Living with early-onset dementia: A thematic analysis of dementia blogging and autobiography

A thesis submitted for the degree of Doctor of Philosophy (PhD)

by

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Declaration

Candidate's declaration:

I, Wendy Erskine, hereby certify that this thesis submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy (PhD), Abertay University, is wholly my own work unless otherwise referenced or acknowledged. This work has not been submitted for any other qualification at any other academic institution.

Signed………. Wendy Erskine……………………….

Date…………..5 April 2019……..…………………..

Supervisor's declaration:

I, Jason Annetts hereby certify that the candidate has fulfilled the conditions of the Resolution and Regulations appropriate for the degree of Doctor of Philosophy (PhD) in Abertay University and that the candidate is qualified to submit this thesis in application for that degree.

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Date….………………………...…….……..

Certificate of Approval

I certify that this is a true and accurate version of the thesis approved by the examiners, and that all relevant ordinance regulations have been fulfilled.

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Date……………………………………………………..……………………

Abstract

Background
Dementia is the biggest cause of death in the United Kingdom (Matthews, 2016). Early-onset dementia (EOD) is a subset of the dementias affecting people between the ages of forty-five to sixty-five (Mercy, 2008). People with early-onset dementia (PwEOD) can find themselves negotiating very different experiences from those who develop the condition in later years. As EOD occurs in prime working-age and parenting years, the implications can therefore be challenging (Beattie et al., 2004; Rayment and Kuruvilla, 2015). PwEOD can still possess good health relative to people with typically older onset dementias. However, due to the under-researched nature of the condition, the number of PwEOD is likely to be underestimated (Kaiser and Panegyres, 2006). As a result, there is a lack of suitable services for PwEOD to access (Withall, 2013). Therefore, EOD represents a significant public health, economic and personal concern with few suitable strategies to address the diverse needs of a younger population, thus making it a much-needed area of research development.

Aims
The aim of the thesis was to establish the experience of EOD from autobiographical and other written content. The focus was upon the impact of having a diagnosis of dementia at working-age. This aim required the collection of deep, rich data, from a sample of PwEOD.

Methodology
The study was conducted from a qualitative perspective grounded in social constructionism and symbolic interactionism. A systematic literature review (SLR) was carried out to identify gaps in the current literature. A meta-ethnographic synthesis was used to synthesise qualitative studies based on experience of EOD (Noblitt and Hare, 1998). Following this, personal accounts by PwEOD were selected to be analysed to understand the personal experiences of living with EOD. Four autobiographies and a blog provided the data for a thematic analysis (TA) to be performed which over two studies examined personal and social effects.

Findings
The findings presented as two studies; Study One considered the personal aspects of the condition and Study Two considered the social and interpersonal aspects.

Study One:
Diagnosis was a pivotal point which indicated the end of one era and the beginning of another. Shock was the initial experience. Whilst also confirming an unwelcome trajectory to life, the writers moved into varying levels of acceptance. The diagnosis was simultaneously wanted and unwanted. Diagnosis formed the first theme.
Notions of separation in an insecure place of limbo were common. Changes occurred; transition had to be negotiated in stages of separation from others. Spatial oddities and matters of chronicity were related to the sense of not knowing the time. These experiences were linked to liminal experiences and the inevitable need to ‘let go’. These ideas formed the second theme ‘Lost in time and space’. The transitional experience of feeling ‘unfixed’ was not always interpreted negatively. Personal identity formed the third theme. Identity was impacted by both the diagnosis itself and the experiences of living with EOD. The writers described how they had lost both their previous roles in life and their sense of self. Writing had been adopted to help reconstruct identity with a diagnosis of dementia.

Study Two:
The idea of contagion was drawn from cultural tropes which evoked ideas of stigmatising contagion. Experiences of feeling rejected through fear of others’ concerns about them were explicitly discussed or implied through the writing. This was understood as blame and shame. There was a disenfranchisement with humanity and belonging. This affected the credibility that struggled with stigma. Fears were voiced that family kin might ‘catch dementia’ from the PwEOD in the way it consumed their lives. This contributed to the

impact of a contagious view of EOD. This inevitably led towards stigmatising effects and contributed to the breakdown of identity. Credibility was found to be crucial to identity. It could be a fluid matter knowing whether an outsider was pitching their belief in the PwEOD being disabled and unreliable in a malignant and deviant sense or a medical fraud. Stigma was sometimes driven by outsiders and their perceptions, making the life of PwEOD more difficult. The activity of PwD as walkers and 'wanderers' was one that was noted frequently. Emphasis on walking helped express feelings of exasperation and helplessness, but there was a discrepancy between walking and wandering and the stigma that was attached to wandering. These issues form the second theme, 'blame and shame'. Managing potential changes to identity provoked problems and behaviours undermining the personhood and wellbeing. This reflected difficulties for the writers to overcome a loss of identity as well as dealing with stigma imposed by others. Using autobiography on the theme of illness offered a boost to regaining a refreshed identity. These ideas formed the theme 'social and interpersonal identity' which discussed the claiming back of a renewed if damaged identity. Social identity therefore could be challenged to restore a renewed and more potent personality with a social message for the self as well as others.

Discussion

The discussion found significance in the diagnostic transition throughout the synthesis of the SLR and studies One and Two. Diagnosis provided a life-defining experience begging the need to address changes to life and living. Life with EOD could be expressed as feeling torn apart with no stable ground upon which to stand. These changes occurred as experiences which could be articulated as vague, elusive and unknowable leading to ambiguity rather than certainty. The journey from chronic illness to face others' reactions could be discriminatory. Situating EOD in a solely biomedical model meant that it was more likely that the stigmatising aspects of EOD made it less feasible to find positive factors. Moving from this, there was evidence of adaptation which looked to reunify body and self accordingly in ways that were workable and socially evident to others as identity forming. A new identity had to be balanced carefully between what was traded away by what could no longer be managed and blended into the new and more inspired identity made up of new accomplishments. Social identity was often found to be present across gender and working roles. Lives could, at the same time, be lost and located to a new location through the pursuit of writing autobiographically. This thesis showed how writing published material allowed for the regeneration of self and how it was possible to make different identity gains than in previous 'healthy' lives. The material is based upon a small sample of writers and adds to the limited research that currently exists in the field of studying qualitative life experiences with EOD. It provides evidence of a skilled and participative subset which can bring more insight to what it is like to have dementia.

Conclusion

Conclusions reflected that with the SLR, many gaps and needs were identified within the limited studies drawn from four available studies by PwEOD. However, of the studies included to expand family kin experience of EOD, many concerning elements were highlighted showing unmet needs and phenomena such as parentification and the loss of childhood and adolescence. However, with the expanded inclusion of Study One and Study Two using TA the findings suggest that PwEOD, are finding increasingly independent and diverse ways of giving voice to their condition. One way of doing this is through autobiography and blogging. This response in turning to this outlet is initiated by a permanent loss of health. From this state, a variety of consequences, both gains and losses could occur. This has implications for identity. With the onset of chronic illness, everyday life upon which former identities hinged, changed. The importance of being able to reconstruct identity suggested this was a pivotal process in living with EOD together with maintaining dignity, stigma, skills, minimising losses along with broadening key social relationships and networks. Identity required empirical validation in daily life with a minimising of credibility gaps which often occurred from social side-lines. A more individual approach may be more effective when diagnosing and planning care for this special subset of individuals with dementia. The concept of identity lies with how people create meanings and act assertively as they interpret their experience. The thesis found that identity goals are changed with a diagnosis of EOD. Future research would benefit from seeking independent qualitative views surrounding EOD for the PwEOD and immediate family kin. By exploring the working-age/parenting nature of EOD context may help build upon the positive and inhibit the negative effects of living with EOD. This may also support growing families whose own identities are affected by having someone in the family with EOD.

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Dedication

Dedication to humanity

‘It’s about the people who stopped believing because the cup of evil has run over’

Dmitry Shostakovich – on the 11th Symphony, ‘The Year 1905’.

‘Don't you see that the whole aim of Newspeak is to narrow the range of thought? In the end, we shall make thoughtcrime literally impossible, because there will be no words in which to express it. Every concept that can ever be needed, will be expressed by exactly one word, with its meaning rigidly defined and all its subsidiary meanings rubbed out and forgotten’. George Orwell ‘Nineteen Eighty-Four’

In memory of

Professor Mo Malek (born May 19, 1949, died March 12, 2001). One of the most highly respected and world-renowned specialists in health economics and healthcare management. For the world of health that he cherished and served, by it, he was ultimately so badly let down himself. ‘We all benefitted hugely from his presence and we will all hold his memory, like Moorsom said, as a "jewel in our hand"’

‘You have to keep breaking your heart until it opens’ Rumi

Table of contents

DECLARATION I

ABSTRACT II

ACKNOWLEDGEMENTS V

DEDICATION VI

IN MEMORY OF VII

TABLE OF CONTENTS VIII

LIST OF TABLES XIV

LIST OF FIGURES XV

GLOSSARY OF TERMS AND ABBREVIATIONS XVI

1 INTRODUCTION 1

1.1 OVERVIEW AND REASONS FOR RESEARCH 1
1.2 RESEARCH PERSPECTIVE 3
1.3 OVERARCHING STUDY QUESTIONS AND AIMS 4
1.4 STRUCTURE OF THE THESIS 4
1.5 SUMMARY 6

2 LITERATURE REVIEW 7

2.1 BACKGROUND 7
2.1.1 Introduction 7
2.1.1.1 Origins of dementia 7
2.1.1.2 Causes of dementia 8
2.1.1.3 Dementia classifications 10
2.1.1.4 Introducing EOD 11
2.1.1.5 Common types and classifications of EOD 12
2.1.1.6 Contemporary global statistics and aetiology of dementia 12
2.1.1.7 Awareness of dementia in Scotland 13
2.1.1.8 Contemporary statistics within Scotland and the rest of the United Kingdom 13
2.1.1.9 Why EOD is different 14
2.1.1.10 Approaches to understanding dementia 15
2.1.1.11 The biomedical approach to dementia 16
2.1.1.12 The psychosocial approach to dementia 17
2.1.1.13 The biopsychosocial approach to dementia 18
2.1.1.14 The unique situation of PwEOD 19
2.1.1.15 The paradox of being young with an old disease 19

2.2 THEORETICAL PERSPECTIVES OF ILLNESS 22
2.2.1 Identity and the body/self dichotomy 22
2.2.2 Temporal and biographical disruption 24
2.2.3 Chronicity in illness 25
2.2.4 Status passage 28
2.2.5 The crisis of broken identity 29
2.2.6 Liminality 30
2.2.7 Stages of liminality 31
2.2.8 Permanent liminality 32
2.2.9 Permanent liminality as 'liminoid' 33
2.2.10 Stigma 34
2.2.11 Identity goals of the stigmatised 36
2.2.12 Social constructions of dementia 37
2.2.13 The sick role 39
2.2.14 Citizenship 40
2.2.15 The intimate citizenship domain of PwEOD 41
2.2.16 Summary 43
2.3 SYSTEMATIC LITERATURE REVIEW (SLR) 43
2.3.1 Introduction 43
2.3.2 Method 44
2.3.2.1 Study aim 44
2.3.2.2 Study inclusion 45
2.3.2.3 Study exclusion 45
2.3.2.4 Scoping 45
2.3.2.5 Search strategy 46
2.3.2.6 Selection of papers 46
2.3.2.7 Approach to systematic and meta-analysis synthesis of studies 46
2.3.3 The role of meta-ethnography in qualitative research 48
2.3.4 Results 50
2.3.4.1 Participant and study design 50
2.3.4.2 Drawing a line of argument from the seven-step process 57
2.3.4.3 Overall themes 62
2.3.4.4 Conceptual themes and Schutz's first and second order constructs (1962). 68
2.3.5 Line of argument 74
2.3.5.1 PwEOD – Biographical disruption 74
2.3.5.2 Diagnosis 75
2.3.5.3 Losing life, friends and competencies 77
2.3.5.4 Liminality and chronicity 78
2.3.5.5 Stigma 80
2.3.5.6 Coping with cautious optimism. 81

2.3.6 Conclusion 82
2.3.6.1 Gaps in the literature and rationale for study 83
2.3.6.2 Strengths and limitations of the review 83
2.3.6.3 Clinical implications 84
2.3.6.4 Future research implications 85
3 METHODOLOGY 86
3.1 INTRODUCTION 86
3.1.1 Aims and objectives 86
3.1.2 Ontological and epistemological approach 86
3.1.3 Positivism 87
3.1.4 The interpretative paradigm 87
3.1.5 Social constructionism 88
3.1.6 Symbolic interactionism 90
3.2 QUALITATIVE APPROACHES 92
3.2.1 Qualitative research 92
3.2.2 Selection of data collection method 93
3.2.3 Participant research 93
3.2.4 Interviews 94
3.2.5 Narrative accounts 95
3.2.6 Narratives accounts of illness 96
3.2.7 Narratives accounts of dementia 97
3.2.8 Autobiography as a form of narrative 99
3.2.9 Blogs as a form of narrative 100
3.3 DATA ANALYSIS 101
3.3.1 Grounded theory 102
3.3.2 Narrative analysis 104
3.3.3 Considering and comparing IPA and thematic analysis (TA) 105
3.3.4 Thematic analysis process 107
3.4 METHODS 110
3.4.1 Ethical approval 110
3.4.2 Sampling 110
3.4.3 Data collection 111
3.4.3.1 Inclusion 111
3.4.3.2 Exclusion 112
3.4.3.3 Data collection method and approach 112
3.5 DATA ANALYSIS 116
3.5.1 Thematic analysis 116
3.5.1.1 Reading and familiarising by immersion in the texts 116

3.5.1.2 Generating initial codes 118
3.5.1.3 Searching for themes 120
3.5.1.4 Reviewing themes 121
3.5.1.5 Creating definition and the naming of themes 122
3.5.1.6 Producing the report 123
3.5.1.7 Rigour of the data 124
3.5.1.8 Reflexivity 127
3.6 SUMMARY OF CHAPTER 128

4 FINDINGS 129

4.1 AIMS AND OBJECTIVES 129
4.1.1 Author 1 129
4.1.2 Author 2 130
4.1.3 Author 3 130
4.1.4 Author 4 131
4.1.5 Author 5 (Blogger) 131
4.2 STUDY ONE: PERSONAL EXPERIENCE 133
4.2.1 Theme 1: The diagnosis 134
4.2.1.1 Subtheme: Diagnosis as pivotal 134
4.2.1.2 Subtheme: Diagnosis as both wanted and unwanted 135
4.2.1.3 Subtheme: Diagnosis brings shock and acceptance 136
4.2.1.4 Summary 138
4.2.2 Theme Two: Lost in space and time 138
4.2.2.1 Subtheme: Liminality 139
4.2.2.2 Subtheme: Lost in space 140
4.2.2.3 Subtheme: Lost in time 141
4.2.2.4 Summary 143
4.2.3 Theme Three: Personal identity 144
4.2.3.1 Subtheme: Loss of role 144
4.2.3.2 Subtheme: Loss of self 148
4.2.3.3 Subtheme: Reconstructing identity with words 149
4.2.3.4 Summary 152
4.2.4 Summary of Study One: Personal experience 152
4.3 STUDY TWO: SOCIAL AND INTERPERSONAL ASPECTS 153
4.3.1 Theme 1: Dementia is contagious 153
4.3.1.1 Summary 155
4.3.2 Theme 2: Blame and shame 155
4.3.2.1 Subtheme: Credibility 157
4.3.2.2 Subtheme: Stigma 158
4.3.2.3 Subtheme: Walking and wandering 159
4.3.2.4 Summary 161

4.3.3 Theme 3: Social identity 162
4.3.3.1 Subtheme: Challenge to social identity 162
4.3.3.2 Subtheme: Constructing a new social identity 164
4.3.3.3 Summary 169
4.3.4 Summary of Study Two 170

5 DISCUSSION 171

5.1 INTRODUCTION 171
5.2 DIAGNOSIS 171
5.2.1 Summary 174
5.3 LOST IN TIME AND SPACE 174
5.3.1 Summary 178
5.4 PERSONAL IDENTITY 178
5.4.1 Summary 182
5.5 DEMENTIA IS CONTAGIOUS 182
5.5.1 Summary 186
5.6 BLAME AND SHAME 187
5.6.1 Summary 190
5.7 SOCIAL IDENTITY 190
5.7.1 Summary 194
5.8 COMMUNITAS AND INTIMATE CITIZENSHIP 194
5.8.1 Communitas 195
5.8.2 Intimate citizenship 197
5.8.3 Summary 199

6 CONCLUSION 201

6.1 INTRODUCTION 201
6.2 AIMS 202
6.3 OVERARCHING STUDY QUESTIONS AND AIMS 202
6.4 SUMMARY OF THE STUDY'S FINDINGS 203
6.5 CONTRIBUTION TO KNOWLEDGE 204
6.6 DISSEMINATION OF THE FINDINGS 205
6.7 FUTURE RESEARCH IMPLICATIONS 206
6.8 STRENGTHS AND LIMITATIONS OF THE STUDY 209
6.8.1 Strengths 209
6.8.2 Limitations 210
6.9 CONCLUDING REMARKS 211

7 REFERENCES 214

8 APPENDICES 235

8.1 APPENDIX 1 – AUTOBIOGRAPHIES BY PWEOD 235
8.2 APPENDIX 2 – EXCLUDED PAPERS 236
8.3 APPENDIX 3 – FIFTEEN-POINT CHECKLIST BRAUN AND CLARKE 237
8.4 APPENDIX 4 - BRAUN AND CLARKE TROUBLESHOOTING 238
8.5 APPENDIX 5 – TOM KITWOOD MALIGNANT PSYCHOLOGY COMPONENTS 239
8.6 APPENDIX 6 – ETHICAL PERMISSION 240

List of tables

TABLE 1- NOBLIT & HARE 7 STEP SYNTHESIS 49
TABLE 2: PARTICIPANT AND STUDY DESIGN 52
TABLE 3:INVESTIGATION OF EXPERIENCES 58
TABLE 4:CONCEPTUAL THEMES 63
TABLE 5:FIRST AND SECOND ORDER INTERPRETATIONS 69
TABLE 6: SIX PHASE STEPS IN THEMATIC ANALYSIS 108
TABLE 7: DATA SELECTION (BOOKS) 114
TABLE 8:DATA SET (BLOG) 115
TABLE 9 TABLE OF THEMES 133

List of figures

FIGURE 1: PRISMA FLOWCHART 47
FIGURE 2 - METHODOLOGICAL FRAMEWORK 88
FIGURE 3 – MEMORABLE JOTTINGS 116
FIGURE 4 – EARLY IDEAS FOR THEMES 117
FIGURE 5 – CODING SAMPLE 120
FIGURE 6 – CODING CATEGORIES 123
FIGURE 7 - SOCIAL AND PERSONAL IMPACTS 171

Glossary of terms and abbreviations

PwD - People with dementia

- Person with dementia

EOD - Early-onset dementia

PwEOD - People with early-onset dementia

- Person with early-onset dementia

TA - Thematic analysis

SLR - Systematic literature review

Dementia is used throughout this paper as an overview term for Alzheimer’s disease and all other sub-types of dementia.

1 Introduction

This thesis presents a qualitative research study, which aimed to understand the experience and meaning of people who received a diagnosis of EOD. The aim of Chapter One is to introduce the reader to the research and offer an overview of the thesis and the need for research in this area. The social and political landscape of the subject will be introduced. Following this, data on the incidence of dementia will be presented on EOD regarding current research, and the relevant clinical background will be included. The motivation for the study will be explained. This chapter will then outline and describe the research questions and how these will be approached throughout the thesis. Finally, the structure of the thesis will be explained.

1.1 Overview and reasons for research

Dementia is the biggest cause of death in the United Kingdom (Matthews, 2016). Current statistics estimate that approximately 850,000 people in the UK are living with the condition, the vast majority being over the age of sixty-five years (Prince et al., 2016). Understanding, treating and caring for the numbers of individuals with dementia remains a national challenge in the four nations of the UK (Alzheimer’s Disease International, 2015). As the increasing incidence rates and cost of care of dementia in the UK rise, there is a heightened momentum to address the challenges involved in living with dementia. The Westminster government has committed to improving levels of diagnosis, care support, and research (Department of Health, 2015). According to Milne (2010), dementia poses serious challenges to health and social care systems at home and abroad. The author of the paper states that there is a need to sharpen knowledge related to all approaches to care and provision for services.

EOD occupies a subset of PwD. Individuals confronted with a diagnosis of this condition can find themselves negotiating very different experiences from those who develop the condition in later years when working and nurturing life is complete. The implications can therefore be challenging (Rayment and Kuruvilla, 2015) with individuals still being in employment, child-rearing and caring for older parents (Beattie et al., 2004). PwEOD can still possess good health relative to people with typically older-onset dementias. However, the acute awareness of creeping mental deterioration, and the associated consequences this may have provokes great stress for both PwEOD and family kin (Kaiser and Panegyres, 2006). Appropriate community services may present difficulties for PwEOD to access as NHS and community resources are targeted upon older dementia subgroups. As a result, there is a lack of suitability of service for those with EOD to access (Withall, 2013). This has perhaps further entrenched the idea that dementia is a condition established in old age (Connelly and Perea, 2013). As a result, this may have helped situate a lack of expectation in health and social services in being confronted with EOD thus, the number of PwEOD is likely to be underestimated (Kaiser and Panegyres, 2006). Therefore, EOD represents a significant public health, economic and personal concern with few suitable strategies to address diverse needs of a younger population.

Contemporary values enshrined in policy and practice lead with goals of dignity, sensitive care provision and the pursuit of engaging with enlightened practice at all levels of interacting with PwD. Thus, there is a moral imperative to strengthen the means by which PwD can enjoy the best quality of life without the associated reduction in rights and consideration that often follow chronic illness and disability:

> ‘People with dementia retain the same rights as anyone else in society, but the nature of their illness means that they often have great difficulty in protecting their own rights. There is still stigma and discrimination against people with dementia, and they and their carers often feel, with some justification, that they are treated with less respect, dignity and understanding than other members of society. These standards relate to everyone with a diagnosis of dementia in Scotland regardless of where they live, their age, the supports they receive or the severity of their illness. This includes younger people, people with a learning disability and people with rare types of dementia. They apply to people living in their own homes, care homes or hospitals, especially general hospitals’. (Standards of Care for Dementia in Scotland 2011, p.1)

These values are the foundation and minimum standards deemed to be acceptable. The inclusion of PwEOD into full social and healthcare acceptance due to the reasons outlined above lags behind other dementia subgroups attached to older age dementias. However, because EOD as a subset of dementia provokes a more diverse range of commitments and needs, differences and gaps in service understanding and provision should be examined. Currently, people over the age of sixty-five in Scotland have entitlement to full personal care for health conditions. However, there is growing legislative pressure to address the offering of care for those with the same conditions under the age division of sixty-five. This debate was initiated by an individual case of EOD[1]. This therefore offered a timely opportunity to investigate and better understand the experience of PwEOD. These factors underlay the rationale for investigating the condition as a distinct subset of the dementia classification. As this thesis was submitted, this legislation has been brought into existence by the Scottish Parliament.

1.2 Research perspective

Alzheimer's Disease International enshrined their own values and expectations in their 2013 conference:

> 'We believe that everyone, everywhere, can and must do their bit to help people with dementia live well throughout the dementia journey. There are enormous power and possibility in families, friends, carers, healthcare professionals, commissioners or purchasers of care, providers, society and governments working together to improve long-term care in their country' (Alzheimer's Disease International 2013, p.1).

This thesis draws from these values and sentiments outlined in the above quote which places importance upon the inclusion of everyone to commit to the provision of quality care for PwD. The motivation for researching the topic selected emerged from training to be a Church of Scotland minister then diverting this spiritual journey to becoming a Quaker. Therefore, after completion of studies, working in 'hands-on' roles with marginalised and vulnerable people felt like a more dynamic way to offer day-to-day practical help. This perspective was extended with a period of five years caring as an unpaid carer for an individual with EOD. Beyond this, another five years was spent employed in care of the elderly, PwD, PwEOD, neuro-cognitive disability, care of the dying, challenging behaviour units, administration of respite facilities including home care visits for people with compromised health conditions. Both by study, research, paid employment, formal and informal volunteering, considering the personal impacts and experiences of others living with end of life health conditions has always spoken to my radical

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[1] Frank Kopel (Frank's Law).

spiritual approach and sentiment towards the lives of others. This provided suitable motivation and energy to embark upon this study.

1.3 Overarching study questions and aims

The aim of the study was to learn more about the personal experiences of people with EOD. This was addressed by meeting the following objectives:

1. Establishing to what extent personal experiences of EOD are present in the extant literature and what this tells us.
2. Using autobiographical and other written content about the self by people with EOD to learn about the experience of EOD.
3. Focusing on the impact of having a diagnosis of dementia at working age and what considerations follow with this status.

These aims and objectives will be met by:

1. An SLR of the experience of living with EOD
2. Identifying and analysing a data set reflecting autobiographical and personal perspectives of PwEOD, from a blog and books
3. Identifying and discussing themes appearing through a TA from the content of the data set.

1.4 Structure of the thesis

The thesis is organised into six chapters, as follows:

Chapter One provides an overview picture of the study and introduces the reader to the research. The social and political landscape linked to having a health condition like EOD is explained. The data on the incidence of dementia is presented on EOD. Current research and relevant clinical background are included. The motivation for the study is explained, and reasons and needs for pursuing it are discussed. This chapter will then outline the research questions and how these will be approached throughout the thesis. Finally, the structure of the thesis will be explained to conclude with a brief summary.

Chapter Two frames the thesis with an overview of the research landscape examining the literature relating to EOD. The literature review will be presented in three sections: The first section will expand upon the background of dementia as it relates to EOD. Beyond the discussion given to its prevalence, types, classifications etc., it will then move on to section two which discusses some conceptual lenses which have linkage with the experience of EOD which were recognised from background reading and the carrying out of the literature reviews The third section is composed of an SLR of first-hand accounts of EOD by PwEOD and their family kin carers available in the current literature.

Chapter Three explains how an appropriate methodology was selected from qualitative research methods supporting experiences from the perspective of the self. The approach required was one acknowledging the individualisation of biographical patterns emerging from the diversity of subcultures and ways that lives are lived within these groups. The chapter continues to discuss the ontological and epistemological positions taken drawing from a social constructionist position. Following matters of rigour and ethics are addressed, including how the data was selected and collected. Further, there is some expansion on why other potentially applicable approaches were considered but ultimately rejected. Finally, the process underpinning the data analysis chapters explain how TA became the preferred tool by which to understand this qualitative study.

Chapter Four forms the findings and analysis section and is framed around two distinct studies; Study One and Study Two. Study One illuminates firstly, the personal aspects of what is discovered across the data set. This is reported separately from the analytical findings from Study Two and involves an analysis of data concerning the social elements of dementia.

Chapter Five critically reflects upon the thesis and dementia, including the impact upon PwEOD. This discussion chapter thesis synthesises the analytical findings and summarises the thesis.

Chapter Six concludes by reflecting upon the holistic elements of the thesis. It reiterates the research questions and how they were answered then offers a summary of significant findings. The findings demonstrate their relation to current literature. It gives recognition to the strengths and limitations of the overall thesis. The conclusion also summarises the potential adoption of the findings and where they might be deployed elsewhere in the social, health and policy fields. Suggestions and concerns are discussed with respect to research implications for the future.

1.5 Summary

This chapter provides an overall framework of the study. It makes explicit the importance of the topic and provides the rationale and motivations for undertaking this piece of research and its intention. It states the research questions and how the answers will be sought. This is followed by a description of the structure of the thesis. The organisation of the study is presented with a following explanation of the individual chapters. The next chapter describes the review of the relevant literature and identifies current gaps in contemporary knowledge at present. This forms the basis of the rationale for this study.

2 Literature review

2.1 Background

2.1.1 Introduction

The research aims were to understand the experience of dementia as articulated in first-person accounts of PwEOD. To present this information in the most informative way, this chapter opens by exploring background about dementia. This will discuss the issues and concerns before moving on to philosophical concepts and contemporary research on PwEOD. In order to situate the thesis in the appropriate research landscape, Chapter Two will examine the literature relating to EOD. The literature review will be presented in three sections. The first section will expand upon the background of dementia as it relates to EOD. Beyond the discussion given to its prevalence, types, classifications, causes and social constructions of dementia, it will then move on to section two which discusses some conceptual lenses which have been shown in the literature to have relevant connections with dementia. These concepts were included as wider reading and showed how using these lenses enhanced the understanding of dementia and EOD with data such as first-person accounts. The final and third section represents an SLR of the representation of first-hand accounts on EOD in the current literature. It includes a qualitative review of first-hand personal accounts given of PwEOD and is expanded to include the experiences of their family kin. Their inclusion was deemed necessary in consideration of the few studies extant solely focussing on qualitative experiential studies of PwEOD.

The following subsection introduces the origins of dementia and how it became understood as a neurological disease.

2.1.1.1 Origins of dementia

Dementia has attracted a steep escalation in contemporary clinical and policy attention since its identification a century ago. It is an umbrella term which encompasses a broad range of progressive neurodegenerative diseases. These diseases, by nature, bring about a decline over time and are currently have no cure

(Mielke et al., 2014). The current contemporary definition of dementia from the World Health Organisation (WHO) is:

> ‘Dementia is caused by disease of the brain, usually of a chronic progressive nature, in which there is disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Dementia mainly affects older people: only two per cent occur before the age of 65 After this the prevalence doubles with every five-year increment in age. Dementia is one of the major causes of disability in later life’. (WHO 2017, p. 42)

The identification of dementia was established in 1906 when a German psychiatrist Alois Alzheimer described the case of Auguste D. as part of an investigation of an ante-mortem history of impaired memory, difficulties of speech, paranoia and delusional ideation (Bowler et al., 1998). Post-mortem examination revealed an atrophied brain showing how neurofibrillary tangles were present. The disorder became established as Alzheimer’s disease. Alzheimer hypothesised that these growths might be the cause or effect of dementia (Small and Cappai, 2006). The condition proved to be a pathologically degenerative syndrome.

A key feature of dementia is the increased risk of the condition as people age. However, the condition is distinct from ‘normal’ cognitive ageing (Sonnen et al., 2011) and it can be experienced by people under the age of sixty-five as well as older people (van der Flier et al., 2011). It progressively causes a decline in cerebrovascular and neurological states of which, Alzheimer’s disease is the most common. It is characterised by progressive cognitive decline typically associated with memory as well as impairment in day-to-day functioning, which results in significant difficulties in daily life. Having dementia can, therefore, mean that the condition is complicated by having other complex conditions linked to ageing. However, there are many types of dementia and many causes for its establishment in the body. How it occurs in the brain in the first place has been established through significant scientific research.

2.1.1.2 Causes of dementia

The human brain is a structure of complexity which consists of two basic components made up of grey and white matter (Cantley, 2001). The grey matter is comprised of neurones communicating through complex chemical signals. These neurotransmitters are responsible for regulating behaviour, sleep, memory, and appetite. Supporting glial cells support nutrients to the neurones, which helps to repair the damage. These cells provide an essential role for brain function because, unlike other cells, neurones cannot replicate themselves. The white matter represents the connective materials, which join neurones in other parts of the brain to others through complex pathways. The interrelated nature of the neurones in the brain influence the activity of those in different locations. Grey and white matter are separated into four lobes. These are referred to as the cerebral cortex with each separate region having distinctive functions. When cognitive disease occurs, it can only affect one part of the brain, which sometimes can contribute to specific symptoms but can also be present with generalised symptoms. The temporal lobes within the brain help regulate mood and memory, whereas the hippocampus is the location for learning. When cognitive degeneration affects the anterior temporal lobe, the ability to understand and produce language is affected along with the frontal lobes affect personality, speech, and behaviour. The cerebellum at the base and back of the head controls movement, balance and posture with the mid-brain and brainstem controlling more of the basic functions such as appetite and sleep. The parietal lobes in the brain influence the perceptions involved in spatial and visual signals and influence an individual’s ability to coordinate motor tasks. The occipital lobes assist with processing the incoming visual images. Diagnosis often indicates the nature and cause of the damage. Ninety per cent of all dementias, can be categorised into one of five main types including combined dementias. A description of the most common types follows in this section (Whitehouse in Binstock et al., 1992, pp. 22-23).

While the disease itself has attracted better understanding through research, why it occurs is still not well understood except for some small number of cases within EOD where genetic inheritance is a known factor (Biernacki, 2007). It commonly, but not always, begins with mild symptoms and progresses slowly through the formation of abnormal protein which appears in the brain. These are called amyloid clumps and they operate to bind together to form plaques. These plaques go on to affect the health of neurones. It is believed that these plaques affect tau. This is another protein believed to damage the structure of brain cells. The damage has an impact on the brain, which impacts on its ability to convey messages essential for mobility, problem solving and language.

2.1.1.3 Dementia classifications

The following offers a description of the most common, prevalent dementia classifications:

Vascular dementia statistics account for approximately 25% of dementias being caused by reduced blood supplies to the brain usually resulting in a more rapid onset. When this occurs, it can lead to attacks of multi-infarct dementia. This can be caused by hypertension, raised blood lipids, smoking and diabetes. This indicates that for some individuals, some reduction in its incidence may be possible by improvements in health and lifestyle changes (Biernacki, 2007; Cantley, 2001).

Lewy body disease is one of the dementia subsets which appears to commonly affect men. Lewy body dementia can present with similar features to Alzheimer’s disease. This can make establishing a correct diagnosis more difficult. Dementia with Lewy bodies is believed to be the result of the development of abnormal structures like the plaques, minus the tangles, of Alzheimer’s disease in the brain. However, the pattern of physically evidenced traits follows visual hallucinations, occasional temporary disturbance in consciousness, a shuffling gait when mobilising, falls with fluctuating levels of cognition and functional ability. These are more commonly seen with this form of dementia. (Graham and Warner, 2009).

Frontotemporal lobe (FTL) dementia accounts for about 2% of all dementias however, it is a common presentation with around 20% of all EOD between the ages of 40-65 years. FTL covers a range of conditions, including Pick’s disease, which is rare as well as a notoriously difficult type of dementia to diagnose (Takeda et al., 2012). FTL dementia is caused by damage to the parts of the brain controlling the emotional responses and behavioural activity. This means that early symptoms may involve changes in emotion and personality (Kertesz and Munoz, 1998). Such changes can have a significant impact on behaviour. A common presentation of this form of dementia includes; changes in behaviour which can appear dramatic with significant personality changes and problems with reasoning. This can affect cognitive processes to reduce normal social inhibitions, fixations with completing tasks and certain processes not understood by onlookers. It can be accompanied by withdrawal of the self and aggression displayed before others (Biernacki, 2007). Thus, this condition can confuse and intimidate family kin and others who cannot sense that the condition may lie with dementia in origin. Other forms of dementia exist such as those found in Creutzfeldt-Jakob disease, Huntington’s disease, neurodegenerative disorders and traumatic brain injury. The differing symptoms that become apparent with dementia are diverse and are always worthy of exploration as dementia is commonly understood as ‘the forgetting disease’. However, symptoms and dementia types display a myriad of differing presentations.

2.1.1.4 Introducing EOD

Whilst EOD shares common aspects with older age dementia, it has many aspects which are more problematic (Beattie et al., 2004). Its onset occurs before the years of sixty-five (Giannakopoulos et al., 1996). The bio-medical position requires that a mandatory requirement for a dementia diagnosis is evidence of a cognitive and thinking decline sufficient to impair everyday life. However, there is a critical difference where EOD performs differently in comparison with other dementias. It presents with unique symptoms other than memory decline with no frailty seen as expected in older age conditions. However, many care strategies involve constructing the PwD as elderly, and, therefore those affected with EOD are forced to draw from resources targeted towards retired people. This is problematic as EOD can vary from mild, atypical and ‘glacially-slow’ progression to accelerated in other cases. This has led some research to conclude that those diagnosed with EOD can be characterised by a faster paced decline with accelerated cognitive impairment occurring with shorter survival period compared to those with older age dementia (Tindall and Manthorpe, 1997). However, other forms of EOD are thought to be recoverable through correct diagnosis and treatment (Rosser, 1994). This cannot be identified if a provision of specialist EOD services in the United Kingdom remain limited (Jefferies and Agrawal, 2009). Added to this, there are insufficient studies on the epidemiology of EOD as most in current existence are registry-based (Alzheimer's Disease International, 2015).

2.1.1.5 Common types and classifications of EOD

Alzheimer's-type dementia accounts for the largest population of PwD in the UK (Ulfacker & Doraiswamy, 2017), Alzheimer's Disease is the most frequently diagnosed aetiology for EOD 42.4%, vascular dementia 13.8% then frontotemporal lobe dementia 9.7 % (Yakota et al., 2005; Garre-Olmo et al., 2010*).* The remaining diagnoses of dementia can occur with Lewy bodies, dementia caused by traumatic brain injury, Creutzfeldt-Jakob disease (McMurtey et al., 2006; Yakota et al., 2005; Mendez, 2006) Huntington's disease, alcohol-associated dementia, Parkinson's disease dementia, and Down's syndrome (Carta et al., 2002). To date, estimates indicate that there are currently 42,325 people in the UK diagnosed with EOD (Prince et al., 2016). The study cautions actual figure could be higher due to under-diagnosis of the condition and might be closer to 6-9% of all PwD. In a 1998 study, an estimate of people in Scotland likely to be diagnosed with EOD was 3,200 with slightly higher figures for females in comparison to males (Harvey, 1998).

2.1.1.6 Contemporary global statistics and aetiology of dementia

A worldwide study of epidemiologic data collected by a team at Kings College realised consensus estimates of dementia prevalence in fourteen of the World Health Organisation regions (Ferri et al., 2005). The panel of experts estimated a projected benchmark of 24.3 million PwD in 2001. Of this group, 60% are living in lower, and middle-class countries. Statistically, it is estimated that each year, 4.6 million more cases of dementia will be added to the statistics. These numbers are reported to almost double over every twenty years until reaching 81.1 million by 2040. More recently, figures cite that between 2010 and 2050, the total number of dependent PwD worldwide will almost double from 349 million to 613 million (Prince et al., 2016). It is estimated that the numbers of older people with needs for care will virtually treble from 101 to 277 million (Prince et al., 2016). While this body of extensive research provides only estimates of dementia prevalence, these various studies have been used as an international springboard and benchmark to realise the extent of the condition.

2.1.1.7 Awareness of dementia in Scotland

Within a Scottish context, the National Health Service has the responsibility to provide primary and secondary health care for the population. Scotland is one of a group of countries that has a dementia strategy with clear and unambiguous goals to support health and social care services. This is backed by a research strategy which informs policy and practice. Nonetheless, a significant challenge exists as the experience of symptomatic onset, recognition and the early stages of dementia differ in every individual from the linear pathway of other chronic and progressive diseases (Buntix et al., 2011). In 2002, the Scottish Parliament passed legislation which offered free personal care for those aged sixty-five and above. However, the Public Petitions Committee met with stakeholders in the Scottish Parliament in September 2013[2], to discuss a proposal intended to provide personal care-free for anyone assessed as requiring it, irrespective of their age, illness or status. PwEOD were highlighted by the committee requiring policy protection with social and health care focus as outlined in the introduction to this thesis.

2.1.1.8 Contemporary statistics within Scotland and the rest of the United Kingdom

It is estimated that approximately 850,000 people in the UK live with dementia, the vast majority being over the age of sixty-five years (Prince et al., 2016). It is further noted by the same report that the combined total of PwD in the UK will likely increase to over one million by 2025 and over two million by 2051. This figure is estimated to be realised if age-specific prevalence does not increase and any rise in figures are due only by demographic ageing. In Scotland, an estimated 90,000 people had dementia in 2017 (Scottish National Dementia Strategy, 2017-2020). This is reflected in the key aims of Scotland's National Dementia Strategy (The Scottish Government, 2017). The key aims in Scotland's dementia strategy are:

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[2] http://www.parliament.scot/GettingInvolved/Petitions/alzheimers Amanda Kopel on behalf of the Frank Kopel Alzheimer's awareness campaign.

- To offer those with dementia, prompt diagnosis and more inclusion during diagnosis so that they may contribute as much as possible to their future care.
- Increase the numbers of people the opportunity to gain quick access to person-centred after-diagnosis care suitable to their needs.
- Ensure more PwD possess the means to have a better quality of life with home support in accordance with their wishes.
- Ensure more people are included in positive pathways post-diagnosis and attain for them access to good quality palliative and palliative care.
- Strengthen the process of dementia diagnosis so that the dementia journey at all points is well signposted and is inclusive of family kin carers. Ensure carers' needs are also addressed.
- Be supportive of the ethical belief that PwD have a right to good quality, dignified and therapeutic treatment.
- Care and support are valued, and practice is implemented throughout all social and health care services.

Despite there being no cure and limited treatments available to slow disease progression, early and accurate diagnosis of dementia nonetheless remains a policy aim to promote access to timely information, support, and care for PwD and their families (Department of Health, 2009). Further complexity exists with the number of different forms that dementia takes with unique aspects prevalent in diagnosed cases of EOD.

2.1.1.9 Why EOD is different

The case has been made so far that a common misapprehension has understood that dementia is a disorder attached to ageing. The knock-on effect of EOD, is that it is more likely to be under-diagnosed, misunderstood, and inadequately treated (Jefferies and Agrawal, 2009). The age category surmised with EOD is predicated upon a traditional and historical cut-off. This relates only to an artificial separation which links to a Western ideal of the working-age prior to retirement (McMurtray, et al., 2006). PwEOD are most likely to have a career and be working upon attaining a diagnosis. Most people can be assumed to have significant financial commitments, such as a mortgage. It should be assumed most will have children and caring responsibilities and, perhaps, dependent parents too. Their lives tend to be more active, and they perhaps assume life will stretch ahead as an open landscape with infinite possibilities prior to retirement (Beattie et al., 2004). As the number of people with EOD is growing, the disease is becoming more recognised with a clinical significance as well as a recognised social problem (Sampson et al., 2004). It has therefore been perceived as a fatal disorder with a downward trajectory in quality of life expectation, no cure and with death appearing before old age (Tindall and Manthorpe, 1997). It has also been reported that those affected feel their families are disregarded (Engelhardt, 2002). These factors mean that EOD is recorded as possessing devastating psychosocial consequences affecting people in their most productive years of life and when they have family responsibilities. This makes EOD a significant public health, economic and personal concern for those affected directly. The background related so far in this chapter has understood that EOD is poorly acknowledged with few suitable strategies to address diverse needs. Such needs are situated in the everyday aims of an age group still working, caring for younger and older family whilst saving for a pensionable old age underscoring the unique circumstances of the nature of the condition. These factors also have wider implications for society.

2.1.1.10 Approaches to understanding dementia

Caroline Cantley, in her 2001 edition of ‘A Handbook of Dementia Care’, stated a broad interest in dementia care had grown significantly in recent years. Until recently dementia services were regarded as one of the ‘Cinderella’ services fostering low professional and organisational status. This remained the case until a growth in professional enthusiasm for practice development in dementia care emerged alongside a policy appetite for change (Cantley, 2001, p.1). This occurred alongside a challenge to the way of thinking in how PwD were treated socially within their clinical care and beyond. The drive to seek and define ‘good practice’ concentrated study upon a range of approaches to practice and service development available to support clinical and social practitioners. The following subsection looks at the theoretical approaches that have been adopted in order to explore and conceptualise dementia within the health and social care domains. It begins with a critical review of the biomedical and social models of health and illness in relation to EOD and moves onto looking at alternative ways to explore health, illness and EOD.

2.1.1.11 The biomedical approach to dementia

Dementia is characteristically defined through the application of biomedical processes in the first instance at diagnosis. It is assessed upon the suspicion that an acquired and unrelenting condition emerges, exposing an impairment of intellect, memory and personality (Richman and Wilson, 2004). The diagnosis of dementia is investigated by taking a medical history and a physical examination. These tests can also locate or rule out any other medical condition. Cognitive assessment and mental state examination are typical procedures to adopt to test for dementia (Newhouse and Lasek, 2006). This model supports what is known as the biomedical approach. It has been contextualised and termed the ‘standard paradigm’ by Tom Kitwood (Kitwood, 1989). This standard paradigm reflects the traditional view of dementia which has occupied the established position (Kontos, 2003; Luengo-Fernandez et al., 2010). The biomedical approach established the lens by which health and illness are at first identified and diagnosed, which is to see the mind and the body as separate compartments. Disease is understood as having an identifiable physical cause whereby malfunction can be restored through the diagnostic abilities of medical science (Nettleton, 2006). This model of health has occupied the dominant hegemony since the Enlightenment (Taylor, 2007). Within the last one-hundred years, there has been an escalation in health and welfare provision, which brought the population under state provision of services through taxation. This has resulted in a medicalisation of society, especially after the Second World War. The profession of medicine alongside the pharmaceutical industry have evolved to hold power and influence in the health and sickness arena (Illich, 1976). In turn, this establishment has helped promote doctors to a position of moral and physical regulation of the body (Turner, 1992). It had however, the effect of imposing the roles of doctor and patient upon the micro-relationship with the expectation that the patient will present symptoms to the expert doctor complying with the treatment which will affect a cure (Parsons, 1951). Failure to comply with this contractual relationship suggested deviance from the symptomatic norms and expectations of traditional ideas of treating and curing disease (Freidson, 1970; Harding and Palfrey, 1997). A consequence of this was to displace and weaken folk medicine over time (Nettleton, 2006). The biomedical model thus has been criticised as diminishing the power of the individual over their illness and actions on their own behalf. The control of the biomedical care model therefore led to the body seen as passive rather than active and intentional (Kontos, 2005). This is because chronic and terminal illness fails to conform with a traditional biomedical model focusing upon a cure and return to normal productivity and participation in life (Freidson, 1970). Where health is not restored beyond the identification and diagnosis of illness, the biomedical model has been criticised for imposing unrealistic expectations regarding the efficacy of medical intervention (Toombs, 2006). This challenge has led to the construction of alternative perspectives with which to understand health. These alternatives were situated around more social perspectives offering more holistic opportunities.

2.1.1.12 The psychosocial approach to dementia

The limitations associated with the biomedical model of dementia outlined above have been recognised across the research field for some time, and alternatives have been proposed broadening the research field considerably. These have been dominated by qualitative perspectives. A social psychological approach to understanding dementia has emerged alongside the more biomedical gerontological approach operating as a corrective to the orthodox biomedical view (Innes & Manthorpe, 2012). Prominent figures within this field were Tom Kitwood (1997) and Steven Sabat (2001). This alternative approach understands dementia as a social phenomenon as well as a clinical condition which involves a significant threat to a socially constructed self (Kitwood and Bredin, 1992). Kitwood’s most important contribution arguably was to recognise the intrinsic moral worth of people regardless of diagnosis and impact on their neurological state. He defined personhood as: ‘a standing or status bestowed on one human being, by another, in the context of relationship’ (Kitwood, 1997, p8). Cassell in1976 (cited in Katz &

Johnson, 2006), suggested that suffering through illness emanates from an individual's perception that he or she is disintegrating and losing their identity. In understanding the impact of dementia through a psychosocial lens it is understood as a social process which is supportive of the emotions of the person. Denying an empathetic approach can result in the individual PwD suffering due to lack of self-esteem with little control over their choices and opinions (Kitwood, 1997). This philosophical way of thinking has been highly influential in dementia care through the structuring and development of person-centred care which has been incorporated into mainstream health practice and social care policy (McCormack et al., 2010). This approach has been implemented in many diverse ways. However, common themes in care environments, both at home and in clinical environments include person-centred practice such as offering choices, knowing something of the individual's preferences and life journey. It has been understood as important to build mutual trust and understanding, lending unconditional positive regard to others and being supportive of a therapeutic environment (McCormack et al., 2010).

The composition of the psychosocial approach provides an alternative way by which others can be understood in conceptualising ill health alongside the biomedical approach. The establishment of the two approaches supporting the journey of PwD logically led to the proposition of a more holistic approach taking account of both the biomedical and the psychosocial perspective, the biopsychosocial approach towards dementia care.

2.1.1.13 The biopsychosocial approach to dementia

The development of the psychosocial alongside the traditional biomedical approach can be understood in the way that neurological and psychological combine to bring about neurological deterioration. The acceptance of this dialectic created a shift in the way dementia was viewed and lent more weight to the individual's needs and strengths. This led to a blending of both approaches whereby the identification of individualised biological and psychosocial factors is necessary to enhance an individual's potential and minimise levels of excess disability (Brody et al., 1971). Spector and Orrell (2010) proposed a revised biopsychosocial model of dementia with the aim of understanding the inter-relationship between both (McDermott et al., 2014). The biopsychosocial model suggests that clinicians and researchers may represent dementia as more optimistic with variable change and settled improvement a possibility as features of an individual's illness trajectory (Spector & Orrell, 2010). In this, provision is made for a comprehensive framework where the impact of dementia is presented as a process rather than viewed as an end which gravitates inevitably towards a downward spiral (McDermott et al., 2013). It is important, however to bear in mind that moving towards a biopsychosocial model should not discount the benefits of the biomedical perspective (Innes and Manthorpe, 2012). For instance, this might consider ways of alleviating symptoms of the condition, and possible factors which may exacerbate or contribute to the physiological experiences. In looking to consider how psychosocial factors can shape people's experiences, the engagement of interpersonal skills occurring within a clinical situation brings a valuable shift in thinking. This enlightened thinking supported the wider engagement of the views of individuals experiencing illness offering opportunities to express something of the lived condition as opposed to the purely prescribed status conferred upon them by a medical specialist focussing on a disease led model.

2.1.1.14 The unique situation of PwEOD

The range and diversity of experiences attributed to PwD and with special reference to PwEOD has been shown so far in this thesis to be problematic. This is because they do not experience a cure, symptoms are not always noted or expected by others, and when they are, they are often not understood. When dementia occurs at a younger age, this can become a highly traumatic and stigmatising condition. The following section expands upon the unique and problematic situations for PwEOD as reported in some of the current literature

2.1.1.15 The paradox of being young with an old disease

Issues specific to PwEOD such as age, employability, economic matters, family dynamic and composition are of perhaps greater concern because of the age of dementia onset. Reports across the literature claim that such matters and tensions are regularly not addressed (Beattie, 2004; Roach & Drummond, 2014). This may mean that financial matters are not in order in younger years. Thus, as well as contending with dementia symptoms, contested ground over other routine matters including preparing potentially for affairs to be surrendered to powers of attorney may invariably cause increased stress for EOD and their family kin (Roach & Drummond, 2014). These experiences were shown so far in the studies to be more challenging when encountering complex everyday demands. These experiences may be typically compounded due to the presence of dependent children still living within the family home. PwEOD may also still be caring for their own ageing parents. This means that a condition like EOD is always undergoing ritual changes driven by normal life patterns as well as illness impacts. This study so far has acknowledged a lack of personal first-hand accounts available about the lived experience with EOD. Instead, biomedicine is most commonly the first official point of contact confirming a diagnosis of dementia. However, this traditional view of orthodox medicine focused on practice to the body inhibits the ‘voice’ that has potential to inform and influence practice in chronic and long-term conditions. This has often led to dementia being understood as a chronic health condition subsumed under a cloak of shame, blame and stigma (Buttrose, 2012; Goffman, 1963). This leads to the idea that the understanding of social processes (through social constructionism and symbolic interactionism, for example) can helpfully relate the ways that a health condition like EOD can be treated with available biomedical interventions but supported with social and person-centred traditions.

For those who work, it is not merely a daily routine repeated across seven days or a pattern of shifts. It is likely to be an economic necessity. This daily practice may become a struggle made more so by attempts to mask bodily and cognitive failings. These issues are generally understood to be lesser concerns with later onset dementias. In considering PwEOD approaching medical support for diagnosis and treatments aimed at abating symptoms, chronological barriers exist. These issues are not easily recognised within health service planning, even when EOD is promptly diagnosed. This is because working-age adult services clash with older age mental health services (Williams et al., 2001). This has traditionally led to

PwEOD failing to meet criteria in age; the need to be sixty-five, therefore failing to access adult services. The assumption that dementia only occurred in retirement years created a situation of disregard for those in a younger population. This situation has been long-standing, and studies have recommended more age-appropriate and flexible services for dementia to be incorporated into health and social services (Chaston, 2011; Svanberg, 2011). As an example; a younger adult with EOD may find themselves to be an employee, spouse and mother functioning across these roles whilst fulfilling a daily carer role for an older parent with later onset dementia whilst having no entitlement to any health or social assistance themselves.

In a working environment, PwEOD have certain problems which are noted to be made more complicated by the nature of their condition and the literature above recommends that more resources and specialist resources should be targeted to PwEOD. However, despite increasing awareness of this condition in people under the age of sixty-five, specialist services have not kept apace with older people's services. The Alzheimer's Society have drawn attention to the needs of this group in their Declaration of Rights of Young People with Dementia (Alzheimer's Disease Society, 1996). This promoted the suggestion of a broad approach relating to many areas of PwEOD's lives. It has therefore been recognised that greater levels of intervention are often required by PwEOD and, in ways that will also meet the needs of their families (Bentham & La Fontaine, 2008). It is commonly noted that older people expect to face more health conditions as they age (Johannessen & Zarit, 1997). It is regarded that of a working-age population, they are expected to be able to engage fully within the economic world and all its Western capitalist expectations. This, therefore, makes the difficulties associated with dementia even more pronounced and obvious (Cox & Keady, 1999).

This has been backed by some research findings which acknowledged that higher levels of intervention are often required by those with EOD including their family kin (Bentham & La Fontaine, 2008). As such, living with dementia, younger age populations find themselves confronting very different social challenges than older people (Cox & Keady, 1999). Older people have been shown to expect to face more health conditions accepting this as a natural part of ageing (Hart & Semple, 1990). However, working-age populations, are expected and, expect of themselves, to be able to engage fully within the economic world and all its capitalist expectations. This, therefore, makes the difficulties associated with dementia even more pronounced and obvious (Cox & Keady, 1999).

The second section of this literature review chapter considers conceptual material emerging from social constructivist and symbolic interactionist perspectives. These perspectives allow illness to be examined through a lens that focuses upon the social as well as the internally experienced impact of the illness, as opposed to only the biomedical imperatives of ascertaining symptoms and diagnosis. Such conceptual ideas are helpful when applied to the study of dementia in qualitative studies looking at representing personal experiences.

