social support in respect of their caring roles
- had different experiences of attempting to request and seek psychological support.

Additionally, scores on the PHQ9 ranged from indicating no clinically significant symptoms of depression to moderately severe symptoms of depression. The varied situations and experiences of carers involved in the study suggests that the model is likely to apply to a wide range of situations.

However, there are limits to how generally the model can be applied. The sample included only 1 male participant and all participants were White British or White European (factors contributing to this will be considered in section 4.0, Strengths and Limitations, of this chapter). Additionally, no carers reported experiencing severe symptoms of depression according to their PHQ9 scores. The model therefore requires further research to clarify whether it accounts sufficiently for variation in experiences and perceptions as a result of gender, ethnicity and race.

Finally, due to the study inclusion criteria, the model was specifically developed based on the perceptions of carers of people with dementia who have not previously accessed psychological therapies for themselves. It cannot therefore be assumed that the model would generalise to carers of people with other difficulties than dementia, or to carers who have some experience of having therapy.

Further research would be beneficial to explore the extent to which the model represents the perceptions and experiences of other groups of carers. It would additionally be useful to compare the present findings with the process for carers who have accessed therapy. Do the categories in this model provide enough flexibility to account for their perceptions and experiences? Are there additional factors which supported those carers to access therapy, such as the social support that Saunders (1993) and Cramer (1999) reported played a role?

With regard to the extent to which the presented model enables a degree of control over the area to which the model applies, at least three aspects can be considered:

- The extent to which the model enables counselling psychologists and other therapists to support carers who are considering therapy or accessing therapy for the first time.
- The extent to which the model supports wider service and system-based decisions which may play a role in carers' perceptions of therapy.
- The extent to which the model enables carers themselves to have some control with regards to the process being considered.

The implications of the findings will be considered more fully in sections 5 and 6 of this chapter (Relevance to Counselling Psychology and Wider Implications of the Findings).

Briefly, however, it is argued that psychologists and therapists can use these findings to inform how they promote their services to carers. This could include promoting therapy in places visible to carers, avoiding technical language and explicitly stating that difficulties coping with the emotional impact of caring are a potential reason why people may consider having therapy. From a broader systems perspective, therapy may need to be made more visible in services such as GP surgeries and to social care staff, with carers additionally suggesting therapy be advertised in libraries and supermarkets during their interviews. Finally, if appropriately shared with carers, these findings may help carers to feel that carers' perspectives are valued, to recognise safety features of therapy, and to consider whether they wish to learn more about therapy and how to access it. It is therefore considered that this model has practical utility for a range of people and services involved in caring for and supporting carers of people with dementia.

4.7 Strengths and Limitations of this Study

4.7.1 Strengths

This study has several strengths. To the best of my knowledge, it is the first study to focus specifically on how carers who have not accessed therapy perceive therapy and how these perceptions influence their decision-making regarding therapy. While much research has considered the impact of caring and the outcomes of psychosocial support including therapy, less research has focused on carers' perceptions of therapy. Those studies that have investigated carers' perceptions of therapy have tended to focus on the perceptions of carers who have completed therapy (eg Elvish et al., 2014). Where both carers who have and have not accessed therapy were included, research has suffered from methodological limitations and did not consider how carers' perceptions relate to their decision-making regarding therapy (eg Walters et al., 2018). This study aimed to help fill this gap by focusing specifically on those carers who have not previously accessed therapy.

This study also extended existing models of help-seeking. The initial focus of this study was on carers' perceptions, and in a similar way, Cramer (1999) and Saunders (1993; 1996) focused on the individual's process of help-seeking. However, the critical realist perspective of ideas, people, organisations and systems as entities with degrees of influence, power and agency (Vincent & O'Mahoney, 2018) underpinning this study additionally highlighted the role of systemic factors in shaping carers' perspectives of therapy. This is apparent in my model, which considers the interactions between individual carers, their ideas about therapy, and the systems in which therapy can be made visible or accessed. An example of this can be seen in how feeling invalidated in interactions with non-therapy services may have contributed to perceptions of therapy as threatening. A further example can be seen in how the lack of information about therapy contributed to carers' assumptions that therapy was not available, which highlighted the importance of therapy being a visible option. My critical realist stance was also reflected in my acceptance of participants' responses as their subjective account of an objective reality (Vincent & O'Mahoney, 2018). For example, I accepted participants' view of therapy as invisible until it was made visible by another entity, such as another person or the advert for this study. An alternative theoretical lens may have framed this as carers not seeing the availability of therapy, rather than therapy not being made visible enough to them, and thus reinforced existing power dynamics by positioning carers as solely responsible for whether or not they access therapy. By taking a critical realist perspective, this study was able to both avoid replicating this and also to further consider the interactions between factors such as perceptions of therapy as threatening, coping style and awareness of therapy. This may help to explain some of Cramer's (1999) findings, as discussed above.

In addition to highlighting the need for therapy to be a visible option, this study also contributed to increasing awareness of therapy by making participants aware that therapy could be available to them and providing information about how to access therapy. Two carers later contacted the researcher to state that they had arranged an initial therapy appointment as a result of the information provided in the study. This indicates that increasing awareness can influence carers' decisions and actions, as one carer stated their decision was influenced by becoming aware of what therapy is, while the other stated learning how to access it efficiently made the difference for her.

Other studies have not tended to report whether participating conferred benefits for carers in terms of access to services. This may be because participants have typically been recruited following therapy (eg Elvish et al., 2014) or via therapy centres (eg Waters et al., 2016). While Ervin and Reid (2015) had a wider recruitment strategy and noted that 7% of their sample were not aware of therapy being available in their area, it is not clear whether participating would have helped carers become aware of it as an option. It would be beneficial for more studies regarding barriers and facilitators to therapy to include addressing whether participants subsequently accessed additional services (including therapy). This would provide further evidence of the role of awareness in facilitating access.

This study also benefits from strengths arising from the choice of method. The use of a grounded theory approach conferred a number of positives, including prioritising the perceptions and views of carers rather than ideas that had been presupposed by the researcher. This enabled space for new concepts to emerge, such as the importance of carers feeling heard and validated by other professionals and the impact of this on carers' perceptions of the relative risk involved in having therapy.

Underpinning my approach to grounded theory from a critical realist perspective additionally provided an important counterbalance to the emphasis in grounded theory on remaining grounded in the data (Glaser & Strauss, 2017). While this principle sounds straightforward, in practice I found that it was not possible to achieve without also considering my own influence on the process of collecting and analysing data. A critical realist perspective therefore highlighted the importance of, and facilitated, reflexivity. I came to the conclusion that remaining grounded in the data required me to first be clear about what I was bringing to the analysis which was not data, but my own values and ideas. This made it easier was to spot ideas which were not fully grounded in the data, differentiate my own views and those of my participants, and highlight the perceptions of the carers taking part in the study. Doing so was important not only to minimise the impact of preconceived ideas on the findings, but also because carers' voices may not always be heard. Some evidence suggests that carers are often viewed more as an additional resource regarding the patient than as a person in need of support in their own right (Arksey & Hirst, 2005). Additionally, Larkin et al. (2018) highlight a lack of consideration of carers' subjective experience as a significant limitation of the evidence base in this area. It was therefore important to prioritise carers' perspectives, which was supported by both the critical realist theoretical lens and the grounded theory method.

The use of semi-structured interviews provided sufficient flexibility to adapt the interview schedule to further explore concepts raised by carers during subsequent interviews. This was balanced with sufficient rigour (through the use of constant comparative analysis and memoing, in particular) to ensure the findings remained grounded in the data. This allowed the findings to be more readily shaped by and responsive to carers' perceptions. It is hoped that this will increase the relevance of the findings to carers as well as to Counselling Psychologists and other professionals involved in supporting carers.

Further strengths arise from the model which resulted from this study. This model extends existing findings and is tailored to a specific population, which may have different experiences than other groups. For example, carers of people experiencing severe psychological distress may have different awareness and perceptions of therapy from carers of people with dementia. Younger people who are not carers may have different perceptions again. While this means that further research to explore the extent to which this model accounts for the experiences of other groups is warranted, it also means that the specific experiences of carers of people with dementia are considered in the model.

Additionally, the findings of this study have clear, practical utility both in research and in clinical practice. These will be discussed briefly here, and more fully in subsequent sections of this chapter.

With respect to research, hypotheses based on the presented model can be tested in future research. This could include, for example, a hypothesis that carers who have already accessed therapy did not experience therapy as invisible, or the hypothesis that providing jargon-free information about therapy would increase carers' understanding and/or use of therapy. Additional qualitative research could also help to increase understanding of how other groups of carers perceive therapy and how this influences their decisions. For example, carers of people experiencing mental health problems may be more aware that therapy is available, but perceive therapy as only for the care recipient. While this could fit within the presented model under Understanding of Therapy, it would also support the idea that different groups of carers may have different needs and different ideas about therapy.

In terms of the practical utility of the findings, some relatively straightforward and low-cost changes can be made to address some of the issues raised by carers. For example, counselling psychologists, therapists and service providers can review the wording of their websites to minimise technical language. They could also provide links to explanations of what their accreditation means and what therapy is. Therapy services could arrange to send a representative to team meetings at other services carers might use, to discuss what therapy is and offer suggestions for how and when to discuss therapy with carers. Services that already produce leaflets or posters could change where they display these to include locations suggested by carers in this study. Making these changes may increase the extent to which the system reflects the needs of carers.

4.7.2 Limitations

Some important limitations of this study should be noted. Firstly, despite the diversity of the sample, it was nonetheless a smaller sample than would have been ideal and some important demographic groups were not represented. Secondly, the use of grounded theory, while allowing the study to focus on issues identified by carers, may also have overlooked some factors which may not have come to mind for carers during the interview but may have been relevant (such as the role of stigma). Additionally, the study focused on a particular subset of carers who have not previously had therapy, and the findings may not represent the perceptions of other carers.

One of the limitations of this study is the small sample size. This contributed to limiting the diversity of the sample with respect to gender, race and ethnicity. It was anticipated that recruitment would be a challenge, and a number of steps were taken to attempt to mitigate this. This included promoting the study in public places such as supermarkets, as well as through carer support services, with the aim of reaching carers who were not accessing services. The term ‘counselling’ was included in the study advert over the term ‘talking therapies’ as a result of reports that carers from Black, Asian and other minority ethnic backgrounds experienced particular stigma in relation to the term ‘therapy’ (Akarsu et al., 2019). Additionally, attempts were made to increase the number of male participants by targeting recruitment at dementia cafés which the researcher had been advised were well attended by men.

While this study would have benefited from reaching a more demographically diverse range of participants, this limitation is not unique to the present study. Men and people from minority ethnic backgrounds are underrepresented in research in this area more generally (Akarsu et al., 2019). There is a substantial need for research regarding carers to find ways to engage more with these groups. Research specifically addressing the needs of these groups is one step towards this, but the ongoing challenge of ensuring representative samples suggests a need for research into how to best encourage participation from these groups.

