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A Mixed Methods Interpretative Phenomenological Analysis of the Experience of Posttraumatic Growth in Young Onset Dementia

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Preface

This portfolio reflects three pieces of work related to my training both as a researcher and as a Counselling Psychologist. The portfolio demonstrates my avid interest in the fields of health and neuropsychology and the intersection of both within the discipline of Counselling Psychology; whilst also reflecting the breadth of research and clinical experience gained over the past three years. The pieces of work presented are associated with experiences of illness-induced posttraumatic stress disorder which resulted from internal, bodily betrayal, and the purposeful movement towards living well alongside disease. Given movement towards the 'integrative practitioner', developing greater understanding of these areas are directly applicable to the discipline of Counselling Psychology. With each new cohort of qualified practitioners, the discipline further evolves, integrating psychological knowledge from a variety of sources. No longer constrained to purely psychotherapeutic settings, Counselling Psychologists are developing into a new type of hybrid-practitioner, bringing with them new levels of expertise and a specialised skill set that will ultimately lead to the formation of new psychological dimensions of knowledge.

This portfolio also reflects my journey of developing and delivering research concerned with experiences of trauma following a young onset dementia diagnosis. This process has provided me with the opportunity to gain awareness, knowledge and skills which have in turn facilitated an understanding of the sensitivities in working with patient populations. This research has brought to my conscious awareness the biases and assumptions that I possess about the experience of living with debilitating disease, and how my early life experiences have influenced these. Whilst conducting this research, I simultaneously worked with clients who were profoundly traumatised by their experiences of illness, as either patient, carer or family member. I have witnessed a range of reactions from grief, to helplessness, to sense-making, to acceptance and peace. These experiences have increased my sensitivity, curiosity and awareness of the complexity of what it means to be human and the struggles that one experiences when faced with their own human fragility.

Section A: Doctoral Research

This section includes the Doctoral Research entitled, *‘A Mixed Methods IPA analysis of the Experience of Posttraumatic Growth in Young Onset Dementia.*’

The doctoral research adopted a sequential mixed methods design to explore the experiences of trauma and personal positive growth following a diagnosis of young onset dementia (YOD). The first phase was quantitative and used an online survey, the second phase involved a series of one-to-one interviews. The Impact Event Scale-revised and Posttraumatic Growth Inventory were adopted as the main measures, alongside the Connor Davidson Resilience Scale and the Self-compassion Scale short-form. Correlational analysis and linear regression analysis were used to understand the relationships between the variables. A series of one-to-one interviews were carried out to explore the experiences of posttraumatic growth, and gain insight into the common and individual factors that influence this. Participants recruited were individuals diagnosed with dementia before the age of 65, and a total of 37 participants completed the online questionnaire which assessed for the existence of both illness-induced posttraumatic stress and posttraumatic growth, and which psychological phenomenon (resilience and self-compassion) influence or mediate their presence. A total of five participants, who were recruited from the first phase of the study, took part in the interviews. Interpretative phenomenological analysis was used for the data analysis where codes and themes were developed. The findings of the research are discussed, and the integration of both strands are explored in relation to existing theories and research within the practice of Counselling Psychology. The strengths and limitations of the study are explored along with future directions and implications for Counselling Psychology are stated, in order to inform and develop the discipline.

Section B: Client Case Study

A case study is present in this section of the project, which explores the work with a client who was referred for psychological support within a specialised NHS psycho-oncology service, following a diagnosis of a rare, advanced-stage colorectal cancer. For many, a cancer diagnosis and accompanying treatments is a highly stressful and potentially traumatic series of events which is punctuated by feelings of deceit by one own body.

The case study emphasises the role that an unexpected life-threatening diagnosis can play in the development of posttraumatic stress disorder. The case highlights the importance of working collaboratively, with the client in order to create a safe therapeutic environment and strong rapport in order support processing of trauma. The integrative approach to this case reflects the multifaceted nature of both disease and trauma, and reinforces the importance of tailoring therapy to the individual needs of the client.

The case was chosen as themes of trust, safety and the difficulties in coping with disease are threaded throughout. It speaks to the challenges of working remotely with trauma and importance of the therapeutic alliance in creating a safe environment for the client to explore the multiple confounding variables which contributed to the development of PTSD. The case also highlights the necessary elements of an effective therapeutic relationship and the implications of these on treatment outcomes.

Section C: Publishable Paper

The journal that was chosen for application for the publishable paper is Dementia. This international peer reviewed journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

The publishable paper focuses on the quantitative phase one of the research study, which assesses for the presence of young onset dementia related posttraumatic stress, posttraumatic growth, and the variables and/or psychological phenomenon that influence these. The aim is to establish whether a young onset dementia diagnosis is a traumatic event, seismic enough in nature to elicit a posttraumatic growth response, and to provide recommendations for potential changes to clinical practice and policy with the aim to develop enhanced and sensitive clinical interventions for professionals working with young people with dementia.

Summary

Dementia research is slowly shifting its focus away from etiology and symptom manifestation towards developing an appreciation for the lived experiences of the diagnosed individual. With the rates of dementia steadily rising, it is now imperative that collectively as a society, we begin to explore how to live well alongside the condition. This portfolio aims to provide insight into how a young person with dementia experiences their diagnosis, makes sense of, and moves forward from it, both from a quantitative and qualitative approach. I hope that the experiences shared within the research can help to give voice to a population that is notoriously underrepresented. I aim for this research to expand the scope of practice for Counselling Psychologists within dementia services and to help inform the development of new and effective clinical interventions. I hope this research can form the basis for other work to further expand on the understanding of what it means to be a young person with dementia, and to further investigate how the phenomenon of posttraumatic growth is experienced in those with cognitive limitations.

Section A: Doctoral Research

A Mixed Methods Interpretative Phenomenological Analysis of the Experience of Posttraumatic Growth in Young Onset Dementia

Candidate: Sarah Isobel Noakes
Supervisor: Dr Trudi Edginton

Abstract

Background: The diagnosis of a life-limiting illness is now known to be able to elicit posttraumatic stress disorder (PTSD) (American Psychiatric Association, 2013). Traditionally research investigating life-limiting illnesses has focused on negative psychological implications. In recent years there has been a push to research the experience of positive psychosocial outcomes. This phenomenon known as posttraumatic growth (PTG) has been studied within clinical populations including cancer and HIV. Yet there have been no attempts to extend the model of PTSD-PTG to dementia; a progressively debilitating condition, affecting cognition, with no cure and very few effective treatments. This research explores the experiences of distress and PTG in those diagnosed with dementia before the age of 65.

Method: A sequential explanatory mixed methods design. Phase One observed 37participants completing a battery of questionnaires including the Impact Event Scale-Revised (IESR), the Posttraumatic Growth Inventory (PTGI), Self-compassion scale short-form (SCS-SF) and the Connor-Davidson Resilience scale (CD-RISC), assessing for presence of PTSD and PTG. In Phase Two Interpretative Phenomenological Analysis (IPA) was employed as the methodological framework for the analysis of interviews with five young people with dementia.

Results: 22 participants met the criteria for a probable diagnosis of PTSD, 10 participants achieved scores that indicated clinically concerning PTSD symptoms in accordance with current DSM-5 criteria. Participants scores on the PTGI were indicative of low to moderate degrees of PTG. Participants scored highest in the domains of new possibilities, appreciation of life and personal strength. Phase two yielded three superordinate themes: ‘Learning to live with dementia’, ‘More to life than the ‘Big D’’ and ‘Life is a lottery’.

Conclusion: A dementia diagnosis at a younger age was seen to be associated with symptoms consistent with PTSD. Young people with dementia can experience varying degrees of PTG, which enhance quality of life and life satisfaction. This study provides the foundations for future exploration into the lived experiences of YPwD and the development of appropriate and sensitive clinical interventions.

List of abbreviations

AD	Alzheimer’s dementia
CD-RISC	Connor Davidson resilience scale
FTD	Frontotemporal dementia
HPA	Hypothalamic-pituitary-adrenal
IES-R	Impact Event Scale-Revised
IPA	Interpretative phenomenological analysis
MI	Myocardial infarction (heart attack)
MVA	Motor vehicle accident
PTG	Posttraumatic growth
PTGI	Posttraumatic growth inventory
PTS	Posttraumatic stress
PTSD	Posttraumatic stress disorder
PTSS	Posttraumatic stress symptoms
PwD	Person (people) with dementia
SAM	Situationally accessible memory
SCS-SF	Self-compassion scale short-form
VAM	Verbally accessible memory
YOD	Young onset dementia
YODR-PTG	Young onset dementia related posttraumatic growth
YODR-PTSD	Young onset dementia related posttraumatic stress disorder
YPwD	Young people with dementia

Chapter 1 Introduction

1.1 Overview

Themes of positive change following adversity have been weaved throughout human history, with Nietzsche's famous dictum, "What doesn't kill me makes me stronger" often quoted following personal hardships (Joseph & Butler, 2010). Exposure to trauma and traumatic events is becoming increasingly common within society. There is an estimated lifetime prevalence of exposure to potentially traumatic events of 43.8% (American Psychiatric Association, 2013; Knipscheer et al., 2020) and a 9% rate for development of chronic posttraumatic stress disorder (PTSD) (Breslau, 2009). In response to this, exploration into experiences of personal trauma and positive change has become increasingly popular within the field of psychology as the discipline strives to gain a more holistic understanding of the impact of traumatic events on the human psyche (Levers, 2012).

Posttraumatic growth (PTG) refers to a series of positive changes (Tedeschi & Calhoun, 1995; Tedeschi & Calhoun, 2004; Joseph & Linley, 2005) which are experienced following the emotional struggle with highly challenging life events. Within this process, a traumatised individual is seen to metaphorically rise from the rubble and to reconstruct their world and integrative belief system to a level beyond that of pre-trauma functioning (Lahav, et al., 2016). There are two main theories of positive change following trauma, the transformational model (Tedeschi & Calhoun, 2004) and the organismic valuing theory (Joseph & Linley, 2005). The former being the theoretical model applied to the present study. According to Tedeschi and Calhoun (1995) PTG is multidimensional and encompasses changes across a variety of life domains such as increased perceptions of personal strength, the presence of new possibilities, closer interpersonal relationships, enhanced religious or spiritual beliefs, and a greater appreciation for life. Literature has revealed the presence of PTG in survivors of several diverse traumatic events including disasters, war, and sexual assault (Calhoun & Tedeschi, 2006; Joseph et al., 2004; Lahav, et al., 2019).

Within the last 21 years, researchers have extended their scope of focus to include PTG in those who have experienced a life-limiting or life-threatening illness such as cancer and HIV (Cordova et al., 2001; Baglama & Atak, 2015). Diverging from typical focuses on negative psychological implications of disease processes, this new wave of research has recognised the adaptive role of PTG in people with health conditions. Hefferon et al.'s (2009) systematic review of physical health processes of trauma and related growth outcomes described four key themes ('reappraisal of life and priorities'; 'trauma equals the development of self'; 'existential re-evaluation'; and 'a new awareness of the body') in relation to the experience of positive growth following a diagnosis. Consistent with the transformational model, PTG in chronic or life-threatening illness is established through the process of losing stability, followed by re-stabilisation through reconnection with the self and body (Salick & Auerbach, 2006). The result of this is a greater sense of wellbeing that has been observed to help one better manage PTSD symptoms (Barskova & Oesterreich, 2009).

Despite this growing body of evidence pertaining to PTG following the diagnosis of a health condition, no attempts have been made to extend the model to young onset dementia (YOD). YOD is viewed by contemporary society to be a life-limiting condition that interrupts expected life trajectory resulting in profound personal loss. A diagnosis of the condition has been observed within the literature to evoke cataclysmic inner turmoil producing substantial psychological distress and dysfunction (Beattie et al. 2004; Clemerson et al., 2014; Evans, 2019). Research into the phenomenon of PTG in YOD could help redefine how wider society views dementia, supporting overall positive adjustment in those diagnosed through the development of a sensitive social narrative and effective therapeutic interventions. A comprehensive review of the literature was conducted between October 2019 and April 2020 and updated in April 2021. Five electronic search engines were used PubMed, JSTOR, Google Scholar, PsycINFO and NCBI. The search keywords included early onset, young onset and young people with dementia combined with, dementia, Alzheimer, vascular dementia, mixed dementia, frontotemporal dementia, quality of life, well-being, posttraumatic stress disorder, PTSD, posttraumatic growth and PTG.

The aims of this chapter are threefold: (1) to present the available research on the lived experiences of young people with dementia (YPwD), (2) to outline the contemporary theories of PTSD applicable to the development of trauma following the diagnosis of YOD, and (3) analyse available research in the areas of PTSD and PTG within the context of life-limiting/life-threatening illness.

1.2 Experiences of Young Onset Dementia

Dementia is socially defined as an “old person’s disease”. Although the condition is typically associated with older adults, the prevalence of dementia in adults in their middle years is steadily rising and YOD now accounts for more than 5% of total diagnoses (Mayrhofer et al., 2017). The majority of research pertaining to the experiences of people with dementia (PwD) is concentrated on older adults. In most instances, YPwD are either sampled into these studies or excluded entirely. This results in very little being known of their experiences of being diagnosed and living with a progressively debilitating condition from a young age. This section reviews the current literature focused on YPwD. It examines the experiences of diagnosis through living and coping with the disease.

1.2.1 Defining Young Onset Dementia

YOD is defined as manifestation of initial symptoms before the age of 65 and excludes cases of childhood dementia. Current literature posits that YOD differs from late-onset dementia on several points, most notably frequency and etiology. A study by Viera et al. (2013) concluded that relative to late-onset dementia, YOD it is less associated with Alzheimer’s disease, which traditionally is the most common form of dementia. The study found that AD accounts for approximately 15-40% of YOD cases, which is significantly less than the 50-70% of AD cases found in late-onset dementia. The study determined that less common forms of degenerative dementias such as frontotemporal (FTD) and Huntington disease are more prominent in younger people. Although direct causation of this remains unknown, researchers have linked certain subtypes of these dementias to mutations on several genes (Young et al., 2018). Vascular dementia, which is caused by reduced blood flow to the brain, damaging and killing cells, has become more common in YPwD. Although there is a relatively wide variability in the cases of vascular dementia, it accounts for approximately 20% of all YOD cases (Alzheimer’s Research UK, 2020). This could be attributed to increases in lifestyle-related risk factors such as diet and physical inactivity which have become more prevalent in contemporary society. Secondary dementias too are more common within those under 65 years of age, accounting for a further 20% of cases. These include alcohol-related dementia, human immunodeficiency virus-related dementia, dementia in multiple sclerosis, and a range of rarer conditions such as metabolic, neoplastic and autoimmune disorders involving hereditary genetic mutations (Rossor et al, 2010; Vieria et al., 2013; Draper et al., 2016).

YOD does not only differ from late-onset dementia in disease typology, but in initial symptoms too (Rossor et al., 2010). According to van Vliet et al (2012) and Draper et al (2016) YOD frequently presents itself through non-memory problems, such as language or visuo-spatial dysfunctions, and impaired executive functioning skills. Behavioural changes including inappropriate social interactions, lack of empathy, poor motivation and general apathy are also considered to be hallmarks of YOD (Sampson et al; 2004). These behavioural and personality changes are often not immediately noticed as they tend to develop gradually and are associated with psycho-social issues such as marital problems, depression, menopause, occupational stress, or alcohol misuse making them even less noticed and reported (Draper et al, 2016). YOD can affect people of all ages under the age of 65, and it is a threatening and confrontational diagnosis regardless. However, studies have found that those who are younger in age at the time of diagnosis are more likely to be faced with more difficult and challenging clinical circumstances including broader variations in differential diagnoses and symptom manifestations.

Kelley et al (2008) explored the etiologic characteristics of 235 individuals diagnosed with YOD under 45 years of age and discovered that atypical neurodegenerative etiologies accounted for 31.1% of the study cohort, with clinical symptoms reflecting the localization of the degenerative process rather than the nature of the underlying histopathology. Symptoms manifested as behavioural alterations with degeneration of the affected area over time leading to impairment of cognition and activities of daily living. For this younger group, they were left with an awareness of what awaited them. Within the media, experience has been likened to living with a ‘ticking time-bomb’ (Hill, 2017). This study yielded another interesting finding in that diagnosis of a neurodegenerative dementia before the age of 33 is very uncommon. This study, whose youngest participant was a mere 17 years old, discovered a diagnosis before the age of 30 was commonly associated with hereditary mutations. It confirmed that the prevalence of atypical neurodegenerative dementias increases in those presenting with onset after the age of 33. Due to delays in onset to presentation to diagnosis, the study suggests atypical neurodegenerative dementias are underrepresented and most likely account for far more than the 31.1%. These results corroborated the findings from Harvey et al's (2003) epidemiological prevalence study of YOD within the London boroughs of Kensington and Chelsea, Westminster, and Hillingdon where similar 'guestimates" were observed.

Reflecting on the similarities found between YOD and late-onset dementia, an interesting finding to emerge from a study by Kay et al. (2000) is younger age at time of diagnosis does not significantly influence the median survival rate. The study reported a median survival of 6.08 years for YPwD, which was comparable to that of late-onset dementia. These results suggest that individuals with YOD have dramatically reduced life longevity. Bracketing these results, it is interesting to reflect on how this trend might impact specifically upon the psychological wellbeing of those diagnosed, who are faced with an unexpected existential crisis and life is seemingly cut short.

What emerged most prominently from the literature was the broad spectrum for YOD. The large variability in frequency, underlying causes and the clinical patient profile makes this condition elusive and difficult to recognise and fully understand. Unfortunately for YPwD, this means there is no typical roadmap that can be followed when navigating the dementia pathways or negotiating the challenges and life changes that will inevitably occur.

1.2.2 The Diagnostic Process

A diagnosis of dementia is devastating at any age but diagnosis in younger people presents a particular challenge. The likelihood of it being an atypical etiology combined with the wide range of presentations and low expectation that dementia could be the underlying cause of problems often results in a daunting and unpleasant diagnostic process (Vernooij-Dassen et al., 2006). There are commonly prolonged delays in confirming the diagnosis which results in significant distress for the individual and their families (Draper et al., 2016). There is limited evidence which focuses on the personal experiences of younger people receiving a diagnosis of dementia. Most research within this area focuses on epidemiological studies, or clinical audits. However, existing literature provides a powerful image of the challenges faced by YPwD.

Beattie et al. (2004) highlighted the hugely detrimental impact of delays in diagnosis and how poor quality of information and non-existent post-diagnostic support often leaves YPwD feeling neglected and abandoned by the healthcare system. This study utilised a mixed approach incorporating a systematic review of the literature, a postal survey of service commissioners and qualitative in-depth interviews with people with dementia. 14 YPwD took part in the interviews and issues around the dementia diagnosis emerged as a central theme with most participants commenting negatively on the time it took to receive a diagnosis, the manner in which it was given, and the uncertainty prior to confirmation of their condition. The diagnostic assessment process was depicted as a distressing and traumatic experience, one participant described the process as ‘blunt and brutal’. A qualitative study by Harris (2004) too spoke to the troubles in obtaining a dementia diagnosis at a younger age. Not looking like a typical dementia patient emerged as a major barrier to not just receiving a diagnosis but beginning the investigation process. Participants reported being dismissed by medical professionals purely on the basis of their age. For many, working up the courage to come forward and share their concerns was confronting, and to have their fears thrown back in their faces resulted in hesitance to come forward again when symptoms worsened.

A more recent study by Rabanal et al (2018) which explored the lived experiences and needs of YPwD in a northern UK city also spoke to the challenges of receiving a YOD diagnosis. Utilising IPA methodology, 14 YPwD spoke extensively about their diagnosis and the impact that this had on themselves and family. Within this study the dementia experience was characterised by the distinction between two phases: pre and post diagnosis. During the pre-diagnostic phase, participants reported first noticing slow burning, subtle changes, which only in hindsight were connections made between these and emergent symptoms. The participants emphasised how the general lack of awareness relating to YOD was highly problematic as for most this delayed the point at which help was sought. Difficulties in obtaining a firm diagnosis and struggling to be heard by health professionals were also highlighted. Most of the participants reported the way in which their diagnosis was delivered was distressing and ‘like getting hit by a sledgehammer’. A lack of empathy from the diagnosing clinician appeared to be a major contributor to this. Within the post-diagnosis phase, a recurring issue was the amount and quality of supporting documentation and information provided. There was a distinct lack of age appropriate, or face to face support available. All the participants lamented that they were not given the offer for emotional support, something that is frequently offered in other NHS services such as oncology, or sexual heath.

Experiences of distressing, uncertain diagnostic period appears to be a theme that transcends geographical boundaries as studies from Canada (Roach et al, 2016), France (Wawrziczny et al., 2015) and Norway (Johannessen & Moeller, 2013) all reported similar findings. Factors such as age, lack of information and insensitive care or disbelief from healthcare professionals leaves YPwD marginalised by the systems that should be there to support them. It appears that for many YPwD, to receive a diagnosis one must fight for this, something which an older person would never have to do.

1.2.3 Adjustment and Coping

‘Psychological adjustment’ is a term that has been used to refer to a process of becoming accustomed to a new situation (Mitchell, 2012). Within the context of a life-limiting illness, this is seen as a series of iterative, necessary interactions and adjustments between the individual, illness and environment. Distress arises when transactions between these elements lead to a perceived discrepancy between the demands of a situation and the resources of the person’s biological, psychological, or social systems (Lazarus & Folkman, 1984; Moss-Morris, 2014). Within this process, the suffering individual is viewed as an active agent for change who can, through a series of behavioural, emotional and cognitive strategies, negate the impact of the stressor (Stanislawski, 2019).

Lazarus & Folkman’s (1984) model of stress and coping, views the cognitive appraisal of stress as a mental process split into two distinct, yet overlapping stages. In the primary stage, the individual seeks to understand the meaning of the situation as it affects their wellbeing with one of three types of appraisals (positive, neutral, negative) arising from this. Secondary appraisals relate to the appraisal of one’s own resources relating to the problem at hand. Alongside positive appraisals of coping it is hypothesised that there is a specific set of factors which contribute to overall adjustment which include: individual views about illness; experiences of losses resulting in frustration and uncertainty; and adaptation to a new role in relationships with family and friends (Mok et al. 2007). Studies examining coping following illness and loss (e.g., Zautra & Wrabetz, 19921; Johannessen & Moeller, 2013) have observed this combination of active coping (e.g., seeking support, taking action, and emotional expression) with positive appraisals of personal efficacy to yield less subjective distress. It is not outside the realms of possibility to assume that individuals diagnosed with dementia also employ this combination of problem-focussed and emotion-focussed coping.

MacRae (2008) interviewed eight individuals diagnosed to be in the early stages of Alzheimer’s dementia. The study’s participants spoke to the traumatic nature of receiving a dementia diagnosis – even if suspected. Time was a necessary factor in coming to terms with, understanding and accepting the difficult feelings that accompanied their diagnosis; and was essential in the process of meaning making of their experience. The predominant theme of this study echoed Charmaz’s (1991) views that whilst chronic illness can take over, most people learn to live with their illness rather than for it. ‘Making the best you can of it’ was the description used by participants to describe their individual processes of coping and meaningful adjustment to their new normal. The study’s findings are congruent with Young’s (2001) research, which suggests that the early stage of the Alzheimer’s dementia can be characterised as a gradual movement through a trajectory of emotional responses towards a point of acceptance, and realisation that one can still live a meaningful life despite dementia. The study called attention to an alternative set of factors for positive adjustment which included personal factors such as premorbid personality traits, early-life experiences, and social and environment factors such as supportive social networks and geographical accessibility to healthcare (Seiffer, Clare, & Harvey, 2005).

A descriptive, exploratory, qualitative study by Ostwold et al (2002) interviewed 56 people living with dementia using only a single question; ‘how have things been going for you lately?’ Thematic analysis was used to draw out themes which focused around experiences of loss, difficult emotional states, and notably, management strategies for these. The participants described the implementation of a wide variety of management strategies to deal with their losses and their feelings about those losses. They described using a combination of cognitive (disclosure, denial and acceptance), social (family support, being helpful to others, isolating self), and behavioural strategies (maintain independence, seeking out activities in which to engage) to support coping. Interestingly, for this group, the key component to coping and adjustment was feeling that those around them understood their memory loss. Once this was done, maintaining existing social connections whilst promoting independence and autonomy appeared to naturally follow.

1.2.4 Transitions and Breaks in Age Related Development

Erikson’s (1998) life cycle approach to development states people will pass through a fixed sequence of irreversible stages at different ages in their life. With each stage comes a unique psychosocial crisis that must be navigated and resolved in order to move onwards to the next stage. Failures to successfully do so result in reduced ability to complete further stages and therefore an unhealthier personality and sense of self. Generativity, the task for middle adulthood is defined by the ability to build a life, master a career, and contribute to wider society. Within this stage, identity and worth is defined by work and relationships with others. Contrasting this to the task of old age, where individuals are expected to review life accomplishments and manage impending death, a YOD diagnosis threatens successful resolution of the mid-life crisis by forcing individuals to face the task of older life too soon (Clemersen et al., 2014). The diagnosis of a degenerative disease is highly threatening as it not only affects how one views themselves in the present, but it erodes all hopes for normal ageing and the future. Again, literature focused on exploring how YPwD cope with breaks in normative age-related development is scarce but what does exist suggests coping with YOD is strongly situated within an individual's life cycle and social context.

A phenomenological study by Clemersen et al (2014) examined living and coping with Alzheimer's dementia in younger life. The study yielded four superordinate and ten subordinate themes related to the experience of living and coping with YOD. Within this study disruption of the lifecycle and feeling out of time emerged as the central themes. Participants spoke to the experiences of grappling with feeling too young to have dementia and how this disturbed their envisaged life trajectory leading to feelings of disconnect from peers and a loss of self. This elicited a profound powerlessness that reflected the impact of living with progressive cognitive decline. Unexpectedly, participants reported that reviewing life and changing expectations of the future became a common way in which they attempted to cope with these experiences. As a result of their diagnosis, and perceived interruptions in life cycle, the participants were forced to address two life-tasks simultaneously. Harris (2004) also examined the subjective experience of people diagnosed with YOD through qualitative research. The grounded theory approach yielded similar themes of disruption to life cycle and social orientation. Unlike Clemerson et al. this study was open to participants with all types of dementias, enhancing the findings generalisability and transferability across the population.

The impact of dementia on normative psychosocial development was also highlighted in Johannessen, et al's (2018) longitudinal study. Focussing on everyday narratives, the study observed how YPwD perceived the course of their condition, their needs and coping strategies. All participants acknowledged changes in their personality over the course of the study and congruent to other research (Clemerson et al., 2014; Harris, 2004) the participants saw preserving selfhood and identity as important. As cognitive decline became more evident, participants reported awareness of this and its interference in their daily lives and relationships. Social connectedness is a central element of self-concept and participants tried to maintain normative social relationships for as long as possible but reported themselves to be gradually retracting. A reformulated grounded theory allowed the researchers to capture the participants' lived experiences of oscillation between personal maintenance and decline and the impact this had on self-concept within the context of developmental life stage.

YOD is associated with considerable life transitions, Roach & Drummond (2014) investigated the causal role of these in psychosocial distress. YOD makes people feel as if they are out of time and that life transitions are not happening within expected chronological order, therefore, disrupting the social clock which leads to significant distress. The transition out of perceived purposeful activity had a profoundly negative impact on the participants. Unlike their older counterparts, at the time of diagnosis, YPwD are often in paid employment, and the diagnosis can lead to issues with employers, pensions and benefits. Interviewing nine family units the study indicated that commonly the ways in which participants left their employment was handled tactlessly. The ramifications of which was considerable psychosocial distress and a momentous sense of redundancy.

1.2.5 Personhood and Identity

A person's identity is associated with their sense of self, of being who they are. This sense of being who one is, or rather 'I', represents continuity in life where despite passing time and life situations change, the 'I' and therefore the person remains relatively stable over time ('Ethical Issues in the Early Diagnosis of Alzheimer Disease', 2011). Identity is shaped throughout life and is influenced by several factors such as life and social experiences, memories, preferences and behaviours. Historically the biomedical model dominated popular views on what it means to have dementia where PwD were viewed as lacking in rationality, capacity and essence of that person was presumed to cease to exist. However, as research into the self and dementia has progressed, supported by Kitwood's theory of person-centred care (1997) there has been a shift toward viewing people with dementia from a biopsychosocial lens taking the whole person into account. Where concepts of identity and personhood are now associated with how the person living with dementia perceives themselves and the influence of this on identity (Hennelly et al., 2018).

Within the modest amount of research into personhood and identity within dementia a handful of studies have extended to the experiences of personhood and identity in YOD. A recent study by Wright (2021) mapped how personal and socially attributed identity shifted as day-to-day life transformed over the span of the dementia continuum. Utilising a selection of corpus data this deductive study focused on themes and subthemes related to disease description/symptomatology, behaviour challenges, and situational needs. Stories which focused on the early phases of the dementia continuum described how inclusion in everyday life activities, their roles within these activities, and interactions with others were key to personal preservation. In these stages the person with dementia retained ownership over personhood with loss linked to social exclusion and isolation from everyday life. In the later phases stories focused on where the responsibility of personal preservation lay. It was seen that as the disease progressed, responsibility shifted from the PwD to external sources such as informal carers. Not surprisingly, given what his known about the concepts of personhood and identity within the wider context of dementia, the themes identified within the study reflected how both preservation and the loss of identity influenced the perceived quality of life.

Harris and Keady (2009) used a grounded theory approach to provide an in-depth understanding of the subjective experience of younger people with dementia and their carers. Drawing on the work of Glaser and Strauss (1967) this study sought to utilise the words of the participants to explain the impact of dementia on their personhood. The analytical framework from which the participant narratives were explored, was formulated around the changing sense of self, whilst also taking into account any constants that remained. The five themes (identity as a worker; identity of abandoned individual; sexual identity; family identity; and identity as an individual engaged in living) revealed insights into what it is like to be a person with young onset dementia. Theme three is particularly insightful as sexual identity plays a crucial role in self-image, although it is not something that many people feel comfortable discussing. The importance of sexual identity to the centrality of a person's definition of self was well documented through the narratives of the participants all who underwent a period of renegotiation of sexual roles, identity and intimacy within relationships. Theme five too was poignant, the participants spoke to the importance of holding onto the core values that pre-diagnosis defined who they were, and to continue living and acting in accordance to these.

For some of the participants being diagnosed with dementia motivated them to face adversity through purposeful, conscious decisions to live life to the fullest, which prior to their diagnosis was simply not a priority.

Drawing on Harris and Keady (2009) findings, Tolhurst et al (2012) collated and synthesised the existing literature looking at personhood in both older and younger PwD and evaluated how emergent age-based factors may impact upon the experience of a YOD. It was reiterated that dementia will be experienced differently by younger people, not only due to symptomatic differences but in psychosocial terms as well. Tolhurst et al argue that personhood is viewed to be fluid and is constructed differently at different ages, it concluded that for YPwD, at the onset of diagnosis, they are not only struggling with the threats to their personhood but also with the awareness that their condition is progressive, and threats to self/identity will be continually reconstructed at each stage of the condition. With each progressive stage, the potential for loss is seen to grow, leaving YPwD with less and less. What emerged from this evaluation was a set of suggestions for supporting personhood throughout the stages of the dementia journey. For those in the early stages of their condition it is essential to promulgate and destigmatise the condition whilst promoting efficacy and continued self-mastery through meaningful social involvement. Whilst for those with more advanced stage, who may no longer be as able, the focus shifts towards promoting positive self-referential thoughts and emotions to maintain personhood and identity.

1.3 Posttraumatic Stress Disorder

Psychological trauma results from witnessing or experiencing a single or series of extraordinarily stressful events that are perceived to shatter one’s sense of security or threaten life (Zisook et al., 1998). These events are incredibly distressing and are often accompanied by intense fear, horror, and helplessness leading to the development of PTSD (Sherin & Nemeroff, 2011). Although the emphasis is on event exposure, initial psychological reactions following a traumatic event are not necessarily pathological in nature and it is accepted most events of a given magnitude will result in a constellation of “expected” reactions. PTSD symptoms, which are defined by presence and persistence over time, sit outside this constellation and include event re-experiencing, avoidance of trauma thoughts and reminders, emotional numbing, negative cognitions or mood and chronic hyperarousal (American Psychiatric Association, 2013). Since its official recognition within the DSM-3 (American Psychiatric Association, 1980), there has been considerable research into the phenomenon which has resulted in significant growth of knowledge, accompanied by the development of numerous theories which have sought to make sense of the human response to trauma. This section reviews relevant contemporary theories of PTSD and will conclude with a discussion around the phenomenon of illness-induced PTSD.

1.3.1 Contemporary Models of PTSD

Drawing on classical and operant conditioning principles, contemporary models of PTSD aim to identify the unique, individual factors that either protect, or make a person vulnerable to PTSD psychopathology. Within these newer theories whilst pre-event factors are acknowledged to account for small amounts of variance in the development of PTSD, the emphasis is on the emotional and cognitive factors that relate to the experience of the traumatic event. Contemporary models contend that PTSD psychopathology arises when emotional stress alters the cognitive networks that process information about perception, meaning, and action responses toward executing goals (Hayes et al., 2012). The result of this is highly accessible information about fear, attentional bias and impaired memory encoding and retrieval of information, which lay the foundation for PTSD symptoms such as intrusive memories and hyperarousal.

The models discussed below are viewed to outline this dynamic interplay between emotion and cognition within the context of PTSD in YOD. Already established as a highly distressing life-event, PTSD is the cumulative result of the emotional stress (e.g., fear, threat, loss, helplessness etc.) experienced following diagnosis and the specific neuropathological processes (e.g. dysfunctions in cholinergic system) that underlie dementia. This combination could be hypothesised to heighten the emotional experiences of distress related to the YOD diagnosis, enhancing symptoms of PTSD such as intrusions, hyperarousal and negative cognitions and mood.

Emotional Processing Models

Emotional processing models propose that fear is activated through associative networks that include information about the feared stimulus, escape or avoidance responses to the feared stimulus, and the meaning of the fear (e.g., threat or danger). The aim of such models is on the processing of emotions and emotional experiences, and these have been instrumental in developing knowledge about how certain emotions (e.g., fear, shame, guilt) can shape the experience of PTSD (Zoellner et al., 2012). Crucially these models underscore the role of emotional processing of the traumatic experience in the experience of recovery.

Stress response theory (Horowitz, 1973; 1997) is one of the first and most influential emotional processing models. It proposes that following a traumatic event, an individual passes through four consecutive phases of a stress response, each of which generates different emotional-cognitive experiences. In the first phase, realisation of the traumatic event evokes emotions such as fear, sadness or rage, and a strong desire to avoid or escape thoughts and reminders of the trauma. This is followed by the second phase of denial and an emphatic refusal to face the implications of the event. The third phase is characterized by alternating intrusions and suppression in which unbidden thoughts, images, and pangs of emotion related to the traumatic emerge. Within the first three phases, intrusive memories develop in response to the trauma information being inconsistent with existing schemata and stored in active memory. Psychological and physiological numbing is employed to defend the traumatised individual against intrusions acting as a barrier to breakthroughs. The fourth phase, characterised the survivor's engagement in working through the event, results in either adaptation to the implications of the event or remaining in chronic psychological distress (Horowitz, 1997). Despite sparse empirical evidence, this model has acted as the foundation for a number of attribution (cognitive) based models of PTSD (e.g., Creamer et al., 1992) and has been instrumental in broadening psychologists understanding of symptomatic patterns of stress-related disorders. By proposing a single category of stress response syndromes that is appliable to wide breadth of clinical presentations this model set the tone for modern day understandings of PTSD and acute stress reactions (Bachem, 2015).

Emotional processing theory initially proposed by Foa and Kozak (1985, 1986), is another model which has sought to understand the role of emotion, specifically fear in the development of PTSD. Early versions of this model which focused on general anxiety disorders proposed the presence of underlying pathological fear structures as the source of the anxiety. These structures were hypothesised to involve excessive response elements that are resistant to modifications, the result of which is inaccurate representations of reality enmeshed within the fear structures themselves. (Foa & Kozak, 1986). Extending this model, Foa and Rothbaum (1998) suggested that in PTSD fear structures differ in that they possess both excessive stimulus and response elements in addition to pathological meaning elements. PTSD fear structures are thought to include two core dysfunctional cognitions that underlie the development and maintenance of PTSD, (1) the world is completely dangerous and (2) oneself is totally incompetent (Foa and Riggs, 1993; Foa & Rothbaum, 1998; Rauch & Foa, 2006). These are considered to reinforce inaccurate representations of reality, perpetuating ongoing sense of threat and unsafety. Within this model, recovery from PTSD relies on emotional processing to occur, resulting in the modification of pathological fear structures through the formation of new memories and cognitions that are incompatible with the fear structures.

This theory has been applied to a number of clinical populations such as sexual assault victims, veterans, prisoners of war and motor vehicle accident (MVA) survivors. Pitman et al (1998) applied emotional processing theory in Vietnam veterans with chronic PTSD. The results of the study supported the presence of emotional processing where following imaginal therapy the participants showed significant activation, within-session habituation, and partial across session habituation of physiologic variables. This study highlighted the role played by habituation within trauma recovery whilst confirming reduction in symptoms is proof that emotional processing has occurred. Alpert et al (2021) expanded on these discoveries, testing the role of emotional processing theory as a framework to examine the process of change in both pathological and adaptive responses to trauma-related content during the trauma narration and processing phase of trauma-focused cognitive behavioural therapy. Examining multimodal (cognitive, emotional, behavioural, physiological) pathological and adaptive trauma responses as predictors of treatment outcomes, the study found curvilinear patterns (increase and then decrease) of responses, which were able to positively predict improvements in PTSD symptoms. These results are significant as they have the capacity to broaden the measurement of emotional processing and processes of change in PTSD treatments to include pathological and adaptive trauma-related responses across multimodal responses (Alpert et al., 2021).

1.3.1.2 Memory and Information Processing Theories

Memory and information-processing models of PTSD highlight the key role that memory encoding and subsequent processing plays in the development of PTSD. Within these models, there is an emphasis on the extreme levels of stress at the time of encoding and the resulting disconnection or lack of integration of the trauma memory within the general autobiographical memory base.

Dual processing models (van der Kolk et al., 1996; Brewin et al., 1996) view trauma memories as qualitatively different from memories of other personal events, and therefore dual processes are at work. Brewin et al’s (1996) dual processing model in particular has helped clinicians and researchers alike gain a better understanding of the nature of trauma memories. This model proposed that all personal experiences (traumatic or normative) are processed by two memory systems; one which accounts for integrated memories and the other for sensory-based experiences. Within the first system, the verbally accessible memory (VAM), memory representations are consciously processed in working memory and then transferred into long-term memory, creating coherent, integrated and easily accessible representations. In contrast within the second system, the situationally accessible memory (SAM), information consists of perceptual experiences of the traumatic event such as sights and sounds and internal bodily responses. These are thought to be too brief to receive extensive conscious attention required to be recorded in the VAM. SAM representations are poorly elaborated, often dissociated from other personal experiences in memory, and are frequently seen to arise in non-deliberate event re-experiencing (e.g. nightmares, flashbacks, and physiologic reactivity). Within this theory, PTSD develops when there is an excess of SAM memories not converted to VAM, which remain poorly inhibited and easily triggered by situational cues and reminders.

The model has successfully been applied to various studies and too has provided essential infrastructure for attribution (cognitive) based models. A review by Kangas et al (2002) employed dual processing as the theoretical model to conceptualise of how PTSD can develop and is maintained following a diagnosis of illness such as cancer. Examining existing evidence on the presence of PTSD in cancer patients, the study determined following a cancer diagnosis, individuals are at greater risk of developing pathological stress reactions in response to being forced to contend with severe stressors (e.g., disease, treatment, prognosis) and the violation of pre-existing assumptions about health and wellbeing. When faced with uncertain prognoses and loss of envisaged future, the stress of this was precluded integration of corrective information about one's safety being into VAM (Brewin et al., 1996).

Kliem et al (2011) drew upon dual processing models to in attempts to understand how perceptual processing bias for trauma stimuli may contribute to the involuntary triggering of intrusive trauma memories. Two studies were conducted which tested the hypothesis that trauma-related perceptual stimuli when compared to neutral stimuli in the environment would contribute to intrusive re-experiencing, and the development of PTSD in MVA survivors. Both studies determined that trauma-related perceptual stimuli were associated with fear and data-driven processing during the trauma. Fear associations were found consistent with the effects of emotional arousal during encoding which led to enhancement and superior recognition of emotionally arousing stimuli (Dolcos et al. 2005). This correlation with data-driven processing reinforced the role of perceptual processing as originally identified within dual processing models of PTSD (e.g., Brewin et al. 1996).

1.3.1.2 Attribution Based Models

Diverging from emotional, memory and Information processing theories, attribution-based models focus on the meanings that an individual makes about themselves, others, and the world around them with reference to the trauma and trauma related stimulus or sequelae. As such, these models offer a useful conceptualisation of PTSD and have played a pivotal role in research and the development of clinical interventions.

Early attribution models, such as Janoff-Bulman's (1992) shattered assumptions model put forth humans develop fundamental, unarticulated, worldviews that allow for healthy functioning by providing one with personal meaning, self-esteem, and the illusion of invulnerability. Following a traumatic event, which damages worldviews, an individual is no longer able to see the world as benevolent or themselves as invulnerable. This 'information shock' results in a state of defenceless, where the terrifying, and confusing awareness of personal vulnerability gives rise to PTSD symptomology (Janoff-Bulman, 1992). This model is popular with clinicians and researchers alike and has been successfully applied to several trauma contexts.

Rodriguez-Munoz et al (2010) extended this model to assess for the prevalence and intensity of PTSD symptoms in victims of bullying. Utilising a matched control design a total of 366 participants (183 bullying victims and 183 control group) took part in the study. 42.6% of the total sample met all DSM-5-TR criteria for PTSD. Notably, in line with Janoff-Bulman's theory, the bullying victims all showed significantly more negative beliefs about the world, the people, and themselves, compared to their non-bullied controls. It appeared that the experience of victimisation left the participants feeling out of control and negatively changed how they viewed themselves (e.g., 'weak' and 'incapable'). Similar results were seen in Tehrani (2004), who also observed significantly negative changed beliefs in a cohort of healthcare professionals who had suffered bullying and met the criteria for PTSD. As well as in Zaluski (2014) where parents of children undergoing oncology treatments presented with higher severity of PTSD symptoms and demonstrated lower beliefs about the benevolence of the natural world, the people, and worthiness of the self.

The shattered assumptions theory was revolutionary in its recognition of and focus on cognitive shifts that occur in response to trauma. It has gone on to provide foundations for other attribution-based models, notably Ehlers and Clark (2000) cognitive model of PTSD.

Within this popular model, PTSD becomes persistent when individuals process the trauma in a way which produces a sense of serious, current threat. The presence of which is influenced by two processes: (1) excessively negative appraisals of the trauma and/or sequalae causing ‘mental defeat’ and helplessness; (2) disturbances in autobiographical memory which is characterised by poor elaboration and contextualisation, strong associative memory, and perceptual priming. Within the latter when the trauma memory is poorly elaborated, it becomes vulnerable to unintentional triggering by matching sensory cues and intentional retrieval is impaired. This model highlights that changing negative appraisals are prevented by a series of problematic behavioural and cognitive strategies including thought suppression and safety behaviours.

Consistent with the main clinical features of PTSD this model has provided the theoretical base for a number of studies which sought to understand the impact of cognition on the development of PTSD. Ehring et al (2008) for example, used the model to investigate the power of cognitive variables to predict PTSD following injury in MVA survivors. 147 individuals were assessed at the accident and emergency department on the day of their accident and 2 weeks, 1 month, 3 months, and 6 months later. The study found that cognitive variables were more predictive of subsequent PTSD than initial symptom severity. Specific individual cognitive processes, notably negative appraisals were key maintenance factors. This study replicated the findings of Ehring et al (2006) providing further evidence in support of the cognitive conceptualizations of PTSD, reemphasising the tenant of contemporary theories of PTSD that individual differences are key factors in predicting PTSD.

1.4 Illness Induced PTSD

Research on trauma has found that the types of events that cause or enable PTSD, such as assault, are more common than uncommon (Kessler et al., 1995) and in response to this, the scope of potential trauma events has been expanded by the DSM-5 to include non-traditional stressors or situations (Mundy & Baum, 2004). Specifically, criterion A of PTSD was amended to omit stressor description as ‘outside the range of normal human experience’ and instead states that the response to the stressor must include intense fear, helplessness or horror (American Psychological Association, 2013). This definition expands the types of traumatic events that qualify for PTSD to include events such as significant personal betrayal, bereavements, and medical diagnoses (Mandy & Baum, 2004). The diagnosis of life-limiting or life-threatening disease, alongside treatment and life transitions, signifies substantial exposure to psychological distress as it can elicit life-threat on biological, emotional, social, and cognitive levels. For many it violates worldviews, creating and reinforcing a sense of unsafety, unpredictability and inescapability as the threat is one's own body.

A myocardial infarction (MI) is an example of this. In addition to being highly unpredictable in nature, it is commonly associated with death and/or profound disability. Examining the presence of PTSD symptoms 6-months following an MI, Bennett and Brooke (1999) determined that the perceived degree of life-threat was found to positively predict the likelihood, severity, and frequency of PTSD symptoms, notably intrusions. Pricip et al's (2018) study, also with MI survivors, mirrored these results and found that the subjective perception of the illness, including higher harmful consequences, illness concerns, and emotional impairment were significantly associated with PTSD symptoms.