2.2 Theoretical perspectives of illness

This section of the literature review looks at literature borne out of the social constructivist and symbolic interactionist perspectives, which views illness in the context of the individual and society. These perspectives allow us to look at illness in a variety of ways which focus on the social and personal impact of the illness, rather than the medical impact. These theories have, or can be, applied to the study of dementia, and are highly relevant to understanding personal experiences. The following subsection begins with an explanation of how identity is conceptualised and Tom Kitwood’s contribution to ideas of ‘personhood’. The values involved helped develop a proposal for broadening the lens of biomedicine showing how social and psychosocial benefits supported the individual at the centre of dementia.

2.2.1 Identity and the body/self dichotomy

The prior description given above on the work of Tom Kitwood supported a focus upon the social/personal effects of illness upon identity (Kitwood,1997). Kitwood’s seminal book, ‘Dementia Reconsidered: The Person Comes First’ (1997), aimed to ‘see’ the person beyond the confines of a medical label. This was helpful particularly for those given a chronic or terminal diagnosis. It would only be fair though, to note origins of this philosophical and social perspective lay with the work of Carl Rogers emerging more than thirty-five years previously (Rogers, 1961). Kitwood later engaged with the idea of personhood linking it to PwD. Nonetheless, the concept can be complex to define. However, it is understood generally to comprise of components that make-up the attributes of being a person (Dewing, 2008). Kitwood saw respect, trust and the personhood of an individual elevated along with their wellbeing. In a positive mode regarding a health care model, personhood referred to individuals feeling supported, facilitated and accorded with rights to shared decision making and the sharing of care decisions (Perez-Merino, 2014). The ethos of person-centred care is established and integrated into practice throughout all in receipt of all forms of health care. Thus, in the UK, person-centred care has been integral to current legislative policy and best practice guidance (Department of Health, 2009).

Kitwood (1997) emphasised, based upon a career of ‘hands-on’ work, how suffering through illness altered an individual’s perception making them feel as if they were disintegrating, becoming lesser, and losing their identity. He noted these characteristics especially as important for PwD because clinical aspects underplayed potential for social interplay in care delivery as well as everyday exchanges. In tandem with the ideas of more compassionate values, Kitwood noted the phenomenon of ‘malignant social psychology’ (1997) to maintain a corrective to poor institutionalised habits.

This concept referred to the way by which PwD in a purely biomedical model may feel invalidated, dismissed and as ‘absent’ during social interaction with others. This framework was based on research undertaken, adopting a critical incident technique informed by social interactionism (Kitwood, 1997). These traits could emerge unconsciously and unintentionally however but, nonetheless, malignant social psychology could lead to an excess of disability which burdened the PwD with more than merely their health condition (Brody, 1971). According to this framework, factors such as environmental and emotional would not be taken-into-account (Hughes et al., 2010). This potentially could lead to the creation of an environment and relationships which exacerbate the effects of neurological impairment provoking the ‘dialectical interplay’ between neuropathology and a malignant social environment (Kitwood & Bredin, 1992). Kitwood constructed a list of behaviours that he understood to trigger distressing symptoms for PwD due to intended and unintended actions in others (Appendix 5). Conduct seen as being challenging in PwD could be understood to arise from a lack of understanding from those interacting and caring from them. The preservation of self is the central task of dementia care which is understood to support the PwD to feel secure within their own identity despite the changes to their neurological condition (Millett, 2011).

Various person-centred theories have been developed alongside and beyond since Kitwood’s premature death. However, his work is by far the most widely referred to in dementia care. This is a useful perspective with which to develop an understanding of the experiences of people choosing to tell their own stories through writing about EOD. The literature noted how individuals seek transformative processes when a change to the self and identity through illness makes it necessary. These constantly challenge and have an impact on preconceived notions of self and selfhood (Sabat and Harre, 1992). The contribution of personhood led by Tom Kitwood developed a sharpening of social and psychosocial benefits alongside biomedical concepts. This allowed a valuable ‘voice’ based around the individual who previously may have served as the ‘done unto’ rather than regarded as capable of giving an insider view with their experience of living with a chronic health condition. This permitted a researcher route and access to listen to the stories told at the centre of personal experience. The following subsection examines the conceptual experiences which have been noted often throughout the literature on how a future felt beyond being informed of a chronic and terminal illness.

2.2.2 Temporal and biographical disruption

One perspective which further illuminated the complexities of chronic illness and attempted an understanding of the chronically ill individual in society lay with Michael Bury, who contributed a theory called biographical disruption (1982). This theory brought a radical shift to the thinking of a newly diagnosed person's biography. It helped shape how those with chronic illness perceived their life with ill health. Bury observed how illness affected the self-assumed trajectory of the individual’s world where chronological certainties could suddenly drift to a future impacted with insecurities. Bury’s (1982) theory of biographical disruption lays its foundations in Mead’s notion of temporality. Both concepts provide powerful frameworks with which to organise an array of sociological concerns and useful imports into chronic health conditions. In Mead’s theory of temporality, an unexpected event emerges as a barrier between the present and the future. The core of Mead’s theory lay in the assertion that although the present implies that there is a past and a future, reality always resides in the present (Mead, 1934). The past always arrives in the memory in slices of images much like photographs, providing a backward limit to the present. The future operates much like the past but is fuelled in the present mind in the form of hopes and ambitions. Providing the boundaries between the three chronological concepts sat at the centre of Mead’s thinking of how time could be socially understood; as the past and future sensitively balanced whilst interpreted in a present mind.

2.2.3 Chronicity in illness

It was with this breaking at the boundaries of a chronological life journey that Bury’s theory departed from Mead’s theory of how time was conceptualised in the social subject’s head. Instead, he accepted that secure chronological steps could suddenly drift to a future perforated with losses and insecurities. Such a shift reflected how perceived losses such as chronic pain and disability, and legitimate fear of impending death provoked a new consciousness within the body. This could be compounded by the self-perceived lack of a ‘fair deal’ in life felt to loom large in the wake of the imposition of a sudden life change. This new status revealed the fragile nature of embodied existence as well as how the individual’s wider community was affected. The changes that illness brought to others involved testing the structures around their lives including relationships with others:

> ‘These aspects of meaning in illness are important to an understanding of the strategies that people employ. In essence, the experience of chronic illness involves testing structures of support and risking meanings within the practical constraints of home and work. Relationships do not guarantee particular responses … meanings change as they are tested and altered when they are put at risk’ (Bury 1982, p. 92).

The ‘meanings’ therefore, of chronic illness were not merely personal. Instead, they were the outcome of shared experiences as well as interactions with others. These relationships may necessarily, with the onset and establishment of chronic illness, require change and a ‘renegotiation’ of existing relationships at work and at home.

Bury’ noted two traditions which medical sociologists had settled upon to understand chronic illness: The first flowed from the relative merits of the Parsonian conceptions of illness as encompassed by the sick role (Parsons, 1951). Talcott Parsons organised his theory around how ill-health accommodated institutional configuration of illness whereby the complexities of health care could be understood within a capitalist society. His focus lay in deconstructing and explaining the experience of being ill. He rooted this in a structural-functionalist viewpoint; Parsons asserted health is a functional prerequisite of society, and as such, illness was a form of social deviance which had to be resolved within the social structure. Those critical of Parsons’ framework proposed that chronic illness fell out-with the model and was not served by the assumptions he made with reference to illness behaviour patterns; in other words, the model failed to serve those who never attained a cure. However, Michael Bury noted that more positive critics referred to separating and developing deviance and adaptive perspective from his theory (Gerhardt, 1979; Gallagher, 1976). Bury’s further research in the field illustrated how illness could bring families and wider social communities face-to-face with the nature of their relationships. This reflected how the normal benign reciprocity and shared support viewed within families could be altered through new types of dependency.

Bury’s second tradition told of an interactionist thread focusing upon empirical enquiry relating to practical handling of manifest symptoms and disabilities. The insights drawn assisted in gaining information from the way that the disclosure and disguise of symptoms were handled. Such insights he reported as largely descriptive with peripheral acknowledgement of reported trends without accessing the reasons behind individuals’ behaviour. The development and identification of Bury’s chronic illness as a major form of life disruption was developed further by other researchers in the field. Giddens' (1991) term, 'critical situation' (Giddens,

1991) proposed that; 'we can learn a good deal about day-to-day situations in routine settings from analysing circumstances in which those settings are radically disturbed' (Giddens, 1991, p.123). This followed a three part formulation of realisation: ‘Coping’, the acceptance that there is a disruption to life which had previously enjoyed taken-for-granted assumptions; ‘Strategy’, the need to possess an outlook accepting a fundamental change of future plans to accommodate the impact of illness and; ‘Treatment and Adaptation’, where a sense of biographical repair could emerge restoring a sense of normality.

The perspective of biographical disruption possesses more complexity than at first established. A more corrective and progressive perspective of the notion appeared across the field attracting the interest of other researchers. These like-minded views provided more extended and connected theories to Bury’s first conceptual notion of biographical disruption. These notions challenged the simplistic assumption that illness narrowly enters lives impacting in a one-off hit to otherwise untouched lives, therefore introducing crises which were evident in a lay population of the chronically ill (Lawton, 2003). Lawton drew enlightened views constructed by Bury (1982) and Charmaz (1983) who both assisted in developing a more accessible understanding of illness as well as the overlapping and interdependent nature of body, self and society. These socially constructed ideas blended with the importance of amalgamating timing, setting and individual biographies all aiming to support the ‘missing voices’ which had previously remained out with the biomedical medium.

Thus, this broader treatment conceded that biographical disruption appeared in not only one life-changing event but from a series of fractures occurring along the chronological lifespan. This understanding was emphasised in the potential for active coping as a response to chronic illness and was socially understood in related but refreshed ways by others. This perspective, for example, drew upon Corbin and Strauss's (1991) notion of ‘comeback’. This concept shared two dimensions: the ‘physical’ referring to the active contribution made by the patient when complying with medical treatment and rehabilitation (relating to Parson’s expectation of the archetypal patient), and the ‘biographical’, the attempt by the patient to bridge the liminal (Turner,1967) gap as they try to return to life as it was prior to diagnosis. The notion of the term ‘coping’ was used in its relativistic sense in terms of the kind of adaptation made by those adjusting to chronic illness. This was opposed to the normative use more commonly referred to as the biomedical aspects of the respected response to the ‘deviant’ patient who refused to get better by becoming chronically ill. Bury joined other researchers to revisit his own original work in work by suggesting that forms of coping include ‘normalisation’ and ‘bracketing off’ of the impact of illness which lessened the effects on identity (Bury, 2001). This referred to the effort individuals made in the sense of keeping their pre-illness lifestyle and identity intact by either presenting a face of coping with little changes affected to lifestyle and by disguising or minimising symptoms. These ideas all combined to agree that shock appeared in the lives of those who received a chronic diagnosis and could go on to alter not with one but several biographic fractures of shocks throughout the illness.

2.2.4 Status passage

Chronic illness could have a dominant impact on other parts of life, creating many stresses and tensions, which helped to underscore the importance of considering additional contextual factors. With specific regard to dementia and EOD, Tolhurst and Kingston (2013) asserted that whilst Bury’s model was a useful guide, their preference was to understand illness impact as a ’status passage’ offering greater conceptual breadth for researchers to take up the subjective views of those with chronic ill health. This referred to the experience of biographical disruption being focused on the subjective responses of others and was illuminated in situations where chronic illness had a crisis effect on life. This is where disruption was often at its most palpable. It was for this reason that the authors conceived the experience of passage a more useful one. However, these issues helped highlight the difficulty in understanding the experience of living with a diagnosis of dementia. Tolhurst and Kingston (2013) commented that the experience of EOD might present organisational and societal barriers. These authors confirmed that due to the cultural association of dementia which tended to define dementia as an ‘old-age’ condition, this could lead to a lack of ‘age-appropriate’ services. The impact of barriers on an individual’s life could understandably affect the way that they saw themselves.

2.2.5 The crisis of broken identity

Kathy Charmaz’ (1983) association of identity arising from chronic illness drew from Bury’s seminal 1982 biographical disruption developing ideas around the assault upon the body and threat reasonably impacting upon the integrity of self. This bolstered Kitwood’s address of the concerns around the individual representing a renewed but ‘salvaged’ self-emerged from chronic illness. Charmaz was concerned to investigate the ways in which the person understood their body when it was subject to a profound, chronic or terminal diagnosis (1991;1994). This affected links between previous body confidence and post-diagnosis uncertainties (Bury, 1982; Charmaz, 1991). Her work took the central dilemmas of how chronic illness which was accompanied by impairment could impact upon a person's daily life and undermined self and identity. Questions arising from these quandaries resided around; what happens in the lives of those with chronic illness challenging previously valued images of their bodies? From there, it was a critical juncture to then gather research upon how beliefs, body images, and expectations of the body affect current identity and future ambitions and hopes. Other questions arose around how future goals compared with future identities after bodily losses threaten to arrive or have already set in as disability.

Charmaz found ways to establish how the body, identity, and self-intersected in illness. This, for Charmaz, lay crucially in adaptation. This adaptation resided around accommodating physical losses but looked to reunify body and self accordingly in ways that were workable and socially evident to others as identity-forming. Adapting implied individual acknowledgement that impairment and rehabilitation become socially and personally seen in acceptable ways. Limitations to social circumstances always exist but are still subject to adaptation when it is possible to accommodate and flow with the experience of illness. This may involve periods of living with limiting illness include ignoring it and struggling (Charmaz, 1991). Reconciliation within reason may even occur when, for example, one writer in the data set reported that he, Richard Taylor (2007), sought the skills of his friend to construct something to allay fears of finding his way to the toilet at night. Thus, such concessions are worked around but perhaps do, at the same time, accept and reject being defined by limitations. This could mean seeking refuge in limited living. However, through a process of struggles with ill health, new identities around body and outlook can be born and managed (Charmaz, 1991). One experience within a form of 'limited living' lay with the experience of being caught 'in limbo'; where a diagnosis of dementia could leave an individual feeling at odds with the self and their world. This conceptual notion drawn from social anthropology is examined in the following section.

2.2.6 Liminality

The research concepts discussed so far reflected ways to represent interpretations of struggles and experiences of chronic illness. It was viewed that some individuals across the research field provided socially constructed evidence of the formation of 'new selves' hovering at the margins of repaired and restored identities. Another supportive concept with which to understand the experience of PwD and EOD arose with liminality. PwEOD have reported feelings of alienation, loss of control, disenfranchisement and stigma. This appeared to accord with combined experiences borrowed from the field of social anthropology whereby to become liminal means to be neither one thing nor the other. Liminality is not a static state but provokes a confusion of categories from ambiguity to disorder, and it instead confers a specialised temporary status.

The theory of liminality was expanded by Victor Turner (1969) whose anthropological work was drawn from his extensive field studies within primal societies. His studies of the Ndembu society and other cultures nurtured and developed a conceptual understanding of liminality based upon rites accompanying radical alteration of the environment, social position and processes involved in the everyday transitions of life (Turner, 1969). Victor Turner referred to liminality as an ambiguous state where the ritual subject becomes the state of being mid-point between a status sequence in a cultural space. The word 'liminal' originated from the Latin limen meaning threshold. This anthropological phenomenon appeared to situate itself well with the experiences that PwEOD may well describe as being a part of their lived everyday lives with dementia as both internally 'felt' experiences and as social experiences.

2.2.7 Stages of liminality

Turner borrowed and extended van Gennep's (1960) original three stages of rites of passage during which, the individual or initiate transforms from one status to another. This was regarded as a pre-liminal or separation stage which performed a transition and finally, a return to a new status (Turner, 1969). Turner developed the understanding of the transition or liminal period to evaluate the ritual process as spreading to many macro and micro areas of sociocultural life. The state was described as one of 'betwixt and between' (Turner, 1969, p.111). The person in the liminal state is neither one thing nor the other; leaving behind one status yet not having moved on to the next. Turner understood the liminal state as being one where the secular distinction of rank and society's values disappeared or were homogenised. He referred to liminal states as coinciding with the ritual powers of the weak. The subjects themselves were understood as 'tabula rasa', that is, a blank slate. This breaking down of the person is instigated and carried out by others which, in doing this, creates preparation for the emergence in the new state. The symbolic breaking down of the person into a base organic state such as mud, clay or mere matter creates an acceptance of the person or initiate that the society imposes their idea of form onto the liminal status of the initiative.

Despite being drawn from the field of social anthropology and primal ritual society, Turner's comprehensive framework of the characteristics of liminality made the conceptual analysis a compelling one to study chronic health (Syme, 2011). Liminality has been used in approaches to health problems such as chronic pain (Jackson, 2005), cancer (Little et al., 1998), mental health issues (Warner and Gabe, 2004; Barratt, 1998) and palliative care ethics (Braude, 2012). Little et al. (1998), proposed a hypothesis that all cancer patients were located, by their very condition, in a liminal process. This state began with the knowledge of their cancer and malignant status. This early acute phase of liminality is recognised by experiences of being removed from a sense of normality. This is like a social space. This is characterised by ritualised processes. This ritualised process seeks to impose a form of separation from others in society. The person's experience of their diagnosis and consequent investigations caused a split which shifted them towards a sustained liminality period. This meant recovery from active treatment was followed by remission. However, the risk to this status was the recurrence and this inevitably placed patients in pockets of liminal spaces (Molzahn et al., 2008). With dementia, the theme of liminality was found in some of the literature (Kelly, 2007; 2008; 2010). Kelly studied the experience of a dementia diagnosis writing about losses appearing from liminal doubts. Traditionally, it has been noted that memory can be regarded as a shared narrative which stores sequences of past events which may be unique to the individual. Kelly (2008), reported that whilst liminality provided a transitory status or space, liminality could become a permanent state of existence for people with AIDS-related dementia.

Kelly (2008) wrote sensitively about Diane and her 16-year-old son Jack. A fire breaking out in their home meant the loss of their possessions. With memory loss setting in, Diane lived with missing memories previously prompted with objects and possessions. Although she had an awareness that she was a mother, she had no real sense of identity as having been one: 'I lost photos in the fire, memories of having a baby' (p. 455). The loss of objects made it difficult for Diane to join the spaces in her life to make sense of what had gone before; 'Memory is dependent upon circumstances, upon objects to carry it forward and to evoke it' (Lattas, 1996, p. 264). This reflected that for some PwD, life with dementia therefore, had to be lived within a permanent cycle of lost jigsaw pieces and incongruity. However, not every experience in life that has the capacity to deliver shock or seperatedness is temporary, such as in the case of chronic illness.

2.2.8 Permanent liminality

The term 'living loss' was used to describe new ways of loss and grief in those who experienced chronic illness, and the term 'liminality' was proposed to feel like a permanent social space rather than simply as an in-between space. Permanent illness was considered by some researchers who considered how individuals coped with chronic illness as a life journey. Williams and Keady (2008) used the concept of 'bridging' to explain how people living with Parkinson's disease were able to maintain a sense of stability and control. They described three stages of bridging; one referred to building on what had gone on in the past, bridging the present and broaching the future which was consistent with the pre-liminal, liminal and post-liminal stages of the rites of passage outlined by van Gennep (1960). Between these chronic illness states and narrative events, the stories gravitated towards describing how life could extend to ‘living in limbo’ waiting indefinitely with uncertainty for the next event to happen. For them, this could mean anything from a decline in their health state to an external life event such as waiting for accommodation suitable for their disability needs. This left people living in a perennial state of doubt and confusion. This could also encompass literature pointing to permanent spatial dislocation and re-organisation (Czikszentmihalyi and Rochberg-Halton, 1981).

2.2.9 Permanent liminality as ‘liminoid’

The consideration of permanent states of liminality encompassed a state referred to as being ‘liminoid’ (Turner,1969) To understand the nature of liminoid is to see it as a feature affecting those who will never return to what they once were. This was relevant in the research because chronic illness such as EOD is a permanent diagnosis. Becoming liminoid however, can form a permanent state of an abnormal structure achieved by choice or obligation, for example, minority groups and movements within large scale established societies (Turner, 1969). This was a way in which people could be regarded as liminoid, by choice such as monks in a monastery and with no choice such as in a terminal diagnosis of an incurable condition. In the case of chronic illness, subjects can be forced into this position, e.g. the hospice community. Froggett (1997) illustrated liminal aspects of the hospice environment giving an example of ‘ideological communitas’ space or ‘spontaneous communitas’ as giving an example of liminoid people. These types of liminal transactions occurred internally and intimately between the members of the same group who understood the liminoid and very permanent nature of their existence.

Understanding aspects of liminality allowed a deeper appreciation of the personal experiences that PwEOD might have in coping with their condition feeling fragmented and at odds with themselves and the environment. These feelings of being separated and experiencing lives that were difficult to explain to others gave an opportunity to investigate other experiences noted in the literature linked to chronic health conditions like EOD. The next section develops experiences with stigma.

2.2.10 Stigma

PwD have recorded experiencing feelings of stigma which, amongst other experiences, contributed to feeling fragmented and ‘at odds’ with themselves and society. One theory which has offered a comprehensive group of conceptual theories to support and explain these experiences and social reactions is Goffman’s theory of stigma (1963). This theory explored the consequences of a ‘spoiled identity’ originating from Erving Goffman’s interest in the interactions between ‘normal’ and ‘stigmatised’ people in this seminal work.

Goffman used the term stigma to refer to attitudes taken that discredited others who presented with a stigmatising effect. According to Goffman, stigma is broadly defined to include; abominations of the body, blemishes of individual character, race, religion as well as social class. An obvious component of stigma lay with ‘labelling’ occurring when interrelated components converged. The first component surrounded the way individuals distinguished and labelled human difference.

The second, was situated within the way dominant cultural beliefs negatively linked others to negative stereotypes. Following this, labelled individuals were placed in distinct categories to accomplish degrees of separation of ‘us from them’ e.g. a refugee camp. Fourthly, labelled individuals could experience status loss and discrimination leading to disadvantaged outcomes.

Goffman recognised that the body was at the centre of the relationship between an individual’s personal as well as social and self-identity (Shilling, 2012). However, according to Goffman, the body was not an autonomous entity; rather it was the case that status was conferred upon it by others understanding themselves as ‘normal’. Goffman argued that individuals with chronic illness and disability were stigmatised in the sense that they were discredited by whatever attribute rendered them ill or disabled (Goffman, 1963). Goffman recognised that those who lived with chronic illness were stigmatised agents in their own right. Thus, their identity of self, emotions and biographies were regarded as deviant or failing by those considered normal. The state between the normal and the stigmatised had the power and effect to alter the status and identity of both parties (Goffman, 1963).

Goffman noted the ways that a spoilt identity could be ‘managed’ through ‘passing’ as normal. This could be achieved by creating a dissociation with the stigma through attempts to subdue the stigmatising feature when interacting in public (Goffman, 1963). These interactions could become informed by symbolically conveying social information labelling the person carrying the stigma as deviant. The trick the spoiled identity had to achieve was to ‘act normal’ and appear as if there was no acknowledgement of deviant conduct. This required a level of agency on behalf of the stigmatised to retain a competent ‘face’ acknowledged by others through a need for management of presentation during interaction. The concept of stigma therefore, for Goffman, was intimately related to that of identity. It implicitly took into account the means by which individuals wish to define themselves. In the case of chronic illness, where identity was spoiled there was a need to draw heavily upon an identity. The preferred identity may have been the one present prior to illness, but as it could no longer be sustainable, another construction had to be produced. Goffman’s example of stigma permits an understanding in the ways in which lack of control over the body may be understood as a lack of competency, and thus, ways could be identified to show a level of concealing a stigmatised condition.

Goffman noted how the need to show competency over stigma led to a performative concept to his theories on stigma (dramaturgy). Goffman noted that individuals, through their microcosmic behaviour, would present dramas to an audience diminishing weakness and boasting strengths to others in their daily interactions. To emphasise performative elements did not suggest identities are typically inauthentic, but that identities were situated rather, and accomplished with an audience in mind who had to be persuaded of that performance. For example, this might suggest an individual who must do public speaking but has a lisp, and they just might begin a speech by making a joke in order to show their assimilation and command over an impediment. Being aware of a weakness, therefore meant a response was required in order to represent this plausibly and favourably to others. This further sharpened focus towards identities.

2.2.11 Identity goals of the stigmatised

Since the origins of Goffman's treatment of stigma (1963), more recently, the field of sociology has broadened this discussion creating a wider understanding of stigma, this identified social processes occurring within the sociocultural environment affecting what could be observed within the individual (Link and Phelan, 2001). Specifically, the model of stigma proposed by the authors (2001) included a component of structural discrimination (that is the institutionalised disadvantages placed on stigmatised groups). This alerted scholars in the field to begin to construct the ways that power; social, economic, and the political, shaped the ways that stigma was understood within a broad social backdrop. This had relevance for the psychosocial understanding of PwD as it gave acknowledgement and scope for their views to be expressed socially without the restraint of maintaining a medical condition within the constraints of illness. Thus, the original observations made by Goffman (1963) of the body flawed by stigma in public was linked in this thesis to the social identity issues suggested above by Kathy Charmaz (Charmaz, 1987). Taken-for-granted identities could be eroded along with the discovery that visible illness and disability could leave an obvious residue of overwhelming stigma attached to the identity (Charmaz, 1991). Due to the inevitable losses occurring through ill health, reassessments had to take place regarding identity. Charmaz saw these as identity goals whereby reconstruction of a sense of normality could occur (Charmaz, 1987; 1991). However, not every identity goal could be easily attained or regarded as a success with positively approved of attributes. Elsewhere in the literature, there was some evidence that dementia could become a catalyst for provoking feelings amidst social relationships that PwD that they had become 'aliens and exiles in their one land'. (Murphy, 1987, p. 111). This arose from a destructive form of anger following guilt and shame accrued by a self-loathing that those with failing bodies experienced.

This could appear throughout cultural and communal sharing of ageless bodily perfection and, failing that; efforts would be required to be made in order to create the best appearance possible for the comfort of others (Glassner, 1988). Such shame was constructed from a failure to meet these standards. Following this could come self-abasement which could follow and intensify the humiliation (Charmaz, 1995). In order to manage identity and social experiences such as shame, or personal liminal experiences of being lost to the self and in location, attempts have been made through different forms of media to bring attention and sharpen focus to conditions which create out-of-the-ordinary experiences.

2.2.12 Social constructions of dementia

The broader implications in understanding the individual as chronically ill created a more diverse and three-dimensional person to study. The development and diversity between the biomedical and psychosocial constructions have allowed for a broader discussion on the understanding of the PwD and PwEOD. This has illuminated a dichotomy between two sharply drawn illustrations of socially constructed views of dementia. Wider cultural representations recently have become popular, exciting press attention and lay debate regarding dementia. The media have been described as a powerful means by which to communicate information about health issues, supporting awareness and influencing perceptions and attitudes (Doyle et al., 2011). Across film, television and literature cultural understanding of dementia has shown contemporary interest (e.g. Emmerdale Farm, ITV, 2016; Wallander, BBC, 2016; Iris, 2001). These representations did not depict dementia only in terms of a failing mind, the accounts given were shown to be transformative to the subject and the viewer or reader. PwD or PwEOD were represented as having lives of intrigue, struggle, wonder and worthy of being watched by millions. Such media content has led to increased appetite from a lay public keen to hear and view something of the inside life of PwD, and, to some extent PwEOD. These representations reflected socially constructed ideas of dementia. However, along with more enlightened narratives and personal stories of life with forms of dementia, it is also the case that negative images of dementia have still been portrayed (Behuniak, 2011). This has perpetuated stereotypes about ageing inciting fear and stigma (Clarke, 2010; Cohen-Shalev, 2012). One common view enshrined in popular cultural symbols is that of the PwD as a zombie (Behuniak, 2011).

In the available literature on dementia, it has been noted by researchers how both dementia and PwD have been positioned with a particular form of stigma; that of the dehumanising emotions situated around disgust and horror (Behuniak, 2011). The blame for negative perceptions of PwD combines with a solely biomedical understanding of dementia, seeing only the symptoms. However, strong emotions based upon revulsion of the condition could evoke emotional responses to dementia also buttressed by the social construction of PwD as zombies and as a repulsive threat to wider society. Found in African myth and folklore the Zombie becomes a feared state of being whilst also as an object of pity (Boluk & Lenz, 2011; Rushton & Moreman, 2011). Dendle (2007) discusses how the figure has been modulated through the decades and fashioned as a dreadful concept representing a dark threat to humanity. Adding to this representation and proffered in the Book of the Dead: 'The complete history of zombie cinema' (2005), Jamie Russell posed; 'ultimately, the zombie is a symbol of mankind's most primitive anxiety: the fear of death' (p. 8). Susan Behuniak clarified how this perspective compounded the diagnosis of dementia as a terminal condition lending it taboo-like dread. Further, this meme has also been given treatment by scholars who have acknowledged the concept as one of generating horror and a threat to civilisation (Aquilina & Hughes, 2006; Behuniak, 2011; Dendle, 2007).

This trope offered researchers elsewhere, and in this study, an example which has been borrowed to encompass the dread of dementia and resemble dementia type behaviour (Behuniak, 2011; Aquilina and Hughes, 2006). Navigating dementia towards being understood as constituted around a variety of phenomena focusing upon negative ideas; this has added emotions of blame for carrying the condition (Herskovitz, 1995). Such extreme popularly held cultural views reflect two common views of the socially constructed beliefs held about PwD. It is these views that were relevant to address and discuss in this thesis as important conceptual ideas that

Pwd and PwEOD contend with in their daily lives. This section of the literature review has discussed social constructivist and symbolic interactionist perspectives viewing health conditions in the context of the individual and society. These perspectives have performed opportunities to consider illness in a variety of ways. These have been reflected as the social effects involved in the dementia experience.

Biographical disruption, liminality, notions of chronicity and stigma have been selected as relevant and conceptually drawn upon ideas by PwD. Thus, whilst the treatment of stigma has not been exhaustive, it has discussed the potential effect and weight upon identity in chronic illness. It has suggested the multidimensional nature of stigma and how it may inevitably impact across many aspects of individuals' personalities in negotiating chronic illness linked to their own expectations in managing an image for others. We have also explored how the concept of stigma has been applied to the study of dementia. The final relevant conceptual caveats required in this thesis in order to understand personal experiences more comprehensively lies with the concepts of sick role and intimate citizenship.

2.2.13 The sick role

As regarding sociological approaches to the relationship individuals shared with their doctor, although the sociology of medicine predates Parsons's (1951) theoretical analysis, Parson's views of a capitalist account of the components and transactions surrounding ill health and the doctor-patient relationship have been introduced above. This section remains for it to be emphasised that the role and duty under which every ill person tries to conform to is complete health. Once this restoration is completed a return to normal life and activity is expected. However, this is not possible with chronic conditions such as EOD. Medical practitioners treat patients according to generalised technical standards of treatment. Parsons saw this occurring inside universalism. This means that an expectation of a cure and return to economic productive normality and contribution is incorporated along with the expectation. The exemption from 'deviant' status is only suspended whilst illness prevails. Adding to voices across the research field noting Parsonian shortcomings of institutionalised patterns in medicine, it was observed that the ‘golden age of doctoring’s role was declining’ (McKinlay, 1973, p. 81). However, this naturally opened a gap for more socially constructed methodologies and voices to be heard from subjective experience. Ken Plummer (1995) applied his interest in fringe and marginal people invested through his underpinning symbolic interactionism the ideas that shame and stigma were forces that could be ‘reintegrated’ as shaming was unproductive (Plummer, 1995). As a counterproductive phenomenon, shaming done within a cultural context could provide for an extraordinarily powerful form of social control. This theory was constructed around criminal correction in society (Braithwaite, 1989) but was galvanised to shift away from punitive social control toward greater emphasis on moralising social control. As such, this offered a more socially constructed contribution to be made by citizenship in society in order to create their own ruling rhetoric within their own personal concerns.

2.2.14 Citizenship

The concept of intimate citizenship is a complex one and founding theories of citizenship will not be addressed here in their historical origins. However, some aspects of citizenship are highly relevant to this thesis. Citizenship refers not only to the legal status of the individual but also is bound to the ways in which citizenship is practiced (Lister et al., 2007). It is generally taken to form a bridge between the individual and the collective (Lister et al., 2007). Habermas (1987) discussed the ways in which citizenship was founded on the Athenian Polis where citizenship was understood as being enacted in public spaces. However, the notion of the citizen is generally taken to be a status bestowed on those who are full members of a community. This would also extend to include all who possess the status of citizen as equal with respect to those rights and duties with which the status is endowed (Marshall, 1950). T.H Marshall’s contribution to notions of citizenship has had considerable influence through a tripartite liberal system of citizenship. This system was underpinned by political, social and civil rights. These rights are characterised by legal justice, political representation and welfare (Marshall, 1950).

Marshall’s citizenship model recognised new forms of inclusion unknown in former models of citizenship (Lister et al., 2007). However, this status was not unilaterally given to individuals. The contract was based upon an exchange between the individual and the state. This relationship relied upon a post-Enlightenment fulfilment of expectations bestowed upon society characterised by productivity, employment and voting (Plummer, 2003). Feminist scholars have since been critical of Marshall’s model of citizenship, positioning it as favouring working class men to the exclusion of other groups in society (Lister et al., 2007). In drawing understanding from the availability of citizenship for PwD, an inherent problem was evident in the contractual nature of being a citizen. For those lacking the ability to engage fully in the role expectations of citizenship through disability and chronic illness, Marshall’s model of citizenship failed the test of inclusivity, and, as such, this meant that; ‘To be a citizen implies “the other” who is not a citizen’ (Plummer 2003, p. 52). Therefore, citizenship has, in the past, lacked levels of inclusion.

2.2.15 The intimate citizenship domain of PwEOD

Ken Plummer offered a corrective to Marshall’s social structure allowing for citizenship theories around ‘feminist citizenships’, ‘sexual citizenships’ and ‘minority citizenships’ in order to recognise intimacy as a relevant aspect of citizenship (Plummer, 2003). Plummer asserted that a move towards intimate citizenship recognised those whose identities and experiences were embedded within intimacies such as single parents, the elderly, surrogate mothers, children and transgendered people, for example (Plummer, 2003). Such groups previously remained unidentified and, in many cases shunned by wider conventional society. Intimate citizenship functions therefore as a sensitising concept (Plummer, 2003) sought to explain a broad range of contested issues associated with everyday actions and processes of intimate life. He sought to do this through the representative of finer grain issues than subjects such as ethnic, nationalist or religious designations and related concerns. This perspective recognises such tensions, contradictions and anxieties flowing from intimate exchanges between people telling difficult stories using citizenship and identity to draw others to the centre of the web in untangling the conceptual problems of difference and unity. As life is attempted to be lived within as well as out with boundaries of what is hoped seems acceptable to others (Plummer, 2003), both unity and difference attempt to carry both cultural weight (identity) and legal weight (citizenship). These two aspects refer to what Plummer referred to as ‘muddled identities’ forged through various debates residing around ‘issues culture’ (2003). This reference to issues culture was enmeshed by the difficult social questions residing around who and what that might previously have been outcast could now be embraced, if tentatively, by society. Plummer referred to an inexhaustive list, of ‘who is in and who is out’; and offered a reframing of how to broadcast difficult roles performed in emerging fields of conflict. Some examples of this would be; the paedophile, the transgender father, cybercitizens who roll out their everyday issues through blogging, the grandparents raising their children’s children and many others competing in the modern ‘cybercitizen’ role (Plummer, 2003). These and other, varied and unorthodox styles of living and needs represent their claim towards mainstream and traditional society unaware of the varied types of lives requiring inclusion. This gave an interesting and contemporary field in which to understand PwEOD who chose writing to forge their identities with their dementia.

There was limited evidence on this subject regarding PwD. Some searching took place through sources, for example; Google Scholar where few journal articles, commentaries, texts on ageing along with an examination of reference lists existed. Few key journals engaged with social gerontology and nursing produced much enlightening information in respect of the sociological and psychological qualitative data. An example of some findings referring to intimate aspects of citizenship was discussed in a small sample of literature, but this centred around care home environments and therefore led away from the design and interest of this thesis (Simpson et al., 2017). This suggested that to apply ideas of Plummer’s intimate citizenship around the lived experiences of PwEOD might be fruitful and informative in order to advance knowledge on this important subset of PwEOD. However, this notion assisted in addressing the internet age and the prolific population of ‘people stories’ and the ‘knowing’ of them that would, not many years ago have been possible for the average citizen to possess. To have access to the thoughts of others at the level of diversity and intimacy that are now an omniscient presence in the lives has become attainable at the click of a button in the four walls of home.

2.2.16 Summary

This second section of the literature review looked at research borne out of the social constructivism and symbolic interactionist perspectives seeing illness in the context of the individual and society. Contemporary ideas about disease and illness were therefore described as being grounded in social constructionism. Chronic disease and illness are many-fold; medical, societal and personal constructions positioned in order to manage the irreversible protracted failure of the body. These were illustrated through how social constructions of dementia represent accumulated historical changes in trends in the knowledge of the nature of ill health. These perspectives allowed us to look at illness in a variety of ways, focussing on the social and personal impact of the illness, rather than the medical impact. liminality, stigma, biographical disruption, sick role and intimate citizenship, were presented as potent and potentially productive ways to understand EOD as subjectively provided in written data. These theories were shown to be applied to the study of dementia, and as such, were critical to the understanding of the following chapters where analysis of personal experiences of EOD was described. What follows is the final section of Chapter Two and the literature review which, is an SLR composed of current qualitative studies on the experiences of PwEOD and their family kin.

2.3 Systematic Literature Review (SLR)

Personal accounts describing EOD have potential to inform clinical and care provision as well as other dementia subsets. Using first person accounts makes this a valuable exercise. This may be assumed as PwEOD possess more faculties with which to tell about lived experience from first person accounts.

2.3.1 Introduction

There is increasing recognition that EOD represents an important social problem affecting economic and social impacts (Johannessen et al., 2018). Recent research has called for greater efforts to be made in consulting with PwD directly (Allen, 2001; Bamford & Bruce, 2000). The condition is understood to occur between the ages of 45 -65 (Mercy, 2008). This makes EOD a sub-group of dementia with numerous differences when compared to later onset dementia. These include the likelihood of still being in work and having a family to bring up. Being responsible for an income and for dependent others is particularly difficult for those affected. Additionally, the social and psychological context for younger people is different (Beattie, 2004). PwEOD are more likely to be physically fitter than those with later onset dementia which may impact on their physical care needs. The existing expectation within health and social care agencies for PwEOD is in keeping within an older people's framework of care which may well be inappropriate. This may have occurred in the past due to biomedical assumptions of the condition (Kitwood, 1997; van Vliet et al., 2010). This also suggests that little attention has been paid to subjective experiences (van Vliet, 2010). The need to elicit the views and subjective experiences of PwEOD is therefore gaining increasing recognition within health and social care research (van Vliet, 2010). Literature has been modestly growing in the subject area to demonstrate how PwEOD have expressed their views and experience of dementia successfully (Page and Keady, 2010; Ohman et al., 2001). However, most of the extant literature is based on family carers (Cabote, 2015; Bekhet, 2014). Whilst carers 'views are important they should not be used as a substitute for the views of younger people with dementia (Whitlatch, 2001). Given the limited research available, the views of PwEOD and their family carers are incorporated into the SLR.

2.3.2 Method

2.3.2.1 Study aim

This SLR paper sought to address the following question:

> 'How do PwEOD as a diagnosed sub group of other dementias and their immediate family experience living with EOD?'

2.3.2.2 Study inclusion

Studies were included and excluded according to the following criteria: a diagnosis of EOD between the ages of 45-65;[3] and research dated between 1998-2018. [1]Searches between 1998-2018 captured the advent and widespread prescription of anti-cholinesterase inhibitor treatment and linked with a key driver as laid out in the Scottish Government's 2009 report making dementia a healthcare and priority for development. Studies had to be in English language; qualitative and peer reviewed papers. The key aim of study inclusion was to capture the experience of living with EOD and reporting directly throughout the literature. Personal experiences were sought in the literature on PwEOD and their immediate family living with the experience post-diagnosis. The scoping review uncovered the relative lack of studies to date on the experiences of PwEOD, therefore studies were inclusive of spouses, partners, children and adult dependents as people living with the PwEOD. Searches were kept broad and unconstrained by further filters in order to capture a fuller picture of the issues and experiences connected to EOD.

2.3.2.3 Study exclusion

Studies focussing solely on people presenting with dementia younger than 45; studies with a predominant interest in; dementia caused by HIV, traumatic brain injury, Down's syndrome, congenital birth conditions likely to include dementia, Huntington's chorea and alcohol-related dementia were excluded. Systematic literature reviews were excluded.

2.3.2.4 Scoping

A scoping exercise of the literature took place prior to the SLR which identified EOD as a sub-group of dementia under-represented in the literature. Google Scholar and Abertay's Library Search including serendipitous searches using prior knowledge of the research field extended the search in preparation for the SLR.

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[3] This definition is in keeping with Mercy (2008) excluding two other studies limiting EOD to 45-60, all others searched for the systematic review including the scoping review referred to 45-65 as the most commonly used criteria for EOD.

2.3.2.5 Search strategy

The author then searched databases which were selected for their social and clinical perspectives through EBSCO host; Web of Science and Cinahl plus with text, Psychology and Behavioural Sciences Collection, Scopus and Sage. The search terms were dement*, early-onset dementia, young onset dementia, presenile, Alzheimer* and working age dementia. These were searched as single terms using Boolean phrasing; 'OR' then once the searches were captured, refined with; 'AND' then stored for scrutiny at the next stage.

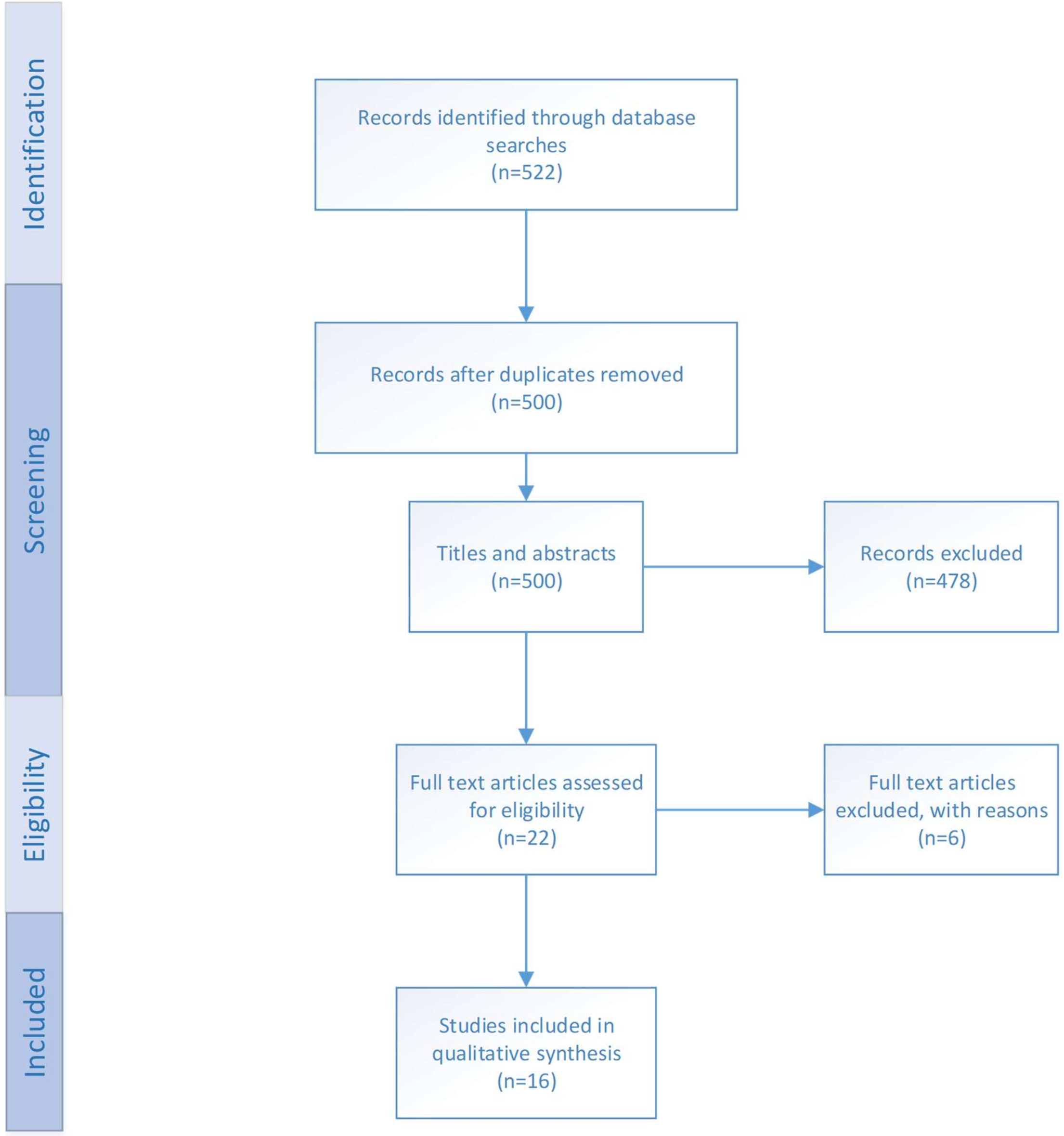
2.3.2.6 Selection of papers

The search located five-hundred-and-fifty-two 522 papers. Duplicates were removed (n= 22). The remaining studies' (n=500) abstracts and titles were screened. Twenty-two studies (n=22) were retained and full texts read. This left sixteen studies (n=16) to be included. The reference lists of the twenty-two studies were also examined. Although two were added from references, they were finally excluded for failing to meet the criteria. With reference to the final six studies excluded, these are listed in the appendices (appendix 2).

2.3.2.7 Approach to systematic and meta-analysis synthesis of studies

The review was guided by the systematic approach preferred by PRISMA (Reporting Systematic Reviews and Meta-Analysis Studies (Moher et al., 2009)). Figure 1 illustrates the process of papers being excluded or included for the SLR based upon the study question. This process sets a standard for the assessment and critique of health focussed studies and interventions assisting the processes for summarising evidence accurately and reliably. However, it is the case that the methods of meta-analysis are not transferable to qualitative health research for a number of pragmatic and epistemological reasons; for example, computer literature searches, statistical data and priorities in quantitative research may fail to capture forms of qualitative research which lack the appeal of more clinical protocols and interventions (Britten et al., 2002). As such, criteria for judging the quality of published research whilst contested in the past have since found established qualitative protocols for comparing studies (Britten et al., 2002). The potential audiences for viewing research through this lens include practitioners across a broad health practice background as well as policy-makers and qualitative researchers (Britten et al., 2002). Therefore, there exists several well recognised methods by which to conduct a systematic review of qualitative literature (Greenwood & Smith, 2016).

Figure 1: PRISMA flowchart



2.3.3 The role of meta-ethnography in qualitative research

The impetus for developing methods of qualitative synthesis has arisen from a need to complement quantitative research. This looked to gain a more complete understanding of phenomena, especially in terms of organisational processes and provision of services (Greenhalgh, 1998). Therefore, a need existed to bring together isolated studies for comparison (Sandelowski et al., 1997). Meta-ethnography provides a way to compare qualitative studies accommodating induction and interpretation (Greenwood & Smith, 2016). It also can synthesise conceptual innovations such as metaphorical and emotionally relevant phenomena (Strike and Posner, 1983). It has origins in the interpretive paradigm and as such, it possesses an alternative to traditional aggregative methods of synthesis retaining qualities or concepts of the qualitative method of the studies they aim to synthesise.

The benefit of applying meta-ethnography to the synthesis of qualitative research and suitability for this study was informed by Noblit and Hare's (1988) seven-step process (Table 1). Narrative literature reviews capture concepts and information in a more eclectic fashion but have in the past been criticised for being singular descriptive accounts based upon the implicit bias of the researcher (Fink, 1998). They have also been condemned for lacking critical assessment. Adopting a more systematic approach to the literature was therefore useful in order to approach a more comprehensive contemporary review of the field. This approach was particularly helpful in investigating EOD as a lesser known sub-group of dementia. Meta-ethnography has proven a sound technique for synthesising qualitative research in health studies (Paterson et al., 1998). It has been successfully employed in publications to date including: lay meanings of medicines (Britten et al., (2002); lay experiences of diabetes and diabetes care (Campbell et al., 2003); what values people seek when they provide unpaid care for an older person (Al-Janabi et al., 2008) and locating how coping experiences appear in chronic fatigue syndrome sufferers (Larun and Malterud, 2007).

Table 1- Noblit & Hare 7 step synthesis

Noblit & Hare’s 7 step qualitative synthesis
1. Getting started: determine the research questions
2. Deciding what is relevant to the initial interest: defining the focus of the synthesis, locate relevant studies, inclusion decisions and quality assessment of included studies
3. Reading the studies: reading the articles multiple times to identify the main concepts
4. Determining how the studies are related: listing the emergent concepts and identifying the related concepts
5. Translating the studies into one another: listing the concepts into a table and then looking for these concepts in each of the included articles
6. Synthesising translations: building a line of argument by exploring the relationships between concepts
7. Expressing the synthesis: how the synthesis is reported

2.3.4 Results

2.3.4.1 Participant and study design

The inclusion criteria sought studies spanning 1998-2018. However, the studies ranged from 2009 to 2018. The mean date was 2015. All studies were performed in Westernised countries (Norway- 6; America- 1; England- 6; The Netherlands- 1; Ireland- 1 & Australia- 1). Where English was not the dominant language it was widely taught and well spoken (Norway and The Netherlands). The participants were predominantly drawn from health environments or services structured to assist PwD or PwEOD such as statutory or voluntary bodies. There was a total of 229 participants after making amendments for those participants drawn from the same sample groups where multiple study authors were included. Johannessen et al. (2014) and Johannessen and Moller (2011) used the same participants. Johannessen et al. (2016) and Johannessen et al. (2017) also shared participants databases throughout the studies. Data were collected through face to face interview mostly using a semi-structured format. These were situated within the statistics of the studies quoted above; PwEOD (4); their family members (2); both spouses (2) and dependents (8) whether still regarded as children living at home or adult children living independently elsewhere). These studies drew together the theoretical approaches to the data founded in grounded theory (5); autobiographical life story narrative (3); phenomenological hermeneutic analysis (2); Thematic Analysis (TA) (2); qualitative semi structured interview (1); conceptual model (1); action research study (1), Interpretative phenomenological analysis (IPA) (1).

Ethnicity was referred to infrequently (n=1) and where ethnic origins were detailed, the sample groups were white/Western. Allen et al. (2009) was the only study to include 25% Asian participants within an English sample. Other studies made no attempt to refer to ethnicity and so a presumption was made that natives of the country of origin satisfied the sample cohorts. This is excepting Sikes and Hall (2017) which reported that the sample participant group was ‘mainly white, British, middle-class, participants’.

Type of dementia was not a focus except for Johannessen et al. (2017) which focused on people with fronto-temporal lobe dementia. Other data reported were related to whether participants (both PwEOD and family) were working, living at home, in studies, in a care home, retired or medically signed off work and living on retirement funds or state benefits. The source for participants overwhelmingly arose from clinical or health focused environments. This particular feature was examined in the discussion of the studies. Having noted the brief characteristics of the studies above, the following tables and sub-sections developed overall themes along with the development of the line of argument.

Table 2: Participant and study design

	Author, year & country	Title	Aims	Sample size	Ages& participant cohort	EOD classification	Ambient relationship setting & recruitment
1.	**Johannessen, A. Moller, A. Haugen, P. Biong, B. (2014) Norway**	A shifting sense of being: a secondary analysis & comparison of 2 qualitative studies on young onset dementia	To investigate and interpret metaphorical expressions of lived experience of PwEOD	20	54-67 PwEOD	YOD	Recruited from 4 hospital memory clinics (drawn from an original study: Johannessen and Moller, 2013)
2.	**Johannessen, A. Moller, A. (2011) Norway**	Experiences of persons with EOD in everyday life: a qualitative study	Locate experience of EOD, implications for practice and development	20 AD 6 FTD & 3 others	54-67 PwEOD	YOD	Recruited from 4 hospitals memory clinics (chosen for cost and saving time on recruitment) telephone and follow up in hospital
3.	**Pipon-Young, E. Lee, K. Jones, F. Guss, R. (2011) England**	"I'm not all gone, I can still speak": The experiences of younger people with dementia. An action research study	Investigating the experiences and challenges of EOD with diagnosis, support, problems and areas requiring change	8	60-67 PwEOD	7 AD 1 mixed dementia	Via clinicians in the NHS Interviewed at home and hospital
4.	**Rostad, D. Hellzen, O. Enmarker, I. (2013) Norway**	The meaning of being young with dementia and living at home	Understanding the challenges and experiences of PwEOD living at home	4	55-62 PwEOD	3 AD 1 mixed dementia	Recruitment via a health coordinator with experience of the client group. Interviewed at home, welfare centre& day care

	Author, year & country	Title	Aims	Sample size	Ages& participant cohort	EOD classification	Ambient relationship setting & recruitment
5.	**Johannessen, A. Helvik, A. Engedal, K. Thorsen, K. (2017) Norway**	Experience & needs of spouses of persons with YO frontotemporal lobe dementia during the progression of the disease	Aim to find out what life is like for PwEOD's (FT) partners & their needs	16	51-69 spouses	9 wives, 6 husbands 1 male cohabitant	7 memory clinics, 1 municipality dementia team and a nursing home. Interviewed at home, in town and at work
6.	**Hoppe, S. (2018) The Netherlands**	A sorrow shared is a sorrow halved: the search for empathetic understanding of family members of a person with EOD	How Dutch family members find empathy for PwEOD in their family and assess barriers to providing care	7 EOD +41 family members, 48 partners, PwEOD, 11 group constellations	55-65 Family kin	EOD	Recruited from the Alzheimer's Society and 3 care institutions. Interviews at home at researcher's office in cafes for about 1 to 2 hours
7.	**Flynn, R, Mulcahy, H. (2013) Ireland**	EOD: the impact on family caregivers	Explore caring from family perspective in looking after PwEOD	7 (over 16)	Under 65 when diagnosed Family kin	EOD	Regional manager recruited via letter to volunteer participants meeting criteria. At offices of Alzheimer's Society Ireland
8.	**Johannessen, A. Engdal, K. Thorsen, K. (2016) Norway**	Coping efforts & resilience among adult children who grow up with a parent with YOD: a qualitative follow up study	How adolescent/adult dependents experience their parent's EOD and how they coped with life situations	14	18-30 Adult dependents	EOD	7 memory clinics, 1 municipality dementia team and a nursing home and from Norwegian National Support Group for Adult Children

	Author, year & country	Title	Aims	Sample size	Ages& participant cohort	EOD classification	Ambient relationship setting & recruitment
							Interviews held at convenience of respondent
9.	**Johannessen, A. Engdal, K. Thorsen, K. (2015) Norway**	Adult children of parents with young onset dementia narrate the experience of their youth through metaphors	To investigate & interpret metaphorical expression of adult dependents of PwEOD. What sense can be made?	14	18-30 Adult dependents	EOD	Heterogeneity attained through diverse geography in Norway/2 memory clinics/1 municipality/nursing home & support group for PwEOD. Interviewed at convenience at home or place of choice
10.	**Hutchinson, K. Roberts, C. Kurrle, S. Daly, M. (2016) Australia**	The emotional well-being of young people having a parent with early-onset dementia	To explore the lived experiences of young people with parents with EOD from the perspective of a social model of disability	12	19-33 + 1 x 10 year old Child/adult dependents	YOD	Advertising via Alzheimer’s Australia for volunteers Interviewed at work, at home or in local library
11.	**Gelman, C. Rhames, K. (2018) America**	In their own words: the experience and needs of children in younger onset Alzheimer’s disease & other dementia families	What are the experiences & needs of children with YOD families & the impact of a diagnosis on children of those families	(14) 4 families 4 mothers 10 children	10-25 Child/adult dependents	YOD	Flyers were displayed at support organisations $25 payment for information. Interviews lasted an hour at participant’s preferred location.

