Exploring the Acceptability and Impact of an Online UK “Dementia Awareness for Caregivers” Course

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Informal caregivers provide a vital role in supporting individuals with dementia. Currently, there is no standardised dementia psychoeducation and support available for these individuals. The main objective of this project is to address this critical gap and explore the acceptability and impact of an online Dementia Awareness for Caregivers (DAC) course delivered to informal dementia caregivers in the United Kingdom (UK). This is a joint project with fellow trainee clinical psychologist, Isabelle Evans.

Part 1 consists of a conceptual introduction outlining essential research and theoretical background, motivating the research project. It discusses dementia, its impact on both individuals and informal caregivers, the support available and importantly, the gaps in this area. The conceptual introduction ends with a review of the literature discussed and the aims of the empirical research project.

Part 2 outlines the research aims and methodology and discusses qualitative findings. Fifteen interviews explored the acceptability and impact of an online DAC course delivered to informal caregivers in the UK and qualitative results provided support for such an intervention. The strengths and weaknesses, as well as implications of the empirical research project are also discussed.

Part 3 forms a reflective summary of conducting the research project. It focuses on the researcher’s perspective regarding the initial setting up of the project and the challenges experienced during participant recruitment and engagement. It also outlines some of the researcher’s personal interests, biases and assumptions and the importance of acknowledging these when analysing data.

Impact Statement

The current thesis contributes to research literature on interventions for informal caregivers of individuals with dementia, offering value academically and clinically. It highlights both the gap in support for these individuals and the gap in research regarding this area. As discussed in both the conceptual introduction and empirical paper, the need for standardised support among informal dementia caregivers is vital. This thesis critically adds to the growing literature area, whilst providing promising findings that can be utilised as a basis for future research, in the hope for standardised delivery of interventions for informal caregivers.

The conceptual introduction: Given the rise in life expectancy and a global aging population, the prevalence of dementia is increasing at a fast pace. Dementia is known to have various effects on the mental and physical health of not only the individual with dementia, but also those that care for them. Despite awareness of this, no standardised psychoeducation and support is available. This gap in support can exacerbate various concerns. The information presented in this conceptual introduction highlights the critical need for support among this population as well as the need for future research and change in this area. Specifically, it promotes research into standardised interventions for informal dementia caregivers, with an aim for these individuals to be appropriately supported in an accessible manner.

The empirical paper: As previously mentioned, prevalence of dementia is increasing, in turn potentially increasing the number of informal caregivers providing support. Offering a brief psychoeducation and support intervention for informal dementia caregivers, can assist in providing them with knowledge, skills, and awareness to support them throughout this caregiving role. This empirical research project highlights the current gap in support experienced by informal caregivers and highlights the need for standardised support offered at point of diagnosis within the NHS. Findings from the study may impact the potential accessibility of services and direct care received by informal dementia caregivers in the future. The project sets the foundation for further testing of efficacy and cost-effectiveness of the Dementia Awareness for Caregivers (DAC) course using randomised control trials within a National Health Service (NHS) setting, with an aim to establish an evidence-base for this intervention and have it delivered across the UK. Qualitative findings show the DAC course to be acceptable and have had a positive impact on caregivers' reported skills, feelings of being a caregiver and confidence regarding their caregiving role, which has previously been found to positively impact the care recipient, reducing their risk of moving into a care home earlier than needed.

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Part 1: Conceptual Introduction

Caring for an Individual with Dementia and the gap in Support Available

1.Introduction

This project provides empirical evidence for a brief psychoeducational intervention delivered to support unpaid, informal caregivers of people with dementia. Informal caregivers provide a large portion of care for individuals with dementia and whilst this role can lead to a sense of gratification and accomplishment (Doris et al., 2018), in many cases informal caregivers experience low mood, loneliness, and heightened levels of stress (Or & Kartal, 2019). Despite awareness of these concerns, there is little formal support available for caregivers (Or & Kartal, 2019). Of the support that is available, mainly third sector services, there is no standardised dementia psychoeducation and support available for dementia caregivers. This project aimed to address this gap by evaluating a new online psychoeducation and support course called ‘Dementia Awareness for Caregivers (DAC)’ course (Stoner et al., 2022). Specifically, it sought to investigate the acceptability and impact of the DAC course. This was done through adapting the course for a United Kingdom (UK) setting, and a wait-list controlled pilot study in which the course was delivered online to unpaid dementia caregivers. Quantitative pre and post measures were used and following completion of the DAC course, semi-structured interviews (n=15) were used to assess the acceptability and impact of the course to unpaid caregivers of individuals with dementia. This work provided preliminary evidence of acceptability and impact of the intervention to inform further development and laid the groundwork for a future randomised control trial, with the hope that the DAC course can be more widely delivered across various services to assist with providing caregivers psychoeducation and support.

This conceptual introduction considers the essential research and theoretical background motivating this study. It begins by describing dementia and the impact it has on individuals diagnosed. It then explores the needs of caregivers, in particular informal caregivers, as well as the impact caring for someone with dementia can have on informal caregivers. Following this, it explores the different support available for informal caregivers and importantly, the gaps in this area. Finally, it takes into consideration the literature reviewed within the chapter and discusses the aims of the thesis.

2.Dementia

2.1 Defining Dementia

Dementia is an umbrella term used to describe a series of neurodegenerative conditions that can affect an individual's cognitive functions such as language, memory, and decision making. It is progressive in nature and the main symptom is the decline in brain function due to physical changes of the brain itself. Dementia, known as neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), is characterised by five criteria (5th edition; American Psychiatric Association, 2013). There must be cognitive decline in one or more cognitive areas based on information provided by a reliable informant or clinician and this must be documented by objective cognitive assessment (criterion A). The individual must experience interference with independence in everyday activities (criterion B). The decline in cognitive ability must not occur exclusively during delirium (criterion C), must not be better explained by another mental disorder (criterion D) and must be due to an etiologic subtype as described in the DSM-5, for example Alzheimer's disease or dementia with Lewy Bodies (criterion E). As noted, dementia has several causes, one of which is Alzheimer's disease. Alzheimer's disease is the most common cause of dementia, followed by vascular dementia and mixed dementia, and then rarer types such as Lewy body dementia and fronto-temporal dementia (Knapp et al., 2007).

2.2 Dementia Prevalence and Models

There are roughly 50 million people with dementia globally (Mauricio et al., 2019), whereby around 885,000 people are diagnosed with dementia in the UK (Wittenberg et al., 2019). Given the rise in life expectancy and a global ageing population, it has been predicted that by 2050 roughly 135 million people across the world will be living with dementia (Cummings et al., 2016). In the UK alone, it has been predicted that by 2051, prevalence of a dementia diagnosis could exceed two million individuals (Prince et al., 2014). Whilst some individuals can be diagnosed with early onset dementia, this is less common (Knapp et al., 2007) and generally the risk of dementia increases with age. There is also some research that suggests risk factors such as lack of education, obesity, hearing loss, hypertension, traumatic brain injury, alcohol misuse, smoking, physical inactivity, and social isolation can contribute to an increased risk of dementia (Livingston et al., 2017).

When trying to understand dementia, various models have been proposed. The medical model assumes that dementia is a disease caused by a deterioration of the brain parts that control cognitive and behavioural functioning and should be managed by medical authorities (Lyman, 1989). The model has been particularly useful in assisting with the development of medication and has predominantly been used in the assessment and treatment of dementia. However, it has been criticised for leading the individual with dementia to be viewed as a 'diseased person' (Lyman, 1989).

To understand dementia from a different perspective, other models were proposed. The Progressively Lowered Stress Threshold (Hall, 1987) takes into consideration the different categories of stress and proposes that the environment must be adjusted when caring for an individual with dementia. A social constructionist model (Sabat & Harre, 1992) understands dementia as a loss of the 'self' and suggests that whilst a person's 'private self' remains intact during dementia, their 'public self' becomes fragmented. However, these models can be limited in providing a holistic understanding of dementia and can be deemed outdated. Kitwood (1993) proposed that importance should in fact be placed on psychosocial factors and noted that when an individual's self-esteem is damaged by "malignant social psychology", when others treat them in an unhelpful way due to social processes, it can lead them to feel discouraged and a failure. The dialectical model of dementia (Kitwood, 1993) suggests that both physical and psychological factors contribute to dementia, and that symptoms are often an interplay of both. Understanding dementia in this way, led to an advanced awareness of the concept of "personhood" (Kitwood, 1997) and person-centred care, where a person's psychological symptoms are considered when treating dementia. The biopsychosocial model of dementia takes the above models a step further and acknowledges that symptoms of dementia are the result of physical symptoms, mental health, and the environment the person is in (Engel, 1977; Spector & Orrell, 2010). Within the model, the physical symptoms include the changes caused by dementia itself as well as the general physical wellbeing of the individual. The mental health aspect includes factors such as mood, personality, and self-efficacy. Given that dementia can impact these factors in different ways, it is also important to consider the person's history and life-story to assist in determining how the dementia may affect the person. Furthermore, this model considers different cognitive and sensory stimulation, such as meaningful activities, an individual may require to maintain their mental well-being. With regards to the environment aspect, this acknowledges that the people in our environment, the interactions we have with them, and the nature of our environment, can impact our general well-being and feeling of independence. The biopsychosocial model suggests that each of the main three aspects are important and should be considered when treating dementia.

3.Impact of Dementia

3.1 Financial Impact

There is already a great economic cost related to dementia and with prevalence rates predicted to increase over the coming years, the cost of dementia is likely to surge (Wittenberg et al., 2019). In 2006, it was estimated that costs associated with supporting those with dementia in the UK was £23 billion (Luengo-Fernandez et al., 2010). Of this, £1.2 billion was due to health care, £9 billion due to social care and £12.4 billion due to the time given by unpaid caregivers. By 2015, these figures increased whereby in England alone, total costs associated to caring for those with dementia was reported to be £24.2 billion (Wittenberg et al., 2019). As such, the need to increase awareness of dementia, as well as diagnosis and care, is of great importance and many countries are now increasing research funding in order to achieve this (Pickett et al., 2018).

3.2 Impact on the Individual with Dementia

Whilst there are different models offering ways to conceptualise dementia, it is known that dementia is progressive in nature and can have a substantial impact on an individual's daily functioning and behaviour. Often many individuals are placed on a waiting list for an assessment and diagnosis of dementia, which can leave the individual and those around them sitting with uncertainty and awaiting support (Hodge & Hailey, 2015). These waiting times from referral to diagnosis across services nationwide are reported to be between 0-102 weeks, highlighting the long length of time individuals are left waiting for answers, whilst continuing to experience psychological, social, and physical changes (Royal College of Psychiatrists, 2022).

3.2.1 Psychological changes

The different types of dementia have varying patterns of progression and individuals experience dementia in their own way. Generally, dementia can reduce an individual's ability to reason, communicate, understand, remember and function (Lewis et al., 2014). Due to these changes, some individuals find it challenging to manage their emotions and behaviours, resulting in changes in their personality (Lawlor, 2002). No longer being able to complete tasks can lead individuals to question their competency, reducing their self-esteem and sense of control (Bahro et al., 1995). Furthermore, qualitative research has highlighted that individuals with a diagnosis of dementia tend to report a loss of identity, which contributes to them experiencing low mood and loneliness (Aminzadeh et al., 2007). Those with moderate or severe dementia, are reported as scoring much lower when assessing quality of life compared to other severe chronic conditions, highlighting the impact the illness can have on an individual (Mesterton et al., 2010). Furthermore, as dementia is a progressive illness and not every individual's dementia symptoms progress at the same speed or in the same way, those diagnosed have to live with a sense of uncertainty, creating heightened levels of anxiety (Aminzadeh et al., 2007).

3.2.2 Impact on Independence

As the symptoms of dementia progress, they can impair an individual's ability to carry out everyday tasks and, in many cases, cause disability and dependency (Henderson & Jorm, 2000; Savva et al., 2009). Most individuals with dementia end up leaving their jobs and, in some cases, this is not always a voluntary decision. In turn, this not only causes a major change in their daily routine and sense of purpose but can also result in financial challenges (Biggs et al., 2019). Furthermore, in some cases where individuals may have difficulty in remembering, understanding, and communicating, they may have less freedom with regards to their finances. Given the changes in functioning and gradual increase in the need for assistance, some people with dementia stop driving, creating restrictions on freedom around travelling (Biggs et al., 2019). Not being able to drive and having to rely on others can cause a loss of identity, limit social interactions with others, and increase feelings of loneliness and burdensomeness (Sanford et al., 2019).

3.2.3 Changes in Relationships

Changes in an individual's ability, lead to a change in their valued lifestyles, social roles, and the relationships they have with others (Katsuno, 2005; Pratt & Wilkinson, 2001). As the dementia progresses, people with dementia often rely on family members and/or friends to assist with everyday tasks. This consequently leads to a change in relationship whereby those providing assistance, begin to take on more of a caring role which in some cases (particularly parent-child or spousal relationships) can be challenging to adjust to (Pratt & Wilkinson, 2001). Research has also noted that people with dementia report an experience of a shrinking social world, whereby over time relationships with others fade and individuals tend to lose social connections with friends and family members (Biggs et al., 2019).

3.2.4 Impact of Stigma

Some may experience the effects of stigma and social 'demotion', which in turn can have an impact on relationships with others as well as an individual's well-being (Harman & Clare, 2006). Stigma around dementia can be a result of various aspects such as a general misunderstanding of what dementia is and the effects of dementia, public fear, as well as the varying cultural views of dementia (Urbanska et al., 2015). Individuals diagnosed with dementia have reported that following diagnosis, many treat them differently due to the stigmatised views held around dementia. People reported being treated as incapable, not being trusted with information, as well as being excluded from social events (Aminzadeh et al., 2007; Harman & Clare, 2006). This can lead to social isolation, lowered self-esteem, anxiety, and feelings of shame (Urbanska et al., 2015).

3.2.5 Physical Health Changes

Many individuals, particularly as the dementia progresses, experience physical health comorbidities further impacting their general well-being (Prince et al., 2016). Some of these comorbidities include stroke, diabetes, visual and auditory impairments as well as fractured or broken bones as a result of falls (Bunn et al., 2014). Managing the changes that occur as a result of dementia, alongside possible comorbid physical health concerns, can further contribute to the experiences of low mood, anxiety, and a general sense of loss of self-identity (Bunn et al., 2014). People with dementia are also more likely to be admitted to a general hospital than individuals of a similar age, particularly for falls, chronic diseases, and urinary tract infections (Prince et al., 2016). Despite this, physical health is not appropriately managed amongst this group and there are missed opportunities to improve physical health and function and in turn, avoid hospitalisation (Prince et al., 2011).

Considering the above, it is no surprise that dementia can have a profound impact on a person and hence it is important to keep this in mind when caring for an individual.

4.Caring for Someone with Dementia

Due to the various symptoms of dementia and the overall slow decline in independence, individuals with dementia often need support from others. This can vary depending on need and availability, but individuals may be able to attend day centres, hospices, residential or longer-term care homes, or remain at home with some professionals offering home visits (World Health Organisation, 2021). In the UK in 2014, 39% of those with a diagnosis of dementia were living in a care home (either residential or nursing home), compared to 61% who were living in the community (Prince et al., 2014). As the dementia progresses, the amount of support an individual requires increases, whereby many people with dementia end up requiring 24-hour support. It has been predicted that the number of individuals with dementia who will require palliative care will quadruple by 2040 across England and Wales (Etkind et al., 2017).

4.1 Informal Caregivers

Given the high demand for health services, in many cases caregivers are relied upon to contribute to care (Haikio et al., 2019; Prince et al., 2016). Most often these caregivers are family members or friends, who provide informal care to people with dementia (Gilsenan et al., 2003). An informal caregiver is defined 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, 2019, para. 1). Informal caregivers often assist with various activities of daily living, provide support with regards to treatment plans, facilitate meaningful activities, as well as assist in providing a safe and supportive environment. In 2019, it was reported that informal caregivers across the world spent over 89 billion hours providing support to individuals with dementia (World Health Organisation, 2021). Furthermore, when calculating the cost of supporting someone with dementia, the cost of informal care accounts for the greatest proportion of the total cost of care, highlighting not just how many informal caregivers there are, but the enormous amount of care they provide (Allen et al., 2020). The large number of informal caregivers across the world has been known to reflect the lack of resources and general support for people with dementia (Messina et al., 2022).

