Understanding the experiences of caregivers for patients with Chronic Traumatic Encephalopathy

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Abstract

The aim of this thesis was to understand the experiences of caregivers for patients with Chronic Traumatic Encephalopathy (CTE) and develop an informative resource to help support these caregivers. Literature on caregiving in other contexts (i.e. neurodegenerative diseases) has consistently shown the prevalence of caregiving burden, and how this causes a range of negative outcomes on a caregiver's mental, emotional and physical wellbeing. Although the number of CTE diagnoses is increasing, the impact this has on the primary caregiver is still not understood. Through conducting interviews and thematically analysing the experiences of older spousal caregivers and younger caregivers with varying relationships to the care-recipients, I explore what it is like to be a CTE caregiver and what elements make CTE caregiving experiences unique compared to other caregiving contexts. While there are overlaps with caregiving in Dementia, unique challenges in CTE caregiving exist. Older spousal caregivers, for instance, often struggle with a heavy perception of burden even after their caregiving ends, leading to difficulties in returning to a normal routine. Younger caregivers, juggling caregiving with parenting and career responsibilities, face a broader impact of burden throughout their caregiving journeys. However, the misunderstanding and lack of support from others, including healthcare professionals, bore the biggest burden on CTE caregivers. Using this understanding, I developed a supportive intervention, namely a podcast, to disseminate and evaluate with CTE caregivers. Through this, I was able to learn about the effectiveness of the intervention and how the feedback from the caregivers can inform the development of the podcast to ensure it supports them during and after their caregiving journeys. Overall, this work sheds light on the experiences of CTE caregivers and develops an intervention to support them through these experiences.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or institute of learning.

I confirm that this thesis is entirely my own work.

Dedications

This thesis is dedicated to

My boyfriend and bestfriend Jake
(For always being my biggest supporter)

&

My mother and father
(For getting me to where I am today)

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I dedicate this thesis to several people who have helped me and supported me throughout the last three years. Firstly, I would like to thank my boyfriend Jake who was always able to give me the encouragement and motivation I needed. To my family, in particular, my mum and dad for always supporting me and giving me guidance through the ups and downs, and to my dog Basil for sitting by my side everyday whilst I wrote this thesis.

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INTRODUCTION

Chronic Traumatic Encephalopathy (CTE) is a progressive neurodegenerative disease that has garnered significant media attention, fueled by recent reports highlighting its diagnosis in former high-profile athletes (Ott et al., 2020). This condition, linked to repeated head injuries and characterised by the accumulation of abnormal tau protein in the brain (Mez, Stern and McKee, 2013), has raised concerns about the long-term consequences of participation in contact sports and activities associated with repetitive head trauma. The heightened public attention on CTE emphasises the importance of research on this condition. This necessity extends beyond a medical perspective from understanding patient symptomatology and risk factors, to exploring the broader implications it imposes on individuals, families and caregivers.

Clinical manifestations of CTE overlap with symptoms observed in other neurodegenerative and neurobehavioural disorders (i.e. Dementia), which poses challenges for healthcare professionals to distinguish CTE from other conditions, based solely on clinical presentation. Although memory loss is the hallmark of many neurodegenerative diseases, including CTE, (Budson & Solomon, 2021), CTE can vary from behavioural changes (aggression, irritability), mood disturbances (depression/anxiety), motor impairments (poor coordination), to speech and language difficulties, and in progressive stages, suicidal ideation (Baugh et al., 2012; Omalu et al., 2010). Despite the similarities of symptomatology shared with Dementia sufferers (Ding and Leung et al., 2021), the distinction between those with a Dementia diagnosis and a CTE diagnosis lies within the age and cause. Simply put, those who suffer from CTE are usually much younger (McKee & Mez et al., 2023; Omalu, 2010) and have a history of repetitive concussive and sub-concussive trauma (Maroon et al., 2015). Due to this feature, the majority of clinical research has found diagnoses in individuals who have a long history of participating in contact sports (i.e. NFL players) or have had long-term exposure to sub-concussive hits (i.e. veterans). While considerable research has been dedicated to understanding CTE from a clinical perspective, the experiences of those caring for individuals with CTE remains unexplored.

Since the publication of neuropathological diagnosis of CTE in 2016, and the diagnostic refinements in 2021, hundreds of athletes involved in contact sports and veterans, have been diagnosed with CTE at the point of postmortem examination (McKee & Stein et al., 2023). Concomitant with this increase in diagnoses, an increase of individuals experiencing CTE symptomatology has been observed. With the increase in individuals experiencing CTE symptomatology, there is likely a corresponding increase in the number of people caring for these individuals. Family caregiving, also known as informal caregiving, is defined as an individual who offers unpaid and continuous aid with activities of daily living or instrumental activities of daily living to a person with a chronic illness, disability, or an older adult who is incapable of managing independently without assistance (Roth, Fredman & Hayley, 2015). With the broad spectrum of symptoms associated with CTE, the behaviours exhibited by the patients may be so problematic that they influence the health of the caregiver. In fact, previous caregiving literature has consistently demonstrated that greater behavioural issues demonstrated by patients correlated positively with how caregivers rated the negative impact on their health (Adelman et al., 2014; Kieboom et al., 2020). Specifically, caregivers commonly experience burnout (Gerain & Zech, 2019), anxiety and depression (Lou & Liu et al., 2015), and their own physical health issues (Etters et al., 2008) as a ramification of a complex caregiving role. However, with the limited understanding of the experiences of CTE caregivers, it is not possible to fully comprehend whether their experiences mimic those of other neurodegenerative disease caregivers, or whether there are unique challenges that affect those caring for individuals with CTE.

With an increase in CTE projected, due to more people playing contact sports and better diagnosis, it is important to understand the experience from the perspective of the primary caregivers. Specifically, we need to explore whether any caregiver characteristics (e.g. gender, age and relationship to the care recipient) plays a role in the challenges experienced by caregivers and how they perceive their burden. Through understanding these experiences and the dynamics of burden, caregivers can gain valuable insights into their own experiences, potentially paving the way for more targeted support and interventions. Simultaneously, researchers may gain fresh insights into the characteristics of caregivers that are associated with increased burden and stress, contributing to a comprehensive understanding of the challenges faced by caregivers in the context of CTE.

The purpose of this thesis is to understand the experiences of CTE caregivers, including the range of challenges and burdens they face as part of this role. Furthermore, the research aims to explore how a range of caregiver characteristics, including age and relationship to the care-recipient may influence the experiences of the caregiver. Caregiver experience may be complex, as perceived burden may be influenced by certain characteristics or factors. By increasing the understanding of caregiver experiences and the interplay of caregiver characteristics on the challenges faced during these experiences, the study aims to provide insight into the potentially unique challenges faced by those caring for individuals with CTE. We hope these findings will help to inform the development of targeted interventions to enhance support for CTE caregivers in navigating the challenges they face during and after their roles. Furthermore, the study aspires to make a positive impact on the lives of CTE caregivers and their families by offering valuable insights that could lead to improved caregiver well-being.

LITERATURE REVIEW

1.1. Experiences of caregiving in neurological conditions

As the ageing population increases, the inherent demand for care also rises (Polder et al., 2002). Consequently, informal caregiving has become an additional role for many within society. The defining characteristic of an informal caregiver typically includes being a person who provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or a disability (Roth et al., 2015). This is a contrast to formal caregivers, who are paid for their professional services (Marinho et al., 2022). In this thesis, the term "caregivers" specifically refers to informal caregiving. However, different studies have various definitions of an informal caregiver.

Historically, Skaff, Pearlin and Mullan (1996) defined caregiving as the “behavioural expression of (one’s) commitment to the well-being or protection of another person” (p. 583). Caregiving is, in and of itself not a role, rather it entails identified actions within the context of a relationship (Pearlin, Lieberman, Menaghan, & Mullan, 1981). A more simple definition put forward is that of Pearlin et al., (1990) who says caregiving underscores a specific intent behind the activities, that is, an emotional component and commitment to the relationship as the basis for actions. More simply, Kiecolt-Glaser et al., (2003); Von Känel et al., (2006) stated that caregivers are simply the co-residing spouses of persons with Dementia who report providing some informal care. Other studies, have a more explicit definition, confirming that caregivers provide help with one or more ADLs or IADLs (i.e. Fredman et al., 2010). Conceptualising the definition of informal caregiving proves challenging due to the diverse and dynamic nature of caregiving roles. The subjective and personal aspects of caregiving, coupled with cultural and societal influences, contribute to the complexity of forming a universally applicable definition (Schulz and Eden, 2016). However, for the purposes of this thesis, we follow the holistic definition of informal caregiving, stated by Roth, Fredman & Hayley (2015);

“Informal caregivers are those who provide some type of unpaid, ongoing assistance with activities of daily living or instrumental activities of daily living to a person with a chronic illness, disability or an older adult who is unable to manage independently without help” (p.g. 310)

The most common types of caregiving include long-term and short-term caregiving. Long-term caregiving involves providing continuous assistance and support over an extended period (Schulz and Eden, 2016). This type of caregiving is often associated with chronic illnesses, disabilities, or age-related conditions that result in a long-term need for help with daily activities, for example caring for elderly family members and individuals with progressive diseases (Caputo et al., 2016;

Eom et al., 2017; White et al., 2006). On the contrary, short-term caregiving is typically associated with providing assistance for a limited duration (Brown & Brown, 2014). This could be during recovery from surgery or rehabilitation after an injury (Kitter & Sharman, 2015). Both long-term and short-term informal caregivers play important roles in supporting individuals in need, but they differ in terms of duration and the level of care required. Informal caregivers also play crucial roles in end-of-life caregiving, offering comfort, emotional support, and assistance to individuals nearing the end of their lives (Motamedi et al., 2021). This form of caregiving is often associated with providing care and support for individuals with terminal stage illnesses such as cancer. Due to the longer caregiving trajectory that comes with caring for an individual long-term, the majority of the caregiving literature focuses on chronic and progressive diseases.

Caregiving for progressive diseases, characterised by conditions worsening over time and demanding evolving levels of care and support (Tramonti et al., 2019) has been explored in detail. In the realm of neurodegenerative disease research, the focus has traditionally centred on conditions like Dementia (especially Alzheimer's-type Dementia) and Traumatic Brain Injuries (TBIs). However, there is a recent surge in attention towards concussions and brain injuries within the sports context, specifically highlighting a progressive condition called Chronic Traumatic Encephalopathy (CTE). The term CTE is used to describe a progressive neurological disorder caused in-part by repeated head trauma (McKee et al., 2013; Nowinski et al., 2022). One of the reasons for the increased attention on CTE is that it has been observed in much younger populations (i.e. people as young as 17) than other neurodegenerative diseases, and thus caregiving can stretch for decades longer. Given that the literature on caregiving in CTE is still developing, researchers and practitioners often rely on existing knowledge from caregiving in neurodegenerative diseases like Dementia and Traumatic Brain Injury (TBI) to inform their understanding and approach. By leveraging the wealth of information available on caregiving in these related contexts we can learn more about what the caregiver experience entails.

Drawing from the literature on caregiving in Dementia and TBI provides valuable insights into the common themes, issues, and best practices that can be adapted to suit the unique needs of individuals affected by CTE. Understanding the similarities and differences in caregiving dynamics across these conditions, can help to tailor interventions and support services that are effective and relevant for CTE caregivers. Moreover, by extrapolating insights from caregiving experiences in Dementia and TBI, caregivers of individuals with CTE can benefit from a diverse range of perspectives and strategies that have proven successful in similar caregiving contexts. These shared experiences can offer valuable guidance on managing the complexities, uncertainties, and emotional toll associated with caring for someone with CTE. In order to comprehend the nuances of caregiving for progressive conditions like CTE, it is essential to consider the effect of caregiving burden on the informal caregiver. Although the literature on caregiving in CTE may be limited, drawing insights from the extensive knowledge base established in caregiving for other neurodegenerative conditions becomes crucial. This approach not only enriches our understanding of the challenges faced by caregivers in the context of CTE but also provides valuable perspectives for improving the quality of care and support extended to individuals affected by this progressive condition.

Many informal caregivers supporting individuals with neurodegenerative diseases characterise their experiences as enduring stress and frustration (Butcher, Holkup & Buckwalter, 2001). The term "caregiver burden" is frequently employed to describe these outcomes. Caregiving burden is defined as a multidimensional response encompassing physical, psychological, emotional, social, and financial stressors associated with the caregiving experience (Kasuya, Polgar-Bailey, & Takeuchi, 2000, p.119). Specifically, caregiver burden is linked to adverse outcomes for caregivers, including depression, anxiety, illness, and diminished quality of life (Schulz et al., 2006). As family members bear much of the informal caregiving responsibility, they must adapt to the evolving demands of the care recipient (Langa et al., 2002). Given the rising number of informal caregivers (Chiao et al., 2015), understanding what constitutes caregiving burden has gained increasing significance.

Literature has extensively explored caregiving responsibilities and the physical and psychological health of the caregiver. (Pinquart and Sorensen, 2003; Pinquart and Sorensen, 2007; Vitaliano et al., 2003). Numerous studies have explored this relationship, highlighting the complex interplay between caregiving responsibilities and the wellbeing of caregivers. Physical tasks such as lifting and assisting care-recipients with mobility, coupled with providing emotional support as their loved one struggles with decline lead to caregivers overlooking their own needs (Bergman et al., 2019). More specifically, the substantial weight of caregiving roles and associated responsibilities yield adverse outcomes, including poor mental health. Many studies assessing the quality of life of caregivers providing for those with Dementia found that they experience high levels of grief, ambivalence and some psychological problems (Kwon & Tae, 2014; Skaalvik et al., 2014). Anxiety and depression are the most common symptoms, reported by more than 50% of caregivers (Ferrara et al., 2008; Garcia-Alberca et al., 2012). Lou and Liu et al., (2015) aimed to understand the relationship between caregiving burden and mental health outcomes such as anxiety through a cross-sectional study. In this study, 310 patients with probable Alzheimer's Disease and their primary caregivers were assessed via the caregiver burden scale, the Nottingham health profile scale (Hopton et al., 1991), sense of coherence scale (Antonovsky 1988) and the euroqol instrument (Balestroni and Bertolotti, 2012). The study found that severity of the neuropsychiatric symptoms in patients in this study positively correlated with reported burden, anxiety and depression. However, the patients did not have a definitive diagnosis. Probable Alzheimer's implies that the patients exhibit symptoms consistent with Alzheimer's disease but have not undergone confirmatory diagnostic procedures such as brain imaging. Without a confirmed diagnosis, there is a risk that some patients included in the study did not actually have Alzheimer's disease. Furthermore, although the Neuropsychiatric Inventory–Questionnaire (NPI; Cummings et al., 1994) is beneficial in capturing neuropsychiatric symptoms, other validated questionnaires such as Behavioural Pathology in Alzheimer's Disease questionnaire (BEHAVE-AD) are more likely to provide greater insight into the impact on caregiver well-being, particularly in assessing the behavioural and psychological symptoms that can significantly influence the caregivers' experiences and overall quality of life. Future research should consider incorporating a combination of assessment tools, such as the NPI and BEHAVE-AD, to comprehensively evaluate the neuropsychiatric symptoms and behavioural pathology in individuals with Dementia to gain a holistic understanding of the impact of these symptoms on caregiver well-being.

The other consequence of long-term care is sleeping problems. Cross-sectional studies that were conducted over the past 15 years indicated that approximately 80% of caregivers have trouble sleeping (McCurry et al., 2007, Lee & Thomas 2011). Poor sleep is also associated with a higher cardiovascular risk, greater depressive symptoms (Goldman et al., 2008), a poorer quality of life and impaired immune function (Peng & Chang 2013). Thus, one may argue that lack of sleep may be a primary cause of caregiving burden, anxiety and depressive outcomes, as detailed by Lou & Liu et al, (2015). Investigating the relationship of sleep and burden, Simon & Bueno et al., (2019) conducted a cross-sectional study involving 201 family caregivers of dependent individuals and 92 non-caregiver controls to investigate the relationship between caregiving burden and sleep quality. Participants completed the Pittsburgh Sleep Quality Index (PSQI; Buysse, 1989) and the Caregiver Burden Inventory (CBI; Novak and Guest, 1989), and provided sociodemographic information. Based on CBI scores, participants were categorised into three groups: high, low, and medium levels of perceived burden, along with non-caregiver controls. The study's results revealed a correlation between increased caregiver burden and lower sleep quality, which was particularly evident amongst caregivers reporting higher levels of perceived burden. Furthermore, the number of daily caregiving hours was found to be associated with both poorer sleep quality and heightened burden, with non-caregivers unaffected by these factors. The findings suggested that as caregivers perceive their burden to be higher, they were more likely to experience disruptions in their sleep patterns and overall sleep quality. However, self-report measures are influenced by individual perceptions and interpretations, which could have introduced inaccuracies or inconsistencies in the data collected. Specifically, participants' subjective experiences and interpretations of their own sleep patterns and caregiving responsibilities may vary widely, which is not considered within the self-report measures. Additionally, the cross-sectional design of the study limited the ability to establish causality between caregiver burden and sleep quality. Longitudinal studies would provide a more robust understanding of how changes in caregiver burden impact sleep quality over time.

Alongside disrupted sleep patterns, another outcome highlighted in the caregiving literature is the feeling of isolation. As the patient's condition worsens, caregivers frequently shift their attention towards providing care, resulting in reduced opportunities for socialising with friends and family due to limited time and energy (Goodhead & McDonald, 2007). Not having a social outlet from the demands of day-to-day care, can leave caregivers feeling alone and isolated as they navigate the support of their loved ones. Lee, Martin & Poon (2017) analysed thirty qualitative interviews with spousal caregivers of individuals with Alzheimer’s disease, aiming to explore their perspectives on the difficulties of being the primary caregiver. For the caregivers interviewed, the caregiving experience significantly reduced the number of interactions with their family members and friends, mainly attributed to the increasing difficulty of leaving the house, influenced by the care recipients' behaviours (i.e. wandering). A few caregivers reported that their friends had stopped visiting them shortly after the diagnosis. We can speculate that friends and family members who have no experience of Dementia may not know how to behave around someone with the condition, which may prevent them from visiting as frequently or at all (Dementia UK, 2023). This lack of understanding could have led the caregiver to experience discomfort or uncertainty, causing them to withdraw from the relationship or avoid interactions altogether. Also shared among the interviewed caregivers was the feeling of loneliness resulting from the changing nature of the relationship with the affected spouses. As the disease progressed, the nature of the relationship underwent significant changes, leading to shifts in roles, responsibilities, and emotional connections. This transformation left caregivers feeling emotionally disconnected or isolated, as they navigated the complexities of caring for a partner whose cognitive abilities and behaviours are likely to be extremely different to what they previously were. However, the participants included within the study were octogenarian (aged 80-89) and centenarian (aged 100-109), which presents generalisability issues. The advanced age of the participants may limit the generalisability of the findings to younger caregivers who may have different caregiving experiences, needs, and coping mechanisms. Older caregivers may face unique physical and emotional challenges associated with ageing, such as decreased physical strength, cognitive decline, and increased susceptibility to health issues, which may not be representative of the experiences of younger caregivers. Therefore, while the study provides valuable insights into the experiences of older caregivers, its findings may not fully represent the diverse experiences and needs of caregivers across different age groups.

In light of this weight of evidence concerning the impact caregiving burden can have on the primary caregiver, researchers have attempted to conceptualise and evaluate models that assess this relationship. One of the most widely accepted and influential frameworks for understanding how individuals perceive and respond to stressful situations is the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). Although this model was not developed to explain caregiving burden, many researchers have used it to understand the stressors experienced by this population (Bastawrous, 2013; Raina, 2004; Swinkels et al., 2019). The model posits that stress is a dynamic process involving the interaction between an individual and their environment, where the perception of stressors and one's coping strategies play a crucial role in determining the individual's response to stress. Specifically, the model applies to caregiving burden by focusing on the cognitive appraisal process, and is commonly used to understand the stress experienced by Dementia caregivers (Hawken et al., 2018; Tremont, 2011). According to this model, caregivers assess the demands of caregiving (primary appraisal) and evaluate the resources available to cope with those demands (secondary appraisal). Numerous studies have supported the key components of the model, such as primary and secondary appraisal, coping mechanisms, and the moderating factors that influence stress outcomes. Skinner et al., (2003) conducted a review and critique of coping classification systems, including those associated with the Transactional Model of Stress and Coping. Their study aimed to understand the categorisation and conceptualisation of coping strategies by examining various coping mechanisms within the framework of stress and resilience. The study's findings suggest that the coping mechanisms proposed in the Transactional Model align with those reviewed, indicating that the model resonates with coping strategies identified in empirical research. This alignment supports the validity and applicability of the Transactional Model, demonstrating that its proposed coping mechanisms are consistent with coping strategies observed in real-world contexts. More recently, Teel, Caron & Gagnon (2022) utilised the Transactional Model to understand variations in parental stress following paediatric concussion. Undertaking surveys at the child's clinic visit and an eleven-question semi-structured interview with twelve parents, this mixed methods design aimed to discover predictors of parental stress. The Transactional Model of Stress was determined as particularly useful in explaining variations in parental stress following paediatric concussion due to its emphasis on the individual's appraisal and coping mechanisms. In this study, parents' subjective appraisal of the impact of their child's concussion on their stress levels was highlighted. The model recognises that stress is not solely determined by the external event (paediatric concussion) but is influenced by how parents perceive and interpret the situation. Moreover, the model's applicability suggests its potential for informing interventions aimed at reducing stress for parents navigating the challenges of their child's concussion. This model offers a comprehensive understanding of how individuals perceive and respond to stressors, emphasising the dynamic interplay between cognitive appraisal processes and coping strategies. By highlighting the subjective nature of stress and the importance of individual interpretations in shaping stress responses, the model has provided valuable insights into the complexities of stress experiences.

However, while the Transactional Model has been widely influential and extensively studied, some questions have emerged regarding its applicability to diverse populations and contexts. Critics argue that the model may oversimplify the stress process and overlook cultural variations in stress appraisal and coping mechanisms. In recent studies such as Teel et al., (2022), the model, by focusing on individual appraisals and coping strategies, may oversimplify the multifaceted nature of parental stress. Other external factors, such as social support, financial implications, or healthcare system interactions, might not be fully captured. Stress is also dynamic in nature (Cassidy, 2022), influenced by changing circumstances and coping mechanisms over time. In this research, the model might not fully capture the evolving nature of parental stress throughout the different stages of a child's concussion recovery. Particularly in a caregiving role that is multifaceted, an individual may not always be conscious of all the factors that are causing them to experience a stress response (Bastawrous, 2013), thus coping may play an even more extensive role within this process.

In their stress process model Pearlin and colleagues (1990) proposed that coping strategies play a significant role in influencing the impact of primary stressors, such as challenging behaviours exhibited by care recipients and daily caregiving responsibilities (Yuan et al., 2021). Within the model, stressors are external events or circumstances that challenge the well-being of individuals, such as caregiving responsibilities or the declining health of the care recipient. Resources, on the other hand, refer to internal or external assets that individuals can utilise to cope with stressors, including social support networks, coping skills, and financial stability. The model posits that the interaction between stressors and resources influences psychological and physical outcomes, such as caregiver distress, depression, and overall well-being. The key difference between the Stress Process Model and the Transactional Model lies in their focus and underlying mechanisms. While the Stress Process Model emphasises the role of external stressors and available resources in shaping caregiver burden and outcomes, the Transactional Model centres on individuals' cognitive appraisals and coping strategies in response to stress. Additionally, the Stress Process Model considers the cumulative impact of stressors over time, highlighting the importance of understanding the long-term effects of caregiving on caregivers' well-being.

Xu and Liu et al., (2021) used the stress process model to test if there was an association between caregiving intensity and caregiver burden. Data from the baseline assessment of the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) (N = 637) were used. Caregiver burden (12-item Zarit caregiver burden scale; Ballesteros et al., 2012), caregiving intensity (caregiving hours), and social support (Lubben social network, received support, satisfaction with support, and negative interactions; Lubben et al., 2006) were the main measurements. In accordance with the Stress Process Model, the study revealed a significant association between caregiving intensity and caregiver burden. Initially, as caregiving hours increased, so did the burden on caregivers. However, beyond a certain threshold, further increments in caregiving hours were correlated with a reduction in caregiver burden, suggesting an optimal level where additional hours may alleviate burden. Furthermore, coping mechanisms may also influence the degree to which primary stressors contribute to the emergence of secondary stressors such as role strain. As neurodegenerative disease related stressors are often persistent and enduring (Chiao et al., 2015) caregivers may gradually acclimatise to their caregiving responsibilities over time. This process of adaptation and adjustment, as highlighted by Pozzebon, Douglas and Ames (2016), could potentially lead to a decrease in emotional sensitivity among caregivers as they become more accustomed to their caregiving role. However, the long-term implications of chronic stress in the caregiving role may not be fully addressed using this model. The model's emphasis on immediate stress appraisal and coping responses may not capture the gradual accumulation of stress and its evolving impact on caregivers as they navigate the challenges of caring for individuals with progressive diseases. However, the study identified three social support indicators through the aforementioned surveys, excluding negative interactions, which mitigated the relationship between caregiving hours and caregiver burden when examined individually. Positive social support indicators, including received support, support network, and satisfaction with support, were found to empower caregivers with mechanisms to combat burden and cope with psychological distress effectively. These findings align with the

Stress Process Model, which views positive social support as a crucial psychosocial resource for caregivers in navigating the challenges of caregiving (Chappell & Funk, 2011; Cohen, 2004; Heo, 2014; Pearlin et al., 1990). However, despite providing valuable insights into stressors and resources associated with caregiver burden, the model overlooks other significant aspects of the caregiving experience, such as the quality of the caregiver-care recipient relationship or the cultural context of caregiving. Recognising these additional dimensions could further enhance our understanding of caregiver burden and inform more comprehensive support strategies.

A commonality between the Stress Process Model and the Transactional Model is their focus on individuals' responses to stressors and the significance of caregiver appraisal in shaping their experience of burden, however they fail to consider a wider range of caregiver characteristics. In order to address this limitation, Gerin and Zech derived the Informal Caregiving Integrative Model (2019) to encapsulate a wider range of risk factors that contribute to the feelings of caregiver burden (see Diagram 1). Their model emphasises the significance of not only focusing on the caregiver, but also considering the environment and the social context. They suggest that when comprehending informal caregiver burden, such conceptualisation should: (1) consider stressors and resources not only in the caregiving setting but also in the caregiver's psychosocial characteristics, (2) take into account the relationship with the care-recipient as a critical component in the understanding of the caregiving experience, (3) consider burnout as a key mediator between stressors and outcomes, (4) integrate the caregiver's appraisal as a core element in the model, (5) consider subjective burden as a measure of appraisal, and (6) include feedback loops. Within the framework they suggest that caregiver burden is likely to be impacted by a range of caregiver characteristics, from age, relationship and even gender. Recognising the importance of a range of factors is paramount to understanding caregiving burden, and developing strategies to alleviate it.

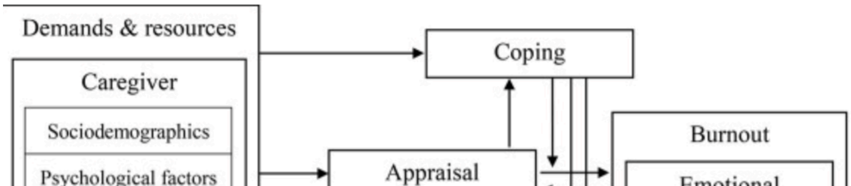


Diagram 1: Informal Caregiving Integrative Model (Gerain & Zech, 2019)

Despite Gerin and Zech's (2019) model underscoring the importance of examining the caregiver but also considering the broader environment and social context, the model currently remains just theoretical and unevaluated, unlike the Transactional Model and Stress Process Model. However, this model does demonstrate that caregiving burden is complex and can be impacted by an array of factors that need to be considered. Testing findings against this model would offer valuable insights into its applicability and effectiveness in guiding interventions to alleviate caregiver burden.

The aforementioned theoretical frameworks have offered valuable insights into the factors contributing to caregiving burden. However, it is equally important to explore whether caregivers can derive positive outcomes from their roles and the factors that contribute to these positive aspects of caregiving. By considering both the challenges and potential positive outcomes of caregiving, we can gain a more comprehensive understanding of the caregiver experience and develop more effective support strategies to enhance caregiver well-being.

Positives of the caregiving experience

One consideration pertaining to all models is whether both positive and negative emotions can co-occur in response to challenging circumstances within caregiving. Positive aspects of caregiving, also referred to as PAC are intrinsic (e.g., feeling more useful) or extrinsic (e.g., strengthened relationship with others) rewards obtained in the process of caring for another person (Cheng et al., 2016). In comparison to research on caregiving burden, there is a relative paucity of literature examining the positive aspects of caregiving. The focus of many studies tends to be on the 'negative' and 'detrimental' aspects of the role, with little attention on the potential positive psychological functioning of caregivers within their experiences. The lack of attention may be due to a variety of reasons. Firstly, with the documented negative impacts on caregivers, most research aims to identify areas of need and inform interventions to alleviate suffering. Consequently, the focus on more urgent/impactul factors such as burden and depression are prioritised. There may also be difficulties in conducting research exploring positive aspects of caregiving. Positive outcomes such as feelings of fulfilment and personal growth can be more subjective and difficult to quantify compared to negative experiences such as stress and anxiety (Doris, Cheng & Wang, 2018; Lindeza et al., 2020), thus it may be hard for researchers to adopt reliable measures. However, there is growing evidence concerning how identifying positive aspects of caregiving can be beneficial for a caregivers wellbeing (Quinn & Toms, 2019). Understanding and acknowledging the positive psychological functioning of caregivers, and how research has utilised the aforementioned models to explain PAC, would provide a more comprehensive and balanced view of the caregiving experience.

Despite the research on PAC being limited, the current literature has demonstrated a range of positive outcomes some caregivers have reported as part of their role. Cheng et al., (2019) administered a range of self-report questionnaires (Positive Aspects of Caregiving Scale; Boerner et al., 2004; Center for Epidemiologic Studies-Depression Scale; Radloff, 1977 and the Revised Memory and Behaviour Problems Checklist; Teri 1992) with 1229 Dementia caregivers recruited from memory clinics, physician offices, and social service agencies. Results highlighted that PAC was found to be associated with fewer mood symptoms including depression and anxiety. Caregivers who were highly troubled by the relative’s challenging behaviours, but who found higher levels of PAC at the same time, experienced better emotional well-being. In turn, focusing on positive aspects may make the burden of caregiving more tolerable, thereby alleviating caregiver distress as care demands increase.

Similarly Yang et al., (2019) undertook a cross-sectional study with 157 family caregivers of non-institutionalised Dementia patients in the rural sector of Western China’s Sichuan Province. They responded to the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1998), and a short version of the Zarit Burden Interview (Bédard, et al., 2001). The findings revealed a significant association between Dementia patients' depression levels and caregiver burden. Furthermore, the caregivers' levels of finding positives in caregiving were found to moderate this association. The researchers found that there was a positive correlation between Dementia patients' depression, and caregiver burden was weaker among the family caregivers with a high level of finding positives in caregiving, compared with those with a low level of positive experiences. Thus, it appears important to support caregivers in finding positives within their caregiving role to help buffer the impact of burden. Despite this research providing valuable insights on PAC, both studies employed a cross-sectional design, limiting the establishment of causal relationships between PAC, mood symptoms, and caregiver burden over time. The fact that participants in the study cared for individuals in the earlier stages of disease, makes this limitation more prominent, as the dynamics of the caregiving experience may evolve as the disease advances. Thus future research should explore how PAC fluctuates in response to changing caregiving demands and stressors over time to determine whether focusing on positives of the role is easier when demands are lower.

Despite the majority of literature focusing on PAC being non-theoretical, some researchers have utilised stress based models to help conceptualise PAC. The Stress Process Model (Pearlin et al., 1990) suggests that possible gains may act as a buffer against the overwhelming burden of caregiving. Caregiving can be associated with positive gains, enhanced meaning, and self-efficacy (Autio & Rissanen, 2017; Petruzzo et al., 2017). Labra et al., (2015) utilised the Stress Process Model to study caregiver's satisfaction. Through administering the Revised Caregiving Satisfaction Scale (Steffan, 2002), ZBI (Zarit et al., 1980), Global Deterioration Scale (Reisberg, 2007) and Caregiver confidence scale (developed by the authors), 101 informal caregivers of patients with Dementia were assessed in relation to their background, stress related factors and mediators. The analysis found that having a consanguinity relationship with the care-recipient, suffering from lower levels of subjective burden and the patient experiencing less extreme symptoms were the most important predictors of caregiving satisfaction. These outcomes highlight the interaction between individual characteristics, subjective appraisals and contextual factors as outlined by the SPM. Specifically, the SPM posits that individual characteristics (i.e. the consanguinity relationship) can influence how stressors are appraised and coped with. Caregivers who shared this bond may have had a stronger emotional connection and thus lead to greater fulfilment and satisfaction within their roles. The participants' lower levels of subjective burden predicting higher caregiving satisfaction corresponds to the SPM’s focus on the appraisal of stressors. According to the model, caregivers' subjective appraisal of caregiving tasks and responsibilities significantly influences their well-being. Caregivers who perceived their caregiving duties as less burdensome were more likely to experience higher levels of satisfaction, as they may feel more competent, capable, and fulfilled in their caregiving role. However these factors accounted for only 20% of the variability in caregivers' satisfaction, indicating the presence of additional unmeasured factors that likely play a role in shaping caregivers' satisfaction levels. Consequently, similar to caregiver burden, the Stress

Process Model overlooks a range of caregiver characteristics that are crucial for comprehensively understanding the caregiver experience. Thus, it is important to consider whether other models provide a more comprehensive understanding of PAC.

Alongside the SPM, the Transactional Model of Coping (Lazarus and Folkman 1984) helps our understanding of PAC through understanding ‘caregiver appraisals’. In an exploratory case series, Bacon et al., (2009) used a cognitive-behavioural approach—namely, the Transactional Stress Model (Lazarus and Folkman, 1984), to investigate associations between appraisals, coping, and gains over a 6-week period in a small sample (N = 4; case series) design involving stroke caregivers. Based on the model, the authors suggest that caregivers continuously engage in cognitive appraisal processes to evaluate the demands of caregiving and their ability to cope with them. These appraisals, along with coping strategies employed by caregivers, interact dynamically to influence their experiences of gains or positive outcomes associated with caregiving. The findings showed that caregivers' perceptions and evaluations of their caregiving experiences evolved positively over time, which was potentially influenced by their coping strategies and appraisals of the caregiving situation. Despite the positive application of the model with this research, caregiving for stroke patients and Dementia patients involves distinct care demands and challenges. Stroke caregivers may primarily deal with physical rehabilitation, mobility assistance, and recovery management, whereas Dementia caregivers often face cognitive decline, behavioural symptoms, and long-term care needs. These differences in care demands may result in varying stressors and coping strategies for caregivers, which is likely to impact their ability to appraise positive outcomes from their caregiving experiences. The insightful research on PAC underscores the complexities of the caregiving experience and the potential for caregivers to derive positive outcomes from their roles. However, the utilisation of theoretical models, such as the Stress Process Model and the Transactional Model of Coping, emphasises the importance of considering a diverse range of caregiver characteristics that influence both burden and positive aspects of caregiving.

Exploring research focusing on caregiving burden, the positives of caregiving as well as the application of theoretical models to elucidate these outcomes has highlighted the complexity and variability in the caregiving experience. However, through this review of literature, it is becoming increasingly evident that a more comprehensive understanding of the impact of the caregiving role (both positive and negative outcomes) requires a better understanding of specific caregiver characteristics, such as age and relationship status. In the upcoming chapter, I will explore these factors in greater detail to uncover their unique contributions to the caregiving experience and implications on caregiving burden.

1.2. Factors affecting caregiving

Caregiving is a multifaceted and ever-evolving role that is influenced by a myriad of factors that can significantly impact the overall experience of individuals who are dedicated to providing care to those in need (Britton, 2021). Recognising and comprehensively understanding these diverse factors is essential for developing tailored interventions, offering appropriate support systems, and ultimately improving the well-being and effectiveness of caregivers. In this chapter, I draw upon qualitative and quantitative research to investigate the range of critical factors that shape the caregiving experience.

Various factors contribute to the caregiving experience, encompassing psychological, social, economic, and health-related dimensions. Psychological well-being is crucial for caregivers, impacting stress levels, coping strategies, emotional resilience, and mental health. Recognising the psychological impact of caregiving enables the development of interventions to manage stress, prevent burnout, and enhance emotional well-being (Ehsan, 2018). Social factors, such as support networks and community resources, influence caregivers' experiences profoundly (Otis-Green & Juarez, 2012). Strong social support offers validation and practical assistance, while isolation can exacerbate feelings of burden. Economic considerations, including financial resources and employment status, play a significant role in caregiving, with financial strain adding stress and affecting care provision (Hurwich-Reiss et al., 2019). Health-related factors are pivotal, affecting both the caregiver's ability to provide care effectively and the care recipient's needs and dependency level (Janson et al., 2022; Litzelman et al., 2014).

Gender and caregiving

The effects of gender on caregiving burden have been extensively studied, revealing significant disparities between male and female perceptions of the role. Several studies have found that female caregivers tend to report more health problems and depressive symptoms than male caregivers (Almberg et al., 1998; Gallicchio et al., 2002; Xiong et al., 2020; Mills et al., 2009; Sutcliffe et al., 2016). In a cross-sectional study conducted by Papastavrou et al., (2009) in Cyprus, involving 172 community caregivers (40 males, 132 females) of individuals with Alzheimer's Disease, the researchers examined the impact of caregiving on caregiver burden and depression. The study included caregivers who had frequent contact with care recipients, provided care for at least one year, and did not have psychiatric or mental illness. Specifically, female caregivers in the study demonstrated higher scores on the Zarit Burden Interview (ZBI; Zarit et al., 1980) and the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) compared to male caregivers. The higher scores among women were particularly evident in ZBI items related to relational deprivation; feeling of being deprived or lacking in meaningful relationships. This indicates that female caregivers may perceive a greater burden and experience more depressive symptoms, especially in the context of challenges related to relationships, for example quality of relationships, the support received from others, the dynamics of caregiving relationships, and the impact of these relationships on the caregiver's well-being. Additionally, when care recipients were living at home, no significant differences were found in overall ZBI and CES-D scores between male and female caregivers. However, females exhibited higher scores in ZBI items related to relational deprivation and lower scores in items related to the management of care. The results suggest that, even when overall burden and depression levels are similar, there may be nuanced differences in the specific aspects of caregiving that impact the experiences of male and female caregivers differently. While other factors (i.e. age) did not show notable differences between male and female caregivers, the study underscores the importance of considering gender dynamics in understanding the impact of caregiving on mental health and well-being.

Friedemann & Buckwalter (2014) explored the effect of gender on caregiving burden. Participants included 424 females and 109 male caregivers who were asked to complete a range of questionnaires including; The Caregiver Health Index (Montgomery, Stull & Borgotta, 1985), Patient Health Questionnaire (PHQ-9; Spitzer et al., 1999) and the Mini Mental Status Exam (Folstein et al., 1975) to assess caregiver health, depression and cognitive status. Findings suggested a gendered approach to self-appraisal and coping. Specifically the male caregivers felt less burden and depression than women who believed caregiving is a female duty. Rather than being highly burdened by added responsibilities, men accepted their caregiving role as a challenge, focused on the task at hand (see also Robinson et al., 2014), and kept emotions separate from the role (see also Calasanti & King, 2007). The literature reports that women, unlike men, see their caregiving function as an extension of their usual role and their caregiving follows the expectation of the family and the society (Calasanti & King, 2007). They may feel obligated to give more of themselves and feel guilty if they do not, therefore experiencing more stress and burden than men (Gallicchio et al., 2002).

In the context of understanding the impact of gender on caregiving burden, widely used tools such as the Zarit Burden Interview (ZBI; Zarit et al., 1980) and Center for Epidemiologic Studies

Depression Scale (CES-D; Radloff, 1977) are essential in assessing the multifaceted aspects of caregiver experiences. However, it is crucial to acknowledge the limitations of these measures. For instance, while the ZBI and CES-D provide valuable insights into caregiver burden and depression, they may not fully capture the nuances influenced by gender dynamics. As demonstrated in studies like Papastavrou et al. (2009), where female caregivers scored higher on burden and depression scales, these tools might detect variations influenced by gender but might not elucidate the specific reasons behind such disparities. Additionally, qualitative research may be able to elucidate this further.

Qualitative research investigating the impact of gender on caregiving burden provides valuable insights into the complex interplay between gender roles and caregiving responsibilities. Brown et al., (2009) undertook a qualitative content analysis from nine previous interviews with male caregivers (from 2004/2005; Brown & Chen, 2007) to understand help seeking behaviours when caring for spouses with a form of Dementia. Brown and colleagues (2009) found that males tended to perceive the role as “care manager” rather than “caregivers”. In the interviews, the authors stated that it became apparent that the male participants were better able to recognise the importance of having time for themselves. Similarly, in their thematic analysis of interviews with twelve caregivers of patients diagnosed with Dementia in Rawalpindi/Islamabad Pakistan, Qadir et al., (2013) concluded that women reported higher levels of stress and burden than males. Not only did these studies identify a higher level of stress and array of challenges faced by female caregivers (Qadir et al., 2013; Brown et al., 2009; Johannessen et al., 2017), they also highlighted gendered perspectives that may have contributed to the observed differences between male and female primary caregivers. Specifically, male caregivers began seeking help earlier and realised the importance of having time to themselves (Brown & Chen, 2008). As such, they were more willing to share some of the caregiving demands and engage in personal activities that provided respite from caregiving. This may explain why most of the studies demonstrated a higher burden amongst female family caregivers. However, these studies lacked methodological rigour through a lack of consideration of other risk factors such as time spent caregiving, relationship and dementia severity (Hayes et al., 2009; Vitaliano et al., 2003) which likely play a key role in the level of caregiving burden one experiences.

To summarise, the comprehensive review of studies on the impact of gender on caregiving reveals significant disparities between male and female caregivers in terms of their perceptions, experiences, and outcomes. Female caregivers consistently report more health problems and depressive symptoms compared to male caregivers, as evidenced by various studies (Almberg et al., 1998; Gallicchio et al., 2002; Xiong et al., 2020; Mills et al., 2009; Sutcliffe et al., 2016). Females also tend to experience greater burden and higher levels of depression, attributed to taking on more caregiving tasks and responsibilities due to their emotional investment in the role. Although qualitative studies have greater ability to increase understanding of the specifics of caregiving burden, the multifaceted nature of the role makes it difficult to isolate the sole impact of gender. Thus it is important to explore other potential influences and factors that may impact the caregiving experience.

Relationship

Specifically within the body of research that has explored the challenges experienced by caregivers, caregiver to care recipient relationship has been shown to heavily influence the level of burden one experiences. In a cross-sectional study by Andren and Elmstahl (2007), 130 Dementia caregivers were asked to complete a range of questionnaires (caregiver burden scale; Elmstahl et al., 1996, the Nottingham health profile scale; Wiklund, 1990, sense of coherence scale; Antonovsky, 1988 and the Euroqol instruments; Busschbachet al., 1999) to understand the relationship between caregiver burden and caregivers perceived health. Results showed that a close relationship resulted in higher burden. Specifically, caregivers with varying relationships to the care recipients (i.e. friends, siblings) experienced a lower burden compared with spouses. The authors concluded that the intimacy and emotional closeness inherent in spousal relationships may contribute to an elevated sense of responsibility and, consequently, increased caregiver burden. This is consistent with findings from Serrano-Aguilar et al., (2006), who concluded based on questionnaire responses with 237 informal caregivers of Alzheimer Disease patients, that the greatest burden is that experienced by spousal caregivers. Specifically, the care needs of the spouses had a greater impact on their health related quality of life, resulting in high feelings of burden. However, in a similar cross-sectional analytic study with 251 patients and their caregivers (112 being spouses) Conde-Sala et al., (2010) concluded that the burden experienced by spouses and adult-children was no better, or worse, but in fact just different. Within this study, adult-children were found to report stronger feelings of guilt (Ankri et al., 2005; Turro-Garriga et al., 2008; Sanders et al., 2008), whereas spouses commonly reported high sense of social isolation (Rinaldi et al., 2005; Ott et al., 2007; Sanders et al., 2008). As has been suggested by Fenton et al., (2022), the observed differences between spouse and adult-child caregivers could be related to the different nature of the relationship involved. Within their study, Fenton and colleagues (2022) analysed caregiver surveys from the Cancer Care Outcomes Research and Surveillance Consortium to assess whether adult-child and spousal caregivers' caregiving responsibilities and social/emotional and financial burdens differed. It was found that although adult-child caregivers spend less time caring for a parent than spousal caregivers and receive more help from others, they experience greater caregiving burden. These differences persisted even after accounting for patients' clinical factors, caregiving time and responsibilities, and caregivers' demographic factors. Consequently, the authors suggest that caregivers find it more emotionally, socially, and financially difficult to care for a parent than a spouse. In the case of spouses, caregiving tasks would be regarded as part and parcel of the 'marital commitment' (Kim, Hayward and Reed, 2014), whereas for adult-child caregivers, such tasks may be felt to have a disruptive effect on their life.

While the study draws on data from the Cancer Care Outcomes Research and Surveillance Consortium, thus enhancing our understanding of cancer caregiver burden, the generalisability is constrained to this specific population. Caring for someone with cancer often involves managing complex medical treatments, uncertainties regarding disease progression and outcomes, and emotional distress related to treatment decisions and changes in the patient's condition (Stenberg et al., 2012). In contrast, caregivers of individuals with progressive neurodegenerative diseases navigate long-term care focused on addressing cognitive decline, managing daily activities, and coping with the gradual decline in their loved one's abilities over time. The duration of care differs as well, with cancer caregiving often intense over a shorter period during active treatment phases (Yabroff & Kim, 2009), while the caregiving trajectory for neurodegenerative diseases likely stretches for decades (Roland, 2022). Moreover, the study's focus on quantifiable measures of caregiving burden may overlook the nuanced emotional and psychological aspects of caregiving that could significantly impact caregiver well-being.

Within their systematic review examining Dementia caregivers, Chiao et al., (2016) verified a range of risk factors of caregiver burden by distinguishing patient and caregiver characteristics. Similar to the aforementioned research, type of relationship proved a prominent factor in caregivers appraisal of their burden. More specifically, spousal and adult children caregivers experienced the greatest burden in comparison to other informal caregivers of people with Dementia. However, nearly all of the participants included in the review were cohabitating with the patient. Despite this proximity making it easier for the caregiver to provide immediate assistance (Montañés et al., 2022), and monitor their wellbeing, caregivers are likely exposed to heavier patient care loads and can result in individuals to feel more overwhelmed with their roles and responsibilities (Vinas-Diez et al., 2017). Montañés et al., (2022) undertook a self-report where 161 caregivers of older Spanish adults completed a questionnaire constructed by the researchers to assess the impact amongst caregiver relationships as predictors of subjective caregiver burden. The results indicated that people cohabiting with care recipients (spouses) experience a greater subjective burden than those who live apart (adult children). This was particularly true for spousal caregivers. Within the study, Montañés and colleagues explained that living and caring in the same household can put a strain on a caregivers relationship to the care recipient as they struggle to seek an outlet for their personal lives. This may suggest why a plethora of literature has concluded that spousal relationships are a predictor of caregiver burden (Chiao et al., 2015; Davis et al., 2011; Friedemann & Buckwalter, 2014; Swinkels et al., 2019). Specifically, spouses are more likely to spend most of their lives living together, thus it is difficult to separate the partner to partner relationship from the caregiver-care recipient relationship.

To summarise, the literature on informal caregiving burden highlights the significant impact of relationship type on caregivers providing care to their loved ones. Research suggests that these factors can influence the level of stress, emotional strain, and overall well-being of caregivers. Specifically, the caregiver-to-care-recipient relationship has been shown to heavily influence the burden experienced by caregivers. Spousal caregivers often experience a higher burden compared to caregivers with different relationships to the care recipients, such as friends or siblings. This is attributed to the intimacy and emotional closeness in spousal relationships, which may lead to an elevated sense of responsibility and increased burden. Studies have shown that spousal caregivers tend to report higher levels of burden, impacting their health-related quality of life. However, research also indicates that the burden experienced by spouses and adult children may not necessarily be better or worse, but rather different. Adult-child caregivers often report stronger feelings of guilt, while spousal caregivers commonly experience a high sense of social isolation. Moreover, research suggests that adult-child caregivers may experience greater caregiving burden despite spending less time caring for a parent than spousal caregivers. This difference in burden could be related to the nature of the relationship involved, with caregiving tasks seen as part of a marital commitment for spouses but potentially disruptive for adult-child caregivers. Overall, the type of relationship between the caregiver and care recipient plays a crucial role in determining the level of caregiver burden. Spousal and adult-child caregivers tend to experience the greatest burden compared to other informal caregivers, with cohabitation often intensifying the subjective burden experienced by caregivers. Living and caring in the same household can strain the caregiver's relationship with the care recipient, highlighting the importance of considering relationship dynamics in understanding caregiver burden.

Age

Alongside care-recipient relationship, age is another caregiver characteristic that impacts caregiver burden (Gerain and Zech, 2019; Vitaliano, 2003). Rinaldi et al., (2005) found that a caregiver's age was a predictor of burden in Dementia caregivers. Specifically in their quantitative survey study, 419 elderly outpatients with Dementia and their caregivers were evaluated with four scales for the assessment of burden, distress related to neuropsychological disturbances, depression and anxiety (Neuropsychiatric Inventory; Cummings, 1997), burden was quantified by the Caregiver Burden Inventory (CBI; Novak and Guest, 1989) and the Brief Symptom Inventory (Derogatis, 2001). Caregivers aged 70+ years old documented three times greater stress than the younger groups, due to their own physical and health difficulties. However, there was a lack of demographic information on the participants, thus, younger caregivers may not have been adequately represented in the study's findings.

Arai et al., (2007) administered a range of questionnaires, including the General Health Questionnaire (Goldberg & Hillier, 1979) Troublesome behaviour scale (Asada et al., 1994) and the Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980) to family caregivers and patients who fulfilled the diagnostic criteria for Dementia and concluded that younger Dementia caregivers experience a greater perception of burden. They found that younger Dementia caregivers face additional problems, as they are more likely to be working and to have dependent children and more financial responsibilities. Younger caregivers are often unprepared for the task and experience increased burden, will need to look after the care receiver for a longer period of time, have fewer appropriate services available to them and feel more isolated. While the study identified greater perceived difficulties in younger caregivers related to patient behavioural disturbances, the lack of significant associations between Dementia type and caregiver characteristics or burden raises questions about the comprehensiveness of the measures used and the potential impact of unmeasured variables on caregiver outcomes. Furthermore, the study failed to report on the impact of other factors such as relationship type which are known to play a role in caregiving burden. The discrepancy in the results of both research studies can be accounted for: older caregivers often have poor physical and psychological health, whereas younger caregivers usually have less experience in caregiving or a feeling of social restrictiveness (Andrén & Elmståhl 2007; Kim et al. 2012; McConaghy & Caltabiano 2005; Sinforiani et al. 2010; Zawadzki et al. 2011).

In summary, while caregiving burden affects every caregiver, the age of the caregiver can significantly influence the dynamics of the caregiving role. Older caregivers may encounter age-related health issues, physical limitations, and potential cognitive decline, which can impact their ability to provide care effectively. They may also have fewer available support systems and resources, leading to increased feelings of isolation and stress. In contrast, younger caregivers may face challenges related to balancing caregiving responsibilities with work, education, and family commitments. They may also experience financial strain, lack of experience in caregiving, and feelings of social isolation due to their caregiving role. Thus, caregiving burden is neither better or worse depending on age, but can affect individuals differently depending on the stage of life they are in. Whilst it is acknowledged that caregiving burden is not a one-size-fits-all experience, the reliance of quantitative measures alone does not capture the complex interplay between age and other caregiver characteristics (i.e. relationship and personality), limiting our understanding of the sole impact of age on caregiving burden. Qualitative techniques, such as interviews, may offer an opportunity to explore the diverse range of factors that contribute to caregiving burden, providing a more holistic understanding of the multifaceted nature of caregiver experiences. By incorporating qualitative methods alongside quantitative measures, researchers may gain deeper insights into the unique challenges faced by caregivers of different ages and backgrounds, ultimately enhancing our understanding of caregiving burden.

Personality traits

Another factor that is likely to influence the caregivers' burden is their personality. Considering personality traits is crucial as particular characteristics can significantly influence how individuals perceive, experience, and cope with the challenges of caregiving (Cejalvo et al., 2021). Based on the five-factor structure of personality traits outlined in the Big Five Inventory (BFI), a commonly used tool for personality assessment (Rammstedt and John, 2007), personality is comprised of neuroticism, extraversion, openness, agreeableness, and conscientiousness. Although research evidence for the implications of personality traits on caregiving burden is relatively scarce, neuroticism has garnered the largest amount of attention. Neuroticism is a relatively stable tendency to respond with negative emotions to threat, frustration, or loss (Lahey, 2009). Although neuroticism as a personality trait consists of multiple facets that may be phenomenologically distinct in their own rights, such as anger, irritability, and excess worries, the personality tendency as a whole has been associated with a higher likelihood of developing psychopathological conditions, including anxiety disorders (Kendler & Prescott, 2007; Anwar et al., 2018; Kotov et al., 2010; Ormel et al., 2013). In a survey study, Kim & Park et al., (2017) administered the following questionnaires to 476 caregivers Clinical Research Center for Dementia in South Korea; The Korean version of the Big Five Inventory10 (BFI-K-10; Kim et al., 2010), ZBI; (Zarit et al., 1980), Short Form Health Survey (SF-36; Han et al., 2004) and The Beck Depression Inventory (BDI; Beck, 1961). The aim was to understand the influence of personality on depression, burden and health-related quality of life. Specifically, the results highlighted that higher levels of neuroticism were associated with increased feelings of depression and caregiver burden experienced by individuals in the caregiving role. Similarly, in a previous longitudinal study conducted with 320 caregivers, individuals with highly neurotic personalities (measured via 48 items from the NEO-PI; Costa & McCrae, 1992), tended to perceive the caregiving situation as more stressful and threatening than those with other personality traits (Wang et al., 2004). Furthermore, a study involving patients with dementia and their caregivers revealed a link between caregiver neuroticism and the accelerated cognitive decline of the care recipient (Norton et al., 2013). Individuals living with Dementia have significant awareness of their caregivers' emotional states, especially those in earlier stages; thus, the authors concluded that emotional instability of caregivers with higher levels of neuroticism exacerbates the cognitive decline of a Dementia patient.

Within the same study by Kim et al., (2017), the researchers found statistically significant negative correlations with the rest of the four traits; extraversion, consciousness, openness, and agreeableness. Specifically, caregivers who scored high in these characteristics, reported lower perceived stress, burden, and depressive symptoms (Soltys et al., 2021; Melo et al., 2011), which is particularly true for highly extroverted individuals. Extraversion or the wish for high levels of social interaction is related to ‘‘positive affectivity’’ (Sun et al., 2017). According to Koerner et al., (2009), extroverted caregivers feel more positive toward their efforts in caregiving, find more pleasing aspects in the task and are more satisfied with the social support they get from family and friends. On the contrary, an individual who has low extroversion may have fewer resources when faced with the stressors in daily caregiving, and consequently be less able to derive any benefits or rewards from the caregiving experience (Koerner et al., 2009). In another self-report survey study, Melo et al., (2017) assessed 105 patients with Dementia and their family members using the Neo Personality Inventory (NPI; Costa and McCrae, 1989; 1992), Zarit burden interview (Zarit et al, 1980), CES-D (Radloff, 1977), The Mini Mental State Examination (Folstein et al., 1975), Neuropsychiatric Inventory Questionnaire (Cummings, 1994), Neuropsychiatric Inventory Caregiver Distress Scale (Kaufer, 1988), and an open question to identify the strategies used by caregivers when faced with BPSD. They showed that neuroticism increased depression and caregiver burden, whereas extraversion decreased depression and caregiver burden. These results are consistent with Kim et al's., (2017) study demonstrating that extraversion had a positive effect on mediated caregiver burden and depression, leading to better physical and mental health related quality of life compared to those with low extraversion and high neuroticism.

The aforementioned studies by Kim et al., (2017) and Melo et al., (2011), utilised short-form versions of some personality scales (BFI-K-10 and NEO-PI-R). Using shortened versions may not fully capture the complexity of personality traits compared to the full-scale ones, potentially impacting the interpretation of results. Also the researchers did not administer questionnaires at a later date, thus they fail to capture changes in personality traits over time as the caregiver deals with new challenges. Furthermore, both studies failed to adequately consider different caregiving contexts, such as caregiver relationships to the person with Dementia, which can significantly influence caregiver burden (Gerin & Zech, 2015). To overcome these limitations, utilising another range of questionnaires can offer a more comprehensive understanding of how personality traits impact caregiving burden.

In summary**,** neuroticism emerges as a key personality trait associated with higher levels of caregiver burden and depression, as individuals with higher neuroticism tend to perceive the caregiving situation as more stressful and threatening. Studies have shown a direct link between neuroticism and increased caregiver burden and depression, with neuroticism also potentially exacerbating the cognitive decline of the Dementia patient being cared for. In contrast, caregivers who score high in extraversion, consciousness, openness, and agreeableness, report lower perceived stress, burden, and depressive symptoms. Research has particularly explored the impact of extroversion on caregiving burden. The literature concludes that in contrast to neuroticism, extraversion has been associated with more positive affectivity, satisfaction with social support, and a more positive outlook on caregiving tasks. Research indicates that extraverted caregivers may derive more benefits and rewards from the caregiving experience compared to those with low extraversion. Evidently, personality plays a significant role in influencing caregiving burden; however, further research is needed to comprehensively understand the interplay between an array of factors, including caregiver relationship dynamics and age, on caregiving burden. This holistic approach will provide a greater understanding of the multifaceted nature of caregiver experiences and outcomes.

