

Running head: Dementia within the Marital Sphere

Dementia within the Marital Sphere - Discourse, Power & Knowledge
Kerri. L. Walster

A thesis submitted for the degree of Doctorate in Clinical Psychology

Department of Health and Human Sciences

University of Essex

Date of Submission: June 2016

Abstract

Introduction: This thesis completed a genealogical enquiry which considered how dementia has been conceptualised historically and contextually, plus the conditions that have allowed for the emergence of certain dementia discourses over others. It explored how dementia has generated biomedical, neuro, psychological, pharmaceutical, technological, charitable and academic forces that in turn, produce and maintain the power of these forces, plus the dominant biomedical model of dementia. It also examined the role of family and marriage in the context of dementia.

Method: Drawing upon Foucault's work and discourse theory, professionally produced leaflets from dementia assessment clinics and NICE (2006) guidelines for dementia were examined. Secondly, participants with diagnoses of Dementia (PWDD) and their spouse were interviewed either jointly or separately (fourteen participants in total). Ten transcripts were analysed from a discourse theory perspective.

Results: The document analysis presented various discursive themes, which corroborated the findings in the transcript analysis. From the transcripts, nine main discourses were identified. For instance, 'the feared fate' constructed the inescapability of dementia in old age relating to dementia facts and figures. 'Pay no mind' involved paying little attention to dementia and setting dementia talk aside. 'The biomedical truth of dementia' depicted professional technologies as 'truths' supporting the biomedical origins of dementia. Spouses with and without diagnoses of dementia tended to adopt dissimilar discourses, resulting in spouses monitoring and correcting PWDD and PWDD's resistance. Marriage discourses constructed the importance of marriage and the need to overcome trials and tribulations.

Discussion: Unexpected findings in the data were strongly gendered discourses, plus, where spouses without dementia were positioned in the role of the 'informal professional' yet also 'the confessing patient'. Marriage discourses appeared to be complimentary in making marriage a natural sphere for caring. Biomedical discourse on dementia was effective in self-management of dementia 'signs' and electing 'ethically bound' spousal support, effective as a modern form of power where there are limited societal resources.

Contents

Abstract	2
1. Introduction	7
1.01 Chapter Overview	7
1.02 The Problem	8
1.03 The Construct of a Disease	10
1.04 Dementia Pre-Nineteenth Century: Broadly Defined Classifications	11
Demence	11
Lethargie, Delirium & Stupor	12
The proliferation of medical knowledge	14
<i>The Poor Law Act</i>	14
<i>Almshouses</i>	15
<i>The social survey</i>	15
1.05 Dementia within Psychiatry.....	15
A new classification system	15
Alzheimer’s case study.....	16
<i>Differentiating presenile dementia from a pathological dementia</i>	17
1.06 Problems with the Discursive Formation of Dementia.....	18
1.07 Dementia within Psychology	20
Technological apparatuses in Psychology	20
<i>Individual differences</i>	21
<i>Intelligence theory & measurement</i>	21
<i>Memory theory & measurement</i>	22
1.08 Dementia in the Twentieth Century.....	22
Violations to the rules of science	22
Smoothing over the controversy: the perceived truth effects of measurement	23
<i>Pragmatic adaptations – the DSM III revised</i>	25
1.09 Resistance & Bidirectionality	25
People with a diagnosis of dementia	25
Professionals.....	26
<i>Fragmentation of NHS healthcare</i>	26
1.11 Person Centred Care	27
The person centred model – a shift in paradigms?.....	27
<i>Kitwood on personhood</i>	27
<i>Person-centred therapies</i>	28
Older adult abuse & policy.....	28
1.12 Marriage & Family	30
The repressive hypothesis	30
<i>Individualisation & industrialisation</i>	31
<i>Counter discourses relating to marriage and family</i>	32
1.13 Dementia & Marriage	33
Qualitative research on dementia & marriage.....	33
Qualitative research on dementia & marriage.....	34
1.15 Chapter summary.....	35
2. Method	36
2.01 Chapter Overview	36
2.02 Research Paradigm	36
Rational for the research methodology	36
Epistemology	36

Social Constructionism	38
Ideology	40
2.03 Methodological Framework.....	41
Discourse analysis	41
Foucauldian Discourse Analysis (FDA)	43
<i>Genealogy</i>	44
<i>Disciplinary technologies</i>	45
<i>Subjectification & objectification</i>	46
<i>Soul effects</i>	47
<i>Power & resistance</i>	48
Summary of FDA framework	49
2.04 Method of Analysis.....	50
Reflexivity	50
<i>Researcher's historical location</i>	50
Ethical considerations	51
<i>Ethics</i>	51
<i>Data management</i>	53
2.05 Procedure	53
Participants	54
Data collection.....	55
Transcriptions	56
Process of Analysis	56
2.06 Chapter Summary	59
3. Results	60
3.01 Chapter Overview	60
3.02 Part One: Document Analysis	60
Summary of the findings	60
Statistics and symptoms	61
Subject positions: inactive/active	62
Seeking professional support	63
An avoidance of professional care & a minimising of dementia	63
Independence, individuality & activity	64
Professional tools	65
Informal Carer or marital partner?	66
3.03 Part Two: Interview Analysis with Spouses and PWDD	68
Summary of the findings	68
Relationships between the discourses	69
3.04 The Feared Fate	71
Old age decline and dementia	72
The feared/inanimate dementia subject.....	73
The prevalence of dementia	74
Counter discourse: It's plain old ageing.....	75
3.05 Pay No Mind.....	76
Preserving the individual.....	77
<i>The person centred discourse</i>	78
<i>Marriage discourses</i>	79
<i>The discourse the feared fate</i>	80
Deviation: A stiff upper lip	80
3.06 Making a Case	80
Dementia: the origins	81

Grouping signs? Grouping people?	82
<i>The dementia subject lacking awareness/insight</i>	82
Resistance: in denial	83
3.07 The Biomedical Truth of Dementia	84
Truth technique (I): the knowing doctor	85
<i>Rejection of 'the knowing doctor'</i>	87
Truth technique (II): measurements as proof	88
<i>Rejection of 'measurements as proof'</i>	89
Truth technique (III): medication to slow down the progression	89
<i>Rejection of 'medication to slow down the progression'</i>	90
Dominant discourse	90
3.08 Sins and Symptoms	91
The inscription of disciplinary technologies	93
A confession on behalf of the 'subject'	94
3.09 Knowing Best	94
Preventing and correcting	95
Keeping them going	97
3.10 Valuing Multi-Professionals	98
<i>Resistance to 'valuing multi-professionals'</i>	99
<i>Rejecting 'valuing multi-professionals'</i>	101
3.11 Marriage Discourse	101
Marriage is the right thing to do	102
Forbidden sex out of wedlock	103
Romance, loyalty & love	103
Overcoming trials and tribulations	104
Marriage problems: a private sphere	105
We	105
<i>Resistance to 'marriage the right thing to do'</i>	105
3.12 Conflicting or Complementary Discourses?	106
3.13 Chapter Overview	108
4. Discussion & Review	109
4.01 Chapter Summary	109
4.02 Study Summary & Appraisal of the Research Aims	109
4.03 How were discourses adopted complementary to the apparatus of power and the expansion of the neuro-hybrid?	112
4.04 'The biomedical truth of dementia' – how may our understandings be improved by post-structuralist discourse theory?	117
4.05 'Pay no mind' a two fold collectivisation of gender and dementia? Perceptions from post-structuralist feminism & identity politics	119
4.06 'The feared fate' and 'inanimate/dangerous' dementia subject – scope for exploring emotions?	121
4.07 Sins & symptoms, knowing best and pay no mind – what other theoretical understandings are there regarding the finding of 'the confession'?	125
4.08 An unhelpful alignment of the person-centred model with biomedical model? Policy, research and clinical implication	127
4.09 Conclusions & Critical Reflections	132
Critical reflexivity	135
Personal reflections	136
References	138
Endnotes	156