An additional challenge which limited the sample size for this study is the impact of covid-19. When the UK went into lockdown, this raised questions regarding both how recruitment of participants might continue and how to ethically conduct further interviews. It was considered that carers may be facing additional burdens as a result of reductions in support services, loss of access to in-person support groups and less time away from their caring role. Furthermore, there were concerns that carers may not be able to speak privately and without interruption if interviews were held remotely via video call. The sixth interview had yielded no new categories, nor had the analysis identified any new properties of existing categories or codes which modified the properties of the categories. As a result of this and the above factors, it was decided that it would be most appropriate not to continue recruiting further participants in the circumstances. This is considered to be in keeping with Glaser and Strauss's (2017) perspective on theoretical saturation.

Glaser and Strauss (2017) note that the number of cases is less important than ensuring that categories and their properties are developed as fully as needed to achieve theoretical saturation; that is, when no new categories or ideas relating to categories continue to emerge from the data. Although complete theoretical saturation may be an unrealistic aim, particularly in smaller studies, it was considered that a sufficient degree of theoretical saturation had been achieved. To attempt to compensate somewhat for the small sample, previously analysed transcripts were revisited following new insights from subsequent interviews and further selective coding was conducted with new codes in mind. This is in line with Glaser and Strauss's (2017) perspective that earlier interviews do not generally need to be recoded unless the dataset is particularly small. Despite this, with such a small sample it is always possible that additional interviews would have yielded additional data which would have further developed the codes, concepts, categories and model, and thus highlighted that theoretical saturation had not been achieved. Glaser and Strauss (2017) note that the theories resulting from their method continue to be refined and developed not only during the analysis and write-up process, but also following completion of these stages and after publication. This seems particularly likely in the context of smaller studies such as this one. Further research to consider whether the findings hold or can be developed further with a larger sample of participants would therefore be warranted.

Although the use of a grounded theory methodology provided several benefits to the study, it also limited the findings in some ways. By focusing only on issues raised spontaneously by carers in response to the interview schedule, it is possible that some relevant aspects may not have come to mind for participants until after the interview had ended. Two possible approaches may have helped overcome this. Firstly, participants could have been sent the interview questions in advance. While this would have allowed participants time to consider the questions and their responses, it was also considered that carers who felt least knowledgeable about therapy might find the questions intimidating and that this might therefore present a barrier to their participation.

An alternative could have been to use a mixed-methods approach. This might have incorporated existing questionnaires regarding perceptions of therapy, such as the Expectations About Counselling- Brief form (EAC-B; Tinsley, 1982) which has been reported to have good psychometric properties (Anderson et al., 2013). Participants' responses to such questionnaires could then have been explored further within the semi-structured interviews. Incorporating a mixed-methods approach would also have enabled greater consideration of the extent to which scores on a measure of distress, such as the CORE-OM (Evans et al., 2000, 2002), and self-perceived coping may have similar or different roles in influencing carers' decisions regarding therapy.

Additionally, this study focused on the perceptions of a very specific group of carers, who were all caring for somebody with dementia and who had never previously had therapy. Although the findings bear resemblance to more general models of how people make decisions to seek help, it should not be assumed that the model automatically extends beyond the group represented in this study. Further research to explore whether the present model is a good fit for carers of people with different conditions would be beneficial in this regard.

4.8 Relevance to Counselling Psychology

While the findings of this study are relevant both to counselling psychologists and beyond the field of counselling psychology, counselling psychologists are well placed to respond to the findings. This is partly because of the nature of counselling psychologists' roles and partly because of the values underpinning counselling psychology.

Counselling psychologists work in a range of roles, including liaising with other professionals, working as part of a multidisciplinary team, working in private practice and taking on leadership and supervisory roles. These roles put counselling psychologists in a strong position to address some of the findings in this research. For example, counselling psychologists may help to increase the visibility of therapy for carers by highlighting to fellow team members that carers can benefit from therapy if they are distressed. Counselling psychologists could also liaise with referrers such as GPs, other members of the multidisciplinary team and social care professionals to educate them regarding the potential benefit of therapy for carers.

Counselling psychologists might contribute to enhancing carers' understanding of therapy by writing articles in clear, jargon-free language aimed at inclusion in, for example, newsletters from carer support services. Additionally, counselling psychologists in private practice, in particular, can review the language used in their website or profiles on other pages where carers may be searching for a therapist. This may include explaining the term 'counselling psychologist' and explaining what HCPC registration means, as well as avoiding technical terms regarding therapy models. It may also be helpful for counselling psychologists with relevant experience to indicate that they have worked previously with carers. Furthermore, counselling psychologists might consider including information addressing common concerns regarding therapy on their website, or in a blog post if they have a blog.

Although the findings of this study may be most obviously related to the stage before carers access therapy, they also indicate some potential considerations during therapy. Counselling psychologists should consider asking carers about their experience of trying to access therapy, including whether other professionals seem supportive of this. Carers who have found this a more challenging experience may benefit from greater explicit expressions of validation and empathy in order to build a trusting relationship with the counselling psychologist. Addressing experiences of invalidation may form an important part of the therapeutic work for some carers.

Additionally, counselling psychology is underpinned by values including the importance of social justice (Kennedy & Arthur, 2014) and valuing each client's subjective experience within their holistic context (Kasket & Gil-Rodriguez, 2011). This may mean that it is appropriate for counselling psychologists to engage with aspects of the findings which are not specific to therapy, such as carers having little time to attend therapy because of their caring commitments. Carers in the study reported a lack of respite care and difficulty attending appointments at specific times because of this. Counselling psychologists may have a role to play not only in providing flexible appointment times where possible, but also raising awareness of the important role carers play in society and the importance of providing adequate support to carers.

4.9 Wider Implications of the Findings: Policy and Practice

In addition to the specific implications for counselling psychology, the findings of this study also have broader relevance to other types of therapist and to other services and professionals supporting carers. With regard to increasing the visibility of therapy as an option for carers, services providing therapy may wish to ensure that service leaflets are available in carer support services. Additionally, carers indicated that information about therapy should be available in a wider range of public spaces, with specific suggestions including libraries, supermarkets, coffee shops, hairdressers and GP surgeries. While therapy services would want to consider the appropriateness of advertising in each of these venues (for example, people may share significant personal information with their hairdresser, but this does not mean they will necessarily be comfortable with their hairdresser seeing them reading information about therapy), it is important that information is provided in the places where it is most readily accessed.

This information should be available in easy-to-use formats and may include links to websites with videos or audio information for carers who have limited time to sit and read information but may be able to download information to listen to later, perhaps while doing other tasks. It is important that this information includes a clear description of what therapy is, avoids technical language, explains any therapy-specific terms that are used and includes guidance on how to access therapy.

It may also be necessary to raise awareness of therapy as an option for carers through education programs aimed at carer support workers, social care professionals and GPs. This may include myth-busting regarding therapy, explaining what therapy is and when it may be useful, and indicating how to make a referral. While carers may benefit from these programs, raising awareness of therapy could also benefit other people in need of therapy.

Awareness-raising education programs may also target carers more directly, for example through a presentation or workshop delivered to carer support groups or at a memory café. Drawing on the service user involvement model (Sainsbury Centre for Mental Health, 2001; 2010), this could include a contribution about their experience from somebody who has had therapy themselves. Hearing from somebody who has had therapy may help reduce perceptions of therapy as something that is not discussed much and may also have more credibility to carers than a presentation purely delivered by a therapist.

It is important that information about therapy is not only clear and visible in places that carers use, but also addresses the information they need. This includes:

- what therapy is
- highlighting that therapy does not need to be a last resort and that it is not solely for people in crisis or severely distressed
- addressing common concerns about therapy (including concerns that it may be overwhelming)
- indicating how to access therapy and
- providing details of how to ask any questions carers may have or where to find further information.

Finally, it is important to note that therapy will not always be the best decision for carers. Some carers will not wish to make use of additional information about therapy, or may decide based on additional information that therapy is not the right choice for them. Increasing awareness may help overcome some of the barriers to accessing therapy reported in this study, but this does not mean that therapy is the only option. Some carers will identify a greater need for practical support or support for the person they are caring for (Jegermalm & Sundström, 2013) rather than for therapy. This is a valid perspective, and the findings of this study should not be misunderstood as implying that all carers require therapy.

4.10 Reflexivity

4.10.1 Methodological Reflexivity

Glaser (2001) argues that constant comparative analysis is sufficient to expose and overcome any impact of the researcher on the data and the theory which is developed, and therefore views reflexivity as unnecessary. However, this view is not in keeping with the critical realist stance underpinning this research, nor with the value given to subjectivity and reflexivity in counselling psychology (Kasket & Gil-Rodriguez, 2011). It was therefore considered that an increased consideration of reflexivity would be important for transparency regarding the ways in which the researcher influences the research process and theory development.

I found grounded theory a useful approach in addressing this research topic. I appreciated being able to adapt my questions to follow up on ideas raised by carers, and found that the combination of constant comparative analysis with frequent memos helped me to spot codes and categories in need of further elaboration. The concept of theoretical sampling was a useful one, and encouraged me to consider the impact of who I was interviewing on the findings as well as whose voice had not been heard. It was disappointing to conclude recruitment due to the impact of Covid-19, although I believe the completed interviews provide a rich dataset for an initial examination of this question.

At the start of the project, I doubted my decision to pursue a grounded theory approach to produce a model regarding how carers' perceptions influence their therapy-seeking decisions. Thematic analysis could have been an alternative approach which would still have elicited carers' perceptions of therapy. Having completed the project, I believe that focusing on process and developing a grounded theory model enhanced the findings and that utilising this method helped ensure that the research extended, rather than replicated, previous findings.

Additionally, I had been concerned that I would find the process of conducting grounded theory overwhelming. While it has at times been challenging negotiating many codes, checking that the codes and categories I was developing were indeed grounded in the data and consistent both within and between categories, I found the structure of grounded theory sufficiently flexible yet clear to support me continuing to move through the process. I particularly valued memoing as a way to explore and document my thought process. Memos were also helpful in enabling me to put my own ideas to one side whilst returning to the data, which supported me in staying as grounded as possible in carers' own words.

I was conscious during the interviews of representing my profession and therapy in general, and wanted to provide an experience which would enable my participants to feel heard and, importantly, would not become a barrier to accessing therapy in the future. This meant that I was constantly weighing up whether asking for more information might feel intrusive, particularly with those participants who identified therapy as potentially intrusive. As has been mentioned previously, this limited the richness of the data, but I was reluctant to probe further and potentially reinforce or heighten participants' concerns about therapy being intrusive or the therapist being overbearing. Considering reflexivity in my memos, as suggested by Munkejord (2009), was important in helping me to strive to balance these concerns.

I am also conscious that, in choosing which categories to present, I have heavily influenced this analysis. Memos were important in helping me to consider why I felt one category was more relevant or saturated than another. During the coding process, I experienced codes and categories as emerging from the data, but in comparing codes and categories, I started to notice how some codes could be interpreted in different ways. For example, 'maybe later' and 'managing at the moment' could be considered as separate codes or as both indicating 'I don't need therapy yet.' Memos helped me to identify that although both codes were about not needing therapy yet, 'maybe later' focused more on therapy and potentially accessing support in the future, while 'managing at the moment' focused more on current coping. In this way, I became aware that on one level, constant comparative analysis does help to highlight researcher influence. At the same time, I was also aware that it was the way I, personally, read and understood the extracts that lead me to code them in this way. Therefore, my own experience of this grounded theory process was that constant comparison highlighted my influence and provided opportunities to reflect on my decisions, but I am not convinced that it counteracted my influence in the way Glaser (2001) argued.