Coping and support

Consistent with the Stress Process Model (Pearlin et al., 1981), research has emphasised the role of coping as a mediator of caregiver burden, playing a crucial part in how caregivers confront and handle the difficulties linked to their caregiving duties (Folkman & Lazarus, 1984). Coping is defined as a process of adaptation to stressful situations, which includes the allocation of cognitive and behavioural resources in response to specific internal and/or external demands that are deemed to exceed the subject's normal requests (Folkman & Lazarus, 1984). A meta-analysis by Pinquart and Sorensen (2003) highlighted that coping strategies adopted by caregivers of people with all Dementia subtypes can predict the quality of life of caregivers (Pattanayak et al., 2011), as well as their levels of anxiety (Cooper et al., 2008), depression (Li et al., 2013) and burden (Del-Pino Casado et al., 2011). In relation to caregiving burden, emotion-focused coping and dysfunctional strategies have been explored the most. Emotion-focused coping seeks to regulate distressing emotions and can include emotional expression, fantasising, and reflecting on positive or negative thoughts (Bauman et al., 2008), whereas dysfunctional coping involves avoiding the situation or memories & the emotions associated with it (Stanisławski, 2019; Riolli and Savicki, 2010). Dysfunctional coping strategies have been consistently linked to higher levels of depression (Kim, Knight, & Longmire, 2007), anxiety (Li and Cooper et al., 2010) and caregiver burden (Wright, Lund, Caserta, & Pratt, 1991) as well as lower satisfaction with life (Sun, Kosberg, Kaufman, & Leeper, 2010).

In a systematic review and meta-analysis, Li et al., (2012) examined 35 studies to understand the relationships between coping and anxiety or depression among carers of people with Dementia. Dysfunctional coping correlated with higher levels of anxiety and depression, whereas emotion-focused and acceptance-based coping correlated with less anxiety and depression. Huang et al., (2015) demonstrated that dysfunctional coping heightens caregiving burden. Within the self-report study, 57 caregivers of patients with Dementia were assessed using the Ways of Coping Checklist (Vitaliano et al., 1985), and burden was assessed using the Chinese version of Caregiver Burden Inventory (Lou et al., 2009). Findings demonstrated that dysfunctional coping was correlated with greater burden, increased depression and lower life satisfaction. Caregivers who tried to cope with the stressors of caregiving by avoiding certain situations, tasks, or emotions were more likely to report greater burden associated with their caregiving responsibilities. These findings imply that avoidance coping strategies, while potentially providing temporary relief from stress, may ultimately contribute to increased feelings of burden among caregivers. Thus emotion-focused coping may prove more effective in managing caregiving burden.

Cooper et al., (2008) carried out a self-report study with 98 people with Alzheimer's disease and their family caregivers. The Hospital Anxiety and Depression Scale (Zigmond, 1983), the ZBI (Zarit et al, 1980) and the Brief COPE (Carver, 1997) were utilised to measure coping strategies. It was found that using emotion-focused coping strategies in response to caregiver burden seemed to protect caregivers from developing higher anxiety levels a year later. However, caregivers were surveyed about their coping strategies using a general measure of coping, rather than being asked specifically how they cope with particular situations. Consequently, individuals, particularly those experiencing anxiety or high levels of stress, may have a tendency to perceive their coping strategies more negatively than they actually are. In other words, anxious caregivers might be more inclined to report that they cope poorly or ineffectively, even if their coping mechanisms are relatively functional or adaptive. Furthermore, the research only considered one type of Dementia in the study, it would be advantageous to conduct comparative research to evaluate disparities in coping strategies and caregiver burden across different forms of Dementia.

Riedijk et al., (2006) compared the coping strategies adopted by Frontotemporal Dementia (FTD) and Alzheimer's Disease (AD) caregivers. 29 FTD and 90 AD caregivers were assessed using the NPI (Costa and McCrae, 1989; 1992), Short Form 36 health survey questionnaire (SF-36; Ware, 1992) and Utrecht Coping List (Schreurs et al., 1993). Although FTD caregivers were more heavily burdened by the caring process than AD caregivers, they found no differences in coping strategies adopted between FTD and AD caregivers, thus it was possible that coping strategies were used, independently of Dementia type. Furthermore, passive coping strategies or dysfunctional coping contributed significantly to decreased Health Related Quality of Life (HRQOL) for both FTD and AD caregivers which stands in contrast to previous research that has highlighted that this form of coping is detrimental to caregivers. However, the study did not consider the availability of resources or support for these caregivers. Given that they were all recruited from the same environment, it is probable that their access to support was similar. Consequently, it is reasonable to propose that this group of caregivers may have lacked adequate resources, and have had to adopt and eventually become accustomed to using dysfunctional strategies in their caregiving roles. Another reason for the adoption of dysfunctional coping may be due to the population being all male. According to Yousaf et al., (2015) men may perceive seeking emotional support as a sign of weakness or vulnerability due to societal stigmas surrounding help-seeking behaviour. Consequently, they may be less inclined to adopt emotion-focused coping strategies and may instead resort to dysfunctional coping mechanisms as a means of managing stress. However, further research has thrown doubts on the efficacy of emotion-focused coping for managing caregiving burden.

Ivarone et al. (2014) found that emotion-focused coping may not be the most effective strategy to minimise burden. In this study, eighty-six caregivers completed assessments using the Caregiver Burden Inventory (CBI; Novak and Guest, 1989) and the State-Trait Anxiety Inventory (STAI Y-1 and Y-2; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Additionally, coping strategies were evaluated through the Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1990). The study found that emotion-focused coping strategies were more prevalent among female caregivers and were associated with high caregiving burden, trait anxiety, and Dementia severity. For this population, these types of strategies seem to predispose the caregiver to a higher burden and distress. However, the authors suggest that it is important to recognise that while emotion-focused coping can help caregivers regulate their emotional responses at the time, it may not directly address the underlying sources of stress and burden (Roche et al., 2015). Therefore, a combination of coping strategies may be most effective in supporting caregivers' overall well-being and resilience in the face of caregiving challenges.

The aforementioned studies have provided valuable insight into the relationships between burden and coping strategies adopted by caregivers. However, the absence of longitudinal design means the caregivers' feelings/perspectives were only captured at that given point in time. Caregiving is a dynamic process that evolves over time, influenced by changing circumstances, relationships, and the progression of the care recipient's condition (Schulz, 2016). Thus, relying solely on quantitative approaches in studies that are not longitudinal may not fully capture the complexity of caregivers' coping strategies throughout their caregiving journey. It might be that dysfunctional coping is adopted at the start where caregivers are in denial about their loved ones prognosis, whereas caregivers, if they have the resources to, can focus on positive aspects of their role and consequently adopt emotion-focused coping. Introducing qualitative methodologies, such as in-depth interviews or focus groups, could offer a more comprehensive understanding of caregivers' experiences by exploring the context, meanings, and emotions associated with their coping strategies. By complementing quantitative findings with qualitative data, we may be able to gain a more holistic understanding of caregivers' coping processes across their caregiving journeys.

In summary, coping strategies significantly impact caregivers' perceived level of burden. However it is important to recognise that burden is a multifaceted construct, shaped by a myriad of factors beyond the type of coping strategy a caregiver adopts. While coping strategies undoubtedly play a crucial role in how caregivers manage stress and navigate the challenges of caregiving, other factors such as relationship, age and gender of the caregiver also contribute to the overall burden experienced. Therefore, while coping strategies are an important aspect of understanding and addressing caregiver burden, they should be viewed within the broader context of caregivers' lives and assessed alongside the multitude of factors that impact their burden and overall well-being.

Summary

The aforementioned review highlights the multifaceted nature of caregiving burden and the various factors that influence it. The review of studies on gender disparities in caregiving sheds light on the significant differences between male and female caregivers, with females often reporting more health problems and depressive symptoms as a result of caregiving. Additionally, the impact of relationship dynamics on caregiving burden is crucial, with spousal caregivers often experiencing higher burden due to the intimacy and emotional closeness in their relationships. Adult-child caregivers may also face unique challenges related to guilt and disruption of caregiving tasks. Furthermore, the age of the caregiver significantly influences the caregiving experience, with older caregivers facing age-related health issues and isolation, while younger caregivers juggle caregiving responsibilities with work and family commitments. Coping strategies are pivotal in caregivers' management of stress and adaptation to the demands of caregiving; nevertheless, research remains inconclusive regarding the optimal strategy. The coping mechanisms employed by caregivers are likely contingent upon various factors, including individual characteristics, demographic variables, and the specific stage of illness of the care recipient, thus it is important to have a holistic approach when developing interventions aimed to minimise caregiver burden.

The commonality between the studies is the reliance on quantitative measures. While valuable, quantitative measures, in particular questionnaires, often fall short in considering the simultaneous impact of multiple factors on caregiving burden. Consequently the results may not fully capture the multifaceted nature of caregiving burden, indicating the need for a more comprehensive exploration of caregiver characteristics. Furthermore, much of the literature alluded to care recipients symptomatology has an impacting factor on caregiving burden, thus it seems appropriate to discuss how type of illness and stage of illness impacts the caregiver.

1.3 Focus on neurodegenerative diseases/syndromes

The severity of the illness or disease of the care-recipient plays a significant role in shaping the caregiving experience and burden for informal caregivers (Roth et al., 2015). Caregivers providing support to individuals with severe illnesses or complex medical conditions often face heightened challenges and responsibilities compared to those caring for individuals with milder health issues. The level of care required, the intensity of symptoms, and the impact on the care recipient's functioning can all contribute to the physical, emotional, and financial strain experienced by caregivers (Ejem et al., 2015).

Research into the impact of brain injury/progressive neurological diseases on caregivers has predominantly centred on Traumatic Brain Injury (TBI), Frontotemporal Dementia (FTD), and Dementia. Examining TBI caregivers alongside Dementia and FTD caregivers is valuable. Each of these caregiving contexts presents unique challenges and complexities that can impact caregiver well-being and the quality of care provided. By comparing and contrasting the experiences of caregivers across different conditions, researchers can gain a broader understanding of the commonalities and differences in caregiving burden, coping mechanisms, and support needs. As the literature on caregiving in CTE continues to evolve, we draw upon established knowledge from caregiving in neurodegenerative diseases to inform our understanding. By exploring the extensive information available on caregiving in these related contexts, we develop our understanding of progressive conditions on the caregiver. We hope to further use this information to understand the differences between caregiving in these contexts and that of the CTE caregiving experience.

Traumatic Brain Injury

Although most chronic conditions involve complex care demands, research on Traumatic Brain Injury and its impact on caregiver burden has gained significant attention in recent years, due to the profound challenges faced by individuals who care for TBI survivors. TBI is a degenerative, non-congenital insult to the brain from an external mechanical force, leading to permanent or temporary impairments of cognitive, physical, and psychosocial functions with an associated diminished or altered state of consciousness (Tabish et al, 2006). Previously, such injuries often resulted in mortality; however, increased access to improved trauma care has resulted in higher survival rates (Gavett and Stern et al., 2010; Wilson et al., 2017). Despite decreased mortality, patients are typically left with significant impairment and often a need for 24-hour care (McAllister, 2008; Qadeer et al., 2017). Specifically, people with TBIs are often left with a range of temporary or permanent deficits affecting motor and cognitive function, behaviour and communication, social functioning and emotions (Joshua 2022; Kohler et al., 2020). Similarly to other neurodegenerative diseases, the caregiving role to people with severe TBI is naturally adopted by friends and family (Lannin and Laver, 2013). The sudden onset and array of symptomatology experienced by TBI patients can be challenging for caregivers to navigate. Unlike progressive diseases such as Dementia, that allow for more planning and preparation for an individual's care, TBI occurs suddenly and unexpectedly, promoting individuals to quickly take on the role of a caregiver. Consequently, caregivers experience a wide range of emotions and behavioural manifestations including shock, anxiety, denial, and frustration (Degeneffe, 2001). The impacts go beyond emotional experiences also encompassing factors such as socioeconomic status, preparedness for caregiving and understanding of injury, stress, burden, and the presence or absence of additional support networks (Lindlöf, 2024). All of these are likely to impact the level of burden the caregivers experience during their role.

As is the case for most individuals with TBI, caregivers experience significant life interruptions following the onset of their new roles and responsibilities, including changes to life plans, expectations, and interruption to other life milestones (e.g., education/career goals, retirement, etc.). In a qualitative study by Kratz, Sander, Brickell, Lange, & Carlozzi (2017) fifty-two caregivers of adults with moderate or severe TBI took part in focus groups to evaluate their perspectives on quality of life. Caregivers reported unexpected responsibilities and burdens, including loss of income, free time, and freedom for life as previously planned (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017), highlighting the profound impact this role can have on a caregiver’s life. Similarly, Carlozzi et al., (2015) undertook nine focus groups with caregivers of individuals with moderate-to-severe TBI to ascertain the effect that caring for an individual with a TBI has on caregiver health related quality of life. Qualitative analysis indicated that caregivers experienced a large impact on their social health (i.e. ability to participate in social roles/activities, companionship and role changes) as well as their emotional health (i.e. level of social isolation and emotional support), physical health (i.e. sleep disturbance, fatigue) and mental health (anxiety/depression). Whilst the aforementioned studies shed light on the significant challenges faced by caregivers of individuals with TBI, it is important to note that these findings may not encompass all caregiver-specific issues. In Carlozzi et al.,’s study, factors such as anxiety related to the caregiver role (reinjury concerns, worry about leaving the person alone), and caregiver strain (burden, stress, feeling overwhelmed) were not evaluated. Gaining a holistic understanding of caregiver experiences is essential for developing targeted interventions to address their specific needs and challenges.

One significant factor to consider is if the patient with TBI has military affiliation. Military service exposes individuals to situations increasing the likelihood of head injuries (Kong & Zhang et al., 2022), such as combat, training exercises, or hazardous environments. Combat deployments involve various stressors elevating the risk of TBIs (Stein et al., 2009). Recognising the military background of TBI patients is essential for assessing their injury history comprehensively and providing tailored interventions and support services.

Research has shown that caregiving for veterans with TBI presents unique challenges compared to caring for civilians with TBI. Keatley et al. (2019) conducted an observational research study examining group differences between caregivers of service members/veterans with TBI and civilians with TBI within the United States. In their study, 473 caregivers (N=344 civilian caregivers, N=129 veteran caregivers) completed assessments online, including the Zarit Burden Interview Scale (Zarit et al., 1980), TBI-CareQOL (Carlozzi et al., 2019), and Mayo Portland Adaptability Inventory, 4th revision (MPAI-4; Malec., 2017). The findings revealed that caregivers of service members were more likely to report feeling trapped by their caregiving duties and experiencing worse emotional and social adjustment compared to caregivers of civilians. This disparity is not surprising, given the unique challenges military caregivers often encounter. Areas that may pose greater difficulties for caregivers of service members include managing additional legal, military, and medical systems. Interactions with the Veterans Affairs healthcare system may evoke heightened emotions, as caregivers fear potential loss of compensation for their caregiving duties and encounter barriers to healthcare access and availability (Carlozzi et al., 2016; Kratz et al., 2017). Furthermore, emotional management may be exacerbated due to the high rates of post-traumatic stress disorder (PTSD), difficulties re-integrating into civilian life, and emotional adjustment issues specific to military service (Vasterling, Verfaellie, & Sullivan, 2009).

The lack of informative resources has been highlighted as a challenging aspect in numerous studies focusing on TBI. In a cross-sectional study, Lieshout and Oates et al., (2020), asked 29 TBI caregivers to complete the Demand and Difficulty subscales of the Caregiving Burden Scale (Carey, 1991) and the Mutuality, Preparedness, and Global Strain subscales of the Family Care Inventory (Archbold, 1982) to explore their levels of burden and preparedness. Regardless of time post-injury, caregivers reported the demanding nature of balancing the support required for everyday essential tasks for the person (e.g., self-care) and the difficulty of coordinating services for the person with the TBI. While the majority of informal caregivers reported feeling relatively prepared for their caregiving role overall, they highlighted specific challenges related to accessing help or information from the health system and managing the stress associated with caregiving responsibilities. Despite this perceived readiness, many caregivers expressed ongoing concerns, particularly regarding the future care needs of their family members who sustained a traumatic brain injury (TBI) either 1–3 years ago or more than 3 years ago. This persistent apprehension underscored the enduring nature of caregivers' worries and responsibilities, suggesting that despite feeling adequately prepared, they remain vigilant about meeting the evolving needs of their loved ones over time. These findings emphasise the importance of ongoing support and resources to assist caregivers in navigating the complexities of long-term caregiving, including access to relevant information, coping strategies, and assistance in anticipating and addressing future care challenges effectively.

Dementia

Currently, the global population comprises approximately 55 million individuals living with Dementia, with nearly 10 million new cases emerging annually (World Health Organization, 2023). The word Dementia is derived from the Latin de (without) and ment (mind), and reflects a decline in mental functioning in a previously unimpaired or less impaired individual (Staniloiu et al., 2020). Dementia is a syndrome that can be caused by a number of diseases which over time destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing (Fortea et al., 2021). While consciousness is not affected, the impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation (Magierski et al., 2020). However, like most neurodegenerative diseases, Dementia affects each person in a different way, depending upon the underlying causes, other health conditions and the person’s cognitive functioning before becoming ill. It is important to explore each subtype of dementia; Alzheimer's disease, Vascular Dementia, Dementia with Lewy bodies, and Frontotemporal Dementia, to understand their distinct characteristics and the ramifications they pose for caregivers.

Causes of dementia

Alzheimer’s disease

Alzheimer’s disease (AD) is the most common form of Dementia and is responsible for about 75% of cases, either on its own or with other forms of pathology (known as ‘mixed dementia’ (Sandilyan & Dening, 2019). Neuropathologically, it features abnormal deposition of insoluble ‘plaques’ of a fibrous protein called amyloid and twisted fibres called ‘neurofibrillary tangles’ in the brain

(Attems & Jellinger, 2013). These neurological changes cause an insidious onset and progressive impairment of behavioural and cognitive functions including memory, comprehension, language, attention, reasoning and judgement (Kumar et al., 2022), accompanied by altered perception, mood disorders and changes in behaviour (e.g. aggression). In the early stages, short-term memory loss is the most common feature (Thomas et al., 2013). Due to episodic memory difficulties, persons with Dementia may demonstrate behaviours such as repeated questioning, challenges with disorientation to time and place, and safety concerns (e.g., wandering, leaving stove on, etc.; Kales, Gitlin, & Lyketsos, 2017). As the disease progresses, greater memory loss and language difficulties alongside anxiety and lack of interest/motivation become apparent. Age is the greatest risk factor for developing AD, with the vast majority of cases occurring after age 60, but it has appeared in people as young as 30 (referred to as young onset AD; Ryan et al., 2016).

Vascular Dementia

Vascular Dementia is the second most common type of dementia after Alzheimer’s disease. Here the brain’s blood supply is compromised by arterial disease, which results in reduced neuronal function and eventually the death of brain cells (Haeberlein et al., 2022). In addition to memory and language difficulties as in AD, slowing of thinking processes, depression, anxiety and apathy are commonly seen in patients (Lustig et al., 2003). While memory and language deficits remain hallmark features, similarly to Alzheimer's disease, Vascular Dementia presents a unique clinical profile characterised by a distinct array of cognitive and neuropsychiatric symptoms. Among these symptoms, patients commonly exhibit a notable slowing of cognitive processes, marked by diminished cognitive functioning. Moreover, individuals affected by Vascular Dementia often grapple with concurrent psychological manifestations, including depression, anxiety, and apathy, which can significantly impact their overall quality of life and functional independence (O'Brien et al., 2003).

Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is the third most common type of Dementia, accounting for around 10 percent of cases (Yang, 2018). Lewy bodies, which are characteristic of this group of diseases, are small aggregations of a protein called alpha-synuclein that occur in neurons in various areas of the brain, including the cerebral cortex (Attems & Jellinger, 2013). Clinical features may include symptomatology seen in AD, for example memory loss, but visuo-spatial deficits (problems with locating positions of objects) are more prominent. Additional clinical features include visual hallucinations, rapid eye movement sleep behaviour disorder and severe neuroleptic sensitivity with increased parkinsonism and a higher prevalence of neuroleptic malignant syndrome (McKeith et al., 2005).

Frontotemporal dementia

Fontotemporal dementia is the least prevalent form of dementia (compared to AD/mixed dementia), and covers a range of conditions that affect frontal regions of the brain responsible for planning, emotion, motivation and language. It is estimated that FTD accounts for approximately 20 to 50% of young onset cases of dementia (Cardarelli, Kertesz, & Knebl, 2010). The onset of FTD is typically insidious and the progression of the disease tends to be slow. The core clinical features of FTD differ from Alzheimer's Disease in that it is restricted to the frontal and/or temporal lobes, and it presents with presenile onset more frequently than AD (Rosso, 2003). Many patients with FTD experience early decline in disinhibition, early emotional blunting, early loss of insight and preceding memory decline (Snowden, Neary & Mann, 2002). The behavioural variant of FTD (FTD-bv) is associated with changes in personality and social functioning. Persons diagnosed with FTD-bv may begin to act in socially inappropriate ways, their temperament may change, and they may begin engaging in odd or characteristically atypical behaviours. They tend to demonstrate a lack of insight and a paucity of empathy toward others (Rosness et al., 2016). Despite its lesser prevalence compared to AD, FTD poses significant challenges for affected individuals and their caregivers due to its distinct symptomatology and progression.

Understanding how different subtypes of Dementia impact caregiving burden is of particular interest due to the varied clinical presentations and trajectories associated with each subtype (Jhang et al., 2019). In a comparative study by Liu et al. (2018), 492 dyads of patients and their caregivers (FTD; n = 131; DLB; n = 36; AD; n = 325) participated. They compared patients with respect to the Neuropsychiatric Inventory (Cummings et al., 1994), Zarit Caregiver Burden Interview (Zarit et al., 2008), Pittsburgh Sleep Quality Index (Buysse, 1989), Patient Health Questionnaire-9 (Kroenke, 2001), and Generalised Anxiety Disorder scale (Spitzer et al., 2006). Caregivers of Frontotemporal degeneration and Dementia with Lewy bodies patients experienced significantly more burden compared to Alzheimer’s disease caregivers. The results showed that DLB patients had more neuropsychiatric symptoms than AD patients. The authors concluded that this led to DLB caregivers feeling more burdened by the caregiving process compared to AD caregivers, particularly due to hallucinations and changes in nighttime behaviour, which are core characteristic symptoms of DLB (Metzler-Baddeley, 2007; Ricci et al., 2009). Furthermore, DLB patients generally had prominent deficits on tests of attentive and executive function (e.g., judgement, organisation, planning; Simard et al., 2000; Collerton et al., 2003) which led to a higher degree of caregiver distress compared to AD patients in the same phase of cognitive decline as shown by the PHQ-9 scores, and GAD-7 scores. The elevated levels of caregiver burden measured through the ZBI, observed in FTD and DLB could be attributed to challenges in accessing adequate support within the healthcare system. Unlike AD, which was more prevalent, FTD and DLB were comparatively less common, resulting in fewer specialised resources and support services tailored to caregivers' needs. This scarcity of resources could leave FTD and DLB caregivers feeling isolated and overwhelmed, as they might struggle to find appropriate information, guidance, and assistance in managing the care-recipient's symptoms. Similarly Kawano et al., (2020) evaluated caregiver burden through the short version of the Japanese version of the Zarit Burden Interview (Hirono, 1998) with 337 caregivers of people with Dementia. They found that caregiver burden was more severe in caregivers of Lewy Body Disease patients than in those of AD, and caregivers of LBD patients experienced significantly more burden compared to those of AD. The authors indicated that the challenges associated with caregiving for LBD patients may be more pronounced and demanding, potentially due to the unique symptomatology and progression of the disease. Furthermore, the comparatively lower prevalence of LBD than AD suggests that there may be fewer informative support and resources available for caregivers (Killen et al. 2016), potentially contributing to the heightened burden reported by caregivers. However, within the study, the number of participants with AD in comparison to Lewy Bodies was not stated. Uneven representation of Dementia subtypes in the study sample could skew the results, leading to misinterpretation or overgeneralization of findings. Despite this, the aforementioned findings underscore the importance of understanding the impact of burden on caregivers with less common forms of Dementia, such as FTD and DLB, to address their unique needs effectively. However, the studies focused primarily on caregiver burden and did not extensively assess caregiver characteristics such as demographics, coping strategies, or social support, which could influence caregiver burden and distress. Models such as Gerin and Zech's informal integrative model of caregiver burden (2019) highlight that demographic variables such as age, gender, and socioeconomic status impact a caregivers' ability to cope with the demands of caregiving. Therefore, future research should consider a more comprehensive approach to assessing caregiver characteristics and their influence on caregiver burden.

However, some reports did not observe any differences in caregiver burden between Dementia subtypes (Yeager et al., 2010; Oliveira et al., 2015; Branger et al., 2018). Branger et al. (2018) compared the Zarit Burden Interview (ZBI; Zarit et al., 1980) scores of 212 patients with AD, Vascular Dementia, FTD, and mixed Dementia caregivers and showed that the caregiving burden was similar irrespective of the Dementia aetiology of the patient. Specifically, patient behavioural symptoms, such as agitation, and their level of functional dependence, proved to be strong predictors of caregiver burden. Additionally, the psychological distress experienced by caregivers themselves emerged as a contributing factor to caregiving burden. Surprisingly, the neuropsychological performance (cognitive abilities and functioning) of the care recipient, did not directly predict caregiver burden. However, the majority of participants within the study were in the early to mid stages of Dementia. Since caregiver burden may vary depending on the stage of Dementia, this limited representation of Dementia severity stages could impact the generalisability of the findings. For instance, caregivers of individuals in the later stages of Dementia may experience significantly higher burden due to increased care needs and behavioural challenges.

Further research has highlighted that there is no link between types of Dementia on caregiver burden. Oliveira et al. (2015) aimed to compare and distinguish demographic and neuropsychiatric features between LBD and late-onset AD for patients and their caregivers. A total of 39 patients with Parkinson disease dementia or dementia with Lewy bodies were matched with 39 *APOE*-ε3/ε3 patients with late-onset AD and were evaluated according to sex and Mini-Mental State Examination (MMSE; Folstein et al., 1975) scores. They found no statistical differences in caregiving burden between caregivers of LBD and AD Dementia. However, the MMSE has a narrow focus on assessing significant cognitive decline rather than providing a comprehensive evaluation of cognitive function. With only 21 or 24 questions, the MMSE may not have captured other crucial aspects of the patient's condition, such as behavioural symptoms, functional impairment, or overall disease severity, which have been shown to impact caregiver burden (Liu et al., 2018; Kawano et al., 2020). Ignoring the significance of these factors could have led to an incomplete understanding of the caregiver's experience and consequently may underestimate the extent of caregiver burden. Hence, quantitative studies should integrate various validated questionnaires (e.g., ZBI, Caregiver Strain Index, Perceived Stress Scale) to thoroughly evaluate the multifaceted dimensions of caregiver burden. However, this approach can increase statistical complexity, and adding more measures raises the risk of encountering false negatives. Despite these limitations, Yeager et al. (2010) also found caregiving burden is not impacted by caregiving for different Dementia subtypes. Within their retrospective case review of patient and caregiver information, collected at a university-based Dementia clinic, results showed there were no differences in the burden of care between Vascular Dementia and AD Dementia. Rather, psychotic symptoms paired with poor functioning generated the most burden. Additionally, being a female caregiver, depressive symptoms, and being an adult child of the care recipient were associated with increased caregiver burden. This highlights the complexity of caregiver burden and suggests that factors beyond the specific Dementia subtype may play a more significant role in determining caregiver burden, such as characteristics of the caregiver.

Recently, Huang et al., (2022) undertook a retrospective cohort study across a 19-month period to compare caregiving burden for different types of Dementia. They enrolled 630 patients and their caregivers from the Dementia Center of Changhua Christian Hospital. The care team performed face-to-face interviews every 6 months, for 18 months from when a diagnosis of Dementia was made. Similarly to Kawano et al., (2020) and Liu et al., (2018), caregivers taking care of patients with LBD had a significantly increased burden compared with those taking care of patients with AD. Also within this study, caregivers of FTD patients revealed a higher care burden compared with caregivers of AD patients at the 18-month follow-up in this study. This same finding has been previously reported by Liu et al. (2018). The authors suggest that the increased burden is due to the higher rate of behavioural and psychiatric symptoms observed in FTD. This suggests that increased behaviour symptomatology has a direct effect on the burden experienced by caregivers. However, due the retrospective cohort design, some information concerning confounding factors (patient symptomatology and caregiver characteristics) were not available and thus were not considered in relation to the level of burden caregivers experienced. Exploring the range of literature on caregiving burden, we understand its multifaceted nature and the various factors that play a role in shaping caregivers' experiences. Therefore, it is essential for future research to adopt methodologies that holistically capture the complexities of caregiving burden.

What are the key differences we need to consider?

Despite the inconclusive findings surrounding the impact of Dementia subtypes on caregiving burden, the research sheds light on a variety of contributing factors that may be more prevalent in some subtypes compared to others.

Dementia with Lewy Bodies

Caregivers of individuals with Dementia with Lewy Bodies (DLB) may experience a greater level of burden compared to those caring for individuals with Alzheimer's Disease (AD), primarily due to the prevalence of more neuropsychiatric symptoms, including hallucinations and changes in nighttime behaviour, which are core characteristic features of DLB (Armstrong et al., 2024). Additionally, DLB patients typically exhibit significant deficits in attentive and executive function, leading to increased caregiver distress when compared to AD patients at a similar phase of cognitive decline (Svendsboe et al., 2016). The heightened burden on DLB caregivers may be further exacerbated by challenges in accessing specialised resources and tailored support services specific to the needs of DLB patients, contributing to the overall increased caregiver burden.

Alzheimer's Disease (AD):

Although Alzheimer's Disease is more widespread, the burden experienced by caregivers of individuals with AD can be influenced by various factors. Firstly, the patient's behavioural symptoms, such as agitation or aggression, can significantly impact the caregiver's experience, potentially leading to increased stress and emotional strain (Isik et al., 2019; Kumar et al., 2023) . Additionally, the level of functional dependence of the AD patient, including their ability to perform daily activities and their need for assistance, can directly affect the caregiver's workload and overall burden. Furthermore, the psychological well-being of the caregiver themselves plays a crucial role in shaping their experience, as feelings of anxiety, depression, or burnout can further intensify the challenges of caregiving for individuals with AD (Bozgeyik et al., 2019; Cheng, 2017). It is important to note that due to the prevalence and awareness of AD, there are generally more resources available for patients and caregivers to navigate the complexities of their caregiving role, providing additional support and guidance in managing the challenges associated with the disease.

Frontotemporal Dementia (FTD):

Caregivers of individuals with Frontotemporal Dementia often faced heightened burden due to the significant challenges they encountered in accessing adequate support within the healthcare system (Tookey et al., 2021). The relatively less common nature of FTD compared to other forms of Dementia resulted in a scarcity of specialised resources and tailored support services, leaving caregivers with limited access to essential information, guidance, and assistance. This lack of readily available support within the healthcare system led to feelings of isolation and being overwhelmed for FTD caregivers (Livingston, 2020), as they strived to navigate the complex and demanding responsibilities associated with caring for a loved one with this particular subtype of Dementia. The absence of sufficient resources and support can exacerbate the already challenging caregiving experience, underscoring the need for greater awareness and targeted assistance for caregivers of individuals with FTD.

Despite the multitude of complex symptomatology exhibited by patients suffering from Dementia making it challenging for caregivers to adapt to ongoing care demands, this challenge seems to be exacerbated by the lack of support available. Liu et al., (2018) suggested that the lower prevalence of certain types of Dementia, such as Frontotemporal Dementia and Dementia with Lewy Bodies, can significantly impact the availability of resources and support for caregivers, consequently leading to higher caregiver burden. With fewer individuals affected by these less common subtypes, there is often a lack of specialised resources and tailored support services within the healthcare system, leaving caregivers with limited access to essential information, guidance, and assistance which may help to buffer the negative outcomes associated with high caregiver burden (Cheng et al., 2017). This scarcity of resources can exacerbate the challenges faced by caregivers, contributing to heightened burden and feelings of isolation (Lindt, Berkel and Mulder, 2020). This relationship may provide us insight into the burden CTE caregivers experience. Specifically, in comparison to Dementia and its subtypes, less is known about CTE, consequently the prevalence of information is relatively scarce. The inadequate comprehension of CTE and its distinctive caregiving requirements may add to the strain on caregivers, who may encounter challenges in seeking suitable assistance and advice to address the symptoms and difficulties associated with this comparatively less recognised form of Dementia.

1.4. A new population caregiving for suspected Chronic Traumatic Encephalopathy patients

Despite exploring the experiences of caregivers for individuals with TBI, Dementia and Dementia subtypes, we need to consider a further population that may be affected. Chronic Traumatic Encephalopathy (CTE) is a progressive neurodegenerative disease that has received considerable media attention due to recent reports of its diagnosis in former high-profile athletes (Ott et al., 2020). First described as 'Dementia Pugilistica' (Castellani and Perri, 2017) in boxers, CTE is now used more widely to describe a neurodegenerative disorder associated with the outcome of repetitive head trauma in a variety of contact sports, as well as TBI sustained in military veterans (DeKosky et al., 2013; Goldstein et al., 2012; McKee et al., 2013). Considering the extensive number of individuals participating in contact sports, active in the military or may be exposed to chronic head injury, CTE emerges as a potential public health concern.

The pathology of CTE is unique, characterised by a pathognomonic lesion consisting of a perivascular accumulation of neuronal phosphorylated tau (p-tau) variably alongside astrocytic aggregates at the depths of the cortical sulci, and a distinctive molecular structural configuration of p-tau fibrils that is unlike the changes observed with ageing, Alzheimer's disease, or any other tauopathy (McKee et al., 2023; McKee, Cantu & Nowinski et al., 2009; Gavett, Stern and Mckee et al, 2010). Although CTE is caused by repetitive head injury (RHI), it is not to be confused with concussion. Concussion is the 'manifestation of a temporary state of axonal and neuronal deterioration*'* (Richey and Rao et al., 2020). Thereafter, temporary axonal and neuronal deterioration invokes a neuroinflammatory response, resulting in symptom onset which typically resolves within 7 to 10 days. CTE is a neurodegenerative disease occurring years or even decades after exposure to recovery from acute and subacute symptoms of head trauma RHI and does not require a concussion history in its diagnostic criteria (Martinez-Perez et al., 2017; Katz et al., 2021). Rather, CTE is caused by repetitive head impacts that can be concussive or sub-concussive in nature (Nowinski et al., 2022). Therefore, CTE can only be diagnosed post-mortem upon autopsy because researchers are still working to find a biomarker more sensitive and specific in detecting CTE neuropathologic change (CTE-NC; Alosco et al., 2021).

Whilst clinical presentation of CTE can vary from one individual to another (Walton & Kerr et al., 2022), it is important to consider common clinical symptoms that are associated with the condition. Unlike injuries such as post-concussion syndrome where symptoms tend to resolve within the first three months (Saulle & Greenwald, 2012), CTE symptoms are degenerative in nature, thus progressing over time. The clinical features associated with CTE pathology include cognitive, mood, behaviour, and motor impairments, with Dementia common in severe disease (Stern et al., 2013; McKee, 2023). Younger individuals tend to present with mood and behaviour symptoms, whereas older individuals more commonly present with cognitive impairment and executive dysfunction (Montejo and Montenegro et al., 2014; Stern et al., 2013). The mood and behavioural symptoms can be difficult to distinguish from depression, anxiety, mental health disorders, and post-concussion syndrome, and the cognitive decline bears similarities to that of other Dementia's.

According to McKee (2013) the p-tau pathology follows an ordered, hierarchical progression of severity, prompting the authors to formulate a staging scheme. Consequently, CTE symptoms have been classified into four stages. These stages help researchers and clinicians to categorise and describe the varying degrees of severity in CTE symptomatology and correlate them with the underlying brain pathology. In the initial stages, individuals suffering with suspected CTE may exhibit nonspecific symptoms, such as headaches, difficulty concentrating, and mild mood changes (LoBou et al., 2020; Walton et al., 2022). As CTE progresses to the second stage, cognitive and behavioural symptoms become more prominent. This may include noticeable memory problems, mood swings, impulsivity, and aggression. The individual's cognitive and emotional difficulties become more pronounced and disruptive (Barr, 2020; Iverson et al., 2019; McKee et al., 2009; McKee et al., 2013). In the advanced stages (stage 3), individuals experience more severe cognitive deficits, such as profound memory impairment and executive dysfunction. Emotional and behavioural symptoms intensify, and they may struggle with relationships and daily functioning. Other symptoms that have been documented include; aggression, irritability, apathy and anger (Stern et al., 2011). In the final stages of CTE patients will experience profound and debilitating symptoms. Specifically, motor dysfunction and substantial decline to their overall quality of life is common. However such challenges are not only experienced by the individual affected with the disease, but also by the family members who may adopt a caregiving role. Prior to developing an understanding on how family members can be impacted by CTE, it is important to discuss what factors may heighten the risk of an individual developing the condition.

CTE risk factors

Substantial research evidence continues to show that repetitive head trauma is the primary risk factor for developing CTE. Athletes participating in high-impact sports such as American football, boxing and rugby are particularly susceptible (McKee et al., 2013). Although it is evident there is a direct correlation between the number of head impacts sustained and the likelihood of developing

CTE, a player's position may also increase or decrease the likelihood of developing CTE. In an observational study by Crisco et al., (2011), a total of 314 players from three National Collegiate Athletic Association (NCAA) football programs (Brown University, Dartmouth College, and Virginia Tech) across 2007, 2008 and 2009 fall football seasons participated to quantify exposures to impacts to the head (frequency, location and magnitude). Analysis observed that impact severity was associated with a player' position on the team. Running backs (RB) and quarterbacks (QB) received the greatest magnitude head impacts, while defensive line (DL), offensive line (OL) and linebackers (LB) received the most frequent head impacts (more than twice as many than any other position) Similarly, McKee et al., (2009) in a histopathological study, found that the five football players diagnosed with CTE, all played similar positions (3 were offensive linemen, one was a defensive lineman, and the other was a linebacker). McKee detailed that these positions weren't of players who took infrequent large impacts, but instead, positions more prone to less severe but more frequent impacts. This relationship between play and likelihood of CTE is also mimicked in the boxing environment. Based on the aforementioned results by McKee and Crisco et al, it is suggested that boxers in lowest weight classes experience less severe but more frequent impacts and therefore are likely to be at an increased risk for developing neurological symptoms compatible with CTE long-term. Despite it being reasonable to conclude that repetitive head trauma is necessary for developing CTE, not all athletes experiencing head trauma develop the disease. Thus, it is important to investigate other factors that may heighten the risk for developing CTE. Alongside exposure related risk factors, recent research has explored the potential role of genetics in predisposing certain individuals to CTE. The apolipoprotein (APOE) ε4 allele has been extensively studied in relation to various neurological conditions, including Alzheimer's disease and CTE. A particular allele of this gene, known as APOE ε4, has been associated with an increased risk of developing CTE and a more severe presentation of the disease. In fact, in a series of clinical studies conducted by Stern et al., (2011) and McKee et al., (2009) using brains with neuropathologically confirmed CTE at the Boston University Center for the Study of Traumatic Encephalopathy brain bank found that there was an overrepresentation of ε4 carriers in a cohort of neuropathologically confirmed CTE relative to population norms. Nonetheless, in a study with a larger sample size (N=103), the observed effect did not attain statistical significance (McKee & Stern et al., 2013). While this lack of significance could potentially be attributed to the notable variability within the sample, hindering the detection of significant effects, it remains crucial to acknowledge that not all individuals carrying the APOE ε4 variant are predisposed to developing CTE, and conversely, not all cases of CTE involve this genetic variant.

Research has suggested that the age at which an individual is first exposed to head trauma may influence their risk of developing CTE. According to Saulle and Greenwald (2012), at younger ages, whilst the brain is still developing, traumatic injury may set in motion cascades of events that may result in symptoms of CTE earlier, as well as giving an individual longer exposure time as they start their years of continuous play. However, Gavett et al., (2011) and Blaylock and Maroon (2012) point to the fact that the brain has more plasticity at younger ages. This means that younger individuals have a greater ability to manage injury than a mature brain, thus may protect young people from experiencing CTE symptomatology early on in life. A risk factor that goes hand in hand with age, is length of play. It has been documented that individuals with longer careers, with prolonged exposures to brain injury are likely to have more severe CTE (Maroon, 2015). In a review by McKee et al., (2009) where 51 cases were examined, 39 boxers had an average career of 14.4 years, and the five football players averaged careers of 18.4 years. These athletes began their sporting careers between the ages of 11 and 19 years old, thus having an increased exposure to the damaging effects of contact sports. Consequently there are a range of factors that potentially increase the risk of an individual developing suspected CTE symptoms. However, the issue of CTE is not only experienced by the individual affected with the disease, but also for family members who may adopt the primary caregiving role.

The unique burden of caring for CTE patients

In contrast to diseases like Dementia where symptoms typically manifest in older age groups (60 years old +; Subramaniam et al., 2015) CTE can be seen in younger ages. Remarkably, the youngest documented case of diagnosed CTE was merely 17 years old (Concussion Legacy Foundation, 2008). Distinguishing itself from other neurodegenerative diseases, CTE presents a unique challenge as it can only be definitively diagnosed post-mortem. Despite the availability of imaging techniques like MRI that reveal brain changes associated with CTE, their current precision falls short for diagnostic purposes (Shetty, 2016). Furthermore, CTE symptoms, such as memory loss or mood changes, overlap with other conditions, complicating diagnosis based solely on symptoms. While the distinctions between CTE and other diseases or syndromes have become apparent for the affected individuals, there remains a notable gap in understanding how these unique factors impact the primary caregiver.

Whilst research in other neurodegenerative diseases has extensively elucidated the impact of the caregiving role on individuals’ mental and physical well-being, it is crucial to examine whether the distinct features associated with CTE, may yield different outcomes for caregivers. Drawing insights from Dementia studies, the understanding of the influence of age on caregiving burden is not conclusive. Pinquart and Sorensen (2006) suggest older caregivers generally exhibit improved knowledge and coping abilities, resulting in less burden. However, CTE, marked by symptoms emerging at younger ages, implies that primary caregivers are also likely to be younger. Consequently, the caregiving trajectory for CTE caregivers tends to be longer, exposing individuals to increased burden. Younger caregivers, as highlighted by Bressen et al. (2020) and Greenwood and Smith (2016), may find themselves at pivotal stages, initiating careers, establishing financial stability, or starting their own families. Juggling caregiving responsibilities alongside these life transitions adds an extra layer of responsibility and stress. However, while older caregivers may bring additional life experience (Seidel & Thyrian, 2019), they may have poor physical health themselves, posing challenges in supporting their loved ones (Lima et al., 2008). Consequently, greater comprehension is needed to understand the impact of age, particularly for CTE caregivers. Examining the impact of CTE on family dynamics, the varied support needs of different age groups, and the overall quality of life for caregivers will help tailor interventions that address the unique circumstances of each demographic. It’s vital to adopt a comprehensive approach, taking into account a range of factors, to enhance the generalisability of the research and inform targeted strategies for supporting caregivers across various life stages affected by CTE.

Another factor contributing to the challenges faced by CTE caregivers is the absence of clear diagnostic criteria. Unlike Dementia, where diagnosis aids in identifying and managing specific symptoms, providing effective treatment and guiding the caregiving process, CTE sufferers can only be diagnosed with ‘suspected CTE’, which can only be confirmed through autopsy. The lack of diagnostic criteria during life may induce anxiety, stress and frustration for caregivers as patients are often left with misdiagnoses (i.e. addiction and alcoholism). The ability for doctors to only provide a ‘suspected’ diagnosis, provides difficulties when administering treatments, which hinders patients from getting symptom relief (Etters et al., 2008). In addition to the lack of diagnostic tools available for CTE, the invisible nature of neurodegenerative diseases creates a greater challenge for patients and caregivers as they attempt to seek support, particularly from healthcare professionals. The term ‘invisible’ has been used to refer to chronic conditions or diseases where the symptoms associated with the condition may not be externally manifested and therefore may be less visible and harder for others to detect (Donoghue & Siegel, 2000; Joachim & Acorn, 2000; Stone, 2005). Given that CTE has been documented in individuals known for their athleticism (i.e. NFL players), the lack of externally facing symptoms of CTE further complicates the caregiver's role as they try to convince others about the struggles their loved ones are facing, amplifying the difficulties in providing care and adapting to the changes associated with the disease. The combination of the invisible nature of CTE and more importantly, the limited diagnostic tools likely presents additional hurdles to the caregiver experience.

Current research/knowledge (on caring for CTE patients)

Despite the distinctiveness of the aforementioned challenges, only a limited number of studies have investigated the impact of CTE on caregivers. Faure and Casnova (2019) conducted interviews with wives of current and former NFL players, revealing their narratives as their loved ones underwent progressive cognitive, emotional and behavioural decline. The interviews provided insight into the irrevocably altered lives of the players, but also how this significantly impacted the wives' lives too. Despite only three of the women interviewed having been married to former players who were diagnosed with CTE after death, all participants describe the huge emotional toll this role had on them. Cognisant of the stories surrounding some concussion prognosis, they lived anxiously waiting for their husbands to demonstrate behavioural changes, lose their identities or exhibit violence. In particular, many wives had a fear for the future as they were unsure if and how their partners were going to succumb to the symptoms of suspected CTE. With the lack of information and resources surrounding CTE and the caregiving role, many wives found it difficult to deal with addictive behaviours such as alcoholism that their partners were expressing. In fact, many of the wives described having this sense of ‘unresolved guilt’ due to the lack of understanding at the time they were caregiving. Evidently, the combination of neurodegenerative decline and a lack of information/available resources is a contributor to the level of burden a caregiver experiences. However, as some participants are current caregivers, we cannot strictly say whether these outcomes were specific to CTE caregivers, until the post-mortem diagnosis is made. Thus it is important we consider further qualitative work that may gain us greater insight into this specific population.

In a further study that contributes to our understanding of caregiving for CTE patients, Smith & Young et al., (2021) undertook interviews with family members of deceased athletes who experienced a deterioration in their neurological health towards the end of their life, and were all diagnosed with CTE postmortem. The study aimed to explore the stressors experienced by these family members, their emotional responses, and any coping strategies adopted. Results were presented as an ethnodrama, to highlight how a decline in cognitive functioning caused athletes to display erratic behaviour, such as increasing aggressive behaviour, inability to follow instructions and adopting strange spending habits (resulting in financial strain). The unknown cause of these exhibited behaviours was highlighted as a potential contributor to the participants' emotional states. These findings support the findings by Faure and Casnova (2019) but illuminate the key emotional consequences including the confusion of not understanding what was happening, a sense of frustration and hopelessness and having uncertainty about how to support their family members. Other emotional responses included embarrassment and shame, fear for their own safety and guilt due to feeling they failed in effectively helping and supporting their family members during their decline. Clearly neurodegenerative diseases have far reaching effects on sufferers and those around them. As a result, greater recognition of the challenges faced by both those living with diseases of the brain, such as CTE, and their carers, is needed (Krutter et al., 2020).

In response to the scarcity of CTE-specific information and resources available for patients and caregivers, Miller-Ott et al. (2020) conducted a self-report study to investigate the impact on CTE caregivers. Specifically, the study focused on understanding the unmet emotional and educational needs of wives of former football players diagnosed with CTE. 64 females who were married to former college, semi professional, or professional football players, were asked to fill out an online questionnaire. Survey items were selected or adapted from studies on traumatic brain injury, dementia and the unmet support needs of caregivers. Following a thorough literature review (Bangerter et al., 2019; Degeneffe et al., 2011; Love & Solomon, 2015; Novais et al., 2017; Peterson et al., 2016) survey questions aimed to gather information on caregivers' educational and emotional support requirements, wives' CTE-related knowledge, and preferences for receiving health-related information. The results revealed that the sources considered highly credible by wives included the Facebook page for NFL wives and CTE-related accounts on social media. Notably, many wives expressed dissatisfaction with various sources, indicating persistent gaps in available information. The most significant discontent was reported for league-sponsored websites and physicians/healthcare providers, underscoring the importance of reputable sources for caregivers in their supportive roles (Cohen et al., 2017). While the study demonstrates the essential need for informative resources for CTE caregivers, the quantitative methodology limits the ability to discern specific types of support sought by these caregivers. Additionally, the sample was limited to just football players. Future work should focus on utilising a heterogeneous sample, including patients from various backgrounds (i.e. veterans) and family members with varying relationships to the care-recipient. Adopting this broader approach will support a better understanding of the types of resources that CTE family members, in general, would find most useful in supporting their experiences.

As summarised, there are a range of factors associated with CTE that may impact the level of burden a primary caregiver may experience. Although the research focused on Dementia, Alzheimers and TBI caregivers may provide some insight into the CTE caregiving role, the unique factors associated with CTE impacts our ability to generalise the finding to this emerging condition. As we have detailed, CTE is a unique disease, with symptoms widely varying depending on the individual, the age range of people who are affected by it, and the severity of the brain injury. Subsequently, the caregiving experience is likely to be subjective too, as family members will have to acquire different caregiving techniques to support the unpredictable behaviours of the patient. Adopting the primary caregiving role for an under-researched disease that has a fast progression with no cure or medication to minimise the symptoms is likely to heighten caregiver stress and burden. This means both the sufferer and caregiver are likely to experience some adverse outcomes to their physical and mental wellbeing. However, this is currently all speculation, thus it is vital we examine this population to understand the experiences they go through from their perspectives. Consequently, the studies conducted as part of this doctoral research endeavour to enhance the understanding of the caregiver experience in CTE. The primary aim is to investigate whether caregiving in CTE differs from other caregiving contexts. Furthermore, the studies seek to investigate the influence of age and the type of relationship with the care recipient on the level of burden experienced by CTE caregivers. Understanding how these demographic and relational factors shape the caregiving experience is crucial for tailoring support interventions effectively. Lastly, the research aims to contribute to the well-being of CTE caregivers by developing and evaluating a supportive resource. This resource will be designed to address the specific needs identified through the investigation, fostering a more informed and resilient caregiving community for those grappling with the complexities of CTE. Through these multifaceted aims, this research aspires to enhance our understanding of CTE caregiving, inform targeted support strategies, and ultimately contribute to the well-being of caregivers in this challenging context.

Summary

Overall, this review of literature has provided insight into the experiences of caregivers and the impact of caregiving burden. Caregiving burden is a well-documented phenomenon encompassing the physical, emotional, and financial strain experienced by those caring for individuals with neurodegenerative diseases and syndromes. With the multitude of tasks and responsibilities that come with the caregiving role, the impact of this burden on caregivers is profound. All caregivers, at one point in their caregiving journeys will experience heightened stress, depression, and diminished overall well-being. Although there is a likelihood caregivers are able to experience positive outcomes from their caregiving role, including increased confidence and self-efficacy (Cheng 2019, Yang et al., 2019), the majority of caregivers will struggle to seek these positives and instead, endure high rates of burden throughout their caregiving journeys. The likelihood of caregivers experiencing either positive or negative outcomes to their role is dependent on a myriad of factors, from age, relationship to the care-recipient, personality and coping strategies they choose to adopt. The literature supports the importance of considering these factors when assessing the level of burden a caregiver experiences in their role, and consequently they should be noted when interventions are being derived to support these individuals.

Importantly, the extent of caregiver burden also varies depending on the specific disease being managed, particularly evident in the context of Dementia. The lower prevalence of certain Dementia subtypes, such as Frontotemporal Dementia and Dementia with Lewy Bodies, can exacerbate caregiver burden due to the scarcity of resources and support services tailored to these less common subtypes. This scarcity not only heightens the challenges faced by caregivers in adapting to ongoing care demands but also contributes to feelings of isolation and inadequacy in addressing the needs of their loved ones. Importantly, the comparison drawn between Dementia caregiving and the emerging knowledge of CTE sheds light on the potential parallels in caregiver burden. With relatively limited understanding and resources available for CTE compared to well-established forms of Dementia, caregivers may encounter similar difficulties in accessing appropriate support and guidance, thereby amplifying the strain associated with caregiving for this lesser-known condition.

Knowing the impact of caregiving burden and recognising the increasing prevalence of CTE, it is critical to investigate the experiences of CTE caregivers. With the prevalence of CTE on the rise, particularly in the context of sports-related injuries and military service, there is an urgent need to comprehend the unique challenges faced by caregivers in this population. My research aims to fill this gap by exploring the experiences of CTE caregivers, uncovering any distinctive challenges they face and how caregiving burden impacts them. This understanding will facilitate comparisons between the caregiving experiences associated with CTE and the well-documented experiences of dementia caregiving. Overall, these insights will inform the development of targeted interventions aimed at providing tailored support and assistance to caregivers navigating the complexities of caring for individuals with CTE.

CHAPTER 5
Methodology

The purpose of this thesis is to understand the experiences of Chronic Traumatic Encephalopathy (CTE) caregivers. This chapter provides an overview of the methodology throughout the thesis, which utilised a qualitative approach to guide the research process and outcome. In this chapter, I outline the reasons for electing to use a qualitative research approach and its congruence with my ontological and epistemological beliefs. Finally, I discuss the range of ethical considerations relevant to the study aims and participants, alongside the techniques used to enhance methodological rigour. My aim for this chapter is to provide a more comprehensive overview of the research design and methods to allow the reader to assess the appropriateness of the methods selected, the decisions behind the approaches I take, and the processes undertaken to enhance the quality and rigour of these processes (Patton, 2002).

5.1 Underpinning research philosophy

To allow for an in-depth exploration of the caregivers' experiences, a phenomenological approach was used (Thomas & Pollio, 2002). Here, Hein & Austin (2001) state that phenomenology is rooted in the notion that all of our knowledge and understanding of the world comes from our experiences. The focus is not on the events themselves but rather on the ways in which we experience things and the meanings these experiences create for us. In essence, there is no objective reality, but rather it is our experiences and perceptions of these experiences (i.e. our lived experiences) that are our reality. **The phenomenological approach allows for an in-depth examination of how caregivers experience unpredictable challenges (i.e., managing symptoms such as memory loss, confusion, personality changes, aggression) on a daily basis, as well as how they make sense of their roles and responsibilities. The emphasis on lived experience is crucial here because the realities of CTE caregiving cannot be fully captured through objective measures or quantitative data alone. Instead, understanding these realities requires attention to the subjective experiences of caregivers, how they perceive the changes in their loved ones, how they cope with the emotional toll, and how they find (or struggle to find) meaning in their caregiving journey. Phenomenology allows for these differences to be explored, providing a richer and more nuanced understanding of what it means to care for someone with CTE. Recent studies on caregiving, such as Mayo et al., (2020) which investigated the experiences of Dementia caregivers and Assfaw et al. (2024), which focused on Dementia caregiving burden, also utilised the phenomenological approach. This further underscores the relevance of this**

methodology in examining the complex and emotional nature of caregiving across various conditions, including CTE. By using this approach, the current study adds to a growing body of research that seeks to capture the richness of caregivers' lived experiences.

Following data collection, I undertook thematic analysis and presented the main emerging themes in my findings. In conducting this research and presenting my findings in this manner, my particular interest was to understand the experiences of CTE caregivers and acknowledge the burden they face whilst they care for their loved one with declining health and ultimately, the death of a family member. This programme of research was also underpinned by interpretivism; ontological relativism and epistemological constructionism, allowing participants to share their individually constructed reality of caregiving for a loved one with post-mortem diagnosed CTE. I also acknowledge the active role I play in the co-construction of knowledge of a phenomenon that cannot be directly observed, through the analysis and presentation of data, as well as the steps taken to enhance methodological rigour.

Qualitative methods were used throughout the thesis, as this methodological approach is best suited to understanding the experiences of CTE caregivers, particularly when my philosophy is underpinned by ontological relativism and epistemological constructionism. These philosophical perspectives emphasise the subjective and socially constructed nature of reality, recognising that individuals interpret and construct their understanding of the world based on their own contexts and perspectives. In the context of studying caregivers of individuals with CTE, qualitative methods allowed me to better understand the nuanced and multifaceted aspects of caregiving experiences, acknowledging the diverse interpretations and meanings caregivers attribute to their roles. By engaging in in-depth interviews, I was able to uncover the complex emotions, challenges, and coping mechanisms experienced by caregivers, capturing the intricacies of their lived experiences. Through this approach, I gained a holistic understanding of the caregiving phenomenon, taking into account the unique perspectives and contexts of each participant, ultimately contributing to a richer and more comprehensive knowledge base regarding the experiences of CTE caregivers.

5.2 Development of my positionality

Besides the research question being one of the primary influences on the choice of methodological approach, as the researcher, I also had to consider my own philosophical beliefs and positionality. I acknowledged the interpretivist nature of my research and reflected on my own positionality, recognising the ways it might have influenced the research process. As a researcher, my positionality was shaped by my personal background, experiences, values, and beliefs. For example, my cultural background, educational experiences, and prior knowledge of the subject matter could all have influenced the questions I asked during interviews, the way I analysed the data, and the conclusions I drew. Additionally, my own biases and assumptions may have inadvertently impacted the research process, potentially leading to the privileging of certain perspectives over others (Savolainen et al., 2023). Therefore, it was essential for me to remain reflexive throughout the research journey, continuously examining and acknowledging my own positionality, and striving to mitigate any potential biases through transparency, reflexivity, and rigorous methodological practices. This practice ensured an authentic representation of both the data and research process. Consequently, it was crucial that I reflected on my position, considering both present and historical context, to contextualise this thesis. To do this, I kept a reflexive diary throughout my PhD, to prompt reflective thinking throughout the research process, and I included extracts from this diary in the current chapter to illustrate this.

Reflexivity was defined as “a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes” (Olmos-Vega et al., 2023, pg. 242). Davis (2020) suggested that interpretation and reflection were the two key elements embedded within reflexive research. The interpretive element recognised that interpretation was not merely based on a simple analysis of the data, which reflected ‘reality’; instead, there was an awareness that interpretation was influenced by the assumptions of the researcher undertaking the research, along with their values and beliefs (Hibbert et al., 2020). I adopted the use of a reflexive journal to critically reflect on my role as a researcher and on the research process, making myself self-aware of how my beliefs and values may have impacted my perception of the data.

The first crucial step in my personal reflexivity involved reflecting on how my previous experiences may impact the research process and how the research process may affect myself, as the primary researcher.

> *“Prior to the PhD research, I had immersed myself, and undertaken studies around sensitive topics (i.e. mental health and body image), thus I felt equipped to deal with potentially vulnerable groups. This previous experience allowed me to have knowledge on how to speak with individuals around sensitive topics, know how to respond if they showed emotional distress and also how to seek support if I experienced any distress as part of the data collection and analysis. Although I had been a part of similar research (looking at the*

> *experiences of wives of those with brain injuries) I was not a part of that data collection process, therefore I had not had a plethora of experience speaking to this particular sample".*
>
> (Extract taken from personal reflection 1st February 2022*)

The key part of this reflection was acknowledging my previous experience/background within this field to consider how it may have impacted the research process. In particular, having a history of conducting research with sensitive groups gave me confidence in navigating conversations around sensitive topics and knowing how to effectively manage emotional responses if participants showed signs of distress during data collection. However, I recognised that despite my background in conducting research with sensitive groups, I hadn't had experience interviewing this particular population of caregivers, who likely had unique experiences. Therefore, it was essential for me to carefully consider how to approach these conversations effectively, ensuring sensitivity, empathy, and understanding in my interactions with participants.