PTSD has been examined across several medical populations, including cancer and HIV patients, and among patients receiving organ transplants. Sumalla et al. (2008) examined the differences between the experience of acute traumatic events and the trauma of cancer. The notable difference between oncological experiences and acute adverse events was the challenge in identifying a single traumatic stressor. Most traumatic events can be characterized by their discrete nature, however, during oncological illness stressors were associated with several variables including diagnosis, severity of illness, and prognosis. This study emphasized that unlike acute traumas, where the recurrence of symptoms is associated with a past traumatic event, in oncological processes the perceived threat and fears are associated with the future. The forward-thinking nature of the trauma makes it a distinct phenomenon. Oncologic disease and its treatment in adolescence represents another unique form of trauma. Studies by Stuber et al (2010) and Koutna et al., (2017) analyzed posttraumatic stress symptoms (PTSS) among teenage and young adult cancer survivors.

Both studies suggested that the incidence of PTSS is related to age at time of diagnosis, subjective disease factors, time intervals following the end of treatment and poor social support. This is attributable to threats to normative life cycle and perceived inabilities to meet age-specific responsibilities and milestones (e.g., fertility).

With the psychological and emotional impact of HIV diagnosis well established, Kelly et al., (1998) investigated the impact of HIV infection on the development of PTSD. Sixty-one HIV-positive men were assessed for a distress response related to the diagnosis of infection. More than 30% of participants met the clinical criteria for a PTSD diagnosis. In one-third of the PTSD cases, onset was greater than 6-months following the diagnosis. The perceived threats were related to undergoing and waiting for diagnostics, the insidious nature of the disease, the impact on future self and and the perceived likelihood of survival. Similarly, Martin & Kagee (2008) found that 40% of their study participants met the criteria for PTSD related to their HIV. These findings suggest that diagnosis and positive status are psychological stressors that frequently result in PTSD. However, it should be noted that both studies failed to consider individual factors that could have influenced the development of PTSD such as cognitive and emotional appraisals or events that occurred just before or after diagnosis. Therefore, it is entirely possible that the HIV diagnosis in isolation does not result in PTSD.

Illness-induced trauma and PTSD is an anomalous phenomenon that is challenging to identify as there are multiple confounding variables which make it difficult to isolate the medical trauma as the source of the distress (Hall & Hall, 2013). What can be gleamed from available literature is that a subjective sense of life-threat, loss and inescapability is paramount for the development of illness-induced PTSD. A key factor observed within the literature to differentiate conventional traumatic stressors and illness stressors is the focus of threat of time (Mandy & Baum, 2004; Sumalla et al., 2008). In general terms, conventional stressors are acute events that give rise to persistent difficulties. These events are clearly situated within the past but continue to impact the present. In contrast, illness-induced traumatic stressors, whilst sharing some of the characteristics above, possesses a distinctly future-orientated aspect wherein, the focus shifts towards fears and worries about treatment, survival, recurrence, stigma, and the persistence of life-threat and new dangers yet to come (Compas & Luecken, 2002). This creates an increased sense of inescapability and hopelessness for those affected and is another major contributor to the development of illness-induced PTSD.

1.5 Posttraumatic Growth

Whilst the diagnosis of a life-threatening illness can be an extremely stressful, traumatic experience, many individuals also report various positive changes, referred empirically as PTG. PTG refers to "positive psychological change that occurs as a result of the struggle with highly challenging life events" (Tedeschi & Calhoun, 2004, p. 1). Often confused with other concepts such as resiliency (e.g., ability to go on with life after hardship and adversity), hardiness (e.g. tendencies toward commitment, control, and challenge in response to life event) and sense of coherence (e.g., the ability to comprehend or understand events, manage or cope with them, and find meaning in them) according to Tedeschi and Calhoun (2004) there are a set of core criteria which have to exist to experience PTG. First and foremost, positive psychological change is the result of a struggle with a highly challenging and disruptive life circumstance which poses a significant threat and/or shatters fundamental schemas. Secondly, the positive changes must be viewed as "as important, and that go beyond what was the previous status quo. Posttraumatic growth is not simply a return to baseline, it is an experience of improvement that for some persons is deeply profound." (Tedeschi & Calhoun, 2004, p 4). These changes are thought to support individuals to achieve a stage of psychological functioning higher than that which existed prior to the traumatic or challenging event (Linley & Joseph, 2004).

People who experience PTG often go on to develop new perspectives about themselves and the world around them that give their lives new meaning and purpose. Because of this, growth can therefore be recognised as a unique phenomenon from other responses to adverse events. Within literature, this phenomenon of growth has been defined in numerous terms including and not limited to adversarial growth (Linley & Joseph, 2004), benefit finding (Helgeson et al., 2006) and stress-related growth (Park et al., 1996) Although conceptually different, these terms share a singular view that positive change following adversity is possible.

PTG has been studied across a variety of populations and traumatic events ranging from natural disasters (Siqveland et al., 2015) sexual violence (Kaye-Tzadok & Davidson-Arad, 2016), prisoners of war (Dekel et al., 2011), terrorism (Ikizer & Ozel, 2020) and serious physical and mental illnesses (Hefferon et al., 2009; Mapplebeck et al., 2015). With regards to illness-induced trauma, this personal growth has been seen within literature to foster overall positive adjustment to illness and in some cases facilitate the process of convalescence.

1.5.1 Prevalence of Posttraumatic Growth

Quantifying the prevalence of PTG in individuals who have reported experiencing an adverse or traumatic event is challenging as differing methodologies, means of data collection (e.g., purposive versus biased sampling) and participant groups all influence how and the rates at which PTG is reported. One empirical review by Linley and Joseph (2004) which looked at 39 studies reported rates of PTG to vary greatly with a range of 95%. The lowest reported prevalence of PTG (3%) was found among a sample of bereaved individuals (Davis, Nolen-Hoeksema, & Larson, 1998) and the highest (98%) among women with breast cancer (Weiss, 2002). Lelorain et al (2010) also reported high prevalence of PTG across a sample of breast cancer survivors with self-reported rates of PTG of 86.3% as measured by the Posttraumatic Growth Inventory (PTGI). Similarly high rates of PTG were found in studies such as that conducted by Shakespeare et al (2003) examining PTG in emergency ambulance personnel (98.6%) and in one study by Laufer and Solomon (2006) which focused on the experiences of Israeli youth following terrorist attack (75%). Conversely, Xu and Liao (2008) determined prevalence rates of only 51.1% in earthquake survivors one year on. Although difficult to establish actual rates of growth, PTG can viewed to be a relatively common outcome across populations, however it is not a universally experienced phenomenon. In actuality it appears to be part of a wider process of psychological adjustment and acceptance. It is important to note that for many, its presence is not synonymous with the absence of distress (Tedeschi & Calhoun, 2004) but instead reflective of an individual’s attendance to their lived experiences and the personal meanings ascribed to these.

1.5.2 Characteristics of Posttraumatic Growth

PTG theory proposes that following an adverse or traumatic event that is seismic in nature, positive psychological growth can occur in response. Life changes associated with the development of PTG occur in five broad domains: appreciation for life, new possibilities, personal strength, relating to others and spiritual growth/change (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004; Triplett et al, 2012). Each of the five domains has a paradoxical element to it that represents a special case of the general paradox of this field: that out of loss there is gain. It is important to stress that PTG is a multidimensional phenomenon and therefore positive changes do not need to be reported across all five domains (Tedeschi & Calhoun, 2004). Furthermore, due to the broadness of each domain and number of potential themes which may fall under each, there are instances where they may overlap which can strengthen the experience of positive growth (Elderton et al., 2017)

1.5.2.1 Appreciation of Life

An increased appreciation for life in general, the more trivial aspects of it, and a changed sense of what is important, is a commonly reported experience for many individuals (Brooks, 2018). The experience of adverse events is thought to lead individuals towards a recognition of their personal vulnerabilities including shortness of time and mortality. As such, events that may have previously been seen as significant now appear frivolous and attention and meaning is relocated from extrinsic goals to intrinsic priorities (Calhoun & Tedeschi, 2014). Individuals typically report significant shifts in how they approach their daily lives such as trying to enjoy and appreciate each day more, or find meaning in new experiences (Kuenemund et al., 2016). Many often report a sense of ‘being so lucky’ (Tedeschi & Calhoun, 2004). For some radical changes in priorities can accompany the increase in appreciation for what one still has. This can enable one to celebrate the positive aspects of their lives to a greater degree (Mapplebeck et al., 2015) and ascribe great value their ‘second chance’ (Joseph et al., 1993).

1.5.2.2 Relating to Others

Enhanced, more intimate, and meaningful relationships with other people is commonly reported to be part of the experience of PTG. This can involve developing a greater awareness of whom one can depend on, or increased desires to maintain close or intimate relationships (Shakespeare-Finch et al., 2013). People often describe increased expressiveness of emotion, a sense of belonging and feeling understood (Mapplebeck et al., 2015). A study of posttraumatic growth in bereaved parents by Calhoun et al (2010) provides good examples of this change. As one participant reported "you find out who your real friends are in a situation like this." Studies have found these improved relationships to promote altruistic desires to help others in similar situations (Vanhooren et al., 2018), wherein the affected individual experiences an increased sense of compassion which is another way in which greater connections are fostered.

1.5.2.3 Personal Strength

In the aftermath of adversity, a sense of increased personal strength, or the recognition of possessing personal strength, is another domain of posttraumatic growth. Perceived changes include more openness, confidence, humility, empathy and an “improved self” (Tedeschi & Calhoun, 1996, p. 456). After overcoming adversity, people may also report an increased capacity to manage future stressors (Shakespeare-Finch et al., 2013). A study by Calhoun et al (2000) showed participants reporting the likes of “I can handle things better” and “Things that used to be big deals aren't big deals to me anymore”. Within this domain individuals also reference regaining control over their lives. Often developing an inner drive to keep going and to attain something better following the emotional struggle with their experiences (Mapplebeck et al., 2015). Interestingly, this identification of strength is paradoxically associated with an increased sense of vulnerability. Therefore, within this domain, growth is experienced as the result of learning that that bad things can and do happen and the subsequent discovery of “what doesn’t kill me makes me stronger.”

1.5.2.4 New Possibilities

Posttraumatic growth can also be seen in the individual's identification of new possibilities for one's life or of the possibility of taking a new and different path in life. Through confrontation with adversity, new life opportunities present themselves. The result of which are changed priorities about what is ‘really important’ and in some cases the choice to follow a new life path. The creation of this new life path is related to the emergence of new life philosophies that change past worldviews and core beliefs leading to new possibilities and opportunities that were perceived to not exist before the trauma (Tedeschi & Calhoun, 1996, 2004). Research presents this as individuals learning new skills, changing careers, or advocating for a new and special cause (Shakespeare-Finch et al., 2013; Staub & Vollhardt, 2008). For others still, new possibilities can take on the form of education, focusing on one's health, or adopting altruistic endeavours.

1.5.2.5 Spiritual Growth

Growth in the domain of spiritual matters is another way in which some individuals experience positive change in their struggles with stress and loss as encounters with traumatic events can prompt engagement with fundamental existential questions. Contrary to popular beliefs, one does not need be religious to experience growth within this domain (Tedeschi & Calhoun, 2004). Yet, as might be expected, this domain has been observed more frequently in religious people than in nonreligious people (Currier et al., 2013). For those who are actively religious, placing their faith in a higher entity can enhance meaning and life direction (Shaw et al., 2005). Whilst for others becoming part of a religious community enhances connectedness with the self, higher powers, and others (Woodward & Joseph, 2003).

Spiritual growth in those with no religious beliefs, is most frequently reported as a greater sense of spiritual connection to the world and nature following adverse events (Shakespeare-Finch et al., 2013). Unlike the other domains, spiritual growth is more likely to be influenced by cultural norms. For example, when comparing Western cultures, Calhoun et al (2010) determined that American samples typically report enhanced spiritual growth in comparison to European counterparts. Notably, within this domain, individuals can go on to report spiritual or religious decline following adverse events as new worldviews are created and shifts in focus and life priorities are made (Walker et al.,2009).

1.6 Trauma and Posttraumatic Growth Following a Young Onset Dementia Diagnosis

As established the diagnosis of a life-limiting disease, associated treatments and transitions often yields significant psychological distress. Being diagnosed with YOD can be a traumatic experience for the individual as the condition is a progressive, ‘terminal’, ‘old person’s’ illness with no cure and very few effective treatments. The disclosure of dementia represents a turning point (Beard, 2004); once diagnosed, the individual is faced with irreparable change and loss. By the nature of these threats to self and the condition symptomology, YPwD often find themselves within a ‘high-risk zone’ for depression, anxiety, and suicidal ideation which they must navigate whilst simultaneously experiencing paternalistic attitudes and stigmatisation from others (Iliffe & Manthorpe, 2004).

A review of the current literature yielded a single study examining posttraumatic stress (PTS) in people with dementia. Dunham et al (2019) used a PTSD screening tool to determine if being diagnosed with dementia shares qualitative similarities with PTSD and to explore whether PTS symptoms are associated with a reduced engagement with services following diagnosis. Within this small pilot study consisting of 11 participants ranging in age from 63 to 90, six revealed scores within the clinical concern scale of the screening tool. This demonstrates that a dementia diagnosis can be associated with symptoms consistent with PTSD. The findings of this study are indicative that there is value in considering PTSD as a factor impacting people following a dementia diagnosis.

Returning to the models of PTSD previously discussed within this chapter and integrating neuropathologic processes this assertion gains further support. The underlying psychopathology of dementia is attributed to damage caused within the hippocampi and prefrontal cortex, two critically important structures in the brain’s memory system, responsible for encoding, consolidation, retrieval, and organization of the memory network. These structures which interact in a bidirectional manner regulate several cognitive functions and alongside the amygdala process emotional information. Dementia disrupts inhibitory processes in both structures making one more susceptible and less able to supress to intrusive memories, images, and flashbacks (Sampath et al., 2017). These disruptions have also been observed to enhance physiological arousal and alter emotional reactivity during fear responses (Hersman et al., 2019). Combined with abnormal dementia-related declines within the cholinergic system this results in inefficient encoding of memories, attentional difficulties and disinhibitory behaviours (Francis, 2005).

Reflecting on Brewin et al's (2000) dual-processing theory the impact of the disinhibited and declining cholinergic system on YPwD's vulnerability to PTSD symptomology can be observed. System dysfunctions prevent the successful conversion of SAM memories to VAM memories which in turn leaves these memories poorly inhibited and easily triggered by situational cues and reminders. Alternatively, employing an attributions-based model such as Elhers and Clark (2000) cognitive model of PTSD, the psychopathology of dementia can be viewed to impede the proper elaboration of memories, increasing sensitivity to unintentional triggering by sensory cues. In attempts to prevent triggering of the trauma memory, YPwD go on to develop a set of disruptive behavioural and cognitive coping mechanisms which when left unaided result in substantial impairment to psychosocial functioning (Bonne et al., 2004).

Moving beyond psychopathology, fear-based rhetoric found within contemporary culture could be viewed by emotional processing theorists (Foa & Kozak, 1985) as responsible for the development of societal-wide fear structures which form the basis for the set of dysfunctional cognitions and threat-based emotional states that underlie the development of PTSD. Dementia is viewed as being an 'old person's disease' which is accompanied by horrifying, ominous mental images of withered, incapacious and bedbound individuals. With this narrative remaining static in society and limited opportunities to modify it, dementia fear structures remain unchallenged, preventing new associations from being formed. This strengthens the existing rhetoric and social assumptions about a dementia diagnosis resulting in a widely feared and accepted view that dementia is 'dangerous' and leaves the affected individual totally helpless and incompetent (Rauch & Foa, 2006).

It is understandable how a dementia diagnosis, especially at a young age could be interpreted as a highly distressing event. For many, the diagnosis symbolizes significant personal loss and destroys expected life trajectory resulting in experiences of threat and inner turmoil. However, this does not mean that YPwD cannot experience positive, meaningful psychological changes as a result of struggling with, and working through, a subjectively traumatic diagnosis (Tedeschi & Calhoun, 2004). The diagnosis of a highly threatening illness or medical condition is viewed as life shattering, prompting a series personal and purposive processing which can elicit positive growth, attenuating the negative impact of PTSS and leading to greater senses of wellbeing.

There is scant research available which has investigated the positive lived experiences of YPwD. Yet, what can be generalised from the existing literature is that the negative psychosocial implications of disease does not preclude the diagnosed individual from being able to experience positive change as a result of the struggle with their experiences of extreme diagnostic distress. It is therefore not out of the realms of possibility to presume that the model of PTG can be extended to include those diagnosed with a progressively, life limiting diagnosis such as dementia.

1.7 Study Aims and Rationale

The present study attempts to address the gaps within the literature and will be the first of its kind to attempt to extend the models of PTSD and PTG to YOD and by doing establish the commonality of both YOD related PTSD (YODR-PTSD) and YOD related PTG (YODR-PTG). It further seeks to establish in what ways is PTG experienced by YPwD, and what may influence this experience (e.g., demographic variables, psychological phenomenon). To note, the term ‘commonality’ refers to the mean PTSD and PTG prevalence estimate for the study’s sample. Due to the subjective nature of trauma not all those diagnosed with YOD will consider their diagnosis a highly challenging or traumatic event and go on to develop PTSD. This is equally so for the experience of PTG which in the absence of the core criteria cannot exist.

Using a mixed methods design will serve to provide a comprehensive view of the experience of being diagnosed with YOD and positive-growth related change. It is important to dedicate research solely to the experiences of YPwD to give this population a collective voice that is not overshadowed by proxy participants, such as family carers, whose views may differ to greatly than the person with dementia (Hubbard et al., 2003). This research aims to destigmatise the condition and to change the associated social narrative. This research wishes to show that a YOD diagnosis does not mean that life is over, and that one can experience positive changes and growth which ultimately results in full and meaningful existence.

1.8 Relevance to Counselling Psychology

In recent decades understanding health and wellbeing has become increasingly important, and treatment of health-related problems has extended beyond that of the physician (Bolton & Gillett, 2019). Consequently, the role of experienced psychologists within health is gradually becoming more important. Counselling Psychologists possess an enormous amount of knowledge and experience in dealing with diverse problems and presentations, and the discipline has a huge amount to offer to medical health care.

A unique specialty, counselling psychology emphasizes a person-centred, strengths-based approach and employs the biopsychosocial model to understand health and health problems (Altmaier & Johnson, 1992; Carmen & Roth-Roemer, 1998; Karademas, 2009). Counselling Psychologists are therefore able to assume a number of roles within health care settings and to take on a wide and varied workload which includes and is not limited to pre and post-rehabilitation, helping clients to change unhealthy behaviours, provision of counselling for dealing with emotional and adjustment difficulties, breaking bad news and helping the dying (Karademas, 2005, 2009). Counselling Psychologists can also offer help to families and carers, and to medical personnel who may need additional support when working with challenging or unruly patients.

With the expected prevalence of dementia in the UK expected to rise to over 2 million by 2051, it is becoming increasingly important to integrate psychological input and care (Department of Heath, 2016). As the diagnosis of dementia can be emotionally distressing and overwhelming for the individual as well as the family, timely support and psychosocial interventions are essential in promoting quality of life in those diagnosed. Within its relative infancy, the discipline of counselling psychology is still carving out its own distinct boundaries of practice. Chameleon-like, the field can appreciate, approach, and adopt new sources of knowledge from better established fields such as neuropsychology, developmental, behavioural and cognitive psychology. Counselling Psychologists are well placed to deliver clinical interventions aimed to support better overall adjustment to health conditions and contribute to the development of new knowledge within the field of health psychology.

This research has the potential to inform the discipline and support Counselling Psychologists to develop a greater understanding of how YPwD process and cope with personal deterioration. This is fundamental for the development of sensitive, appropriate interventions that maximise quality of life (Clare, 2002). Given the wide breadth of potential roles for Counselling Psychologists, such knowledge could not only be used to provide timely person centred support, but also be used to inform public policy care protocols which could improve care pathways and interventions from the onset and throughout.

1.9 Summary

The literature identifies that YOD is a highly unique sub-group, although most diagnoses occur in those aged 45-65 (Mercy et al., 2008), there are documented cases young as 17. As such, this population has a unique set of experiences and needs that have been to date under-represented within the literature. The diagnosis of YOD is a distressing, even traumatic event, in most cases, the diagnosis is unexpected and occurs at later stages of the condition due to its relative rarity and the inexperience of diagnosing professionals. The result of which is the diagnosed individual being left with less time for processing and coping. This has been seen to elicit a myriad of emotional responses ranging from disbelief to grief to terror. For many YPwD, their future is seemingly ripped away from them. This has been observed to shatter worldviews, and leave the diagnosed individual in a seemingly irreparable state.

Reviewing contemporary theories of PTSD, the common thread uniting them all is the belief that it is the experience of an event as traumatic and it how this is emotionally and cognitively processed that acts as the critical factor in the development of PTSD (Brewin et al., 2000). The DSM-5 having expanded criterion A to include a health condition as something that can precipitate PTSD has resulted in growing interest in PTSD in within the context of illness. Research now suggests that PTSD occurs in 12-25% of survivors of acute life-threatening medical events (Edmondson, 2014). What appears to separate illness-induced traumas from the prototypical discrete/external past traumatic events, such as combat or assault, is that illness traumas are rarely discrete events with defined endpoints and as such safety seems impossible. In traumatic life-threatening or life-limiting illness there is often an acute manifestation of a permanently disrupted physiological system, the consequences of which may last for years and place an ongoing threat squarely in the body of the survivor, where escape is impossible (Tang et al. 2007).

Despite such traumatic experiences individuals have been observed to experience positive personal change as a results of their struggles and willingness to learn to cope with the health condition and its physiological and psychological consequences (Martz et al., 2018). Distinct from other psychological concepts such resilience, individuals who experience PTG, do not merely return to pre-trauma baseline functioning but instead advance to higher than pre-trauma levels in one or more life domains, including self-perception, relationships with others, emotional expressiveness, appreciation and enjoyment of a more meaningful life, and heightened spirituality (Tedeschi & Calhoun, 1996, 2004). As noted by Tedeschi and Calhoun, the experience of PTG does not negate nor decrease emotional distress because growth after extreme life crises may require existential struggles in order for world views to be rebuilt. It is emphasised that "for most trauma survivors, posttraumatic growth and distress will coexist, and the growth emerges from the struggle with coping, not from the trauma itself" (Tedeschi & Calhoun, 2004, p. 60).

The adaptive significance of PTG has been highlighted and discussed. It has been identified that that more research is required to investigate specific disease-related profiles of PTG and the complex mechanisms which underlie the relationships between PTG and the process of convalescence or, in the case of conditions such as dementia, the acceptance of a new normal. There has been no research into the experience of illness-induced trauma related to a YOD diagnosis and subsequent opportunities for PTG. Dementia is a socially and personally feared diagnosis. Greater research in this area is required to help redefine societal views of dementia, develop sensitive and effective interventions and to support adaptive adjustment following diagnosis.

1.10 Hypotheses and Research Questions

The research has been split into two phases to address the above aims. Phase one focuses on quantifying the commonality of YODR-PTSD and YODR-PTG, and assess which variables influence or contribute to this experience. This will be done by addressing the following research questions and hypotheses;

(1) Do individuals diagnosed with YOD experience trauma following their dementia diagnosis (as measured through symptoms aligned with PTSD)?

Primary hypothesis: YPwD will report experiencing trauma associated with their diagnosis, great enough to elicit a PTS/PTSD response

(2) Is the extent of trauma great enough to elicit PTG despite cognitive limitations?

Primary hypothesis: The trauma is significant enough to elicit PTG.

Secondary hypothesis: People with YOD can experience PTG.

(3) Which sociodemographic variables (age, gender, ethnicity, identified religion, sexual orientation, education level, relationship status and length of time since diagnosis) and psychological phenomenon (resilience and self-compassion) best predict how one perceives a dementia diagnosis?

Primary hypothesis: Variables such as educational level, relationship status and time since diagnosis will have a greater impact on how one perceives the diagnosis.

Secondary hypothesis: Participants with greater levels of self-compassion and resilience will be more likely to report the presence of PTG than those with lower levels.

Phase two will qualitatively address the experiences of both PTSD and PTG by answering the following question: In what ways do individuals diagnosed with YOD experience PTG? This investigation will aim to explore participants' lived experiences of PTSD, experiences of a YOD diagnosis and any personal positive growth that may have occurred. The objective is to explore the factors implicated in the process of traumatisation and subsequent PTG. A particular focus will be around the impact of personal interpretation of one's lived experience of diagnosis and living well with dementia.

Chapter 2 Methods

2.1 Introduction

This chapter outlines the mixed methods methodology selected to explore the experience of YODR-PTG. In recent years the phenomenon of PTG has gained considerable attention within the realms of positive psychology and there have been numerous studies examining PTG in the context of life-threatening and life-limiting illnesses (Dahan & Auerbach, 2006; Nightingale, et al., 2010; McDonough et al., 2014; Baglama & Atak, 2015). This study seeks to extend the model of PTG to YOD; adopting a sequential mixed methods design within a pragmatist paradigm. This chapter will explain the positioning and use of this paradigm alongside the validity and usefulness of the data collection and analytical process, taking into account ethical considerations and reflexivity throughout.

2.2 Methodological and Epistemological Considerations of the Study

Within the context of complex real-life health problems, Psychologists will encounter challenges related to the multiplicity of conflicting forms of knowledge (Cornish & Gillespie, 2009). The same could be said for mixed methods research which has historically encountered difficulties fitting to a corresponding philosophical paradigm (Johnson, 2011) due to issues arising from seemingly conflicting epistemologies (Creswell, 2003; Guba & Lincoln, 1994; Johnson & Onwuegbuzie, 2004).

When faced with two staunchly opposing worldviews, pragmatism as a research paradigm offers a set of approaches to address this philosophical disagreement. Rejecting metaphysical concepts such as truth and reality and embracing a plurality of methods, pragmatism operates based on the premise that social science inquiry cannot always access reality solely through a single scientific method; and researchers should use the philosophical and/or methodological approach that works best for the research problem at hand (Cotton et al., 1999; Kaushik & Walsh, 2019). By doing so pragmatism as a paradigm accepts that there can be single or multiple realities that are open to empirical inquiry (Kaushik & Walsh, 2019).

A pragmatist approach to mixed methods research acknowledges epistemological differences between qualitative and quantitative approaches but does not see these forms of inquiry as entirely incompatible. Instead, it campaigns for a shared aim for all research - to produce a positive change in the world (Bishop, 2015). Discordant with realism, pragmatism does not rest upon ambitious claims about knowledge reflecting an underlying reality. Equally unlike idealism, pragmatism rejects the idea that the mind is the basis of knowledge, and therefore directly opposes rationalism, disagreeing that abstract rationality is the path to reliable knowledge (Maxcy, 2003).

Pragmatism instead claims that knowledge is always based on experience where one's perceptions of the world are influenced by social experiences and contexts. Individual experiences are unique (Kaushik & Walsh, 2019) and practical activity is the bedrock and test of knowledge, which is formed and judged according to its consequences in action (Cornish & Gillespie,2009). Not viewed as reality, knowledge is contextually constructed with a purpose to better manage one's existence in the world (Giladi, 2015). Instead of asking the question 'Does this knowledge accurately reflect the underlying reality?' a pragmatist instead seeks to determine 'Does this knowledge serve our purposes?' (Gross, 2003). The assumptions of pragmatism are, therefore, well suited for guiding the work of merging the two approaches to create a more holistic understanding.

This study adopts the pragmatist position on account of this flexibility and orientation towards practical problems. This is congruent with a critical realist ontology, an interpretative phenomenological framework and a contextualist epistemology which recognises that knowledge and reality are based on beliefs and habits that are socially constructed but are dependent on the context in which they exist (Dillon et al., 2000). This combination offers this study a middle ground wherein the world and knowledge cannot be reduced to "unknowable chaos or a positivistic universal order" (Clark et al., 2008; E68). The critical realist approach will minimise conflict between positivism and interpretivism through the acknowledgement and valuing of recurrent patterns of contexts within the lived experiences of YPwD, and the possible means by which they have occurred. Epistemic contextualism accepts that an individual's experience of the world constitutes a unique reality, and the resultant knowledge is influenced by social, political, economic, ethnic, and cultural factors (Pynn, 2016).

For the researcher investigating the phenomenon they are assumed to be interactively linked with the subject. Rooted within the hermeneutic circle the IPA framework provides space for an iterative process of moving back and forth between observations and the entirety of the phenomenon. This aims to reconcile any disharmonies and construct a consistent account across diverse subjective viewpoints and experiences. In this way, the researcher is actively involved within the creation of data. There is an unspoken acceptance that any knowledge collected is influenced by the researcher's interpretative decisions (Morgan 2007).

Within pragmatist positioning, arguments exist which state the focus should be on methodology over that of epistemology as it is through the mechanical methods that data and subsequent knowledge is garnered. However, in reality, the pragmatist researcher must retain a dual focus giving equal weighting to both. In the context of this research, the methodological framework will be used as a tool, connecting thoughts about the nature of knowledge and the attempts to produce it (Morgan, 2007; Kashik & Walsh, 2019).

The proposed stance melds well with the discipline of counselling psychology which is phenomenologically focused and concerned with understanding people's inner worlds and uncovering subjective truths (Douglas et al., 2016). It reflects the primary aim of the study, which is to investigate, interpret and report the lived experience of YODR-PTG in a rich and meaningful way that gives a voice to the wider group in contrast to seeking a single universal truth (Maxcy, 2003).

2.3 Reflexivity

As evidenced in the literature review, there is a gap in research regarding the lived experiences of YPwD. As rates of dementia rise there is increased value in understanding the factors which may help to inform how to live well with the condition. Having originally trained as a nurse, I learnt that every health condition brings with it a unique set of challenges. During my own experiences of working within dementia services I bore witness to the cognitive, psychological, emotional, and societal impact of the disease; and the negative narratives almost entirely focussed on what the disease had seemingly 'stolen' (e.g., functional abilities, memories, and personhood).

This contributed to developing my own assumptions about what it must be like to live with dementia. Unlike conditions such as cancer, HIV or stroke where narratives exist accounting for positive experiences and/or outcomes resulting from diagnosis (e.g., a new lease on life or improved relationships with others) (Mystakidou et al, 2008; Rzeszutek, 2017; Zhang et al., 2012) for PwD, their diagnosis appears to signify the beginning of the end. One day my assumptions were challenged as I read an article about a young man with dementia who instead of focussing on the negative implications of his diagnosis, chose to draw attention to how life had changed and evolved towards living well with dementia. This seemingly novel concept sparked my curiosity which influenced my desire to explore this further.

Being reflexive within research enables the researcher to acknowledge what they bring to the research, acting as a vehicle for growth through analysis of the personal, intersubjective and social processes or contexts in which the researcher exists (Greene, 2006; Finlay & Gough, 2003). As working within a pragmatist paradigm requires the researcher to take on an active role in knowledge construction throughout the analysis, the researcher must maintain awareness of their role as instrument within the study and the influences that their unique and socially shared worldviews may have on interpretative decision making. This is achieved through a dynamic approach known as abduction (Bugg & Dewey, 1993; Morgan, 2014). During which the researcher goes through several rounds of designing the research, selecting the methods, reflecting on the choices made, and reconsidering the research question.

Through this active reflection on the nature of the problem, potential solutions and the likely actions inevitably come to life. This reflexive process was of particular importance given the juxtaposition between the quantitative and qualitative methodological approaches and inevitable power struggle which occurred. Fortunately, for a pragmatist, the overriding issue is whether the philosophical assumptions and the methodology, are useful in producing desired or anticipated results (Goles & Hirschheim 2000). As such, the research question is placed above philosophical considerations (Tashakkori & Teddlie 2008). Rejecting traditional philosophical dualism of objectivity and subjectivity, the pragmatist outlook supported me in managing conflicts between the critical realistic ontology and the IPA methodology (Biesta

2010). This refusal to become involved in contentious metaphysical arguments maintained my openness towards the existence of all realities, single or multiple. Through the act of doing this, I was able to focus my attentions on achieving the research goal to understand the experience of PTG in the context of YOD.

Within my position of researcher, I adopted a curious, sensitive, and non-judgemental stance. I was conscious of my role within the double hermeneutic of interpreting others' interpretations of their lived experiences where I sought to probe beyond surface meanings and read between the lines of the transcripts for deeper interpretation. The iterative process of interpretation involved a high level of personal reflection and acknowledgment of the dynamic relationship between my encounters with the participants and my knowledge and expertise as a clinician and researcher (Tuffour, 2017). Through an audit trail in the form of documentation (reflexive research diary, interview notes) and the inclusion of a further reflexivity statement within this thesis (Banister, 2011) attempts were made to bracket (Creswell, 2007) any personal biases, assumptions, and interpretations. To encourage my own process of self-examination and self-exploration during the research process, I engaged in regular personal therapy, reflective supervision, and exploratory conversations with my peers about the nature of knowledge and reality.

2.4 Rationale for Combining Qualitative and Quantitative Approaches

The role of the psychologist-researcher is to learn and understand all aspects of human existence, from neurological processes to moral agendas. As such there is a strong argument for the necessity to use both quantitative and qualitative methods in psychological inquiry to gain a complete understanding of humans within humans and societies (Yilmaz, 2013). To answer the research questions this study adopted a mixed methods approach.

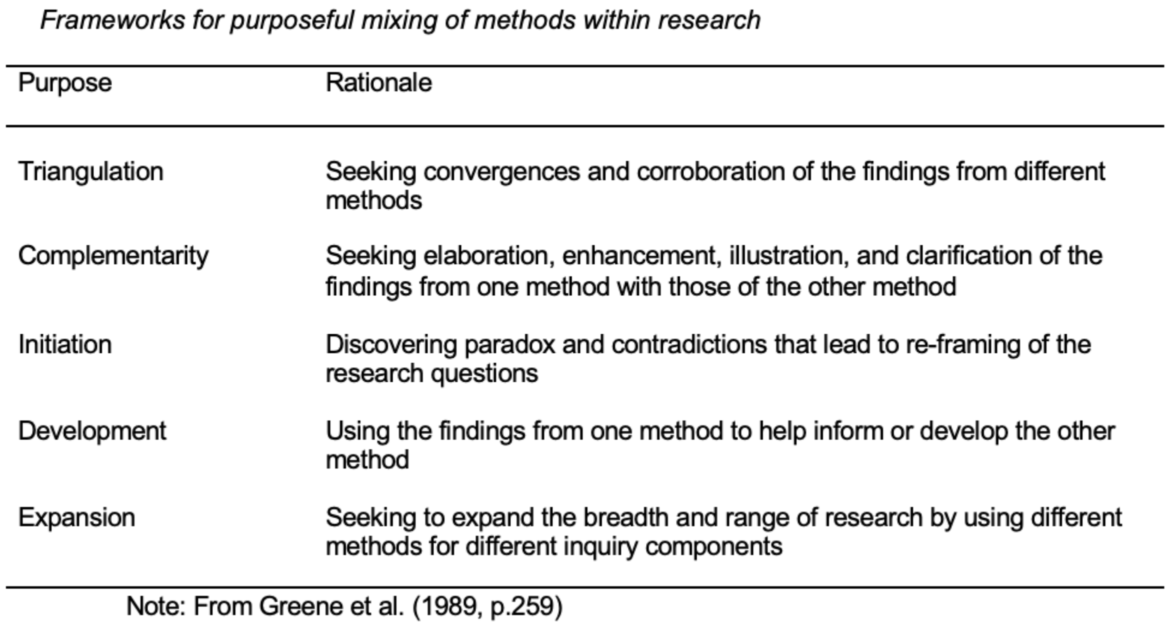
Advocates for mixed methods speak to its ability to capture the complex multi-dimensionality of human life on both micro and macro scales; an undertaking which neither quantitative nor qualitative approaches alone can fully achieve (Mason, 2006). It is through the purposeful integration of both approaches that researchers can capture multiple perspectives and create a more balanced and panoramic view of research (Shorten & Smith, 2017). The rationale for synthesising both types of data being these datatypes are neither incompatible nor mutually exclusive, but within psychological research can work synergistically to enrich theory and practice (Holloway & Wheeler, 2010).

Within mixed methods research, several methodological quandaries need to be addressed, notably the priority weight given to each method of data collection and analysis (Creswell et al., 2003). Appropriate implementation and integration of methods is essential for a defensible and coherent mixed-methods design. Therefore the process of selection should consider the research aims, and the choices made regarding interaction, priority, timing and mixing are thoughtful and deliberate.

According to Caracelli & Greene (1997) mixed methods designs cluster within one of two classifications: component designs and integrated designs. Within component designs the implementation and integration of methods is discrete and remain distinct throughout the inquiry. The combination of differing components occurs at the level of interpretation and conclusion. In contrast, within integrated methods, the combination of methods is at the design level (e.g., data collection or analysis) where methods are mixed in such a way that integrate elements of opposing paradigms giving way to deeper, more insightful understandings of the phenomenon. Greene et al. (1989) provide a framework for which to identify the purposes of combining methods (Table 2.1). Once a framework is established, potential design typologies must be considered, deliberated, and reflected upon prior to exclusion (Table 2.2).

For the present study, the first typology to be excluded was sequential exploratory design, rejected on the grounds of phase prioritising. This approach was not an apt fit as the study sought to first establish the presence or absence of YODR-PTSD and YODR-PTG and to then gain a better understanding YPwD’s lived experiences. An exploratory design would be better suited for future research should one wish to use the study’s data to develop new trauma measures or to aid in the development of a PTG measure which accounts for declining cognition and the other limitations associated with a dementia diagnosis.

Table 2.1

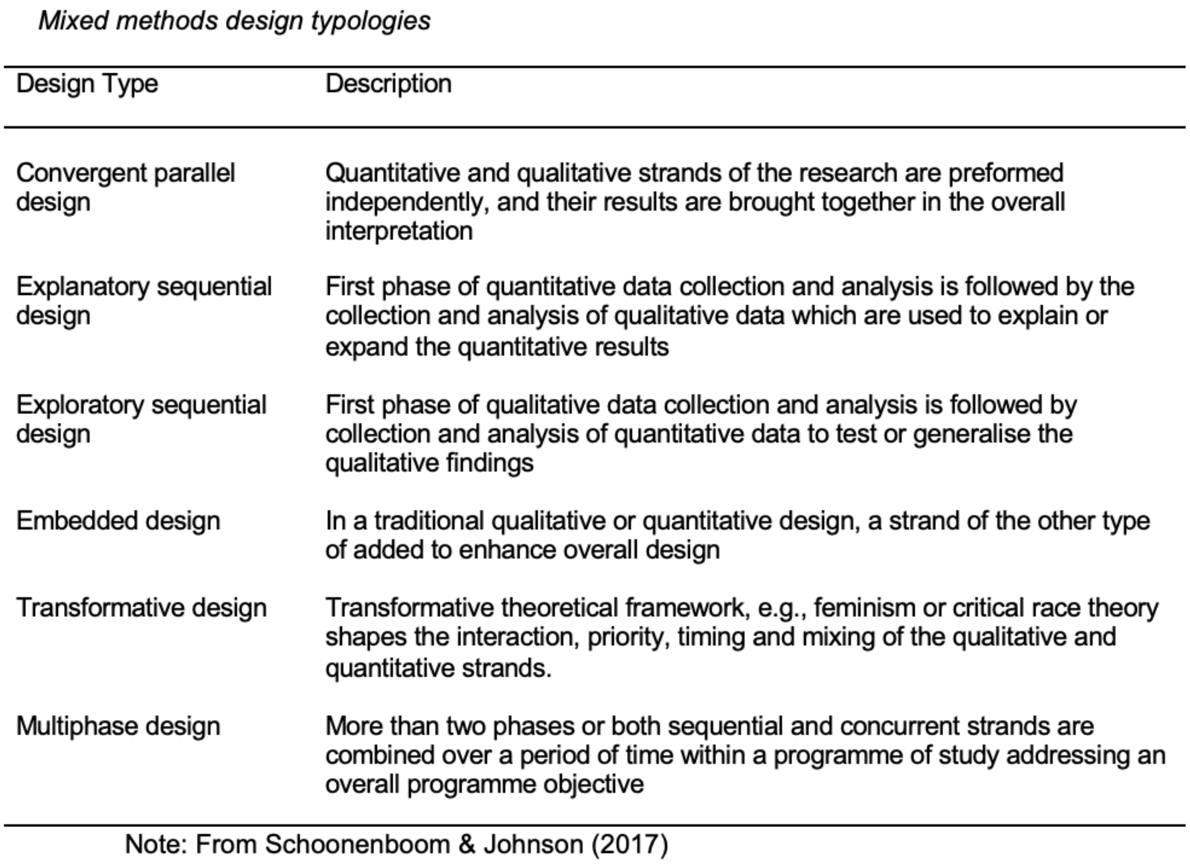


Frameworks for purposeful mixing of methods within research

Purpose	Rationale
Triangulation	Seeking convergences and corroboration of the findings from different methods
Complementarity	Seeking elaboration, enhancement, illustration, and clarification of the findings from one method with those of the other method
Initiation	Discovering paradox and contradictions that lead to re-framing of the research questions
Development	Using the findings from one method to help inform or develop the other method
Expansion	Seeking to expand the breadth and range of research by using different methods for different inquiry components

Note: From Greene et al. (1989, p.259)

Table 2.2.



Mixed methods design typologies

Design Type	Description
Convergent parallel design	Quantitative and qualitative strands of the research are preformed independently, and their results are brought together in the overall interpretation
Explanatory sequential design	First phase of quantitative data collection and analysis is followed by the collection and analysis of qualitative data which are used to explain or expand the quantitative results
Exploratory sequential design	First phase of qualitative data collection and analysis is followed by collection and analysis of quantitative data to test or generalise the qualitative findings
Embedded design	In a traditional qualitative or quantitative design, a strand of the other type of added to enhance overall design
Transformative design	Transformative theoretical framework, e.g., feminism or critical race theory shapes the interaction, priority, timing and mixing of the qualitative and quantitative strands.
Multiphase design	More than two phases or both sequential and concurrent strands are combined over a period of time within a programme of study addressing an overall programme objective

Note: From Schoonenboom & Johnson (2017)

In convergent parallel design, quantitative and qualitative data are simultaneously collected and analysed, bringing together results at the interpretation phase (Creswell & Plano

Clark, 2017). This too was excluded on the rationale that the study wished not to compare two separate strands of data but instead use the results of one to provide a base for further exploration using the other. Embedded design where either a qualitative or quantitative design is carried out using the opposing method as a minor enhancer to the overall design (Creswell & Plano Clark, 2017) was briefly considered. However, this study views both data strands as crucial in answering the research questions, this resulted in exclusion.

After much deliberation and reflection, a sequential explanatory design was determined to be the best fit. Such designs are typically employed in research where the topic of study is novel or understudied (Subedi, 2016); with the careful mixing of the two approaches at specific stages providing a fuller view of the phenomenon that is being studied, laying the ground for future research. As established within chapter one, the available literature detailing the lived experiences of YPwD is sparse at best, and unlike in other life-limiting or life-threatening health conditions, the phenomenon of PTG has never been studied. This approach was felt to be the most suitable choice, as PTG research in the context of other illnesses, predominately adopts quantitative approaches, excluding the participant voice from the overall research narrative (Marzilano et al., 2020; Rzeszutek & Gruszczyńska, 2018). A highly attractive aspect of this approach was the utilisation of qualitative data to provide a more in-depth view and elicit greater information on the complex and nuanced, social and contextual experiences of YODR-PTG (Willig & Rogers, 2008; Rzeszutek & Gruszczyńska, 2018).

Further rationale for opting for a mixed methods explanatory design over a purely quantitative or qualitative approach were two-fold. Firstly, the depth and richness of the research is enhanced by the triangulation of methods and contexts of data collection. Where the strengths of one methodological approach compensates for the weakness of another (Taylor, 2015). Secondly, it provided opportunities to obtain a more complete and comprehensive understanding of the research questions than either approach could do alone; enabling the research to generate new knowledge about an under-researched phenomenon.

2.5 The Mixed Research Design

Literature frequently cites mixed methods approaches to research as problematic in that it is difficult to assign a singular philosophical viewpoint that fits both strands (Doyle et al, 2009). Quantitative research is associated with positivist or realist approaches, meanwhile qualitative research, although often dependent on methodological choices is most frequently relativist at its core (Johnson & Onwuegbuzie, 2004). The likes of Willig and Rogers (2008) suggest that whilst epistemological differences exist between these two positions, external reality exists in versions that are created through inquiry.

Through its pragmatist positioning this research holds a dual critical realist-interpretivist approach which views reality as based on social constructions and beliefs which are context-dependent and require interpretative understanding. The creation of knowledge about YODR-PTG is through social actions, demi-regularities, and the context of living with the condition. The sequential mixed methods design facilitated the gathering of information through questionnaires, establishing the presence of the psychological phenomenon; whilst the use of semi-structured interviews elaborated the lived experiences of such phenomenon. The design promoted the opportunity to attain rich data interpreted through investigation and observation of correlations which gave way to deeper explorations into understanding of inner worlds and uncovering subjective truths (Woolfe et al., 2003). The sequential design reflects the aim of the study, to investigate, interpret and report the lived experience of YODR-PTG.