There are many other reasons why individuals become informal caregivers, for example, due to a sense of love, spirituality, social or cultural pressures, or duty (Eisdorfer, 1991; McCleary & Blain, 2013). Research into the demographics of informal caregivers has reported that most people with dementia were cared for by their spouse (67%) and the majority of informal caregivers were female (67%) (Wimo et al., 2013). Women were also 2.5 times more likely to provide 24-hour care and 2.3 times more likely to provide care for over a five-year period compared to men (Alzheimer’s Research UK, 2015). Furthermore, 63% of caregivers reported to be retired, 18% were still in paid employment, and 15% noted they had to give up their employment in order to carry out their caring responsibilities (NHS

Digital, 2016). Whilst there are a high number of informal caregivers, some do not identify themselves as caregivers or are not recognised as a caregiver by health and social care (Riffin et al., 2017). This may be due to lack of awareness of what classifies as an informal caregiver, cultural beliefs around the role of caregiving, and/or specific eligibility criteria set out by authorities (Aldridge & Hughes, 2016; Brandao et al., 2016). As such, they may not have access to appropriate support which can negatively impact both themselves and the individual with dementia.

4.2 Impact Caring has on Unpaid Caregivers

Some research has suggested that caring can lead to a sense of gratification and accomplishment (Doris et al., 2018) and in some cases strong family bonds to be built (Tao & McRoy, 2015). Furthermore, the caregiving role has been found to have a positive impact particularly with regards to personal growth and purpose in life when caregivers are provided with appropriate support (Doris et al., 2018). However, in many cases without the appropriate support, informal caregivers experience various negative effects (Laparidou et al., 2018).

4.2.1 Social Impact

4.2.1.1 Independence. Given the various symptoms of dementia, many caregivers are required to assist with tasks such as bathing, dressing, feeding, assisting with toileting, and managing the psychological changes the individual with dementia may experience. In some cases, caregivers have to be constantly aware of the unpredictability with regards to the behaviour that may arise such as wandering and/or aggression, providing little time for the caregiver to be ‘off-duty’ due to having to supervise the care recipient (Hall & Skelton, 2012). Often, these tasks are carried out alongside the caregiver’s own activities of daily living and as such, many informal caregivers experience a loss of independence and time as well as a change in their current lifestyle (Livingston et al., 2020; Quinn et al., 2008). Findings have highlighted that often caregivers find it challenging to balance their own needs and those of the individual living with dementia, leading to their sense of well- being subsumed by their role as carer (O’Shaughnessy et al., 2010). In some cases, individuals are left with little option but to reduce or give up employment hours as well as change their lifestyle to meet caregiver demands. It has been reported that across England in 2016-17, 36% of caregivers spent over 100 hours per week carrying out caring duties whereby 15% of dementia caregivers had to give up work due to caring responsibilities (NHS Digital, 2017). This can create a huge financial burden on informal caregivers, however despite this, there is little financial support available (World Health Organization, 2021).

4.2.1.2 Relationships. Many caregivers report limitations with regards to their social life whereby due to caring responsibilities, they are often no longer able to attend social events they enjoyed prior to their caring role (Capus, 2005). Research has noted that caregivers of people with dementia are more likely to prioritise their caregiving role over engaging in their own leisure activities and as such, tend to engage in fewer leisure activities than non-caregivers (Ho et al., 2014; Schuz et al., 2015). Given the limited time to socialise or engage in activities that enable relationships to be built, informal caregivers often report an increase in social isolation (Capus, 2005).Furthermore, moving into a caregiving role brings about changes in the relationship between the caregiver and the care recipient. For some caregivers the caregiving role can aid in strengthening the existing relationship (Ablitt et al., 2009). For others, it can be challenging to adjust to, and findings have noted caregivers report difficulty in balancing these relationships, particularly given the ongoing changes in the care recipient’s presentation (Capus, 2005; Quinn et al., 2008). In the case of spousal relationships, findings have reported caregivers not only face challenges in adapting to the caregiving role, but also significant losses with regards to their couple relationship (O’Shaughnessy et al., 2010). These challenges are often exacerbated due to the limited support and information caregivers are offered, and research has highlighted the need to provide caregivers with information around dementia, the effects it has, as well as practical skills in being able to manage their caregiving relationships (Quinn et al., 2008).

4.2.2 Burden

Various research studies have explored the experience of caregiver burden as well as the different determinants that might contribute to burden. Caregivers of individuals with dementia are reported as being likely to have higher levels of burden compared to other caregivers (Brodaty & Donkin, 2009; Messina et al., 2022,) and that this is often related to factors such as uncertainty with regards to the future, frustration, and embarrassment, as well as the direct impact of caregiving itself (Smith et al., 2018). Another review noted that the strongest predictors of burden amongst caregivers were caregiver overload (burnout and fatigue), a sense of “role captivity” (feeling ‘trapped’ in the role), adverse life events that occur outside the role of caring, and the quality of the relationship (Campbell et al., 2008). Research has also suggested caregiver burden is likely to increase as both the severity of the dementia increases and the amount of care required increases (Capus, 2005; Chiao et al., 2015; Langa et al., 2001; Newbronner et al., 2013).

Given the impact caregiver burden can have on an individual, various models have been proposed in order to gain further understanding. The stress process framework (Pearlin et al., 1990) suggests that caregiver burden is a consequence of interrelated aspects including the characteristics of the caregiver (socioeconomic and resources), as well as primary (concerns directly related to the caregiving role) and secondary (concerns outside of the caregiving role) stressors. Lazarus & Folkman (1984), provided a conceptual model, proposing that caregiver burden is not an automatic response to a stressful event, but rather is dependent on the individual’s appraisal of that event. This was further supported by empirical research highlighting the various individual differences in response to caregiving stress (Haley et al., 1987). A systematic review of different models of caregiver burden highlighted that the majority of findings report care recipient behavioural concerns, caregiver coping and personality traits as well as caregiver competence, as being the most consistent determinants of caregiver burden (Van der Lee et al., 2014).

However, as noted above, individual differences exist with regards to burden experienced by caregivers and hence burden levels are known to vary across cultures, gender, and caregiver role (Liu et al., 2022, Losada-Baltar et al., 2022; Smith et al., 2018). Based on the model proposed by Lazarus & Folkman (1984), the sociocultural stress and coping model was developed to understand caregiver stress and coping processes among various cultural groups (Aranda & Knight, 1997). This was later revised, and findings suggest that cultural values and differences between cultural groups influence the caregiver’s choice and use of coping strategies, therefore in turn, impacting the experience of caregiver burden (Knight & Sayegh., 2010). Whilst much research focuses on caregiver burden, it is also important to consider the experience of caregiving as positive, rather than negative. Some findings have noted that greater involvement in caregiving is related to decreased anxiety and depression, and that the ability to provide care and help others can assist with counterbalancing the suggested negative experiences of caregiving (Beach et al., 2000), as well as increase caregiver satisfaction (Kramer, 1997). Other findings of adult-child caregivers reported that the more help provided was related to fewer depressive symptoms and an increase in positive affect (Lawton et al., 1991). Importantly, research has noted that when caregivers are provided with support, information, practical skills, education and advice, the experience of caregiver burden is reduced, in turn increasing the experience of positive aspects of caring, quality of life and the mental and physical health of caregivers, suggesting a need for interventions targeting these areas (Abdollahpour et al., 2018; Van der Lee et al., 2014).

4.2.3 Psychological Impact

Given the changes in social circumstances, burden levels and financial circumstances, caregivers are often at higher risk of developing a mental health disorder (Lewis et al., 2014). Family caregivers of people with dementia are likely to have higher stress levels, experience psychological concerns and health difficulties compared to non-caregivers (Brodaty & Donkin. 2009). Research exploring the psychological impact of caregiving has noted that often caregivers experience emotional strain which in turn is reported to cause challenges in being able to manage the role of caregiving (Cascioli et al., 2008). Often caregivers report experiencing emotions such as fear, guilt, helplessness, grief, confusion, and resentment (Benbow et al., 2009; Callaby, 2012). Findings have also noted that this emotional impact of caring can lead to various psychological concerns for caregivers, such as anxiety and depression, and in turn, this can have an impact on their behaviour towards the care recipient (Cooper et al., 2018; O'Shaughnessy et al., 2010).

4.2.3.1 Anxiety. Dementia can lead to individuals displaying unpredictable behaviours and often this requires caregivers to be alert. Managing these behaviours, not knowing what or when they may happen, can be tiring and anxiety provoking (Cooper et al., 2007). Furthermore, from the point of diagnosis through to end-of-life care, important and challenging decisions are often needed to be made regarding ongoing care and support. Frequently, caregivers are involved in making these decisions and research has noted caregivers often find this a challenging, anxiety-provoking situation at all stages of the caring journey (Livingston et al., 2010). Given the various aspects caring for an individual with dementia involves, it is not surprising that dementia caregivers are found to report high rates of anxiety, with these rates increasing with those who provide more intensive care (Hirst, 2003; Hirst, 2005). This in turn, may put them at higher risk of perceived stress, physical and other psychological concerns, as well as lower life satisfaction and self-esteem (Schulz et al., 1995). Research looking into the self-reported needs of caregivers has highlighted that caregivers felt being provided with information and support early in their caregiving journey, would assist with reducing anxiety around the caregiving role (Cascioli et al., 2008).

4.2.3.2 Depression. In addition to anxiety, rates of depression have also been found to be higher amongst caregivers of individuals with dementia (Brodaty & Donkin, 2009; Cooper et al., 2008). Carrying out caregiving tasks can be both stressful and challenging, particularly when caregivers have little control over the symptoms an individual might experience. Often this can lead to caregivers experiencing a lack of confidence, higher stress levels, and depression (Pinquart & Sorensen, 2003). Furthermore, as the dementia progresses, individuals require more intensive support and findings have noted that severity of cognitive impairment of the individual living with dementia is significantly associated with severity of caregiver depression (Ballard et al., 1995). These increased rates of depression are also noted among those caregivers who are reported to be first-degree relatives (Coope et al., 1995). Often, caregivers are required to change their lifestyles reducing their engagement in meaningful activities to support the care recipient, leading to experiences of loneliness, fatigue, and depression (Capus, 2005; Gao et al., 2022).

4.2.4 Physical Health Concerns

Depression amongst caregivers of people with dementia, has also been correlated with increased physical health concerns (Brodaty & Donkin, 2009)**.** Some have suggested that higher rates of physical health concerns amongst caregivers are due to the physical exertion required when carrying out some caring tasks, changes in lifestyle such as diet and exercise, as well as the physiological effects of psychological concerns (Parkinson et al., 2017; Shaw et al., 1997). Other research has noted that lower levels of social support are related to an increase in poor physical health among caregivers, highlighting the need for caregiver support (Schulz et al., 1995). Additionally, increased length of time as a caregiver, higher levels of burden and depression, increased progression of dementia, along with lower levels of informal support, have all been found to be related to an increased risk of physical health concerns among caregivers (Pinquart & Sorensen, 2007). Of those caregivers that report wanting to engage in physical activity, barriers such as fatigue, lack of time, difficulty changing the care recipient’s routine and lack of independence are noted, suggesting aspects of the caregiving role itself are likely to contribute to poor physical health among caregivers (Horne et al., 2021).

5.Support for Caregivers of Individuals with Dementia

5.1 Research Interventions

Research has stressed the importance of being aware of caregiver needs and ways to address them. Various research has investigated what interventions may be best suited for caregivers of individuals with dementia. Some findings have suggested that providing interventions focused on increasing the caregiver’s understanding and awareness of dementia can have a positive impact on the way in which they then provide care (Kahn et al., 2016). This is supported by research that suggests increasing knowledge of dementia and the nature of its progression, can assist with caregiver’s mental health, reduce stigma and burden, as well as encourage them to provide person-centred care (Jensen et al., 2015; Kahn et al., 2016; Mitchell et al., 2009; Wenborn et al., 2016). Other research has stressed the importance of structured multi-component interventions and have found this could also reduce the risk of being moved into a care home prior to it being needed and assist with maintaining the psychological health of caregivers (Evans et al., 2020; Kurz et al., 2009; Mittelman et al., 2006; Pinquart & Sorensen, 2006). Interventions focussed on psychosocial aspects of dementia have been known to enhance resilience of caregivers, maintain quality of life whilst reducing depressive symptoms and stress (Nguyen et al., 2019; Teahan et al., 2020; Zhu et al., 2021). As such, it is hoped that by developing interventions targeted at caregivers of individuals with dementia, psychological concerns, burden, and other forms of distress can be eased among this group (Gallagher-Thompson et al., 2012).

5.1.1 REACH Project

In the United States of America (USA), the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project was established in 1995 and aimed to test potential interventions to enhance the ability and confidence of caregivers of individuals with dementia (Wisniewski et al., 2003). The REACH project analysed nine different interventions, with two control conditions, across different sites in the USA to examine the feasibility and outcomes of each intervention. Results showed that those in the active interventions reported reduced caregiver burden compared to those in the control conditions. Given that different interventions were delivered across the different sites, results provided an indication on which intervention type benefitted which group of individuals more so than others. For example, findings noted that wives of people with dementia who exhibited high anxiety, benefited most from an automated telecare intervention (Mahoney et al., 2003). At a different site, African American caregivers benefited more from a behavioural skills training intervention than White caregivers, and similar results were found for non-spouse caregivers compared to spousal caregivers (Burgio et al., 2003). Following the results of the REACH project, a follow-up study, REACH II project, was designed to test a single behavioural based intervention across multiple sites with an ethnically diverse population. Results suggested the behavioural intervention could be a feasible tool in providing support to caregivers of individuals with dementia (Nichols et al., 2017). However, a few limitations are noted with the REACH II project. Aware that caregivers' time can be limited due to the nature of the caregiving role, it is important to consider the length of this intervention (six months) and the overall impact this might have on the caregiver having to take time to attend, which may not always be feasible. Furthermore, one of the eligibility criteria required caregivers to report distress associated with caregiving at the baseline assessment (Belle et al., 2006). As previously mentioned, it is key that services provide support as early as possible to ensure preventative, rather than reactive support, assisting caregivers in their caregiving role (Jensen et al., 2015; Kahn et al., 2016).

5.1.2 START Project

Another caregiver intervention within the USA, "Coping with Caregiving" was developed and comprised of five modules delivered across 13 sessions. Results indicated levels of depression and anxiety amongst those caregivers who engaged in the intervention reduced, whilst self-efficacy improved (Gallagher et al., 1985). This intervention was then adapted for delivery within the UK National Health Service (NHS) and was evaluated in the Strategies for Relatives (START) project (Livingston et al., 2013). The START intervention comprised of eight sessions of a manual based coping strategy delivered on an individual basis over 8-14 weeks and this was compared to a treatment as usual group (Livingston et al., 2013). The eight sessions included stress and wellbeing, reasons for behaviour, making a behaviour plan, behaviour strategies and unhelpful thoughts, communication styles, planning for the future, introduction to pleasant events and your mood and finally, using your skills in the future. In between sessions caregivers were asked to practice the strategies in the manual and listen to a CD which comprised of different relaxation techniques. Results from the project showed that those who engaged in the intervention compared to treatment as usual, had a higher quality of life, were less likely to have case level depression and scored lower on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), both in the short-term and 24 months later (Livingston et al., 2014). However, it is noted that baselines scores of depression and anxiety were already high, increasing the likelihood of a score change at post-test and may account for the changes reported (Livingston et al., 2014). Furthermore, given the number of resources required to deliver the START project, it is deemed too expensive for health services to deliver, further highlighting the need for a brief psychoeducational and support intervention for dementia caregivers that is feasible to be run across services (Amador et al., 2021).