Alongside reflecting on my previous experiences from a research standpoint, personal reflexivity also involved consideration of how my own characteristics can impact the research process. With this in mind, I made a conscious effort to reflect on these factors prior to data collection.

> *"As a 22 year old female researcher [at the start of the PhD] with no personal experience of being a caregiver, no children and no familial history of brain injury, I found myself in a unique position whilst delving into learning more about the experiences of CTE caregivers. Acknowledging my own characteristics and life experiences I am mindful of the potential impact they may have on my understanding and interpretation of the caregivers narratives. Whilst lacking personal exposure to the challenges faced by CTE caregivers, I approach this research with a genuine curiosity and commitment to understanding their challenges. My lack of experience in a caregiving role, allows for an objective exploration, but I recognise the importance of remaining open-minded, empathetic and reflexive throughout the research process"*
>
> (Extract taken from personal reflection 10th February 2022*)

This reflection highlighted some of the advantages and disadvantages of my own positionality in the research process in the early stages of data collection. While my lack of personal experience as a caregiver and absence of familial history of brain injury could have provided a fresh and objective perspective, it also highlighted the possible constraints in fully understanding the intricate challenges encountered by CTE caregivers. Overlooking these distinctions hindered my capacity to pose relevant follow-up inquiries during the initial interviews.

Alongside my personal experiences, it was important to consider the researcher-participant relationship. *Interpersonal reflexivity*, refers to how the relationships within the research process influence the context, the people involved, and the results (Walsh, 2003). In particular, the interaction between myself and the participants needed some thought. It is important that I reflected on the participants' unique knowledge and perspectives, and how that impacted the research process (i.e how they interpret interview questions). Acknowledging the researcher-participant relationship, included reflecting on pre-existing relationships with the participants (if they exist), how this may impact the people involved, and finally if there are power dynamics to be considered. Prior to first data collection for study one, I had developed relationships with the participants, which I reflected on;

> *"When I first met some of the participants at the Concussion Legacy Foundation huddle in Las Vegas (Feb 2022), I engaged in conversations with many caregivers about my research and collected contact details from those interested in participating once I returned to the UK. Despite not having any prior involvement with the CLF or interactions with these individuals, the sensitive conversations during the huddle fostered a strong participant-researcher relationship. It's noteworthy that some participants for the research were recruited through the CLF database, and I had no personal interactions with them before the research. Consequently, I had to carefully consider and document how these differing interactions might impact my data collection process. For those participants with whom I had a pre-existing relationship due to the CLF huddle, it became crucial to navigate the potential influence of our previous interactions on the interviews. While the established rapport encouraged open communication, I had to be vigilant about mediating any preconceived thoughts based on our prior conversations. This was essential to prevent these thoughts from inadvertently limiting the scope of my interview questions. Conversely, with participants I had not interacted with before the research, I reminded myself of the importance of spending time at the beginning of the interview introducing myself and establishing rapport. This was a deliberate effort to equalise all participant-researcher dynamics and ensure a fair and unbiased data collection process"*
> (Personal reflection on 1st April 2022*)

It was important for me to acknowledge the benefits and limitations of having a pre-established participant-researcher relationship with some caregivers prior to the initial data collection for study one. As the research topic was particularly sensitive, and caregivers would be sharing their vulnerable stories, it was imperative for me to develop a strong sense of trust between myself and the caregivers. I acknowledged that I did not have the opportunity to do this with all of the participants within the same setting (i.e., the CLF huddle), thus I ensured to commence the start of the interview with the purpose of gaining that rapport. Although I believed the pre-existing conversations did not impact my perceptions of their experiences, instead they were beneficial in supporting flow within the interview, I could not fully eliminate the possibility of any unintended biases or assumptions influencing the data collection process. Therefore, I remained diligent in maintaining a neutral stance and approaching each interaction with an open mind.

Contextual Reflexivity is the last type of reflexivity I considered. It demonstrates how the research questions and answers are embedded in and influenced by a social field of assumptions and practices (Naidu and Sliep, 2011). According to Walsh (2003) and Bishop et al., (2002), the goal of ethical research is to have a positive impact on the contexts in which it is conducted; fresh perspectives can be gained from observing how participants' reflections or participation in the study influence their practices and context. Being contextually reflexive required me to consider the setting of the study. If the interviews were held face-to-face, this environment would be more prominent to consider and reflect on; for example, if I were to have interviewed a caregiver in the caregiving facility their loved one was in, I would have had to consider how this environment may impact the data collection (i.e. high distraction, more emotional). However, as the participants were all based in the US, and I was in the UK, all interviews were held over Zoom (an online meeting platform). Although this wasn’t optional due to location demands, allowing the participants to partake in the interview in an environment most suited and comfortable to them, eradicated aforementioned contextual demands that are likely to impact during the data collection process. In addition, I reflected on how my research may have impacted the caregivers within their environments;

> *“I held informal conversations with fellow colleagues/supervisory team members about how my research questions may impact the caregivers (i.e. asking them about their hardest caregiving challenges, whilst they are partaking in the interview in the place where they cared/potentially lost their loved ones). In turn, we discussed ways to support caregivers during data collection if their environment was acting as an emotional cue (i.e. take your time, would you like to take a break?”). Noticing how my position may impact the*

> *participants within their environments, enhanced my interviewing capabilities and flexibility throughout data collection"*
>
> (Personal reflection on 10th April 2022*)

Here, I reflected on the advantages and disadvantages of conducting interviews over Zoom, whereby caregivers were in their own environments. The familiarity and comfort of their surroundings may have encouraged participants to share more openly and authentically, leading to richer data and insights. However, I acknowledged that conducting interviews in the same environment where caregivers provided care for their loved ones could also be triggering. Thus, it was vital for me to consider both the advantages and disadvantages of the context of the interviews to ensure I created a supportive and respectful environment for participants while maximising the depth of communication and understanding in the research context.

Over the course of the research process, my positionality evolved and changed as I gained more experience communicating with the caregivers and a strong researcher-participant relationship developed. For the initial study, I had minimal interactions with the caregivers, and focused primarily on the data collection at hand. However, as the research progressed and I engaged more deeply with the caregivers, I found that developing relationships with them significantly enhanced the research process. These relationships allowed me to gain deeper insights into their experiences, perspectives, and needs, enriching the quality of the data collected. Moreover, the trust and rapport built with the participants facilitated open and honest communication, enabling them to share their stories more candidly. As a result, the later studies benefited greatly from these strengthened researcher-participant relationships, contributing to a more comprehensive understanding of the caregiving phenomenon surrounding CTE.

After conducting the first study of the PhD my experience within this population had developed immensely which enabled me to commence data collection for Study Two with greater confidence. However the change in the participant demographics and also my personal experience required me to reflect on my positionality prior to interviews.

> *"After spending the last two years researching this population, I have a strong foundation of knowledge and understand the nature of the CTE caregiving role. Now that I am fully immersed in the world of CTE caregivers, I have established strong relationships with the participants, which has enabled deeper conversations and a greater understanding. Specifically, I have spent the last year talking to these individuals everyday, which has*

> *allowed me to understand their experiences and sympathise with what they have/are going through. This means I knew how to effectively navigate discussing sensitive topics. More specifically to the research question, I am closer in age to some of the participants. Not only does this allow me to relate to them more, but has enabled me to develop a greater relationship and understanding of what it would be like to go through their experiences"* (Personal reflection on 18th October 2022*)

Within this reflection, I acknowledged how my position changed throughout the research process. After spending two years researching this population, I had built a strong foundation of knowledge and understanding of the nature of the caregiving role. Being fully immersed in the world of CTE caregivers, I had established strong relationships with the participants, enabling deeper conversations and a greater understanding. As the participants for this study had already been interviewed by me to understand their experiences of caregiving, I had developed an understanding of this context and was more aware of how to effectively navigate conversations around sensitive topics. Specifically, from speaking to these individuals previously, I understood the importance of support to them, which encouraged this current work.

5.3 Enhancing methodological rigour

As highlighted by Braun and Clarke (2006), the credibility and trustworthiness of thematic analysis is grounded in systematic and transparent procedures. In these studies, two primary methods were employed in aiming to enhance methodological rigour: engaging critical friends and maintaining reflexive journals.

5.3.1 Critical friends

During data analysis, recruiting a critical friend contributed to the methodological rigour and credibility of the findings. As suggested by Nowell et al,. (2017), the engagement of a critical friend brought an additional dimension of scrutiny and impartiality to the analysis. Within this context, a critical friend served as "a sounding board, for asking challenging questions and analysing data" (Ragoonaden & Bullock, 2016, p.30). Others exploring the role of a critical friend in research studies defined them as "a trusted person who asks provocative questions, provides data to be examined through another lens, and offers critique of a person's work as a friend. A critical friend takes the time to fully understand the context or the work presented and the outcomes that the person or group is working toward" (Costa and Kallick, 1993, p.50). This process aligned with the principles of transparency and reflexivity advocated by Braun and Clarke (2006), ensuring that the interpretation of themes remained accountable and free from undue biases.

I led the data analysis process and sought input from two critical friends, who encouraged me to further reflect on my analytical decisions. These two critical friends provided different perspectives based on their own backgrounds and experiences. One individual had expertise in qualitative methodology and a background in researching brain injury, offering a nuanced understanding of CTE caregiving experiences and potentially identifying subtle nuances within the data. Conversely, the second critical friend lacked extensive research experience in the field, providing a fresh and unbiased viewpoint. Their impartiality allowed for a more objective examination of the themes and findings, helping to mitigate potential researcher biases. Further details regarding the contributions of the critical friends to the analysis will be provided within the respective methods sections of each study.

5.3.2 Reflexive journal

The second method I employed in striving to enhance methodological rigour involved maintaining a reflexive journal, which served as a tool for acknowledging and evaluating my own biases, assumptions, and evolving perspectives throughout the research process (Olmos-Vega, 2023). In this chapter, I had already used quotes from my reflexive journal to consider how my own positionality may have impacted on the research process. The reflexive journal was also important in verifying the quality and trustworthiness of the research findings, as it allowed for transparent documentation of my thought processes and decision-making throughout the data collection and analysis. For example, reflecting on the pilot interview allowed me to assess my methodology choices and decide on the most effective approach moving forward;

“The depth and uniqueness of the caregivers' stories during these interviews led me to reassess whether grounded theory is the most appropriate method. After consideration, I initially leaned towards a narrative inquiry, drawn by the richness and depth of the experiences shared in the pilot interviews. However, as I delved deeper into the data, the diversity and complexity of the caregivers' experiences became apparent, therefore I decided that opting for a thematic approach will allow me to identify the common patterns amongst the caregivers' stories”.

(Extract taken from personal reflection on 1st April 2022*)

By openly reflecting on how my own positionality evolved and how interactions with caregivers shaped my understanding, I demonstrated a commitment to transparency and reflexivity. This level of introspection not only enhanced the credibility of the research but also fostered greater trust between myself and the reader. Through documenting the development of my positionality, I provided valuable insights into the dynamic nature of my engagement with the research topic, further enriching the depth and authenticity of the findings.

5.4 Methodological choices

As the research on CTE caregiving was relatively limited, it was important that the initial studies focused on understanding the population. Within the first two research studies, the aim was to understand the experiences of CTE caregivers, particularly older spousal caregivers and younger caregivers with varying relationships to the care recipients. Not only did I want to understand the experiences they went through as part of their caregiving role, but also gain clarity on the impact relationship and age had on these experiences and the burden caregivers faced. With these aims in mind, it was imperative to assess a range of qualitative approaches to determine which methodology would be most appropriate for my research question.

With the lack of research examining this population, a grounded theory (GT) approach initially seemed appropriate. Grounded theory focuses on the systematic generation of theory from data (Glaser & Staurss, 1968). This approach is particularly well-suited for examining complex and unresearched phenomena, like the experiences of CTE caregivers. Specifically, GT involves a flexible and iterative process of data collection and analysis, allowing patterns to emerge organically from the data, rather than being predetermined by existing theories. In the context of this study, whereby the CTE caregiver experience is not yet understood, GT provided an opportunity to explore the multi-faceted nature of caregiving without imposing preconceived notions. This approach aligned with the interpretivist paradigm and ontological relativism, emphasising the importance of understanding subjective realities and allowing for a nuanced exploration of the diverse perspectives within the caregiving context. Despite the approach aligning with my own philosophical beliefs, the emphasis of this research was to understand the caregivers' experiences, rather than generating a theory. I reflected on this thought process at the start of data collection.

> *"After conducting my pilot interviews, I find myself reflecting on the chosen methodology and its effectiveness. The depth and uniqueness of the caregivers' stories during these interviews led me to reassess whether grounded theory is the most appropriate method. It*

> *became evident that the caregivers' experiences were so different that attempting to fit them into a generalised model might risk oversimplification. In light of this, I reconsidered my methodology. It seems more suitable to allow the caregivers to share their stories without imposing a rigid theoretical framework. Moving forward, I am eager to pivot towards a more narrative-based approach, to account for the unique experiences these CTE caregivers have. This reflection demonstrates the importance of being methodologically reflective, acknowledging the benefits and limitations of my decisions. This example also demonstrates the need to continuously evaluate the alignment of our paradigm and research questions, when making methodological decisions in data generation and analysis"*
> (Extract taken from personal reflection on 1st April 2022*)

This reflection illustrates the reasoning behind my decision to move away from a grounded theory methodology due to the diverse and intricate nature of the caregivers' narratives. The depth and uniqueness of the caregivers' stories during these interviews led me to reassess whether grounded theory is the most appropriate method. It became apparent that the caregivers' experiences varied significantly, suggesting that trying to categorise them within a standardised model could lead to oversimplification.

Another common methodology often employed in qualitative research is narrative inquiry. Narrative approaches revolve around capturing personal stories and experiences, providing researchers with a means to "experience the experience," as noted by Clandinin & Connelly (2000, p.80). When investigating Dementia and TBI caregivers, this approach has proven valuable in revealing the subjective nature of caregiving roles and showcasing the diverse emotional dimensions involved in caring for individuals with complex conditions (Shim, Barroso, and Davis, 2012; Varley, 2008). Specifically, through narrative analysis, researchers gain an understanding of the broader context by examining how individuals construct and convey their stories. In the context of CTE, narrative approaches could provide a rich understanding of the multifaceted challenges experienced by caregivers. By listening to and analysing the stories that the caregivers share, I was likely to gain perspectives into the emotional, social, and practical elements of their caregiving roles. This methodology had the potential to capture the intricacies of CTE caregiving experiences and better understand the lived realities of these individuals. I reflected on the consideration of adopting this approach.

> *"Upon thoughtful consideration of research methodological approaches, I initially leaned towards a narrative inquiry, drawn by the richness and depth of the experiences shared in*

> *the pilot interviews. However, as I delved deeper into the data, the diversity and complexity of the caregivers' experiences became apparent. This realisation prompted a shift in my choice of methodologies. The sheer variety in these caregivers' experiences, I felt, demanded a more structured and systematic analysis. Consequently, I decided that opting for a thematic approach will allow me to identify the common patterns amongst the caregivers' stories. Conducting the pilot interviews served as a crucial reflective exercise in refining my methodological approach. Specifically, they functioned as a key catalyst in prompting a shift towards a thematic approach, which, upon further consideration, I believe will be the most effective strategy for capturing the diversity within the caregiver narratives"*
> (Extract taken from personal reflection 10th April 2022*)

This reflection illustrated the reasoning behind my decision to undertake a thematic analysis to present the caregivers' experiences. The richness and depth of the pilot interviews initially encouraged me to adopt a narrative approach, however, as I immersed myself in the data, the need for a more structured analysis became apparent. The varied nature of the caregivers' experiences called for a method that could effectively identify common patterns and themes across their stories. The pilot interviews served as a pivotal reflective exercise that guided me towards adopting a thematic approach, which I believed would be the most suitable choice for capturing the diverse range of experiences shared by the caregivers.

5.5. Interviews

In qualitative research, interviews serve as a valuable method for gathering in-depth insights and understanding participants' experiences, perceptions, and emotions. There are several interview formats commonly used, including unstructured, structured, and semi-structured (Alsaawi, 2014). Unstructured interviews are open-ended and free-flowing, with no predetermined set of questions (Chauhan, 2022). Structured interviews involve asking a set of predetermined questions in a standardised order, typically closed-ended with limited room for elaboration (Rogers, 2008). Semi-structured interviews involve a set of core questions or topics that guide the conversation, but the interviewer has the flexibility to explore additional areas based on the participant's responses (Adams, 2015). With the aim of the research being to understand the experiences of CTE caregivers, adopting a semi-structured approach allowed for a more natural and conversational interaction, enabling caregivers to share their unique perspectives and stories in a comfortable and open manner (Chua and Adams, 2014). The semi-structured format encouraged a deeper exploration of the caregivers' experiences, emotions, challenges, and coping strategies, providing valuable insights for understanding and supporting this specific caregiving population effectively. Within the individual methods section of each study, I discuss the interview guides and rationale behind the questions asked.

Interview process

All interviews were audio recorded with the permission of the participants. Written consent for recording was obtained from individual participants before the start of the first interview. Verbal confirmation was sought before initiating the audio recording in subsequent interviews. Given the volume of interviews conducted, recording was deemed necessary to ensure accurate transcription and capture potentially crucial data for the study. Additionally, recording facilitated a more thorough examination of the interview context and communication nuances, including non-verbal cues. It provided an accurate record of the interviews for analysis purposes. As participants' identities were to be anonymised, only voice recording via Zoom was utilised, without capturing participants' faces.

Each interview was transcribed verbatim as soon as possible following the interview to preserve context. While transcription was time-consuming, it served as an initial form of data analysis (Gibbs et al., 2007). Therefore, I opted to transcribe the interviews myself. This approach allowed for reflection on my interviewing style, preliminary open coding of the data, and identification of topics for further exploration in subsequent interviews. Transcripts included non-verbal utterances and extended pauses, as they were deemed important for conveying participants' feelings in specific contexts. Additionally, all transcripts were emailed to participants for review, affording them the opportunity to suggest any revisions or additions. All participants expressed satisfaction with their transcripts.

During interviews, I minimised note-taking to ensure full engagement with the participant. Key points were recorded as keywords to preserve focus on the conversation. However, immediate observations and impressions were documented after each interaction, either in written form or via audio recordings. These notes encompassed impressions of the interview, general observations (e.g., participant demeanour), and reflections on interview dynamics. Early in the research process, I often noted perceptions and ideas for improvement. An example of field notes made during an interview is provided in Appendix 1.

5.6 Ethical considerations

In qualitative studies, ethical considerations have a particular resonance due to the in-depth nature of the study processes. (Arifin, 2018). As this research utilised human subjects, it is imperative that appropriate ethical principles were applied.

Participant well-being.

It was acknowledged that participants might experience emotional distress during the interviews and podcast episodes due to the sensitive nature of discussing their caregiving experiences and the loss of their loved ones. While the podcast episodes were not intended to induce stress, guests' narratives about caring for someone with CTE could evoke emotional responses. The interview questions delving into personal and sensitive aspects of caregiving for individuals with CTE heightened the potential for emotional reactions. To address this, participants were informed of their right to discontinue or withdraw from the research at any stage, up until data analysis. During interviews, participants were reassured that they could decline to answer questions or take a break as needed. There were a few instances during interviews when participants became upset while discussing their experiences. In response, I offered to temporarily pause the recording (though this offer was generally declined) and ensured that my questioning did not exacerbate their distress. Participants were encouraged to discuss their experiences and any emotional impacts resulting from their participation. Following each study, a debriefing session was conducted to inform participants about the research findings and their significant contribution to understanding CTE caregiving. During these sessions, participants were provided with a list of resources, including telephone advice lines and contact information for professional organisations, should they wish to seek support after discussing their caregiving experiences (see within information sheet in Appendix 4).

Researcher well-being

Considering the potential emotional impact on myself as the researcher was essential. I recognised that engaging with participants who shared emotional experiences might evoke a range of emotions for me as well. Specifically, I was aware that discussions about participants' traumatic caregiving experiences and conversations surrounding loss and grief could lead to researcher distress. However, before initiating data collection, I acknowledged the importance of managing these emotions to maintain objectivity and ensure the ethical treatment of participants. To address this, I established a support system that included the ability to communicate with my supervisors and allocated time for personal reflection to navigate any emotional impact from the research responsibly. Although I did not seek these services, I ensured that I could contact Oxford Brookes University counselling services if I needed further professional support.

> *"As I delved into the research process, I recognised the importance of acknowledging the potential emotional toll on myself as the researcher. It was clear to me that engaging with participants sharing their emotional journeys could elicit a range of feelings within me. I was mindful that discussions on traumatic caregiving experiences and themes of loss and grief might elicit an emotional response from me. However, I understood the importance of managing these emotions to maintain objectivity and ensure the ethical treatment of participants. To proactively address this, I put in place a support system that included open communication with my supervisors and dedicated time for personal reflection. Having this support network in place helped me to feel more comfortable heading into the interview process"*
> (Extract taken from personal reflection on 2nd April 2022*)

Recognising the potential emotional impact of the research process was imperative to ensuring that I prioritised my own well-being as the researcher, while also creating an environment where I had the confidence to support the participants if they were feeling distressed or emotional during the data collection. Having a level of self-awareness about how this process may affect me too was key to maintaining objectivity. Through open communication with my supervisors, I felt supported in navigating any emotional challenges that arose. Additionally, dedicating time for personal reflection allowed me to process my feelings and approach participant interactions with empathy and professionalism.

Confidentiality and anonymity

During the recruitment process participants were provided with an information sheet and consent form, alongside a privacy notice prior to data collection. Within this, the participants were provided extensive information regarding the rationales of the research, potential risks and benefits of participating before voluntarily giving their signed consent. Following University guidelines, no participant could provide consent until 48 hours after receiving the PIS/Privacy notice. Participants were unable to partake in the study unless the consent form was completely filled out, signed and returned to the researcher via email. Those who partook in interviews were reminded what the interviews would involve and asked for their verbal consent to record the interview. Participants were explicitly informed of their right to withdraw from the study at any point (up until the write up of results). In study three, as the follow-up interview was optional, it was important that the survey responses of those not wanting to partake, were anonymised. Thus, participants who wished to partake in the interview were asked to email me directly, rather than providing their contact details on the form (to avoid linking identifiers to their responses to the survey).

The link to the importance of security and anonymity is crucial in further establishing trust with the participants. To enhance trust, I implemented measures to safeguard the confidentiality of the participants. Specifically, identifiable information such as names and personal details were anonymised during data analysis and reporting. Participants' transcripts were assigned random numerical identifiers (e.g., 1-12 for study 1 & 2 and 1-18 for study 3) before data analysis, and these identifiers were used in the study write-up. All identifying information was securely stored separately from the research data on a password-protected laptop, accessible only to me as the lead researcher.

As the interviews were conducted via Zoom, it was important to consider how to maintain confidentiality during this process. The interviews were on Zoom from the researchers home in London. The interviewer ensured to use headphones for privacy reasons. An OBU based/managed meeting room was not used instead due to the time difference (all participants are based in the USA). Podcast episodes were all recorded on Zoom from the researcher's home in London. The same protocol as above (use of headphones) will be utilised for privacy reasons.

Data storage and protection

Ensuring the security and protection of participants' data enhances trust by demonstrating a commitment to safeguarding their confidentiality and privacy. All of the data was kept in a digital format. The recordings of this study remained on my laptop in an mp4 format. I used the Zoom transcription service to transcribe the interviews in Word format, which were then converted to a PDF. The online consent forms and my notes were scanned and converted to PDF format. Once converted to digital format, all paper documents were subsequently destroyed. All digital files, both audio and PDF, were saved and kept on a password-protected (secure) laptop with access only by me, the researcher. Overall, these measures convey to participants that their data is being handled with utmost care fostering a sense of confidence and trust in the research process.

5.7. Conclusion

In this chapter, I elucidate the methodological framework employed in this thesis, focusing on the exploration of caregiver experiences in Chronic Traumatic Encephalopathy. Embracing an ontological relativism and epistemological constructionism standpoint, guided my understanding of the subjective experiences of caregivers within the context of CTE. A significant aspect of the methodology was the rationale behind selecting thematic analysis over alternative approaches such as narrative approaches or grounded theory. Thematic analysis offered me a systematic yet flexible approach to identifying common themes between the CTE caregivers' experiences. As such, the collection and analysis of data encapsulates the diverse experiences of CTE caregivers.

CHAPTER 6- Study One

Understanding the experiences of older spousal CTE caregivers

6.1. Introduction

The literature review presented in Chapters 1-4 focused on the experiences of informal caregivers, shedding light on the challenges they encountered while tending to loved ones with neurodegenerative conditions. From assisting with daily tasks to adapting to unpredictable behavioural changes, caregivers often grappled with feelings of being overwhelmed, frustration, anxiety, and depression (Chiao et al., 2015). The progression of diseases like Alzheimer's and other Dementia subtypes, such as Frontotemporal Dementia, prolonged and intensified the caregiving role, placing additional strain on caregivers who could also develop psychological issues themselves (Ory et al., 2000; D'Aoust et al., 2015). Researchers have attempted to understand factors that heightened or alleviated caregiver burden, focusing on the dynamics of the caregiver's relationship with the care recipient. While some studies yielded inconclusive findings, the majority suggested that spousal caregivers bore a greater burden, influenced by factors like age, retirement, and increased isolation as grown children no longer required care (Chiao et al., 2015; Montañés et al., 2022; Serrano-Aguilar et al., 2006). However, insights from Alzheimer's/Dementia literature might not be directly generalisable to CTE caregivers due to unique circumstances.

Alongside the unavailability of diagnosis during life, CTE can be observed in much younger populations (i.e. observed in people as young as 17 but symptoms do not generally appear until years after the onset of head trauma) than other neurodegenerative diseases, and thus caregiving burden can stretch for decades. Despite knowing what is unique about CTE as a disease, we still do not know if, and how, these factors may impact the primary caregiver and the burden they experience as part of their role. Although many symptoms of CTE overlap with those observed in Dementia/AD (i.e. confusion and memory loss), we are unable to conclude whether CTE and other aforementioned diseases share similarities in the caregiver experience. In addition to the limitations in generalising other caregiving literature to CTE, the absence of qualitative research poses a challenge to the depth of insight on the experiences of caregiving we can derive from previous studies.

Despite the caregiving role being multi-layered and subjective, the majority of the extant research has adopted a quantitative methodology (Lee, Martin & Poon 2017; Lou & Liu et al., 2015; Simon & Bueno et al. 2019). Although this approach has enabled an understanding of outcomes for primary caregivers (i.e. anxiety and depression) and the level of burden spouses experience compared to children/siblings (i.e. Cheng, 2017; Penning & Wu, 2016), the measurements utilised in these studies fail to account for confounding factors and consequently, do not afford the same insight as qualitative work is likely to offer. In order to understand the experiences caregivers go through, it is vital we hear their perspectives .

The purpose of the first study in this PhD thesis was to gain a greater insight into the experiences of older spousal CTE caregivers. This focus was driven by the fact that in other caregiving contexts, such as Dementia, the majority of caregivers tend to be older adults. By examining the experiences of older spousal CTE caregivers, we aimed to determine if and how the unique aspects of CTE, as compared to more well-studied conditions like Dementia, might impact the level of burden experienced by this population. With the research on this population currently being limited, it is important we listen to the stories of these individuals, to understand what the experience was like from their perspectives. The qualitative approach also allows for the exploration of similarities and differences between the experiences of CTE caregivers and those in dementia contexts, which is an important part of the first study's purpose. Thus, the purpose of the first study in this PhD thesis is to develop our understanding of the experiences of older spousal caregivers of individuals suspected to have Chronic Traumatic Encephalopathy (CTE) and understand the similarities and differences of their experiences with caregivers in Dementia contexts.

6.2 Methodology

6.2.1 Study design and sample

A qualitative research design was used in the present study. To allow for an in-depth exploration of the caregivers' experiences, I conducted interviews that allowed the participants to share their stories in the way they felt comfortable in doing so. A thematic analysis was used to explore similarities between the caregivers' experiences. This approach enabled flexibility in the data analysis (Braun and Clarke, 2006), which was important to me, as the caregiving experience is highly subjective, and I wanted this to be reflected effectively in the results. Due to the sensitive nature of the topic, volunteer sampling was deemed as most appropriate as it only involved participants who understood the research question. The participants in the study were required to meet several inclusion criteria. Firstly, they had to be primary caregivers to an individual, whether currently living or deceased. Additionally, participants needed to have been caregiving for a minimum of 1 year past the patient's death. This was important as it allowed for a sufficient period of time to have elapsed since the caregiving experience ended, providing participants with some distance and perspective on their experiences. It also ensured that participants had time to process the loss of their loved one, which hopefully would minimise any distress during the interviews. They were also required to be or have been caregivers to their partners who have been diagnosed with CTE or have probable CTE/sport-related neurodegeneration. Furthermore, participants had to be aged 60 years or older. According to the literature (Pickard, 2018; Thelwall et al., 2021) the ages of 60 and above are classified as the beginning of older age. As the focus was to investigate older spousal caregivers, it made sense to recruit participants from this age bracket. Participants also needed to have digital equipment, such as a computer, to access study materials and participate in interviews if they opted to do so. English proficiency was another criterion, and participants had to speak English fluently.

The final sample comprised 12 female spouses from various states within America, aged between 60-87 years old (M=72, SD=7.26). The 8 other individuals who were contacted, did not wish to participate as they felt unready to share their stories. All of the participants had been a primary caregiver for over 10 years (M=11.5) to a loved one who lost their life to Chronic Traumatic Encephalopathy as diagnosed through post-mortem examination (by the VA-BU-CLF brain bank).

6.2.2 Recruitment and access

The study had received ethical approval from Oxford Brookes University (UREC approval number 211551- see appendix 2). Twenty primary caregivers were contacted via email and were presented with the outline of the research project as well as a link to an online consent form. Specifically, the Concussion Legacy Foundation (CLF) contacted (see advert in appendix 3) 12 people from their database (who had signed up for future research opportunities and matched the criteria) that matched the study criteria. The CLF sent over the study details and my contact details if they wished to participate. The other eight participants were contacted directly via myself as the lead researcher. I met these individuals at the CLF huddle in Las Vegas 2022, where I discussed the research with potential participants and collected relevant contact information from those interested. Once back in the UK, I contacted them to invite their participation. Participants were recruited using a volunteer sampling technique (Alvi, 2016) that matched the relevant inclusion criteria for the study. Out of the 20 contacted participants, 12 agreed to take part. Each participant participated in one interview, during which they were broadly asked to share their story as a caregiver. I provided each participant with an outline of the interview aims and process in advance to allow them time to reflect on their experiences. Only the participant and I were present at the interview.

The interviews, conducted via Zoom, lasted between 62 and 115 minutes (M= 96 minutes) and were transcribed verbatim.

6.2.3 Interviews

The primary method employed for data generation was qualitative interviews, which were undertaken between April 2022 and June 2022.

Pilot

A pilot test is an essential component of interview preparation (Turner, 2010) as it is beneficial in helping the researcher identify strengths and weaknesses in the interview process. During the pilot process, I tested the interview protocol with a caregiver to someone with Dementia, following the same procedures as the actual research interviews. Undertaking this process assisted me in testing the other interview questions, examining the recording process, and preparing for the actual interviews. I made appropriate changes, including changing the initial question of "how long have you been a caregiver for?" to one that was open-ended; "can you tell me your caregiver story", and refined the interview questions based on the feedback received during the pilot interview.

Interview process

Upon virtually meeting the participants, I dedicated time to familiarising myself with their backgrounds and discussed the broad purpose of the research before completing the documentation relating to project information and informed consent (see appendices 4 and 5). A number of participants expressed interest in understanding my professional background and motivations for conducting the research, to which I provided comprehensive and transparent responses. Interviews lasted between 62 minutes and 115 minutes long. I was guided by individual participants regarding the length of the interviews. I ensured that I had ample time following interviews for further conversation and did not appear rushed. Participants were encouraged to ask me any questions they wished too. Interview length varied greatly between participants. I was particularly conscious of watching signs of emotional fatigue in the caregivers as I was aware the topic can be draining for them. Interviews were transcribed verbatim as soon as possible after interview completion.

Interview guide

The first stage of the interview was an introductory stage, focusing upon providing the participant with the purpose of the study, and providing information to them regarding disclosure of their anonymity and confidentiality. The introductory phase was developed by reminding participants of my involvement in the previous research they were part of, as well as my background of knowledge and experience in CTE caregiving work. Furthermore, I reiterated their reason for wanting to undertake the project: to understand the experiences of CTE caregivers. This meant the participants were reassured by my genuine desire behind this study and subsequently made them feel more comfortable before delving into the rest of the conversation. The opening question ("can you tell me your caregiver story?") was intentionally broad to allow participants to direct the interview and share significant and meaningful experiences. The next stage of the interview was based upon the work of Lindeza et al., (2020) who investigated the emotional outcomes of caring for someone with dementia (i.e. what emotions/feelings did you experience during caregiving? Can you describe the events that preceded these emotions?). Through asking participants to reflect on the range of emotions they experienced during their caregiving journey and to describe the specific events that preceded these emotions, the aim was to gain a nuanced understanding of the emotional impact of caregiving.

The next stage of the interview involved asking the participants about burden (i.e. what does burden mean to you?). Many studies in caregiving literature address caregiver burden (Chiao et al., 2015; Liu et al., 2020). Some researchers characterise burden as an outcome, while others suggest it leads to symptoms such as anxiety (Unsar et al., 2021). Asking the participants about what burden means to them, allowed them to define it for themselves and discuss their experiences in relation to it. Following on from this, the last stage of the interview involved asking the caregivers the impact of the role on their lives (i.e. can you talk to me about how your life has changed since caregiving). This question was based on a study by Pendergrass et al., (2019) that explored the impact of caregiving on one's personal life. Through asking this question, I aimed to explore the broader implications of caregiving beyond the immediate emotional and psychological effects, shedding light on how the role has influenced various aspects of their daily lives, relationships, and personal well-being. Throughout the interview I did have a set of prompts I could refer to, to ensure the research questions were answered but they were not used regularly (i.e. “going back to your experiences as a caregiver, how did the role affect your personal life?). Following the aforementioned questions, an opportunity for me or the participant to ask any additional questions/make any further responses was provided. Once the semi-structured interviews with all the participants were completed, transcription began.

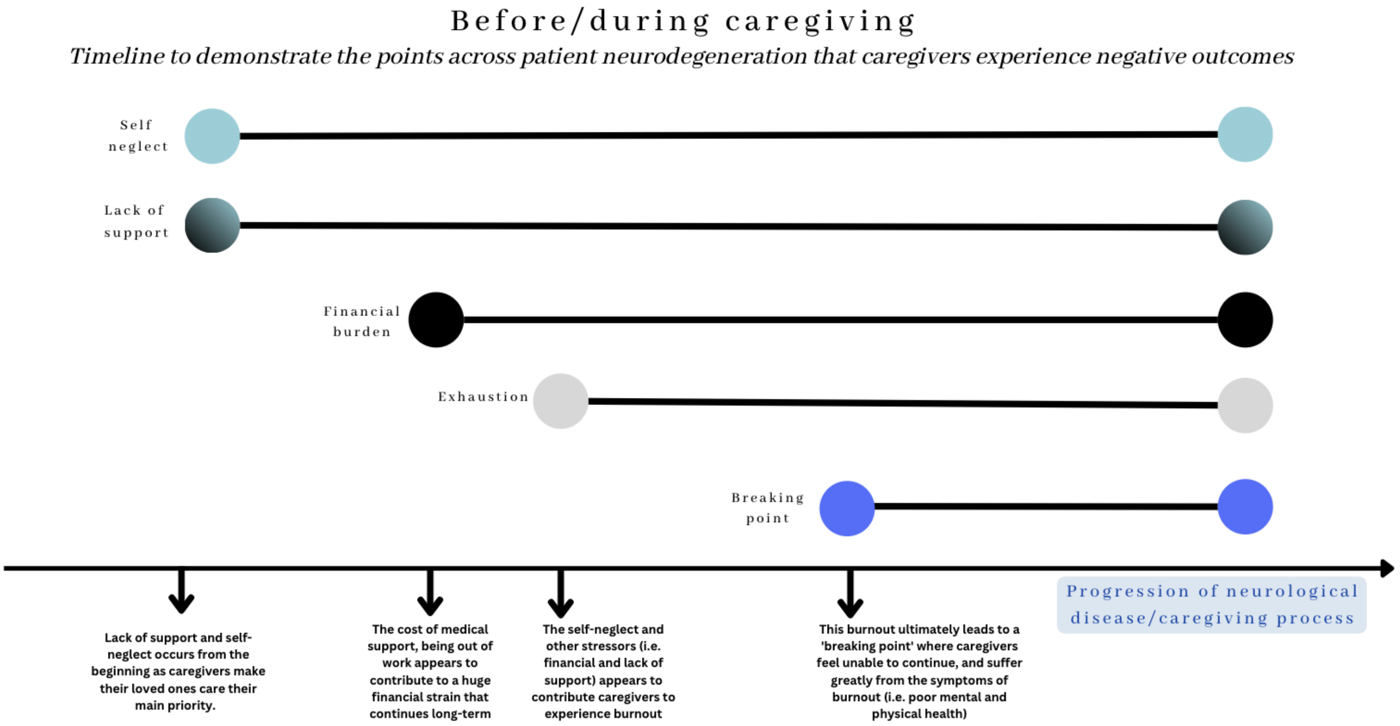
6.2.4 Analysis

During the initial part of the analysis, I found there to be a clear difference between the caregivers' perception of their experiences during their roles and after their role. Thus, I decided to have these as two overarching themes from the beginning. Keeping these temporal distinctions in mind, I continued to review the data to identify emerging sub-themes. During this process, I made notes of repetitive quotations across interviews (i.e. many caregivers spoke about feeling like they had lost themselves during the role). These quotations were all grouped together into provisional categories (e.g. identity struggles) to organise the data for the final stages of analysis. The aim of the analysis was to search for key experiences the caregivers went through and how they impacted them to learn what is unique about caregiving in this context. Utilising critical friends, the data was re-analysed to conclude if the data formed a coherent pattern, and that the theme titles summarised the data contents. Within this step, critical friends asked thought provoking questions such as "what is unique about this data compared to other contexts?". This discussion helped to give me a new perspective when going through the analysis of the data. The critical friends also questioned whether there were any further subtitles that had been overlooked. After this discussion, many of the theme titles were re-adjusted to represent the data more effectively, for example identity struggles became loss of purpose to represent the data more effectively. After this step, the sub-themes were all finalised and reflected my interpretation of the data coherently. Under the first temporal theme 'before/during caregiving' the finalised sub-themes included; breaking point, personal influences, self-neglect and financial burden. Under the second overarching theme, 'after caregiving', the finalised sub-themes included; loss of purpose, perceptions of burden and lessons/advice for others.

6.3 Results

In the following section, data is presented in two temporal themes; life before/during caregiving, life after caregiving. I also present a final theme; advice for others. Within the first two themes, a diagram containing the number of sub-themes is presented to illustrate and discuss pertinent aspects of how caregiving has impacted on the participants. Diagram 1 outlines the themes and the times at which they appear to occur during the caregiving process.

Before/During the caregiving role



Lack of support and self-neglect occurs from the beginning as caregivers make their loved ones care their main priority.

The cost of medical support, being out of work appears to contribute to a huge financial strain that continues long-term

The self-neglect and other stressors (i.e. financial and lack of support) appears to contribute caregivers to experience burnout

This burnout ultimately leads to a 'breaking point' where caregivers feel unable to continue, and suffer greatly from the symptoms of burnout (i.e. poor mental and physical health)

(Diagram 1. Temporal themes occuring before/during the caregiving role across patient neurodegeneration)

Self-neglect

With the lack of time and support available for the caregivers, they still managed to keep up the care for their loved ones, but at the jeopardy of their own health and wellbeing. Demonstrated in Diagram 1, self-neglect appears to begin at the start of the caregiving process and continues long-term, as the individuals put their lives to the side as they care for their loved ones. Within the conversations, the caregivers explained the physical and mental outcomes they experienced as a ramification of caring full-time for their loved ones.

"I knew what it was doing to me but I didn't want to deal with it. I couldn't deal with it. It was too big. It was gonna cause a nervous breakdown. This whole thing is so destructive, I mean destructive to yourself" (C7)

This quote suggests a sense of denial/avoidance, where the caregiver may be neglecting their own needs and well-being in order to prioritise the needs of their partners. This pattern of neglecting one's own health and self-care, often in favour of fulfilling caregiving responsibilities, is commonly experienced by these caregivers. The previous quote encapsulates the emotional strain and the internal struggle faced by caregivers who recognise the toll of their responsibilities on their mental health but find it challenging to confront or address these issues.

"Putting somebody else first for so long and never yourself. I just cannot see what goes on. Like I was in such a hole that I was just like you're really cutting yourself off from everybody" (C8)

This quote highlights the profound personal cost of caregiving and the emotional toll of prioritising someone else's well-being to the detriment of one's own. The participants almost deemed it as a 'sacrament' (C7) to never give up and to be there for their loved ones through 'sickness and health'. As part of caring for their partners full-time, and having no mental break from the role, caregivers found their sleep patterns to be extremely disturbed.

"So inside I was dying and the damage came in weight gain from just not eating right and stress hormones. The not sleeping like for two years I had the most messed up sleeping pattern. Anxiety and depression. I became so bitter too" (C10)

Here the caregiver vividly describes the profound impact of the caregiving experience on their physical and mental well-being. The mention of "inside I was dying" suggests a deep internal struggle and emotional turmoil. The adverse effects are enumerated, including weight gain due to poor eating habits, disrupted sleep patterns lasting for an extended period, and the development of anxiety and depression.

"There was never any downtime. Even when I used to put him to bed I would just be anxiously waiting for him to call me to take him to the toilet or I would be listening out incase he had a fall, I just couldn't sleep" (C5)

The caregiver expresses the pervasive nature of their responsibilities, highlighting the constant vigilance and lack of respite. The caregiver's anticipation of potential calls or emergencies during what is typically considered a downtime, emphasises the continuous nature of caregiving duties. The quote illuminates the heightened level of stress and the challenges in finding moments of relaxation illustrating the exhaustive and consuming nature of the caregiving role. However, this lack of sleep affected the carers' lives holistically with many of them detailing how it changed their personal lives and identities;

"I remember looking in the mirror one day and I didn't even recognise myself. I didn't go out with my friends anymore, I didn't do anything besides look after him" (C4)

The caregiver articulates a moment of self-realisation when looking in the mirror and feeling a disconnection from their own reflection, symbolising the emotional and physical toll of their caregiving responsibilities. Having to limit social interactions, captures the sense of identity loss and social isolation that can accompany the intense demands of caregiving. Another caregiver discusses the physical impact of the role;

"I had gone from a size three, when he was first diagnosed to a size 12 in 2010, because I was not working out, I was stress eating, you know, managing everything. I'd always been very fit but working out was impossible but then my doctor finally told me that I was pre-diabetic and to hear those words were like god not me surely not" (C5)

This caregiver details the physical consequences of the stress and lifestyle changes brought on by caregiving. The significant weight gain is attributed to stress eating and the challenges of managing caregiving responsibilities. The caregiver's mention of their previous fitness level highlights the contrast and the impact caregiving had on their physical well-being. This quote illuminates the intricate connection between the physical and emotional aspects of caregiving, emphasising the need for holistic support for caregivers to maintain their well-being.

Despite self-neglect being highly prevalent during the years these individuals were caregiving for their partners, the outcomes of self-neglect such as mental and physical health implications are ones that the caregivers have to live and deal with after they lose their loved ones. Clearly, the carers not only lose their loved ones, but feel as if they have lost a sense of themselves too.

Lack of support

Many of the caregivers described how isolating and lonely their experience was, due to the lack of support they received from friends and family. Particularly, many described their struggle in getting those around them to understand the difficulties they were experiencing as their loved one's neurology declined. The lack of information and resources available to CTE caregivers made it more challenging for them to navigate their role and ‘convince’ others that there is a real problem with their loved one. The invisible nature of the disease (you cannot tell from the outside the person is struggling), means this lack of support begins right at the start of the caregiving role (see Diagram 1), and continues for the duration of their loved ones’ disease progression (depending on the support system around them), as seen on the model above.

“When I was having a hard time understanding my husband's behaviours and changes that were happening, I really needed my friends to vent too, but it was like everyone just disappeared. No one believed what I was saying, that there was something really wrong. Instead they just thought he was just a jerk and an addict” (C3)

This quote poignantly captures the profound sense of isolation and disbelief experienced by the caregiver as they grapple with the challenging behaviours and changes in their husband. The caregiver expresses a genuine need for understanding and support from friends during a difficult period. However, the response they receive is disheartening, with the friends seemingly being unpresent. Feeling neglected within friendships was an experience many caregivers had;

“*It really showed me who was there for me and who wasn’t. My friends who I had known for years acted like they didn’t even know me anymore. All because of what was going on with my husband, I didn’t get invited out anymore, no-one called me to check if I was ok, I literally had no support from anyone”* (C2)

The caregiver describes a significant change in the behaviour of friends.The friends' apparent distancing and acting as if they didn't even know the caregiver anymore indicates a notable shift in the dynamics of these relationships. The caregiver attributes this change to the ongoing challenges with their husband, suggesting that the complexities of caregiving had strained or altered these friendships. Furthemore, the lack of communication from friends to check on the caregiver's well-being highlights a sense of isolation and lack of support during a challenging period. The caregiver's experience of having "literally no support from anyone" underscores the emotional toll that caregiving can take not only on the caregiver-patient relationship but also on the broader social connections of the caregiver. Alongside many of the caregivers experiencing a lack of support from their closest friends, sadly many of their immediate family members distanced themselves as a result of the unpredictable changes exhibited by their partners.

"His parents did not want to believe anything I was telling about him and what was happening. Instead of trying to come to terms with it all they completely backed off. It was really sad as that was their son at the end of the day" (C9)

Here the caregiver demonstrates a pertinent challenge as key family members refused to acknowledge the reality of the husband's situation. Although this lack of belief may stem from denial, disbelief, or an inability to come to terms with the challenging circumstances, having to manage their partner's decline alongside dealing with responses from relatives is extremely challenging. This support is likely to have proven beneficial to caregivers during their roles. Many caregivers felt that if they had a diagnosis or help from medical professionals, that they would have had more support from their loved ones and friends. However, with the lack of knowledge on CTE, particularly when these individuals were caregiving (10+ years ago), this support was not available either.

"I remember once I took him to the doctors and explained what was going on, and the doctor laughed. He said there's nothing wrong with him, he's just an addict, you need to be taking him to rehab not to see me. I was shocked and just thought, if a doctor won't believe me, who is?" (C7)

"I spent hours, days, weeks searching his symptoms but everything just said early Dementia, but I just knew it was something more than that. I had taken him to neurologists and they couldn't even give me an answer. I know we have come a long way now but back then, there was no information, no resources, no help. All I wanted and needed was help and I didn't have any" (C8)

These quotes demonstrate the caregiver's struggle to find answers and support for their husband's symptoms. Despite dedicating significant time and effort to research and consulting neurologists, these caregivers faced a lack of conclusive answers or guidance. Evidently, it appears to be really important to caregivers that they have a good support system around them during their time in the caregiving role. Not having help from friends, family and even medical professionals may result in caregivers feeling isolated and alone. Despite the lack of emotional support, the lack of information around the disease also appears to have contributed to caregivers feeling unsupported.

Financial burden

Concerns around finance was a huge topic many of the caregivers discussed. Specifically, the caregivers detailed that the financial strain placed on them heightened their stress and anxiety. Demonstrated in Diagram 1, financial burden appears to begin near the start of the caregiving process and continues long-term into life after caregiving (Diagram 2), as the caregivers must pay for medical support, neurologist appointments, medications and even deal with the financial strain their loved ones have put them in as part of their neurological decline (i.e result of gambling and addiction). Particularly without the free health care in the United States and the amount of medical support needed including neurology appointments, ambulances, and medication, became a large burden upon the caregivers. This was particularly prevalent in caregivers who had to leave work to care full time for their partners. The caregivers' experiences give us an insight into how financial security is an important contributor to limiting burden.

"Financially I found it more of a burden than emotionally because I had to stop working which meant we were living off our pensions at a much younger age than we wanted to be" (C10)

"Caring full time without work is not a sustainable living. I had to go back to work in my retirement years because I became so financially insecure from it. That was the biggest burden on me" (C3)

Here the caregivers express that the financial aspect of caregiving has been more burdensome than the emotional toll. The decision to stop working to provide full-time care means relying on investments (i.e. pensions) at a younger age than anticipated. This shift not only affects the financial stability of the caregiver but also alters their retirement plans, introducing financial strain earlier than expected. Clearly, the economic implications of caregiving can be as substantial as the emotional ones. Having limited financial resources placed additional strain on the caregivers as they are having to balance further responsibilities.

"I mean everything was so expensive, the hospital appointments, medication, calling the ambulances if he had a bad fall. We were lucky our children are grown up with their own families as there was no way I would have been able to afford to support a whole family not working" (C7)

"We were in a hole, and I will never forget that feeling, it's such a helpless feeling" (C2)

The extent of outgoings for medical appointments, medications and the cost of living left caregivers feeling helpless. Acknowledging the inability to financially support an entire family while not working due to caregiving responsibilities, exacerbates the profound impact of financial burden on these families. One participant further reiterated the necessity of financial security during caregiving for someone with CTE;

"I was lucky that we were financially secure, I don't know how people do it without that because everything costs so much. Particularly as no-one really believed me when I said I think its CTE, so we spent so much money going to so many different doctors and neurologists until one would listen to me" (C4)

In general, the financial consequences of caregiving for individuals with CTE are viewed as significant, resulting in stress, anxiety, and a profound effect on both caregivers and their families. Many caregivers perceived financial concerns as a heavy burden, leading to stress and anxiety due to the necessity of leaving employment and relying on savings for support.

Exhaustion

With caregivers experiencing a lack of support during their roles, and subsequently having no time to look after themselves, so many appeared to succumb to complete exhaustion. Such a feeling was likely to have occurred as many of the care-recipients needed assistance during the day (i.e. feeding and dressing) and during the night (i.e. incontinence and hallucinations), which meant that the caregivers never got a mental or physical break from their caregiving role. Although self-neglect commenced as soon as the informal caregiving role started, feelings of exhaustion appeared to come later (see Diagram 1), when the caregivers realised that their loved ones were not going to get any better.

"I have three children, and being a mother, I mean that's the most tiring job, so I thought. I can't express how exhausted I was. Physically exhausted, mentally exhausted and I couldn't escape it, even if I had a good caregiving day, if there is such a thing… I was just drained" (C11)

Comparing caregiving to being a mother, a role already known for its demands and challenges, she emphasises the intense physical and mental toll caregiving takes on her. The caregiver feels completely drained, highlighting the relentless nature of caregiving responsibilities that leave her feeling exhausted regardless of how well the caregiving tasks may have gone on a particular day.

This quote captures the overwhelming sense of fatigue and emotional strain that can accompany the role of a caregiver, illustrating the constant and exhausting nature of providing care to others.

"I went to bed tired, I woke up tired, I spent most days tired but there was no improvement in that exhaustion. I had to get on with it, I had to care for him, I wanted to care for him. I sometimes think, if I had prioritised rest, would I have been a better caregiver, but really there was no way for me to do that.. Being exhausted became such a norm for me, I actually didn't know any different" (C1)

In this quote, the caregiver conveys the persistent exhaustion and fatigue they experience as a caregiver. The caregiver describes a continuous cycle of tiredness from morning to night, with no respite or improvement in their energy levels. Despite feeling constantly exhausted, the caregiver acknowledges their commitment and desire to care for their loved one, which drives them to continue despite their own fatigue. Besides the caregiver having many demands (i.e. feeding, dressing, dealing with medications) during the day, many spouses spoke about how exhausting it was to look after their loved one during the night too.

"I actually don't think I slept for 2 years. I mean properly slept, like I was getting up every hour or so with him. He would either be trying to get up to the toilet but not going to the bathroom, or I would find him downstairs shouting when he was having one of his hallucinations, so I just found myself exhausted all of the time" (C2)

Here the caregiver describes a period of extreme sleep deprivation due to the caregiving responsibilities. The caregiver's sleep was constantly interrupted by the needs of the person they were caring for. The lack of uninterrupted sleep resulted in the caregiver feeling exhausted all the time, highlighting the physical and emotional toll of continuous caregiving duties. For some caregivers, this exhaustion was so extreme, they were unable to function properly in daily life.

"Tired didn't cut it. I could barely function. I was so exhausted. No sleep, no exercise, poor nutrition, I did not have the energy for anything else other than making sure he was ok. I didn't have the energy to look after myself" (C8)

The lack of adequate sleep, exercise, and proper nutrition due to the demands of caregiving left them with little energy for self-care. The caregiver's focus was solely on ensuring the well-being of the care recipient, to the extent that they neglected their own needs and well-being. These quotes illustrate the overwhelming fatigue and sacrifice that caregivers often experience while prioritising the care of their loved ones. It was clear that complete exhaustion became a 'norm' for these caregivers, and they were unable to avoid this due to the demands of the role becoming greater as their loved ones' disease progressed. Evidently, the caregiving role is a 24/7 job, which is why so many of the caregivers reached a point where they felt too exhausted to carry on, with levels of exhaustion seen to be heightened by a lack of sleep.

Reaching a breaking point

When the caregivers were discussing their stories and experiences, it was clear that life during caregiving brought about an abundance of challenges. Despite the lack of information and medical support for CTE which caregivers alluded to heightening their stress levels during the role, factors such as lack of support, perception of others and general life dynamics impacted the caregivers largely. This lack of understanding of CTE, particularly years ago when the information was not as readily available, made it really challenging for these caregivers to understand the irrational behaviours exhibited by their loved ones. This, paired with the inability to diagnose CTE until autopsy, left caregivers questioning their caring abilities, and encouraged feelings of stress and total exhaustion. Subsequently, when the participants were asked about the impact of the caregiving role, they all described a period in their role whereby they felt they had reached a point where they couldn't see how they were going to continue. Other elements shown in the Diagram 1 (i.e., lack of social support, exhaustion and financial burden) all appear to contribute to the caregivers reaching such a breaking point and feeling like they can't continue caring for their partner.

"It broke my heart, every day it broke my heart. All of a sudden I sat there one day and I thought I don't have the energy to get up. I can't face this day one more time. I just couldn't even think how to continue" (C5)

Here the caregiver expresses profound emotional distress and exhaustion in their caregiving role. The constant heartbreak they experience from witnessing the challenges faced by their loved one reaches a breaking point where they feel completely drained and overwhelmed. The caregiver reaches a moment of despair where they struggle to find the energy and motivation to face another day of caregiving responsibilities, highlighting the emotional toll and strain of their role. For some caregivers, these challenges became too overwhelming;

"One day I drove myself to the local hospital because of something my husband had said. I think I was just overcome with that feeling that you're doing so much and it's a kind of feeling of betrayal. I don't really know how to explain it, I think I might have had a mini mental breakdown, because I

wasn't even thinking straight . The doctor was walking me towards the psych ward and that's when my senses started kicking back in and I said I think I'm just really tired, but that was probably my lowest point. I mean trying to care for a 6ft 5, nearly 300 lbs man alone is not easy, I was just totally wiped out all of the time" (C10)

This quote vividly describes a moment of extreme emotional distress and vulnerability experienced by the caregiver. The caregiver reached a breaking point, feeling overwhelmed by the magnitude of caregiving responsibilities and possibly a sense of betrayal, likely stemming from the emotional and physical exhaustion, and managing demands alone. Evidently, the caregiving role was both emotionally and physically draining for these caregivers. The extremities of day to day challenges and being the primary point of care clearly is not a sustainable way to live, especially as it resulted in many neglecting their own care. Interestingly, caregiver 7 had been a primary carer for her mother in law and her own mother, both diagnosed with Alzheimer's disease prior to her husband's neurodegenerative decline. Despite this previous experience as a full-time carer, this did not prevent her from undergoing challenges to her mental and physical health;

"It was just so so different. I couldn't understand his behaviour, he would change day to day and I didn't know how to react. No one understood it, not even the doctors, so I got no help. Doing the same thing day in and day out was exhausting, I have never felt lower" (C7)

Above, caregiver 7 encapsulates the difficulties of having a lack of professional support during her role. Having no information and medical help was a common factor many of the participants dictated as causing negative outcomes, and ultimately the main element leading to a 'breaking point'. With CTE being an 'invisible' disease, whereby you cannot generally tell the patient is struggling from face value, it makes it even more difficult for caregivers and their loved ones to be taken seriously by health care professionals. Similarly, caregiver 5 explains how the lack of resources and support aided the loneliness she experienced during the role;

"I had everything and then I had nothing. There was no help, no-one to go to, no-one really understood what was going on, even the doctors weren't listening to me. I was so stuck inside my own head as I only had me to go to. I mean there wasn't even a support group or a website I could go to for information. I went through a constant time where I was just blaming myself for everything, it was so dark and lonely, I could never imagine going back to that place" (C5)

Both of these caregivers share their experiences of loneliness, exacerbated by a lack of resources and support during their caregiving journey. The absence of help, understanding, and information left the caregiver feeling trapped within their own thoughts and struggles. The caregiver's sense of loneliness and self-blame reflects the emotional burden of caregiving without adequate support systems in place.