Appendices	160
Appendix A: Reflexive journal extract (pp.1-2)	160
Appendix B: Initial working out from three leaflets	162
Appendix C: Discursive patterns identified across the leaflets.....	165
Appendix D: Key developed to analyse/code interview transcripts	166
Appendix E: Separate interview transcript annotated using key (pp. 1 of 7).....	167
Appendix F: Joint interview transcript annotated using key (pp. 1 of 8).....	174
Appendix G: Mapping of discursive elements in marriage discourses	182
Appendix H: Mapping of discursive elements in ‘pay no mind’	194
Appendix I: Participant information letter (pp.1-4)	195
Appendix J: Consent to contact form.....	199
Appendix K: Informed consent form	200
Appendix L: Debrief script	201
Appendix M: Approval from University of Essex.....	202
Appendix N: NHS Research Ethics Committee Approval (pp.1-4).....	203
Appendix O: Approval Research & Development (pp. 1-2)	207
Appendix P: Co-sponsorship indemnity & insurance agreement (pp.1-2)	209
Appendix Q: Inclusion/exclusion criteria	211
Appendix R: Semi-structured interview guide.....	212
Appendix S: Transcription guide	213
Tables & Figures	
Table 1. <i>Diagnostic Statistical Manual Third Edition (DSM-III) criteria</i>	24
Table 3. <i>Study research aims</i>	35
Table 3. <i>Participant’s demographic details</i>	54
Table 4. <i>Questions to support the genealogy</i>	57
Table 5. <i>Questions to support the data analysis</i>	59
Figure 1. <i>Main discourses & their relationships with one another</i>	69
Figure 2. <i>The discourse ‘the feared fate’, elements & a counter discourse</i>	71
Figure 3. <i>‘Pay no mind’, elements & complimentary discourses</i>	76
Figure 4. <i>‘Making a case,’ elements, rejections & resistances</i>	81
Figure 5. <i>‘The biomedical truth of dementia,’ elements & rejections</i>	85
Figure 6. <i>‘Sins & Symptoms,’ elements & complementary discourses</i>	91
Figure 7. <i>‘Knowing best,’ elements & complementary discourses</i>	95
Figure 8. <i>‘Valuing multi-professionals,’ elements & complementary discourses</i>	98
Figure 9. <i>Marriage discourses & complementary discourses</i>	102
Leaflets	214
Leaflet 1: Drugs to relieve behavioural & psychological symptoms in dementia ..	214
Leaflet 2: Worried about your memory ?.....	215
Leaflet 3: Care-Cameras, secure, private: Caring for an elderly relative?.....	216
Leaflet 4: Helpline A.....	217
Leaflet 5: Helpline B	218
Leaflet 6: Power of Attorney.....	219
Leaflet 7: Your care & the Care Programme Approach.....	220
Leaflet 8: NHS free health check	221
Leaflet 9: Products & services designed for the over 50’s.....	222
Leaflet 10: Admission for patients removed by police under a court warrant	223
Leaflet 11: Affected by your memory? We’re here to help	224
Leaflet 12: Inpatient Carers group	225
Leaflet 13: Active Minds.....	226
Leaflet 14: Planning end of life care	227

1. Introduction

1.01 Chapter Overview

This chapter follows a genealogical approach heavily influenced by Michael Foucault (Foucault, 1977). It aims to present some of the contingent moments that constitute contemporary understandings of dementia and the historical conditions of possibility that allowed for the emergence of certain dementia discourses over others. Here, discourse refers to sets rules, systems of thought, and procedures; it is viewed as incomplete, ambiguous and complimentary to forming and producing power, knowledge, action and material structures that in turn continue to uphold discourse¹ (Foucault, 1991).

Typical to genealogical enquiries, this chapter begins with a set of questions, problematising the concept of dementia while justifying the need for a critical consideration of its formation and functioning. It then includes the examination of the concept dementia through different time points to show how constructions of dementia are subject to prevailing models of thought, and change. Attention to the way various political sites, such as, psychiatry, psychology, legal, ethical and commercial, structure understandings and practices relating to dementia, are argued to be central. Marriage and family are considered to a lesser extent from a similar, social and historical perspective.

In developing a genealogy, Foucault (1991) emphasised the need for an accumulation of source materials, as a way of critically assessing the complex circumstances that allow for discourse to form and fade. In this chapter there is an examination of primary data, including Alzheimer's (1906) case study and his related publications, plus previous editions of the Diagnostic Statistical Manual criteria for diagnosing dementia. Likewise, secondary data is used, such as academic and professionals quotations from the 16th, 17th and 18th centuries regarding memory loss and disease (e.g. see, Berrios, 1987).

It is notable that this genealogy is not a complete or historical tracing of a discourse; it is an attempt to construct an argument advancing a different view of dementia by isolating some principal scenes and roles. Many events upholding dementia discourse will not be accounted for in this analysis (Hook, 2007). Also, where this thesis follows Rawlinson (1987) and Hook (2010) models for the application of discourse analysis, *how* a discourse has *arisen* is the task of the genealogy (presented in chapter

one); however, *why it functions* is chiefly encompassed in a subsequent analysis (chapter three). Chapter three includes the analysis of professional leaflets and guidelines, and interview data from spouse dyads when one spouse has a diagnosis of dementia. It considers the dominant and alternative discourses that are operational concerning dementia. The genealogical analysis is presented as follows.

1.02 The Problem.

For a number of years there has been a Political argument that elder adults are placing significant pressure on societal resources and health care budgets (House of Parliament, 2010, 2015). This is often related to epidemiology research presenting a growing population, people living longer and a high prevalence of disease among elder adults – amongst these diseases, of chief concern is dementia (e.g. Ferri et al., 2005; van der Flier, 2005). Epidemiology research is often juxtaposed with the argument that if welfare is not cut and public services are re-structured then this may result in the fragmentation of the National Health Care System. Robertson (1990) has described this as the “bankruptcy hypothesis of old ageing where upcoming hoards of elderly deplete national healthcare budget through an apocalyptic demography” (p. 429). While there are alternative representations of elder adults (i.e. stoic and heroic war survivors, earnest past workers, entitled to formal care, pension programmes and so forth) such images may be seen as contingent upon the societal demand elder adults are seen to place (Biggs & Powell, 2001). Limitless suggestions of a demand too great, particularly in the context of the proposed high dementia prevalence, may be seen to maintain a dominant discourse of disease, decline, burden, and dependency in old age.

Despite Political arguments about the social cost elder adults generate (House of Parliament, 2015), increased utilisation and living longer but sicker arguments have been contested by a number of sources (e.g. Barer, Evans, Hertzman, & Lomas, 1987; Myles, 1983; Roos & Shapiro, 1981). In the case of dementia, even if recognising individuals diagnosed with and treated for dementia *may* receive more health and social care support, it may be argued that this is generated by neuro, pharmaceutical, technological, commercial, and academic forces that gather to form a ‘cognitive culture’, which in turn, produces and maintains the power of the cognitive culture – explored further.