5.2 Third Sector Interventions/Support

Third sector organisations within the UK generally have a large reach to caregivers (Amador et al., 2021). Often these organisations are charities, social enterprises and voluntary groups offering support to those in the community. Surveys have noted that these services provide information and advice, social support such as memory cafes, dementia-friendly libraries and leisure centres, and caregiver support groups (Frost et al., 2020). The UK's largest dementia charity, Alzheimer's Society (Amador et al., 2021), provides activity groups, information and guidance which is available online, in person and via telephone, caregiver groups, peer support groups, as well as campaigning and supporting various research. The START project teamed up with the Alzheimer's Society to explore effectiveness of the delivery of the START project through a third sector organisation. Results showed scores for anxiety and depression reduced following engagement with the intervention and both facilitators and caregivers rated the intervention positively, but this was not statistically significant (Amador et al., 2021). Furthermore, incidence rates of depression and anxiety across the participants were relatively high at baseline (67%), which in itself, increases the likelihood of a score change at post-test (Amador et al., 2021).

5.3 Impact of COVID-19

Access to dementia care was known to be varied depending on sociodemographic characteristics prior to the COVID-19 outbreak (Pham et al., 2018), and this was found to have been exacerbated during the pandemic and following the various restrictions put in place (Giebel et al., 2020). Of the services that are available, many were closed in line with government regulations, causing delays in diagnosis and post-diagnosis care (Wang et al., 2020). Respite programmes and social settings were no longer accessible, further increasing caregiver burden and social isolation and consequently impacting their mental and physical health (Cohen et al., 2020). Government regulations required individuals to work from home, and whilst some companies provided special allowances for childcare, support for informal caregivers was often neglected (Giebel et al., 2021). This meant that many informal caregivers had to work from home full time, alongside carrying out their caregiving tasks, further increasing stress and burden (Barros et al., 2020). These increased negative effects on caregivers are important to note as research has suggested that this, as well as poor physical health, is a risk factor in managing caring responsibilities, potentially causing negative effects on the care recipient and, increasing the likelihood of them being placed in long-term residential care (Hebert et al., 2001; Navaie-Waliser et al., 2002).

Research has explored the impact of changes in the services provided prior to COVID-19 and during COVID-19 as well as the experiences of dementia caregivers. Whilst support was varied pre-pandemic, services tended to provide support such as residential care, in person support groups, befriending and social activities (Giebel et al., 2020). In a UK survey including 285 unpaid caregivers, findings showed that use of these support services decreased during COVID-19, and caregivers reported heightened levels as depression and anxiety (Giebel et al., 2020). Other qualitative research highlighted that prior to COVID-19 caregivers reported transport, finances, and location as being barriers to accessing support (Giebel et al., 2021). With COVID-19 restrictions put in place, these caregivers reported these barriers as being exacerbated and noted that services were slow to adapt, resulting in a loss of support (Giebel et al., 2021).

5.4 Online Interventions

However, whilst COVID-19 has impacted caregivers in various ways, it provided services with time to reflect on different ways of adapting their service provision. For example, findings from one study noted the pandemic as allowing services to conduct visits, consultations, and offer support remotely, which in turn enabled them to extend their reach to caregivers who lived further away, or who were unable to have time to travel (Wheatley et al., 2022). Even prior to the COVID-19, interventions that are delivered online have been suggested as an alternative to in person interventions to assist with providing support to a large number of individuals at a suggested lower cost, particularly given the increase in dementia prevalence (Martin-Carrasco et al., 2009). Across the world various online interventions have been proposed consisting of caregiver information and support (Torp et al., 2008), information websites along with telephone support (Glueckauf & Loomis, 2004), and information websites along with individual work and discussions with other caregivers (Ducharme et al., 2011; Marziali & Garcia, 2011). One systematic review of online interventions reported improvements in caregiver self-efficacy, depression, and confidence, with interventions comprising of multiple components that are tailored to the individual (Boots et al., 2014). Another study reported that those who engaged in an online intervention reported increased self-control, lower health risks, greater self-efficacy and perceived their caregiver role to be less threatening (Ducharme et al., 2011). With regards to online group interventions, one systematic review and meta-analysis noted significant effects on reducing caregivers' depressive symptoms (Yu et al, 2023), whilst another study noted that providing online video conferencing support groups contributed to improving caregivers' mental health and reducing caregiver stress responses (Marziali & Garcia, 2011). It is also known that offering online interventions assists with access concerns for those who have challenges accessing in-person support (Serafini et al., 2007), as well as allowing caregivers to access support from their own home without having to leave the care recipient (Boots et al., 2014). However, whilst there is various support for online caregiver interventions, there is great variability in their focus, length, and type, hence further research is required.

5.5 Gap in Services

Despite the need for support amongst dementia caregivers being widely known and reported on, there remains concern with regards to the support available and offered to these individuals. Literature reviews have noted caregivers' experiences of services across the UK as being largely negative (Francis & Hanna, 2022), with many noting a perceived lack of support specifically designed for caregivers (Sutcliffe et al., 2015).

Findings have highlighted the need for a single point of access to information and support that all caregivers can receive (Gorska et al., 2013). As previously mentioned, not all informal caregivers identify as a caregiver and hence this may leave them unable to access any support that may be available for caregivers, due to them not holding a formal caregiver status (Riffin et al., 2017). As such, interventions that are offered as part of a standard package of care to all carers, regardless of whether they hold formal caregiver status or not, are required to assist with overcoming these concerns and ensuring consistency in whom support is provided to.

Whilst third sector organisations can provide forums and/or peer support groups for caregivers of people with dementia, these services are not part of a nationally mandated service specification for carer support and hence variability in being offered this support exists. Community services are often subject to high demand with constrained funding whereby funding for services and staffing are reliant on fundraising, donations, and/or commissioning arrangements within that particular geographical area. This in turn creates increased pressure and long waiting lists whereby in some cases, caregivers are unable to access support when needed (Chadborn et al., 2019). Given this and the challenges with obtaining outcome measures due to the short-term nature of funding and/or service format, these services have low rates of programme evaluation (Chadborn et al., 2019), making it challenging to see whether there are any significant benefits for caregivers of individuals with dementia. In one national survey investigating post-diagnostic care across England, findings highlighted inconsistencies in service provision, commissioning arrangements, as well as which service provided what support (Frost et al., 2020). Furthermore, it is suggested that this inconsistency could be due to the lack of clear recommendations on service provision for post-diagnostic care, highlighting the need for an intervention that is offered as a standard package of care which is part of a nationally mandated service specification for carer support. Offering an intervention in this way could also assist with allowing for continuous monitoring to ensure services are providing appropriate, effective support for caregivers (Gorska et al., 2013).

Another challenge that arises when there is no standardised dementia psychoeducation or support available, is that often the onus is on the caregiver themselves to seek out appropriate services for support. As such, having to seek out support, in what might be an unfamiliar area for some, can be time-consuming, something that not all caregivers are able to give. Research has also highlighted that caregivers of individuals with dementia often find it challenging to seek out support on their own accord due to cultural, environmental, and personal factors (Brodaty et al., 2003; Messina et al., 2022). Findings from a qualitative literature review have noted both the lack of awareness and difficulty in accessibility of support available among caregivers, in turn contribute to low service use (Francis & Hanna, 2022). These findings are supported by others, stressing the need for an intervention provided as a standard package of care to allow for easier accessibility and a consistent approach that is offered to all caregivers (Gorska et al., 2013; Laparidou et al., 2019; Sutcliffe et al., 2015).

Support available is often offered at point of crisis rather than at an earlier point to provide preventative care (Aldridge et al., 2020). Consequently, individuals with dementia then require more intensive support, which often is too expensive to be delivered, resulting in individuals being placed in care (Aldridge et al., 2020). Research has also suggested that reactive care could be due to various reasons such as caregivers' limited awareness of services available, lack of availability of services, and/or long waiting times to be seen by services (Brodaty et al., 2005). Findings from focus groups carried out across England found that caregivers felt information and support provided was often too late, whereby timeliness of information was noted as being particularly important (Sutcliffe et al., 2015). This is also noted in other findings in which caregivers reported a lack of preparedness to provide effective care and felt being provided with information and skills early on in their caregiving journey would have assisted with overcoming this (Laparidou et al., 2019). Additionally, as previously mentioned, providing caregivers with skills and appropriate information they can utilise in their caregiving role, can also assist with reducing the risk of the individual with dementia being placed in residential care earlier than needed as well as with maintaining the psychological health of caregivers (Evans et al., 2020; Kurz et al., 2009; Mittelman et al., 2006; Pinquart & Sorensen, 2006).

Despite caregiver psychoeducation and skills training being recommended by the National Institute for Health and Care Excellence (NICE) dementia guidelines (NICE, 2018), many caregivers experience a lack of support and information from services (Gorska et al., 2013; Sutcliffe et al., 2015). As highlighted above, there are challenges with awareness and accessibility of services as well as inconsistency in the availability, content, and implementation of interventions that are offered to caregivers of individuals with dementia across the UK. Qualitative findings from caregivers in the UK have noted that services tend to provide inadequate or no support and advice on how to manage the differing behaviours of the individual living with dementia, general educational information on dementia prognosis and progression, skills on interacting with the individual living with dementia, general support for the caregiver themselves, as well as services available for further general support (Laparidou et al., 2019). Providing a brief psychoeducational intervention that is part of a nationally mandated service specification for carer support, which offers support, education, skills, and guidance, at the start of a caregiver's journey in caregiving, can assist with overcoming the concerns highlighted above and is therefore of great importance.

6.Summary and aims of the Thesis

6.1 Summary

Given the increase in life expectancy and a global ageing population, it has been predicted that the prevalence of a dementia diagnosis in the UK alone could exceed two million individuals by 2051 (Prince et al., 2014). Informal caregivers are known to provide a large proportion of care to individuals with dementia and often these caregivers are family members or close friends (Prince et al., 2016). Due to the nature and progression of dementia, the caregiving role can be demanding, having an impact on caregiver's physical and mental health, their independence, finances, as well as other aspects of general wellbeing (Brodaty & Donkin, 2009; Chiao et al., 2015; Langa et al., 2001). The importance of being provided information about the prognosis and impact of the illness, the availability of practical and emotional support, as well as communication skills and coping strategies following diagnosis, has been noted across various research (Gormley, 2000; Killen et al., 2016). Despite this, caregivers of individuals with dementia are often poorly supported at the point of diagnosis and are provided with little information to assist them, leaving them feeling unprepared and less confident in being able to carry out their caregiving role (Allen et al., 2020; Killen et al., 2016; Mason et al., 2020; Werner et al., 2017). As such, it is vital that standardised support for caregivers of individuals with dementia is developed and widely implemented.

6.2 Aims of the Thesis

The overall aim of this thesis was to evaluate the acceptability and impact of a new psychoeducation intervention for caregivers of individuals with dementia in the UK called "Dementia Awareness for Caregivers" course (DAC). An international team from the UK, Brazil, India, and Tanzania (as part of an internationally funded project) developed a half day dementia awareness course (Stoner et al., 2022). This was built around the biopsychosocial model of dementia and incorporated principles of good communication. This thesis adapted and evaluated the course for a UK sample as a public health intervention for informal caregivers.

The following key research questions were investigated:

1. Do participants feel the DAC course is acceptable? This was evaluated by looking at whether participants completed the whole course as well as through qualitative data around participants' experience of the DAC course collected via interviews.

2. Were any changes observed following the DAC course? This was evaluated using qualitative interviews to establish if there was any change that was not picked up by quantitative outcome measures.

3. Did participants feel the outcome measures used in the study were acceptable? This was evaluated using qualitative interviews to establish whether participants felt the outcome measures were acceptable in terms of their relevance and ease of completion.

The evaluation of the acceptability and impact of the DAC course across the UK could have important and clinical implications. These include further development of a standardised psychoeducation and support intervention for caregivers of individuals with dementia. It can assist in laying the groundwork for a future randomised control trial, with the hope that the DAC course can be more widely delivered across the NHS to assist with providing caregivers psychoeducation and support and minimising the possible concerns experienced by caregivers.

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Part 2: Empirical Paper

Exploring the Acceptability and Impact of an Online UK "Dementia Awareness for Caregivers" Course

Abstract

Aims: Informal caregivers provide a large proportion of care to individuals with dementia. This role can be demanding and can impact caregivers' mental and physical health. Despite awareness of this, there is no standardised dementia psychoeducation and support available. This study aimed to address this critical gap by exploring the acceptability and impact of a new online psychoeducation and support course called 'Dementia Awareness for Caregivers (DAC)'.

Method: The DAC course was adapted for a UK setting and delivered online to unpaid dementia caregivers. This study consisted of a qualitative design, whereby following completion of the course, participants engaged in a semi-structured interview. A data-driven inductive and deductive approach was used to explore the acceptability and impact of the course.

Results: Fifteen participants completed the DAC course and engaged in feedback interviews. Qualitative analysis generated eight subthemes organised into three over-arching main themes; 'acceptability of course', 'impact of course', and 'reflections on outcome measures used'.

Conclusions: The DAC course was found to be acceptable among dementia caregivers across the UK. It was also found to have a positive impact for both caregivers and individuals with dementia, including increased hope and insight regarding the future and the caregiving role, increased confidence in utilising skills discussed to provide person-centred care, as well as several caregivers seeking peer support following participation. Further research is recommended to determine the effectiveness of the DAC course, among a larger population of dementia caregivers.

1.Introduction

Every year across the world there are nearly 10 million new cases of individuals diagnosed with dementia (Jeste, 2021). Across the United Kingdom (UK) alone, it has been predicted that by 2051, prevalence of a dementia diagnosis could exceed two million individuals (Prince et al., 2014). In England, total costs associated with caring for those with dementia in 2015 was reported to be £24.2 billion and with prevalence rates increasing, the already great economic cost related to dementia is likely to surge (Wittenberg et al., 2019).

1.1 Caring for an Individual with Dementia

Dementia is progressive in nature and can have a substantial impact on an individual's psychological, social, and physical well-being (Bender & Cheston, 1997; Lewis et al., 2014; Prince et al., 2016). In many cases, individuals with dementia often require support from others and given the high demand on health services, often this support is provided by informal caregivers (Prince et al., 2018). An informal caregiver is defined 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, 2019, para. 1). Informal caregivers often assist with various activities of daily living and their input is increased as the care recipient becomes more dependent due to the progression of dementia. In 2019, it was reported that over 89 billion hours were spent by informal caregivers providing support to individuals with dementia (World Health Organisation, 2021).

1.1.1 Needs of Informal Caregivers

When caregivers are provided with appropriate support, the caregiving role has been found to have a positive impact, particularly with regards to providing a purpose in life (Doris et al., 2018). However, appropriate support is often not provided, and many informal caregivers experience psychological concerns, high levels of burnout and stress, as well as a loss of independence (Lindeza et al., 2020; Or & Kartal, 2019). Nearly 50% of caregivers are reported to have considerable levels of caregiver burden (Collins & Kishita, 2020) and roughly a third of caregivers report symptoms of anxiety and depression (Kaddour & Kishita, 2020). Additionally, psychological concerns such as depression, have been found to be correlated with increased risk of physical health concerns, further highlighting the impact caregiving can have on an individual (Brodaty & Donkin, 2009).

Informal caregivers often become the “invisible second patient” (Brodaty & Donkin, 2009) and as such it is important that appropriate support is offered to assist them in being able to carry out their caregiving role effectively whilst being able to maintain their well-being. Furthermore, research has found providing structured multi-component interventions to dementia caregivers not only benefits themselves, but also reduces the risk of the individual with dementia being moved into a care home earlier than needed (Kurz et al., 2009; Mittelman et al., 2006). Aware of the increase in dementia prevalence as well as the demand on the economy, the individual diagnosed, and those around them, the World Health Organisation adopted a worldwide plan. The plan calls on governments to meet targets for the development of dementia awareness, diagnosis, care, and treatment, as well as more support for care partners and research (World Health Organisation [WHO], 2017). However, care for individuals with dementia and their caregivers often falls short of what is required and there is great variability in what is offered (Schmachtenberg, 2022).

1.2 Support for Caregivers

1.2.1 Third Sector and Research Interventions

The large number of informal caregivers across the world has been known to reflect the lack of resources and general support (Messina et al., 2022). Across the UK, third sector organisations such as charities, voluntary groups, and social enterprises, offer support to caregivers (Amador et al., 2021). Often the support includes information and advice, memory cafes, activity groups, and leisure centres (Amador et al., 2021; Frost et al., 2020). However, not all services are easily accessible and often due to high demand and increased pressures, services are left with long waiting lists and caregivers are not always provided with support (Chadborn et al., 2019; Or & Kartal, 2019).