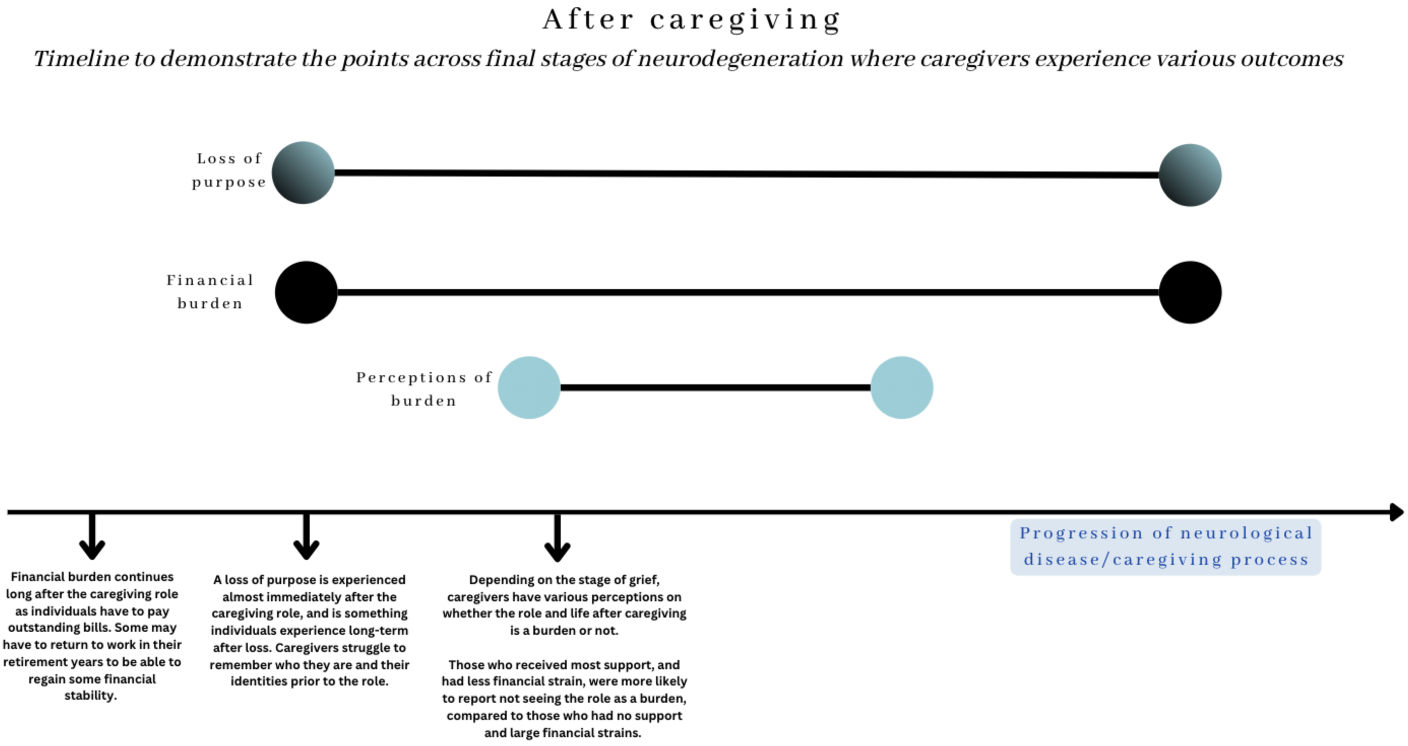
Evidently the challenges of providing care in retirement years is extremely difficult. Not only are these individuals struggling for an outlet due to not being in work, but also many of their children/families have grown up and naturally moved on with their own lives, which makes this an extremely lonely experience.

"It was the worst day of my life, at times I thought that he might kill me. I just said, I can't do it anymore, that was the worst day of my life, and getting over that was extremely difficult. I was at work just mourning a cry that I could not control, no doubt I have never felt worse than that day. March 10th 2009 was the day that did it for me. The most traumatic part. Very traumatic. I will never get over that because that's the moment I broke completely" (C12)

Despite the caregivers discussing their 'breaking points' at a time during their roles it is clear that the outcomes are long-term, with many of them struggling to even talk about their experiences now. Besides there being a lack of available resources to these individuals during their caregiving role, this is also likely to be a ramification of lack of CTE specific help available to them post-caregiving.

After caregiving

It was evident from conversations that life for caregivers of someone with CTE, after the death of their loved ones, some challenges continued (e.g. financial burden), whilst other challenges emerged. This theme is subdivided into loss of purpose and perceptions of burden. Diagram 2 outlines the themes and when they occur during the caregiving process.



Financial burden continues long after the caregiving role as individuals have to pay outstanding bills. Some may have to return to work in their retirement years to be able to regain some financial stability.

A loss of purpose is experienced almost immediately after the caregiving role, and is something individuals experience long-term after loss. Caregivers struggle to remember who they are and their identities prior to the role.

Depending on the stage of grief, caregivers have various perceptions on whether the role and life after caregiving is a burden or not.

Those who received most support, and had less financial strain, were more likely to report not seeing the role as a burden, compared to those who had no support and large financial strains.

(Diagram 2: Temporal themes for life after caregiving)

Loss of purpose

When the participants were asked about the difficulties of life after caregiving, the evidential problem was this feeling of a ‘loss of purpose' in their lives. Many of these caregivers had looked after their partners as the primary caregiver for over a decade and most of these individuals received no extra support from care facilities, due to a lack of understanding of CTE within the healthcare systems. Having this lack of medical support and understanding from others, meant these carers were solely looking after their loved ones full-time, whilst attempting to manage other life commitments (i.e. going to work). The natural degeneration of these patients meant routine was particularly important for them, therefore it is not unsurprising that many of these caregivers now struggle with having no routine in their lives anymore:

"There is an emptiness after. It's like going to a job everyday for 20 years and then you don't have a job anymore, I just don't know where I belong right now" (C1)

The caregiver grapples with a lack of purpose and belonging after dedicating themselves to caregiving for an extended period, highlighting the significant adjustment and emotional impact that can accompany the transition out of a caregiving role. Similarly, another caregiver reflects on the significant adjustment they face after the end of their caregiving duties;

Similarly, caregiver 2 said:
"Not to have that routine, it's a massive change for me now because I don't have to do that anymore and it's just really strange"

The caregiver describes the absence of their caregiving routine as a massive change, emphasising the strange adjustment that comes with no longer having to fulfil those responsibilities. The shift away from the familiar routine of caregiving can leave caregivers feeling unsettled and unsure about how to navigate this new phase of life, underscoring the profound impact that caregiving can have on one's sense of identity and daily structure. Many of the caregivers further explain how now being in their retirement years heightens this loss of purpose even more, as their children are moved away with their own families, they no longer work, and they now have no one to care for besides themselves anymore.

"I feel very lost. I'm alone, I don't work anymore, my kids are moved out with their own families, I mean I have no one to care for besides me anymore and that's a hard thing to get used too" (C4)

The caregiver expresses a profound sense of feeling lost and alone after their caregiving role. This transition from being a dedicated caregiver to having to focus on self-care can be challenging and unfamiliar, leading to feelings of emptiness and adjustment as they navigate this new phase of life. Similarly, another caregiver reflects on the difficulty of shifting focus back to self-care after years of prioritising the needs of their loved one.

"I don't even know how to care for me anymore? I know that sounds crazy but I haven't been my priority for years now, it's just a weird feeling" (C7)

The caregiver acknowledges the significant shift in priorities that caregiving demands, where their own well-being often takes a backseat to the needs of the care recipient. This realisation that self-care has not been a priority for an extended period creates a sense of disorientation and unfamiliarity with how to care for oneself, highlighting the challenges of readjusting to a new normal where personal well-being becomes the focus once again.

Caregiver 3 said:
"Now I am just trying to figure out how to create a new normal, I don't have that daily routine anymore that was always very much important to have so I am just trying to find a whole new groove of my whole new normal"

Both caregivers reflect on the challenge of adapting to life without the daily caregiving routine that had been a significant part of their life. With the familiar routine no longer in place, the caregivers describe the process of trying to establish a new normal and find a new rhythm in their daily life. This period of transition involves seeking out a new routine and adjusting to a different way of living that does not revolve around caregiving, highlighting the need to navigate this change and create a sense of stability and purpose in their post-caregiving life. In particular, the participants alluded that what is encouraging this feeling is the realisation of not having their spouses in their retirement years and subsequently not being able to enjoy older life together.

"I mean living with the aftermath of CTE is hard enough, but also trying to remember who you were before and realising your life partner is never coming back is just horrible to think about. I know I will never get back to who I was before, CTE changes you so much even if you're not the one suffering with it. I just feel so sad I won't be able to enjoy our older years together that we spent so long talking about" (C8)

The realisation that their life partner will never return to their former self due to CTE is heartbreaking, leading to a deep sense of sadness and loss. The caregiver acknowledges that CTE not only affects the individual with the condition but also profoundly alters the dynamics of their relationship and future plans. The caregivers see this as a 'lost dream', which heightens the feelings of sadness and loneliness that they were already experiencing.

Financial burden

The financial problems that were seen during the caregiving process also appeared to continue throughout the 'after caregiving' process (see Diagram 2). Despite their loved ones not being with them anymore, caregivers discussed how they had to repay debts, including medical bills, for years after they lost their partners. For most of the caregivers, they had completely depleted their savings during the role, so they had to return to work in their retirement years in order to repay the money they owed. Some caregivers still reported struggling with financial burden 10+ years after the loss of their loved one.

"*This whole thing, caring for your partner is so so challenging, physically and emotionally, but no one ever talks about the financial side of it. I was repaying medical bills, prescriptions etc for years after he passed away. So the caregiving role doesn't really stop after you lose your partner, having to deal with the admin, the finances, is a constant reminder of how burdening it is"* (C3)

Here the caregiver sheds light on the often-overlooked financial aspect of caregiving for a partner. The caregiver emphasises that while the physical and emotional challenges of caring for a loved one are widely recognised, the financial implications can be equally burdensome. The caregiver shares their personal experience of facing ongoing financial responsibilities even after their partner has passed away, such as repaying medical bills and covering prescription costs. This ongoing financial burden serves as a reminder that the caregiving role extends beyond the loss of their partner, requiring them to continue managing administrative tasks and finances related to the care provided. For some caregivers, they became so financial burdened that they had to return to work in their retirement years;

"*Us caregivers had enough to worry about, without worrying about going bankrupt too. By the time he died I must have had a few $100 to my name and $1000's of bills through my door. I had to go back to work in my late 60's. I am 70 now and I am only just back in a position where I am not feeling the financial burden*" (C2)

The caregivers' stories demonstrate the significant financial sacrifices and hardships that caregivers often endure while providing care for their loved ones. However, the caregivers explained how the demands of being a caregiver were delayed for a long time after their loved ones passed away, due to the strain of financial issues. Many were left in a position that continued their struggles for years as they worked to afford their own bills (i.e. mortgages, food) and simultaneously pay back their spouses medical bills.

"*You work your whole life to enjoy your retirement comfortably, but I could never do that because caring costs so much. Not knowing what was wrong with my husband meant I racked up $1000's bills from different medical appointments, different medications, different scans that I had basically had no money left. The stress of this just kept going and going, long after he passed away. As the caregiver you are left to pick up all the pieces. So yes its a burden, but financially, wow it's tough"* (C12)

The uncertainty surrounding their loved ones' condition led to accumulating substantial medical bills from numerous appointments, medications, and scans, depleting the caregiver's savings. Even after their partners passed, the financial stress persisted, leaving these individuals to manage the aftermath and financial repercussions alone. The caregiver describes the ongoing burden of financial responsibilities as a significant challenge, emphasising the enduring impact that caregiving costs can have on one's financial well-being long after the caregiving role has ended.

Overall, the accounts of caregivers underscore the enduring nature of financial strain even after their caregiving responsibilities have ceased. Especially for spouses approaching retirement or already in their retirement years, the stress of managing substantial bills without the support of employment becomes evident. The prolonged duration of this financial burden is not surprising, contributing to sustained challenges and additional strain on caregivers.

Perceptions of burden

Within the interviews, the participants were encouraged to talk about what burden meant to them. It was interesting to get a range of perspectives, as some caregivers said that they have never looked at this as a burden, whereas others felt it was a huge burden on their lives. The emotional dimensions of caregiver burden are diverse, but resentment, sadness and frustration are dominant themes within the caregivers stories

"I mean the burden is probably just in my mind now, because we can't do the things we always planned on doing, we can't be a couple anymore" (C6)

This caregiver expresses a sense of loss and disappointment as they come to terms with the fact that the plans and dreams they had for the future with their partner can no longer be realised. It is clear an element of resentment is being demonstrated here, which is a very natural emotion for a primary caregiver to have, particularly when they have lost their loved one and also their quality relationship. As the caregiver said ‘the burden was probably in my mind’, it is likely they never considered it as a burden at the time, but instead were saddened by the change in their life dynamic. Despite feeling burdened for the loss of their relationship, burden was also experienced through the unknown;

“I felt a burden because I didn’t know how my new life was going to be after I lost my husband. It was just such an overwhelming time and it still is sometimes, I mean I feel sad, I feel lost, I feel guilty but angry, it’s just such an emotional rollercoaster, so yes it is a burden on me, but it wasn’t when he was here. I think I was just so focused on caring for him back then I didn’t even think about my feelings, but clearly it's all starting to come out now” (C10)

The caregiver expresses a sense of uncertainty and overwhelm about how to navigate their new life without their partner. The transition to this new phase is emotionally challenging, leading to feelings of sadness, loss, guilt, and anger. The caregiver describes this experience as an emotional rollercoaster, highlighting the complex and conflicting emotions they are grappling with. While caring for their husband, the caregiver was focused on providing support and did not have the space to process their own feelings. However, with the passing of their husband, these suppressed emotions are now surfacing, contributing to the sense of burden and emotional turmoil they are currently experiencing. The caregivers narrative demonstrates the profound impact of caregiving and loss on the caregiver's emotional well-being and the complexities of navigating grief and adjustment after the caregiving role has ended.

Interestingly, some of the caregivers do not see their lives as being burdened now;

“I loved him, I would do anything for him, even if he was still with me now. I don’t see what happened as a burden on me now, I am just grieving and learning to re-adjust to a different life” (C9)

The caregiver expresses deep love and devotion for and devotion for their partners. Instead of perceiving the experience as a burden, they view the current phase as a period of grieving and adjusting to a new life without their loved one. The focus is on processing their emotions, navigating the grief of loss, and learning to adapt to a changed reality. The caregiver's perspective reflects a profound sense of love, acceptance, and resilience as they come to terms with their loss and work towards finding a new sense of normalcy in their life without their loved one. However, for the majority of caregivers, burden is something they are still struggling with day to day;

"I just feel like his burden was relieved but then it was placed a lot on my shoulders. I mean nothing prepares you for this, but carrying the burden after and having to try and get back into some sort of normal life again, nothing can prepare you for that feeling" (C4)

The caregiver expresses a sense of relief that their loved one's burden has been eased, but they also acknowledge that a new burden has been placed on their shoulders in the aftermath. The transition from caregiving to adjusting to a life without their loved one is described as overwhelming and unexpected. The caregiver highlights the difficulty of carrying this new burden and attempting to strive for a sense of normalcy after the caregiving role has ended. Caregiver 9 reiterates the perspective that heightened emotions (particularly during the process of grief) can encourage feelings of burden, particularly when trying to navigate a 'new normal' again. Evidently, navigating burden after loss is a process that takes time and adjustment;

"I am just so narrow-minded right now. Everything feels like a burden. I just have to get out of that funk" (C5)

This caregiver indicates that they are struggling with negative emotions and challenges that are affecting their outlook and well-being, and causing them to perceive everything as a 'burden'.

For some caregivers, this burden remains a continuous process, and they express a struggle in navigating this feeling;

"I still feel a sense of burden and I don't know how to let go of that" (C7)

Evidently, emotional burden is perceived differently for everyone. Despite this, it is apparent that life after caregiving is a burden on many individuals as they are learning to readjust to a new life whilst trying to grieve the loss of their partners.

It was evident from conversations with all of the caregivers that life after losing their loved ones brought about its own unique challenges. The participants explained how life after caregiving may be equally as challenging as living in the caregiving role, due to a sudden change in routine, a loss of their life partner and trying to live with the burden. Particularly with the participants being older and many being away from family or retired from work, the dynamic of their lives after caregiving completely changes. Learning to begin a new life or to learn how to live a new normal proves extremely challenging and overwhelming for these individuals. The key issue is that these individuals have been the sole caregiver which has placed additional burden on them as they have received little support due to the lack of knowledge around CTE.

Lessons and Advice for others

One important question asked to the caregivers was any advice they would give to a caregiver going through this now, or someone who may go through it in the future. As a result of the lack of research and resources for CTE caregivers, we must understand as many caregiver stories to learn how to support them. Many of the caregivers were able to provide advice based on lessons they learnt about themselves and the role itself;

"You really learn, you know how strong you are and what you're made of dealing through all of this. I mean it's not until you're on the other side of it you truly understand what you went through and how you managed to get through it. Seeing the positive side to it really takes a lot of time, but be patient and you'll get there" (C4)

This caregiver reflects on the experience of caregiving and the personal growth that comes from facing these challenges. They acknowledge that going through difficult times reveals inner strength and resilience that may not have been apparent before. It is only after coming out on the other side of these challenges that the caregiver is able to truly comprehend the depth of what they have endured and how they managed to navigate through it. The caregiver emphasises the importance of recognising the positive aspects of the experience, even though it may take time to see them clearly, and encourages patience in the process of finding that perspective. Discovering inner strength through adversity was a shared sentiment amongst the caregivers;

"You know you never really think you can do something as extreme as what you have dealt with until you've been thrown into it. I mean, never in a million years would I have thought I would be in this position, but I got through it somehow. It's taken everything out of me but left me knowing what I am made of" (C8)

Besides the hardships and impacts on the caregivers' lives during and after their role, they were able to see a positive side of the situation. Specifically, the caregivers learnt a lot about their inner strength, their perseverance and determination through the challenges, which is a valuable asset to one's personal growth. From being on the other side of it, the caregivers were able to provide advice based on their experiences. Specifically, caregivers found comparing themselves and their relationships to others who are not going through the same challenges was adding to the negativity and self-neglect even more.

"You don't want to compare yourself to anybody, just don't make comparisons and don't be so hard on yourself. I mean, no-one really knows what you are going through unless they have been through it too so just try and focus on yourself and your loved one, as no one else matters" (C12)

Alongside this, the caregivers provided various practical advice for other CTE primary caregivers;

"It's a lot easier to give advice when you're out the other side of it, as when you're in it it's a tunnel vision feeling of just doing everything you can to care for them, but I would say try and find time to carve out for yourself because you really need that. I didn't do that and that's a regret because now I struggle with guilt of going out and doing things for me" (C10)

The caregiver acknowledges that when immersed in the caregiving role, it can feel like there is a singular focus on providing care for the loved one, meaning personal needs are often neglected. The caregiver advises others in similar situations to try to carve out time for themselves amidst the caregiving responsibilities, emphasising the necessity of self-care. This caregiver shares a feeling of regret about not prioritising self-care during their caregiving journey and highlights the struggle with feelings of guilt that can arise from taking time for oneself. Evidently, it is important to balance caregiving offers insight gained from their caregiving experience.

"Focus on the right things. They need a relationship more than they need to be cured. They need love more than they need help. I spent so much time fighting back because I didn't understand it. I was trying to fix something that couldn't be fixed. I had my priorities all wrong, so I would just say make the most of them being there, every minute, love them, support them, even in the moments that are really hard to do so" (C3)

This caregiver emphasises the significance of relationships and love in caregiving, suggesting that these elements are more essential than trying to fix something that couldn't be. This individual reflects on their past approach of focusing on trying to fix something that was beyond repair, leading to misplaced priorities and potentially missed opportunities for meaningful connection. The caregiver advises others to cherish the time spent with their loved ones, focusing on nurturing their relationship, providing love, and offering support even during challenging moments. This quote highlights the importance of prioritising love and connection in caregiving, emphasising the value of being present and supportive for the care recipient. Alongside focusing on connection with their partners, many of the caregivers suggested that finding other caregivers, or attending support groups would be a great way to aid someone through the role.

"There's no such thing as the perfect caregiver, it is maybe one of the hardest jobs, and something we are not getting paid to do, so try not to be hard on yourself. Even the strongest people need help and that's more than ok. Try and find other caregivers to speak too as I know that would have helped me. I am so glad that now there are more resources and information available about CTE, I wish I had that when I started caregiver, so use it all, ask the questions, and don't live in guilt, you are doing something not many people are cut out to do" (C1)

Here the caregiver offers reassurance by emphasising that there is no such thing as a perfect caregiver and acknowledges the immense difficulty of the caregiving role. The caregiver encourages caregivers not to be too hard on themselves and reminds them that even the strongest individuals may need help, which is perfectly acceptable. Another caregiver suggests seeking support from fellow caregivers highlighting the importance of connecting with others who understand the challenges of caregiving;

"Connect with other caregivers, participate in support groups and find things that will help you so that you can be stronger for the person you are caring for" (C5)

It appears that having others around you that are relatable and understand your experiences, is an effective support mechanism and subsequently may aid to diminish some of the struggles (i.e. isolation, loneliness) that are associated with the caregiving role. Alongside the caregivers personal environment, some participants spoke about the importance of creating a supportive environment for their loved ones;

"Make the environment your partner is in feel safe and supportive. I know my husband felt like he couldn't go to anyone about what he was dealing with, but at home was his safe space, so try your best to keep it that way" (C7)

Creating a safe and supportive environment is clearly essential in caregiving. Caregivers should strive to establish a space where the care recipient feels comfortable and open to communication.

By fostering a safe space for dialogue, caregivers can build trust and encourage the sharing of thoughts and feelings. This supportive environment not only allows for better understanding of the care recipient's needs but also provides a sanctuary where they can feel secure and valued. Prioritising a safe and nurturing atmosphere at home can enhance the caregiving experience and contribute to the well-being of both the caregiver and the care recipient. Based on the caregivers advice, possessing a strong support network and practising self-care can prove advantageous in assisting caregivers in their responsibilities and enhancing their capacity to care for their loved ones effectively.

6.4 Discussion

This study explored the experiences of older spousal caregivers of individuals with Chronic Traumatic Encephalopathy. The findings highlighted the range of challenges faced by caregivers in this context, including their experiences and the implication of these experiences. In this section, I will discuss how the experiences of older spousal caregivers of individuals with Chronic Traumatic Encephalopathy (CTE) align with or diverge from the experiences of caregivers in Dementia contexts. This comparison will provide valuable insights into the unique challenges faced by CTE caregivers and contribute to a broader understanding of caregiving in the context of neurodegenerative diseases.

One of the key similarities between the experiences of CTE caregivers and caregivers in Dementia contexts was the financial burden they faced. Specifically, this study revealed that older spousal caregivers in the American context faced significant financial challenges during and after their loved ones passed away. With medical bills, medications and neurology appointments to pay, caregivers were left depleting their savings to repay their debts. Furthermore, many of these caregivers had transitioned into retirement, which affected their financial situation and consequently added additional stressors onto their caregiving responsibilities. This aligns with Liu et al.'s (2020) study, which was also primarily based on studies conducted in the US healthcare system. Their analysis argued that the cost of care is one of the key indicators of caregiving burden, with financial and economic restraint being raised as one of the most important factors associated with caregiving burden. Similarly, Chiao et al. 's (2015) systematic review, focused on Dementia caregivers in the US, also found that financial status was a contributing factor to caregiving burden. However, Liu et al., (2020) and Chiao et al., (2015) note that the negative impact of financial burden can be mitigated if caregivers receive support in other facets of their role, such as emotional support from family or medical assistance from healthcare professionals. Nevertheless, what emerged prominently in the experiences of CTE caregivers in this American context was a lack of support in other domains of their caregiving responsibilities, leaving financial burden largely prominent in their experiences. This highlights the importance of considering the broader healthcare and social support system when examining caregiver burden, as the availability and accessibility of resources can significantly impact the financial strain experienced by caregivers. The ramifications of this lack of support will be revisited in the general discussion.

When comparing our findings to those of other older spousal caregivers, numerous similarities emerge. All of the caregivers expressed their unwavering commitment to their loved ones, vowing to support them through 'sickness and health', often at the expense of neglecting their own well-being in favour of prioritising their spouses. Furthermore, caregivers found themselves residing and providing care within the same setting, leading to a sense of being trapped in their caregiving duties without an escape. This mirrors the findings of Montañés et al. (2022), who underscored how cohabitation and caregiving within the same household strain the caregiver's relationship with the care recipient, complicating efforts to strike a balance in their personal lives. Specifically, spouses, who typically spend most of their lives together, struggle to differentiate between their partner-to-partner relationship and their caregiver-care recipient relationship (Chiao et al., 2015). However, studies asserting that spouses bear higher burdens (Campbell et al., 2008; Chiao et al., 2015; Pozzebon et al., 2016) lacked a comparative sample (e.g., adult-children caregivers), hence precluding definitive conclusions regarding spousal caregivers' burden levels. Likewise, within our study, it is imperative to recognise that such comparisons cannot be established at this point, given our exclusive focus on spousal caregivers without contrasting them with CTE caregivers of varying relationships.

One of our key findings suggest that CTE caregivers experienced greater difficulties after their caregiving role compared to during caregiving, something that differs from caregivers in Dementia contexts. Specifically, the caregivers of individuals with CTE in this study articulated encountering greater challenges to other Dementias in their lives post-caregiving role compared to during their caregiving role. They discussed the challenge of adapting to a new routine following the loss of their loved ones. For these older individuals, who previously served as sole caregivers, navigating life without their partners proved immensely daunting. Transitioning into older age, ceasing work, and managing grown-up families, the caregivers experienced a notable sense of purposelessness. This pronounced feeling of "lack of purpose" became even more prominent after the passing of their loved ones. In contrast, Ott, Sanders, and Kelber (2007) observed in other caregiving contexts that many former Dementia caregivers overcome such challenges and recognised personal growth stemming from their caregiving experiences, benefiting from available resources. However, Ott's study employed the Marwit and Meuser Caregiver Grief Inventory (MM-CGI-SF; Marwit & Meuser, 2005), an instrument to measure the grief reaction rather than the long-term impacts of burden. Employing instruments not tailored to assess burden experiences post-caregiving, potentially overlooks struggles that Dementia caregivers may also face during this stage. Thus, it may not be a matter of Dementia caregivers not grappling with post-caregiving burdens, but rather a limitation in methodology that fails to adequately capture these experiences. Thus, further research is warranted to ascertain if this finding is a consistent pattern across various populations of CTE caregivers.

In summary, certain overlaps exist between our findings concerning CTE caregivers and those from existing literature on caregiving contexts, such as impact of financial burden. However, it is important to acknowledge that our understanding of the experiences of CTE caregivers is still in the early stages. Thus, further exploration involving various subgroups within the CTE caregiving community (i.e younger caregivers with varying relationships) is warranted to elucidate both the similarities and differences between CTE caregiving and other caregiving contexts, such as those caregiving to individuals with Dementia. Such investigations will provide valuable insights into the experiences of CTE caregiving and inform the development of comprehensive support strategies tailored to the diverse needs of caregivers in this context.

CHAPTER 7- Study Two

Understanding the experiences of younger CTE caregivers

7.1 Introduction

Study One developed our understanding of the demands of being an older spousal caregiver to someone with CTE. Specifically, the findings suggested that financial burden had a profound impact on the caregivers mental and emotional wellbeing. Older caregivers also struggled navigating post-caregiving life, whereby they experienced heightened burden. Although this work provided an initial insight into the CTE caregiver experience, the findings demonstrated many overlapping experiences with spousal caregivers in Dementia caregiving contexts. This suggests that the burdening outcomes experienced by the older CTE caregivers may have been more closely tied to the spousal relationship they shared with the care recipient, rather than the specific demands of the CTE disease. Consequently, there is a need to investigate other populations within the realm of CTE caregivers to fully comprehend the multifaceted nature of their experiences. By exploring diverse caregiver profiles, such as younger spouses, adult children, or non-spousal family members, a more comprehensive understanding can be created of the unique challenges and support needs across different caregiver relationships.

The literature on Dementia caregiving has shown that the relationship between the caregiver and care recipient is an important predictor of caregiver burden. Survey studies have found that caregivers with a closer relationship, such as spouses, tend to experience higher levels of burden compared to those with more distant relationships, like friends or siblings (Huo & Kim, 2023; Chiao et al., 2015; Andren & Elmstahl, 2007). However, these studies have been limited by not considering the impact of other factors such as age, as the spousal caregivers who participated were often older. Conversely, other research has suggested that younger caregivers may actually experience greater burden, as they have less experience with caregiving and may feel more socially restricted (Andren & Elmstahl, 2007; Kim et al., 2009; McConaghy & Caltabiano, 2005; Sinforiani et al., 2010; Zawadzki et al., 2011). The inconclusive nature of these findings highlights the need for a more in-depth, qualitative exploration of how the caregiver-care recipient relationship and age interact to impact caregiver burden, particularly in the context of CTE. A qualitative approach could provide valuable insights into the experiences of younger CTE caregivers and help elucidate whether the patterns observed in dementia caregiving align with or diverge from the experiences of this population. By listening to the stories and perspectives of younger CTE caregivers, researchers can gain a deeper understanding of what drives their perception of burden, and how factors like relationship closeness and age may play a role. This nuanced understanding could then inform the development of tailored support strategies to address the unique needs of CTE caregivers across different age groups and relationship contexts.

With CTE mainly affecting younger age groups in comparison to other neurodegenerative diseases, it is likely that the primary caregivers for CTE patients will be younger as well. Thus, it is important that we explore the experiences of younger CTE caregivers with varying relationships to the care recipients (i.e., children, parents, siblings, spouses). Undertaking a similar qualitative approach to that of the first study, this research will seek to understand the experiences of younger CTE caregivers. Extending the insights gained from the exploration of older spousal CTE caregivers, this work will aim to elucidate how the caregiving experiences of younger individuals may be similar or different to those observed in other caregiving contexts. By capturing the perspectives of a broader range of CTE caregivers, we can develop a more comprehensive understanding of the factors shaping the caregiving burden and support needs within this population.

7.2 Methodology

7.2.1. Study design and sample

A qualitative research design was used in the present study. Specifically, the researcher recruited participants from the Concussion Legacy Foundations (CLF) family huddle back in February 2022 where they attended a three day conference and spoke to family members. Additional participants were recruited via the CLF database. To allow for an in-depth exploration of the caregivers' experiences, the researcher conducted interviews that allowed the participants to share their stories in the way they felt comfortable in doing so. The participants also needed to meet various inclusion criteria, which included being primary caregivers to individuals, whether currently living or deceased, diagnosed with CTE or probable CTE, must be or have been caregivers to their partners, parents, siblings, or children. Additionally, participants had to be over 18 years old for ethical reasons, possess access to digital equipment for study material access and potential interviews, and be proficient in English.

The final sample consisted of 11 primary caregivers aged 32-42 years old (M=37.5, SD=3.43), all based in the United States. Young-adult caregivers are typically defined as being aged 16-25 (King et al., 2019). However, for this study, the sample is defined as young in relation to the usual caregiving age for those with neurodegenerative diseases. For example, Pickard (2019) suggests being above 60 years old is more ‘usual’ for caregivers. Out of the sample, 10 were female and one male, with 5 being children, 3 were siblings and 3 having a spousal relationship to their loved ones. As this study had no focus on gender influences on caregiving experiences, there were no concerns over the ratio within the sample. 10 of these participants had lost their loved ones to pathologically diagnosed CTE as diagnosed through post-mortem examination (by Boston University brain bank), and one participant was still caring for their loved one with suspected CTE at the time of the interview. Since the interview, this participant's loved one has been post-mortem diagnosed with CTE. The majority of the caregivers had looked after their loved one for 3-8 years (M= 7.5).

7.2.2. Recruitment and access

The study had received ethical approval from the Oxford Brookes University Research Ethics Committee (UREC approval number 211551- see appendix 2). 18 primary caregivers were contacted via email and were presented with the outline of the research project as well as a link to an online consent form. Email addresses were provided by the Concussion Legacy Foundation via their database of people who had indicated that they would be prepared to take part in research. Participants were recruited using a volunteer sampling technique (Alvi, 2016) that matched the relevant inclusion criteria for the study. If participants were interested in partaking, they were encouraged to contact me through the details in the study advertisement sent by the CLF and I then sent over the participant information sheet and consent form for the study. The participants who agreed to take part in the study participated in one online interview, during which they were broadly asked to share their story as a caregiver. Each participant was provided with an outline of the interview aims and process in advance of the interview to allow them time to reflect on their experiences. Only myself and the participant were present at the interview. The interviews lasted between 48 and 97 minutes (M= 72 minutes), were audio recorded via Zoom and transcribed verbatim. Transcriptions were returned to each participant to provide them with an opportunity to verify the content (Braun & Clarke, 2013).

7.2.3. Interviews

The semi-structured interview format was adopted. Due to increasing confidence with the interviewing process, and increased rapport with the sample, the interviews became a little more unstructured. I still asked the initial open ended question of “can you tell me your caregiver story” as this encouraged the participants to lead the conversation and share what they felt comfortable with at the start of the interview. Based on their responses, I then asked appropriate follow up questions such as “can you talk to me about how that particular experience made you feel?” and “what made that time in your caregiving journey so challenging?”. I did have the interview guide from Study One to hand as those questions supported the aim of understanding the caregivers experiences, however I felt confident in allowing the conversation to follow a natural course, thus I rarely referred to the guide.

7.2.4. Data analysis

A thematic analysis was used to generate similarities between the caregivers' experiences. This approach enabled flexibility in the data analysis (Braun and Clarke, 2006). The initial analysis phase involved familiarisation with the data by listening to the audio-recordings and repeatedly reading transcripts to appreciate the depth and breadth of material. Once familiar with all aspects of the data, handwritten notes on the transcripts were made to assist generating an initial list of ideas for coding (i.e. noting down similarities in the data). As I re-read the data to discover other emerging themes and sub-themes, it became clear that there were differing experiences discussed by the child and sibling caregivers compared to those sharing a spousal relationship to the care recipient. During this process I looked for commonalities in the data (i.e. many caregivers spoke about having a new sense of purpose educating others and raising awareness around CTE). These quotations were all grouped together into provisional categories (i.e. a duty to share) to organise the data for the final stages of analysis. Utilising critical friends, discussions were had regarding the coherency of the data. Specifically, the critical friends and I referred back to the data multiple times in order to decide on a thematic structure that effectively presented the caregivers experiences. Our discussions involved talking about the differences between the experiences in this sample in comparison to Study One, did any of their experiences correlate to caregivers in other contexts and what experiences are unique for younger CTE caregivers. Having multiple conversations about the content and presentation of the data ensured representation of the caregivers' stories throughout my provisional themes. The critical friend further challenged me on the theme titles, which encouraged me to revisit the transcripts again and check whether the theme titles summarised the data contents. Consequently, many of the theme titles were re-adjusted to represent the data more effectively. For example ‘damage of exposure’ was changed to ‘seeing children adversely affected’’ as I noticed that the caregivers experienced difficulties in masking the realities of their situation to their young children. After this step, the themes were all finalised and they reflected the researchers interpretation of the data coherently. The finalised themes included; balancing life and caregiving, children adversely affected, coping with personal grief and their children’s grief, challenges of a misunderstood illness and a desire to help others.

7.3. Results

In the upcoming results section, the following five themes of key challenges faced will be presented; balancing life and caregiving, children witnessing behaviours, coping with personal grief and their children's grief, challenges of an invisible illness and the desire to help others. Within each theme, the range of impacts will be highlighted.

Balancing life and caregiving

The majority of the younger caregivers had a range of priorities in life such as looking after their young children, running a home, pursuing their careers, alongside the caregiving role. Many of the caregivers discussed how challenging it was to balance the responsibilities of the caregiving role alongside supporting a family.

"I think I thought it would help to have other things to focus on, like my job and looking after my own little family but I really struggled to balance it all at times. I mean don't get me wrong, I think it was good not to think about caregiving all of the time but it was like working 3 full time jobs all at the same time, I was so exhausted and overwhelmed" (C4)

The caregiver reflects on their attempt to find balance between caregiving, work, and their own family responsibilities. The caregiver initially believed that having other aspects of life to focus on, such as their job and caring for their own family, would provide a welcome distraction from the demands of caregiving. However, the reality proved to be challenging as the caregiver found it difficult to juggle all these responsibilities simultaneously. The caregiver describes the experience to be similar to working three full-time jobs concurrently, leading to feelings of exhaustion and being overwhelmed by the sheer volume of tasks and obligations. Despite the intention to distract themselves from caregiving, it was challenging to manage the multiple roles effectively, highlighting the immense strain and pressure that can come from trying to balance caregiving with other significant responsibilities. One caregiver explained that this balance became more challenging as the role became more demanding;

"Although my brother was my priority, he wasn't my only one. I was building my career, I had just got remarried and had children to look after. Having all of those life roles was challenging to manage, especially when my brother was declining. The more his symptoms progressed, the more demanding caregiving became. CTE puts everything in your life on hold, which is hard to grapple with" (C3)

As the patient's condition deteriorated, caregiving became more demanding, adding to the complexity of balancing all these roles. The progression of their loved ones' symptoms heightened the challenges of caregiving, impacting the individual's ability to fulfil their various responsibilities (i.e work and parenthood) effectively. The quote demonstrates the universal struggle many caregivers face when trying to navigate caregiving alongside other important aspects of their lives, especially when faced with the disruptive impact of a progressive condition like CTE. Although all of the caregivers experienced this struggle to balance multiple roles, some individuals expressed how living with the care recipient makes this feeling more profound. Similarly, another caregiver spoke about the challenge of balancing multiple roles whilst living in the same household as the care recipient.

“I think it helped that I was technically ‘young’ still on the caregiver spectrum if you were to call it that. Like although it was hard, I had the energy to take care of him and work and look after the kids. I mean I understand why my mum struggled so much, she was having her own health issues, she wasn’t sleeping, she didn’t want to burden us. There's definitely such a difference being a caregiver living with the person compared to not” (C10)

Here, another caregiver reflects on the struggle of juggling multiple roles while living in close proximity to the care recipient. The caregiver, being relatively young in the realm of caregiving, found that their energy levels allowed them to care for their loved one, work, and attend to their children effectively. Contrasting their experience with that of their mother, who faced health challenges and sleep issues while trying not to burden the family, the caregiver acknowledges the distinct differences between caregiving while living with the care recipient versus in a separate setting. These quotes provide insight into the complexities and unique dynamics that caregivers face when sharing a living space with those they care for.

The experience of being a younger caregiver for an individual with CTE highlights the intricate balance required to manage diverse roles, including advancing in one's career while tending to the needs of a young family. The demands of caregiving, which necessitate substantial time and emotional investment, often lead many caregivers to experience a sense of being stretched thin and overwhelmed by the weight of their responsibilities. This delicate balancing act underscores the significant challenges faced by caregivers who must navigate the complexities of caregiving alongside other essential aspects of their lives.

Seeing children adversely affected

The impact of the caregiving role on children and the relationships within the family unit is a significant aspect that many caregivers have shared insights on. The challenges and complexities of caregiving often spill over into the lives of children, influencing their emotional well-being, behaviour, and overall development. Caregivers frequently expressed concerns about how their caregiving responsibilities may shape their children's perceptions, coping mechanisms, and future outlooks. The dynamic interplay between caregiving duties, family dynamics, and children's experiences shows the intricate web of relationships and emotions that caregivers navigate while providing care for their loved ones. For example, the following quote illustrates how children viewing behaviours at a young age resulted in long term impacts.

"So yes, the bad side of having three kids is that they witnessed everything. And that does a lot of damage to your children. My two older ones were like 13 and 11 when it started to get really bad. They're 23 and 20, now, my little guy was two. So my youngest son grew up with a mentally ill father, and that was very damaging. He's in a special school now, he's in a therapeutic setting. He couldn't cope even just this morning, because he learned these behaviours from his father. So that's a bad side of having children around because they witnessed it and they pick up those behaviours, and those are learned behaviours, some of your emotional reactions are learned" (C1)

Here the caregiver highlights the significant negative impact that caregiving for a mentally ill family member, in this case, the father, can have on children who witness and grow up in such an environment. The speaker reflects on the adverse effects on their children, particularly the youngest, who has exhibited learned behaviours from the mentally ill parent. The mention of the youngest son being in a therapeutic setting suggests the extent of the challenges faced by the family in dealing with the consequences of caregiving on the children. Evidently, the impact of CTE goes beyond the patient and the caregiver, but also affects anyone within the immediate environment. Caregivers have to manage concerns over their loved ones wellbeing, their own wellbeing, but more significantly, concerns over the potential harm to children's well-being. For many of the caregivers, how this experience was going to affect their own family and children was a big concern.

"I was away from a lot during the most formative years of her life, you know, from about 11 to 14 and there was damage done there that I didn't even realise was happening. There's guilt with that,

because in order to do everything you can do for someone else, you have to neglect yourself, in your own family, sometimes your own little family, right?" (C7)

Clearly there are unintended consequences of the caregiving role that carers struggled to mitigate during their experiences. For this caregiver, they expressed a heavy sense of guilt. This was associated with the realisation that, in the pursuit of providing extensive care for their father, they inadvertently neglected their own family, specifically their young child. The caregivers narrative captures the emotional conflict and sacrifices that these individuals often face, acknowledging the challenges of balancing care responsibilities with personal and family needs, which can lead to unforeseen and lasting impacts on relationships. One factor that proved challenging to these caregivers was trying to communicate with their children about the realities of the situation;

"You know, both of my boys at different times said to me, within probably the last, like 12 years, at separate times, they said to me, when he was just being just, you know, just out of order, they would say, and I just remember it just like was like a dagger in my heart. They said, why would you marry somebody like him? Mom? Why would you marry someone like that? I told them so many times this isn't the man I married, but trying to give a reason why to your kids when you don't even know the answer was so so hard" (C8)

Despite the caregiver's efforts to justify her decision to her children, she found it challenging because she herself didn't have a clear answer as to why her husband changed. This illustrates the challenging task young caregivers face in communicating information to their children when they lack a clear understanding themselves. Specifically, caregivers had to find an equilibrium between telling their children the truth, but also protecting them from the realities of the situation;

"I didn't understand what was going on, so how was I supposed to tell my six year old and eight year old what was wrong with dad, and why dad was acting weirdly. You are torn between not wanting to hide anything from them, but also protecting them from the realities of what was going on. It's not like I could ask my husband what to do as he wasn't in his right brain, so it was a hard situation to be in and I was not sure what decision was the right one" (C2)

Here, the caregiver further expresses a sense of confusion and uncertainty about how to communicate with their young children regarding their father's unusual behaviour. The difficulty arises from the caregiver's lack of understanding of the situation and the challenge of protecting her children from the harsh realities of their father's condition. The caregiver acknowledges the dilemma of wanting to be transparent with her children while grappling with the absence of guidance from her husband, who is not in a mental state to offer support or advice. This captures the emotional and practical challenges faced by the caregiver in making decisions about how to address the situation with her young children.

The impact of caregiving on children and family dynamics is a significant concern among caregivers, with the challenges extending to the emotional well-being and development of children. Younger caregivers, in particular, face the added complexity of addressing these issues with their children. The narratives underscore the unintended consequences of caregiving, revealing how children witnessing a mentally ill parent can have lasting effects. Young caregivers express worries about the potential harm to their children's well-being and future outlooks, recognising the sacrifices made in balancing care responsibilities with personal and family needs. Communication with children about the complexities of the situation proves challenging, reflecting the emotional and practical difficulties faced by younger caregivers. The narratives highlight the challenges of being a younger caregiver go beyond impacting the caregiver themselves, but their children too.

Coping with personal grief and their children's grief

With individuals being young on the caregiving spectrum, many discussed the feelings of grief they had towards the loss of their futures. This was not only true for the caregivers, but for their children as well. The caregivers articulate the challenges they and their children faced in grieving for their fathers/grandfathers.

"I was struggling to let go of the life I thought me and my husband were heading towards, but at the same time my kids had lost their dad. They had their own little plan in their heads of fun things we were going to do as one big family, vacations we had spoken about. Losing a spouse is heartbreaking, but watching your kids lose their father is even harder. We were grieving for him, and the forever change in our lives" (C12)

This reflects the emotional struggle and heartbreak experienced by a caregiver who is not only mourning the loss of their spouse but also witnessing the profound impact on their children who have lost their father. The caregiver grapples with the difficulty of letting go of the envisioned life they had planned with their husband and the shared dreams of family vacations and future experiences. This captures the deep grief and the significant, irreversible change that has occurred in the family's life, as a ramification of CTE. The caregiver emphasises the pain of watching one's children cope with the loss of their father, adding an extra layer of emotional complexity to their caregiving experience.

Similarly, another caregiver discusses the challenges of managing grief for themselves and their young children.

"I was struggling to process it all at 35 years old, but how are a 5 year old and a 8 year old meant to deal with it? That was probably the hardest challenge throughout this process as I had to support them in a different way to how I was trying to support myself. I think I grieved all over again just watching them lose their dad" (C9)

The caregiver reiterates the heightened difficulty of supporting and guiding their young children through the process. The narrative highlights the profound impact being a younger caregiver, and having young children has on processing this experience. Specifically, the caregiver acknowledges that in addition to grappling with their own grief, they are confronted with the heartbreaking task of witnessing and helping their young children cope with the loss of their father. The caregiver highlights the unique and complex layers of emotional burden that come with caregiving, particularly when children are involved, adding another dimension to their caregiving responsibilities.

Evidently, it is extremely difficult to grieve for a partner, but supporting young children grieve for their fathers is a different challenge that many of the caregivers struggled to navigate.

"My youngest, he was 6 at the time, kept on asking me 'where's dad' and 'when's dad coming home' and I just didn't even have the words, like what are you meant to say to that. I was heartbroken to lose my best friend, my soulmate but gosh that pain I felt when I had to try and tell my kids, I never want to feel that again" (C11)

The emotional weight and heartbreak experienced by the caregiver is evident here. The caregiver's words capture the complex challenges of grief, which were heightened through supporting their children through the process of loss too. One caregiver further explained how supporting their children through the grief of their fathers, accelerated their own grief.

"Anyone who has been through this knows how tough this situation is, but having young children in the environment too just is so so hard. My kids always come before me right, so when we lost him I couldn't even think about myself, I just had to be there for them, but looking back it definitely made the whole thing harder to process as I was taking on my children's grief on top of my own, it's a lot of emotion for just one person" (C7)

This caregiver expresses the priority of placing their children's needs above their own, highlighting the inherent selflessness in caregiving. Despite this commitment, the caregiver acknowledges the toll it took on their own ability to process the situation. Taking on the grief and emotions of their children, in addition to their own, made the entire experience even more emotionally demanding. This narrative demonstrates the multifaceted nature of caregiving, where the caregiver must not only cope with their personal grief but also provide support and understanding to their children, amplifying feelings of burden.

Overall, facing the loss of their loved ones, evokes feelings of heartbreak and sadness, particularly for caregivers who grapple with the realisation that their anticipated futures are no longer attainable. Whilst comprehending this reality is challenging for the caregivers, the difficulty lies in supporting their children through the grieving process too. Caregivers find themselves mourning not only the envisioned future with their partners but also the life they had envisioned for their children, as they grow up.

Challenges of a misunderstood illness

Many caregivers experienced times of extreme loneliness and isolation throughout their caregiving roles. The majority of caregivers said these feelings were encouraged due to the lack of support they received from friends, family and health care professionals. Specifically, the caregivers explained their struggles of getting others to understand what their loved one was going through. Here, they explain the difficulties of caring for an invisible illness and how that impacted their feelings of loneliness.

"I can't explain how challenging it was trying to just get people to understand what was happening. That is one huge downside about CTE being in younger people, is that no one associates young people to have these sort of memory issues, behavioural issues and everything else"

The caregiver highlights that the lack of awareness or understanding from others about CTE in younger individuals adds an additional layer of difficulty for the caregiver, as they face the challenge of breaking preconceived notions and educating those around them about the realities of the condition. Similarly another caregivers discussed the challenges of having a young diagnosis;

"And it's really hard to deal with CTE when you're younger, because especially, you know, medical professionals wouldn't take us seriously, no one believed us because physically health wise, again, you know, my, my husband was a really good, you know, specimen of a human being right, like on the outside" (C4)

Evidently, being a young patient and a young caregiver adds to the complexity of CTE. The caregiver expresses the challenge of being taken seriously by medical professionals and others because the affected individual, in this case, the caregiver's husband, appeared physically healthy on the outside. The emphasis on the individual being a "good specimen of a human being" highlights the disconnect between the visible physical health and the hidden, yet significant, impact of CTE on cognitive and behavioural functions. The quote suggests that the external appearance of well-being can create scepticism regarding the presence and severity of CTE, making it challenging for caregivers to convey the complex nature of the condition to medical professionals and others. Due to this "invisibility" of CTE (i.e. you cannot tell from the outside the person is struggling), caregivers were left with inaccurate diagnosis, which fuelled feelings of frustration and isolation.

"Every other doctor that he saw, and he saw dozens just told him to stop drinking and grow up" (C2)

Here, the caregiver highlights the challenges faced by both themselves and the patient in receiving appropriate understanding and support from healthcare professionals. This suggests a lack of nuanced understanding and a tendency to oversimplify the complex issues associated with the condition. The response implies that the medical professionals may not have fully grasped the multifaceted nature of the challenges presented by the condition. However, the poor understanding and support from those in the medical profession extended to the caregiver too.

"All three psychiatric neurologists that we had, they didn't understand the caregiver or how bad it really was. All I needed someone to say was I know what you're going through, that's it, as simple as that" (C3)

The caregiver expresses a need for understanding and empathy for the challenges they were experiencing navigating care for their loved one. This highlights the emotional and psychological strain on caregivers who, besides dealing with the practical aspects of caregiving, also grapple with a sense of isolation and a lack of empathetic support from healthcare professionals.

Similarly another caregiver said;

"It is exhausting going from doctor to doctor just to be told that your loved one is an addict or is just mentally unstable, like we went through so many without getting any answers, I started questioning myself, like am I making this all up? It so horrible to feel like that, just completely lost and helpless" (C10)

Many caregivers experienced profound loneliness and isolation during their caregiving roles, exacerbated by a lack of support from friends, family, and healthcare professionals. This isolation was fueled by the difficulty in making others comprehend the invisible nature of CTE in younger individuals. Younger caregivers faced unique challenges as they had to break stereotypes and educate others about the cognitive and behavioural impacts of CTE, especially when the affected individual appeared physically healthy. The invisibility of CTE resulted in inaccurate diagnoses, intensifying feelings of frustration and isolation.

Desire to help others

Many of the younger caregivers, driven by a sense of inspiration, actively share their personal experiences to educate others about CTE and its realities. Their heightened awareness of the increasing diagnosis of CTE impels them to urgently advocate for their stories, aiming to garner support and raise awareness about the condition. Beyond aiding others, many participants note that this sharing process serves as a therapeutic outlet for themselves.

"CTE awareness slaps me on fire, man, it lights me on fire, because this is going to help an entire this is going to help humanity, right? Like this changes the face of what we have known. It's like the

beginning of something so big, and I won't live long enough to see the big change. But to know that I'm this little bitty tiny part of it, likes my fire. And it isn't an ego thing. It's giving back. So my job is to pay it forward. And there's something about it that, like I said, it just kind of lights it lights a fire in me. It's it just gets me out of bed in the morning" (C7)

Particularly with the lack of current information and support for CTE caregivers, many participants emphasised the importance of sharing their experiences as a valuable source of education for others. Caregivers even articulated how the process of sharing served as a source of relief for them on occasions too.

"It's funny because when you're in the situation, you almost predict how you think you are going to react etc when your loved one goes but I really surprised myself. I feel like I have this duty to share my brothers story, like I have a complete new purpose in life and I think that has really helped me since he passed away" (C4)

This demonstrates how the impact of grief is so subjective. The caregiver was surprised by a newfound sense of duty to share their brother's story. This sense of purpose has become a source of strength for many of the caregivers in coping with the loss. Specifically, another participant explained how sharing helped them process their own grief;

"*I know my dad would have wanted me to advocate, but after he passed I just felt this overwhelming sense of purpose to raise awareness and speak about what we had gone through. I thought I was going to find it too hard to speak about what happened, and there are times where I am like man this just brings it all back..but sharing has actually helped me. Like it has helped me go through each stage and process it all. It's my therapy" (C3)*

The significance of sharing experiences is unmistakably crucial for caregivers dealing with CTE. Some find therapeutic value in openly discussing their stories and challenges, while others transform their difficult experiences into a newfound sense of purpose by advocating for and supporting those facing similar situations.

7.4. Discussion

This study explored the experiences of younger CTE caregivers. Some of the key findings emerged from this study include the differences in experiences for young spousal caregivers compared to young adult children and sibling caregivers, the challenges of navigating an invisible illness and the complexities of bringing up a young family alongside the caregiving role. In this section, I will briefly explore these primary findings and elucidate the similarities and differences observed between these younger CTE caregivers and those caring for individuals with Dementia.

With the majority of the caregivers balancing parenthood alongside caregiving responsibilities, one of the key findings from this study was the impact on the caregivers' children. Managing impressionable young children proved extremely challenging for CTE caregivers, as they had to strike a delicate balance between acknowledging the situation and shielding their kids from its realities. These caregivers were not only concerned about how their own experiences affected their well-being but also about the impact on their children. Despite their efforts, caregivers realised they could not shield their children from all the challenges, particularly as they were living with the care recipient. Consequently, the roles of CTE caregivers extended beyond the passing of their loved ones as they supported their children through grief. This impact on the wider family, in particular their children, is a finding that has not been examined in Dementia caregiving contexts. This will be revisited and discussed in greater depth within the general discussion.

Furthermore, we observed differences in the experiences of young spousal caregivers compared to those of young adult and children caregivers. Specifically, younger spousal caregivers faced challenges in managing multiple roles, such as being both a caregiver and a parent. Many of these caregivers experienced role overload, struggling to cope with the various demands placed upon them, resulting in additional burden and psychological distress (Iwata & Horiguchi, 2015). Conversely, many non-spousal caregivers found having multiple responsibilities beneficial as it provided them with an outlet away from caregiving. While research in Dementia caregiving contexts has shown a positive relationship between work demands and caregiving burden, the implications of multiple roles, such as parenthood, have not been extensively studied in these contexts. For instance, a study by Ploeg et al. (2020), focusing on older Dementia caregivers, highlighted the challenge of balancing family and work commitments, with some participants expressing they felt sad at not being able to spend as much time with their children or grandchildren due to the intensifying demands of caregiving. However, this research did not explore the mental and emotional impact this had on the caregivers. This might be attributed to the fact that Ploeg's (2020) study exclusively targeted older caregivers, whose caregiving roles and experiences may vary significantly from those of younger caregivers. Nonetheless, such comparative research has not been conducted within the realm of Dementia caregiving contexts. Therefore, it remains uncertain whether the challenge of managing multiple roles is unique to younger caregivers in general or specific to younger CTE caregivers. Further investigation is needed to discern why this emerged as a prominent finding among younger caregivers in contrast to older spousal caregivers in Study One, a topic that will be explored in greater detail in the general discussion.

The findings illuminate the challenges inherent in caring for individuals with an 'invisible' illness. Similar to Dementia, the symptomatology of CTE lacks physical detectability, leaving caregivers grappling with the search for answers and appropriate support for their loved ones. While research has addressed the feeling of invisibility and neglect experienced by those with a Dementia diagnosis (Hutchinson et al., 2018), little attention has been given to understanding its impact on caregivers. Particularly due to the limited medical knowledge surrounding CTE compared to Dementia subtypes, misconceptions about CTE are often compounded by misdiagnoses from medical professionals, as highlighted in our findings. Within our study, caregivers reported having to navigate their loved ones being diagnosed with addictions or various forms of mental illnesses due to disbelief that a physically fit individual could be experiencing neurodegenerative symptomatology (Hale & Marshall, 2017). This led to ineffective treatments, poor symptom management, and frustration for caregivers. Consequently, caregivers experienced a heightened sense of isolation as the broader community may not fully acknowledge the difficulties they face. While some may argue that caregivers of individuals with early-onset Dementia also navigate multiple roles while coping with an 'invisible' illness, the crucial distinction lies in the availability of informative resources and education. With Dementia diagnoses widely understood, caregivers have access to more resources and support groups, enabling them to seek external assistance in managing the burden of caregiving responsibilities (Chiao et al., 2015; Stokes et al., 2014) – a luxury currently unavailable to CTE caregivers. This complex interplay between navigating a misunderstood illness without support is something I will refer to in more detail in the general discussion.

Given that both older and younger caregivers faced an array of challenges including struggling to navigate medical support due to misunderstandings around CTE, balancing multiple roles and learning how to support young children in a caregiving environment, the scarcity of support and resources further compounded their struggles. Thus, there is a need for further research to consider how support can be offered to this specific group of caregivers, to provide resources to aid CTE caregivers throughout their journeys.

CHAPTER 8- Study Three

Creating and disseminating a supportive resource

8.1. Introduction

Study One and Study Two both provided insight into the ways in which CTE caregivers felt unsupported during and after their roles. Although the experiences of older spousal caregivers shared overlaps with caregivers in Dementia contexts, the lack of information and CTE specific resources available to these caregivers heightened feelings of isolation and confusion in their post-caregiving trajectories. With the younger CTE caregivers, their necessity for support, resources and information came from experiences of being misunderstood by medical professionals and consequently the misattribution of symptoms to other causes (i.e. addiction). Consequently, having a supportive resource specific to CTE caregivers, that provides information, guidance, and emotional support, may help caregivers cope with the challenges of caregiving, reduce feelings of isolation, and enhance their overall well-being.

Adapting to the evolving challenges of caregiving for individuals with neurodegenerative decline necessitates continuous adjustments in roles and responsibilities. Dementia caregivers have found varied support methods beneficial in navigating their changing roles. Interventions targeting caregiver mental health, such as behavioural approaches (Selwood et al., 2007), relaxation, and cognitive-behavioural therapy, have shown significant improvements (Carter et al., 2020; Hopkinson et al., 2019). Psychosocial care interventions involving facilitated peer support have also proven effective in reducing caregiver psychosocial stress (Cheng et al., 2019). Utilising other caregivers as peer support has notably alleviated caregiver burden and feelings of isolation. This highlights the importance of exploring alternative methods for caregivers to access peer support without the need for regular contact with fellow primary caregivers, addressing their need for empathetic connections and shared experiences.

One accessible way caregivers could access peer support is through a podcast. The inherent accessibility and convenience of podcasts allow caregivers to obtain support and information at their preferred time and place (Sutton-Brady et al., 2009). Considering the time constraints faced by caregivers with multiple responsibilities, traditional face-to-face support groups can pose challenges, as observed in the struggles of dementia caregivers (Dam et al., 2016). Podcasts offer an educational and easily accessible format, and the flexibility in accessing them caters to the time-restrictive schedules of primary caregivers (Fauth et al., 2012;

Pimmer et al., 2012). In the context of limited caregiving information on CTE, a podcast platform where caregivers share their stories may foster a sense of community and mitigate feelings of isolation, aligning with Ducharme et al. 's (2011) suggestion to normalise situations and create a sense of belonging. Integrating real-life caregiver narratives with educational resources, coping strategies, and practical tips in podcast content may also support caregivers to navigate the complexities of caring for someone with CTE, enhancing their personal well-being and caregiving skills. Thus, the podcast could serve not only as a source of peer support for caregivers but also as an educational tool, helping both current and future caregivers learn how to better support loved ones experiencing suspected CTE symptoms.