The way I have presented my findings was influenced not just by the grounded theory approach, but also reflects the influences of critical realism. While Glaser (2001) argues that the theory emerges from the data as a result of constant comparative analysis and therefore offers accurate observations of the objective world, from a critical realist perspective the findings are viewed as an account of reality (Vincent & O'Mahoney, 2018). It seemed important to reflect this in the language used when writing this thesis; I have referred to my findings rather than to results precisely because I am conscious that the model I presented represents my own account and synthesis of the data. Working with accounts of reality also influenced how I developed and named categories, as it was important that categories were flexible enough to reflect differing accounts. For example, some carers described caring as challenging and difficult to cope with, while others described themselves as coping well. Self-perceived coping as a category needed to be flexible enough to reflect both these accounts. In this way, critical realism and my approach to grounded theory worked well together as both emphasised the importance of categories which can account for a variety of situations and experiences within the area being studied (Glaser & Strauss, 2017; Vincent & O'Mahoney, 2018).

Additionally, I was very aware of the double-role I held as a researcher and therapist. This seems significant in potentially influencing how participants experienced the research interview and what they felt able to disclose. Ruth asked me after the interview whether I would be working as a researcher or clinician after I qualify, so participants may have been less aware of my dual role than I was. I was also careful to explain that there was no right or wrong answer and that I was keen to hear their honest opinions. Nonetheless, it is possible that participants may not have felt comfortable to fully disclose any concerns they may have held regarding therapy.

4.10.2 Personal Reflexivity

Undertaking this project has had a significant impact on me both personally and professionally. As a trainee counselling psychologist, it has deepened my understanding of the importance of considering both an individual's subjective experience and the wider context in which that experience is situated. I was particularly struck by the sense from carers that therapy was completely invisible to them, which prompted me to reflect on the idea that awareness of therapy is in itself a privilege. My background caring for somebody with mental health problems has meant that I have always been aware that therapy is available, should I want it. I was incredibly saddened by the realisation that the carers in this study did not have that knowledge. The experiences carers described of feeling unheard misunderstood by other professionals did not surprise me, but reflecting on these experiences in conjunction with the other findings of this study has left me with a sense of carers being as invisible to therapy services as therapy seems to have been to the carers in this study. I am passionate about equality and improving access to services where support is needed, and completing this project has reinforced this drive.

I was very intrigued that carers told me they had no sense of therapy as an option that was available to them and that it was rarely spoken about – and yet often could tell me a fair amount about what therapy is and relate this to the experiences of people they knew. It is possible that they were focusing specifically on therapy for carers when they spoke about not being aware of therapy – this would also fit with their perceptions of therapy as not being for daily life problems but for more severe distress. Given that most carers in this study also felt that therapy would be relevant to carers, it may be that increasing the visibility of therapy specifically as an option for carers is important as a separate focus from raising awareness of therapy more generally.

Before starting this project, I had been thinking about how my interest in working with carers might play out in my career. I was conscious that most carers support services in my local area did not have access to a therapist of any description; while this seemed the most natural area for me to work in, it was not an area with jobs available. Equally, NHS services that support carers in my area tend to be specialist services that support carers as an adjunct to their primary clients. At the same time, carers may not be in a position to afford private therapy. Thus, despite the existence of services such as IAPT, I have felt that carers may be correct in their assumption that therapy is not available which will consider the impact of their caring role. I am still working through how this will impact my career choices, but in the meantime, it has prompted me to deliver training on working with carers for the local IAPT service with which I completed one of my placements.

Finally, one of the most unexpected outcomes from this project was being contacted by two participants who told me that they had accessed therapy following the interview with me. Both expressed gratitude for the project and for the information I had provided about local options to access therapy, as well as what therapy is. I had not expected that this project would make an immediate impact, but my impression from my participants is that the project itself increased the visibility of therapy for them and provided an opportunity for them to ask questions about therapy and learn how to access it. This was incredibly humbling and highlighted the very real interaction between research and practice.

4.11 Suggestions for Further Research

The findings from this study indicate a number of areas for further research, many of which have already been mentioned. Further studies might examine how the presented model represents the experiences of a wider range of carers, including carers from a broader range of ethnic backgrounds and caring for people with difficulties other than dementia. Additionally, it would be useful to investigate how carers who have accessed therapy overcame the barrier of therapy being perceived as a battle to access. Furthermore, research that attempts to unpick how carers move from deciding to access therapy to actually attending their first appointment would extend the findings of this study.

As has been noted throughout this chapter, aspects of the model presented here bear similarity to findings regarding help-seeking in student populations, while a number of the findings in relation to the threat level of therapy, self-perceived coping and the perception of therapy as a battle to access are similar to ideas about therapy reported in the general population. This suggests that the model may have wider applicability to other groups beyond carers of people with dementia. Further research could therefore explore whether the present model also accounts for how people in other groups make decisions regarding accessing therapy, such as:

- carers of people with conditions other than dementia
- younger people
- men
- people from marginalised groups

It may be particularly important to explore the experiences of people from marginalised groups independently of each other (for example, considering separately the extent to which the model accounts for how LGBTQIA+ people, disabled people and people from minoritized ethnic groups make decisions regarding accessing therapy). People in these groups are likely to experience different barriers and challenges in accessing therapy and to have different considerations. Further research is therefore needed to clarify whether the categories in the current model provide sufficient flexibility to account for their experiences. Some experiences are likely to be specific to different groups; for example, understanding that therapy can potentially help with what you are experiencing can be influenced by cultural and linguistic factors, such as whether there is a word for an experience in a given language and whether that experience is culturally conceptualised as warranting therapy or as similar to other general challenges in life (Loewenthal et al., 2011). Other experiences may be similar amongst marginalised groups, such as concerns about whether the therapist will have sufficient understanding of the group(s) individuals belong to and practice in a non-discriminatory way (Goldbach et al., 2019; Loewnthal et al., 2011; Smith & Turell, 2017).

Additionally, stigma and social support were found to play in important role in previous models of help-seeking (Cramer, 1999; Saunders, 1993, 1996) but were not highlighted by carers in the current study. Given the oppression experienced by people from minority and minoritized groups, these factors may be particularly saliant to their experiences. The high levels of stigma regarding therapy and mental health problems in Black, Asian and minoritized ethnic (BAME) groups (Loewenthal et al., 2011), for example, may be part of the perceived threat level of therapy. However, it could also be found to form a separate category in its own right, which may in turn influence visibility of therapy, coping strategies, perceptions of therapy as threatening and the challenge of accessing therapy. It is also possible that stigma may have other roles which were not highlighted in the current findings. Further research aimed at establishing the extent to which the current model accounts for or needs adapting to account for the experience of BAME and other minority groups is therefore warranted. Such research may also benefit from considering the role of intersectionality.

It could be particularly beneficial for future research to utilise a mixed-methods approach, for example to gain both a qualitative and quantitative understanding of how therapy is perceived using a combination of interviews and the expectations about counselling (EAC-B) questionnaire (Tinley, 1982). This might allow perceptions and expectations to be explored which might not have been mentioned in the study, either due to carers not thinking of them during the interview or due to the potential that carers may have felt uncomfortable disclosing concerns about therapy to a researcher with a dual role as a therapist. While the questionnaires might highlight additional concerns, combining these with interviews would provide the opportunity to explore these concerns in more depth and also explore whether there was anything participants identified as missing from the questionnaires.

It would also be useful for further research to consider combining quantitative data regarding how many participants go on to access therapy and how long it takes for them to attend an appointment with qualitative exploration of their hopes and fears and practical experience of attempting to access therapy. This may help to illuminate further differences between groups who decide to access therapy, decide not to access therapy, successfully access therapy, or attempt to access therapy without success. In turn, this may provide further insights into what actions could be implemented to make it easier for those who wish to access therapy to do so.

4.12 Concluding Remarks

Caring for someone with dementia can have a significant negative impact on carers' physical and psychological well-being. Evidence suggests that therapy may help address this impact, but that carers do not always seek therapy despite significant distress. Previous research has suggested that carers who completed therapy appreciated the safe space to talk. This study aimed to investigate how carers perceive therapy and how these perceptions influence carers' decisions regarding accessing therapy. The resulting model provides insight into this process and extends existing models of help-seeking. The findings highlight the interaction between systemic factors (such as how services are made visible) and carers' perceptions of therapy. The crucial role of becoming aware of therapy in carers' decision-making indicates the importance of accurate, visible information about therapy being available to carers.

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Appendices

Appendix A: Approach Taken for Systematic Literature Review

To identify published articles, the following databases were searched: EBSCOHost, PsychINFO, Web of Science.

To identify policy documents and grey literature, such as reports from carers' organisations, a general search was also conducted using Google.

Search terms were initially generated by reviewing papers I was already aware of, thinking of potentially relevant terms, and using a thesaurus to identify synonyms. The search terms and synonyms used are outlined in Table A1.

Table A1

Search Terms and Synonyms Used

Initial Search Term	Synonyms/Alternative phrasing
Care* (to identify results using carer or caregiver)	Unpaid relative, friend or family support, family member, support network
Dementia	Alzheimer's, memory loss
Mental health	Psychological wellbeing, burden, depression, anxiety, stress

Each search term was used in combination with each synonym. The title of each paper was initially reviewed to determine relevance. The abstracts of seemingly relevant papers were reviewed and the full article was obtained where the abstract suggested the article was or might be relevant. The keywords of relevant articles were reviewed to identify any additional search terms to add. The reference lists of relevant articles were reviewed to identify any further papers.

Articles were included if they:

- were written in English
- considered either the impact of caring on psychological wellbeing or interventions to improve carers' psychological wellbeing (either as the sole focus or alongside a focus on people with dementia themselves), and
- either focused specifically on carers of people with dementia or included at least some carers of people with dementia in their sample

Articles were excluded if they:

- were not written in English
- focused solely on a subgroup of carers other than carers of people with dementia
- focused only on the psychological wellbeing of the person with dementia and did not also consider the carers' wellbeing

While priority was given to studies published between 2005-2020 to capture recent developments, key papers from earlier dates were also included. These were identified from the reference lists of other included studies.

As the literature review progressed, more specific searches were subsequently carried out following the initial review. These particularly aimed to identify benefits of caring, perceptions of therapy and interventions to support carers. Aside from a tighter focus for later searches, inclusion and exclusion criteria remained the same.

Search terms used for benefits of caring: Benefits, positives, joys; combined with synonyms for care* and dementia noted in above table.

Search terms used for interventions: Interventions, support, programmes, treatment, therapy, counselling, psychology, psychological; combined with synonyms for care* and dementia noted in above table.