To address this, research has investigated what structured interventions may be suited for dementia caregivers. Interventions focused on increasing caregivers' awareness and understanding of dementia can have a positive impact on their mental health whilst reducing stigma and burden (Jensen et al., 2015; Kahn et al., 2016; Wenborn et al., 2016). Research interventions such as the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project (Wisniewski et al., 2003) and the Strategies for Relatives (START) project (Livingston et al., 2013), found that engaging in interventions can lead to a reduction in burden (Wisniewski et al., 2003), case level depression, and a higher quality of life (Livingston et al., 2013). However, both interventions had limitations. The REACH project was six months in length, requiring caregivers to use their already limited time to be able to attend. Furthermore, caregivers had to report distress at baseline to be eligible, highlighting the intervention to be more of a reactive approach rather than preventative, with the latter being more beneficial for caregivers (Jensen et al., 2015). Within the START project, it was noted that baseline scores of depression and anxiety were already high, increasing the likelihood of a post-test score change (Livingston et al., 2014).

1.2.2 Gap in Support

Despite some services being offered, as previously mentioned, many dementia caregivers are not provided with appropriate support. Dementia caregivers display higher levels of mental and physical unmet need and lower levels of service use compared to other caregivers, highlighting need for standardised support among this population (Stirling et al., 2010).

1.2.2.1 Awareness of Support. Whilst the impact of caring for an individual with dementia on a caregiver has long been reported in research (Messina et al., 2022; Motenko, 1989; Prince et al., 2015), many caregivers are unaware of the services on offer (Bieber et al., 2019). Findings report a lack of information provided to caregivers throughout the caring journey (Carers' Trust, 2013). Caregivers involved in qualitative research have highlighted that following diagnosis they are often left to seek out support on their own: "*we didn't get any help at all. I didn't get sent anywhere*" (Sutliffe et al., 2015, p. 773), "*they were like, here's your diagnosis see you later*" (Biggs et al., 2018, p. 30). Seeking out support in an unfamiliar area can be both a challenging and time-consuming task for caregivers, particularly given that caregivers are also having to provide care and attend to their own well-being (Messina et al., 2022). When assessing caregivers' need for support, findings noted that whilst more help from services was reported by caregivers, this was not correlated with use of services, highlighting the elevated levels of unmet service need (Stirling et al., 2010). As such, standardised support is needed to provide caregivers with appropriate information and support to assist them in being able to carry out their caregiving role effectively, whilst maintaining their own well-being.

1.2.2.2 Access to Support. Of those that are aware of services, many report support is not offered in a timely manner (Gorska et al., 2013). Informal caregivers experience challenges with accessing services, which in turn can put increasing pressure on the caregiving role and in some cases lead to early hospital/residential admission (Kerpershoek et al., 2016). Furthermore, often services are offered as a reactive response to a sudden change in the individual with dementia and/or the caregiving situation (Stephan et al., 2018). Caregivers of people with dementia have reported timely access to services can be extremely beneficial noting, "*we should have requested help much earlier*" (Stephan et al., 2018, p. 8) and "*the right time is when a person receives the diagnosis*" (Stephan et al., 2018, p. 8). Providing preventative rather than reactive support, can not only benefit the caregiver in feeling more supported, therefore assisting with their well-being, but can also in turn benefit the individual with dementia (Stephan et al., 2018). However, within England services can often be fragmented, increasing the challenges in accessing them. This disparity in the services available is also noted when comparing rural and urban areas, again contributing to challenges with regards to accessing services (Arsenault-Lapierre et al., 2023). Additionally, due to health and social care services being commissioned independently, at times care may not be collaborative which can lead to caregivers' needs not being appropriately met (Aldridge et al., 2019).

1.3 Dementia Awareness for Caregivers (DAC) Course

As highlighted, interventions focussed on supporting dementia caregivers are needed. In response to this need, a brief educational course, the DAC course (Stoner et al., 2022), was developed as part of the ongoing Cognitive Stimulation Therapy (CST) International programme (Spector et al., 2019). It incorporates information, advice, and the biopsychosocial principles of CST (Spector et al., 2003). The course was created using a four-stage iterative process whereby following a review of the literature, specific modules were agreed upon and from this, an international version of the course was created. Finally, this international version was used as a template for countries to adapt and create local versions for delivery (Stoner et al., 2022). Results from an initial acceptability test among dementia caregivers in Brazil, India, and Tanzania, indicated the DAC course as being well received (Stoner et al., 2022). Caregivers valued the peer-learning nature of the course, the use of psychological models as a way of understanding dementia, as well as finding the different modules informative. Whilst these initial results are promising, to establish whether the course can be utilised on a wider scale, further testing in other countries is required.

1.4 Summary and Aims of Thesis

1.4.1 Summary

With a global ageing population, prevalence of dementia is likely to increase at a fast pace (Prince et al., 2014). In many cases, informal caregivers provide a large portion of care to individuals with dementia (Prince et al., 2016). Due to the nature of dementia, the caregiving role can have various psychological, physical, and social demands and this can have a negative impact on caregivers' mental and physical health, particularly when caregivers are not provided with support (Brodaty & Donkin, 2009). Despite awareness of this, there are lower levels of service use among dementia caregivers (Stirling et al., 2010). In many cases, informal caregivers report a lack of awareness of services as well as challenges with regards to accessibility of those services that are available (Brodaty et al., 2005; Gorska et al., 2013). As such there is a need for standardised support for caregivers.

1.4.2 Aims of Thesis

The DAC course was deemed acceptable when tested among dementia caregivers in Brazil, India, and Tanzania (Stoner et al., 2022). The aim of this thesis was to explore the acceptability and impact of the DAC course among dementia caregivers in the UK with the hope that findings can assist in the development of a standardised psychoeducation and support intervention that can be delivered across the National Health Service (NHS).

The main aims of the thesis are:

1. To explore whether caregivers of individuals with dementia in the UK feel the DAC course is acceptable.
2. To explore the impact on caregivers and their care recipients following completion of the DAC course.
3. To explore acceptability of the research design; specifically, whether outcome measures were perceived as acceptable by caregivers.

2.Methods

2.1 Setting and Ethical Approval

This research was conducted online with participants accessing the intervention via the videoconferencing software, 'Microsoft Teams' on their personal devices from their own homes across the UK. Ethical approval was sought and obtained from the University College London ethics committee (appendix A). All participants provided informed consent prior to participating in the study and were informed they were able to withdraw at any point up until data analysis.

2.2 Participants

The inclusion criteria consisted of participants being over 18 years of age, an unpaid caregiver, able to communicate and understand English and have access to the internet. Participants were recruited via an online dementia research database, 'Join Dementia

Research’ (www.joindementiaresearch.nihr.ac.uk). A study advert (appendix B) was placed on their website and participants were sent opt-in emails. Study recruitment took place over three months between June to August 2022 and covered four bases across England, Wales, Scotland, and Ireland.

Sixty individuals opted in to take part in the study. They were sent an information sheet and consent form (appendix C) to complete. Of 60 interested, nine did not meet the inclusion criteria. The remaining 51 were randomised into the control group (25 participants) and intervention group (26 participants). Of the 26 participants in the intervention group, six individuals did not attend with no prior explanation and six individuals cancelled on the day of the course and provided reasons. All 12 were reinvited to join the group on another date. A total of 15 individuals attended the DAC course and attended a follow-up interview one month after completing the course. The first and second course consisted of five participants, the third course consisted of three participants and the last group of two participants. See appendix D for a recruitment flow-chart.

2.3 Design

This research used a pre-post intervention parallel group design with a treatment group and a control group. The treatment group engaged in the DAC course and the control group was defined as treatment as usual (TAU), meaning that participants were not offered the DAC course, but could access their usual services outside of the study. The study was mixed in design, incorporating both quantitative measures (pre and post measures) and qualitative interview data. Quantitative data relating to the acceptability of the research design and the DAC course, investigating recruitment, retention, and attrition, is reported in a separate doctoral thesis by joint-researcher Isabelle Evans. The current thesis focuses on the qualitative aspect of the study exploring the acceptability and impact of the DAC course as well as the acceptability of the outcome measures used, in terms of their relevance and ease of completion. An overview of each researchers’ contributions for the joint project are noted in appendix E.

2.4 Development of the Intervention

The brief, educational DAC course used in this study was developed using the international template, DAC-International (Stoner et al., 2022). The international template included a course guide consisting of seven sections including guidance on running the course for caregivers. The international template also included a 75-slide PowerPoint presentation including welcoming group members and introductions, the three modules of the course which incorporated activities, group discussions and lecture-style PowerPoint slides, followed by feedback and reflections. In line with the guidelines set out by Stoner et al. (2022), the international template was adapted, and a local version was created including UK specific dementia myths, facts, examples, activities, medication, as well as support and guidance offered across the UK (see Table 1).

Table 1.

Overview of Content Included in DAC Course.

Section	Description of content
Welcome	Introductions, purpose of course, confidentiality and peer learning.
Module 1: What is dementia?	Background of dementia and dementia in the UK, pathology, prevalence, and models of dementia.
Module 2: Positive engagement	Psychological concepts and activities for positive communication and engagement (personhood, malignant social psychology, mental stimulation, promoting strengths, maximising potential).
Module 3: Caring for someone with dementia	Practical information on caring (activities of daily living, nutrition, risk management), services (non-drug treatments, CST, medication) and the effects of caring (impact, caregiver needs, signposting in the UK).
Reflections on course	Questions, feedback on course.
Ending	Thank you for attending, closing of course.

Following the completion of adaptations to the DAC-International template, six individuals were recruited through personal contacts to review the local version of the DAC course and provide feedback. They were sent an email including the local version of the DAC course PowerPoint along with questions requesting for feedback on the course, as well as the adaptations made. Two dementia caregivers, two professionals working in dementia care and two individuals diagnosed with dementia provided feedback on the course. All stakeholders were reimbursed with a £10 voucher.

2.5 Procedure

Participants who opted-in to the study and signed the consent form were screened by the researchers to ensure they met the inclusion criteria. Participants were then randomly allocated to either the DAC or TAU group using an online randomisation website (www.randomlists.com). The DAC course was delivered online by one trainee clinical psychologist as a one-off, four-hour course. Participants were sent an email confirming the date and time of the course as well as a Microsoft Teams link to join on the day. The course was run on three separate occasions and groups of 6-10 unpaid dementia caregivers across the UK were invited to attend. Participants that cancelled and did not attend were re-offered a date to attend the course and a fourth course was therefore run for these individuals. Two groups were delivered in the morning and two in the afternoon to accommodate for differing needs amongst the caregivers attending. Following the first course, researchers found that emailing a reminder a week before and again a day before the course, as well as calling individuals to confirm attendance, assisted with people attending and hence this was done for the remaining course dates.

Following course completion, participants were sent an email containing the relevant hand-outs and signposting materials from the group. They were also provided with a Microsoft Teams link to their post-group interview which was held one month later. Interviews were conducted by the researcher who did not run the DAC course for that particular participant to assist with the participant feeling more able to be open and honest with their feedback. Interviews were semi-structured and lasted 30 minutes each. Questions and prompts covered participants' acceptability of the course as well as the impact of the course (appendix F). The semi-structured interview questions and prompts were originally developed by the DAC International team to obtain feedback on courses they were planning to run across India, Brazil, and Tanzania. They were reviewed by the researchers to ensure they covered the current study's research aims.

2.6 Analysis

All interviews were recorded with participant consent and following anonymisation, were uploaded to Scrintal (online transcription service). Whilst Scrintal assisted with transcription, it is still necessary for researchers to re-read and check the accuracy of transcription, leading to familiarisation of the data. Prior to choosing an appropriate approach for analysis, a review of previous feasibility studies and the literature around qualitative approaches, specifically thematic analysis, was carried out. This was discussed further with the research team and an external qualitative lecturer in the field. Subsequently, a data-driven inductive approach (Boyatzis, 1998) and a deductive a priori template of codes approach (Crabtree & Miller, 1999), was applied to interpret and understand the data. Transcripts were printed onto paper and data was systematically coded by hand and then organised into meaningful groups. Whilst analysing data, thought was taken through pausing and checking the origin of interpretations, being aware of any biases held. Following a process of reviewing and refining the coded data, visual tables were used to gain a sense of how coded extracts may be sorted into overarching and sub-themes (appendix G). A fellow trainee clinical psychologist provided credibility checks on a random sample (20%) of the transcripts by reviewing and providing feedback on initial codes. Any differences between researchers' coding were discussed, and final main and sub-themes were developed.

3.Results

3.1 Course Adaptations

Two dementia caregivers, two professionals working within dementia care and two individuals with dementia provided feedback on the local adaptations made to the DAC course. No demographic data beyond them self-identifying as being a caregiver, professional or individual with dementia was collected, due to this being public and patient involvement and engagement rather than formal data collection. All individuals felt the adaptations were applicable to the UK, found the course content relevant and insightful, and felt no changes were needed. The final version of the local DAC was reviewed and accepted by two members of the DAC-International team.

3.2 Sample

A total of 15 individuals received the DAC course and all these individuals attended their post-DAC interview a month later. Participant demographics can be found in Table 2 below. Most participants were female (80%) with an average age of 61.8 years (*SD* = 8.7). Several participants had no other caring responsibilities (66.6%). Others were caring for their parent (53.3%) and/or did not live with the care recipient (53.3%). All participants were White British.

Table 2.

Participant Demographics.

Age (years)	Mean *(SD)* 61.8 *(8.7)*	Range 46-81
Characteristics	*N*	%
Gender		
Female (%)	12	80
Male (%)	3	20
Ethnicity		
White British (including Irish/Welsh/Scottish/English)	15	100
Marital Status		
Married	10	66.67
Single	3	20
Living with partner	1	6.67
Separated	1	6.67
Relation to care recipient		
Child	8	53.33
Spouse	5	33.33
Son-in-law/daughter-in-law	1	6.67
Other relative	1	6.67
Living with the care recipient?		
Yes	7	46.67
No	8	53.33
Caring for anyone else?		
Yes- Child(ren)	4	26.67
Yes – Other adult(s)	1	6.67
No	10	66.67

3.3 Description of Thematic Framework

The final analysis generated eight sub-themes which related to the research aims. These sub-themes were organised into three over-arching main themes; ‘acceptability of course’, ‘impact of course’ and ‘reflections on outcome measures used’. Table 3 outlines the main thematic structure. Each main theme and sub-theme is presented in more detail below, with illustrative quotations.

Table 3.

Thematic Framework.

Main Theme	Sub-Theme
1.Acceptability of Course	1a: Preferences of Course Format 1b: Preferences of Course Content 1c: Views on the Point of Delivery of Course
2.Impact of Course	2a: Use of Peer Support 2b: Looking After Myself 2c: Caregivers’ reflections on use of Skills from Course
3.Reflections on Outcome Measures Used	3a: Experience of Outcome Measures 3b: Suggested Improvements for Outcome Measures

3.4 Main Theme 1: Acceptability of Course

This main theme related to participants overall view regarding the acceptability of the DAC course. It encompasses participants’ preferences on the way in which the course was delivered, the course itself, as well as their view on when the course could be delivered. As such, it was subcategorised into three sub-themes; ‘preferences of course format’, ‘preferences of course content’ and ‘views on the point of delivery of course’.

3.4.1 Sub-theme 1a: Preferences of Course Format

With regards to the length of the course, some participants felt it was “*quite a long session*” (P3) and that the course could be “*shortened so it’s like an hour shorter*” (P6). In discussion, participants felt unable to concentrate for that length of time with some stating “*it is hard to stay on the ball for four hours*” (P6). However, most individuals found the length appropriate, “*I learned a lot. And, the time went so quickly, I couldn't believe it was over*” (P7).

> “*And the length of time, you know, I think I felt it was probably just about right. It was enough time to get a decent amount of information over, but not that you were thinking, when will we finish?*” (P8)

No participants had concerns with regards to the DAC course being run online. Nearly all reported they preferred the online delivery due to it saving on travel time. Participants stated “*it's much easier to do it on the screen than face to face. It makes it easier for people to attend because they don’t have to worry about travelling*” (P14).

The reduction in travel time was also found to be particularly important for those who have limited time due to caring for others.