From a health education perspective, podcasts could play an important role in providing caregivers with the knowledge and skills needed to make informed decisions about their caregiving roles (Sharma, 2021; Whitehead, 2004). Effective health education has the potential to enhance caregivers' understanding of CTE, help them manage stress, prevent burnout, and improve their caregiving practices (Heisler, 2010; Souza et al., 2007). Given that many CTE caregivers feel misunderstood by healthcare professionals, podcasts featuring expert advice from neurologists, doctors and healthcare specialists may help bridge this gap. This approach aligns with Freire's (1970) participatory education model, which emphasises interactive learning, encouraging caregivers to engage with the material and apply it to their real-world experiences. Creating a two-way interaction between caregivers and experts could transform the podcast into an actionable health communication resource, equipping caregivers with both medical insights and practical caregiving strategies. Hopefully, this educational approach may help alleviate the caregiving burden that many experience both during and after their caregiving roles.

In addition to education, podcasts also have the potential to promote health literacy, a key component of effective caregiving. Health literacy is defined as the ability to obtain, process, and understand basic health information (Institute of Medicine, 2004). By offering accessible and comprehensible information about CTE and practical caregiving strategies, podcasts could enhance caregivers' ability to make informed decisions and navigate complex healthcare systems. Research findings have suggested that health education delivered via digital media, such as podcasts, can improve health outcomes and increase patient satisfaction (Gagliano, 1988; Keleher & Parker, 2013). Narrative-based health education, where caregivers share their lived experiences, can offer a contextualised and relatable form of learning that makes

the educational content more applicable to real-life situations (Greenhalgh et al., 2016). The inclusion of real-life caregiver stories in podcasts may help normalise caregiving challenges, foster emotional support, and build a sense of solidarity among caregivers (Ducharme et al., 2011), further supporting both emotional and practical aspects of caregiving.

Lastly, advocacy could be a crucial function of a podcast, as it offers caregivers an opportunity to raise their voices and push for systemic changes in medical and social support systems, aligning with Christoffel's (2000) definition of public health advocacy. This type of advocacy is particularly important for CTE caregivers, many of whom report feeling isolated and misunderstood both during and after their caregiving roles. The lack of recognition and support can leave caregivers marginalised and without the resources they need. By hearing from others who have faced similar challenges, caregivers may gain therapeutic benefits and find the emotional and practical support they have been missing. Sharing personal stories on a podcast could not only raise awareness about the unique struggles of CTE caregiving but also serve as a powerful tool for advocating for greater recognition of caregivers' needs and more tailored resources.

This study aimed to explore the efficacy of a podcast-based resource in supporting the well-being of CTE caregivers, recognising the vital role of accessible and convenient peer advice for caregivers' mental and emotional health. This innovative approach involved creating and evaluating a podcast as a supportive resource, featuring caregiver experiences, insights from neurologists/doctors, and fostering community connection. The evaluation contributes valuable insights for the ongoing development of supportive tools tailored to the unique needs of CTE caregivers. Overall, the aim of the current study was to examine the dissemination of this resource, in order to understand how it might provide them support. A further aim was to consider the content and format of the podcast in considering how it might be developed further to enhance this as a resource to support family members in the future.

8.2. Methodology

8.2.1. Study design and sample

A qualitative research design was adopted in the present study. To explore the caregivers' experiences, I disseminated an initial survey and a short follow-up interview. The survey responses, although not utilised in the analysis phase, were implemented to get initial feedback on the format of the resource, its usefulness and accessibility. The follow up interviews aimed to explore the participants' responses further. A thematic analysis was used to uncover key themes and insights related to the experiences, needs and perspectives of the caregivers. The participants also needed to meet various inclusion criteria, which included being primary caregivers to individuals, whether currently living or deceased, diagnosed with CTE or probable CTE, must be or have been caregivers to their partners, parents, siblings, or children. The participants were a mixture of the participants (both younger and older) from the first two studies of the thesis. Additionally, participants had to be over 18 years old, possess access to digital equipment for study material access and potential interviews.

The final sample included 20 primary caregivers aged 32-80 years old (M=45.5), all based in the United States. Out of the sample, 18 were female and two were male. 13 were spouses, 5 were children and 2 were siblings to the care recipient. All of these participants had lost their loved ones to pathologically diagnosed CTE as diagnosed through post-mortem examination (by Boston University Brain Bank). The caregivers had looked after their loved one for 4-12 years (M=8).

8.2.2. Recruitment and access

The participants for this research were recruited through a volunteer sampling method to ensure their genuine interest in the research aims and to minimise the potential for harm, especially given the sensitive nature of the topic and the potential for emotional distress. Individuals who are part of the Concussion Legacy Foundation (CLF) database and have expressed interest in participating in research were sent advertisements and asked to contact the researcher if interested. There was no coercion from the CLF to the research participants, and those who opted in were selected based on their voluntary expression of interest. Once participants expressed interest, they received the participant information and consent sheet from the researcher to confirm their eligibility and willingness to participate.

The study had received ethical approval from Oxford Brookes University (231681- see appendix 5). The participants were recruited from the CLF database and the participants of studies 1 and 2 of the researcher's PhD project. Among the reselected participants, all of them were primary caregivers to someone with suspected or diagnosed Chronic Traumatic Encephalopathy (CTE). Notably, 12 of these participants were female spousal caregivers, aged between 60-87 years old (M=72, SD=7.26), with over 10 years of caregiving experience. The remaining 12 participants, aged between 35-59 years old, included 11 females and one male, with 5 being children, 4 siblings, and 3 spouses to their loved ones. Eleven of these participants had lost their loved ones to pathologically diagnosed CTE, while one participant was still caring for their loved one with suspected CTE. The majority of the caregivers had provided care for 3-8 years. All participants, even those who had previously consented for other research tasks, were required to provide explicit consent for their participation in this specific study due to its distinct nature and potential emotional impact. Once consent had been provided, two podcast episodes (averaging 40 minutes each in length) to listen to were sent to each participant. The development and assessment of the interventions will be discussed below.

8.2.3. Development of the intervention

It was important to provide the participants with varied resources, so we could evaluate which content was most effective for the caregivers. After the consent forms were returned, two podcasts were sent to the participants. I had created a podcast series prior to the study with my co-host who was a former primary caregiver to her spouse living with CTE. Initially, our aim was to establish a platform where individuals could freely share their stories. However, as I progressed with my current research and explored supportive tools available in other caregiver contexts, it became evident that the podcast could serve as a valuable supportive resource for caregivers. This realisation was further reinforced by feedback from caregivers who participated in the podcast discussions, expressing how the experience positively impacted them. Thus, the podcast emerged not only as a means for storytelling but also as a potential avenue for offering support and assistance to caregivers. Howeverfor this research project, I developed new episodes. This approach ensured that the podcast content directly resonated with the focus of the research, offering insights and support relevant to the participants' experiences and challenges as spousal caregivers for individuals with CTE. The focus of the current study involved evaluating these two specific episodes. To ensure ethical practices in the podcast production, consent was obtained from the two podcast guests prior to recording. Each guest was provided with a consent form outlining the purpose of the podcast, topics to be discussed, and their rights regarding the recording and distribution of the episode. Additionally, consent was sought from my co-host, who was a former caregiver to her partner. As a co-host and a participant in the podcast, she was also required to provide informed consent, acknowledging her role in the discussions and the recording process. Two podcast episodes with different formats were created.

Podcast 1

Within the first episode, I was joined by a caregiver who shared their story of caregiving for her husband, who passed away with diagnosed CTE 8 years ago. The caregiver shared her unfiltered perspective of the joys, challenges and struggles she went through during her caregiving journey. This episode was less about me asking probing questions, but instead allowing the caregiver to share their story in any way they wanted to. For this individual they started by speaking about how their life was before caregiving to demonstrate how much CTE impacted their lives. However, the few questions I did ask were formulated based on responses from participants in Study One and Two. In both studies caregivers emphasised the sentiment that "people don't understand what this is like until they go through it themselves," highlighting the isolating nature of their experiences. Thus, I asked questions such as “how did you alleviate the loneliness” and “how did you feel most supported” to increase understanding into their coping mechanisms and how they alleviated caregiving burden. I aimed for this episode to serve as not only a platform for caregivers to resonate with similar experiences and as a means for them to feel connected to a community and less isolated by hearing someone else navigate similar challenges, but also to help provide practical tips and suggestions for current caregivers.

Podcast 2

During this podcast episode, I was joined by a doctor who offered valuable clinical insights into CTE. In both Study One and Study Two of my research, caregivers consistently highlighted the significant impact of lacking medical support in their caregiving journey. This recurring theme underscored the importance of addressing this within an intervention programme. Consequently, it became imperative to design a podcast episode specifically tailored to meet the needs of caregivers who struggled with this challenge. Over the course of 30 minutes, we delved into a comprehensive discussion, exploring various aspects of CTE, including its aetiology, symptoms, diagnostic criteria, treatment options, and prognosis. We also had a 5 minute question and answer session whereby the doctor answered various questions sent in by the caregivers (i.e. is there a way we can naturally treat CTE symptoms? And “how do SPECT scans work?”). The doctor's expertise and firsthand clinical experience enriched the conversation, providing listeners with a deeper understanding of the complexities surrounding CTE.

8.2.4. Evaluation of the podcast

Alongside the episodes, participants received a short survey through a Google Form link (please see Appendix 6) that included a mix of open and closed questions to assess the effectiveness of the podcast and that helped to stimulate interview questions. Within the survey, participants were asked, via the Google Form link, if they were willing to take part in a brief follow-up semi-structured interview lasting around 30 minutes. It is worth noting that participants who expressed interest in the interview were requested to contact me directly via email, rather than providing their contact details in the form (to prevent linking identifiers to their survey responses). During the interview, I delved deeper into the participants' survey responses. The development of the interview guide and survey is discussed below.

8.2.5. Pre-interview survey

The purpose of the survey was to help stimulate interview questions. Questions within the first part of the survey were formulated to ask participants their initial thoughts on the podcast and how accessible they found it (for example; “Do you find podcasts to be a useful source of information” and “how often would you listen to CTE Talk?”). The survey then focused on more specific details of the podcast (i.e. what did you enjoy the most about our episodes? Which of the topics discussed did you find most useful? Which style of podcast did you enjoy the most- i.e. interviews with family members or open topic chats with hosts). Through asking these aforementioned questions, I gathered some initial feedback regarding the participants' thoughts on the podcast content. This meant I was able to question this element more deeply in the interview stages, and ultimately advise development of the podcast to make it more effective for caregivers.

8.2.6.Interviews

18 caregivers participated in the follow-up interview. As the purpose of the interview differed from study one and two, I decided to undertake two pilot interviews to ensure the interview guide contained questions suitable to the research aims. Only the researcher and the participant were present at the interview. The interviews lasted between 25 and 52 minutes (M=32), were audio recorded via Zoom and transcribed verbatim.

The first stage of the interview was an introductory stage, focusing upon providing the participant with the purpose of the study, and providing information to them regarding disclosure of their anonymity and confidentiality. The next stage of the interview was focused upon the accessibility of the podcast, and how easy/challenging the caregivers found it to incorporate it into their days (i.e. How easy/challenging did you find it to incorporate listening to the podcast into your day? What were the benefits? What were the hindrances?). These questions were based on the work of Rockhill, Pastore & Johnston (2019) who investigated the effectiveness of podcasts in sports management education (particularly focusing on accessibility benefits). Next I went on to explore the mental/emotional outcomes of the podcast (for example; “To what extent did you feel listening to the podcast helped you with any symptoms of caregiver burden i.e. anxiety, loneliness or loss of purpose and “What emotions did you feel whilst listening to the podcast?- did it provide more positive or negative emotions? What were they and why?). These questions were formulated based on the outcomes of Study One and Study Two. These studies focused upon understanding the CTE caregiver experience and found the most significant factors in causing caregiver burden. Through this stage, I gained an understanding of (if so) what elements of the podcast targeted these significant factors (determined in Study One and Two). Additionally, through these questions I was able to gain an understanding of how the participants felt during and after listening to the podcast episodes, which helped to formulate the next question; “At what stage of the caregiving role do you think having this supportive intervention would be most beneficial to you? (i.e. Do you think this is more helpful to you during your life after caregiving? Or do you think this would be more beneficial during the caregiving role? If so, why?). This question was also asked based on the work Petursdottir et al., (2020) who stated the importance of implementing caregiver interventions before/during and after loss, to minimise symptoms of those who are experiencing a high level of grief.

The last stage of the interview was focused upon feedback (i..e “Would you recommend this to a fellow caregiver, or someone who may go through it in the future? If so, why? / If no, why? And “In your opinion, what would make the podcast a more effective tool to support you as a caregiver?” - i.e. shorter/longer episodes, having certain guests on- I.e. doctors/family members). Lutz et al., (2015) explains the importance of user-focused feedback in making more effective supportive tools, thus these questions were asked to advise development of the intervention to help target greater aspects of caregiver burden. Following this, an opportunity for myself or the caregivers to ask any additional questions/make any further responses was provided. Once the semi-structured interviews with all the participants were completed, transcription began.

8.2.7. Data analysis

A thematic analysis was undertaken (Braun and Clarke, 2006). When reading the data and deriving initial codes, I was searching for the two focuses of the research question. Firstly, I coded the data based on the participants' responses to the podcast's content, exploring their reactions and emotions. I wanted to understand the impact of the podcast on the caregivers during the listening process. Secondly, I coded the caregivers reflections and thoughts on the overall presentation of the podcast, including their perceptions on format, structure and style. After transcripts were read numerous times, codes were generated based on the participants' reactions from listening and perceptions on the podcasts format. Codes were generated into provisional themes, which were reviewed by critical friends who questioned the organisation of the data and theme titles. I had titled one provisional theme “finding gratitude and hope”, however my critical friend questioned whether these were more outcomes of reflection. We collaboratively decided that “promoting reflection” was more appropriate for demonstrating the outcomes of listening to the podcast on the caregivers. Based on the research question, there are two overarching categories; i) around the content and the impact it had, and ii) around the format. Within the first category we developed the following four themes; promoting reflection, considering experiences in context, moving from loneliness to connection and creating a sense of hope. Within the second category, we present the following three themes, flexible support, the power of narratives and enhancing the podcast.

8.3. Results

In the results section, the findings are organised into two overarching categories, providing a comprehensive analysis of the caregivers' experiences after engaging with the two podcasts. The first overarching category covers the caregivers' responses to the content of the podcast, exploring their reactions, emotions, and insights, with particular focus on how it offers support. This section aims to capture the immediate impact of the podcast on caregivers during the listening experience, and within this, themes were developed. The second category focuses on caregivers' reflections and thoughts regarding the overall presentation of the podcast. This includes their perceptions of the podcast's format, structure, and style, shedding light on how these aspects influenced their engagement, and within this, themes are presented. A third overarching category about elements to consider how to improve the podcast further is also presented.

Caregiver responses to the content

In this section, I present four themes that emerged from the caregivers' responses, providing insights into their experiences with the podcast.

Promoting reflection

As the caregivers engaged with the podcast, they frequently expressed that it transported them back to their own caregiving experiences, prompting a deep introspection into their personal journeys. For most caregivers, the podcast enabled them to have a period of reflection that they hadn’t engaged with before. Having this time to reminisce on their experiences and role as a caregiver encouraged a range of positive outcomes. Feelings of gratitude, connection and hope were extremely prevalent

"It really provided me a time to reflect, which I feel like I've not done since my husband passed away. Although it was emotional going back to that time, it helped me to to remind myself that none of this was my fault and I really needed that reminder" (C7)

The quote signifies how the podcast prompted the caregiver's self-reflection, offering a dedicated time to revisit their caregiving journey. Despite the emotional challenges, it provided a crucial reminder that the difficulties faced were not their fault, serving as a therapeutic tool. Another caregiver describes how this self-reflection is encouraged by listening to someone share similar experiences;

"As a CTE caregiver, hearing the raw, unfiltered stories of others in similar roles through the podcast became a powerful catalyst for self-reflection. It was a reminder that our stories, though they are unique and different in so many ways they also do share a common thread of strength and compassion" (C3)

Engaging with the podcast and hearing unfiltered stories from others who have experienced a similar situation, served as a catalyst for self-reflection. The narratives shared through the podcast served as a reminder that, despite the unique and diverse aspects of each caregiver's story, there exists a common thread of strength and compassion that binds them together. Similarly another caregiver discussed how it prompted her to revisit her own story;

"When you have gone through something so challenging and difficult, it can be easy to just block it out of your brain and almost avoid ever going back to that place mentally, I think I was scared to do that..but hearing another caregiver share their story, naturally made me reflect and go back to that place and it made me realise how important it is to do that, to help process everything. It went from being something I was scared to do, to being a therapeutic experience" (C5)

Here the caregiver explains how they were able to find strength in reflecting on their own experiences through hearing another caregiver's story. The process, initially feared, turned into a therapeutic experience, emphasising the importance of revisiting and processing challenging memories for personal growth and understanding. Evidently, the narratives served as a reminder of shared strength and compassion among caregivers, fostering a sense of solidarity and reinforcing commonalities in their journeys.

Overall, the shared sentiment among these quotes highlights the profound impact of the podcast on caregivers, emphasising a collective experience of not feeling alone in their CTE caregiving journey. Unlike other Dementias with established communities and support groups, CTE caregivers may lack such resources. Thus, the podcast can serve as a crucial avenue for caregivers to connect with shared struggles, fostering a sense of validation, understanding, and community. This shared experience proves beneficial, offering a therapeutic outlet and encouraging caregivers to reflect on and share their own stories.

Considering experiences in context

Some caregivers, upon engaging in self-reflection prompted by the podcast, expressed that this introspective process instilled a sense of gratitude regarding their own caregiving experiences. The act of revisiting their journeys through the lens of others' stories allowed them to recognise the unique aspects of their own challenges and triumphs. Considering their own experiences in context to another caregivers story encouraged feelings of gratitude, stemming not only from acknowledging the strength and resilience exhibited in their personal caregiving narratives but also from the realisation that their individual stories contribute to a broader experience of shared struggles and support within the CTE caregiving community. For most caregivers, hearing someone else's challenges made them grateful positive aspects of their own caregiving experiences;

"Listening to that story did bring up a lot of emotion as naturally it took me back right to those years I was caring for my partner. But wow it did make me realise that actually we had it rather easy compared to others, our ending was much more peaceful and listening to someone else story made me so grateful for that" (C12)

The quote reflects how listening to a caregiver's story on the podcast evoked emotions by revisiting the speaker's own caregiving years. Despite feeling emotional, it led to the realisation that their own caregiving experience was comparatively easier. This triggered a deep sense of gratitude for their unique journey. Similarly one caregiver discussed how self-reflection validated their feelings;

"After listening to the podcast I found myself reflecting on my own experiences. Just hearing someone else go through it and almost getting that validation that the way I felt and maybe reacted

at times was completely understandable. It sounds silly but I actually just really needed that time to let myself do that reflection" (C6)

The validation from hearing someone else's similar journey provided understanding for their own emotions and reactions. This reflective moment was deemed essential, emphasising the significance of the podcast in fostering a sense of understanding and acknowledgment for the caregiver's feelings and responses. Similarly, another caregiver alluded that listening to the podcast provided a sense of being heard;

"For the first time ever I felt heard, and I am so grateful for that, grateful for my own experiences, as it made me realise wow some people have it way worse. I think just hearing someone else speak about the struggles and challenges I dealt with, allowed me to reflect and realise I did everything I could for my partner at the time and actually it encouraged me to speak about my own story more. I think there is just something quite therapeutic about doing that, which I wouldn't have done without listening to this podcast" (C5)

The feeling of gratitude is expressed in two ways. Caregivers were grateful for their own experiences and gratitude for the opportunity to reflect. The caregiver acknowledges that hearing someone else articulate similar difficulties facilitated a deep reflection on their own caregiving journey, instilling a sense of reassurance about their caregiving role. The therapeutic aspect of sharing one's story is highlighted, emphasising how the podcast played a crucial role in encouraging the caregiver to openly discuss their experiences, fostering a sense of healing and connection.

Overall, the caregivers highlight how listening to fellow caregiver stories on the podcast evoked emotions and led to reflections on their own caregiving experiences. Caregivers found validation, understanding, and a sense of being heard through these stories, fostering gratitude, reflection, and therapeutic benefits. The podcast served as a platform for caregivers to process their own journeys, promoting positive outcomes such as a sense of healing.

Moving from loneliness to connection

Listening to others who went through similar challenges brought a sense of peace and belonging for the caregivers. The caregivers noted that hearing someone else's story resonated with their own struggles and the intense loneliness they felt for years. This shared experience helped them realise they were not alone in their journey, fostering a deep sense of connection and understanding among caregivers facing similar hardships. The podcast appeared to transform feelings of isolation into a sense of belonging and community;

"It really turned the isolation of caregiving into a shared dialogue. You just get this feeling of peace when listening to other people who have gone through a similar thing. I just think hearing someone else story echoed my own struggles and that intense loneliness I felt for years, I don't know it just made me feel a part of something all of a sudden" (C6)

Clearly, the podcast, in turn, provided a sudden and powerful sense of connection, making the caregiver feel part of something larger and more supportive. Whilst experiencing intense loneliness, some caregivers highlighted that the podcast offered a moment of being heard and connected.

"Everyone who has been through this knows the feeling of these moments of intense loneliness, like I really have never felt loneliness like that before and I hope I never have too, but listening to the podcast where the spouse was sharing her story, I felt heard, I felt this feeling of connection that I haven't experienced in so long" (C9)

The caregiver emphasises the shared experience of loneliness, noting that hearing someone else express the same sentiments was reassuring. One caregiver even described the necessity in having such a resource they were caregiving;

"I was desperate for something when I was a caregiver. I mean, I truly did feel like I was completely alone and I know, um, at least one of the other People that I listened to said that same thing as like, you really, really do feel like you are completely alone, and listening to someone else admit that was really reassuring and made me feel less lonely if that makes sense" (C5)

Evidently, the acknowledgment of shared feelings made the caregiver feel less alone, providing a sense of comfort and understanding. One caregiver mentioned how listening to the podcast served as a reminder that they are part of a larger caregiving community.

"Listening really allowed me to remember that all of us caregivers are just part of a big community. That loneliness we all felt does not last forever, and not that I wish this on anyone but it is just so nice knowing that there are other people who share a similar experience with you" (C7)

Overall, the podcast provides a platform for caregivers to resonate with other caregivers' stories, making them feel less alone and encouraging a feeling of connection that they have not been able to seek elsewhere.

Creating a sense of hope

Hearing the experiences of another caregiver who has transitioned out of the caregiving role offered a sense of hope. It also motivated them to share their own stories more openly. This reflection on the journeys of those who have navigated past caregiving responsibilities instilled a renewed sense of optimism and possibility in these caregivers, showing them that there is light at the end of the tunnel and that life can evolve beyond the challenges they face in the present;

"One thing I really struggled with when I was caregiving was having any sense of hope, I think because you are told that there's no real recovery from this, it's more so delaying how quickly it all progresses, like knowing what the outcome is going to be, it is really hard to have a positive mindset. So being able to listen to someone else in the same position who has gotten through it, would have given me hope that it will all be ok, even if I didn't feel like it at the time" (C15)

Knowing the outcome of a progressive disease such as CTE is extremely difficult to understand and cope with, particularly when there is a lack of resources and support. Listening to someone else in a similar position who has overcome such challenges would have provided the caregiver with a sense of hope and reassurance, even during difficult times. Another caregiver acknowledges the the impossibility of connecting with every individual with CTE caregiving experiences, emphasising the podcast's role in making these stories accessible;

"These stories are so inspiring, like um and I know there's no possible way to connect to every single person who has had an experience with CTE caregiving so being able to hear the stories you wouldn't necessarily get to hear like wow it is so inspiring, and even my son who is eighteen now, and he was a young boy when this was all happening with my dad, but he listened to one of the episodes and now he is advocating at school, and his football team, so these stories can inspire anyone who is willing to listen" (C5)

The caregivers' response suggests that these stories have a broad-reaching and motivational effect, influencing not only caregivers but also younger individuals like the speaker's son to engage in advocacy and support. Furthermore, many of the caregivers discussed their appreciation for hearing another caregivers story, especially when the circumstances closely mirror their own;

"It is so refreshing to hear another caregivers story, particularly when they are in a very similar situation to you, like losing my partner and having young kids… Listening to how they talk about their lives now and how far they have come was really what I needed to hear right now, I just needed some reassurance and hope that things do get better" (C11)

Many of the caregivers find solace in listening to another caregiver who is further along in their journey, particularly when they speak positively about their current life;

"I am quite new out of the caregiving role, and trying to navigate this new life has been challenging. Hearing another caregiver speak who is a bit further along than me, and hearing them talk about their life now in a positive way, is really what I needed, umm it really has just giving me the hope I needed" (C3)

Listening to the caregivers discuss their current life in a positive manner, is particularly impactful for the participants. This positive perspective serves as a source of hope and inspiration, provides the participant with the assurance that there is a positive trajectory ahead and that navigating the challenges of the new phase in life is possible.

Presentation of the podcast

In this section, we present three themes that emerged from the caregivers' responses, providing insights into their perspectives on the format of the podcast.

Flexible support

With the caregiving role being extremely time consuming, caregivers discussed convenience and accessibility of the podcast format as a supportive tool.

"It is nice to know that I can listen to it when I want. Everyone who has been a caregiver knows how time consuming it is, like you barely have a minute to yourself, so being able to listen on the go is such a great aspect. I think that's probably the reason why I listened to the podcast versus reading

the newsletter, right? Because in the time frame you can, you have the opportunity to do other things" (C5)

Many of the caregivers appreciated the flexibility of listening to the podcast. The following caregiver echoes this sentiment, emphasising the portability of the podcast, allowing them to absorb information while engaging in daily activities such as house chores or commuting.

"One thing I loved was that I could just get the information on the go, like it's so portable so I used to listen to it when doing the house chores or when I was driving to work, my son even downloaded it on his phone as he was very close to my dad, his grandad, so it was nice he listened to it too, but he listened to and from his way to school. Its a modern day way of learning" (C4)

Evidently, the podcast is perceived as a practical and adaptable resource for caregivers and those close to them. One caregiver discussed the flexibility and lack of commitment associated with the podcast format compared to traditional support group attendance;

"Some days I am not in the mood to be even thinking about CTE and others all I want to do is be around people who have also gone through it, so one thing I think is great is that there's no commitment with the podcast like there would be attending a weekly support group or something, like I can listen to it when I want, where I want and I think that makes it even more beneficial" (C14)

The caregivers appreciate the option to engage with the podcast only when they feel like it, accommodating their life demands and varying emotions. The on-demand nature of the podcast allows them to access relevant content without the obligation of a scheduled commitment, contributing to the perceived benefits of this resource. The flexibility of the resource is echoed by the following caregiver;

"I just loved how easy it was to put on and listen to, I have to commute everyday for work so I just put it on in the car. Not that I am caregiving anymore but I know for a fact having something like this would have been so helpful because I didn't have the time to be travelling to support groups, not that any were even CTE related but I just like I can listen and get the support when I feel like I need it, in a super quick way" (C12)

Similarly, the caregiver highlights the practicality of incorporating the podcast into their routine, and understanding the value of this if they were still in their caregiving role. Specifically, the ability to receive support quickly and efficiently aligns with their busy lifestyle, emphasising the value of the podcast's accessibility and adaptability to individual schedules.

The power of hearing personal narratives

Caregivers were provided two different podcasts, one including a medical professional discussing clinical explanations of CTE. Caregivers acknowledge the importance of factual information and medical knowledge but stress that the podcast's distinctive qualities, including the format of storytelling, use of personal narratives, hearing authentic voices of caregivers, and accessibility, amplify the impact of conveying the genuine essence of the caregiving experience through unfiltered perspectives and raw emotions shared in personal stories.

"That medical information is almost more valuable in a way. We need our facts and our information and stuff. It's very important. But, um, those real stories give us something that we, we can't get from the experts who haven't lived it" (C2)

While recognising the significance of factual information, the caregiver highlights that real stories from individuals who have lived through similar experiences offer something unique and irreplaceable. The value of hearing fellow caregivers stories is echoed;

"I love my research, I love my facts and having all of that information but there's nothing like hearing the real story. Like listening to someone's experiences are the real facts, that is the information people really need to know" (C4)

These caregivers highlight the importance of firsthand experiences, suggesting that personal narratives from other caregivers contribute a depth of understanding that expert knowledge may lack. In particular, caregivers acknowledged that there is a potential disconnection between the information they provide and the lived experiences of caregivers;

"I think that stories from everyday people are wonderful too though. And, the experts can be great. Um, But sometimes the experts say things that might not be true to our stories, and that can feel a little frustrating. Mm-hmm. And when you're hearing someone's actual story that lived it, that's, that's a true story. That's a reality of the disease" (C14)

The caregivers recognise that these unfiltered perspectives and honest narratives align more closely with the reality of the caregiving experience.

"As someone who has gone through this now and spent so much time trying to find information, I can't tell you how helpful it is to just speak to people in the same position. We need the unfiltered perspectives, we need the honesty, as hard as some of it is to hear and listen too, unfortunately it is the reality" (C9)

This caregiver highlights the importance of unfiltered perspectives and honesty in these conversations, even if some aspects are difficult to hear. They acknowledge that confronting the reality of caregiving, however challenging it may be, is essential for gaining a deeper understanding of the experiences shared by others in similar situations. The value of of honest conversations was reiterated by another caregiver;

"Listening to the podcast felt like I was stepping into another caregivers world for 45 minutes. You could hear every emotion, and it was just a great way to hear someone else's story. Like I have read so many caregiver stories but actually hearing them say it was so powerful" (C15)

Here, the caregivers express the need for honesty and genuine experiences, recognising the power of hearing someone else's story directly. The immersive nature of the podcast, allowing listeners to step into another caregiver's world, is emphasised as a powerful way to connect with and understand the realities of caregiving. In addition, one caregiver explains the irreplaceable nature of the instant support felt when hearing another caregiver share their journey.

"I love having the facts and I have spoken with many doctors in the field, and it's interesting stuff, but the instant support you feel when listening to a fellow caregiver speak about their journey, can't be replicated elsewhere, in my opinion" (C4)

While the individual acknowledges the value of medical facts and discussions with doctors, there's a distinctive, immediate connection and understanding that arises from hearing someone else who has experienced similar challenges as a caregiver. The personal narratives contribute a level of support and empathy that is deemed incomparable to other informational sources.

Further considerations

In the following section we discuss the caregivers feedback on how to improve the resource. This includes the length of the episodes and need for more resources.

Timing of the podcast

Here the caregivers discuss their perspectives on when they think the podcast would be most useful in their caregiving trajectories. It is important to consider the timing when a caregiver listens to the podcast in relation to their caregiving journey (i.e. before, during, or after) because the content's relevance and impact can vary based on the caregiver's current circumstances. During caregiving, the podcast can offer support, validation, and guidance in real-time, addressing immediate concerns and providing a sense of connection with others going through similar experiences. Whereas listening after caregiving can serve as a form of reflection, healing, and continued learning. It can offer a space for caregivers to process their experiences, gain closure, and find comfort in shared stories and insights that resonate with their own journey. The caregivers within this study explain how the personal narratives shared in the podcast are seen as relevant and useful to caregivers not only during their active caregiving role but also after, highlighting the enduring impact of the podcast. Specifically, the features of storytelling and the implementation of host questions creates a valuable resource that caregivers can engage in no matter the stage of their caregiving journeys.

"It's suitable for everyone. I think that if I'd have had it when I was going through What I was going through and I could have listened to that going down the road. It would have helped me now keep in mind I Went out on my own and connected with these people" (C6)

Here the caregiver explains that such a resource not only would have aided them in the past but also emphasises the potential for connecting with others who share similar experiences, highlighting the podcast's ability to foster a sense of community and support.

One caregiver acknowledges the emotional difficulty of listening to the podcast during the challenging phases of their journeys. However the caregiver suggests that finding positives and understanding how caregivers navigate life beyond the challenging middle phase could be comforting.

"I think when you are like in the middle of the role, you're right, it's gonna be hard to listen to that middle bit where the. Symptoms are really bad and everything's really, really hard and difficult. But

then equally it might be quite nice to listen to how the caregiver's actually able to have a life after and and the positives are of the situation if you are right. I think it's probably quite individualistic" (C5)

Participant two's response indicates that the podcast's effectiveness varies, potentially depending on the caregiver's personal situation and the stage of their caregiving journey.

"I think people take away what they want to hear and what they want to listen. So even if they might not resonate with the whole 40 minute hour episode, there are probably a couple of quotes or messages that they can take from it. Um, So, yeah, I, I think there's, I think hopefully it'll be supportive to a range of people" (C2)

The caregiver explains how individuals may derive different meanings from the podcast based on their personal preferences and experiences. Even if someone doesn't connect with the entire episode, they believe there could be specific quotes or messages within it that resonate with the listener. As a ramification, the caregiver expresses that the podcast can offer support to a diverse audience by providing varied content that relates to different experiences in meaningful ways. Furthermore, the caregiver's responses highlight that through offering varied content that touches upon different experiences and perspectives, the podcast can effectively provide support and validation to a diverse range of listeners, regardless at what stage of caregiving they are at.

Need for greater resource detail

Here, the caregivers provide insightful suggestions for enhancing CTE caregiver podcasts. Some caregivers explained the benefit of referencing the up-to-date research each week to provide more information for individuals looking to seek it.

"Maybe you could do like a shout out, like, and this week's suggestion is Dr. So-and-So has done a TED Talk on blah blah. You might wanna reference it or this week, um, before we start our story, we just wanna reference you to this neurologist who just came out with this report, if you'd like to read further, maybe you could just do like shoutouts" (C4)

Caregivers explain that by offering these references, listeners can access additional information related to the topics discussed in the podcast, enhancing their understanding and providing them with opportunities for further exploration. This is echoed by the following caregiver;

"I think adding links to websites or relevant articles under the episodes would be really helpful too, as it allows people to do their own research if they wanted to after, and like we know it would be coming from a good source if it's under the podcasts recommendations. Like say you had one episode that was discussing addictions associated with suspected CTE, it would be helpful to have some research surrounding that, as it may help caregivers know how to respond and care more effectively for their loved ones" (C7)

Through providing access to credible sources under the episodes, caregivers can explore specific topics, such as addictions associated with suspected CTE, and gain insights that can help them respond and care more effectively for their loved ones. This approach would not only empower listeners to expand their knowledge but also ensures that they are accessing information from reputable sources recommended by the podcast.

One caregiver recognises the emotional weight of the topics discussed and suggests that providing immediate access to relevant resources could be helpful for listeners who may need support or guidance during challenging moments.

"I think having also, like, and you might already, you might have this, and I apologise if I didn't see it, but also like the suicide number to call, you know, or, um, I think just having lot like those resources for people to actually just be able to go through these emotions which are heavy and then see the resources right in front of them. Yeah. Um, might be helpful" (C2)

The caregiver acknowledges the emotional weight of the topics discussed and highlights the need for readily accessible support resources for listeners who may be experiencing intense emotions or distress. By providing direct access to such resources, caregivers and listeners can find immediate help and guidance when dealing with challenging emotions, ensuring that essential support is readily available for those who may require it during difficult moments. Alongside providing additional resources, caregivers provided feedback regarding the length of the podcast too;

"I guess, Anything in around a 30 minute chunk is usually pretty good, cuz I've had just enough but not too long that it, you know, I lose the momentum of it. I think part of it's just, cuz any, in, in our town, we, I live in a pretty big town, but we, it takes about 30 minutes to get anywhere. So I feel like that's a good chunk" (C8)

However, another caregiver had an alternative view;

" I just think you can't put a timer on this kind of story, and also with the podcast if I was busy or needed a break from listening, I could just pause it and come back to it..I mean generally speaking I think an hour is a good maximum, but only if the conversation is very clear and easy to understand if you get me..no one wants to listen to long episodes if that additional time isn't providing additional value" (C9)

Caregivers suggest that the length of the podcast is something that needs consideration. Despite their responses demonstrating this element is subjective, having a suitable duration allows them to engage with the podcast content effectively without feeling overwhelmed or losing interest, making it a convenient and manageable length for their listening experience.

The caregivers provide valuable recommendations to improve the podcast. The caregivers' perspectives on podcast episode length highlight the importance of considering audience preferences and needs when creating content. While one caregiver values concise episodes for maintaining engagement and convenience, another emphasises the significance of content clarity and added value over strict time constraints. By incorporating a range of episode lengths and ensuring that each episode delivers meaningful content, the podcast can cater to different listener preferences and provide a well-rounded listening experience.

8.4. Discussion

The study explored an innovative approach to enhancing support for CTE caregivers through the creation and assessment of a supportive resource, namely a podcast. After disseminating the podcast and speaking with the caregivers, I was able to gather feedback on the participants' thoughts on the presentation of the podcast (i.e. accessibility) and their responses, including exploring how the podcast content made them feel, identifying both positive and negative elements of their listening experience.

Participants in the study discussed that engaging with the podcast led to profound introspection into their caregiving journeys. Despite facing challenges in revisiting emotionally taxing experiences, caregivers conveyed gratitude and a sense of peace as they reflect on their experiences through the podcast. The narratives shared prompted deep self-reflection, offering a dedicated space for caregivers to contemplate their roles and experiences. These reflections evoked emotions while also providing validation, understanding, and a sense of community among caregivers. Listening to the podcast fostered a profound sense of peace and belonging among CTE caregivers, resonating with their struggles and alleviating feelings of isolation. Moreover, the shared narratives instilled hope, particularly as caregivers listened to stories of transition out of the caregiving role, inspiring them to share their own experiences openly. Alongside the positive experiences caregivers shared from listening to the podcast, it is important to consider the practical elements of the podcast.

When creating a resource, it is essential to consider knowledge translation and dissemination to ensure that the information reaches the intended audience effectively. Knowledge translation involves the process of transforming research or knowledge into practical applications such as interventions (Straus et al., 2009), whereas dissemination is concerned with the distribution and sharing of information to reach the target audience (Lafreniere et al., 2013). With the podcast being based off of caregivers sharing their stories, it is important to consider the impact of narratives as a knowledge translation tool. Smith et al., (2015) explored use of narratives or ‘stories’ as a knowledge tool for disseminating physical activity knowledge to spinal cord injured adults and health care professionals (HCPs) working with this population. Findings highlighted that evidence-based stories were an effective means for disseminating knowledge, however several attributes of the story were important for making it effective. Within the podcast episodes in the current study, caregivers shared their experiences including challenges, victories and emotional turmoil they experienced whilst caring for their loved one with CTE. The honest and authentic perspective encouraged caregivers to engage and resonate with their stories. This authentic content and dialogue aligns with the attributes deemed as effective in Smith et al’s., (2015) study. Interestingly the caregivers did not find the podcast episode with a medical professional as effective as the caregivers story, likely due to the narrative not following a ‘story’. Therefore, an authentic and compelling narrative plays a pivotal role in effective knowledge dissemination, allowing for greater engagement and resonance with the audience.

More recently, Leggat et al., (2023) acknowledged the importance of integrated knowledge translation (iKT) for qualitative research. IKT is characterised by "active collaboration between researchers and research users throughout all stages of the research process, encompassing the formulation of research questions, methodological decisions, participation in data collection and tool development, interpretation of findings, and dissemination and implementation of research results" (Graham and Tetroe, 2007, p. 21). IKT fundamentally involves collaboration among various communities (e.g., academics, athletes, coaches, practitioners), to enhance knowledge uptake in practice and encourage resultant behaviour change of secondary importance (Jull, Giles, and Graham 2017). The podcast as an intervention tool aligns with various elements of the iKT. The podcast serves as a direct means of disseminating research findings and insights to those who are directly impacted by CTE caregiving. The podcast, featuring a caregiver's narrative on CTE caregiving, embodies iKT by directly disseminating research findings and practical insights to those impacted. By involving caregivers in its creation and dissemination, researchers actively collaborate with practitioners, recognising their expertise and experiences. The qualitative nature of the podcast allows for a nuanced understanding of caregiving contexts, showcasing unique challenges and needs. Moreover, its flexibility aligns well with iKT's adaptive approach, encouraging researchers to tailor their methods to suit the preferences and requirements of those in practice settings. Ultimately, this integrated approach aims to enhance knowledge uptake in practice, fostering meaningful collaboration between researchers and practitioners and contributing to improved support for caregivers and individuals affected by CTE.

Within this study, the podcast not only provided crucial information and education to caregivers but also created a space for emotional support and community-building. As a health education tool, the podcast effectively disseminated information, facilitating knowledge translation through the authentic sharing of caregiver experiences, resonating with listeners or other caregivers, and offering practical insights into caregiving. However, the podcast also served an advocacy role by elevating caregivers' voices, highlighting their struggles, and fostering understanding among a broader audience. By validating their emotional experiences and reducing isolation, it empowered caregivers to share their own stories and become part of a collective dialogue, thereby advocating for better recognition and support for caregivers. In this sense, the podcast transcended mere education, functioning as an advocacy platform aimed at changing perceptions and encouraging societal awareness.

Our findings also aligned with Reid et al., (2017) who assessed narrative-based knowledge translation tools for parents with a child with paediatric chronic pain. A 48-page e-book was developed to characterise the experiences of a family living with a child with chronic pain. The e-book was a composite narrative of the parent interviews and encompassed descriptions of the effects the condition has on each member of the family. In that study, parents reported that having elements of the narrative (story) mirror their experience validated their emotional reactions to their child’s condition and also provided assistance in managing the situation. In fact, this element of the supportive tool increased parental knowledge by 21.4%, highlighting the benefits of narratives as a knowledge translation tool. Similarly, in our podcast study, caregivers sharing their experiences allowed for validation of their emotional responses and provided valuable insights into managing the challenges of caring for individuals with CTE. This underscores the power of authentic narratives in offering support and understanding to individuals facing similar caregiving experiences.

CHAPTER 9

General Discussion

The purpose of this thesis was to understand the experiences of CTE caregivers, including the range of challenges and burdens they face as part of this role and derive an intervention that aims to target these unique experiences. Through exploring the experiences of both older spousal caregivers and younger caregivers with varying relationships to the care-recipient, I was able to gain insight into the experiences they go through during and after their caregiving journeys and how these correlate with the experiences of caregivers in Dementia contexts. The key findings from this research are the challenges of navigating life post-caregiving, the impact of caregiving on children and the difficulties of providing care for a misunderstood disease. In this chapter, I explore the unique aspects of CTE caregiving and examine their implications for caregivers, as well as their contributions to the broader caregiving literature, including the necessity for intervention.

Our findings support Gerain and Zech Informal Caregiving Integrative Model (2019), which emphasises the interplay between caregiving stressors, resources, and psychosocial characteristics of the caregiver. The model emphasises the importance of considering the relationship with the care-recipient as a critical component in the understanding of the caregiving experience. The findings of Study One and Study Two suggested that spousal CTE caregivers experience a more profound sense of burden. Regardless of age, both older and younger spousal caregivers of individuals with CTE discussed greater feelings of loneliness, isolation and anxiety during their caregiving roles compared to adult children and sibling caregivers within Study Two. The ICIM explains this by considering the caregivers psychosocial characteristics alongside their caregiving setting. As documented in Dementia caregiving contexts, spousal caregivers share a unique bond as part of the ‘marital commitment’ (Cheng et al., 2019), which leaves caregivers tending to prioritise their loved ones needs, regardless of how much of an impact it is having on them. In addition to this bond, spousal caregivers are less likely to have an outlet from the caregiving role, due to cohabitation with the care-recipient. Study One and Study Two provided insight into how living and caring within the same environment can prove challenging. For these CTE caregivers, they struggled to find an escape which led to increased feelings of anxiety and burnout.

Alongside managing these emotions, CTE caregivers explained how they felt like they were grieving “two losses”. Here the caregivers described feeling like they were losing their loved ones as they experienced neurodegenerative decline, and losing them again when they passed away. This phenomenon of anticipatory grief, where caregivers mourn the impending loss before it occurs (Aldrich, 1974), has been well-documented in the broader caregiving literature. For instance, a study by Holley and Mast (2009) found that anticipatory grief was significantly associated with increased caregiving burden among dementia caregivers, regardless of their relationship to the care recipient (child vs. spouse). While the CTE caregivers in the current research articulated this "grieving two losses" experience, it is important to recognise that anticipatory grief is not unique to the CTE context, but rather a common challenge faced by many informal caregivers grappling with the progressive decline of a loved one. The key distinctions may lie in how this anticipatory grief is navigated and the resulting burden, which can vary based on contextual factors like the caregiver's relationship, living situation, and access to support systems, as emphasised by the Informal Caregiving Integrative Model.

The findings from Study Two highlighted distinct differences in the experiences of younger spousal CTE caregivers compared to their younger adult child and sibling counterparts. Consistent with the Gerin and Zech Informal Caregiving Integrative Model (2019), these different experiences can be attributed to the unique psychosocial characteristics and contexts of the different caregiver groups. For instance, younger spousal caregivers contended with additional responsibilities such as managing work and raising young children alone, which limited their capacity to find positives in their caregiving role. The ICIM model suggests that these compounding demands and lack of respite likely heightened the burden and distress experienced by these younger spousal caregivers. In contrast, younger adult children and sibling caregivers benefited from greater flexibility and support from their partners, which enabled them to navigate the caregiving challenges more effectively and be more open in sharing their experiences. The ICIM emphasises the significance of the caregiver-care recipient relationship in shaping the caregiving experience, and these findings indicate that the spousal dynamic may present unique difficulties that are not as pronounced for younger caregivers with more external support systems. Additionally, the model suggests that caregiver burden is influenced by the caregiver's appraisal of their role and experiences. Younger and older spousal caregivers appraised their caregiving experiences differently from younger adult children and sibling caregivers. The lack of awareness and understanding of CTE during the time older spousal caregivers were providing care may have impacted their appraisal, making it challenging for them to find positives, as noted in Study One. Conversely, younger adult children and sibling caregivers may possess a more nuanced understanding of CTE, enabling them to appraise their experiences differently and find positives in their role.

One of the key similarities between the experiences of CTE caregivers and caregivers in Dementia contexts was the financial burden they faced. In both Study One and Two, caregivers expressed how financial strain had a significant impact on their feelings of stress and anxiety in their caregiving roles. Many caregivers either had to leave their jobs to provide full-time care or were left depleting their savings to cover healthcare expenses. This financial burden persisted even after the caregiving role ended as caregivers had to repay debts accumulated across their loved ones' decline. Despite the prominence of financial difficulties for older and younger caregivers, our findings suggested that this seemed particularly more challenging for the older caregivers. As mentioned earlier, during the time these older spousal caregivers were caregiving, there had been no diagnoses of CTE, thus the knowledge and support for patients and their caregivers was non-existent. Consequently, these caregivers had to navigate a healthcare support where information and assistance for CTE patients were non-existent. This situation appeared to increase their financial burden as they sought answers and support, leading them to visit various doctors and neurologists in search of a diagnosis and appropriate care. The absence of readily available resources specific to CTE likely resulted in additional medical expenses and potentially unnecessary treatments or consultations, further exacerbating the financial strain experienced by these caregivers. This financial burden was less prevalent for some of the younger caregivers as their caregiving journeys were more recent, as they were able to receive funding from the 88 Plan; a reimbursement or payment of medical and custodial expenses of Former NFL Players due to Dementia, Parkinson's Disease, or ALS. However, for the young caregivers whose loved ones didn’t play professional support, they were left to manage funding care whilst running a family home alone, thus financial burden was more profound for these individuals. Financial burden is a common experience for CTE caregivers, mirroring the challenges faced by caregivers in similar circumstances (Chiao et al., 2015; Zhang et al., 2023).

Similarly within Dementia caregiving contexts, the cost of care has been highlighted as a key contributor to caregiving burden. A concept analysis by Liu et al., (2020) using a total of 33 articles surrounding Dementia caregiving burden, suggested that one of the key antecedents of caregiving burden is in fact, financial strain. Although the finding from the current studies aligns with Chiao et al., (2015) who found in their systematic review on Dementia caregivers that financial status was a contributing factor to caregiving burden, the studies included failed to use measurements that focused solely on financial burden. Specifically within Liu et al’s., (2020) study, only two of the six instruments used within this study included questions that assessed an element of economic impact (Caregiver Reaction Assessment Scale and Zarit burden caregiving scale). Still, these instruments are derived to prioritise understanding caregivers' emotional burdens rather than financial burdens. However, it is likely financial burden wasn't as prominent for these caregivers due to the support they received within their caregiving role. Liu et al,. (2020), in conjunction with Chiao et al., (2015), noted that the negative impact of financial burden can be mitigated if caregivers receive support in other facets of their role, be it emotional support from family or medical assistance from healthcare professionals. The existing studies on Dementia caregiving have shown that caregivers experience significant burden, but the measurements used in these studies have failed to capture the financial aspects of this burden in detail. Therefore, we cannot directly determine whether the financial burden experienced by caregivers of individuals with CTE is similar to that of Dementia caregivers.

Although some of the caregivers experiences, aligned with those of caregivers in other contexts (i.e. Dementia), there were some unique challenges faced by these CTE caregivers. For the older spousal caregivers, many of their challenges arose during the stage after caregiving was no longer necessary. Particularly, with the participants being older and many being away from family or retired from work, the dynamic of their lives completely changed. Learning to begin a new life or to learn how to live a 'new normal' proved extremely challenging and overwhelming for these individuals. Previous research on caregiving in various contexts (i.e Dementia) has primarily documented grief-related challenges experienced by caregivers (Bravo-Benítez et al., 2021; Sanders et al., 2008) after the end of the caregiving role. However, the sense of purposelessness experienced by caregivers of individuals with CTE appears to be a distinct aspect of their post-caregiving journey. Unlike caregivers in other situations (i.e. Dementia) who may grieve the loss of their loved ones but are still finding purpose (i.e. engaging in advocacy or volunteer work/joining support groups or reflecting on how they made a positive difference in their loved one's quality of life) from their caregiving role (Doris, Cheng and Wang, 2018; Polenick et al., 2018), these CTE caregivers struggled to discover meaning and purpose in life after caregiving ended. This challenge may have arisen from the unique circumstances surrounding CTE, including the prolonged caregiving journey, the impact of CTE-related behavioural symptoms on family dynamics, and the significant changes in the caregiver's identity and role within the family unit. Moreover, the lack of awareness and understanding of CTE within the broader community exacerbated feelings of isolation and purposelessness for caregivers once their caregiving role concluded. Given that caregivers in Dementia contexts benefit from more readily available support and information due to the better understanding of the disease (Bressan et al., 2020), it may elucidate why there is a scarcity of research addressing challenges post-caregiving in the Dementia context. Consequently, the "lack of purpose" experienced by this sample of CTE caregivers is particularly profound, further underscoring why they struggled to find positives in their roles and derive meaning from sharing their caregiver stories.

The challenges the older CTE caregivers experienced with a loss of purposefulness in their lives after being a caregiver can be explained by the post-caregiving trajectory proposed by Larkin (2009). This outlines three distinct phases: (a) the post-caring void, marked by a profound loss of purpose and identity; (b) closing down the caring time, as caregivers let go of former activities and behaviours and adapt to new routines; and (c) constructing life post-caring, characterised by rebuilding abandoned relationships, engaging in leisure activities, and potentially pursuing caring roles such as volunteer or paid work for caregiving organisations (2009). Corey et al. (2018) support Larkin's model and further suggest that the pursuit of additional caring activities may serve as an attempt to fill the post-caring void and redefine or maintain one's life purpose. Similarly, Ott, Sanders, and Kelber (2007) found that many former Dementia caregivers eventually moved past these challenges and recognised personal growth stemming from their caregiving experience. However, in the context of the present study focusing on caregivers of individuals with CTE, many caregivers, despite feeling they possessed a natural aptitude for caregiving, expressed uncertainty about assuming a caregiving role again. Consequently, grappling with this profound sense of purposelessness post-caregiving proves to be exceedingly difficult for these caregivers, particularly when they lack access to relevant support and resources (Gerain & Zech, 2019). This highlights the unique challenges faced by caregivers of individuals with CTE in navigating the post-caregiving phase, underscoring the importance of tailored support mechanisms to address their specific needs and facilitate their transition to life beyond caregiving. The profound sense of purposelessness experienced by CTE caregivers in the post-caregiving phase seems to be a prominent issue that warrants further exploration. Specifically, future studies should adopt longitudinal approaches to see whether these caregivers are able to eventually rediscover purpose and fulfilment, or if the post-caregiving void persists over an extended period.

One key finding that was distinctive for the younger CTE caregivers, was the impact on the wider family. Although all of the older spousal participants had children, they were all adults during the time of caregiving, thus the challenges experienced were not the same as the younger caregivers faced. Specifically, these individuals had to balance being a parent, or even working full-time alongside managing the caregiving role. This aspect may have been overlooked in previous research, possibly due to most other Dementias occurring predominantly in older age (Chen et aal., 2015). Interestingly for the younger caregivers who were not a spouse to the care recipient, they did not struggle balancing multiple roles. In fact, one caregiver discussed how striving for a balance had a positive impact on how they appraised the burden of caregiving. Specifically, this caregiver found having to look after a young family and work, alongside caregiving made her more determined and productive. Based on extensive research grounded in role theory, juggling multiple social roles has been shown to reduce objective burden and yield favourable outcomes, including enhanced social support, heightened self-complexity, and an increased sense of personal value (Bainbridge et al., 2006; Nordenmark, 2004). In this particular scenario, the caregivers derived a sense of purpose from managing not only their caregiver role but also parental and work responsibilities. According to Bastawrous (2013) by navigating these diverse roles, individuals can tap into social resources, allowing them to find fulfilment and assistance in one aspect of life when facing challenges in another. For the young caregivers who were able to balance caregiving alongside roles like parenthood and employment, this ability to handle multiple responsibilities may have functioned as a coping mechanism. This notion resonates with the Stress Process Model (Pearlin, 1981), which underscores the significance of coping resources in alleviating stress. Through effective management of various roles, these caregivers may have developed coping strategies that enabled them to perceive caregiving burdens more positively and maintain a sense of effectiveness and resilience. However, this ability to balance multiple roles was found to not be easy for the majority of the younger CTE caregivers.

Balancing multiple responsibilities alongside the caregiving role seemed to be more challenging for younger spousal caregivers. When discussing being a young caregiver, some spouses used words such as “impossible” and “unmanageable” when explaining their search for balance. Although role theory enables an understanding of the positives of multiple roles, the research utilising this framework consistently suggests the significant negative impact on caregivers who have other responsibilities (Bastawrous, 2013). Mello et al., (2017) suggests that the accumulation of roles, such as being a parent at the same time as being an informal caregiver, heightens the strain experienced by caregivers. Specifically, Mello et al., (2017) states that roles can differ between social family roles (e.g. caregiving, marital and parental roles) and non-family roles (e.g. paid work, leisure and friendship). This theory proposes that multiple demands placed on the person (i.e. a primary CTE caregiver, working and being a parent) will have negative consequences such as role overload (not having enough time and resources to balance these roles). This may lead to additional burden and psychological distress (Iwata & Horiguchi, 2016). Within this study, many younger spousal caregivers expressed having "no time" for anything beyond caregiving, feeling as though the role had put an ‘instant pause’ on their lives. Role theory suggests that juggling multiple roles increases the likelihood of role conflict and family-role overload, leading to a lack of time and energy to address these demands. These findings align with the Stress Process Model (Pearlin, 1981), emphasising the importance of coping resources in managing stress. The experiences of younger spousal caregivers highlight how insufficient coping resources can worsen stress and lead to psychological distress. The distinction in role balancing perceptions between younger spousal caregivers and other young caregivers supports the idea that those with better personal resources and support experience fewer caregiving burdens. However, for the young caregivers who struggled to balance caregiving alongside other roles, in particular, parenthood, burden was found to have an impact on other aspects of their lives.

Caring for loved ones whilst having young children yourself was a key challenge within the young caregivers experiences. The limited literature surrounding early-onset Dementia has led to a significant oversight in understanding the ramifications of caregiving burden on children within affected families (Hutchinson, 2018). While considerable attention has been paid to the challenges faced by caregivers themselves, particularly those caring for children, scant research has considered the unique experiences and burdens endured by the children immersed within the caregiving environment. However, within this study, younger CTE caregivers expressed the difficulties of balancing caregiving responsibilities with parenthood and highlighted how this dual role affected their children negatively. Given the prevalence of CTE in younger age groups, it becomes increasingly crucial to consider the impact on children within these families.

When discussing parenthood, many of the young caregivers discussed the challenges of shielding their children from the realities of the situation. Specifically, the caregivers struggled to prevent this at times, particularly as the caregiving role and parental role were happening within the same household. This was particularly prevalent for spousal caregivers who were having to run a family and care for their partners within the same environment. According to Spinelli et al., (2021), children are particularly sensitive to changes in their environment and the emotional states of their parents. Thus, witnessing the decline of their father and the role changes in their mother can impact the parent-child relationship and potentially affect the wellbeing of the child. Furthermore, children learn through the modelled behaviours of their parents and people around them (Goodall, 2013). If children are witnessing problematic behaviours related to having/suffering from CTE (i.e. aggression) for a long period of time, they can become normalised and they likely end up mimicking these (McLeod and Sutherland et al., 2017). This was the case for one caregiver, who discussed how one of her children started exhibiting similar problematic behaviours that her husband had displayed. In this situation, the caregivers had to then work to support and teach their children to un-learn those behaviours. For some caregivers, they had to seek external help from professionals to support their children through understanding normalised behaviours. Gerin and Zech's ICIM (2019) underscores the significance of considering the caregiving environment and social context in understanding caregiver burden. This broader perspective recognises that the challenges of caregiving and parenting occur within a complex social environment that can impact both caregivers and their children. Therefore, the complexities of having young children immersed in the caregiving environment can be detrimental not only to the children but also to the caregivers themselves.

Understandably, the caregivers faced a range of emotional complexities as a result of managing their own grief, as well as supporting their children through the process. The caregiving role was extremely time-consuming, leading caregivers to prioritise caring for their loved one. Consequently, some caregivers felt a significant sense of guilt for neglecting their own families, particularly during crucial formative years for their children. This emphasises the internal conflict they faced between prioritising the care-recipient and caring for their young families. Furthermore, caregivers discussed how communication became a significant challenge, as they found it difficult to explain the changes in their loved ones to their children, resulting in emotional distress. Although the impact of supporting children throughout the caregiving role has not been widely discussed in the context of Dementia caregiving, research has documented the importance of communication in minimising caregiving burden. For Dementia caregivers, studies have shown that communication breakdowns between the caregiver and the person with Dementia can lead to a decline in the quality of their interaction and relationship (Quinn, Clare and Woods, 2009; Watson et al., 2012). Thus, younger CTE caregivers may need additional support in how to communicate with their children in order to be transparent, whilst protecting them from the realities of the disease. Ultimately, the caregiving role extends beyond supporting their ill partners to helping their children grieve, creating a complex and emotionally challenging dynamic within the family home. Future research should continue to explore the complexities of being a caregiver whilst supporting young children through this experience. This may include investigating the emotional and psychological impacts on children who witness the decline of a parent with CTE and the changing dynamics within the family. Research should explore how these experiences affect the parent-child relationship, the development of coping strategies, and the potential impact of CTE-associated behavioural issues on children’s behaviour. Additionally, studies should assess the effectiveness of communication strategies used by caregivers to explain the situation to their children, aiming to identify best practices that balance transparency with protection. Despite the differences in their experiences, both older and younger CTE caregivers discuss the challenges they face in life after caregiving, highlighting the need for continued support and resources to facilitate their transition out of their caregiving roles.