2.6 Ethical Considerations

This research was conducted abiding by BPS and HCPC codes of ethics and conduct. Participants were given information regarding the research and informed of their rights to withdraw from the study at any point up until the data had been analysed. Participants were required to give informed consent and confidentiality was explained. People with dementia are considered a vulnerable population because their diagnosis can result in compromised capacity and decision-making abilities (Ellajosyula & Hedge, 2016) thus safeguarding their rights was crucial. A major ethical consideration was how best to respect participants' abilities to make decisions and determining their capacity to give consent. Often considered to be a fluid phenomenon, rooted within the current moment, capacity can be very difficult to assess in people with dementia. Adopting a best practice approach to protect the rights of the participants, the study continuously reassessed individual abilities to engage with components of decision-making whilst regularly informing participants of their rights.

Several strategies were employed which facilitated obtaining informed and voluntary consent from participants. These included for each study phase developing a set of specialized information, consent and debrief forms tailored for PwD with input from a Clinical Psychologist, specializing in this field (Phase One Appendix A, Phase Two Appendix B). Following the Alzheimer’s Society (2020) recommendations for dementia friendly documents these forms were concise and avoided the use of jargon and abbreviations. Information was broken into blocks text utilizing a table format to aid in the ease of reading. Sensitive language was used throughout, and all made efforts were made to avoid distressing or upsetting labels.

In Phase One, to ensure continued capacity, each participant completed a midway reassessment which consisted of four questions assessing the fundamentals of capacity as set out by the Mental Capacity Act (2005). If the participant was unsuccessful in this, Phase One was automatically stopped, and the participants were shown a debriefing document which outlining why the survey was terminated (Appendix C).

In Phase Two a ‘preliminary telephone meeting’ with potential participants was conducted to discuss the study and build rapport (Dalby et al., 2011; Dewing, 2002; Hubbard et al., 2003). During this conversation the research aims, participant commitments and confidentiality were reiterated. Current research on gaining informed consent from people with dementia recommends that researchers verbally explain the participant information sheets and consent forms (Cridland et al., 2016). Therefore, prior to the start of the interview, each participant was read the forms out loud using plain language. Verbal summaries were used to maintain momentum and rapport with the participant. Throughout the interviews, both verbal and nonverbal ques were assessed, and verbal ‘check-ins’ were conducted when required.

Under the Data Protection Act (2018) sensitive information such as health, race, ethnic background, and trade union membership requires stronger protection. Data from this study is stored electronically on the password protected, encrypted City University One Drive. Although guidelines state that data should be retained for a minimum of 10 years, it is recommended that students keep their data until after graduation. Data shall therefore be kept on the encrypted platform for one year following the researcher's graduation after which it will be destroyed. Although all efforts were made to address potential ethical concerns, there was always a possibility that unforeseen issues could have arisen. A top priority throughout all stages of the research was to be ethically attuned and to constantly reassess the needs and rights of the participants. Ethical approval to conduct this research was approved by City University Research and Ethics Committee under reference ETH1920-0091 (Appendix D).

Utilising an internet-based questionnaire raised further considerations about how one knows who is completing the questions (Watkins & Gioia, 2015). Although this project was aimed towards people diagnosed with dementia in the UK, under 65 years of age, it could not be guaranteed that the desired sample group will complete it. In attempts to mitigate this, the participation criteria were explained and reiterated within the initial online information and consent forms that participants had to e-sign before starting the survey. Although this does not eliminate the potential for others to partake in the questionnaire, it may help in reducing this from happening.

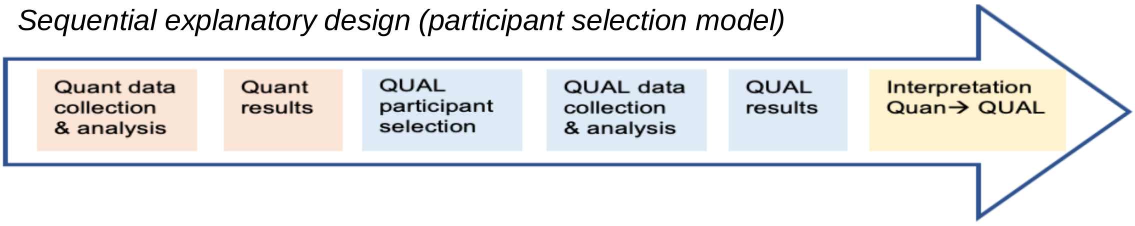
2.7 Quantitative Research Methods

2.7.1 Experimental Design

This study followed the traditional application of a sequential explanatory design which begins with the collection and analysis of quantitative data prior to that of the qualitative. This first phase is closely followed by the second phase consisting of collection and analysis of qualitative data. Within explanatory designs, integration of the quantitative data with that of the qualitative typically takes place at three key points; the present study was no exception. First this occurred at the study design level where the conceptualization of the study began, and the explanatory design was selected. The second point of integration, at the methods level occurred following the collection and analysis of quantitative data. Within the sequential explanatory design, the sequence in which data is analysed means that the researcher does not go into the second phase of the research completely uninformed, as the first phase is used to inform or influence the second. For this research, which adopted a participant selection approach, the quantitative results were used to determine commonality of both YODR-PTSD and YODR-PTG, and to identify appropriate participants to speak more about their experiences of positive growth-related change; thus, providing a richer understanding of the lived experience of YODR-PTG (Creswell & Plano Clark, 2007). The final point of integration occurred at the interpretation and reporting level, where the two datasets were effectively mixed to form the final narrative account, answering the research question (Fetters et al., 2013). The sequence of the participant selection sequential explanatory design (Creswell & Plano Clark, 2007, p. 73) can be seen below in figure 2.1.

Figure 2.1

Sequential explanatory design (participant selection model)



This study uses a semi-dependent interaction indicated by the fact that the two phases are implemented independent of one another, interacting at point of participant selection and again in greater depth at the point of drawing conclusions and evaluating the interpretation (Tashakkori & Teddlie, 2008). The priority phase for this research was the qualitative, however this is not to say that the quantitative phase was not of importance as both elements played important roles within this design.

2.7.2 Normality of Data

An assessment of the normality of data is a necessity for most statistical tests because normal data is an underlying assumption in parametric testing (Mishra et al., 2019). There are two main methods for assessing normality: graphical and numerical. Whilst graphical interpretation has the advantage of allowing good judgment to assess normality in situations when numerical tests might be over or under sensitive, they require a significant experience to avoid incorrect interpretations. For those of novice status, it is best to rely on numerical methods. The two main statistical methods for doing so are the Kolmogorov–Smirnov test and the Shapiro–Wilk test. The latter of which is a more appropriate method for sample sizes of less than 50. Therefore, for this research, with a sample size of 37, the Shapiro–Wilk test was carried out with visual inspections of histograms, QQ plots and boxplots for each of the questionnaires which included the Impact of Events Scale-Revised (IES-R) (N=37), the Posttraumatic Growth Inventory (PTG)I (N=37), the Self-compassion Scale- Short Form (SCS-SF) (N=34) and the Connor Davison Resilience Scale (CD-RISC) (N=34). The histograms and box plots showed that scores were appropriately normally distributed for all data analysed.

2.7.3 Analytic Strategy

Descriptive statistics were used to understand variations in responses to the questionnaires as they succinctly summarise large sets of observations and communicate these in a straightforward way (Bhatti, 2019; Gupta, et al., 2019). Bivariate correlations were used to explore the relationships between the major variables of PTSD, PTG, and secondary measures of self-compassion and resilience. Linear regression was used to explore the predictive nature of the relationships between socio-demographic variables and major variables. This study adopted an opportunistic recruitment style and there was no upper limit to the number of participants needed to complete the questionnaires. 37 participants completed the first half of the questionnaire phase of the study, three participants were unsuccessful in the midway re-assessment of capacity and did not complete the self-compassion and resilience scales. Given the small extent of the missingness for the purposes of analysis missing data was imputated using sample and group mean substitution as recommended by Fox-Wasylyshyn & El-Masri (2005).

2.7.4 Participants and Recruitment

37 participants completed the questionnaires, and this information was entered into the Statistical Package for the Social Sciences (SPSS) statistical analysis. The inclusion criteria for Phase One of the study was as follows: participants needed to be 18years old or over and received their diagnosis of YOD from an NHS memory service greater than six months prior. Internet access was required to complete the questionnaires. Participants were

opportunistically recruited using a recruitment poster (Appendix E). Dementia UK (formally Young Dementia UK) promoted the poster on their social media. Utilising the 'Support across the UK' page on their website, charities, community-based groups and dementia engagement and empowerment project groups across the UK were contacted directly. These organisations also promoted the project via social media. At the end of Phase One, the questionnaire study, the participants were asked to indicate their interest in participating in Phase Two. Brief details of the second study were given and if they wished to be contacted to participate further, they were asked to leave a name and contact details. For the purposes of Phase Two a purposive recruitment sample was used due to the criteria needed to participate.

Ensuring adequate sample size is a crucial part of the mixed methods design as the number of participants will influence different parts of the study as the sample sizes will correspond to the two phases (Watkins & Gioia, 2015). As such, a larger sample group was recruited for Phase One (quantitative) which sought to establish commonality of YODR-PTSD, YODR-PTG and to understand the correlations between these and the secondary measures (SCS-SF and CD-RISC). In the qualitative phase, the sample size was smaller to appropriately answer the research question which sought to gain a better understanding of the ways in which a YPwD may experience PTG.

Watkins and Gioia (2015) suggest that the sample size of various methods need to reflect the questions that it is addressing. According to Bonett and Wright (2000) within a correlational design the minimum sample size to yield sufficient results is N=25, whilst Bujang and Baharum (2016) proposed a minimum of sample size of N=29 to determine a reasonably high correlation between two variables. To determine the appropriate sample size for Phase One, a power analysis calculator was used with the values set as follows: P value <.05. Confidence levels were set to 90%, margin of error at 14%. Presently in the UK there are approximately 1 million people diagnosed with dementia, YOD accounts for approximately 5% of this. It was determined that a sample size of 35 would be sufficient for phase one.

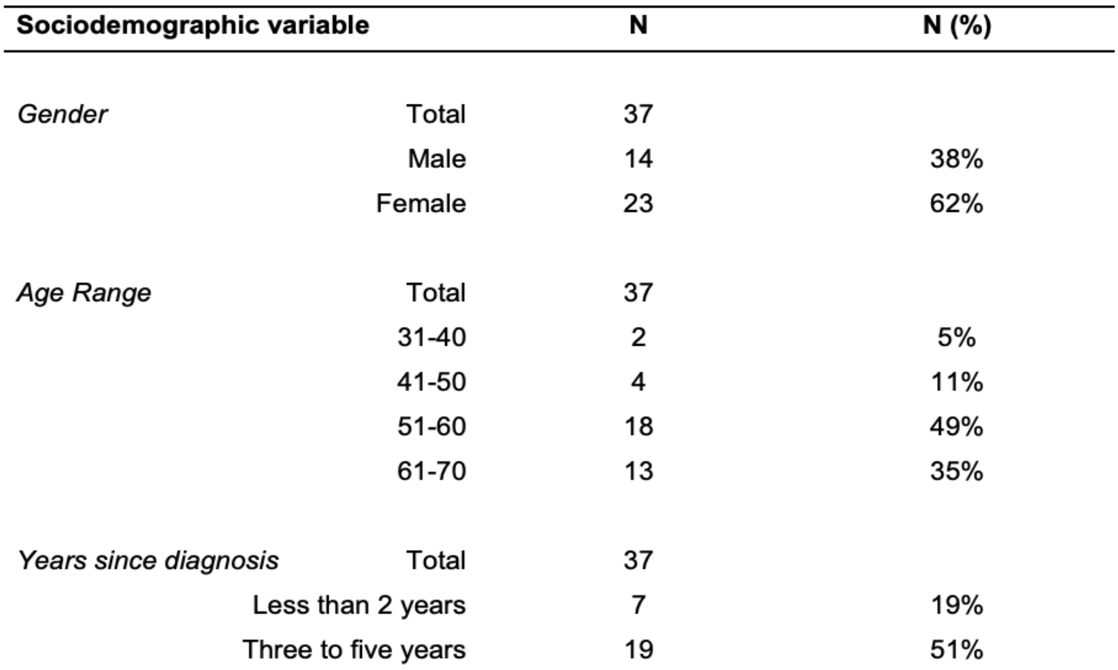
For studies utilising interpretative phenomenological analysis (IPA) researchers will generally seek to generate a purposive, homogeneous sample; ensuring the study holds relevance and personal significance to respondents, allowing the researcher to explore and capture detail on the phenomenon (Noon, 2018). Whilst Smith et al (2009, p. 56) suggested that in IPA research, “there is no right answer to the question of... sample size”, Polkinghorne (1989), advises that researchers should interview between five to 10 participants as this number is ideal to capture the commonality of experiences. Given research constraints (time and expertise) a sample size of five was selected to ensure adequate attention was given to each account.

2.7.5 Demographic Characteristics of Research Participants

Descriptive statistics of the demographics captured by the online questionnaire are displayed in Table 2.3. The table shows the range of participants that completed the online questionnaires. Sociodemographic variables are either categorical or continuous in nature, the response options were numerically coded within SPSS, starting with the number 1 moving upwards until the number of response options was reached. For example, gender coding was as follows: 1=male, 2=female, 3= transgender, 4= other, 5= prefer not to say. In the table below, the options with no responses were excluded.

Table 2.3.

Demographic information for participants from the online questionnaire



Sociodemographic variable		N	N (%)
Gender	Total	37	
	Male	14	38%
	Female	23	62%
Age Range	Total	37	
	31-40	2	5%
	41-50	4	11%
	51-60	18	49%
	61-70	13	35%
Years since diagnosis	Total	37	
	Less than 2 years	7	19%
	Three to five years	19	51%

	Five years or more	11	30%
Marital status	Total	36	
	Married	22	61%
	Cohabitating	2	5%
	Widowed	1	3%
	Divorced or separated	5	14%
	Single	6	17%
Education Level Total		*36*	
	GCSE/ O Levels	7	19%
	A Levels	7	19%
	Bachelor's degree	7	19%
	Master's Degree	5	15%
	Doctorate / PhD	2	6%
	Not completed Secondary education	8	22%
Ethnicity	Total	36	
	White	32	89%
	Mixed race	3	8%
	Any other ethnic background	1	3%
Religious background Total		36	
	No religion	16	44%
	Christian	17	47%
	Any other religion	2	6%
	Prefer not to say	1	3%

2.7.6 Quantitative Materials

Both validity and reliability are essential requirements for research. Within quantitative research, validity includes a demonstration that the measures are avoidant of bias and measure what they were designed to. Reliability refers to principles of stability, equivalence, and internal consistency (Cohen et al., 2018). A reliability analysis was carried out on all four study measures using Cronbach's alpha (α), a test used to assess the reliability of a set of scale or test items (Tavakol & Dennick, 2011). This is calculated through correlating the score for each scale item with the total score for each response and then comparing that to the variance for all individual item scores. it is expressed as a number between 0 and 1, where a measure with a score of greater than 0.7 is considered to have acceptable reliability. Cronbach's alpha can also be used to test the internal consistency of a measure and therefore can determine the validity of a measure. This is done by calculating reliability estimates which are used to show the amount of measurement error in a test. If the items in a test are correlated to each other, the value of alpha is increased.

It is important to note that a high coefficient alpha does not always reflect high degrees of internal consistency (Tavakol & Dennick, 2011). In some cases, it is acceptable to have scores that show unreliability due to the diversity of what some items are measuring (Kline, 1999) because the Cronbach's alpha score is calculated partly by the number of items of the scale squared. Meaning the more items on a scale can lead to a higher α score. Therefore, a high α score cannot always be attributed to meaning it is reliable. Phrasing of items can also affect α, for example if scores are reversed.

Demographics Questionnaire.

This consisted of specific socio-demographic variables which were hypothesized to influence PTSD and PTG and included: gender, marital status, years diagnosed, education level and faith.

Impact of Event Scale Revised (IES-R).

The impact of even scale (IES) is a commonly used self-report measure of subjective distress in response to a traumatic event. Originally consisting of two subscales of intrusion and avoidance (Horowitz et al, 1979) the measure was revised in 1997 to include a third major symptom cluster; persistent hyperarousal (Weiss & Marmar 1997). Maintaining comparability to the original, the authors made minimal changes to IES intrusion and avoidance items; there was an additional question added to the intrusions scale to address flashbacks and the original sleep item was split into two questions. The scale now consists of 22-items, both the avoidance and intrusion subscales contain eight-items. Six new hyperarousal items were developed targeting sleep, irritability, concentration, hypervigilance, startle response, and physiological arousal (Creamer et al., 2003; Weiss & Marmar 1997). Items are measured on a five-point Likert scale from 0 (not at all) to four (extremely). The instructions were modified, and participants are now asked about the subjective distress caused by the symptoms versus their frequency (Appendix F).

Cronbach's alpha for the IES-R showed that the questionnaire had an excellent internal consistency α = 0.96 and all items considered to be worthy of retention. This is consistent with Creamer et al's (2003) study investigating the psychometric properties of the IES-R in two samples of male Vietnam veterans where Cronbach's alpha was also α = 0.96. Subscales of the IES-R measuring the symptom clusters of intrusions, avoidance and hyperarousal had good internal consistency with alphas of 0.92, 0.89 and 0.89 respectively. This is slightly higher than Sveen et al's (2010) study assessing the psychometric properties of the scale in burn patients where Cronbach's alphas were 0.88 (intrusion), 0.90 (avoidance), 0.85 (hyperarousal), and 0.95 (total).

Posttraumatic Growth Inventory (PTGI).

The PTGI is the most used instrument for assessing positive outcomes following traumatic events (Steffens & Andrykowski, 2015). Developed by Tedeschi and Calhoun (1996) it consists of a 21-item scale. Each item corresponds to one of the five domains. Respondents are asked to rate their perceived level of change on a six-point Likert scale where a score of 0 implies no change through to five which implies a very great degree of change. Summative scores are used to determine overall growth with higher scores implying grater positive change. An advantage of this scale is the categorization of scores according to the five domains which are reflective of the areas where growth is prominent (Lepore & Revenson, 2006), allowing for the researcher to gain insight into what has specifically changed.

As the domains consist of differing numbers of items, in more recent years researchers (Kleim & Elhers, 2009; Murphy et al., 2016) have suggested scoring the individual domains by taking the mean score, which results in a standardised score ranging from zero to five, providing a more accurate reflection of the degree and depth of transformation (Appendix F). The Cronbach alpha for the PTGI was good with α = 0.83. This is lower than a study recently conducted with Turkish cancer patients by Aydin & Kabukcuoglu (2020) where the Cronbach alpha was found to be 0.93. Variations such as this are to be expected given the alpha rises and falls with the intercorrelations between the scale items. Depending on factors such as the study population and the phenomenon being measured items may mean different things to different people, resulting in these natural variations.

The Self-Compassion Scale Short-Form (SCS-SF).

The SCS-SF examines the relationship of self-compassion to positive psychological health and the five-factor model of personality. It was developed as an economical alternative for the widely used self-compassion scale (SCS). It consists of 12-items assessing six subscales of self-compassion: self-kindness, self-judgement, common humanity, isolation, mindfulness, and over-identification. Respondents rate how they typically respond to themselves during times of hardship on a five-point Likert scale ranging from 1 ('almost never') to five ('almost always') (Appendix F). For this study, the brevity of this measure was a considerable advantage given factors such as decreased attention span and fluctuating capacity in PwD (Kotera & Sheffield, 2020; Raes, et al., 2010). It was viewed to have adequate internal consistency $\alpha = 0.72$. This is consistent with studies such as Bratt and Fagerstrom (2019) which tested the psychometric properties of the SCS-SF in older adults ranging in age from 66 to 102. In the younger study participants, whose ages were not far from those of the present study, the scores of internal consistencies ranged from 0.68 and rising to 0.76. It was found that deleting items would decrease the internal consistency versus improving it.

The Connor Davidson Resilience Scale (CD-RISC).

The CD-RISC, developed by Connor & Davidson (2003) was created to improve on existing measures of resilience in relation to PTSD which to that point had largely failed to extend to the world of clinical practice and patient-based research. The CD-RISC is comprised of 25 items each rated on a 5-point scale (0-4). Possible scores range from 0-100, with higher scores reflecting greater resilience. It measures several components of resilience including the abilities to adapt to change, deal with uncertainty, cope with stress, to not become discouraged in the face of failure and the ability to handle unpleasant feelings. The measure is universally used; it has been translated into different languages and used to study a variety of populations, including trauma survivors, Alzheimer's caregivers, and patients in treatment for PTSD (Singh & Yu, 2010; Windle, Bennett & Noyes, 2011).

The scale has been adapted into shorter versions consisting of two and ten items. Both the 25 and ten item measures would have been suitable for this study. The original 25 item scale was selected as it had been suggested by Stoner et al. (2015) as having a strong translatability potential to people with dementia (Appendix F). Similarly, to the IES-R, the measure was found to have excellent internal consistency with an alpha of 0.94. From the 25 items on the scale exclusion of any would not increase the Cronbach's alpha.

2.7.7 Quantitative Procedure

The recruitment poster included a brief description of the study, the name and email of the researcher as well as the link to the Phase One questionnaire study, hosted on the online Qualtrics platform. The participants were required to read an information sheet outlining the research which reiterated the study requirements stated in section 2.7.4. The process of taking part was explained along with what would be required of the participants and how long that might take. The nature and importance of confidentiality was outlined along with anonymity and their ability to withdraw. The title of the study and who they could contact for further information was provided. Participants were required to select a consent option (yes or no). If no was selected the participants were redirected to a thank you statement. If yes was selected, they were directed to the questionnaires.

Participants were first asked to share socio-demographics following which they were presented with the four measures and reassessment of capacity assessment in the following order: IES-R, PTGI, capacity assessment, SCS-SF, CD-RISC. After the last measure, participants were asked if they would be interested in participating in a follow up interview. For those who selected no, they were directed to the debrief statement that provided information about the purpose of the study and the contact details for further support if it was required. For those who responded yes, they asked to provide their name and contact details. Following which they were directed to the debrief statement. The data was exported from Qualtrics to both SPSS and Excel. A combination of descriptive statistics, correlations and linear regressions were used to analyse the data. This was to establish the commonality of both YODR-PTSD, YODR-PTG and to enable observations of any correlations between the major variables and secondary variables and between the socio-demographic variables and the major variables.

2.7.8 Quantitative Data Analysis

All data was analysed using SPSS statistics version 25 for Apple. Alpha levels were set to $p<0.05$. Scores for the questionnaires were calculated according to the description given for each, ensuring that reverse coding was created for those that required it. All data entered was screened prior to the analysis to check for errors in the entry, this was done by observing the range of scores. The full set of data that was completed to debrief stage was analysed. Of the 37 participants, 34 completed the questionnaire in its entirety. Three participants completed the questionnaire to the reassessment of capacity stage. To ensure no missing data would be reported when analysing the data, the average was taken from both the SCS-SF (M=3.08) and CS-RISC (M=74) measures and inputted into the three missing data scores. To identify outliers, box plots for each variable were examined which indicated that there were no extreme outliers to remove.

2.8 Qualitative Research Methods

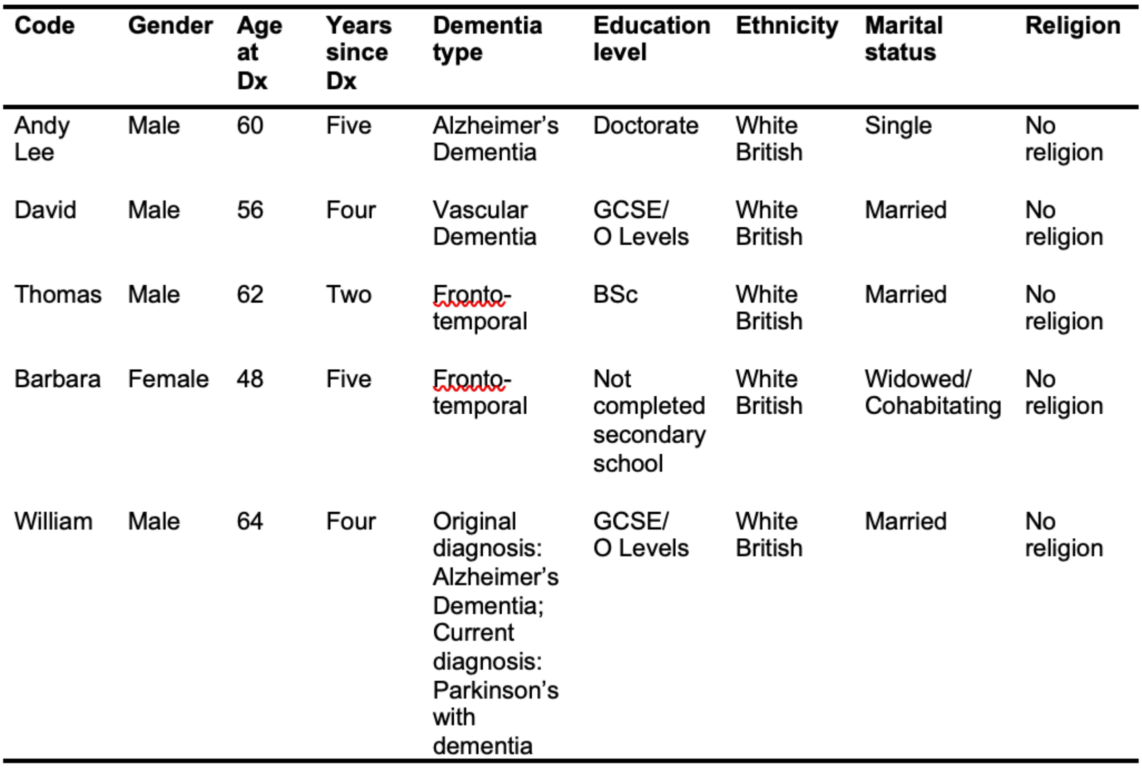
Phase Two of the research consisted of a series of one-to-one semi-structured interviews. The interviews were a space where participants were asked to explore their views and experiences of being diagnosed and living with YOD. The aim was to elaborate on the Phase One results and to gain an in-depth understanding of the ways in which the participants experienced PTG, and the factors which may have influenced their individual experiences. Six open questions were asked, with prompting questions prepared to elicit further reflection and information. Data collection was audiotaped following consent and transcribed verbatim.

2.8.1 Participants and Recruitment

Participants for Phase Two of the study had consented to be contacted during Phase One which involved the same inclusion criteria as seen in section 2.7.4. If consenting, participants were contacted via email and initial follow-up telephone call. This phase utilised purposive sampling and the participants were selected based on their IES-R and PTGI questionnaire results. A total of five participants took part in the interviews (N=5) (Table 2.4).

Table 2.4

Codes used for interview participants: gender, age at diagnosis (Dx), type dementia, years since diagnosis (Dx), education level, ethnicity, marital status, religion



Code	Gender	Age at Dx	Years since Dx	Dementia type	Education level	Ethnicity	Marital status	Religion
Andy Lee	Male	60	Five	Alzheimer's Dementia	Doctorate	White British	Single	No religion
David	Male	56	Four	Vascular Dementia	GCSE/ O Levels	White British	Married	No religion
Thomas	Male	62	Two	Fronto-temporal	BSc	White British	Married	No religion
Barbara	Female	48	Five	Fronto-temporal	Not completed secondary school	White British	Widowed/ Cohabitating	No religion
William	Male	64	Four	Original diagnosis: Alzheimer's Dementia; Current diagnosis: Parkinson's with dementia	GCSE/ O Levels	White British	Married	No religion

2.8.2 Qualitative Materials

Interviews are one of the most common forms of qualitative research due to compatibilities with a multitude of data analyses (Willig, 2008). The schedule of semi-structured interview questions (Appendix G) was created in a way that allowed the participants to speak openly about their experiences of YODR-PTG. According to Giorgi (2009), the key principle of a phenomenological interview is to aim to collect a fully comprehensive description of the of the experience that a participant has lived through. The interview protocol for the present study was therefore designed to be flexible to enable this and by doing so bring forth a "conversation with a purpose" (Smith et al., 2009, p. 57).

Mirroring the sequential explanatory design of the study, questions started off broadly. The participants were first asked to share with the story of their diagnosis to give insights into the nature of their diagnostic trauma, for which without this, the experiences of PTG cannot occur. Questions then became more specific to experiences of personal change and growth as the connection and rapport with the participants grew (Willig, 2008). The questions sought to be open, and curious to create meaningful and reflective conversations with the participants. The focus on both the past and present lived experiences of loss, change, growth and hope was a unique aspect of the schedule as the integration of the pre and post diagnosis phases were necessary to collect as complete a description as possible of the lived experiences of the participants.

2.8.3 Qualitative Procedures

The names, email addresses and telephone numbers of the participants interested in participating in the one-to-one interviews were collated into a spreadsheet kept on the City, University of London One Drive. A numerical ranking of the participants based on their IES-R and PTGI scores was created. Those who scored highly on both the IES-R (score $\geq$ 33 indicative of probably diagnosis PTSD) and PTGI (scoring $\geq$3, indicative of moderate PTG across minimum of four domains) were contacted first. Next participants with ‘clinically concerning range’ IES-R scores (score between 24 to 32) and PTGI scores greater or equal to three across three domains were contacted. A third wave of contact was determined (IES-R scores between 24 to 32 and PTGI scoring $\geq$3, across two domains) but not required.

The potential participants were first contacted via email to ascertain if they were still interested in participating in the interview. Those who indicated interest then had a ‘preliminary telephone meeting’ specifically to discuss the study aims, build rapport, and assess for capacity. The participants were asked again if they were willing to consent to participate in the interviews. Once confirmed a mutually suitable date/time within one week of the telephone call to conduct the interview was agreed and confirmation was sent via email to the participant, this included the participant information sheet and consent form as attachments. The consent form was signed and returned prior to the interview.

Due to the Covid-19 pandemic, face-to-face meetings were not possible. All interviews took place via Zoom, an online video chat platform provided to all City, University of London students. Although face-to-face interviews would have been preferable, current research suggests that in-person study interviews are only marginally superior to videocalls in that interviewees may feel the need to say more (Krouwel, Jolly and Greenfield, 2019). To access the videocall, the participants entered a unique password which had been emailed to them prior to the interview. Once both parties were in the videocall, reintroductions were made and the aims of the study were reiterated by reading out loud the participant information sheet which also served to remind participants of the purpose of the study and that the interview would be recorded (Phillipson et al., 2015). Verbal consent was gained from the participants to continue in the interview.

The approved interview protocol was followed, and the participants had additional time to process, reflect and respond the questions. Prompting questions were used to further elicit response or to clarify. The interviews lasted between 40 to 65-minutes. Conscious of the potential for participants to become fatigued, the interviews followed their lead regarding pacing. At the end of the interviews the participants were informed when the recording had ended. They were asked if they had any further questions about the research, and if they would like to receive an executive summary of the research once completed. Participants were emailed a participant debrief sheet that included a summary of the study, who to contact if there were any questions and signposting for participants if they experienced any distress.

2.8.4 Qualitative Data Analysis

Phase Two of the overall study sought to understand how the participants had experienced and made sense of positive psychological growth within their lived context whilst simultaneously experiencing loss and decline. This phase of the study required careful consideration as to what would be the most appropriate qualitative approach to meet the research aims.

A grounded theory (GT) approach was first considered as it is a popular approach for examining and explaining action and interaction (Frost et al, 2010). It is particularly suitable for areas of inquiry where when little is known about a phenomenon; with the aim being to produce or construct an explanatory theory (Tie et al, 2019). The adaptability of GT enables it to bridge paradigms across post-positivism, interpretivism and constructionism, thus making it a highly suitable candidate for mixed methods research (Avenier & Thomas, 2015; Bhatti, 2019). Through a process of identification and making links to explain an action the researcher is tasked with identifying repeating themes within the data. This labour-intensive process involves careful coding the emergent themes with keywords and phrases; grouping the codes into conceptual hierarchies; and then categorizing the concepts through relationship identification (Padgett, 2016). GT seeks to achieve saturation and draws heavily on the conceptual skills of the researcher who is required to check, refine, and develop their ideas and intuitions about the findings as the data is collected. Despite its suitability on paper, GT was discounted; it did not align strongly with aims of the project which were to understand the lived experiences of PTG in YPwD versus creating a theory about them (Willig, 2014).

Narrative approaches which seek to understand how research participants construct story and narrative from their own personal experience (Wang & Geale, 2015) were briefly considered. The subjectivity of narratives which offer an open window into personal experience of daily life, was viewed to complement many aims of the study. However, the novelty of the present study acted as grounds to ultimately reject this approach. It was felt that there was a need to first explore and establish whether such an approach would be feasible given attentional and cognitive limitations of the participants; which could potentially impact their abilities to engage in deep, meaningful conversation around their experiences. Drawing on the experiences of the present study, future research should consider adopting narrative approaches as this analytic strategy is particularly useful for uncovering the underlying ideologies and revealing the social world in ways that lead individuals to see human happenings in fresh, never noticed before ways (Bruner, 1991; Wong & Breheny, 2018)

Thematic analysis (TA) is another approach that could have been considered as a viable contender. Braun and Clarke (2006) argue that thematic analysis is an accessible means to analysing qualitative data, and not one that should be dismissed quickly. TA is typically employed when researchers wish to report patterns within a large data set it enables the researchers to be able to describe large amounts of data in rich detail (Braun & Clarke, 2006). Its flexible approach to doing so with ease sets it apart from other methods of qualitative analysis (Terry et al., 2017). As it does not require detailed technical knowledge, TA is considered be an inclusive and welcoming approach (Braun & Clarke, 2006) and unlike IPA or GT, TA is not constrained or theoretically bound, and it provides the researcher with the freedom to select the theoretical framework which matches what the research is trying to know and achieve (Braun & Clarke, 2006).

However, to effectively carry out a research project utilising TA, there are several decisions that must first be made, including what counts as a pattern or theme, how rich of a description of the data set one wants to achieve and will it adopt an inductive, deductive or hybrid approach to identifying the themes. Several factors made this approach a highly attractive option for the current research notably, the inclination to encourage the autonomy of the researcher through its openness to a variety of orientations ranging from realism to existentialism to constructionism to contextualism (Willig, 1999). Within the study's pragmatist positioning, critical realist ontology and contextualist epistemology a hybrid TA approach could have been an apt fit. However, it was rejected as it also fails to align fully with the aims of the study to explore in great depth the encompassed experience of YODR-PTG

Phenomenology, specifically IPA, as a method of qualitative study concentrates on human perception, emphasizing personal experiences as they happen, seeking out meaning found within the context of progressive interpersonal relationships and creating rich, deep descriptions of human experiences (Smith, 1996; Smith & Osborn, 2014; Fallah et al., 2012). As clinicians and researchers move away from the biomedical model of disease and illness towards the biopsychosocial model, IPA has become of particular relevance for health and counselling psychology research (Brocki & Wearden, 2006). Alongside an increasing recognition of the social construction of illness, most Psychologists have realised the importance of understanding their clients' experiences, perceptions of their experiences and the meanings which they assign to them (e.g., Leventhal, 1984). IPA allows for the exploration of these subjective experiences and helps researchers to describe and understand the respondents' accounts of the processes by which they make sense of these experiences. IPA is an apt fit for this research, as Phase Two is concerned about the subjective experiences of positive personal growth following a diagnosis of YOD.

The aim of IPA is to explore in detail the ways in which participants make sense of their own experiences. This is achieved by looking at the respondents' accounts of the processes they have been through and seeking to utilise an assumed existing universal inclination towards self-reflection (Chapman & Smith, 2002; Smith et al., 2009). Thus, IPA research tends to focus on the exploration of experiences, understandings, perceptions, and views (Reid, et al., 2005). The 'processes' including all aspects of self-reflection, refer to the way in which IPA assumes that participants seek to interpret their experiences into some form that is understandable to them (Reid et al., 2005). Given its focus on individuals' subjective reports rather than the formulation of objective accounts (Flowers et al.,1999), it recognizes that research is a dynamic process (Smith, 1996), and draws upon the fundamental principles of phenomenology, hermeneutics, and idiography.

Phenomenology, an eidetic method, originally developed by Husserl (Smith & Osborn, 2014) is concerned with attending to the ways in which things appear to individuals, identifying the core components of a phenomena or experience which makes them unique. Phenomenologists try to recognise which components make the phenomenon special to that person through focussing on how the individual perceives and talks about the object or event. (Pietkiewicz & Smith 2014). To do so, the researcher is required to engage in a process known as 'bracketing' wherein any preconceptions are placed to one side, within 'brackets', allowing for the phenomena to speak for itself without interruption (Tuffour, 2017). Critics of phenomenology claim that it is too philosophical of an approach, and that to attain the ultimate human experience is impossible because 'pure experience' is elusive and inaccessible because the experience is almost always witnessed after the event (Smith et al, 2009).

Modern IPA has emerged as identifying more strongly with the hermeneutic traditions (Tuffour, 2017). Developed by Heidegger (1962), hermeneutics focuses on the ontological questions of existence itself (Pietkiewicz & Smith 2014). By metaphorically standing in the shoes of the individual the researcher attempts to understand their mindset and the language used to reflect upon these experiences; and by doing so translate underlying messages and experiences (Smith et al, 2009). Within hermeneutics, meaning is fluid and something that can be continually revised, interpreted and reinterpreted (Tuffour, 2017). As such the researcher is an active participant who influences the extent of access to the participant's experiences and how they make sense of the individual's personal world (Pietkiewicz & Smith 2014). The double hermeneutic, is a phrase that is frequently discussed within IPA research, as it refers to the dual interpretation processes whereby the researcher makes sense of the participant's sense-making through assuming a central role in the analysis (Smith et al., 2009). This is achieved through the practice of description and interpretation, with the focus continually shifting between the participant's essential perspectives and the researcher's interpretation of those perspectives. Through this iterative process, specific themes related to the participant experiences are illuminated.

Idiography, in its simplest terms refers to the in-depth analysis of a single case at a time, through which the researcher fully examines and reflects upon the individual perspectives of the study participants within their unique contexts before moving on to the next participant (Pietkiewicz & Smith, 2014). This approach ensures that each case is prized and undergoes a nuanced analysis. Only after each case has undergone this process can the researcher make specific statements about the phenomenon, identifying similarities and differences amongst the participants.

Given the above, IPA, when used as part of a mixed methods explanatory design, is particularly useful in exploring topics which are complex or where an issue is personal. Unlike TA where a generalized, systematic coding processes is followed (Langridge, 2007), IPA contributes to the understanding of the area of interest through a deeper, individualised analysis (Kay and Kingston, 2002). It allows researchers to take advantage of its flexibility and potential for creativity when exploring individual perceptions of experiences and encourages reflection within both the participants and researcher (Taylor, 2014).

Ultimately, IPA was selected over other qualitative approaches (e.g., narrative analysis, TA or GT) on the basis of its focus on participants' subjective experiences of the world, which assumes that people can 'experience' the same objective experience in radically different ways (Wilson et al., 2018). IPA is concerned with the development of deeper, intimate knowledge about a phenomenon. This approach aligns best with the aim of this research, which is to better understand whether people diagnosed with YOD interpreted their diagnosis, and how they experience similarities and individual differences in any subsequent positive psychological growth from this.

2.8.5 The Qualitative Procedure

The study followed the six-step approach to IPA analysis as recommended by Pietkiewicz & Smith (2012). To begin, I transcribed the interviews verbatim, listening and re-listening to the audio recordings throughout to ensure accuracy, whilst noting initial feelings or emotions that emerged within the research journal. This was followed by the reading and re-reading of the individual transcripts. To ensure immersion the audiotapes were listened to simultaneously with the written transcripts. This placed the participant within the focus of the analysis, allowing for bracketing. During the initial coding process, exploratory comments were used versus detailed notes and interpretations. Given its interpretative nature, and ability to extend to differing levels (Smith, 2004), the commentary was coded into three categories and colour-coded for ease of reference. Emotive words were highlighted throughout the transcripts and conceptual coding explored the underlying meanings behind the participant's accounts of their experiences. During this process the conceptual commentary became more abstract, adopting a curious and open stance.

The transcripts were re-read with commentary and the developing themes were noted on a separate sheet of flipchart paper titled with the participant's pseudonym. These consisted of statements and phrases which were felt to capture the spirit of the participant's experiences, reflecting the synergy found within the iterative process of description and interpretation (Smith et al., 2009). Once emergent themes developed, I sought to connect the themes by revisiting the emergent themes, re-listing them on a separate piece of paper along with any supporting quotes. Clusters were formed and given tentative theme labels to summarise their essence (Willig 2008).

I repeated this process in its entirety for each transcript being mindful to treat each case as a separate, unique entity, to ensure consistency and integrity. Although bracketing was utilised, inevitably, subsequent cases were influenced by previous findings. Following the preliminary analysis, a review of the super and subordinate themes was performed. Drawing on Smith et al. (2009) suggestions the transcripts were revisited to ensure quotes proved an accurate representation of the participants. The individual pieces of paper for each participant were lined up next to one another and a further piece of paper was used to document connections, reconfigurations, or relabelling (Appendix H). Here the analysis transformed itself, moving towards the theoretical and the recognition of higher order concepts. This process required re-organisation and re-naming to acknowledge the convergences and divergences within the narratives. This specific approach allowed for me to retain the authentic voice of the participants, whilst integrating my own interpretative commentary (Pietkiewicz & Smith, 2012), the outcome of which was three superordinate themes and nine subordinate themes.

2.9 Validity and Reliability

In qualitative research, validity and reliability are more difficult to assess due to the subjective, interpretative nature of the data itself. Validity is often assessed using terms such as honesty, depth, richness, scope of data, and researcher objectivity (Cohen et al., 2018), whilst reliability is often used interchangeably with terms such as consistency, trustworthiness, transferability and dependability (Lincoln & Guba, 1985).

For qualitative researchers ensuring the consistency of data is achieved through careful and honest examination of items such as raw data, data reduction products and process notes (Golafshani, 2015). Several steps were taken to ensure external and internal validity, reliability and objectivity within the qualitative phase of the study. This started with the development of a semi-structured interview protocol which was used to provide a level of standardisation across interviews (Silverman, 2014). Lincoln and Guba (1985) suggest confirming rigor of a naturalistic inquiry such as phenomenology, is best operationalized using the criteria of credibility, transferability, dependability, and confirmability. Credibility, being the accurate and truthful depiction of a participant's lived experience (Murphy et al., 1998) was achieved through triangulation where prolonged engagement through pre-interview contact and longer interviews were used to build trust and deepen contextual understanding.

Transferability was enhanced through purposive sampling (Palinkas et al., 2015) and intentional design of the interview protocol to elicit deep description and robust data. A wide range of information was gained through the detailed and accurate descriptions of the participants' lived experiences of dementia. This was maintained by immersion with the phenomenon through continuously returning to the texts throughout the analysis.

Lincoln and Guba (1985) refer to the notion of ‘‘dependability’’ within qualitative research, a concept which corresponds to the notion of ‘‘reliability’’ in quantitative research. Dependability was achieved by including the research supervisor, a Clinical Psychologist with experience working within dementia care throughout the analytical processes.

2.10 The Reflexive Researcher

As a Counselling Psychology trainee and doctoral researcher, I am interested in the intersection between illness and age, and I was excited to explore this specific focus within this clinical population. At the time of selecting and creating the questionnaire I had reservations about how impersonal the process felt, for example, being unable to tailor the questions I feared that potential participants could take offense to simplistic lay language used and believe that I was trying to undermine or infantilize them on account of their dementia diagnosis. I was mindful of this concern and throughout all stages of this research tried my upmost to ensure that all participants felt respected, and I aimed to convey that their opinions and experiences were appreciated. As my concerns passed with each survey completed, I was then faced with my next challenge of addressing the data in front of me.

To start, I found myself overwhelmed and my confidence and motivation to approach the quantitative analysis with vigour temporarily evaded me. I had to push myself to face the intimidating numerical data and over time, I did eventually enjoy the procedural aspects of the analysis. However, I could not help but look forward to conducting interviews and analysing the qualitative data. I truly enjoyed making personal connections with participants and immersing myself within their lived experiences. In many ways I felt like an eager child awaiting story time. As I read and re-read the transcripts I uncovered new bits of the tale that I had initially missed. I found myself developing a fondness for my participants. In many ways these five individuals were my main motivation for completing this research to the highest possible standard. They were brave enough to come forward and to share with me a deeply personal, and at times painful experience. I felt as though I was their mouthpiece, and it was my duty to ensure that their stories and experiences were heard.

As the themes began to emerge from the data it seemed as though the story materialising from the analysis was something out of a film. I felt as though I was witnessing the most compelling fall to rise character arcs. The analysis of this research was illuminating, inspiring, and so enjoyable. There is a significant lack of research detailing the lived experiences of younger people with dementia, and I am filled with pride to be contributing to this area. Through this piece of work, I hope to carve out a place within the ‘research world’ for not only YPwD, but myself as potential expert within the field.

Chapter 3 Results

This chapter describes the results and findings of this sequential mixed methods research study. The phases of the study will be presented to represent and understand the sequential format of analysis. This chapter will first present the analyses to test the hypotheses of the quantitative strand, this will be followed by the presentation of the themes of the analysis of the qualitative strand of the study.

3.1 Analysis for Quantitative Strand

The following section describes the results of the analysis to test the hypotheses and examine the research questions in Phase One of the study. It is divided into the following parts (1) the descriptive data for the major variables of interest, (2) correlations between major variables and secondary measures, (3) regressions between major variables and socio-demographic variables and (4) results from the analysis to test hypotheses one, two, three and four.