> “*Doing it online and in the convenience of your own home was nice…If I had to travel, I probably wouldn’t have come because I just don’t have the time to fit that in*” (P12)

Even for those participants who had reservations around attending online appeared to have found it manageable stating, “*I'm not so keen on talking online, but it was alright once I got started. It wasn’t too full on, and I enjoyed it*” (P15). One participant did comment on the challenges of noticing and interpreting body-language when online, “*I didn’t mind it being online, I guess when you're there in person, all that kind of social cues and body language is much easier to gauge, that's all*” (P4).

Individuals reported having no concerns with the size of the group reporting “*actually it was quite nice*” (P5) and *“it was a good number; I think you could even have more, and it would still be okay”* (P11). All participants commented on the benefits of running the course as a group. Individuals found listening to other caregivers’ stories and experiences as being particularly “*useful*” (P2), “*interesting*” (P7), “*valuable*” (P4), and “*powerful*” (P9). Furthermore, participants felt the group format allowed them to “*share our ideas and learn from each other*” (P1).

Finding the group format of the DAC course a supportive environment was mentioned by all participants, particularly with regards to reducing the feeling of loneliness. Individuals reported the group format “*reminded me there are others out there*” (P7), “*it is* *quite a funny, lonely sort of business…so, yeah it was a lovely opportunity, and I would definitely tell any other carers to do it"* (P12) and "*you feel very isolated, but this helped me remember I'm not alone and I can do this*" (P8).

> "*It's interesting because you've all got a common thing, and the relationships just get birthed even during just a short training. I feel that's the most contagious thing, when the course builds into a little community, and you have that support*" (P13)

3.4.2 Sub-theme 1b: Preferences of Course Content

Many individuals reported finding the course content "*interesting*" (P4), "*thought-provoking*" (P10), "*non-threatening*" (P13), and "*helpful*" (P15). Individuals also commented on the course content as *"covering all the main bits that you need to know in one place, so I didn't have to go round looking at lots of different bits of information, it was all there in one session"* (P7).

> "*You know, sometimes as carers, you don't have time to read a great big book on dementia, and you wouldn't understand it half the time. A lot of people who were carers might not have the capacity to be able to do that kind of learning. So having this course shown to them is really valuable, I'd definitely recommend it*" (P6)

Individuals felt the course content provided them with "*insight"* (P1) and "*hope that there is a life after a dementia diagnosis"* (P14). Others reported the course content assisted with their ability to provide care stating, *"I'm more empathic, understanding, and patient now"* (P1), *"I feel more confident and knowledgeable than I was before the course. Definitely more prepared"* (P10) and "*I'm glad I was offered this course, because I've learned so much"* (P1).

Various aspects of the course appealed to different individuals for example, one individual stated, "*some of the like myth busting, I think that was quite helpful because, certainly it's been quite difficult with relatives and things, but also just for my own knowledge, knowing what's true and not*" (P1). Many individuals mentioned the focus on psychosocial aspect of dementia was helpful stating, "*talking about psychological models, social interaction and promoting strengths, as opposed to just focusing on medical models, like other courses do, was very informative and interesting. You see the person as a person and* *not just the disease*." (P8). Other individuals commented on the information about dementia as being helpful, "*the information about, dementia itself, the types and how it progresses and the prevalence, that was really interesting and helpful and helped just normalise dementia for me*" (P9).

All individuals found the activities and hand-outs helpful. The activities were described as "*fun and useful*" (P4), and individuals stated, "*the activities that made us think and share after a bit of information was given, that was for me was the best thing*" (P11). Others reported "*all the information that you provided, that was so helpful, you don't get that elsewhere*" (P15), and "*there was a lot of good signposting, that was really helpful for me*" (P4).

One participant commented on missing content stating, "*there was nothing about new technology…we use technology quite a lot, so it would've been nice to hear a bit more about that and how we can use it*" (P3).

3.4.3 Sub-theme 1c: Views on the Point of Delivery of Course

A vast majority of individuals commented on the lack of support they received when their loved one was diagnosed with dementia. Individuals mentioned having to "*take responsibility for finding stuff out*" (P11) and that "*most people end up just fumbling their way through because there isn't much out there*" (P2).

> "*The doctors kind of go to you, right, your parents got Alzheimer's or vascular dementia, and here's a leaflet and they go, and you literally have no clue what to do because they say go and talk to the Alzheimer's society. Okay, right. Where do I start? Where do I get the information?*" (P10)

These experiences led participants to reflect on at which point in the dementia journey they felt would be helpful to receive the DAC course. All individuals felt having the course offered at point of diagnosis would be "*really helpful*" (P7), "*would help to give you an idea of the things that could happen*" (P2), and "*would give you the skills you can then start using and help signpost you to the places you can get further support, because you don't get that kind of help and information generally*" (P1).

> "*And if everyone could access it, that needed to, they would find it very beneficial, because again, when someone goes say for a diagnosis, it's a lot to take in, it's a bit of a minefield and you don't have a clue. Whereas if they got a diagnosis and then automatically get offered your course, maybe even record it to go back to as well, that would be really helpful. Certainly, from my experience we would have been more prepared and felt more supported*" (P4)

Some individuals felt if they had received the course at an earlier point in their caregiving journey, they may have been able to utilise more of skills discussed in the course.

> *"[X] is quite unwell at the moment…if we were at an earlier stage and I had this course, then I would have done things differently after the course, that's why I think it's helpful to have it early on*" (P4)
>
> "*I think you know, if say, I'd taken part in it a few years back, then I think I would've been able to use more of the skills compared to now, I wish I'd had it back then because I really would've benefited*" (P1)

3.5 Main Theme 2: Impact of Course

All participants commented on the impact engaging with the DAC course had on themselves as caregivers as well as their interactions with the individual living with dementia. This main theme was subcategorised into three sub-categories, 'use of peer support', 'looking after myself' and "caregivers' reflections on use of skills from course".

3.5.1 Sub-theme 2a: Use of Peer Support

Several individuals reported seeking peer support following engaging with the course. Participants commented on "*joining a few groups*" (P13), "*going to social groups*" (P5), "*reaching out for support from others*" (P7) and "*using helplines*" (P9). Many felt attending the course contributed to their ability to seek support, "*I went to one the other day and it was great, so I'm glad I came to the course because it helped me do that*" (P12).

> "*The course was a nice reminder of do you know what, I really need to go on the helpline. So I looked for some peer support and you know I think others would too.*

> *It's lovely being able to share with other people in similar situations, so yeah that was definitely off the back of the course*" (P10)
>
> *"You know, during the course different types of support was talked about in the group, like the online forums and stuff, and then I went away and thought about it and decided to give it a go, and it's been amazing for me. I would never have thought let me give that a go, it was only because I came on this course and heard about it, so I really think if others do the same it would be great because you don't even know half these things exist"* (P13)

A couple of participants noted they had not sought peer support following the course. They mentioned having support in the form of family and friends, "*because I have the regular contact with my siblings, I use that as my sounding board*" (P3) and seeking peer support as not being something they would generally do, ""*not really, I'm just not that sort of person, so wouldn't really do that*" (P4).

3.5.2 Sub-theme 2b: Looking After Myself

Many participants commented on the course as being a reminder to look after themselves as caregivers. Individuals reported "*paying more attention in looking after myself*" (P3), "*putting down a few more boundaries than I did before*" (P8) and "*just stopping and taking care of myself, having time where I try to just focus on me*" (P4).

> *"I felt like I had just been continuously going through each day every day and after coming to this course I was like, yeah you're right, I really need to slow down and look after myself because I'm human too, I need my time"* (P10)

Individuals also commented on speaking about caregiver needs in the DAC course and the impact this had on them.

> "*Just even speaking about it you know; it just made me think that actually this is really hard, and I do need to take time to look after myself. It just highlighted things like, having time with my husband and our German Shepherd is really important for my mental health. So I'm going to make an effort to look after me too. So yeah, speaking about it really got me thinking about what I need to do*" (P7)

3.5.3 Sub-theme 2c: Caregivers' reflections on use of Skills from Course

Individuals commented on the different skills covered in the DAC course they were able to put into practice following completion of the course. A vast majority of individuals reported giving the individual with dementia more independence following attending the course.

> "*It's very easy to take over all of those skills. You can do them twice as fast, but I've learnt from the course the importance of letting him do more things on his own and I've already noticed a bit of a difference in him since doing that*" (P5)

Individuals also reported using other skills such as "*not contradicting him if he's got something wrong*" (P2), "*involving her more in the decision making*" (P11), "*keeping him active and including more hobbies for him to do*" (P6), "*changing the way I speak to him, you know the part of the course we went through ways of saying things, I've really taken that on board*" (P5), as well as encouraging individuals to "*think about how I can change some of the things I do when I'm looking after him*" (P15).

> "*I guess after the course, I'm just more aware of what I'm doing and how I'm caring for him. Even when other people are around him, I notice myself thinking back to the course and being like, oh maybe we should change the way we do that and just things like that. It's really made me think about how I care for him*" (P13)

Others felt the course assisted in their ability to be "*more mindful of the future and trying to be a bit more understanding rather than being frustrated*" (P12).

> "*The course really helped me to just remember that there is a reason why she is behaving that way or doing something and how it's going to be really helpful for me to keep that in mind going forward as the dementia progresses*" (P14)

3.6 Main Theme 3: Reflections on Outcome Measures Used

As previously mentioned, all participants completed pre and post outcome measures. Quantitative results of these outcome measures are reported in a separate doctoral thesis. During the semi-structured interviews, participants were asked of their experience completing the pre and post measures and this main theme is related to their responses. It was sub-categorised into two sub-categories, ‘experience of outcome measures’ and ‘suggested improvements for outcome measures’.

3.6.1 Sub-theme 3a: Experience of Outcome Measures

All participants described the questions asked in the outcome measures as being “*relevant*” (P1). Many individuals reported completing the outcome measures was “*fine*” (P11) and they had “*no problem with doing it*” (P13). All participants felt no other domains needed be included in the outcome measures, stating, *“not really, I think everything was covered, there wasn’t anything that made me think oh why didn’t they include that”* (P10).

> “*I found it pretty simple to complete and found all the questions relevant. It does make you think, day to day you go along and then someone asks you a question, or like you complete these; it actually makes you think about things*” (P7)

3.6.2 Sub-theme 3b: Suggested Improvements for Outcome Measures

Whilst all individuals reported having no concerns with the outcome measures some identified ways in which they could be improved. One individual commented on the wording of questions stating “*one of the questions that we got…said is it important not to become too attached to residents? I mean, is that what my husband is, a resident?*” (P4).

Another reflected on how they felt the outcome measures did not take the past into consideration when asking participants to rate whether their relationship had changed with the care recipient explaining, “*it made me kind of think, it really depends what relationship you have with that person before they become unwell. I’ve said it didn’t change but that’s because it was great before not because the course wasn’t helpful*” (P4).

Three individuals felt it would have been helpful to have a ‘not applicable’ check box when answering questions stating, “*I felt there wasn't a bit that said not applicable. And I felt that in some cases, that would have been quite helpful because there were some questions that really weren't applicable to me*” (P5).

4.Discussion

This study sought to explore the acceptability and impact of a Dementia Awareness for Caregivers (DAC) course among dementia caregivers in the UK. Fifteen participants engaged in the DAC course and completed semi-structured interviews. With regards to acceptability, participants' experience of receiving the DAC course, in particular the extent to which they considered it to be appropriate, their perceived effectiveness, satisfaction, and ability to meet their needs, were explored. With regards to impact, participants' views on the different ways in which the DAC course had an impact on their caregiving role, themselves, and care recipient, were explored. Analysis of these interviews generated eight sub-themes which were organised into three over-arching main themes; 'acceptability of course', 'impact of course', 'and 'reflections on outcome measures used'. The current study demonstrated that the delivery of the DAC course to dementia caregivers in the UK, and the outcome measures used, were acceptable. It has also demonstrated that engaging in the DAC course can have a beneficial impact on various aspects of the caregiving role. These findings will be explored further below.

4.1 Acceptability

4.1.1 Acceptability of Course Format

Regarding the format of the course, participants shared more positive reflections than negative. All individuals reported they would recommend the DAC course to other dementia caregivers, indicative of a high degree of 'acceptability'. Participants reported they had no concerns with regards to the course being run online. The reasons for this were varied, including saving on travel time and cost, as well as not taking up too much of caregivers already limited time. Since the COVID-19 pandemic, the use of digital technology has increased at a rapid rate (Clipper, 2020). As such, some individuals may have felt more comfortable attending online due to many services now utilising online platforms and individuals being more exposed to using this format. However, some individuals expressed initial reservations about attending online. Through engaging in the course online, their perceptions appeared to shift and during the interviews, participants noted despite having had reservations, they enjoyed the course and would attend again online. In clinical practice, the use of prior-participant testimonials could assist in encouraging others when recruiting for online groups if this presents as a barrier.

Whilst some participants felt the length of the course was too long and reported finding it challenging to remain focussed, the majority felt the length was appropriate. All individuals felt running the DAC course as a group intervention was beneficial. Caregivers mentioned the group aspect helped individuals feel less alone and hearing others' experiences was powerful, interesting, and created a supportive environment. It is clear that relationships were built during the course, with some individuals requesting to keep in touch with each other following the completion of the study. Furthermore, the smaller group sizes of 6-10 participants appeared to help foster a contained environment and allowed participants to feel able to share and build inter-personal bonds. These findings highlight how the group format of the DAC course enables caregivers to feel supported, less isolated, and talk openly about their experiences and challenges with other caregivers, despite being held online. This is consistent with research that has suggested online relationships are able to be formed in similar ways to in-person relationships (Lomanowska & Guitton, 2016), providing further support for the online group delivery of the DAC course. Additionally, sharing experiences with other caregivers can help to normalise dementia and in turn assist caregivers in feeling more confident and prepared regarding the future.

4.1.2 Acceptability of Course Content

The UK version of the DAC course was developed using the DAC International template which took into consideration the need for information and practical advice, whilst incorporating the biopsychosocial principles of CST. As previously mentioned, the DAC course was co-developed with a team from four countries, representing different cultural perspectives and increasing generalisability. The course was then adapted to include UK specific myths, examples, information and advice. Findings from the current study suggest that the content included in the course was felt beneficial and overall, all participants felt the course content was interesting and helpful, indicating a high level of 'acceptability'. Furthermore, specific aspects of the course appealed to different individuals depending on their interests and/or challenges they had experienced. Providing information on dementia and its progression along with dispelling common myths was found to be a useful part of the course content and aided in normalising aspects of dementia. Unique to the DAC course is the strong focus on the biopsychosocial aspects of dementia and positive communication, compared to a much more diagnosis focus within other researched courses (Stoner et al., 2022).This focus on psychological principles as well as the social aspect of dementia, assisted in providing caregivers a different narrative for understanding dementia. Participants noted an appreciation for this, and reflected on how the course assisted in addressing stereotypes that may be reinforced by medical models. Furthermore, the activities and hand-outs included in the DAC course were deemed to be helpful and enjoyable. Feedback provided by caregivers identified that often accessing information was challenging and therefore being provided with this on the course, was valuable.

One individual did comment on missing content for the course, namely the use of new technology and its use in assisting with the care of people with dementia. Technology such as video devices, GPS trackers and security devices have been known to help individuals with dementia and their caregivers with safety, security, socialising, and memory aids (Miskelly, 2001; Topo et al., 2004). However ethical concerns can arise with regards to when to use them (Olsson et al., 2012). Research has suggested providing information regarding the use of technology at an early stage of diagnosis could facilitate joint decision-making regarding its use (Olsson et al., 2012). As such, including information on the different uses of technology in the DAC course, if delivered at an early stage of the dementia journey, may be useful for caregivers when making decisions later.

4.2 Impact of DAC Course

The DAC course appeared to have had a positive impact on caregivers and in turn, the individuals they care for. Caregivers commented on how the course helped provide them with hope and insight regarding the future and left them feeling more confident and prepared with regards to their caring role. Individuals also mentioned being more mindful in the way they interact with the individual with dementia as well as having more understanding regarding their presentation. Increasing knowledge of dementia is known to assist with caregiver's mental health, encourage person-centred care as well as reduce burden (Jensen et al., 2015; Kahn et al., 2016). As such, the impact of the DAC course is likely to not only assist caregivers in feeling more prepared in being able to provide care but, can also contribute to reduced burden and the individual with dementia being provided person-centred care.