Search terms used for perceptions of therapy: Perceptions, perceived, ideas, expectations, hopes, wishes, desires, fears, concerns, assumptions.

Appendix B: Text Advert for Newsletters and Online Forums

CITY
UNIVERSITY OF LONDON
EST 1894

Volunteers Needed!

Carers of people with Alzheimer's are invited to take part in research into carers' understanding of psychological therapy. **We are keen to hear from you if you care for someone with Alzheimer's for 10 or more hours per week and have not accessed therapy in the past**. It is hoped that this research will help us understand more about what carers think about the possibility of therapy. You do not need to know anything about therapy or what it might involve to take part – we are interested in your views and ideas.

You will initially be invited to speak in confidence to the researcher by telephone, during which time you will have the opportunity to find out more about the research and complete a brief questionnaire about your mood. This allows both you and the researcher to check that taking part is right for you at this time. Following this, you will usually be invited to attend an individual meeting to discuss your understanding of therapy, which will be audio-recorded and is expected to last around 60-90 minutes. Travel expenses that are less than the cost of a 1-day London Zones 1-6 Travelcard can be reimbursed, and the meeting can be arranged at a location of your choosing, as long as this allows you to speak freely.

If you are interested in taking part or would like to find out more, please contact Lucy Harris at [redacted]

This study has been reviewed by, and received ethics clearance through the Psychology Research Ethics Committee, City, University of London [PSYETH (P/F) 16/17 77] and the

Health Research Authority (London-Brighton and Sussex Research Ethics Committee) [17/LO/1515].

Appendix C: Leaflet to be shared with potential participants identified by assessment staff at a local IAPT service

Lucy Harris
Psychology Department
School of Arts and Social Sciences
City, University of London
Northampton Square
EC1V 0HB
E-mail: [redacted]

Dear [insert name],

Thank you for your interest in hearing more about a research study that [INSERT SERVICE NAME] is supporting. Please read this information carefully before deciding whether to take part.

My name is Lucy Harris, and I am a Trainee Counselling Psychologist conducting research to understand how carers of people with dementia view therapy, as part of my Doctoral thesis. I am keen to hear from you if you are **caring for someone with dementia for at least 10 hours per week and you have not previously had any therapy**. You do not need to know anything about therapy or what it might involve to take part – we are interested in your views and ideas. It is hoped that this research will help us understand more about what carers think about the possibility of therapy.

If you decide to take part, you will initially be invited to speak in confidence to the researcher by telephone, during which time you will have the opportunity to find out more about the research and complete a brief questionnaire about your mood. This allows both you and the researcher to check that taking part is right for you at this time. Following this, you will usually be invited to attend an individual meeting to discuss your understanding of therapy, which will be audio-recorded and is expected to last around 60-90 minutes. Travel expenses that are less than the cost of a 1-day London Zones 1-6 Travelcard can be reimbursed, and the meeting can be arranged at a location of your choosing, as long as this allows you to speak freely.

It is entirely your choice whether you wish to take part in this study. Please be assured that the support you receive from this service will not be affected in any way by your decision. If you do decide to take part, your participation will remain anonymous. Your participation will not be documented on your file at [INSERT SERVICE NAME], and no-one involved in carrying out the research will be involved in the support you receive from [INSERT SERVICE NAME].

If you are interested in taking part or would like to find out more, please contact Lucy Harris at [redacted]

This study has been reviewed by, and received ethics clearance through the Psychology Research Ethics Committee, City, University of London [PSYETH (P/F) 16/17 77] and the Health Research Authority (London-Brighton and Sussex Research Ethics Committee) [REC reference 17/LO/1515].

Thank you for taking the time to read this information.

Best wishes,

Lucy Harris
Trainee Counselling Psychologist
City, University of London

Appendix D: Recruitment Flyer

Lucy Harris

Psychology Department

School of Arts and Social Sciences

City, University of London

Northampton Square

EC1V 0HB

E-mail: [redacted]

Department of Psychology

City, University of London

DO YOU PROVIDE CARE FOR A FRIEND OR FAMILY MEMBER WITH DEMENTIA, FOR 10 OR MORE HOURS PER WEEK?

We are seeking volunteers to take part in a study exploring your ideas about therapy. If you have never had therapy or counselling, we would like to hear from you.

You would be asked to speak with the researcher, in confidence, twice:

1) A 10-minute telephone call to complete a brief questionnaire about your mood and check that taking part is right for you

2) A one-to-one, audio-recorded interview (lasting approximately 60-90 minutes, in a place of your choosing) regarding your understanding of therapy.

In appreciation for your time, travel expenses up to the cost of a 1-day London zones 1-6 travelcard can be reimbursed.

For more information about this study, or to take part, please contact:

Lucy Harris (Researcher), City, University of London Psychology Department
Email: [redacted]

This study is supervised by Prof. George Berguno [redacted]). It has been reviewed by, and received ethics clearance through the Psychology Research Ethics Committee, City University London [PSYETH (P/F) 16/17 77] and the Health Research Authority (London-Brighton and Sussex Research Ethics Committee) [REC reference 17/LO/1515].

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on 020 7040 3040 or via email: Anna.Ramberg.1@city.ac.uk

Appendix E: Participant Information Sheet

Lucy Harris

Psychology Department

School of Arts and Social Sciences

City, University of London

Northampton Square

EC1V 0HB

E-mail: [redacted]

Title of study A Grounded Theory Analysis of Dementia Carers' Perceptions of Psychological Therapy

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

This study aims to explore what you understand about psychological therapy, including your thoughts about therapy as a possibility (or otherwise) for you. We are interested in your views and ideas, whatever these are, in an open way. Psychological therapy is sometimes also called talking therapy, or just therapy or counselling. This study is interested in the perceptions and ideas carers of people with dementia have about therapy, including their understanding of what therapy is, and their hopes, expectations and concerns about therapy. We hope that this will help us to explain what therapy is more clearly and tailor therapy more effectively for carers of people with dementia (including understanding when therapy does not seem relevant to carers). The study is being undertaken as part of the researcher's Professional Doctorate in Counselling Psychology.

Why have I been invited?

You have been invited as an adult carer of someone with dementia to help us further our understanding of carers' views. We are seeking the views of people who have not previously accessed therapy. You do not need to know anything about therapy or what it might involve to take part – we are interested in your views and ideas.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in part or all of the project. Once analysis has begun, it will not be possible to withdraw your responses, as they will have been anonymised and collated with responses from other participants. You can choose not to continue with the study at any point prior to this.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw as outlined above and without giving a reason.

What will happen if I take part?

- You will be asked to speak, in confidence, with the researcher by telephone. During the telephone call, you will be asked to complete a brief questionnaire regarding your mood and will have the opportunity to find out more about your participation and ask any initial questions you may have. This allows both you and the researcher to check that taking part in this study feels right for you at this time.
- If you and the researcher agree to meet following speaking on the telephone, you will meet with the researcher for approximately 60-90 minutes to discuss your understanding of psychological therapy. This will include considering how your

experiences as a carer may impact on the extent to which you feel psychological therapy is (or is not) relevant to you. This meeting will be audio-recorded.

- The meeting will be held at a time and place of your choosing, as long as you are able to speak freely and confidentially.
- After the meeting, your responses and those of other participants will be analysed to identify themes regarding carers' views of therapy.

Expenses and Payments

Travel expenses up to the current cost of a London Zones 1-6 one-day Travelcard will be reimbursed.

What do I have to do?

You will be asked to meet with the researcher to discuss your perceptions of and views about talking therapies. The researcher will ask some questions about this to help prompt you.

What are the possible disadvantages and risks of taking part?

Although unlikely, some people may find it distressing to talk about their views on talking therapies, or find that it brings up unpleasant emotions related to their experience of caring. If this happens, you are welcome to stop the conversation, and the researcher may ask if you wish to stop if you are visibly upset. You will also be offered information about support and therapy services at the end of the meeting, should you wish to take this.

What are the possible benefits of taking part?

While there are no explicit benefits of taking part, some people find that participating in research gives them a sense of satisfaction in making a contribution, or a feeling that they are helping others by sharing their experience.

What will happen when the research study stops?

Information will be stored in locked filing cabinets and password-protected files on the researcher's password-protected computer for up to five years after completion of the study. These files will only be accessible to the researcher and their supervisor. All data will be securely destroyed after this time.

Will my taking part in the study be kept confidential?

- Your information will only be accessible to the researcher and their supervisor.
- Names and identifying information will be removed and replaced with a pseudonym of your choice to preserve confidentiality in any written transcript of the interview and any write-up of the findings.
- The audio-recording will be transcribed and stored in a password-protected file accessible only to the researcher and their supervisor, and will be destroyed once analysis is complete.
- Direction quotations from your interview may be used in the researcher's thesis or any future publication of the findings. Any potentially identifying information associated with quotations will be carefully changed or removed to preserve confidentiality.
- The information you provide will only be used for the purposes of this study.
- Confidentiality will only be broken where this is deemed necessary by the researcher and supervisor to prevent significant imminent harm to you or someone else. This is rare, but if it does happen it will be discussed with you prior to sharing your information, unless discussing it with you would increase the risk of significant harm occurring. Generally you will be made aware of the reasons for breaking confidentiality and who your information with be shared with. Your consent is usually sought to share information in this way.

Who is the data controller for this research project?

City, University of London is the data controller for the personal data collected for this research project. If you have any data protection concerns about this research project, please contact City's Information Compliance Team at dataprotection@city.ac.uk

What will happen to the results of the research study?

The results will be written up and included as part of the researcher's doctoral thesis, in partial fulfilment of their Professional Doctorate in Counselling Psychology. They may be published or presented at academic conferences. A summary will be made available to participants on request; please contact Lucy Harris using the details below if you would like a summary. Every effort will be made to ensure that anonymity is maintained, no matter how the results are shared or where they are published.

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

You are free to stop the interview and leave, without explanation or penalty, at any time up to the point at which analysis has started. After this point it may no longer be possible to identify your individual responses, as they will have been made anonymous.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speakto a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *A Grounded Theory Analysis of Alzheimer's Carers' Perceptions of Psychological Therapy.*

You could also write to the Secretary at:

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City, University of London
Northampton Square

London

EC1V 0HB

Email: Anna.Ramberg.1@city.ac.uk

City, University of London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City, University of London Psychology Ethics Committee, [PSYETH (P/F) 16/17 77] and the Health Research Authority (London-Brighton and Sussex Research Ethics Committee) [REC reference 17/LO/1515].

Further information and contact details

Researcher: Lucy Harris, Trainee Counselling Psychologist, [redacted]

Supervisor: Prof. George Berguno, Counselling Psychologist and Lecturer, [redacted]

Thank you for taking the time to read this information sheet.