Dementia has been constructed as a progressive and pathologically degenerative syndrome, affecting thinking capacities, particularly memory. Countless studies report that there is an increased likelihood of developing the disease above the age of sixty-five

(e.g. see, Alzheimer's Society, 2014)². The most recent definition of dementia from the World Health Organisation (WHO) is:

“A syndrome due to 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. Impairments of cognitive function are commonly accompanied, and occasionally preceded by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs particularly in Alzheimer's disease, cerebral vascular disease, and in other related conditions” (WHO, 2006, p. 42).

As common, this definition aligns with a biomedical model of dementia, which categorizes signs and symptoms into meaning disease groupings. The task of medicine has always been the disappearance of disease. Correspondingly, disciplines of psychiatry and psychology (psy disciplines) have been occupied with the management of ‘mind’ diseases (Rose, 2007). The concept of disease has been essential for the evaluation of the condition of the patient, and in the bringing about of a relationship between knowledge and the patient. Yet, there is ambiguity in all of this; *does the disease exist as a collection of disturbances in the mind/body or as a result of medical activities and decisions that generate power for professionals? Is it a combination of both or something else entirely?*

Furthermore, dementia is reported to be the fourth leading cause of death amongst older adults in the UK (WHO, 2012). Worldwide, thirty six million people are presented to have the disease and twenty eight million people predicted to have the disease undetected (WHO, 2012). Figures such as by 2050, one hundred and fifteen million people will be diagnosed, are frequently cited and justify the arguments that dementia has reached an epidemic (e.g. see, Alzheimer's Society, 2014). The estimates of the prevalence in the UK for of different types of dementia are: Alzheimer's disease, 62%; Vascular dementia, 17%, Mixed dementia, 10%, Lewy Body dementia, 4%; Frontotemporal dementia; 2%, Other 5% (Alzheimer's Society, 2014). However, *are upwards dementia prevalence rates reflective of population trends, or is this the expansion of a diagnostic classification system with uncertain boundaries hidden in a discourse of medical certainty?*³

1.03 The Construct of Disease

To begin addressing the above-mentioned questions, the role of medicine and the construct of disease will be explored. Foucault, (2010) in his work *The Birth of the Clinic* traced the historical origins of modern medicine. Although he did not give much attention to the construct of dementia, he studied the rise of clinical classifications in a particular time frame, within which knowledge and power are embedded. Foucault (2010) traced eighteenth and nineteenth century industrialisation and urbanisation, and he depicted that in order for a productive and docile workforce, legal, professional and academic settings began to effectively monitor social deviants, proliferating medicine, and the psy disciplines success. This was effective through a humanist and liberalist discourses of reform and remediation in asylums, clinics or communities.

Coinciding with this, Foucault (2010) developed the concept, *episteme*, meaning a dominant understanding or school of thought in a particular given time or “the possibilities of all knowledge, whether expressed in theory or silently invested a practice” (Foucault, 2010, p.168). During the enlightenment, the signs and the surfaces of the body were thought of as fixed to the bodies interior system. The physician’s task was to examine, probe, and spatialize the body to determine how visible signs marked inner states (Foucault, 2010). The body was represented as a visible anatomical map on which disease could be localised and disciplinary knowledge’s around the body could be co-ordinated. This exposed the limits of existence and moulded the person into a singular and finite object to be known and controlled (Davis, 2004).

Contrastingly, in premodern society, disease or conditions, such as poor memory, orientation, judgement and so forth (associated with dementia) were likely to have been viewed as mysterious forces, ranging outside of the body (Katz, 1996). Resolution was not the task of the physician alone; equally important was the unpredictable, external forces and the patient’s actions, implications being to balance humours, fluids, diet and improve one’s sex life, or to resolve moral dilemmas (Dillmann, 1990). Canguilhem (1988) argues premodern medicine called for watchfulness and support from the healer, whereas modern medicine required a more activist orientation from the physician.

According to Foucault (2010) there was a shift in episteme and a beginning to medicine as opposed to a series of progressive discoveries, which enabled medicine to pioneer and to appear as a neatly defined discipline. Medicine required exactitude, not just degrees or shades of knowing. Both fundamentalism (that is, testing theories, priori reasoning and hypotheses against observations) and normativism (interpreting specific

types of social deviance from normality) were constructed to replace former, more intuition based, methods (Davis, 2004).

“By a realistic shift in which medical positivism was to find its origin, surface, hitherto a structure of the onlooker had become a figure of the one observed... hence, the appearance that pathological autonomy assumed at the outset: that of an objective, real and last unquestionable foundation for the description of diseases” (Foucault, 2010, p. 129).

Foucault (2010) presents how science and medicine like history made use of particular rhetorical devices such as the notions of reality, neutrality and measurement, to present it in the best light. Under this historically located veil of objectivity, the biomedical nature of dementia is rarely open to challenge.

1.04 Dementia Pre-Nineteenth Century: Broadly Defined Classifications

Demence. Berrios (1981a, 1981b, 1987, 1992)⁴, an academic and a psychiatrist, has completed a series of works surrounding the conceptual history of dementia, including English, French, and German translations of texts from the seventeenth and nineteenth century (also see, Berrios & Hauser, 1988). In his work, he has argued that although the term dementia is often linked to Pinel in 1879, the Latin application of the word *demens*, meaning ‘out of ones mind’, and the adjectival application, both circulated prior to this. For instance, Berrios (1987) cites dementia as “a passion of the minde, bereaving it into the light of understanding, when man’s perceivance and understanding of all things is taken away” in the late 1500s (Coslin, 1592) and “folie, extravagance, egarement and alienation of spirit” in the late 1700s (Sobrino, 1791) (pp.830-831). Nonetheless, in contrast to Berrios’s interpretation that there is scientific consistency in understandings of dementia, through reviewing these cited sources of data, definitions before the nineteenth century appear to relate to a broad and undefined concept relating to the loss of mind or historical understandings of madness (e.g. see Porter, 2010). From a Foucauldian perspective, this is perhaps fitting with a period of thought where the medical frame was not the dominant or prevailing one; instead external forces would be seen to influence a change in spirit, as argued above.

Lethargie, Delirium & Stupor. The task of tracing the concept dementia is a difficult one, at odds with the infinite number of psychiatric classifications available to date. Nonetheless, few concepts common to this time were delirium, psychosis, lethargie, and stupor; conceptually dementia is linked to each of these (Berrios, 1981a; 1981b; 1987). The following extract referring to Lethargie, a condition of significant “forgetfulness”, represents this:

“Lethargie is a notable forgetfulness of all things almost, that heretofore a man hath knowen: so that one often times forgetteth also his owne name, calleth anything by a wrong name, and beginning to speake, forgetteth what he had saide afore, and what hee meant to say after. This distempreture and weaknes cometh by some blow or sickness” (Cosin, 1592; as cited in Berrios, 1987, p.830).

Equally, the use of Delirium in the 1700s, which accounted for most presentations where the person’s thinking capacity was affected, with and without fever, has been linked to dementia (Berrios, 1981). From a discourse perspective, delirium, lethargie and related constructs, may be thought of as expansive and broadly specified constructs – the definitions of *what they were* and *what they were not* do not appear to be particularly defined. Again, it is argued that was operational at the time; there was no imminent political need for a distinctly defined dementia. Notions of truth, certainty, accuracy and predictability, plus medicine’s diagnostic classification system were yet to emerge and to gain a societal purpose.