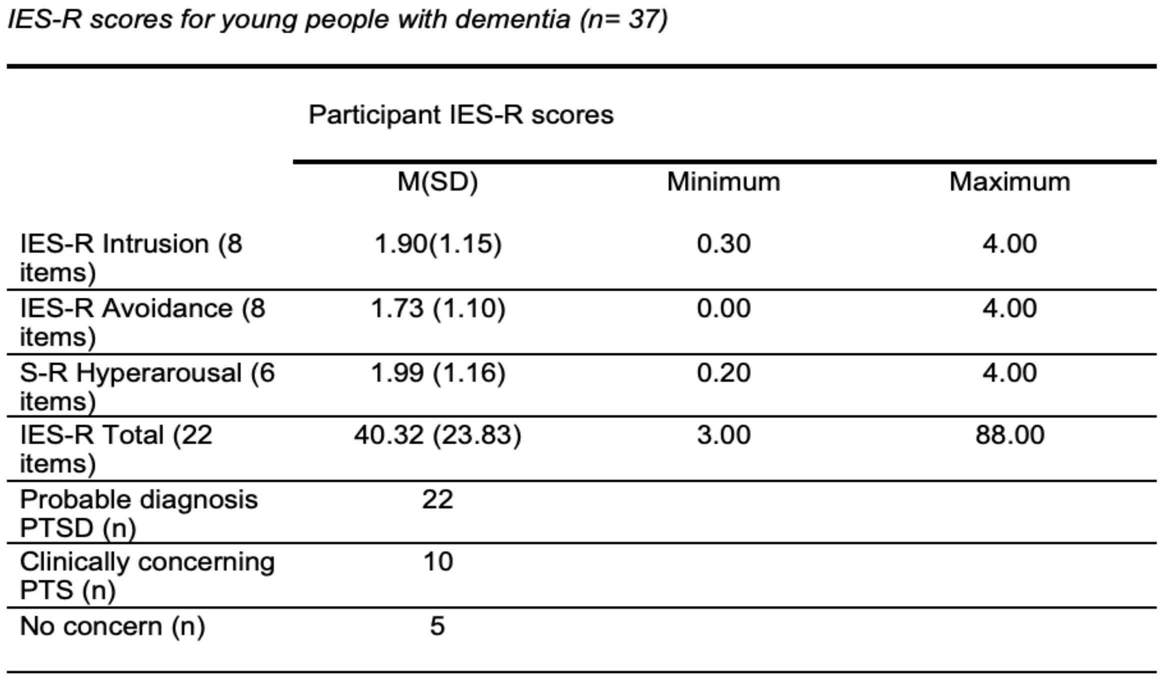
3.1.2 Descriptive Data for the Major Variables

PTSD that results from a medical diagnosis can be challenging to isolate to a specific antecedent. Pre-existing mental health conditions, and past traumas can confound results, increasing the difficulty to isolate the medical trauma as the source of the reaction (Hall & Hall, 2013). For the study to assess the presence of the major variable of PTSD, participants were asked to respond solely with the YOD diagnosis in mind. The PTSD variable, measured by the IES-R, captures three subscales: avoidance, intrusions and hyperarousal. The second major variable, PTG, was measured by the PGTI, five domains: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. The mean scores and standard deviations for both major variables are provided below.

The mean IES-R score within this demographic was M=40.32, with one participant scoring a maximum score of 88, indicating a level of PTSD that is high enough to supress immune functioning (Kawamura et al., 2001). To contextualise these findings a previous study by Mehner and Koch (2007) used the IES-R to assess PTSD in breast cancer patients and found mean scores of M=42.9, whilst Sullivan et al (2009) used to the IES-R as a measure for

PTSD in whiplash victims and found the mean score to be M=32.05. These scores highlight that PTSD is a highly personal experience and is expressed differentially based on subjective experiences of threat, influenced by factors such as personality, type of trauma and proximity to the trauma event (Weinberg & Gil, 2015; Boals, 2018). Therefore it is therefore not unusual within trauma studies to observe a large range in the distribution of values on measures. This trend has been seen in studies by Nishi et al. (2010) and Tiemensma et al (2018) where ranges of 53 and 72 were observed respectively. The present study is consistent with this and presents a range of 85, indicating a vast difference between the lowest IES-R score (3) and the highest (88) reflecting individual differences in the perception of a YOD diagnosis as a traumatic event. The scores on the IES-R (Table 3.1) represent the degree to which the study participants interpreted their dementia diagnosis as a traumatic event. 22 of the participants met the criteria for a probable diagnosis of PTSD, 10 achieved scores that indicated clinically concerning PTSD symptoms (Weiss, 2007). Participants scored higher in the subdomains of hyperarousal and intrusions. This may indicate participants experience frequent unbidden strong pangs or waves of feelings related to the diagnosis as well as challenging emotional responses including anger and irritability (Weiss & Marmar, 1997; Mystakidou et al., 2007).

Table 3.1



IES-R scores for young people with dementia (n= 37)

	Participant IES-R scores		
	M(SD)	Minimum	Maximum
IES-R Intrusion (8 items)	1.90(1.15)	0.30	4.00
IES-R Avoidance (8 items)	1.73 (1.10)	0.00	4.00
S-R Hyperarousal (6 items)	1.99 (1.16)	0.20	4.00
IES-R Total (22 items)	40.32 (23.83)	3.00	88.00
Probable diagnosis PTSD (n)	22		
Clinically concerning PTS (n)	10		
No concern (n)	5		

It is generally accepted the higher the PTGI score, the more likely the presence of PTG (Murphy et al., 2016). with total scores ranging from 0 to 105. Studies vary within how PTGI scores are interpreted. Some, such as Milam (2004) and Danhauer et al. (2015) use the summative scores to determine presence of PTG. However, as the five domains of the PTGI consist of differing numbers of items, this approach has been seen to under-report PTG. Studies such as those conducted by Kleim & Elhers (2009) and Murphy et al. (2016) suggest scoring the individual domains by taking the mean score, the result of which is a standardised score ranging from zero to five. Presently, evidence to suggest one approach is more efficacious than the other is sparse, and selection of scoring is typically determined by the preferences of the researchers.

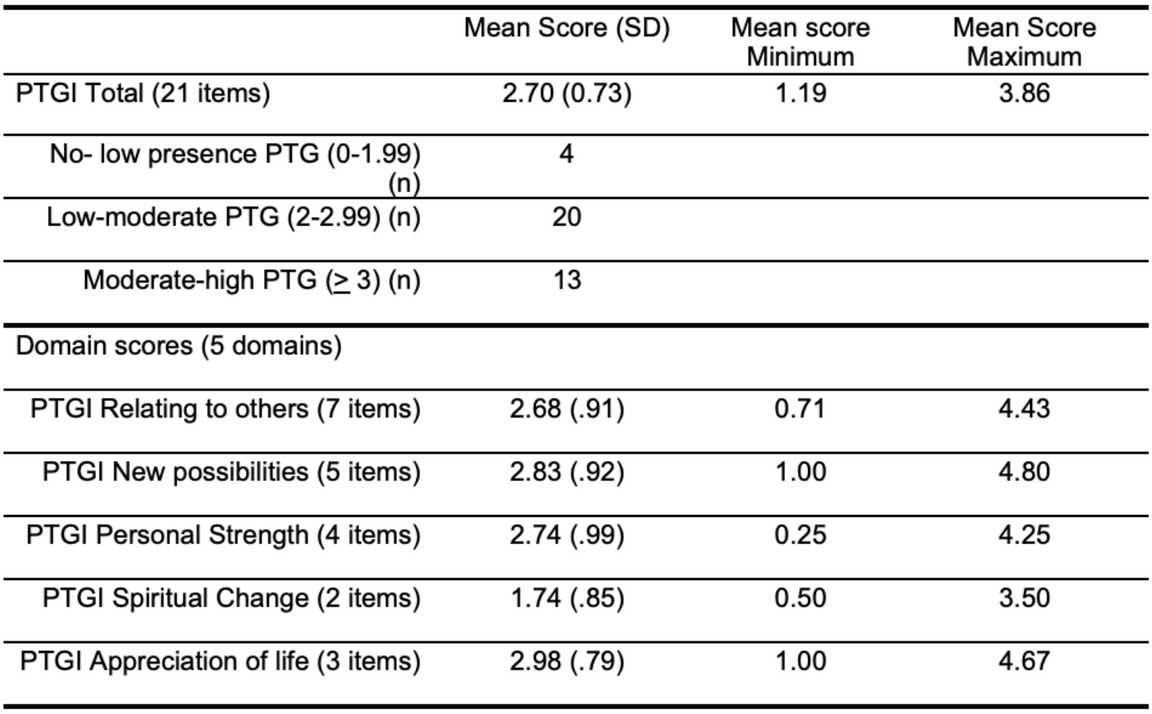
To assess if one method of data interpretation was more effective than the other in correctly assessing for the presence of PTG, a sensitivity and specificity analysis was conducted. The analysis showed that the sensitivity between the two approaches was nearly identical at 76.7% (summative scoring) and 75.8% (mean scoring) however there was a marked difference in specificity at 57.1% (summative-scoring) and 75% (mean-scoring). This indicates that both approaches are equally effective in measuring the presence of PTG in YPwD. However, the mean-scoring approach is more accurate in accounting for the absence of PTG. Given these results, the present research adopted a mean-scoring approach to data interpretation.

Within the literature cut-off values for evaluating the strength of PTG have rarely been discussed. For the purposes of this research, given that a mean-approach was adopted, cut-off values defining the presence of PTG were determined using Jansen et al. (2011) a priori approach as follows: Not at all (0), very small degree (1), small degree (2), moderate (3), great degree (4) and very great degree (5). To assess for overall presence of PTG the PTGI total mean scores were determined first. For the participants of this study, it was found that M=2.7, which is indicative of low-moderate levels of PTG. This is considerably higher in comparison to other studies which also utilised the mean approach (e.g., Kliem and Ehlers, 2009, Murphy et al, 2016) which observed scores of 1.59 and 1.55 respectively. Once overall presence of

PTG was established, the mean score for each domain was found. Participants scored highest on domains 2 (New possibilities), 3 (personal strength) and 5 (appreciation of life) which is not dissimilar to Kliem and Ehlers where the highest scores were found for appreciation of life and personal strength.

Table 3.2

PTGI scores for young people with dementia (n= 37)



	Mean Score (SD)	Mean score Minimum	Mean Score Maximum
PTGI Total (21 items)	2.70 (0.73)	1.19	3.86
No- low presence PTG (0-1.99) (n)	4		
Low-moderate PTG (2-2.99) (n)	20		
Moderate-high PTG (≥ 3) (n)	13		
Domain scores (5 domains)			
PTGI Relating to others (7 items)	2.68 (.91)	0.71	4.43
PTGI New possibilities (5 items)	2.83 (.92)	1.00	4.80
PTGI Personal Strength (4 items)	2.74 (.99)	0.25	4.25
PTGI Spiritual Change (2 items)	1.74 (.85)	0.50	3.50
PTGI Appreciation of life (3 items)	2.98 (.79)	1.00	4.67

3.1.3 Correlations Between Major Variables and Secondary Measures

A Pearson correlation analysis was conducted with the scores of the following variables included: (a) IES-R total score and three subscales, (b) PTGI mean score and five domains, (c) the SCS-SF total score and (d) the CD-RISC total score. Results of the correlation analysis (Table 3.3) revealed a significant correlation between IES-R total score and total mean PTGI score (r=.326, N=37, p<.05) indicating that participants who scored highly on the IES-R measure are likely to score higher on the PTGI. Within the subscales of the IES-R, the hyperarousal scale had a significantly positive relationship with the PTGI spiritual change domain (r=.327, N=37, p<.05). The SCS-SF had significant negative correlations across the total IES-R score (r= - .478, N=37, p<.01) and all three subscales indicating that participants who had higher IES-R score were more likely to have lower SCS-SF scores. The CD-RISC failed to significantly correlate with the total mean PTGI (r=.311, N=37, p=.061), however, it correlated highly with the domains of new possibilities, relating to others, personal strength and appreciation of life.

It is necessary to note that the total measures scores and their corresponding subscales are not usually independent measures, and therefore there are statistical limitations when drawing multiple comparisons. One such problem when calculating numerous correlations is that the risk of a type I error (Curtin & Shulz, 1998), which is typically mitigated for using Bonferroni's correction. In the context of this study the decision was made to treat the total scores and subscales as independent variables. Although the inferential causal nature of YODR-PTSD – YODR-PTG could be determined using only the total scores, what was concerned would be lost in this process would be the opportunity to examine the persuasive nature of PTSD symptomology on chronic YODR-PTSD, to identify the presence cognitive processing mechanisms required for PTG and observe the influential degree of differing subdomain strengths on the experience of YODR-PTG. This choice, guided by the likes of Chopko (2010), recognised that whilst the risk of falsely significant correlations was present, this did not outweigh the risk of a PTG type 2 error, which following the specificity analysis remained at a substantial 25%.

3.1.4 Regressions Between Major Variables and Socio-Demographic Variables

A series of standard linear regression analyses were conducted between major (dependent) variables and the socio-demographic (independent) variables. This approach is the most common form of regression for measuring the correlation between the observed values of the dependent variable and its predicted values. The independent variables included marital status, age at time of diagnosis, years since diagnosis, level of education, and religion. Following standard protocol, all predictor variables were entered into the regression equation simultaneously.

As the independent variables were of categorical data, taking the recommendations made by Sage (2018), dummy variables automatically created by SPSS were used to complete the analyses. In the context of the present study because there is no obvious order to the independent variables they were coded as 1 to indicate the presence of some attribute and as 0 to indicate the absence of that attribute to be included into the overall regression model. The number of dummy variables required to capture a categorical variable is always one less than the number of categories because the last category is perfectly predicted by the others. For example, within the present study, when assessing the impact of gender on PTS and PTG, only one dummy variable was required, coded as “1” for male and “0” for female.

For the major variable of PTG the regression analysis revealed no significant relationships with the socio-demographic variables as follows: marital status F(4,31) =.753, p=.563 with r=.298 ; age range at diagnosis F(3,33) = .132, p=.940 with r=.109; years since diagnosis F(2,34) =.696, p=.505 with r=.198; level of education F(5,30) = .315, p=.900 with r=.223; religious status F(3,32) = .736, p=.538 with r=.254.

The regression analysis for the major variable, PTSD also revealed no significant relationships between it and the socio-demographic variables: marital status F(4,31) =.622, p=.622 with r= .273; age range at diagnosis F(3,33) = .757, p=.526 with r=.254; years since diagnosis F(2,34) = 1.98, p=.153 with r=.324; level of education F(5,30) = 1.438, p=.240 with r=.440; religious status F(3,32) = 1.73, p=.181 with r=.373. This indicates that participant’s scores on the IES-R and PTGI are not influenced by socio-demographic variables and are unlikely to be predictive of a YPwD developing PTSD or PTG following diagnosis.

Table 3.3

Pearson's correlation matrix between IES-R, PTGI, SCS-SF, CD-RISC

Variables	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
1. IES-R	-	.935**	.933**	.933**	.326*	.183	-.091	.124	.328*	-.020	-.478**	-.201
2. ss-Avoidance	-	-	.845**	.805**	.315	.195	-.014	.206	.291	.062	-.329*	-.139
3. ss- Intrusions	-	-	-	.872**	.310	.162	-.114	.104	.308	-.004	-.541**	-.229
4. ss-Hyperarousal	-	-	-	-	.301	.186	-.107	0.22	.327*	-.098	-.465**	-.185
5. PTGI	-	-	-	-	-	.783**	.750**	.632**	.307	.554**	-.220	.311
6. d-Relating to others	-	-	-	-	-	-	.572**	.501**	.228	.418*	-.152	.325*
7. d- New Possibilities	-	-	-	-	-	-	-	.517**	-.035	.611**	.209	.471**
8. d- Personal Strength	-	-	-	-	-	-	-	-	.031	.579**	.040	.345*
9. d- Spiritual change	-	-	-	-	-	-	-	-	-	-.131	-.246	-.018
10. d- Appreciation of life	-	-	-	-	-	-	-	-	-	-	.184	.375*
11. SCS-SF	-	-	-	-	-	-	-	-	-	-	-	.412*
12. CD-RISC	-	-	-	-	-	-	-	-	-	-	-	-

**p<0.01 level (2-tailed)
*p<0.05 level (2-tailed)

3.1.5 Results from Analyses to Test Hypotheses One through Five

Hypothesis one states that YPwD experience trauma following their diagnosis, as measured through symptoms aligned with PTSD. The descriptive data as seen in Table 3.1 confirms this, of the 37 participants, 32 scored above the clinically concerning PTSD cut off point. Hypothesis three posits that YPwD can experience PTG. The descriptive data as seen in Table 3.2 confirms this, where a significant number of participant scores on the PTGI (n= 33) indicated the presence PTG ranging from a small (mean score falling between 2-3) to moderate degree (mean scores falling between 3-4).

Hypotheses two and three state that the trauma of the YOD diagnosis is great enough to elicit PTG and YPwD can experience PTG. As seen in Table 3.3, there is a significant positive relationship between the IES-R and PTGI scores. Whilst correlations cannot imply causation, according to Calhoun et al (2000) a struggle with a traumatic event is required for development of PTG, and these scores could be considered to be indicative of this struggle. It should be noted that participants scored highly in within the intrusions subcategory of the IES-R. According to Linley and Joseph (2004) rumination and intrusions are positively associated with growth and are indicative of the necessary cognitive processing required for the rebuilding of shattered world views following trauma. Therefore, given the confirmation of hypothesis one, the positive linear relationship between IES-R and PTGI, and presence of what appears to be cognitive processing related to the trauma of YOD diagnosis, hypothesis two and three are considered to be met.

Hypotheses four and five suggested socio-demographic variables and secondary measures (self-compassion and resilience) would influence how the diagnosis of dementia is perceived and how the presence of PTG is interpreted. It was determined that for the research population, socio-demographic variables of marital status, age range at time of diagnosis, time since diagnosis, education level and religious status did not have any significant predictive influence over either PTS or PTG. Therefore, hypothesis four was not met.

Referring to Table 3.3, a strong positive relationship can be seen between CD-RISC and PTGI domains. These results are not surprising given previous research has confirmed directly positive relationships between the two phenomena whilst also identifying overlapping factors such as self-confidence, mobilizing aid, problem-solving and awareness of abilities (Ewert & Tessneer, 2019; Duan et al., 2015). It therefore seems reasonable to expect the present study's ability to demonstrable the relationship between the variables to follow the same vein.

A strong negative relationship was found between SCS-SF and IES-R total score and all three subscales. These results are also not unexpected as previous research has proven that self-criticism and shame, thought suppression and negative rumination are phenomena associated with trauma and PTS (Stiel & Ehlers, 2000; Thompson & Waltz, 2008). The presence of shame is closely linked to low levels of self-compassion (Winders et al, 2020) and is known to act as an internal threat following trauma perpetuating PTSD symptomatology. A dementia diagnosis brings with it negative stereotypes and fear associated with the condition (Nwadiugwu, 2020), and for younger people this can be a very shaming experience due to the stigma associated with the condition, and varied symptoms which often break social norms (Johannessen et al., 2018). Taking the above into account, hypotheses five was partially met as significant relationships were found to exist between the major variables and the secondary measures. However, there was no predictive significance seen for the presence of high self-compassion and PTG.

Phase one of the study concludes that a significant proportion of the participants presented with PTS symptoms just for probable PTSD diagnosis. A significant proportion scored above cut values defining the presence of PTG. There was a significant positive relationship found between the IES-R and PTGI, indicating a degree of causality between YODR-PTSD and YODR-PTG. It can be summarised that amongst YPwD, the diagnosis of dementia is a traumatic event which can give way to the experience of PTG. Poor self-compassion can be considered a predictor for greater levels of perceived trauma. Resilience can be considered a positive predictor for the development of PTG. Sociodemographic variables are not indicative of whether one will perceive a diagnosis as more or less traumatic nor act as contributing factors to PTG.

Analysis for Qualitative Strand

The qualitative analysis section expands on the data obtained during phase one and seeks to answer the following research question: *In what ways do YPwD experience PTG?*

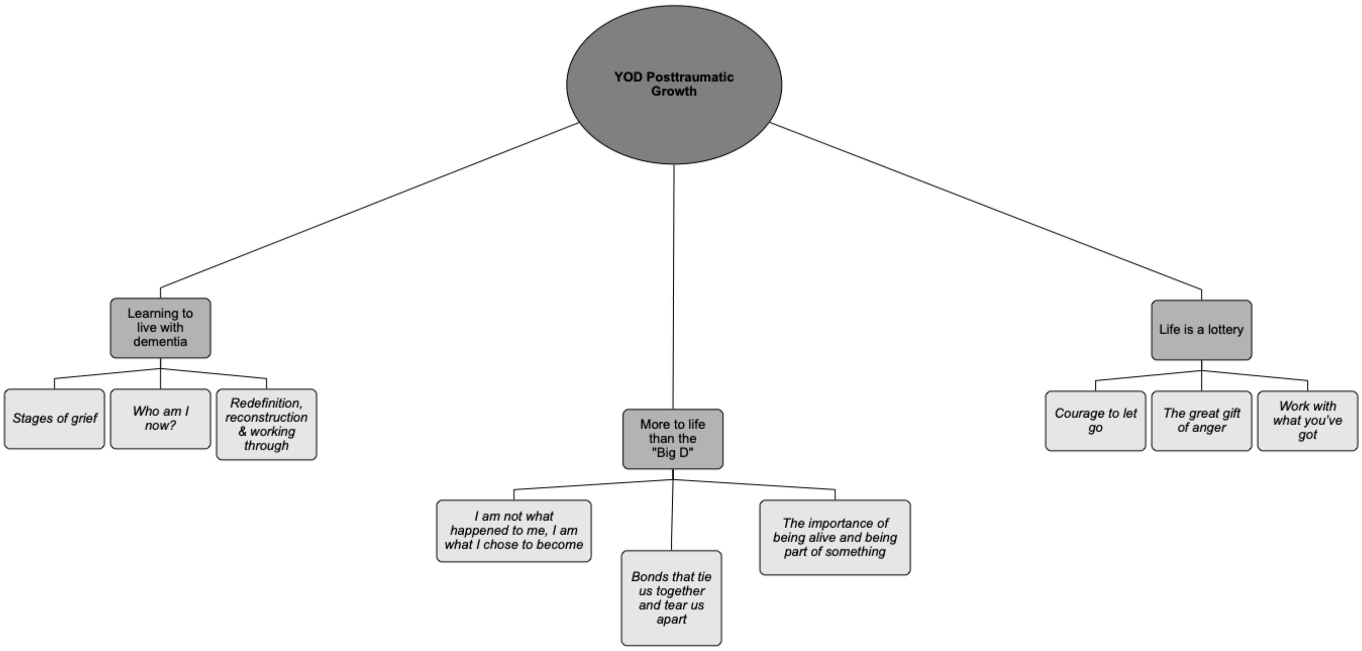
The interviews followed a semi-structured format, guided by the interview protocol (section 2.8.2). The interviews provide detailed individual accounts of the diagnostic process, the impact of diagnosis in terms of life stage, experiences of positive growth/change; as well as highlighting the need for a shift in public perceptions of what it means to live with YOD.

The qualitative data adopted an IPA analysis method based on the six-step approach as recommended by Pietkiewicz and Smith (2012). This portion of the analysis utilises Larkin et al (2006) suggestions to place the participants account within a broader social, social and theoretical context so as to render the interpretations of the experiences in a more meaningful way. Three superordinate themes emerged from the analysis, representing the participants' journeys towards positive personal growth beyond that of their former selves. Each superordinate theme encompasses subordinate themes which were interconnected to enhance the account of participant's experiences and meaning making. Each theme discussed is supported by participant quotations interspersed with interpretations. The extracts chosen were thought to best reflect and represent participant's experience and sense-making. Pseudonyms have been used within all extracts and this extends to any third parties mentioned and identifying information replaced with a description of the information such as: [organisation]. The symbol […] indicates the removal of dialogue to ensure relevance to the theme being discussed, whilst three dots (…) indicate pauses in participant's accounts.

The themes as seen in Figure 3.1 are: Learning to live with dementia, which refers to how participants worked through their personal diagnostic trauma, ultimately arriving to a place where positive growth could occur; More to life than the "Big D", refers to the ways in which participants have experienced positive change and growth following their dementia diagnosis; Life is a lottery refers to a set of internal experiences, personal attributes and external circumstances that may enhance the experience of positive change and growth.

Figure 3.1

Superordinate and subordinate themes



Learning to live with dementia

All participants contributed to this major theme which brings together issues related to life course, adapting to change, grief and loss. Each reported experiencing immense loss following their diagnosis which prompted a journey of self-discovery, self-reflection and personal reconstruction in relation to their illness. Learning how to live with dementia versus being dictated to by it.

Stages of grief

Grief is a complex, all-consuming phenomenon. For individuals living with chronic or life limiting illness, grieving oneself following diagnosis can be an unexpected, unpleasant challenge. For the YPwD in this study, the diagnosis posed a profound threat towards identity, functional independence, and self-efficacy whilst also leading to adverse changes in their perceived intellect, self-esteem, and personality. For the participants, the progressive loss of these integral parts of themselves could be conceptualised to represent 'little deaths' of their former self. These 'little deaths' forced the participants to face their losses head on and mourn not only themselves but their imagined futures which brought forth a myriad of highly challenging emotional experiences including aloneness, denial, guilt, anger and desperation. For the participants, negotiating the stages of grief and mourning themselves appeared an essential part of their experience of learning to live with young onset dementia.

Often the early signs of the condition in younger people are not immediately identified as belonging to dementia, it is only in hindsight that the individual is able to pinpoint the onset of the condition "Because I can now in retrospect, I can go back 10-15 years, and I can see errors that I was making at that time that I believe now was very, very early stages." (Andy Lee). For many YPwD, their symptoms are frequently brushed off, attributed incorrectly to stress resulting from critical life incidences such as divorce or bereavement, or as newly emergent mental health issues. William's dementia for one initially manifested itself as restlessness and insomnia, and his route to diagnosis began within adult mental health services: "And the first investigation was done by the adult mental health services. That's a bit you're not clear about how you got into the loop. Ahh. Yeah, I did I didn't realize, right now, I didn't ah what's involved […] And initially the mental health services before the CAT scan, thought it was, you know, mental health issues, depression." (William) Taken aback by this diagnostic experience and sudden onslaught of objectively negative labels resulted in William himself believing that his initial symptoms were related to mental health issues and he went as far as to begin taking Sertraline as a way to "take the edge off the anxiety". This experience was not unique to William, all the participants reported missing the initial symptoms, believing them to be a manifestation of something else. This enabled the participants to live in a state of denial.

> "So I thought, well maybe, because it was some of the same symptoms that you can display with anxiety, you know gapping a-a-and not being able read things, so you can -I was, I was like supposing someone had looked at my written work they'd want to send me for a dyslexia assessment […] I was displaying signs or presenting signs that could have been um s-someone living with dyslexia. So there was lots and lots of things." (Andy Lee)

Given the relative rarity of YOD, for the participants, this initial state of denial was frequently reinforced by health professionals who too believed their patient's underlying difficulties were not sinister in nature.

> Barbara: "Because it was unthinkable that, that I could have it. That they weren't- that they – Everyone though, even my own doctor said, well you're too young to have dementia. And thought, fuck off. I know I am. I ain't got that. […] I went to the cognitive testing, and then you know, the Specialist, oh, no. 'You're too young but we'll investigate it'. Oh no. 'You're too you have to have dementia'."

Having the diagnosis confirmed was a distressing, disconcerting experience. For Thomas, his initial reaction was one of panic and he found himself desperately arguing with the diagnosing clinician: "I just said, no, no, no, no, no you know, that's not right. He said, 'nope there's absolutely no question about it'. So I think my first reaction was complete shock. I-I knew something was going on. It never, it never entered my mind that it could be any, anything of that nature." (Thomas) Anger, bargaining and depression quickly replaced denial as the participants began to understand the gravity of their new reality. For some, like William, the gradual loss of his functional independence was difficult to cope with. He found himself forced to shut down his sign writing business, selling off his prized machinery and just a short while later giving up his driver's licence and the freedom that it brought: "it's difficult when you lose your independence with driving […] It's a bit of a blow really."

David also reported struggling with the impact of losses he was incurring. Unlike William, his were much more internal and integral elements to his personality and therefore how he viewed himself as a person. As a result of his struggles with existential aloneness he began to shy away from the person he was pre-dementia becoming enslaved to his aloneness.

> David: "I used to be very er talkative to say, but now watcha call it, not so much. I mean, I'm, I'm talkative in this like this. Right? But generally speaking, I'm not very talkative […] because I'm not doing anything with me life, so there's nothing for me to communicate about."

The combination of a seemingly wicked diagnosis and numerous personal losses resulted in the participants feeling enraged and resentful towards their newly found life-circumstances. The direction of the participant's anger varied. All described a degree of inwardly directed anger, perhaps in reference to not recognising symptoms sooner: "I think I kinda noticed some changes in 2007 […] I put it down to like sort of PTSD sort of thing […] but then it got worse over the years. Things – it was like things were disappearing, and then I was accusing the kids of missing things. It was me moving them. Um so I just went to my doctor. I think I went in 2011." (Barbara)

Thomas, Barbara and David all directed their anger outwards toward the means in which they individually received their diagnosis and lack of tangible post-diagnostic support available to them as younger people. They expressed feeling varying degrees of abandonment, isolation, and helplessness. For three highly capable and grown adults this was an infuriating experience which was intensified when they saw what was available for older adults both within the NHS and third sector. "For me, th-the, watcha call it, the diagnosis, you know it could have been delivered better, you know i-i-i-it was very matter of fact kind of thing you know eh, and post-diagnosis support was you know non-existent, and you know it's, I had to find my own way forward." (David)

Acceptance of the diagnosis eventually occurred for all participants, however the timeline in which this occurred varied significantly. For both William and Andy Lee following their period of mourning, acceptance was a natural progression, which appeared to be made easier by pre-existing pragmatisms and in the case of Andy Lee, a pre-existing plan.

> Andy Lee: "And after they gave me the diagnosis, I said, okay, thank you. Well it wasn't totally unexpected. And he said 'that's it?' So I said, w-well yes. So he said 'well have you got nothing else to say about it?' So I said, look, I have been perfectly candid. So I have been a supporter of human voluntary assisted dying all my life, I'd already made a decision after watching my dad suffer with dementia, knowing that there's no cure for it. That I'd got on a path of certain

> […] you know I will n-now take the steps t-to kind of apply f-for the, an assisted death so I can put it under my belt so to speak."

Whilst for others such as David and Thomas, both who reported experiencing and struggling with negative thoughts about their diagnosis, acceptance took longer, requiring a more conscious and purposeful approach.

> Thomas: "I accept it, you know, we've got to accept it […] we came across something that said, 'Don't let what you can't do stop you from doing what you can do'. And, and, and so, so um you know w-we've remained positive, um although things are very different and of course it's still very frightening."

For the participants the process of grieving emerged as being instrumental in their individual journeys towards understanding, accepting, and making room for their diagnosis. Following successful resolution of their period of grief and mourning, a newfound sense of freedom arose from their struggles. Not dissimilar to the classic phoenix rising metaphor the ending of this period could be thought to signify a re-birth of the self. David for one, now no longer saw himself as trapped within a purgatory state and felt that he could begin to make forward movements into his new dementia life.

> David: "Once you got the diagnosis you can move forward in your life, making plans and that…You know, because th-th-there's nothing more than dealing with the unknown kind of thing. You know once, once you know there is a sense of relief because you can, you can make plans with your life, you can move forward."

Who am I now?

With the middle adult years primarily defining one's identity through relationships and work, for the participants, the experience of dementia-related life disruptions left them feeling rather directionless. It was as though they had strayed off the path of life and into deep into the woods without a compass. Their narrative accounts touched on losses of core aspects of their personhood, and the impact of this on elements of 'the self' including personal mastery, self-concept and self-esteem.

> David: “Most of my problems manifested themselves in work…I used to hold like a senior role and um I was demoted twice…Em memory was going, my personality was changing. At one time, I used to be ehh a very popular person in work, you know, always joking, always jovial, but my personality was changing and I just couldn’t be bothered talking to people, I just became more and more insulated.”

The threat to ‘the self’ was significantly influenced by individual perceptions of dementia, which for some impacted their ability to identify as someone with the disease. In the early days following diagnosis, this could have accounted for some difficulties with initial acceptance. “And of course, my.... knowledge of what dementia was tends to be we all think of end stage. You know i-it's something we have in our mind, you know the person who can't remember who they are or where they are and, and you know needs total care and all that.” (Thomas) What stood out from the accounts was the systemic threat that a YOD diagnosis poses towards several important middle-life domains such as autonomy, relationships, livelihood, and identity.

Synonymously all the participants acknowledged the need to respond to these threats through making sense of how their lives and self would change as a result of their dementia. This was interpreted as the participants’ initial steps towards warding off future threats to ‘the self’ and active attempts towards assimilating their dementia into self-identity: “S-so for myself, my thoughts were okay, this is going to mean massive changes to my life. Ah what I’ve got to be careful of it that I don’t lose my identity because I can’t be an academic anymore.” (Andy Lee)

For some, this was done through holding on to their former, or rather existing ‘self’ for as long as possible “like it takes away your brain, it takes away your personality, it takes pieces. It doesn’t take away everything all at once. It just takes away pieces.” (Barbara) For others, such as Andy Lee and William, adopting new societal and familial roles drawing on an existing skill set was helpful as it brought a new, or rather renewed sense of purpose and focus. William shared that he was about to become an active ‘double grandparent’ as two of his daughters recently had children. He expressed excitement at the prospect of utilising his skills as a tradesman to help his son-in-law with various ‘baby-proofing’ projects. Whilst Andy Lee was keen to continue to utilise skills as an academic to support students within a non-academic role: “I've managed to ah, I’ve managed to work with students that ar-are doing you know, undergrads, postgrads, I-I went to [City Name] universities, used to work there. And I was helping out some students there.”

Redefinition, reconstruction and working through

Given the threat posed by dementia to identity, the act of redefining oneself and/or reconstructing one’s world in partnership with the dementia emerged as a means of stabilising self-identity. This move towards identifying with their diagnosis and achieving a more robust sense of self seemed to be an integral part of the process of positive growth.

For the participants defining themselves within the context of dementia was divisive. Some like Thomas chose purposeful cutting off from the old self and throwing himself into new hobbies with the hopes that they might provide the scaffolding needed for him to stay erect: “So there’s some things that I used to do that I don’t do. In terms of I used to paint a lot and draw a lot and that completely stopped. Um but I’ve been learning to play the piano […] It’s something I enjoy doing and it’s something I have got, I mean I didn’t-I don’t know where playing the piano came from, because I’ve never played a music instrument in my life.”

Both David and William also spoke about purposeful shifts within their relationship roles with their wives. Both men reported having to accept their wives stepping into more ‘managerial’ roles: “Now me wife you know, because like she's like me carer and she tends to um take responsibility for things I used to take responsibility for.” (David) For David these changes, although intentional, were nonetheless painful as they forced him to acknowledge the things that he could no longer do and challenged his previously held views of himself as a “fiercely independent person” and he initially rebelled against these changes. In comparison to the other participants, he had an extended period of oscillation between the subordinate themes of ‘stages of grief’ and ‘who am I now?’ as he begrudgingly made his way towards being more acceptant of the inevitable life changes that were before him; eventually making room for the person he was with dementia and his future to come. Returning to William, these relational shifts were viewed as advantageous as they almost immediately enabled him to begin the process of moving away from the old self and towards the person he was becoming; and like Thomas, William began to explore new facets of himself.

Conversely, Andy Lee used the process of redefinition as opportunity to finally align himself with his core values. This brought a new sense of purpose and agency which was felt to be a positive outcome of the diagnosis.

> Andy Lee: “I’ve been a long-standing trade unionist throughout my life, I’ve always been a campaigner and ah was already supportive of assisted dying and I run a Facebook page called [The Organisation], it’s part of an international group. But next thing is I can’t work a-as I could do… But what I want to do is start developing the campaign. So I’ve got a focus, I’ve got you know more of a purpose. I’ve got more.”

For Barbara it too remained important to continue to hold onto elements of herself which had proved useful in her pre-dementia life. However, she appeared to contribute equally to both sides of the dichotomy of holding on versus letting go: “When you’re in that situation with this disease or Illness, or whatever you want to call it, I’d say, I can’t say it makes you stronger because I’m that anyway, clearly it’s just me. I’ve got a strong personality […] I’ll stand by my guns […] but um personality-wise like then, I’d think about something, now I just don’t think I’ll go in headfirst.” (Barbara)

For the participants the process of reconstruction and subsequent working through involved an enhanced form of acceptance, beyond that achieved in ‘stages of grief’. Instead of simply accepting the presence of the dementia and the associated losses, all the participants had to undergo an intense period of learning how to acknowledge the new elements of themselves, accept their presence and figure out how best to integrate these and their new dementia-self into their current lives. Regarding Barbara, who has been living with her diagnosis for longest period of time, this appeared to have been a gradual adjustment: “It’s like living with a fucking evil twin. Do you know what I mean? You kinda get used to it […]

it's like living with two people […] that is my reality. Uh, it's a pain the ass to live with." Andy Lee, took a more non-conventional approach and instead of viewing the dementia as something that needed to be caged and contained, he viewed the process of assimilating his dementia as though he was purposely entering in a relationship and as such took a very active approach.

> Andy Lee: "But what I decided was okay, this is like being in a relationship, it's, it's one day one partner will have the upper hand and the other day the other partner is got the upper hand! So I decided to treat it like a relationship and I decided that I couldn't not like it, I couldn't not accept it and I couldn't not value it. Because it's part and parcel of me and it's taken me 50 years of constant practice and change t-to love myself and to appreciate myself and to value myself. So the Alzheimer's is part of me, so I can't say I unconditionally love myself, apart from because that's an oxymoron isn't it? So…so, so that was my approach."

Participants spoke to the challenges of having to constantly prove and validate the existence of their dementia-self which inevitably had negative impact on the individual processes of reconstruction and resulting stabilisation: "When you say, 'oh, by the way, I have a form of dementia', it ugh, really? And it's a, a very different reaction. I think that's the hard thing with, with the diagnosis that you have, that you find you have to explain yourself in a way um that you don't expect to explain yourself. So, I tend not to mention it. You know and it's a bit weird that." (Thomas) One could interpret this intentional non-disclosure of the diagnosis as a potential obstruction to the 'working through' period where once completed participants were finally able to view themselves as a whole again, versus as fragmented pieces of who they used to be.

Not surprisingly David appeared to struggle the most with this process of redefinition and reconstruction of the self with dementia. He described his experiences as painful and destabilising.

> David: “Now no longer function the s-same way that I-I-I used to, which you know is a huge upheaval in your life, like it destroys your self-confidence, y-y-your self-belief and that. And getting back to what I’ve said, it’s quite frustrating having to ask for support with things. You know again, there-theres the fact that I used to always be fiercely independent”

David’s difficulties could be attributed to a number of things, from his subjective perceptions of changes in his fundamental core; to the presence of difficult emotions such as embarrassment, shame and blame associated with feeling incapable; to pre-existing difficulties in engaging with self-compassion. What can be learned from the participants, and David’s accounts in particular, is the sheer amount of effort and hard work that goes into the re-construction of oneself. It cannot happen swiftly, it requires blue prints and planning permissions, an architect, a foreman, a team of builders and the appropriate materials in order to be considered safe and inhabitable.

If a YOD diagnosis was not difficult enough to navigate, four of the participants have since been diagnosed with co-morbid health conditions. For some this has posed additional challenges attempting assimilate this into their newly constructed self. William however, who has since been diagnosed with Parkinson’s disease found the process of reconciling this new bit of himself this to be easier than his experience of doing so with dementia because of its relative societal acceptability “Parkinson’s er, ah more so than the dementia...I’ve found so many people recognise that rather than ah, well rather than the dementia.”

More to life than the ‘Big D’

A YOD diagnosis is a catastrophic event, it threatens successful resolution of the midlife crisis of generativity, compromising one’s perceived place within the world. Following their individual experiences of self-mourning, existential aloneness and questioning and personal redefinition and reconstruction, the participants accounts revealed how each was able to successfully establish modified assumptive world models, accounting for their diagnosis. To reach these the participants nurtured new or evolved beliefs about themselves, others and world, whilst developing a (re)new(ed) sense of purpose for them as an individual with dementia. This theme is felt to highlight the participant's lived experiences of growth and change; highlighting how through a profoundly distressing life event each was able to move forward beyond that of their pre-dementia self and find enhanced life satisfaction.

I am not what happened to me, I am what I choose to become

Following their diagnosis all the participants expressed for a time feeling defined by their dementia and no longer seen by others and society as the as the unique individuals they were prior their dementia. For David, his perceived loss of social value was incredibly damaging, eliciting depressive symptoms which lead to increased social exclusion: "When you get a diagnosis like that. One of the things y-y-you feel devalued you know you feel like y-y-you got no purpose in life, you know that you just going to be sat in, just staring at the telly all the time." (David) A key sub-ordinate theme that emerged from the analysis was the journey each participant took to maintain or rediscover both their personal and societal sense of value, whilst making sense of how they could still actively engage with the world around them. For all the participants this journey was long, arduous, and complicated by the fact there was no map to follow. Returning to David, following two demotions at work and an unwanted early retirement, he was forced to face his own perceptions about his loss of autonomy and life-role. Feelings of personal useless, disconnection and un-involvement were seen to emerge, which for a time had a significantly negative impact on his beliefs of his own value and abilities to contribute in a meaningful way to the world around him:

> David: "There's a saying, there's three yous, there-there's em ah h-how people see you, how you see yourself and who you actually are. You know and it's ah so... for me, I see somebody who struggles a lot for ah-he-em, …being fiercely independent. You I know I don't watchya call it, I won't talk about things that I can struggle with. It' not that I-I-I don't want to, it's just I … em I feel ah, embarrassed to for want of a better expression I'm insular…it's made me very insular."

Although work had been drying up in the few year's prior, following his diagnosis, William was forced to shut down his business and take early retirement. Much like David, William too noticed himself becoming increasingly inactive and isolated. The result of which was a decreased sense of self-worth and self-esteem. To remedy this William, with support from his wife sought out new activities and clubs with the hope that through re-engagement in meaningful activities William would be able to discover new interests and a sense of purpose: "The idea was you should keep active, social, try to stay in the real world and I've - I still try to live like that." (William)

Given the sudden interruptions in life plans, all the participants spoke about having to re-adjust their expectations of what they as individuals could offer to the world around them. This in itself was overwhelming, Andy Lee who had dedicated his life to academia was suddenly left feeling as though his options were limited: "I am retired now, but I never intended you know, 65 and retire as a pensioner. I always felt that I'd do s-some kind of research, reading or supervision etc. So, there's that impact on it." (Andy Lee) This re-adjustment generally involved the participant's reflecting on what was meaningful to them at their core and taking committed action to incorporate new activities, roles and opportunities that aligned with these. David for example who has always valued professionalism and reputation was able to overcome his perceived loss of social value and subsequent intra and interpersonal disconnects through becoming involved with a number of dementia workforce committees where he was able to find social value again: "Um well, i-it's very satisfying. You know y-y-you're in an environment where you know y-you are accepted as an equal kind of thing because you know t-t-there's not a decision made that I-I'm not involved in that I-I have a vote. So you know it's very reassuring and you know i-it's very influencing for your mood, self-respect and your dignity."

Upon reflection of this, David came to the realisation that had he never been diagnosed with dementia, he would have not had the drive to engage in meaningful work. He now has real job satisfaction, a positive outcome of this diagnosis which he never would have expected.

> David:" I mean the thing is w-when I was working, I was th- you know I was there because it was getting paid kind of thing and that's only…I didn't particularly like the job […] You know the way jobs are now in England, whatcha

> call it, if you get a job, you just stay with it kind of thing. You know so what I'm doing now is a-eh, more productive and you know whatcha call it I feel that I am making a difference."

Barbara, Thomas and Andy Lee all spoke about the different ways in which they ultimately opted to renew their sense of personal value and place in the world. This appeared to stem from individual self-reflection where the participants took stock of themselves, what they have previously valued or not valued about themselves and reacting accordingly. Andy Lee prior to his diagnosis shared that he often sought external validation to confirm his value and place in the world. Reflecting on this, he was mildly shocked yet pleased to share that his sense of self-value and esteem have actually improved since his diagnosis and giving up his formal place in academia: "I have found that the more I achieve in terms of prominent places in academia, the less esteem I've had […] now, so, you know, yeah, I don't think I feel any less valued, well actually… I don't give a sod what people value me as [...] But um you know, I don't feel worth any less to me than I ever have done."

Barbara is adamant that a dementia diagnosis should not define one's value or self-worth: "See. Exactly! […] I don't feel worthless or useless. I never have done. I didn't before and I don't now." (Barbara) Speaking about her time on a television documentary Barbara highlighted the devastating effects that the YOD diagnosis had on her colleague's self-confidence and subjective self-worth. She identified the importance of feeling useful, helping others to develop a sense of personal and societal value. A sentiment echoed by Thomas, who also feels it is important to minimise the victim narrative associated with the condition, viewing this as a contributor to perceived loss of value:

> Thomas: "You know it's important…not to, I don't know…be a victim or something or you know kind of like, you always get this kind of somebody suffers from something you know? He suffers from dementia; he suffers from this you know. And of course, it's not, it's not a lifestyle choice I can tell you. Yeah but […] it's happened."