	Author, year & country	**Title**	**Aims**	**Sample size**	**Ages& participant cohort**	**EOD classification**	**Ambient relationship setting & recruitment**
12.	**Allen, J. Oyebade, J. Allen, J. (2009) England**	Having a father with young onset dementia. The impact on wellbeing of young people	To investigate and explore the impact on young people's well-being in light of them having a PwEOD	12	8-31 (mean 19) Child/adult dependents	British 75% Asian 25% Families of EOD	Recruited from Alzheimer's Society throughout the Midlands. Interviewed from 45-90 minutes
13.	**Sikes, P. Hall, M. (2018) England**	"It was then that I though what? This is not my dad". The implications of the 'still the same person' narrative for children & young people who have a parent with dementia	To investigate the 'still the same' narrative through children of PwEOD to assist future plans to support others in the same situation	19	8-31 age selecting accordance with the UN and WHO guidelines of what qualifies for ages in youth Child/adult dependents	EOD	2 interviews based upon self-selecting participants from web advertisement
14.	**Sikes, P. Hall, M. (2017) England**	"Every time I see him, he's the worst he's ever been and the best he'll ever be": Grief and sadness in children and young people who have a parent with dementia.	Aims to represent grief related to perceptions and experience of children and young people who have a parent with EOD. Gathering the information will assist future planning.	22	6-31 age selecting accordance with the UN and WHO guidelines of what qualifies for ages in youth	EOD	Snowballing, advertised on website, self-selecting, temporal effect desired so interviewed over two years

	Author, year & country	Title	Aims	Sample size	Ages& participant cohort	EOD classification	Ambient relationship setting & recruitment
					Child/adult dependents		
15.	**Hall, M, Sikes, P. (2016) England**	From "What the Hell is going on? To the "Mushy middle ground" to "Getting used to it as a new normal": Young people's biographical narratives around navigating parental dementia	To navigate through EOD family experience seeking temporal journeys of a biographical nature looking to location disruption to lives.	22	7-31 Child/adult dependent	EOD	Advertised through social media (Facebook, Twitter, Alzheimer's Society, Young Dementia UK). 2 0r 3 interviews over 16 months
16.	**Lakeridge S. Simpson J. (2012) England**	The experience of caring for a partner with YOD: How younger carers cope	To explore the coping strategies adopted by 6 carers to assist with adaptation in their relationship with their partner with YOD	6	3 male 3 female Spouses		Recruited from regional branches of Alzheimer's office. 50-90 minute interviews in participant's home or local Alzheimer's office

2.3.4.2 Drawing a line of argument from the seven-step process

Noblet and Hare (1988) refer to a meta-ethnographic line of argument which emerges to articulate a larger phenomenon drawn from the data. This is achieved by following the steps. After selecting an aim and study question (step one and two), the studies were read to fulfil step three. This was followed by populating the tables with typical broad characteristics (table 2) and investigation of experience (table 3). Following this, steps four, five and six produced more concepts (table 4) and themes (table 5) were populated taking care to ensure the data remained true to the original studies. Step seven provided for a discussion through the line of argument of what fresh data was discovered.

Table 3:Investigation of experiences

	Author, year	Title	Experience investigated	Sample method	Inclusion criteria	Data collection	Approach to data analysis
1	**Johannessen, A. Moller, A. Haugen, P. Biong, B. (2014) Norway**	A shifting sense of being: a secondary analysis & comparison of 2 qualitative studies on young onset dementia	Interpret metaphorical expressions	Anthropological	YOD catchment from hospital appointmt.	Thematic question interview based	Grounded theory
2	**Johannessen, A. Moller, A. (2011) Norway**	Experiences of persons with EOD in everyday life: a qualitative study	Living with EOD	Theoretical	Post diagnosis	Semi-structured interviews	Grounded theory
3	**Pipon-Young, E. Lee, K. Jones, F. Guss, R. (2011) England**	"I'm not all gone, I can still speak": The experiences of younger people with dementia. An action research study	Living with EOD, changes to health and practical needs. Transitional experience and health expectations	Purposive	More than 6 months from diagnosis	Semi-structured interviews	1st phase: thematic 2nd phase: framework
4	**Rostad, D. Hellzen, O. Enmarker, I. (2013) Norway**	The meaning of being young with dementia and living at home	Living with a diagnosis of EOD	n/s*	Diagnosed with EOD, living at home and diagnosed with EOD	Narrative constructed interviews	Phenomenological & hermeneutic
5	**Johannessen, A. Helvik, A. Engedal, K. Thorsen, K. (2017) Norway**	Experience & needs of spouses of persons with YO frontotemporal lobe dementia during the progression of the disease	Spouses living with FTLD during disease progression	Sampling	YoFTLD + family members	Qualitative interviews	Grounded theory

	Author, year	Title	Experience investigated	Sample method	Inclusion criteria	Data collection	Approach to data analysis
6	**Hoppe, S. (2018) The Netherlands**	A sorrow shared is a sorrow halved: the search for empathetic understanding of family members of a person with EOD	PwEOD& family members	Purposive sampling	EOD + family	Semi-structured qualitative interviews	NViVO transcription of interviews to extract 3 cases
7	**Flynn, R, Mulcahy, H. (2013) Ireland**	EOD: the impact on family caregivers	Physical, social, emotional and financial experience sought	Purposive	Open invitation to those within criteria	Face to face semi-structured in-depth	Chou (2000) conceptual analysis tool
8	**Johannessen, A. Engdal, K. Thorsen, K. (2016) Norway**	Coping efforts & resilience among adult children who grow up with a parent with YOD: a qualitative follow up study	Transition and resilience	Purposive sampling	EOD diagnosis made 6 months include adult children	Interview face to face	Grounded theory
9	**Johannessen, A. Engdal, K. Thorsen, K. (2015) Norway**	Adult children of parents with young onset dementia narrate the experience of their youth through metaphors	Emotional trauma and distress	Purposive sampling	Family of EOD	Individual qualitative interviews Seeking metaphors from interview	Phenomenological, hermeneutic. T.A.
10	**Hutchison, K. Roberts, C. Kurrle, S. Daly, M. (2016) Australia**	The emotional well-being of young people having a parent with early-onset dementia	Purposive sampling	Children of PwEOD	Semi-structured interviews		Social model of disability
11	**Gelman, C. Rhames, K.**	In their own words: the experience and needs of children in	Experience of social impact	Purposive sampling	Children of PwEOD	Face to face interviews	Thematic narrative analysis

	Author, year	Title	Experience investigated	Sample method	Inclusion criteria	Data collection	Approach to data analysis
	(2018) **America**	younger onset Alzheimer's disease & other dementia families					
12	**Allen, J.** **Oyebade, J.** **Allen, J.** **(2009)** **England**	Having a father with young onset dementia. The impact on well-being of young people	Emotional impact and psychological experience	Purposive sampling	Children of PwEOD	Face to face interviews	Grounded theory
13	**Sikes, P.** **Hall, M.** **(2018)** **England**	"It was then that I thought what? This is not my dad". The implications of the 'still the same person' narrative for children & young people who have a parent with dementia	Autobiographical meanings	Purposive and self-referring	Children and young people of PwEOD	Collection of in-depth personal stories and biographies	Autobiographical/life histories interviews &T.A
14	**Sikes, P.** **Hall, M.** **(2017)** **England**	"Every time I see him, he's the worst he's ever been and the best he'll ever be": Grief and sadness in children and young people who have a parent with dementia.	Seeking individual grief related responses to having a parent with EOD	Self-referring from internet advertisement & snowballing	Children and young people of PwEOD	Invitation to tell a story to the researcher	Autobiographical/specially life history
15	**Hall, M,** **Sikes, P.** **(2016)** **England**	From "What the Hell is going on? To the "Mushy middle ground" to "Getting used to it as a new normal": Young	How different biographies meet common ground with the study cohort	Self-selecting from advertisement	Children of PwEOD	Narrative biographical seeking interview	Thematic approach as in K Reissman

	Author, year	Title	Experience investigated	Sample method	Inclusion criteria	Data collection	Approach to data analysis
		people's biographical narratives around navigating parental dementia					
16	**Lakeridge, S. Simpson, J. (2012) England**	The experience of caring for a partner with YOD: How younger carers cope	General experience of caring for someone with EOD	Purposive sampling	Primary carer of PwEOD	Semi-structured interview using IPA	IPA

2.3.4.3 Overall themes

By the time Table five was completed at stages five and six in accordance with Noblit and Hare’s seven step process, new data was emerging to realise conceptual themes crystallised into themes which formed the expression of the new information. The expression of the synthesis followed the tables discussed theme by theme.

Table 4:Conceptual themes

	Author/Title/Year	**Concepts**							
		Losses	**Chronicity and lost time**	**Biographical disruption**	**Stigma & judgment**	**Diagnosis**	**Isolation & social identity**	**Emotions**	**Coping**
1.	**Johannessen, A. Moller, A. Haugen, P. Biong, B. (2014) Norway**	Loneliness	Life changes will appear		Masking & hiding	Difficult and lengthy to achieve	Sliding away & falling from life once taken for granted	Anger Fear Reticence Living in limbo	Coping Claiming dignity
2.	**Johannessen, A. Moller, A. (2011) Norway**	Lack of normality Confusion in every day contexts Dignity lost	Dislocation & lack of certainty Constraint s on time and planning		Dismissed by others Status lost	Diagnostic struggles & shock	‘feeling outside others and time Relationship changes	Diminished & rejecter Irritation	Stronger together going on
3.	**Pipon-Young, E. Lee, K. Jones, F. Guss, R. (2011) England**	Losing ideas of how to relate		Calm for now but afraid of the future	Saving face with others, shielding truth	Diagnosis feels in the wrong time & stage	‘Out of step’	Resilience	Keeping ‘in the swim’ & retaining new social identities
4.	**Rostad, D. Hellzen, O. Enmarker, I. (2013) Norway**	Loss of power Loss of humanity, Loss of identity	Wrong time for diagnosis		Reduced sense of belonging in the eyes of others		Trapped by circumstances		Preservation of hope and resilience Desiring to live well and managing
5.	**Johannessen, A. Helvik, A.**			Moving apart	Stigma		Distanced, emotional,	Coping	Calm and resilient

	Author/Title/Year	Concepts							
		Losses	Chronicity and lost time	Biographical disruption	Stigma & judgment	Diagnosis	Isolation & social identity	Emotions	Coping
	Engedal, K. Thorsen, K. (2017) Norway								
6.	**Hoppe, S. (2018) The Netherlands**	From certainty of health to the uncertainty of disease		Lifestyle burnout when too young	Barriers to acceptance of EOD condition	In between ideas of health and illness	Living in a state of confusion	Trepidation Guilt	Communing with friends increasing strength
7.	**Flynn, R, Mulcahy, H. (2013) Ireland**	No means to support and care	Waiting times for news and change			Different diagnoses given Big delays Diagnosis denial	Doubts over how to go forward differently	Fear Loneliness	
8.	**Johannessen, A. Engdal, K. Thorsen, K. (2016) Norway**	Lost childhood of child dependent						Feeling freedom Feeling like themselves Guilt on top of freedom	Relief Making a stand
9.	**Johannessen, A. Engdal, K. Thorsen, K. (2015) Norway**	The loss of a parent sliding away The shock of losing the parent inside		Stilted development	Covering up the diagnosis		Waiting to begin life	Confused	Emotional chaos. Escaping from doubt to cope

	Author/Title/Year	**Concepts**							
		Losses	**Chronicity and lost time**	**Biographical disruption**	**Stigma & judgment**	**Diagnosis**	**Isolation & social identity**	**Emotions**	**Coping**
		& no one left behind							
10.	**Hutchison, K. Roberts, C. Kurrle, S. Daly, M. (2016) Australia**	Loss compounded with grief			Being judged			Fear of being trapped, hopelessness, frustration 24/7 nature of caring is overwhelming Normality of family weighted against normality of self	24/7 nature of caring is overwhelming Normality of family weighted against normality of self
11.	**Gelman, C. Rhames, K. (2018) America**	Abruption – interruption of child/adolescent development Losing the natural order of parents & children	Waiting for others to ‘get it’- disbelief of diagnosis	Living with lies, terror, dread & ‘freak-outs				Fear, Embarrassment, exasperation	Adaption, acceptance, growth & change
12.	**Allen, J. Oyebade, J. Allen, J. (2009) England**	Loss of status; working parent, credible parent,	Waiting to become a child but needing to	Loss of parent loss of childhood & youth	Disjunction of childhood experience	Delays in diagnosis		Fear, fright, unease despair	Engaged, Knowledgeable Better understandi

	Author/Title/Year	Concepts							
		Losses	Chronicity and lost time	Biographical disruption	Stigma & judgment	Diagnosis	Isolation & social identity	Emotions	Coping
		comforted child	be a parent instead Parentification						ng of way forward
13.	**Sikes, P. Hall, M. (2018) England**	The loss and receding of the self (parent) Leaving the idea of the parent loss of role 'mum is an utter bitch'	The slipping away of parent & child	Disconnect of parenting	The 'Hollywooding' of the demented- the romanticising of dementia		No warning of losses & happenings	Crumbling spirit,	
14.	**Sikes, P. Hall, M. (2017) England**	Missing important stages and rites of passage in life	Life on hold Worrying about death & funerals 'out of time'				Liminal grief Uncertainty of future	Envy of other families in health deemed normal Post-carer symptoms of depression	Relief after death or after caring
15.	**Hall, M, Sikes, P. (2016) England**	Shock realisation of death after illness for children of PwEOD	Irrational behaviour only takes on meaning after time Time lag of diagnosis	Disruption to the natural expectation of life with dementia- children don't		Epiphanic moment of realisation Time lag in	Stuck in the middle ground of not knowing what may happen next	Shock sadness of unexpected death. Sadness of loss of parent in life & death	

	Author/Title/Year	Concepts							
		Losses	**Chronicity and lost time**	**Biographical disruption**	**Stigma & judgment**	**Diagnosis**	**Isolation & social identity**	**Emotions**	**Coping**
				understand dementia is terminal		diagnosis			
16.	**Lakeridge, S. Simpson, J. (2012) England**	Loss of social status Uncertainty over position in future life beyond caring, Threat to self over EOD being diagnosed.			Rejected by social life and society Left out of the loop as carers of EOD which is not understood by other health care roles/services.	Lack of awareness of EOD as a condition Futility of giving a negative diagnosis.	Denial of what is happening in everyday life.	Anxiety, Self-denial, In denial, Shock, Disappointment, Distress, Anger, Bitterness at treatment as carers, Feeling bullied by service providers into accepting unwanted services,	Finding help from others in same position.

2.3.4.4 Conceptual themes and Schutz's first and second order constructs (1962). The table below concludes the development of the line of argument. Noblit and Hare adopt Schutz' notion of first and second order constructs to assist the progression of themes. Schutz utilised the term first-order construct in referring to the everyday constructs and understandings of ordinary lay people. The second-order construct refers to those constructs familiar to social science researchers. The table below (Table 5) reveals how the themes take their place within the constructs drawn in accordance with Schutz's terms. The final themes arising were: i) biographical disruption ii) diagnosis, iii) losing life, friends and competences, iv) liminality and chronicity, v) stigma, and vi) coping with cautious optimism. The table below finalised the creation of new concepts which are followed by discussion of the themes.

Table 5:First and second order interpretations

Key concepts	1st order interpretation			2nd order interpretation		
Losses encountered through experience with condition	Loneliness experience throughout changes to life can disrupt and cause other feelings & experiences	Dignity lost to those personally affected	Confusion & uncertainty over lost health can be felt with diagnosis	Liminal experiences		
	Loss of power, social status, financial, role	Loss of self-experienced, things are not normal	Missing ‘normal’ shape of life events and expectations	Missing ‘normal’ rite of passage in life-Liminality		
	Loss of financial/emotional security is another side effect of a diagnosed chronic illness which can threaten the ability to work	Loss of childhood experienced in dependents	increased fears of job loss, threat to home and future hopes less thought of in older age dementia		Loss of identity	
Liminality	Feeling outside life and out of step with events	Trapped in the middle of nowhere		Identity shifting and fragmenting	The process on the way to diagnosis including & post period can alter the perception of the self in life, others & life activities-Life shock	

Key concepts	**1st order interpretation**			**2nd order interpretation**		
	Doubts and fears about going forward with uncertainty	No sense of belonging to or possessing order to life living with EOD			Liminal doubts from social and spatial confusion	
	Out of step with others and expectations of health personnel & family can occur with EOD. It can make the person feel displaced in their own lives.					
Biographical disruption	Stilted development for especially younger children of PwEOD	Dependents not able to experience transition to develop				
	Loss of normal sequence to life e.g. child-teenager-adult	Disruption to everyday living			Biographical disruption heightens negative experience of diagnosis, this can alienate hopes & expectations of moving forward positively through life stages	

Key concepts	**1st order interpretation**			**2nd order interpretation**		
	Parentification of younger family members of PwEOD			Life shock	Losses	
Stigma & dealing with the presentation of self	Rejection by others	Feeling left out		Passing type attempts to negate others' negative attention drawn to illness effects. Goffman's micro sociological understanding	Masking occurs in PwEOD& their families as they try to cope with social responses -Goffman	'Hollywooding' by society of the condition prohibits those directly affected from speaking their truth which is less glamorous- views rooted in biomedicalisation
	Lack of cohesion & sense of belonging with others.	Covering up deficiencies	Indecision through shame		Overarching stigma in everyday life	Stigma can seem worse due to the younger onset nature of an illness unexpected
Diagnosis & the nature of changes emerging from disclosure	Diagnosis difficult to gain & to realise, not being taken seriously by others.	Other conditions are preferred in diagnosis due to professional reluctance to consider dementia.	Emotional exhaustion at eventual diagnosis- mild relief/depression.	Changes are out of step with expectations. Liminal	Every day challenges are heightened. - Biographical disruption	Personal alteration to previous identity

Key concepts	1st order interpretation			2nd order interpretation		
	Epiphanic welcome & feared news at eventual diagnosis			Interim doubts and lack of knowing	Liminal transition and hope for communitas	
Chronicity & the articulation of & effects of time	Dislocation & lack of certainty about present, past & future	Waiting for confirmation, services, results, sense of self to emerge	The indecision, shock & lack of knowing with an EOD diagnosis leads to lapses, lags & sensory feelings of time &times not fulfilled as expected	Biographical disruption	Liminality	Liminality Chronicity
	Difficulties to plan time after being given a diagnosis					
Coping & emerging from suffering positively	There can be 'room to live with it' helps to see life more positively after	Collaboration from others helps to be positive		Communitas	Intimate citizenship	
	With understanding plans can be made to bond with post diagnosis life	Lessons to teach others emerge can occur with acceptance		Communitas	Intimate citizenship- Once a stage of acceptance has been met, beyond this is a reintegration with a normal life once more but as changed, informed with an	

Key concepts	**1st order interpretation**			**2nd order interpretation**		
					optimistic outlook of self & others	
	Desiring to manage & flourish with new knowledge			Communitas		

2.3.5 Line of argument

2.3.5.1 PwEOD – Biographical disruption

A prevailing theme within eleven of the synthesised sixteen papers reflected disruption of future life plans for PwEOD and their families (Pipon-Young et al., 2011; Hall and Sikes, 2018; Gelman and Rhames, 2016; Johannessen et al., 2016; Johannessen et al, 2017; Johannessen et al., 2015; Johannessen and Moller, 2011; Rostad and Hellzen, 2013; Allen et al., 2009; Sikes and Hall, 2017; Sikes and Hall, 2018). Biographical disruption is the conceptual term provided by Michael Bury (1982) to acknowledgement the threat to self when health and life is challenged by a serious health condition. As way of response, individuals look for ways in which to bridge this disruption and give meaning to this experience

A synthesis of these studies showed how participants' awareness of feeling too young to face a dementia diagnosis prevailed (Pippon-Young et al., 2011). For dependents, living with a parent with EOD could alter the experience of ideas of childhood. Hall and Sikes (2017) suggested how life could be on hold. From this position, Hall and Sikes (2018) noted how there was no parental template to draw upon for support. Sikes and Hall (2018) expanded upon their own authorship of other papers and described the 'Hollywooding' of the experience of dementia. This referred to the way film and media positioned dementia to a lay public. However, participants reported that this perspective did not equate to their lived reality. Gelman and Rhames (2018) reflected upon the chaos and uncertainty of living with EOD and how life lacked any sense of continuity. Johannessen et al. (2016) and Johannessen et al, (2017) noted that the overall burden of EOD on the family was a major biographical consideration. Shock was recorded prior to and beyond diagnosis with the reshaping of life plans (Johannessen and Moller, 2011; Rostad and Hellzen, 2013). Sikes and Hall (2017) suggested that life could be experienced as hectic prior to diagnosis. Following this, post diagnosis held no changes to a life continuing in crisis or fear of crisis. These feelings extended to include both children and teenagers who were immersed in the difficulties in trying to achieve, enjoy and establish lifetime goals that others took for granted (Hutchinson et al., 2016; Hoppe, 2018; Hall and Sikes, 2016) Extending from this, Allen et al. (2009) and Johannessen et al., (2015) described levels of parentification which became normal ways to react to living within a family. Gelman and Rhames, (2016), spoke of developmental hitches occurring to both emotional and psychological development. The ways that this could be reported lay with noticing that a sibling had stopped smiling and laughing. Hall and Sikes (2016) reported a lack of awareness in children that dementia was terminal.

Some studies discussed how being in the workplace represented feelings of exposure with others noticing changes (Johannessen and Moller, 2011). This could lead to queries by colleagues over observable drops and changes in performance (Johannessen and Moller, 2011). Although early retirement caused by EOD could be a life changing departure it could come as a relief when struggles became overwhelming (Johannessen and Moller, 2011). Johannessen et al. (2016) reported how the younger members of families with a PwEOD struggled to define themselves. This had consequences for their own identity. Johannessen et al. (2015) suggested that the integrity and identity of the family as a whole was diminished in certain participant groups. The parental role was eroded through illness as was the child/teenager’s role interrupted. Therefore, this could feel like, as discussed, how life changing situations at home felt like a continuous life threat (Hall and Sikes, 2018).

In conclusion it appeared that although biological disruption is a common theme, it can be experienced differently. Participants could experience it with a sense of not knowing what the future held thus making plans and expectations hard to follow to enjoy. This could arise from not understanding the trajectory of the illness and at the same time understanding that changes would be unpredictable making life plans difficult to gauge and direct.

2.3.5.2 Diagnosis

A dominant theme appeared throughout fourteen of the studies indicating that the periods before and after diagnosis could be pivotal (Flynn and Mulcahy, 2013; Johannessen and Moller, 2011; Allen et al., 2009; Hall and Sikes 2018; Johannessen et al., 2017; Lockeridge and Simpson, 2012; Sikes and Hall, 2017; Sikes and Hall, 2018; Johannessen et al., 2016; Johannessen et al., 2015; Pipon-Young, 2011; Rostad and Hellzen, 2013; Gelman and Rhames, 2018; Hutchinson et al., 2016).

A summary and synthesis of similarities reflected that the period running up to diagnosis could be triggered by major crisis events attracting the intervention of authorities as well as minor events which were not exposed to public scrutiny (Lockeridge and Simpson, 2012). It could prove an exhausting journey (Sikes and Hall, 2018). Diagnosis could provide the catalyst for lifestyle changes (Gelman and Rhames, 2018). However, Lockeridge and Simpson (2012) reported that the road towards the clarity and certainty provided by diagnosis was not always welcomed. When dementia was feared or suspected it could take some time to convince a family member to address the matter through a clinical diagnosis (Lockeridge and Simpson, 2012).It was also acknowledged (Allen et al., 2009) that family carers felt despondent over the quality of diagnosis; the competence of the doctor being able to diagnose dementia and ability to offer any supportive strategy thereafter. Johannessen et al. (2017) reflected how each member of the triad reacted to diagnosis; the clinician, the PwEOD and family. Some evidence uncovered how participants' credibility was affected (Johannessen et al., 2017; Johannessen and Moller, 2011) as participants felt they were not believed by a clinical audience. However, Johannessen et al. (2017) and Sikes and Hall (2017) reported relief at diagnosis as it gave a rational account of the recent past. But contrasted to this was experiences of loneliness could set in with no one to talk to about the diagnosis (Johannessen et al., 2015). In Johannessen and Moller (2013), diagnosis meant that an explanation was provided for odd behaviour or withdrawal from previous interests. However, this would be tempered by the fact that EOD still represented a terminal illness (Johannessen and Moller, 2011).

Experiences and feelings of blame did permeate the diagnostic period. Such conflicts meant that there was a variety in responses from those affected personally by EOD (Hall and Sikes, 2018). Because doctors were unlikely to suspect EOD often subjective criticism and blame directed towards the family members occurred (Johannessen et al., 2017). Some spouses were not often welcomed in the consulting room and their input was not valued (Johannessen et al., 2017). Often diagnosis was finally achieved after investigation of a string of plausible conditions had proven fruitless (Allen, 2009).

The certainty of diagnosis could allow for exploration of potential future pathways. Attempts could be made to incorporate new approaches to health like new treatment therapies and healthier lifestyles (Hall and Sikes, 2018). While some participants felt relief in reaching a diagnosis, suicidal feelings could manifest immediately after diagnosis (Hutchinson et al., 2016). However, diagnosis could also provide the catalyst for making life changes such as giving up career plans for both the PwEOD and their family (Gelman and Rhames, 2018). Acceptance helped make the best of the situation (Rostad et al., 2013). Contrasting with acceptance was the way that the diagnosis period played out outside the clinician's consulting room with one participant being outpaced by his wife's determination to locate a diagnosis that the participant lagged in their knowledge and acceptance of the diagnosis (Rostad et al., 2013). Lockeridge and Simpson (2012) illustrated how spouses felt conflicted whilst pursuing a diagnosis. They reported that they felt a level of deceit in reporting symptoms at home.

To conclude, when facing a diagnosis of EOD, there were obstacles. These were present prior to diagnosis with lack of realisation of EOD and a desire to not acknowledge a life changing condition. Medical authority often failed to identify the condition and as a coping mechanism blamed the family who were consulting them. Families coped in different ways where optimism could be a feature, but predominantly negative feelings were voiced. Whether positive or negative experiences prevailed, families found their lives following very different paths after the delivery of a diagnosis.

2.3.5.3 Losing life, friends and competencies

Eight studies reflected themes connected to losses; (Rostad et al., 2013; Gelman and Rhames, 2018; Flynn and Mucahy, 2013; Allen et al., 2009; Sikes and Hall, 2018; Hutchinson et al., 2016; Sikes and Hall, 2017 and Johannessen et al., 2014).

The synthesis located the diverse effects which could be considered as losses. Rostad et al. (2013) represented ideas expressed over losses to humanity. This was described as loss of self-identity, esteem, determination and respect which extended to becoming dependent upon others. This led to increased inactivity and passivity. Gelman and Rhames (2018) stated that a lack of finite resources to provide for and recognise needs in the family led to permanent feelings of loss. Sikes and Hall

(2018) reported loss of the PwEOD and bereavement and grieving occurring before the death occurred and discussed how life was lived alongside these feelings. In Allen et al. (2009) there was a reported loss of a father role in the family and the loss of expectation of being parented. In Hutchinson et al. (2016) a loss was recorded in opportunities due to mandatory care responsibilities being required to be covered in the household. Sikes and Hall (2017) reported a downward spiral effect of losing a normal perspective. In the Johannessen et al. (2014) study, losses were discussed as losing social role, health, quality of life, ability to work and cognitive capacity. Flynn and Mulcahy (2013) positioned their study to understand losses as being service driven and they often fell short of sufficiency for the PwEOD and their family carers. Restrictions were financial, social, emotional and physically felt by the participant group; the family carers (Sikes and Hall, 2017). To conclude, losses could be understood personally as well as socially.

Experiences around how ‘normal’ life was now dislocated, particularly after the certainty of a diagnosis, were notable and diverse. These experiences could venture into aspects of life which were connected to feelings and perceptions of identity, autonomy and selfhood. This could reflect how it was difficult to isolate claims into disparate concepts. Instead they tended to rely upon linking and merging into each other. Conceptual losses could thus be understood within a number of interlinking experiences.

2.3.5.4 Liminality and chronicity

Themes drawn from eleven of the sixteen studies revealed experiences around liminality. This effect can arise when people feel ‘out of this world’, ‘betwixt and between’ and in situations divorced from their perception of normal life. Notions of chronicity prevailed with feeling that time did not follow a normal pattern: (Rostad et al., 2013; Johannessen and Moller, 2011; Johannessen et al., 2014; Lockeridge and Simpson, 2012; Gelman and Rhames, 2018; Hutchison et al., 2016; Johannessen et al., 2015; Sikes and Hall, 2017; Sikes and Hall, 2018; Flynn and Mulcahy, 2013 and Johannessen et al., 2017).

The synthesised results led to the following understanding: Johannessen and Moller (2011) noted feelings of confusion and not knowing what was happening to them in the interim period prior to diagnosis. Gelman and Rhames (2018) reported experiences of chaotic feelings of ‘otherness’ and ‘outsiderhood’ in relation to change as well as leading to feelings of failure to cope (Rostad et al., 2013; Johannessen et al., 2014; Johannessen and Moller, 2011). These experiences read to reflect sensory fracturing away from others or normality (Allen et al., 2009). Spouses could feel rejected and confused over how to cope (Johannessen et al., 2017). Lockeridge and Simpson (2012) outlined being lost with feelings of rejection and how carers could feel bullied into accepting services they did not wish or feel necessary. Allen et al. (2009) reported in accordance with the Gelman paper feelings of disconnection whereby other family members could appear co-dependent with the PwEOD. This could lead to epiphanic, revelationary and euphoric traits present whereby certain family members could advocate for the day when the PwEOD recovered or different causes could be found for symptoms. Johannessen et al., 2017; Sikes and Hall (2017) reported how family carers observed feelings of rejection and confusion about everyday life. Johannessen et al. (2016) articulated lifetime rites of passage and aggregated experiences that were under threat such as marriage, graduations and childbirth. Therefore, there was an articulated experience of achievements going unnoticed. Within this failed recognition, a detachment could form with dependents based upon feelings of exclusion and indifference (Hutchinson et al. (2016). This led to background fears of impending decline and death. Sikes and Hall (2017) reported further reflections around the experiences of time and waiting. By the time a diagnosis did arrive, emotional exhaustion prevented diagnosis from providing a ‘Eureka moment’. There nonetheless remained a feeling that life was on hold and there was no destination end to the journey. Themes related to chronicity were noted. Time could feel more burdensome in the way that every declaration and event had to be waited upon. Such experiences were provoked by waiting for news, diagnosis, service provision and uncertainty about the future (Johannessen et al., 2016; Sikes and Hall, 2018). Johannessen et al. (2015) articulated the conceptual meme of feeling ‘zombified’ by the experience and taint of EOD. The family reported coping in ways that were more; more dislocated, spatially lost and remote (Flynn and Mulcahy, 2013; Johannessen et al., 2017; Johannessen et al., 2015) recorded metaphorical experiences of ‘slipping away’ of being ‘in another world’ and ‘spinning in a centrifugal machine’.

These concluded experiences of life in limbo concluded the thematic descriptions of dealing with often chaotic experiences of EOD. The experiences were overarching the confusion that EOD symptoms often provoked in PwEOD and reflected how family felt wrong-footed over daily routines and how to react in a ‘new normal’ life. These led to situations of feeling ‘betwixt and between’ with regard to not finding or locating a comfortable place to occupy in the family as the roles of child/adult, young adult/parent lost definition.

2.3.5.5 Stigma

Eleven of the sixteen studies reflected stigma was prevalent being reported by both PwEOD and with spouses and dependents; Hutchinson et al. (2016); Pipon-Young et al. (2011); Allen et al. (2009); Johannessen and Moller (2011); Sikes and Hall (2017); Johannessen et al. (2016); Lockeridge and Simpson (2012); Hoppe (2018); Gelman and Rhames (2018); Johannessen et al. (2014) and Hoppe (2018).

The available literature on stigma bears significant influence of Erving Goffman’s theory of stigma (1963). Stigma is defined as something which prevents an individual from being accepted by others. It is the response to characteristics perceived as dishonourable or disgraceful and individuals with these negative attributes are perceived as tainted and therefore stigmatised. Goffman (1963) could be pervasive crossing many forms and social environments. He identified three types of stigma: physical, group association, and character. Physical stigma associates itself with an individual’s physical appearance or deformity. Character stigma could be associated with an observable aspect of an individual’s personality and clashes with accepted systems of ethical values by which society evaluates acceptable norms. Group association stigma imposes a negative burden upon an individual because of their association to a particular group and can be based upon ethnic, religious and political affiliations, but also through other describable deviant groups. Therefore, stigma has a wide application and has the ability to affect the study participants as well as their family kin.

Johannessen and Moller (2011) reported how suicidal thoughts could be the outcome of not being confident about being in company with others due to their cognitive abilities. This could be shown in self-harm (Allen et al., 2009). However, most stigma emerged with interaction with others. This is where stigma could manifest obviously. Pipon-Young et al. (2011) discussed ‘saving face’ as a way by which people covered up their dementia through embarrassment and coped socially with potentially discriminating features of their lives. Johannessen and Moller (2011) described how PwEOD could feel marginalised through having no control over what others knew about them. Stigma by association[4] affected participants across some studies (Allen et al., 2009; Hutchinson et al., 2016). Dependents felt stigmatised by having a parent with EOD. At any time, the participants reflected how difficult it was to manage their accounts to others often changing information dependent upon to whom they were directing their conversation (Hutchinson et al., 2016) Participant family carers vacillated between guilt and a form of coping. This form of coping allowed family carers to operate daily life whilst trying to shield the PwEOD from difficulties in the aftermath of a dementia diagnosis. Some studies reported how strategies were found to cope and deflect stigma both in the self and other family members (Sikes and Hall, 2017; Johannessen et al., 2016); Lockeridge and Simpson (2012) and Hoppe (2018). Crucially these experiences of being judged negatively emerged when interfacing with medical services (Sikes and Hall, 2017; Johannessen et al., 2016). Gelman and Rhames (2018) reported stigma like experiences reported through loss of status, self-efficacy and credibility. As a result of stigma, dependents could be left with feelings of irrecoverable lack of confidence.

The experiences concluding EOD stigma demonstrated how PwEOD, their spouses and children were affected in different ways; some of which were rooted in the micro-relationships within the family and physician relationships, others emerged within social life in society.

2.3.5.6 Coping with cautious optimism.

Under the theme of coping, eleven of the sixteen studies reported evidence of participants thriving with EOD; Johannessen et al. (2017); Johannessen et al. (2016); Rostad et al. (2013); Pipon-Young et al. (2011); Lockeridge and Simpson (2012); Millenaar et al. (2016); Johannessen et al. (2015); Gelman and Rhames (2018); Allen et al. (2009); Hutchinson et al. (2016) and Hall and Sikes (2018).

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[4] Stigma by association is the placing of strain on family members arising from the connection with the marked person (Erving Goffman 2009).

Pipon-Young et al. (2011), related how PwEOD negotiated positive ways to live well with dementia; keeping active and involved and sharing a social society. Rostad et al. (2013), Lockeridge and Simpson (2012) and Johannessen et al. (2017) reported participants as being able to reach acceptance and live with their diagnosed condition. Mental health issues affected coping resulting from unmet needs and lack in provision of support (Millenaar et al., 2016) with reference to young carer literature[5]. Johannessen et al. (2016) and Johannessen et al. (2015) showed that part of coping was enabled by detaching from everyday suffering in life to gain a safe perspective. Getting used to a 'new normal' was possible alongside negotiating the difficulties of life drawing parallels with Parsonian obligations to work and contribute to self and society (Hall and Sikes, 2018). This impacted upon coping themes related to competing in a job market. Gelman and Rhames (2018) and Allen et al. (2009) drew upon claims that coping meant adjusting to living with fear and taking one day at a time. Hutchinson et al. (2016) reported how the identity could be developed which enhanced strategies of coping.

Overarching the views on coping was securing a blend of normality which could be achieved provided economic pressures could be minimised or set aside. Resilience helped dependents distance themselves from traumatic family events and overwhelming tension. This meant that part of being a 'new normal' could result in not being economically competitive.

2.3.6 Conclusion

The review focused on the experiences of living with EOD. The results indicated that there was variation in the sample sizes, patient type, models and study design. Meta-ethnography was the selected approach to systematically review the literature. The main themes extracted were; i) biographical disruption ii) diagnosis, iii) losing life, friends and competences, iv) liminality and chronicity, v) stigma, and vi) coping with cautious optimism. The findings do reflect broad consensus that EOD prompts some different needs within the dementias' classifications. To this end, further research and development in the field is suggested in order to provide more

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[5] Domestic estimates in Scotland suggest mental health difficulties amongst young carers indicate are reported twice as much as is reported by non-carers (Scottish Government, 2017).

knowledge for those providing and receiving care and services with particular sensitivity to each personal perspective in the triad of PwEOD, spouse and children.

2.3.6.1 Gaps in the literature and rationale for study

The literature review conducted in this chapter reflected the gap in the literature capturing the lived experience of PwEOD as reported in their own voice. As a result, only four studies were located reflecting the views of PwEOD were expanded with the experiences of family kin reporting on life at home with the PwEOD; Johannessen et al. (2014); Johannessen and Moller, (2011); Pipon-Young et al. (2011); Rostad et al. (2013). Little previous work located the lived experiences of PwEOD from their own voice. The other studies projected the experiences from family kin who were part of the living and caring experience of the PwEOD. This study aim therefore intended to investigate the direct experiences of PwEOD as they chose to reveal what living with the condition was like in everyday life. The SLR contributes to the modest amount of experiential studies currently in the field reporting on PwEOD. Of the available literature meeting criteria, there was still a tendency for the literature to seek family kinship views as opposed to drawing upon the PwEOD’s views where these opinions and views could be provided. Given the gaps in current research, it is important to investigate further the challenges and opportunities for researchers and practitioners in researching, planning, implementing, and evaluating appropriate educational, supportive, and therapeutic services for individuals affected by EOD. Without a firm policy steer, PwEOD in Scotland and the wider UK may be at risk of not receiving age-sensitive appropriate care.

2.3.6.2 Strengths and limitations of the review

Methodological strengths of this review include its reproducible and systematic nature including the application of a meta-ethnographic tool (Noblit and Hare, 1988). The process allowed like concepts to be compared through a similar system of values enabling a full review of all available literature meeting the criteria. There were a number of limitations with the review. Weaknesses were located around the paucity of studies located highlighting experience of EOD by PwEOD. This was dealt with by expansion to encompass family kin. This allowed inclusion of a wide variation in age ranges and eclectic family role dyads. The literature illustrated that there are many legitimate perspectives involved and affected by EOD. However, as the variation in the studies was so wide, the synthesis could not fully account for the influence of these factors in the findings. Some of these specific aspects could be given valuable treatment in future studies. additionally, included studies were conducted within Western cultures and within traditional ‘nuclear families’. This had the effect of restricting generalisability of findings to other family structural systems. Finally, studies were included from clinical settings which may distort some of the findings and assumptions.

2.3.6.3 Clinical implications

Participant views are deemed to be important for the planning of service provision and delivery. The results suggest strongly that planners of health and social care will be required to be flexible with an audience which is differently populated out with traditional age groups for dementia. Within any population of EOD there may likely be people who form part of the working population with children who still require support from parents both financially and emotionally. Care providers and planners must be cognisant that EOD is a chronic condition which whilst terminal, occurs in individuals and families with acute and vital ongoing needs. It is critical that qualitative research takes on board the nature of biographical disruption in an EOD diagnosis and considers the needs of a younger population. This is critical to the needs of other workers in the family including the vulnerability of children who need ongoing nurturing and relationships with parents to be a positive and nurturing as possible.

One noteworthy consideration in qualitative studies gathering person-centred-views is awareness of location and channel through which studies are performed. The studies relied upon hospital based or clinically led studies. Most made provision to ensure participant convenience and comfort. However, it is the case that ethical concern must be drawn to what extent participant groups may suspect that there are right answers or wrong answers. Scientific medicine still is situated as the dominant hegemony governing care in times of medical frailty where people fear demise and death. It may be believed that by complying with presumed correct responses, it may help participants to gain access to medication, clinical trials or enhanced service provision. Such situations may potentially arise where ‘correct’ answers may be thought to bring ‘rewards’. For these reasons, concern should be taken over recruitment paths for selection. This will ensure that participants are not unclear about what their data may realise for them personally in the short to medium term. This also applies to media representations of dementia, one of which is to hint at seductive and attainable cures such as drinking wine and doing crosswords. In order to ethically and respectfully manage the expectations of participants, the aims and likely outcomes of studies should very clearly be illustrated to potential participants so that ‘media manipulation’ and ‘miraculous’ science should not be a part of any trial or prescribed treatment.

2.3.6.4 Future research implications

Further contributions to the research body including qualitative studies on experience could help to sensitise policy-makers, health and social care providers to factors affecting PwEOD. Where particular problems to this subgroup are raised special focus might act to enhance service provision and care. EOD is a classification which brings its own separate concerns from those presenting in later onset dementias. Therefore, it may be fruitful for future research to explore further the experience of PwEOD in environments such as the home, workplace and living socially amidst others. This would relate to both the personal impacts as a distinct condition with different symptoms to that of older onset conditions as well as experiences of coping within work and family settings. Personal views in the literature of PwD are still limited, more limited are the views of PwEOD (Johannessen et al., 2014; Johannessen and Moller, 2011; Pipon-Young et al., 2011; Rostad et al., 2013). This means that EOD still remains a little researched and written about subgroup.

The three tensions; the global incidence of dementia, the policy position of dementia at the top of the health and social care agenda and the need to provide research-driven data and care policies provided an overarching justification for this study. However, the opportunity to research a critical concern reflected where gaps were demonstrated around the subjective understanding of what it is like to have dementia from an individual point of view. It was shown throughout the literature the limitations of the lack of personal subjective research evidence relating to EOD. This lack impacts upon domestic Scottish based research clearly suggesting a need for further research in this area. This is important in order to understand both the meaning and experience of EOD which might have a valuable role in illuminating other dementia subtypes.

3 Methodology

3.1 Introduction

This chapter discusses how a methodology appropriate to the study aims was decided upon. The methodology supports the aim to explore the views and experiences of PwEOD. This chapter discusses the ontological and epistemological positions taken in this study, which contributed to forming the methodology which drew from a social constructionist position. The specific methods used were selected from research methods aiming to illuminate individual experiences from the participant's own perspective.

3.1.1 Aims and objectives

The aim of the study is to learn more about the personal experiences of PwEOD. This will be addressed by meeting the following objectives:

- Establishing to what extent personal experiences of EOD are present in the extant literature and what this tells us.
- Using autobiographical and other written content about the self by people with EOD, to learn about the experience of EOD.
- Focusing on the impact of having a diagnosis of dementia at working age.

3.1.2 Ontological and epistemological approach

Ontology concerns itself with the nature of social reality, that is, to question the nature of existence. From this position, questions can be raised about what there is to know about the world. The dominant ontological questions within social research reside around whether social reality exists in ways independent of human interactions and interpretations. Ontology considers if there is a common, shared social reality or rather, instead, there are multiple realities. From considering these issues, questions can be asked whether social behaviour is generalisable (Snape and Spencer, 2003).

Epistemology seeks to describe the theory and nature of knowledge and how others acquire this quality (Crotty, 1998). It seeks to examine how we know what we know, and further, what represents knowledge. In this way, ontology and epistemology are inextricably linked, because what we accept as the nature of social reality impacts upon how we seek to understand it. This area is characterised by two dominant paradigms across the fields, positivism and interpretivism.

3.1.3 Positivism

It can be argued that the dominant paradigm in the field of disciplined inquiry since the Enlightenment has been positivism (Langdridge, 2007). A positivist paradigm performs a dominant position in the natural sciences and remains dominant in the social sciences (Ashworth, 2008). According to Ashworth, positivism is based on three assumptions. Firstly, a single unitary ‘real’ world in which human phenomena display enduring and clearly defined characteristics must exist. Secondly, the world can be described in terms of measurable variables, and these must relate to each other via cause and effect relationships. Finally, there is a logic which underlies the process of generating knowledge which must be deductive. This involves the marrying of research to a pre-existing theory to prove or disprove hypotheses through the sophistication of argument. When adopting a positivist stance, the researcher’s task is to maintain objectivity and remain detached and value-free (Langdridge, 2007). Communication between subject and researcher during a positivist study involves the transmission of quantitative information (Lather, 2006). However, this was not the kind of information that was sought from an inquiry seeking the views of others. For example, it would be difficult to elicit a view of a biographical experience of bereavement using measurement and standardised research templates and situations.

3.1.4 The interpretative paradigm

An alternative to the positivist paradigm is interpretivism. The ontological assumption of this paradigm is based on the interpretative paradigm accepting reality is complex as well as holistic. From this, it is wholly dependent upon the context (Lincoln and Guba, 1985). This means that a subjective stance rather than objective is preferred and given more support from within the researcher’s lens. This study sought to understand the way that PwEOD understand their world and wanted to share it with others, which is by nature, subjective. Therefore, this ontological stance is appropriate for the research.

The interpretivist paradigm assumes that the meanings people attach to their actions, and the reactions of others are important. However, positivism seeks facts in the form of building blocks to be further verified (Guba and Lincoln, 2005). In this paradigm, intersubjectivity between researcher and the focus of the inquiry is recognised and nurtured. This means that the creation of knowledge within the interpretivist paradigm is likely to be inductive rather than deductive. Interpretivism emerged as a post-positivist phenomenon to lend support an ontology which understands meaning as inherent within an object waiting to be discovered (Schwandt, 1994). From this paradigm the development of fresh theory and knowledge will emerge rather than be uncovered through the testing of hypotheses (Lincoln and Guba, 1994). Interpretivism thus, is associated with qualitative approaches involving the generation and interpretation of detailed descriptions within individual experience based upon the relationship of individual’s interaction with their world. There is no singular, unified, qualitative approach. Instead, different strands possess a variety of philosophical underpinnings with methodological approaches and practices.

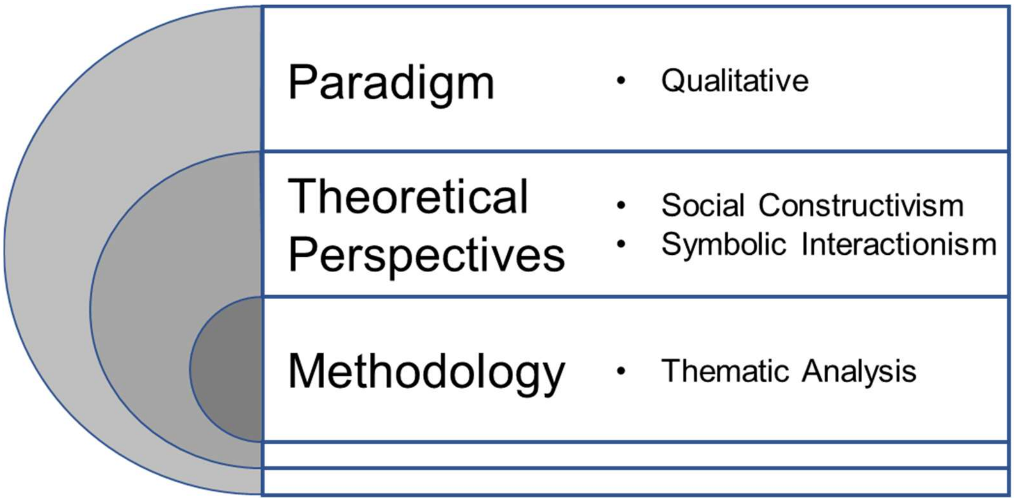


Figure 2 - Methodological framework

3.1.5 Social constructionism

One such approach within the interpretivist tradition is social constructionism, appearing as one strand, subsumed under overarching constructionism (Flick, 2014). Gergen (1994) stated that social constructionism refers to the way that we account for the world by understanding ourselves as part of a world where we see ourselves situated and culturally situated amidst the interchanges between one person and another. This perspective favours a worldview that understands that the world cannot be understood as a simple account of given facts but constructed from a dynamic and participative process of active construction and production (Flick, 2014). Indeed, social constructionism does not present as a unified and homogenous qualitative product. In the tradition of Schutz (1962), Berger and Luckman (1967) and Gergen (1985), social constructionism supports inquiry of the social conventions, taken for granted knowledge and everyday life observations. Its principal aim lies with explicating those processes through which individuals account for the world in which they live. This accounting is articulated with the understanding that any interpretation of the world today may differ from an account of the same thing in the past or in the future. There are, therefore, different definitions of what social constructionism is although ‘a family resemblance is a good way to understand the varieties’ (Burr, 2003). Given this perspective, knowledge of the world is not regarded as a product of induction, nor is it based upon the building and testing of general hypotheses. The world, therefore, represents social artefacts situated within historical interchanges among people. Empirical validity becomes less important through a social constructionist lens and, instead, relies more upon the changing fortunes of such social processes as communication, negotiation and conflict. Rules applied to locate definitive answers are not welcome, rather social artefacts are by their nature ambiguous and continuously evolving (Gergen, 1994). Such an approach can prove highly applicable when trying to gain insight and the ‘truth’ of another’s life. Forms of negotiated understanding hold a critical significance in social life, holding a connection with the myriad of social activities in which people engage.

This methodology chapter of the thesis looks at social constructivist and symbolic interactionist perspectives viewing illness in the context of the individual and society. These perspectives provide an appropriate epistemological stance in order to allow us to look at illness in a variety of ways which focus on the social and personal impact of the illness, rather than the medical impact. These theories have, or can be, applied to the study of dementia, and are highly relevant to understanding personal experiences. The following subsection begins with an explanation of how identity is conceptualised and Tom Kitwood’s contribution to ideas of ‘personhood’. The values involved helped develop a proposal for broadening the lens of biomedicine, showing how social and psychosocial benefits supported the individual at the centre of dementia.

3.1.6 Symbolic interactionism

Symbolic interactionism emphasises how the self is constructed through language and communication (Blumer, 1969; Goffman, 1959; Mead, 1934). While social constructionism appears on a macro level expanding upon a theory which seeks to explain socially constructed theories of knowledge, the symbolic interactionist perspective views society as a micro product of everyday social interactions of individuals, but also studies how people shape symbols to create meanings from ideas such as deviance.

The theory of symbolic interaction is comprised of the four elements of symbols, socialisation, mind and self. As a micro-sociology, this theory describes a sociological perspective with foundations in pragmatism which deals with the philosophical concerns of how living things manage adjustments to their environment (Hewitt, 2002). It has been used extensively in health and illness research, and it is from this perspective that the methodology for this study has been designed. A principal figure in the development of symbolic interactionism was George Herbert Mead (1863-1931) whose work was extended by Blumer (1962). A symbolic interactionist framework conceives identity as a method by which an individual defines and differentiates the self from others. It negotiates how people balance their own preferred identities and the perceptions and goals that they identify as desirable. Such identity requires empirical validation in daily life, however, with the onset of chronic illness, everyday life upon which former identities have been invested will be altered. Bearing this in mind, Kitwood described having an identity as;

> ‘To know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a ‘narrative’, a story to present to others’ (Kitwood 2007, p. 83).

This reflected that although cognitive impairment could affect self-perception, goals and identity, nonetheless, life could still be recognised as salvageable if not with retention of perfect memory. Mead’s Mind, Self and Society (1934) contained a reference to the relationship between time and the construction of the self. There is a temporal dimension in Mead’s conception of the ‘I’ and the ‘me’ in that both the ‘I’ and the ‘me’ are discovered experientially in memory images of what individuals have done in the past (Mead, 1934). Three key tenets support explanation of the symbolic interactionist position, the first being that; individuals are conscious of themselves as objects, meaning humans become self-referential and people take their feelings and their interests into account when they act (Blumer, 1962). This awareness implies that self-esteem and well-being is forged with self-focused feelings over interaction with others (Hewitt, 2002). For example, according to Goffman (1959) people generally present themselves in the best possible light during social interaction as a reaction to not only present the best 'face' but to 'mask' the worst. Secondly, individuals are active social agents perpetually interpreting situations and aligning themselves with others to adopt roles and avoid exclusion (Blumer, 1962). Through language and symbol, we interpret our social world according to how we understand ourselves within it. Finally, symbolic interactionism conceives that self and identity are critical in any social environment. Therefore, an individual's selfhood is bound up within a set of characteristics which define their unique humanity and are expressed through their social conduct and shared and constructed with others (Blumer, 1962).