In contrast, over a century later, Georget (1820) presented two parallel understandings of delirium: one resulting from general illness and another that was a disorder of intellect, personality, new ideas, and intelligibility which he argued should be differentiated. The syndrome *delire aigu* was described as a chronic disorder of intellect, personality, new ideas, and intelligibility and the syndrome *sans fièvre*, a short term impairment of consciousness caused by fever (as cited by Berrios, 1981). This appears to be one of the first foundations for later nineteenth century distinctions, where the discursive formation of dementia was beginning to be shaped.

In line with this, throughout the enlightenment, with a gradual emergence of an ontology⁵ (referring to a way of being, becoming or existing that becomes to be taken as a reality) that supported that the mind and body were separate and mechanistic entities was catalysed. This led to the reasoning that medical practice ought to capture the internal

nature of physically displayed disturbances. To use stupor to exemplify this, Willis (1684) described six conditions signified by this classification. 1) a hereditary condition one is born with; 2) foolishness by the mere declining of age; 3) “bruising to the head” such as from a “fall from a high place,” 4) repeated drunkenness or use of opiates, 5) violent passions or vehement sadness; 6) a cruel disease inside the head such as, epilepsy (as cited in Berrios, 1987, p.831). Willis (1684) argued stupor, whether innate or acquired could not be cured. Similar to Georget (1820), Willis (1684) was one of the first physicians to begin to employ dichotomies, such as congenital or acquired, affecting the young or the old, temporary or permanent (Berrios, 1987). He was seemingly differentiating presentations into more defined boundaries.

Further exemplifications of the importance of the emerging mind and body parallelism and its importance in shaping dementia practise, are presented in extracts from Cullen (1827) and D’Aumont (exact date unknown). Here, a change in intellect and behaviour (described as the “disease” demence) were associated with an imbalance in the interior body structures – the nervous system or “fluids” and the “excitement” in the brain:

“It is very possible that the state of the intellectual functions depends chiefly on the state and condition of what we call, nervous power, or as we suppose, a very moveable fluid... a medullary substance of the brain and nerves, which in living and healthy man, is capable of being moved or ... may excite at differing times in the same way as sleeping and eating... it may depend on some inequality in the excitement if the brain” (Cullen, 1827; as cited in Berrios, 1987, pp. 834-835).

‘Demence is a disease... resulting from abolition of the reasoning faculty. It must be distinguished from Fatuitas, Morosis, Stultitia and Stoliditas ... Those affected by demence exhibit foolish behaviour and cannot understand what they are told, cannot remember anything, have no judgement, are sluggish and retarded... [it] is difficult to cure as it results from damaged brain fibres or from a reduction in nervous fluids or... old age’ (D’Aumont, exact date unknown, approximately the 1870’s, as cited in Berrios, 1987, p. 829).

In contrast to earlier mentioned concepts of dementia, in the above extracts, there is the objectifying of what dementia is, and what it is not, through the separation of the concept demence from mania and other concepts, and the identification of symptom clusters.

The proliferation of medical knowledge.

In Foucault's (1991) work *Discipline and Punish*, such objectification is argued to have justified and increased the need for *disciplinary technologies*, referring to various institutional, physical and administrative mechanisms and knowledge structures that govern the individual subject whilst enhancing and maintaining the rationality of power for organisational/institutional governing (see methodology). Jewson, (2009) argues medical statements became to be not just statements about the world but ways of relating to others in the world; they reflected and projected concepts of order and identity onto a network of relationships, which then constituted medical knowledge (Jewson, 2009, p.623). As dependent upon medical statements and networks, and the conditions of possibility in a given time and space, including the Poor Law Act, Social Survey and Almshouses, dementia entered in to increasingly defined and politically maintained boundaries.

The Poor Law Act. In fifteenth and sixteenth centuries, there was a sharp increase in begging, vagrancy and food riots in England (Parker, 2005). Disorder emerged in society amongst the poor, leading to consideration on the distribution of resources. "The government enacted several poor law rulings between 1531 and 1576, "as much to effect the beliefs, attitudes and behaviour of working class people generally as it was to discipline or provide for those who received [its relief]" (Parker 2005, p.62). Under this law a poor tax was endorsed which generated an income for three categories of people: children, able-bodied and the infirm – older adults are likely to have been grouped in to the latter two (Parker, 2005). Zarastsky (1986; as cited in Katz, 1990) argued that this was the start of classification discourses that emphasised types of persons rather than religious thought relating to the quality of the soul; classification was an effect of structural changes to methods of charity and legislative-rationalist perspectives.

Almshouses. The Poor Law generated a tax, which supported the steady the development of almshouses or workhouses, where indoor relief, food, clothing, employment and medical care were provided for those without family support (Parker,

2005). In the 1800s there was one almshouse in every town in the UK; the task was to reform criminals, mentally ill, unemployed persons and orphans, and elder adults. However, liberalist-humanitarian movements argued against the overcrowded and poorly maintained conditions in the almshouses (Parker, 2005). By the 1850s it was emphasised that not only did the almshouse fail to solve the problems of poverty and dependency, it perpetuated them. Their revised concept was to introduce established and specialised institutions and greater medical care with stricter supervision, the beginnings of an institutional explosion (Katz, 1996). This was also the time of the industrial revolution, where the population seemed to be reaching unprecedented sustained growth.

The social survey. In response to the population's growth, in the 1800s the development of the social survey allowed for the collection of demographic information to monitor, and control, population trends (Bulmer, Bales, & Sklar, 1991). Statistics about the population were part of what Foucault described as bio-politics a new technology of power that exists on a different level and scale that makes use of very different instruments (Foucault, Rabinow, & Hurley, 1997). More than a disciplinary mechanism, Foucault's biopolitics acts as a control apparatus exerted over a population as a global mass (Foucault, Rabinow, & Hurley, 1997). This is the making of populations as a material process whereby people are divided into sources of economic productivity, objects of statistical measurement, and transgressors of social order (Katz, 1996). Jewson (1976) states the state became to increasingly rely on the advice of the scientific community when distributing resources. Medical investigators were able to assert their disciplinary interests over educational, institutional and professional sites.

1.05 Dementia within Psychiatry

A new classification system. Amongst others in the late eighteen hundreds, Emil Kraepelin, a German psychiatrist, critiqued disease classifications for not being distinct enough (Dillman, 1991). He argued that where prior distinctions had been made between acute and chronic diseases, these lacked 'empiricism', which had become part of the hegemonized discourse of medicine. The word hegemonized refers to a relatively fixed discourse that has come to be taken for granted and that arranges, and is arranged by, discursive structures (Howarth, 2000). Using the system of empiricism, Kraepelin proposed that for each disease, symptoms could be used as criteria to generate a classification system for patient diagnosis. The combining of separate disciplines,

neuropathology and psychiatry, were assumed by Kraepelin to enable this, in allowing new methods and streams of research technologies with increasing 'rigor'. Observation, measurement, experimentation and classification, as well as the influence of social factors discussed, present a complex array of conditions that allowed for the emergence of a discourse of a non-age related disease, dementia, discussed further.