The findings underscored a pervasive lack of support experienced by caregivers, stemming primarily from a deficiency in education and understanding about CTE. Caregivers encountered challenges in obtaining accurate diagnoses, accessing appropriate support and resources, and securing comprehensive care for their loved ones. This lack of recognition and misunderstanding, particularly within the healthcare community, contributed to additional stress and burden for caregivers. For older spousal caregivers, these challenges were exacerbated by frequent misdiagnosis of their loved ones with Dementia. While our findings illustrated the level of misunderstanding experienced by all CTE caregivers as they sought professional help, which appeared to create higher levels of burden, the findings also suggest this was more profound for younger caregivers. Typically, individuals with suspected neurodegenerative diseases such as Dementia are in older age groups, usually aged 65 and above (Centers for Disease Control and Prevention, 2023). Consequently, younger patients may not align with the expected demographic for CTE (although it is prevalent in younger age groups), leading to instances where caregivers encountered healthcare professionals who overlooked their loved ones' symptoms. Within Study Two, the younger caregivers discussed how they had to endure misdiagnosis of their loved ones such as addictions (drugs/alcoholism) and mental health illnesses (depression and schizophrenia). Although symptoms could have been easily misattributed as the cognitive, emotional, and behavioural symptoms of CTE overlap with other conditions like depression or anxiety (Morgan et al., 2021), caregivers explained how the age of them and their loved one proved to be the biggest challenge in seeking support.

Varma et al., (2021) noted that typically there is a social perception that young people are resilient and less prone to severe health issues (Varma et al., 2021). Thus, seeking help for an invisible or misunderstood illness, such as CTE, as a young patient proved nearly impossible for these caregivers. Consequently, young caregivers seeking medical assistance from professionals who either lacked education on CTE or underestimated the long-term effects of head injuries on these individuals' health often faced dismissal. As a result, caregivers often found themselves advocating tirelessly for their loved ones, navigating through a healthcare system ill-equipped to address the complexities of CTE. With the lack of readily available support during these caregivers journeys, caregivers had to seek their own support, usually in the form of connecting with other caregivers. Interestingly, caregivers did discuss the benefits of speaking with fellow caregivers about their experiences, with many of the caregivers adopting a perspective of ‘you only truly understand this if you have been through it yourself’. With the increase in confirmed diagnoses for the younger CTE caregivers at their time of caregiving, these individuals had a greater opportunity compared to the older spouses, to reach out to fellow CTE caregivers to share their experiences and seek support from each other. This enhanced sense of community and shared understanding likely facilitated their ability to derive more positive aspects from their caregiving role (Doris, Cheng and Wang, 2018). However, it is important to understand why peer support may be particularly beneficial for CTE caregivers.

The importance of support

According to Conway (2016), peer support offers a unique form of validation and empathy that may not be easily attainable from individuals who have not experienced similar circumstances. Sharing experiences with others facing similar challenges can alleviate isolation and foster a sense of belonging and understanding (Keyes et al., 2016). Peer support groups provide a safe space for caregivers to express emotions without fear of stigma or misunderstanding (Conway, 2016). The benefits of peer support have been extensively shown in dementia contexts. Keyes et al. (2014) undertook a qualitative analysis of peer support in Dementia care, and discovered that it had a positive emotional and social impact that was rooted in identification with others, a commonality of experience and reciprocity of support. Specifically, these caregivers felt peer support made them realise that ‘there is life after a diagnosis of Dementia’ (Clare et al., 2008: pp. 21–22). The focus was on the realisation that there were others in a similar position, which could lead to friendship, a sense of belonging and re-engagement with life in the context of loneliness, isolation, loss and struggle (as highlighted within work by Clare et al., 2008 and Fung & Chein, 2002). Consequently, peer support may be particularly beneficial for the older spousal CTE caregivers who felt a loss of purpose and identity after their caregiving roles.

Keyes et al., (2014) reiterated previous work that peer support helps to reduce isolation (Ward et al., 2011) and brought a sense of belonging and social acceptance (Willis et al., 2018). With all of the CTE caregivers struggling with others misunderstanding their loved ones condition, peer support may encourage a sense of community through developing 'new friendships' within formal and informal caregiving environments (Armstrong and Alliance, 2019). For CTE caregivers who have faced adversity in seeking support of a misunderstood disease, having a supportive tool that enables them to speak to fellow caregivers, may not only help them to learn coping strategies and get emotional support but also limit the loneliness so many reported experiencing. As caregivers reflect on the advantages of speaking with fellow CTE caregivers, future interventions should draw upon insights from peer support experiences. Although older spousal caregivers and younger caregivers had differing experiences with seeking support during their time of caregiving, all of the caregivers alluded that their burden would not have been so prominent if they had received appropriate help. Despite the considerable research attention surrounding Dementia, resulting in greater availability of supportive interventions for caregivers (Walter & Pinquart, 2020), the exploration of interventions specifically for CTE caregivers remains scarce despite the growing understanding of their needs.

CTE caregivers appear to go through a variety of challenges throughout their caregiving journeys. Similar to caregivers in other contexts, CTE caregivers experience a high level of burden during and after their roles. Both older and younger caregivers seem to experience self-neglect, feelings of isolation, poor mental health and financial difficulties at some point in their caregiving journeys. For some caregivers, these outcomes of burden were more profound and appeared to stretch their caregiving trajectory for longer periods. Despite the overlap between some aspects of CTE caregiving to caregiving in Dementia, the findings did suggest challenges that are maybe unique to CTE. In particular, older spousal caregivers experienced a high perception of burden long after their caregiving role ended. With a heavy loss of purpose as they navigated life without a caregiver identity, these individuals struggled to return back to a ‘normal’ routine. On the contrary, the range of roles younger caregivers adopted alongside caregiving, including being a parent to a young family and managing their careers, left them experiencing a wider impact of burden during their caregiving journeys. Specifically, younger caregivers had to support their children through adversity and grief whilst trying to protect their own wellbeing. The array of challenges experienced by CTE caregivers reinforces a necessity of having effective and tailored support, something that wasn’t available to these caregivers at their time of caregiving. Given the caregivers' recognition in needing supportive resources, the value in sharing personal stories and the benefits of peer-based support in other caregiving contexts (Carter et al., 2020), it appeared pertinent to develop an intervention grounded in these principles. Drawing from the positive experiences observed in other caregiving settings, the aim of the final study in this thesis was to create an intervention that harnesses the power of personal storytelling and peer connections to support caregivers facing the unique challenges of caring for individuals with CTE.

Considering supportive interventions

Although the benefits of peer support groups are well documented in Dementia caregiving literature (Carter et al., 2020; Visser et al., 2008; Willis et al., 2018), these studies highlighted that with caregivers' limited free time, face-to-face support may not always be a convenient or accessible option for caregivers. Thus, Study 3 involved developing a resource in a podcast format to encapsulate peer support in a more accessible format. Study One and Two highlighted that caregivers experienced intense loneliness as part of their roles and also felt burdened by the lack of support from healthcare professionals. Consequently, it was important that the podcast spoke to both of these elements. Through disseminating two podcast episodes to the caregivers, one being a caregiver sharing their personal story and the second being an informative episode in which a doctor shared the signs, symptoms and medical information on CTE, the aim was to consider the efficacy of the podcasts as supportive resources. The findings illustrated how engaging in the podcast, and specifically listening to another caregivers experience, encouraged participants to reflect on their own caregiving experience. Although many of the caregivers found it challenging at times to revisit such challenging and emotional times, the caregivers expressed that listening to someone else's story, put their own experiences into context, leading to feelings of gratitude and peace as they revisited their journeys through engaging in the podcast. The stories shared by the caregiver on the podcast episode prompted self-reflection, providing a dedicated space to reflect on their own caregiving roles and experiences. These reflections naturally evoked a range of emotions, but also offered validation, understanding, and a sense of community amongst the caregivers.

Reflective functioning, or the capacity to reflect on one's own thoughts, feelings, and behaviours (Yule & Grych, 2024; Jin & Goud et al., 2023), emerged as a crucial factor in how caregivers processed and coped with the challenges of caring for a loved one with CTE. Research has shown the benefits of reflective functioning in other caregiving contexts, including reduced anxiety and depression (Lenzo et al., 2022) and increased responsiveness (Dexter & Wong, 2024). The podcast enabled caregivers to feel heard, validated their emotions, and encouraged self-reflection. One caregiver explained the podcast to be "a catalyst of self-reflection", enabling them to look back on their experiences as a caregiver. For current caregivers listening to the podcast, this introspective process may facilitate a deeper understanding of their own needs, reactions, and boundaries, which could enhance their capacity to provide more effective and compassionate care. This highlights the podcast's importance in providing support, understanding, and a sense of community for CTE caregivers, who may lack established resources compared to dementia caregivers. By engaging in reflective processes, caregivers gained insight into their emotional responses, motivations, and coping strategies, helping many find peace in their caregiving role. Reflective functioning also helped caregivers navigate complex emotions, such as guilt, grief, and stress, by offering a framework for processing and deriving meaning from their experiences (Steele et al., 2015). The heightened self-awareness enabled caregivers to better understand their own needs, reactions, and boundaries, enhancing their capacity to provide more effective and compassionate care. However, the podcast was not provided to them during their active caregiving responsibilities.

The CTE caregivers expressed that hearing another caregiver's story resonated with their own struggles and feelings of intense loneliness, transforming their isolation into a shared dialogue. When providing feedback on the podcast, the caregivers emphasised the value of listening to other caregivers' firsthand experiences. Although many found the medical-focused episodes insightful, all the caregivers described the power of hearing another caregiver share their personal narrative. The caregivers highlighted the irreplaceable nature of listening to the perspectives of those who had undergone similar experiences, which helped them feel less alone in their own struggles. This aligns with Social Identity Theory (SIT), a framework that explores how individuals define themselves based on their membership in social groups (Reicher, Spears, & Haslam, 2010). According to SIT, individuals derive a sense of identity and belonging from the groups they belong to, such as the caregiving community in this context. By listening to and resonating with the stories of others who share similar experiences, the caregivers strengthened their social identity within this community (Cooper, 2022). This process of identification and connection with those who understand their struggles provides a crucial source of social support, which research has shown to be vital in mitigating negative outcomes for primary caregivers (Carr & Utz, 2020). As Weiss' loneliness theory (1973) suggests, the lack of close attachments and an engaging social network can lead to emotional and social isolation. Despite their grief, the CTE caregivers' social isolation was exacerbated by the lack of current support. However, the podcast provided a powerful connection, fostering a sense of community. This aligns with research highlighting the importance of shared experiences in reducing isolation among caregivers (Velloze et al., 2022). The caregivers emphasised the significance of feeling heard and connected through the podcast, underscoring its value in providing comfort and understanding during their challenging experiences. Listening to others in similar situations helped eliminate the social isolation the CTE caregivers had faced.

It is important to note that the podcast was not provided to the caregivers during their active caregiving responsibilities. Future research should therefore evaluate the effectiveness of reflective tools and interventions implemented concurrently with the caregiving experience. This could provide valuable insights into supporting CTE caregivers in real-time, rather than solely in retrospect. Examining reflective functioning during active caregiving may help determine if the positive impacts observed in this study, such as reduced burden, increased coping, and enhanced emotional well-being, can be achieved through more timely interventions. Additionally, it would reveal how reflective practices can be integrated into the daily lives of CTE caregivers to offer meaningful and practical support as they navigate the complex challenges of their roles. Further research could also explore the specific mechanisms by which listening to other caregivers' narratives benefits CTE caregivers during the active caregiving phase. For instance, studies could investigate whether this process enhances feelings of social connection, reduces a sense of isolation, provides practical coping strategies, or fosters a stronger sense of community and shared identity among caregivers. Uncovering the underlying psychological and social processes at play could inform the design of more targeted and effective interventions to support CTE caregivers in real-time. Additionally, longitudinal studies could examine the long-term impacts of incorporating reflective practices, like listening to other caregivers' stories, into the daily lives of CTE caregivers. This could shed light on whether the benefits observed within this study are sustained over time and lead to improved caregiver outcomes, such as reduced burnout, better mental health, and enhanced quality of life. Ultimately, this could further inform the development of support programs that address the needs of CTE caregivers during the active caregiving phase.

Benefits of accessible support formats

Similarly, just as individuals with Dementia advocate for themselves and others, caregivers sharing their stories on a CTE podcast are also taking an active role in shaping narratives and advocating for their needs within the CTE community. By sharing experiences and insights, caregivers contribute to altering public perceptions of CTE caregiving and the impact of CTE itself. Moreover, caregivers listening to these stories can find inspiration, validation, and practical strategies for their own caregiving journey (White 2022), fostering a sense of community and empowerment within the CTE caregiving community. This collective sharing and listening serve to promote positive change in how CTE caregiving is perceived and supported in society (Sawatzky and Fowler‐Kerry, 2003. However, although previous intervention research has not investigated the benefits of a podcast format for aiding social support, other online formats based around peer support align with SIT.

Being a member of the online support groups has been found to have positive benefits for caregivers, such as coping better, improved mood, reduction in social isolation and being able to be a better carer (Knepper & Arrington, 2018). Daynes-Kearney & Gallagher (2023) undertook eighteen semi-structured interviews with members of a family caregiver online support group in Ireland and found it to foster group identity, creating a supportive space where caregivers can seek advice, emotional support, and enjoy a sense of community, thus alleviating loneliness and isolation. In relation to our intervention, the podcast served as a supportive tool by providing caregivers with a platform to navigate and resonate with the stories of those shared. Similar to online support groups, the podcast offers a safe space for caregivers to renegotiate their roles as "carers" and to explore their identities both as caregivers and as individuals. Through listening to stories and insights shared on the podcast, caregivers found validation, understanding, and practical strategies for coping with the challenges they face. This process of listening and engaging with others' experiences allows caregivers to reflect on their own roles and identities, fostering a sense of empowerment and connection within the caregiving community. Gaining more value from fellow caregivers' stories over medical professionals' discussions on the podcast can be explained by Gerin and Zech's Informal Caregiving Integrative Model (2019). The model emphasises the significance of considering the environment and social context in understanding caregiver burden. Specifically, the model highlights the importance of recognising the caregiver's psychosocial characteristics, relationship with the care-recipient, and subjective appraisal of burden. In the case of CTE caregivers, hearing from a fellow caregiver provides a relatable and emotionally connected experience. This aligns with the model's emphasis on the caregiver's psychosocial characteristics and the importance of considering their subjective appraisal of burden. By listening to someone who has experienced similar challenges, caregivers feel validated and understood, reducing their sense of isolation and burden. Furthermore, other CTE caregivers offer practical insights and coping strategies based on their firsthand experiences, which can feel more relevant and applicable to the daily realities of caregiving. This aspect aligns with the model's recognition of the importance of integrating the caregiver's appraisal and considering subjective burden as a measure of appraisal. Overall, the podcast serves as a valuable resource for caregivers to navigate the complexities of their caregiving roles and to find support in their journey, aligning with the principles of the ICIM and providing a platform for caregivers to connect, share experiences, and find validation.

Improving the podcast

While the podcast episodes have proven beneficial to caregivers, it remains crucial to solicit their feedback on areas for improvement in the resource. This ensures its evolution into an effective tool that adequately supports them through their unique experiences of caregiving for someone with CTE. One of the main considerations, provided in the feedback from the caregivers involved providing additional resources. Specifically, the caregivers explained the benefit of referencing the up-to-date research each week to provide more information for individuals looking to seek it. These additional resources may encourage CTE caregivers to feel more supported for multiple reasons. Access to up-to-date information and relevant resources may not only validate caregivers' experiences but also empower them with knowledge and skills to navigate their caregiving journey more effectively (Kinnane and Milne, 2010). By learning about the latest research and evidence-based practices, caregivers can develop a deeper understanding of CTE and its management, leading to better care outcomes for their loved ones. Moreover, access to additional resources fosters community building and support among caregivers, providing them with a platform to connect, share experiences, and seek emotional support, an element that proved beneficial for these CTE caregivers. Overall, these resources play a crucial role in equipping caregivers with the tools, validation, empowerment, and support needed to improve the quality of life for both themselves and their loved ones with CTE.

To develop the podcast as an effective supportive resource, another element that needs consideration is the timing of the podcast. Specifically, it is important to consider the timing when a caregiver listens to the podcast whether it's prior to, during, or following their caregiving responsibilities. This consideration is vital as the relevance and effectiveness of the content may fluctuate depending on the caregiver's present situation. Some caregivers explained how it may be challenging to listen to a caregivers story at the initial stages of the caregiving process, as listening to someone's experiences, particularly in the latter stages of CTE may induce a sense of worry and concern for new caregivers. This is where the medical based episode may prove more beneficial, as caregivers can become educated on CTE including information on symptomatology, treatment options and coping mechanisms. However, the caregivers explained how the impact of the podcast is likely as individualistic as the caregiving experience, thus listeners may not take away everything from the episode, but instead the information that they feel is most useful and important to making them feel supported. Furthermore, it's essential to note that in our study, caregivers were only exposed to two types of episodes: one featuring a caregiver's personal story and another focused on medical aspects. This limited scope highlights the importance of expanding the range of episodes available. Future research should expand the range of content available to better cater to the diverse needs and preferences of CTE caregivers. Providing a wider variety of narratives, such as perspectives from caregivers at different stages, dealing with varying symptom profiles, or using unique coping strategies, can increase the likelihood that caregivers will find deeply resonant content. Additionally, incorporating episodes featuring guidance from experts on practical, emotional, and relational challenges can further enhance the podcast's effectiveness as a comprehensive support resource. Such diverse content may more effectively meet the diverse needs of CTE caregivers, helping them navigate their complex roles with greater ease and resilience.

Through my aforementioned studies, we have advanced the understanding of what is unique about CTE caregiving. Specifically, it is clear that a lack of supportive resources amplifies burden and therefore the studies I have conducted provide an opportunity to develop and test a resource and provide (with more research), tailored support given the apparent differences between younger and older caregivers. The following section outlines the implications of this work, the inherent limitations and the recommendations for future study.

9.1 Limitations

Within the research, there are some limitations that are important to consider. Firstly, the sample in Study One consisted of only female participants, and Study Two only one male participant participated. This gender imbalance aligns with the demographic among CTE caregivers, where a substantial majority are female. While the study provides valuable insights into the unique challenges faced by younger CTE caregivers, the limited representation of males underscores the need for future research to understand the potentially distinct experiences encountered by male caregivers. However, with the emergence of the first case of CTE in a professional female athlete (Heather Anderson) in 2023, there is potential for an increase in male caregivers if more female athletes are diagnosed with CTE. It would be interesting to investigate gender on caregiving burden, however, it is acknowledged that such investigations are currently challenging due to the predominant pattern of diagnosed CTE patients being male and caregivers being female.

Another limitation applicable to both older and younger CTE caregivers is the absence of symptom severity data for CTE in care-recipients at different points in their life course (Liu et al., 2017; Mohamed et al., 2010). All care-recipients in the studies were pathologically diagnosed with either stage 3 or 4 CTE, and exploring the effects of earlier stages on caregiver burden could provide valuable insights. Understanding the different challenges experienced by caregivers at each stage of neurodegeneration will enable more tailored support programmes and resources to be generated. Assessing caregivers over time was not within the scope of this study; however, participants detailed long-term psychological, emotional, and physical issues, warranting further research on the epidemiological cross-sectional and longitudinal assessment of caregivers to understand how long-term burden is experienced. Furthermore, the studies relied on the participants' recollections of their caregiving experiences, which may be susceptible to memory bias. Notably, these participants had not been in the caregiving role for at least three years, and over time, perspectives and attitudes towards their caregiving experiences may undergo changes. This introduces the possibility of discrepancies between their recollections during the research and their initial experiences.

In regards to the podcast, assessing the effectiveness of a supportive podcast for CTE caregivers who are no longer in the caregiving role presents a limitation in terms of evaluating the direct impact of the intervention on active caregivers. Caregivers who have transitioned out of their caregiving roles may have different perspectives, needs, and challenges compared to those currently providing care. Their feedback may not fully capture the real-time experiences and benefits that active caregivers derive from the podcast. Additionally, caregivers who are no longer in the role may have had time to reflect and process their experiences differently, potentially influencing their perceptions of the podcast's effectiveness. As a result, their feedback may not accurately reflect the immediate and ongoing support needs of current caregivers facing the daily challenges of caregiving for individuals with CTE. This limitation highlights the importance of obtaining feedback from both current and former caregivers to gain a comprehensive understanding of the podcast's impact across various stages of the caregiving journey.

Furthermore, the participants were interviewed 2-3 weeks after listening to the podcasts. In this scenario, the study's short follow-up period of three weeks may not capture the long-term effects or sustained impact of the podcast intervention on caregivers' well-being and coping strategies. By only assessing caregivers' experiences immediately after listening to the podcast and not following up at later time points, the study may miss out on understanding how the benefits or changes observed in the short term evolve or persist over an extended period. Longitudinal follow-up assessments at multiple time points would provide a more comprehensive understanding of how the podcast intervention influences caregivers' experiences and outcomes over time.

It is also important to reflect on my own strengths and limitations as a researcher throughout this process. With all of the participants (besides one) being female, as the researcher, I acknowledge that my own background and perspectives may have influenced the interpretation and framing of these findings. As a female researcher, I may have been more attuned to the experiences shared by the predominantly female participants. This could have influenced my analysis and the focus of the research by leading to the inclusion of overly sensitive questions. To mitigate this limitation, I aimed to maintain objectivity and consider multiple viewpoints throughout the research. I achieved this by engaging in reflective processes and having regular discussions with my supervisory team, who challenged my approaches and encouraged reflection at each stage of the research process. However, I recognise the importance of including more diverse perspectives, particularly from male caregivers, in future studies to gain a more comprehensive understanding of the CTE caregiving experience.

My knowledge and understanding of the CTE caregiver experience, gained through in-depth interviews and immersion in the research context, as well as my empathetic approach that helped to foster trust and open dialogue with the caregiver participants, were key strengths that enabled me to gain valuable insights into the unique challenges faced by this population. These experiences have helped me develop as a more thoughtful and nuanced researcher, deeply attuned to the perspectives and needs of CTE caregivers. Through this immersive process, I have cultivated a greater sensitivity to the complexities of the caregiver experience, which has informed my approach to data collection and analysis. I have learned to prioritise building trust and rapport with my participants, recognising the significance of creating a safe space for them to share their personal narratives. I did this through taking the time to cultivate relationships, through spending time at the start of interviews talking to the caregivers and stressing the importance of the research. This, in turn, has allowed me to gather richer, more authentic data that provides insight on the CTE caregiving journey. Overall, the process of conducting this in-depth research on CTE caregivers has been instrumental in shaping me as a more empathetic, nuanced, and versatile researcher.

9.2. Future recommendations

The results of these studies indicate directions for future research. Firstly, future investigations should consider conducting longitudinal studies to track caregivers' perspectives of their experiences over an extended period. By speaking with caregivers at various intervals and documenting their experiences over time, researchers can gain a deeper understanding of how caregiving burden evolves and fluctuates throughout the caregiving journey. Exploring caregivers' levels of burden at different time points would offer invaluable insights into the dynamic nature of caregiving, allowing for a more nuanced comprehension of the challenges and changes that caregivers encounter over time. Such longitudinal investigations would not only enhance our understanding of the evolving nature of caregiving burden but also provide valuable information that could feed into the development of targeted interventions and support programs tailored to the specific needs of caregivers at different stages of their caregiving journey. Furthermore, evaluating the podcast contributed valuable insights for the ongoing development of supportive tools tailored to the unique needs of CTE caregivers. The podcast episode featured a single caregiver sharing their personal experience, focusing on a specific aspect of caregiving. To provide more comprehensive support for future caregivers, it might be beneficial to cover a broader range of topics relevant to caregiving, such as coping strategies, accessing resources, managing caregiver stress, or navigating healthcare systems. This could ensure that a diverse array of experiences and challenges faced by caregivers are addressed, offering a more holistic perspective and valuable insights for listeners. In terms of evaluating the podcast, future research should aim to incorporate a control group to assess the effectiveness of the podcast on caregiver outcomes. A control group would help researchers isolate the effects of the podcast intervention from external variables or placebo effects, providing more conclusive evidence of the intervention's impact on caregivers' well-being. By including a control group, researchers can enhance the internal validity of the study and strengthen the credibility of the findings by demonstrating a clear cause-and-effect relationship between the podcast intervention and its outcomes.

9.3. Summary and concluding thoughts

This thesis provides valuable insight into the experiences of Chronic Traumatic Encephalopathy (CTE) caregivers. The findings have highlighted that caregiving burden is profound amongst this group, with both older and younger CTE caregivers reporting a range of challenging outcomes, from poor mental health (anxiety, depression) to feelings of loneliness and burnout as they navigate the complexities of caring for someone with a neurodegenerative disease. While there are some overlapping experiences between CTE caregivers and those caring for individuals with Dementia, the unique challenges faced by CTE caregivers have emerged as a key focus of this research. Older spousal CTE caregivers, for instance, struggled with a heightened and enduring sense of burden even after their caregiving role had ended, as they grappled with the loss of purpose and the difficulty in returning to a "normal" routine. In contrast, younger CTE caregivers, many of whom were balancing caregiving with parental and professional responsibilities, experienced a wider impact of burden that extended to their children and broader family dynamics. These findings underscore the pressing need for tailored support and interventions to address the multifaceted challenges encountered by CTE caregivers throughout their journeys. Importantly, the research also highlights the value of longitudinal investigations to track the evolving nature of caregiving burden, as well as the potential benefits of incorporating control groups to more rigorously evaluate the effectiveness of caregiver support programs, such as the supportive podcast intervention explored in this thesis. By shedding light on the unique experiences of CTE caregivers, this thesis contributes to a deeper understanding of the caregiving landscape and provides a foundation for the development of targeted resources and strategies to better support this population during their profoundly challenging yet vital role.

From my perspective, researching the caregivers' stories has been a humbling and eye-opening experience, one that has truly underscored the profound sacrifices and challenges these individuals face on a daily basis. The findings have painted a vivid picture of the immense caregiving burden experienced by both older and younger CTE caregivers. Witnessing the struggles of the older spousal caregivers, as they grappled with the loss of purpose and the difficulty in returning to a "normal" routine, was particularly poignant. And seeing the wider impact of burden on the younger caregivers, as they balanced their caregiving responsibilities with the demands of parenthood and careers, was a sobering reminder of the all-encompassing nature of this role. What struck me most, however, was the resilience and determination displayed by these caregivers, even in the face of overwhelming adversity. Their accounts of finding solace and connection through the supportive podcast intervention were a testament to the power of shared experiences and community in alleviating the profound loneliness so many of them reported. As a researcher, I feel a deep sense of responsibility to ensure that the voices and needs of CTE caregivers are heard and addressed. This thesis is just the beginning of a journey to better understand and support this population, and I am committed to continuing this important work. Moving forward, I believe the key priorities should be to continue the understanding of the CTE caregiving experience in hope to inform development and evaluation of comprehensive, tailored support systems for CTE caregivers. This includes specialised support groups, educational resources, and mental health interventions that cater to their unique needs. Additionally, further longitudinal research is essential to track the evolving nature of caregiving burden and the long-term impacts on the wellbeing of CTE caregivers. Ultimately, my hope is that this thesis will serve as a catalyst for a more holistic and compassionate approach to supporting CTE caregivers. By amplifying their stories and advocating for their needs, we can work towards minimising the burdens experienced by CTE caregivers during and after their roles through providing informative resources and support.

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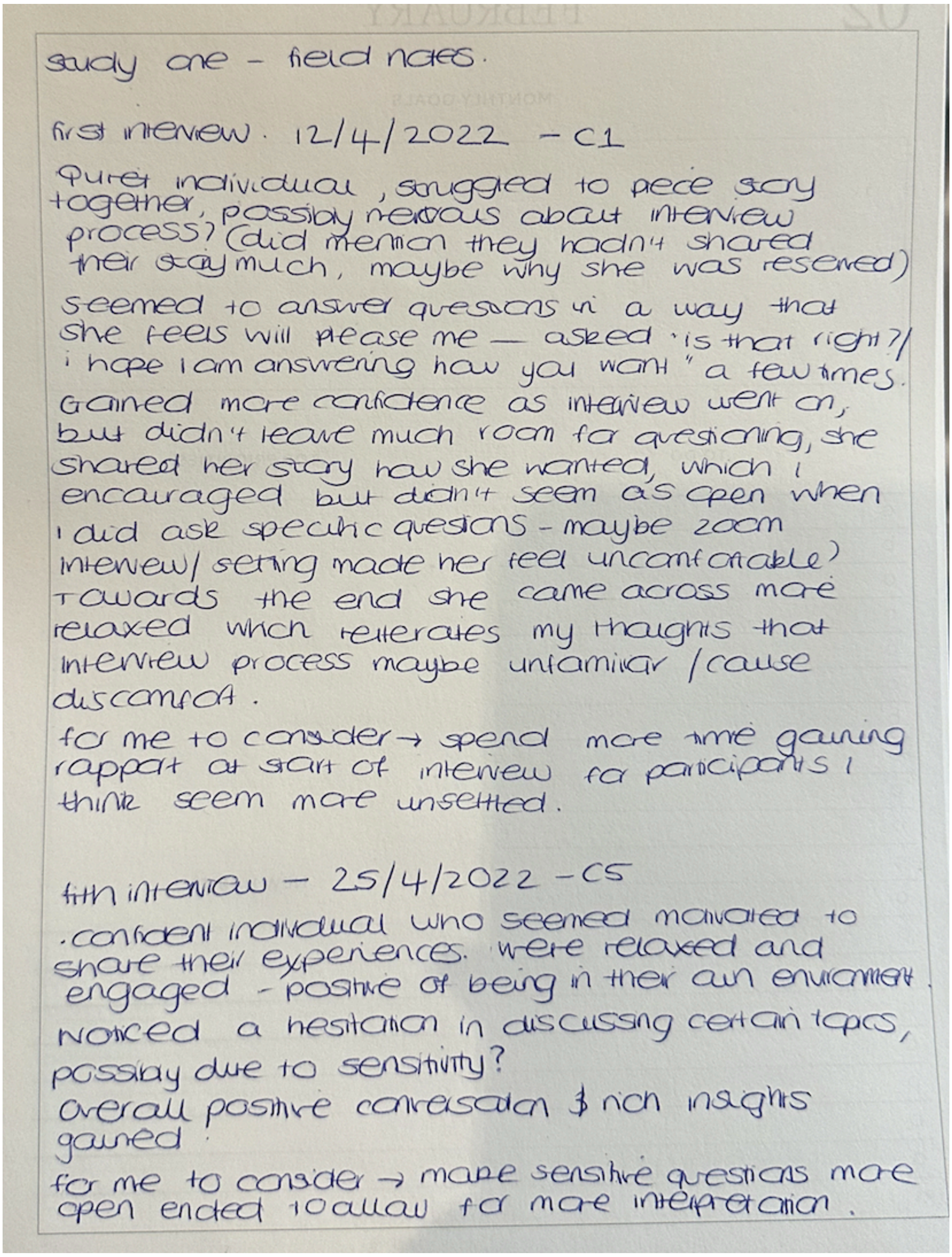
Appendices

Appendix 1: Field notes from study one



study one - field notes.

first interview. 12/4/2022 - C1

Quiet individual, struggled to piece story together, possibly nervous about interview process? (did mention they hadn't shared their story much, maybe why she was reserved)

seemed to answer questions in a way that she feels will please me — asked 'is that right?/ i hope i am answering how you want" a few times.

Gained more confidence as interview went on, but didn't leave much room for questioning, she shared her story how she wanted, which i encouraged but didn't seem as open when i did ask specific questions - maybe zoom interview/ setting made her feel uncomfortable?

Towards the end she came across more relaxed which reiterates my thoughts that interview process maybe unfamiliar / cause discomfort.

for me to consider → spend more time gaining rappart at start of interview for participants i think seem more unsettled.

fith interview - 25/4/2022 - C5

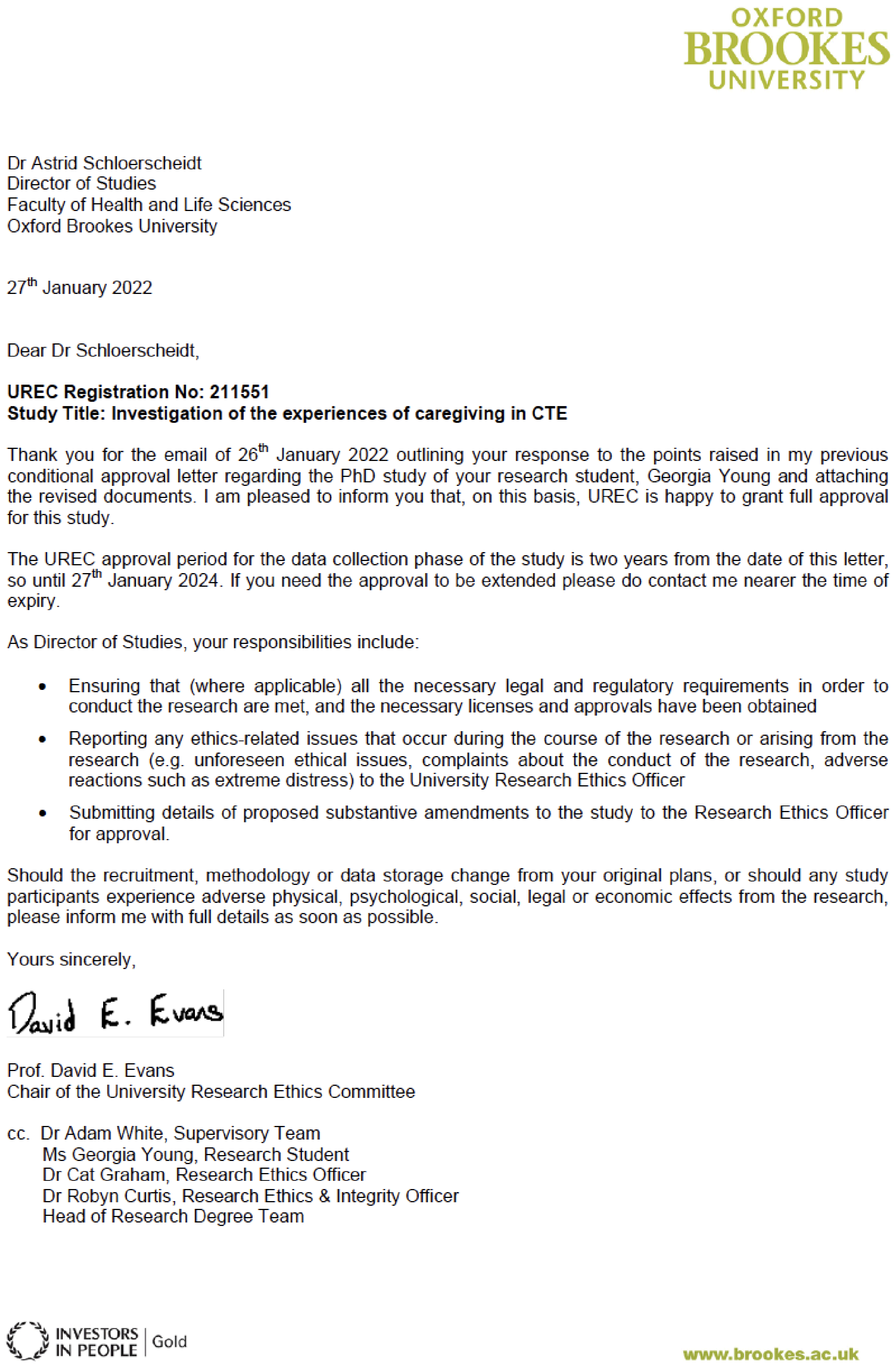
. confident individual who seemed motivated to share their experiences. were relaxed and engaged - positive of being in their own environment.

Noticed a hesitation in discussing certain topics, possibly due to sensitivity?

overall positive conversation & rich insights gained.

for me to consider → make sensitive questions more open ended to allow for more interpretation.

Appendix 2: Ethical approval and ethics forms for Study One and Study Two



OXFORD
BROOKES
UNIVERSITY

Dr Astrid Schloerscheidt
Director of Studies
Faculty of Health and Life Sciences
Oxford Brookes University

27th January 2022

Dear Dr Schloerscheidt,

UREC Registration No: 211551
Study Title: Investigation of the experiences of caregiving in CTE

Thank you for the email of 26th January 2022 outlining your response to the points raised in my previous conditional approval letter regarding the PhD study of your research student, Georgia Young and attaching the revised documents. I am pleased to inform you that, on this basis, UREC is happy to grant full approval for this study.

The UREC approval period for the data collection phase of the study is two years from the date of this letter, so until 27th January 2024. If you need the approval to be extended please do contact me nearer the time of expiry.

As Director of Studies, your responsibilities include:

- Ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained
- Reporting any ethics-related issues that occur during the course of the research or arising from the research (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress) to the University Research Ethics Officer
- Submitting details of proposed substantive amendments to the study to the Research Ethics Officer for approval.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

Yours sincerely,

David E. Evans

Prof. David E. Evans
Chair of the University Research Ethics Committee

cc. Dr Adam White, Supervisory Team
Ms Georgia Young, Research Student
Dr Cat Graham, Research Ethics Officer
Dr Robyn Curtis, Research Ethics & Integrity Officer
Head of Research Degree Team

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UNIVERSITY RESEARCH ETHICS COMMITTEE

APPLICATION FOR APPROVAL OF A PROJECT INVOLVING HUMAN PARTICIPANTS, DATA OR MATERIAL

Registration No. *(office use only)*

This application form should be completed by Staff, MPhil/PhD and other professional doctoral researchers at
Oxford Brookes University and external researchers wishing to seek approval to recruit participants from the University.
Taught postgraduate and undergraduate students should seek approval via Faculty procedures:
https://www.brookes.ac.uk/Research/Research-ethics/Review/UG-Masters/

Further details about the process, including deadline dates, templates for participant information sheets and consent forms are available at: https://www.brookes.ac.uk/research/research-ethics/

To ensure a high standard of research ethics review there is a limit of **12 applications** at each UREC meeting. Once this limit has been reached, applications will be held over to the next meeting date. A list of dates and deadlines are available at:
https://www.brookes.ac.uk/Research/Research-ethics/Review/Staff/University-research-ethics-committee#dates

Applications must be completed on the form; answers in the form of attachments will not be accepted, except where indicated. Applicants should contact the appropriate Research Ethics Officer (REO) to establish procedures for ethics review in the Faculty:
https://www.brookes.ac.uk/Research/Research-ethics/Review/Research-ethics-officers/

Applicants must go through Faculty or Directorate procedures and applications must be signed off by the relevant Research Ethics Officer before being submitted to the University Research Ethics Committee.

Once the application is complete and has been signed off by all parties (see page 2 of this form) it may then be submitted, along with the relevant accompanying documentation, to the UREC Administrator. **Please do not staple the original documents as they will be scanned for committee use.**

Potential research participants must not be contacted until written approval has been received from the Committee

PROJECT TITLE:	***Investigation of the experiences of caregiving in CTE***

THIS PROJECT IS:		**Staff Research Project**

(tick as many as apply)	✓	**Research Student Project** Has your research degree programme already been approved by the relevant Research Degree sub-committee: Yes
		Project by External Researcher *(please give details)*
		Project by member of staff at another institution (*please give details of Post and Institution, including address)*
		MPhil/PhD or professional doctorate student at another institution (*please give details of Department and Institution, including address)*
		Masters student at another institution (*please give details of Department and Institution, including address)*

RESEARCH TEAM: *PhD and doctoral students SHOULD be listed after their supervisors. The Director of Studies should also be identified.*

TITLE & NAME	*POST*	*DEPT & FACULTY / DIRECTORATE*	*PHONE*	*EMAIL*
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Georgia Young	PhD student	Faculty of health and life sciences	+44 7891542828	19154046@brookes.ac.uk

DECLARATION BY INVESTIGATORS

The information contained herein is, to the best of my knowledge and belief, accurate. I have read the University's Code of Practice for Ethical Standards for Research Involving Human Participants, and accept responsibility for the conduct of the procedures set out in the attached application in accordance with the University's Procedures.

I and my co-investigators or supporting staff have the appropriate qualifications, experience and facilities to conduct the research set out in the attached application and to deal with any emergencies and contingencies related to the research that may arise.

Signatures of the research team are required before submission to University Research Ethics Committee

Signature(s) of the Research Team: Date

Dr Astrid Schloerscheidt 20/09/21

Dr Adam White 20/09/21

M Smith

Dr Matt Smith 20/09/21

Dr Michael Alosco

DECLARATION BY RESEARCH ETHICS OFFICER

DATE APPLICATION RECEIVED: ....../......./…………

DATE ETHICS REVIEW COMPLETED ....../......./…………

The Faculty/Directorate Research Ethics Officer or Committee has reviewed this project and considers the methodological/technical and research ethics aspects of the proposal to be appropriate to the tasks proposed and recommends approval of the project. The Faculty/Directorate REC or REO considers that the investigator(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in the attached application, and to deal with any emergencies and contingencies that may arise.

Comments/Provisos:

Signature of the
Research Ethics Officer

Date ....../....../…………

UNIVERSITY RESEARCH ETHICS COMMITTEE USE ONLY

Date application received: ....../....../…………

Date of meeting: ...../....../…………

1. PROJECT DETAILS

1.1	**PROPOSED DURATION OF DATA COLLECTION COMPONENT OF PROJECT**	From:	October 2021	To:	April 2023

1.2 LAY DESCRIPTION, JUSTIFICATION AND AIM OF THE RESEARCH: *Provide a brief outline of the project, including what participants will be required to do. This description must be in everyday language which is free from jargon. Please explain any technical terms or discipline-specific phrases and explain any acronyms or abbreviations. You should also state the aims and significance of the project and a justification as to why this research should proceed and an explanation of any expected benefits to the community.* ***Please provide full references for any work referred to****. (No more than 600 words):*

Research on caregiving for someone with Chronic Traumatic Encephalopathy (CTE- A form of dementia caused by repetitive head impacts) is virtually non-existent. As CTE has not received the same attention as other neurodegenerative diseases such as Alzheimer's or dementia, there is no surprise that the literature is yet to examine the caregiver experience. Although the literature looking at other brain diseases details the hardships of any caregiving role, it is likely that CTE has its own unique challenges for the caregiver, such as symptom prevalence can begin in younger ages, and the four stages of CTE development creates a complex caregiving experience. Thus, we need more research to understand how to support carers in this unique environment. Furthermore, the incidence of concussion through sport is likely to increase the incidence of caring for CTE sufferers. Therefore, research is needed now to understand, and support carers in this area.

As a result of the lack of information we currently have on CTE and the caregiving experience, a qualitative approach with grounded theory principles will be taken initially to establish a theoretical framework regarding pertinent predictors and outcomes the current brain injury literature has referenced as most impactful on caregivers wellbeing. Specifically, this framework will be used as an elicitation device within interviews with 30-50 caregivers of individuals still living and deceased and will be adapted/developed depending on the participant's responses. We are hoping that increased understanding of the caregiving experience will ultimately lead to the design of interventions to minimise the negative effects of the caregiving burden.

1.3 PROPOSED METHOD: *Provide an outline of the proposed method, including details of data collection techniques, tasks participants will be asked to do, the estimated time commitment involved, and how data will be analysed. If the project includes any procedure which is beyond already established and accepted techniques please include a description of it. (No more than 500 words):*

Participants will be provided with a Participant Information Sheet and give their written consent before partaking in any research. No participant under the age of 18 will be included, thus no safeguarding processes are required.

To answer the research question, a grounded theory approach will be utilised. Unstructured interviews (lasting approx. 1 hour) will be undertaken to elicit themes that will help to inform and shape the development of a theoretical framework. Specifically, the framework will demonstrate factors that the caregivers perceive to be the most influential on the quality of their experience and how they may lead to specific outcomes (i.e. poor quality of life). Subsequently, the participants' responses from the interview will develop/adapt the framework to capture the caregiver experience holistically. The interviews will be audio recorded for transcription purposes, but participant consent will be given prior to recording. The full questions included in the interview guide are attached at the end of this document. It's important to note that the research is about a relationship with a person who is deceased at the time when the research is taking place. The most likely scenario is that participants may reveal mental health issues and they will be referred to the CLF crisis helpline and other support organisations in the US that are independent and free to access.

Participants will be recruited via the Concussion Legacy Foundation (CLF). A gatekeeper letter is attached below with the email confirmation of approval (Appendix 1). The CLF has a mission to support athletes, Veterans and all affected by concussions and CTE; to achieve smarter sports and safer athletes through education and innovation; and to end CTE through prevention and research. Within this research, the CLF will be involved in recruitment of the participants as they have a network of people (kept on a database) that are signed up for partaking in research and have agreed to be contacted about studies. Collaboration enables access to their networks of patients and caregivers. We collaborate through Dr Michael Alosco, who is employed by Boston University. His department has links with the CLF. Michael is also an associate at Oxford Brookes. So the collaboration is with the CLF through Michael. Michael will have access to the data in his capacity as an Associate at Oxford Brookes. As there is no formal collaboration with Boston University, a data sharing agreement is not required. The CLF will be provided with the participant information sheet and privacy statement, thus they will forward this onto the potential participants.. If the participant opts to participate, contact details of the research team (see above) will be forwarded to gain further information regarding participation. The data collected from these interviews will only be accessible to the research team listed above and no data will be shared elsewhere.

Data collection will take place after ethical approval, ideally commencing in January 2022.

1.4 **INVESTIGATORS’ RELEVANT RESEARCH EXPERIENCE AND SKILLS:** *List the relevant experience and outline the skills relevant to this project that the researchers, their supervisory team and any supporting staff have in carrying out the research and in dealing with any unexpected outcomes that may arise* (Please do not include links to profile pages or copies of CVs):

Director of Studies: Dr Astrid Schloerschiedt is an experienced experimental psychology researcher with a focus on quantitative research. She has supervised a number of quantitative and qualitative investigations at MSc level and two PhD candidates. Some of this work involved vulnerable groups (e.g., young people with eating disorders, patient with diagnosed schizophrenia). Astrid chaired the Dundee University Research Ethics Committee for 5 years and has experience assessing the ethical dimensions of work with vulnerable groups and how to mitigate risk.

Supervisor: Dr Adam J White is a Lecturer in Sport & Coaching Sciences and co-lead of the Inclusion, Diversity and Gender Network. He is a widely published inter-disciplinary researcher, including on injury and wellbeing. He has led and supervised dozens of research projects using a variety of approaches.

Advisor: Dr Matt Smith is a social psychologist with particular research interests in leadership and group dynamics. In addition, his research interests include mental health in sport and implications of head injury in sport. Currently, he is involved in research examining conflict in sports teams, dealing with difficult team members, and effective communication in teams. He is also involved in interdisciplinary research considering the experiences of family members who have an athlete in their family who have suffered traumatic brain injury, and research considering the efficacy of community activity schemes for stroke patients. Dr Smith has a particular interest in qualitative research methods, which includes the use of autobiographical data in research, using different stimuli to facilitate qualitative data collection, and presenting qualitative findings in novel ways.

Co-Supervisor: Dr. Michael Alosco is a licensed clinical neuropsychologist. He completed his undergraduate studies at Providence College and he earned his doctoral degree in clinical psychology, with a focus on neuropsychology, in 2015 from Kent State University. He completed his clinical internship in neuropsychology at the VA Boston Healthcare System. Dr Alosco completed his post-doctoral studies in neuropsychology via NIH-funded training Awards (T32, F32) at the Boston University Alzheimer’s Disease Research Centre and CTE Centre. In 2018, he became an Assistant Professor of Neurology at Boston University School of Medicine and he was promoted to Associate Professor in 2019. Dr Alosco has > 140 peer-reviewed publications, is the recipient of an NIH/NINDS K23 Award, is the Project Lead of an NIH-funded multisite U54 grant, and serves as a PI and/or co-investigator on numerous federal and non-federal funded grants. He has also written numerous book chapters, and he is the co-Editor of the OxfordHandbook of Adult Cognitive Disorders which was published by Oxford University Press in 2019.

Researcher: Georgia Young is an aspiring qualitative researcher, with an undergraduate and postgraduate qualification in Sport Psychology. Particularly, her interests lie in health and wellbeing psychology, with a specific research background in body image, self-presentation and caregiving. She is the first author for a paper currently in review titled; “Social media makes it inevitable to feel bad about your body”: Examining self presentation and body image of female collegiate athletes” and also a second author for the following paper (also in review); “Exploring the emotions and coping strategies of family members of athletes who have suffered with neurodegenerative disease”. Georgia is excited and passionate for her future work within CTE caregiving, with her overall aim being to help those in need through research.

1.5 PLEASE EXPLAIN WHEN, HOW, WHERE AND TO WHOM RESULTS WILL BE DISSEMINATED, *including whether participants will be provided with any information on the findings or outcomes of the study:*

All participants will have the option to opt-in to receiving the findings of the research directly from the research team via email. To do this, participants will be asked for their personal details (Name and Email) after the interview. This will be stored on Oxford Brookes Google Forms and the data privacy for this is contained within the privacy statement.

This research will also be disseminated via peer-review academic publications in research journals, and at conferences. There may also be opportunities to share the findings of this research with the public, via the media, and with policy makers and politicians (particularly given the need to raise awareness of the general public on this topic area)

1.6 WILL THE RESEARCH BE UNDERTAKEN *ONLY* ON-SITE AT OXFORD BROOKES UNIVERSITY (including all campuses)?

YES, only on-site	NO, not only on-site	**Overseas**

*(If **NO**, give details of off-campus location, including other sites where research is being undertaken and other countries providing data):*

Research will be primarily conducted at the CLF Family Huddle in Las Vegas in February 2022. Due to the iterative process, I will be undertaking (i.e. transcribing, reflecting and analysing after each individual interview to develop the theoretical framework) carrying out interviews just at the family huddle will not be enough time. Subsequently, some interviews will be conducted online using Google Meet and/or Zoom. The researcher will organise interviews via email with the participants at a time most suitable for them. The same procedures that occur in face to face conditions will be used for online data collection..

1.7 OTHER APPROVALS REQUIRED

Has permission to conduct the research in, at or through another institution or organisation (e.g. a school or a business) been obtained?

N/A

***If YES**, please specify from whom and attach a copy:*

Is clearance required from the Disclosure and Barring Service (DBS check)?
(https://www.brookes.ac.uk/human-resources/working-here/employment-policies/dbs-certificate-information/)

NOT APPLICABLE

If Yes, confirm this has been undertaken by the Faculty / HR department:

Please note: Due to the confidential nature of the DBS check, UREC does **not** require a copy of the application or certificate for DBS clearance and this should be stored securely by the researcher.

2. PARTICIPANT DETAILS

2.1 DO YOU INTEND TO RECRUIT:

	YES	NO
a) students or staff of this University (i.e. recruitment on-site at Brookes)		✓
b) adults (over the age of 16 years and competent to give consent)	✓	
c) children/legal minors (anyone under the age of 16 years)		✓
d) patients or clients of professionals		✓
e) anyone who is in custody, custodial care, or for whom a court have assumed responsibility		✓
f) any other person whose capacity to consent may be compromised		✓
g) a member of an organisation where another individual may also need to give consent		✓

2.2 NUMBER, AGE RANGE AND SOURCE OF PARTICIPANTS

Provide number, age range and source of participants and state any exclusion or inclusion criteria:

This research aims to recruit between 30-50 participants, which is in line with other high-quality qualitative research studies. Recruitment will occur through a research advert (see pg 31) posted via the CLF. Individuals on the CLF database opting into research opportunities will receive the advert and details on how to participate if they wish to do so. To add, the CLF organises a family huddle, with the next one being carried out in Las Vegas in February 2022. Some participants will therefore be sourced and interviewed during this time. Other participants will be interviewed via Google Meet and/or Zoom.

The participants will need to match the following inclusion criteria to participate:

- Participants will be over the age of 18 (therefore there are no safeguarding issues)
- Participants are caregivers to an individual living or deceased.
- Participants must be caregivers to patients who have been diagnosed with CTE or have probable CTE/sport-related neurodegeneration

2.3 MEANS BY WHICH PARTICIPANTS ARE TO BE RECRUITED

Please provide specific details of how you will be recruiting participants. How will they be approached and asked if they are willing to participate? Please explain how you have obtained or will obtain names and contact details. This information will need to be included in the participant information sheet. If a recruitment advertisement/poster is to be used, please ensure you attach a copy to this application:

As mentioned above, the participants will be recruited via the Concussion Legacy Foundation (CLF). An advert including the information sheet will be provided to the CLF who will recruit from their database. Those who opted into partaking in research will be sent the advert and instructions that details the next steps if they wish to be a part of the research. This will entail being sent the participant information and consent sheet, to confirm if they match the inclusion criteria (see in 2.2) and to determine they still wish to participate. After, they will be invited to partake in an interview (lasting approx. 1 hour) to discuss their experiences with caregiving. Interviews will be carried out primarily at the Las Vegas Family huddle (organised by the CLF) in February 2022. I have received confirmation from the CLF that I am able to conduct some of my interviews at the huddle (see on last page). If participants are unable to attend the Family Huddle, interviews will be arranged over Google Meet and/or Zoom (as described above in section 1.6)

The participants are thus selected via volunteer sampling and there is no coercion from the CLF to the research participants (i.e. can still access services). Participants will contact the lead researcher with the CLF not necessarily knowing who participates unless the participants disclose this information. Due to the sensitive nature of the topic and potential for emotional distress, this is deemed most appropriate to minimise as much harm as possible. Plus, it means those partaking have a genuine interest in the research aims, which hopefully will generate a greater level of data.

As this research is voluntary, there is a risk of under-recruiting. However, the CLF is widely known and has a strong database of individuals who have consented to be contacted about potential research opportunities, thus every effort will be made to promote the study until we are able to obtain our desirable sample.

2.4 WILL PARTS OF THIS PROJECT BE CARRIED OUT BY INDEPENDENT CONTRACTORS? *(for example transcription of interviews)*

YES **NO**

If YES, *please explain who the independent contractors are, what their role will be and how their work will be monitored. Responsibility for proper conduct of the project remains with the lead researcher. The completion of the data compliance template may be required (https://www.brookes.ac.uk/Documents/Research/Ethics/Confidentiality-template)*

2.5 ARE ANY OF THE PARTICIPANTS IN A DEPENDENT RELATIONSHIP WITH ANY OF THE INVESTIGATORS, PARTICULARLY THOSE INVOLVED IN RECRUITING FOR OR CONDUCTING THE PROJECT?

Research involving persons in dependent or unequal relationships (for instance, teacher/student) may compromise a participant's ability to give free consent. Therefore UREC recommends that, where possible, researchers choose participant cohorts where no dependent relationship exists. If, after due consideration, the investigator believes that research involving people in dependent relationships is justified, then UREC will require additional information detailing how risks inherent in the dependent *relationship will be managed. UREC will also need to be reassured that refusal to take part will have no impact on a participant's position or studies.*

YES **NO**

If YES, *please explain the relationship (e.g. teacher/student, student/lecturer, employer/employee) and the steps to be taken by the investigators to ensure that participation is purely voluntary:*

2.6 PAYMENT OR INCENTIVES: DO YOU PROPOSE TO PAY OR REWARD PARTICIPANTS?

YES **NO**

If YES*, what type of incentive and for how much?*

3. RISK AND RISK MANAGEMENT

3

DOES THE RESEARCH INVOLVE:	**YES**	**NO**
- Accessing, using or downloading security sensitive material or activity? **(If yes please complete section 3.2 below)**		✓
- Research overseas?	✓	
- Use of a questionnaire or similar research instrument or measure? (attach copy)		✓
- Use of written or computerised tests		✓
- Interviews or focus groups? (attach interview questions)	✓	
- Diaries? (attach diary record form)		✓
- Participant observation?		✓
- Observation of participants (in a non-public place) without their knowledge?		✓

● Wearable technology (e.g. body worn cameras, biometric devices etc.)		✓
● Monitoring devices		✓
● Audio-recording interviewees or events?	✓	
● Video-recording interviewees or events?		✓
● Access to personal and/or confidential data (including student or client data) without the participant's specific consent?		✓
● Administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process?	✓	
● Performance of any acts which might diminish the self-esteem of participants or cause them to experience embarrassment, regret or depression?		✓
● Investigation of participants involved in illegal activities?		✓
● Procedures that involve deception of participants?		✓
● Administration of any substance or agent?		✓
● Collection of body tissues or fluid samples? (in line with the Human Tissue Act 2004)		✓
● Collection and/or testing of DNA samples? (in line with Human Tissue Act 2004)		✓

3.2 SECURITY SENSITIVE RESEARCH OR ACTIVITY:

Security sensitive materials are defined here as materials that are covered by the Official Secrets Act 1989 and the Terrorism Act 2006, materials that could be considered 'extremist' according to the Counter Terrorism and Security Act 2015, defined as 'vocal or active opposition to fundamental British values, including democracy, the rule of law, individual liberty and mutual respect and tolerance of different faiths and beliefs', and materials that require security clearance before accessing.

The University guidelines and notification form are available at:
https://www.brookes.ac.uk/Research/Research-ethics/Review/Security-sensitive-research/

If you are unsure whether or not your research falls into the security sensitive categories, please talk to your Research Ethics Officer before proceeding.

If your research involves accessing, using, or downloading security sensitive material or activity, have you completed and attached the notification form (url given above).

YES	**NOT APPLICABLE**
	✓

3.3 POTENTIAL RISK TO PARTICIPANTS AND RISK MANAGEMENT PROCEDURES

Identify, as far as possible, potential risks to participants (e.g. physical, psychological, social, legal or economic), associated with the proposed research. Please explain what risk management procedures will be put in place:

The main risks for this research are:
Emotional distress: Some participants may experience emotional stress through answering some of the questions within this research project due to the personal and sensitive nature of the topic. Participants are allowed to discontinue with the research and withdraw at any stage. During the interviews, participants will be told they don't have to answer a question if they don't want to, and also that they can take a break if they wish to do so. There will be clear support pathways identified on the participant information sheet, such as free services that may be able to support mental health concerns and to access advice if necessary.