The shift from interpretative sociology to 'symbolic interactionism' primarily deals with the meanings underlying the interactions that take place between individuals and groups (Nelson, 1998). The self however, will engage in an inner conversation (Mead, 1934). The use of shared symbols is an important means by which individuals can understand the other in interactions. They constitute the basis for language and communication and therefore, how reality is contextually viewed (Blumer, 1962). This provides for a subjective interpretation of everyday life which supports the definition of being able to define an identity through differentiating the self from others (Hewitt, 1992). George Herbert Mead's work through symbolic interactionism provided a link between identity and the significance of temporality in the self (Mead, 1934). One significant finding in the SLR in Chapter Two and the broader literature in experiences of PwD and PwEOD, was the way in which time could feel burdensome and confusing therefore, suggesting the notion of chronicity. Chronicity refers to the social construction of chronic illness and how time can appear different and weigh heavily on the individual who is prevented from fulfilling the time they have in life in other ways due to the limitations placed upon them through ill health.

As a means by which to take on chronic illness, for example, individuals may motivate themselves towards future goals, plans and wishes whilst having to acknowledge present difficulties (Charmaz, 1994) This motivates individuals in a state of permanent illness to realise future identities and acknowledge present ones. Through doing this, implicit identity 'goals' are formed (Charmaz, 1987). The concept of identity goals assumes that individuals crave meanings and act purposefully in the interpretation of experience and interaction within the world. Some identity goals may be implicit, unstated, and understood; just as others may fulfil explicitly preferred identities.

Mead suggested that temporality is integral to his conception of the development of the self, consciousness, and role-taking. This was accompanied by a belief that the past and future are perennially reconstituted in light of the 'emergent' in the present. This ability to reconstruct involves an interweaving of objective events which reside in the past. This past impacts upon the present and the symbolic reconstruction of the past into the present. Mead's work suggests that the self-concept does not simply have a temporal aspect. Rather, temporality is integral to the self-concept in a more fundamental way. Temporal experiences in chronic ill health or rather, chronicity, has significance in Mead's symbolic interactionist understanding of the social world. Therefore, Mead accepted that temporal structure manifests itself with the appearance of novel or emergent events in every experience.

Given the aims of this study to understand the experience of PwEOD dementia, from their own perspective, Symbolic interactionism provides a relevant base from which to design a methodology, which will be described below.

3.2 Qualitative approaches

3.2.1 Qualitative research

By positioning this research within the symbolic interactionist tradition, and in consideration of the integral aims and objectives, I elected to follow a qualitative design. For Silverman (2000), qualitative research can be utilised to provide deeper meanings and understanding of social life and phenomena that would otherwise be inaccessible through quantitative data alone (Silverman, 2000). This type of approach supports the emergence of otherwise unheard voices and allows excluded or marginalised groups’ experiences to be heard. The chapter continues to expand upon consideration of related but different styles of data analysis approaches.

Qualitative research is concerned with understanding the meanings that people attach to their experiences within their social world (Ritchie et al., 2003). It investigates written or oral data to obtain rich information about an experience and the larger meanings in participants’ lives. It therefore, provides good insight into human behaviour (Lincoln and Guba, 2005). The same authors state that within qualitative designs, paradigms offer a shape to basic beliefs, which are subjective and cannot be ultimately established in eternal truth (Lincoln and Guba, 1994). The aim of this study was to seek the views of PwEOD as they understood their world and wanted to share it with others. The rationale behind using qualitative methods was that I felt that these would best achieve deep, rich data and would make space for participants to provide narratives around their own experiences.

3.2.2 Selection of data collection method

In order to ascertain the experiences of PwEOD, several methods were considered, including participant research, primary data collection, such as interviews, and secondary data collection, such as identifying already existing narrative accounts.

The nature of ethical problems in qualitative research studies can present as subtle and different compared to problems located in quantitative research (Orb et al., 2001). Because of the nature of the PwEOD, there were specific ethical concerns about vulnerability, ability to partake in research, and ability to give informed consent. Potential ethical conflicts also exist in how researchers gain access to a participant group and in the effect the researcher may have on participants. Punch (1994) claimed that ethical failures in qualitative research are rarely highlighted in the literature. However, Batchelor and Briggs (1994; cited in Orb et al., 2000) claimed that the failure of researchers to address ethical issues has often resulted in examples of lack of preparedness in coping with the unpredictable nature of qualitative research studies.

3.2.3 Participant research

One prior intended data collection process in this study originally lay with using participant observation and interview study with PwD in their own homes, while operating as an unpaid carer of which I had significant experience. Participant observation has been a hallmark of sociological studies. Qualitative methods of data collection include interviewing, observation, and document analysis. Participant observation has been defined as the systematic description of events, behaviour and artefacts all situated within the social setting for the study undertaken (Marshall and Rossman, 1989). Participant observation is comprised of the process enabling researchers to learn about the activities of others studied in the natural setting through observing and participating in those activities. It can provide the context for the development of sampling guidelines and interview guides (DeWalt and De Walt, 2002).

Observation methods are useful to researchers in a variety of ways. They provide researchers with the means to check; nonverbal, emotional expression, noting interactions and become informed about how participants communicate with each other (Schmuck, 1997). Participant observation allows researchers insights to participant conduct and to observe events that informants may be unable or unwilling to share ordinarily. (Marshall & Rossman, 1995). Reasons which make participant observation popular research is its ability to make possible many forms of data, reduces the likelihood of the study group reacting falsely, helps the researcher to form more insightful questions which are culturally relevant and offers a credible account of a group which may not be broadly known about in society (Bernard,1994). These reasons offer some examples of why participant observation is an effective method of study. This option which is a popular one for research students of clinical and nursing science, was initially hoped to be supported ethically through engagement with participants. However, significant changes imposed by Tayside NHS ethics committee meant that the study would not be able to be carried out authentically and ethically. An approach was made to the Scottish Dementia Clinical Research Network to locate participants, but this did not occur in a timeous fashion. Therefore, alternative routes were located in order to complete the study within the specified time allowed.

3.2.4 Interviews

Another method which has been widely used in qualitative research is interview, particularly semi-structured interviews (Gubrium and Holstein, 2001; Kvale, 2007). Interest in this approach with collecting data and gaining new insights is linked to expectations that the interviewed subjects' viewpoints are more likely to be expressed in an openly designed interview situation sensitive to their situation and experience. Several types of interviews can be distinguished for the purposes of research, but semi-structured interviews have proved a useful resource in health studies where personal views of individuals living with health conditions are sought (Rabionet, 2011). The use of semi-structured interviews provides most potent tools across qualitative studies where the opinions are sought from the participant group in question, however, a certain level of previous study in the research topic area is generally required previously to the interviews (Kelly, 2010). Often the questions are determined before the interview and formulated using the interview guide (Rubin & Rubin, 2012). It can offer a focused structure for discussion during the interviews but is not adhered to exactly. Instead, the exploration of the research area by collecting similar types of information from each participant supports the following line of questioning thereafter with participants (Holloway & Wheeler, 2010).

Ashworth (2017) recently used interviews in a study comparing EOD with later onset dementias (Ashworth, 2017) using a mixed-method design with questionnaires assessing feelings and experiences of stigma elicited from PwEOD and their family kin carers. This study used a combination of measurement tools with which to gauge experiences of lived experience with EOD. However, this study was achieved in many NHS sites across Scotland, and this level of access was not possible for me to ethically attain. Therefore, the reasons for not applying interviews as a strategy for this study lay with not having access to the study group. I was also concerned about the quality of responses from interview questionnaires, which may have relied upon carer help which would not be explicitly admitted to in the process. Thus, for ethical and quality issues, this was not a process that I pursued beyond investigation.

3.2.5 Narrative accounts

I ultimately decided to draw upon an extant data set provided by PwEOD, who published their own experiences of dementia, in order to ascertain their experiences of living with EOD. Such narratives exist in both autobiography and blog form.

Many scholars hold the position that it is through narrative that our lives are understood and as such, the telling of stories, whether about oneself or others, is universal (Plummer, 2005). Plummer suggests that not only do language and narrative help sustain and create the fabric of everyday life, but they also feature prominently in the salvaging of meanings. Under conditions of hardship, people often feel a compulsion to re-examine and re-fashion their personal narratives in attempts to maintain a sense of identity. Therefore, in telling life stories to ourselves and to others, we seek to bring order and meaning to our involvements in the world (Bury, 2001; Frank, 1995). For example, Richard Taylor (2010), one of the selected authors in the data set, said of himself and the purpose that lay behind his desire to tell;

> ‘Yesterday, a physician friend of mine asked if I would join him in speaking to the American College of Physicians. Of course, I jumped at the opportunity. It is a personal goal of mine to show them one of the newly discovered faces of Alzheimer’s disease-early-onset, early stage-to as many physicians as I can before I lose the ability to communicate effectively with them. Later in the day, he sent me an e-mail confirming my acceptance and noted the place, date, and time of the presentation.’ Richard Taylor 2010; p. 28).

This quote reflects a need for stories to be ‘witnessed’ for personal changes to be brought about in response to illness. The witnessing of stories is necessary in order to bring listeners to the realms of understanding a story told (Frank, 1995). In this, the telling of stories has the power to configure the ‘self-that-I-might-be’ or even ‘what I think might make me valued by others’ (Luttrell, 2003). This perspective suggested that individuals are narrative beings who tell stories to others, which then graduate to become the story spreading from the listeners to new listeners. This suggests that narrativity is essentially an inter-personal activity. From this personal and social phenomenon, stories told by the marginalised or ‘dispossessed’, can effectively channel the routes towards subverting the status quo moulding regenerated narratives around newly emerging identities (Ewick and Silbey, 1995). This description of the narrative self is a concept that held similarities with the role of agency (Riessman, 1993) confirming that individual narratives represent the agency of the teller of the story.

Such stories can be considered agential because human agency is linked with imagination determining what will be combined with as well as excluded in the process of narrativisation (Riessman, 1993). Along with this, individuals ‘construct past events and actions in personal narratives to claim identities and construct lives’ (Riessman, 1993, p.2).

3.2.6 Narratives accounts of illness

Narratives have been indicated to possess differences from speaking about illness as they offer an uninhibited way by which emotions can be expressed without the effect on others being witnessed (Carlick & Biley, 2004). Thus, the enticement of real-life and death stories resides within the attempts of others constructing and deconstructing identities. These identity constructions can morph into new states challenging as well as provoking new realities. In discussing emergent narrative stories presented by the self, Plummer (2001) illuminated the significant shift and turn to cultural studies within the social sciences where much work focused upon narratives, storytelling and semiotics. He reiterated and refreshed Norman Denzin's viewpoint in having claimed that the domain of reporting and commenting upon no longer singularly belonged to the academic ethnographer. Instead, the domain had now been impacted by the moral life of those inspected who now wished to enrich the conversation with their own voices (Denzin, 1997). Connecting this view with that of Caplan's: 'Writing a personal narrative is perhaps worth a try because the prize is very great: that of some degree of transcendence of difference, of reaffirmation of common identity' (Caplan, 1997, p. 17), Plummer expresses these 'Warholian moment(s)' were an attempt to broaden the platform from stories and versions previously told by an elite to stories told by those whose stories previously had been silenced. These stories came from many sources. Plummer carves a demarcation between the thinking of the biomedical fraternity who believe the stories of others as symptomatic of an underlying condition and those who 'hear the story as told, as formative in its own right' (Plummer, 2001, p. 244). Those stories told through illness narratives have been regarded as empowering because they provide a space outside the domain of biomedicine for the patient voice to be heard (Hyden, 1997; Riessman, 2003). At the same time, tales told about illness have helped to mend the disruption of identity often brought on by illness (Bury, 1982; Egerod et al., 2011).

3.2.7 Narratives accounts of dementia

Whilst the multiplicity of new story worlds can become emergent through narrative methods and approaches (Plummer, 1995), Julian Hughes refers to dementia as a 'conceptual mess' (Hughes, 2003, p.17). In this, it is difficult to adopt appropriate ways to describe messy and muddled fields 'because simple clear descriptions don't work if what they are describing is not itself very coherent' (Law, 2004, p.2). Stories of dementia may conflict therefore with prior views held where stories of PwD have not commonly been heard. Nonetheless, the competing tensions between the telling a new story which may be difficult to hear and make the possibility of researching illness narratives one worth investment within the research fields.

Based on the use of narrative accounts in illuminating the experience of living with other illnesses (Bury, 1982; Frank, 1995) illness narratives seemed suitable to encompass the broad questions of this study into lived experience of PwEOD. The analysis of autobiographies of PwD is not yet commonplace, but in keeping with this idea of person-centred approaches, the shift towards seeing the patient as a social being in the medical world has nurtured stories of PwD. These PwD have thus far begun to emerge with personal accounts of their lives. Personal narratives have been accepted in the research field as a form of case-centred research (Mishler, 1999) over several decades. This has, in part, been built upon a tradition of sociology (Mills, 1959), which has seen the approach bring focus to the intersection meeting biography, history, and society. However, many accounts located around dementia have been crafted by carers, traditionally family spouses and adult children who offered insight into their parent’s dementia (Philips, 2010; Suchet, 2011). This was due to an expectation that it would be difficult to extract useful accounts from PwD themselves. Gloria Sterin (2002) challenged this view by offering a powerful account of her dementia experience, complaining that her life felt like it had been stolen by others. She also illustrated how life could be changed due to the transformation of roles; from having to receive care from carers. In locating first-person accounts, the subjects did not represent frail-elderly people who endured complex health issues combined with dementia. (McGowin, 1993; Rose, 2003). Demonstrating the voice of PwD, these autobiographical accounts challenged their world by permitting a level of insight not before known to outsiders. Such accounts offered an opportunity to move away from third-party representations of others which were delivered in contemporary accounts by a biomedical authority with a comprehensive certainty that may not have contained a holistic perspective (Booth, 1983). Harris and Keady (2009) provided accounts of how some people touched by EOD found their voices through access to their own subjective accounts, which they termed ‘illness narratives’. They reported that limited work consideration had been given in the research field with EOD narratives authored by the self. Given the relative lack of research into the insight offered by those with EOD and their ability to be able to report on their condition, this thesis sought to gain fresh data as a contribution to the experience of living life with dementia.

Little is known about the experiences of PwEOD, with limited research having been carried out, including their perspectives (Aggarwal, 2003). This has traditionally been the case with other dementia subgroups typified in later onset groups (Kitwood, 1997). The position may have prevailed due to PwD being characterised via the dominance of biomedical perspectives. Such a perspective tended to solicit the opinions from family carers and healthcare providers on the experiences and capability of PwD (Aggarwal, 2003). It has however, been reported across the literature that incorporating the voices of PwD could assist with information about the experience of having dementia (Nygard, 2006). This based on the growing body of research spanning two decades argues that a sense of self is retained, even in the final stages of dementia (Kitwood, 1997). In keeping with this idea of person-centred approaches, the shift towards seeing the patient as a social being in the medical world has nurtured stories of PwD who have emerged with personal accounts of their lives. This thesis accords with the research perspective that suggests that valuable insider-led insights might be lost by excluding the direct experiences of PwD, which could inform other research perspectives. Personal narratives have been accepted in the research field as a form of case-centred research (Mishler, 1999) over several decades. Given the significance of dementia across the globe and the attention paid to the policy, economic, social and health impacts of dementia, this thesis sought to investigate autobiographical writing of PwEOD through published books and blog.

3.2.8 Autobiography as a form of narrative

The study of autobiography belongs to the genre of testimonial research and is situated within an interpretive research paradigm (Johnstone, 1999). It is suggested that it remains a useful but underused research technique, which promises to make substantive contributions to health inquiry and knowledge (Johnstone, 1999). This is especially the case where health research contributes to sociologically focused subjects which; (i) aim to make subjective experiences more visible and intelligible, (ii) focus upon the search for meaning across the broad existential human experience and, (iii) demand an observer’s view to accept a paradigm shift to acknowledge multiple realities lived experience (Johnstone, 1999).

One concern to address in using autobiography as data lies with the editing process. It has been suggested that researchers may risk the loss of rich data as word content may be manipulated to fit with editorial demands (Cherot, 2009). Further, the use of stories previously written for public space and debate is profitable for researchers as there is no ethical requirement for identity markers to be eliminated prior to analysing and publishing results (Cherot, 2009). It is noted that where the narrative has shown ‘cleansing’ through editing processes, including others’ intervention, the thought and word structure remain intact. This is what is required for the sake of collecting narrative data through the different methodological approaches (Cherot, 2009). One study also considered the decisions made within the writing to exclude material and ‘truths’ to make partial presentations of accounts offering richer credence to benefit the writer (Becker, 1997). The author did not distinguish between the difference of autobiographical accounts in text to data extracted through interview where the interviewee has ample scope to withhold and present an account comfortable and sense-making to them, which forms a type of editing within the internal thinking processes (Becker, 1997). This offered evidence that the written, edited and published word is still appropriate to analyse in accordance with qualitative methodologies.

More recently, autobiographies written by those living with illness have been shown to represent readily available sources of data (Ravenek, 2017). A small but extant amount of data have provided researchers with data as already produced (Charmaz, 2006), and such data has been used to resolve research questions. Some research therefore, is underway to study those texts already in free public circulation (Charmaz, 2006; Page and Keady, 2010). These form an important source of data drawn from books on conditions reported by the self (Glaser and Strauss, 1967; Page and Keady, 2010). Autobiographies form a different source from biographies or sources of data derived from specific questions posed to that person, such as in an interview (Ravenek, 2017). The story told by the author in their own words is therefore independent of the intervention and direction of a researcher or interviewer and represents a raw and direct account (Ravenek, 2017).

3.2.9 Blogs as a form of narrative

Data from a wide diversity of blog genres have emerged since the blogging era began in the nineteen-sixties. Blogging currently fulfils a role within personal diary writing, a forum for the discussion of social media, for political debate, journalistic comment, the pursuit of personal causes and a general means by which a variety of media such as text, pictures and videos are deployed to mediate bloggers' thoughts. Blogging bypasses such formal restrictions. Whilst it enjoys very contemporary research attention blogging provides researchers with a medium to study instinctual conduct displayed by research subjects. Preconditions to researching online data are; that the subject can use the internet, that the researcher can access the necessary content for research and that qualitative research is suitable as opposed to, for example, quantitative research. Personal blogs are most common (Herring et al., 2004) and serve as a 'middle space' to mediate thoughts and beliefs where other avenues and media would otherwise make such potential wide broadcasting possible.

Although expressive writing in medicine has been researched over the past decades, the digital communication platform of the internet has expanded the ability to express emotional experiences of pain or illness to a larger, immediate audience. These experiences are not only expressed but shared and commented upon by others. Use of Internet-based tools such as blogs allows this expression to take place (Pennebaker, 1997). Illness blogs allow individuals and kinship carers a valuable forum in the exchange of ideas, experiences, knowledge and the formation of new relationships (Heilferty, 2009). Contemporary research has not yet uncovered the meanings and unique attributes of blogs which distinguish this type of storytelling from more traditional narratives of illness (Heilferty, 2009). Therefore, it is suggested that within the relatively unexplored recent concept of illness blogs, much might be learned through research on the subjective experience during illness experiences.

3.3 Data analysis

One of the most challenging aspects of carrying out qualitative research resides with the analysis of the data (Priest et al., 2002). Data analysis comprises of the interpretation and classification of linguistic material. The goal is to make both explicit as well as implicit dimensions or structures of meaning-making in accordance with the subject of study (Flick, 2014). I sought to research the most suitable methodological approaches which would provide the best 'fit' for my study. These did not fulfil an exhaustive list of possible approaches but includes approaches that may be considered in order to fulfil the aims of my study and which were repeated as researcher techniques in the studies that I read and researched. The data analysis techniques which were considered in making a choice were as follows; grounded theory, IPA (interpretative phenomenological analysis), narrative analysis, and TA (thematic analysis).

3.3.1 Grounded theory

Grounded theory is a popular qualitative approach (Glaser and Strauss, 1967), with its conceptual orientation in symbolic interactionism (Blumer, 1969). It is a familiar analytical tool in health studies and for nurse researchers. Data is collected in the natural context using a variety of methods such as interview and observation. Grounded theory aims to generate theory through the examination of data in subject areas that may be difficult to access with traditional quantitative research methods (Rennie et al., 1988). It prefers the use of research question which resides around an interest in social processes and what influences certain phenomena. Also stressed in the method are specific methods of data collection, such as qualitative interviews followed by a set of analytic procedures. These procedures assist with theory building. This theory building is accompanied by the researcher's prior expertise in the field. However, this expert knowledge is not used to set up a preformulated hypotheses that the research then seeks to verify. Theory building is understood to be the main aim of grounded theory (Urquhart et al., 2010). Glaser and Strauss (1967) however, forged a new development in 1967 stating that the researcher did not aim to approach reality as a 'tabula rasa' (clean slate) but should instead hold a perspective that will assist with the abstraction of significant categories from the data. This prompted researchers following in the field to speak of the difference between having an open mind but an empty head (Dey, 1999).

Since their publication in 1967, Strauss moved away from joint formulations with Glaser and developed grounded theory in a different way. The main difference lay with the identification of broad research questions which could be identified prior to the study which was informed by personal experience and the available literature. This allowed for subsequent stages to be more guided. Strauss also introduced the concept of 'axial coding' as a means by which the organisation and development of categories.

The emergence of constructivist grounded theory was a later development accounting for the role of others as constructors of events. This meant that data from which the theory develops is seen through the eyes of participants, and again, through the eyes of the researcher. This describes a co-construction between researcher and participant. (Charmaz, 1990). This accepts the researcher as bringing with them, a general perspective of their discipline, previous experiences in the field, and their own personal history (Charmaz, 1990). Such a perspective produces a method that is transparent and more congruent with the wider qualitative tradition that the Glaserian perspective saw the researcher as a reflective tool in the process.

Glaser and Strauss (1967), invested in grounded theory as a complete methodology providing a clear structure resulting in a 'theory' grounded in data. Since its inception, many variations have been devised, and many researchers now draw upon the principles and methods of grounded theory without using the methodology in its complete form, and without aiming for a theory. For example, it is common to read of studies which have used analysis from grounded theory but have not collected data according to it, or reached a theory.

In terms of analysing and collecting data, Glaser and Strauss (1967) describe a set of systematic procedures that they term the constant comparative method. Kathy Charmaz tackled this philosophical position by integrating explicit acknowledgement of the researcher's subjectivity (Charmaz, 2005). This gave the grounded theory template a positivist approval by incorporating a constructivist revisioning (Charmaz, 2005). This underscored grounded theory's popularity with health researchers (Urquhart et al., 2010). This methodology appeared to offer my own study many benefits also. However, grounded theory supports approaches where formal or substantive theories are used in the analysis (Glaser and Strauss, 1967). My own study questions linked to an extant field of autobiography PwEOD which was comprised of a very modest and fragile data set. Therefore, to follow grounded theory study suggested a limited fit for a study based on a small field of study with little theory of EOD experiences having a prior establishment in the field.

Charmaz (2006) latterly understood grounded theory as an approach rooted in positivism which has provided much research into social processes but has often been recorded as less interested in open-ended and phenomenological questions. My study was a more solitary study having to work full time. This reason also brought me to the understanding that this methodology might not be as suitable for my study.

Charmaz's (2006) publication; constructing grounded theory (2006), provided an advanced and alternative perspective on as compared to Glaser and Strauss' original formulation articulating it as a methodology flexible enough to manage a range of theoretical perspectives:

> 'Grounded theory guidelines describe the steps of the research process and provide a path through it. Researchers can adopt and adapt them to conduct diverse studies … I view grounded theory methods as a set of principles and practices, not as prescriptions or packages" (Charmaz 2006, p.9).

This flexability implied (Charmaz, 2006) that grounded theory allowed some potential to understand how the construction of tentative themes and qualified generalisations drawn directly from the data might provide a good fit between the analysis. These claims within the analysis appeared to support proof of researcher claims which helped consistency and transparency of data content describing method and reported analysis as appearing consistent. The language and concepts used in the report are consistent with the epistemological position of the analysis. TA likewise provides for an analysis which, when worked through, can tell a convincing story about the central themes found in the data. Both Braun and Clarke (2006) advocate a good balance to be visible through the data where a balance of analytic narrative and the extracts illustrated. Those aspects gained in reading about grounded theory studies supported me to understand how the analysis process allowed for triangulation and the means by which to recheck that those subthemes were robust and consistent across the data set. These pointers and background that I gained in reading about grounded theory made me aware of positive perspectives which I could adopt and retain within the route I would eventually select.

3.3.2 Narrative analysis

Narrative analysis draws from philosophy, sociology, psychology and sociolinguistics (McLeod & Balamoutsou, 2000) in its diverse origins. Since the nineteen-sixties, personal stories have grown in the field of research (Labov and Waletzky, 1967). It is an approach which has been used to understand people's experience of health and illness (Bury, 2001; Frank, 1995). Bury (2001) carried out extensive work on narratives, principally with people with rheumatoid arthritis. He distinguished between narratives of chronic illness that tried to make sense of the experience of illness and those that address a changed self. These insights were disclosed by interviewees where discussion grew around concepts such as stigma drawn from chronic illness. It has broad appeal in its different approaches to data collection and analysis, including biography, autobiography, life history, autoethnography, life narrative and the sociology of story-telling. A narrative approach has been linked across a range of accounts drawn from an interview, of which, the content and the form of the interviewee's account and interactions with the interviewer are the focus of how the analysis occurs. A narrative approach then questions to locate e.g. 'Why is the interviewee narrating this incident in this particular way?', 'What might be the purpose of this story?' or 'Why does it occur at this point in the conversation?'. Narrative analysis has a socially responsible approach to research having analysed abortion activists (Ginsberg, 1989), divorce (Riessman, 1990), disclosure of gay children to parents, (Ben-Ari, 1995) and women's health (Riessman, 1993). Narrative research typically refers to any text or discourse focusing on those stories told by individuals. However, I was mindful that the data set included represented a body of work in published texts by a subgroup that has not yet benefitted from much exposure across research fields. This meant that I was one of the first researchers to look at narratives of PwEOD, and therefore, I sought to look across the data set for similarities and differences across the accounts. Out with this focus, narrative analysis is concerned more with wider context and underlying meanings. Because the voices within my data set represented rarely heard marginalised voices, I sought to bring their accounts into the realms of research and represent the texts in a way that remained faithful to the way the authors may have intended to be heard. Finally, in searching throughout other related studies, I noted that other research underpinned by narrative analysis was based upon interview data rather than textual data like autobiography, therefore for these reasons, this I looked towards other methods of data analysis.

3.3.3 Considering and comparing IPA and thematic analysis (TA)

Similar to grounded theory, IPA is usually understood as a fully contained methodology (Flick, 2014). Braun and Clarke imaginatively describe IPA as 'a piece of ready-made furniture' (Braun and Clarke, 2013) with all the design choices already combined and ready to install without further effort on the part of the buyer. IPA provides; the ontological and epistemological underpinnings of the research (critical realism and contextualism), the theoretical framework that informs the research (usually phenomenology), the form of research questions proposed, (usually experiences and perspectives), the sampling strategy adopted, and how data should be collected (usually qualitative interviews). It is of benefit when a wide range of research questions are asked of the experiences of others. It is a recently developed analytical tool (1990's) and draws upon conceptual ideas from phenomenology, hermeneutics and ideography (Smith et al., 2009).

Phenomenology concerns the exploration and understanding of human experience (Langdridge, 2007). The aim is to uncover the meaning of an individual's experience of a given phenomenon through focusing on a concrete experiential account grounded in everyday life, such as the experience of living with Parkinson's disease (Bramley and Eatough, 2005). Phenomenology, therefore, defines the aims of IPA, which are to uncover the essence of people's experience of a phenomenon. IPA has a dual focus on the unique characteristics of individual participants and on patterning of meaning across participants. In contrast, TA focuses mainly on patterning of meaning across participants (this is not to say it can't capture difference and divergence in data).

TA aims to identify common thematic elements across data (Riessman, 2003). It allows for the researcher to collect stories and inductively create and produce conceptual categories from the data. Regarding coding, it has features in common with IPA which refers to both 'descriptive' and 'conceptual' aspects of the text which is very similar to 'semantic' and 'latent' codes in TA. In terms of procedures for theme development, there are two levels of thematic development in IPA and one level in TA. In IPA, these are referred to as 'emergent' and 'superordinate' themes. Emergent themes are noted on the data item. Superordinate themes are then developed from emergent themes. As coding and theme development is complete for each data item, the researcher then develops superordinate themes across the entire dataset. Generally, there are typically more emergent themes generated from an IPA compared to the number of themes generated from a TA. IPA seeks to produce approximately the same number of superordinate themes as the number of themes generated from a TA. However, another difference is that superordinate themes in an IPA provides an organising framework for the analysis, and it is the emergent themes that are discussed in detail in the write-up.

In terms of analytic procedures, both IPA and TA involve coding and theme development, but these processes are somewhat different for each method. Coding in TA begins after a process of data familiarisation, in which the researcher notes any initial analytic observations about each data item and the entire data-set. The researcher then codes across all the data items. The researcher either collates the data relevant to each code as they code, or they collate all the relevant data at the end of the coding process. By contrast, coding in IPA consists of a process of 'initial commenting' or 'initial noting,' in which the researcher writes their initial analytic observations about the data on the data item (if working with interview transcripts, initial notes are usually recorded in a wide margin on the right-hand side of the transcript). These initial notes are brief commentaries on the data (rather than succinct codes). This means initial noting in IPA lies somewhere between data familiarisation and coding in TA.

Another difference is that in IPA, the researcher codes their first data item then progresses to developing themes for that data item, rather than coding across the entire dataset, and then progressing to theme development. So, IPA focuses on developing each stage of the analysis for each data item, before moving to the next; whereas TA involves developing each stage of analysis across the whole dataset.

Overall, IPA procedures help the researcher to stay close to the data because the development of codes and themes are situated on the actual data item. This allows for the unique characteristics of each individual participant to emerge. By contrast, the procedures of TA help the researcher to identify patterns across the entire data-set. IPA is a highly effective form with which to work if the data sample worked with is small and the focus is idiographic. However, TA allows a more patterned meaning to appear across the data-set. Due to the little research done in this area of PwEOD and autobiography, I selected to opt for this form of study.

3.3.4 Thematic analysis process

Thematic analysis follows a process of identifying patterns or themes within qualitative data. In the contemporary account given by Braun and Clarke in their 2006 paper, a six-phase process is recommended to be applied when analysing data in accordance with TA. They propose that there has been little clarity regarding the approach, and how it should be done in the past (2006, 2014). It has been criticised by the authors as failing to occupy the ‘named’ status that other methods have achieved for example grounded theory. This has led to confusion between ‘named’ analyses which, when examined critically, proves to be something else, for example, discourse analysis (Braun and Wilkinson, 2003). In order to bring greater clarity and rigour to the process, the authors have sharpened the focus of research process with TA. Their proposed six step process is as follows:

Table 6: Six phase steps in thematic analysis

Phase	Describing the process
Familiarising yourself with your data	Reading and rereading the data, noting down initial ideas
Generating initial codes	Coding potentially meaningful features of the data systematically across the entire data set
Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
Reviewing themes	Reviewing themes relate to the coded extracts (level 1) across the entire data set (level 2) to generate a thematic map of the analysis
Defining and naming themes	Ongoing analysis refining the specifics of each theme and the overall story drawn from analysis generating clear definitions for each theme.
Producing the report	The final analysis of selected extracts, relating the analysis to the overarching components of the study to ensure cohesive completion producing a scholarly report of the analysis

Braun & Clarke (2006) state TA should be considered as a useful tool as ‘it provides core skills that will be useful for conducting many other kinds of analysis’ (Braun and Clarke, 2006, p.78). Braun and Clarke stress how TA is likened to the researcher building their own furniture rather than a ready-made kit which other approaches appear to offer to the authors (2013). The benefit to this is the freedom and flexibility offered across the epistemological and ontological spectrum for researchers to use. TA can be realist or constructionist and address a wide range of research questions of people’s experiences and perspectives. It can provide a method to identify, analyse and report the thematic patterns across data sets offering a comprehensive as well as transparent process for researchers to demonstrate explicit research processes. It can help seek latent or semantic themes within any data set. Semantic themes relate to those explicit within the text. Latent themes refer to identifying themes underlying ideological ideas contained within the texts. Beyond this, it can interpret many aspects of the research topic (Boyatzis, 1998). TA also is suitable for most types of qualitative data, including interviews and textual data found in diaries and autobiography. Its potential strength for the study was an ability to provide a robust and systematic process for coding qualitative data. This process then allowed for linking identifying patterns in the dataset in common with the research question. There is relative freedom left to the interpretations made from the patterns, which will allow me to look at the resulting themes through a variety of theoretical lenses. It is recognised by the authors as being a ‘toolkit for researchers who want to do robust and even sophisticated analyses of qualitative data. However, this approach still allows a focus to present thematic results in a way which is readily accessible to those who aren't part of academic communities’ (Braun and Clarke, 2014, p. 2). This has been shown to be helpful in health research where levels of practicality are required, particularly in policy or practise, which health care often is situated.

Autobiographical writing was the chosen route of study to gain a close-up view of the subjects in the study, PwEOD. TA provided a means by which the autobiographical dataset could be analysed, allowing coherent and meaningful patterns in the data to be realised. This was applied through inductive TA themes and subthemes being drawn from the data. The data was viewed through a constructionist lens rather than realist thus supporting the recognition of the latent themes. The authors make a distinction between latent and semantic themes. However, as semantic refers to views superficially or practically spotted by the lay people as well as the researcher, this did not represent the only way the study was approached. By taking an inductive, constructionist approach latent themes were also drawn across the data set in order to gain the richest picture across a collection of diverse voices experiencing similar experiences. Therefore, this method was selected as it is best suited to exploring and presenting testimonies of lived experience of dementia.

3.4 Methods

3.4.1 Ethical approval

Ethical approval was not required as the data were in the public domain (Ravenek, 2017). In other studies, researchers were reported to have taken a variety of approaches to ethical concerns, including either concealing or revealing the authors of the works they studied. These decisions were dependent upon the need to maintain privacy and the need to attribute copyright rightfully to the material. Current ethical opinion reflects that policies from a variety of sources confirmed that none is required to use publicly available or published data (O'Brien and Clark, 2010). As narratives form an author's intellectual property, this should be recognised in the use of data sets (O'Brien and Clark, 2010). The use of the blog content was deemed appropriate, given that her autobiography was not going to be available until after thesis submission. In the interests of good practice; however, ethical approval was nonetheless sought from Abertay University. The study was approved with no issues (see appendix 6).

3.4.2 Sampling

The approach taken towards the data set and the condition of EOD was enshrined in the principles of autonomy, beneficence, and justice (Orb et al., 2001). This study reflected standard guidelines for researchers which addresses the initial and ongoing ethical issues between the needs and goals of the research which include the rights of any participants, including those who have authored a secondary data source. There was a concern to adopt a just approach grounded in unconditional positive regard (Mann et al., 2004). This approach helped underpin the rationale by which the data was collected. Ways were sought to locate approaches that did not contravene the researcher's own personal beliefs as a Quaker; seeing all people through radical spiritual egalitarianism. This meant that there was a concern to avoid seeing others through a power and privileged position. This was why this approach was taken in the study of autobiographies under investigation.

3.4.3 Data collection

3.4.3.1 Inclusion

This study included autobiographical writings of PwEOD, each of whom had an official diagnosis of dementia. The study aim was to elicit the direct experience of PwEOD in their own words as far as possible. Each writer explicitly related the fact of diagnosis across their writing. This may have been because the event represented a critical point from which to discuss their condition. Some scholars have argued that a diagnosis of dementia impedes the ability of individuals to construct coherent narratives of the self. Due to fluctuating awareness, PwD have difficulty making sense of what is happening to them, affecting their ability to construct coherent identities (Phinney, 2002). As symptoms intensify, the presentation of an illness narrative can become further disruptive and chaotic (Frank, 1997). Elsewhere, other researchers have suggested that individuals with dementia do not lose their sense of self or ability to narrate in the early stages. Instead, they construct biographical work to maintain and preserve aspects of their identity. MacRae (2009) utilised a symbolic interactionist framework to argue that PwD constructed narratives of self that could preserve and protect identities from the threat of loss of self. Elsewhere, authors of another study found that diagnosed individuals actively used emotion-oriented and problem-solving coping strategies to manage the challenges of dementia (de Boer et al., 2007). This study, therefore accepted that content might have been supported by family members and the editing of publishers. English speaking texts only were included in order that no translation was required, which adds an extra level of interpretation to the data. The content specifically included four autobiographies and one blog. The cognitive abilities of the data set were not an issue as the nature of published texts already meant that they had passed editorial scrutiny as reaching a standard as a marketable product. The principles driving inclusion criteria were to acknowledge diversity and inclusion, but this had to be managed given the paucity of autobiographies written by PwEOD. A mix of male and female, geographical location, diversity of life experience and working background and style of expressing themselves with their health condition were sought for inclusion also.

3.4.3.2 Exclusion

Texts which did not explicitly claim that an official diagnosis had been made were excluded. This was explicitly noted in the literature, allowing me to understand whether this requirement had been met. Texts written by family kin or carers were excluded as whilst they reflect valuable experiences and insight; they do not offer the same lived experience and insight as desired from PwEOD. Additionally, any texts which were significantly contributed to by others were excluded. The authorship of autobiographical content was typically described in the description of the text. Often the inclusion of a spouse or ‘ghost’ was outlined in the text and therefore illuminated how little existed of a data set wholly written by the PwEOD. Internet searches, websites such as Amazon, Alzheimer’s UK and reading reviews all were helpful beyond academic journal searches in order to find titles.

3.4.3.3 Data collection method and approach

To locate autobiographies of PwEOD, English book titles on Google and Amazon.com were searched. The phrases used were ‘dementia autobiographies’; ‘young onset dementia’; ‘early-onset dementia’, ‘writing about dementia’.

Five autobiographies written by PwEOD were located. One additional book written by Kate Swaffer had not been published by the time I had completed data search. The date of publication was planned for six months beyond the planned data collection and analysis period. In fact, this date was further extended again postponing the publication of the book. I managed to contact the author and she suggested the study of her blog. After some consultation with the author over her publication date, it was decided to include her blog, which constituted a suitable and interesting approach to take alongside the four other autobiographies. The available texts for potential selection appear in the Appendix 1. Of what was available, only one other was excluded as it formed the second published book by one author already included in the data set. Therefore, four autobiographies of PwEOD were selected alongside one blog after reviewing the available emergent literature on blogs and illness blogs.

All authors including in the dataset were white, Western and wrote in English. After purchase and daily reading of the daily online blog, the texts were read once to ensure that the body of work would be of sufficient number, length and content for a doctoral thesis. These constituents were judged to be suitable as the writers within the data set were able to write to a published standard independently, and all had an official clinical diagnosis of EOD. The data selection below (tables 6 & 7) outline the final data set.

Table 7: Data selection (books)

Name	Title	Career	Year	Diagnosis	Age	Gender	National origin
Christine Bryden	Dancing with Dementia	Senior	2005	YOD	46	Female	Australia
Richard Taylor	Alzheimer's from the inside out	psychologist	2006	Alzheimer's	58	Male	America
Tom di Baggio	Losing my mind-	Herb grower/journalist	2003	Alzheimer's	57	Male	America
Richard Davis	My journey into Alzheimer's Disease	Pastor	1984	Alzheimer's	58	Male	America

Table 8:Data set (blog)

Name	Title	Career	Year	Diagnosis	Age at diagnosis	Nation
Kate Swaffer,	Creating life with words: inspiration, love and truth https://kateswaffer.com/daily-blog/	Nurse/conference speaker	2009	Dementia	49	Australia

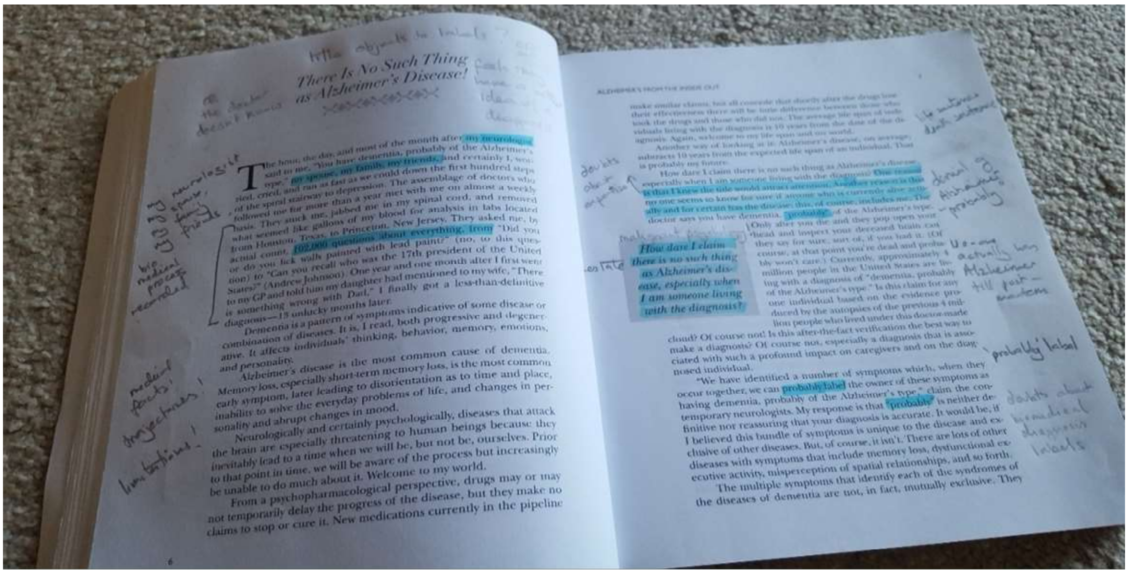
3.5 Data analysis

3.5.1 Thematic analysis

3.5.1.1 Reading and familiarising by immersion in the texts

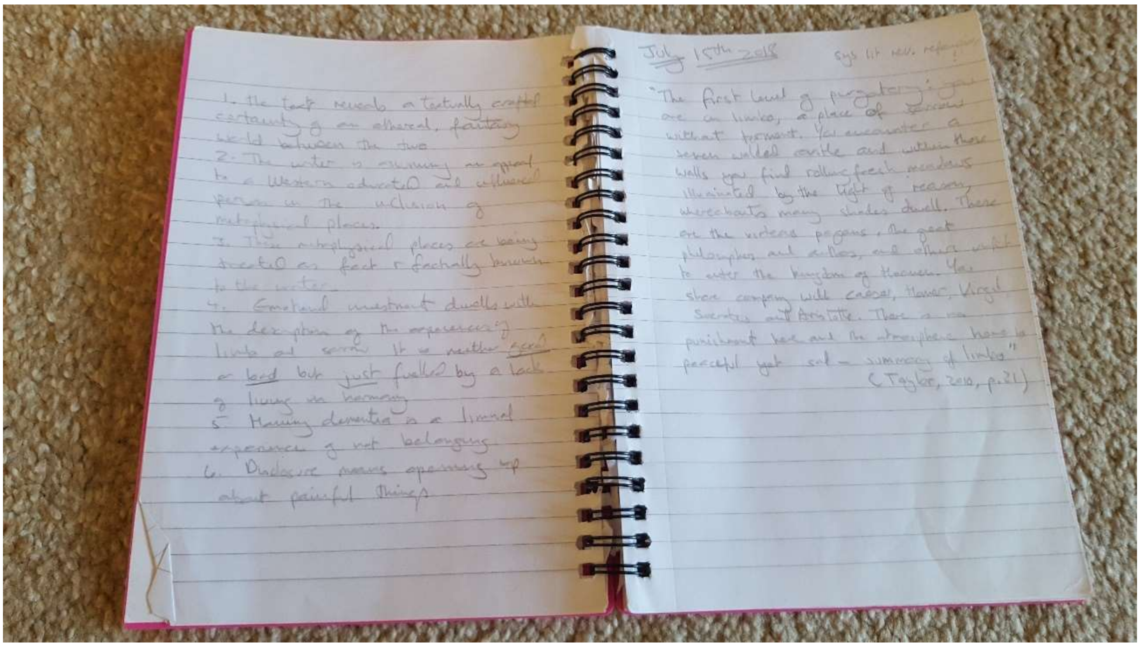
In keeping with all forms of qualitative analysis, the first stage of data analysis involved immersion in the data by reading and rereading the four books and blog. The initial reading had occurred prior to final data collection decisions to include the material in the data set. The first reading took place as a naive researcher, meaning there was a concern to avoid the concreting of researcher views before immersion with all the data set and repeated reading. However, mindful notes were kept with marker pens and pencil notes throughout the texts to make further reading more familiar (see figure 2 below).

Figure 3 – Memorable jottings



Following this, field notes as preliminary jottings based upon reading were created. Preliminary words or phrases for codes which could be framed as analytic memos were noted with the understanding that such memos at a later point may alter in importance in the analytical coding. Such ideas at that point did not have to be finalised or set in stone however, they helped implant more progressive thoughts as my reading continued. By making and retaining a coherent record of thoughts on potential codes, this helped to highlight items potentially of interest as well as helping the reading for codes as opposed to merely being a reader of a good book. Reading data in this way helped with the process of reading critically and analytically. This way supported the avoidance of taking on the opinions of the writer in each text. Figure 3 below illustrates a brief example of the content of field notes which were initially kept in a book for this purpose.

Figure 4 – Early ideas for themes



1. The text reveals a textually crafted certainty of an ethereal, fantasy world between the two
2. The writer is assuming an appeal to a Western educated and affluent person in the inclusion of metaphysical places.
3. These metaphysical places are being treated as fact & factually known to the writer.
4. Emotional investment dwells with the description of the experiences of limbo and sorrow. It is neither good or bad but just fuelled by a lack of living in harmony
5. Having dementia is a liminal experience of not belonging.
6. Disclosure means opening up about painful things

July 15th 2018 Sys lit rev. [illegible]

"The first level of purgatory: you are in limbo, a place of sorrow without torment. You encounter a seven walled castle and within these walls you find rolling fresh meadows illuminated by the light of reason, whereabouts many shades dwell. These are the virtuous pagans, the great philosophers and authors, and others unfit to enter the kingdom of Heaven. You share company with Caesar, Homer, Virgil, Socrates and Aristotle. There is no punishment here and the atmosphere here is peaceful yet sad – summary of limbo"
(Taylor, 2010, p.21)

Being able to make jottings of this type helped to reveal rich material for analytical findings in Chapter Four. Whilst not every line produced ideas worth noting, this was not an issue. In fact, this offered a more objective and sometimes abstract landscape with which to see the codes emerge. What emerged was textual chunks which began to suggest possible ideas for themes or inter-connecting subthemes. This phase helped in creating familiarity and intimacy with the data so that notes would eventually realise a coherence with the research question. At this stage, the data set was read twice. Braun and Clarke (2006, 2014) state how a theme captures a common, repeating pattern across an entire data set which clusters around a central organising concept. However, a theme tends to give a description to different facets to a singular idea which demonstrates the theme's pattern across a data set. Therefore, overarching ideas were created in the jottings, but there was a deliberate effort to prevent a drift towards fixed concluded thematic ideas. Thus note-making remained observational without applying any systematic process. The guiding instinct was to allow a detached stream of creative consciousness rather than willing the data analysis to reach completion before it naturally worked through the TA principles.

3.5.1.2 Generating initial codes

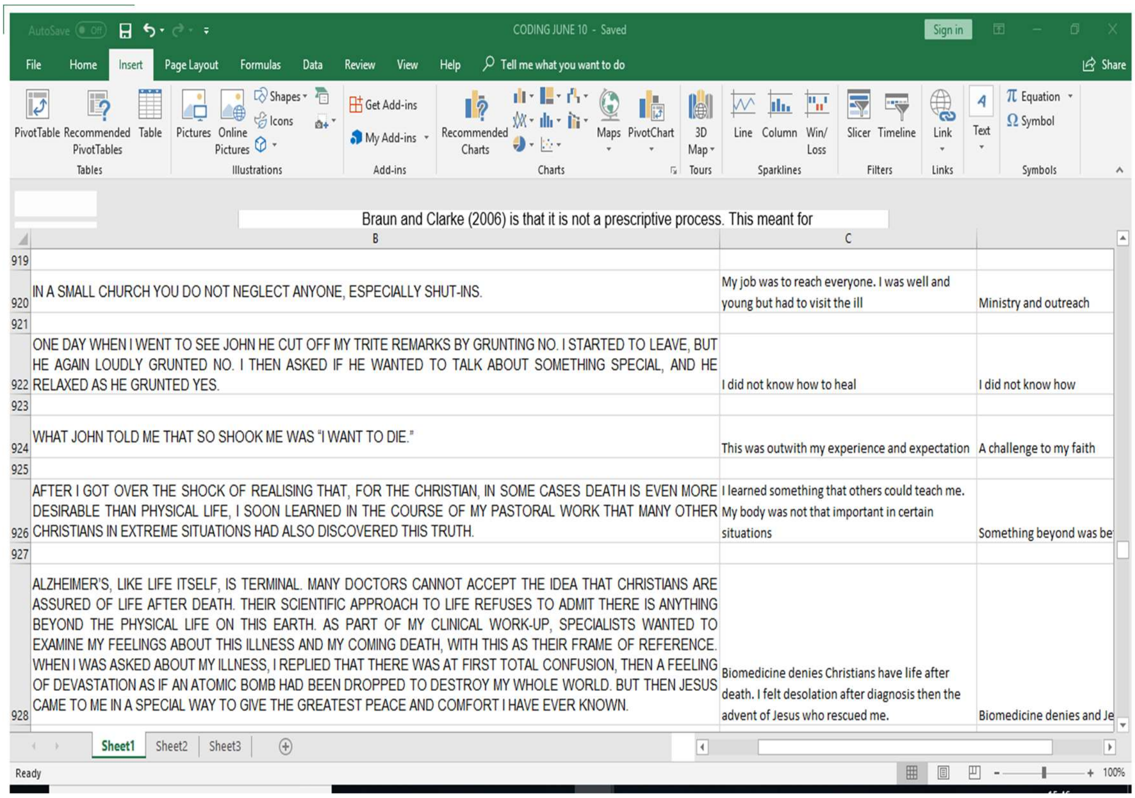
In this phase, the organisation of data were set out in a meaningful and systematic way which would make each step ahead coherent. Coding, as a process reduces large chunks of data into smaller chunks of meaning. It was the case that through thinking thematically, the codes could have been organised as data-driven or theory-driven. Whilst the study questions were kept to the forefront throughout the TA, the aim of allowing the data to emerge from the texts was retained, therefore the study took a more inductive approach as opposed to a theoretical one. The main reason for this was that the data studied was unknown prior to beginning research and reading, and there was no hypothesis involved. Assumptions on PwEOD were not appropriate for this type of qualitative study which had indicated throughout Chapter Two that the data set had benefitted from a modest amount of research. For this reason, an inductive approach was taken. It was also the case though that from the data-driven themes, confidence grew with time and experience because evidence through coding did not contradict the prior SLR in Chapter Two and this helped fuel more confidence in the material uncovered and collating in the analysis process.

Each segment of data that captured something interesting about the research questions was included for coding. At this stage, the texts became more familiar, and it became easier to support and identify labels for potential data later in the analysis. Braun & Clarke (2006) distinguish between two levels of themes: semantic and latent. Semantic themes '…within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said or what has been written.' (p.84). The analysis in this study identified themes at the semantic level, which were uncomplicated to observe as explicit themes. As these were studied and considered, it was possible to regard the analysis as more than description. Instead, it became possible to interpret the ideas. Thus, it became natural to observe the latent level looking beyond what had been written as it started'…. to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies - that are theorised as shaping or informing the semantic content of the data' (p.84). Once the explicit level of understanding through the semantic meanings was established, the search scanned the data for more latent underpinning material through inductive processes.

Latent codes focus less upon explicit information allow for a deeper thematic meaning (Braun and Clarke, 2006). In rereading the data, early ideas from initial jottings provided the coding process with interpretive meanings from the data content. In coding this meant, based upon the continuing example used above, a coding theme of ‘living in limbo and difficulties in telling about the inner world of dementia’ offered a conceptual interpretation of what underlay the text. This may not have been the intention of the writer to expose this theme, however, but the account was interpreted through this framework (Adam, 1998). It was accepted that the codes could be interim and subject to change further along the process.

How to manage coding is a personal matter (Braun and Clarke, 2014), but it is worthwhile spending time prior to working through analysis how this should be approached. Therefore, I took some courses through the academic librarians on NVivo alongside many other researcher skill courses. However, as the analysis progressed, both jottings in paper journals and computer notes were used. After training with NVivo to the extent of comfortable familiarity, there was doubt over its limitations in being able to adapt from early ideas of the data set moving between paper jottings with pencil and marker pens to electronic recording. This was the preferred way of working with the text in hand. Knowing that levels of coding would alter and mature, a selection of file cards in a box with headings was kept, and the themes were manually noted in the early stages. This was also backed up with Excel coding (see figure 4 below for data sample). One manual process instigated the electronic process as thinking continued and matured working between the manual reflective process to the electronic database. This is also supported by Braun and Clarke’s (2006) approach to coding. The physical act of coding is flexible, provided it complies with being inclusive, comprehensive, and systematic. As coding continued, the existing codes were modified to advance the coding process and incorporate new material. At this point, early coding was consolidated, and the phase was complete. This completed the data capture and both the diversity and patterns reported in the data could be understood.