Alzheimer's case study. Alzheimer, a close acquaintance of Kraepelin, wrote two papers on the case study, Auguste D. in 1906 and 1907, various clinical case notes and he presented a lecture 1911; these are considered as part of this genealogy (translations obtained from Alzheimer, Förstl, & Levy, 1991 & Maurer & Maurer, 2003). In 1901, Auguste D, a 51-year-old woman who was legally sectioned in a clinic in Frankfurt. She was described by Alzheimer as having "jealous delusions about her husband who had left her for another woman," memory disturbance, disorientation, delirium and auditory hallucinations (Alzheimer, 1907; as cited in Maurer & Maurer, 2003, p.20). Alzheimer also uncommonly applied novel laboratory technologies (i.e. Nissl staining of brain cells, microscope) newly proclaimed to measure internal brain structures. He stated that in conjunction, clinical observation and brain measurement had enabled the distinction of a disease process different from other 'known' diseases. These required further refinement and an inclusion in medical texts, ostensibly to support other clinicians to recognise and diagnose it:

"Numerous neurons, especially in the upper cell layers, had totally disappeared. Dispersed over the entire cortex, and in large numbers, especially in the upper layers. It was even possible to recognise these without staining, but they were more evident once stained. On the whole, it is evident that we are dealing with a peculiar, little-known disease process... This fact should stimulate us to further study and analysis of this particular disease. We must not be satisfied to force it into the existing group of well-known disease patterns. It is clear that there exist many more mental diseases than our textbooks indicate... We must reach the stage in which the vast, well-known disease groups must be subdivided into many smaller groups, each one with its own clinical and anatomical characteristics" (Alzheimer, 1907; as cited in Maurer & Maurer, 2003, p.21).

Originally, Alzheimer stated his case study suffered from presenile dementia, a mental decline as a natural process of ageing. Other conceptualisations of dementia operated at this time, although it seemed that presenile definition of natural ageing was the most common conceptualisation (see, Berrios & Porter, 1998). Presenile dementia was a popular term amongst the emerging specialism of geriatrics. “Geriatrics is a term I would suggest is an addition to our vocabulary to cover the same field, in old age, that is covered by the term paediatrics, in childhood... considering senility and its diseases... assign it to a separate place in medicine” (Nascher, 1909; as cited in Berrios & Porter, 1995, p.59). Yet, at this time, psychiatry’s classification of dementia as a disease would have been functional: it would have separated it from other competing disciplinary fields and designate it to psychiatric study and practice. In line with this Alzheimer withdrew his initial case formulation and instead endorsed that the pathology exemplified was a different type of dementia, illustrated in the above extract.

Differentiating presenile dementia and a pathological dementia. Alzheimer’s rationale to separate presenile dementia and dementia was the presence of brain plaques and tangles in dementia, ‘proven’ by Auguste D.’s cell staining measurements. Alzheimer also claimed that that this case could not be suffering age related degeneration and decline (presenile dementia) due to the age of onset change occurred – the case was aged fifty-one (Alzheimer, 1907; as cited in Maurer & Maurer, 2003). Alzheimer reasoned that where Auguste D. presented with language disturbances and “spasticity”, this too was uncommon to presenile dementia (i.e. where memory or cognition may be effected though not language). Thus, based on Auguste D. Alzheimer claimed the discovery of a new condition: an accelerated degenerative disease of the brain that cannot be attributed to specifically to any one age. It is worth noting here this is different from the contemporary definition of dementia as cited above, prevalent mostly above aged sixty-five, including language difficulties (WHO, 2006). Also, in the extract below Alzheimer is shown to have specified that ‘similar’ presentations occurred in old age, which should be labelled presenile dementia, but that these cases were not definitively a disease processes. He differentiated disease related presenile dementia or atypical cases, to further confirm or justify the distinct condition dementia that he had outlined.

“As similar cases of disease obviously occur in the late old age, it is therefore not exclusively a presenile disease, and there are cases of presenile dementia which

do not differ from these presenile cases with respect to the severity of disease process. There is, then, no tenable reason to consider these cases as caused by a specific disease process. They are presenile psychoses, atypical forms of presenile dementia... in order to avoid misdiagnosis it will therefore have to be the task of future research to collect a larger number of such cases ... to substantiate their position with respect to presenile dementia on an even firmer basis" (Alzheimer, 1907; as cited in Maurer and Maurer, 2003, p. 32).

Alzheimer goes on to report that there were multiple "observations in the department" of this non-age related disease causing accelerated decline, thus, it "should not be too rare to establish the symptomology" (Alzheimer, 1907; as cited in Maurer and Maurer, 2003, p. 32). Alzheimer worked with several psychiatrist's: Bonfiglio, Fischer, Hübner, Myake, Perusini, Pick, Redlich and Sarteschi and Simchowicz (Maurer & Maurer, 2000). Yet, it appears that there were in fact only five other published papers referring to this new classification of dementia, and the listed colleagues reproduced Alzheimer's case study in four of these papers; Perusing (1910) was the only separate case fitting with Alzheimer's account of this new disease (see, Maurer & Maurer, 2003).

Despite the sound empiricism that was supposedly representative of the psychiatric discipline, soon after this, a separate classification was embedded into Kraepelin's taxonomy, in his book on the practise of psychiatry (Kraepelin, 2002). He labelled it, Alzheimer's disease, defined as a non-age related form of cognitive deterioration through loss of brain matter (Kraepelin, 2002).

1.06 Problems with the Discursive Formation of Dementia

It has been presented that Alzheimer himself was not so certain of the category Alzheimer's disease (Dillmann, 1990). Alzheimer (1911) later presented another case study that showed the symptoms of his formerly presented case, Auguste D., yet, the absence of neurofibrillary tangles (as cited in Alzheimer et al., 1991). Alzheimer concluded that internal changes within the brain could be very small, even with severe behavioural disturbances. This presented the question and dilemma, was dementia the result of normal ageing alone rather than a distinct or pathological disease as proliferated? Yet this did not receive much attention, *why?*

Kraepelin's proliferation of a relationship between mind and brain, a law-like parallelism, was significant. The precise relationship between the brain with the psychic

functions was not known, yet Kraepelin assumed that it was law-like (Dillmann, 1990). The construction of the existence of 'organic' disease provided the opportunity to have studied this parallelism justifying biomedical understandings and treatments, or certain rules, procedures, systems and discursive practises – the will to know (Foucault et al., 1980). Kraepelin was emphasising mental disease had to be found in the brain and its functions, *and* that this needed to be approached through neuropathology, physiology and experimental psychology with qualitative and quantitative methods. Foucault has also discussed the 'gaze' of the physician, and described how the physician originally used the scalpel to investigate the signs and surfaces of the body, followed by the microscope, to look at the body at a cellular level. The gaze went beyond the visible surfaces and the domains of observation with the use of new tools and branching disciplines (Hook, 2010). Despite the obvious ambiguities in the development of classifications such as Alzheimer's disease from the sparse case studies mentioned, plus, social actor's motivations, the medical discourse was not condemned to falsify its statements owing to its assumed precision and neutrality.

Almshouses and institutions, as mentioned, faced difficulty – the homogenous grouping of inmates, where people of mixed ages and genders, resided together for disparate reasons, with far ranging conditions was problematised (Katz, 1986). The introduction of a precise classification system was a logical means to channel treatments and reduce long-term dependency on this system, which was particularly dominated by older adults (Katz, 1986). If presenile dementia was not designated as a disease, on a structural level, this would have prevented professionals deciphering diagnoses and support for elder adults. Berrios & Porter, (1998) have argued that the classification of dementia avoided being ageist or pessimistic by assuming all aged will become 'demented', however, as mentioned, it has gradually indicated that those who were 'aged' may be more at risk of the disease justifying the medical gaze upon them.

Linking back to statistics given on the increasing risk of developing dementia with age – dementia has gone from a relatively rare phenomenon (a few published case studies) to the fourth most common cause of death in the UK and affecting thirty six million worldwide (WHO, 2012). Such an increase in figures undoubtedly presents the advantages, in the context for struggles in leverages and funds, the increase is not completely related to a 'pure' disease matter. Sufficient channels of communication and funding influenced the knowledge and power of the discipline of psychiatry, allowing for clinical practise and research to coincide. There was a motivation to empower the psy-

professionals as a means of ensuring bureaucratic order over the population. This generated professional struggles, while justifying the need for disciplinary technologies. This was an effective regime of power over the population.