A sense of value and worth within the middle years is often tied to feeling as though one is making significant, lasting contributions to the world and by doing so carve out a designated ‘place in which to exist’. For the participants, their dementia diagnosis flung them far away from their original whereabouts and a core experience shared by all five was the process of exploring the new place they found themselves in and how to make the best of them being there. Each reported discovering a range of new opportunities that had not been considered in life prior to their diagnosis. As such participant’s views of themselves, their sense of purpose, place in the world and individual strengths began to shift as they uncovered their life path within their new whereabouts. For William, this adventure began just a stone’s throw from home; with support from his wife, he re-situated himself within the local community and become involved in dementia groups and supported local beauty through various gardening projects. He also touched on the future contributions he will make in the raising of his grandchildren: “Just try to keep us busy within our you know […] and also be sociable, that you know and we love a garden don’t we, we love garden projects and being outside and we will be involved in you know the growing up of our grandchildren which is nice.” (William)

Barbara and David found new belonging in public facing service and advocacy roles. David now is involved in multiple steering committees and sits on public boards, directly influencing local and national policy through his work. “I sit on a er a-a board called the eh the Strategic Review Board and this board has watcha call it the budget for [Locality] em for all dementia services and em I get a say h-how that money is spent.” Having previously stated how his diagnosis left him feeling devalued and depersonalised, for David, being able to offer something concrete to the world has helped to increase feelings of productivity, improved his self-esteem and gave way to a new found personal pride and enhanced sense of fulfilment.

> David: “Definitely. You know it’s um I mean ah, ah, I-I do get a lot out of it, you know but I-I wouldn’t do it if I wasn’t getting anything out of it […] I find what I do you know it is you know very productive. You know and the level of responsibility that I’ve gotten, you know some of the people that I work with hold real high office […] I’ve actually spoken at Parliament. You know so I’-it’s

> to be trusted in that capacity, you know I-I-I must be doing it right because they're not gonna allow me to you know that level of eh involvement if they didn't consider me suitable."

At the time of her diagnosis Barbara was the youngest person ever diagnosed with dementia in the UK. Immediately following her diagnosis, she attempted to research her condition only to find limited information available targeted towards older people. Her response to this was to take on the role of 'Dementia Warrior' and to raise public awareness of YOD and of the needs of those diagnosed.

> Barbara: "And because there was no literature on it, 'cause I googled it […] so um, I went to do a memory walk. And when you do a memory walk […] you have to have to do, um, like, fill this thing and do you want the press, blah, blah, blah. I thought, well yeah. Might as well. And then that's when it all, you know, shit hit the fan. I was everywhere, do you know what I mean? But basically, just coming forward and saying, look at me. I'm 48, I've got you know, a-a life limiting illness that no one's every bloody heard of because you associate dementia with old people […] And there's nothing out there for us […] I was furious at the fact that there was nothing out there. So that's when I got on my high horse, and I didn't get off. And yeah. I and I just you know, I-I put it out there […] but it had to be told. And as soon as I did, fucking hell, low and behold, you google it now, you google frontotemporal dementia, it's everywhere […] that's what I wanted to achieve, and I did that. I'm bloody proud of that."

For Barbara, her message and motivators are clear, YOD is a reality for many, the information and care being offered is not enough and things need to change: "The thing is, if they're – if people aren't gonna wake up and smell the coffee and start helping people like us, then we've got to do it ourselves, you know? I've tried. I've done TV shows, I've done everything and, and still nothing's changed, well there's little changes but no-no big ones, do you know what I mean?" Her life plan shifted following her diagnosis from being a stay-at-home mother to now being a high-profile advocate and mouthpiece for the YOD community.

Advocating for the needs of YPwD appeared across all the participants accounts. For Thomas and William, along the same vein as Barbara, they feel it is an urgent matter to get the word out that dementia happens to young people. They believe that only through broadening the public's understanding and perceptions of dementia, can positive action be taken. Both men feel the first step in achieving this is for YPwD to become actively involved in projects and working groups where lived experiences can be shared, common themes discovered and a community established. Thomas in particular is passionate about educating the public in order to change the labels and stereotypes associated with dementia: "In terms of dementia, it's, it's…I think a lot of people including health professionals, have the same kind of notion that people with dementia re kind of old you know…and do, they said to me, well you don't have dementia, you know, you hold- have a conversation. […] I think th-th-there's a lack of appreciation that…younger people…you know can be diagnosed with dementia that it affects their life."

David's focus is slightly different, he chooses to build awareness for the practical improvements that need to be made to decrease barriers for people with dementia, improving inclusivity: "I also sit on the [Locality] airport accessibility forum and they're building a brand new terminal at the airport and em whatcha call it I've been acting as an advisor from the [Organisation] as to its suitability for people with dementia […] and you know made recommendations and that, you know."

Having witnessed his father suffer with advanced dementia, Andy Lee has chosen to lobby for one's right to a dignified death; a movement which he incredibly passionate about. He hopes to ensure that YPwD's rights to self-determination are recognised, and that one's ability to maintain control over their life and to make informed decisions about their future is honoured.

> Andy Lee: "I think the thing about dementia is, the f-first thing that people need to accept about it is there's no cure and there's no treatment and there's no foreseeable cure of treatment. Then I think what they need to understand, in my opinion is, 'what choices have I got?', and make their choices […] and once

> they've made their choices, then t-they need to kind of p-put into the plan. They need to accept these are the things that I can do or I can't do anything about it, these are the things I can do, which is how I'm going to go about it."

It can be seen that despite their diagnosis each participant retained the belief that their diagnosis does not define them, nor make them faulty or incapable of engaging with and contributing to the world. Through their involvement within the present study alone, each has stepped into the role of expert by experience and are contributing to the dementia landscape which will ultimately help other YPwD and lead to positive change. A fact that was not missed by William who when asked if he would like to receive a copy of the final study write up responded with, "It would be good to read wouldn't it, to think we've been part of something."

Through purposeful engagement in meaningful activity the participants seemed to strengthen or rediscover their sense of personal value, using this to guide the way forward within their new world. It appears feeling valued and valuable is critical and significantly contributes to one's ability to confront their illness with a positive attitude and to discover new, highly meaningful paths in life which were, prior to dementia, never considered.

The bonds that tie us together and tear us apart

Following their diagnosis all the participants noticed their relationships with friends, families and partners changing. For some, their interpersonal relationships appeared to strengthen as extended family and friends rallied around them; "Our friends are on standby […] we've got some very close friends." (Thomas) Knowing that there is a safety net of loved ones around appeared to enhance not only the participants' sense of security, but it contributed to the participants' sense of being a valued person despite their dementia.

Barbara identified how it has been important that those closest to her not be afraid of her, nor treat her differently. Speaking about her children specifically, Barbara believes that by maintaining their pre-existing relationship dynamics and way of interacting with one another the family actually became closer following her diagnosis.

> Barbara: "Um, now, I suppose the kids, just-just they don't treat me any different. Do you know what I mean? If I say, but you know uh, you know my

> daughter say, ‘oh, you didn’t do that?’ I’ll say well of course I, I didn’t, I’ve got fucking dementia, you idiot. She’ll go ‘oh, that old chestnut. You use that far too often mother.’ I know! Ah, I know…but.. and do you know that I mean? So they-they just take it in stride. They just treat- they haven’t treated me any different. It’s – they haven’t, you know, they haven’t – which is great. It’s a good thing.”

The way that her family have responded to and treated Barbara could also have contributed to her ability to hold onto her identity and sense of personal value as demonstrated in themes above. Barbara was and still is simply ‘mum’ versus ‘mum with dementia’.

For some of the participants in addition to maintaining their existing interpersonal bonds, there was also a deep need to seek out new relationships with like others following on from their diagnosis. The sharing of their diagnosis and similar lived experiences enhanced a sense of belonging that perhaps helped the participants to become more accepting of their condition through the virtue of realising that they are not the only ones. William for example found his active involvement in a local YOD dementia service to be an invaluable source of support. He spoke about the benefits of being able to form comraderies with other YPwD and how engaging in new activities helped him to remain connected to the world around him.

> William: “Oh yes. Um yes, we, we have got various days out. Yeah, t-they organise days and say y-you know w-who would like to go and carry out ah if there’s sports events that we get involved in, golfing and um, walking football, that was so funny. I can’t explain how, funny, th-that’s the whole point to get, to find out h-how much fun it is.”

Commenting on the rarity of YOD, often YPwD are left feeling marginalised or lumped into groups with older people. This can exacerbate feelings other otherness and in some cases isolation. For Thomas, he described a range of emotions the first time he found himself in a room with other YPwD, “I mean it's interesting, because I said I went to this conference in [City], I know I was kind of like, what, w-who are all these people? It was, it was a mixture of... um being very reassuring, but also quite overwhelming.” Being able to connect with his peers and hear their stories was a turning point for Thomas. Realising that there is a whole community of YPwD who have gone through similar experiences Thomas felt motivated to begin his quest of challenging social stereotypes of YOD as a way to support his peers.

For those participants in romantic partnerships, they appeared to have developed both a greater appreciation and desire to maintain their relationship, recognising their partner's value and positive impact. Thomas and William both spoke about their respective relationships with their wives commenting that they could not have coped with their diagnoses without their support. William, the oldest of the participants, acknowledged that his relationship with his wife has also changed. However, it remains unclear to him how much of this is due to his dementia, versus the natural transitions that relationships take over their course. Already very close, Thomas believes that the diagnosis in some ways changed his relationship with his wife, reflecting on this he came to the conclusion that his relationship was strengthened in the face of adversity.

> Thomas: I mean, we've always had a very good relationship and that's a fact […] I suppose in the very early stage of being diagnosed, I think that was the most difficult time, because you know we're both dealing with what it meant for us as individuals and as a couple […] Um, well y-you know I-I think it's fair to say it put a strain on us, because it's just such an overwhelming and unexpected thing to happen. Um, I would say, I don't know if you can say closer or no. No I don't know if th-that works, but we were always very close. You know um, that hasn't, that hasn't changed. I think, it might be strengthened."

David also feels that his relationship with his wife and family have changed as a result of his diagnosis. As a proud Northerner, asking his children and wife for additional support was initially very difficult and at times felt like a sign of weakness, "you know so yeah, the ah t-the balance of power has changed." Referencing the early days following his diagnosis, where he found himself feeling the most vulnerable, David expressed a profound sense of gratefulness, admiration and remorse for what his wife put up with from him: "my wife took the brunt of it because I was so frustrated and angry, I was really, really angry. You know, some whatcha call it me...me-me- wife took the brunt of it because it-its like she was the only one there." David and his wife appear to have overcome this bumpy period in their relationship and he shares that they are now very close. In many ways, she acts as a source of inspiration for his advocacy work. Realising how difficult his diagnosis was on her, he is motivated to improve the support available for her as a carer.

Barbara who was widowed in the early days of her diagnosis spoke about the challenges of being in a relationship with a person with substance abuse issues whilst coming to terms and with and managing her diagnosis: "So over the years, he got progressively worse, so that put a massive strain on the relationship. Do you know what I mean? More of a strain than having this." When her husband suddenly passed away Barbara and her children were left to rally together, and to pick up the pieces:

> Barbara: "So, I had to make the decision to turn off the life-life support machine. And I-I didn't know whether I was doing the right thing or the wrong thing, but I had to do it, you know, because my kids were there as well, and I had to do it quick 'cause I knew that if I prolonged it, it would hurt them. Okay, it hurt me as well, but I had to deal with it […] then it's less pain for them, not for me. 'cause I wasn't thinking about me. I was thinking about them. They were in bits, the kids. I-I was, but you can't be, you know. When you're in that situation, you can't-you can't crumble. You can't break down. You gotta stay strong for them, because that's the last thing they want […] I gave him the best send off, uh, me and the kids and everything. I did it on my own with frontotemporal dementia."

She has not let her previous experience deter her. She has dabbled with online dating and has gone on to find love since her diagnosis, recently becoming engaged.

> Barbara: "So I sent him a message […] and he sent me a message back […] We got engaged in May. […] So, yeah, and we decided we're gonna get married this year […] But, you know, I can't waste time. I can't waste time. You know, everyone is like, oh, isn't it quick? Fuck off, I haven't got time, mate. If I had time, I'd take it slow, but I haven't got time. I haven't got years. Well, I have, but not many. [laughs] Do you know what I mean?"

Closer relationships can lead to increased expressiveness of emotion, a sense of belonging and respect and feeling understood. Unfortunately, not all the participant's relationships changed for the better following their diagnosis. David appeared to experience social rejection following the disclosure of his diagnosis as several longstanding friendships faded off, with people appearing to not want, or no longer know how to interact with him, something which strikes a nerve to this day:

> David: "It can be a bit depressing because I work with a lot of people and it helps a lot of people. And since the d-ehh-ahh day I retired, I think about maybe one or two phone calls, you know and ahh that's it kind of thing. […] When you work for people for nearly 20 years you know it's em and you know you've helped a lot of people, you would expect you know th-the odd phone call kind of thing. It's a even, even like on Facebook, I've got a couple of friends there that I used to work with. You know but they're friends only in the sense that on Facebook, that's what they're called friends. I don't consider them to be friends because they never asked me how I am, you got a private message facility. You know whatcha call it, e-e there's no contact whatsoever."

He reported activating his 'built in safeguards' in response to feeling let down and abandoned. This triggered a period of reflexive thinking about his relationships where David began to assign more meaning to his newer professional, dementia-based relationships whilst acknowledging the weakening and ending personal ones: "You know um, people keep in touch you know like making…th-they're the only people that 'ave kept in touch, you know been getting regular emails and phone calls. You know so, it's em yea, whatcha call it, I really do appreciate that." Interestingly, he reported feeling no sadness towards the loss of friendships: "I'm fairly nonchalant, whatcha call it, there's no sadness. You know, it's ah I don't ah miss them." This could be thought to reflect David's 'safeguards', or rather the psychological defences which were put in place earlier to protect him from the pain of rejection or abandonment due to his diagnosis.

Andy Lee the only single participant reports that his dementia diagnosis has led him to feeling more isolated. This is primarily because his diagnosis prevents him from engaging in the activities and hobbies such as extensive travelling or trekking, that he would normally do in the company of another. This is not to say his dementia entirely precludes him from getting out and about; an avid football fan, he still attends games with friends. However, it has been through his involvement in campaigning and ties to academia that he reports discovering and cultivating positive professional relationships, meeting lots of new people he would have never met otherwise. These new relationships are a place where his knowledge and experiences are sought and respected.

> Andy Lee: “One of my friends is a psychiatrist [Friend’ Name]. And um he’s written a book. Um yeah [Friend] he’s got a brilliant sense of humour, h-he’s a bit older than me but we live in that same […] and he keeps sending me things. Andy Lee do us a favour, look through this, look through that, ju- and just kind of changing things around. And then he got the book, I-I’m heavily referenced in the book.”

In the aftermath of their diagnosis the participants sought out support from family, friends and wider networks. As a result of directly disclosing and sharing their personal experience of YOD diagnosis with others, the participants all experienced varying degrees of enhanced closeness and intimacy within their interpersonal relationships. Some spoke to the formation of new emotional connections which brought with them feelings of warmth and acceptance whilst for some, close bonds were broken by the diagnosis, not to be repaired.

The importance of being alive and being part of something

For the participants of the study, following their diagnosis, the recognition of both the fragility of life and the human condition led to changes in the degrees of importance each ascribed to certain events, endeavours and material objects. All the participants went through objectively negative life changes following their diagnosis including the loss of valued employment, increasing dependence on others and being forced to give up meaningful possessions or enjoyable hobbies. For William, succumbing the pressures to downsize and leave his beloved home of twenty-five years was heart-breaking. The house was in many ways William's personal legacy, having devoted many years to upkeep and home improvements. For him, the pain of this loss was at times intractable and something which is still felt to this day: Moving. Ah, yeah. Ah, we…looking back on it, it was, it was quite it was you it was…difficult." However, the move to the new home, a bungalow, better suited to his practical needs has not been all terrible. The house has a number of unexpected perks notably, being closer to town, which means that William can walk or bus most places. This has gone a long way towards getting back a bit of the independence which he felt he had lost; "It-it's grand isn't it […] start to get a bit of your own freedom back don't you."

The participants shared details of how they began to pay to pay greater attention too and develop a new found sense of appreciation for things that once seemed unimportant. The result of which was an enhanced quality of life and a recognition that life still had much to offer. Andy Lee expressed finding a degree of inner peace once he stopped fixating on future 'what-ifs'. He now directs his focus towards acknowledging and meeting his basic needs, which are in his opinion are all that one needs to be happy and contented.

> Andy Lee: "There's nothing I know more certain than I'm here today and what's happened yesterday. I don't know what's going to happen in 10 minutes […] I'm sure you're aware of Maslow's hierarchy, well you know what? I-I've been in that bottom line, because I think when you start going above that, you've got problems, food, shelter, warmth, security."

Changes in personal priorities were also spoken about and these appeared to be accompanied by increased enjoyment and an appreciation of life and the little things that make it worth living. With the onset of the COVID pandemic, William's involvement with local community and dementia groups was effectively put on hold. Watching his calendar of events dwindle towards stagnation, he was left feeling that his life lacked distinct purpose and enjoyment. However, having recently moved house, William was able to realise the benefits that restricted could have. Instead of going out, by staying at home, William was able to take the time to learn about the systems, technology and appliances that came with his new house.

The result of which were several homecooked meals and an enhanced sense of self-efficacy and mastery. “Getting used to cooking with the oven was bit of a problem occasionally […] I’ve trouble remembering where everything is, you know […] but I made risotto! […] it takes prep and concentration.”

Once sceptical of giving up his frenetic life, this forced period of slowing down has enabled, and in many ways empowered William to take more control over his day-to-day life, versus defaulting responsibilities to his wife. Without the pressures of time, his social life and the perceived requirements to keep busy, William has had the space to perhaps reflect on what he wants to, which has led to the emergence of new life priorities. In particular, William is keen to have his family properly settled within their new home. Drawing on his skills of a tradesman he has taken control over the garden renovation and has been instructing his wife on the proper use of a sledgehammer for the hole for a pond that she is working on: (William) “Yeah, so it’s a nice job we’ve made of it… trying to make a go of it […] You did it correct, it was nice.” William appears to have found a new daily structure that works for not only him, but his wife, which has led to greater levels of contentedness and happiness overall.

With the realisation that their dementia-related decline would be gradual versus immediate the participants were able to momentarily pause to take stock of the world around them, figure out what was truly meaningful to them and to act accordingly. As Barbara remarked “You-you don't-don't sit down and mope about it and, you know, that you don't deserve it. No, you don't deserve it, […] Nobody deserves it. I don't deserve it. All of the other people, the other young people don't deserve it, but if you got it, it's tough and shit. You've got it, you just got to deal with it.”

Thomas for one decided it was of the upmost importance to live in the present moment, focusing on what he viewed to purposeful actions that brought with them a sense of fulfilment and enjoyment. He spoke about the importance of acceptance and working towards a ‘new normal’ versus getting caught up with negative thoughts about his condition and the ‘what-ifs’ of the future.

> Thomas: “once we'd kind of started...to believe the diagnosis um it’s, and once we could see that my decline, if that's the word, you know, ah, er, hasn't been rapid, you know it has been quite slow uh and we...we still made sure that we went on long walks, we used to go on very long hikes and stay places, you know kind of walking and um, and um you know we still enjoy life you know. Um and that it was...You know it's important […] we don't think about the future. You know w-we don't, we don’t kind of look at, you know ...when people talk about... you know the end stages and all of that […] we don't know what’s in the future for us, you know what I mean? And so it's kind of y-y-you push that away. Um and you can't spend your time kind of... thinking about...that, you can’t, because you can't live.”

Andy Lee, Barbara and William also spoke about the positive impact of focusing in on what they still have versus have lost and how from this, each discovering unexpected positive outcomes which have positively contributed to life enjoyment and new-found sense of gratitude. Andy Lee for a time felt he had lost his ability to read, a hobby he immensely enjoyed, and as an academic contributed significantly to his sense of self and identity. It was only after a friend asked him to review a book that he was writing that Andy Lee had the following moment of clarity whilst on a coach trip to watch his favourite football team:

> Andy Lee: “I’ve just been sat with me nose in the book the whole time reading it. And she said, ‘I thought you couldn't read any longer’ and I said to her well, well I’m not being offensive to [Friend], I said this is a really good book but h-he’s just telling ya, you know he’s just giving you information and it’s, it's not some deep critical evaluation analysis, and it's not rea- like reading post-structuralism w-which I used to read. And t-this was a learning moment for me, she's just laughing, I said, what you laughing that? She said, ‘you do realize that 98 percent of the population can't read French post- structuralism’ […] So that, that was great. So I um, eh I-I persevered with [Friend’s] book, which I wouldn’t have done before […] You know I-I've started reading […] that's picked

> up slightly. Yeah. So that's another positive, actually. That's one for your tick box."

The participants were all able to attribute positive changes in their lives following their dementia diagnosis. All remarked on experiencing to some degree an increase in their enjoyment and appreciation for life that they were now leading. Even participants like David who found himself highly traumatised by his diagnosis reported being less concerned with life's trivial matters and is better able to focus on the things that bring him personal fulfilment: "I'll continue doing it as long as I've got the capacity. You know it's ah cause I mean, I'm enjoying it, you know feel like you're making a difference. You know so why, w-w-why fix something that's not broke?" (David)

Despite the many stressors, challenges and changes that may come as a result of dementia, all the participants spoke about the ways in which their diagnosis helped each to slow down, reflect upon and in some cases revise their personal priorities, the result of which was a real improvement in life satisfaction. This satisfaction appeared to at a level that could only be achieved when the participants were able to see through life's inconsequential distractors and instead focus on what truly is important and valuable to them. Reflecting on how precious life is and there was a unanimous consensus on the importance of living it to the fullest: "I don't see life as sacred in terms of some white God up there in the sky. But do value it and I do love it and I do celebrate it, and I love existing." (Andy Lee)

Life's a lottery

It's well known that chronic or life limiting illnesses such as dementia have the potential to profoundly impact the diagnosed individual's day to day life. Although the participants of this study all reported objectively positive growth and change as a result of dealing with the confrontation of their dementia diagnosis, this is not universal experience. What emerged from the data was a set of shared personal attributes which appeared to have been influential to the participant's experiences of this positive growth-related personal change.

Courage to let go

For the participants of the study, their PTS symptoms appeared to be maintained by trauma cues which included threats to personhood, premature aging, increased dependence and the loss of life purpose: "I know a lot of people with dementia […] it's cost them daily. Some people, the consequences f-for them makes the consequences for me fade into insignificance." (David) It is thought that when trauma-related cues are met with openness, awareness and a desire towards living a good and meaningful life recovery is not only possible but inevitable. It was only when the participants decided to let go of their rigid responses to their individual trauma cues were they able to begin to see their dementia diagnosis as less threatening as it once appeared. Thus, creating a sense of space for the personal reflection and exploration which was necessary for their experiences of self-mourning, redefinition, reconstruction and positive growth.

> Thomas: "suppose if you'd interviewed me two years ago, you'd have been having a very different experience, well I don't know how different but there would have been something that was not the same as now, I would have been far more anxious and far more concerned about the future and, and um....also, quite resentful [...] Um but, but it-it's not the same anymore, you know? It's, it's ah...so it was very hard to kind of be positive in-in-in-in those first few months. Yeah because it... Whereas now, it's-it's um it's an inconvenience."

For the participants who from the onset maintained an open, flexible and mindful awareness of their diagnostic trauma, a rare opportunity for further self-reflection was made available. Through a rediscovery of lost values which were perhaps misplaced amongst the chaos of pre-dementia life, participants spoke about how reconnecting with these values supported their individual recovery from the trauma. Providing opportunities to connect with their values were found to promote a greater appreciation of life, and renewed commitments to meaningful relationships and activities and personal pursuits. For Barbara this included her brief stint on television where she was able to meet and support other people with dementia whilst spreading her message of awareness.

> Barbara: “I said, I'm in. I said, it's gonna get the word out there and it's going to show people that we're not old […] needed something to do as well... to occupy me and my mind. So I thought, why not? I'll give it a shot. So, yeah. It was great. It was, [chuckles] you know. It was brilliant meeting all the different people, you know. The, you know, different walks of life, different ages, different types of dementia.”

The degree to which they viewed themselves as open and flexible also appeared to influence how the participants utilised their diagnosis as either negatively defining the self as ‘someone with dementia’ or more advantageously regarding themselves as ‘a person living alongside dementia’. For David the strong attachment to his self-conceptualization of the ‘fiercely independent person’ he was prior to his diagnosis bred a degree of dysfunction. The rigid attachment to this subjective element of himself and the ‘loss’ of this led to him experiencing significant distress and difficulties in accepting his diagnosis. This could be considered to have, to a degree, slowed down his positive growth. However, once ready to let go of this static version of himself David developed an intrinsic sense of courage through which he was able meet himself as ‘David who lives with dementia’. Consequently he discovered a whole new range of life possibilities that were available to him and readily jumped at the opportunities to engage with those that fit who he was now.

In contrast, Andy-Lee who adopted a form of flexible perspective-taking, felt empowered to let go of the subjectively formed self and instead observe his direct experiences with on-going self-awareness, without overidentifying with his diagnosis or trauma-cues and acknowledging that he as a person is dynamic and ever changing. His high degree of openness and personal flexibility decentralized the trauma, supporting movement towards viewing himself as ‘a person living alongside dementia’, resulting in more positive growth.

> Andy Lee: “It's... like a metamorphing process really. Um, I've never had a fixed, never had a fixed feeling of self. It’s self is always, if self in my opinion, if self isn’t, um ah, I-I’m struggling for the word, self is fluid, I’m constantly changing,

> […] And I think it comes back to what I was saying earlier on, you know this is me, therefore I accept me."

The great gift of anger

Following all their diagnoses, the initial period of struggle elicited a swell of strong negative emotions. David, Thomas and Barbara all felt angry and resentful that they were and still are neglected by dementia services that promote inclusive support for all those affected. Reflecting on his experiences David highlighted that this experience was not unique to him and that many YPwD are left to fend for themselves following their diagnosis, evoking considerable distrust and anger towards the systems that are meant to protect them.

> David: "What I can't cope with is whatcha call it, you know organizations that should have p-provided that support to me who didn't. And then you know th-th-they prided themselves. Because it's not unique to me again, now you have got the benefit of you know meeting and other people with dementia and it's a common factor, that you know th-th-they don't receive the report eh, the support that organizations insisted they provide kind of thing, people are j-j-just thrown to the wolves basically, right, you've got you diagnosed. So it's learn to live with it […] I was so frustrated and angry, I was really, really angry."

In the years following her diagnosis Barbara in particular feels as though she is actively waging war against those organisations which she felt wronged by:

> "I had to, uh, basically had to fend for myself with dementia, do you know what I mean? It's like, fucking hell. And-and that's shocking because everybody and this-this is the shit kicker, they apo-- I hate [Organisation], we're at war, me and them. I-- And-and [Organisation], I hate both societies. I think they're wankers. […] Do you know what they said to me? They apologized to me, to my face that I was off the radar, that's why I didn't get any help. That's not fucking good enough."

Her anger which has fuelled this oppositional stance has also empowered her to feel more confident and able to 'tell it like it is' and to 'call out' those in positions of power and authority for their shortcomings. This anger has been particularly helpful in her role as 'Dementia Warrior', enabling Barbara's voice to carry much further.

> Barbara: "I went to, um, I did a conference in 2018, I think it was at the, um, is it the [Conference Centre] in Westminster where I stood up and, uh, fucking loads of them […] Neurologists, um, there was a few from like the top hospitals in London and all that bollocks, um, was it to help the aged or whatever they're called over there? All the-the big heads, do you know what I mean? So, yeah, so I had to tell them, um […] It's just basically I just told them to get their fingers out of their asses and start fucking looking and it's not like, you know, it's gone up now, how many people, young people, under the-- It's not under the age of 65, that's fucking bollocks and it's not even under the age of 60. It's under the age of 50 and the amount of people-- and they're diagnosed every fucking day under the age of 50, do you know what I mean? So I just basically told them they've got to get their fingers out of their asses and start, you know, supporting people because nobody supported me, nobody did anything for me. I had to do it all by myself. Nobody put an arm around my shoulder and said, Oh, there, there, Barbara. It's gonna be okay. We'll do this and we'll do that. Oh, no, I had to fucking do it all myself. And I've heard some scary stories, you know, through people who've been diagnosed and they've wanted to kill themselves."

Andy Lee grappled with anger and disappointment after feeling forced to accept a diagnosis of depression on the basis of his belief system: "That was the worst part of my diagnosis, if I'm being perfectly honest. Not the fact that I've got it, but the reaction of a really educated man was not being able to understand the difference between somebody who's suicidal and the person that wants to pursue a humane, voluntary death." (Andy Lee) This experience acted as another motivating factor for his campaign to ensure that all humans, with dementia or not, have the right to a self-determined and dignified end of life.

A positive relationship between and anger and positive growth-related personal change seems almost counter-intuitive. Anger as an emotion is often associated with negative connotations as something that causes one to be miserable and harmful. Yet, what surfaced from the participant's accounts was that their experiences of anger, were not unfavourable, but actually appeared to be rather protective and proactive in nature, prompting committed actions towards living life to its fullest. "I suppose trying to think of what to do and cram everything in in the next few years. What else could you do? […] You think, right. I can either lay down and just die and just, you know, be all doomy and gloomy or I can say, fuck it. Just get up and say-- bring it on." (Barbara)

For this study's participants, their anger was not something to succumb to, instead it served the purpose to promote a sense of conviction that mobilised adaptive coping behaviours which prompted the likes of David and Barbara to take on high profile public facing advocacy roles which served a dual purpose to (a) achieve some form of vindication for all the wrongs they suffered during their early days post diagnosis and to (b) protect other YPwD from experiencing what they did. For Thomas, who is usually quite mild-mannered, his experiences of anger filled him with drive to speak up and dispel myths about what a typical dementia patient is. Thomas is also passionate about the need change diagnostic procedures which in his view are ill-suited for younger people and to educate hospital staff on how to respond more sensitively to their patients who present with a dementia diagnosis alongside another condition.

> Thomas: "you know the f-first point getting referred to a memory clinic you can be asked ridiculous questions, you know doesn't really help. It's quite belittling. Um and then one time, I was in, uh I think one of the cardiac units and then the nurse said 'oh' when I said I've got dementia and she said 'I want you to count 20 for me'. And that's quite demeaning really."

In the context of the current study, the participant's individual experiences of anger, which resulted from perceived social injustices could be thought to have contributed to their experiences of positive growth-related change through creating a desire to make positive change in the world around them. This is clearly demonstrated throughout the participant accounts where their behavioural responses to the presence of their anger resulted in purposeful engagement with new, meaningful tasks and experiences.

Work with what you've got

Specific combinations of individual factors such as personality traits, early-life experiences, as well as social and environment elements all appeared to be influential in the participants' experiences of both learning to live with YOD and positive growth-related personal change. Within their accounts, all the participants referenced specific personal characteristics including being “chilled” (William), “hardworking” (David), “strong” (Barbara), “cooperative” (Andy Lee) and “open” (Thomas) which they believed to be constructive. For William and Barbara, they cited their personality and character as being immensely important in helping them cope in the early days. Barbara credits her inner strength and resilience to have helped her through not only her diagnosis and the death of her husband but to have played a pivotal role in pushing herself forward during times of hardship.

> Barbara: I had to be the strong one. I had to step up. I had to shove my frontotemporal behind me, and, you know, think what I had to do […] You can't break down. You gotta stay strong for them […] But that's just me because I've got one-- You know, when you have a lot of bad things happen to you in your life, it makes you a lot stronger. And the stronger you get, the more resilient you are to bad things. So if bad happens now, you just shrug it off and go, well, it's happened. Deal with it. Do you know what I mean?

Barbara expressed gratitude for these traits, acknowledging that without them, her experiences of YOD and positive growth would have been very different. Recognising these differences between herself and peers, Barbara has been able to use her infectious personality to help brighten the lives of other YPwD who are struggling with the condition. Supporting other YPwD in this way fills Barbara with an immense amount of pride and joy, whilst positively reinforcing her new life purpose of being a ‘Dementia Warrior’.

For David his industrious nature eventually proved to be highly useful during the period of redefinition and reconstruction. His pride, innate sensibility and strong sense of justice provided him with a strong platform, for which once ready, to seek out truly meaningful and purposeful work. Once on the verge of succumbing to his perceived loss of self, these personal traits and characteristics acted as protective factors. Drawing on his earlier life experiences as a trade unionist, David shifted his focus away from the threats posed by his dementia, and instead directed his attention towards various advocacy roles, using his early and present lived experiences to help like others.

> David: "Well, I'm always one to speak up for the underdog, you know like whatcha call it em in work, whatcha call it you know I was a member of a trade union emm and you know and I was a steward, so I would be going to management w-w-with whatcha call it emm arguing where things were going wrong where people were being treated right that kind of thing. So, I've always had you know whatcha call it em s-stood up for like whatcha call it the people who were weaker."

Andy Lee credits the accessibility of healthcare to have been instrumental in his experience of having a relatively positive diagnostic experience. In comparison to participants such as Thomas, William and Barbara whose diagnoses took years, the time from initial concern about symptoms to actual diagnosis was a matter of days. Andy Lee spoke highly of his local NHS trust and minus his experiences with the diagnosing psychiatrist, found the process to be collaborative, exploratory, and non-judgemental.

> Andy Lee: "Really fortunate up here, because I mean, I hate to say there's the postcode lottery with the NHS, and I live in the postcode, that doesn't suffer badly from that […] And literally, within two or three days, I got a phone call from somebody from the memory clinic and they said, you were aware that was going to call? Yes, they did the memory assessments, say well, that isn't, that's not a particularly good score. And what we'd like to do is like you to come into the... I think, that was on a Wednesday, ah and they said, what I'd like to do is for you to come into to me to the memory clinic the following week, so that was the following Friday, so like a week on Friday which is amazing. Isn't it?

> And, um but we'd also like you to go for a scan if that's alright. So, I had the scan on the Thursday, I thought that's crazy, cause there's no way the results of scan coming on about Friday morning, but again, lucky postcode, it was."

It appeared that this short turnaround left Andy Lee with less time to focus his worry on the 'what-ifs' which had the benefit of managing the perceived threat posed by a potential and later actual dementia diagnosis. Reflecting on his life experiences of being raised within 'hippie culture', Andy Lee is adamant that this helped him to not only avoid getting caught up in the 'what-ifs' but also bolstered his ability to navigate and process the trauma of his diagnosis bringing him to a place of acceptance.

> Andy Lee: "Do you know what I-I-Ive was always gone through life on the basis that d'you know I was born in 50s, I was brought up in the 60s and it was a pretty chill lifetime. […] hippie wasn't a fashion statement. It was an ethos. And it was a belief system. […] If that's what hippie was, then I've not changed. And this. And a big part of that was acceptance […] there was still that core value if you accept things."

For all the participants their diagnosis disrupted emotional equilibrium and quality of life. The presence of an accepting, supportive and strong network of social support was seen across all the participant's accounts as being beneficial to the process of adjustment and return to equilibrium. Thomas in particular spoke at length about the role that his wife took in preventing isolation and promoting wellbeing. He is adamant that without his wife's support, his life would look very different to how it does in the present.

> Thomas: "I will say that um [Wife] s been um the driver on all of that, you know. Um whereas I, I think, you know it would be easy to see you get very inward, very inward. Um, and um...so although, o-our world is shrunk in many ways uh and things have to be very carefully worked out and... managed, um we...we carry on. You know w-w-w-we go forward […] I think [Wife]'s kind of very strong when it comes to um… you know, I think she worries about me more than I worry about me [laughter]. You know because I don't know if I do worry about

> myself anymore...um you know but you know she’s um...she will have to cajole me sometimes and say look should we do this and I’m, um one thing that I’m really bad at is, is, is, is um... …. planning, you know. And s- and um my first reaction and um [Wife] knows it's not so important to kind of listen to my first reaction to something you know… it might be the next day I’ll say well actually that’s quite good isn’t it, you know [laughter]. You know?”

What can be inferred by the experiences of the present study’s participants is that one’s experience of PTG is influenced by a number of internal and external factors. It appears to be a gradual process that cannot be expected to occur simply overnight. For the participants of this study iterative and incremental development and change seems to have been their vehicle for achieving PTG following their diagnosis. Wherein after each challenge faced, there was a period of reflection and adaptation to the new normal.

This truly embodies the central theme of this research, which is, as astutely stated by Barbara: “They can do anything. They’ve just got to know that they can do it. Once they know they can do it, they can do it. Do you know what I mean?... There’s more to life then the big D word. Do you know what I mean?”

Chapter 4: Discussion

4.1 Introduction

The main aims of this mixed methods study were (1) to establish the commonality of both YODR-PTSD and YODR-PTG and (2) to explore in great depth the ways in which YPwD may experience their diagnosis as traumatic and the individual experiences of positive growth that may have resulted from their struggles with it. This chapter will seek to summarise the results and findings from both quantitative and qualitative methods, along with the sequential integration of both results and findings to best address and answer the hypotheses and research question. This chapter will also identify the strengths and weaknesses of the study. Directions for potential future research within this area will be identified, as well as the implications of the current study findings towards the discipline of Counselling Psychology. Reflections of my own experience as a researcher will be explored and finally a conclusion will be drawn.

4.2 Study One: Quantitative Findings

Due to the sequential nature of this research, it has been split into two phases to address the research aims. Phase one focuses on the quantification of the commonality of both of YODR-PTSD and YODR-PTG and to determine if socio-demographic variables and/or specific psychological phenomenon influenced or contributed to the experiences of YODR-PTSD and YODR-PTG. The following section will present the three main findings from the study as tested by hypotheses one through five.

4.2.1 Finding 1: YODR-PTSD

The first quantitative finding strongly suggests the diagnosis of YOD is a catastrophic event which can elicit a trauma reaction. In Phase One, participants responded to the IES-R questionnaire based on their experience of being diagnosed with YOD; 86% of participants fell within the category for ‘clinically concerning PTS’ or ‘probable diagnosis PTSD’. Participant scores were relatively high across all three subscales; however, scores within the subscales of intrusions and hyperarousal were particularly high for this sample. Returning to the literature these results reflect not only the link between the underlying psychopathology of dementia and threat responses, but also the experiences of psychosocial distress following the diagnosis of a progressively debilitating disease at a younger age.

A YOD diagnosis is typically associated with profound dysfunction and disability. Prematurely faced with aging and perceived threats to livelihood and life longevity, YPwD have frequently reported an overwhelming sense of loss, grief and betrayal following diagnosis (Clemerson, et al., 2014). This reaction could play an important role in the development of YODR-PTSD where fears and worries about future survival, social stigma, and the persistence of new and ongoing life-threat creates a sense of inescapability and hopelessness. For some YPwD, the sudden and complete loss of control could be considered the trauma event itself.

Given the high degrees of personal interpretation and subjectivity related to how traumatic events are received and processed, the objective severity of the dementia diagnosis itself is an important factor to be considered in the context of YODR-PTSD. Studies examining PTSD within illnesses associated with significant personal loss/loss of function found far higher levels of traumatic stress than in ‘low-risk’ conditions (Butler et al., 1999; Chalfant et al., 2004; Meentken et al., 2017; Posluszny et al., 2011). Regarding the present study’s findings, variables like insensitive diagnostic experiences, real or perceived loss of valued work and life role are highly distressing experiences that likely contribute to the extreme objective severity of diagnosis, providing the foundation for YODR-PTSD.

The distress is very likely heightened by elements of psychopathology including physiologic changes to brain structures and dysfunctions within the cholinergic system. Hippocampal atrophy is considered to be a hallmark of dementia and has been observed to impact not only memory and learning but spatial navigation, emotional behaviour and importantly, the regulation of hypothalamic functions (Dhikav & Anand, 2012; Vijayakumar & Vijayakumar, 2013). During adverse or traumatic events (e.g., diagnostic testing or confirmation of dementia diagnosis) activation of the hypothalamic-pituitary-adrenal (HPA) axis triggers a cascade of events resulting in the release of cortisol, a neurotransmitter which typically facilitates the stress response and promotes return to homeostasis and allostasis (Schulkin et al., 1994). In dementia, hippocampal damage results in an excess of free cortisol, which over time is known to result in receptor desensitisation. This impedes return to allostasis, which in the presence of trauma cues leaves the individual with increased susceptibility to symptoms of hyperarousal and/or intrusions (Greenberg et al., 2014).

Following trauma-events cholinergic deficiencies within the hippocampus could be hypothesised to also contribute to YODR-PTSD. Cholinergic dysfunction and deficits in transmission have been observed to influence many aspects of human cognition and behaviour from information processing and memory encoding to disturbances in emotional experiences to disinhibition and increased susceptibility to distraction and novelty (Mega, 2000; Weber, 2008). Dementia-related dysfunctions within the cholinergic system at the time of a trauma-event can lead to difficulties in supressing thoughts and emotions related to the experience. This leaves the individual more vulnerable to experiencing an overwhelming uncontrollable onslaught of negative threat-based emotions which could be a major component of the trauma itself. The disinhibitory effects of dementia-related declines within the cholinergic system was demonstrated throughout Barbara's accounts by her labile mood and use of explicit language. Her descriptions of living in constant battle between 'herself' and her 'dementia-self' further highlighted her struggles of living with and responding to PTSD symptoms "you're fighting with it every day, and it's like, I'm gonna say something. It's like, no, you're not."

The results of Phase One confirm the first research hypothesis which stated YPwD may experience trauma associated with their initial diagnosis. These findings are consistent with present literature which suggests the diagnosis of a life-threatening or life-limiting illness can shatter one's sense of safety within the world resulting in the development of PTSD. The findings from the current study are important as to date only a single study has attempted to ascertain if the experience of receiving a dementia diagnosis is a traumatic event that fulfils criterion A of PTSD as seen within the DSM-5 (Dunham et al., 2020). The current study findings confirm that illness-induced PTSD can be an outcome of a YOD diagnosis whilst also establishing commonality of this experience within the sample.

Established within the literature and echoed by the participants of Phase Two, a diagnosis of YOD is a highly objective and subjective distressing event for several reasons. Firstly, due to their relatively young age, the diagnosis is much less expected than for older people. This has been seen to make obtaining a diagnosis particularly difficult. Research has uncovered that many YPwD felt that their initial concerns were dismissed by professionals. This resulted in feelings of fear, anxiety and shame which made the individual less likely to seek follow up support or a second opinion. A participant in the study by Beattie et al (2004) referred to their experiences with diagnosing professionals as “absolutely brutal … It went from being casual to an extreme. It’s just so unprofessional” (p. 363). Conflicts between the individual’s young age, and societal stereotyping of what it means to be a typical ‘dementia sufferer’ can be thought to add a degree of horror to the diagnosis. Phase Two participants recalled that following diagnosis, images of late-stage dementia sprung to mind, leaving the individual with the view that life itself was slipping through their fingers. This already difficult situation is compounded by loss of abilities which can elicit a profound sense of helplessness (Rabanal et al., 2018). Therefore, it is both the diagnosis and symptoms that are viewed as a threatening experience as it feels as though “somebody had pulled the plug out of everything” (Rabanal et al., 2018, p. 4).

4.2.2 Finding 2: YODR-PTG

The second quantitative result indicated that participants experienced varying degrees of positive growth following their dementia diagnosis. The statistically significant positive relationship found between the total IES-R score and PTGI score confirmed that the dementia diagnosis was an event seismic enough in nature to shake the fundamental schemas, beliefs, and goals of the individual (Tedeschi & Calhoun 2004) acting as a catalyst for cognitive processing and subsequent growth. This supports both the second and third research hypotheses that YODR-PTSD can elicit a PTG response and despite cognitive limitations, YPwD can experience PTG. It is widely known that the key manifestation of dementia is progressive cognitive impairment, which worsens over time. As such, one could draw the assumption that it would not be possible for an individual with dementia to experience PTG, a cognitively mediated process. The results of this study are therefore significant in that it has been able to establish both presence of PTG and commonality of this within the participant group wherein 54% reported experiencing low-moderate growth, and 35% indicated experienced moderate-high positive growth.

Cognitive processing is viewed to be an essential step in the process of PTG. It consists of both intrusive cognitive processing, such as negative and unwanted ruminative thoughts (Ehlers & Clark, 2000), as well as more deliberate cognitive processing (Calhoun & Tedeschi, 2006) which is characterised as being purposeful in nature and includes sense-making of the trauma and problem solving (Davis, 2000; Martin & Tesser, 1996). Calhoun and Tedeschi (2006) suggest that the two types of processing are sequential but generally co-exist. The cognitive processing that occurs in the immediate aftermath of a traumatic event is primarily intrusive whereas deliberate cognitive processing has been observed to occur later on. For the participants of this study, their diagnosis was considered highly threatening as it was viewed to compromise several core elements of the self, threaten the successful resolution of the midlife crisis of generativity and jeopardise one's perceived place within the world, giving way to the period of intrusive rumination and mourning as seen in the qualitative subordinate theme of '*the stages of grief*' with the beginnings of deliberate processing seen in the qualitative subordinate themes of *'who am I now?'* and *'Redefinition, reconstruction and working through'*.