Concussion Legacy Foundation helpline:
Link to support form: https://concussionfoundation.org/helpline

Mental health America:
Phone: 1-800-273-TALK
Website: https://mhanational.org/get-involved/contact-us

National Alliance on Mental Illness
Phone: 800-950-NAMI (6264)
Email: info@nami.org
Website: https://www.nami.org/help

Caregiver Action Network
Phone: 855-227-3640
Website: https://www.caregiveraction.org/helpdesk

3.3.1 **ARE THERE ANY SPECIFIC RISKS TO RESEARCHERS THAT ARE GREATER THAN THOSE ENCOUNTERED IN NORMAL DAY TO DAY LIFE?** (Where research is undertaken at an off-campus location, whether in the UK or abroad, researchers should consult the University guidelines regarding risk assessment. The Dean of Faculty or the Director has the overall responsibility for risk assessment regarding the health and safety of researchers. Useful advice for the safety of researchers is available on the Social Research Association website at: *http://the-sra.org.uk/sra_resources/safety-code/* or consult the guidelines of the relevant professional and/or academic organisation.

YES **NO**

***If YES**, please describe:*

3.4 ADVERSE / UNEXPECTED OUTCOMES

Please describe what measures you have in place in the event of any unexpected outcomes or adverse effects to participants arising from involvement in the project:

No additional unexpected or adverse outcomes are expected in addition to the above outlined in 3.3.
Although, as mentioned above, the sensitive nature of the research may result in participants being emotional during the interviews, and subsequently is something the researcher (myself) will have to deal with in a professional but empathetic manner.

If the researcher (myself) experiences emotional distress after the interviews, I will ensure I speak to my supervisory team if I feel necessary and get extra support if deemed essential.

However if something arose that I had not prepared for/considered, I would ensure I seek support and advice from the research team, and contact the relevant helplines (stated in 3.3) if necessary.

3.5 DEBRIEFING, SUPPORT AND/OR FEEDBACK TO PARTICIPANTS (as appropriate)

What debriefing, support or feedback will participants receive following the study and when? Participants may need to talk about issues it has raised for them. The offer of additional support for participants during/after the study (e.g. external counselling may be advisable. How the results of the research will be disseminated to participants should be outlined).

After the interviews, participants will be signposted to a variety of support mechanisms, such as the CLF helpline and more. The details are above in section 3.3.

Participants will be able to opt in to receiving information and feedback on the project and this will include copies of any reports and publications. To do this, they will be asked to voluntarily submit their name and email address after the interview. Specifically, debriefing will occur with the participants after the interview. This will allow them the opportunity to ask questions about the study if they wish to do so.

3.6 MONITORING

Please explain how the conduct of the study will be monitored, for example via your Associate Dean for Research and Knowledge Exchange or supervisory team, (especially where multiple people are involved) to ensure that it conforms with the University's Code of Practice and any guidelines published by your professional association:

This research will be monitored by the Supervisory Team, in particular, Dr Astrid Schloerschidt as Director of Studies.

4. INFORMED CONSENT

4.1 **HAVE YOU ATTACHED TO YOUR APPLICATION A COPY OF THE PARTICIPANT INFORMATION SHEET?** *Guidelines for drafting this are provided on the UREC web page at:* https://www.brookes.ac.uk/Research/Research-ethics/Review/Guidelines-for-informed-consent/. *Whenever possible, Oxford Brookes University letterhead or logo should be used for information sheets*

YES NO

If NO, please explain:

4.2 **HAVE YOU ATTACHED TO YOUR APPLICATION A COPY OF THE CONSENT FORM?** *if you are not obtaining consent in* ***writing*** *please explain how the informed consent process is to be documented. Guidelines for drafting this are provided on the UREC web page at* https://www.brookes.ac.uk/Research/Research-ethics/Review/Guidelines-for-informed-consent/. *Whenever possible, Oxford Brookes University letterhead or logo should be used for consent forms.*

Following the implementation of GDPR in May 2018, participants MUST give their active consent to take part. Opt-out consent is not an option.

YES NO

If NO, please explain how consent will be documented:

5. DATA CONFIDENTIALITY / ANONYMITY AND PRIVACY

5 WILL THE RESEARCH INVOLVE:

	YES	NO
● Complete anonymity of participants (i.e. researchers will not know the identity of participants as participants are part of a random sample)?		✓
● Anonymised samples or data (i.e. an irreversible process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers?		✓
● De-identified samples or data (i.e. a reversible process in which the identifiers are removed and replaced by a code. Those handling the data subsequently do so using the code)?	✓	
● Participants having the option of being identified in any publication arising from the research?		✓
● Participants being referred to by pseudonym in any publication arising from the research?	✓	
● The use of personal data? (If YES, please ensure that all processing of personal data is in accordance with UK law and specifically the Data Protection Act (2018), prior to any research commencing. It is essential that the processing of personal data is compliant with the University's Data Protection Policy.	✓	

Important considerations about data confidentiality:

1. Where the sample size is very small, it may be impossible to guarantee anonymity/confidentiality of the participant's identity. Participants involved in such studies need to be advised of this limitation in the participant information sheet.

2. Where research studies involve the collection of large personally identifiable datasets or use privacy-intrusive technology (e.g. biometrics, body worn cameras, monitoring devices) it may be necessary to complete a privacy impact assessment. A template is available (.brookes.ac.uk/WorkArea/DownloadAsset.aspx?id=2147586227). The IT Services Information Management Team will review these if needed to determine whether or not a comprehensive privacy impact assessment is required (contact info.sec@brookes.ac.uk).

5.2 WHICH OF THE FOLLOWING METHODS OF ASSURING CONFIDENTIALITY OF DATA WILL BE IMPLEMENTED? Please select all relevant options**.**

● data and codes and all identifying information to be kept in separate secure locations	
● access to computer files to be available by password or other appropriate levels of protection	✓
● other *(please describe)*:	

5.3 **LEGAL LIMITATIONS TO DATA CONFIDENTIALITY:** Are p*articipants being informed that the confidentiality of the information they provide can only be protected within the limitations of the law - i.e. it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.*

YES **Not applicable**

NO (please explain):

6 DATA PROTECTION, ACCESS AND SECURITY

6.1 WHO WILL BE RESPONSIBLE FOR THE SECURITY OF DATA COLLECTED?

(Provide details of who in the research team will have the overall responsibility for the security of the data collected during the life of the study):

Dr Astrid Schloerscheidt

6.2 ACCESS TO DATA

● Access by named researchers only	✓
● Access by people other than named researcher(s) *(Please explain and identify):*	

6.3 STORAGE OF DATA

By data, the University means not just datasets but artwork, recordings, images, videos or any other form of data that researchers collect in the course of undertaking their research. Staff and students should be aware of research data management information and tools, available at: https://www.brookes.ac.uk/research/research-support/data-management/	
● **Stored at Oxford Brookes University** If **YES**, please provide the following information:	Yes
➢ How will the data be stored? Data will be stored on password protected Google drive folders only accessible by the doctoral student and supervisory team during data collection and data analysis. Data will be stored electronically only. Once the study and write up of the thesis is completed data will be transferred to Radar in anonymised form. Data will include the anonymised audio files, which do not contain personal information and the anonymised transcripts, which will also not contain personal information. **Electronically only**	
➢ Where will the data be stored? Data will be stored on Google Drive throughout the course of the Project and then anonymous data (audio files and transcripts) will be transferred to Radar for long-term storage. Data will be deleted after 10 years unless publisher requirements demand otherwise.	
➢ In what format will the data be stored? PDF transcripts and audio files only, both anonymised	
● **Stored at another site** *Please explain where and for what purpose. Data stored in the field should be on a password protected device or stored and shared via Google Drive for which the university has a security agreement.* See the data sharing and file management matrix for advice	No

- **Stored in a secure shared repository – after completion of the project, e.g RADAR or a subject specific repository** *(This should be explained to participants in the information sheet and privacy notice)* Data will be stored on RADAR. Data will be destroyed after 10 years unless publication requires storage beyond that term.	Yes

6.4 DOES DATA STORAGE COMPLY WITH THE UNIVERSITY'S GUIDELINES FOR THE MANAGEMENT OF RESEARCH DATA AND RECORDS? *(See Oxford Brookes University Code of Practice for Academic Integrity, at:* https://www.brookes.ac.uk/Documents/Research/Policies-and-codes-of-practice/academic_integrity

YES No **If NO**, please explain:

6.5 PRIVACY NOTICE

In line with the EU GDPR, now passed into UK law as the Data Protection Act 2018, research participants must be adequately informed about why they are providing information, how it will be used and who will have access to it. A privacy notice must be created for each research study and made available to participants. A template is available at: https://www.brookes.ac.uk/Documents/Research/Ethics/Privacy-notice-for-researchers/ (If the data being collected is completely anonymous or does not include information that can be combined with other data to identify an individual, this privacy notice is *not r*equired).

Have you attached a copy of the privacy notice for this study?

YES Not required

7. FUNDING

7.1 IS THIS PROJECT BEING EXTERNALLY FUNDED? *(This does not include funded PhD programmes)*

YES **NO** *(skip the remaining questions in section 7)*

7.2 SOURCE OF FUNDING *(This must be stated in the participant information sheet)*:

7.3 DOES THE PROJECT REQUIRE APPROVAL BEFORE CONSIDERATION BY A FUNDING BODY?

YES **NO**

If YES, what is the deadline for the funding body?

8. CHECKLIST

Please check that the following documents are attached to your application. Please note that where questionnaire or interview questions are submitted in draft form, a copy of the final documentation must be submitted for final approval when available.

	ATTACHED	**NOT APPLICABLE**
• Recruitment advertisement (question 2.3)	✓	
• Participant information sheet (question 4.1)	✓	
• Consent form (question 4.2)	✓	
• Privacy notice (question 6.5)	✓	
• Evidence of external approvals related to the research (question 1.7)		✓
• Questionnaire (question 3.1)		✓
• Interview Schedule (question 3.1)	✓ draft	
• Other (please specify:		✓

For further details about completion of this form, please contact your Research Ethics Officer in the first instance.

Privacy Notice for Research Participants

This Privacy Notice provides information on how Oxford Brookes University (Oxford Brookes) collects and uses participant's personal information when they take part in one of our research projects. Please refer to the research Participant Information Sheet for further details about the study and what information will be collected about you and how it will be used.

Oxford Brookes is the Data Controller of any data that you supply for this research. This means that we are responsible for looking after your information and using it lawfully. We will make the decisions on how your data is used and for what reasons.

Why do we need your data?

Your data will be used to answer our research question, that investigates into how a range of predictors influence the mental health and wellbeing of CTE caregivers, and how the negative connotations associated with these ramifications can be minimised to improve the welfare of the caregivers.

Oxford Brookes' legal basis for collecting this data is:

Public task: your Personal Data will be used in academic research. Oxford Brookes University is a public body and staff and students carry out research in line with the University's legal powers and constitution.

Your consent is an ethical requirement.

Oxford Brookes University's legal basis for processing your Personal Data (or information) is as set out in Art 6 UK GDPR.

What type of personal data will Oxford Brookes use?

The electronic data that you provide, which includes your name, contact details, demographic information and your transcript from the interview. This data will be stored on Google Drive throughout the course of the Project and then anonymous data (audio files and transcripts) will be transferred to a data repository (Radar) for long-term storage. Data will be deleted after 10 years unless publisher requirements demand otherwise.

Who will Oxford Brookes share your data with?

Your data will only be accessible to the research team listed in the participant information sheet. Data will be stored in a password protected Google drive folder only accessible by the doctoral student and supervisory team during data collection and data analysis. Data will be stored electronically only. Once the study and write up of the thesis is completed data will be transferred to Radar (a data repository) in anonymised form. Data will include the anonymised audio files, which do not contain personal information and the anonymised transcripts, which will also not contain personal information.

Will Oxford Brookes transfer my data outside of the UK?

As specified, data will be stored on Google drive (which does store data outside of the UK), however this data is all anonymised and only accessible to the research team through a secure password.

What rights do I have regarding my data that Oxford Brookes holds?

- You have the right to be informed about what data will be collected and how this will be used
- You have the right of access to your data
- You have the right to correct data if it is wrong
- You have the right to ask for your data to be deleted
- You have the right to restrict use of the data we hold about you
- You have the right to data portability
- You have the right to object to Oxford Brookes using your data
- You have rights in relation to using your data in automated decision making and profiling.

Your rights will depend on the legal ground used to process your data

Where did Oxford Brookes source my data from?

The data will be sourced directly from you through partaking in an interview (lasting roughly an hour)

Are there any consequences of not providing the requested data?

There are no consequences of not providing data for this research. It is purely voluntary. If you like to withdraw part way through the research, the Participant Information Sheet includes this information. It may be that some of the data that you have provided has already been used in the research. If you would like more information about this, you should feel free to contact the research team.

Will there be any automated decision making using my data?

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation.

How long will Oxford Brookes keep your data?

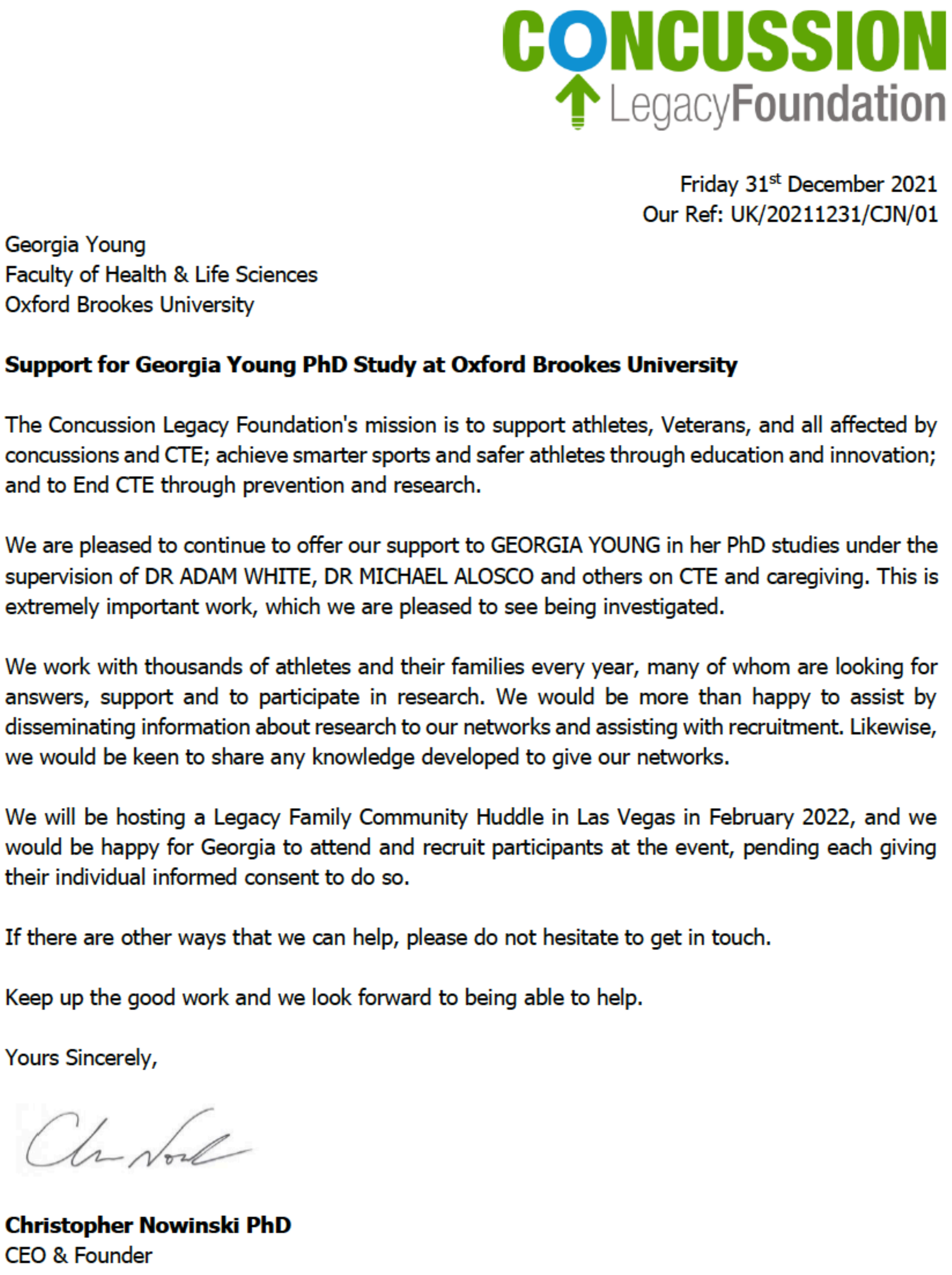
In line with Oxford Brookes policies data generated in the course of research must be kept securely in paper or electronic form for a period of time in accordance with the research funder or University policy. Specifically, data will be destroyed after 10 years unless publication requires storage beyond that term.

Who can I contact if I have concerns?

In the event of any questions about the research study, please contact the research team in the first instance. Their contact details are listed on the Participant Information Sheet. If you have any concerns about the way in which the study has been conducted, please contact the Chair of the University Research Ethics Committee at ethics@brookes.ac.uk. For further details about information use contact the Information Security Management team on info.sec@brookes.ac.uk or the Data Protection Officer at brookesdpo@brookes.ac.uk. You can also contact the Information Commissioner's Office via their website ico.org.uk.

Appendix 3: CLF advert and letter for Study One and Study Two

Gatekeeper Letter & email confirmation of data collection:



CONCUSSION
LegacyFoundation

Friday 31st December 2021
Our Ref: UK/20211231/CJN/01

Georgia Young
Faculty of Health & Life Sciences
Oxford Brookes University

Support for Georgia Young PhD Study at Oxford Brookes University

The Concussion Legacy Foundation's mission is to support athletes, Veterans, and all affected by concussions and CTE; achieve smarter sports and safer athletes through education and innovation; and to End CTE through prevention and research.

We are pleased to continue to offer our support to GEORGIA YOUNG in her PhD studies under the supervision of DR ADAM WHITE, DR MICHAEL ALOSCO and others on CTE and caregiving. This is extremely important work, which we are pleased to see being investigated.

We work with thousands of athletes and their families every year, many of whom are looking for answers, support and to participate in research. We would be more than happy to assist by disseminating information about research to our networks and assisting with recruitment. Likewise, we would be keen to share any knowledge developed to give our networks.

We will be hosting a Legacy Family Community Huddle in Las Vegas in February 2022, and we would be happy for Georgia to attend and recruit participants at the event, pending each giving their individual informed consent to do so.

If there are other ways that we can help, please do not hesitate to get in touch.

Keep up the good work and we look forward to being able to help.

Yours Sincerely,

Christopher Nowinski PhD
CEO & Founder

Letter for advert approval:

Advert Text

Title: Investigation of the experiences of caregiving in Chronic Traumatic Encephalopathy (CTE)

Are you currently or have previously been a caregiver to a loved one with CTE or probable CTE?

Do you want to talk about your experiences on the role and factors that have contributed to the burden you may have experienced?

If so, this research may be for you. We will undertake semi-structured interviews to establish how a range of predictors influence your mental health and wellbeing throughout the caregiving role. From these interviews it is hoped we can develop a framework that demonstrates the most influential factors on the caregiver experience. Caregiving in CTE is an area that is not well researched and we hope to elucidate the factors that define the caregiving experience for individuals with CTE. This will help to raise awareness and ultimately support the development of appropriate support interventions for caregivers caring for a person with CTE..

If you would like to find out more or consider participating, please read this participant information sheet [insert link here]. If you then decide you would like to participate, please contact the principal investigator Georgia Young (contact details below)to organise a suitable time for an interview.

We take the use of your data seriously and therefore please do take a moment to read our privacy statement on how we will use and protect your data here [insert link].

We encourage you to ask questions and make sure you are happy and comfortable to participate. If you do have any questions, please contact any member of the research team on the contact details below:

Principle Investigator:	*Georgia Young*	19154046@brookes.ac.uk
Co-Investigators:	*Dr Adam J White*	AdamWhite@brookes.ac.uk
	Dr Astrid Schloerscheidt	aschloerscheidt@brookes.ac.uk
	Dr Michael Alosco	malosco@bu.edu
	Dr Matt Smith	matt.Smith@winchester.ac.uk

Appendix 4: Information sheet for Study One and Study Two

Investigation of the experiences of caregiving in Chronic Traumatic Encephalopathy (CTE)

You are being invited to take part in a doctoral research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?
The purpose of this study is to learn more about the experiences of caregivers for people with CTE. Through understanding its uniqueness, we hope to gain a greater comprehension of specific factors that influence a caregivers experience so we can create interventions that best support them.

Participants will be required to take part in an interview lasting approximately 1 hour. As part of this interview, questions will be asked to help us understand more about CTE caregivers as a population in order to develop a framework defining the caregiver experience.

Why have I been invited to participate?
You have been invited to participate as you are currently, or have previously, been a caregiver to someone with CTE/suspected CTE and have agreed with the Concussion Legacy Foundation to be contacted about opportunities to participate in research.

Do I have to take part?
It is up to you to decide whether or not to take part in this research study. If you do decide to take part, you will be given this information sheet along with a privacy notice (explaining how your data will be collected and used) and be asked to give your consent. If you decide to take part, you are still free to withdraw at any point and without giving a reason. Any data collected from you can be withdrawn, up to the point of analysis.

What will happen to me if I take part?
You will be invited to take part in a face-to-face or virtual (subject to participant choice) interview lasting approximately one hour. All interviews will be audio-recorded with your permission, and transcribed verbatim. Examples of questions asked in the interview are:

1. Tell me about what happened in regards to your caregiving role

2. What emotions/feelings did you experience during caregiving?

3. Could you describe the events that preceded these emotions?

What are the possible disadvantages and risks of taking part?
The interview should take approximately one hour of your time. There is a potential that the questions may invoke some strong emotions, distress and concerns. Should you experience any of these, you can pause or stop the interview at any time and you will be able to access free and independent support from the following organisations:

Concussion Legacy Foundation helpline:
Link to support form: https://concussionfoundation.org/helpline

Mental health America:
Phone: 1-800-273-TALK
Website: https://mhanational.org/get-involved/contact-us

National Alliance on Mental Illness
Phone: 800-950-NAMI (6264)
Email: info@nami.org
Website: https://www.nami.org/help

Caregiver Action Network
Phone: 855-227-3640
Website: https://www.caregiveraction.org/helpdesk

What are the possible benefits of taking part?
Your participation in this research will increase our current knowledge on what factors influence the CTE caregiving experience, which will inform future work that aims to develop appropriate support for caregivers.

Will what I say in this study be kept confidential?
All information collected about you will be kept strictly confidential. Only members of the research team (named below) will have access to the data. Where research findings are disseminated, any data used will be anonymised and untraceable to individuals involved. Data will be stored on a password protected laptop and on Google Drive, for which the University (Oxford Brookes) has a security agreement.

Data generated by the study must be retained in accordance with the University's policy on Academic Integrity, as such data generated in the course of the research must be kept securely for a period of ten years after the completion of the research project.

What should I do if I want to take part?
If you would like to participate, please contact any of the research team by email (see below for contact details). You will be required to give your informed consent at the start of the interview to participate.

What will happen to the results of the research study?
The results of this study will be shared, using pseudonyms to ensure participant anonymity, via academic research publications and conferences. Participants can give their contact details voluntarily to access copies of any outputs from this project.

Who is organising and funding the research?
This research is conducted by a PhD student and staff from the Faculty of Health and Life Sciences at Oxford Brookes University in collaboration with the Concussion Legacy Foundation. This research has received no external research funding and is not linked to any third-party organisations.

Who has reviewed the study?
This research has been approved by the University Research Ethics Committee at Oxford Brookes University. Reference number: (to be added when ethics is approved)

Contact for Further Information
For more information, please contact any member of the research team on the below contact details:

Director of Studies:	Dr Astrid Schloerscheidt	aschloerscheidt@brookes.ac.uk
Supervisors:	Dr Michael Alosco	malosco@bu.edu
	Dr Adam J White	adamWhite@brookes.ac.uk
	Dr Matt Smith	MattSmith@brookes.ac.uk
Doctoral Researcher:	Georgia Young	19154046@brookes.ac.uk

If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk

Thank you for taking the time to consider participating in this research

Appendix 5: Consent form for Study One and Study Two

CONSENT FORM

Investigation of the experiences of caregiving in Chronic Traumatic Encephalopathy (CTE)

Director of Studies:	Dr Astrid Schloerscheidt	aschloerscheidt@brookes.ac.uk
Supervisors:	Dr Michael Alosco	malosco@bu.edu
	Dr Adam J White	adamWhite@brookes.ac.uk
	Dr Matt Smith	MattSmith@brookes.ac.uk
Doctoral Researcher:	Georgia Young	19154046@brookes.ac.uk

	Please initial box
1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.	
3. I agree to take part in the above study.	

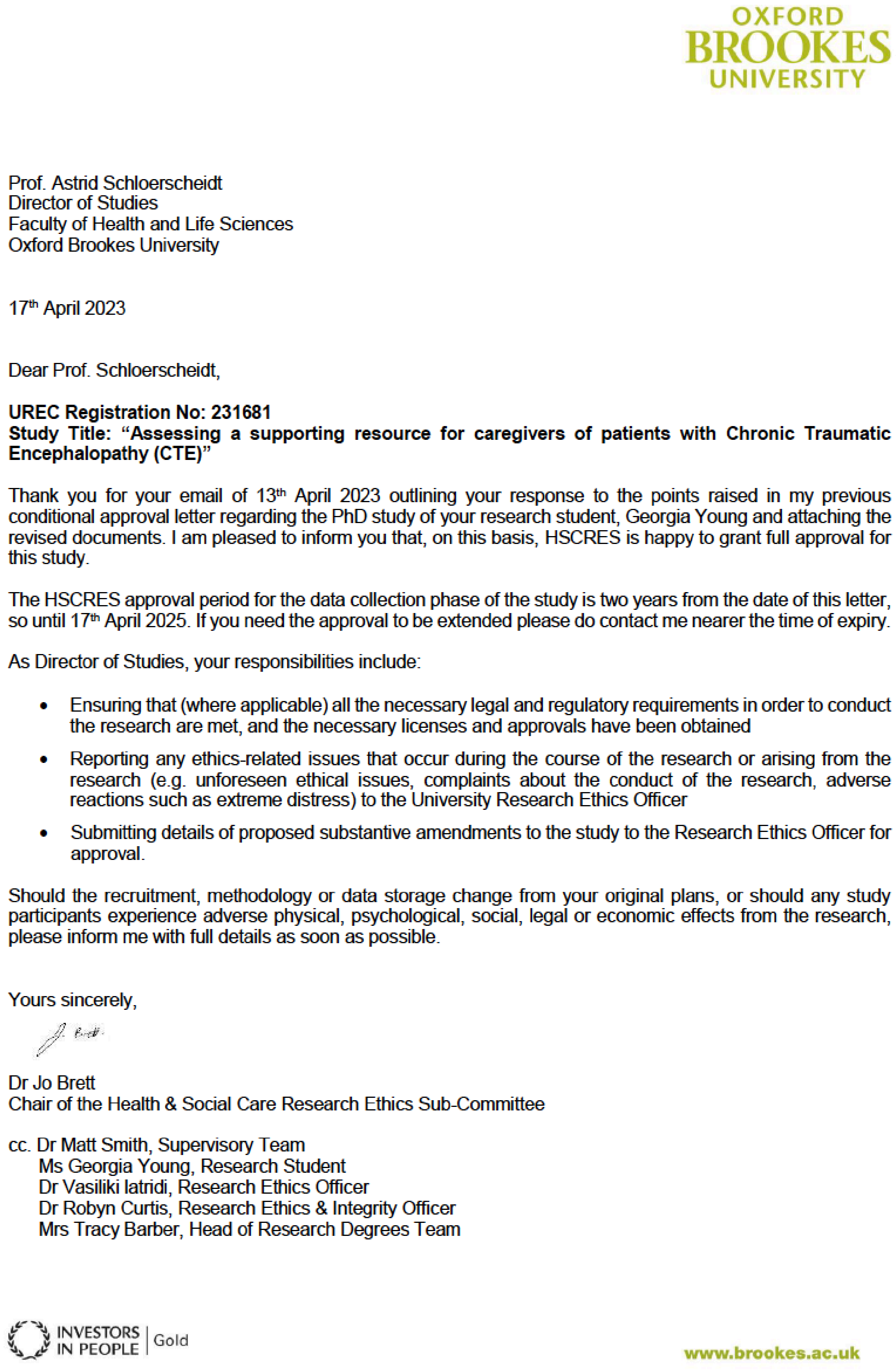
Please initial box

	Yes	No
4. I understand that the interview will be audio-Recorded		
5. I agree to the use of anonymised quotes in publications		

7. I agree that an anonymised data set, gathered for this study may be stored in a specialist data centre/repository relevant to this subject area for future research

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix 6: Study Three ethical approval and ethics forms



OXFORD
BROOKES
UNIVERSITY

Prof. Astrid Schloerscheidt
Director of Studies
Faculty of Health and Life Sciences
Oxford Brookes University

17th April 2023

Dear Prof. Schloerscheidt,

UREC Registration No: 231681
Study Title: "Assessing a supporting resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE)"

Thank you for your email of 13th April 2023 outlining your response to the points raised in my previous conditional approval letter regarding the PhD study of your research student, Georgia Young and attaching the revised documents. I am pleased to inform you that, on this basis, HSCRES is happy to grant full approval for this study.

The HSCRES approval period for the data collection phase of the study is two years from the date of this letter, so until 17th April 2025. If you need the approval to be extended please do contact me nearer the time of expiry.

As Director of Studies, your responsibilities include:

- Ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained
- Reporting any ethics-related issues that occur during the course of the research or arising from the research (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress) to the University Research Ethics Officer
- Submitting details of proposed substantive amendments to the study to the Research Ethics Officer for approval.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

Yours sincerely,

Dr Jo Brett
Chair of the Health & Social Care Research Ethics Sub-Committee

cc. Dr Matt Smith, Supervisory Team
Ms Georgia Young, Research Student
Dr Vasiliki Iatridi, Research Ethics Officer
Dr Robyn Curtis, Research Ethics & Integrity Officer
Mrs Tracy Barber, Head of Research Degrees Team

UNIVERSITY RESEARCH ETHICS COMMITTEE
E2U Form (April 2022)

APPLICATION FOR APPROVAL OF A STUDY INVOLVING HUMAN PARTICIPANTS, DATA OR MATERIAL

UREC Registration No. *(office use only)* ☐☐☐☐☐☐

This application form is for Staff, MPhil/PhD and Professional Doctoral students only and should be submitted as **1 PDF document** to the UREC Secretary at ethics@brookes.ac.uk

- For all other forms please refer to the Oxford Brookes University Research Ethics Review Page.
- Further details about the process and guidance please refer to the Research Ethics Intranet Page.
- For further assistance completing this form, please contact your Research Ethics Officer.
- PhD students should refer to their supervisor in the first instance.
- Potential participants **must not be contacted** until full formal written approval has been received.

PLEASE CONFIRM:	
Applicant has read University Research Ethics Code of Practice	YES
Applicant has completed Information Security Awareness Training Course	YES

THIS APPLICATION IS FOR:		
Staff Research Study		
Staff Programme of Studies		
Student Research Study	X	
Has your research degree programme already been approved by the relevant Research Degree Sub-Committee?	**YES**	
External Researcher Project		

RESEARCH TEAM:

The Principal Investigator or Director of Studies should be listed first and students should be listed after their supervisory team.

TITLE & NAME	**POST**	**FACULTY**	**EMAIL**
Prof Astrid Schloerscheidt	Director of Studies Dean of HLS	Dean Faculty of Health and Life Sciences	aschloerscheidt@brookes.ac.uk

Dr Matt Smith	Supervisor Senior Lecturer in Psychology	Faculty of Health and Wellbeing, University of Winchester.	matt.Smith@winchester.ac.uk
Georgia Young	PhD student	Faculty of Health and Life Sciences	gyoung@brookes.ac.uk

Programme/Study title:	"Assessing a supporting resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE)"

Section 1 – Study Details			
1.1	**PROPOSED DATA COLLECTION DATES** *Please note data collection must not commence until after full ethics approval.*	From: March 2023	To: May 2023
1.2	**LAY DESCRIPTION OF THE RESEARCH**: *This should be a brief lay summary of the study in **easy to understand language for a non-expert audience**. Any unavoidable technical terms, discipline-specific phrases, acronyms or abbreviations should be clearly explained. Please include the significance of the project and expected benefits to the community, in a format appropriate for a lay reader. (**No more than 300 words**).*		
	This study involves assessing a supportive resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE). There is currently no research on CTE caregivers and subsequently, the resources they have available to them, to help them through their challenges, are limited. It was concluded in the researchers' two initial studies looking at older and younger CTE caregivers that lack of access to resources or informational tools was a big contributor to the burden they experienced. It is hoped that the resource will be effective in minimising burden related symptoms (i.e. anxiety and loneliness) and will provide an information point for CTE caregivers. Thus, this study involves disseminating two podcast episodes (created by the researcher) focused on the CTE experience from the perspective of the family members and primary caregivers. These episodes and a newsletter version (so individuals have the option of preferable resource) will be sent out to 20-30 caregivers of patients with CTE alongside a short survey asking a range of open and closed questions regarding the caregivers initial thoughts on the effectiveness of the podcast/newsletter and its accessibility. As part of the survey, participants are given the opportunity to opt into a further interview (lasting approximately 30-60 minutes) that will explore their survey answer in more depth. Through designing and evaluating a resource aimed at supporting CTE caregivers, we will subsequently develop and refine it so that it can be disseminated as a wider intervention, and help CTE caregivers more widely (both current and previous caregivers).		
1.3	**JUSTIFICATION & AIM OF RESEARCH:** *This should clearly present the research question/hypothesis, justification and aims of the study in a format appropriate for peer review. (**No more than 300 words**)*		

Background :

Research on caregiving for those with suspected Chronic Traumatic Encephalopathy (CTE- a form of dementia caused by repetitive head trauma) is virtually non-existent. Therefore, the researcher (GY) undertook two initial qualitative studies that focused upon understanding the CTE caregiver experience. Results showed that the experiences of older spousal CTE caregivers were similar to caregivers in other neurological diseases (i.e. dementia), for example, neglecting their own physical/health issues, and experiencing a huge sense of loneliness. However, contrary to other forms of dementia, CTE caregivers were seen to experience a significant loss of purpose after their caregiving role stopped (i.e., the death of their loved one). Unlike the older caregivers, younger CTE caregivers found the role less physically demanding but reported stronger feelings of isolation, and reported a larger sense of burden during and after caregiving. Both groups of CTE caregivers reported the lack of support and resources as a significant contributing factor to the burden they experienced, and attributed this to their self-neglect and feelings of isolation. Other neurodegenerative diseases, such as Alzheimer’s, have been heavily researched, thus intervention programmes for caregivers have been proposed and evaluated in this context (Walter & Pinquart 2020) . This may explain why these caregivers have been shown to experience less negative outcomes (both short and long-term).

Aims:

Based on this result, the proposed study will disseminate and evaluate the effectiveness of a supportive resource, namely a podcast (also available as a newsletter for those who may not be comfortable or familiar with the podcast format). Having a resource that focuses on supporting the CTE caregiver, tailored to both during and after they give care, may help to alleviate some of the negative implications (i.e. burden, anxiety, loneliness, loss of purpose) that were seen to occur (in the findings of study 1 and 2). Subsequently, through designing a resource that aims to offer support to CTE caregivers and then evaluating it, we can develop and refine that resource so that it can be rolled out as a wider intervention, and help other caregivers dealing with CTE patients.

1.4 **PROPOSED METHOD:**

Provide an outline of the proposed method, including details of data collection techniques, tasks participants will be asked to do, the estimated time commitment involved, and how data will be analysed. ***(No more than 500 words)***.

Participants will be recruited from studies 1 and 2 of the researchers PhD project, where they have given consent to be contacted for further research studies. This consent was provided to the Concussion Legacy Foundation (CLF) where individuals had to give consent to being sent future research opportunities. The CLF has a database with these individuals and they will consent with the CLF to be sent research opportunities that may arise. As I recruited participants for previous study (with previous ethics application- (ethical approval 211551- see appendix 9) through the CLF, for this study those individuals will be sent the research information automatically as they have consented through the CLF as mentioned above. So that consent is between the participants and the CLF. Not all of the researchers' previous participants may partake in this study, but they will all be sent the study information as part of being signed up to the database with the CLF and will have to give further consent after the researcher contacts them directly with the PIS and consent form. With the volume of individuals on the CLF database, it is likely that new participants will also be recruited via the CLF for this particular study. For a full description of participant recruitment see section 3.3.

In this study, participants will be presented with CTE specific podcasts. The aim of the podcast is to raise awareness and educate others about the realities of CTE and also provide some comfort to family members whose experience can resonate with the stories being told. The individuals who wish to participate, will be sent the PIS alongside the consent form and privacy notice (via email- see appendix 1-3). Once consent has been provided to the researcher, two podcast episodes (averaging 40 minutes each in length) will be sent to the participant. All participants will also be sent a newsletter version of the podcast episode (so they have the option to use the material in different modalities), in case they struggle with online accessibility. The newsletter will be created by the researcher, and it will contain the exact transcription of the relevant podcast episode (I will provide the audio version and the newsletter to the ethics committee once created, but the podcast episodes will not be created until ethical approval). The participants will have 2 weeks to listen to or read the episodes.

As well as the episodes, the participants will be provided with a short survey via a Google Form link (please see Appendix 2) that asks a mixture of open and closed questions to explore the effectiveness of the podcast. It is important to note that receiving the podcast is contingent on agreeing to complete the survey, thus participants can only participate if they agree to completing the survey. The aim of the survey is to get initial feedback on the format of the resource, its usefulness and accessibility. The survey questions were developed through a combination of the researchers' knowledge (from study 1 and 2) and literature surrounding podcast effectiveness (see appendix 5). As part of the survey, participants will be asked via the Google Form link (Appendix 4) if they are willing to participate in a short follow-up semi-structured interview (30-60 minutes). In the interview, the researcher will explore the participants' survey responses further. The interview guide will be developed based on the survey results but a draft one with indicative questions has been formulated based on literature (please see Appendix 8 for full details). The indicative interview guide can be found at the end of this document (Appendix 6 & 7- a full version will be submitted for review after analysis of survey responses). At the start of the survey participants will be informed about the process of anonymisation within this research. Specifically, participants will be asked to provide their name and contact email address. However, if they decide they do not want to partake in the short follow up interview at a later date, participants will be asked to remove their contact details from the survey. When the form is submitted without name and email, the researcher will see it as "1 response" rather than the name of the participant.This way, the researcher will not be able to detect the link between the survey responses and the participants of those NOT partaking in the interview. This will then allow me to contact the individuals who wish to join me for the follow up interview. Participants being interviewed will be informed that they will be given a pseudonym to protect their identity. The researcher will give pseudonyms once transcripts are written up and prior to analysis.The interview data will be analysed under this pseudonym, thus effectively anonymising the data yet allowing for linkage. Only pseudonyms will be used in any publications. The interviews will be audio recorded via Zoom (on the Brookes Zoom account) for transcription purposes (so the researcher can manually transcribe post interview), but participant consent will be sought for the interview to be recorded, prior to recording. The digital recordings of the interviews will be deleted as soon as transcription is completed. As the interviews will be conducted online, the participants will be advised to find a confidential space for interviews.

Participants will all be debriefed after the interviews. This debriefing process will include speaking to the participants about their involvement, asking if they have any questions regarding the research process, and reminding them of links to use (included in the privacy notice) if they feel they need to reach out for further help post-interview (i..e mental health support). In terms of analysis, the researcher will go through the survey responses, and will report the response values of the questions. However, no quantitative statistics will be undertaken due to the small number of participants the survey is being distributed to. Emerging trends will be used to inform the interviews. The interviews will undergo thematic analysis, to determine the participants experiences, views and opinions on listening to the podcast episodes as a supportive tool.

REFERENCES:

If necessary, please provide no more than 10 references to support Sections 1.2 to 1.4.

Cabote, C. J., Bramble, M., & McCann, D. (2015). Family caregivers experiences of caring for a relative with younger onset dementia: A qualitative systematic review. *Journal of Family Nursing*, *21*(3), 443-468.

Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International nursing review*, *62*(3), 340-350.

Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic analysis. *Qualitative psychology: A practical guide to research methods*, *222*(2015), 248.

Creese, J., Bedard, M., Brazil, K., & Chambers, L. (2008). Sleep disturbances in spousal caregivers of individuals with Alzheimer's disease. *International psychogeriatrics*, *20*(1), 149-161.

Demerouti, E., Bakker, A. B., Nachreiner, F., & Schaufeli, W. B. (2001). The job demands-resources model of burnout. *Journal of Applied psychology*, *86*(3), 499.

Gaugler, J. E., Anderson, K. A., Leach, C. R., Smith, C. D., Schmitt, F. A., & Mendiondo, M. (2004). The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias®*, *19*(6), 369-380.

Lee, K., Martin, P., & Poon, L. W. (2017). Predictors of caregiving burden: impact of subjective health, negative affect, and loneliness of octogenarians and centenarians. *Aging & Mental Health*, *21*(11), 1214-1221.

Nissen, K.G., Trevino, K., Lange, T. and Prigerson, H.G., 2016. Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer. *Journal of pain and symptom management*, *52*(6), pp.841-849.

Oliveira, D. C., Vass, C., & Aubeeluck, A. (2018). The development and validation of the dementia quality of life scale for older family Carers (DQoL-OC). *Aging & Mental Health*, *22*(5), 709-716.

Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *58*(2), P112-P128.

Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. *The American Journal of Geriatric Psychiatry*, *19*(6), 491-496.

1.5 **DISCLOSURE AND BARRING SERVICE CHECK REQUIRED:**

If the proposed participant pool is a legally defined vulnerable group a DBS check is required by the University. If yes, please indicate in Section 1.6 the members of the research team who have clearance. ***Please note:*** *Due to the confidential nature of the DBS check, UREC does not require a copy of the application or certificate for DBS clearance. This should be stored securely by the principal investigator.*

Please mark as applicable:			**N/A**

1.6	**RESEARCH TEAM RELEVANT EXPERIENCE AND SKILLS:** *List the relevant experience and outline the skills **relevant to this study*** *(**No more than 300 words**. Please do not include links to profile pages or copies of CVs).*		
	Director of Studies: Prof Astrid Schloerschiedt is an experienced experimental psychology researcher with a focus on quantitative research. She has supervised a number of quantitative and qualitative investigations at MSc level and two PhD candidates. Some of this work involved vulnerable groups (e.g., young people with eating disorders, patient with diagnosed schizophrenia). Astrid chaired the Dundee University Research Ethics Committee for 5 years and has experience assessing the ethical dimensions of work with vulnerable groups and how to mitigate risk. Supervisor: Dr Matt Smith is a social psychologist with particular research interests in leadership and group dynamics. In addition, his research interests include mental health in sport and implications of head injury in sport. Currently, he is involved in research examining conflict in sports teams, dealing with difficult team members, and effective communication in teams. He is also involved in interdisciplinary research considering the experiences of family members who have an athlete in their family who have suffered traumatic brain injury, and research considering the efficacy of community activity schemes for stroke patients. Dr Smith has a particular interest in qualitative research methods, which includes the use of autobiographical data in research, using different stimuli to facilitate qualitative data collection, and presenting qualitative findings in novel ways. Researcher: Georgia Young is an aspiring qualitative researcher, with an undergraduate and postgraduate qualification in Sport Psychology. Particularly, her interests lie in health and wellbeing psychology, with a specific research background in body image, self-presentation and caregiving. Georgia is excited and passionate for her future work within CTE caregiving, with her overall aim being to help those in need through research.		
1.7	**RESEARCH LOCATION:** *Please give details of **ALL** locations where the research and data collection is being undertaken. For example, at Oxford Brookes University sites, online, UK locations, international sites.*		
	The surveys will be administered via a Google Form link from the researchers computer. The interviews will be held on Zoom from the researchers home in London. The interviewer will ensure to use headphones for privacy reasons. An OBU based/managed meeting room will not be used instead due to the time difference (all participants are based in the USA). Podcast episodes will all be recorded on Zoom from the researcher's home in the UK. The same protocol as above (use of headphones) wil be utilised for privacy reasons.		
1.8	**GATEKEEPER APPROVALS REQUIRED: (Mark as applicable)**	YES	
	If yes, please give details below of how this permission will be sought. Please also confirm that, prior to research commencing, this will be forwarded to the ethics@brookes.ac.uk once received. Please note: Gatekeeper permissions are required to conduct research in, at or through another institution or organisation.		
	Letter of permission is attached at the end of this document (see appendix 7).		
1.9	**INDEPENDENT CONTRACTORS: (Mark as applicable)**		**NO**

	This includes the use of transcription, translation or recruitment services. If yes, please give details below of the organisations and the confidentiality agreement.		
	Transcription will be conducted manually.		
1.10	**EXTERNALLY FUNDED: (Mark as applicable)**		**NO**
	If yes, please give details of the source of the funding and confirm if the study requires ethics approval prior to consideration by a Funding Body, along with the deadline for this. ***Please note:*** *Studies that are externally funded must clearly state this on the Participant Information Sheet.*		

Section 2 – Risk and Risk Management			
2.1	**THE RESEARCH STUDY INVOLVES:**	**YES**	**NO**
	A questionnaire, survey or similar research instrument	✓	
	Written or computerised tests		✓
	Diaries – recording form attached		✓
	Interviews or focus groups – questions attached	✓	
	Participant observation		✓
	Audio-recording of participants or events	✓	
	Video-recording of participants or events		✓
	Observation of participants (in a non-public place) without their knowledge		✓
	Monitoring devices		✓
	Wearable technology (e.g. body worn cameras, biometric devices etc.)		✓
	Administration of any substance or agent		✓
	Administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process	✓	1§
	Access to personal and/or confidential data (including student or client data) without the participant's specific consent		✓

	Performance of any acts which might diminish the self-esteem of participants or cause them to experience embarrassment, regret or depression	✓	
	Procedures that involve deception of participants		✓
	Investigation of participants involved in illegal activities		✓
	Collection of body tissues or fluid samples (in line with the Human Tissue Act 2004)		✓
	Collection and/or testing of DNA samples (in line with Human Tissue Act 2004)		✓
	Accessing, using or downloading security sensitive material or activity (***If yes please complete section 2.2 below***)		
2.2	**SECURITY SENSITIVE RESEARCH OR ACTIVITY:** *Security sensitive materials are defined here as materials that are covered by the Official Secrets Act 1989 and the Terrorism Act 2006, materials that could be considered 'extremist' according to the Counter Terrorism and Security Act 2015, defined as 'vocal or active opposition to fundamental British values, including democracy, the rule of law, individual liberty and mutual respect and tolerance of different faiths and beliefs', and materials that require security clearance before accessing. Please refer to the University Security Sensitive Guidelines. If you are unsure whether or not your research falls into the security sensitive categories, please talk to your Research Ethics Officer before proceeding.*		
	Security Sensitive Research Notification Form attached.		
2.3	**PARTICIPANT RISK MANAGEMENT PROCEDURES:** ***All researchers*** *should clearly Identify, as far as possible, the potential risks to participants (e.g. physical, psychological, social, legal or economic) and explain the risk management procedures in place. Participants may need to talk about issues raised and should be offered additional support during or after the study. Please note that details of external pathways of support must be included for identified risks.*		

The main risks for this research are:

Emotional distress: Some participants may experience emotional stress through listening to the podcast episodes. Despite that not being the aim, the podcast will have guests who are sharing their experiences as a family member to someone with CTE. Thus, the participants may get upset/distressed when listening to parts that resonate with them. The interview questions may also result in emotional responses given the personal and sensitive nature of the topic. Participants are allowed to discontinue with the research and withdraw up to the point of interview analysis. During the interviews, participants will be told they don’t have to answer a question if they don’t want to, and also that they can take a break if they wish to do so. There will be clear support pathways identified on the participant information sheet, such as free services that may be able to support mental health concerns and to access advice if necessary.

Concussion Legacy Foundation helpline:
Link to support form: https://concussionfoundation.org/helpline

Mental health America:
Phone: 1-800-273-TALK
Website: https://mhanational.org/get-involved/contact-us

National Alliance on Mental Illness
Phone: 800-950-NAMI (6264)
Email: info@nami.org
Website: https://www.nami.org/help

Caregiver Action Network
Phone: 855-227-3640
Website: https://www.caregiveraction.org/helpdesk

2.4

ADVERSE / UNEXPECTED OUTCOMES

All researchers *should describe their procedures for the management of any adverse effects and unexpected outcomes to participants arising from involvement in the study not identified in Section 2.3. This should include specific responsibilities related to the researchers listed in Section 1.6.*

‘There are no unexpected outcomes’ *is not an acceptable response to this section and researchers should think through who they would contact or actions they would take if the unexpected occurs.*

No additional unexpected or adverse outcomes are expected in addition to the above outlined in 3.3. Although, as mentioned above, the sensitive nature of the research may result in participants experiencing strong emotions during listening to the podcasts and participating in the interviews which is something the researcher (myself) will have to deal with in a professional but empathetic manner.

However if something arose that I had not prepared for/considered, I would ensure I seek support and advice from the research team, and contact the relevant helplines (stated in 3.3) if necessary.

2.5	**SPECIFIC RISKS TO RESEARCHERS:** *The safety, health and wellbeing of researchers in relation to the study **must** be considered.* *The Dean of Faculty or the Director has the overall responsibility for risk assessment regarding the health and safety of researchers. Useful advice for the safety of researchers is also available from the Social Research Association or consult the guidelines of the relevant professional and/or academic organisation*		
	If the researcher (myself) experiences emotional distress after the interviews, I will ensure I speak to my supervisory team if necessary and get extra support if deemed essential.	**YES**	**NO**
	Potential physical, psychological, social, legal or economic risks have been fully assessed	✓	
	The University guidelines regarding risk assessment have been consulted.	✓	
	The University guidelines on Working Alone Safely have been consulted.	✓	
	If there are potential risks greater than those encountered in normal day to day life, provide details below.		
	N/A		
2.6	**MONITORING:** *Provide the name and position of the person who will monitor the conduct of the study and ensure that it conforms to the University's Code of Practice and any guidelines published by your professional association. This person must be external to the Research Team, normally your Associate Dean for Research and Knowledge Exchange or Department Research Lead. In the case of research students, monitoring is usually by your supervisory team,*		
	This research will be monitored by the Supervisory Team, in particular, Prof Astrid Schloerschidt as Director of Studies.		

Section 3 – Participant Details			
3.1	**PARTICIPANTS WILL BE:**	**YES**	**NO**
	Students or staff of Oxford Brookes University		✓
	Adults (over the age of 18 years and competent to give consent)	✓	
	Young Adults (over the age of 16 and competent to give consent)		✓
	Children/legal minors (anyone under the age of 16 years)		✓
	Patients, students or clients of members of the research team		✓
	Members of an organisation where another individual may also need to give consent		✓

	Persons in custody, custodial care, or for whom a court have assumed responsibility		✓
	Persons whose capacity to consent may be compromised		✓

3.2 **NUMBER, AGE RANGE, INCLUSION AND EXCLUSION CRITERIA:**

Please provide a proposed sample size and age range of participants. ***Explicitly state*** *all exclusion or inclusion criteria. Details should be included in the Participant Information Sheet.*

This research aims to recruit 20-30 participants, which is in line with other high-quality qualitative research studies (Kratz et al., 2017). Out of this group, a minimum of 10 individuals will partake in interviews.

The participants will need to meet the following inclusion criteria to participate:

- Participants will be over the age of 18 (therefore there are no safeguarding issues)
- Participants are primary caregivers to an individual living or deceased
- Participants must be a minimum of 1 year past a patient's death
- Participants must be or have been caregivers to patients who have been diagnosed with CTE or have probable CTE/sport-related neurodegeneration
- Participants must have access to digital equipment (i.e. a computer) to access study material and to be interviewed (if opt in)
- Participants are all required to speak English
- Participants must be based in United States of America

3.3 **MEANS BY WHICH PARTICIPANTS ARE TO BE RECRUITED:**

Provide specific sources and details of how you will be recruiting participants, detailing how contact details will be obtained and how participants will be contacted. This should be included in the Participant Information Sheet. All recruitment material used, including emails, social media posts, physical posters must be submitted with the application. Where the sample size is very small, it may be impossible to guarantee anonymity/confidentiality of the participant's identity. Participants involved in such studies need to be advised of this limitation in the Participant Information Sheet.

	The study aims to recruit 20-30 participants for the survey, with at least 10 of these participating in the follow-up interview. As mentioned above the participants will be recruited from the CLF database (via an email containing advertisement and PIS- see appendix) and the participants of studies 1 and 2 of the researchers PhD project (directly via email). Within the reselected participants (who agreed to be contacted for future studies) all of them are primary caregivers to someone with suspected/diagnosed CTE. Specifically, 12 of these participants are female spousal caregivers, all from various states within the US, aged between 60-87 years old (M=72, SD=7.26). These individuals had been a caregiver for over 10 years. The other 12 participants are younger primary caregivers aged between 35-59 years old. Out of the sample, 11 were female and one male, with 5 being children, 4 were siblings and 3 were spouses to their loved ones. To add, 11 of these participants had lost their loved ones to pathologically diagnosed CTE, and one participant is still caring for their loved one with suspected CTE. The majority of the caregivers had looked after their loved one for 3-8 years. Initially, these individuals were recruited into Studies 1 and 2 via the Concussion Legacy Foundation (CLF). The researcher did meet many of the participants at the CLF huddle in Las Vegas, in February 2022.

	As mentioned above, in addition to those participants recruited from studies 1 and 2, participants for Study 3 will also be recruited through the Concussion Legacy Foundation (CLF). An advert including the information sheet will be provided to the CLF (see appendix 8) who will then contact potential participants currently in their database. Those who are part of the CLF database and express an interest in participating in research as part of that database will be sent the advert and will be asked to contact the researcher if interested. Once the participants express their interest through contacting the researcher, they will be sent the participant information and consent sheet by the researcher, to confirm if they meet the inclusion criteria and to determine if they still wish to participate. The participants are thus selected via volunteer sampling and there is no coercion from the CLF to the research participants (i.e. can still access services). Participants will contact the lead researcher in response to the advert sent to them, which means that the CLF will not be aware who has opted into the research . Participants from study 1 and 2 will be contacted directly via email by the researcher with the privacy notice, information sheet and consent form (if they previously consented to being contacted for future research). Participants will be encouraged to read through the whole information sheet to familiarise themselves with the aims of the research before they sign and return the consent form back to the researcher via email. Despite some of this sample already partaking in my research, this participation will still require consent from all individuals (even though previous participants consented to take part in other research tasks). Due to the sensitive nature of the topic and potential for emotional distress, volunteer sampling is deemed most appropriate to minimise as much harm as possible. Plus, it means those participating have a genuine interest in the research aims, which hopefully will generate a greater level of data. With any qualitative research focused on a sensitive topic, there is a risk of under-recruiting. However, the CLF is widely known and has a strong database of individuals who have consented to be contacted about potential research opportunities, thus every effort will be made (by sending out study advertisement to individuals signed up to the CLF research opportunities) to promote the study until we are able to obtain our desirable sample.
3.4	**IDENTIFY ANY POTENTIAL DEPENDENT RELATIONSHIPS:** *Provide specific details of any unequal relationship between researchers, third party organisations and/or participants – for example teacher/student, student/lecturer, employer/employee, clinician/patient. Please detail the process for mitigating any dependencies or perceived dependencies.*
	N/A
3.5	**DETAIL ANY PAYMENTS OR REWARDS TO PARTICIPANTS:** *If participants are to receive any remuneration or incentive, please provide full details. Please note that these should be equally accessible to all participants, unless there is a specific justification.*
	N/A

3.6	**<u>DETAIL DISSEMINATION OF STUDY RESULTS TO PARTICIPANTS:</u>** *Dissemination of findings to participants in a form they can access and understand is a requirement of all research studies. Provide details of how the results will be disseminated to participants.*	
	Participants will be able to opt in to receiving information on the project and this will include copies of any reports and publications. To do this, they will be asked to voluntarily submit their name and email address after the survey and interview (to those who opt to participate). Specifically, debriefing will occur with each participant after their interview.	
3.7	**<u>PLEASE CONFIRM THE BELOW ARE COMPLETED:</u>** *Please note: <u>Any material</u> to be provided to participants must be included.*	
	Participant Information Sheet	✓
	Recruitment Material	✓
	Interview questions	✓
	Questionnaire	✓

Section 4 – Informed Consent	
4.1	**<u>DETAIL METHOD OF FOR COLLECTING CONSENT</u>:** *Please explain the process for collecting and documenting participants' informed consent. Please note: Participants **<u>MUST</u>** give their active, explicit consent to take part having first received the details of the study (Participant Information). Opt-out consent is not an option. Participants should normally be given a minimum of 48 hours between receipt of the Participant Information Sheet and the collection of consent.*
	All participants will be emailed over a consent form, alongside the information sheet and privacy notice. Participants cannot partake in the study unless the consent form is completely filled out, signed and returned to the researcher via email. Following University guidelines, no participant can provide consent before 48 hours after receiving the PIS/Privacy notice. Thus, the researcher will follow these guidelines before sending over the resource and survey. This protocol will be included in the email to all participants. All consent forms will be kept within a folder, separate from the collected data, only accessible by the researcher. The consent form, information sheet, and privacy notice can be found at the end of this document.
4.2	**<u>PLEASE COMPLETE:</u>**
	Consent Form ✓

Section 5 – Data Management		
5.1	**<u>THE DATA FOR THIS STUDY INCLUDES:</u>** (*Mark as appropriate)*	
	Complete anonymity of participants (Researchers will not know the identity of participants)	X
	Anonymised data (Researchers complete an **irreversible** process, removing personal identifiers and replacing with a code; no identifiable records are retained)	X

	Pseudonymised data (Researchers complete a **reversible** process removing personal identifiers and replacing them with a code. Personal data is retained in a separate secure location but not used during analysis)	✓
	Participants having the option of being identified in any publication arising from the research	X
	Participants being referred to by pseudonym in any publication arising from the research	✓
	The use of personal data. *If YES, please ensure that all processing of personal data must be in accordance with UK law and specifically the Data Protection Act (2018), prior to any research commencing. It is essential that the processing of personal data is compliant with the University's Data Protection Policy.*	✓
	The collection of large personally identifiable datasets or use of privacy-intrusive technology (e.g. biometrics, body-worn cameras, monitoring devices, etc.) *It may be necessary to complete a Data Privacy Impact Assessment. Please refer to the IT Services Information Management Team for review (contact info.sec@brookes.ac.uk).*	X
5.2	**DATA CONFIDENTIALITY WILL BE ENSURED BY:** (*Mark as appropriate)*	
	Password protected files	✓
	Data encryption *See - A User Guide to File Encryption*	✓
	Data and personal identifiers located in separate secure locations	✓
	Other: *(please describe)*	
5.3	**DATA PROTECTION:**	
	Specify who in the research team is responsible for ensuring data security throughout the life of the project: Prof Astrid Schloerscheidt	
5.4	**ACCESS TO DATA WILL BE LIMITED TO:** *(Mark as appropriate)*	
	Members of Research Team only	✓
	People other than named Research Team Members: *(If yes, please identify and specify reason)*	

5.5	**DATA STORAGE:** *Please note this refers to any and all data, in any form collected during the course of this study. Refer to research data management information and tools - see Research Data Management. Please note, USB or External Hard Drives are not recommended.*	
	Short-term Data Storage - Where will data be stored? *Provide details of data storage for in-field collection, as well as campus based.*	
	Data will be stored on password protected OBU Google drive folders only accessible by the doctoral student and supervisory team during data collection and data analysis. Data will be stored electronically only.	
	Short-term Data Storage - In what format will the data be stored?	
	Transcripts (written in google docs and exported as PDF) and audio files only, both anonymised. The survey responses will be collated from google forms and stored as a PDF.	
	Long-term Data Storage – Where will raw data be stored? *Please refer to Publishing and Archiving Research Data.*	
	Once the study and write up of the thesis is completed data will be transferred to Arkivum for long-term archiving in anonymised form. Data will include the anonymised audio files and PDF survey responses, which do not contain personal information and the anonymised transcripts, which will also not contain personal information. This will be stored in case they are needed during the publication process.	
	Long-term Data Storage – Will published data be stored on a secure, shared repository. *In line with Open Access requirements, please indicate the repository (e.g. RADAR) on which publications and associated data sets will be made available*	
	Data will be stored on Arkivum. Data will be destroyed after 10 years.	
5.6	**PLEASE CONFIRM**: Data storage complies with the University's Guidelines for Research Integrity – Data Management.	✓
5.7	**PLEASE CONFIRM**: Participants have been informed that the confidentiality of the information they provide can only be protected within the limitations of the law - i.e. it is possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions	✓
5.8	**PLEASE CONFIRM**: A Privacy Notice has been completed. *In line with the UK GDPR (2018) research participants must be adequately informed about why they are providing information, how it will be used and who will have access to it. The latest template is available at Research Ethics Forms & Templates. If the data collected is completely anonymous a privacy notice is not required.*	✓

Section 6 – Declaration

6.1 **DECLARATION BY RESEARCH TEAM:**

The information contained herein is, to the best of my knowledge and belief, accurate. I have read the University's Code of Practice for Research Ethics, and accept responsibility for the conduct of the procedures set out in the attached application in accordance with the University's Procedures.