On the other hand, several sources have reported the disease related concept dementia did not become popular amongst clinicians until the 1980's when further technological developments were seen to verify the presence of plaques and tangles as more reliable sources of 'evidence.' Epistemological positivism would become more firmly into the grips of power, sanctioning certain versions of reality, and political and ideological forces (see, 1.07). At this time (early 1900s) the biomedical discourse of dementia faced several challenges and rearrangements relating to conflicting studies and motives. Nonetheless, from this discussion, what may be inferred is that the biomedical discourse of dementia has been the inclusion of some possibilities and the exclusion of others, contingent to the social and historical constructions, open to change.

1.07 Dementia within Psychology

Technical apparatuses in Psychology. As depicted, medicine had once related to case-note taking and observations to understand the patient; the discourse of science then broadened. It included the ontology of a mapable world using numbers. During the nineteenth century, probability theory was applied to mental disorders, and measurement and statistics were applied to higher order functions such as memory (e.g. Esquirol, 1838; Pearson, 1978). Where there was the Kraepelin movement assuming correlations between molecular measurement and behaviour, within the emerging field of psychology there was an assumption that sensation correlated with subjectivity. Psychological laboratory assessments measured physiological variables such as pulse, perspiration, pupil size, muscle performance and so forth, which were assumed to relate to mental functions. Like psychiatry, psychology established a whole technical apparatus with its own rules and traditions, designating who was competent to speak and what objects can be spoken of (Rose, 2007). This was alongside a network of professional journals disseminating psychological research. "At this time, it was not simply the establishment of a discipline of psychology, but of a psychological complex – a heterogeneous, regulated domain of agents and practices, discourses and apparatuses, which had definite conditions of existence and specifiable effects" (Rose, 2007, p.6).

Individual differences. Psychology is considered to have had two movements: 1) the emergence of a scientific psychology through systematic observation and research, and 2) the concern with the *subject* rather than *man-in-general* – also described as individual differences. Similar to the argument placed above regarding psychiatry and dementia, Burt (1927) claims the success of these movements were linked to a number of practical concerns:

“...this new field must be traced to the pressure of practical needs. The psychology of education, industry, and of the war, the study of the criminal, the defective and the insane, all depend on the sound analysis of individual differences; and the investigation of the more practical problems has already begun to pay back its debt, by furnishing fresh data of the utmost value to the mother science... it aims at almost mathematical precision, and proposes nothing less than the measurement of mental powers” (Burt, 1927; as cited in Rose, 2007, p.5).

Intelligence theory and measurement. Standard texts in psychology relay pioneers of intelligence theory including, Galton, Spearman, Pearson, and so forth (Moser, 2008). Texts are often presented in a chronological order drawing upon a discourse of progression that usually simplifies events. For instance, strong debates occurred within the psychology discipline around the validity of ‘g-intelligence’, and the controversies of heredity and environmental intelligence. This did not allow for a smooth discourse on intelligence – it was not clear how it should be understood nor measured. Yet, often a seamless and complete discourse is offered, upholding a psychological discipline worthy of institutional and research funding.

In relation to dementia, Jaspers (1910) used intelligence measurements to support the case to further classify dementia. “Any failure in performance, whichever way it is assessed is called dementia. The concept therefore, is so wide, that, like other encompassing notions, is in danger of being empty of any real content” (Jaspers, 2010; p. 568). He argued that better tests and diagnostic classifications are needed to differentiate dementia. However, Jasper (1910) discerned that as well as in organic conditions, other mental health conditions can cause a failure of thinking. However, he is careful to differentiate an organic or disease specific dementia to align with and justify psychometric measurement: “organic processes in presenile dementia, usual destroys in a

far-reaching manner... comprehension, speech, memory and the powers of organization” (Jasper, 1910; p.568). Jasper (1910) discussed that for one to receive a diagnosis of dementia, both psychometric testing and a detailed historical and clinical history to consider individual variables, should be used. The psychology of the individual is shown here: the object is seen as both measurable and identifiable, but the object is constituted for and through psychology.

Memory theory & measurement. In the early 1900s, the psychoanalytic movement added another dimension to forgetting. This was through the notion of a structural conscious and unconscious, whereby repressed material was seen to materialise in the form of emotional or behavioural disturbances. Through therapeutic intervention the unconscious memories were assumed to move into conscious, resolving inner conflict. At the same time, experimental research and phrenology emphasised the link between matter and function, in brain localization theories (see, Hacking, 1996). Broca and Wernicke were two scientists who worked upon associating parts of the cerebral cortex with written and verbal language use, distinguishing normal from abnormal memory (Hacking, 1996). Ebbinghaus (1850), in his book *Memory*, also described his development of a measurement of memory functioning, which he developed through experimenting on himself. This added another psychological ownership of memory, alongside intelligence (Katz, 2012).

Another influential case for proliferating the field of psychology in relation to memory measurement was H.M. (Scoville & Milner, 1957). H.M. was one of ten patients who received an experimental partial frontal lobotomy (removing the hippocampus) aimed to resolve severe epileptic seizures. H.M. in particular, remembered experiences prior to the surgery, yet failed to retain any new knowledge after surgery. Later, detailed theories on the anterior hippocampus, hippocampus gyrus and basal ganglia were developed in relation to the encoding of new memory (Dillman, 1990).

1.08 Dementia in the Twentieth Century

Violations to the rules of science. Drachman, (1974) influenced by psychology and localisation activities, completed a series of large-scale studies based on the hypothesis that Cholergenic neurones in the hippocampal structure were causal and indicative of dementia. He concluded that Cholergenic neurones could not be a reliable measurement for pathological degeneration, as behavioural presentations did not align

with the level of brain pathology indicated. There was also a vast amount of conflicting and inconclusive evidence from smaller studies presenting high levels of atrophy in the hippocampus corresponding with dementia symptoms, while on the other hand, high levels of atrophy in the absence of dementia symptoms (Dillman, 1990). If engaging with the relatively formed argument of intelligence, this conundrum seems foreseeable, given not all brain capacities or abilities would be the same. Someone with a higher capacity of intelligence would be expected to show less behavioural disturbances with more neuronal pathology, and vice versa. This presented a problem with the mind and brain parallelism populated by Kraepelin in the attempt to establish psychiatry.

Also, throughout in the 1960s and 1970s professionals were continuing to state their knowledge about what presenile dementia and dementia was in conflicting and opposing ways. One understanding was that presenile dementia related to any form of degeneration caused by mental disorders or alike; another was it related to a form of degeneration occurring in specifically in late adulthood and a further understanding was that presenile dementia was caused by arteriosclerosis (now known as vascular symptoms) supposed to progress to pathological levels in some cases, though this was expected in all older adults as part of general ageing (Dillman, 1990). It may be considered that at this particular time the discursive field relating to dementia was being rearranged in the context of competing knowledge's and power struggles. There was also a series of impracticalities for professionals and researchers – violations to the rules of science regarding tests and measurements. In the twentieth century the biomedical construct of dementia was insecure and lacked hegemony.

Smoothing over the controversy: The perceived truth effects of measurement.