Appendix F: Consent Form

Lucy Harris

Psychology Department

School of Arts and Social Sciences

City, University of London

Northampton Square

EC1V 0HB

E-mail: [redacted]

Title of Study: ***A Grounded Theory Analysis of Dementia Carers' Perceptions of Psychological Therapy***

Ethics approval code: [PSYETH (P/F) 16/17 77]

Please initial box

.	I agree to take part in the above City, University of London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I have been given the opportunity to ask any questions about the study and these have been satisfactorily answered. I understand that my participation will involve: • Completing a questionnaire regarding my mood • being interviewed by the researcher	

	• allowing the interview to be audiotaped • use of direct quotations in the written thesis and other potential publications, on the understanding that my responses will have been made anonymous and I will not be identifiable to others from the quotations used.	
.	This information will be held and processed for the following purpose(s): • To answer the research aims explained in the Participant Information Sheet • For the researcher to complete and write up their doctoral thesis, and potentially to publish the findings of the study • For a summary of findings to be provided to participants on request. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. The only exception to this in the rare case when it is necessary to share information in order to prevent risk of significant harm to myself or others. I understand that in this case I will be informed of the reason for sharing this	

	information and where it will be shared and my consent to share the information will be sought, unless the researcher and supervisor both agree that discussing this with me would increase the risk of significant harm occurring.	
.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw up until the point at which analysis has started, after which it may not be possible to identify my individual responses due to these having been made anonymous.	
.	I agree to City, University of London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the General Data Protection Regulations 2018.	
.	I agree to take part in the above study.	

If you would like a summary of the results once the study has been completed, please indicate how you would like to receive this:

☐ I do not want to be sent a summary of the results

☐ I would like a summary sent by e-mail. Please send it to this e-mail address:

☐ I would like a summary sent by post. Please send it to this address:

____

____

____________________	____________________________	____________
Name of Participant	Signature	Date
____________________	____________________________	____________
Name of Researcher	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Appendix G: Initial Interview Schedule

Please could you tell me a bit about how long you have been caring and what support you get with this?

What do you know about therapy?

What have you heard about therapy? Prompt for anecdotes.

Have you ever considered having therapy? If yes: What thoughts did you have about therapy? Prompt for: Expectations, hopes, anxieties, factors in decision. If no: Can you tell me a bit about what makes you say no? Prompt for: Particular concerns, anxieties.

Is there any other support which might feel more useful to you than therapy? Probe to understand why alternatives are seen as more useful

Is there anything else you would like to tell me about your views on talking therapies?

Backup questions:

Can you tell me what might put you off accessing therapy?

What might make it easier for you to access therapy, if you wanted to do so?

Appendix H: Revised Interview Schedule

Please could you tell me a bit about how long you have been caring and what support you get with this?

Can you share a bit with me about what the impact of caring for someone with dementia has been for you? Prompt: Impact on lifestyle, relationships

Before you heard about this research project, did you know the psychological therapy might be available to carers? (If so, prompt for how they knew this. If not, is it information they would have liked to know? Where/whom from?

What are the first three words or images that come to mind when you think about psychological therapy? Prompt: Can you say more about what those words/images mean to you? Where/how do you think you learned those ideas about therapy?

What have you heard about therapy? Prompt for anecdotes.

Have you ever considered having therapy? If yes: What thoughts did you have about therapy? Prompt for: Expectations, hopes, anxieties, factors in decision. If no: Can you tell me a bit about what makes you say no? Prompt for: Particular concerns, anxieties.

Is there any other support which might feel more useful to you than therapy? Probe to understand why alternatives are seen as more useful

Is there anything else you would like to tell me about your views on talking therapies?

Backup questions:

Can you tell me what might put you off accessing therapy?

What might make it easier for you to access therapy, if you wanted to do so?

Appendix I: Ethics Approval Letter from City, University of London Psychology Ethical Review Committee

Psychology Research Ethics Committee

School of Arts and Social Sciences

City University London

London EC1R 0JD

27th March 2017

Dear Lucy Harris and George Berguno

Reference: PSYETH (P/F) 16/17 77

Project title: A Grounded Theory Analysis of Alzheimer's Carers' Perceptions of Psychological Therapy

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

(a) Recruit a new category of participants

(b) Change, or add to, the research method employed

(c) Collect additional types of data

(d) Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee ([redacted]), in the event of any of the following:

(a) Adverse events

(b) Breaches of confidentiality

(c) Safeguarding issues relating to children and vulnerable adults

(d) Incidents that affect the personal safety of a participant or researcher

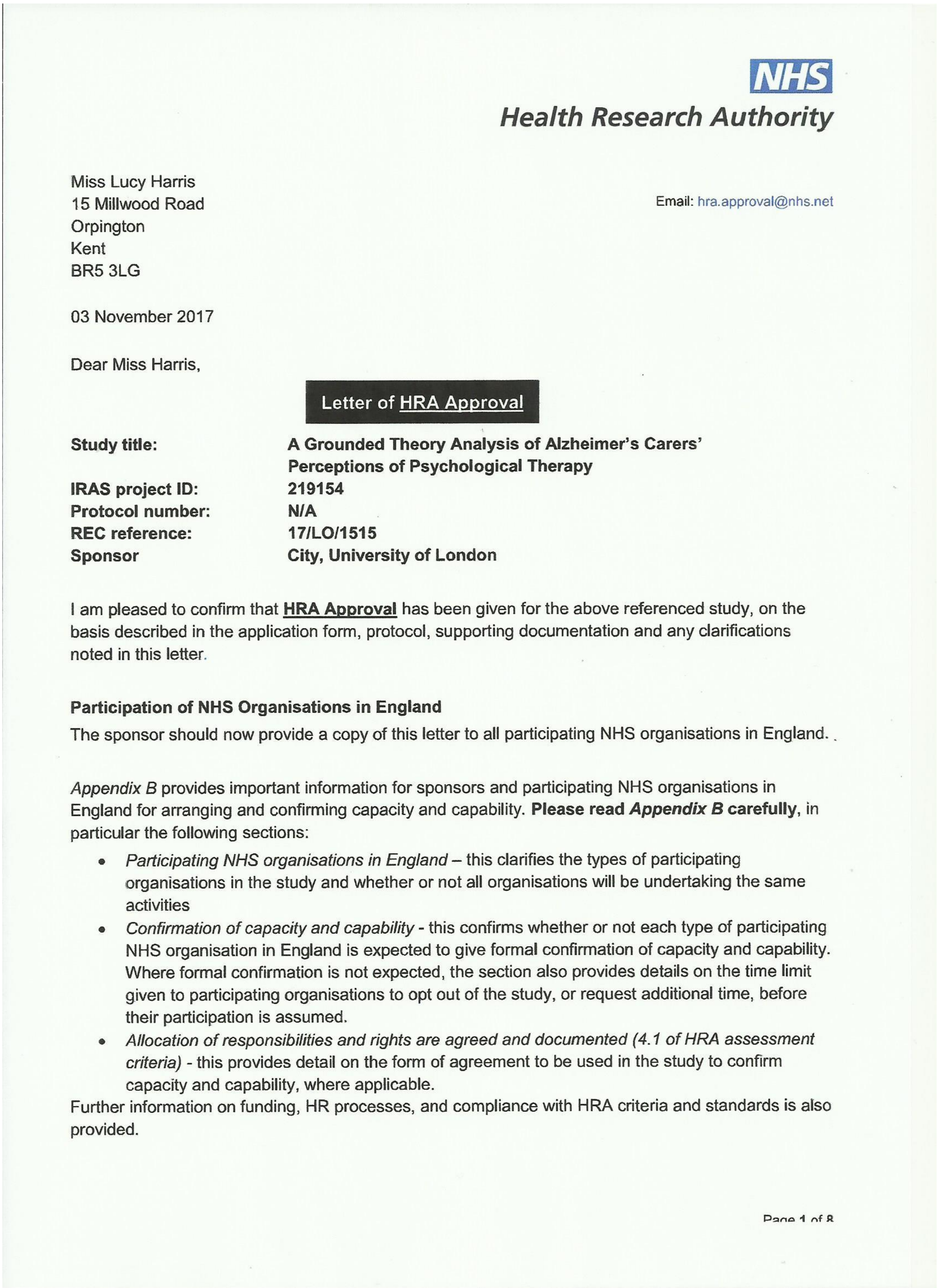
Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford	Richard Cook
Course Officer	Chair
Email: [redacted]	Email: [redacted]

Appendix J: Ethics Approval Letter from the Health Research Authority



NHS
Health Research Authority

Miss Lucy Harris
15 Millwood Road
Orpington
Kent
BR5 3LG

Email: hra.approval@nhs.net

03 November 2017

Dear Miss Harris,

Letter of HRA Approval

Study title:	**A Grounded Theory Analysis of Alzheimer's Carers' Perceptions of Psychological Therapy**
IRAS project ID:	**219154**
Protocol number:	**N/A**
REC reference:	**17/LO/1515**
Sponsor	**City, University of London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

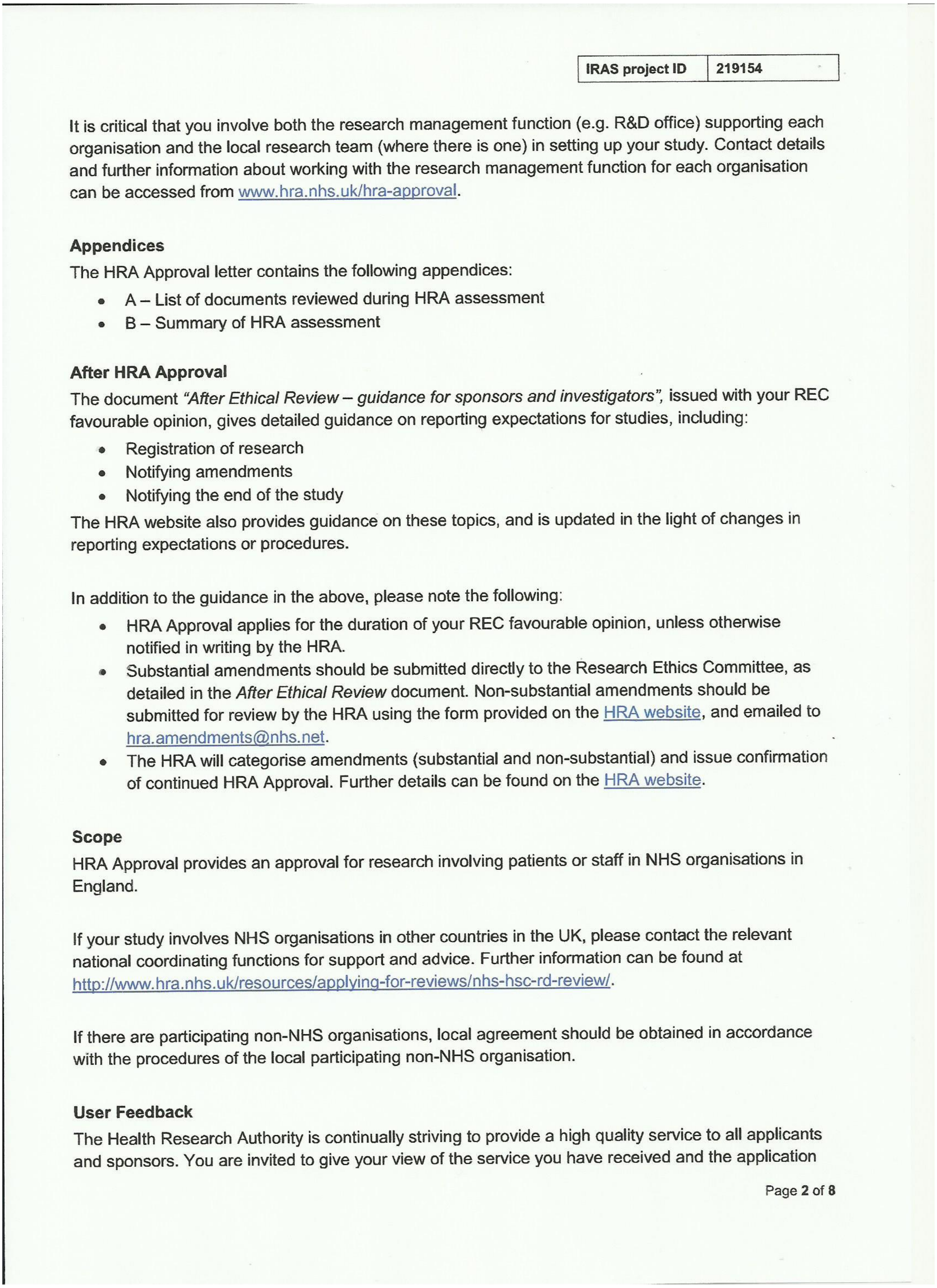
Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.