Figure 5 – Coding sample



Braun and Clarke (2006) is that it is not a prescriptive process. This meant for

	B	C	
919			
920	IN A SMALL CHURCH YOU DO NOT NEGLECT ANYONE, ESPECIALLY SHUT-INS.	My job was to reach everyone. I was well and young but had to visit the ill	Ministry and outreach
921			
922	ONE DAY WHEN I WENT TO SEE JOHN HE CUT OFF MY TRITE REMARKS BY GRUNTING NO. I STARTED TO LEAVE, BUT HE AGAIN LOUDLY GRUNTED NO. I THEN ASKED IF HE WANTED TO TALK ABOUT SOMETHING SPECIAL, AND HE RELAXED AS HE GRUNTED YES.	I did not know how to heal	I did not know how
923			
924	WHAT JOHN TOLD ME THAT SO SHOOK ME WAS "I WANT TO DIE."	This was outwith my experience and expectation	A challenge to my faith
925			
926	AFTER I GOT OVER THE SHOCK OF REALISING THAT, FOR THE CHRISTIAN, IN SOME CASES DEATH IS EVEN MORE DESIRABLE THAN PHYSICAL LIFE, I SOON LEARNED IN THE COURSE OF MY PASTORAL WORK THAT MANY OTHER CHRISTIANS IN EXTREME SITUATIONS HAD ALSO DISCOVERED THIS TRUTH.	I learned something that others could teach me. My body was not that important in certain situations	Something beyond was be
927			
928	ALZHEIMER'S, LIKE LIFE ITSELF, IS TERMINAL. MANY DOCTORS CANNOT ACCEPT THE IDEA THAT CHRISTIANS ARE ASSURED OF LIFE AFTER DEATH. THEIR SCIENTIFIC APPROACH TO LIFE REFUSES TO ADMIT THERE IS ANYTHING BEYOND THE PHYSICAL LIFE ON THIS EARTH. AS PART OF MY CLINICAL WORK-UP, SPECIALISTS WANTED TO EXAMINE MY FEELINGS ABOUT THIS ILLNESS AND MY COMING DEATH, WITH THIS AS THEIR FRAME OF REFERENCE. WHEN I WAS ASKED ABOUT MY ILLNESS, I REPLIED THAT THERE WAS AT FIRST TOTAL CONFUSION, THEN A FEELING OF DEVASTATION AS IF AN ATOMIC BOMB HAD BEEN DROPPED TO DESTROY MY WHOLE WORLD. BUT THEN JESUS CAME TO ME IN A SPECIAL WAY TO GIVE THE GREATEST PEACE AND COMFORT I HAVE EVER KNOWN.	Biomedicine denies Christians have life after death. I felt desolation after diagnosis then the advent of Jesus who rescued me.	Biomedicine denies and Je

One major goal in the early jottings' period was a need to keep in mind the questions the research sought to answer. A feature of TA as propounded by Braun and Clarke (2006) is that it is not a prescriptive process. This meant that whilst the data was read repeatedly, there was no demand to produce codes for every line of data. In fact, provided the coding was based upon a thorough reading and applying the six phases with as much sincere focus as possible, there was versatility in how much was gathered from the chunks of data. At this stage, phase three was approached but alongside keeping interplay in my head with notes and potential changing ideas.

3.5.1.3 Searching for themes

After coding and collating had been identified, the analytical lens was refocussed at a broader, overarching level of themes as opposed to codes. Potential themes on a Word document were listed to be printed off and adjusted with coloured pencils. Through this process, the codes helped to form overarching themes. The collected content was divided into themes from which sub-themes were linked and the extracts of data were accorded to them. Whilst the significance of the themes was beginning to form according to the findings, no themes were dismissed. These remained until fresh review took place in detail to determine whether any of the themes required to be reconfigured and allotted elsewhere. At this stage, the process of reading and re-reading helped structure develop an interpretation of the following theme development through immersion in the data (Cohen et al., 2000). Through the repeated reading of the transcripts, this supported a process of reflective thinking, and a gradual sense of the hidden meanings of the narratives began to emerge. Streubert and Carpenter (2011) relate to this as interpretive reading. Codes were reviewed, both the overarching ones and those linked as sub-themes to the broader codes. When these had all been amassed, considered and reconsidered, the thematic map of the analysis was completed. Finally, notes were gathered into an order where the common ground in each sub-theme section could be seen (see figure 5 below). This phase reached completion once the overarching themes enabled a picture of the thematic strands that the PwEOD provided in the data set.

3.5.1.4 Reviewing themes

Braun and Clarkes (2006, 2014) recommend at this stage of the phased steps the adoption of a selection of candidate themes. This phase involves a recursive process whereby the developing themes are reviewed and renewed the coded data and entire data set. Potential themes were compared against collated extracts of data and sought to pursue suitable themes across the whole data set. Should any potential themes not fit, it may be that boundaries must be redrawn or relegated for the time being. This was an issue for some of the codes and potential themes as some of the codes appeared to offer great similarity making decisions over categories difficult to see. For example, the theme of losses for PwEOD could be realised in other sections under slightly different themes. It could be understood as stigma with the loss of status, or equally, losses could be understood as zombieism, which was described as a voided person with no mind. This equally could be understood as a loss; of person, position, human contact and acceptance. However, after moving around the associated sub-themes and codes, they began to gel under broader candidate themes. However, through repeated reading and rechecking, this bolstered reflective thinking and helped to reach a gradual awareness of the hidden meanings within the narratives. Streubert and Carpenter (2011) refer to this as ‘interpretive reading’. Acknowledging this, the codes were reviewed, and parent codes more firmly established a thematic map of the analysis.

Two levels are suggested at this stage. Level one involves reviewing at the level of the coded data extract, so all the collated extracts for each theme were reread and considered as to whether they appeared to form a coherent pattern which allowed progression to level two. Level two provided a similar process to follow to check that the candidate themes accurately reflect the data set. At the end of this phase, the themes appeared consistent fitted together well in the context of each sub-theme.

3.5.1.5 Creating definition and the naming of themes

With a satisfactory thematic map of the data defined and refined, the themes were able to be presented for analysis. The essence of each theme was captured so that a story could emerge from the thematic identity. At this stage, a narrative began to emerge around the stories from coherent and internally consistent accounts. Braun and Clarke (2006) maintain that a theme should capture something important about the data in relation to the research questions and represent something of a patterned meaning within the dataset. It is therefore, necessary to assess how typically a theme might appear across a dataset. The frequency of the theme repeating does not automatically indicate that it shares the same importance as another (Braun & Clarke, 2006). This is because in qualitative analysis, the significance of a theme is reflected in the extent to which it ‘speaks to’ the theoretical position in-keeping with the overarching research questions. For each individual theme, a detailed analysis was written. As part of the refinement, themes were checked for overlap with sub-themes. Finally, themes’ working titles were added in the interim period. These were as follows; Negative Tropes, Diagnosis, Stigma, Losses and the Power of Protest (see figure 5). To support the analytical process, Braun and Clarke cite a fifteen step list supporting researchers throughout the six phases in the appendices was checked throughout stages (appendices 3 and 4).

Figure 6 – Coding categories

3.5.1.6 Producing the report

Although the final phase of TA lies with the production of a report, I did not understand the final write up to be a phase that only began at the end. The process of writing and analysis are thoroughly interwoven in qualitative research especially within the TA tradition of Braun and Clarke (2006, 2014). The purpose of my report aimed to provide a compelling story about what I found and articulated throughout the analysis chapters. The aim of the final report is for it to be read like a story in that it should be convincing but illuminating including, the complexities of fresh insight. I understood that themes were not ‘emerging’ from the text and respected my input as a researcher which meant my involvement demonstrated subjective interpretation. The order of themes presented was connected in a logical and meaningful way building upon previous themes which provided a means from which to tell a coherent story about the data. Approaching the analysis and writing in this way was a more intuitive and interesting manner in approach to the generation of new data and being able to relate it to the reader.

3.5.1.7 Rigour of the data

As qualitative study gains more ground in health research, it is of importance that matters of rigour provide researchers in qualitative fields with methodical means to yield meaningful and useful results. In order to do this, there must be a robust demonstration that the data analysis has been produced in ways that expose precise, consistent, and exhaustive processes. These inevitably involve the recording and systematic disclosure of methods of analysis, reflecting enough detail to enable the reader to determine levels of credibility of the overall process. Although there are numerous examples of how to conduct qualitative research, few sophisticated tools are available to researchers for conducting rigour and relevance as in this study, TA. Because the value of any research, qualitative or quantitative endeavours lies with an evaluative process (Krefting, 1996), traditionally positivistic quantitative researchers find rigorous and explicit description of methods within their methods to explain their results (Payton,1979).

Schmid (1981) proposes that qualitative research performs a study of the empirical world but from the viewpoint of the person under scrutiny. Two principles govern those underlying; that behaviour is influenced by the physical, sociocultural, and psychological environment, thus providing the means for naturalistic inquiry and secondly that behaviour extends beyond what is observed by the inquirer. Subjective meanings and perceptions of the subject provide the focus in qualitative research, and it is for the researcher to access these. Agar (1986) suggests that the terms, reliability and validity are relative to a quantitative lens and fail to conform to fit the demands of qualitative research. However, in some qualitative approaches, the aim is to generate hypotheses for future investigation rather than to test them (Sandelowski, 1986). Therefore, this means that external validity is less of an issue and, as such, Agar (1986) proposes a different language for a qualitative view. This language must replace reliability and validity with qualitative values such as credibility, the accuracy of representation and authority of the writer. Thus, the goal is to describe the experience of the phenomenon accurately under study and not to generalise to theories or models (Field & Morse, 1995).

Nonetheless, Thorne (2000) added that data analysis represented the most complex phase of qualitative research, but one that can suffer the least thoughtful discussion in the overall study process. Both qualitative and quantitative research set out to be conducted in a systematic approach which can be transparently communicated to others (Malterud, 2001; Sandelowski, 1995). Qualitative researchers in the past have often been exposed to having failed to provide a detailed description of how analysis is conducted within published research reports (Tuckett, 2005). With special regard to TA. Braun and Clarke (2006) have argued that researchers must have a clear vision of what and why they are doing it which will within the rigorous form, include a clear description of analysis methods (Braun & Clarke). In other words, if readers are not clear about how researchers analysed their data or what assumptions informed their analysis, evaluating the trustworthiness of the research process is difficult.

Much literature exists about grounded theory, ethnography, and phenomenology but less has been commented upon in respect of TA. Lincoln and Guba (1985) refined the concept of trustworthiness by introducing the criteria of credibility, transferability, dependability, and confirmability to parallel the conventional quantitative assessment criteria of validity and reliability. The procedures for fulfilling the trustworthiness criteria are familiar within a research body with expansive differences in epistemology and ontology, as they rely on methodological arguments and techniques (Green, 2000). While others have more recently presented expansive and flexible markers of quality in qualitative research in many different approaches (Tracy, 2010), I elected to retain the well-trusted and widely accepted criteria introduced by Lincoln and Guba to demonstrate trustworthiness in my study. This choice helped support a pragmatic choice as I was concerned to represent each writer in my findings credibly as important stakeholders with the power through their words to inform on the lived experience of living with EOD. These trustworthiness criteria will be briefly defined to describe the robust processes involved in conducting a trustworthy TA study.

Speaking of one of the four corners of the rigorous process of qualitative analysis, Guba and Lincoln (1989) claimed that the credibility of a study was concluded when readers confronted with the experience found it to be recognisable. As such, credibility addressed the ‘fit’ that should exist between those representing the data; the personalities of the voices, that of the researcher between respondents’ views and the researcher’s representation of them (Tobin & Begley, 2004). Lincoln and Guba (1985) provided ideas around addressing credibility, including activities such as prolonged engagement with the data and persistent checking of the data collection and analysis. Checking had to be done by extensive reading of previous studies as I had not supervisory team or colleagues with whom to discuss or provoke greater insight (Lincoln & Guba, 1985).

The second aspect of rigour refers to transferability as a part of the generalised nature of the inquiry. In qualitative studies, the researcher is blind to knowing appropriate sites with which to transfer the findings. Nonetheless, this still allows for the researcher to be responsible for providing thick descriptions. By investing in the process of transferability, the researcher can judge their success (Lincoln & Guba, 1985). The third component resides around dependability. To achieve this feature of rigour, I sought to ensure the research process was logical as well as traceable and clearly documented (Tobin & Begley, 2004). This meant that when the research was examined, a better judgement could be brought to the dependability of the research (Lincoln & Guba, 1985).

Finally, confirmability concerns itself with establishing that the researcher's interpretations and findings are observably derived from the data. This level of confirmability requires the researcher to demonstrate how conclusions and interpretations are reached (Tobin & Begley, 2004). According to Guba and Lincoln (1989), they propose confirmability is established when credibility, transferability, and dependability all combine to be achieved. Koch (1994) further recommends researchers include markers that act to show the reasons for theoretical, methodological, and analytical choices throughout the entire study. This supports ways in which others may understand how and why decisions were made on the journey throughout the research. For example, the way that Noblit and Hare's seven stepped process (Britten, 2002) encompassed qualitative emotional experiences accorded with the later inclusion of the qualitative nature of Braun and Clarke's prominent papers (2006, 2013) on TA to bring the 'truths' of the contributors in the data set to the fore.

In summary, rigour was addressed by documenting and discussing each step taken and illustrating the philosophical underpinnings which supported them. This was done whilst seeking compatible processes which addressed any concerns about trustworthiness and reliability. Procedures were undertaken at all stages of the study to reflect dependability of the study. Other checks were implemented by reviewing

Braun and Clarke's (2006, 2014) TA phased stages of data analysis. These processes reflected the approach to the rigour of the study.

3.5.1.8 Reflexivity

Qualitative analysis, in its purest form is led by inductive approaches (Strauss & Corbin, 1998). It forms inductive analysis which shows patterns, themes and categories of analysis that emerge from the data rather than having views imposed on them prior to data collection and analysis (Patton, 2002). These are driven by what the inquirer wants to know and how the inquirer interprets what the data informs others. This fresh information will manifest according to subscribed theoretical frameworks, subjective perspectives, ontological and epistemological positions and intuitive understandings. This approach adopted the use of TA and was in keeping with a social constructionist lens. This approach allowed the social and emotional relation to the subjects within the data set to be an important element of reflexivity (Mauthner and Doucet, 2003).

The purpose of this thesis did not attempt to reach total objectivity (Mauthner and Doucet, 2003). As such, the expectation of reflexivity required the impact of the researcher's own history and issues on their understanding of their study. The research topic selected for this study was based on beliefs and experiences held prior to and during the work. My own academic background is eclectic. This was married between an academic background of diverse studies along with work in the pastoral care of the vulnerable, which underpinned the rationale for the study alongside working and voluntary background caring for others. There was awareness that the 'choices' made with the research topic were matters for reflexivity. However, the adoption of the study topic and research method is bound up not only with personal biographies but the interpersonal, political and institutional dynamics surround the researcher as the inquirer, and these all shape others' decisions (Bell & Roberts, 1984). It is part of process of a continual internal dialogue and critical self-evaluation of any research process and outcome (Stronach et al., 2007). Koch and Harrington (1998) rely upon this assertion to promote the use of reflexivity as an effective way of signposting what is happening at each stage throughout the study thus assisting both the researcher and the audience. The 'reflexive turn' in the social sciences has acted to clarify understanding of theoretically and empirically based knowledge construction processes. This reflexivity acknowledges how the field of qualitative study acquires knowledge and how it organises and interprets it to relevant claims made (Altheide and Johnson, 2011). It is described as an approach which fulfils a social activity which is culturally, socially and historically embedded (Haraway, 1988).

3.6 Summary of chapter

To summarise, reflexivity involves taking a sensitive approach to the ways a researcher may impact their study and how the assumptions that they previously held going into the study may impact on the data analysis and interpretation (Litva and Jacoby, 2002). Being mindful of these issues was the approach I took with reflexive matters in this study in tandem with TA and its social constructionist compatibility.

This chapter has provided an explanation of the methodology and philosophical underpinnings of the research. I have considered ethical issues in relation to the research and outlined the way in which data sources were sought and identified. I described how TA was used to analyse the data and identify themes whilst examining the plausible approaches. I explored issues of quality and rigour, and finally, aspects of reflexivity were also described. The aim of the overall study was to gain fresh insight into the lived experience of PwEOD as they wrote about life with the condition. The next chapter discusses the thesis' analysis findings. These are followed by the discussion and conclusion chapters.

4 Findings

To remind the reader of why this thesis was carried out, it was investigated for thematic material offering fresh qualitative experiences as described by independent authors of PwEOD, of whom four were autobiographical, and one was a blogger. A reminder of their details and the relevant background is given below for the benefit of the reader, and the aims and objectives are illustrated once more.

4.1 Aims and objectives

The aim of the study was to learn more about the personal experiences of PwEOD. This was addressed and meeting the following objectives:

1. Establishing to what extent personal experiences of EOD are present in the extant literature and what this tells us.
2. Using autobiographical and other written content about the self by PwEOD, to learn more about the experience of EOD.
3. Focusing on the impact of having a diagnosis of dementia at working age.

The findings are presented as two chapters. Study One presents an analysis of the texts which was concerned with the personal experiences of PwEOD, and Study Two presents an analysis of experiences situated within the social and interpersonal realm.

Each of the texts studied was of an autobiographical nature, in the form of a book, except for one, which was a blog. I provide a brief pen portrait of each writer below.

4.1.1 Author 1

Christine Bryden was both a civil servant with a demanding career role and a single mother of three children when diagnosed with dementia at the age of forty-six. Her career established itself in biochemistry and the pharmaceutical industry in the UK, moving into science publishing in the UK, Netherlands, and Australia. Working later as a senior executive in the Australian public service, she provided advice to the Prime Minister on science and technology. She became an activist in her approach to challenge common taboos and stigma against stereotypes of PwD in writing, 'Dancing with Dementia' (2005). Stigma was a very significant issue for Christine Bryden and her writing was boosted by continued campaigning, travelling around conferences, and speaking at national conferences. She is the author of two books on dementia; the other being ‘Who Will I be When I Die?’ (Bryden, 2012). Bryden offers an account of her experiences living with dementia, exploring the effects of memory problems, loss of independence, difficulties in communication with special mention of the exhaustion of coping with simple tasks, a career, new marriage, advocate for dementia whilst having EOD. A primary concern was in losing her identity in how the social world observed and understood her. Both asserting her identity and seeking a spiritual relationship with God, Bryden reflected in her book the concern to reach a meaning of transcendent life beyond EOD.

4.1.2 Author 2

Richard Taylor was diagnosed with dementia, probably of the Alzheimer’s type, when he was 58 years old. He was married with two daughters. He began his working life as a teacher, finally ending his working career as a psychologist. He shared accounts based upon the changes in his life from EOD through a slow transformation and deterioration. This affected relationships and Richard Taylor commented upon the growing division between his inner world and the world of those others who were outside the dementia experience. Using candour, humour and protest, he commented upon the loss of independence and personhood that came with the condition. He also commented upon his observation of unwanted personality shifts, communication difficulties, along with the declining ability to perform everyday tasks. He wrote and spoke to the public about living with the disease and challenged those on the outside of the disease to read his description of Alzheimer’s disease. He sought to tell others how the person inside remained intact although they may at times find expression difficult. The book sought to change philosophies within person-centred care.

4.1.3 Author 3

One of the earliest and most prominent of EOD accounts is Robert Davis’s 1984 book,’ My Journey into Alzheimer’s’. In the book, Davis records lucid reflections on daily life while he believed he was capable of. As a Miami pastor, he hoped to communicate to give hope to, especially Christians who might feel spiritual despair whilst the progress of the condition baffled them. Robert Davis left a farming family and community behind to pursue his academic and sporting studies finally completing his education with theological studies at Seminary. Following this, he was ordained into the Methodist church as a pastor. He was married with two daughters and provided pastoral duties and care for several churches before retiring early due to his diagnosis of EOD. Robert Davis chose to write his autobiography about Alzheimer's Disease within months of his diagnosis about his EOD at the age of fifty-three. His perspective was viewed as an American Christian pastor. He was keen that readers on the outside of the dementia experience would understand through his writing his own view of the difficulties and feelings that he failed to find meaning for his life and link with God often.

4.1.4 Author 4

Thomas di Baggio was of Italian descent with his family emigrating to America to settle before he was born. Prior to a career in journalism, he left his university degree without graduating preferring instead to combine writing with running a herb business referring to it as urban farming. He was married with one son. His diagnosis of EOD arrived at the age of fifty-seven whereupon he began writing his book; 'Losing my Mind' (2002). He hoped the book would act to document his daily life and reminisce upon a varied life before dementia. This effect was achieved by italicising his past life events and returning to standard text when discussing the present.

His unconventional style was described through three narrative types to illustrate the strengths of his memory lay as well as where weaknesses were present. He sought through writing and adopting his three-phased narrative approach to help others understand the inner mind and experiences of what it is like to have EOD. He too sought to try to break down the shame and taboo often affecting those with dementia. The book was written with the belief that human stories were much more profitable to listen to other than directing all responsibility and definition towards doctors.

4.1.5 Author 5 (Blogger)

Kate Swaffer was forty-nine when she was diagnosed with a rare type of EOD and was promptly advised by her health care professionals to order and prepare her life for the surrender of career and life as she knew it and hand over her affairs into the hands of others. She represents the blogging posts which comprised part of this thesis. This diagnosis of EOD occurred for her at a time she was leading a hectic life, with a full-time career and, while raising her two teenage sons. She was also embarking upon university life as a student. To be requested or expected to surrender her life was contrary to everything that she believed and might have expected. Kate Swaffer, despite the fatalistic views of primarily her medical fraternity, her determination to continue to live a fulfilling life resulted in her strength and purpose to travel the world advocating for a human rights approach to dementia. In 2014 she co-founded Dementia Alliance International. This is a non-profit organisation committed to representing and improving the quality of life for the 50 million people worldwide who have been diagnosed with the disease. Much of the day to day awareness of this organisation appears through Kate Swaffer's daily or frequent blogs.

The analysis was undertaken as two distinct studies, which concentrated separately on personal aspects of the writer's experience (1) and social and interpersonal aspects (2). The themes for each study mirror each other to a degree and give the opportunity to view the same experiences from two distinct angles, which inevitably overlap. The table below sets out the themes discussed in studies One and Two.

Table 9 Table of themes

Study 1		**Study 2**	
Theme 1	The diagnosis	Theme 1	Dementia is contagious
Subthemes	*Diagnosis as pivotal*		
	Diagnosis as both wanted and unwanted		
	Diagnosis brings shock and acceptance		
Theme 2	Lost in space and time	Theme 2	Blame and shame
	Liminality		*Credibility*
	Lost in space		*Stigma*
	Lost in time		*Walking and wandering*
Theme 3	Personal Identity	Theme 3	Social identity
	Loss of role		*Challenge to social identity*
	Loss of self		
	Reconstructing identity with words		*Constructing a new social identity*

4.2 Study One: Personal experience

Study One set out to investigate the personally felt and expressed the effect of having EOD related through writing. Section one and therefore, the resulting themes and subthemes are situated around the personal and the self. As each writer divulged their diagnostic experience as the event which authenticated their right to write, this theme appeared to raise issues which were highly personal and offered a rich comparison with experiences prior to diagnosis and beyond confirmation.

Following the introduction of the diagnosis period, subthemes appear as being pivotal to life’s journey, wanted and unwanted news and, along with this, this could likely bring about a shock reaction but followed by acceptance as often symptoms had prevailed long prior to diagnosis.

4.2.1 Theme 1: The diagnosis

Diagnosis was an important and key personal theme arising from all the autobiographical accounts. This theme represents the writers’ exploration of their diagnostic period and its personally experienced effects. The diagnosis period was critical. Whilst a diagnosis could constitute an event of the sudden confirmation of a positive result of dementia, it also could emerge as a result of long-held fears and suspicions. This could mean that the discovery of EOD occurred as part of a journeyed path of doubts, the dismissal of doubts and the tension of whether an official admission could or should be addressed in a biomedical context.

4.2.1.1 Subtheme: Diagnosis as pivotal

The writers described the diagnosis of dementia as a pivotal experience, and it was from this pivotal point that the journey of dementia began:

> 'The hour, the day and most of the month after my neurologist said to me, “You have dementia, probably of the Alzheimer’s type”, my spouse, my family, my friends, and certainly I, worried, cried and ran as fast as we could down the first one hundred steps of the spiral stairway to depression. The assemblage of doctors who followed me for more than a year met with me on almost a weekly basis. They stuck me, jabbed me in my spinal chord, and removed what seemed like gallons of blood for analysis in labs located from Houston, Texas to Princeton, New Jersey. They asked me, by actual count, 102,000 questions about everything from, “Did you or do you lick walls with painted with lead paint?” (Taylor 2010, p. 6).

Being given a diagnosis of a serious and ultimately terminal condition was crafted as an important part of every individual’s story. Each gave an account of the diagnosis using it as useful leverage and springboard:

> ‘There is the cognitive outer self, which is the self – the mask – that we are presenting, when we are at work or at home. Organising, planning, writing, speaking, shopping, cooking, all sorts of complex activities make up what we think is who we are. We have labels for ourselves, names, jobs, addresses, memories about our past, ideas for our future. We communicate these as part of defining our outer masks. When we meet each other, it is a description of our masks that we seek when we say, “What is your name, where do you live, what do you do?”’ (Bryden 2005, p.159).

Dementia could be thought of as being pivotal not merely because it was information that was likely to instigate immediate changes to life, plans and directions but because it could exhibit a shift. This could have significant impacts on identity. This could be the first legitimised experience of being treated differently and being presented by clinical diagnosis, something of a new and unexpected life ahead. It was therefore, in many of the accounts shown that naturally, the news was not met with pleasure. However, this was where some contributions of this type reflected the writers' experience of a perceived lack of being treated with the same status prior to diagnosis. This provided suggestion of a significant fracture to identity, which will be explored further in Theme 3, 'Identity'.

4.2.1.2 Subtheme: Diagnosis as both wanted and unwanted

The process of diagnosis could be feared. This could occur because it had been long suspected as being an inevitable and necessary step, and in this sense, was simultaneously wanted and unwanted. It appeared that the immediate diagnosis period could often provide a challenge, as despite being unwanted, it was often fought for, and could involve many protracted months and procedures in order to reach clarity. The idea of a right to a medical confirmation of EOD, however was specified clearly in writing by the writers:

> 'Why should there not be a diagnosis? After all, this is the age of miracle medicine. After spending weeks in the hospital and almost $40,000, the very least they could do was to come up with a positive diagnosis! All this time and money and I was still lost in confusion and darkness. Finally, I could stand it no longer. I shouted at Betty, "I have had enough. If they do not have a diagnosis, why am I using these inhalers and medicine that are about killing me? If I am going to die, I would just as soon die natural and comfortable. Let's leave all of the unessential medicine behind, and let's leave all the doctors and hospitals behind, and let's leave the telephone and all the unanswerable questions behind, and let's just get in the car, and even if we only drive fifty miles a day let's just leave and head for the West" ' (Davis 1989, pp. 51-52).

This quote reflects how the diagnosis was at the same time wanted and rejected and this could appear as if the experience was not handled in the right way for the writer in receipt of news. This feature was more understandable when the diagnosis had been long denied by clinicians. Exasperation was a common experience providing evidence of how diagnosis could have been better handled in hindsight.

All writers expressed such feelings of being entitled to gain and be given diagnoses, as it would allow life to move on. Therefore, a diagnosis was sought out and gained by each writer:

> 'The first step to helping us is to make sure we get the right diagnosis, and that we are followed up regularly. There are around 70 causes of dementia. Of course, many are quite

> rare, but all too often a diagnosis of Alzheimer’s is given, with the assumption made that the person will deteriorate rapidly according to expectations’ (Bryden 2005, p.123).

Being told of a confirmed diagnosis of EOD was not news that was regarded as positive, but it was sometimes admitted to as a relief to know that symptoms had not been imagined. This could occur particularly where a long drawn out period had existed before the diagnosis. Relief could be absent; instead it could be replaced by shock. However, it was believed that there was a right to receive a diagnosis; it did confirm behaviours and experiences. Based upon this new status, each writer addressed the truth in their own way, processing the information at their own pace.

4.2.1.3 Subtheme: Diagnosis brings shock and acceptance

Accounts of diagnosis provided descriptions of often harrowing and enduring processes. The overall focus was one of helplessness and the shock impact of news of a terminal diagnosis attached to a potential decline in body and mind. The writers all gave accounts of the diagnosis period and the period, the process of delays, errors in diagnosis and elongated procedures of tests and treatments were contributed. These accounts were often contrasted with accounts of previous accounts of good health. There was also reports of the difficulty involved in the way that diagnosis was delivered. Whilst there could be a demand for a diagnosis, it often was received with shock:

Shock was present while processing the news of an official acknowledgement. From the disclosure of diagnosis to the point of submission to dementia, the medical outcome had impacted upon the person in what they could now expect life to mean for them. This could be understood to be like a spectrum in each individual case:

> ‘The dementia script- the shock of diagnosis and horror of prognosis-is a turning point in our lives. That moment is etched in our memories. What the weather was like and what people said emerge from the fog of our distorted memories as one clear crystal picture. For some of us it is a relief. At last there is an explanation for our confusion, our slowness, memory loss and daily difficulties. But we must still face up to what the future now holds. For others, diagnosis leads to disbelief. There is nothing wrong with us, surely! No one can think we are anything like those people in nursing homes, who don’t know who they are or who their families are? And for others, like me, it is a time of trauma. I faced an awful awareness of my future, of what lay ahead for me and my girls. I would have to stop work, and still support the family. My world had collapsed. Everything had changed. I faced a defeat of spirit and hope’ (Bryden 2005, p.155).

The news that a definite diagnosis brought could understandably or induce shock and a lack of processing. However, once the process of news took place, levels of acceptance could be seen in reported experiences. Some experiences related to how beyond the shock, different psychological processes came into play to override bad news, this could occur in the shape of religious faith or communion with the universe:

> ‘My life changed dramatically when I faced the shock of diagnosis. It feels like a curse when the doctor says, “You have dementia. There is no cure.” Alzheimer’s, like life itself, is terminal. Many doctors cannot accept the idea that Christians are assured of life after death. Their scientific approach to life refuses to admit there is anything beyond the physical life on this earth. As part of my clinical work-up, specialists wanted to examine my feelings about this illness and my coming death, with this as their frame of reference. When I was asked about my illness, I replied that there was at first total confusion, then a feeling of devastation as if an atomic bomb had been dropped to destroy my whole world. But then Jesus came to me in a special way to give the greatest peace and comfort I have ever known’ (Bryden 2005, p.95)

This counteracted the shock of bad news and the clinical focus in the delivery of the news. In a few cases, the shock of the diagnostic confirmation was counter-balanced by other beliefs that shored up positive feelings often, through personal beliefs, or rationalisation of the situation. Once the news was delivered, it was up to each writer to embrace the practicalities of a different life journey with altered plans or it could be embraced through an immediate rejection and distancing of the news. In such cases, it could take time to process the news on the future dementia journey. Out with the clinician’s room where the diagnosis was delivered, it became a personal experience to relate to the environment as a PwEOD who now had to reconfigure life outside the clinical domain.

Fears were discussed in different ways, from fearing for the wellbeing of those left behind to grieve for a presumed future that would now not be possible. However, alongside fear of death, it was possible to become familiar and perhaps even comfortable with this life threat:

> ‘At first I viewed the diagnosis as a death sentence. Tears welled up in my eyes uncontrollably; spasms of depression grabbed me by the throat. I was nearer to death than I anticipated. A few days later I realized good might come of this. After pussyfooting with words, I finally had a story to tell’ (DeBaggio 2003, p.1).

It was evident at some points that ideas of comfort and reshaping could be conceptualised back into life if treatments or health practices were offered and appeared to work. Equally, a reinvigorated passion or personal ‘jihad’ was a way to cope and understand the bodily impact of ill health; ‘*I finally had a story to tell*’.

There was a suggestion of powerlessness felt in the wake of a diagnosis delivery where ready acknowledgement and acceptance of the condition existed. The gradual onset of illness was a prominent issue around the diagnosis period. This was possible because it was common for the writers to have adjusted to the probable diagnosis through the realisation that something had been seriously wrong in the long run-up to receiving a diagnosis. Acceptance was reached partly because even prior to diagnosis, life had irrevocably changed. With a diagnosis of dementia, therefore, the issue could be understood and therefore begin to be assimilated.

4.2.1.4 Summary

Diagnosis within the writers took on a heterogeneity, despite the different journeys to that point. The diagnosis was what all writers in the data set had in common as a rite of passage. It was a pivotal point which indicated the end of one era, and the beginning of another, it was both wanted and unwanted as it made sense of experiences, while also confirming an unwelcome trajectory to life. This fed into the shock that was experienced by all writers before they moved into varying levels of acceptance. Beyond the pivotal point of diagnosis and coming to terms with that, to whatever degree possible, lay the experience of living with dementia day-to-day, and this is explored in the following Theme 2, ‘Lost in time and space’.

4.2.2 Theme Two: Lost in space and time

The concept of being lost in time and space has been chosen to represent the experience of living with dementia, as expressed by the writers, as these concepts were repeatedly used both to describe empirical experiences, and as an analogy to describe psychological experiences. This theme contains the sub-themes liminality, being lost in space and feeling unsure of a chronological experience of life. Across the entirety of the texts, people reported stories which displayed life in limbo, representing feelings of disjointed alienation. The ideas of being lost in space and time overarch descriptions given of feelings of oddity surrounded by the apparent normality of others and things in the world. The writers often used descriptions of physical confusion which, while descriptive in and of themselves, are also analogous to their internal state. Without signposts of linkage to people and places, the self could disappear:

> ‘Most of the time I live in the space I can see and the time called “now” … it is almost a “virtual world” … I move … and a new space opens to view … like a new room in a computer game

> … there is a type of cheese, I forget its name, that when thinly sliced is very lacy … my life feels like that – so full of spaces that it barely holds together … or like a tree in a gusty wind … branches touch and connections are made but fleetingly … made and unmade, little sense of cohesiveness … even my rootedness to my place in space feels tenuous … as if I might be torn loose, uprooted, blown away' (Bryden 2005, p.99).

4.2.2.1 Subtheme: Liminality

This experience could take many forms and could emerge and retreat in and out of life-giving an intermittent but ever-present experience. The writers described feeling permanently trapped in a limbo-like existence:

> 'I am lonely in my dead life. Even when I am with people and laughing with them, I am alone, isolated from the normal world, unable to remember this morning, constantly trying to recapture the moment just past. I live in a strange place of isolation' (DeBaggio 2002, p.200).

Experiences of bodily separation from the mind and the everyday world could manifest as a sense of loss and provoke feelings of personal alienation. One way that these experiences were reported across the data in different ways was through a central theme of liminality, representing insecurity of person and not feeling 'in place'. These experiences included different but connected ideas such as; feelings of exclusion, disorientation and being in neither in one place nor another in mind, self and location. Exploration of the texts found that within this special feeling of 'outsiderhood' the individual could be situationally or temporarily suspended from others, themselves and the activities to which they were previously bonded:

> 'I was good at managing my time. I was good at writing down my goals and objectives and the timelines to meet them. I was good at leading a purposeful life. I no longer apply good habits to my activities, because I no longer have purposeful activities. I have fallen into meaningless patterns; not all of the time, of course, but more than in the past' (Taylor 2010, p. 119).

The idea of having retreated from life was an experience that was driven by the cognitive condition of those writing. Retreating could support feelings of being lost and confused by reality. Being 'lost' could feel productive in itself:

> 'One reason I live in my feelings is because I have grown weary of thinking about myself and my future. I'm tired of trying to figure it out, because I am in a constant state of flux. There is no consistent figuring, because I keep switching the base I am using to determine the value of the numbers I am trying to figure out. One moment I am in base 10, familiar to me since grammar school, and the next moment I am in a base I do not recognize and whose rules I do not and probably cannot understand. So what do I use to fuel the blast furnace of intellectual curiosity, self-exploration, and the need to know which has defined me for the past 60 years or so' (Taylor 2010, p. 128).

This passage illustrated how when social harmony could not be fostered with others, the challenge to keep up with others could become too difficult to achieve. This could lead to feelings of self-consciousness compounded by disorientation. The following passage demonstrated how having EOD could feel a permanent and as well as passing, frightening and familiar at the same or proximate times. Although the experience was one of not knowing where the self or memories were, there was a recognition that the memory failure was temporary and caused by illness.

This disjointed sense of purpose and loss of place prevailed within personal experiences. This sense of liminality could make prevalent a dislocation which gave rise to spatial loss of place.

4.2.2.2 Subtheme: Lost in space

Everyday tasks requiring motor skills and sensory awareness were discussed through the personal ways the writers experienced their cognitive changes as they tested their skills. This was a common site of fear and nervousness amongst the writers who feared 'losing face' in not understanding their environment:

> 'When I am holding a glass of liquid, it is a huge effort to try and keep it from spilling. I have to look at the glass, look at my body take care of how my body is placed in space – there are innumerable actions and reactions in this seemingly simple task. For me, carrying a drink has become a major challenge. Where is each part of me in space? Where is that glass and why does it slosh over unless I stare at it? Why does it bang into objects suddenly in its path when I lift it across the table? How come when I reach out, I knock things over and make a big stain? It's like being blindfolded, looking through a tunnel. My peripheral vision seems to be more limited and I startle at or keep getting distracted by apparent movement around me. It's as if I have blinkers on. If I walk past a mirror, I can be startled by the strange person in the room with me. I often knock things over in the kitchen or bathroom. I misjudge distance and bump into things. Patterns can confuse me, so I may stumble if walking across a smooth yet patterned floor. It just seems that all I can see is in front of me, and someone has blindfolded me so I cannot see what is alongside me or around me.' (Bryden 2005 p. 104).

Feelings around everyday routine experiences were acknowledged as being out of step and often filled with trepidation at the dislocation of events and processes. These semantic observations were evident in many aspects of everyday events and processes:

> 'Waking up from sleep is a real experience. I have no idea where I am at times, and also I am totally lost. I have run into more objects in our bedroom and have more bruises from getting up and wandering around in the middle of the house than I care to state. Therefore, after I sit on the side of the bed to get myself orientated, I have to turn on the light in order to see. I am totally lost and forget the pattern of my own bedroom, even though it has been my bedroom for the last ten years. At my worst time, I cannot bring myself out of this stupor. I need something to shock or stimulate me awake. I had a talk with one of my friend's about making a battery-operated shocking device to try and bring me out of this quickly, but we decided against it as we did not know what the effects would be. One of my dear friends, Dr Joe Davis, a psychologist who has helped me with this crisis came up with a very simple solution. He said that if I lay the roughest kind of indoor-outdoor carpet on my bedroom floor as a path between my bedroom and bathroom, I could then follow the carpet with my bare feet, and

> probably the pain on my feet would rouse me from this state. It is an excellent suggestion, and one that should be considered. Again, suggestions of this nature are hard to find because so little has been researched and written' (Robert Davis 1989, pp. 93-94).

There was prominent evidence in the texts revealing a lack of feeling secure in understanding the environment; both physical and social, which compounded feelings of being overwhelmed. This played upon the state of being permanently lost but not feeling secure in one place or in cognitive understanding:

> 'Part of our rising levels of anxiety is losing our way, not knowing where we are. I have somehow lost the map in my head or at least the way that it connects to reality around my house. Finding my way is now becoming increasingly difficult. When Paul and I go for walks, I hang on his hand - he is my global positioning system. I usually have no idea where we are, which direction we are going. In May 2000, I went by myself to a university residential in Bathurst, as part of my counselling diploma. It was a nightmare – I was unable to find my way from the residence, to the dining room, to the lecture room, only a distance of say, 50 metres each time, and just had to follow familiar places (of course, never familiar names – I had no idea what their names were). It was the last time I tried to go anywhere unfamiliar without a care partner to guide me.' (Bryden 2005, p. 116)

At times of expressing being lost, narratives ranging from confusion to self-adjustment were present across the texts in the way that discussion was given to the sensory changes that were taking place:

> 'There are times when I feel as if I am a stranger in a strange land, when the reality of the situation is that I am really myself in my own house. It will be impossible for me to announce just when my condition has reached the point where I am unable to be a rational and equal participant in conversations about me, my behaviour, and how I should best be managed for my own good and to lessen the fears of others. My family acts as if the point has come and gone, but I feel and think that it has not yet arrived. Perhaps there is no clear line of transition from taking care of myself to being taken care of by others, but as this time approaches, I would still like to feel a part of what is going on. I would like other people to listen to me and I would like to listen to other people. I would like other people to tell me what they hear and what they feel, and I would offer them the same from me' (Richard Taylor 2010, p. 150).

4.2.2.3 Subtheme: Lost in time

Time is an experience reflecting the spatial and temporal nature of life, and as such, chronicity was a relevant feature. Therefore, time could feel like it was shifting and passing but not in ways that seemed normal. The experience of linear and chronological time was a reflective experience supporting a description of how life was changing with chronic and terminal condition:

> 'Time does not mean much to me now. I do not know and I seldom care if it is a Monday or Wednesday or Sunday. I do not know if it is 10 a.m., 1 p.m., or 4 p.m. I do not know if it was January 1 or February 15 or March 13. I do not care. It does not make a difference to my life' (Taylor 2003, p.119).

Within the texts, time was associated with feelings of rootlessness and not knowing what the future held. Transition could not take place without the consideration of time as a familiar marker and one that could cause confusion:

> 'I awake in the dark morning without awareness of what day of the week it is. I wait for the newspaper or the radio to locate me in time. The day of the week, the hour of the day has little meaning for me even when I remember. I float in my own chaotic world, grateful to know I am still alive.' (DeBaggio 2002, p.148).

Regular routines could provoke feelings of 'separateness' from what was once familiar. When such validation was difficult to secure and rely upon, such as, for example, the newspaper arriving, it became hard to anchor the self in the familiar place and time sought after in order to feel familiar and secure. These confusing experiences could be linked to events which were situated in time. This type of experience had consequences for impacts on identity. Losing the self in a place, held many doubts and insecurity, and it was difficult to hold on to the self:

> 'We put all of our energy into now, not then or later. Sometimes this causes a lot of anxiety because we worry about the past or the future because we cannot 'feel' that it exists' (Bryden 2005, p.99).

Mention of linear time-spaces that provided places of sanctuary supported semantic admission of loss of the social, political, intellectual and contemporary meanings of day to day life. This was a place to occupy when uncertain. This was helpful when it was not possible to ascertain a sense of belonging. It was not always easy to experience a sense of belonging in an inclusive and certain world. This could be considered a safer place to be when the world seems to speed along, leaving the person behind or when time appears too unreliable to trust:

> 'The world goes too fast and I am too slow. As a passenger I am a driver's worst nightmare as I assume you have my slow reaction times and get very stressed out at the speed you are going, how close you are to the car in front and how quickly things are happening around us. So I startle, shriek, tense up, make comments! Paul's middle name is patience when it comes to driving me anywhere! And I get exhausted by city traffic, so much so that we carry an airline mask to cover my eyes. This helps a great deal, especially at night, when all the lights and movements are much too fast for me' (Bryden 2005, p. 104)

By having a person to share in the experiences such as a spouse, this could offer mediation between the confusion of speed and time.

Being lost in time was also expressed as a form of loneliness. This loneliness could arrive bringing doubt about the present and the future as well as the conceptualisation of the pain of going from one place to another:

> ‘The unreliability of my memory is as if the printer is running low and it sometimes works and sometimes doesn’t. Some days I can remember this morning, but on other days I can’t. It is such a hit and miss approach to a life gone by. Your memory is erratic. Sometimes it feels as if a black curtain has fallen over what has just gone by. You are in a continual present, but through that curtain is a vivid past that existed some years ago. Yesterday or today, last week or the week before, are a blank. Just writing in a diary might be a help but then we have to remember to find the diary and look at the right page.’ (Bryden 2005, p.106).

Ideas of blackness added to betwixt and between experiences. The duality of day and night which brings the everyday world certainty merely could bring further confusion for some of the writers. These ideas or images were prevalent in the texts:

> ‘At night when it is total blackness, these absurd fears come. The comforting memories cannot be reached. The mind-sustaining Bible verses are gone. The old emotions are gone as new, uncontrolled, fearful emotions sweep in to replace them. The sweetness of prayer and the gentle comfort of the Holy Spirit are gone. I am alone in the blackness. Suddenly, ridiculous, absurd fears creep into my mind. I know they are ridiculous, and unreal, but they still come. Suddenly, in spite of my best efforts my mind becomes fixed upon these things-glued to them so strongly that I do not have the power to get my mind off these absurd, ridiculous, devastating fearful things. I have become so frightened that I have drenched the bed with sweat. I personally discovered the full meaning of what the psalmist called “the terror by night” (Ps. 91:5). By faith I know the Lord is here to give me all the protection mentioned in this long-ago memorised psalm, but in the darkness and weakness of night, my shattered emotions shout louder than my faith to my frightened spirit. Sometimes these fears come in the daylight as I am gripped in a trancelike state. In such a condition, people can even talk to me and I can grunt a response while those speaking to me have no idea what is happening inside me’ (Davis 1989, pp. 107-108).

4.2.2.4 Summary

Connections that were once taken for granted were recognised as being harder to establish. These could prevail all around the person. Notions of separation and time spent in an insecure place of limbo was common. Changes were inevitable for the writers, some of which were understood and some not so clearly understood. Not every liminal experience was felt as negative. Transition, which was reported as being part of feeling lost, had to be negotiated around steps and stages of separation from others. Transition could be reported in the time it took for individual writers to meet a stage. Spatial and matters of chronicity could be to the extent that one writer reported ‘time does not mean much to me now’ related how the sense of not knowing the time was linked to limbo and the inevitable need to ‘let go’. These changes impacted upon identity, which will be explored as Theme 3. The full impact of feeling lost in and out of place was widely reported and had obvious effects on other experiences such as feelings of stigma, which will be further explored in Study Two, which looks at the social and interactional impact of dementia

4.2.3 Theme Three: Personal identity

The third major theme was one of identity which was found in the texts where previous roles and ideas of self were felt to be in question. The stripping or removal of status could occur viscerally in for example, a clinical appointment either at diagnosis or at attendance at an appointment in the aftermath of diagnosis. Based upon what was being said (often by clinical parties) it became obvious that an identity shift had occurred, and it could be difficult to ‘catch-up’ with the changes. From this point, something new had to be gathered from the changes which had arrived through diagnosis and a change of health status. Sub-thematic concepts lay with loss of role, self and reconstructing the self through words.

Accounts were provided across the data set which revealed that a diagnosis of EOD had an impact upon the writer’s sense of identity. Within the texts was a shared characteristic of feeling that the diagnosis from the medical point of view, was not handled as well as it might:

> ‘One doctor paused at the door and turned to my wife and said: “You need not come back until he pulls down his pants and pisses in the middle of the living room”. The other three seemed quite content that they had done something for me, and other than offering to treat the inevitable depression and anxiety which seems to have bonded with the disease, this pill was their best shot’ (Taylor 2010, p. 42).

The text represents both the exclusion of patient and a taking away of their dignity. The sense of indignation could be thought of as linked to the shock involved in the inevitable shift in identity, a health threat undermined the self. This was derived from physical symptoms and related to everyday life and exchanges with others but internally felt. The writers described feelings of ‘outsiderhood’ where the individual was situationally or temporarily disengaged from others and the normal everyday world.

4.2.3.1 Subtheme: Loss of role

The writers selected for the data set held positions in their working lives of note; whether successfully self-employed, skilled published writers or holders of secure and elevated positions in life, they all were held in respect and had to now contend with a loss of income, forced retirement and therefore a complete renegotiation of selfhood. It was apparent that a diagnosis of dementia could provoke life changes which impacted the person’s sense of identity. The diagnosis had potential impacts on life not expected in those diagnosed with older age dementias:

> 'Why should this happen to me at this time, at the very apex of my career? Had I sinned, lost my faith, betrayed my calling, grown weary of the cross of Christ or any other such worldly thing? No! My mind swirled anew as the words of the neurologist echoed on my head: "I wish I could tell you that you have cancer. There is more chance for recovery. I'm sorry to tell you that you have the Alzheimer's pattern on your PET scan. As you know, Alzheimer's is an irreversible, incurable, terminal disease' (Davis1989, p. 20).

Diagnoses could occur with warnings to give-up work, driving, and living independently, some of which experiences could have delayed onset effects for some diagnosed with serious chronic illness, however, with dementia, this disruption tended to be immediate. The textual content directed towards work revealed ideas of an end or restriction of career. This was inevitably and widely understood as a loss across all texts. This passage reflected the fears of receiving a diagnosis and facing the potential loss of career:

> 'It was 12:30 p.m. I was totally exhausted. My pulpit robe lay on the communion table where I had placed it during the worship service. I leaned against the communion table and wept uncontrollably. The tears cascaded down my already tear-stained face. Why the tears? Because I had just preached my last sermon to the congregation that I loved so dearly. I had just shut the book on this ministry that I felt would soon explode to reach greater heights. The cold fact of the matter was I had just finished preaching the last sermon I would ever preach- at the age of fifty-three'. (Davis 1984, p.19)

The extract above illustrates the decision to be confronted with giving up work, which could follow either from the shock of diagnosis or from many months of realising that life was becoming a struggle and a daily puzzle. The writer below writes about the impact of a dementia diagnosis along with the effect that it might have on their working life. Within the processing of diagnosis and the relief of certainty, the lack of certainty prevailed over the loss of practical working life. It was notable that as well as the threat to the loss of work, stigma replaced the more positive labels of being an independent individual:

> 'The day before my diagnosis I was a busy and successful single mother with three girls, and a high-level executive job with the Australian government. The day after I was a label – person with dementia. No one knew what to say to me, what to expect of me, how to talk to me, even whether to visit me. I had become a labelled person, defined by my disease overnight. It was like I had a target on my forehead, shouting out for all the world to see that I was blindfolded, no longer able to function in society.' (Bryden 2005, p. 156).

The combination of cognitive and some physical symptoms could make day to day life complicated meaning that by the time diagnosis occurred, it could provoke reluctant relief to end working careers. A dementia diagnosis could certainly impact the territory of careers and economic stability very quickly. Where this was mentioned across the data set, it was apparent that there were gender differences in the approach to surrendering a paid career of employment, and that for women, surrendering domestic duties could be equally challenging to their sense of self:

> ‘In a blog comment this week about me handing things over to my BUB, I responded with this; ‘I have had to give up a couple of things this week, and hand the responsibility over to Pete.’ I felt physically SICK doing this, and incompetent, and guilty having to do so… even though I know he does not mind at all.’ I had suggested there was a blog in this, and the more I think about it, the more I know it is an important blog to write’ (Creating life with words. 2013. Kate Swaffer March 27. 2013).

Here, the role was being reversed where the husband had to, at the request of the female blogger, switch roles from provider to provider/carer whilst his wife had to surrender to being cared for instead of being able to nurture and care in the expected female role. Also, for the male writers, not only were careers lost, but roles within relationships shifted:

> ‘My wife, Bett, and I have been married for almost thirty years. During this illness our roles have changed. Suddenly she is not only the wife I have loved, but now she is also my caregiver. She has to guide me through daily living as I have become a care receiver, unable to fully care for myself’. (Davis 1989, p. 56)

This was contrasted by the writers to their previous lives:

> ‘That January, my fifty-seventh birthday, was pleasant and eventful and I began to adjust to middle age. I no longer noticed how small facial lines became wrinkles. I was active and happy. My son Francesco, home from California, joined Joyce and me in the family herb-growing business in Virginia. I was equipped with a thin body free of aches and pains. (DeBaggio 2003, p. 1)

The writers in their texts often revealed a gap between their expectations and reality. The writer below, due to his age and stage in life, had different expectations to his fellow group members:

> ‘When I was first diagnosed, I joined a support group, and all of the members were older than I. Most of them denied they had the disease because-I believe-they could not conceptualize it. Since they didn’t understand it, why should they believe others who told them they had something they couldn’t see, feel, or conceptualize? The group leader encouraged us to tell each other how we felt. Most of them felt okay. They were a little irritated that they could not drive or handle money, but for them, life was mostly on track’ (Taylor 2010, p. 18).

Both male and female writers were similar, in that the onset of dementia challenged their role expectations. However, the experiences which were shared by both genders reflected different experiences with EOD which hinged on their own perspective and role in life. Kate Swaffer, the blogger could identify their daily lives and feelings through an instant online community. This provided a virtual world which could open-up to those putting up posts and for those who read them. Because the blog was dedicated to PwD, it created a space in which its participants were free to express themselves without the worry of the embarrassment of forgetting or misunderstanding. Time could be taken for ideas to be garnered and mediated before submitting across the internet. With autobiography, the presumption was there was an interested readership who would buy published books on the topic of illness narratives with reference to EOD or PwD. The female writers exposed the layering of life as a family member, earner, mother and nurturer carrying a chronic illness whilst interfacing with and mediating between the world and her family. There was some evidence that seemed to suggest more guilt, and emotional conflict round existed for the female writers:

> ‘What the hell happened to my brain?
> Diagnosed with dementia when I was much too young
> My children still at school
> A deadly, terminal disease effecting
> Memory, thinking, perception, judgment, language and speech
> But worse than that, effecting my
> Life, family, friendships, my sense of self, my identity
> And a bucket load of guilt
> Truckloads of stigma, discrimination and isolation
> Loss of dreams, and grief
> Sadness, disbelief, lost employment’ (Swaffer blog dated November 28. 2015)

This had consequences for a woman’s identity. With dementia, the roles that they occupied which relied on hanging on to various lists of tasks and obligations potentially diminished and this, for them, could mean a loss of feeling as the mother they wanted to be, or remaining as the spouse or career and community lynchpin:

> ‘The symptoms of dementia can sometimes get in the way of compassion, and often the PwD is ‘blamed’ for their behaviours; for being obstinate, or difficult, or for refusing to acknowledge they have dementia, or for not accepting help, or for mistrusting those who are trying to help, or… or… or… there are so many times I read or hear about the carer blaming the PwD, not the symptom of a terminal disease, for ‘their’ troubles. In many cases, PwD are also blamed for the changed roles of family members as they have to take on the role of carer.’ (Reactions to dementia. Kate Swaffer March 29. 2013).

For the writers, there was a contrast between positive hopes and dreams dashed:

> ‘I looked forward to a life to rival my Midwestern grandmother’s 104 years, I was buoyant and displayed, occasionally, the unbecoming arrogance of youth. Then came a beautiful Spring day later that year. It was the day after the tests were finished and the results reviewed. It was the day I was diagnosed with Alzheimer’s. What time had hidden was now revealed. Generic secrets, I locked inside before my birth, were now in the open.’ (DeBaggio 2003, p.1)

4.2.3.2 Subtheme: Loss of self

Emerging from the exposure of a diagnosis, writers expressed elements of objectification and a distancing of the body as it let down the writer's expectation of what life in the future with a natural ageing experience would be:

> 'By August 1995 I was well enough to do a complex battery of exhausting psychometric tests, and the report noted 'difficulties in attention/concentration, speed of information processing, and application of strategies to more complex and novel verbal and visual material, (which are) consistent with frontal lobe damage'. The report noted the generalised cerebral atrophy visible on the scans and said, 'a provisional diagnosis of early stage of Alzheimer's disease seems the most likely' (Bryden 2005, p.90).