Firstly, where presenile dementia could relate to all numbers of disorders, this faded in the 1980's with the influence of the Diagnostic Statistical Manual- Third Edition (DSM-III) shaping the practices of clinicians and their understandings. The DSM had come to be based on large epidemiology studies regarding the clinical course of patients used to support clinical practise in dealing with separate and distinguishable conditions. There was a shift from a unified view to a differentiated view to classify disease based upon clusters of signs and symptoms. Existing knowledge and classifications were made to bear on the diagnosis procedure of dementia. Patients began to be identified according categories, yielding a group of very diverse subjects into one homogenous group.

Table 1. Diagnostic Statistical Manual-Third Edition criteria for diagnosing dementia

A) Loss of intellectual abilities sufficient to interfere with social or occupational functioning
B) Memory Impairment
C) At least on of the following:
(1) Impairment of abstract thinking, as manifested by concrete interpretation of proverbs, inability to find similarities and differences between related words, difficulty in defining words and concepts on similar tasks
(2) Impaired judgement
(3) Other disturbances of higher cortical function, such as aphasia (disorder of language due to brain function), apraxia (inability to carry out motor activities despite intact comprehension and motor function), agnosia (failure to recognise or identify objects despite intact sensory function), constructional difficulty (inability to copy three dimensional objects, assemble blocks, or arrange sticks in specific designs)
(4) Personality change i.e. alteration of premorbid traits
D) State of consciousness not clouded (does not meet the criteria for delirium or intoxication)
E) Either 1 or 2:
(1) Evidence from history, physical examination, or laboratory tests, of a specific organic factor judged to be etiologically related to the disturbance
(2) In the absence of such evidence, an organic factor necessary for the development of the syndrome can be presumed, if other conditions other than Organic Mental Disorders have been excluded and if behavioural change represents cognitive impairment in a variety of areas

In addition, ability testing was distinguished more as a logical means of determining a diagnosis of dementia to permit reliable conclusion. This began to command a new field, clinical neuropsychology. A steady stream of pen and paper tests such as digit span, storage retrieval, free recall and word storage, were taken as a firm diagnostic criterion to indicate dementia, alongside professional committees, research journals and specialist trainings in neuroscience. On the following page, an extract presented in a table from the diagnostic statistic manual three (DSM-III) shows how these neuropsychological based tests almost ‘blur’ the discrepancies around classifying this condition from normal ageing. In this table, it is evident that language difficulties are included into the classification of dementia, despite Alzheimer’s initial differentiation. Diagnostic criterion is based heavily upon pen and paper test outcomes e.g. “ability to copy three dimensional objects, assemble blocks and arrange sticks”.

Other proposed instruments were blood tests, x-rays, electrocardiogram and clinical evaluations, deemed to insure accuracy which required diverse branches of professional disciplines. Here, the incomplete nature of this discourse around dementia again appears to be smoothed over, through the perceived truth-effects of measurement and exactitude among the professions, securing their position.

Pragmatic adaptations – the DSM III revised. To highlight a few problems, not uncommon to critiques of the DSM: 1) the borders for what dementia is, or is not, are fuzzy – patients do not have to meet all criteria, therefore classified group members can be substantially varied yet still fit into the category; 2) there are a series of abstract terms, which lead to questions around subjectivity and inference, for instance, what is occupational disturbance and what determines personality? Is this not the choice of the clinician? 3) Despite the formerly presumed parallelism between the internal systems and the external presenting symptoms, it was argued earlier on in the text that in dementia physical symptoms could be excluded while specified symptoms could be present. Rather than epistemological positivism, the DSM and other developments at this time seem to have been developed according to *what works*. Another example of this is later addition to the diagnostic criteria (DSM-III revised) of mild, moderate and severe cases of dementia, as well as the option from a ‘probable’ diagnosis, meaning that a clinician could diagnose probable dementia with the absence of repeated and time consuming measurements. These pragmatic additions were similarly added to the International Statistical Classification Manual 10th revision (ICD-10) (Huppert, Brayne, & O’Connor, 1994).

1.09 Resistance and Bi-directionality to Dementia

People with diagnosis of dementia. People with dementia and their spouses are likely to at times resist the dominant discourse that memory loss is linked to a degenerative disease. One means may be through evading professional encounters all together, in other words not confessing to the expert and avoiding institutional sites. Yet, scientific and professional vocabularies or jargon, revealing scores, averages, percentages, plaques and neuro-fibular tangles, are currently likely to restrict biomedical dementia discourse as open to the expert and closed to the person being spoken about – in a Foucauldian sense this may be explained as, *the rituals of speaking*, where sets of gestures, behaviours, signs and circumstances accompany a qualified speaker of discourse (see, Hook, 2007). This may have the effect of masking political, economic, legal and moral discourses, into a purely scientific one through the taken for granted assumption science is value free. This perhaps effectively results in a large proportion of the population being passive recipients of medical services, rather than active agents.

Professionals. Given this, why are professionals, in an informed position, with the ritual to speak, not resisting the biomedical discourse of dementia?

“Clinical psychologists have had long training in research methods at both undergraduate and graduate levels. They are therefore well placed to comment on poor scientific practices, but have seemed reluctant to do so. Conversations with colleagues suggest their ability to act as applied practitioners in their workplace to develop their understanding by undertaking research appears to have been lost, or very severely restricted... Don't they have responsibility to develop effective therapeutic techniques?” (Bender, 2014, pp. 54-55).

Fragmentation of NHS healthcare. Currently in the UK there is a strong discourse problematizing the NHS, endorsing the need to tighten the health and social cares expenditure to enable free-health care. One outcome of this has been the justified fragmentation and privatisation of NHS services amongst politicians, supposedly ensuring best value for money services and a ‘healthy’ competitive culture within a care-based organisation. However, one perception is that this has resulted in a culture where organisations and workers are continually assessed and monitored by managers, commissioners and even patients and their families. Under complicated managerial regimes, concerning resource management and corporate objectives to cut spending, professional workers may internalize budgetary disciplines, as well as limited professional autonomy. This links to Foucault’s (1988) notion of *technologies of the self*, where in order to function as an effective worker, professionals may need to work on themselves rather than challenging more structural regimes.

This is a shift in the organisation and management of professionals in terms of the distribution of power and knowledge outlined previously, where the psy-disciplines were the primary power site maintaining bureaucratic order. Yet, caution is taken to oversimplify this matter. In particular, the psy-disciplines have a relationship with healing *and* self-interest. Genuine concern of psy-professionals to alleviate suffering goes hand in hand with achieving prestige, fund raising and so forth. The growing concept of dementia and its prominence, present shared and common interests amongst politicians, professionals, scientists, and the public alike, meaning resistance or bi-directionality towards the biomedical dementia discourse appears limited.

1.10 Person Centred Care

The person centred model (PCM) - a shift in paradigms?

Amongst dementia literature, it is often portrayed that in the last two decades there has been a shift in paradigms from a biomedical homogenisation of dementia to an emphasis on person centred care (Parker, 2005). The more recent paradigm is understood as focused on individual biography and subjective experience: “person centred care involves knowing life history and individuals with dementia” to shape and sustain a person’s sense of self (Beard, 2004, p.416). It is also centred on notions such as including the ‘voice’ of the service user, founded upon humanist and liberalist notions of individual. Within NICE (2016), as well as the medical basis for dementia, a person centred approach features heavily. Queries are, *has there been a shift from one approach to another? What power effects does the discourse relating to person centred care generate to account for its success and prominence?*

As discussed within this genealogy, debates relating to the self and memory are not recent, and can be traced to unconscious memory theories in psychoanalysis, rendering a wealth of literature and art on the meaning of the self. Also, in the 1600s functions of memory were seen to be a guarantee of rational personhood, fitting with the enlightenment where the relationship between mind, and body was reordered with rational individualism and empiricism (Locke, 1995). In this sense, the discourse and importance of personhood is not new – it has functioned as an element in the emergence of a scientific discourse. At odds with this, Kitwood’s (1997) work is often portrayed to be the starting point of person-centred care.