The experiences of the present study's participants are not unique, previous studies have observed in the period following diagnosis many YPwD experience negative and intrusive thoughts related to age and perceptions of dementia, the impact of the diagnosis on life, and potential future losses (Pippin-Young et al., 2011). Following the initial shock of diagnosis there is a felt need to 'save face' and cover up the diagnosis to protect oneself from the uncertainty of others' reactions and perceptions of them (Pippin-Young et al., 2011; Aldridge et al., 2017; Nwadiugwu, 2020). For many YPwD, and certainly the participants of the present study, shame and self-criticism appear to mediate the negative intrusive ruminations experienced immediately following diagnosis. This observation is supported by

Harman and Lee (2010) who too observed the presence of shame as associated with self-criticism in trauma presentations. It appears the act of evaluating oneself in a negative manner not only maintains levels of shame, but also contributes to other difficulties commonly associated with trauma (Boyer et al., 2014).

There are no studies explicitly examining deliberate rumination in YOD, however what was highlighted in Pippon et al's. (2011) study was the importance of YPwD being purposely active and involved. By doing so this appeared to give YPwD a reason to keep on living versus becoming entrapped within dementia-related deficits, whilst promoting the view that being diagnosed with dementia is not a helpless situation. The narrative accounts found both within Pippon et al and the present study emphasised the importance of deliberately focusing on the positives and using intact skills to maintain a sense of worth, control and continued engagement with the world. This is hypothesised to be a crucial step towards positive growth-related change and PTG.

It was observed that following their individual processes of intrusive (self-mourning) and deliberate (personal redefinition and reconstruction) processing, the participants were able to successfully establish modified assumptive worlds. Reaching new world views whilst developing new beliefs and goals which resulted in PTG. Of the five domains, the participants scored highly across relating to others, new possibilities, personal strength, and appreciation of life. This could be for several reasons; viewed as directly relating to domains of new possibilities, personal strength and appreciation of life (Calhoun & Tedeschi, 2006; Lindstrom et al., 2013) the participant's engagement in deliberate rumination was seen to involve considering the possible positive repercussions of their diagnosis (e.g., "I am much stronger than I had thought') and how they wanted to change their day to day lives moving forward (e.g. "I am going to live each day to the fullest"). Throughout all the participants' accounts, there appeared to be purposeful and conscious attempts to remind themselves of benefits experienced as a result of being forced to face a difficult diagnosis (e.g., Barbara and David adopting advocacy causes).

The timing of cognitive processing is influential in the degree of PTG experienced. Those who engage in deliberate rumination sooner after the event are seen to experience greater posttraumatic growth in comparison to those who engage in extensive intrusive cognitive processing (Taku et al., 2009). Studies have shown that within clinical populations (e.g., cancer patients), time since diagnosis is a factor strongly associated with PTG (Helgeson et al., 2006). Time since diagnosis has been observed to be directly related to greater reported levels of PTG. A possible explanation for this is that for those recently diagnosed with a life-limiting illness, there has not yet been opportunities to develop knowledge and coping or to derive meanings and/or benefits from their condition. The results of the present study corroborate this; YPwD diagnosed two or more years ago reported higher levels of PTG. It should be noted this was not a significant relationship and is more likely reflective of a combination of adjustment, active coping, and deliberate rumination.

Disclosure of dementia status could also contribute to the participant's experiences of PTG. The general psychological benefits of disclosure have been well-documented (Lepore & Smyth, 2002; Niederhoffer & Pennebaker, 2009) and research indicates that self-disclosure can be related to growth across all five domains (Henderseon et al., 2001; Tauku et al., 2009). In the context of a dementia diagnosis, and the present study's participants, the act of self-disclosure may help to address and alleviate shame. When the diagnosis is no longer viewed as a 'dirty secret' the individual is effectively freed up to begin the process of deliberate rumination and look for new ways forward with life. The act of disclosure also has the potential to unearth new opportunities, to meet like others and to engage in new and meaningful activities, all of which have been documented to contribute to greater levels of PTG across the five domains (Taku et al., 2009). This was directly observed across almost all the accounts of the Phase Two participants where the likes of Thomas and William experienced the benefits of being able to form new and/or deeper social ties following disclosure of their dementia.

Sociocultural influences are also considered an important component to the development of PTG (Weiss & Berger, 2010). Research has found that if themes of PTG are made readily available to people coping with major stressors, they are more likely to report growth. For example, the ‘warrior’ narrative associated with fundraising campaigns for cancer is seen to promote both personal strength through the resolve to ‘fight’ the illness and appreciation for a ‘new lease on life’ once it is overcome. Unfortunately for those diagnosed with YOD, such a narrative has yet to be developed. It was observed across the Phase Two participant’s accounts that the lack of positive sociocultural associations in relation to dementia contributed to their experience of diagnosis as a trauma event. Drawing on their own experiences of discomfort caused by negative sociocultural experiences of dementia Barbara, Thomas and David used this as an opportunity to become involved in awareness raising and advocacy to help reframe sociocultural narrative for future generations of YPwD. By doing so each was prompted to engage in varying degrees of deliberate cognitive processing the outcome which was observed to be directly related to their individual experiences of positive growth-related change.

4.2.3 Finding 3: Influencers of PTG

The third finding of this study focuses on what variables influence the experience of YODR-PTSD and YODR-PTG. Sociodemographic variables including marital status, education, age range at diagnosis, time since diagnosis and religion were found to be unrelated to both YODR-PTSD and YODR-PTG. This disconfirmed hypothesis four that sociodemographic variables will impact on both how traumatic one perceives the diagnosis and subsequent experiences of positive growth.

Given the progressive nature of dementia and the immense sense of vulnerability it projects on to the diagnosed individual, these findings are surprising but not entirely unexpected. Exploring the impact of such variables in other clinical populations including cancer, HIV and cardiac patients, there appears to be no clear-cut consensus on the role sociodemographic variables play in the development of PTSD or PTG, and substantial disparities appear within the literature (Bennet & Brooke, 1999); Dinenberg et al., 2014; Jeggesen et al., 2012; Roberge et al., 2008; Copland & Dunmore, 2009; Vilchinsky et al., 2017). This supports the notion that the psychological impact of disease is not uniform across patient groups; and whilst sociodemographic variables can be influential, this is highly dependent on the contextual factors surrounding the condition, and how individual variables may intersect this.

The study results determined the psychological phenomena of self-compassion and resilience were influential on the development of YODR-PTSD and YODR-PTG respectively. Self-compassion, as measured by the SCS-SF was found to have a significantly negative relationship with IES-R scores, indicating that individuals with lower levels of self-compassion were more likely to view their diagnosis as a traumatic event. A likely explanation for this would be the presence of social stigma and shame in relation to the dementia diagnosis. Shame has been documented to be closely linked to poor levels of self-compassion (Winders et al, 2020), and the role that it plays in PTSD has been acknowledged within contemporary models of PTSD such as dual representation theory of PTSD (Brewin et al., 1996) and Ehlers and Clark (2000) cognitive model. The latter which proposes that persistent PTSD only develops if the individual processes the trauma in way that results in ongoing current threat. Although fear is the emotion that relates most obviously to threat, within this model, attention is paid to other emotions and the roles that they play in threat-maintenance. Threat is therefore viewed as both external (e.g., seeing the world as a dangerous place) and internal (e.g., viewing oneself as a less capable or acceptable human). The presence of persistent shame can pose high levels of internal threat as it attacks an individual's sense of self and psychological integrity resulting in feelings of powerlessness, inferiority, and a diminished sense of self-worth.

In the context of the present study, it could be hypothesised instead of fear YODR-PTSD is maintained by helplessness, shame and ongoing self-criticism (Lee et al., 2001; Stiel & Ehlers, 2000). Externalised and internalised stigma result in shame through problematic emotional and cognitive experiences of embarrassment, self-criticism, and self-blame (Cheston, 2015; Preston et al., 2007; Mitchell et al., 2013). Cheston (2015) who comments on elements of the experience of shame, suggests that fears of losing control or losing oneself are central to the experience of shame in dementia. Interviews and excerpts from therapeutic groups (Snow et al., 2015; Watkins et al., 2006) as seen in Cheston (2015) exemplify this and provide examples of participants' fears of 'going mad' and 'ceasing to be' (p. 13). Further studies by Lishman et al (2014) and Aldridge et al (2017) show how dementia symptoms have been found to make people feel different and afraid of being judged, leading to shame-driven social withdrawal. In Phase Two David in particular spoke to his experiences of shame following diagnosis, sharing how these lead to negative personal transformation from an outgoing and gregarious to insular and afraid. Andy Lee too referenced a time following his diagnosis where he experienced high levels of judgement from the diagnosing clinician, which lead to experiences of shame towards not only the diagnosis but his long-standing beliefs. The experience was traumatic and as Andy Lee put it "was the worst part of my diagnosis, if I'm being perfectly honest".

Resilience as measured by the CD-RISC was found to not have a significant relationship with overall PTGI scores, however significant positive correlations were found between it and the domains of relating to others, new possibilities, personal strength and appreciation of life. Often confused with the process of resilience, Tedeschi and Calhoun (1996) emphasise the transformational nature of the phenomenon of PTG; distinguishing that process resiliency is the ability to move forward following adversity whilst PTG is the movement beyond pretrauma levels of adaptation. In the context of this research, resiliency is treated as a broad cluster of personal traits (e.g. optimism, hardiness, strong self-esteem, positive affect, psychological flexibility, and a tolerance of negative emotions and failures) which act as a conduit for movement beyond pre-trauma levels (Connor & Davidson, 2003; Oginska-Bulik & Kobylarczyk, 2016). This is thought to be achieved through activation of positive appraisals (challenge) which then give way to active coping and positive adjustment (Roesch et al., 2002). For the participants of this study individual differences in trait resiliency are likely mediators for both recovery from diagnostic trauma and positive growth-related change.

A YOD diagnosis yields a huge amount of uncertainty and insecurity in the context of autonomy and self-efficacy, employment and finances, changes in relationship dynamics and heightened fears for what the future may hold. It could be thought that YPwD with high trait resiliency are more likely to respond flexibly, and change their cognitive, affective and behavioural responses in order to successfully attenuate distress, adapt to their new circumstances and experience positive growth-related change. This was observed within Barbara and Andy Lee's accounts of coming to terms with their diagnosis and adapting to post-diagnostic life. Their high degree of trait resiliency appeared to minimise periods of intrusive rumination giving way to deliberate rumination and meaning-making faster. In contrast, for the likes of David his lower degree of trait resiliency appeared to extend his period of intrusive rumination, decelerating his forward movement towards positive growth. It could be concluded that trait resiliency plays an important role in the participant's experience of PTG.

These findings are important for research into the area of YOD and highlight the detrimental impact that wider societal and contextual perceptions of illness and disease can have on the people who have been diagnosed. A YOD diagnosis results in feeling as if one is out of time and represents a significant loss of control. YPwD are vulnerable to self-judgement, self-criticism, and shame, reinforced by negative stereotypes, lack of global representation and poor diagnostic experiences. Furthermore, YPwD have reported feeling marginalised and pressured to succumb to negative appraisals of loss and threat due to individual and social perceptions of what constitutes a person with dementia (Nwadiugwu, 2020). Encouragingly, this study has found that contrary to popular opinion, a dementia diagnosis does not mean that one's life is over. As soon to be discussed in section 4.3, the diagnosis, whilst unwanted has the potential to act as a catalyst for personal re-evaluation and positive growth.

4.2.3 Summary of findings related to hypotheses

The first hypothesis tested within this study was YPwD will report experiencing trauma associated with their diagnosis, great enough to elicit a PTS/PTSD response. Phase One sought to establish the commonality of YODR-PTSD. Hypothesis one was met with 86% (n=32) of participants achieving 'clinically concerning PTS' or 'probable diagnosis PTSD' scores as measured by the IES-R. Literature supports the hypothesis that being diagnosed with a life-limiting illness such as YOD can be a traumatic event which violates worldviews, creating a sense of current and ongoing internal threat. The findings of this study support those of Dunham et al. (2020) and confirm that a dementia diagnosis can elicit significant fear, shame, and a profound sense of helplessness which feels inescapable.

The second and third research hypotheses, which sought to establish the commonality of YODR-PTG were notably met. The literature revealed that PTG is a process which takes time and is influenced by several factors. However, it is the engagement with both intrusive and deliberate cognitive processing that is viewed as essential to experience PTG (Ehlers & Clark, 2000; Calhoun & Tedeschi, 2006). The results of this study are significant as they confirmed YPwD can experience cognitively mediated phenomenon such as PTG, and directly challenge the assumption that YPwD would struggle or are unable to engage with such phenomenon due to disease-related impairments.

The fourth and fifth hypotheses which state that specific sociodemographic variables and psychological phenomena would influence the experiences of PTSD and PTG following a YOD diagnosis were partially met. Significant correlations were found between YODR-PTSD and self-compassion and YODR-PTG and resilience. The literature highlights the influential nature of both phenomena on individual appraisals of dementia and ones' ability to readily engage in deliberate cognitive processing. A significant positive relationship was found between self-compassion and resilience, demonstrating that YODR-PTSD and YODR-PTG are influenced by the relationship found between trait resilience and self-compassion. It could be further hypothesised that YPwD with greater self-compassion will also demonstrate trait resilience; a combination which was seen in the present study's participants to be advantageous in facing challenges posed by their dementia.

4.3 Interview findings

In phase two, IPA was adopted to analyse the data from the semi-structured interviews that aimed to answer the research question: In what ways do individuals diagnosed with YOD experience PTG? The results of this phase focussed on how YPwD made sense and worked through their diagnostic trauma, moving towards and eventually experiencing positive change and growth. Three superordinate themes emerged from the data during the analysis process (1) 'Learning to live with dementia', (2) 'More to life than the "Big D"' and (3) 'Life is a lottery'.

The superordinate and subordinate themes reflect the participants ‘story telling’ about their experience of YOD, in which they chronologically shared their experiences of their dementia.

The first theme, *‘Learning to live with dementia’* encompasses the participants’ experiences from initial symptom manifestation through to present day. It represents a classic rise and fall character arc wherein the participants were faced with a seemingly insurmountable obstacle (i.e., their diagnosis) and how they eventually overcame this, ultimately changing the way in which they see and experience the world.

The subordinate theme of *‘Stages of grief’* highlights the difficulties faced by the participants in coming to terms with their diagnosis. For the participants their version of ‘dementia grief’ arose from being forced to face the harsh reality of living with a debilitating condition and what this meant for their future. The dementia trajectory is one of cognitive, emotional, behavioural, psychological, and social deterioration, the knowledge of which elicited inwardly focused anticipatory grief responses whereby each participant simultaneously mourned the loss of their past self, whilst also mourning their envisioned future and expectations. Such responses are typically experienced when a person has physically died; thus, for the participants, to be mourning themselves, when very much alive was a particularly unsettling experience. This evoked a range of difficult and intensified emotional reactions to their diagnosis including panic, existential aloneness, denial, sadness, anger, guilt, and desperation (Joy et al., 2010; Hottensen, 2010; Large & Slinger 2013). The participants were seen to oscillate through the various stages of grief from denial to over-involvement, anger, guilt and finally acceptance. Although strongest during the early stages of the process, the grief intensity was seen to vary from participant to participant depending on which loss they were working through, and the individual value ascribed to this (Meuser & Marwit, 2001).

The second and third subordinate themes of ‘*Who am I now?’* and ‘*Redefinition, reconstruction and working through’* represent the upwards movement of the arc. The participants having, successfully grieved themselves, were faced with a ‘what now?’ moment. Aware that the presumed losses were not as imminent as originally assumed each participant was tasked with challenge of re-establishing their individual equilibrium, taking the dementia into account. A key task was to discover and protect their new 'dementia identity' through purposeful actions. In essence throughout these two subordinate themes the participants reconstructed their assumptive worldviews, integrating their dementia-selves and adopting personal safeguards to ensure fortification against future threats. What resulted was a new, robust sense of self and agency. In its totality, this theme, along with its subordinate themes provide an account of the participants' struggles with YODR-PTSD, how they were able to resist the urge to succumb to their trauma, and ultimately move beyond their pre-trauma levels of adaptation (Tedeschi & Calhoun, 2004).

The central theme '*More to life than the "Big D"*' picks up where '*Learning to live well with dementia'* ended and refers to the ways in which participants have experienced positive change and growth. Tedeschi and Calhoun describe PTG as having three broad areas of growth; personal, interpersonal, and existential (Joseph & Linley, 2006; Tedeschi, 2011). Personally, people go onto develop new ways of seeing themselves in light of their hardship, and by doing so develop an appreciation for the strengths they have developed throughout their struggle. There is an acceptance of the loss of control and the world may appear to re-open with the emergence of new assumptive models. Interpersonally, individuals will place increased value on family and friends, with newfound importance of empathy towards others. Existentially there are changes in perceptions of the world, spirituality, religion, and/or philosophies of life (Jones et al., 2020). The three subordinate themes which emerged from the participant accounts can be viewed to roughly align with the PTG domains.

The subordinate theme of *'I am not what happened to me, I am what I choose to become''* relates to the PTG domains of personal strength and new possibilities. It is an account of how the participants strengthened and/or rediscovered their sense of personal value, using this to guide the way forward within the world. For many YPwD, following their diagnosis, they are left feeling defined by their dementia, no longer seen by others as unique individuals with purpose or value to the world (Hunt, 2011) this can elicit depressive symptoms, increasing risk of social exclusion (Steger & Kashdan, 2009). However as observed within the participant accounts, through the act of confronting their diagnosis head on in the previous superordinate theme, they were able to make peace with their losses, past, present and future. The participants found themselves better able to connect to their resiliency and by doing so "take the good out of the bad", viewing their struggles as opportunities to explore unique abilities and find hidden potential. Searching for a new sense of direction was crucial in the experiences of PTG as it provided an organising framework in which participants directed their thoughts and behaviours towards constructing new personal meaning and purpose (McKingiht & Kashdan, 2009). This was exemplified by David, Andy-Lee and Barbara who eventually found themselves taking on highly successful public facing consulting, advisory and advocacy roles and by doing so uncovered a range of untapped skills and abilities. It is likely that without the onset of their dementia this personal growth and the sense of value and achievement gained through these new roles and abilities would not have occurred (Chun & Lee, 2010).

'The bonds that tie us together and tear us apart' is reflective of the interpersonal area of PTG and domain of relating to others. Self-disclosure and the act of sharing one's struggles with trauma and adversity is thought to be an essential step towards PTG. The act of trauma disclosure facilitates deliberate cognitive processing whilst also providing opportunities to address more difficult emotional experiences such as shame and guilt (Levi-Belz, 2019; Dong et al., 2015; Hassija & Turchik; 2016). The participants of the current study reported mixed experiences within this theme. For Thomas, William, and Barbara whose disclosure and information sharing were met with openness and support, positive psychological outcomes such as higher emotional closeness with friends, family and partners others were reported. In contrast David's disclosure of his diagnosis was met with negativity, which resulted in feelings of shame, exclusion and a need to keep his dementia a secret. David appeared to become entrapped in negative thoughts related to this perceived social rejection, encumbering deliberate rumination. These findings are similar to Kamen et al (2016) who found in a sample of HIV-positive people greater levels of PTG related to positive experiences of disclosure and emotional support from sexual partners, in comparison to negative experiences of disclosure.

The act of disclosure was also seen to unearth new opportunities for the participants including meeting like-minded others and story sharing. Given the relative rarity of YOD, all the participants reported feeling under-represented and isolated at one point or another. By taking action to attend YOD specific groups and events, participants such as Barbara, William and Thomas reported being able to find their new place of belonging. It appears when mutual disclosure, is met with empathy and understanding it has the capacity to facilitate greater levels of PTG within the domain of relating to others (Taku et al., 2009).

The subordinate theme, *'The importance of being alive and being part of something''* relates to the domain of appreciation of life. Recognition of their personal fragility acted as a catalyst for the participants to re-evaluate what was valuable to them and change the degree of importance ascribed to certain events, endeavours and material objects. By doing so participants began to pay greater attention to both the little things and the present moment, which was found to yield greater joy and life satisfaction. This experience of appreciating the little things closely relates to the concept of gratitude wherein through their experiences of the other domains of PTG the participants were able to notice and acknowledge value and meaning within their diagnosis and from that feel a positive emotional connection to it (Kim and Bae, 2019). Encouragingly, all the participants were able to attribute positive changes in their lives following their dementia diagnosis. This evidences the need for further exploration into experiences of living with YOD.

The final superordinate theme, *"Life is a lottery"* references a set of factors which appeared to facilitate the participants' experiences of positive growth-related personal change. Given the highly personal experience of coping and living with debilitating illness, these factors are unlikely to be globally experienced by all YPwD. For the all participants of this study the combination of the three subordinate themes '*Courage to let go'*, '*The great gift of anger'* and '*Work with what you've got'* appeared to result in a greater ability to cope with and adjust to the diagnosis in such a way that facilitated YODR-PTG.

Research shows that event centrality, or rather the degree to which trauma is perceived is integral to one's worldviews and personal identity, has a substantial impact on recovery from trauma (Boykinet al., 2020) with higher centrality being found to equate to both greater distress and growth. For the participants, event centrality associated with their dementia diagnoses was high as the condition poses substantial threat to personhood and life longevity. To overcome this, and to gather the courage to move forward into the unknown, the participants showed themselves to each possess a psychologically flexible orientation and openness towards emotionally negative experiences. To varying degrees each participant demonstrated the ability to flexibly engage with the more painful aspects of cognitive processing, enabling them to view the diagnosis as less and less threatening. This minimised event centrality and provided space for the participants to open their minds to the possibility that their lives were not over. This openness then supported values-driven meaning-making and discovery which was crucial for the participants experiences of PTG as seen within the main theme 'More to life as the "Big D"'.

An interesting discovery within this study was how the participants inadvertently used 'negative' emotions such as drive, disappointment and anger to mobilise themselves following their diagnosis. Leaning into the emotion of anger appeared advantageous for the participants as this was seen to prompt behavioural activation, acting as a motivating factor to live life to the fullest. The participants were seen to seek out opportunities to 'right past wrongs' or 'show up' those who may have doubted or wronged them, in the period following diagnosis. Studies assessing the relationship between so called 'negative emotions'' such as anger and PTG, are sparse, with only a single study by Park et al (2008) identifying a link between anger and PTG. Therefore, this particular theme is highly based on the author's interpretations of the participants' accounts and further studies would need to be conducted to formally confirm negative emotional factors as a contributing factor to PTG.

The final subordinate theme, *'Work with what you've got',* references the participants' individual personality traits, early-life experiences, social and environmental factors, which they believe to have played an important role in their experiences of learning to live with YOD and their subsequent experiences of PTG. Trait resiliency has been established as a mechanism which supports positive growth through activation of positive appraisals, supporting active coping and positive adjustment (Roesch et al., 2002). For the participants of this study, their unique, individual combination of trait factors were instrumental in helping them to work through negative ruminations associated with the early days of their diagnosis. Degrees of optimism, hardiness, strong self-esteem, and positive affect (Connor and Davidson, 2003) were seen throughout as supporting the participants' deliberate processing. These traits prompted the participants to seek out new ways in which they could maintain generativity; often achieved through contributing to the development of the YOD landscape via public facing engagements and involvement in research, the present study included. Environmental and social factors such as strong support network and geographical proximity to effective NHS trusts were believed by participants to minimise psychosocial distress.

Although each participant's experience of dementia is unique to them alone, what emerged from this study is that YPwD can experience positive growth following their diagnosis. For the participants, although life is not what they had envisaged for themselves, what emerged from their accounts is that, despite their dementia, life is non the less fulfilling and something to be cherished.

4.4 Integration of findings

Research into the experiences of YPwD is sparse, and this population is often sampled into older groups, with their unique experiences lost amongst the fray. As such, the true experiences of YPwD, as they are lived is under-reported (Nolan et al., 2002), resulting in a lack of 'truthful knowledge' relating to what it is like to live with YOD. This is a disservice to this population as it leaves YPwD exceedingly vulnerable to social stigmas related to what a 'dementia patient' is whilst minimising opportunities for social change or growth to occur (Sikes & Hall, 2016). This study sought to create an opportunity for YPwD to speak to both their experiences of YODR-PTSD and YODR-PTG and by doing so contribute to the small but growing body of research highlighting that a YOD diagnosis does mean life is over, or make it any less worth living.

The study confirmed the presence of YODR-PTSD, with an overwhelming majority of the participants achieving clinically concerning or clinically significant scores on the IES-R scale. There are several potential reasons for why a YPwD might find their diagnosis to be a traumatising event. The process leading to up diagnosis is long, complex and overwhelming; a systemic lack of awareness relating to the condition means signs and symptoms are frequently brushed off and/or misdiagnosed as something else. Given the high levels of day-to-day stress commonly experienced by adults in their middle years (e.g., maintaining employment, raising a family, caring for elderly parents, financial commitments) many of their symptoms, which often occur in isolation, are not immediately seen as indicators of a single underlying condition. Inexperience of diagnosing clinicians is viewed as highly problematic by YPwD as it increases the likelihood of misdiagnosis. Barbara's experiences exemplify this, she underwent seven years of distressing, dehumanising and often invasive diagnostic testing to obtain her diagnosis. Sadly her experience is not unique, for many YPwD, the trauma of their condition starts with the fight to be heard and recognised within a healthcare system that makes no room for them.

Many YPwD report feeling as though the system is 'working against' them, in an almost brutalist fashion where tests and assessments needed to gain a diagnosis aggressively highlight personal incompetence (Johannessen et al., 2018). Upon receiving a diagnosis, even if suspected, the literature and the results of the present study highlight the profound level of psychological distress and personal devastation that is experienced, and the consequences of this on psychosocial wellbeing (Rabanal et al., 2018; Pippon-Young et al., 2011). For YPwD, this distress is commonly related to perceptions of loss of independence, autonomy, and envisaged future. Due to the relative rarity of the condition, and lack of visual representation within popular culture, YPwD are often left to compare themselves to older counterparts. Intrusive images and thoughts of elderly bed bound individuals are burned into their minds, reinforcing the idea that life, as they know it, is over.

Yet, what has been reported within the literature exploring what is like to live with a chronic, life-limiting illness, is that a diagnosis is not necessarily the 'end of the road'. This too appears to be the case for YPwD. Within the present study the scores from the PTGI showed most participants had undergone low-moderate to high-moderate degrees of growth across four of the five domains of PTG. The significantly positive correlation between the PTG and IES-R scores indicate that the trauma of being diagnosed with YOD can elicit a positive growth response. These findings are consistent with other literature in the field of illness-induced PTSD and PTG (Compas & Luecken, 2002; Koutna et al., 2017; Marziliano et al., 2020) which have found significantly stronger relationships between PTSD and PTG in cases where the disease was viewed as more advanced or life threatening versus cases where the condition was viewed as less serious or personally threatening conditions. Comparing such results to those of the present study, not dissimilar to those with advanced stage illnesses, YPwD objectively have much more to lose than their older counter parts and the diagnosis itself is so unexpected it can be truly life shattering. This reinforces Tedeschi and Calhoun's (2004) argument that to elicit a PTG response, the trauma event must be seismic in nature, whilst also reflecting the paradox of PTG that out of immense loss there can be immense gain.

Although not explicitly investigated, the role of cognitive processing in the development of PTG was indirectly observed across both phases. In Phase One participants scored highly within the IES-R subscale of intrusions reflecting presence of intrusive ruminations following diagnosis. As observed within the narrative accounts, this period was characterised by negative thoughts and feelings about the self and expectations for future which led to a further shattering of worldviews and activation of negative self-schemas, which engulfed the participants (Scher et al., 2005). The intensity and presence of these intrusive ruminations was likely heightened by psychopathological processes of dementia where combination of hippocampal damage, elevated cortisol levels and abnormal cholinergic declines inadvertently activated traumatic memories making them more prominent, and harder to control (Kolli et al., 2013). As seen across the accounts of the Phase two theme living *'Learning to live with dementia'* all the participants reported experiencing negative thoughts about themselves and their abilities. This gave way to feelings of shock and horror and intensified shame-based ruminations which were very difficult to manage and contain. Expanding upon the findings and interpreting the gaps from the quantitative study, what was seen within the narrative accounts, was a period of self-mourning heavily steeped within negative thoughts and emotions.

Although an objectively negative experience, for the participants of this study, these intrusive ruminations could also be viewed as advantageous as they later provided cues for engagement with more deliberate cognitive processing. Overtime, participants could be thought to have developed a tolerance to the negative emotions which enabled gradual shifting of focus away from intrusive thoughts towards thoughts centred on problem-solving and meaning making (Affleck & Tennen, 1996; Taku et al., 2008). The narrative accounts saw the participants, move between the stages of grief and over time began to make sense of their diagnosis, the impact this was having on the self in the present, and would have on the self in the future. Stages of denial, anger and bargaining aligned with negative intrusive ruminations, which created opportunities and cues to move towards stages of bargaining (initial beginnings of deliberate ruminations) and eventually acceptance. Through the subordinate themes of *‘Who am I now?’* and *‘Redefinition, reconstruction and working through’* the participants were observed to engage in deliberate rumination as they began the process of reconstructing the self, leading to re-stabilisation. Once this period was complete the participants assimilated this information into their new understandings of the world, the self and others, which resulted in PTG as highlighted within the main superordinate theme of ‘*More to life than ‘the Big D’’.* Within this theme the participants spoke to the specific ways in which they noted positive growth and change following their diagnosis within the PTG domains of relating to others, new possibilities, personal strength, and appreciation of life.

The integration of the findings at this point, encapsulates the study aims of establishing whether YPwD find their diagnosis to be a traumatic event, significant enough to elicit and PTG response, and to elaborate on the ways in which the process of PTG is undertaken and subsequently experienced.

4.5 Strengths and Limitations of the Study

This study aimed to establish commonality of YODR-PTSD and YODR-PTG whilst seeking to gain an understanding of the lived experiences of both these phenomena. To my knowledge this is the first study of its kind to be conducted not only in the UK, but worldwide.

There is a small, growing body of literature which is concerned with the lived experiences of YPwD, and this foundational narrative has been instrumental in the development of the present study. Predominately qualitative in nature, these studies have provided insights into issues faced by YPwD such as diagnostic experiences (Beattie et al., 2004), identity (Clare et al., 2008), self-hood (Harris & Brady, 2009), changes in relationships (Wawrziczny et al., 2016), personal deterioration (Johannessen et al., 2018) and coping with dementia in younger life (Clemerson et al., 2014; Roach & Drummond, 2004). It has only been in the last year that a single study has been conducted which is suggestive that a dementia diagnosis is a potentially traumatic life event (Dunham et al., 2020). However, this study, was focused on the experiences of older adults, who comparatively to their younger counterparts have much less to lose.

A key strength of the present study is its mixed methods approach. Despite the influences of the bio-psychosocial model, the majority of mainstream psychological inquiry leans towards an 'either or approach' to data collection and the development of knowledge. Yet, what has come to be known, is that for some research questions a single approach cannot adequately reflect the realities of people's experiences. Given the complexities associated with understanding chronic conditions such as dementia, utilising a multiphase, mixed-methods approach provided this study with a unique vantage point for better understanding the experiences of both PTSD and PTG in a relatively straight forward way. Utilising processes such as triangulation, complementarity, development, initiation and expansion (Greene, 2007; Green et al., 1989), the strengths and weaknesses of each approach compensated for the other to create a more in-depth and complete understanding of YODR-PTSD and YODR-PTG then could have been achieved by either approach alone. Combining two types of data this study benefited from both the detailed, contextualized insights of the qualitative data and the generalizable, externally valid insights of the quantitative data, and this was viewed to enhance the overall credibility of the research.

The sequential explanatory design was useful in linking theory to real life experiences as they are lived by the participants, which in the context of the present study provided a greater understanding of the mechanisms underlying both YODR-PTSD and YODR-PTG. The participant selection design was a particular strength of the study as it provided strict parameters for purposive sampling which generated a highly homogenous sample for Phase Two, which is essential for IPA methodology. A slight limitation to this approach is that by opting for the participant selection design, the study missed out on opportunities afforded by the follow-up explanations approach which would have allowed for further exploitation of the quantitative results (e.g., developing the interview questions to specifically address and explain the initial quantitative findings).

Within dementia research, both quantitative and qualitative studies tend to focus on the experiences of Alzheimer’s dementia due to its commonality. However, in younger populations, it has been established that atypical neurodegenerative typologies such as FTD and vascular dementias are more prevalent. A strength of this study is that the inclusion criteria was open to all dementia types. It was thought that to best understand this population, it was essential to acknowledge the within and between differences that may exist, and by not comparing one dementia typology to another, prevent differing dementia types from being equated together to what may be seen as the ‘norm’. This was exemplified within Phase Two, where, of the five participants, four different dementia typologies were present.

Phase One asked participants to complete an online survey. This required participants to have access to a computer and the internet, be literate, and have comprehension to understand the questions that were being asked. This can be seen as both a strength and limitation to the present study. The online element of the questionnaire enabled the study to be distributed UK-wide, and the questionnaire could be completed over multiple sessions at a convenient time for the participants. This resulted in a relatively large sample size for this population, and therefore supports the concept of generalisability. However, the online data collection approach, may also have limited this study, as some YPwD may struggle to use technology, and fluctuating capacity resulted in some individuals being unable to complete the second half of the questionnaire upon unsuccessful completion the midway capacity assessment. This raises an important question, how in a world where we are moving more and more towards digitalisation, can researchers better include YPwD whilst minimising potential ethical issues around capacity, consent, assent and dissent?

All the measures used were validated and had good internal reliability, which was another strength to this study. To date, there is no one set questionnaire which is recommended for the assessment of illness-induced PTSD. The IES-R as a measurement of illness induced in trauma is limited by its role as a screening tool versus a comprehensive test with clinical focus. The Posttraumatic Diagnostic Scale for the DSM-5 (PDS-5) (Foa et al., 2016) may have been a more suitable choice as it recognises serious life, threating illness is recognised and listed as a potential trauma. Unlike the IES-R which has yet to be updated to included negative alterations in cognitions and mood, the PDS-5 assess symptoms corresponding to the four DSM-5 symptom clusters.

An obvious limitation to the study was the lack of ethnic diversity. The majority of participants (N=33) identified themselves as white (e.g. British, Irish, any other White background). This is somewhat surprising considering rates of dementia are 40% higher in ethnic minority populations (Mayeda et al., 2016). However, this lack of diversity could be attributed to limited opportunities to participate in research as, historically, ethnic minority populations are less likely to receive a formal diagnosis or support following. It was hoped that through opportunistic sampling and by having several different services distribute the questionnaire, it would increase accessibility of the study to minority populations; unfortunately, this hope did not come to fruition.

4.6 Directions for future research

This study has created an opportunity for future studies to build on its findings. It has established commonality for both YODR-PTD and YODR- PTG, however, as these findings are correlational, they cannot indicate a direct cause and effect response. Yet, with direct cause and effect responses already established within other life-threatening/limiting illnesses (e.g., cancer), there is fertile ground for further research into the causal link between YOD and PTSD.

Future studies will also need to be targeted and tailored to explore YODR-PTSD and YODR-PTG in ethnic minority groups as a priority for researchers to address the significant gap in dementia research in this area. As a direct result of this lack of research and understanding PwD from ethnic minority backgrounds face additional inequalities in diagnosis and access to care. A study by Mueller et al (2020) found that at the time of diagnosis, PwD from minority groups were more likely to have symptoms be misdiagnosed as mental health issues, and more likely to be taking antidepressants. Qualitative research into the diagnostic experiences of YPwD from ethnic minorities are essential to understand how inequalities can impact upon the development of PTSD following diagnosis. Such information could be used to better inform screening services and to develop a greater understanding of how dementia typologies present themselves across ethnic groups.

What stood out within Phase Two was the rich use of metaphors and language by the participants when describing their experiences of being diagnosed and living with dementia. Future research may wish to understand how language is used not only amongst this demographic but the influence of language on the perceptions of general society and how this contributes to the ideology that dementia is something that should be feared. Within this study, stigmatising vernacular can be viewed as contributing factors for the development of PTSD. How stories of dementia were framed and shaped by public narratives, influenced the participants initial perceptions of their diagnosis. As seen in Blix et al (2013) a dialogical relationship between individual life stories and public narratives exists, implying that individual stories can shape and revise dominant public narratives. However, to do so, the number of stories must increase in order to create capacity for change. This provides significant support for more qualitative and mixed methods research into varied life experiences of YPwD.

4.7 Implications for Counselling Psychology Practice

This novel study has successfully sought to extend the models of illness-induced PTSD and PTG to YOD. Clinically, the results of this study are significant as knowledge regarding how YPwD process and cope with the condition can be used to help inform assessment and outcome measures, psychological therapies and care planning. With the discipline of neuropsychology opening to Counselling Psychologists, an increasing number of posts will be made available within memory assessment services. The results of this study will be able to support this transition enabling more Counselling Psychologists to work directly with PwD.

This research supports the assertion that YPwD are an already marginalised group, vulnerable to impact of social stigma on the development of shame and self-blame, and highlights the need for clinicians working with YPwD to acknowledge and validate lived experiences of trauma. Through formal recognition of YODR-PTSD, Counselling Psychologists can contribute to the development of sensitive and effective interventions (e.g., compassion-focussed approaches to treating YODR-PTSD) which could support YPwD to process their trauma in such a way that results in or enhances experiences of YODR-PTG. Further this research provides evidence and argues for the inclusion of post diagnostic counselling as part of standard treatment protocol. This could support YPwD to address feelings of difference, isolation and vulnerability (Charuvastra & Cloitre, 2008; Clemerson et al., 2013) whilst promoting holding on to selfhood, the combination of which could reduce YODR-PTSD. Counselling Psychologists are well placed to undertake such work, as the discipline's roots within the development of psychotherapeutic interventions, situated within a relational framework, support the use of Kitwood's (1988) person-centred approach. This promotes healing, built around the needs of the individual and are contingent upon knowing and supporting each unique individual to maintain the self via the therapist-client relationship.

Echoing Pipon-Young et al (2011), the results of this study show that YPwD, are not only able to, but desire to, be included within meaningful work, as their diagnosis does not mean that they 'are all gone' or have 'lost their voice to speak'. As highlighted by David, dementia can strip away one's confidence. This study reiterates the need for counselling psychology research to continue to move towards greater inclusion of service users, such as YPwD, not only within research but in the development of public policy and care pathways.

Including the voices of service users and drawing on their lived expertise may also act as a means to facilitate natural attempts to cope with the disease through engagement in self-reflection and meaning making. Encouraging YPwD to take back control is strongly associated with purpose and agency which were two factors that were reported as lost during the initial periods of intrusive rumination. Furthermore, the inclusion in meaningful work, provides the opportunity to widen society's understandings and assumptions related to what it means to be a PwD, and by doing so play a crucial role in reducing stigma.

4.8 Final Reflections

If I were to sum up my doctoral experience into four words it would be intimidating, stimulating, challenging, and rewarding. Developing this research project and carrying it out through to fruition has been the largest undertaking of my life, something that has pushed me to my limits, and forced me to develop personally as well as researcher and practitioner. From the onset, I was determined to conduct a mixed methods study. Despite moments of complete overwhelm where I wished I had taken an easier route, to have persevered has been a humbling and rewarding experience. I feel enormously proud to have carried out a study which I believe can create systemic change within policy, healthcare, and society.

I truly believe that a diagnosis of dementia does not make one incapable or less of a person – a fact often overlooked or ignored within contemporary society. All too often PwD are infantilised or ostracised as their place within the world is taken not only by illness but by those who stigmatise and marginalise them. My involvement in the Mindcare-City University YOD project has further strengthened my views that more should be done to advocate for and support the dignity of YPwD. The participants of the project, affectionately known as the 'YODAs' (Young Onset Dementia Activists) reaffirmed why I chose this research topic. For some group members the YODAs helped them to rediscover their sense of self and confidence, for some it provided sense of purpose and structure, whilst for others it appeared to renew their zest for life. It was a surreal experience to observe my research coming to life in real time. By conducting this research and through my involvement with the YODAs, in the future I hopefully will be able to inform and educate others on what it means to be a YPwD.

Reflecting on my skills as a researcher, from where I began this doctorate to where I am now as this research study ends, I feel that I have grown immensely not only in relation to skill development, but also as a person. I feel that this research has helped to give me focus and drive, and it has encouraged my decision to undertake further studies in neuropsychology with the discipline newly opened to Counselling Psychologists. Involving myself within this research has been highly self-reflective and has resulted in the unearthing of pieces of myself that I was not aware were present. What I take forward from this, drawing on the experiences of my participants, is that I am braver than I believe; stronger than I feel; smarter than I think; and more resilient that I am aware.

4.9 Conclusions

This study has undertaken an in-depth exploration into the experiences of PTSD and PTG in YOD. It challenges the popular opinion that a dementia diagnosis means ‘life is over’, whilst providing evidence that YPwD can experience PTG through undertaking the act of cognitive processing. The mixed methods approach to this study acknowledges the presence of YODR-PTSD, YODR-PTG and factors which may influence these. This combined with the one-to-one interviews further substantiates the experiences of both, whilst uncovering individual attributes and circumstances which were seen within the participants of this study, to further influence the development of YODR-PTG. The quantitative assessment measures, which were conducted online, proved to not only be convenient for the participants but also highlighted that YPwD, possess the technological capabilities to be included in online research in the future. The study was able to recruit a relatively large sample size for this population, and the results provide a foundational generalisability. However, future studies should aim to recruit a more representative sample which would be beneficial in the application of knowledge to such a richly diverse group. Given that this is the only study of its kind, further research is essential in determining replicability of the study results of which could be used to emphasise and raise awareness of the needs of YPwD. This would enable Practitioner Psychologists to work more effectively with YPwD and inform future service and treatment development.

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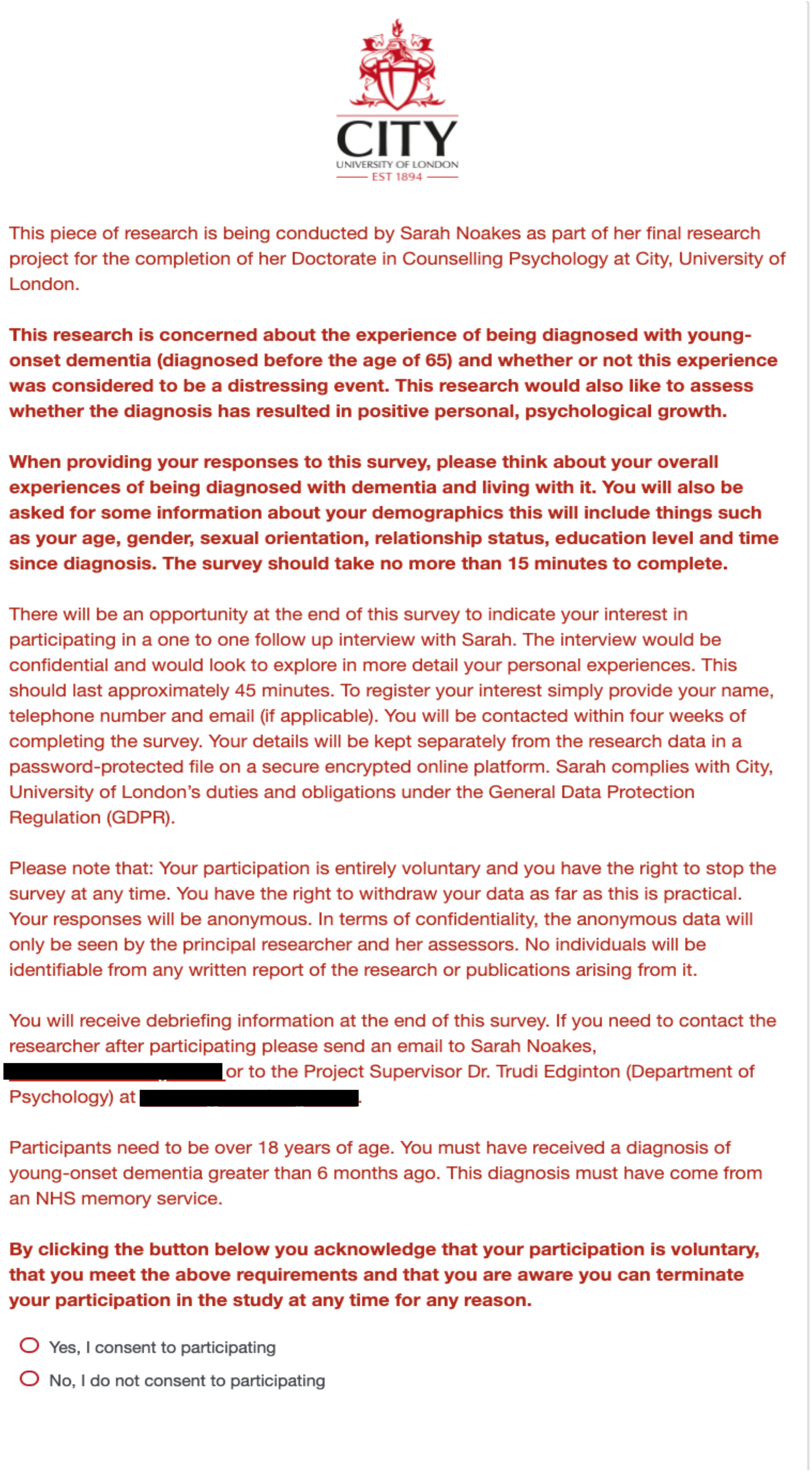
Appendix A

Phase One Participant Forms



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This piece of research is being conducted by Sarah Noakes as part of her final research project for the completion of her Doctorate in Counselling Psychology at City, University of London.