Caring for an individual with dementia can at times become an isolating experience leading to caregivers feeling burdened and lonely (Ferrara et al., 2008). Through attendance of the DAC course, caregivers reported a reduction in feelings of isolation and felt reassured that other individuals are also in similar situations. Several participants went on to seek peer support following engaging with the DAC course, highlighting the important impact the DAC course can have. Individuals reported the course contributed to their ability to seek support whereby individuals joined groups, used helplines, and asked for support from others. Furthermore, a group of participants requested to keep in contact with each other to share information and materials, further demonstrating the impact the DAC course can have with regards to peer support and reducing loneliness.

As well as assisting individuals in seeking peer support, several participants reported the DAC course as being a reminder to engage in self-care. For some, caregiving can contribute to various psychological concerns and a lack of independence (Kuo et al., 2014; Lewis et al., 2014). Having space to discuss caregiver needs in the DAC course was viewed as valuable and individuals reported being reminded of the importance of self-care, with some feeling more able to take time to look after themselves following completion of the DAC course. Aware of the unhelpful impact not engaging in self-care can have on caregivers (Lewis et al., 2014), these findings support the important beneficial effects participating in the DAC course can have on caregivers' mental and physical health.

Participants commented on the various skills they learnt from the course and had started to put into practice including, providing the individual with dementia more independence, involving them in decision-making, engaging them in hobbies and activities, as well as changing the way they speak to them. Equipping caregivers with skills they can utilise in their caregiving role can not only help caregivers feel more prepared, confident, and able to care, but can also assist with reducing the risk of the care recipient being placed in a care home earlier than needed (Jensen et al., 2015; Pinquart & Sorensen, 2006). These findings provide further support for the vital impact of the DAC course not only on caregivers, but also on individuals with dementia.

4.3 Strengths and Limitations

There are certain strengths identified in the current study. The DAC course was initially co-developed with a team across four countries, allowing for representation of different cultural perspectives and increasing generalisability of the course itself. The course was then tested across India, Brazil and Tanzania and was deemed acceptable among dementia caregivers (Stoner et al., 2022). Along with the current findings, this highlights how the DAC course is a manualised intervention that can be easily replicated, enabling future research findings to be compared and explored. Whilst the content of the DAC course may well have similarities to other supportive interventions available, it is unique in that is has a strong focus on the biopsychosocial aspects of dementia and positive communication, whereas other researched courses tend to have much more of a diagnosis focus. The findings in the current study provided support for this, whereby participants reported an appreciation for this focus. Another strength is the use of stakeholder consultation in the development of the local UK version of the DAC course. This aspect of the DAC course development is key as it allowed professionals, individuals with dementia and caregivers to provide reflections. Furthermore, stakeholder consultation is reported as being an essential part in creating new interventions, as it allows for topics to be identified that the researchers may not be aware of (Duncan et al., 2020). Whilst the study sample may be considered as small, all participants who attended the DAC course attended their follow-up interview. This enabled researchers to gain an overview of how all participants experienced the course and may be an indication of the acceptability of the course.

Despite these strengths, some limitations are noted. The majority of caregivers included in the study identified as female. Whilst this appears to be a reflection of the estimated gender balance of dementia caregivers, with more caregivers being female (Wimo et al., 2013), it limits the findings in terms of capturing the experiences of male dementia caregivers. It also highlights the need for more research around male dementia caregivers to ensure their views do not become inadvertently missed within research. Further research on a larger scale, with a more equal representation of participant gender, may assist in obtaining a more generalisable understanding of the acceptability and impact of the DAC course across the UK.

It is worth noting that all participants who engaged in the study were of White British ethnicity. Caregivers of ethnic minority groups are known to experience various barriers to accessing support both in person and online (Kenning et al., 2017). Furthermore, information regarding support available for caregivers is often limited throughout the dementia journey (Schmachtenberg, 2022). Not having caregivers from ethnic minority backgrounds engaging in the study limits the extent to which findings can be generalised and therefore the extent to which the DAC course is deemed acceptable or to have had an impact amongst this group. Given that caregivers of ethnic minority groups report lower awareness of support available (Kenning et al., 2017), it is possible that this group of individuals may not have been aware of the specific online dementia research advertising platform used to recruit participants, and hence future research utilising other sources may assist with overcoming this limitation., Furthermore, use of this method of recruitment also inadvertently privileged those who had pre-existing skills in using technology, which may have contributed to the acceptability of the online format and the recruitment of a specific demographic of caregiver.

Whilst stakeholder consultation was used during the development of the local version of the DAC course, the study did not utilise stakeholder involvement when developing information sheets and consent forms. This may have allowed for forms to be more appropriately tailored to meet the needs of those receiving and/or completing them. As such, it would be suggested that future studies consider wider consultation from stakeholders in all aspects of study development.

Another limitation of the study is the absence of the use of reflexive exercises with regards to analysis. Whilst it is noted that the researchers regularly paused and questioned the origins of their interpretations, it is important to note that their background, preconceptions, and personal views may have, to some extent, influenced the study. Future studies should consider the use of reflexive exercises with the research team prior to conducting data collection and analysis, in order to consider these different perspectives and the influence on findings.

The DAC course was intended to be attended by 6-10 carers, however due to some individuals not being able to attend the group, the course was run with fewer individuals (between 5-2 carers per group). As such, the intended group size may not have been deemed acceptable as this was not met. Furthermore, participants reflections on acceptability of group size are focused on actual group size rather than intended group size hence further exploration of this is warranted. Trialling the DAC course among a larger sample size may provide further insight into acceptability of group sizes. Those participants who were invited but did not attend the DAC course, provided reasons such as work commitments, loss of care recipient, and illness. Whilst they were unable to attend, they reported being interested in attending if further course dates were announced. Whilst not in the scope of the present study, interviews with this group of participants may provide further information around acceptability given the drop-out between randomisation and course attendance and should be considered in future research.

4.4 Implications

Despite there being a great need for caregiver support, many are often poorly supported and are provided with little information to assist them in their caregiving role (Killen et al., 2016). The findings from the current study suggest that the delivery of the DAC course to dementia caregivers across the UK, is acceptable and can positively impact caregivers and their care recipients. As such, the current study presents a foundation for a larger randomised control trial to be run, to establish the efficacy and cost-effectiveness of the DAC course among a wider population of caregivers. The inclusion of larger sample sizes with caregivers who represent different ages, genders and ethnic backgrounds is suggested, to assist with wider generalisation of findings.

Whilst most individuals felt the length of the DAC course was acceptable, some individuals felt it was too long. Aware that concentration levels during online courses can vary depending on an individual's age and gender (Kara et al., 2019), it is important to consider ways of managing this. The findings from the current study share insight into ways this can be managed, for example, trialling the course with frequent shorter breaks, or as three separate sessions. Findings also highlighted the lack of support and information caregivers felt they received at point of diagnosis. Many felt that being offered the course as part of a standard package of care following diagnosis would have been beneficial in not only providing them with information, but also in helping them to access support and feel more prepared and confident regarding the future. Furthermore, caregivers felt attending the course at an earlier point in the dementia journey would have enabled them to utilise more of the skills discussed, due to the nature of dementia at a later stage. The findings from the current study also highlighted that the outcome measures used, were deemed both relevant and easy to complete, suggesting these could be repeated in future studies.

Running a larger randomised controlled trial at point of diagnosis within the National Health Service, utilising findings from the current study, would assist in further identifying the practical and clinical implications of the DAC course among this population of caregivers. For example, future studies could explore the acceptability and practicality of the DAC course being run as a standard package of care whereby, following the individual being diagnosed with dementia, caregivers involved are offered and encouraged to attend the course. Utilising the current findings, and findings from future studies exploring feasibility, acceptability, practicality, and cost-effectiveness, it is hoped that the DAC course can be offered to caregivers and delivered on a regular basis by different members of trained multidisciplinary staff. Furthermore, the longer-term hope is for the DAC course to become part of a nationally mandated service specification for carer support, in order for carers to be provided with information, advice, skills, and support to assist them with their caregiving role.

4.5 Conclusion

A Dementia Awareness for Caregivers course was adapted from an international template (Stoner et al., 2022) for delivery to caregivers across the UK. Findings from the current study indicated the course was well received by caregivers and was noted as having a positive impact on caregivers and in turn care recipients. Additional testing on a larger scale and at a point of diagnosis will assist in further determining the acceptability and impact of the course among this population.

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Part 3: Critical Appraisal

1.Introduction

This critical appraisal outlines my reflections on conducting a piece of empirical research as part of the doctorate in clinical psychology. It will begin by discussing decisions made regarding the methodology of the project, specifically delivering an intervention online. Challenges with participant recruitment and early engagement are also discussed. Finally, the appraisal will consider some of the researcher's personal background, interests, and assumptions, and how the researcher attempted to distance the process of data analysis from these.

1.1 COVID-19 and the Impact on the Project

When developing the methodology of the project, the original intention was to deliver the Dementia Awareness for Caregivers (DAC) course in person to caregivers of people with dementia across the United Kingdom (UK). My interest in this area was grounded in my previous experiences of delivering psychoeducational support groups to caregivers of individuals accessing mental health support in both acute crisis teams and community settings. I had the privilege of learning about the importance of supporting caregivers and the helpful impact this can have, not only on the caregivers themselves, but also the care recipient. Delivering these groups in person I was able to witness caregivers share their experiences through discussions as well as form supportive peer relationships following engaging in the group.

The risk of being diagnosed with dementia increases with age, with many individuals being diagnosed over 65 (Prince et al., 2014). This same age group were also deemed 'high risk' during the COVID-19 pandemic and were encouraged to stay at home along with their caregivers (Zhang et al., 2023). At the time of developing the methodology, there remained uncertainty of whether any further guidance or restrictions would be put in place, and older adults were still being advised to remain cautious as well as those who had direct contact with them. As such, following discussion, it was agreed that the DAC course would be delivered online rather than in person.

Having previously run caregiver support courses in person and seen the benefits of these, I was initially saddened by the choice to move the delivery of the DAC course to online. However, following a review of the literature, I became aware of how online caregiver forums have been found to be effective in supporting caregivers and those with dementia (Carter et al., 2020). Research has also highlighted that online relationships are able to be formed in similar ways to in-person relationships (Lomanowska & Guitton, 2016), suggesting online delivery may not affect this aspect of the course. Given the limited independence and time dementia caregivers often have, along with potential health and mobility concerns (Dai et al., 2020), exploring the acceptability and impact of an online caregiver course, could assist in finding other means of accessing and supporting this population. Furthermore, given the economic climate and reducing service funds, the online delivery of groups is definitely worthy of investigation.

Despite not being able to offer the DAC course in person, it was important to not put anyone’s health at risk whilst being able to conduct the research. Following a review of the literature and expanding my awareness of possible benefits of online delivery, I became hopeful that through exploring online delivery of the DAC course, we could evaluate the impact of the course as well as explore the acceptability of online delivery among this group of individuals. Informal caregivers of individuals with dementia were known to experience social isolation, increased caregiving demands, little support particularly following the sudden closure of support services and increased physical and mental health concerns during the COVID-19 pandemic (Alzheimer’s Society, 2020). I feel awareness of this further increased my motivation and hope for the online delivery of the project, in being able to identify different ways to reach and support dementia caregivers during the pandemic and beyond, in turn assisting with the concerns caregivers’ experienced.

1.2 Participant Recruitment

Conducting research can often be a challenging process. During the COVID-19 pandemic, some of these challenges were exacerbated. At times the process felt isolating, particularly as setting up and running the study was being conducted online. It was important at these times, to consider the different skills of a psychologist and how these can be utilised to overcome such challenges. Furthermore, setting up regular online meetings with my research partner facilitated in staying connected during these times.

Given the importance of stakeholder involvement in research, particularly in research that directly relates to the care they receive in public provision (National Institute for Health Research [NIHR], 2021), we chose to include the views of stakeholders when developing the local version of the DAC course. I felt this was a particularly important aspect of the development, as it enabled for an outside perspective of the course and offered an opportunity for stakeholders to review and possibly identify areas that we, the researchers, may have missed. As stakeholders were recruited via personal and professional contacts of the researchers, both myself and my fellow research partner, this aspect of recruitment was not as slow or challenging as I had initially anticipated.

In the absence of traditional in-person recruitment methods, such as face-to-face third sector and charity liaison, attendance at caregiver forums and poster distribution, an online method of recruitment was adopted. The study utilised a large online dementia research advertising platform whereby we were able to upload details of our study for individuals to then register their interest. However initial recruitment was extremely slow, with only a couple caregivers registering interest, leading me to feel deflated and impatient. Given the initial stakeholder recruitment was relatively quick, I feel I had hoped that recruitment for the study would have been equally rapid. Additionally, having used an online dementia research advertising platform, my assumption was that those signed up would be actively looking for studies to engage with, hence making recruitment a slightly easier process. As a doctorate trainee, the pressure of meeting university timelines for participant recruitment and data collection, was also at the back of my mind, further contributing to my impatience. Meeting regularly online with my joint project partner assisted with maintaining motivation as well as reducing feelings of isolation. It was in one of these meetings together, whereby we agreed to send out opt-in emails to participants whose profile appeared to meet the inclusion criteria for our study, as an attempt to boost participant recruitment. This process was lengthy and time-consuming, however it felt worthwhile when a number of participants started to make contact and requested to engage in the project.

The sudden interest from participants made me reflect on what may have caused this as well as the initial assumptions I held. Aware that caregivers often have limited time (Livingston et al., 2020), I wondered whether they had been unable to actively search for our project, whereas when they received an opt-in email, it was easier for them to respond and register interest. Furthermore, during the study, those that were unable to attend the specified course dates, reported that despite being unable to attend, they were extremely keen to be kept in mind if another course date was offered as well as to read the findings of the project following completion, as they felt it was a particularly needed and important project. This highlighted to me that although some caregivers may not have actively been able to register or had time to participate, they still appeared to have interest in the project, suggesting the vital need for support among this population.

Within the study, it was noted that all participants were of White British ethnicity. This was disheartening to see, especially being an individual of ethnic minority myself and having some awareness of the need for support among this group of individuals. It led me to reflect on the various reasons as to why this might have been. Caregivers of ethnic minority groups are known to experience various barriers to accessing support both in person and online (Kenning et al., 2017). Furthermore, information regarding support available for caregivers is often limited throughout the dementia journey (Schmachtenberg, 2022). As such, I wondered whether these individuals were aware of the online dementia research database from which we recruited individuals from, and whether more ethnic minority caregivers would have been recruited if we had utilised other sources. Offering the DAC course as a standard package of care within the National Health Service, may assist in those of ethnic minority groups being more aware of the support available. This in turn may assist in their ability to access the support. It is, however, important to consider other barriers to accessing and engaging in support, such as availability and ability to utilise online technology, cultural views and stigma, as well as any potential language barriers. Offering the DAC course both online and in person could assist with overcoming barriers such as technology. Further research investigating cultural views, stigma, and ability to offer support in various languages, could assist in more awareness of these barriers, as well as identifying ways to overcome these.

Having conducted participant recruitment in this way and now having completed the project, it emphasizes to me the importance of creating a course for caregivers that is easily accessible. Conducting further randomised control trials within a National Health Service context, can assist in exploring whether offering the DAC course to dementia caregivers as a standard package of care, enables support to be accessible, acceptable, and have a positive impact on caregivers and their care recipients. It is important to take into consideration caregivers limited time, yet their ability to fit their caregiving role around their general daily life, when setting up and offering the DAC course to caregivers. For example, the DAC course could be offered as a standard package of care with various course dates and times, so that caregivers are able to fit accessing the support they need, around the various other tasks they may have.