There was evidence that the diagnosis was conveyed with an objective distancing tone commonly used as a biomedical description of ill-health. This objectification reinforced ideas of objectification; of something happening to the body that was not desired. Therefore, by putting it into the clinical language of the medical profession and clinical notes, the body's failings could be distanced. This suggested a separation of the body from the essential person. This may have been an essential strategy in the face of a disease which threatened to overwhelm the self:

> 'Once a disease is named, especially if it's Alzheimer's, you begin to understand it and that means recognizing it in everyday things. It's not long before you are under the spell of the disease. Its heartbeat is your heartbeat. There is danger here in trying to understand evil, especially when it is so close to you, gaining control of your brain. I worry I will become too conversant with this disease in me, and it will hijack my life with my permission' (DeBaggio 2003, p.12).

There was also evidence that the changes which dementia forces upon the self and others could be considered something akin to a loss felt through bereavement. As such, this grieving could happen whilst the individual is still living. The losses experienced by the writers also directly affected their partners and families, and all involved struggled to find meanings for the changes to life that came with a dementia diagnosis:

> 'Alzheimer's creates private family pain, the kind hidden and denied. It is so corrosive it can leave scars on the soul and disrupt relationships. I stepped in foolishly without a thought of the future or those around me whom I love. I believed it was my pain and I had the right to expose it, but now realize my pain has engulfed my family; my pain has become theirs' (DeBaggio 2003, p. 108)

The writers also had to negotiate the way they were perceived by others, into their own sense of self:

> 'It is also important to think about our lack of ability to speak. In what way does this limit you in valuing us, in giving us dignity and personal space? I know that when I am no longer able to

> speak, I could become violent quite easily. People make you do things that you don't want to do, and you have no word for 'no, thank you.' (Bryden 2005, p.128).

Deeper investigation contributed to the idea of the self being challenged leading to identity crisis:

> 'I want to face this disease with clarity and reality. It is hard for me to do but it is harder I think for Joyce and Francesco, I think. They see me differently' (DeBaggio 2003, p.41).

People could therefore, feel identity was negotiable dependent upon how they felt and who they interacted with.

4.2.3.3 Subtheme: Reconstructing identity with words

Despite the challenges to self, the writers had all found ways in which to reconstruct an identity with a dementia diagnosis, and its physical, psychological and social effects. These identities hinged upon finding liminal space with which to reconstruct new identities. Some writers had engaged with local dementia support groups:

> 'over the next few months, I found out about a new Internet support group that Morris' friend Laura Smith had set up, called Coping With Personal Memory Loss. By the time of World Alzheimer's Day that year when a few of them gathered together for a memory walk in the USA, this group became the Dementia Advocacy and Support Network (DASN). It was wonderful to get e-mails from friends in the USA and Canada who also had a diagnosis of dementia, and yet like me were still able to communicate, willing to speak out and wanting to challenge the accepted view of the late stages of the disease. Most of us were taking anti-dementia drugs, and we were not willing to accept being categorised into a medical model of decline according to set stages.' (Bryden 2005, p. 50)

However, this community was largely created in virtual space around the internet or across the readership, which chose to read the books. This sense of community was evident in some places through levels of personal disclosure. Writing and blogging could allow a space in which to be open about fears, stigma and the limitations of others who did not have dementia or EOD.

The writers used writing to explain a broad range of contested issues associated with everyday actions and processes of intimate life. The finer grain issues which did not centre around medical care and opinions could be aired. Subjects such as ethnic, nationalist or religious designations and related concerns could expressly or implicitly be present. These topics and ways of speaking could be helpful for those seeking answers whilst not falling into a pattern of typical life alongside others. The data set reflected a diverse and rich subtheme of content which spoke of redefining social space through writing about illness and new-found identity and purpose:

> ‘My journey with dementia has been a journey of self discovery about who I really am. My first book asked ‘Who will I be when I die?’ It expressed the fear of ceasing to be and assumed somehow that the journey of dementia was somehow a loss of self’ (Bryden 2005, p. 158)

Within a crisis of identity, agentic voices could suggest a form of activism that lay in the ‘telling’ of the story. Agency in the form of activism underpinned the rationale for the blogger in the data set, creating a daily journal of content and thoughts. Therefore, throughout the texts drawn from the data set, activist discourses were raised to promote unfairness or indignation at circumstances but also to reveal evidence of conquest and success. This supported a fresh environment for new views proclaimed by those experiencing the condition and life with EOD. In producing narratives about their lived experience with EOD, each writer had a perspective and rationale for writing. This could contribute to a form of community. Therefore, there was an assumption that an audience would be available to read the content:

> ‘There were personal risks, but more important, it took a lot of time. I had a job to go to and plants to husband. I began the book to expose my inner self in words from the deepest cavities of my being to help people understand the large picture of Alzheimer’s, as well as the very personal one. I decided the book was more important. It had a potentially larger impact on public awareness. I felt more comfortable with words than with doctors and scientists’ (DeBaggio 2002, p.31).

The same author expanded upon the meaning of writing. Moving from finding ways to speak out with a biomedical paradigm was important and therapeutic. As a response to writing, once the book had been accomplished and published, there was a greater sense of achievement once the project was complete:

> ‘My intention in both this book and the radio interviews is to break through the sense of shame and silence Alzheimer’s has engendered. I want people with the disease to come forward, unafraid of exposing their illness, and tell the world what it is like. Doctors and advocates can help, but there is nothing like personal stories to humanise the silent, destructive power of this illness. The more we talk about it and expose Alzheimer’s, the greater the chance a cure will be found quickly’ (DeBaggio 2003, p. 141).

The feeling that others would connect with the words written helped establish an emergent sense of community, and this helped mediate with the ‘personal risks’ involved in taking a chance to write on a highly sensitive and personal subject. The evidence of this community was present across some of the texts. For the writers, how it helped them personally and cathartically or allowed them to feel they were helping others provided good enough reasons to write. It could provide the means by which they ‘wrote themselves’ into a new phase of life or identity. The matter of writing was one both of personal importance which could deliver wide audience appeal at the same time.

The diagnosis was typically regarded as a bridge that had been crossed and so there was evidence that this could mean social isolation. Given the losses that this could incur, this strengthened reasons to write and gain attention and respect for their personal journeys. Self-revelation was a powerful reason to write as was advocacy and agency. By responding to the threat of losing their 'voice' or status in society, this brought an urgency to telling stories of life with dementia and the social isolation that could accompany losses:

> 'All of us travelling this journey have a right to be heard, to be listened to, and to be regarded with respect. There is no time to lose to hear our voice as we struggle to communicate' (Bryden 2005, p.48).

By taking up the position of agency through advocating for a 'voice' and change to treatment by outsiders who lacked understanding about PwEOD, it was possible to use confession to develop a sense of community. This appeared to suggest that PwEOD do not lose their sense of self or ability to narrate. Rather, writing performs as biographical work to maintain and preserve aspects of their identity. In using dementia as a means to reach out to and create a community, the writers seek to deploy strategies of self-preservation to maintain a consistent sense of self. Individuals with dementia constructed narratives of self to preserve and protect their identities from the threat of loss of self. Such a community gave room and respect to the experiences of the writers along with the concerns and worries which could be understood as shameful or embarrassing.

A crisis or threat to the self could cause a problem with the 'old' identity. The restructuring of identity could arise most effectively through the data set of writing the four autobiographies and the blogging posts. Writing had brought success which indicated a new sense of self, identity and purpose. To varying degrees, activism was a role that each writer took up citing reasons to write as something which would help other PwD, PwEOD and the public improve attitudes to dementia. This restructuring reflected frequently mentioned remarked throughout the dataset that by writing, this was one way to construct a new identity on their own terms. This was one way to underpin latent threats to the self. There was evidence that others should connect with the words written to create, build and enhance a community. This ‘trade-off’ helped mediate with the ‘personal risks’ involved in taking a chance to write on sensitive and private subjects. Writing could be cathartic, informative and illuminating, but underneath semantic reasons, latent threats to identity could be changed through writing and thereby challenging the damage from a terminal diagnosis.

4.2.3.4 Summary

Loss of role, status and position within the family career and the wider social world could be painfully felt. At working age, whether male or female, all writers in the data set worked or had done up until the point of diagnosis. Beyond diagnosis, work continued, had to be redefined or a complete role change. Provision had to be made for early retirement or cessation of work. Shock was evident. Whilst changes had to be made by writers who confessed they could not work at the same pace as they could when fit; it was hard to step down. This could feel like a failure. This impact could affect how people felt about their gender, job and identity before others.

Beyond the challenge to the role, was the threat to the PWEoD sense of self. Writing about life with EOD was used to help each of the writers to reconstruct a new identity. This was done by exploring the issues they were faced with every day. In doing so, they could help build new components to identity and descriptive personalities played out for the benefit of others from within. In this section, the very personal aspects of role and self have been presented, but this inevitably interacts with more social aspects of identity, such as credibility and stigma, which are now discussed in Study Two.

4.2.4 Summary of Study One: Personal experience

Study One has explored the personal experiences of people with PwEOD, beginning with diagnosis, which was presented by writers as pivotal, and bringing contradictory emotions including being both wanted and unwanted, and reactions of both shock and acceptance. Beyond the diagnosis, writers described their day to day experiences as living with dementia, much of which could be described as feeling lost in time and space. Identity was impacted by both the diagnosis itself and the experiences of living with dementia, and the writers described how they had lost both their previous roles in life and their sense of self. Not all dislocation however, was negative. Writing had been used to help reconstruct identity with a diagnosis of dementia.

Study Two progresses to explore the social and interpersonal aspects of the experiences of PwEOD, many of which mirror their personal experiences, yet allow the opportunity for exploration from a different angle of a social connection and inclusion.

4.3 Study Two: Social and interpersonal aspects

Study Two addressed the social aspects of lived experience of PwEOD. The themes and subthemes throughout Study Two allowed insight into PwEOD describing their experiences socially amidst others in their everyday world. The central themes which developed from the data set were the notion of dementia as a contagious condition of which others were afraid. From contagion, there continued the themes of blame and shame and identity. From these flowed subthemes linking to the major themes selected from the data set which highlighted semantic and latent aspects of the everyday lived experience of EOD.

4.3.1 Theme 1: Dementia is contagious

The diagnosis period was of interest in the analysis of the study as the writers themselves drew attention to this as an important period and event, in both a social sense as well as personally. This event contributed to the way in which they represented the condition to others in writing, exhibiting how they experienced reactions surrounding their diagnosis. The idea of contagion was drawn from the words of a contributing writer, ‘some people even think dementia is contagious!’ as it appeared to reflect how, although dementia, like cancer for example, was popularly understood as a life threat, and therefore evoked sympathy, it also evoked ideas of stigmatising contagion. Experiences and textual representations of contagion were prevalent in a number of places across the data set and considered important because it captured something significant in relation to the nature of a cultural understanding of being rejected through fear in others that they might be somehow infected or inconvenienced by it. These could be explicitly discussed or implied through treatment through other social actors during certain situations or events. While it is known that dementia is not ‘contagious’ in the usual use of the word, the writers reflected concerns about making others feel uncomfortable through having dementia:

> ‘As soon as my diagnosis was announced, some people became very uncomfortable. I realize the shock and pain, especially to those who have a parent with this disease, are difficult to deal with at first. It was strange that in most cases I had to make the effort to seek out people who were avoiding me and look them in the eye and say, “I don’t bite. I am still the same person. I just can’t do my work anymore. I know that one of these days I will not be in here anymore, but for now, maybe for another year or two, I am still home in here and I need your friendship and acceptance.’ (Davis 1989, p.100).

In company, there was a disenfranchisement with humanity and belonging. The following text continued to expose levels of isolation and spoke of acute loneliness and alienation arising out of feeling contagious:

> ‘Isolation is a real problem for us. Many of us feel that some people even think dementia is contagious! We don’t see any friends any more. It seems as if people treat us differently now, because they know we have dementia, and they don’t know what to do’ (Bryden 2005, p.121).

With little understanding of causes and ways to cope with the condition, the understandable reaction was to fear and reject those with the condition:

> ‘What happens when you tell people you have Alzheimer’s disease? My experience has been that the announcement is initially met with silence. People then express their sorrow, mention something about an article they read about new advances in the fight against the disease, and then change the subject. The next time we meet, they apologize for not “saying more”, and then with watery eyes they tell me their experience with the disease in a relative, friend or neighbour’ (Taylor 2010, p. 51).

This suggested some reflection of family kin being afraid that they might ‘catch’ dementia or be consumed by the symptoms and way of life of it:

> ‘Frequently, my caregivers acknowledge that they don’t understand me. Sometimes, they admit to being temporarily depressed. Always, they see me as the cause of their own problems. Oh, sure in the beginning they said it was the disease talking. Now they don’t hear the disease; they hear mostly me. Therefore, I am the cause of whatever changes they are experiencing in their own personalities’ (Taylor 2010, p.64).

Dementia could have a detrimental effect on members of the family, with an acute awareness of this by the PwEOD. Fears about coping with dementia suggested being affected by the condition itself. Whilst PwEOD may struggle to find and retain the self or redefine the self within a dementia diagnosis; the family carers are indicated to have similar doubts about their own cognition and abilities to cope:

> ‘I believe as carers see the same signs as I (and they see many more, because I am at a place where I can’t see or understand my mistakes), they too develop an existential fear about who they are, if they can make it, and will they be successful, and they try harder instead of withdrawing’ (Taylor 2010, p.70).

Losses were difficult to quantify, and as a result, PwD and their family kin could experience difficulties in expressing their grief and emotional conflict. This could impact upon the individual creating loneliness:

> ‘I have purposely stayed away from Francesco as much as possible, although it hurts me. Every time I have talked to him about how I feel and what we can do to transition the business to him, I end up choked with emotion and wet-eyed. He has to be cleansed of my emotion. He will have to take care of his mother, as well as himself and Tammy, after I die. I am afraid I may have passed the genes for this disease to him, as I think my father or mother may have unknowingly passed them on to me. The thought of transmitting this hellish disease to someone you love is almost more than anyone can bear, and it fills my eyes with tears’ (DeBaggio 2003, pp. 68-69).

This passage articulated well the concerns and fears surrounding dementia and the fear and guilt of potentially passing on the condition to future generations of the family. This could be driven by the presence of the PwEOD in the home and further entrenched by media stories producing narratives of disease statistics and discussing serious illness in ways that could communicate epidemic levels of disease prevalence.

The impact of this contagious view of EOD inevitably led towards stigmatising effects being felt and contributed to the breakdown of identity discussed in Study One. The theme of contagion and the experiences that described exclusion were based upon deliberation of blame and shame, which appeared to be woven into daily social negotiation.

4.3.1.1 Summary

This theme linked the experience of personal identity drifting within a framework of liminality. It reflected how the writers felt impacts regarding their role, their selves as they understood their lives in society and from this, it was possible to restructure their lives within their written material. These attempts revealed how identity was managed in the face of the experiences of having dementia. Feelings of liminality were not ideal experiences however, this finding was part of a larger theme which spoke of stigmatising experiences which made the writers express notions of shame and discomfort with their new identities.

4.3.2 Theme 2: Blame and shame

The second theme was titled blame and shame. Writers expressed awareness about the way they were treated. This centred around reactions to mistakes made. The label of dementia changed the way they were perceived so that mistakes made were inevitably ascribed to dementia:

> ‘For example, any housewife can forget a pan on the stove and burn dinner. She and her family just laugh about it and get a can of something else out for supper. If a person with Alzheimer’s gets caught burning something, it is a severe tragedy, another marker of the progress of her incompetency for self-sufficiency. In all likelihood it will take away forever her opportunity to cook unless she has a very loving, understanding family who will allow her to cook but keep an eye on the stove without her knowing it. For the healthy person, this oversight will just be an honest mistake but for the person with Alzheimer’s it may be the end to a whole line of productivity’ (Davis 1989, pp. 91-92).

These doubts and dilemmas were carried around in the heads of the writers. This could refer to the juxtaposition of trying to negotiate levels of blame guided towards the PwEOD, and therefore the difficulty of having to endure feelings and experiences of shame. Further to this, these writers felt that the dementia diagnosis meant they were now carefully watched:

> ‘Who cared if I got a traffic ticket? Who cared if I got lost going to someplace new? Who cared if I messed up a meal because I forgot a key ingredient? Who really cared if I didn’t close the front door all the way? If my family didn’t know where I was for a couple of hours, no one was concerned. Who cares now? Everyone!’ (Taylor 2010, p. 157).

Levels of surveillance could be felt indoors and outdoors with people who were known to the writers but also those outside who knew about the diagnosis:

> ‘I recently spent a week with my brother and his family. We see each other five or so times a year, and we frequently talk on the phone. He worries a lot about me. Early in the visit, we spoke of my illness, but fortunately it did not seem to interfere with the rest of the visit. One morning, I arose unusually early and ensconced myself in the bathroom at the far end of their house. As my brother and sister-in-law walked out of their bedroom, they noticed the door to my bedroom was open and I wasn’t in there. They looked in the bathroom that I had been using and I wasn’t there. They each began to search the various rooms of the house, shouting, “Richard, Richard, where are you?” I cracked open the door to the bathroom and replied, “I’m in here”. Apparently, they didn’t hear me. Suddenly, my brother rushed out of the house and started hollering, “Richard, Richard, where are you? Where are you? Where have you gone?” My sister-in-law rushed out of the back door of the house and began searching the backyard. Where was Richard? I put down the newspaper I was reading I was reading and leaned over, opened the door, and again said, “I’m in here!” Again, no one heard me. I hurriedly finished my bathroom activities and came out and announced in a voice loud enough for both of them to hear: “I’m here, in the house”. Both of them returned to the house and we all had a good laugh.’ (Taylor 2010, p. 184).

Essentially, these semantic examples described levels of surveillance based upon family fears for the PwEOD however, these examples indicated a latent representation of trust lacking in those affected by dementia. This latent aspect placed the PwEOD in a place where they felt that the elements of being blamed for their condition and as a result, shame. These examples of treatment by others were further explored by looking at sub-themes: credibility; stigma; and the concepts of walking and wandering.

4.3.2.1 Subtheme: Credibility

A dementia diagnosis affected credibility. Even before the diagnosis, credibility could have begun to have been eroded as an internal note to the self. This inevitably had consequences for how identity was affected and shaped:

> ‘’After 61 years, lots of people knew me as the pronoun Richard Taylor. I was a consistent, caring and comfortable pronoun. Gregarious and outspoken, as I was, people had a good idea of how I thought and in what I believed. I was, dare I say, predictable. I offered no surprises when I opened my mouth. My way was the best way, until someone convinced me otherwise. It took a strong verb to get me to change my mind. I pretty much ignored the nouns around me and did what I thought needed to be done, not what the nouns or for that matter, the verbs said should be done. I was a strong pronoun, seldom influenced by annoying verbs. When I said I would do something, I did it. When I thought I understood a problem, I solved it. I was consistent, straightforward, and dependable’ (Taylor 2010; p. 84).

There was an acknowledgement that prior to diagnosis, matters of respect, status and dignity were taken for granted issues. Beyond diagnosis, there was a new need to manage fears and external assumptions:

> ‘Earlier this year, I had a few days of trauma following being bullied by three people at a family function. It was almost teenage school yard gangster style, two in a smiling passive aggressive way, one person openly nasty and in front of others. Thanks (!!) to Mr dementia, I am no longer able to hold my own in situations like this, and consequently spent a few days crying into my hankies. I am over it, and as always have learnt some life lessons from it.’ (Swaffer, Reactions to dementia 8 March 2014).

Where PwEOD operated with accomplishment amidst the social world, this could lead to accusations that the condition was part of a fraudulent or delusional state, conversely threatening credibility in the opposite way:

> ‘At a nearby table, the Executive Director of one of the other State Associations said, ‘But she lacks credibility as a person with dementia’. He was questioning whether I really could speak on behalf of people with dementia. I did not fit his stereotype of someone in the later stages. I was devastated. In what way did I lack credibility? Did he think I was faking it in some way? Why would I lie about having this illness that everyone feared and was ashamed of?’ (Bryden 2005, p. 47)

These remarks made were uttered on the basis of knowing the writer had EOD and also held a position of some status. However, the remarks reflected how it was still possible to fail to offer the same level of respect that people without dementia automatically received. Although the two writers highlighted here did perform with credibility, cynicism still prevailed:

> ‘When you answer, “I have Alzheimer’s disease,” There is a strange look and uncomfortable silence. When Mayor Steve Clark and Commissioner Clare Oesterle, on behalf of the board of Dade county commissioners, presented me with a certificate of appreciation, this strange treatment was illustrated. Commission meetings are aired live on a cable channel and again in the evening for the benefit of those who are working during the day. That evening my family and I watched the presentation on television. During the shifting back to their seats, some of the commissioners, unaware that their microphones were open, were laughing and commenting, “He sure talks fine for someone with Alzheimer’s.”’ (Davis 1989, p. 101).

The issue of credibility could be attacked in many ways, and there were difficulties into what extent and in what ways others in the social world accepted the diagnosis of someone with EOD. Choices remained as to what extent others were able to accept a terminal condition, particularly when the PwEOD appeared youthful and well. This created a variety of stigmatising events and representations which were socially constructed.

4.3.2.2 Subtheme: Stigma

Coping day to day could be difficult, particularly when interacting with health facilities and staff who were dementia focused. This led to helplessness as the writers often could find no way to reassert old identities of credibility and non-judgement. The writers reflected astute recognition of their health condition and its drawbacks, at the same time, there was strong awareness of the shortcomings of others. Across the data set, there were many examples of acute awareness of losses and the lack of understanding in others:

> ‘The myths and fears about dementia – the stereotype of someone in the later stages of the disease that cause dementia – give rise to stigma which isolates us. You say we do not remember, so we cannot understand, do not know, so it is ok to distance yourself from us. And you treat us with fear and dread. We cannot work, we cannot drive, we cannot contribute to society. I am watched carefully for signs of odd words or behaviour, my opinion is no longer sought, and I am thought to lack insight, so it does not matter that I am excluded’ (Bryden 2005, p.40).

The treatment of the PwD/PwEOD as a result of the stigma attached, was described by the writers as an additional burden:

> ‘Do what you can to prevent the stigma of dementia. We people with dementia have two burdens from our disease. The first is the struggle with the illness itself. The second is the battle we have with what I call the ‘disease of society.’ (Bryden 2005, p.142).

This passage articulated stigma as driven by societal behaviours and responses and not those of the PwEOD. The comment below effectively separates the dementia condition from the stigma that could be carried with the condition:

> ‘But it is sometimes assumed that our confusion, our lack of speech, and apparent lack of understanding, place us beyond reach of normal spiritual practices, of visiting shrines, worshipping alongside you, and being in communion with God and with others. But to what extent are these assumptions due to the limits placed upon us due to the stigma of our dementia?’ (Bryden 2005, p.151).

Experiences noted could reflect attempts to conceal stigma in two ways. One way was to mask everyday appearances and exchanges. The other was to minimise obtrusiveness when the stigma is apparent:

> ‘It took me three years before I could speak openly about my diagnosis, overcoming the hopelessness and depression that exacerbated my dementia and took me on a downward spiral of dysfunction’ (Bryden 2005, p. 39).

For PwEOD, they could especially find heightened difficulties in firstly having to live with dementia but then be accused of not fulfilling others’ expectation of dementia. This suggested that PwEOD faced challenges on two fronts; on the one hand to minimise their differences and on the other hand, make sure that assumptions were not made by others so that they felt outpaced:

> ‘This has to be the longest intermission of my life! it started about a year ago, with the end of act one of my Alzheimer’s disease. I was afraid of act two because I heard I would be required to drift in and out, back and forth, from my old self to my new self. playing two characters, both at the same time; I wasn’t looking forward to being someone with someone with two identities….you know they aren’t you, but they are!’ (Taylor 2010, p. 57)

The following passage clarified the nature of others’ beliefs when confronted by an individual with a health condition who presented out -with expectation. Invisible illnesses or conditions did not permit the person affected to identify themselves as 'normal' or as 'disabled', or at any rate, in the way that they would prefer:

> ‘I don’t believe he has lung cancer. I cough just like he does! I don’t believe my mom has Alzheimer’s. I forget my keys too, and sometimes I get confused.
> He doesn’t have a genetic disorder. He has a blood disease. I know one when I see it. He doesn’t have Alzheimer’s disease. He has mental problems of you know what I mean.
> He can’t have diabetes! He is too young. He can’t have Alzheimer’s disease! He is too young……I thought only old people got Alzheimer’s disease. Hell, she’s 40 years old. Why should we even be talking about this? She is just plain off her rocker’ (Taylor 2010; pp. 194-195).

4.3.2.3 Subtheme: Walking and wandering

The activity of PwD as ‘wanderers’ is one that was noted frequently and was handled in a number of ways across the data set. Emphasis on walking helped express exasperating feelings about being monitored and surveilled by others. There was a discrepancy in the writer’s own perception of ‘walking’ as a purposeful activity and something which could provide relief from dementia symptoms. There was also the perception of others of that same activity as ‘wandering’, a problematic issue indicative of cognitive decline. This contrast in perceptions provides a poignant illustration of the blame and shame theme:

> ‘Wandering around and restlessness is one of the by-products of Alzheimer’s disease. Many people have tried to guess why Alzheimer’s disease patients are so restless and want to walk around at all hours of the day and night. I believe I might have a clue. When the darkness and emptiness fill my mind, it is totally terrifying. I cannot think my way out of it, it stays there and sometimes images stay stuck in my mind. Thoughts increasingly haunt me. The only way that I can break this cycle is to move. Vigorous exercise to the point of exhaustion gets my mind out of the black hole’ (Davis 1989, p.96).

Defences and practical reasons were offered in the passage for legitimate movement. Walking assisted with helping the mind out of the ‘black hole’. Being in familiar environments such as the home, local community or workplace could present as worrying provoking nervousness in the writers’ lives. Walking seemed to offer a sense of purpose and could be carried out successfully. It could expose feelings of being ‘at-odds’ with others, including estrangement and the perceived paranoia in other.

The texts, therefore reflected how walking without a purpose was frightening when feeling physically lost and cognitively confused alongside the judgement of others who viewed ambling or showing a stilted gait as strange. Aspects of dementia can be covert and masked by the PwD. Walking however, is not a covert activity. Walking was understood as being purposeful but wandering not. For example, it is regarded as mentally healthy, pensive and optimistic even to be witnessed ‘strolling’ however, ‘wandering’ attracts a whole different judgement from society, especially with reference to PwD:

> ‘On a number of occasions, I’ve been separated from my wife in a mall and in large crowds. I never thought I was lost, but others assumed I had wandered off. We’ve all heard stories about people with Alzheimer’s disease wandering off into the neighbour’s house and sleeping in their guest bed’ (Taylor 2010, p. 184).

The writer below reflects upon the perception of care providers and others of walking and wandering in PWD:

> ‘I’ve read a lot of articles, tweets and blogs in the last few months about how to manage ‘wandering’ of people with dementia. Just for a change (!!!) I’ll be very up front here, and say they are annoying me greatly.
> When I go walking, even if I get lost, I am not a wanderer… I am a person.
> Sometimes people like to go for walks, even people with dementia.

> Sometimes people get lost, even people without dementia.
> Sometimes people walk because they are looking for something, even people with dementia.
> Sometimes people go walking because they are bored, even people with dementia.
> Sometimes people go walking because they might be trying to "escape" or "manage" the boredom of living in an aged care facility, or feeling like they are in prison, when they have done nothing wrong.
> Sometimes people walk for exercise, even people with dementia.
> People with dementia are still "real" people, living their lives just as they did before acquiring the label of dementia. We are not wanderers, poor feeders, aggressive, or demented sufferers. We are often trying to live well, with very little support from others for our well-being or quality of life' (Swaffer July 29th 2014).

However, while writers justified their walking and wandering behaviour, they also expressed insight into the concern of others:

> 'Patients usually do not realize they are lost, and they seldom seek help and often do not respond when addressed. Passers-by, meanwhile, may avoid them, mistakenly attributing their behaviour and appearance (patients may be dressed only in a nightgown, and act confused or disoriented) to drugs, or alcohol for example. Whether patients become lost just a few blocks away from home, or travel quite far, they are vulnerable to exposure to the elements, hunger, traffic, and personal injury; and all the while, their families are left frantic with worry' (DeBaggio 2003, p. 34).

Finally, the following selected text presented a positive view of walking for reasons that it provided a release and was not associated with anything negative:

> 'I started walking again and each morning I stroll three, easy, flat familiar miles, always the same route. In the past, when I took this circuit, I came home with an invigorated mind full of the images and words eager to preserve for later use' (DeBaggio 2003, p. 58).

Outsiders or others could allot blame, but that did not necessarily mean that it was always absorbed in the form of shame or stigma. Certain limitations were accepted gracefully without too much regret or decline in mood and state. The effect of surveillance was an experience that was often referred to in the texts and often was interpreted as shameful in a way that felt like being blamed. It was often borne with patient irritation spanning to fear as the individual writer writing of experience or event recognised that there might have been some need for family concern and alarm.

4.3.2.4 Summary

Credibility, stigma, and walking and wandering constituted three sub-thematic concepts of the overarching theme of blame and shame, where the writers described how they had come to be seen in other's eyes. Credibility was crucial to identity. Before diagnosis, issues related to respect and status were taken for granted. Once a diagnosis took place, it could be a fluid matter knowing whether an outsider was pitching their belief in the PwEOD being disabled and unreliable in a malignant and deviant sense or a medical fraud. Stigma was another aspect of the experience, driven by outsiders and their perceptions, but making the life of a PwEOD more difficult.

4.3.3 Theme 3: Social identity

Under the final theme of identity lie two subthemes; the challenge to social identity and the reconstruction of social identity in the wake of a diagnosis of EOD. So far, the evidence drawn from the texts illustrated how chronic illness could be experienced as an assault on the body and mind of the person. It has been established in Study One that this can threaten the integrity of self.

4.3.3.1 Subtheme: Challenge to social identity

Managing of potential changes to identity from a diagnosis could not only be an issue for the PwEOD, but it could also be apparent in the eyes of others. The texts suggest that having dementia, particularly as a younger person, could provoke problems and a range of behaviours that undermine the personhood and wellbeing of PwD. These behaviours were hurtful and discriminatory by nature, although often unintended. These depersonalising tendencies could often occur due to a lack of specialised education in healthcare settings. Negative treatment could be felt and given as PwD can be regarded as invisible in society and, as a result, individuals could be treated with a lack of dignity and humanity:

> ‘I am an individual, with a disease of my brain, the part of my body that is very much influenced by my personality, by my attitude. Certainly, the disease is affecting me, steadily taking away more and more of my ability, but surely my individuality means it is going to be hard to categorise my decline so easily and with such confidence. And such charts and graphs and stages deny me my individuality, stripping me of any credibility at still being able to speak after years of living the journey of dementia’. (Bryden 2005, p. 49).

Much of the challenge to social identity related to being treated as a child or as if the individual with dementia was ‘vacant’. The phenomenon of being treated as a child was frequently referred to across the data set and provoked hurt and angry responses:

> ‘I am not a child. Even if sometimes I act like one, check me out- I AM NOT A CHILD!’ (Taylor 2010, p. 190)

This remark was coupled with the following statement from the same writer and reflected the anguish of being infantilised by others. Semantic content referred to not being taken seriously and being exposed to a treatment which was not fitting for an adult to receive. Latent content suggested a loss of identity by being managed by others as child-like with no responsibilities.

> 'One of the easiest ways for me to become angry is to perceive that someone is treating me like a child. "There, there, Richard, let me help you with that". "Don't touch that!" "Didn't I just tell you that?" "Now listen to me!". Unfortunately, from where I sit, there are no good models of behaviour that we can observe as children and then apply as adults to interactions with older and younger adults who have some form of dementia. I remember how people treated my grandmother when she was 92 and I was seven years old. I see how people talk and behave around older people. I have visited Alzheimer's care facilities and watched staff and caregivers relate to the guests. Through my haze, the future looks bleak. It is not so much what people say; it is how they say it. It is their body language. It is the look in their eyes as they lean slightly forward, place their hand on my elbow, look at me directly in the eyes in a way they would never look at another adult who did not have Alzheimer's and slowly enunciate their words. They emphasise the end of each sentence. Sometimes they speak louder than usual, as if I am hearing impaired' (Taylor 2010, p.189)

There were many statements and textual statements made across the data set where negative experiences were reported. These experiences could be annoying to anyone, but with the taint of EOD this was frustrating and stigmatising:

> 'I am repulsed by activity directors on cruise ships, much less some twenty-year old trying to get me to play childish exercises to rock music. I'm sure I would try to get back to my room and if stopped in this attempt I would become churlish and belligerent. If this insensitive director continued to push or become condescending and begin to pat my arm, I would probably explode with all the violence pent up in my six-foot-seven frame. If I were then restrained or tied in my chair, my fury would take me right out of my mind. Why? Is this a result of Alzheimer's disease? No, this is how I would react in my best state of mind. I cannot stand the beat of rock music or the bouncing around or even senior citizen aerobic exercise classes. Human dignity demands that I have the right of refusal for any activity or entertainment that I do not perceive as entertaining. I deserve the right to withdraw from any situation and go to a place of quiet and calm that I have appreciated over the years' (Davis 1989, p. 102).

Being treated as absent was equally disturbing and fostered notions of not existing:

> 'I have become keenly aware of a patterned response from some individuals as soon as they find out I have Alzheimer's disease. They switch their eye contact and attention to whomever I am with. It is as if knowledge of the disease immediately cloaks me in invisibility. Richard has left the room. My body may still be here, but no one can understand what I am is at home! This happens with doctors, suit salespeople, hair cutters, produce managers, appliance repair persons, and many others. I am buying a suit at a department store and digging through my wallet for the card upon which I have printed all the accurate vital information I need to provide. The sales clerk notices my Alzheimer's bracelet and asks me if it is a medical alert bracelet. I say "Yes, I have Alzheimer's disease". He turns his back to me and attempts to complete the rest of the transaction with my spouse' (Taylor 2010, p. 152).

The concept of ‘being there’ and ‘not being there’, was highly relevant to identity. The writer below noted that other people strive to categorise the PWD as ‘not being there’. There was an appearance of finding it difficult to negotiate the middle ground:

> ‘For some reason, some segments of society have a hard time dealing with a person who is just partly here. If you are unable to carry on all the responsibilities of your work, you should be bedfast or at least drooling on yourself. One of the children at church illustrated this very well. After the final sermon and tearful farewell party and our very abbreviated trip, we returned to church to worship. This precious child of about eight years old, unhampered by the restrictions of manners, greeted me with his honest questions, “Dr Davis, why aren’t you dead yet?” I gently explained, “The disease just kills your brain a little bit at a time, and I will probably be around for a while longer. I will worship here at the church even though I can’t be a minister anymore.”’ (Davis 1989, p. 101).

The writers presented an opportunity to investigate ideas around how identity and self-construction could be affected, and what followed from this was the rebuilding of a new identity.

4.3.3.2 Subtheme: Constructing a new social identity

Latent understanding recognised the need to formulate and consolidate a new self. This could reflect how identity had to be managed in order to process personal loss in health as well as a feared loss of status in society within the family and workplace and produced. The reconstruction of individual identity was a process of amalgamating and assimilating their former with the new identity post-diagnosis.

A static conception of identity could no longer be assumed or enjoyed instead, a constant revision and reclaiming of a new identity could be sourced throughout the text whilst telling a story appreciated for its factual history as a sequence of events:

> ‘I have made a mess of a life designed with much promise. Instead of a glowing resume, I have a tattered life of insignificance. A life in backroom picture frame shops and steam-hissing tailor shops. A life of dirt and exhaustion. It turns out, to my recent surprise, a life that touched a few people and made them happy, or so they say in their kind letters’ (DeBaggio 2002, p.46).

In acknowledging a biographically disruptive event in their lives, it was evident that ways could be found to mediate between news of diagnosis and how that could be separated from former life before dementia was diagnosed. The potential conflict was apparent as the writers strove to preserve identity and autonomy in the face of losing former status and position, such as working life and having a profile in a community.

The texts suggestion that through acceptance of the diagnosis of dementia, new identities were brought into play, via a process of engaging with the dementia community. This identification with others with dementia was more than simply a sharing of experiences, but a new understanding and way of seeing the world, as illustrated below:

> ‘Why did I feel revulsion at the rat, while I love dogs and cats, all equally human companions and scavengers? We have made cults of birds, equal in scavenging and carrying diseases. Do we not have a long history ourselves of carrying deadly diseases around the world? Humans crave intimacy and it is easily had with dogs, cats, birds, and fish. But a cantankerous rat, carrying the weight of centuries of hate and misunderstanding, becomes a target of fear. This is a fear we carry with us and perhaps it is now part of our genetic code’ (DeBaggio 2002, p.100).

The writer, in this case, contributed feelings of ‘outsiderhood’ in speaking out. The passage reflected a strong sense of identity and whilst speaking of others, ‘humans who crave intimacy’, this recognition was given parity with the animals who integrate with one another and their environment. The latent understanding of this was suggestive of the separation of the writer from others, sited at the margins but sought to return changed, with the flaws amalgamated into the reformed person. The assumption of humankind as it is understood, socially pitches them at the top of ecological society with rats falling somewhere near the bottom. Here, in this text drawn from the data, the writer embraces and warms to the rat both in the way it has been hated and resented as vermin by humanity whilst humans have also damaged and caused death across the globe throughout history. This feeling of outsiderhood brought an understanding place of belonging which was connected to the concept of community. Although rejected, stripped and humbled, new integration and reintegration within a new community could occur. The connections made demand a reconsideration of thinking and priorities before dismissing others:

> ‘What we do not understand, wild animal or human, we fear with murderous hate and it has taken great nations and small and laid them waste. A disease like Alzheimer’s has the same power to destroy as a bullet or a scourge, through fear and misunderstanding. Death is a natural by-product of life and we should not fear it; we must accept it whether we call it a disease or the end of life. Now every morning I throw extra fish pellets into the lower pool for the rat’ (DeBaggio 2002, p. 100).

Whilst regular day to day work in employment, for example, was no longer possible and the expectation is that the opportunity to join in with being economically viable and relevant is over, some examples showed how contesting their situation, made them reject subjugation underneath authority:

> ‘The publication of my book catapulted me reluctantly into the public eye in mid-1998, as someone with dementia who could still speak, and who was also prepared to talk openly about this disease and what it felt like to be on the journey from diagnosis to death. It was the first time anyone in Australia had ‘owned up’ to having dementia. I had ‘come out’, disclosing my disease, rather like those with AIDS must feel, brave enough to admit to a disease that people dread, dementia was a shameful disease, to be feared or denied, not one to be acknowledged and battled with’ (Bryden 2005, p. 93).

New and positive pathways located beyond the diagnosis of dementia were identified. Within the content, there was evidence of finding a new lease of life through contact with others who had similar diagnoses reflecting competencies and skills that others may have suggested would not be available post-diagnosis. Notably, therefore, this seemed to suggest that the community did not reflect identities of negative discrimination and discredited characterisations when joining together, therefore bringing a sense of balance and normality. This approach contextualised and managed the threat to loss of work by replacing a career with a new career of optimism, activity and advocacy. In this one aspect, a new job of work lay in the reshaping of their condition and presentation. Thus, in the example showing an unwillingness to accept the medical model alone, the ‘medical model’ was indicated to be insufficient by the new community of PwEOD and PwD:

> ‘During the next six months, I continued to go to my friends’ group, as my new life was unfolding with Paul. I shared with them my hopes and fears for the future. Soon Paul became interested in helping with the Alzheimer’s Association. By the beginning of 1999, he was able to have two days free each week, and so offered to help the Association to set up another group as well. We met in a community centre, sharing cups of tea or coffee and sometimes we would have outings or picnics. Often, we had circular discussions as we could not remember what we had just said, so a frequent comment was ‘I may have told you this before, but…!’ There was a lot of humour, a lot of openness, and a feeling of all being in this together. All of our friends from the group were invited to our wedding, to share in our joy. It was wonderful!’. (Bryden 2005, p. 43)

This passage continued to reflect support and optimism. For this writer, there was a demonstration of how their social life was expanding with her own as well as others’ engagement. The success of this was evident in ‘all of our friends’ joining in the celebrations around the wedding. This at a more latent level, suggested that by marrying, there was also an engagement with having credentials in the world’s expectations. This was because marriage indicated a moral, emotional and economic worth and investment in the individual. This investment could be regarded as self-developed around a sense of protest in not accepting giving in to a serious health concern.

Semantic meanings around the text offered an account of an event. Latent examination suggested the location of a social space which could support and introduce a safe place to display and present a new identity and way of approaching life post dementia diagnosis despite carrying a chronic health condition:

> ‘Emerging evidence is showing it is possible to slow down and even reverse cognitive decline in some types of dementia, when diagnosed in the very early stages or at the pre-dementia stage. We need to embrace this emerging evidence, or the negative impact to dementia care and our prognosis will be impacted greatly if we don’t. Professor Dale Bredesen is proving with his MEND protocol it is possible to reverse cognitive decline in people with MCI or early stage Alzheimer’s Disease, with lifestyle and other changes. We need everyone to get behind this research, and this way of managing people with dementia, as so far, the drugs trials for either a cure or for modifying the disease continue to FAIL. Of course, I’d like a cure, who wouldn’t?!’ (Swaffer 2017, January 11).

The quote revealing ‘emerging evidence’ of advances in being able to impede the rate dementia specifically placed the writer at the centre of the debate in locating better ways to treat dementia. It was evident that the blogger had a significant investment in scientific progress. However, more latent understanding could regard the blogger’s place as a marginal one seeking inclusion.

These examples are evidence of complex negotiating around identity, which may involve simultaneously seeking credibility in the wider social context, while also being strengthened by identification with the dementia community. The following short examples from the data set was clear in the way credentials were borrowed to produce a form of credibility and belonging:

> ‘I choose a new identity as a survivor. I want to learn to dance with dementia.’ (Brydon 2005, p. 170).

The choosing of a new identity is an activity of the self, using agency to opt for a new self on their own terms, and could also define a new agential purpose:

> ‘Since I started writing, I am more confident and more comfortable with who I believe I am. I am marginally less afraid of the future. I have a better understanding of why and how I am changing’ (Taylor 2010, p.220).

The option to belong and integrate with a damaged and broken self was achieved by siting the self as the subject of discourse. As a self-reflective agent constructing a distinctive identity, this flourished in mediating through others in the company around them. This allowed the writer to accomplish a newly defined self, having shed previously discredited personae in the eyes of others:

> ‘A few days later, a beautiful sunny, warm May morning, I received the galley proofs of my first book. They looked great! Maybe they would act as a ‘prop’ for talking to someone at the association, maybe they would prove I was someone with dementia, give me the necessary credentials somehow?’ (Bryden 2005, p41).

In a Post-Enlightenment environment having credentials are important to prove worth particularly when paid work is no longer a possibility. Despite not being able to earn an income as was possible prior to their diagnosis, the writer, in this case, had the prospect of the publishing of a book to engage their credibility. Doubts could be moved aside as the evidence of the book as a published piece of work erased the dubiety provoked by a state of illness.

Special communities, by their nature, include a certain group of people who are designated citizens belonging to that unitary group. Those not qualifying are left to linger at the margins. This means that those carrying stigma, flaws and representing the vulnerabilities of fragile and broken lives, are welcomed to contribute to a forum where differences are transcended for the benefit of all. The engagement of the writers provided evidence that they elected, in writing, to transcend their marginalised status to one of belonging:

> ‘When we asked people what difference coming to the group had made, all the answers were very positive. For example, Jack (not his real name) who was in his 70s and always happy to make cups of coffee, said, ‘This is the happiest I have been for a very long time, it’s like a very big happy family. I feel 100% better and wouldn’t now what to do otherwise. I have more chance to talk, and no one is irritated-everyone understands and listens. We are all in the same boat’. (Bryden 2005, p. 45)

As such, the examples of communities identified across the data set encouraged members to reframe themselves to seek new identities in the new collective personae:

> ‘Her words resonated with me, as they very much captured my feelings. The hopelessness and despair that I had felt after diagnosis were diminishing as I shared my feelings with others. I no longer felt alone, and knew that the Association, particularly Michelle, was there to help me. I was making new friends and going on outings, and I felt as if I was helping doing something worthwhile. I felt valued and given back my human dignity and respect. During that year I relaxed into this newfound safety net of support and put my energies into helping out at the Association’ (Bryden 2005 p. 47).

This passage was contributed by the same writer and was written in a similar vein to their previous comments however it offered a rich description of a biographical belonging to a community group sharing in all their highs and lows. This structure is at its most effective and powerful when biographies such as life crises and illness create a shared structure around a group of equals who have journeyed through suffering but have survived to institute a new identity.

The act of writing itself was not only used for personal identity reasons but inevitably and purposefully was a way of engaging with wider society. By writing, new groups and sensitive conditions and topics could be ‘written in’. Whilst the language of decline and economic losses were vocalised throughout the texts creating a demonstration of disenfranchisement from others and the world; some texts reflected that salvation had entered their lives. This challenged the need to recognise or value individuals solely as employees productive in work every day. Ultimately, this led to the expression of a more holistic journey, which had brought them to self-declaring a point of new community and citizenship. To do this, they brought their own diverse voices to the texts to be understood in society when the individual is taken over by chronic ill-health. This allowed the lack of productivity and contribution to work (paid or otherwise) to be sublimated as other qualities were raised. Ultimately, the personal nature of writing was a useful concept with which to understand as an inclusive experience within the vast range of experiences in society. It allowed for crucial areas of intimacy not normally determined as appropriate or well understood in society to be articulated and assimilated from the private to the public arena to create emancipatory discourses.

4.3.3.3 Summary

Managing potential changes to identity from a diagnosis could not only be an issue for the PwEOD, but it also included other social actors present in the social world. The texts suggested that having EOD provoked problems and behaviours undermining the personhood and wellbeing of PwD and PwEOD. This, therefore reflected how it was difficult for the writers to overcome a loss of identity as well as dealing with stigma a which, often imposed by others. This added struggle to gain a desirable identity. It was clear from Study One that writing was a strategy used to re-establish identity on a personal level. On a social and interpersonal level, identifying with a community of other PwD helped forge an identity, including the condition. This supported ways that the writers rebuilt a social and interpersonal identity.

By finding ways to cope with a diagnosis of EOD, the bodily limits and social circumstances of losses felt and experienced by PwEOD forged an adaptation to that loss. From this could emerge acceptance. Thus, an accommodation and flow of new identities emerged as in writing, previous credible lives could be underscored by the knitting together of a new identity as credible with illness now as it had been before illness had settled into their lives.

4.3.4 Summary of Study Two

Study Two again began with the pivotal experience of dementia, but this time explored the impact of other responses to the diagnosis, which were expressed through ideas of contagion. Parallel to the writer's personal experiences of living with dementia symptoms was the ability to see these symptoms through the eyes of others. This was expressed as blame and shame, in the form of challenges to credibility and stigma. The issue of 'walking and wandering' was used to illustrate the lack of cohesion between the writer's experiences and how they were perceived by others. These experiences challenged their social identity, just as the inward experiences challenged their personal identity, and as writing was used to reconstruct personal identity, so was becoming part of a dementia community used to reconstruct a social identity. The following chapter discusses the findings followed by the conclusion.

5 Discussion

5.1 Introduction

Autobiographical content throughout the analysis produced the writers' ideas of negotiating with the self as damaged by EOD. However, through writing ultimately, they explained their way to new self-constructions and identities. These emerged from battles with negative or unfamiliar experiences about the body and its condition. This could also lead to personal effects on the self, which could set in motion a drift from the mainstream and lead to an intimate bonding with a new identity which replaced the previous pre-diagnosis identity. The first theme identified was the diagnosis. This was viewed through a personal experience lens and was investigated from different aspects of the diagnostic experience. What follows is the discussion around the thematic concepts which arose from the findings starting with diagnosis.

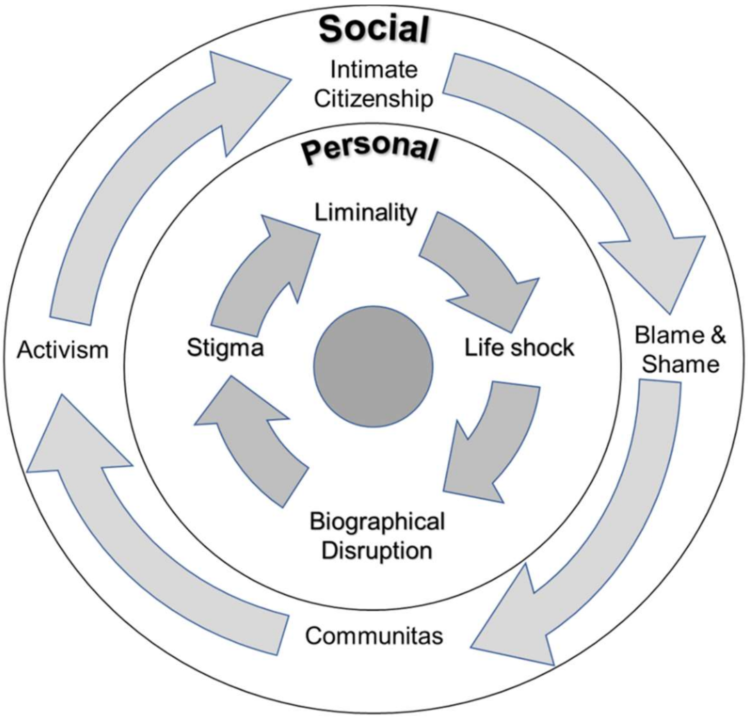


Figure 7 - Social and personal impacts

5.2 Diagnosis

The diagnosis period was a focus for the writers themselves. Each writer gave an account of the diagnostic impact of a serious and ultimately terminal condition. This was an opportunity that contributed to the way they represented the condition to others in writing and exhibited how they experienced reactions surrounding their diagnosis. It also provided a legitimate event from which the writers could draw meanings; life meanings, illness meanings and new meanings for the way ahead. A summary of experiences which appeared to be important to the writers was; diagnosis as pivotal, diagnosis as both wanted and unwanted and diagnosis as shock and acceptance.

The writers across the data set and present study presented diagnosis as a pivotal point in their stories. This was also a dominant theme in some of the SLR in Chapter Two; e.g. Flynn and Mulcahy (2013); Johannessen and Moller (2011); Allen et al. (2009). Other literature in Chapter Two supported the same findings (Jefferies and Agrawal, 2009).

Both in my findings and the SLR (Lockeridge and Simpson, 2013), it was found that small ruptures of events or larger crises provoked intervention and a need to confront a diagnosis situation. These situations could create exhausting journeys for those involved (Sikes and Hall, 2018). One writer in the data set, a former pastor of the church spent weeks suffering a wracking cough for which there was no remedy despite much medical attention and tests; '*After spending weeks in the hospital and almost $40,000, the very least they could do was to come up with a positive diagnosis!'.* Such tensions were tiresome and confusing; '*let's leave all the doctors and hospitals behind'*. This could make the uncertainty more draining.

As each writer in the data set wrote in depth about their diagnosis, the dementia experience was a journey upon which, with hindsight more clarity was brought to how that experience happened and what response was given. In writing, this offered an opportunity for exposure and was the catalyst for the initial response to the prospect of living with EOD; *'The hour, the day and most of the month after my neurologist said to me, "You have dementia, probably of the Alzheimer's type", my spouse, my family, my friends, and certainly I, worried, cried and ran as fast as we could down the first one hundred steps of the spiral stairway to depression'.* In the SLR, Lockeridge and Simpson (2012) also reported that the road towards the clarity and certainty provided by diagnosis was not always welcomed. Observing these issues referred to levels of wanting to know in order to return to normal and yet maintain a more blinkered view finding answers elsewhere.

In the data set, the diagnosis could be feared even if it was long suspected as being a required and necessary step. The SLR also provided evidence of this contradictory response to diagnosis. The desire to want an answer and at the same time, preferring to reject the ultimate diagnosis of EOD was present across the findings and the literature in Chapter Two. Some evidence in the SLR uncovered how participants' credibility was affected as participants felt they were not believed by a clinical audience (Johannessen et al., 2017; Johannessen and Moller, 2011). The diagnosis period was typically situated in the clinician's consulting room with differing levels of wanting to know the truth. Lockeridge and Simpson (2013) illustrated how spouses felt conflicted whilst pursuing a diagnosis. They reported that they felt a level of deceit in reporting symptoms at home. Whilst the data set sought to seek the direct experience from the PwEOD themselves without input from family kin, the writers themselves referred to their families both the impact and the support that occurred through a diagnosis. This meant that spouses could reflect their own despondency. Because doctors were unlikely to suspect EOD, often subjective criticism and blame directed towards the family members occurred as noted in the SLR (Johannessen et al., 2017). Some spouses were not often welcomed in the consulting room and their input was not valued (Johannessen et al., 2017). Often the diagnosis was finally achieved after investigation of a string of plausible conditions had proven fruitless in the data set; *'Dr Davis, why aren't you dead yet?''.* Denial was a plausible path to take given the novelty of the condition and was evident in the SLR as an adjustment to truth took place (Allen, 2009).

In Johannessen and Moller (2013), a diagnosis meant that an explanation was provided for odd behaviour or withdrawal from previous interests, and the certainty of diagnosis could allow for an exploration of potential future pathways. On the other hand, experiences and feelings of blame permeated the diagnostic period. Such conflicts support a variety of emotions in response to diagnosis (Hall and Sikes, 2018).

The writers in the data set all, in their own separate accounts, spoke of their disappointment; *'I wasn't looking forward to being someone with someone with two* *identities'.* Similarly, findings from studies included in the SLR suggested that whilst attempts could be made to incorporate new approaches to health like treatment therapies and healthier lifestyles, it was inevitable that the PwEOD would often feel discouraged (Hall and Sikes, 2018) and that suicidal ideation could manifest immediately after diagnosis (Hutchinson et al., 2016).