This research is concerned about the experience of being diagnosed with young-onset dementia (diagnosed before the age of 65) and whether or not this experience was considered to be a distressing event. This research would also like to assess whether the diagnosis has resulted in positive personal, psychological growth.

When providing your responses to this survey, please think about your overall experiences of being diagnosed with dementia and living with it. You will also be asked for some information about your demographics this will include things such as your age, gender, sexual orientation, relationship status, education level and time since diagnosis. The survey should take no more than 15 minutes to complete.

There will be an opportunity at the end of this survey to indicate your interest in participating in a one to one follow up interview with Sarah. The interview would be confidential and would look to explore in more detail your personal experiences. This should last approximately 45 minutes. To register your interest simply provide your name, telephone number and email (if applicable). You will be contacted within four weeks of completing the survey. Your details will be kept separately from the research data in a password-protected file on a secure encrypted online platform. Sarah complies with City, University of London's duties and obligations under the General Data Protection Regulation (GDPR).

Please note that: Your participation is entirely voluntary and you have the right to stop the survey at any time. You have the right to withdraw your data as far as this is practical. Your responses will be anonymous. In terms of confidentiality, the anonymous data will only be seen by the principal researcher and her assessors. No individuals will be identifiable from any written report of the research or publications arising from it.

You will receive debriefing information at the end of this survey. If you need to contact the researcher after participating please send an email to Sarah Noakes, [redacted] or to the Project Supervisor Dr. Trudi Edginton (Department of Psychology) at [redacted].

Participants need to be over 18 years of age. You must have received a diagnosis of young-onset dementia greater than 6 months ago. This diagnosis must have come from an NHS memory service.

By clicking the button below you acknowledge that your participation is voluntary, that you meet the above requirements and that you are aware you can terminate your participation in the study at any time for any reason.

○ Yes, I consent to participating

○ No, I do not consent to participating

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Thank you for participating as a research participant in the present study examining your experiences of being diagnosed and living with young onset dementia.

This study has sought to learn more about your experiences of being diagnosed with dementia and any subsequent positive psychological growth which may have occurred as a result of your diagnosis.

If you know of any friends or acquaintances that are eligible to participate in this study, we request that you do not discuss it with them until after they have had an opportunity to participate. Prior knowledge of the questions asked during the study can invalidate the results. We greatly appreciate your cooperation. If you have any questions regarding this study please feel free to contact the researcher at [redacted]

If you would like access to the final research report this will be available to you through the organisation or service from which you found out about the study. Contact them directly to gain access. Alternatively, contact Sarah Noakes at the email above and you will be emailed or posted the final report directly.

In the event that you feel psychologically distressed by participation in this study, we encourage you to contact the principal researcher Sarah Noakes via the email above or Research Supervisor, Dr Trudi Edginton at [redacted]

If you are feeling distressed please contact the organisation or service which you found out about the study from or contact your GP or Community Care Coordinator. If this is not possible please contact a 24-hour telephone hotline such as Samaritans (ring 116 123) or National Dementia Hotline (ring 0300 222 11 22)

Thank you again for your participation.

Sincerely

Sarah Noakes, BScN, RN, MSc

Appendix B

Phase Two Participant Forms

Face-to-Face Interview Participant Information Sheet

Researcher: Sarah Noakes

REC reference number: ETH1920-1436

Title of study: Experiences of a young onset dementia diagnosis and personal growth

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

The following study aims to explore what it was like to be diagnosed with young onset dementia and what it is like to live with it. We are particularly interested in exploring positive psychological growth as a result of the dementia diagnosis. This study is being undertaken as part of Sarah Noakes' fulfilment requirements for her Doctorate in Counselling Psychology at City, University of London.

You have a diagnosis of young onset dementia and have previously completed the online survey portion of this research (phase one). At the end of the survey you consented to follow up contact with Sarah and to participate in a one to one 45-minute confidential interview (phase two). You have been chosen for an interview because of your responses in phase one.

Like phase one, participation in phase two of the project is voluntary, and you can choose not to participate in part or all of the project. You can withdraw at any stage of phase two without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part. If you do decide to take phase two you will be asked to sign another consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. For the purposes of this project once your interview has been transcribed you are no longer able to withdraw your anonymised data.

Phase two of this research consists of a 45 minute face to face semi-structured interview via Zoom vide chat. Sarah is concerned about learning about your experiences and will ask for you to describe them in as much detail as you are comfortable. You are welcome to bring a family member or friend (trusted nominee) with you to the interview. This person can be in the room with you but we ask them to not impart their views. We ask that this person does not tell you what to say. During the interview you may find yourself feeling sad or distressed because the nature of the

questions aim for you to think about your diagnosis experience which you consider to be traumatic. If this happens let Sarah know and you can stop the interview.
There has been very little research looking at the experiences of people with young onset dementia. By taking part in the study you will be contributing to the production of knowledge about the experiences of people with young onset dementia. This study aims to help improve services and practitioner communication. It hopes to act as a guide for developing more age appropriate and sensitive interventions. If you are still interested in participating within this research please complete the following consent form and return this to Sarah Noakes.

What happens to my data?

Your participation in phase two of this study will be kept confidential. No personal identifiable information will be audio recorded. These audio recordings will be available to Sarah Noakes, the principal researcher. Recordings will be kept on a secure, encrypted online platform (City, University of London Onedrive) and are deleted following transcription. The transcriptions will also be stored on Onedrive. These will be kept for 10 years following which they will be deleted/destroyed. Participants will be referred to by pseudonyms that will be used to reference to any direct quotes used. Your data may be used in future studies that have gained ethics approval. You may wish to be contacted for future studies. You can indicate this at the time of the interview by indicating your preference on the consent form below. As researchers, we are increasingly encouraged to make research data available, accessible, discoverable and usable. This data gathered as part of this research will be published on Figshare and/or the UK Data Archive.

What will happen to the results?

The results of this study will be included in Sarah Noakes' Doctoral Thesis. It is possible that in the future additional publications may arise as a result of this research. In this event the anonymity of your data would be maintained.

Conflicts of interests

There are no conflicts of interest held by the researcher, the research supervisor or City, University of London.

Funding

This research is receiving no external funding.

Who has reviewed the study?

This study has been approved by City, University of London Psychology Research Ethics Committee.
If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: The

Experience of Posttraumatic Growth in Young Onset Dementia Patients

You can also write to the Secretary at:
[redacted]Research Integrity Manager
City, University of London, Northampton Square, London, EC1V 0HB
Email: [redacted]

Further information and contact details

Contact details of someone who will answer any inquiries about the research (include details of supervisor/s if the researcher is a student). Only City email addresses and phone numbers should be used.
If you have any queries about this study please contact:
Sarah Noakes, Researcher at [redacted]
Dr. Trudi Edginton (Department of Psychology), Project Supervisor at [redacted]

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information please see https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only people at City who will have access to your identifiable information will be Sarah Noakes. City will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how City handles data by visiting https://www.city.ac.uk/about/governance/legal. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) https://ico.org.uk/.

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

Face-to-Face Interview Participant Informed Consent Sheet

Researcher: Sarah Noakes

REC reference number: ETH1920-1436

Title of study: Experiences of a young onset dementia diagnosis and personal growth

		PWD	TN
1A	I am able to confirm that I have the mental capacity* to participate in this research.		
1B	I lack capacity however I have a trusted nominee who will be able to provide consent for me to participate in the study. The name of my nominated individual is: ____________________ Their relationship to me is: ______________________________ I provide assent for this person to consent to my participation in this study.		
2	I confirm that I have read and understood the participant information for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.		
3	I can confirm that I am over the age of 18 years old and have a diagnosis of young onset dementia from an NHS memory service.		
4	I understand that my participation is voluntary and that I am free to withdraw without giving a reason without being penalised or disadvantaged.		
5	I understand that if there are any questions I do not wish to answer, I do not have to answer them.		
6	I understand that my responses will be treated with full confidentiality. No individuals will be identifiable from a report of the research.		
7	I understand that I will be able to withdraw my data up to the time of transcription.		
8	I agree to the interview being audio recorded.		
9	I agree to the use of my direct quotes.		
10	I understand that my anonymous data will be made open access to underpin journal publications		
11	I understand that the researcher may wish to reuse my anonymous data for future studies which have been given ethics approval. I give consent for the research to reuse my data.		

12	I understand I will receive written debriefing information upon the completion of the interview. This document will provide me with information, explaining in detail as to what the study is about.		
13	I would like to be informed of the results of this study once it has been completed and understand that my contact details will be retained for this purpose.		
14	I consent for my data to be used in future studies provided ethics approval has been gained and to being contacted for future studies.		
15	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) explained in the participant information and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).		
16	I agree to take part in the above study.		

* Capacity as defined by the Mental Capacity Act 2005 means that I am able to understand the necessary information required to make a decision, and to communicate any decision made.

____________________ ____________________________ _____________
Name of Participant Signature Date

____________________ ____________________________ _____________
Name of Researcher Signature Date

--

I, __________________ (TN name) consent to being in the room with the participant during the interview. I understand that I am only present to provide support and reassurance to the participant. I am aware that I am not to impart my views or experiences. I am aware and consent to my voice being audio recorded and any contributions I make to be captured in the transcripts.

Name of TN:

Signature

Date

Face-to-Face Interview Participant Debrief Sheet

Researcher: Sarah Noakes

REC reference number: ETH1920-1436

Title of study: Experiences of a young onset dementia diagnosis and personal growth

Dear

Thank you for participating as a research participant in the present study examining your experiences of being diagnosed and living with young onset dementia.

This study has sought to learn more about your experiences of being diagnosed with dementia and any subsequent positive psychological growth which may have occurred as a result of your diagnosis.

If you know of any friends or acquaintances that are eligible to participate in this study we request that you don not discuss it with them until after they have had an opportunity to participate. Prior knowledge of the questions asked during the study can invalidate the results. We greatly appreciate your cooperation. If you have any questions regarding this study please feel free to contact the researcher at [redacted]

If you would like access to the final research report this will be available to you through the organisation or service from which you found out about the study. Contact them directly to gain access. Alternatively contact Sarah Noakes at the email above and you will be emailed or posted the final report directly.

In the event that you feel psychologically distressed by participation in this study we encourage you to contact the principal researcher Sarah Noakes via the email above or Research Supervisor, Dr Trudi Edginton at [redacted] If you are feeling distressed, please contact the organisation or service which you found out about the study from or contact your GP or Community Care Coordinator.

If this is not possible please contact a 24-hour telephone hot line such as

- Samaritans (call 116 123)
- Sane (call 0300 304 7000).

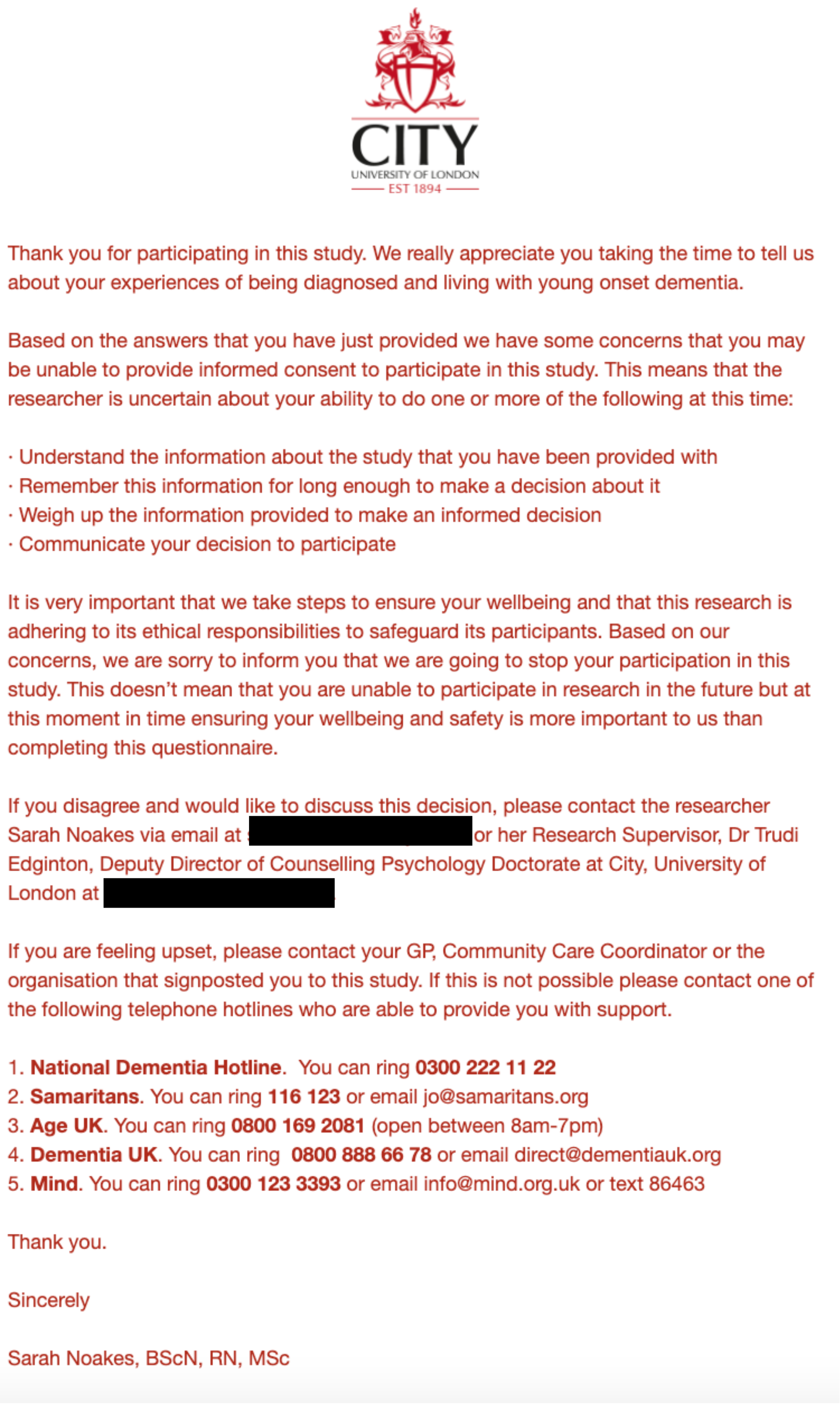
Thank you again for your participation.

Sincerely

Sarah Noakes, BScN, RN, MSc

Appendix C

Unsuccessful Midway Capacity Assessment Debrief



Thank you for participating in this study. We really appreciate you taking the time to tell us about your experiences of being diagnosed and living with young onset dementia.

Based on the answers that you have just provided we have some concerns that you may be unable to provide informed consent to participate in this study. This means that the researcher is uncertain about your ability to do one or more of the following at this time:

- Understand the information about the study that you have been provided with
- Remember this information for long enough to make a decision about it
- Weigh up the information provided to make an informed decision
- Communicate your decision to participate

It is very important that we take steps to ensure your wellbeing and that this research is adhering to its ethical responsibilities to safeguard its participants. Based on our concerns, we are sorry to inform you that we are going to stop your participation in this study. This doesn't mean that you are unable to participate in research in the future but at this moment in time ensuring your wellbeing and safety is more important to us than completing this questionnaire.

If you disagree and would like to discuss this decision, please contact the researcher Sarah Noakes via email at [redacted] or her Research Supervisor, Dr Trudi Edginton, Deputy Director of Counselling Psychology Doctorate at City, University of London at [redacted].

If you are feeling upset, please contact your GP, Community Care Coordinator or the organisation that signposted you to this study. If this is not possible please contact one of the following telephone hotlines who are able to provide you with support.

1. **National Dementia Hotline**. You can ring **0300 222 11 22**
2. **Samaritans**. You can ring **116 123** or email jo@samaritans.org
3. **Age UK**. You can ring **0800 169 2081** (open between 8am-7pm)
4. **Dementia UK**. You can ring **0800 888 66 78** or email direct@dementiauk.org
5. **Mind**. You can ring **0300 123 3393** or email info@mind.org.uk or text 86463

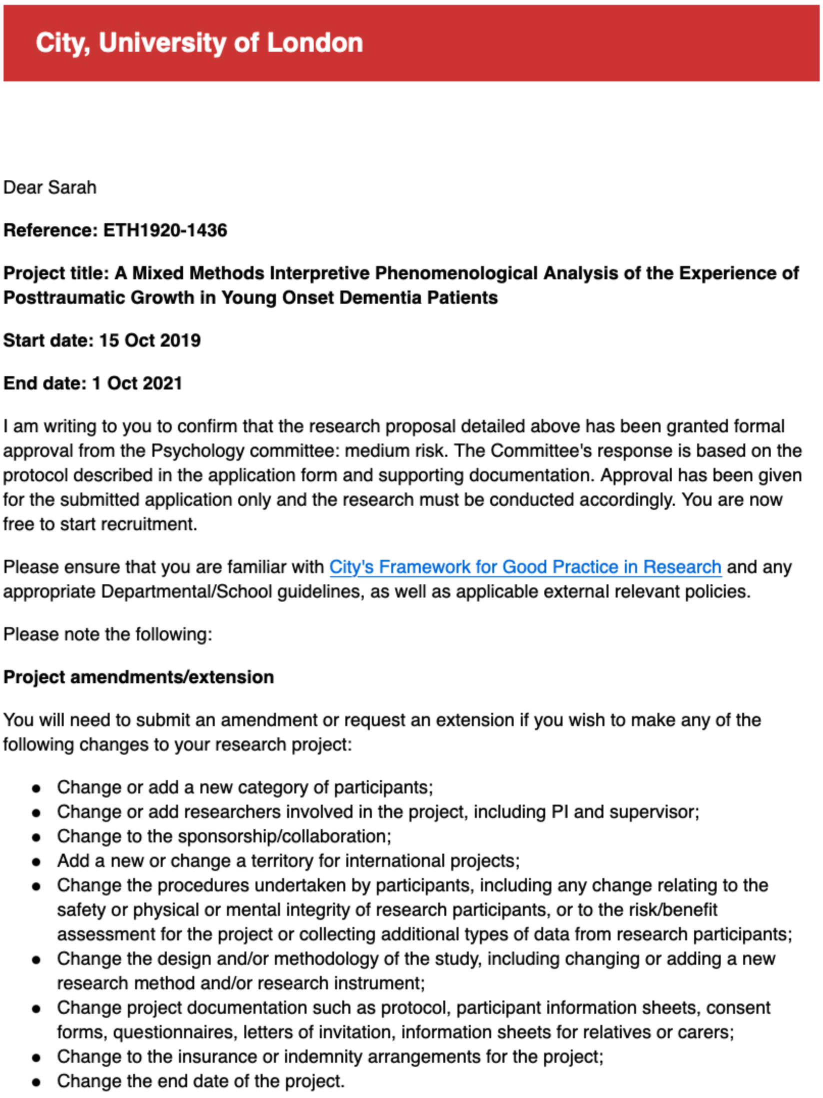
Thank you.

Sincerely

Sarah Noakes, BScN, RN, MSc

Appendix D

City University Research and Ethics Committee Approval



City, University of London

Dear Sarah

Reference: ETH1920-1436

Project title: A Mixed Methods Interpretive Phenomenological Analysis of the Experience of Posttraumatic Growth in Young Onset Dementia Patients

Start date: 15 Oct 2019

End date: 1 Oct 2021

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

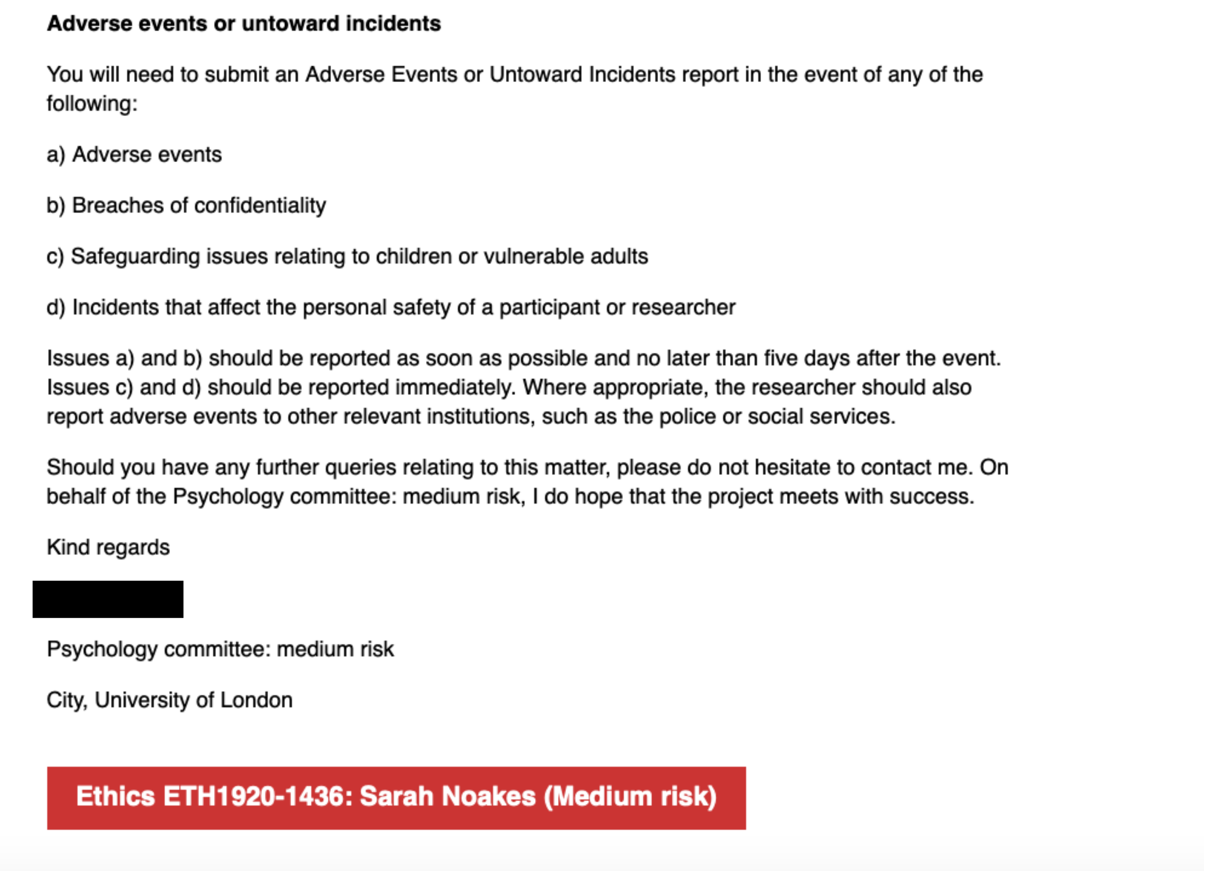
Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- Change or add a new category of participants;
- Change or add researchers involved in the project, including PI and supervisor;
- Change to the sponsorship/collaboration;
- Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research participants;
- Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;
- Change to the insurance or indemnity arrangements for the project;
- Change the end date of the project.



Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

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

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

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

Kind regards

[redacted]

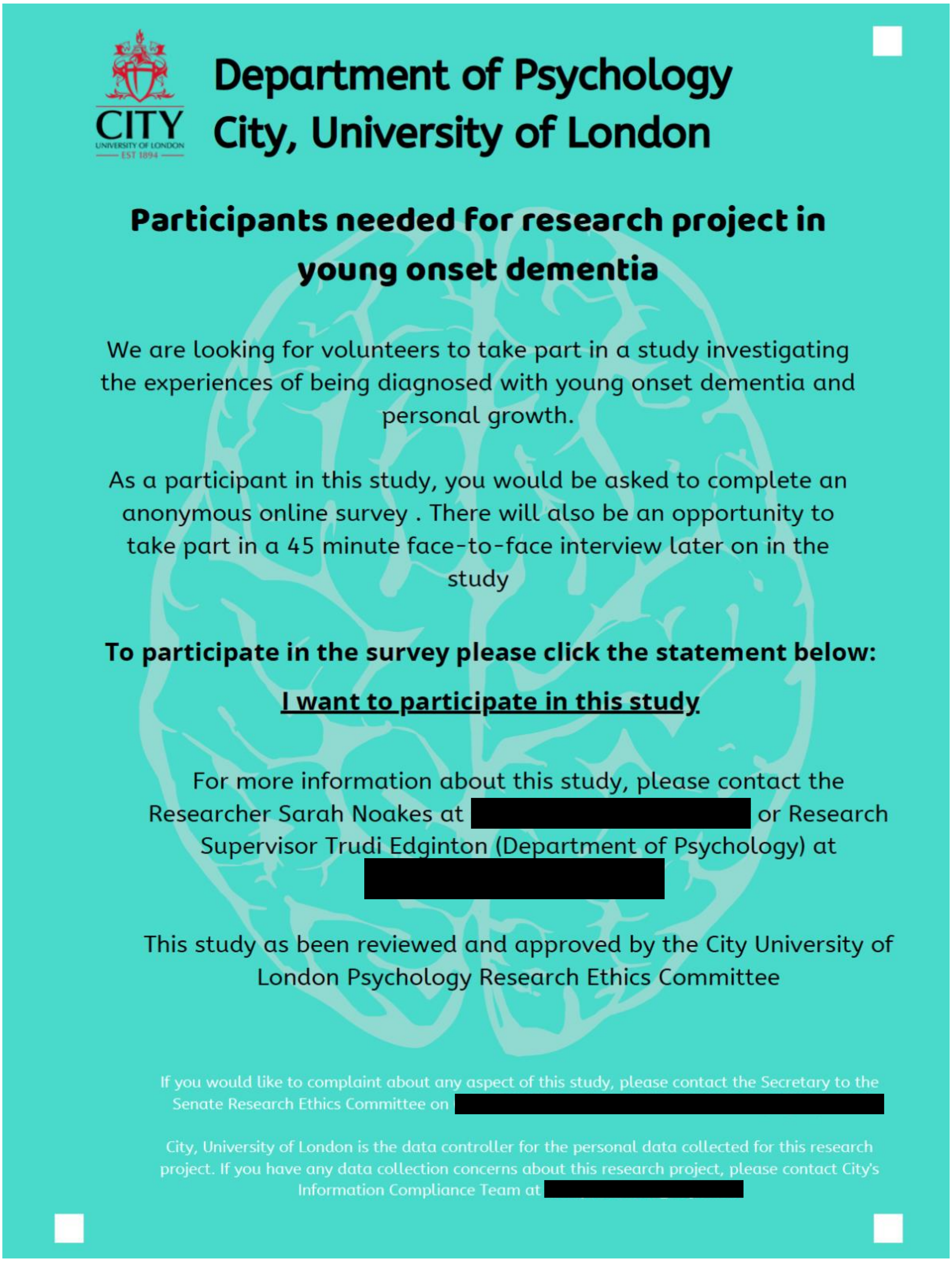
Psychology committee: medium risk

City, University of London

Ethics ETH1920-1436: Sarah Noakes (Medium risk)

Appendix E

Recruitment Poster



Department of Psychology
City, University of London

Participants needed for research project in young onset dementia

We are looking for volunteers to take part in a study investigating the experiences of being diagnosed with young onset dementia and personal growth.

As a participant in this study, you would be asked to complete an anonymous online survey . There will also be an opportunity to take part in a 45 minute face-to-face interview later on in the study

To participate in the survey please click the statement below:

I want to participate in this study

For more information about this study, please contact the Researcher Sarah Noakes at [redacted] or Research Supervisor Trudi Edginton (Department of Psychology) at [redacted]

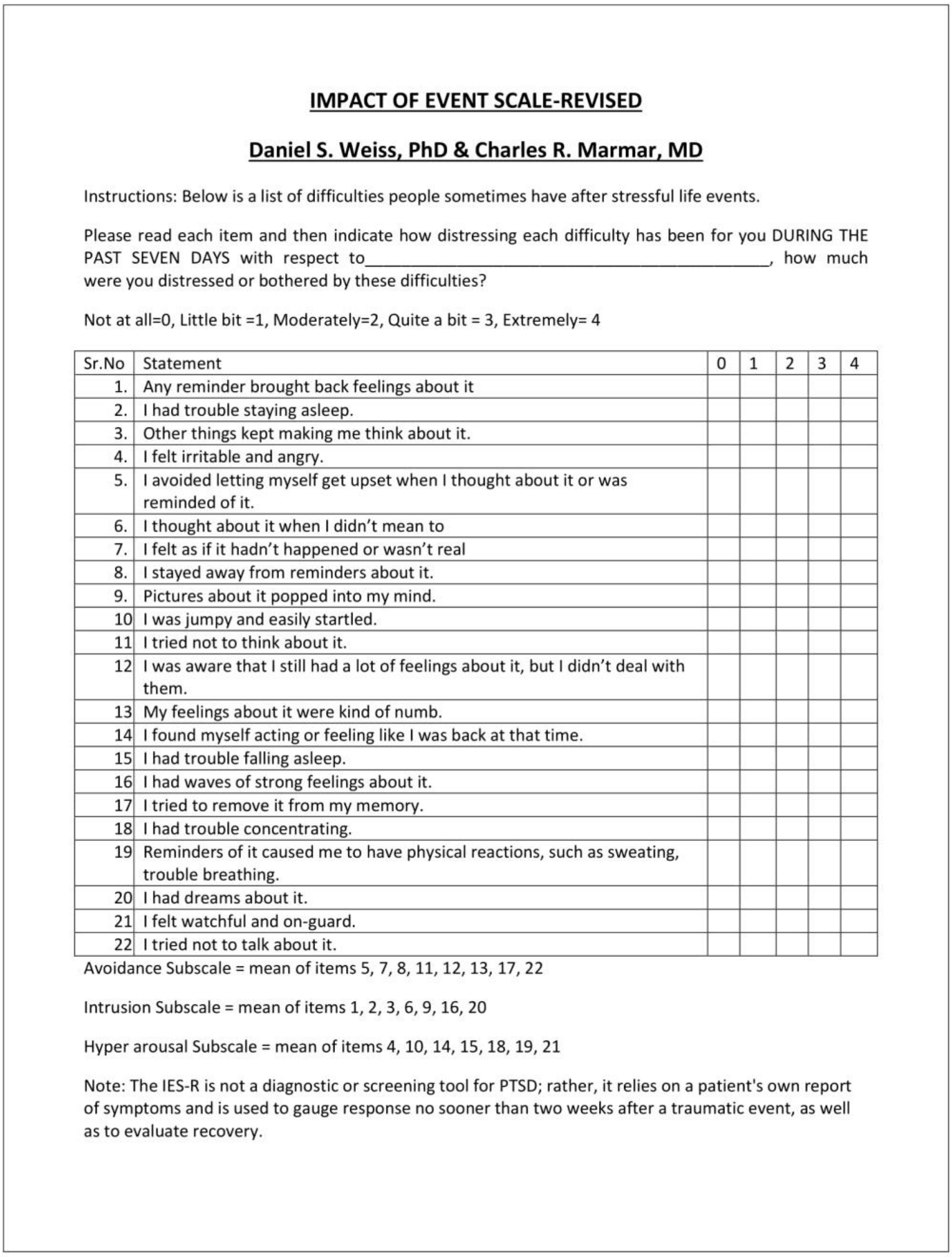
This study as been reviewed and approved by the City University of London Psychology Research Ethics Committee

If you would like to complaint about any aspect of this study, please contact the Secretary to the Senate Research Ethics Committee on [redacted]

City, University of London is the data controller for the personal data collected for this research project. If you have any data collection concerns about this research project, please contact City's Information Compliance Team at [redacted]

Appendix F

Phase One Questionnaires



IMPACT OF EVENT SCALE-REVISED

Daniel S. Weiss, PhD & Charles R. Marmar, MD

Instructions: Below is a list of difficulties people sometimes have after stressful life events.

Please read each item and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to____, how much were you distressed or bothered by these difficulties?

Not at all=0, Little bit =1, Moderately=2, Quite a bit = 3, Extremely= 4

Sr.No	Statement	0	1	2	3	4
1.	Any reminder brought back feelings about it					
2.	I had trouble staying asleep.					
3.	Other things kept making me think about it.					
4.	I felt irritable and angry.					
5.	I avoided letting myself get upset when I thought about it or was reminded of it.					
6.	I thought about it when I didn't mean to					
7.	I felt as if it hadn't happened or wasn't real					
8.	I stayed away from reminders about it.					
9.	Pictures about it popped into my mind.					
10	I was jumpy and easily startled.					
11	I tried not to think about it.					
12	I was aware that I still had a lot of feelings about it, but I didn't deal with them.					
13	My feelings about it were kind of numb.					
14	I found myself acting or feeling like I was back at that time.					
15	I had trouble falling asleep.					
16	I had waves of strong feelings about it.					
17	I tried to remove it from my memory.					
18	I had trouble concentrating.					
19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing.					
20	I had dreams about it.					
21	I felt watchful and on-guard.					
22	I tried not to talk about it.					

Avoidance Subscale = mean of items 5, 7, 8, 11, 12, 13, 17, 22

Intrusion Subscale = mean of items 1, 2, 3, 6, 9, 16, 20

Hyper arousal Subscale = mean of items 4, 10, 14, 15, 18, 19, 21

Note: The IES-R is not a diagnostic or screening tool for PTSD; rather, it relies on a patient's own report of symptoms and is used to gauge response no sooner than two weeks after a traumatic event, as well as to evaluate recovery.

Post Traumatic Growth Inventory

Client Name:_________________________________ Today's Date:________________

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.

0 = I did not experience this change as a result of my crisis.
1 = I experienced this change to a very small degree as a result of my crisis.
2 = I experienced this change to a small degree as a result of my crisis.
3 = I experienced this change to a moderate degree as a result of my crisis.
4 = I experienced this change to a great degree as a result of my crisis.
5 = I experienced this change to a very great degree as a result of my crisis.

Possible Areas of Growth and Change	0	1	2	3	4	5
1. I changed my priorities about what is important in life.						
2. I have a greater appreciation for the value of my own life.						
3. I developed new interests.						
4. I have a greater feeling of self-reliance.						
5. I have a better understanding of spiritual matters.						
6. I more clearly see that I can count on people in times of trouble.						
7. I established a new path for my life.						
8. I have a greater sense of closeness with others.						
9. I am more willing to express my emotions.						
10. I know better that I can handle difficulties.						
11. I am able to do better things with my life.						
12. I am better able to accept the way things work out.						
13. I can better appreciate each day.						
14. New opportunities are available which wouldn't have been otherwise.						
15. I have more compassion for others.						
16. I put more effort into my relationships.						
17. I am more likely to try to change things which need changing.						
18. I have a stronger religious faith.						
19. I discovered that I'm stronger than I thought I was.						
20. I learned a great deal about how wonderful people are.						
21. I better accept needing others.						

Self-Compassion Scale- Short Form

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never				**Almost always**
1	**2**	**3**	**4**	**5**

_____1. When I fail at something important to me I become consumed by feelings of inadequacy.
_____2. I try to be understanding and patient towards those aspects of my personality I don’t like.
_____3. When something painful happens I try to take a balanced view of the situation.
_____4. When I’m feeling down, I tend to feel like most other people are probably happier than I am.
_____5. I try to see my failings as part of the human condition.
_____6. When I’m going through a very hard time, I give myself the caring and tenderness I need.
_____7. When something upsets me I try to keep my emotions in balance.
_____8. When I fail at something that’s important to me, I tend to feel alone in my failure
_____9. When I’m feeling down I tend to obsess and fixate on everything that’s wrong.
_____10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
_____11. I’m disapproving and judgmental about my own flaws and inadequacies.
_____12. I’m intolerant and impatient towards those aspects of my personality I don’t like.

Connor-Davidson Resilience Scale (CD-RISC)

Instructions:

Please answer the following questions according to how you have felt over the last month.
not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all of the time (4).

___________1 Able to adapt to change

___________2 Close and secure relationships
___________3 Sometimes fate or God can help
___________4 Can deal with whatever comes
___________5 Past success gives confidence for new challenge
___________6 See the humorous side of things
___________7 Coping with stress strengthens
___________8 Tend to bounce back after illness or hardship
___________9 Things happen for a reason
___________10 Best effort no matter what
___________11 You can achieve your goals
___________12 When things look hopeless, I don’t give up
___________13 Know where to turn for help
___________14 Under pressure, focus and think clearly
___________15 Prefer to take the lead in problem solving
___________16 Not easily discouraged by failure
___________17 Think of self as strong person
___________18 Make unpopular or difficult decisions
___________19 Can handle unpleasant feelings
___________20 Have to act on a hunch
___________21 Strong sense of purpose
___________22 In control of your life
___________23 I like challenges
___________24 You work to attain your goals
___________25 Pride in your achievement

Appendix G

Phase Two Interview Protocol

Establish Rapport: My name is Sarah and I am a Trainee Counselling Psychologist completing my PhD at City University of London. This interview is part of my doctoral research project exploring people's experiences of being diagnosed and living with young onset dementia and a psychological phenomenon called posttraumatic growth. I want to thank you for volunteering to speak with me today.

Purpose: I would like to ask you some questions about your dementia diagnosis and your life since then. I am particularly keen in learning about your experiences of personal positive growth. To facilitate my note-taking, I would like to audio tape our conversations today. During the questionnaire that you completed a few months ago you completed a consent form and an additional section agreeing to participate within the interview portion of the research. I have another consent form that I will read out to you. If you agree to this I will need your signature again.

Time Line: The interview should take no more than 45 minutes to an hour after which I we are both free to go. I will be available afterwards to answer any questions you may have. I will also make the results of this research available to you.

Do I have your consent to proceed with this interview? Thank you so much and let's begin.

1.Can you please tell me about your dementia diagnosis?

Prompts:

How old were you
What had been going on in your life prior to your diagnosis?
When did you begin to notice your symptoms?
How did you respond when you found out? How did you feel?

2. It seems to me that your experience was quite distressing. What specifically about your experience stands out as being difficult to cope with or perhaps traumatic?

Prompts: Can you tell me more about this?

3. How has life changed for you since your diagnosis?

Prompts: health, work, relationships, sense of self, financial situation

4. What do these changes mean to you? And in what ways do you think you have perhaps experienced something positive as a result of your diagnosis?

Prompts:

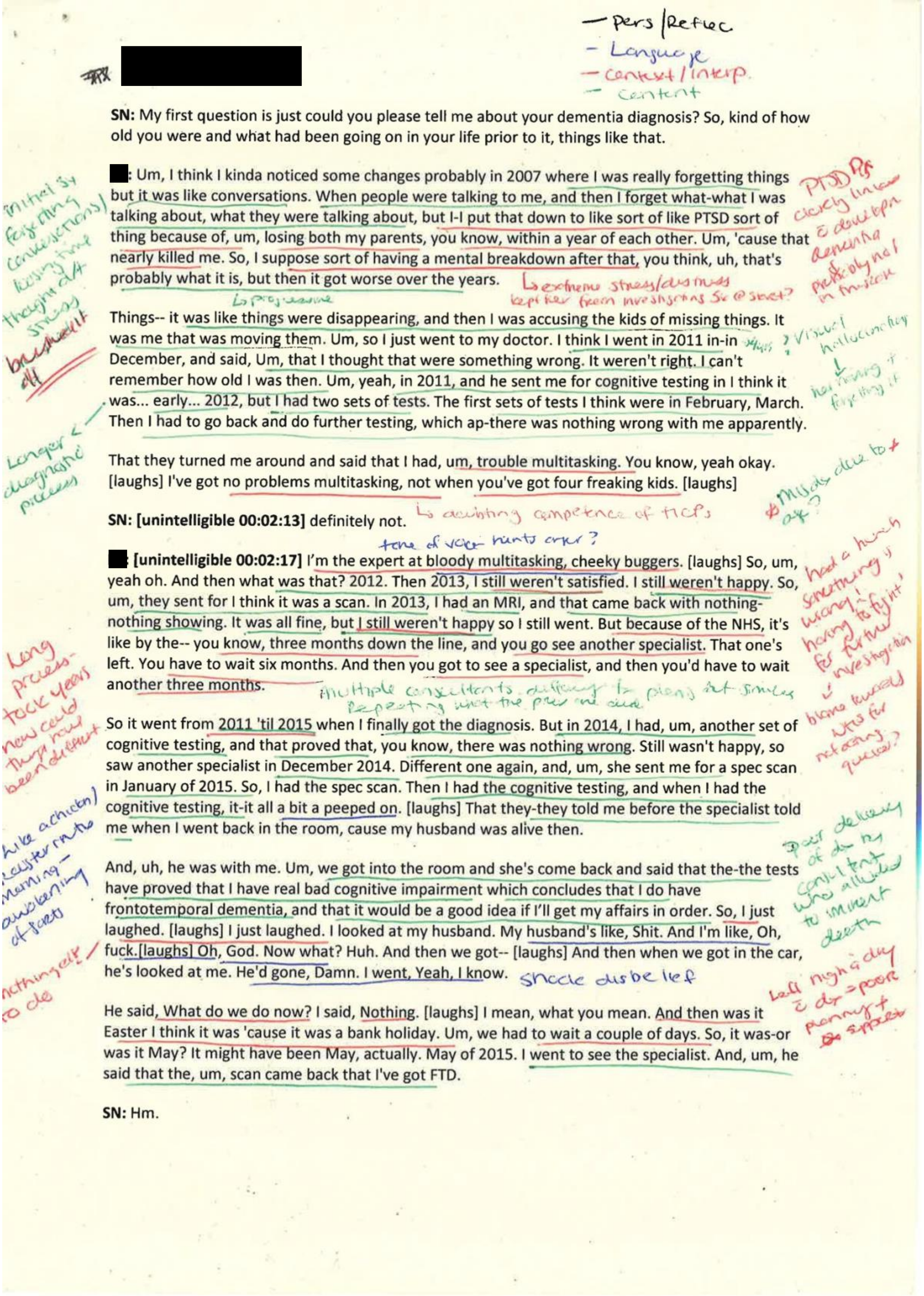
- Are there ways in which you found yourself being more grateful for what you have and for those around you? (Appreciation of life/ relating to others)
- How did your relationship with others change as a result of your experience? (Relating to others)
- Has your life changed? (New possibilities/ personal strength)

5. How do you see the future for yourself?

6. Is there anything else that you would like to share with me?

Appendix H

Sample of IPA Coding



— Pers | Reflec
— Language
— Context / Interp.
— Content

[redacted]

SN: My first question is just could you please tell me about your dementia diagnosis? So, kind of how old you were and what had been going on in your life prior to it, things like that.

[redacted]: Um, I think I kinda noticed some changes probably in 2007 where I was really forgetting things but it was like conversations. When people were talking to me, and then I forget what-what I was talking about, what they were talking about, but I-I put that down to like sort of like PTSD sort of thing because of, um, losing both my parents, you know, within a year of each other. Um, 'cause that nearly killed me. So, I suppose sort of having a mental breakdown after that, you think, uh, that's probably what it is, but then it got worse over the years.

↳ progressive

↳ extreme stress/distress kept her from investigations sx @ start?

initial sx forgetting conversations) loosing time thought d/t stress

[illegible]

PTSD RF clearly linked c̄ development dementia & [illegible] in [illegible]

Things-- it was like things were disappearing, and then I was accusing the kids of missing things. It was me that was moving them. Um, so I just went to my doctor. I think I went in 2011 in-in December, and said, Um, that I thought that were something wrong. It weren't right. I can't remember how old I was then. Um, yeah, in 2011, and he sent me for cognitive testing in I think it was... early... 2012, but I had two sets of tests. The first sets of tests I think were in February, March. Then I had to go back and do further testing, which ap-there was nothing wrong with me apparently.

+4yrs ? visual hallucinations ↓ [illegible] + forgetting it

Longer diagnostic process

That they turned me around and said that I had, um, trouble multitasking. You know, yeah okay. [laughs] I've got no problems multitasking, not when you've got four freaking kids. [laughs]

$ misdx due to age?

SN: [unintelligible 00:02:13] definitely not.

↳ doubting competence of HCPs

tone of voice hints anger?

[redacted] **[unintelligible 00:02:17]** I'm the expert at bloody multitasking, cheeky buggers. [laughs] So, um, yeah oh. And then what was that? 2012. Then 2013, I still weren't satisfied. I still weren't happy. So, um, they sent for I think it was a scan. In 2013, I had an MRI, and that came back with nothing-nothing showing. It was all fine, but I still weren't happy so I still went. But because of the NHS, it's like by the-- you know, three months down the line, and you go see another specialist. That one's left. You have to wait six months. And then you got to see a specialist, and then you'd have to wait another three months.

multiple consultants difficulty to [illegible] but similar repeating what the prev one did

had a hunch something is wrong ∴ 'fight' having to fight for further investigation ∴ blame towards NHS for not acting quicker?

Long process - took years how could things have been different

So it went from 2011 'til 2015 when I finally got the diagnosis. But in 2014, I had, um, another set of cognitive testing, and that proved that, you know, there was nothing wrong. Still wasn't happy, so saw another specialist in December 2014. Different one again, and, um, she sent me for a spec scan in January of 2015. So, I had the spec scan. Then I had the cognitive testing, and when I had the cognitive testing, it-it all a bit a peeped on. [laughs] That they-they told me before the specialist told me when I went back in the room, cause my husband was alive then.

like a chicken) [illegible] in the morning – awakening of sorts

And, uh, he was with me. Um, we got into the room and she's come back and said that the-the tests have proved that I have real bad cognitive impairment which concludes that I do have frontotemporal dementia, and that it would be a good idea if I'll get my affairs in order. So, I just laughed. [laughs] I just laughed. I looked at my husband. My husband's like, Shit. And I'm like, Oh, fuck.[laughs] Oh, God. Now what? Huh. And then we got-- [laughs] And then when we got in the car, he's looked at me. He'd gone, Damn. I went, Yeah, I know.

shock disbelief

Poor delivery of dx by consultant who alluded to imminent death

nothing else / to do

He said, What do we do now? I said, Nothing. [laughs] I mean, what you mean. And then was it Easter I think it was 'cause it was a bank holiday. Um, we had to wait a couple of days. So, it was-or was it May? It might have been May, actually. May of 2015. I went to see the specialist. And, um, he said that the, um, scan came back that I've got FTD.