1.3 Participant Engagement

Participants attending the DAC course were sent an email a day before the course, confirming the date and time of the course as well as a Microsoft Teams link to join on the day. However, when running the first round of the DAC course, only a couple participants initially joined the link. At first this was slightly disheartening, particularly all the effort we had put into recruitment and preparation for running the DAC course. However, reflecting on previous concerns we had with participant recruitment, I chose to contact the participants that had not attended. It became apparent following a phone call that some had forgotten the course was being run. Whilst some were able to quickly log on and join the course, others were unable to attend due to work commitments. This reminded me of the challenges that arose with participant recruitment and how often caregivers are conducting their caregiving role alongside their daily life, providing them with limited time and many things to remember (Livingston et al., 2020). Furthermore, similar to recruitment, participants informed that whilst they were unable to attend due to work commitments, they were still very much interested in the project and wanted to be considered if further course dates were announced, particularly as many felt the area of research was an important one. This left me feeling even more motivated to ensure the project ran well and that I was contributing to an area of research that was both vital and needed.

Following the first course, I met with my joint project partner, and we reflected on this. It was agreed for the next round of the DAC course, to send an email reminder a week before and again a day before the course, requesting participants to confirm attendance. Those who did not respond were called and attendance was confirmed via phone call. This greatly assisted with attendance of the DAC course, and during reminder phone calls, participants stated that they were thankful for the reminder given their busy lives. As such, the same procedure was followed for remaining rounds of the DAC course. Adapting the procedure part way through in response to participant engagement, was something that was carefully considered by myself and my joint project partner, with supervision from our supervisors. I felt initial engagement during the first round of the DAC course enabled us to be aware of potential barriers that could arise and offered us a moment to problem-solve and adapt. It was important for us to consider the population of individuals the DAC course was targeting, and the different ways barriers could be overcome. Furthermore, I felt it highlighted the pressure dementia caregivers are often under and the incredible need for support among this population. Offering accessible support, whilst considering the needs of dementia caregivers is vital and consideration around the procedures used in this study should be taken when conducting further research.

It is worth noting that utilising the online dementia research advertising platform did inadvertently privilege those individuals who had pre-existing skills in using technology. Additionally, as previously mentioned, all participants identified as White British which could be due to the lower awareness of dementia support available and/or limitations in being able to access support among ethnic minority dementia caregivers. It is hoped that by running a larger randomised control trial within the National Health Service, utilising the findings of the current study, a wider more generalisable group of dementia caregivers can be reached.

1.4 Influence of Personal Factors on Data Analysis

It is helpful to reflect on the possible influence of personal factors on qualitative data analysis in order to gain an awareness of how the data may have been interpreted. Within the current study, no particular reflexive exercise was carried out by the researchers and hence it is important to note that our background, preconceptions, and personal views may have, to some extent, influenced the study. There were, however, moments where I felt I took into consideration these personal factors, which I will discuss below.

As previously mentioned, my prior experience in running caregiver support groups in other contexts sparked my interest in conducting this piece of research. Furthermore, having recently taken on a caregiver role for my grandmother, I felt somewhat aware of some of the challenges caregivers experienced. I believe these experiences, along with the ‘we can do it’ attitude during the COVID-19 pandemic, created a vested interest within me in wanting the intervention to be useful for dementia caregivers. Aware of this bias going into the project, I attempted to keep it in mind throughout the process, particularly during coding and thematic analysis of the data. When analysing the data, I repeatedly questioned the origin of my interpretations to ensure my bias was not influencing the way in which I interpreted what participants reported. Reading through the transcripts multiple times assisted with the process, allowing myself to be immersed into the data. Furthermore, having a second researcher code a portion of the data using the coding table I had developed, also assisted with ensuring that my interpretations were not biased.

During the transcription process, I became aware that although researchers had a semi-structured interview protocol, some degree of influence from the researchers was inevitable. For example, whilst the interview was semi-structured, at points, the interview relied on interviewers to encourage participant elaboration. During the interviews, I reminded myself of the biases I held and tried to actively put these aside. However, I wondered on reflection, whether this caused me to unintentionally fail to encourage participants to elaborate on some of their responses, due to worry that I was following a line of thought that was connected in some way to my biases. The interviews were carried out by both myself, and my joint project partner. Aware that she had previously worked in an older adult service and had a similar vested interest in wanting the DAC course to be a helpful contribution to the area of research, I wondered whether she too had unintentionally failed to encourage participant elaboration due to the same worries. I regretfully did not explore this with my joint project partner at the time and wonder what she may have identified as her own biases coming into the project. When transcribing the interviews, I became aware of interesting themes, however some were not always explored further by the interviewers. This became frustrating at times, particularly as I wanted to obtain as much useful information from the interviews as possible. On reflection, I wonder whether an early reflexive exercise with the interviewers, where they were able to discuss their biases and ways of managing them throughout the interviews, may have assisted with increasing confidence to proceed with encouraging participant elaboration. Having now reflected on this, I would suggest that this is something that is considered prior to conducting further research.

2. Conclusion

Whilst COVID-19 changed some of the way in which the research project was conducted, it allowed for an exploration of the acceptability and impact of the online delivery of the DAC course to dementia caregivers across the UK. Furthermore, findings from the empirical study provided insight into the benefits of online delivery experienced by dementia caregivers, and assisted in identifying different ways in which this population can be reached and supported. The reflections on participant recruitment, engagement, and data analysis outlined above, help in providing insight into possible challenges and ways of overcoming these. It is hoped that should the study be replicated, the reflections discussed above are considered. I am immensely proud of the overall project and feel that its contribution to the research area is valuable. I hope that it sets a foundation for a larger randomised control trial within the National Health Service to be conducted, in order for dementia caregivers to access standardised psychoeducation and support.

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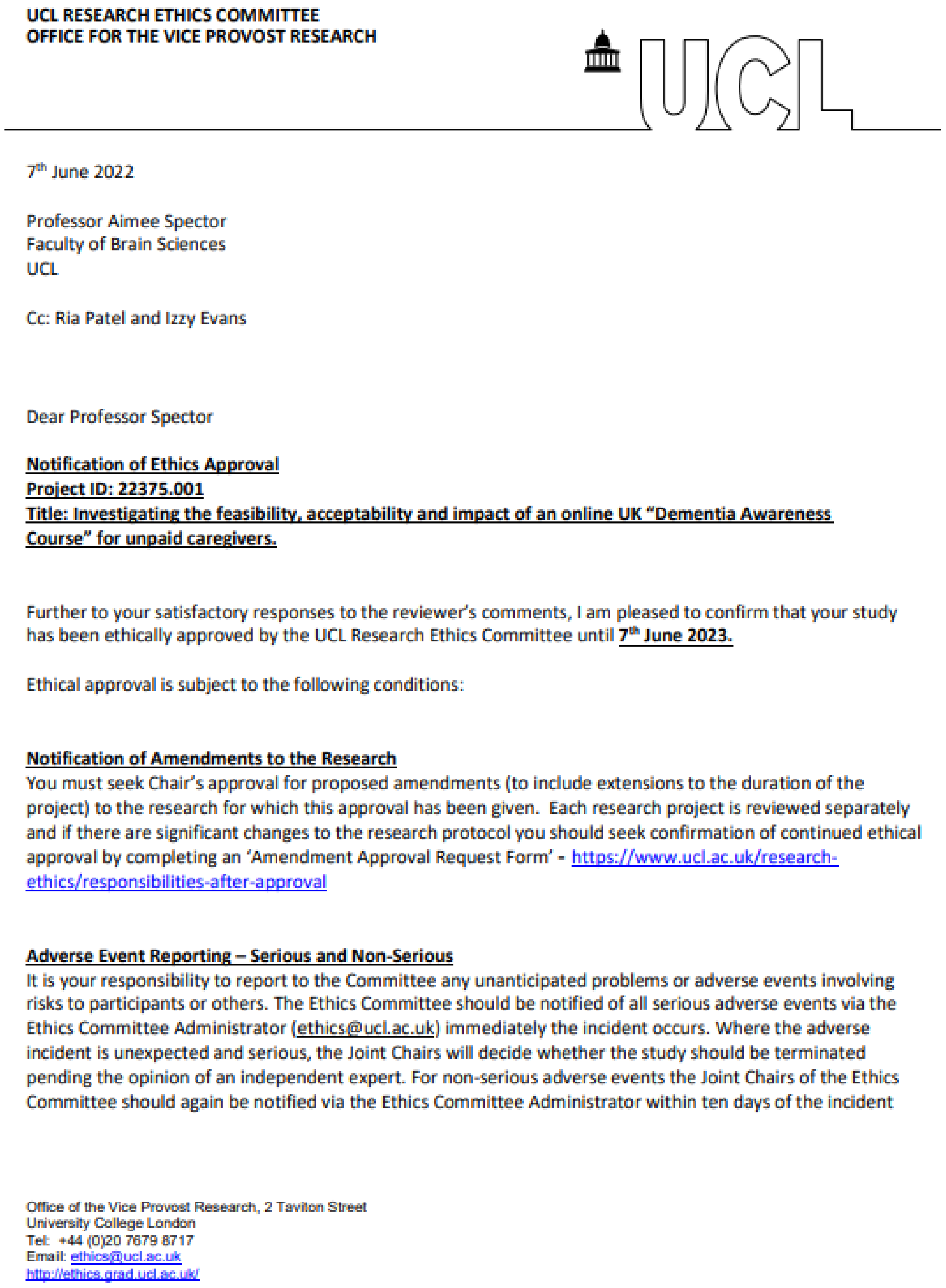
Appendices

Appendix A: Ethical approval



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

7th June 2022

Professor Aimee Spector
Faculty of Brain Sciences
UCL

Cc: Ria Patel and Izzy Evans

Dear Professor Spector

Notification of Ethics Approval
Project ID: 22375.001
Title: Investigating the feasibility, acceptability and impact of an online UK "Dementia Awareness Course" for unpaid caregivers.

Further to your satisfactory responses to the reviewer's comments, I am pleased to confirm that your study has been ethically approved by the UCL Research Ethics Committee until **7th June 2023.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' - https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

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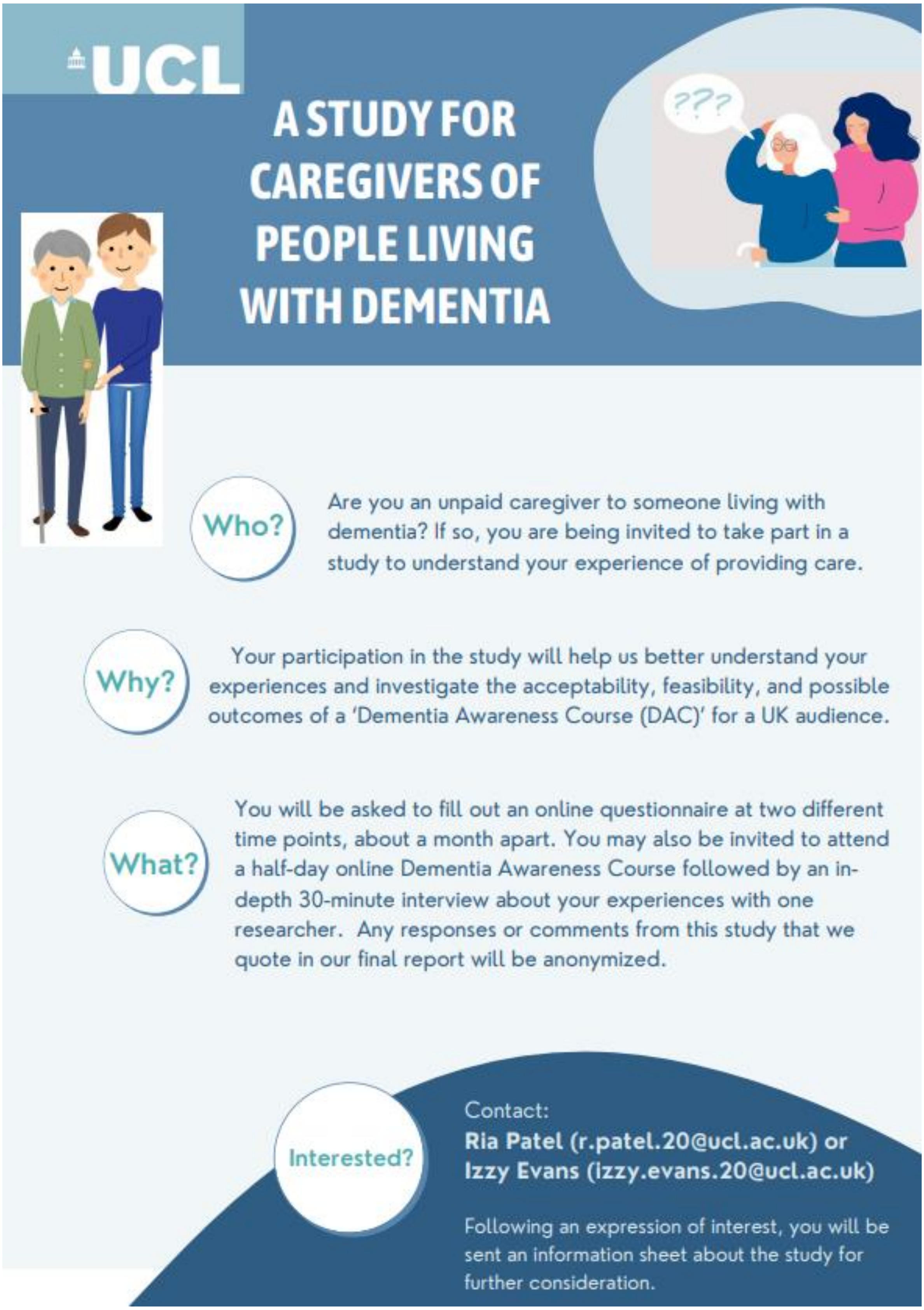
Appendix B: Study Advert



UCL

A STUDY FOR CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA

Who?

Are you an unpaid caregiver to someone living with dementia? If so, you are being invited to take part in a study to understand your experience of providing care.

Why?

Your participation in the study will help us better understand your experiences and investigate the acceptability, feasibility, and possible outcomes of a 'Dementia Awareness Course (DAC)' for a UK audience.

What?

You will be asked to fill out an online questionnaire at two different time points, about a month apart. You may also be invited to attend a half-day online Dementia Awareness Course followed by an in-depth 30-minute interview about your experiences with one researcher. Any responses or comments from this study that we quote in our final report will be anonymized.

Interested?

Contact:
Ria Patel (r.patel.20@ucl.ac.uk) or
Izzy Evans (izzy.evans.20@ucl.ac.uk)

Following an expression of interest, you will be sent an information sheet about the study for further consideration.

Appendix C: Information Sheet and Consent Form

02.2022

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: 22375/001

Title of Study: Investigating the feasibility, acceptability, and impact of an online UK "Dementia Awareness Course" for unpaid caregivers.

Department: Clinical, Educational and Health Psychology, Faculty of Brain Sciences, Division of Psychology and Language Sciences, UCL

You are being invited to take part in a study to trial a new online Dementia Awareness Course, that is designed to support unpaid caregivers providing care to a person living with Dementia in the community. The study also aims to understand more about the experiences of these caregivers and how this may relate to the course content. This project can help us understand the benefits, barriers, acceptability, and feasibility of the course and whether it could be helpful if it could be delivered to caregivers more widely in the UK.

This doctoral research study is being conducted through the University College London by Ria Patel and Isabelle Evans, supervised by Professor Aimee Spector and Dr Charlotte Stoner. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide if you would like to take part in this study. Thank you for taking the time to read this information sheet

What is the purpose of this study?

The purpose of this study is to investigate the possible impact of our 'Dementia Awareness Course' for caregivers alongside understanding your caregiving experiences and collecting your feedback. Your participation can help us to assess whether the course is a feasible and helpful intervention and shape our future delivery and planning.

What is the Dementia Awareness Course?

The course will be led by a Trainee Clinical Psychologist and will take place on one day over 3 – 4 hours with regular breaks. The course will be online using Zoom. Our aim is to deliver it to small groups of caregivers (5-10 individuals) with lots of space for interaction, sharing and discussions. The modules covered have been designed for a UK audience and cover these areas:
- What is Dementia?
- Positive Engagement
- Caring for someone with Dementia

Doctoral Programme in Clinical Psychology
University College London Gower Street London WC1E 6BT
General Enquiries Tel: +44 (0)20 7679 1897
http://www.ucl.ac.uk/clinical-psychology

Why have I been invited to take part in this study?