It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

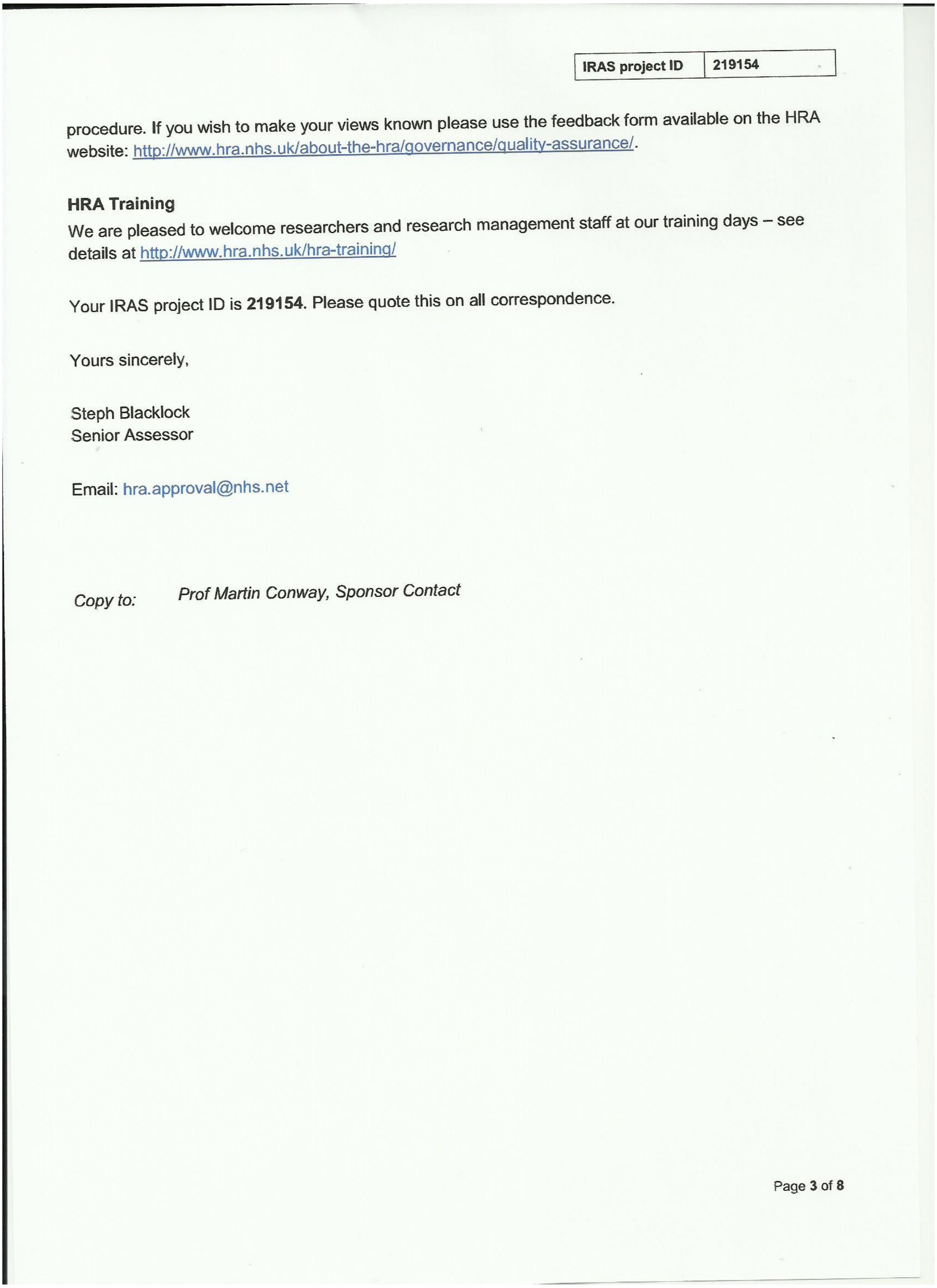
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application



procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **219154**. Please quote this on all correspondence.

Yours sincerely,

Steph Blacklock
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Prof Martin Conway, Sponsor Contact*

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [City, University of London REC Approval letter]		27 March 2017
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Agreement in Principle from Bromley and Lewisham Mind]	N/A	20 January 2017
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Correspondence with Talk Together Bromley (then known as Bromley Working for Wellbeing)]		
Contract/Study Agreement template [University Ethics Approval Letter]		27 March 2017
Copies of advertisement materials for research participants [Text Advert]	1.1	25 June 2017
Copies of advertisement materials for research participants [Recruitment poster]	1.1	25 June 2017
Covering letter on headed paper [Cover letter]	1	21 July 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Document]		
Interview schedules or topic guides for participants [Initial Interview Schedule]	2.1	25 June 2017
IRAS Application Form [IRAS_Form_22082017]		22 August 2017
Letter from sponsor [Sponsorship letter]	1	17 July 2017
Letters of invitation to participant [Invitation letter]	1.1	25 June 2017
Participant consent form [Participant consent form]	2.0	08 October 2017
Participant information sheet (PIS) [Participant debrief sheet]	1.1	25 June 2017
Participant information sheet (PIS) [Participant information sheet]	1.3	08 October 2017
Research protocol or project proposal [Brief Research Proposal]	1	21 July 2017
Summary CV for Chief Investigator (CI) [Lucy Harris CV]	1	25 June 2017
Summary CV for student [CV Lucy Harris]	1	25 June 2017
Summary CV for supervisor (student research) [CV Prof George Berguno]	1	25 June 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol]	1	21 July 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol]	1	21 July 2017
Validated questionnaire [PHQ-9]		

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

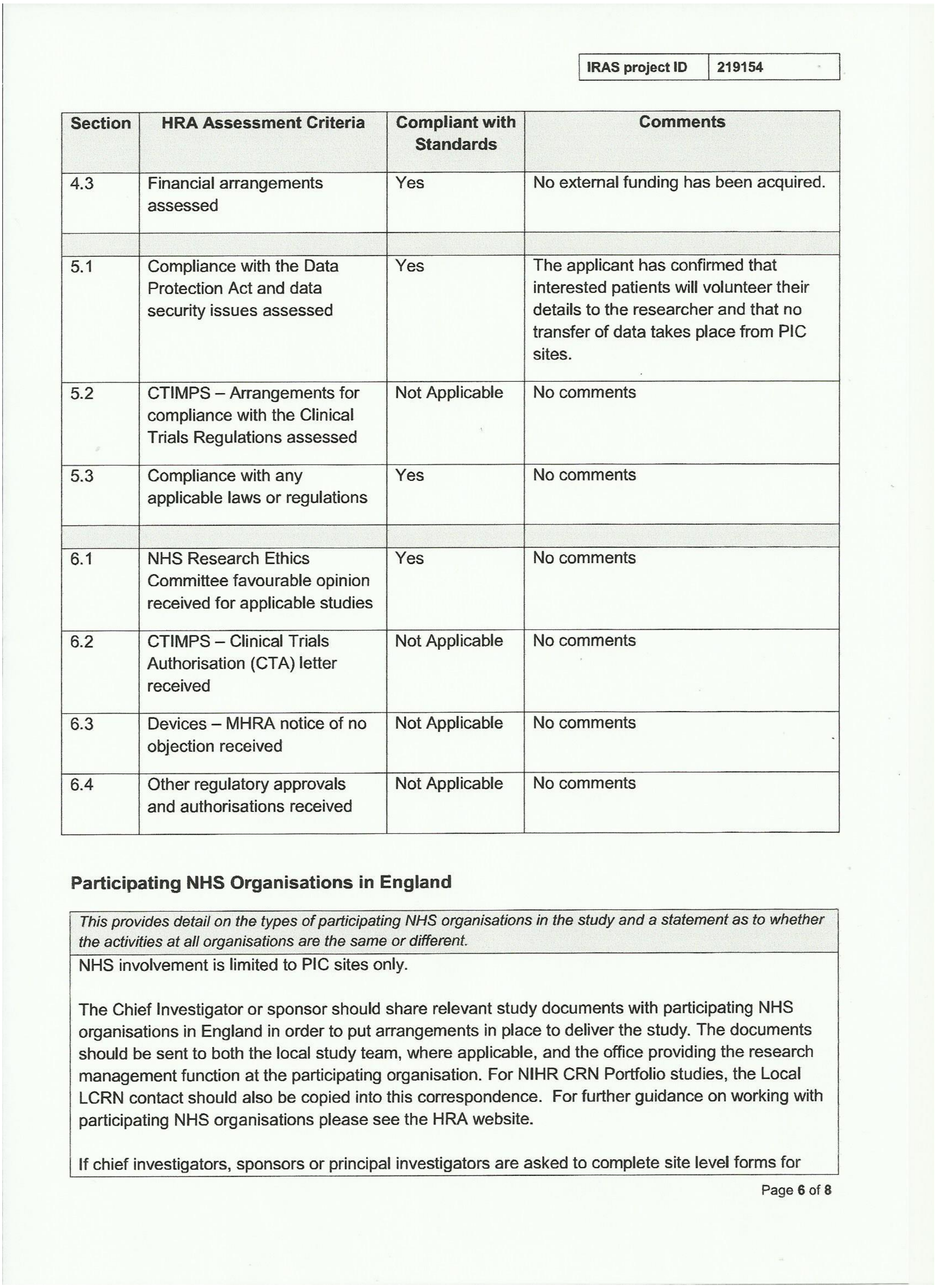
For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Miss Lucy Harris
Email: Lucy.Harris@city.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	HRA Approval applies to the use of the PIC site(s) only.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	No Statement of Activities and Schedule of Events provided for the NHS organisations.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study



Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.3	Financial arrangements assessed	Yes	No external funding has been acquired.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The applicant has confirmed that interested patients will volunteer their details to the researcher and that no transfer of data takes place from PIC sites.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