However, the diagnosis could also provide the catalyst for making life changes such as giving up career plans and total competence and reliability for both the PwEOD and their family for those included in the data set*; 'When I said I would do something, I did it.'.* Ultimately diagnosis was a step in the journey to acceptance for building a life as a PWEOD. The SLR also indicated the same viewpoint (Gelman and Rhames., 2018). Acceptance helped make the best of the situation (Rostad et al., 2013). Johannessen et al. (2017) and Sikes and Hall (2017) reported relief at diagnosis as it gave a rational account of the recent past.

5.2.1 Summary

The SLR reviewed in this thesis supports findings in the area of diagnosis. The two bodies of work, the SLR and the data set findings drew strong parallels. There was evidence of diagnosis being a pivotal incidence, diagnosis could be wanted and unwanted, also be a shock that eventually brought acceptance, and it was a catalyst for change. However, due to the findings being based on individuals who were published writers, they may be higher functioning than the average equivalent population, and therefore must be understood in terms of the small sample they represented.

5.3 Lost in time and space

This theme included conceptual ideas around feeling lost in space and time. Experiences about space and time were repeatedly referred to explicitly as well as implicitly. They were outlined as those experiences which could be understood and articulated as vague, elusive and unknowable; a state that led to ambiguity rather than certainty. These were experienced as being neither in one place or another. The findings reflected that experiencing being lost in space and time could be frightening, it could be baffling, or it could be an experience that was curiously different and not necessarily a negative one*; 'I float in my own chaotic world, grateful to know I am still alive'.* Such experiences are often referred to as liminality and chronicity and have been used in the fields of health research to write about chronic health conditions. The experience, therefore appeared under a wide variety of descriptions and sensations throughout the SLR and wider literature chapter. There was a divide between the SLR results, and the findings of the current study as the descriptions offered by PwEOD in the present study tended to expand upon their own internal and unprompted experiences. These were marginally less focused on clinical states and financial fears than experiences discussed elsewhere. With regard to dementia, the theme of liminality was found in some of the literature (Kelly, 2007; 2008; 2010). The results of the SLR were clinically led and based around semi-structured interviews, and this may have accounted for the more negative and fearful responses concentrating on issues making people feel lost or out of time and place (Rostad et al., 2013; Johannessen and Moller, 2011). However, it was a strong theme in both the SLR and the findings, ultimately reflecting that the shift from certainty to ambiguity had consequences for PwEOD. These consequences were tied up with identity as the inner person could feel lost to themselves. Where these experiences were admitted or could be evidenced by others, they could impact identity and status in society.

Living with EOD sometimes meant that sense-making and structuring rational sense from daily life was difficult: '*it is almost a "virtual world"*'. This notion was supported by the findings of the SLR, for example, Johannessen and Moller (2011) noted feelings of confusion and not knowing what was happening to them in the interim period prior to diagnosis. Gelman and Rhames (2018) reported experiences of chaotic feelings of 'otherness' and 'outsiderhood' in relation to change as well as leading to feelings of failure to cope (Rostad et al., 2013; Johannessen et al., 2014; Johannessen and Moller, 2011). Experiences of bodily separation from the mind in everyday life could manifest as a sense of loss and increase feelings of personal alienation. These feelings prompted these experiences to reflect sensory fracturing away from others or normality (Allen et al., 2009). The findings of the present study gave many overt examples of the oddity of the days going by which were not altogether negative but inevitably had consequences for identity and how PwEOD could integrate their lives with others; '*You are in a continual present.'* Johannessen and Moller (2011) noted feelings of confusion with a lack of feeling informed about what was happening to them in the interim period prior to diagnosis. This could feel like waiting was an eternal process and added to feelings of confusion. It was difficult to shape a normal life with secure identity with some of these pressures of being lost and lacking understanding was always difficult with life often feeling obscured.

Spatial and temporal aspects of liminality were identified in the present study. Ideas of space could be very confusing with PwEOD finding it hard to constantly trying to recapture the moment just past. Victor Turner's (1969) development of liminality made progress in understanding spatial ritual activity with Turner's concept of 'abnormal time'. Social dislocation was found elsewhere in the studies too (Harjunen, 2003; Kelly, 2007; 2008; 2010; Hale et al., 2010). Themes connecting experiences of losing time and space were drawn together by notions of liminality and chronicity across the data set, supported by the findings of the SLR, and discussed in the background sections of Chapter Two. This was expressed by writers in the current study as insecurity of person and not feeling 'in place'. These included different but connected ideas such as; feelings of exclusion, disorientation and being in neither in one place nor another in mind, self and location. Most studies in the SLR revealed experiences around liminality. Williams and Keady (2008) used the concept of 'bridging' to indicate how people with Parkinson's disease were competent to maintain a sense of stability and control. This was described as three stages of bridging; building on the past, bridging the present and facing the future, these concepts were consistent with the pre-liminal, liminal and post-liminal stages of the rites of passage outlined by van Gennep (1960). Johannessen et al. (2016) articulated lifetime rites of passage such as marriage, graduations and childbirth, which were under threat due to EOD. Therefore, there was an articulated experience of fears of achievements going unnoticed. Within this failed recognition, a detachment could form with dependents based upon feelings of exclusion and indifference (Hutchinson et al., 2016). The SLR reported families coping in ways that were more dislocated, spatially lost and remote (Flynn and Mulcahy, 2013; Johannessen et al., 2017). This was described in very similar ways to my findings on this theme. Johannessen et al. (2015) recorded metaphorical experiences of 'slipping away' of being 'in another world' and, 'spinning in a centrifugal machine'. Another writer wrote; '*my life feels like that – so full of spaces that it barely holds together'*.

The permanence of the status of liminality was referred to as liminoid. Exploration of the texts in the present study found that within this special feeling of ‘outsiderhood’ the individual could be a situationally or temporarily suspension from others but that this could become permanent taking individuals away from family kin and activities to which they were previously bonded. This could be a lonely experience as one writer wrote about, he was left ‘*unable to remember this morning, constantly trying to recapture the moment just past’.* The findings reflected that these were mainly negative feelings; *‘I am lonely in my dead life’.* Findings of studies in the SLR also indicated that those affected by such experiences could feel a drift from those they cared for and the places they recognised in the SLR (Allen et al., 2009). However, experiences of EOD and experiencing being lost and ‘out of step with time’ was not seen merely to be a state that provoked confusion of categories from ambiguity to disorder. It conferred a specialised status which had previously been explored in literature (Turner, 1969). In the present study, the liminal experience for PwEOD could be either a positive or negative experience but could also manifest as merely unusual, not easy to explain or describe; *‘my life feels like that – so full of spaces that it barely holds together.* Spaces and times like these could be referred to as a ‘virtual world’. The SLR provided some evidence to show that the often meandering nature of diagnosis, treatment and prognosis of the PwEOD could mean that whilst there were experiences of a strong ‘disconnect’ from things and people, euphoric traits could tempt those with and around EOD to a near point in the future where things might improve (Allen et al., 2009). Whilst this could be considered to be living with false hope, it was feasible that PwEOD and their kin could expect good trends and some underlying causes and symptoms to be treated, and improvements emerge.

It was reported in the SLR that some aspects of liminality were expressed as the burden of time passing seeming heavier in the case of chronic illness. The feeling of tension and waiting was present; the waiting on test results and to see if symptoms abated and there were periods of feeling better. Sikes and Hall (2017) reported reflections around the experiences of time and waiting. This was also reported by the writers in the present study; ’*Time does not mean much to me now’*. Time could feel more burdensome in the way that every declaration and event had to be waited upon. Such experiences were provoked by waiting for news, diagnosis, service provision and uncertainty about the future (Johannessen et al., 2016); Sikes and Hall (2018). By the time a diagnosis did arrive, emotional exhaustion prevented diagnosis from providing a ‘Eureka moment’. There nonetheless remained a feeling that life was on hold and there was no destination end to the journey. Bury’s biographical disruption theory was based upon Mead’s theory of how time was conceptualised in the social subject’s head. However, he proposed that in certain cases secure chronological steps could suddenly drift to a future perforated with losses and insecurities. This shift reflected the impact that EOD could fracture previous life with good health and shed legitimate fear of impending death, leaving the person with legitimate confusion and mistrust of time.

5.3.1 Summary

Most prior studies of liminality in health domains have explored some of the negative aspects of experiencing liminal spaces. Such literature has dealt with the ambiguity and confusion involved in liminal experiences; however, the structure of liminality extends further than a confused state of being neither one thing or the other, or in one place or the other opportunity for reflection and freedom from everyday routines. However, his present study found that the writers did not always describe this feeling or experience as a wholly negative one. Being able to explore issues of time and space, and liminality within the texts provided a unique opportunity to understand the meaning of these concepts as experienced day to day, by PwEOD.

5.4 Personal identity

One significant theme that arose from the findings was one of personal identity. How the individual took on the challenge of processing their customary self which, on the other side of a diagnosis of EOD, posted them at a crossroads. Previous ideas of roles, status, and notions of self were now in question. This was a permanent situation of seeking contingency plans where the person’s personal identity feared the task of being unable to bridge the past from future, old to new, health to ill-health whilst gaps emerged. These gaps emerged to distort the picture of the person’s past and future representations, making the present a tangle to sort out the broken parts to be mended. This made the task of sense-making a greater struggle than it had in the past.

The broader literature in Chapter Two reflected the ways that personal identity could be deconstructed with the effect of knowing that an individual had dementia or saw themselves exhibiting thoughts or actions attributed to the condition. Researchers in the field emphasised how suffering through illness altered an individual’s perception making them feel as if they were disintegrating, becoming lesser and losing their identity (Kitwood, 1997). Tom Kitwood noted these characteristics especially as important for PwD because clinical aspects underplayed potential for social interplay in care delivery as well as everyday exchanges. What was notable in his findings was how the PwD was affected by the social treatment they received from others. This was explained in Chapter Two and termed ‘malignant social psychology’. Examples of this were regularly described in their writing; ‘*One doctor paused at the door and turned to my wife and said: “You need not come back until he pulls down his pants and pisses in the middle of the living room”’.* This revealed the struggle that the self had in holding on to who they were and what they represented to themselves. Occasions and remarks like this assisted in deconstructing the old self leaving diminished self and doubt over who they were as individuals. The wider literature in Chapter Two noted how dementia challenged preconceived notions of self and self-hood, and how PWD sought transformative processes during changes to the self and identity. (Sabat and Harre, 1992).

A common binding conceptual perspective which illuminates the complexities of chronic illness in the individual is Michael Bury’s concept of biographical disruption (1982). This theory supports evidence that a diagnosis of permanent ill-health brings a radical shift to the newly diagnosed person's biography. This helps understand how a shock in the life pattern of everyday expectations of reasonable health and access to any planned or hypothetical life plan can be altered permanently. The data set prominently and consistently described experiences of fears of the changes within them; *‘We have labels for ourselves, names, jobs, addresses, memories’*. These reflected how such details were leaving the mind’s memory and left the person feeling void and obsolete to themselves whilst this crumbling of the self could be witnessed by others.

The SLR accorded with biographical disruption with themes around the fracturing of life upon diagnosis and in the aftermath. Gelman and Rhames (2018) reflected upon the chaos that occurred as well as the perennial uncertainty of living with EOD.

There were many examples of personal experiences of fragmentation across the findings of the present study. *'I worry I will become too conversant with this disease in me, and it will hijack my life with my permission'*. The findings of the present study showed how the illness affected the self-assumed trajectory of the individual's world where chronological certainties could suddenly drift to a future impacted with insecurities. Getting about doing everyday things could become a struggle, never mind larger-scale plans for the future; '*I have somehow lost the map in my head or at least the way that it connects to reality'.*

In the SLR, Johannessen et al. (2016) and Johannessen et al. (2017) noted how the overall burden of EOD on the whole family was a major biographical consideration. In these studies, shock was recorded prior to and beyond diagnosis. This occurred with the need to reshape life plans (Johannessen and Moller, 2011; Rostad and Hellzen, 2013; Sikes and Hall, 2017; Gelman and Rhames, 2016), spoke of developmental hitches occurring to both emotional and psychological development. The ways that this could be reported lay with noticing that a sibling had stopped smiling and laughing. Hall and Sikes (2016) reported a lack of awareness in children that dementia was terminal. This reflected the SLR's focus on family kin as well as the PwEOD and suggested that whatever life fracture occurred with the individual PwEOD in the family, the ripples were felt in other family members. This presented difficult and life-changing evidence that the dependents of PwEOD, as children and adolescents still living at home, found that their own life trajectory was altered, and their expectations were affected by their parent's condition. This led to descriptions of levels of parentification, which became normal ways to react to living within a family (Allen et al., 2009 and Johannessen et al., 2015). The wider impact of dementia on family members and friends was also acknowledged by the writers in the present study; *'Alzheimer's creates private family pain, the kind hidden and denied'.*

The evidence of my own findings acknowledged the fears about losses to the self which were found across all of the literature. The writers were aware of the fracture in their biographical lives and they were finding ways to establish and explicate how their identity could travel along a life journey with dementia. With the writers, this lay with adaptation which was situated around accommodating physical losses but looked also to reunify body and self-image; ‘*we were not willing to accept being categorised into a medical model of decline’*. In adapting the personal identity, it was possible to try and make a new person who represented the old but had to be assimilated within the individual. This supported the process of allowing social acceptance. This involved the individual acknowledging that impairment and temporary levels of rehabilitation became socially and personally seen and integrated personally and socially. One example was given of a practical situation with one of the writers in the data set when they unburdened themselves to a friend who came up with a solution to aid one symptom of EOD. This reflected how by way of disclosing and unburdening, the writers were able to relate their difficulties from their perspective and make new bonds as newly engaged people. Writing was the route by which this was proven. Whilst limitations to social circumstances always existed it was possible by adaptation, thereby accommodating the flow of illness in the lives of PwEOD.

By accepting the state of being a broken but salvageable person, it was possible to persevere with reasonable or high accomplishment. In the findings, two prominent writers had high profile campaigns, two others held more modest positions as activists and the remaining was active and accomplished in being able to write and publish a book. This demonstrated how accomplishment could travel with ill health even if this meant sometimes ignoring it with a struggle; ‘*and yet like me were still able to communicate, willing to speak out and wanting to challenge the accepted view’*.

These findings accorded with the explanation of Kathy Charmaz’s (1995) link with identity in Chapter Two, which emerged from Bury’s conceptual 1982 biographical disruption. This connected with the consideration of the impact of the assault the body and threat that impacted upon the integrity of self. This also aligned Kitwood’s address of the concerns around the individual. This meant that what the individual was fighting for was a renewed but damaged self. Charmaz was concerned with investigating the ways in which the person understood their body when it was subject to a chronic or terminal diagnosis (1991;1994). This ties in with Bury and Kitwood in shining a light on previous body confidence, and post-diagnosis uncertainties (Bury, 1982; Charmaz, 1991).

5.4.1 Summary

Ways could be found to establish and explicate how the body, identity, and self-intersected in illness. This lay crucially in adaptation, which resided around accommodating physical losses but looked to reunify body and self accordingly in ways that were workable and socially evident to others as identity forming. Adapting implied individual acknowledgement that impairment and rehabilitation become socially and personally seen in acceptable ways. Limitations to circumstances always exist but are still subject to adaptation when it is possible to accommodate and flow with the experience of illness. This could be seen elsewhere in the literature review. It involved periods of living with limiting illness include ignoring it and struggling (Charmaz, 1991). Reconciliation within reason may occur when, for example, one writer, Richard Taylor sought the skills of his friend to construct something to allay fears of finding his way to the toilet at night. Thus, such concessions are worked around but perhaps do, at the same time accept and reject being defined by limitations. This may mean seeking refuge in limited living. However, through a process of struggles with ill health, new identities around body and outlook can be born and managed (Charmaz, 1991).

Biographical disruption was a useful conceptual term provided by Michael Bury (1982) to acknowledge the threat to self when health and life were irrevocably changed by a serious health condition. Kitwood's (1997) theories around the treatment of PwD and Kathy Charmaz offer a useful platform upon which to understand qualitative experiences of PwEOD in this thesis. The aim for PwEOD was to look for ways in which to bridge this disruption and give meaning to their experience. The conceptual issues around personal experience in this section reflect that my findings do concur with the SLR which have borrowed the conceptual ideas in the wider literature review in Chapter Two to understand the experiences of having EOD. Therefore, my findings are not untypical. What they do present as unique is the added voice of the PwEOD affirming a combination of many of these conceptual ideas

5.5 Dementia is contagious

The social construction of PwD in the media and society has often been negative. The idea of contagion was initially drawn from the words of a contributing writer from the data set, *‘some people even think dementia is contagious!’*. This reflected how other health conditions like cancer or multiple sclerosis, although a life threat, tended to provoke tolerance, sympathy and understanding from others, whereas dementia often caused revulsion or dismissal. Experiences and textual representations of contagion were prevalent in places across the findings therefore, it was considered important. It was regarded as important because it captured something significant in relation to the nature of a cultural understanding of being rejected through fear. The SLR reflected these findings with reports of ‘dementia-by-association’, not in a literal self but in the sense of its effects being felt by family members. Ideas around contagion and stigma, which were evident in our findings; ‘*The thought of transmitting this hellish disease to someone you love is almost more than anyone can bear’*, were also reflected in the SLR. In some of the studies, it was reported that association with EOD created a need to frame stories and give different accounts to different people about the family member’s EOD (Hutchinson et al., 2016). The findings were also supported by theoretical concepts discussed in Study Two, for example, Goffman’s theory of stigma (1963) explored the consequences of a ‘spoiled identity’ originating from his interest in the interactions between ‘normal’ and ‘stigmatised’ people. Social impacts upon identity were keenly felt, and stigma is a sympathetic lens through which to explore theories of contagion.

The definition of contagion is given as; ‘the situation in which a disease is spread by touching someone or something’. Consequently, one of the theoretical, conceptual themes around stigma lay with ‘labelling’ which occurs when interrelated components converge. Such labels categorise the individual, using dominant cultural beliefs to negatively invest in the person marked out as different and then, accomplish degrees of separation of an ‘us from them’ organisation. Finally, labelled individuals experience a fall from status, loss and discrimination leading to disadvantaged outcomes.

Examples of stigma permitted an understanding of ways in which there was a lack of control over the body and seen as a lack of competency. In the data set, there was a broad and prolific discussion about discrimination due to EOD. These revealed the formation of stigma; ‘*The myths and fears about dementia’*, these were stated to distress and discourage the writers from attempting to retain normal function; – ‘*the stereotype of someone in the later stages of the disease that cause dementia – give* *rise to stigma which isolates us'*. The SLR reported the lack of confidence in being around others made PwEOD suffer suicide ideation (Johannessen and Moller, 2011). These feelings emerged through fears of rejection over cognitive abilities and the fear that in company, this would be magnified, and a sense of rejection would set in (Johannessen and Moller, 2011). This form of stigma by discrimination could be shown in self-harm (Allen et al., 2009). Suicidal thoughts were only mentioned once by one of the writers. The issue of stigma was present throughout the text whether latent or explicitly stated; 'And you treat us with fear and dread'. Johannessen and Moller (2011) in the SLR, described how PwEOD could experience stigma and marginalisation through having no control over what others knew about them, which could be personally frightening. This lack of control referred to going out or being around company out with an immediate family kin situation. Stigma dominated the fear that something might be said out of place and cause embarrassment; embarrassment that the PwEOD would be aware of as well as a fear that they might not even manage to judge their error. Whilst the root of stigma lay with what others thought, it was also notable in from the data set that; *'We cannot work, we cannot drive, we cannot contribute to society'*, therefore this provided a dilemma between being embarrassed in public. As a result, this operated to personally marginalise themselves by self-imposed or authority driven exclusion. Levels of surveillance were often noted and mentioned in self-conscious modes; '*I am watched carefully for signs of odd words or behaviour'*. The SLR reported Pipon-Young et al. (2011) discussing 'saving face' as a means by which people covered up their dementia through embarrassment and coped socially with potentially discriminating features of their lives. Although stigma operated to provoke those affected in order to conceal their situation, it was the case that often the writers would claim annoyance and disappointment that; *' my opinion is no longer sought*' and that they were; '*thought to lack insight'*, and therefore, '*it does not matter that I am excluded*'. The ability and opportunity to write and publish by book and blog meant that the data set had to be judged as competent even although in writing they frequently referred to how they were not trusted in life and, in fact, there were periods of the days when they did not trust themselves and had doubts around their ability to manage socially, and function like others.

Stigma-by-association affected participants across some studies (Allen et al., 2009; Hutchinson et al., 2016). These were present in the SLR because most of the journal peer-reviewed papers were focused upon family kin in order to glean experiences of living with EOD. Dependents felt stigmatised by having a parent with EOD. At any time, the participants reflected how difficult it was to manage their accounts to others, often changing information dependent upon to whom they were directing their conversation. This could make it hard to retain a sense of control (Hutchinson et al., 2016). Participant family carers in the SLR exposed feelings of guilt emerging from stigma-by-association in trying to foster a form of coping. This form of coping was focused upon trying to shield the PwEOD from difficulties in the time beyond a dementia diagnosis. The SLR reported how strategies were found to cope and deflect stigma both in the self and other family members (Sikes and Hall, 2017; Johannessen et al., 2016; Lockeridge and Simpson, 2012 and Hoppe, 2018). Crucially these experiences of being judged negatively emerged when interfacing with medical services (Sikes and Hall, 2017; Johannessen et al., 2016). Gelman and Rhames (2018) reported stigma like experiences reported through loss of status, self-efficacy and credibility. As a result of stigma, dependents could be left with feelings of irrecoverable lack of confidence. The findings of the present study also presented themes around stigma; *‘Frequently, my caregivers acknowledge that they don’t understand me’.* These accounts also contained fears for their family kin; ‘*Sometimes, they admit to being temporarily depressed. Always, they see me as the cause of their own problems’.* There was regret that they did feel that they burdened and embarrassed their families and made them draw heavily on resources both emotional and otherwise; ‘*Therefore, I am the cause of whatever changes they are experiencing in their own personalities’*. Sympathy and fears were extended to families. Where this was broached in the SLR a number of ways were adopted by the immediate family network to find strategies to cope and deflect stigma both in the self and other family members (Sikes and Hall, 2017; Johannessen et al., 2016; Lockeridge and Simpson, 2012 and Hoppe, 2018). Crucially these experiences of being judged negatively emerged when interfacing with medical services (Sikes and Hall, 2017; Johannessen et al., 2016). These were comprehensively written about in the data set in the present study.

Goffman noted how the need to show competency over stigma led to a performative element (dramaturgy). This referred to the ‘actings’ that individuals passed through in their micro-cosmic behaviour like a drama being played-out to affect an audience. This could protect against being viewed as failed or flawed. This was recognised in the data set by one writer who often did refer to stigma and explicitly and actively campaigned for its decline; In this, there was recognition from the writers in the present study that; ‘*all sorts of complex activities make up what we think is who we are*’. It was evident that through the freedom afforded in published books by authors and the one blogger that they could indicate an awareness of their self-consciousness and they were acutely aware of others surveilling them. This acknowledgement led to the understanding that the writers in the present study were aware of an audience whilst they possessed diminishing weakness and yet feeling obliged to be boasting strengths to others in their daily interactions. To emphasise performative elements did not suggest identity are typically inauthentic, but that identity was situated and accomplished with an audience in mind who had to be persuaded of that performance. This drew focus on identity.

Goffman argued that individuals with chronic illness and disability were stigmatised in the sense that they were discredited by whatever attribute rendered them ill or disabled (Goffman, 1959). Goffman recognised that those who lived with chronic illness were stigmatised agents in their own right. Thus, their identity of self, emotions and biographies were regarded as deviant or failing by those considered normal. The state between the normal and the stigmatised had the power and effect to alter the status and identity of both parties (Goffman, 1963). This awareness had an impact on how the individual felt and dictated their conduct and dominated their experience of EOD.

5.5.1 Summary

The concepts of contagion add theoretical weight to the findings under the theme ‘dementia is contagious’. The idea of ‘contagion’ affected PwEOD, their spouses and dependents in different ways. Some of this experience was rooted in the micro-relationships within the family and physician relationships; others emerged within social life in society. Gelman and Rhames (2018) reported stigma like experiences through the loss of status, self-efficacy and credibility. For PwEOD in company, there was a disenfranchisement with humanity and belonging. Therefore, given exploration in the research studies in this thesis, along with the writers included in the present study, levels of isolation were exposed, which reflected acute loneliness and alienation arising out of feeling contagious. These ideas have previously prevailed around an individual or group of people exhibiting or harbouring something unpleasant, for example, AIDS or leprosy. This reflected a recognisable negative trope aligned to a cultural collective rejecting anyone considered contagious. This could be regarded as another unwelcome shift and nudge from society, to further remove the individual from full social acceptance. As such, it was the case that preferred identities lay with the ones people had before the health condition was diagnosed and had set into the body. However, these preferred images would not return after a diagnosis of EOD. The literature included in Chapter Two matched the findings drawn from the data set closely over many of the subthemes and forms of stigma.

The study found gaps in the literature, pointing to positive living experiences exhibited by PwEOD. The writers in the present study did exhibit this ultimately in many places throughout the writing. All the books and the blog posts demonstrated suffering, anger, personal diminishments and social snubs with many examples of negative and limiting assumptions by clinicians. However, with the weaving of the storied lives of experience, the writers managed to convey accomplishment, skill and worthy of standing alone on a stage before an audience.

5.6 Blame and shame

The stigma attached to credibility as well as walking and wandering constituted sub-thematic concepts of the overarching theme of blame and shame, where the writers described how they had come to be seen in other’s eyes. Credibility was therefore, crucial to identity, whether explored personally or socially. Before diagnosis, issues related to respect and status were taken for granted. Once a diagnosis took place, it could be a fluid matter knowing whether an outsider was pitching their belief in the PwEOD being disabled and unreliable in a malignant and deviant sense or a medical fraud. This was a stigmatising aspect of the experience, driven by outsiders and their perceptions, but making the life of a PwEOD more difficult. The notion of blame and shame outlined ideas around circumstances of PwEOD who, with years of life ahead, had to contemplate how to cope with an uncertain period of time ahead under uncertain conditions whilst they still held responsible roles to nurture the needs of family and earn salaries, or at least, have the full expectation of being able to do so. In this section, it was recognised how these choices were now narrowed. Life had to be formed around acceptance of having an undesirable condition, and ways had to be found to reinvigorate their new life-path whilst acknowledging that things would never be the same again. Therefore, credibility driven by the need to have a positive identity was critical.

The findings suggested that credibility was a hard currency to live without. The previous section focused on negative constructions of dementia and Goffman's stigma. Stigma is also relevant to the sub-theme of credibility. However, in this case it is not necessarily intended or unkind. At home, there was often a taint to the normal smooth running of living in their own home. The effect of surveillance was an experience that was often referred to in the texts. It was an issue to step from trusted citizen and family member to dangerous toddler overnight; '*any housewife can forget a pan on the stove and burn dinner'*. The data set gave many descriptions and examples of how the biographical shift felt for them; '*She and her family just laugh about it…... If a person with Alzheimer's gets caught burning something, it is a severe tragedy*', and this was noted to thereafter condemn trust and confidence in their competence. Conversely, there could also be a problem of appearing too 'well', and therefore not having credibility as a person with dementia; '*In what way did I lack credibility? Did he think I was faking it in some way?'*. It was noted in the literature that difficulties that could arise from appearing outwardly well and not fitting in with pre-conceived ideas of illness. Johannessen and Moller (2011) described how PwEOD could feel marginalised through having no control over what others knew about them. These small events spoke of stigma and something of biographical fracture as it appeared there was always someone to remind the PwEOD that they were incomplete and lacking credit as people. The SLR gave less opportunity for these voices to come forward. This, however, must not be taken to understand that these sentiments would not be voiced. It was perhaps the case that environmental and other unknown considerations meant that less discriminatory experiences were evident. It was therefore often difficult to know whether those reporting the experiences felt as if they were understood as unreliable in a deviant sense or as a medical fraud.

Within the studies in the SLR, reference was made to experiencing concern at what others might think of a drop-in work rate (Johannessen and Moller, 2011). In such cases, some were relieved to attain early retirement (Johannessen and Moller, 2011) thus avoiding further issues connected to their work, identity and credibility. However, the main notable issue was the threat to the entire family's credibility and identity (Johannessen et al., 2016). Particularly adolescents and the young, experienced identity issues related to uncertainty and shame (Johannessen et al., 2015). This led to a lack of being able to define themselves. This had consequences for their own identity. Johannessen et al. (2015) suggested that the integrity and identity of the family as a whole was diminished in certain participant groups. The parental role was eroded through illness as was the child or teenager's role interrupted. Therefore, this rupture felt like a continuous threat and in turn, there were not the resources to meet the needs of these families and individuals. However, the SLR did not expose the same level of concern, as did the writers in the present study. Again, this should not be simplified to assume it would not be an issue, merely that the interviewing focus did not lie there, and more studies focused upon the family kin's views.

Walking and wandering constituted an important sub-theme referred to in a number of places by the writers in the present study with reference to residential and hospital as well as home care. Within health and social care settings there is a tendency to refer to walking in people with dementia as 'wandering' and therefore people who were located walking around could feel being called 'wanderers' as discriminating and shameful. This thematic concept, therefore coincided with blame and shame. This was because as still skilful people, albeit with deficits, the PwEOD across the data set felt that sometimes when they were on the move, they were not trusted. There were feelings that too many people took an interest on PwEOD whenever they were on the move or had tasks to do; '*Who cared if I got a traffic ticket?'*. This was disconcerting and added to stress; *'If my family didn't know where I was for a couple of hours, no one was concerned. Who cares now? Everyone'.* Therefore, even although moving this felt like a loss of liberty as going anywhere was tracked, preoccupied someone else's mind or monitored, or perhaps banned outright.

Credibility was a critical element in retaining an intact identity. The tag of ‘wanderers’ was therefore resented. Walking was discussed as being therapeutic and to address the restlessness symptoms which can appear with dementia. Whilst the feeling of being surveilled was unwelcome, it was understandable that opinions and attempts to explain something that is usually taken for granted existed. The efforts individuals made in the sense of keeping their pre-illness lifestyle and identity intact by either presenting a face of coping with little changes affected to lifestyle and by disguising or minimising symptoms.

Walking and wandering was not specifically referred to in the SLR and emerged as significant in the present study, due to the use of first-hand accounts from PWD. It provides a unique insight into the discrepancy between the PWD’s perception of activity as functional and potentially therapeutic, and others’ perceptions of it as problematic and a sign of deterioration. It links with the concept of stigma, which acts of a lens through which outsiders see the activities of people with dementia.

5.6.1 Summary

The journey from chronic illness to face others’ reactions could be discriminatory.

The findings continued to repeat that situating EOD in a solely biomedical model, when it did occur or could be traced back to traditionally clinical views of the body, meaning that it made it less easy to ease the burdensome aspect of chronic illness with regard to potentially stigmatising activities. It was not possible to find positive factors, strategies and a strong social footing standing on principles if a sense of blame and shame were pervasive in those around the PwEOD. Only beyond this point being addressed could a positive view of identity be taken on and retained. My findings show that with the experience of feeling a lack of credibility, identity could not be restored as far as possible with lifestyles and skills, and further, an opportunity to define themselves out with models of care and philosophy.

5.7 Social identity

The final section of the analysis’ findings dealt with the social aspects of having a diagnosis of EOD. This explored the two subthemes; the challenge to social identity and overcoming the challenge with a reconstruction of social identity in the wake of a diagnosis of EOD. These two sub-themes were pertinent to the notions around biographic disruption and Parson’s sick role (1951), from which more contemporary development had been added to the literature, including Giddens' (1991) term, 'critical situation'. This critical situation understood that much could be learned about everyday events in routine life when disruption enters. This perspective saw a three-part trajectory of chronic illness and the realisation of its impact on a person’s life. The trajectory was comprised of; coping, in accepting the interference illness brought, strategy, which explained the need to possess an outlook which accepted the change brought in by illness and treatment and finally, adaptation. Adaptation arrived when repair came in to restore a new sense of normality and identity. As researchers have focused more on this disruptive effect of illness, the concept has been refined. In realising that illness can be permanent, Lawton (2003) drew enlightened views constructed and Charmaz (1990) both assisted in developing a more accessible understanding of illness. They suggested that when faced with chronic illness the self relates to the most available identity. This identity had to be one that was situated in a chronic illness setting meaning that prior identities and roles had to be set aside. This could be seen in the writers in our dataset, who incorporated EOD as a significant part of the new reformed identity. For the writers in the data set, coping meant the surrender of the past. Early retirement caused by EOD could be a life-changing departure which was not welcome but offered relief when struggles became overwhelming in the workplace and embarrassment of others observing a drop in work rate was too much. This finding was supported by studies in the SLR (Johannessen and Moller, 2011). Both the SLR and the data set made significant mention of impacts on social identity.

As has been noted throughout this discussion chapter, the SLR focused less on social identity than did the writers of the data set. This was because in writing autobiography and a blog, this could reveal a process was which provoked extended discussion around social identity, deconstruction, and then new formation of a fresh identity. It was seen in the SLR that a lack of definition to promote an identity meant a failure to promote an identity to others. Johannessen et al. (2016) reported how the younger members of families with a PwEOD struggled to define themselves. Johannessen et al. (2015) suggested that the integrity and identity of the family as a holistic group was diminished in certain participant groups. This could have consequences for the individual members were impacted equally. Each relationship dynamic had the power to have further negative effects as each member could build in resentment at the limitations foisted on them by EOD. Not being able to ‘be their usual selves’ had significant social impacts, and particularly for adolescent, this threatened their abilities to integrate into the social world and develop their adult identity. The data gave examples of the efforts of the writers trying to maintain ‘face’ whether they believed they had been successful or not; ‘My *experience has been that the announcement [of having EOD] is initially met with silence’*. This was a recurring pattern for the writers in the present study and was also reflected in the SLR. PwEOD tried to ‘manage’ accounts given to others; (Sikes and Hall, 2017; Johannessen et al., 2016; Lockeridge and Simpson, 2012 and Hoppe, 2018). Crucially these experiences of being judged negatively emerged when interfacing with medical services through ‘passing’ as normal (Sikes and Hall, 2017). The mastery of a spoiled identity lay with acting normally and appearing as if there was no acknowledgement of deviant conduct. This skill required a level of agency on behalf of the PwEOD in maintaining a competent ‘face’. The writers in the present study provided candid and open examples of how this hope was futile; ‘*People then express their sorrow, mention something about an article they read about new advances in the fight against the disease, and then change the subject*’. This taint of contagion containing stigmatising elements was limiting. Feeling attached to ideas of contagion were representative of culturally held beliefs and held meaning for the individual who might be acutely aware of the taint attached. As such, the ‘meanings’ attached to chronic illness were not solely personal. Instead, they became the outcome of shared experiences as well as the interactions with others. These relationships with the onset and establishment of chronic illness, required change and a ‘renegotiation’ of existing relationships at work and at home. The writers in the data set were able to promote the times when they experienced success in rebuilding identity; ‘*During that year I relaxed into this newfound safety net of support’.*

The managing of potential changes to identity from a diagnosis could not only be an issue for the PwEOD, it could be apparent in the eyes of others. The texts suggested that having dementia, particularly as a younger person, could provoke problems and a range of behaviours that undermine the personhood and wellbeing of PwD. These behaviours were hurtful and discriminatory by nature although, often unintended.

These depersonalising tendencies often occur due to a lack of specialised education in healthcare settings, but as a result, individuals could be treated with a lack of dignity and humanity; '*I am an individual, with a disease of my brain………And such charts and graphs and stages deny me my individuality'*.

This writers in the present study adapted to identity challenges partly through narration, which provided the opportunity to create a new self from a broken one. Enduring losses such as health and the previous certainty of a long life meant that biographical disruption was a matter of concern tied up with having sufficient credentials to 'float' an authentic identity before others; *'I received the galley proofs of my first book…maybe they give me the necessary credentials somehow*?' (Bryden, 2005, p.41). Publication and broadcasting boosted the writers' data set credibility. Doubts could be moved aside as the evidence of the book as a published piece of work removed any doubts like erased the dubiety provoked by the impact of EOD in the writers' lives. The sense of keeping pre-illness lifestyle and identity intact by either presenting a face of coping with little changes affected to lifestyle and by disguising or minimising symptoms; '*We met in a community centre, sharing cups of tea or coffee'*. The re-establishment of joining in with others as evidence of how a refreshed identity meant that it could be traded with the identities of others. This was a part of belonging and feeling included. This finding was unique to this study and had not been previously explored in relation to EOD. However, we can find support for the process of reconstructing identity through theoretical lenses such as biographical disruption. In these theories, the idea of the life story is implicit – narratives are the stories we tell about ourselves, but in the present study the life story takes form in books and a blog and becomes explicit.

Good and bad experiences were contingent upon how the self felt and how it felt it was projected to others all contained by how those others treated them. Respect could be damaged by the good intentions of individuals and organisations. As the writers and wider data in Chapter Two, struggled with their diagnoses, 'social attacks' upon their person could be difficult. One adult dependent in the literature spoke of their irritation of the 'Hollywooding of dementia' (Sikes and Hall, 2018). This is related to contemporary films and other media material which, when it was not catastrophising the condition, it was making it sound glamorous and as if it occupied an envied state. For this participant, they found that whilst the topic of having and living with dementia was aired regularly, it did not have an honest picture to present to the public. In the data set, there was occasions of annoyance when well-intentioned friends or strangers got in contact to discuss miracle cures for dementia. These all represented attempts which may have been well-meant but added to the deconstruction of the person that they had to battle daily. The focus on their condition or it being framed in the wrong way but one that the lay public found acceptable. These effects had an impact on identity and how PwEOD were socially understood.

5.7.1 Summary

Amid serious illness, identities could be reformed. When identity is broken down by illness, strategies could be applied as a means of trying to get back to ‘new normal’. The social aspects of a person’s identity could be played out in public. A new identity had to be balanced carefully between what was traded away in what could no longer be done and blended into the new and more inspired identity made up of new accomplishments. The writers across in the present study achieved significant impacts for their own individual careers and character thus restoring and perhaps making bigger more impressive identity gains than in their previous healthy lives.

While this has not been discussed previously in the literature around EOD, this process fits into conceptual notions of biographical disruption and extended the concept through the dynamics of self-construction in the midst of chronic illness by borrowing from Bury (1982); Charmaz (1983; 1990); Giddens (1979) and Parsons (1951).

5.8 Communitas and intimate citizenship

The previous discussion in this thesis has reflected upon how ideologies of post-Enlightenment clashed with a life of chronic illness. This aspect referred to in the previous section was sick-role conduct which underlined how values are based and predicated upon on those of individual autonomy, independence, hard work and individual responsibility. It was stated throughout the thesis that chronic illness like EOD became the arena in which these values were pursued, contested, and played out. Western capitalist society has hinged upon the productivity of its citizens, meaning that people function when they are ‘normal’ and healthy. When this functioning breaks down, any individual could be referred to as ‘deviant’ for the duration of their illness. Further difficulties arise when illness becomes permanent. This immediately puts a burden on those who cannot work for health reasons. This section dealt with how those affected in this category may define themselves or be defined by others.

Throughout this study, writers demonstrated their ‘voice’ through the medium of illness narratives. The autobiographical content in the data set reflected the writers’ ideas of negotiating with the self as damaged. However, through writing, they explained their way to salvation and new self-constructions. The final discussion section discusses how the writers included in the data set developed their form of ‘telling it like it is’ stories into a contemporary form of an autobiographical account of their experiences. They achieved this by process of showing the reader an adaptation from healthy, to decline, to redeemed once more. They represented ‘salvaged’ people who delved into themselves to develop recrafted selves. In this. They represented a form of communitas and intimate citizenship, which were explained in Chapter Two as two theoretical ideas which complement the processes the writers have presented throughout their combined texts as brought together as a data set.

5.8.1 Communitas

As an aspect of liminality, communitas was described earlier in Chapter Two of this study as offering a haven to those who will never achieve a crossing over to a place of normality within the mainstream. Communitas was understood to be a condition of exclusivity and difference. It offered a haven to those who will never achieve a crossing over but will adapt to claim a status both within their own ranks and yet still offer a representation to others outside communitas as belonging to an identifiable group, exclusivity and difference. Turner (1969) explained these boundaries of what occurs within and without as part of a dialectical process. Individuals excluded from functional day-to-day activities seek to find a sense of belonging and ‘getting on’ with life suspended in ritual liminality and, as such, became a kind of spontaneous sociability. This is best described as unconditional love for fellow man, fostering committed feelings of solidarity, brotherhood and equality. The process involved in the journey to a new, repaired identity could be referred to as a ‘cultural space’ from which, a strong sense of bonded togetherness occurred. In the analysis, these cultural spaces fell within the social bonds of communitas; a place where social distinctions and structure became less relevant and a collective identity could emerge (Turner, 1969)

This ‘cultural space’ was made up of the individual liminoid characters who accepted their permanent liminality. For them, communitas became a way of life. In this liminoid, permanent state of liminality, a comfortable state could be formed. Through an illness transition from salvaged individual, optimism could be brought to a new position of strength. For the writers across the data set, security and authenticity could be found through activism; ‘*I found out about a new Internet support group that Morris’ friend Laura Smith had set up’*. This reflected a sense of bonding within the group.

A diagnosis of EOD was the commonly shared reason that brought the group together as writers through bringing a voice to the condition through writing; *’We are all in the same boat’*. Once the identity shift had taken place, this provided a useful means by which to understand some of the dynamics that occurred with the writers in their representations. There was a consistent pattern in most of the writers’ books and blog which did express liberal happiness and credibility. These findings reveal identity gains. *’There was a lot of humour, a lot of openness, and a feeling of all being in this together’*. A sense of new identity and belonging were established for the writers in many examples. This relief could be represented as being constructed around a variety of factors relating to physical and virtual (e.g. blogging) groups. *’I feel 100% better and wouldn’t know what to do otherwise*’. The writers’ narratives from the data set described struggles with EOD, which were prevalent across the subthemes, but within redefining positive lives, there was perpetual crafting of a new outlook. Some writers were wholly activated and committed to raising awareness for them which may have boosted feelings of communitas. Of the writers whose careers had shifted to international activism on behalf of PwD and PwEOD, this outlook pointed to optimism and positive engagement with the future and those around them. These benefits arose beyond marginalised and excluded experiences of the recent past to a new transitioned state with a reshaped identity. This felt good to the writers whose activism brought others, social groups, invitations and media attention ‘*I have more chance to talk, and no one is irritated-everyone understands and listens*’.

This was not represented in the SLR. This was for the obvious reason which has been previously cited in this thesis, that clinical or research-driven questions, unless they specifically look for this quality (communitas and togetherness drawn from being apart from others), will be more difficult to discern. However, that is not to say that the quality of communitas was not present in the SLR. Under the theme of coping, many of the studies reported evidence of participants thriving with EOD although this would tend to include more family kin than PwEOD (Johannessen et al., 2017; Johannessen et al., 2016; Rostad et al., 2013; Pipon-Young et al., 2011). The SLR was more framed in ‘keeping active’ and ‘sharing a social life’. Johannessen et al. (2016) and Johannessen et al. (2015) in showing that coping enabled a detaching from everyday suffering in life to gain a safer perspective arguably was speaking of a form of communitas through acceptance which would be a necessary component the concept. Getting used to a ’new normal’ was also arguably a form of communitas (Hall and Sikes, 2018). However, this added little information regarding identity, except that by offering acceptance of living with the ‘new normal’ a liminal transition had taken place. The SLR’s results, rather more proposed how people could feel better and more supported and optimistic in their outlook. Therefore, the findings suggest that the SLR was capable of locating positive viewpoints and actions living with EOD, but it was difficult to extract communitas in the way that the writers’ body of work reflected.

5.8.2 Intimate citizenship

Intimate citizenship conceptually compliments how others seek to find their conventional role in a society often viewing them as often an unconventional fit. This could relate to individuals who had or were made to feel that they felt outcast and marginalised. Therefore, the data set which correlated to this phenomenon reflected a sharing of experiences through narratives on the matter of EOD but emerged to make positive sense and understanding of the situation. Intimate citizenship locates itself as a sensitising concept to negotiate with accompanied fresh thinking the diversity and plurality of public discourses and stories prevailing across the complexities of contemporary life. This form of intimacy allowed the writers to express with the freedom that which was previously unknown ways of living and being within social domains, Previous engagement with those considering themselves mainstream are expected to comment and criticise those indicating ‘otherness’. The aim of intimate citizenship thus is to fit in those who would be regarded as ‘different’, marginalised or excluded and offer ways to allow inclusion on terms that can be accepted by others into the social world on their own terms.

This perspective was appropriate to recognise such tensions, contradictions and anxieties. These anxieties flowed from intimate exchanges between people telling difficult stories to draw others to the centre of the web in untangling the conceptual problems of difference and unity; *‘I have made a mess of a life designed with much promise’*. Such a remark appeared to report a humbled honesty which arose from reflecting upon life before EOD. Beyond diagnosis, a different perspective could be gleaned; ‘*Instead of a glowing resume, I have a tattered life of insignificance’*.

Intimate citizenship conceptually explained a way of understanding that illness had implications for people who had stories to tell about ‘negative news’ or adverse impacts upon their lives. Using a personal form of writing revealed that they were, in some cases, keen to demonstrate their status which sought equal status requiring others to pay attention. One writer who had taken up activism about dementia and EOD claimed that she had ‘*owned up’* to having dementia’. In this respect, she had *‘come out’* and been the first Australian to do so. There were similarities with coming out stories; ‘*those with AIDS must feel, brave enough to admit to a disease that people dread*’. This reflected the creation of the comfort zone that was being created out of others (or the writer’s) potential discomfort. This was evident because; ‘*dementia was a shameful disease, to be feared or denied, not one to be acknowledged and battled with’*. Thus, whilst the language of decline was vocalised throughout the texts demonstrating disenfranchisement from others and expectations from society, there was evidence of salvation of the mind and body; ‘*The publication of my book catapulted me reluctantly into the public eye’*. This holistic journey brought self-direction and diverse voices along with the demand to be understood as individuals taken over by chronic ill-health*; ‘maybe they would prove I was someone with dementia, give me the necessary credentials somehow*?’. The consequences for identity was significant and how the self, now radically altered by illness could reform with credibility and compete as different but normal. This catered for the creation of emancipatory discourses and the reshaping of identity-based upon embracing their EOD in order to address life as part of their everyday community. These aspects again were less like the SLR. A sense of belonging was less prominent. This was possibly due to the different approach in gaining the data. However; for the writers of the data set, people '*like me were still able to communicate, willing to speak out and wanting to challenge the accepted view'*. This supported the will to bring new stories out of sheltered anonymity and suffering to take their place in legitimate public spheres.

5.8.3 Summary

The theoretical status of communitas and intimate citizenship were conceptually borrowed to illuminate the personal and social experiences of being diagnosed with EOD. In looking through this lens, it was possible to show that the process of adaptation and a sense of belonging outlined a window on unity between body and self in illness. Concerning the texts, this allowed for crucial areas of intimacy not normally well understood or articulated in society to be discussed. Such a shift was performed from the private suffering of individuals to a public arena where stories could be told. The obvious gap in the literature was the lack of being able to discern these experiences and examples with any certainty in the SLR. There were no studies which gave examples of allowing PwEOD the opportunity to be heard from studies looking at communitas or intimate citizenship. Two studies were found which related to dementia and the concepts but had a wholly different perspective. These studies were examining the ambience of residential care homes. They did not focus on individual sense of liberty, reinvention and experience of having 'crossed-over' to a different state. For this reason, it was not within the remit of this thesis to comment further on the SLR.

What these findings added to the literature illuminated the role and consequences for identity, how people felt about themselves. It demonstrated and defined a new self for social presentation and understanding where having assimilated illness had regained a new identity. Having EOD and enduring crises, complications, and flare-ups, the writers emerged and re-entered the social world newly intact. Communitas and intimate citizenship encouraged the writers to contextualise themselves within the parameters of a new community as salvaged individuals whose identity had turned around to the extent that challenged the writers combatted being 'written out' of the script in their social worlds but finding ways to re-engage as a represented group with the condition of EOD. These confessions were published as emancipatory discourses which opened-up previously hidden and closed-off worlds.

Therefore, it was possible to identify examples of communitas and intimate citizenship from the data set.

6 Conclusion

6.1 Introduction

The thesis aimed to understand what it is like to have EOD. This experience was understood through the medium of four autobiographies of PwEOD and one blog, which were the chosen methods of the writers in telling an audience about the experience of having dementia. This offered a methodology in-keeping with a qualitative approach. The findings provide a small but valuable insight into the experiences of individuals able to engage with personal accounts of what it is like to have dementia and how it makes them experience the social world.

This thesis concluded that stories both harrowing and unlikely can successfully be embedded in the wider world. Individuals who were considered in some of the clinical research as unlikely to be able to speak for themselves each gave an account of their lives with EOD. Being able to produce these stories in autobiography and blog posts, provided a more holistic view of the person with a chronic illness. An SLR supported the data set, which was synthesised together and provided findings, discussion and conclusion. The theoretical perspective lay with social constructionism and symbolic interactionism. These perspectives have a specific definition of identity: ‘Personal identity can be defined as the person we think we are. It is the self we know’ (Christiansen, 1999, p. 548). TA was used as a methodology as developed by Braun and Clarke (2006, 2014). This provided a versatile and sympathetic method and methodology to approach a yet small and fragile subset of dementia drawn from a small number of people.

The thesis found that identity goals are built upon the aims, hopes and goals of the future. Identity required empirical validation in daily life. However, with the onset of chronic illness, everyday life upon which former identities hinged also change. Further, when the person becomes lost with the impact of a terminal diagnosis, their former actions, lives and selves become set against an illness backdrop. At this juncture, it is possible to identify fractures to the previously certain and unblemished life journey. The notion of losses appearing with chronic illness and dementia is commonly observed throughout the literature. However, these findings found that there are more complexities for PwEOD. They must balance what is to date, still seen as a disease of the elderly and yet they still carry the many roles that people in mid-life have with family and career. This dilemma suggested significant fractures and shifts occurred to identity, which reflected a clear picture of the repeatedly mentioned present and potential impacts on life.

The concept of identity lay with how people create meanings and act assertively as they interpret their experience and interact within the world. Some identity goals are implicit, understated, and clear to see; for others, they possess explicit preferred identities. By writing, this provided an effort to reinvent, reinvigorate, and regenerate the self as new and different. Being articulate sufficiently to be able to describe their lives, this allowed for versatility of admitting vulnerability as well as resilience. This thesis found that at times, people with a chronic illness will adjust what they can manage in life as they live with a health condition. Expectations can gradually raise their hopes of a competent and happy life. Previously lowered expectations can be heightened to increase their identity goals and enjoy a positive course. At other times, lowered identity goals form an opportunity to be able to describe this competently from a stable and renewed identity. Adaptation to bodily loss and change articulated through writing was a support act to relate to others.

Writing allowed a valuable insight into life with EOD revealing that individuals may assume their preferred identities through the stories they construct and tell as they allow a new identity to emerge. However, emerging from the data, predominant in the SLR especially is a picture of potential impacts felt by not only by PwEOD but their family kin. Some of these impacts, present difficulties ahead for social and health care providers and planners who will encounter fractured families were age-related rites of passage have been ruptured and breached by the effects of EOD. This conclusion includes a summary of those contributing factors to the overall picture.

6.2 Aims

The aim of the study was to learn more about the personal experiences of people with EOD.

6.3 Overarching study questions and aims

The study aim was addressed by meeting the following objectives:

1. Establishing to what extent personal experiences of EOD are present in the extant literature and what this tells us.
2. Using autobiographical and other written content about the self by PwEOD to learn about the experience of EOD.
3. Focusing on the impact of having a diagnosis of dementia at working age and what considerations follow with this status.

The aims and objectives which were set out in order to help support the questions were as follows:

1. A systematic literature review of the experience of living with EOD
2. Identifying and analysing a data set reflecting autobiographical and personal perspectives of PwEOD, from a blog
3. Identifying and discussing themes appearing through thematic analysis from the content of the data set.

6.4 Summary of the study's findings

The writers in the data set through writing about their lived experience with EOD provided person-led narratives which ultimately achieved the following points that they; a) exist as a capable part of the population or b) do not intend to resign themselves to the same group perception of frail elderly well beyond retirement years. Instead, the writers in the data set challenged common assumptions and perceptions, that having dementia meant a living death with a predictable path paved to medical care and institutional care provision. In a younger population with dementia, there are threats to PwEOD who face losing a wage in the working world along with credibility, future hopes and goals for themselves, including immediate family members.

To surrender to a diagnosis of EOD may be to impose loss of a role in the family, community, as a parent, employee, homeowner and provider. In their writing, rebuilding and, at times struggling with their condition, it was possible to pinpoint movement towards a demand for a new and intimate citizenship model of dementia. This represented a framework within which PwD and PwEOD could find empowerment for the self. These views were comprehensively covered in the present study. If one of the writers felt diminished by any experience with another, the freedom of writing at their own pace afforded them the means to vent; ‘*The assemblage of doctors who followed me for more than a year met with me on almost a weekly basis.’*, This may have suggested the ‘professionals’ were stumbling in their efforts to cope with the task of controlling dementia within the person.

The SLR did not afford opportunities due to the nature of how the research was run in order to provide a large-scale plan. It was rational for the peer-reviewed journals in the SLR to have a clinical/research origin, but this did tend to narrow responses. This meant that although semi-structured interviews, for example, do lend room for the interviewer to follow the answers of the participant in order to generate a fresh line of inquiry, there is always a concern that the participant is aware of the nature of questioning and its aims. Published material offered opportunities for the writers to extend their circumstances in life to reinvent their new character. This character was salvaged from disaster and could be reborn; not perfect but redeemed through suffering. This offered an opportunity to overcome the taint of contagion and hopelessness.

The implications of this thesis, therefore, lie with the suggestion that the reach of personal narratives connected with this subgroup will continue to develop. The views exposed in the SLR and throughout studies One and Two extend into previously secretive, humiliating as well as taken for granted conventional ideas over our bodies and identities. Contemporary research has been reflected throughout Chapter Two. The data set, by electing to expose their stories of shock, suffering and salvaged identity provide for a model of citizenship which is relevant in explaining a contemporary history of health care and illness experience.