You have been invited to take part because you are an adult (18 years and above) largely involved in caring for a person living with dementia. You may have received information through the Join Dementia Research network, through a social media advertisement or through a local charity or group that you are connected to.

Do I have to take part?

Participation in this study is voluntary. It is up to you to decide if you would like to take part in this study. If you do decide to take part, you will be given this information sheet for your reference and asked to sign a consent form. You may withdraw from the study at any time up until data analysis. You do not have to give a reason for withdrawal. If you decide to withdraw you will be asked what you wish to happen to the data, you have provided up to that point. Taking part will not in any way affect any support you may or may not receive around your role as a caregiver.

What will happen to me if I take part?

The study is made up of two different groups. The first group will be invited to complete two sets of online questionnaires, a month apart, that should take no more than 30 minutes to complete at each time point. The second group will be invited to complete these questionnaires and also, to attend the Dementia Awareness Course. One month following this, these participants will also be invited to attend a brief interview with one researcher to give their thoughts and feedback on the course.

You will be randomly allocated to one of these two groups, so there is a 50% chance that you will take part in the Dementia Awareness Course and interviews. This is so we can compare responses from people who took the course and people who did not.

All interviews will be recorded, and this recording will be stored securely. The recordings will only include audio and will not include video footage. In our reports, you will not be identified by name, but by a code number. We will analyse the voice recordings and questionnaire responses on secure computers that will only be accessed by members of the research team. Any responses or comments from this study that we quote in our final report will be anonymized

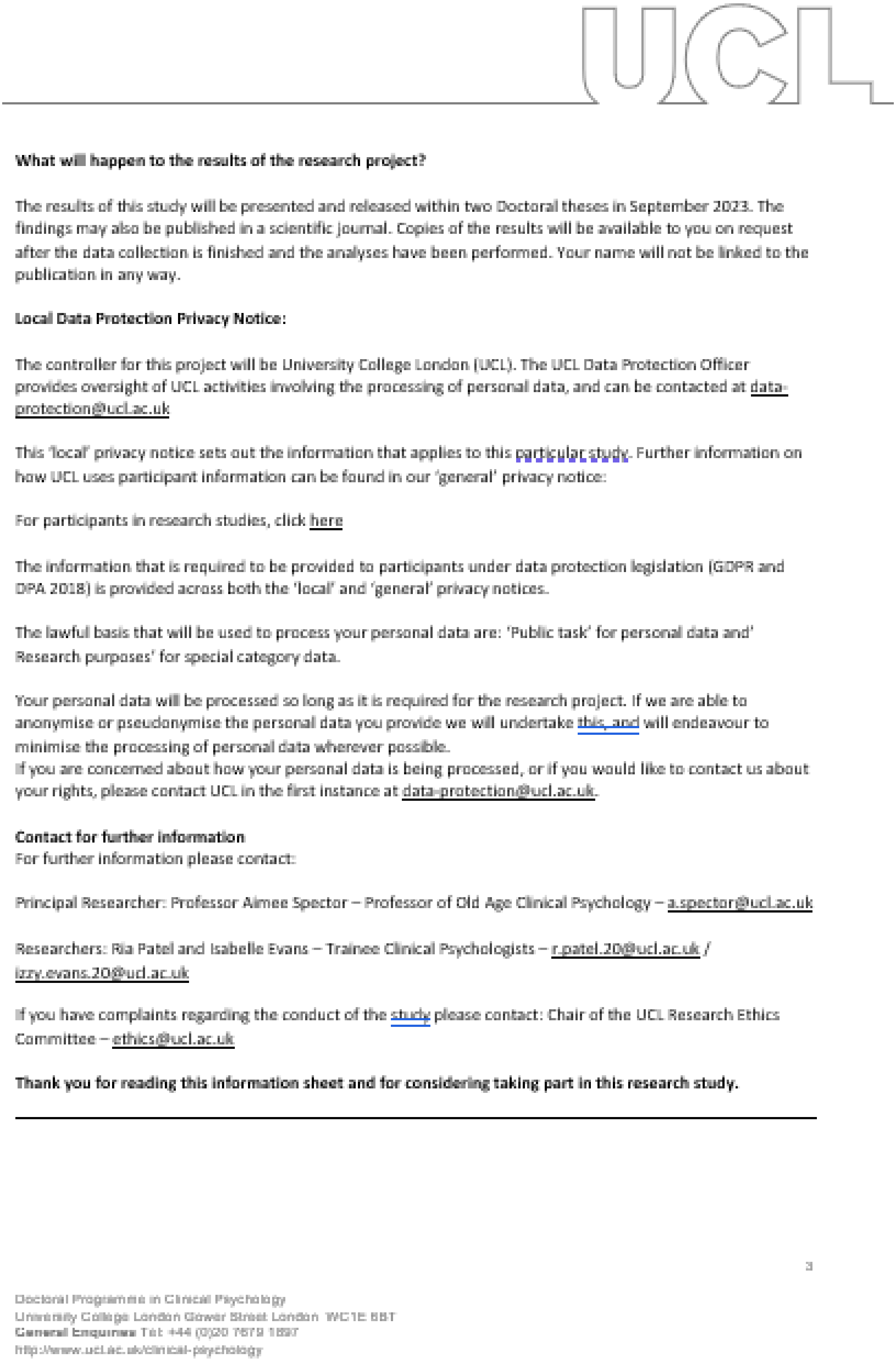
What are the possible disadvantages and risks of taking part?

This study may take up some of your time and we will ask you to reflect on your personal experiences. There are no other disadvantages or risks in participating in this study.

Will my taking part in this project be kept confidential?

All the information that we collect about you during this study will be kept strictly confidential and any external agencies used for transcription and analysis will be compliant with data protection legislation (General Data Protection Regulation, 2018). You will not be able to be identified in any ensuing reports or publications.

Please note that there are limits to confidentiality and the research team has a legal duty to report to the relevant authorities, possible harm or danger to the participant or others, professional misconduct or disclosures of criminal activity.



What will happen to the results of the research project?

The results of this study will be presented and released within two Doctoral theses in September 2023. The findings may also be published in a scientific journal. Copies of the results will be available to you on request after the data collection is finished and the analyses have been performed. Your name will not be linked to the publication in any way.

Local Data Protection Privacy Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.
If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Contact for further information
For further information please contact:

Principal Researcher: Professor Aimee Spector – Professor of Old Age Clinical Psychology – a.spector@ucl.ac.uk

Researchers: Ria Patel and Isabelle Evans – Trainee Clinical Psychologists – r.patel.20@ucl.ac.uk / izzy.evans.20@ucl.ac.uk

If you have complaints regarding the conduct of the study please contact: Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research study.

CONSENT FORM

UCL Research Ethics Committee Approval ID Number: 22375/001

Title of Study: Investigating the feasibility, acceptability and impact of an online UK "Dementia Awareness Course" for unpaid caregivers.

Department: Clinical, Educational and Health Psychology, Faculty of Brain Sciences, Division of Psychology and Language Sciences, UCL

Name and Contact Details of the Researcher(s): Ria Patel (r.patel.20@ucl.ac.uk) & Izzy Evans (izzy.evans.20@ucl.ac.uk)
Name and Contact Details of the Principal Researcher: Professor Aimee Spector (a.spector@ucl.ac.uk)
Name and Contact Details of the UCL Data Protection Officer:
This study has been approved by the UCL Research Ethics Committee: Project ID number:

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Participant Identification Number for this project: ______________________________

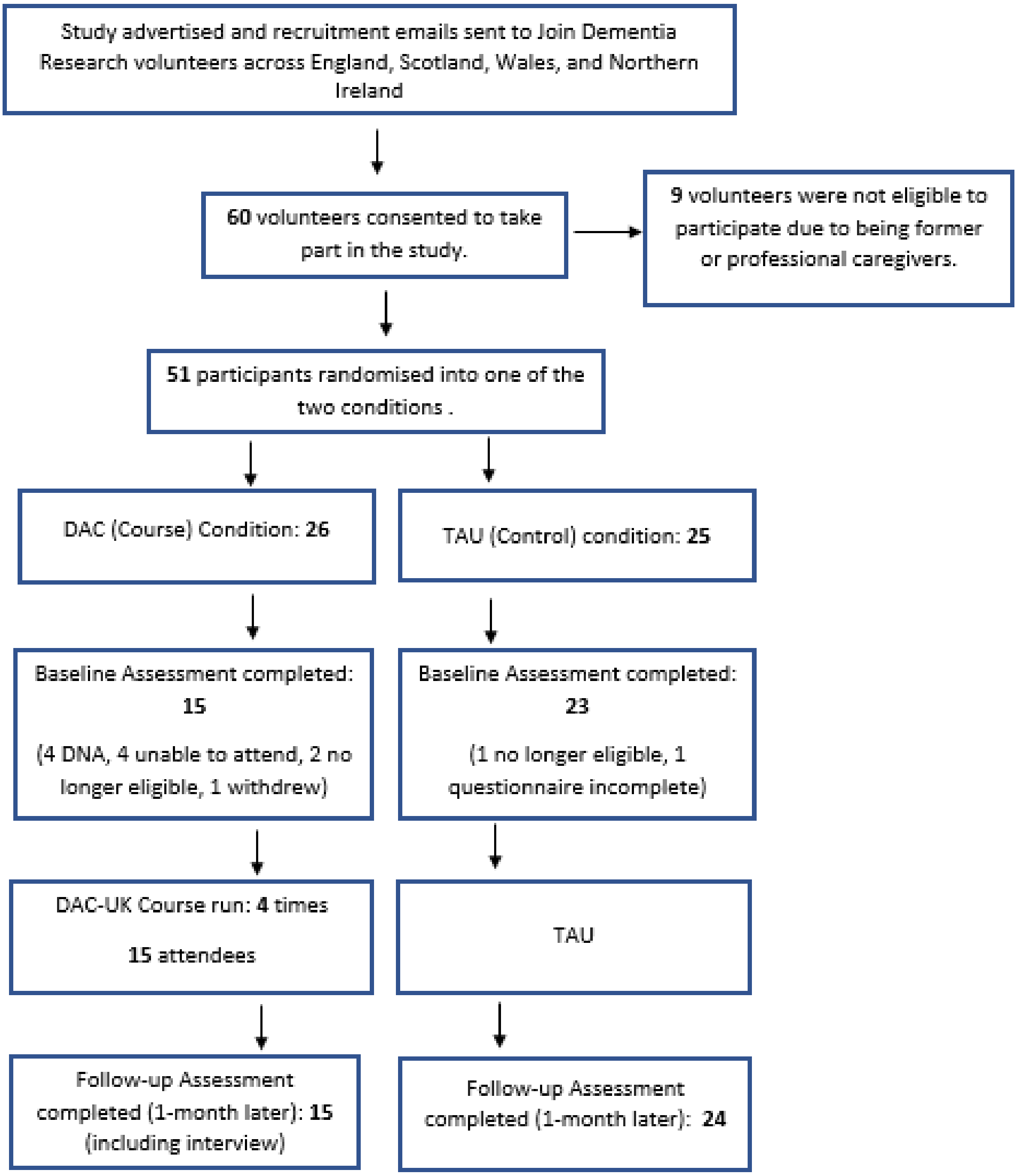
1	I confirm that I have read and understood the Participant Information Sheet dated 02.2022 for the above project. I have had the opportunity to consider this information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, up until data analysis. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	☐

3	I consent to participate in the study. I understand that my personal information (age, ethnicity, gender, telephone number, email address) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	☐
4	**Use of the information for this project only** I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified (unless you state otherwise, because of the research design or except as required by law). I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	☐
5	I understand that my information may be subject to review by responsible individuals from the University (to include sponsors and funders) for monitoring and audit purposes.	☐
6	I understand the direct/indirect benefits of participating.	☐
7	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	☐
8	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	☐
9	If I am asked to engage in an interview as part of the study, I consent to my interview being audio recorded and understand that the recordings will be stored anonymously, using password-protected software and destroyed immediately following transcription.	☐
10	I consent to information and quotations from the transcript of the interview being published in the final report (confidentiality and anonymity will be maintained and it will not be possible to identify you from the publication).	☐

11	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	☐
12	I am aware of who I should contact if I wish to lodge a complaint.	☐
13	I voluntarily agree to take part in the above project.	☐

Name of Participant **Date** **Signature**

Appendix D: Recruitment Flow-Chart



Appendix E: Overview of contributions in this joint thesis project

Task	Contributor
Conceptual Introduction	RP
Systematic Literature Review	IE
Systematic Review quality appraisal	IE (RP supported in inter-rater reliability checks)
Design of empirical study	RP and IE, under supervision of Professor Aimee Spector and Dr Charlotte Stoner
Ethics Application	RP and IE
Development of local version of DAC Course	RP and IE. Reviewed by Dr Charlotte Stoner
Stakeholder Feedback	RP and IE
Study Poster	RP (reviewed by IE)
Signing up with Join Dementia Research	IE (discussed with RP)
Recruitment	RP and IE
Development of Outcome Questionnaires	IE (reviewed by Professor Aimee Spector and Dr Charlotte Stoner; discussed with RP)
Development of Interview Questions	RP (reviewed by Professor Aimee Spector and Dr Charlotte Stoner; discussed with IE)
Delivery of DAC course	IE delivered 3 rounds of the DAC course. RP delivered 1 rounds of the DAC course
Collection of post-DAC outcome measures	IE
Post-DAC interviews	IE conducted 6 interviews. RP conducted 9 interviews
Data Entry and Storage	RP and IE
Transcription of Interviews	RP
Data Analysis	RP completed analysis on qualitative feedback interviews (IE supported in inter-rater reliability checks) IE completed analysis on quantitative outcome measures

Appendix F: Semi-structured Interview Question Prompts

- What did you hope to learn/ achieve from the course? Did you achieve this?
- What was the most helpful part of the course?
- What was the least helpful part of the course?
- Is there anything we did not cover that you think should be included?
- What do you think about the format of the course (length, number of participants, activities)? How would the course be best run/when would it be best run?
- Did you find the course being run as a group of individuals helpful ? What was helpful ? Has this encouraged you to seek more peer support ?
- What do you feel could be done to improve this course?
- Would you recommend this course? Why?
- Did you do something different based on the things you learnt during the Dementia Awareness Course? Which part? What happened/ what was different?
- How, if at all, has your relationship with the person you're caring for changed as a result of the course? What part of the course influenced this change?
- What has the impact been on the PLWD of you attending the course?
- Are there any activities or parts of the course that you have used or tried to use in your own time (e.g. the handouts)? How did this go?
- How are you feeling as a caregiver as a result of the course?
- How did you experience the questionnaires we sent? Did any feel more/less relevant? Any areas we didn't ask about that feel important? If we were to provide a questionnaire, what would we need to be asking about?

Appendix G: Example Coding Table

Sample Transcript	Codes	Sub-Theme	Sub-Theme	Main Theme
“It is hard to stay on the ball for four hours”	Course too Long	Length of Course	Preferences of Course Format	Acceptability of Course
“I learned a lot. And actually, the time went so quickly, I couldn’t believe it was over”	Course Length Okay			
“You know that you’re not alone or you’re not the only person getting frustrated. So, whilst other people’s experiences aren’t always going to be the same, I learned loads and kind of felt a lot of support from the group”	Reflection of Group Format	Group Format		
“Actually, it was quite nice”	Reflection on Number of Participants			
“it’s much easier to do it on the screen than face to face. It makes it easier for people to attend because they don’t have to worry about travelling”	Online Format of Course	Online Format		
“Some of the like myth busting, I think that was quite helpful because, certainly it’s been quite difficult with relatives and things, but also just for my own knowledge, knowing what’s true and not”	Course Content	Content, Group Activities and Handouts	Preferences of Course Content	
“The activities that made us think and share after a bit of information was given, that was for me was the best thing”	Course Activities			
“There was nothing about new technology…we use technology, quite a lot, so it would’ve been nice to hear a bit more about that and how we can use it”	Missing Content from Group	Missing Content		
“Most people end up just fumbling their way through because there isn’t much out there”	Lack of Support at Diagnosis	Experience of Support at Diagnosis	Views on Point of Delivery of Course	
“Would really help to have this at the start of someone’s journey so they know what skills to use and what’s to come”	Point of Delivery of Course	Delivery of Course		