Left high & dry c̄ dr = poor planning + support

SN: Hm.

[redacted]: So, frontotemporal dementia. So, I was 40-- 47 when the cognitive testing came back as having it, and then 48, cause my birthday was in March. So, it was 48 when they officially diagnosed me. And then, when they officially diagnosed me in 2015, I was the youngest in the country.

SN: I was going to say, that was very young!

the youngest = scary?
~~FTD~~ Dementia associated
c ppl 2x age.

[redacted]: I know.

SN: Ackh.

a sense of achieving / being special?
↳ probably not

[redacted]: I know. And-and because there was no literature on it, cause I googled it, I googled it and it was on Wikipedia. I thought, Oh, you're having a laugh. Do you know what I mean? And I thought, Fuck it. I can't be arsed to reading all that bollocks. So, um, I-I went to do a memory walk. And when you do a memory walk, when you sign up for a memory walk, you have to do, um, like, fill this thing and do you want the press, blah, blah, blah. I thought, Well, yeah. Might as well. And then that's what it all, you know, the shit hit the fan.

Explosion

need to research → found nothing or v. little for YP

bollocks – not specific to a YPwD

impulsive which lead to a big Δ
↗ not present attack

I was everywhere. Do you know what I mean? But, basically, just coming forward and saying, Look at me. I'm 48. I've got, you know, a-a life limiting illness that no one's ever bloody heard of because you associate dementia with old people, with 90-year olds sitting in a freaking high-backed chair in and old people's home. Do you know what I mean? And the-there's nothing out there for us. There's-there's no-- I mean they didn't say, Oh, you know, you've only got a few years to live. Poor you. We'll put you through counselling. We'll do this for you.

Left feeling abandoned / penalised of disease.

interesting Acc. illness specially for [illegible] ppl

note she used limiting not "life is over"

Fuck all. I had absolutely nothing. I literally had to go home and think, shit. You've told me I'm gonna die, and that's it. Do you know what I mean? So, and I was furious at the fact that there was nothing out there. So that's when I got on my high horse, [laughs] and I didn't get off. [laughs] And, yeah. I-- and I just, you know, I-I put it out there. I put the nitty gritty out there. I put what it was like, you know, the-the, um, the mood swings and everything, and the vicious attacks and things like that, you know. And I put it all out there, everything that comes with it.

uncovering / disclosing / sharing nitty gritty → not ashamed

initial panic following dx

social injustice @ being d/x @ young age

clear imagery of what a typical versus atypical PCD looks like.

Because, you know, it-it's not like... you can't paint a pretty picture with this. It's actually quite nasty.

SN: Yeah.

didn't see the point in sugar coating it. Honest account make ppl understand what its like.

[redacted] But it had to be told. And as soon as I did, fucking hell, low and behold, you google it now, you Google frontotemporal dementia, it's everywhere. Uh, they even got their own NH-NH-- and that's what I wanted to do. That's what I wanted to achieve, and I did that. I'm bloody proud of that, I tell you, because when I found out what I got and I Googled it, no information on that was on Wikipedia. Now, what? Five years down the line, you google it now, it's everywhere.

Feel / Feels it's her duty to get the word out there

→ positive for other
quite selfless
- large achievement
↳ new pass?

→ need to help the max # of ppl through info / knowledge production

New information, the help. Not that anybody gets it, but it's there. Do you know what I mean? So.

SN: Hm. Yeah. No, I think it's amazing. I know when I did my nursing training, um, back home with my first degree, when we talked about dementia, it was only Alzheimer's and only old people.

showing! anomaly

LB: Yeah, yeah. Exactly, but it's not.

[redacted]: No, it's not. Definitely not. I know 'cause my-my auntie had dementia, and she was in her 40s. Uh, she developed dementia as an adjunct to MS. And that's one of the reasons I got really interested in this because I was like, she's a young-a young woman in her 40s similar. What happened?

→ wanted to solidify connection by sharing own experience → remove the researcher / participant barriers.

young ppl have more to lose? taken too soon?

[redacted] Yeah, exactly. Yeah. It shouldn't be happening to young people, but it does, unfortunately, and there's so many different types as well. You wouldn't believe it. I mean mine is quite rare. Mine's a genetic form.

↳ singling out ↳ YPED already uncommon, now even more singling out!

SN: Yes.

[redacted]: Yeah.Yeah. So, that clearly comes from my parents, but I wouldn't know because I'm adopted.

dementia causes - some known some not FTD often unknown cause

ppl she doesn't know gave her dementia

SN: Hmm.So-hm?

[redacted]: You know, had-had, um, had I not been adopted, then my parents probably, because one of them is, you know, gene carrier, I suppose, and, uh, one of them would've had it in their later years or early years, whatever.

If she had known could measures been taken?

SN: Hmm.

more anxiety? If parents had it could have prepared more? ↳ could have time getting dx?

[redacted] It depends and I would've known, but I didn't. So, yeah. They-they told me it's genetic, so.

SN: It seems like your diagnostic experience was just a battle, like having to go for test after test and be like, I'm not moody.

HCPs not considering it Reflect lack of experience in young dementia

[redacted]: Yeah, yeah. And because it was, um, unthinkable that-that I could have it. That they weren't-that they-- Everyone thought, even my own doctor said, well, you're too young to have dementia. And I thought, fuck off. I know I am. I ain't got that. Do you know what I mean? And then when I-I went to the cognitive testing, and then, you know, the specialist also, oh, no. You're too young, but we'll investigate it. Oh, no. You're too young to have dementia, but we'll do this. No, you're too young. That's all I ever got. You're too young. You're too young. But I wasn't happy.

she didn't believe dementia option at all

Life span norms

Age as reasoning. It can't be

I wasn't satisfied and I-and I refused to move until they'd done something. Do you know what I mean?

is consistent personality trait → sign resilience - refuses to give up!

SN: Yeah.

[redacted]: I know it took a long time, but, you know, it took a few years, [laughs] but I got-I got, you know, I got there in the end, but it shouldn't be that now. I mean now, luckily, it's not. Because I've got it out there because I've got the word out there that this does exist, you can get it when you're in your 40s, even younger now. Do you know what I mean? Then, you know, you can walk into a doctor and say, right. I'm having memory problems, they'll send you straight to the testing. Not taking three or four bloody years. [laughs]

Used her own experience as cautionary tale for others. Helped to improve present day procedures

SN: I know. That's crazy. Especially considering that you noticed things, like, literally eight years before you were diagnosed. You're like, I don't think something's right.And it took that long. It's crazy.

→ need to protect others from what she went through? Championing?

[redacted]: Yeah. But because-because it is not something that I would've thought about because it's unheard of, because it's only for old people, that's what we're all led to believe. This is why I had to go public because we were all led to believe, even myself, that it's old people's disease. Nah, it's not, you now.

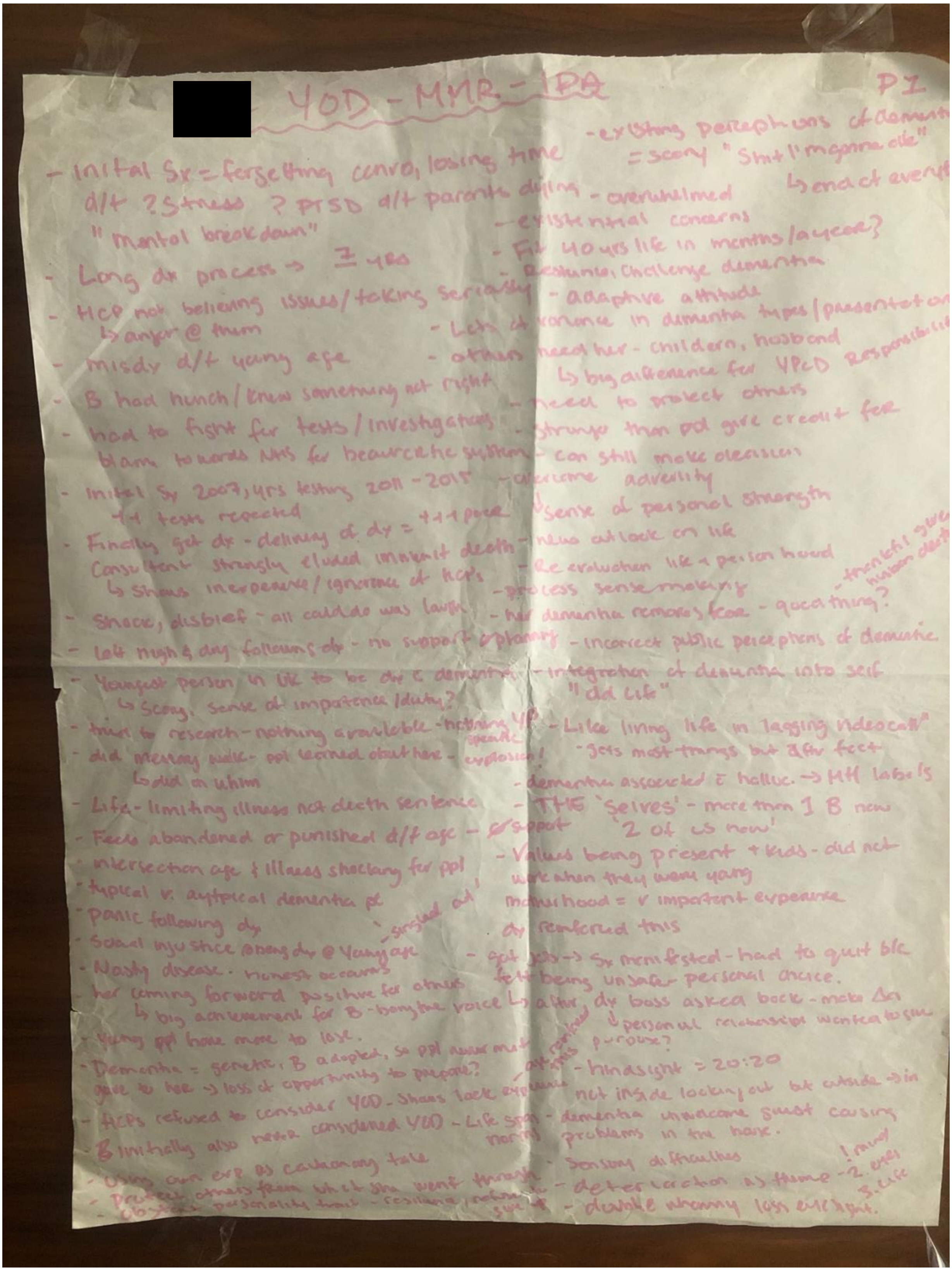
population perception of dementia

individual perceptions of what means to have dementia

SN: Hm, Yeah. You said something, um, you said when you found out, you-you thought, shit. I'm gonna die.

↳ using her words exactly

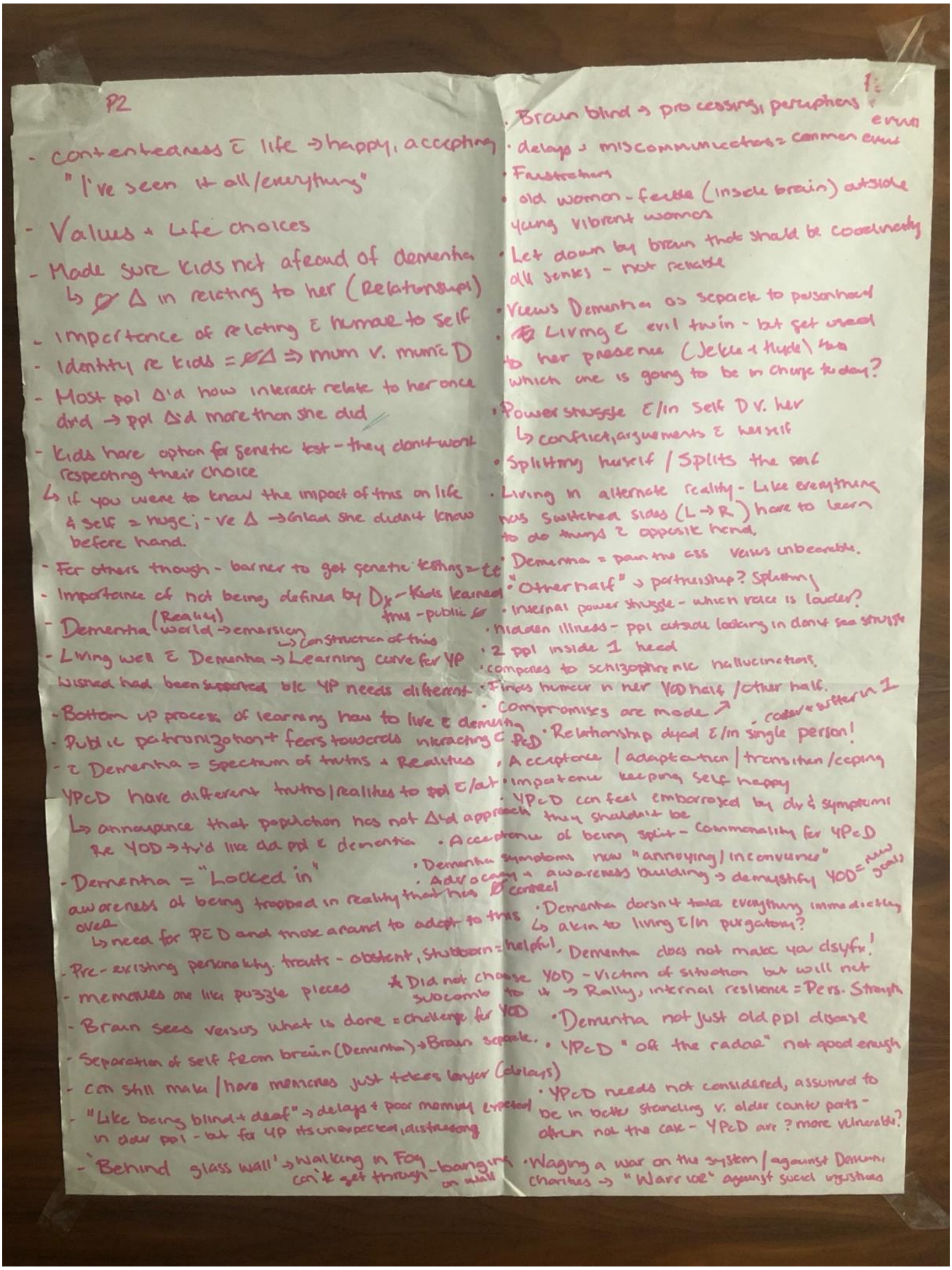
[redacted]: Mm-hmm.



[redacted] YOD - MMR - IPA P1

- Inital Sx = forgetting convo, losing time
  d/t ?Stress ?PTSD d/t parents dying
  "mental breakdown"
- Long dx process → 7 yrs
- HCP not believing issues/taking seriously
  ↳ anger @ them
- misdx d/t young age
- B had hunch/knew something not right
- had to fight for tests/investigations
  blam towards NHS for beaurcratic system
- Initial Sx 2007, yrs testing 2011 - 2015
  ↑↑ tests repeated
- Finally got dx - delivery of dx = ↑↑↑ poor
  Consultant strongly eluded imminent death
  ↳ Shows inexperience/ignorance of HCPs
- Shock, disbelief - all could do was laugh
- left high & dry following dx - no support & planning
- Youngest person in UK to be dx c̄ dementia
  ↳ Scary. Sense of importance/duty?
- tried to research - nothing available - nothing YP specific
- did memory walk - ppl learned about her - explosion!
  ↳ did on whim
- Life-limiting illness not death sentence
- Feels abandoned or punished d/t age - ✗ support
- intersection age & illness shocking for ppl
- typical v. atypical dementia pt
- panic following dx — 'singled out'
- Social injustice being dx @ young age
- Nasty disease. honest accounts
- her coming forward positive for others
  ↳ big achievement for B - being the voice
- Young ppl have more to lose.
- Dementia = genetic, B adopted, so ppl never met gave to her → loss of opportunity to prepare? / others reinforced this
- HCPs refused to consider YOD - Shows lack experience
- B initially also never considered YOD - Life span norms
- Using own exp as cautionary tale
- Protect others from what she went through
- Obstinate personality trait - resilience / refusing to give up

- existing perceptions of dementia = scary "Shit I'm gonna die"
  ↳ end of everything
- overwhelmed
- existential concerns
- Fit 40 yrs life in months/a year?
- Resilience, challenge dementia
- adaptive attitude
- Lots of variance in dementia types/presentation
- others need her - children, husband
  ↳ big difference for YPCD Responsibilities
- need to protect others
- Stronger than ppl give credit for
- can still make decisions
- overcome adversity
  ↓ sense of personal strength
- new outlook on life
- Re evaluation life & personhood
- process sense making
- her dementia removes fear - good thing?
- thankful given reason dementia
- incorrect public perceptions of dementia
- integration of dementia into self
  "old life"
- "Like living life in lagging videocall"
  - gets most things but after fact
- dementia associated c̄ halluc. → MH labels
- THE 'selves' - more than 1 B now
  '2 of us now'
- Values being present & kids - did not work when they were young
  motherhood = v important experience
  dx reinforced this
- got job → Sx manifested - had to quit b/c felt being unsafe - personal choice.
  ↳ after dx boss asked back - make Δ & personal relationship wanted to give purpose?
- hindsight = 20:20
  not inside looking out but outside → in
- dementia unwelcome guest causing problems in the house.
- Sensory difficulties
- deterioration as theme - 1. mind 2. eyes 3. life
- double whammy loss eyesight.

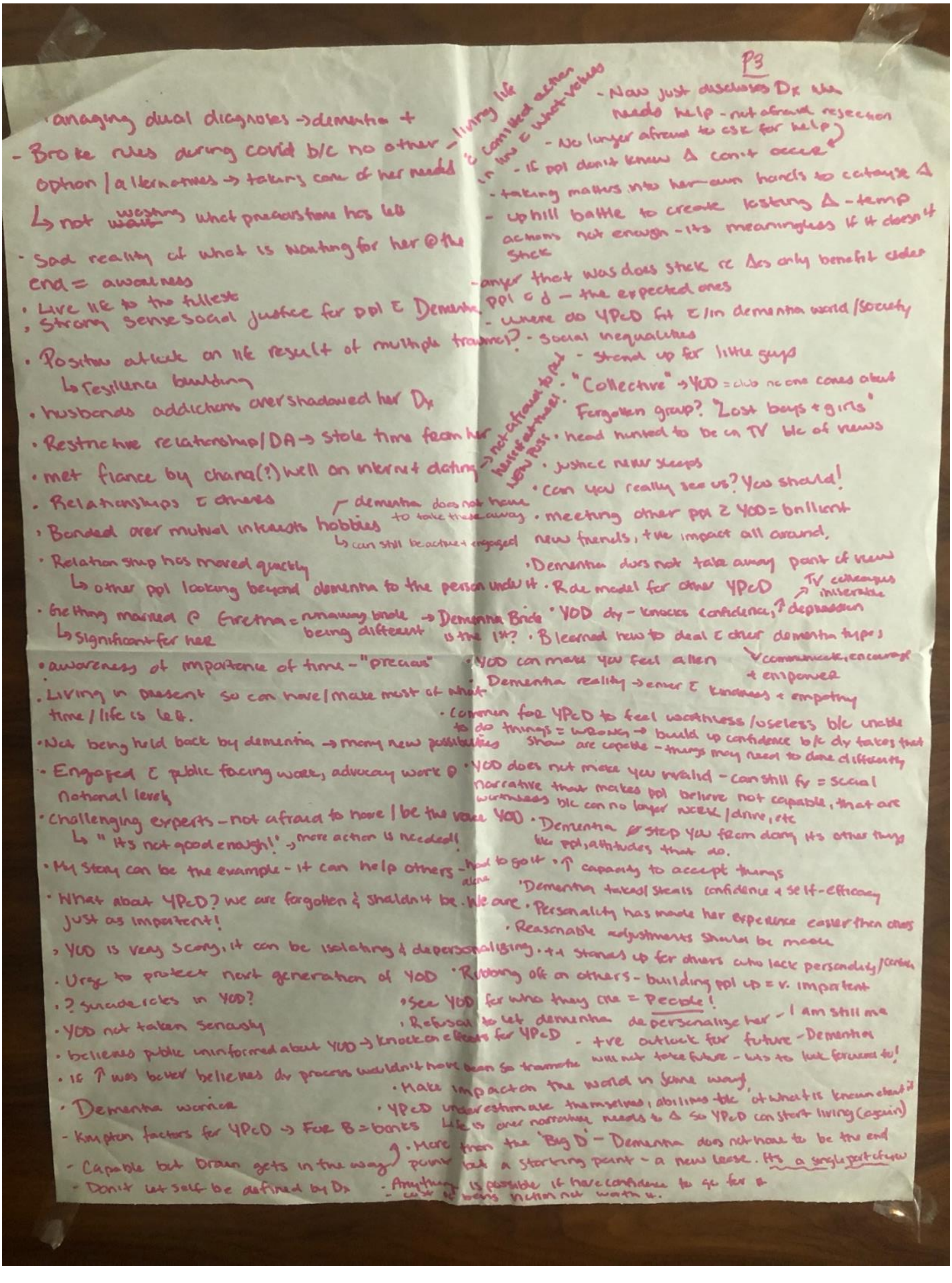


P2

- contentedness c̄ life → happy, accepting
  "I've seen it all/everything"
- Values + Life choices
- Made sure kids not afraid of dementia
  ↳ ∅ Δ in relating to her (Relationship)
- Importance of relating c̄ humour to self
- Identity re kids = ∅Δ ⇒ mum v. mum c̄ D
- Most ppl Δ'd how interact relate to her once dx → ppl Δ'd more than she did
- Kids have option for genetic test - they don't want respecting their choice
  ↳ if you were to know the impact of this on life & self = huge; -ve Δ → Glad she didn't know before hand.
- For others though - barrier to get genetic testing = ££
- Importance of not being defined by Dx - Kids learned this - public ∅
- Dementia (Reality) world → emersion
  ↳ construction of this
- Living well c̄ Dementia → Learning curve for YP
  Wished had been supported b/c YP needs different
- Bottom up process of learning how to live c̄ dementia
- Public patronization + fears towards interacting c̄ PcD
- c̄ Dementia = spectrum of truths + Realities
  YPcD have different truths/realities to ppl c̄/at
  ↳ annoyance that population has not Δ'd approach re YOD → tx'd like old ppl c̄ dementia
- Dementia = "Locked in"
  awareness of being trapped in reality that has ∅ control over
  ↳ need for PcD and those around to adapt to this
- Pre-existing personality traits - obstinate, stubborn = helpful
- memories are like puzzle pieces
- Brain sees versus what is done = challenge for YOD
- Separation of self from brain (Dementia) → Brain separate.
- can still make/have memories just takes longer (delays)
- "Like being blind + deaf" → delays + poor memory expected in older ppl - but for YP its unexpected, distressing
- 'Behind glass wall' → Walking in Fog - can't get through - banging on wall

P

- Brain blind → processing, perceptions errors
- delays + miscommunications = common errors
- Frustrations
- old woman - feeble (inside brain) outside young vibrant woman
- Let down by brain that should be coordinating all senses - not reliable
- Views Dementia as separate to personhood
- Living c̄ evil twin - but get used to her presence (Jekyll + Hyde) two which one is going to be in charge today?
- Power struggle c̄/in self D v. her
  ↳ conflict, arguments c̄ herself
- Splitting herself / Splits the self
- Living in alternate reality - Like everything has switched sides (L → R) have to learn to do things c̄ opposite hand.
- Dementia = pain the ass versus unbearable.
- "Other half" → partnership? Splitting
- Internal power struggle - which voice is louder?
- hidden illness - ppl outside looking in don't see struggle
- 2 ppl inside 1 head
- compares to schizophrenic hallucinations
- Finds humour in her YOD half / other half.
- Compromises are made ↗
- colder + wetter in 1
- Relationship dyad c̄/in single person!
- Acceptance / adaptation / transition / coping
- importance keeping self happy
- YPcD can feel embarrassed by dx & symptoms they shouldn't be
- Acceptance of being split - Commonality for YPcD
- Dementia symptoms now "annoying/inconvenient"
- Advocacy + awareness building → demystify YOD = new goals
- Dementia doesn't take everything immediately
  ↳ akin to living c̄/in purgatory?
- Dementia does not make you dysfx!
- ★ Did not choose YOD - Victim of situation but will not succumb to it → Rally, internal resilience = Pers. Strength
- Dementia not just old ppl disease
- YPcD "off the radar" not good enough
- YPcD needs not considered, assumed to be in better standing v. older counterparts - often not the case - YPcD are ? more vulnerable?
- Waging a war on the system / against Dementia charities → "Warrior" against social injustices



P3

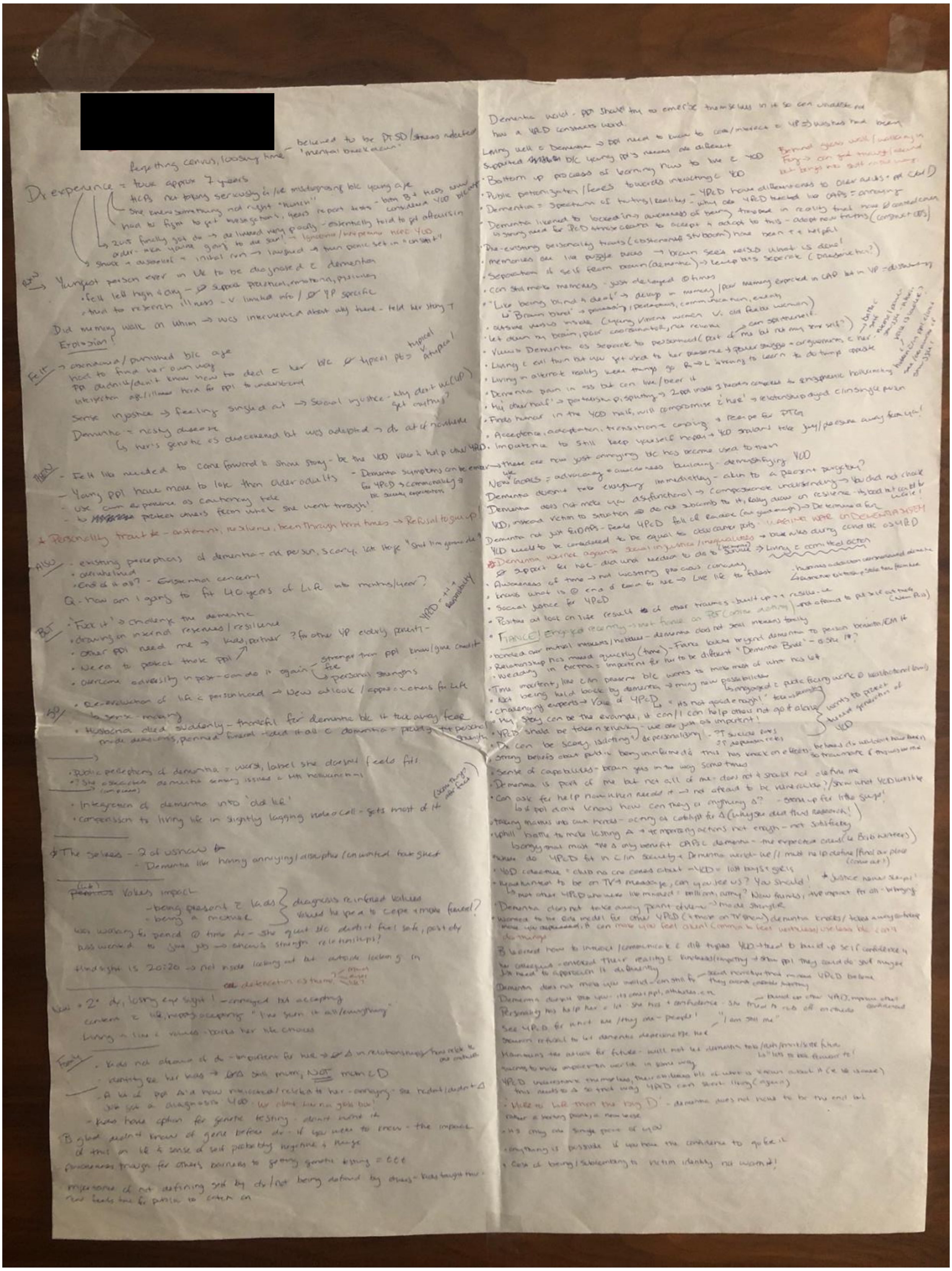
- anaging dual diagnoses → dementia +
- Broke rules during covid b/c no other option / alternatives → taking care of her needs
  - ↳ not ~~wait~~ wasting what precious time has left
- Sad reality of what is waiting for her @ the end = awareness
- Live life to the fullest
- Strong sense social justice for ppl c̄ Dementia
- Positive attitude on life result of multiple traumas?
  - ↳ resilience building
- husbands addictions overshadowed her Dx
- Restrictive relationship / DA → stole time from her
- met fiance by chance(?) well on internet dating
- Relationships c̄ others
- Bonded over mutual interests hobbies
  - ↱ dementia does not have to take these away
  - ↳ can still be active + engaged
- Relationship has moved quickly
  - ↳ other ppl looking beyond dementia to the person under it.
- Getting married @ Gretna = runaway bride → Dementia Bride is the 1st? being different
  - ↳ significant for her
- awareness of importance of time – "precious"
- Living in present so can have / make most of what time / life is left.
- Not being held back by dementia → many new possibilities
- Engaged c̄ public facing work, advocacy work @ national level
- Challenging experts – not afraid to have / be the voice YOD
  - ↳ " It's not good enough!' → more action is needed!
- My story can be the example – it can help others – had to go it alone
- What about YPcD? we are forgotten & shouldn't be. We are just as important!
- YOD is very scary, it can be isolating & depersonalising.
- Urge to protect next generation of YOD
- ? suicide rates in YOD?
- YOD not taken seriously
- believes public uninformed about YOD → knock on effects for YPcD
- If ↑ was better believes dx process wouldn't have been so traumatic
- Dementia warrior
- Kimpton factors for YPcD → For B = banks
- Capable but brain gets in the way
- Don't let self be defined by Dx

– living life c̄ committed action in line c̄ what values

- Now just discloses Dx when needs help – not afraid rejection
- No longer afraid to ask for help
- If ppl don't know Δ can't occur
- taking matters into her own hands to catalyse Δ
- uphill battle to create lasting Δ – temp actions not enough – it's meaningless if it doesn't stick
- anger that was does stick re Δs only benefit older ppl c̄ d – the expected ones
- where do YPcD fit c̄/in dementia world / society
- social inequalities
- stand up for little guys

→ not afraid to put herself out there! New Poss.

- "Collective" → YOD = club no one cares about
- Forgotten group? "Lost boys + girls"
- head hunted to be on TV b/c of news
- justice never sleeps
- Can you really see us? You should!
- meeting other ppl c̄ YOD = brilliant new friends, +ve impact all around.
- Dementia does not take away point of view
- Role model for other YPcD ↗ TV colleagues invaluable
- YOD dx – knocks confidence, ↑ depression
- B learned how to deal c̄ other dementia types ↘ communicate, encourage + empower
- YOD can make you feel alien
- Dementia reality → easier c̄ kindness + empathy
- Common for YPcD to feel worthless / useless b/c unable to do things = wrong → build up confidence b/c dx takes that. Show are capable – things may need to done differently
- YOD does not make you invalid – can still fx = social narrative that makes ppl believe not capable, that are worthless b/c can no longer work / drive, etc
- Dementia stop you from doing its other things like ppl, attitudes that do.
- ↑ capacity to accept things
- 'Dementia takes / steals confidence + self-efficacy
- Personality has made her experience easier than others
- Reasonable adjustments should be made
- +ve stands up for others who lack personality / confidence
- Rubbing off on others – building ppl up = v. important
- See YOD for who they are = People!
- Refusal to let dementia depersonalize her – I am still me
- +ve outlook for future – Dementia will not take future – lots to look forward to!
- Make impact on the world in some way.
- YPcD underestimate themselves, abilities b/c of what is known about it
- Life is over narrative needs to Δ so YPcD can start living (again)
- More than the 'Big D' – Dementia does not have to be the end point but a starting point – a new lease. It's a single part of who
- Anything is possible if have confidence to go for it
- cost of being victim not worth it.



[redacted]

forgetting convos, loosing time – believed to be PTSD/stress related 'mental breakdown'

Dx experience = took approx 7 years
- HCPs not taking seriously [illegible] misdiagnosing b/c young age
- She knew something not right "hunch" – both B + HCPs never considered YOD b/c age
- had to fight to get investigations, years repeat tests
- ↳ 2015 finally got dx → delivered very poorly – essentially told to get affairs in order – aka you're going to die soon! → Ignorance/inexperience HCPs YOD
- → shock + disbelief = initial rxn → laughed → then panic set in "onslaught"

Rxn → Youngest person ever in UK to be diagnosed c̄ dementia
- felt left high & dry – Ø support practical, emotional, physically
- tried to research illness – v. limited info / Ø YP specific

Did memory walk on whim → was interviewed about why there – told her story ↑

Evolution?

Felt → abandoned/punished b/c age
had to find her own way
PP didn't/don't know how to deal c̄ her b/c Ø typical pt → typical v atypical
intersection age/illness hard for ppl to understand

Sense injustice → feeling singled out → Social injustice – why don't we (YP) get anything?

Dementia = nasty disease
↳ her's genetic as discovered but was adopted → dx out of nowhere

THEN
- Felt like needed to come forward & share story – be the YOD voice & help other YPD.
- Young ppl have more to lose than older adults – Dementia symptoms can be embar[illegible] → for YPwD – commonality b/c society expectations
- use own experience as cautionary tale
- to ~~[illegible]~~ protect others from what she went through!

* Personality trait – stubborn, resilience, been through hard times → Refusal to give up!

ALSO
- existing perceptions of dementia = old person, scary, late stage "shit I'm gonna die!"
- overwhelmed
- End of it all? – Existential concerns

Q – how am I going to fit 40 years of life into months/year?

YPD = ↑↑ responsibility

BUT
- 'Fuck it' → challenge the dementia
- drawing on internal reserves/resilience
- other ppl need me → kids, partner ? for other YP elderly parents –
- Need to protect those ppl ↗
- overcome adversity in past – can do it again – stronger than ppl know/give credit for ↳ personal strengths
- Re-evaluation of life & personhood → New outlook / appreciations for life & sense-making
- Husband died suddenly – thankful for dementia b/c it took away fear; [illegible], planned funeral – dealt it all c̄ dementia = proving her personal strength

———→
- Public perceptions of dementia = worst, label she doesn't feels fits
- ? She associates dementia sensory issues c̄ her hallucinations (unclear)

———→

(some things are fixed)
- Integration of dementia into 'old life'
- comparison to living life in slightly lagging video call – gets most of it

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* The selves – 2 of us now
- Dementia like having annoying/disruptive/unwanted house guest

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(Life) ~~[illegible]~~ Values impact
- being present c̄ kids
- being a mother

} diagnosis reinforced values
values helped to cope + move forward?

was working for period @ time dx – she quit b/c didn't feel safe, partly [illegible] boss wanted to save job → shows strength relationships?

Hindsight is 20:20 → not inside looking out but outside looking in

[illegible] as theme? < mum / wife / life?

Now • 2° dx, losing eye sight! – annoyed but accepting
content c̄ life, happy accepting "I've seen it all/everything"
Living in line c̄ values – backs her life choices

Family
- Kids not aware of dx – important for her → Ø Δ in relationships/how relate to one another
- identity as her kids → she's still mum, NOT mum c̄ D
- A lot of ppl Δ'd how interacted/related to her – annoying – she hadn't/didn't Δ just got a diagnosis YOD – we don't turn into gold fish!
- kids have option for genetic testing – doesn't want it

B glad didn't know of gene before dx – if you were to know – the impact of this on life & sense of self probably negative & huge

Awareness though for others barriers to getting genetic testing = £££

Importance of not defining self by dx/not being defined by others – kids taught her – now feels time for public to catch on

Dementia world – ppl should try to emerse themselves in it so can understand how a YPD constructs world.

Living well c̄ Dementia → ppl need to know to com/interact c̄ YP ⇒ wishes had been supported ~~[illegible]~~ b/c young ppl's needs are different

Brain fog [illegible] / walking in fog → can get through/around but [illegible]

- Bottom up process of learning how to live c̄ YOD
- Public patronization/fears towards interacting c̄ YOD – YPwD have different needs to older adults + [illegible]
- Dementia = spectrum of truths/realities – why are YPwD treated like OAPs = annoying
- Dementia likened to locked in → awareness of being trapped in reality that now Ø control over ↳ strong need for PwD [illegible] to accept & adapt to this – adopt new truths (construct [illegible])
- Pre-existing personality traits (stubborn) have been ↑ & helpful
- memories are like puzzle pieces → brain sees versus what is done!
- Separation of self from brain (dementia) → keeps this separate (dissociation?)
- can still make memories – just delayed @ times
- "Like being blind & deaf" → delay in memory/poor memory expected in OAP but in YP = disturbing
  - ↳ "Brain bleed" → processing/perceptions, communication, events
- outside versus inside (young vibrant women v. old feeble women)
- let down by brain, poor coordination, not reliable → can split herself
- Views Dementia as separate to personhood (part of me but not my true self?)
- Living c̄ evil twin but now got used to her presence → power struggle = arguments c̄ her
- Living in alternate reality where things go R→L having to learn to do things opposite
- Dementia pain in ass but can live/bear it
- 'My other half' → partnership, splitting → 2 ppl inside 1 head compared to schizophrenic hallucinating → relationship dyad c̄ in single person
- Finds humor in the YOD half, will compromise c̄ 'her'
- Acceptance, adaptation, transition c̄ coping → recipe for PTG
- Importance to still keep yourself happy → YOD shouldn't take joy/pleasure away from you!

→ these are now just annoying b/c has become used to them

New GOALS = advocacy + awareness building – demystifying YOD

Dementia doesn't take everything immediately – akin to a present purgatory?

Dementia does not make you dysfunctional → compassionate understanding → you did not choose

Dementia does not [illegible] – its bad but could be worse!

YOD, instead victim to situation ⇒ do not succumb to it, rally draw on resilience (not good enough) → Determined [illegible]

WAGING WAR ON DEMENTIA SYSTEM

Dementia not just for OAPs – feels YPwD [illegible] to older counter parts → [illegible] during covid b/c as YPD

YOD needs to be considered to be equal to [illegible]

* Dementia warrior against social injustice/inequalities → Living c̄ committed action

Ø support for her – did what needed to do to survive (dementia)

- Awareness of time → not wasting precious commodity
- knows what is @ end of road for her → Live life to fullest
- Social justice for YPwD
- Positive outlook on life result of other traumas – built up ↑ resilience – not afraid to put self out there
- FIANCÉ! Engaged recently – met fiancé on [illegible] (online dating) – dementia does not [illegible]
- bonded over mutual interests/hobbies – Fiancé looks beyond dementia to person beneath
- Relationship has moved quickly (time) – important for her to be different "Dementia Bride" – is she 1st?
- Wedding in cinema
- Time important, live in present b/c wants to make most of what has left
- Not being held back by dementia → trying new possibilities ↳ engaged c̄ public facing work
- challenging experts → Voice of YPwD ↳ "its not good enough!"
- My story can be the example, it can/I can help others not go it alone } wants to protect future generations of YOD
- YPwD should be taken seriously – we are just as important!
- Dx can be scary, isolating, depersonalizing! – ↑ suicide rates, ↑ depression rates
- Strong beliefs about public being uninformed & this has knock on effects
- Sense of capabilities – brain gets in the way sometimes
- Dementia is part of me but not all of me – does not & should not define me
- Can ask for help now when needed it → not afraid to be vulnerable? / show what YOD is like
  - ↳ if ppl don't know how can they or anything Δ? – stand up for little guy!
- Taking matters into own hands – acting as catalyst for Δ (why she did this research!)
- Uphill battle to make lasting Δ → temporary actions not enough – not satisfactory
  - ↳ angry that [illegible] Δ only benefit OAPs c̄ dementia – the expected crowd
- Where do YPwD fit in c̄ in society & Dementia world – we'll must help define/find our place (come out!)
- YOD collective = club no one asked about – YOD = lost boys & girls
- [illegible] to be on TV → message, can you see us? You should! * Justice never sleeps!
  - ↳ met other YPwD who were like minded = millions, army? New friends, the impact for all
- Dementia does not take away point of view → made stronger
- Wanted to be role model for other YPwD (& more on TV show) dementia knocks/takes away [illegible] makes you depressed, it can make you feel alien! Common to feel worthless/useless b/c can't do things

B learned how to interact/communicate c̄ diff types YOD – tried to build up self confidence & her colleagues – entered their reality c̄ kindness/empathy → show ppl they could do stuff maybe just need to approach it differently

Dementia does not make you invalid – can still [illegible] – social narrative that means YPwD believe they cannot contribute anything

Dementia doesn't take you – its other ppl, attitudes etc

Personality has help her c̄ life – she has ↑ confidence – she tried to rub off on others – based on other YPD, improve their confidence

See YPwD for what we/they are – people! – "I am still me"

Stubborn refusal to let dementia depersonalize her

Maintains the outlook for future – will not let dementia take/ruin [illegible] future ↳ "lots to look forward to!"

Wanting to make impact on world in some way

YPwD underestimate themselves, their abilities b/c of what is known about it
this needs to Δ so that way YPwD can start living (again)

- 'More to life than the big D' – dementia does not have to be the end but rather a starting point, a new verse
- It's only one single piece of you
- anything is possible if you have the confidence to go for it
- Cost of being/subscribing to victim identity not worth it!

*"More to life than the Big D"   *Intersection age & illness

* Acceptance, adaptation, coping + transition = PTG recipe

*ppl c̄ YOD deserve to be happy too
don't let dx take that - why should it?

[redacted]

Bumps/Barriers/Dx Experience

- started c̄ forgetting things - thought PTSD/breakdown "Hunch"
- Long experience 7+ years; fighting c̄ HCPs for tests; blames age
- never thought would be YOD - dx delivered poorly insinuated going to die
- shock, youngest person ever in UK - no info from her on YOD } Felt abandoned + punished b/c age Singled out
- left high & dry once dx'd; no support practical or psychological
- people didn't know to react or deal c̄ her (typical v. atypical dementia pt)
- her dx genetic + she was adopted - no warning - existing perceptions dementia = scary label

PERIOD TRANSITION - NOW WHAT? - how will I fit 40 yrs life into years?

- angry, lost - injustice; Did fundraiser ⇒ explosion of media attention
- Realized nothing for younger ppl + have more to lose
- Need to Rally to be there for kids - people rely on me, (common for YOD) - importance of maintaining relationship
- Reflection - I've overcome adversity in past - can do it again
- Acceptance, living life in lagging time - the dementia reality - Dementia like locked in syndrome or Brain Blind
- recent 2° dx eye issues - seen it all, its ok
- is cost being victim worth it? → NO!
- learning to be brain deaf/blind

dx reinforced what was important to her

NEGOTIATION/LEARNING, REALIZATION - re-evaluation of life + personhood - new outlook sense-making

- What do I value? My kids, being mum - dementia won't take that - views dementia as both, separate + part of her
- how to integrate the selves (2 ppl inside 1 head, evil twin), negotiate relationship c̄/in self
- will not define self by dementia dx
  - ↳ dementia Ø dysfunctional
- bottom process of learning life c̄ Dementia
- dementia can be scary + isolating - shouldn't be!
- recognizing social injustices for YPCD
- Strong sense capabilities + limitations - asks for help when needs it - not afraid
- learning how to navigate dementia reality
- Dementia freeing in that sense
- developing strong beliefs about public being uninformed + impact of this
- precious time is + make the most
- determined not be held back by dementia
- My story can be an example
- Live life c̄ committed action - importance to make yourself happy - dementia doesn't mean don't deserve this

PTG - proving ppl wrong - sense purpose

- life goal/focus to get word out on YOD
- improved Relationships c̄ kids - teaching them still mum
- Engaged - found love by taking a chance
- Advocacy + national attention about court - Dementia Warrior
- planned husband funeral - surprised self; can do anything!
- Support other YPCD, improve their confidence
  act as Role model for other YPCD
- Future viewed as positive + open to all new poss.
- Meeting other YPCD, making friends, acting as leader
- social justice ← → Dementia doesn't stop you other ppls attitudes do!
- Research
- determined to create lasting Δ

Contributing Factors

personality traits - stubborn - obstinate - confident

anger towards system

Resilience

humor

compassionate understanding dual effect

* self-confidence

Section B: Client Case Study

An Integrative Approach to Supporting Recovery from Illness-Induced Trauma

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Part C: Publishable Paper

Exploring the Impact of Posttraumatic Stress and its Relationship with Posttraumatic Growth in Young Onset Dementia: A Pilot Study

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