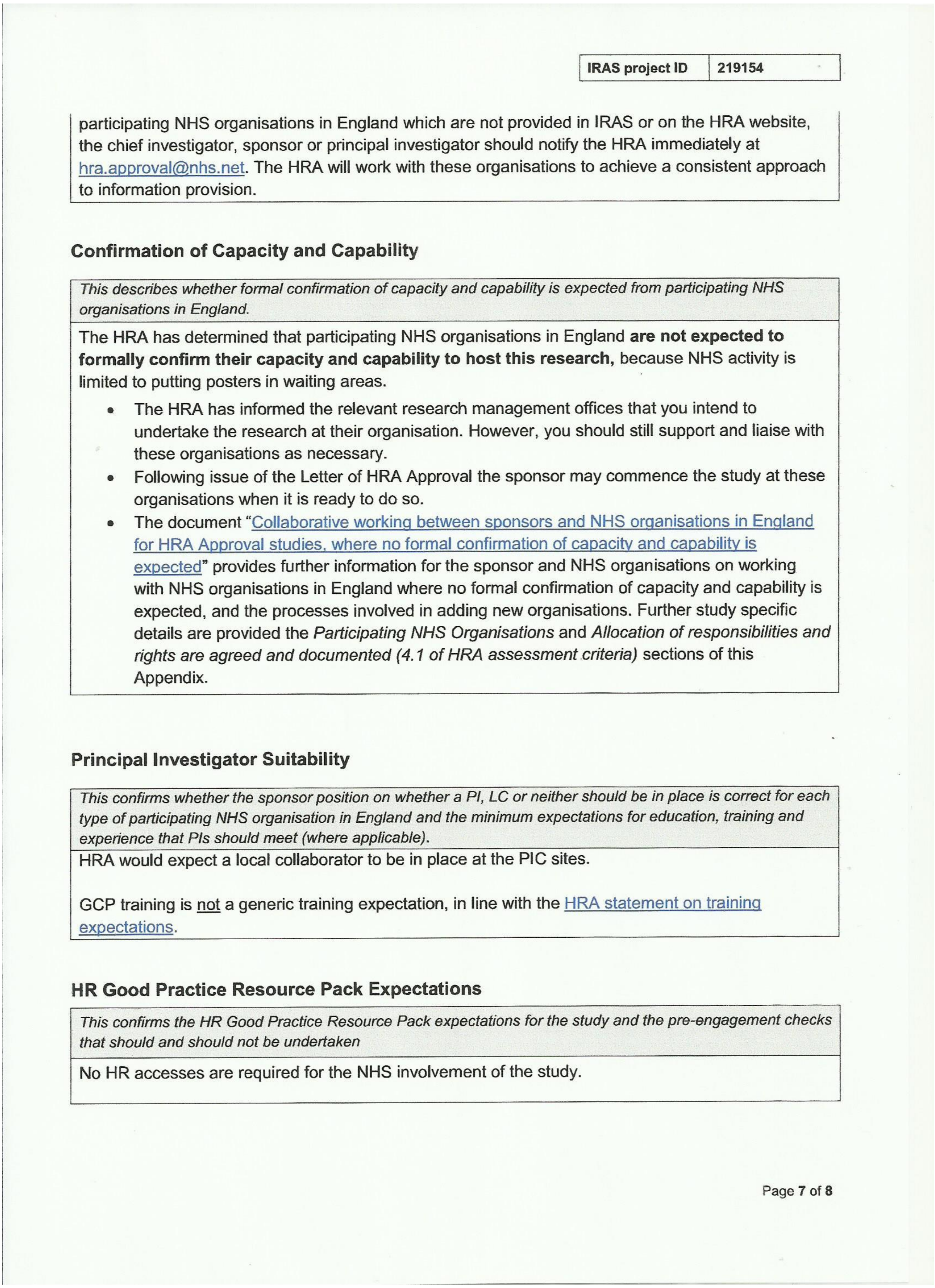
Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

NHS involvement is limited to PIC sites only.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for



participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

The HRA has determined that participating NHS organisations in England **are not expected to formally confirm their capacity and capability to host this research,** because NHS activity is limited to putting posters in waiting areas.

- The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary.
- Following issue of the Letter of HRA Approval the sponsor may commence the study at these organisations when it is ready to do so.
- The document "Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

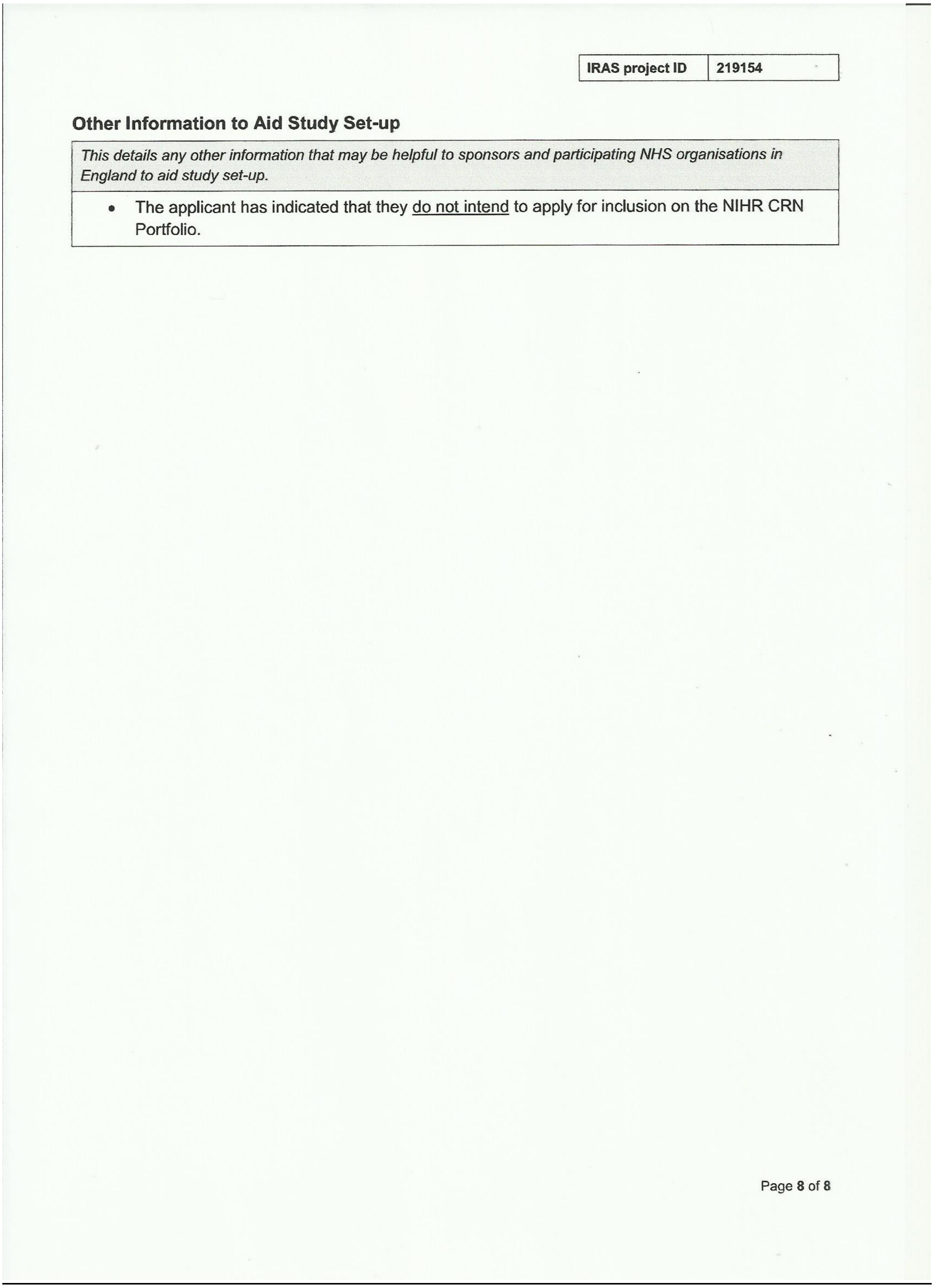
HRA would expect a local collaborator to be in place at the PIC sites.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

No HR accesses are required for the NHS involvement of the study.



IRAS project ID	**219154**

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
• The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix K: Approval of Amendment Documents from the London-Brighton and Sussex Research Ethics Committee.

IRAS Project ID 219154. HRA Approval for the Amendment

[redacted]

Tue 04/12/2018 09:51

To:

- Harris, Lucy [redacted]
- UG-Ramberg, Anna <[redacted]

[redacted] UG-Ramberg, Anna <[redacted]

Dear Miss Harris,

IRAS Project ID:	219154
Short Study Title:	Alzheimer’s Carers’ Perceptions of Psychological Therapy V1
Amendment No./Sponsor Ref:	
Amendment Date:	29 October 2018
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [redacted]

Please contact [redacted] for any queries relating to the assessment of this amendment.

Kind regards

Hayley Kevill

Health Research Authority

Ground Floor | Skipton House | 80 London Road | London |
SE1 6LH

E.[redacted]

W. www.hra.nhs.uk

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IRAS Project ID 219154. HRA Approval for the Amendment

[redacted]

Mon 07/10/2019 16:05

To:

- Harris, Lucy <[redacted]>;
- UG-Ramberg, Anna <[redacted]
- UG-Ramberg, Anna <[redacted]>

CAUTION: This email originated from outside of the organisation. Do not click links or open attachments unless you recognise the sender and believe the content to be safe.

Dear Miss Harris,

IRAS Project ID:	219154
Short Study Title:	Alzheimer's Carers' Perceptions of Psychological Therapy V1
Amendment No./Sponsor Ref:	2, 15/07/2019
Amendment Date:	19 July 2019
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact [[redacted] for any queries relating to the assessment of this amendment.

Kind regards

Dr Ashley Totenhofer

Technical Assurance Officer/Interim Amendments Specialist

Health Research Authority

Ground Floor | Skipton House | 80 London Road | London | SE1 6LH

[redacted]

W. www.hra.nhs.uk

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Appendix L: Participant Debriefing Sheet

Lucy Harris

Psychology Department

School of Arts and Social Sciences

City, University of London

Northampton Square

EC1V 0HB

E-mail: [redacted]

A Grounded Theory Analysis of Dementia Carers' Perceptions of Psychological Therapy

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it is finished, we would like to tell you a bit more about it.

This study aimed to investigate what perceptions and ideas carers of people with dementia have about therapy, including their understanding of what therapy is, and their hopes, expectations and concerns about therapy. We hope that this will help us to tailor therapy more effectively for carers, and consider whether we are able to address some of the concerns raised.

We hope that you have enjoyed your participation. Thank you for taking the time to share your thoughts with us.

If you wish to seek further support following taking part, there are a range of support options:

If you do not feel able to wait and need urgent support, or are feeling suicidal or unable to keep yourself safe, please contact your GP or go to your nearest A&E department. You can also contact the Samaritans by telephone on 116 123.