6.5 Contribution to knowledge

This thesis offers a unique insight. It adopted a combination of separate but related philosophical concepts through which a unique view was taken of the data set. These included Goffman's theory of stigma, Bury’s biographical disruption, sick role, theories around communitas and intimate citizenship and the ritual experiences of liminality as provided by the field research of van Gennep and Turner. These supported an illumination of the lived experience PwEOD. The data set comprised of very personal reflections that a small subset of PwEOD brought to the general public through their published content. The contribution to knowledge lies within a deeper understanding of younger individuals with dementia who still hold their own life expectations and obligations to others. The insight into their lives as expressed under their own direction offered valuable knowledge into the needs and possibilities for service provision and social integration in the future. This lends potential to policymakers and care providers across diverse social and clinical fields some small evidence of the ability to offer testimony and insight into the experiences of PwEOD. This may contribute, in time, the possibility to inform understanding of the practice, perceptions and stimulate new interpretations for all family members affected by the condition of dementia. It also raises concerns around potential impacts upon the family kin surrounding PwEOD. These concerns suggest families living with chronically ill parents in relatively young age may be suffering from not reaching and passing stages in maturity with everyday life opportunities being missed due to their home circumstances.

6.6 Dissemination of the findings

The dissemination of some of the findings in this thesis has already occurred. Two articles have been published. The SLR was accepted for a peer-reviewed journal[6] and, an opinion journal piece on social care models for the elderly and PwD was also peer-reviewed and printed in another Middle Eastern journal.[7] The intention is to continue publishing in peer-reviewed journals internationally drawing either single themes from the thesis or using the overall findings and discussion connected to this thesis. The findings also will be disseminated to Crossreach, the Church of Scotland's Board of Social Responsibility. My aim is to use a pastoral care route to consolidate the Church of Scotland's social learning programme to help congregations, church elders and others who volunteer or are charged with visiting or caring for people who have a) dementia, b) are elderly, c) vulnerable, d) have special needs, and e) unpaid family carers. The social learning programme aims to use the platform for learning, developing, connecting, to inspire and give confidence and competent training to the congregations and church leaders. These skills will be used when visiting and contacting vulnerable groups nationally.

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[6] World Family Medicine/Middle East Journal of Family Medicine Volume 17 Issue 3, March 2019

[7] Middle Eastern Journal of Psychiatry and Alzheimer's, December 2018 Volume 9 Issue 2.

More work with the same special groups focusing on the elderly and dementia will be carried out with Muslims in Dundee extending special projects completed in the past commissioned by His Highness Sheikh Hamdan Bin Rashid Al Maktoum of the United Arab Emirates. These projects will be extended by spending time in the Middle East working in a faith-based atmosphere with the hope of embedding social care policy across the Middle East and North African (MENA) region. Currently, in many countries across this region, care is provided for everyone living at home and supported by the family structure and servants. However, whilst there is excellent hospital care for acute cases, often chronic conditions are undetected. Families shield vulnerable and sick family members in the home unaware of a correct diagnosis. This situation often results in families either paying for them to remain in hospital indefinitely or at home where family and servants are unaware of diagnosis and have no knowledge of how to care for the person.[8]

6.7 Future research implications

Identity issues arose in the thesis and were examined and discussed throughout the thesis however, a few notable issues and possibilities were observed during the thesis which could not be enlarged upon. Potential impacts can be borne in mind by researchers in the field. One prominent issue related to gender impacts. The female writers who were married and were mothers as well as having careers exposed a need to defend or compete to maintain nurturing roles. They exposed some dilemmas about requiring to be looked after by family carers; *'Women diagnosed with dementia are deeply impacted, stigmatised, discriminated against and isolated'*. This contrasted with the three males who were represented in the data. Where modest representation by the male contributors were made which could be linked to gender or masculine hegemony, the data did not appear to reflect strong and overt representation or claims by the men. This may suggest that men were more comfortable with their hegemonic status and that as such it, therefore, did not require

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[8] In March 2018, I self funded a visit to Kuwait for one week to attend a conference at the Emir's palace Kuwait Development and Investment and Promotion Authority (KDIPA) which allowed visits to hospices, junior schools and meetings with parliamentary members of the democratic council with the concern about care and dementia. In October, 2018, I self funded a trip to Berlin to the European Union (EU) conference in medicine for the elderly where I met Middle Eastern doctors for the elderly. In April 2019, I will travel to Dubai with dementia as the main agenda.

to be explicitly discussed. Being cared for did not reflect the levels of anxiety and discussion as it did with the female writers. The women may have indicated more unrest at being incapacitated but still attempting to ‘hold it together’ whilst fearing negative social commentary from other family members. This was an interesting topic for future research expansion. The reason for this is the relative novelty of EOD occurring in the working years. This means that whatever conditions existed for working parents prior to a diagnosis of EOD, many changes were likely to take place, but the spousal, parental and family obligations remain intact. The dynamics within the family circle, therefore, are worthy of future exploration as are the obligations of nurture and care when they are disrupted by a diagnosis of EOD. The effect upon women, especially if they are wives and mothers are critical. Therefore, study of gender roles in families with a PwEOD might propose an interesting but concerning avenue for future exploration.

A significant part of this concern that emerged from the SLR as well as indicated in the two studies One and Two. This lay with the impact upon young carers. The precise number of young carers is fraught with difficulty when trying to determine true numbers because young people often do not identify themselves as carers because they are not aware of the unnatural nature of their daily lives and, as a result, remain hidden from the outside world (Boumans and Dorant, 2018). As a result, they are beyond the reach of special support services. This Dutch study elicited the following facts based upon interviews with young caregivers of single parents diagnosed with multiple sclerosis; demonstrating that the young carers felt silent, invisible and unacknowledged and in receipt of limited professional assistance. In the Netherlands, 10–13% of the children were currently being raised by a parent with a chronic medical condition. This is an obvious concern that young people, children and adolescents are daily tasked with significant care roles for parents therefore, all social, health service, and education sectors should research, plan and have policies in place to support these young people.

Within the issues affecting young carers, there are many concerns which range from everyday childhood and schooling but extend further. This gap in knowledge remains in the literature. The problem of young children requiring nurturing in homes where levels of their parentification may go fully ignored or are unknown by family insiders, educational and health and social outsiders suggest significant problems for society overall. Failing to learn how to be a child and adolescent inevitably affects adult function and the ability to nurture future generations and provokes serious concern. There are fears surrounding parentified children who appear across society presently in Scotland and elsewhere through absent parents, drug addiction, premature death of a parent, chronic ill-health, neglect physical and psychological abuse outside the condition of EOD. Amidst future research concerns there should be a sharpening focus on the individual with EOD, but this should not discriminate against the inclusion of family kin. As these reflect additional lives which may be undergoing unseen and unobserved negative changes profoundly affecting their adult lives out with existing alongside EOD.

The concepts involved in recognition of personhood, liminal outsider feelings connecting to malignant psychology, biographical disruption, sick role and identity problems are all established concepts in the field concerning research and discussion around dementia. However, there is a gap between the SLR and the findings. The SLR drew profound qualitative experiences, but they were predominantly drawn from family kin, with emphasis on young, adolescent dependents expressing many unmet needs. The findings reflect that more views from PwEOD should be encouraged. What they describe as experiences would be worth more investment from research to understand the less frightening aspects as well as seeking to reassure on the negative aspects. By researching more in-depth the forms of liminal and lost space and time experiences, more could be understood to provide more productive relationships and positive everyday therapies for PwD and PwEOD. Understanding experiences would be of interest to clinical research identifying different types of dementia to liminal thoughts and behaviour aside from the social benefit of understanding and supporting others well. The inclusion of the internet, for example, in current times means that for most of the population, there is immediate access to the thoughts of others, which comment variously and many about the thoughts of others. This reflects the level of diversity and intimacy which are all attainable immediately at the click of a button located within the four walls of our homes. This has become the ‘middle space’ which now mediates our thinking and how we calculate the moral and social worth of others. This tends to suggest that the future may belong more to Gramsci’s ‘thinking society’ rather than an obliging audience waiting upon the ideology of the day served from above to assist them with what they believe.

6.8 Strengths and limitations of the study

This section considers the practical strengths and limitations of the study which, may have affected the findings.

6.8.1 Strengths

The main strengths of this study lie in the examination of a little evaluated and understood subset of dementia; PwEOD by the assembly of an SLR in Chapter Two which provided a qualitative synthesis of contemporary experiences of EOD. This reported a limited number of studies currently available in the field. None could be found of a doctoral level which examined the qualitative experiences of PwEOD delivering their own experiences through published material. A modest amount of literature has recently turned to consider the subgroup of EOD, but most commonly adopts structured or semi-structured interviews. Whilst sometimes these were conducted at the PwEOD or PwD's home, the individual or family knew their inclusion was as part of a clinical organisation's protocol which was financed by state authorities. Many of the studies were created to assess or justify specific programmes already up and running or in the planning stages. Some interviews of family carers' experiences were elicited for the benefits of sharpening the perspective of the health projects or to boost the research field. Few studies have yet had the opportunity to look at PwEOD who have delivered their unfiltered (apart from editorial changes) views, especially looking at a working-age population's needs making this piece of work original. Studies based around interviews and overseen by clinical research staff while very valuable were, therefore, narrower in their aims than the scope of my own study. The gathering of data was completed by studies One and Two borrowed from a selection of different but interlinked social conceptions which helped illuminate the experiences of PwEOD. Therefore, this thesis demonstrates findings from the words of individuals who have constructed their own issues and are found to have much in common to most experiences, showing more freedom within the reported qualitative experience. This supported reflection upon a more rounded perspective of what the writers across the data set experience emotionally, spiritually, financially, physically and cognitively. These are set in ways that are in keeping with the current contemporary person-centred values in health and social care settings. Further contributions to the research body, including qualitative studies on experience could sensitise policymakers, health and social care providers to the factors likely to enhance service provision and care. EOD is a classification which brings its own separate concerns from those presenting in later onset dementias. Therefore, it may be fruitful for future research to explore further the experience of PwEOD. This would relate to both the personal impacts as a distinct condition with different symptoms to that of older onset conditions as well as experiences of coping within work and family settings. This thesis adds to the small body of evidence which has discovered the experiences of PwEOD in the form of person-led accounts of their own experiences.

6.8.2 Limitations

Limitations included the limited number of perspectives which were incorporated into the study. The SLR involved only four studies from PwEOD; the rest were comprised of family kin’s views. The data set in the findings chapter included the views of four PwEOD and one blogger with EOD. Studies included were conducted within a Western cultural framework within traditional family settings with a spouse and adults children engaged in supporting the PwEOD. The SLR did not afford opportunities due to the sample size to offer a larger scale study. The review included peer-reviewed journals in the SLR to have a clinical/research origin, but this did tend to narrow responses. This meant that although semi-structured interviews, for example, do lend room for the interviewer to follow the answers of the participant in order to generate a fresh line of inquiry, there is always a concern that the participant is aware of the nature of questioning and its aims. By reading published material, this offered opportunities for the writers to extend their circumstances in life to reinvent their new character as salvaged from disaster and now reborn; not perfect but redeemed through suffering.

The first-person dementia narratives were authored exclusively by American and Australian middle-class, well-educated people involved in some form of public service (for example, education, church ministry, civil administration). Gathering data from a narrow perspective had the effect of restricting generalising the findings to other family structural systems which, given global estimates of dementia prevalence, the experiences and problems present in very different parts of the world situated in diverse cultures are critical to gain. The possibility of examining a wider cohort to address these concerns was not possible within the scope of this thesis. For people in other parts of the world in different cultural settings, the findings in this thesis may have little meaning or resonance.

Whilst it should be supposed that experiences of dementia between PwEOD and that of older, less articulate or frail and disadvantaged people will be different, there is value in asking those who can speak for others with the same condition. This is preferred rather than relying on outsider health and social care practitioners making assumptions. However, the narratives do lack voices that reflect the diversity of the lived experience of dementia. Issues around culture, ethnicity, gender, sexual orientation and those of working age PwEOD are under-represented.

6.9 Concluding remarks

This awareness of the role that stigma plays in the lives of PwD and PwEOD is still a significant one. It is the main aim of the Scottish Association for Mental Health (SAMH) linked to the See Me campaign to reduce stigma in relation to mental health. This goal is a permanent aim with the organisation to diminish stigma levels that still exist for people with mental health conditions. While there has been much research on stigma (Thornicroft, 2006), there remains much work to be done. Therefore, stigma was an overwhelming finding of the research rivalling that of salvaged identity. Despite the findings revealing that people expressed what it was like to experience going from health, to chronic illness and then regaining a new identity gained alongside health condition, it was not a battle merely of the body but of social attitudes too.

As different conditions and states of being are frequently brought to the fore in the media and the public’s attention is drawn to them, some ground can be lost and damaged by the good intentions of individuals and organisations. As the writers and wider data in Chapter Two struggled with their diagnoses, ‘social attacks’ upon their person were considered to create stigmatising effects through assumptions about ill-health. One adult dependent in the literature spoke of their irritation of the ‘Hollywooding of dementia’ (Sikes and Hall, 2018). Optimistic framing of a condition that was described as causing significant disruption to life for all those directly affected could appear to be ‘making light’ of the reality. This was related to contemporary films and other media material which, when it was not catastrophising the condition, it was making it sound glamorous. For this participant, they found that whilst the topic of having and living with dementia was aired regularly, it did not provide an honest picture to present to the public. These represented attempts which may have been well-meant but added to the writers' experience of feeling deconstructed and disregarded. It might be borne in mind by policy and social planners that stereotypes of people encountering health challenges do not when asked, always wish to be defined as 'heroic' or faintly glamorous as they diminish in life. The thesis illuminates the voices of PwEOD and their kin who do not find succour in this description.

This thesis was carried out with the best of intentions. It would be hoped that the authored stories recounted in the books and the blog act as an inspiration for further research and integrated policies being put into action in communities that include health and social care agencies. But this likely will require to draw upon communities' own energies and decisions to intervene positively in each other's lives, particularly where they see the need and recognise finite available economic and emotional resources. The findings and discussion suggested that when faced with the deconstruction of the self, PwEOD attempted to construct something anew through their person-led stories. In some cases, some of the new aspects of identities lay in being to greater and lesser extents, activists and stated that they wished to be a 'voice' for others hopeful of educating others. This left some concluding thoughts; Ricoeur (1984, p.132), argued that the self only forms through the process of 'telling of the life story'. Ezzy (1990) built a narrative framework by integrating it with George Herbert Mead's discussion of consciousness, and concluded, 'The plots of narrative identities are formed in a complex interaction between events, imagination, significant others, routines and habits, and the structure of the soliloquy that forms a person's self-narrative' (1998, p. 251). The narratives of selves have been highlighted recently through a domestic interest and agenda in gender diversity. Often writing on just this subject, Plummer (2003) elaborates upon private decisions and public dialogues. These are situated in everyday life and potentially can be transformed from the territory that is often socially conflicted and differently understood to a new place of acceptance. In this place of acceptance, people who face challenges through health, or some other social description can find opportunity ro ‘redraft’ themselves before others as they proceed through life.

Finally, the aim of research in the social sciences is ‘to understand something of each individual’s perspective’ (Proctor, 2001, p. 361) and of the interaction between individual and public narratives. Beyond these aims, this research recognised that; ‘People with dementia may tell us something about what it means to be a human being, beyond our accepted cognitive definition’ (Barnett, 2000, p.26). Further ahead, these findings and thoughts may suggest a positive direction for PwEOD and PwD to prevail in storying their lives. In doing so, they have the potential to reinvent themselves as salvaged and repaired in authentic and engaging ways. This supports and compliments their mission to deliver a fresh narrative with reduced sense of despair and distaste.

7 References

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8 Appendices

8.1 Appendix 1 – Autobiographies by PWEOD

Name	Title	Career	Year	Diagnosis	Age	Gender	National origin
Christine Bryden	Dancing with Dementia	Senior	2005	YOD	46	Female	Australia
Christine Bryden	Who Will I Be When I die?	Civil servant	1998	YOD	46	Female	Australia
Richard Taylor	Alzheimer's from the inside out	psychologist	2006	Alzheimer's	58	Male	America
Tom di Baggio	Losing my mind	Herb grower/journalist	2003	Alzheimer's	57	Male	America
Richard Davis	My journey into Alzheimer's Disease	Pastor	1989	Alzheimer's	58	Male	America

8.2 Appendix 2 – Excluded papers

Excluded papers	**Rationale for failing to meet final inclusion**
Millenaar et al., (2016) Exploring perspectives of young onset dementia caregivers with high versus low unmet needs. Ch 3. In Young Onset Dementia. Towards a better understanding of care needs & experience. Neuro Psych Publishers. The Netherlands 2016	Seeking outcomes for future service needs-no investment in reported experiences
Millenaar et al., (2016) The experiences and needs of children living with a parent with young onset dementia. In Young Onset Dementia. Towards a better understanding of care needs & experience. Neuro Psych Publishers. The Netherlands 2016	Quantitative approach to study findings
Beattie et al., (2004) “How can they tell?” A qualitative study of the views of younger people about their dementia and dementia care services	Too focused on service outcomes
Williams et al., (2001) From pillar to post- a study of younger people with dementia	Seeking epidemiological data for service development
Kaiser et al., (2007) The psychosocial impact of young onset dementia on spouses	Stress on quantitative information and concern with clinical conditions not experience
Harris & Keady (2009) Selfhood in younger onset dementia: Transitions and testimonies	Focus groups
Johannessen et al., (2017) Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease	Focus on gaining information to inform GPs and IT services

8.3 Appendix 3 – Fifteen-point checklist Braun and Clarke

A 15-point checklist of criteria for good thematic analysis (reproduced from Braun & Clarke, 2006)

1. Transcription: The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for ‘accuracy’
2. Coding: Each data item has been given equal attention in the coding process
3. Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive
4. All relevant extracts for all each theme have been collated
5. Themes have been checked against each other and back to the original data set
6. Themes are internally coherent, consistent, and distinctive
7. Analysis: Data have been analysed – interpreted, made sense of - rather than just paraphrased or described
8. Analysis and data match each other – the extracts illustrate the analytic claims
9. Analysis tells a convincing and well-organised story about the data and topic
10. A good balance between analytic narrative and illustrative extracts is provided
11. Overall: Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly
12. Written report: The assumptions about, and specific approach to, thematic analysis is clearly explicated
13. There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent
14. The language and concepts used in the report are consistent with the epistemological position of the analysis
15. The researcher is positioned as active in the research process; themes do not just ‘emerge’

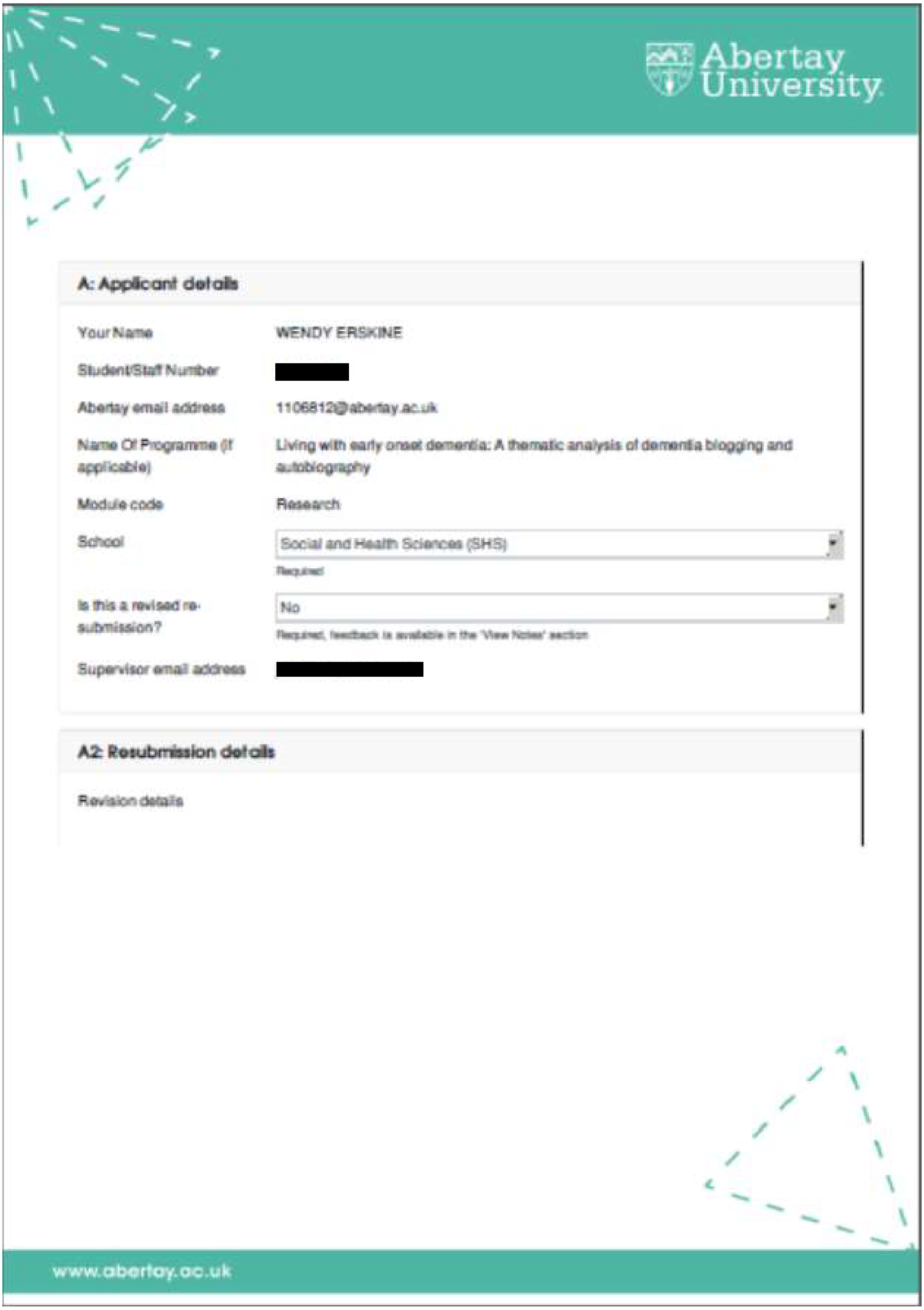
8.4 Appendix 4 - Braun and Clarke troubleshooting

What are some of the common problems I should avoid?
Have the data actually been analysed or have they just been reported ad paraphrased? Does the analysis go beyond the content of the data to tell me something about what the data might mean, and the implications of the patterns identified? Data need to actually be analysed.
Does the researcher claim that the themes ‘emerged’? This is a key problem, as it suggests themes ‘exist’ in the data waiting to be discovered, when analysis is really a more active process of developing themes through our interaction with the data?
Are there a lot of data extracts with very little analytic narrative? Aim for a good balance of data and analytic narrative
Are themes weak and poorly organised? Are they thin and sketchy or overly complex and unwieldy? Do they lack coherence? Aim for themes that are coherent and have a clear and identifiable central organising concept?
Is there lots of overlap between the themes? Is the relationship between the themes unclear? Do the themes fail to work together to tell a story about the data? Aim for a set of themes in which each theme is distinctive from the other themes, but there is also a clear relationship between other themes.
Overall do the themes provide a rich and coherent analysis that answers the research questions? The TA needs to provide a compelling and plausible answer to each question.
Is the analysis plausible? Do you see what the researcher’s claims they see in the data? Your analytic claims need to be seen in the data.
Are the assumptions around TA-and the form of TA used-clearly spelled out? The approach you use needs to be explained
Is there a lot of overlap between themes? Is the relationship between the themes unclear? Do the themes work together to tell a story about the data?
Is the analysis theoretically correct?
Do the claims made about the approach to TA used (inductive v deductive, latent v semantic, essentialist v constructionist and how the data actually analysed fit? Use of TA needs to be theoretically coherent. You need to do what you say you do.

8.5 Appendix 5 – Tom Kitwood malignant psychology components

Tom Kitwood - Seventeen components comprising malignant psychology
Infantilisation Treating the person like a child. Intimidation Causing the person to feel fearful as a result of threat or physical power.
Labelling Referring to people inappropriately, for example ‘elderly mentally infirm’.
Stigmatisation Treating the person as if they were an outcast. Outpacing Providing information or choices too quickly thus potentially making information difficult to understand. Invalidation Not acknowledging the reality of the person. Banishment Excluding the person either physically or emotionally. Objectification Treating the person as an object, for example during washing or dressing. Ignoring Conversing with others in the presence of the person as if they are not present. Imposition Forcing the person to do something. Withholding Failure to provide attention or meet an obvious need. Accusation Blaming a person for their misunderstanding or inability. Disruption Suddenly disturbing a person and interrupting their activity or thoughts. Mockery Making fun or joking at the expense of the person. Disparagement Telling the person that they are worthless. Treachery The use of deception to distract or manipulate behaviour.

8.6 Appendix 6 – Ethical permission



Abertay University

A: Applicant details

Your Name	WENDY ERSKINE
Student/Staff Number	[redacted]
Abertay email address	1106812@abertay.ac.uk
Name Of Programme (if applicable)	Living with early onset dementia: A thematic analysis of dementia blogging and autobiography
Module code	Research
School	Social and Health Sciences (SHS) Required
Is this a revised re-submission?	No Required, feedback is available in the 'View Notes' section
Supervisor email address	[redacted]

A2: Resubmission details

Revision details

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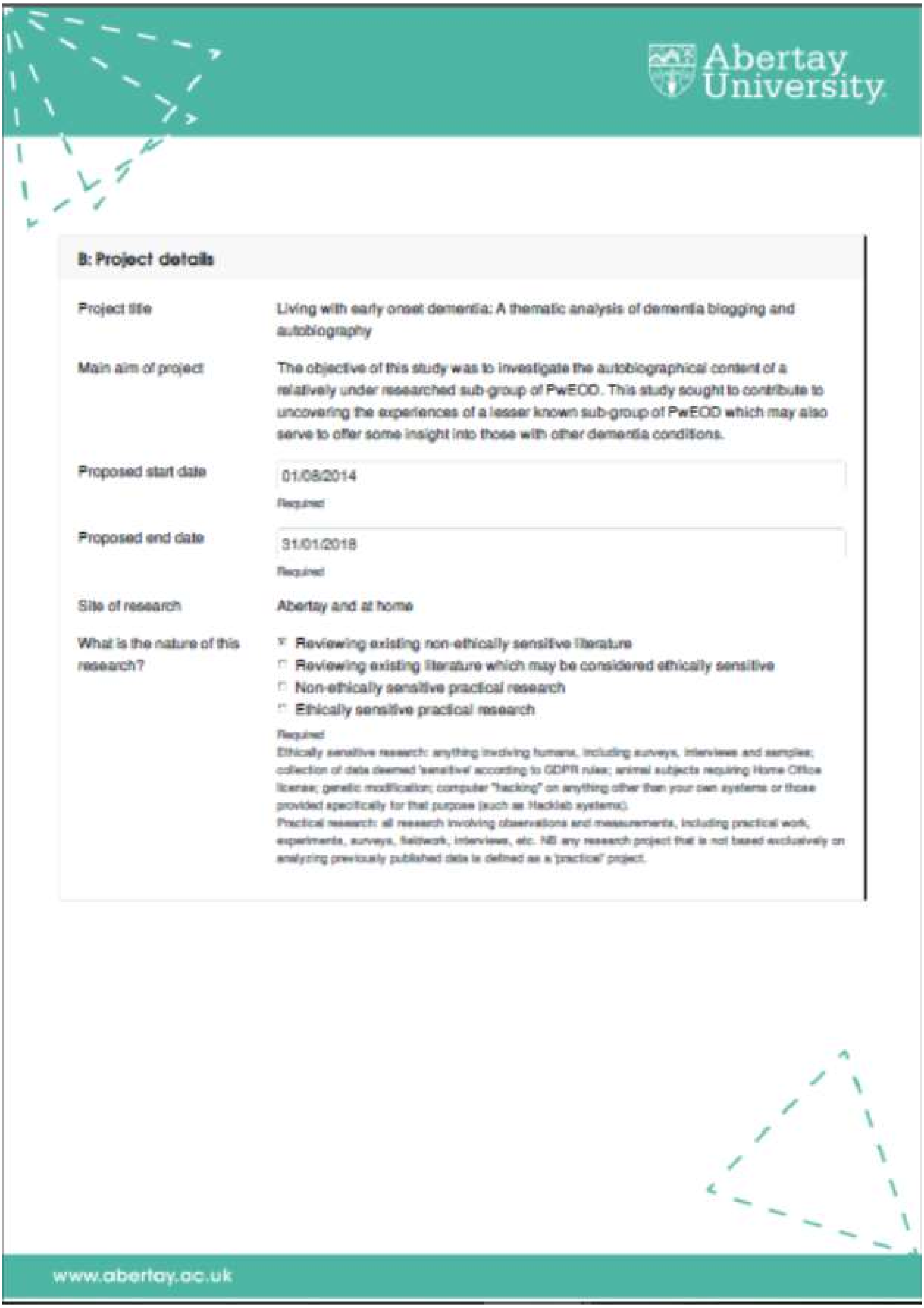
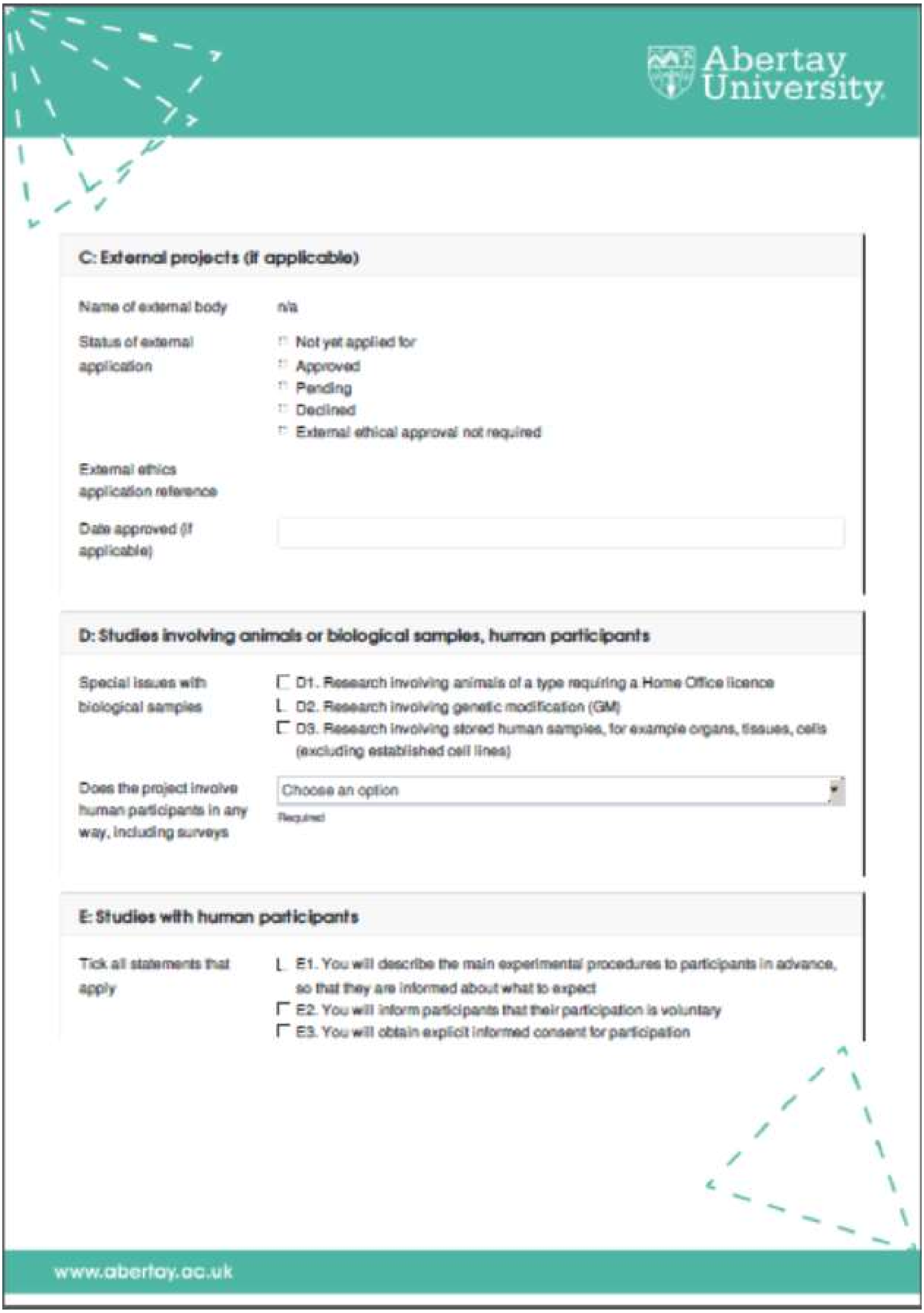


B: Project details

Project title	Living with early onset dementia: A thematic analysis of dementia blogging and autobiography
Main aim of project	The objective of this study was to investigate the autobiographical content of a relatively under researched sub-group of PwEOD. This study sought to contribute to uncovering the experiences of a lesser known sub-group of PwEOD which may also serve to offer some insight into those with other dementia conditions.
Proposed start date	01/08/2014 Required
Proposed end date	31/01/2018 Required
Site of research	Abertay and at home
What is the nature of this research?	☒ Reviewing existing non-ethically sensitive literature ☐ Reviewing existing literature which may be considered ethically sensitive ☐ Non-ethically sensitive practical research ☐ Ethically sensitive practical research Required Ethically sensitive research: anything involving humans, including surveys, interviews and samples; collection of data deemed 'sensitive' according to GDPR rules; animal subjects requiring Home Office license; genetic modification; computer "hacking" on anything other than your own systems or those provided specifically for that purpose (such as Hacklab systems). Practical research: all research involving observations and measurements, including practical work, experiments, surveys, fieldwork, interviews, etc. NB any research project that is not based exclusively on analyzing previously published data is defined as a 'practical' project.



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C: External projects (if applicable)

Name of external body	n/a
Status of external application	○ Not yet applied for ○ Approved ○ Pending ○ Declined ○ External ethical approval not required
External ethics application reference	
Date approved (if applicable)	

D: Studies involving animals or biological samples, human participants

Special issues with biological samples	☐ D1. Research involving animals of a type requiring a Home Office licence ☐ D2. Research involving genetic modification (GM) ☐ D3. Research involving stored human samples, for example organs, tissues, cells (excluding established cell lines)
Does the project involve human participants in any way, including surveys	Choose an option Required

E: Studies with human participants

Tick all statements that apply	☐ E1. You will describe the main experimental procedures to participants in advance, so that they are informed about what to expect ☐ E2. You will inform participants that their participation is voluntary ☐ E3. You will obtain explicit informed consent for participation

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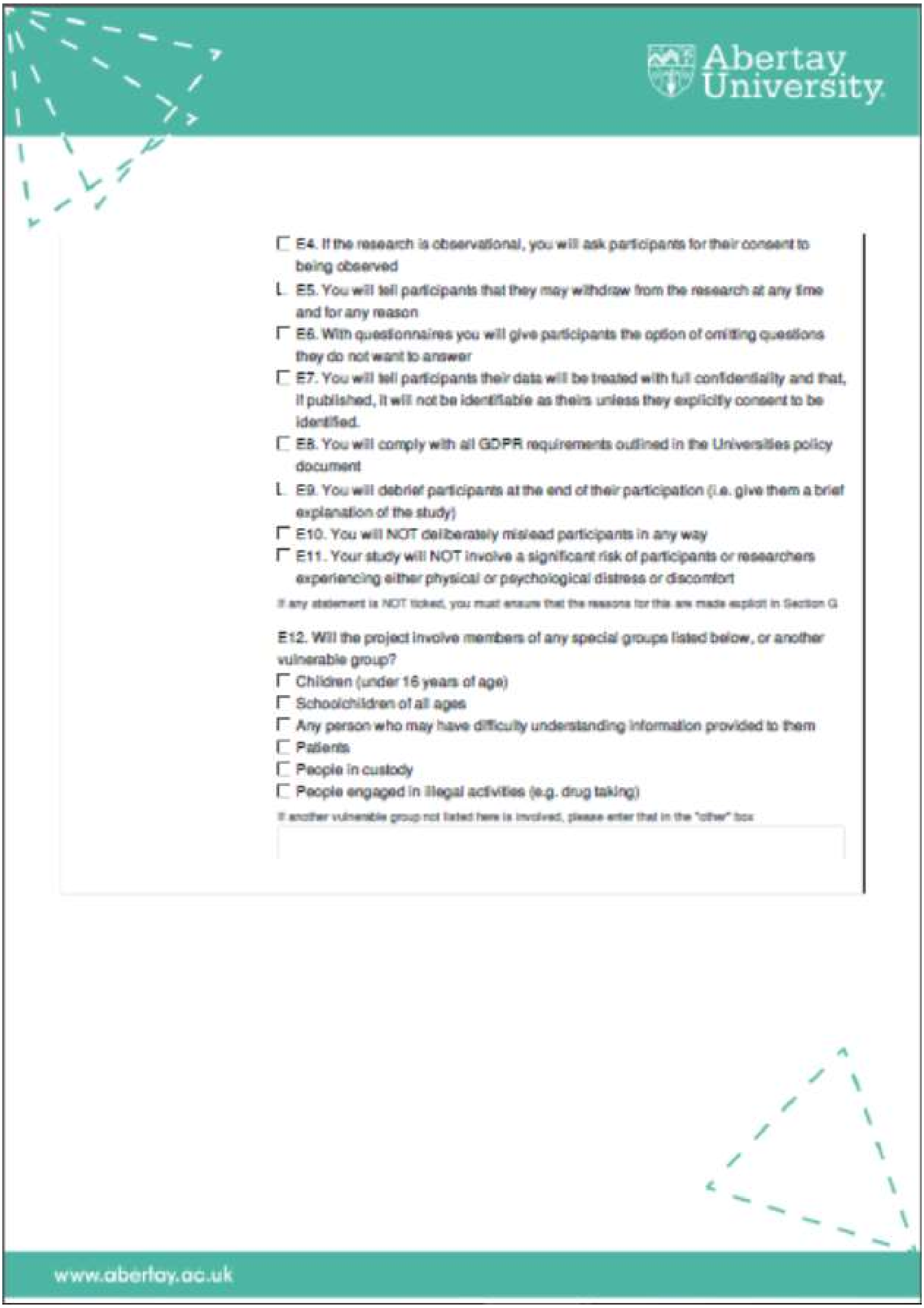

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☐ E4. If the research is observational, you will ask participants for their consent to being observed

☐ E5. You will tell participants that they may withdraw from the research at any time and for any reason

☐ E6. With questionnaires you will give participants the option of omitting questions they do not want to answer

☐ E7. You will tell participants their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs unless they explicitly consent to be identified.

☐ E8. You will comply with all GDPR requirements outlined in the Universities policy document

☐ E9. You will debrief participants at the end of their participation (i.e. give them a brief explanation of the study)

☐ E10. You will NOT deliberately mislead participants in any way

☐ E11. Your study will NOT involve a significant risk of participants or researchers experiencing either physical or psychological distress or discomfort

If any statement is NOT ticked, you must ensure that the reasons for this are made explicit in Section G

E12. Will the project involve members of any special groups listed below, or another vulnerable group?

☐ Children (under 16 years of age)

☐ Schoolchildren of all ages

☐ Any person who may have difficulty understanding information provided to them

☐ Patients

☐ People in custody

☐ People engaged in illegal activities (e.g. drug taking)

If another vulnerable group not listed here is involved, please enter that in the "other" box

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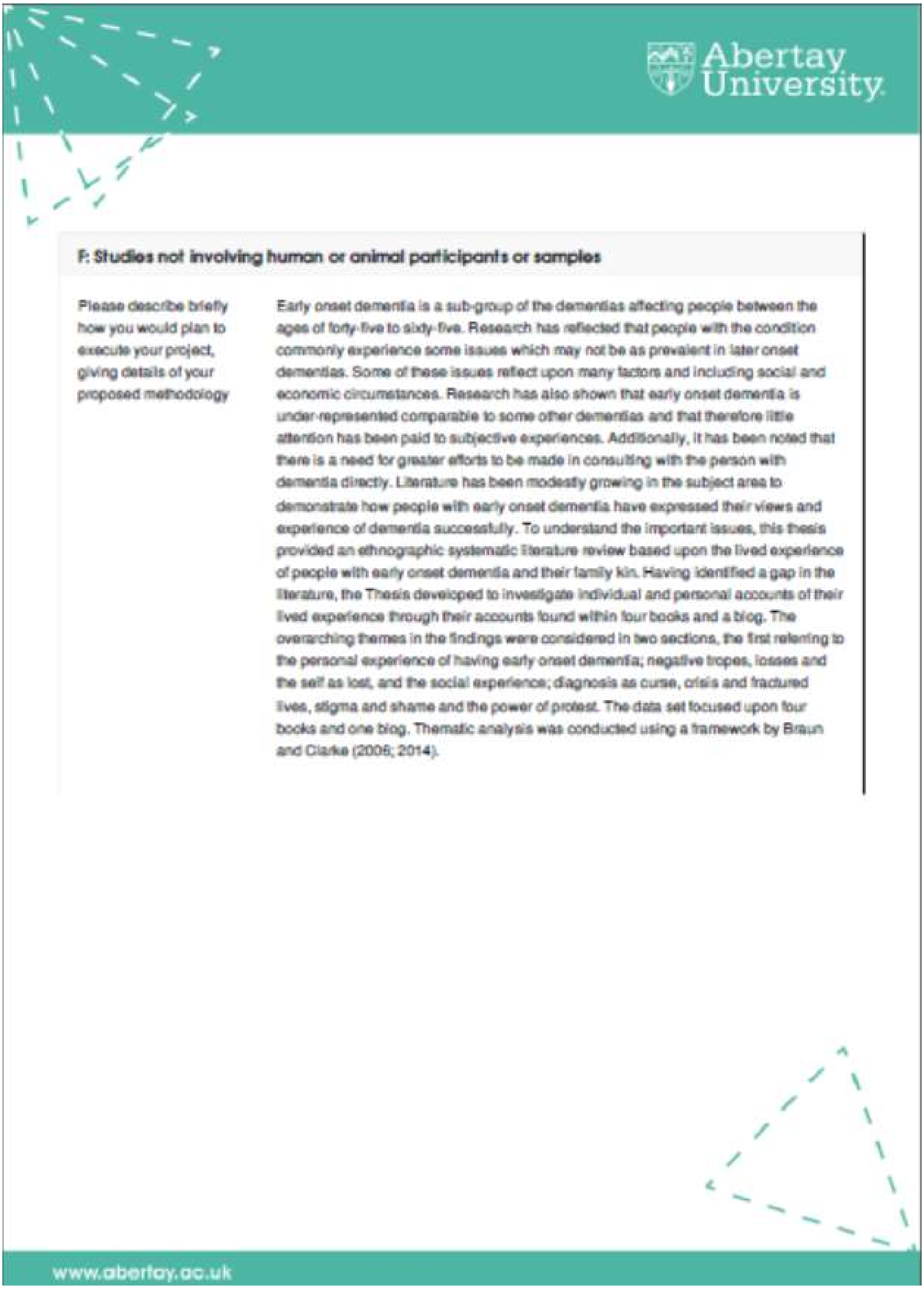

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F: Studies not involving human or animal participants or samples

Please describe briefly how you would plan to execute your project, giving details of your proposed methodology	Early onset dementia is a sub-group of the dementias affecting people between the ages of forty-five to sixty-five. Research has reflected that people with the condition commonly experience some issues which may not be as prevalent in later onset dementias. Some of these issues reflect upon many factors and including social and economic circumstances. Research has also shown that early onset dementia is under-represented comparable to some other dementias and that therefore little attention has been paid to subjective experiences. Additionally, it has been noted that there is a need for greater efforts to be made in consulting with the person with dementia directly. Literature has been modestly growing in the subject area to demonstrate how people with early onset dementia have expressed their views and experience of dementia successfully. To understand the important issues, this thesis provided an ethnographic systematic literature review based upon the lived experience of people with early onset dementia and their family kin. Having identified a gap in the literature, the Thesis developed to investigate individual and personal accounts of their lived experience through their accounts found within four books and a blog. The overarching themes in the findings were considered in two sections, the first referring to the personal experience of having early onset dementia; negative tropes, losses and the self as lost, and the social experience; diagnosis as curse, crisis and fractured lives, stigma and shame and the power of protest. The data set focused upon four books and one blog. Thematic analysis was conducted using a framework by Braun and Clarke (2006; 2014).

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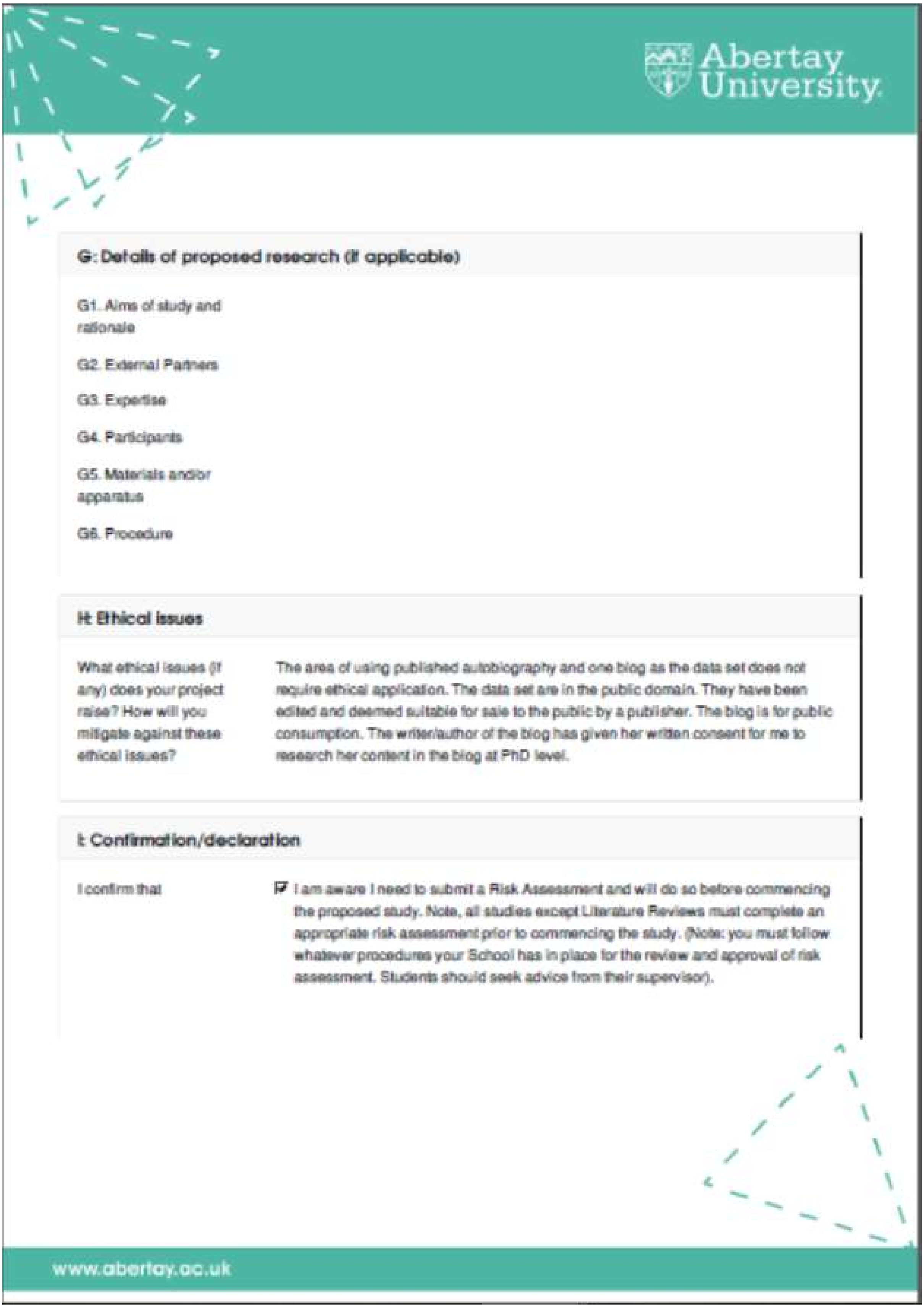


G: Details of proposed research (if applicable)

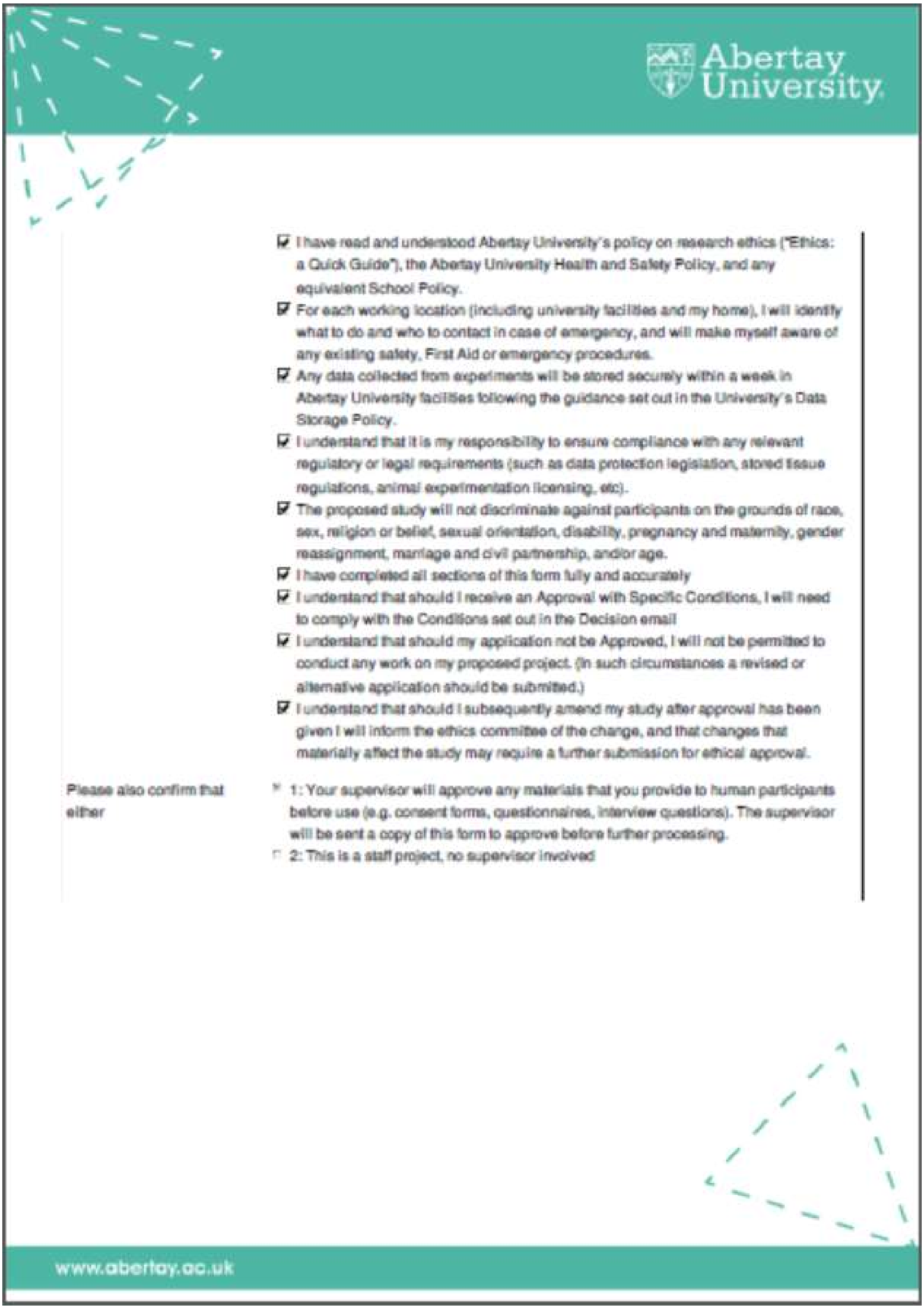
G1. Aims of study and rationale	
G2. External Partners	
G3. Expertise	
G4. Participants	
G5. Materials and/or apparatus	
G6. Procedure	

H: Ethical issues

What ethical issues (if any) does your project raise? How will you mitigate against these ethical issues?	The area of using published autobiography and one blog as the data set does not require ethical application. The data set are in the public domain. They have been edited and deemed suitable for sale to the public by a publisher. The blog is for public consumption. The writer/author of the blog has given her written consent for me to research her content in the blog at PhD level.

I: Confirmation/declaration

I confirm that	☑ I am aware I need to submit a Risk Assessment and will do so before commencing the proposed study. Note, all studies except Literature Reviews must complete an appropriate risk assessment prior to commencing the study. (Note: you must follow whatever procedures your School has in place for the review and approval of risk assessment. Students should seek advice from their supervisor).



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☑ I have read and understood Abertay University's policy on research ethics ("Ethics: a Quick Guide"), the Abertay University Health and Safety Policy, and any equivalent School Policy.

☑ For each working location (including university facilities and my home), I will identify what to do and who to contact in case of emergency, and will make myself aware of any existing safety, First Aid or emergency procedures.

☑ Any data collected from experiments will be stored securely within a week in Abertay University facilities following the guidance set out in the University's Data Storage Policy.

☑ I understand that it is my responsibility to ensure compliance with any relevant regulatory or legal requirements (such as data protection legislation, stored tissue regulations, animal experimentation licensing, etc).

☑ The proposed study will not discriminate against participants on the grounds of race, sex, religion or belief, sexual orientation, disability, pregnancy and maternity, gender reassignment, marriage and civil partnership, and/or age.

☑ I have completed all sections of this form fully and accurately

☑ I understand that should I receive an Approval with Specific Conditions, I will need to comply with the Conditions set out in the Decision email

☑ I understand that should my application not be Approved, I will not be permitted to conduct any work on my proposed project. (In such circumstances a revised or alternative application should be submitted.)

☑ I understand that should I subsequently amend my study after approval has been given I will inform the ethics committee of the change, and that changes that materially affect the study may require a further submission for ethical approval.

Please also confirm that either

● 1: Your supervisor will approve any materials that you provide to human participants before use (e.g. consent forms, questionnaires, interview questions). The supervisor will be sent a copy of this form to approve before further processing.

○ 2: This is a staff project, no supervisor involved

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