I and my co-investigators or supporting staff have the appropriate qualifications, experience and facilities to conduct the research set out in the attached application and to deal with any emergencies and contingencies related to the research that may arise.

All members of the research team *are required to sign the application before submission to the University Research Ethics Committee.*

Name:	Signature:	Date:
Georgia Young		8/12/22
Astrid Schloerscheidt		18/12/22
Matt Smith	M Smith	18 /12/22

6.2 **DECLARATION BY RESEARCH ETHICS OFFICER:**

The Faculty/Directorate Research Ethics Officer has reviewed this project and considers the methodological/technical and research ethics aspects of the proposal to be appropriate to the tasks proposed and recommends the application to the University Research Ethics Committee. The Faculty/Directorate REC or REO considers that the research team have the necessary qualifications, experience and facilities to conduct the research set out in the attached application, and to deal with any emergencies and contingencies that may arise.

Date first draft application received:	23/12/22
Date revised application received:	
Date ethics review completed:	

Additional Comments/Proviso:

Name of Research Ethics Officer: Vasiliki Iatridi

Signature of Research Ethics Officer: Date:

Section 7 - Final Checklist:

Please **double check** all the necessary documents are attached, including all material to be provided to participants and the application is fully completed. Once complete please submit as **1 PDF document** to ethics@brookes.ac.uk. Please note: links to proposed documents is not acceptable.

7.1	All sections of E2U Application Form completed	✓
	E2U Application signed by all members of the Research Team	✓
	E2U Application signed off by the Faculty Research Ethics Officer	
	Participant Information Sheet attached	✓
	Recruitment material attached	✓
	Interview questions attached	✓
	Questionnaire attached	✓
	Consent Form/Script/Online form attached	✓
	Privacy Notice attached	✓

UNIVERSITY ETHICS OFFICE USE ONLY:	
Date application received:	
Date of UREC meeting:	

Privacy Notice for Research Participants

This Privacy Notice provides information on how Oxford Brookes University (Oxford Brookes) collects and uses participant's personal information when you take part in one of our research projects. Please refer to the research Participant Information Sheet for further details about the study and what information will be collected about you and how it will be used.

Oxford Brookes is the Data Controller of any data that you supply for this research. This means that we are responsible for looking after your information and using it lawfully. We will make the decisions on how your data is used and for what reasons.

Why do we need your data?

Your data will be used to answer our research question, that investigates the effectiveness of a CTE podcast as a supportive tool for primary caregivers of patients with diagnosed/suspected Chronic Traumatic Encephalopathy.

Oxford Brookes' legal basis for collecting this data is:

Public task: Your Personal Data will be used in academic research. Oxford Brookes University is a public body and staff and students carry out research in line with the University's legal powers and constitution.

Your consent is an ethical requirement.

Oxford Brookes University's legal basis for processing your Personal Data (or information) is as set out in Art 6 UK GDPR

What type of personal data will Oxford Brookes use?

The data that you provide includes your name, contact details, survey responses, audio files and transcripts from the interview.

Who will Oxford Brookes share your data with?

Your data will only be accessible to the research team listed in the participant information sheet. Data will be stored in a password protected Google drive folder only accessible by the doctoral student and supervisory team during data collection and data analysis. Data will be stored electronically only. Once the study and write up of the thesis is completed data will be transferred to Arkivum for long-term archiving in anonymised form. Data will include the anonymised audio files and interview transcripts, which do not contain personal information and the anonymised transcripts, which will also not contain personal information. Anonymisation will involve replacing your name with a number (i.e. P1 for participant 1). This will be maintained in any publications of the research, and will not correspond with the order the interviews take place.

Will Oxford Brookes transfer my data outside of the UK?

As specified, data will be stored on Google drive (which does store data outside of the UK), however this data is all anonymised and only accessible to the research team through a secure password.

What rights do I have regarding my data that Oxford Brookes holds?

- You have the right to be informed about what data will be collected and how this will be used
- You have the right of access to your data
- You have the right to correct data if it is wrong

- You have the right to ask for your data to be deleted
- You have the right to restrict use of the data we hold about you
- You have the right to data portability
- You have the right to object to Oxford Brookes using your data
- You have rights in relation to using your data in automated decision making and profiling.

Your rights will depend on the legal ground used to process your data

Where did Oxford Brookes source my data from?

The data will be sourced directly from you through completing a short survey and partaking in an interview (lasting roughly 30-60 minutes)

Are there any consequences of not providing the requested data?

There are no consequences of not providing data for this research. It is purely voluntary. If you like to withdraw part way through the research, the Participant Information Sheet includes this information. It may be that some of the data that you have provided has already been used in the research. If you would like more information about this, you should feel free to contact the research team.

Will there be any automated decision making using my data?

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation.

How long will Oxford Brookes keep your data?

In line with Oxford Brookes policies, data generated in the course of research must be kept securely in paper or electronic form for a period of time in accordance with the research funder or University policy. Data will be transferred to long-term storage after the manuscript has been written. All the data collected is electronic (i.e. google survey and online interview transcripts), thus there is no concern about privacy breach of physical data. Specifically, data will be destroyed after 10 years unless publication of the study into an academic journal requires storage beyond that term.

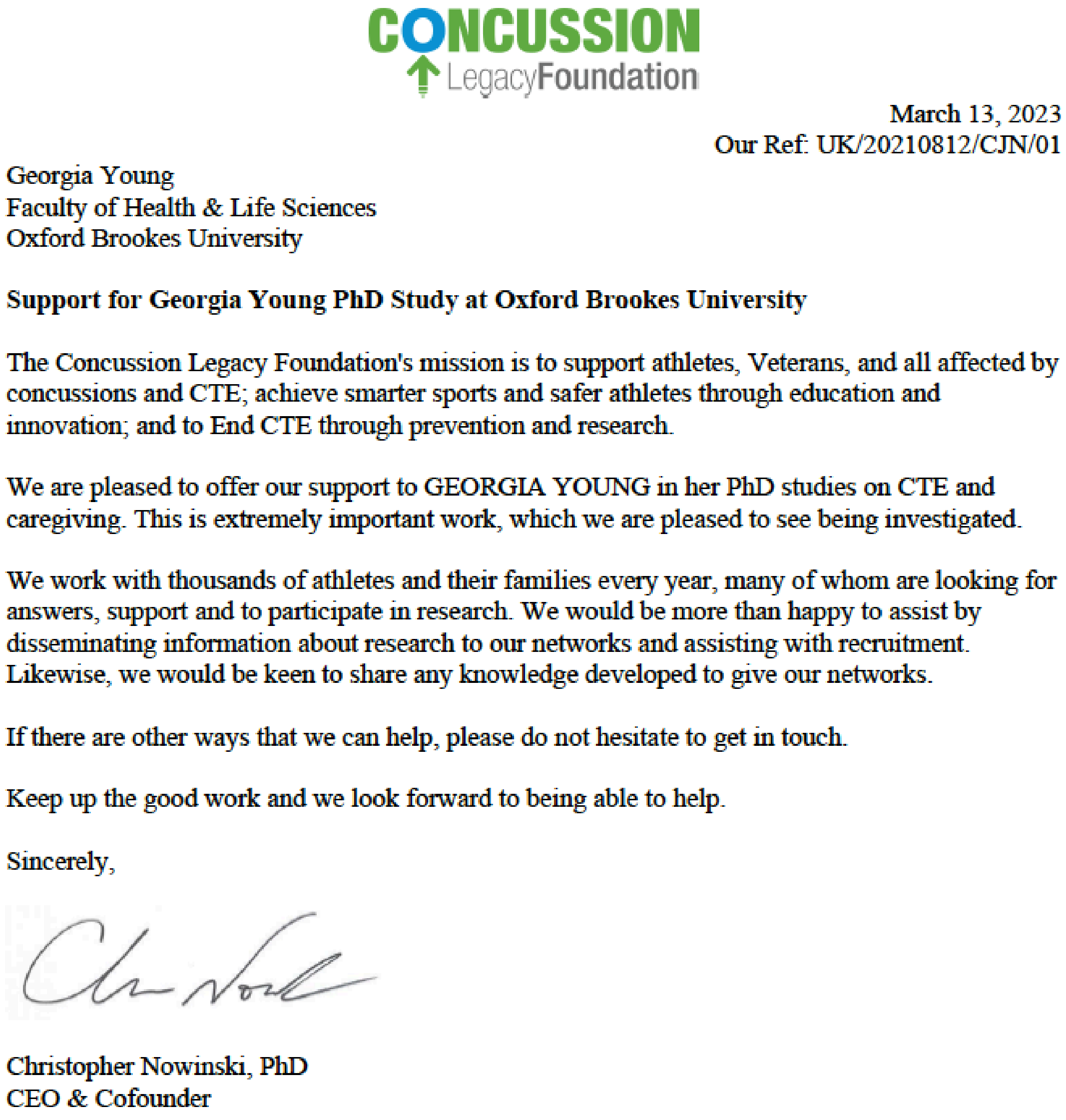
Where can I find the privacy notices for the platforms being used in the study?

Please find the Zoom privacy notice here: https://explore.zoom.us/en/privacy/
Please find the Google privacy notice here: https://policies.google.com/privacy

Who can I contact if I have concerns?

In the event of any questions about the research study, please contact the research team in the first instance. Their contact details are listed on the Participant Information Sheet. If you have any concerns about the way in which the study has been conducted, please contact the Chair of the University Research Ethics Committee at ethics@brookes.ac.uk. For further details about information use contact the Information Security Management team on info.sec@brookes.ac.uk or the Data Protection Officer at brookesdpo@brookes.ac.uk. You can also contact the Information Commissioner’s Office via their website ico.org.uk.

Appendix 7: Gatekeeper letter



CONCUSSION
LegacyFoundation

March 13, 2023
Our Ref: UK/20210812/CJN/01

Georgia Young
Faculty of Health & Life Sciences
Oxford Brookes University

Support for Georgia Young PhD Study at Oxford Brookes University

The Concussion Legacy Foundation's mission is to support athletes, Veterans, and all affected by concussions and CTE; achieve smarter sports and safer athletes through education and innovation; and to End CTE through prevention and research.

We are pleased to offer our support to GEORGIA YOUNG in her PhD studies on CTE and caregiving. This is extremely important work, which we are pleased to see being investigated.

We work with thousands of athletes and their families every year, many of whom are looking for answers, support and to participate in research. We would be more than happy to assist by disseminating information about research to our networks and assisting with recruitment. Likewise, we would be keen to share any knowledge developed to give our networks.

If there are other ways that we can help, please do not hesitate to get in touch.

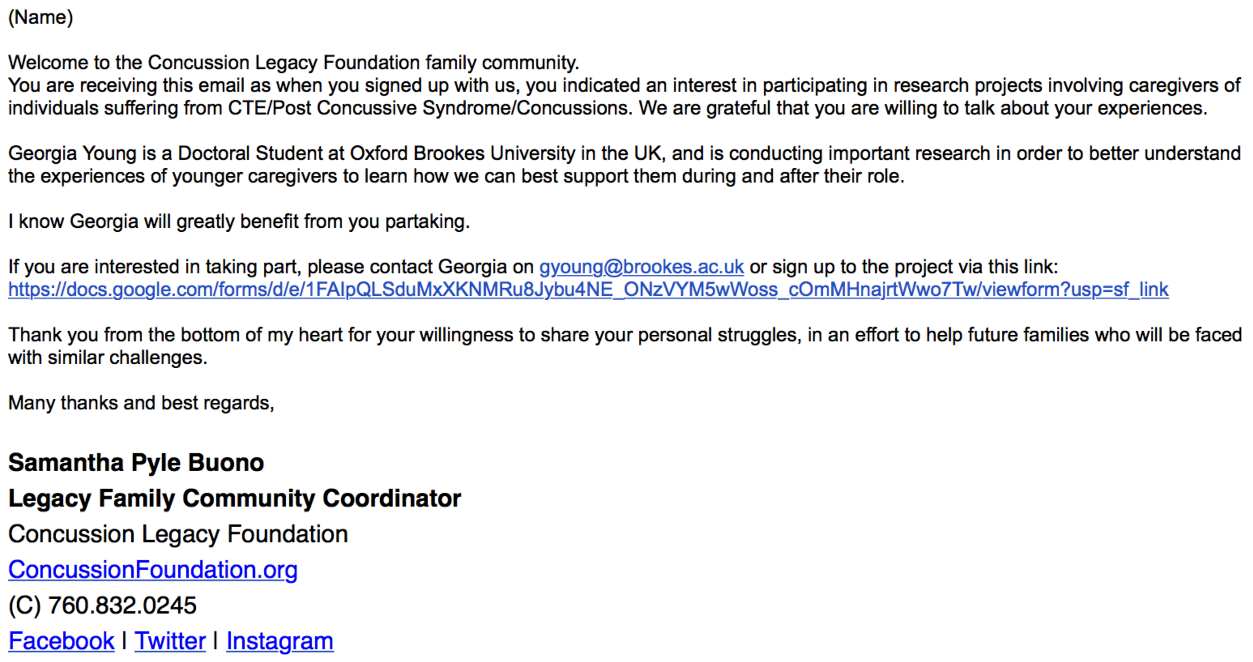
Keep up the good work and we look forward to being able to help.

Sincerely,

Christopher Nowinski, PhD
CEO & Cofounder

7.1. CLF advertisement

Below shows an example letter of advertisement the CLF will send out to the individuals on their database that have signed up to research opportunities and match the inclusion criteria of this study (the researcher notified the CLF of this criteria list prior to advertisement). The email encourages potential participants to contact the researcher directly if they are interested, or register their interest via using a Google Form link (that the researcher provided to the CLF). Samantha Buono is the director of programs at the CLF, and coordinates with family members as part of this role. She will be sending the advertisement email to the relevant individuals. Just to note, the Legacy Family Community (LFC) is the family relations community within the Concussion Legacy Foundation (where members of the CLF communicate with the family members of those affected by CTE).



(Name)

Welcome to the Concussion Legacy Foundation family community.
You are receiving this email as when you signed up with us, you indicated an interest in participating in research projects involving caregivers of individuals suffering from CTE/Post Concussive Syndrome/Concussions. We are grateful that you are willing to talk about your experiences.

Georgia Young is a Doctoral Student at Oxford Brookes University in the UK, and is conducting important research in order to better understand the experiences of younger caregivers to learn how we can best support them during and after their role.

I know Georgia will greatly benefit from you partaking.

If you are interested in taking part, please contact Georgia on gyoung@brookes.ac.uk or sign up to the project via this link:
https://docs.google.com/forms/d/e/1FAIpQLSduMxXKNMRu8Jybu4NE_ONzVYM5wWoss_cOmMHnajrtWwo7Tw/viewform?usp=sf_link

Thank you from the bottom of my heart for your willingness to share your personal struggles, in an effort to help future families who will be faced with similar challenges.

Many thanks and best regards,

Samantha Pyle Buono
Legacy Family Community Coordinator
Concussion Legacy Foundation
ConcussionFoundation.org
(C) 760.832.0245
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Appendix 8: Participant Information Sheet (survey)

Study title:

“Assessing a supporting resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE)”

Invitation:

You are being invited to take part in a doctoral research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?

The purpose of this study is to evaluate the effectiveness of a CTE based podcast as a potential intervention to alleviate caregiver burden symptoms. This study will run over the course of 2 months. Participants will be required to listen to two podcast episodes from the podcast CTE Talk or read a newsletter containing the podcast contents. Alongside this, a short survey will be provided asking the participants their initial thoughts on the podcast. In this survey, the participants will be asked if they are willing to partake in a short follow-up interview.. As part of this interview, questions will be asked to get more in depth feedback based on the responses provided in the survey. This will allow the researcher to understand how effective the podcast episodes were to the caregivers, and to get feedback on how to make it a more effective supportive tool going forward.

Why have I been invited to participate?

You have been invited to participate as you are currently, or have previously, been a caregiver to someone with CTE/suspected CTE and have agreed with the Concussion Legacy Foundation to be contacted about opportunities to participate in research. You also match the following inclusion criteria for the study:

- Participants will be over the age of 18 (therefore there are no safeguarding issues)
- Participants are primary caregivers to an individual living or deceased
- Participants are a minimum of 1 year past patient’s death
- Participants must be or have been caregivers to patients who have been diagnosed with CTE or have probable CTE/sport-related neurodegeneration
- Participants must have access to digital equipment (i.e. a computer) to access study material and to be interviewed (if opt in)
- Participants are all required to speak English
- Participants must be based in United States America

Up to 30 other individuals, matching the inclusion criteria have also been invited to participate.

Do I have to take part?

It is up to you to decide whether or not to take part in this research study. If you do decide to take part, you will be given this information sheet along with a privacy notice (explaining how your data will be collected and used) and be asked to give your consent. If you decide to take part, you are still free to withdraw at any point and without giving a reason. Any data collected from you can be withdrawn, up to the point of analysis. Choosing to either take part or not take part in the study will have no impact on your current/future use/involvement in the Concussion Legacy Foundation.

What will happen to me if I take part?

You will be invited to listen to two podcast episodes from CTE TALK (a podcast recorded by the researcher about being a CTE family member) and fill in a short online survey (via Google forms) asking you a mix of open and closed questions about your initial thoughts on the podcasts effectiveness and ts accessibility. There will be an opportunity to partake in a short interview (30-60 minutes) however this is only if you agree to participate (which you will state at the end of the survey alongside your contact details). All interviews will be held via Zoom and audio-recorded with your permission, and transcribed verbatim. Examples of questions asked in the interview are:

1. What emotions/feelings did you experience whilst listening to the podcast?
2. How did listening to relatable stories make you feel? (i.e. did it provide relief or did it arise negative feelings)
3. How easy/challenging did you find it to listen and engage in the contents of the podcast?

The study will occur over 2 months. You will have 2 weeks to listen to the podcast episodes and fill in the survey. The interview (if you wish to participate) will be conducted 2 weeks after the survey. You will be required to read another information sheet and sign a consent form prior to the interview. At the end of the interview, you will have a debriefing period lasting 15-20 minutes. This will give you an opportunity to ask any questions you may have regarding the aims of the study and your involvement in it.

What are the possible disadvantages and risks of taking part?

There is a potential that the content of the podcast and interview questions may evoke some strong emotions, distress and concerns. Should you experience any of these, you can pause the podcast/reading the newsletter, or stop the interview at any time and you will be able to access free and independent support from the following organisations:

Concussion Legacy Foundation helpline:
Link to support form: https://concussionfoundation.org/helpline

Mental health America:
Phone: 1-800-273-TALK
Website: https://mhanational.org/get-involved/contact-us

National Alliance on Mental Illness
Phone: 800-950-NAMI (6264)
Email: info@nami.org
Website: https://www.nami.org/help

Caregiver Action Network
Phone: 855-227-3640
Website: https://www.caregiveraction.org/helpdesk

What are the possible benefits of taking part?

Participation in this research will help evaluate an intervention which may ease some of the challenges you have experienced for future CTE caregivers. This process will help refine the resource so it can be used to help other family members/caregivers in the future.

Will what I say in this study be kept confidential?

All information collected about you will be kept strictly confidential. Only members of the research team (named below) will have access to the data. Where research findings are disseminated, any data used will be anonymised. However due to the small sample size, it may be impossible to fully guarantee anonymity/confidentiality of participants' identity. Data will be initially stored on a password protected laptop and on Google Drive, for which the University (Oxford Brookes) has a contract with Google for cloud-based services. This contact has the necessary security features to maintain the privacy of the data.

Data generated by the study must be retained in accordance with the University's policy on Academic Integrity, as such data generated in the course of the research must be kept securely for a period of ten years after the completion of the research project. .

What should I do if I want to take part?

If you would like to participate, please reply to this invitation by contacting the researcher Georgia Young (via the contact details below) or the Concussion Legacy Foundation. You will be required to give your informed consent at the podcast and survey stage of the study (via a google form). You will also be required to verbally give consent at the start of the interview to participate.

What will happen to the results of the research study?

The results of this study will be shared, using pseudonyms to ensure participant anonymity, via the researchers thesis, academic research publications and conferences. Participants can give their contact details voluntarily at the end of the survey to the researcher, to be sent copies of any outputs from this project.

Who is organising and funding the research?

This research is conducted by a PhD student and staff from the Faculty of Health and Life Sciences at Oxford Brookes University in collaboration with the Concussion Legacy Foundation. The researcher is receiving a studentship from the Faculty of Health and Life Sciences, Department of Sport, Health Sciences and Social Work) to carry out this PhD research.

Who has reviewed the study?

This research has been reviewed by the Health and Social Care Research Ethics Sub-Committee (UREC Registration No: 231681)

Contact for Further Information:

For more information, please contact any member of the research team on the below contact details:

Director of Studies:	Prof Astrid Schloerscheidt	aschloerscheidt@brookes.ac.uk

Supervisors:	Dr Matt Smith	MattSmith@brookes.ac.uk
Doctoral Researcher:	Georgia Young	g.young@brookes.ac.uk

If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk

Thank you for taking the time to consider participating in this research

8.1 Participant Information Sheet- interview

Study title:

“Assessing a supporting resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE)”

Invitation:

You are being invited to take part in a doctoral research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?

The purpose of this study is to evaluate the effectiveness of a CTE based podcast as a potential intervention to alleviate caregiver burden symptoms. This study will run over the course of 2 months. Participants will be required to listen to two podcast episodes from the podcast CTE Talk or read a newsletter containing the podcast contents. Alongside this, a short survey will be provided asking the participants their initial thoughts on the podcast. In this survey, the participants will be asked if they are willing to partake in a short follow-up interview.. As part of this interview, questions will be asked to get more in depth feedback based on the responses provided in the survey. This will allow the researcher to understand how effective the podcast episodes were to the caregivers, and to get feedback on how to make it a more effective supportive tool going forward.

Why have I been invited to participate?

You have been invited to participate as you selected ‘yes’ to participate in a follow-up interview in a recent survey. You also match the following inclusion criteria:

- Participants will be over the age of 18 (therefore there are no safeguarding issues)
- Participants are primary caregivers to an individual living or deceased
- Participants are a minimum of 1 year past patient’s death
- Participants must be or have been caregivers to patients who have been diagnosed with CTE or have probable CTE/sport-related neurodegeneration
- Participants must have access to digital equipment (i.e. a computer) to access study material and to be interviewed (if opt in)
- Participants are all required to speak English
- Participants must be based in United States America

Do I have to take part?

It is up to you to decide whether or not to take part in this research study. However, if you do wish to participate, it's important to note that you can’t withdraw after the interviews have taken place. This is because you will be given a pseudonym on your data for confidentiality reasons. This will mean the researcher will not be able to know which participant links to which interview transcript, and thus will not be able to remove your data if you decide to withdraw. If you do decide to take part, you will be given this information sheet along with a privacy notice (explaining how your data will be collected and used) and be asked to give your consent. Choosing to either take part or not take part in the study will have no impact on your current/future use/involvement in the Concussion Legacy Foundation.

What will happen to me if I take part?

You will be invited to partake in a short interview (30-60 minutes) that will investigate your previous survey responses in further detail. All interviews will be held via Zoom and audio-recorded with your permission, and transcribed verbatim. Examples of questions asked in the interview are:

4. What emotions/feelings did you experience whilst listening to the podcast?
5. How did listening to relatable stories make you feel? (i.e. did it provide relief or did it arise negative feelings)
6. How easy/challenging did you find it to listen and engage in the contents of the podcast?

The interview (if you wish to participate) will be conducted 2 weeks after the completion of your survey. At the end of the interview, you will have a debriefing period lasting 15-20 minutes. This will give you an opportunity to ask any questions you may have regarding the aims of the study and your involvement in it.

What are the possible disadvantages and risks of taking part?

There is a potential that the content of the podcast and interview questions may evoke some strong emotions, distress and concerns. Should you experience any of these, you can stop the interview at any time and you will be able to access free and independent support from the following organisations:

Concussion Legacy Foundation helpline:
Link to support form: https://concussionfoundation.org/helpline

Mental health America:
Phone: 1-800-273-TALK
Website: https://mhanational.org/get-involved/contact-us

National Alliance on Mental Illness
Phone: 800-950-NAMI (6264)
Email: info@nami.org
Website: https://www.nami.org/help

Caregiver Action Network
Phone: 855-227-3640
Website: https://www.caregiveraction.org/helpdesk

What are the possible benefits of taking part?

Participation in this research will help evaluate an intervention which may ease some of the challenges you have experienced for future CTE caregivers. This process will help refine the resource so it can be used to help other family members/caregivers in the future.

Will what I say in this study be kept confidential?

All information collected about you will be kept strictly confidential. Only members of the research team (named below) will have access to the data. Where research findings are disseminated, any data used will be anonymised. However due to the small sample size, it may be impossible to fully guarantee anonymity/confidentiality of participants' identity. Data will be initially stored on a password protected laptop and on Google Drive, for which the University (Oxford Brookes) has a contract with Google for cloud-based services. This contact has the necessary security features to maintain the privacy of the data.

Data generated by the study must be retained in accordance with the University's policy on Academic Integrity, as such data generated in the course of the research must be kept securely for a period of ten years after the completion of the research project.

What should I do if I want to take part?

If you would like to participate, please reply to this invitation by contacting the researcher Georgia Young (via the contact details below) or the Concussion Legacy Foundation. You will be required to verbally give consent at the start of the interview to participate.

What will happen to the results of the research study?

The results of this study will be shared, using pseudonyms to ensure participant confidentiality via the researchers thesis, academic research publications and conferences. Participants can give their contact details voluntarily at the end of the interview to the researcher, to be sent copies of any outputs from this project.

Who is organising and funding the research?

This research is conducted by a PhD student and staff from the Faculty of Health and Life Sciences at Oxford Brookes University in collaboration with the Concussion Legacy Foundation. The researcher is receiving a studentship from the Faculty of Health and Life Sciences, Department of Sport, Health Sciences and Social Work) to carry out this PhD research.

Who has reviewed the study?

This research has been reviewed by the Health and Social Care Research Ethics Sub-Committee (UREC Registration No: 231681)

Contact for Further Information:

For more information, please contact any member of the research team on the below contact details:

Director of Studies:	Prof Astrid Schloerscheidt	aschloerscheidt@brookes.ac.uk
Supervisors:	Dr Matt Smith	MattSmith@brookes.ac.uk
Doctoral Researcher:	Georgia Young	g.young@brookes.ac.uk

If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk

Thank you for taking the time to consider participating in this research

CONSENT FORM

Appendix 9 : Consent form 1 (Survey)

CONSENT FORM

Full title of Project: "Assessing a supporting resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE)"

Name, position and contact address of researcher: Georgia Young (lead researcher) gyoung@brookes.ac.uk

	Please initial box	
1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions		
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason		
3. I understand that I cannot withdraw my survey responses due to them being anonymised.		
	YES	**NO**
4. I understand that I do not have to take part in an interview if I don't wish to do so.		
5. I agree to the use of anonymised quotes in publications		
6. I agree that my anonymised data gathered in this study may be stored in a specialist data centre/repository and may be used for future research related to this study		
7. I agree to take part in the above study		

Name of Participant:	Date:	Signature:
Name of Researcher:	Date:	Signature:

9.1. Consent form 2 (interview)

CONSENT FORM

Full title of Project: “Assessing a supporting resource for caregivers of patients with Chronic Traumatic Encephalopathy (CTE)”

Name, position and contact address of researcher: Georgia Young (lead researcher) gyoung@brookes.ac.uk

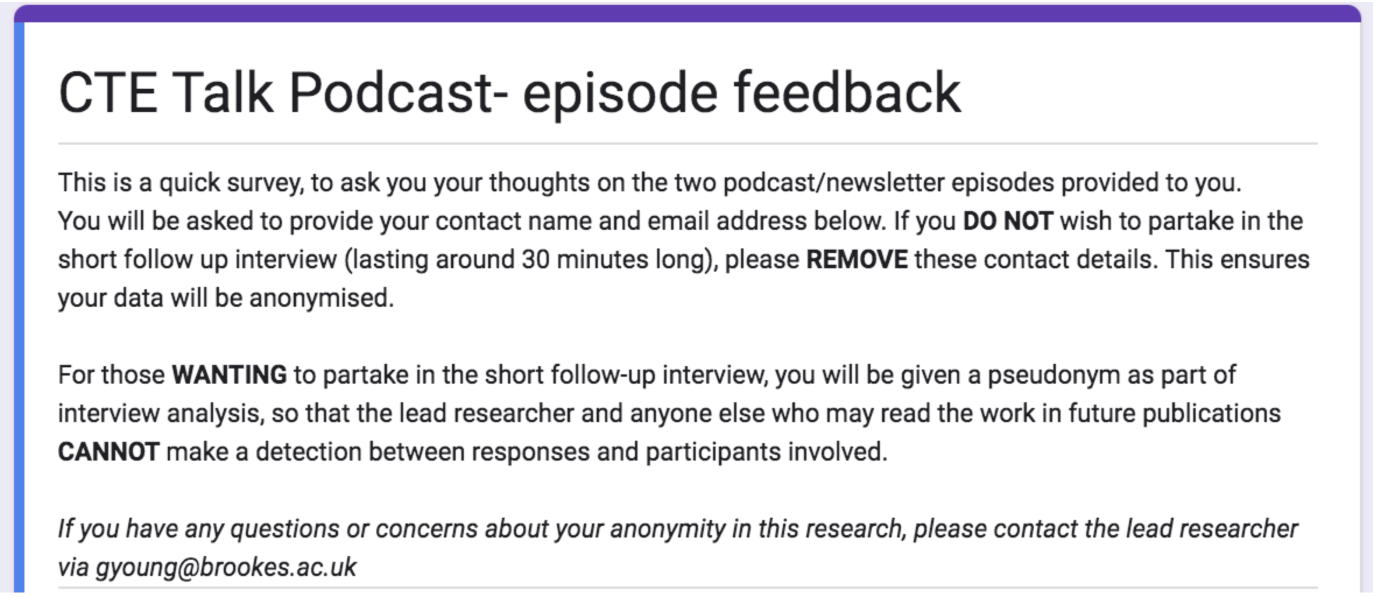
	Please initial box	
1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions		
2. I understand that if I cannot withdraw my interview data as a result of the use of pseudonyms (the researcher cannot detect responses to participants due to this)		
	YES	**NO**
3. I agree to the interview being audio recorded		
4. I agree to the use of anonymised quotes in publications		
5. I agree that my anonymised data gathered in this study may be stored in a specialist data centre/repository and may be used for future research related to this study		
6. I agree to take part in the above study		

Name of Participant:	Date:	Signature:
Name of Researcher:	Date:	Signature:

Appendix 10: Survey via Google Forms

Link to the survey:
https://docs.google.com/forms/d/e/1FAIpQLSdXZFm8ORCRwkPWSXXCUbZHUCUroAGfoGSpts3nnsmVNCG7wQ/viewform?usp=sf_link

PLEASE NOTE THAT THE INFORMATION SHEET AND CONSENT FORMS WILL FORM THE FIRST MANDATORY PAGES TO THE SURVEY.

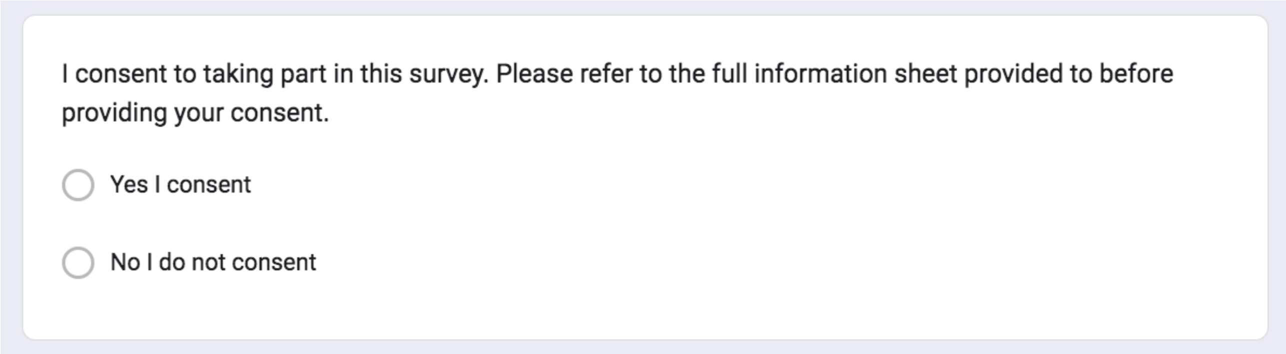


CTE Talk Podcast- episode feedback

This is a quick survey, to ask you your thoughts on the two podcast/newsletter episodes provided to you. You will be asked to provide your contact name and email address below. If you **DO NOT** wish to partake in the short follow up interview (lasting around 30 minutes long), please **REMOVE** these contact details. This ensures your data will be anonymised.

For those **WANTING** to partake in the short follow-up interview, you will be given a pseudonym as part of interview analysis, so that the lead researcher and anyone else who may read the work in future publications **CANNOT** make a detection between responses and participants involved.

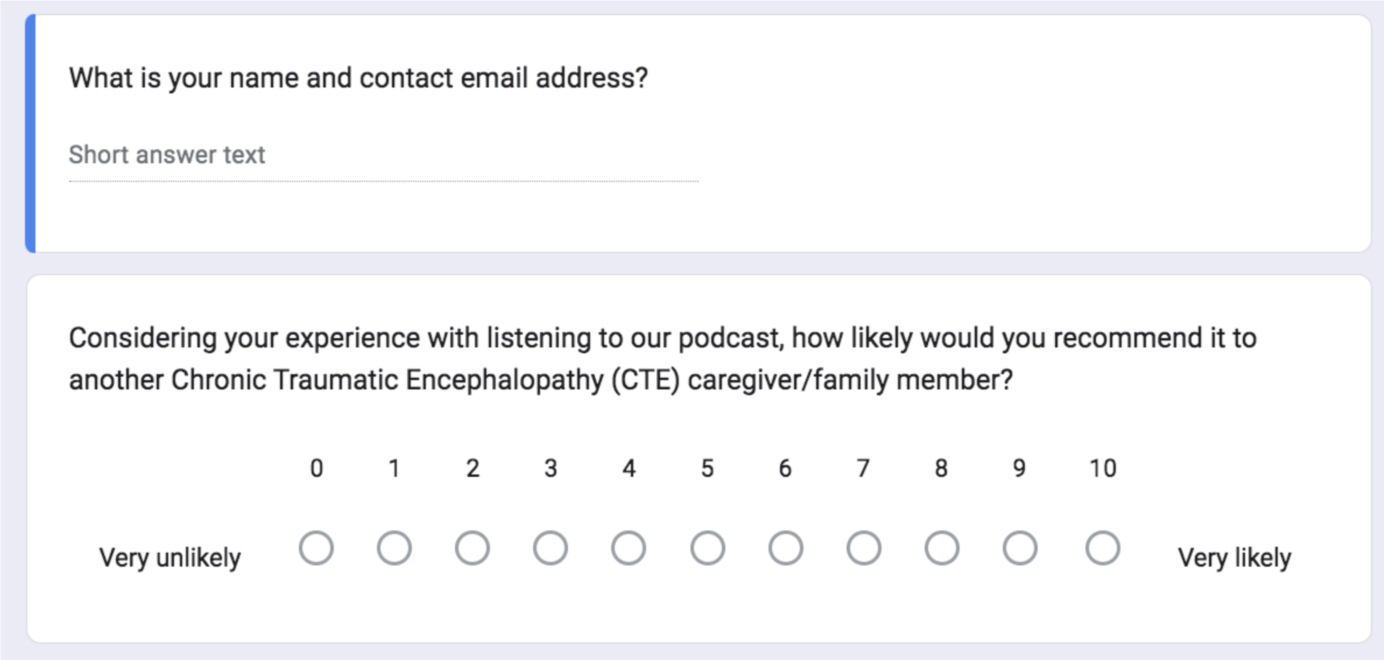
If you have any questions or concerns about your anonymity in this research, please contact the lead researcher via gyoung@brookes.ac.uk



I consent to taking part in this survey. Please refer to the full information sheet provided to before providing your consent.

○ Yes I consent

○ No I do not consent

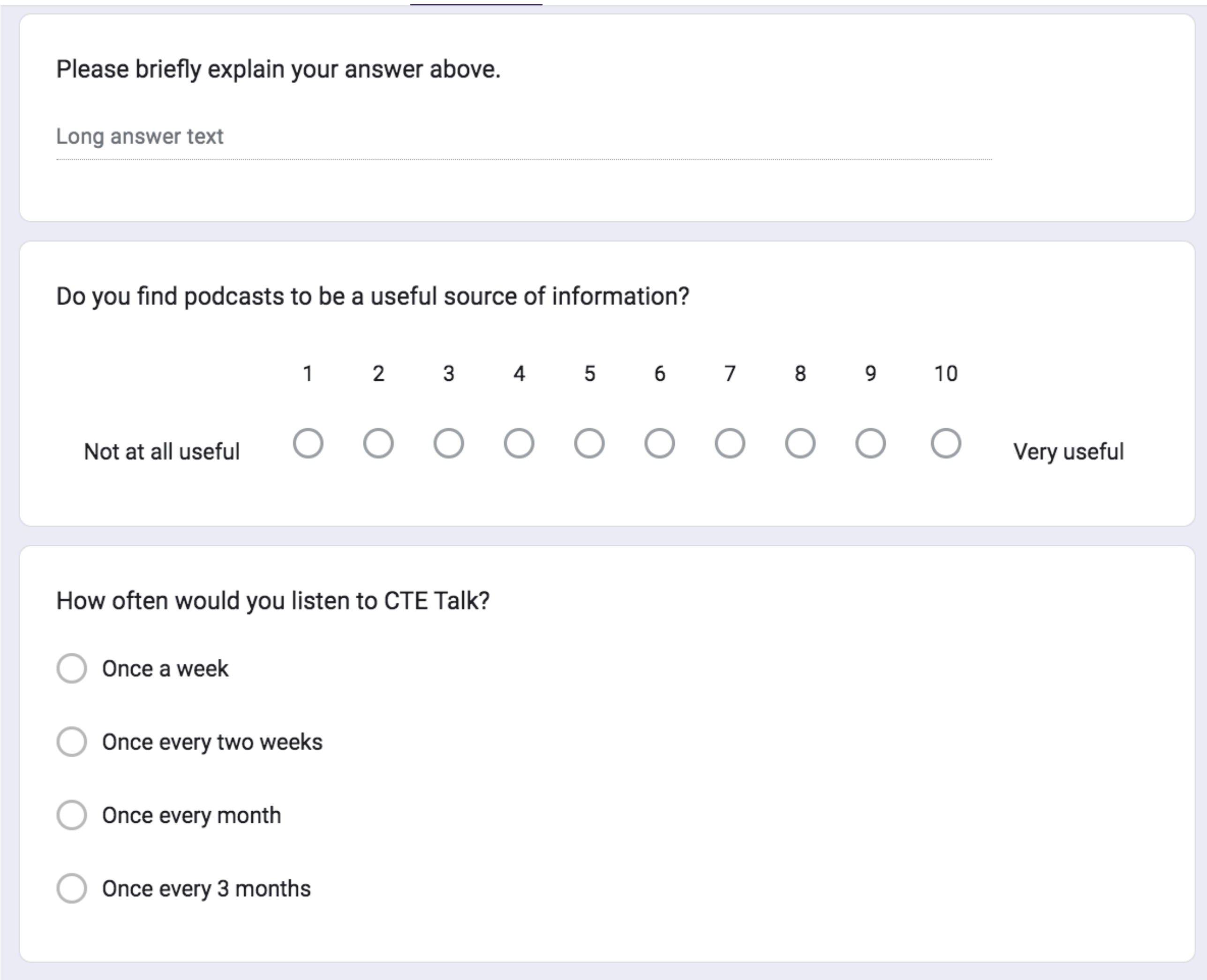


What is your name and contact email address?

Short answer text

Considering your experience with listening to our podcast, how likely would you recommend it to another Chronic Traumatic Encephalopathy (CTE) caregiver/family member?

	0	1	2	3	4	5	6	7	8	9	10	
Very unlikely	○	○	○	○	○	○	○	○	○	○	○	Very likely



Please briefly explain your answer above.

Long answer text

Do you find podcasts to be a useful source of information?

	1	2	3	4	5	6	7	8	9	10	
Not at all useful	○	○	○	○	○	○	○	○	○	○	Very useful

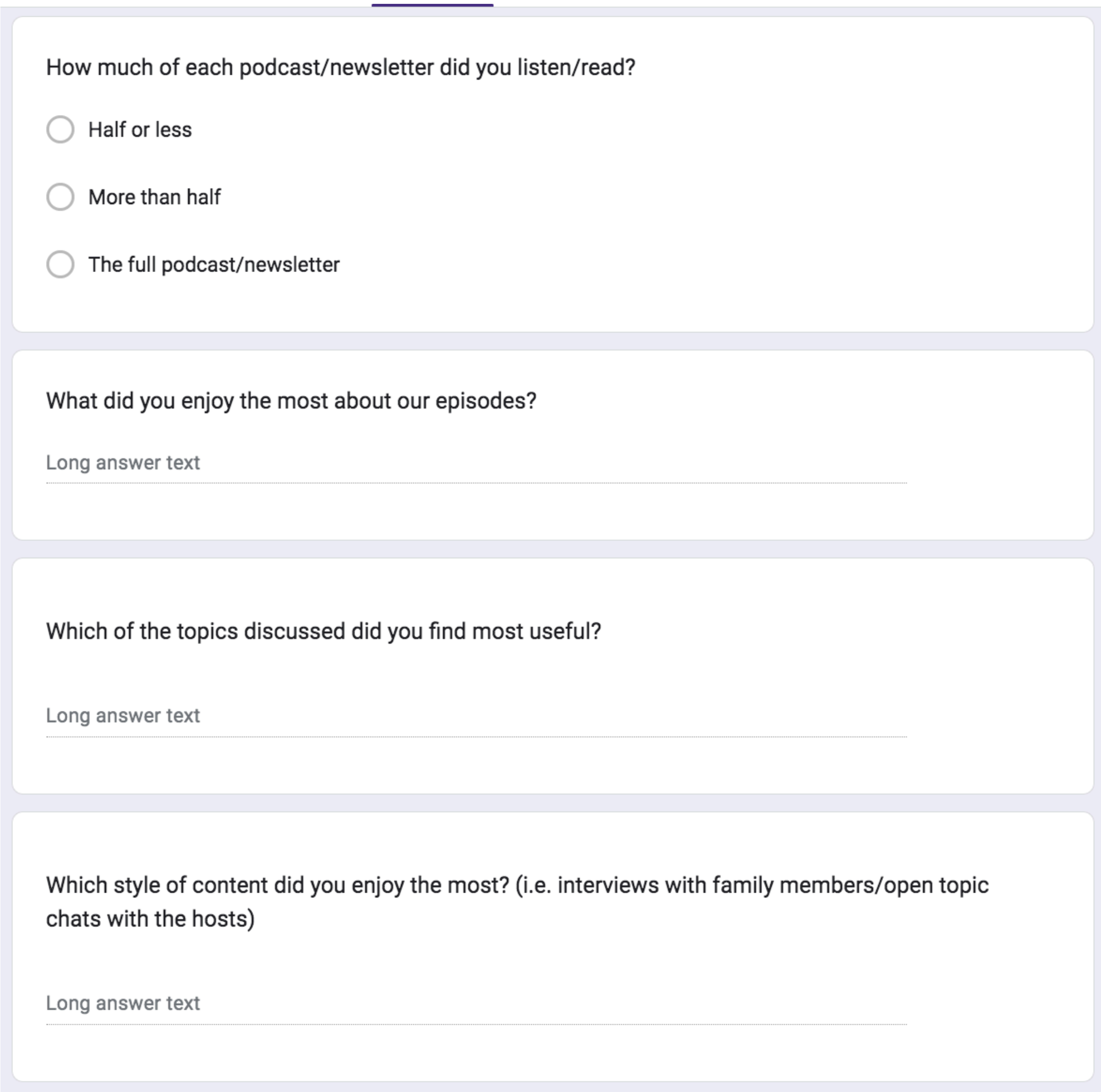
How often would you listen to CTE Talk?

○ Once a week

○ Once every two weeks

○ Once every month

○ Once every 3 months



How much of each podcast/newsletter did you listen/read?

○ Half or less

○ More than half

○ The full podcast/newsletter

What did you enjoy the most about our episodes?

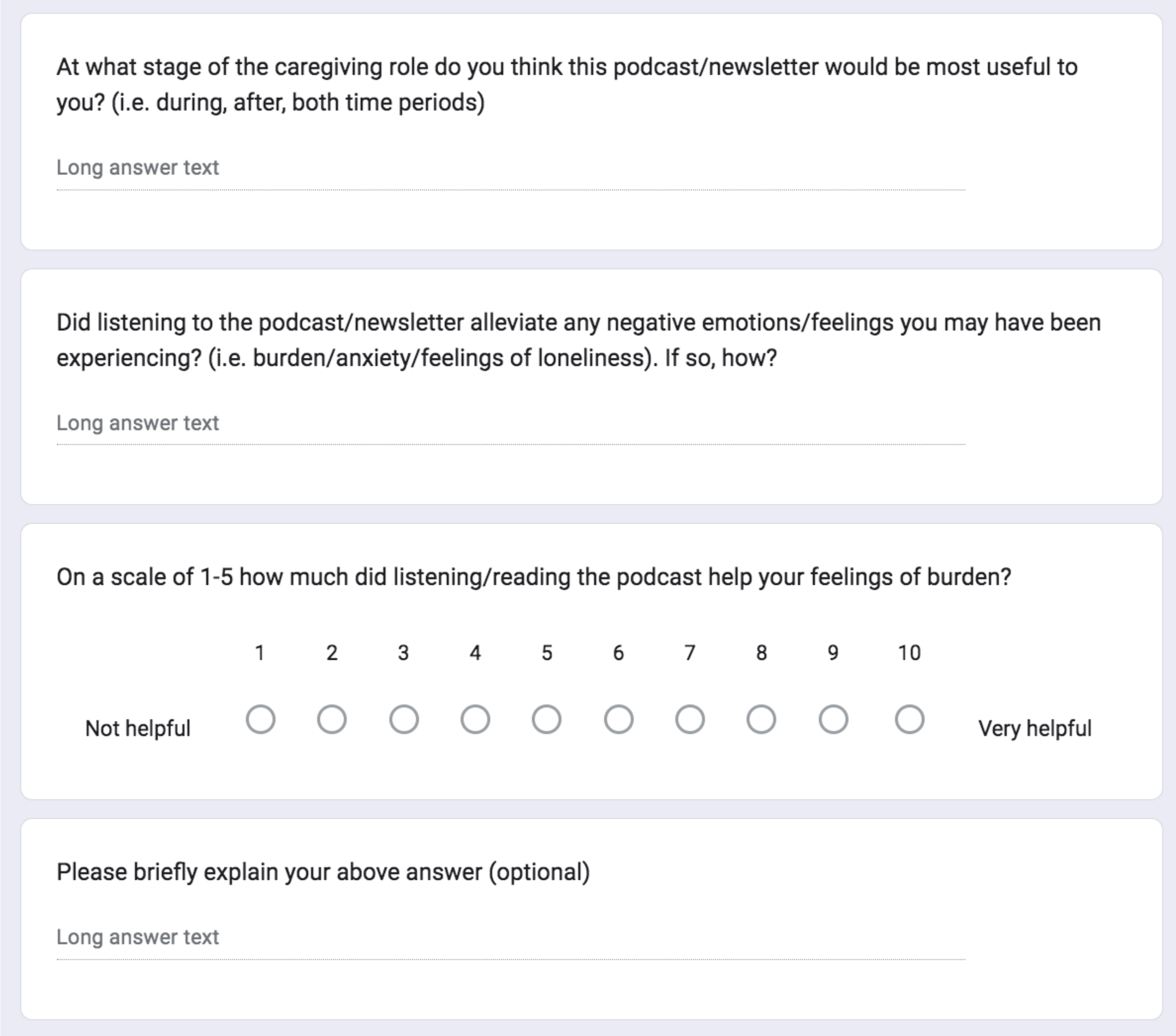
Long answer text

Which of the topics discussed did you find most useful?

Long answer text

Which style of content did you enjoy the most? (i.e. interviews with family members/open topic chats with the hosts)

Long answer text



At what stage of the caregiving role do you think this podcast/newsletter would be most useful to you? (i.e. during, after, both time periods)

Long answer text

Did listening to the podcast/newsletter alleviate any negative emotions/feelings you may have been experiencing? (i.e. burden/anxiety/feelings of loneliness). If so, how?

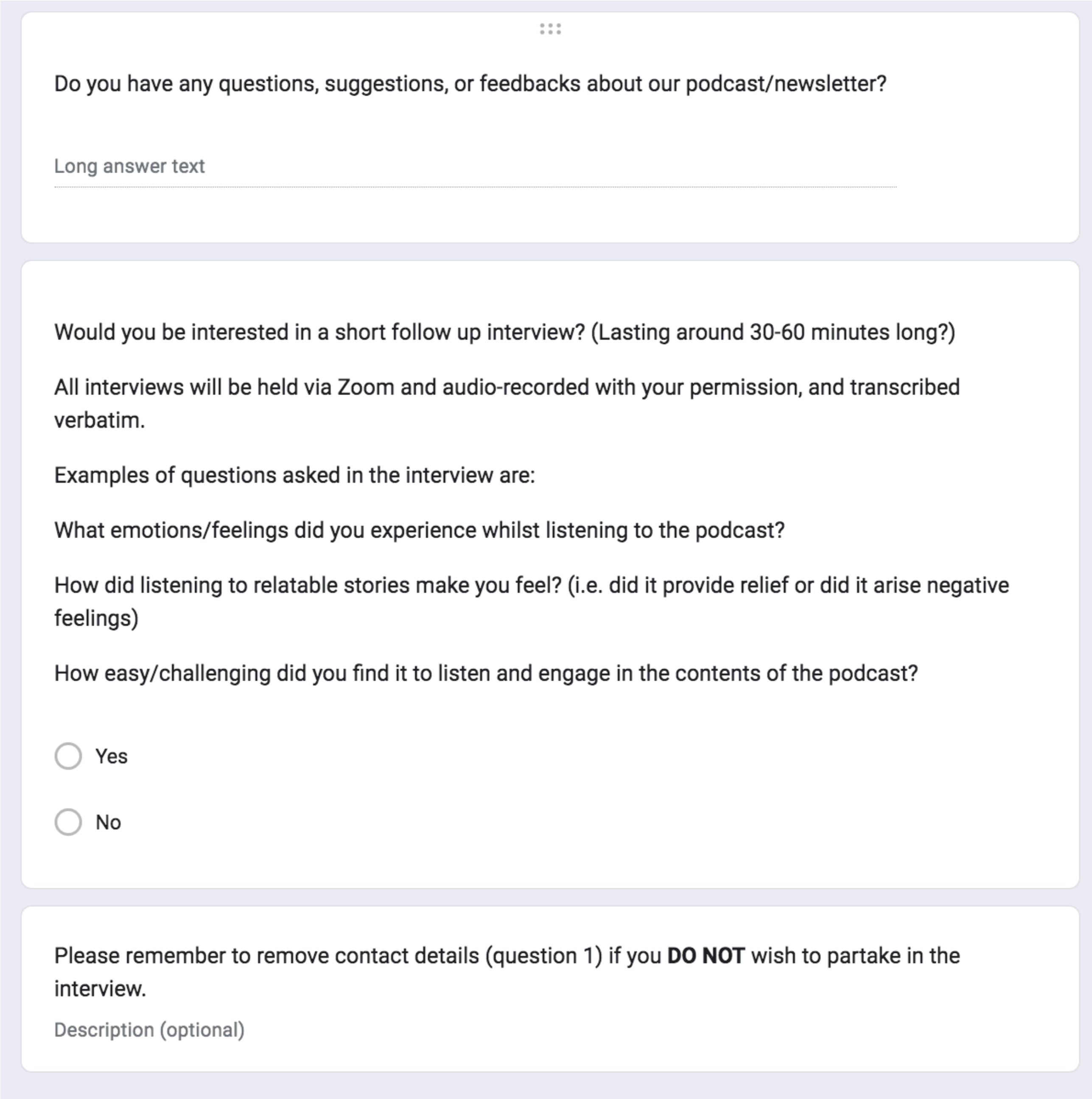
Long answer text

On a scale of 1-5 how much did listening/reading the podcast help your feelings of burden?

	1	2	3	4	5	6	7	8	9	10	
Not helpful	○	○	○	○	○	○	○	○	○	○	Very helpful

Please briefly explain your above answer (optional)

Long answer text



Do you have any questions, suggestions, or feedbacks about our podcast/newsletter?

Long answer text

Would you be interested in a short follow up interview? (Lasting around 30-60 minutes long?)

All interviews will be held via Zoom and audio-recorded with your permission, and transcribed verbatim.

Examples of questions asked in the interview are:

What emotions/feelings did you experience whilst listening to the podcast?

How did listening to relatable stories make you feel? (i.e. did it provide relief or did it arise negative feelings)

How easy/challenging did you find it to listen and engage in the contents of the podcast?

○ Yes

○ No

Please remember to remove contact details (question 1) if you **DO NOT** wish to partake in the interview.

Description (optional)

Appendix 11: Interview guide for the effectiveness of the podcast

What were your initial thoughts when you were asked to listen to a CTE focused podcast?

Have you engaged in any supportive intervention/programme revolving around CTE before?

- If so, what was it?
- How did listening to a podcast compare to this?

How easy/challenging did you find it to incorporate listening to the podcast into your day?

- What were the benefits (i.e. portable)
- What were the hindrances (i.e. hard to engage in whilst meeting demands of the caregiver role)

What emotions did you feel whilst listening to the podcast?

- Did it provide more positive or negative emotions?
- What were they and why?

What topics did you find most beneficial to listen to and why?

To what extent did you feel listening to the podcast help you with any symptoms of caregiver burden (i.e. anxiety, loneliness or loss of purpose)

At what stage of the caregiving role do you think having this supportive intervention would be most beneficial to you?

- I.e. Do you think this is more helpful to you during your life after caregiving?
- Or do you think this would be more beneficial during the caregiving role? If so, why?

Would you recommend this to a fellow caregiver, or someone who may go through it in the future/

- If so, why? / If no, why?

In your opinion, what would make the podcast a more effective tool to support you as a caregiver? (i.e. shorter/longer episodes, having certain guests on- I.e. doctors/family members)

Is there any other feedback/final thoughts you have on the podcast?

APPENDIX 11: Interview guide for the effectiveness of the newsletter

What were your initial thoughts when you were asked to read a CTE focused newsletter?

Have you engaged in any supportive intervention/programme revolving around CTE before?

- If so, what was it?
- How did reading a CTE focused newsletter compare to this?

How easy/challenging did you find it to incorporate reading the newsletter into your day?

- What were the benefits (i.e. portable)
- What were the hindrances (i.e. hard to engage in whilst meeting demands of the caregiver role)

What emotions did you feel whilst reading the newsletter?

- Did it provide more positive or negative emotions?
- What were they and why?

What topics did you find most beneficial to read about and why?

To what extent did you feel reading the newsletter helped you with any symptoms of caregiver burden (i.e. anxiety, loneliness or loss of purpose)

At what stage of the caregiving role do you think having this supportive intervention would be most beneficial to you?

- I.e. Do you think this is more helpful to you during your life after caregiving?
- Or do you think this would be more beneficial during the caregiving role? If so, why?

Would you recommend this to a fellow caregiver, or someone who may go through it in the future?

- If so, why? / If no, why?

In your opinion, what would make the newsletter a more effective tool to support you as a caregiver? (i.e. more/fewer pages, having certain guests to feature on- I.e. doctors/family members)

Is there any other feedback/final thoughts you have on the newsletter?