[redacted] Well provide a range of services to carers in [redacted], including peer support groups, practical training courses and respite/sitting service (at an additional cost). You can find further information online at [redacted] or call [redacted]

[redacted] Dementia Support Hub provides free information, advice and support to people with dementia and their carers in [redacted]. Support aimed specifically at carers includes 1:1 advice, personalised coaching to help you cope with caring, and group workshops. Further information can be found online at [redacted] by contacting the helpline on [redacted].

[redacted] provides brief, NHS-funded psychological therapies for anyone experiencing stress, anxiety or depression who has a GP in [redacted]. You can find further information on their website at [redacted]/ or by contacting them on [redacted]

[redacted] Counselling Service offers therapy for up to 3 years, with a sliding fee scale based on your income. Further information can be found on their website at [redacted] or by contacting them on [redacted]

[redacted] Counselling Service offer therapy for up to 24 sessions. Their fees take into account how much you feel you can afford to pay. You can find further information online at [redacted] or contact them on [redacted]

We hope you found the study interesting. If you have any other questions or need information about support available outside the London Borough [redacted], please do not hesitate to contact us at the following:

Researcher: Lucy Harris, Trainee Counselling Psychologist, [redacted]

Supervisor: Dr George Berguno, Counselling Psychologist and Lecturer, [redacted]

Ethics approval code: *[*PSYETH (P/F) 16/17 77*]*

Appendix M: Example Memo 1

Memo: Reflections Immediately Following Interview with ‘Gina’ (pseudonym)

The first thing that struck me when Gina started speaking was the sense of urgency as she almost tripped over her own words to tell me her experience. It was difficult to interrupt and I had the sense that she felt a need to tell her story or be heard. I wonder if that’s how it was for her? Will that impression remain in the transcript, or be supported when I review her interview later? It seems at odds with her determination that she does not need therapy, although that could perhaps be linked to her sense of therapy as something for people who are struggling more than her – there was the sense of her thinking about patients and her sibling. I wonder what struggling ‘enough’ to need therapy would have looked like for Ruth, or meant to her? What would needing therapy have meant when juxtaposed with her roles as a carer, as a [medical professional]?

That urgency quickly had the interview feeling very similar to a first therapy session – it was difficult to find a balance of not exploring too deeply into that, and closing it down with empathy whilst also encouraging her to think about and explore her ideas about therapy. But maybe my efforts to do so contributed to the sense of urgency – it will be interesting to see if any other participants speak in such a way. I wonder if there will be any relationship there, between how much participants seem to need to share their experience and how they view therapy? Or am I reading too much into it, too soon?

Appendix N: Example Memo 2

Memo: Reflections on Interviewing Technique with ‘Ruth’ – Exploring Similarities/Therapy v Research

Transcribing Ruth’s interview made me think about how I follow up on areas of similarity, as well as difference. When she mentioned the role of religion in how she feels, I didn’t hesitate to ask more about that. It was different to my experiences, and therefore easy to spot that I didn’t know enough to be confident I had a reasonable understanding of what she meant, let alone how that might link back to therapy. My question could have been less blunt – trying not to slip into therapy mode, I couldn’t quite find a subtle way to ask about how guilt impacts her as a carer and then loop back round to exploring what her thoughts and feelings are in terms of how those feelings of guilt might affect how she considers therapy. That’s a better strategy, perhaps, if something similar happens again.

But when she mentioned ideas that were similar to my own, did I question them enough? Some she spoke freely about at length, such as the need for human connection. Could I have asked more about this? About what ideas she had for what that connection may look like in therapy, how she would feel about therapy if it did/didn’t match those ideas? Probably. Although she did discuss much of that, in her thoughts about the importance of somebody to talk to who isn’t personally involved in the situation… but it would be useful to bear that in mind for future interviews. To ask participants to clarify what they mean by ideas even when – perhaps especially when – those ideas are familiar to me. What would she talk about, even – would it be the same kind of starting point as what she told me? Does it matter, would I really want to ask that given that I have no idea what it could open up? Probably not that question specifically, then. But definitely to keep in mind the idea of questioning my own assumptions more, to think about how completely I can describe my participants’ views in their words and where the gaps are before moving on. It won’t be perfect, I’m sure there will always be things I’ll miss. But at least to have that nudge, that – sense of what does it mean to you when you say [you want someone to talk to].

I would say that kind of thing in therapy – perhaps that’s part of the problem, trying so hard to not overlap too much with therapy while also being aware that I may be perceived as representing therapists. Perhaps that’s something to be more explicit about – that the interview won’t be the same as a therapy session. But would I be saying that for me, or for my participants? And Ruth didn’t seem to realise before the interview that counselling psychologists are therapists as well as researchers; that might have played a role, too. Perhaps at the end of the interview then, if it feels important? My participants so far have each wanted me to explain what therapy is to them, perhaps saying that it’s different than the interview and explaining how could be part of that?

Appendix O: Example Memo 3

Memo: Is 'Becoming Aware of Therapy' fully grounded in the data?

I'm looking at 'becoming aware of therapy' potentially being my core category – greater awareness of therapy seems linked to each of my categories. But it seems so intuitively obvious that I'm concerned it's just my own idea. It certainly seems logical to me that greater awareness and understanding of therapy would make it easier to weigh up whether or not to have therapy. Would I have said that before starting this study? Hmm... I think I'd have said that knowing more about therapy would help. I wouldn't have said becoming aware, because I was operating from the assumption that people already are aware. So that part I've picked up from my participants. Perhaps the knowing part is partly from me, but I think it's there in the data too – when Katherine and Ruth talked about not knowing how to access it or what it is, and when Gina talked about understanding it from her professional perspective.

What about the links with the categories? Obviously, visibility is linked – who was it, I think Ruth said something like 'now I know it's an option I would want therapy' – I should check that…. Yes, that's there, although it was Barabra who said it, not Ruth. Ruth mentioned about increasing her understanding of therapy as having helped her realise she would consider it for herself – so that links becoming aware of therapy with understanding of therapy, although I should review that for any evidence contradicting it too. The link between awareness and coping is quite similar, in terms of increasing awareness that you don't need to be in crisis – there's also the role of coping and I guess that could even go the other way, where the more aware you are of needing to talk as part of therapy, the more you pull away from therapy or the more threatening therapy feels. I should go back to the data on that – Barbara spoke quite a bit about that and I think Gina and William said something too. What about Katherine? She spoke more on safety features of therapy, and was more aware of therapy… Hmm that one I should double-check, she definitely said both those things but is that relationship more my presupposition than the data? So I should review the transcripts with that relationship in mind and just clarify what might play a role in that relationship, perhaps… are there any other covariates? Or any other coding families from Glaser that might be helpful to think about? Could look at process too I guess, what order did things happen in.

But then awareness links back to the battle for access easily with needing to know how to access it, Katherine and Ruth both spoke to that. Did William mention it as well? He had a different perspective on therapy to Katherine and Ruth so that will be worth checking out.

Seems like there are a lot of links there in the data – some things to go back and check. Need to keep looking for anything to suggest alternative interpretations though, it's getting easy to slip into confirmation bias at this stage. I should keep asking myself what other ways things could be interpreted and looking for anything that doesn't quite fit or that contradicts my theory so far, too.

Appendix P: Excerpt from Interview Transcript with Early Coding

[Redacted for confidentiality reasons].

Appendix Q: Summary of Categories and Subcategories

Table Q2

Summary of Categories and Subcategories

Category	Subcategories
Visibility of therapy	Therapy for carers as invisible
	Therapy as not discussed much
	Therapy as hard to picture
	Missing therapy as gap in support
	Awareness is a prerequisite for access
Understanding of therapy	Therapy as talking
	Potential therapy aims
	Problems people take to therapy
	Therapy as a last resort
Self-perceived coping	Coping styles
	I’m coping
	Managing at the moment
	Maybe later
Threat level of therapy	Therapy as risky
	Safety features of therapy
	Validation and feeling heard
Battle for access	Scarcity of support resources
	Navigating the system
	Lost in jargon
	Role juggling

Appendix R: Example Memo 4

Memo: Self-Perceived Therapy Knowledge: Subcategory or Inter-Group Difference?

I’m not sure yet if self-perceived knowledge of therapy is a subcategory of ‘understanding of therapy’ or if it’s more that there are two different groups naturally occurring here. On the one hand, level of understanding of therapy seems like a logical subcategory – but what does it really tell us on its own? I suppose it seems like people with higher self-perceived knowledge seem more… what? More likely to access therapy?I’m not sure that’s not making assumptions beyond what’s in the data, unless I find someone who sees themselves as knowledgeable about therapy and does not want therapy. It’s hard enough to find carers already without trying to target something that specific!

Or is it a lens through which to compare two groups? Is this really a difference that’s present, or might I be artificially creating it because it seems logical that people know different amounts about therapy? Although I was surprised that Gina felt she knew more than average and yet hadn’t considered therapy as a potential option for carers. That’s quite different to the [people doing the same job as Gina] who I’ve worked with! So I guess that suggests it’s probably not coming from me, since it surprised me. And if I think about it as a lens for comparing groups of carers, that raises some useful questions for looking at the data from different angles. Do those who feel more knowledgeable actually have a different understanding that those who don’t? Do they identify different aspects of therapy, or additional aspects, compared to those who don’t feel knowledgeable? Even those who said they know nothing were later able to share some things that were accurate – will those who see themselves as more knowledgeable be more accurate? (Although, how am I determining accuracy, since there’s no scale to measure against except my own view of therapy? Maybe that’s not the most helpful/objective question to be asking right now… worth parking for later in case, though).

Conclusion: Go with self-perceived knowledge as creating natural groups for now, but you'll need to revisit depending on how future participants describe their knowledge. “More than most” compared to “Nothing” comes from how participants have categorised themselves, so I'll need to be careful not to artificially create or squash any other groups participants bring up in terms of this.

Section B: Combined Case Study and Process Report

Balancing the Experience of Therapy as Safe or Overwhelming

Lucy Harris

[Redacted for confidentiality reasons]

Section C: Publishable Paper

How do carers of people with dementia perceive psychological therapy?

Formatted according to the author guidelines for the journal Dementia (see Appendix T).

Carers of people with dementia and psychological therapy: A grounded theory analysis of how perceptions influence decisions about having therapy

Harris, L. A., & Berguno, G., *Department of Psychology, City University London, Northampton Square, London, EC1V 0HB, United Kingdom*

Short title: How do carers of people with dementia perceive psychological therapy?

Keywords: Carers, caregivers, psychological therapy, psychotherapy, counselling, talking therapy, dementia, help-seeking, barriers, access, perceptions

Abstract

Caring for someone with dementia can have a significant negative impact on carers' physical and psychological well-being. Evidence suggests psychological therapy may be helpful in addressing this impact, but that carers do not always seek therapy despite significant distress. Previous research has suggested that carers who completed therapy appreciated the safe space to talk. This study focused on carers who have not accessed therapy. It aimed to investigate how carers of people with dementia perceive therapy and how these perceptions influence carers' decisions regarding accessing therapy. The resulting model provides insight into this process and indicates the importance of accurate, visible information about therapy being available to carers.

[Full paper redacted for copyright reasons]