Kitwood on Personhood. Kitwood (1997) illustrated how family members, particularly spouses, could begin to relate with PWDD in ways that endorse the PWDD withdrawal from social interaction. Kitwood (1997) related such social processes to the way dementia comes to be known and worked with by the ascriptions associated with it – arguably a more novel and social constructionist epistemological position (refer to method). Nonetheless, within this framework Kitwood (1997) reasoned that where some cognitive decline was a socially produced and reversible, ‘*rementia*’, other cognitive decline was neuropathological and irreversible, ‘*dementia*’. Kitwood’s theory works alongside the scientific discourse of pathology, rather than shifting away from it. This model has since been developed in health and social care practices and community based cognitive rehabilitation (J. Parker, 2005). Dementia person centred care treatment has

branched into community care, co-ordinated by community nurses, occupational therapists, care workers, social workers, and voluntary, private and statutory agencies.

Person-centred Therapies. Current and popular, person-centred interventions for PWDD include Reality Orientation, Reminiscence, Cognitive Stimulation and Life Review therapies. To exemplify one these, Cognitive Stimulation Therapy (CST) appears to be a consists of fourteen, hour-long sessions running twice weekly in small groups. Activities include using money and word games, discussion of past activities and experiences usually with the aid of tangible prompts such as photographs. Spector, Woods and Orrell and colleagues (e.g. 2000; 2003; 2012; 2013; 2014) have argued that cognitive rehabilitation methods lead to improvement on PWDD cognitive testing performance, and their quality of life or life satisfaction ratings (e.g. see Spector et al., 2003). Other studies, such as Ishizaki and colleagues (2002) presented only a one-point increase on the cognitive test though specified improvements in quality of life.

Biggs and Powell, (2001) discuss the reflexive relationship between power and knowledge, where professional power is reinforced by the questions professionals ask and the data they collect (e.g. both cognitive testing and quality of life scores). This knowledge often progresses to a certain definition of the problem area that feeds back to stabilise the original formation of the problem itself - a biomedical understanding of dementia. In other words, the idea that cognitive improvement can occur through person-centred rehabilitation is based on the argument that dementia is linked to complex structures in the brain, as professionals and scientific investigations purport. The administering of these treatments promotes the human sciences that define human subjectivity and creates PWDD as objects, through discourses that limit and give possibility. Correspondingly, Harper and Speed (2012) problematize the vagueness of the concept quality of life, and the individualising effect it has, accompanying medicalised understandings of distress. This obscures structural, political and social problems.

Older adult abuse and policy. One argument relating to the success of the person-centred care model within dementia, it that it has also functioned in relation to policy created around the prominence of institutional and familial reports of abuse of older adults and more specifically PWDD in recent years (Acierno et al., 2010; Alexandra Hernandez-Tejada, Amstadter, Muzzy, & Acierno, 2013; Klein, Tobin, Salomon, & Dubois, 2008; O'Keeffe, 2007). Within these studies, there are trends that abuse is largely

under reported as it tends to occur in the older adults home, and/or within family contexts. According to a helpline in the UK sixty four per cent of older adult abuse occurred in the home, twenty three per cent in residential care and five per cent in hospitals (Hidden Voices, 2005; as cited in Neno & Neno, 2005). In 2002 the World Health Organization brought attention to the issue of elder abuse, and in 2006, the International Network for Prevention of Elder Abuse (INPEA) highlighted ways to challenge worldwide abuse (Rinker, 2009). In NHS settings, disproportionately high mortality rates have been found among elderly patients linked to a lack of basic standard care (Mid Staffordshire NHS Foundation Trust et al., 2013).

Amongst several abuse related policies *The Dignity in Care Campaign* focuses upon zero tolerance of abuse and disrespect for older people (National Dignity Council, 2016)⁶. It endorses a change in the culture of care services and places emphasis on improving the quality of care and the experiences of citizens in sites such as NHS Hospitals, community services, care homes and home support agencies. Also, *Living Well With Dementia* sets out the government's commitment to individuals with dementia and their family carers to ensure high quality care (Department of Health, 2009b).

One the one hand it could be viewed that these policies are founded on the betterment of familial and institutional care for elder adults. On the other hand, it could be argued that such policies fit with a hegemonic discourse of cognitive decline, dependency, and the burdensome of older adults and PWDD maintaining the very positions of vulnerability and susceptibility to abuse purported. Exemplified policy also justifies endless reasons for professional intervention, relating to moral and legal foundations in society. For instance, within the rise of social work in the 1950's there was the view that some families will be able to bare the care of dependent family members, whereas others would require state intervention aside from the private sphere (Biggs & Powell, 2001). Scrutiny toward abuse is also likely to increase the technologies of the self in relation to family or spousal carers – they may better themselves as more compassionate workers.

In sum, it is not that the person-centred model completely rejects a bio-medical model of disease as it is perhaps portrayed, and, perhaps more hidden aspect of person-centred care is the rejection of institutional abuse.

1.11 Marriage and family

Marriage and family have become structures so ingrained in society they often exist without debate or contention; one is raised to believe certain truths, views and opinions concerning marriage and family and are also often governed by these. As depicted in this genealogy up until now, epistemological positivism and subjectivity or individual differences have created a culture of individuality and subjectivity. Torrant (2011) contends that individualising knowledge of a subject's consciousness, sentiment, love, commitment and instincts that are embedded within marriage and family discourses, are political and ideological structures, explored further.

In the 1600's, producing offspring was necessary for producing grain. In western countries and the US the average marital couple had over seven children (Parker & Aggleton, 2007). Marriage was reportedly dominant for survival purposes and in accordance with this, the act of matrimony was socially and spiritually celebrated. Although sexual activity between those of the same sex was documented at this time, once married, sexual acts outside of wedlock were condemned and punished (Parker & Aggleton, 2007).

By the nineteenth century the family was construed as a means to form a satisfying and mutually enhancing relationship between man and women, creating an environment fit to nurture children (Parker and Aggleton, 2000). The family was *seemingly* disconnected from the public world of work and production, and was viewed as something existing within a 'private sphere'. Panu (2009) depicts how influential institutions, such as the church, promoted marriage as the only morally acceptable way to perform. It has been argued by Zarastsky (1976) that sexuality outside of the marital dyad was associated with the acts the underclasses, in the context of an increasing middle class.

The repressive hypothesis. Relative to this, Foucault (1998) has illustrated the notion of the *repressive hypothesis*, whereby common historical accounts portray a lack of, or a repression of, sexual discourse during the Victorian era. On the contrary, he argues that there was a 'discursive explosion' on sexuality. As one means of illustrating this Foucault (1998) presents how there were extensive discussion on the inappropriateness of sexual acts with children, demonstrating one province of the vast range of speech on the 'order of sex' at this time. Foucault adds that sex was dominated by technical and legal vocabularies, as well as scientific studies belied with the publics increasing obsession with sexual relationships and desire (Foucault, 1998). Sex, and in

turn, family and marriage, were made into a public matter, forced into a discourse of something that society sought to control its influence over within the human body – a liberal apparatus. From the eighteenth century onwards, the apparatus of sexual activity was the interface that allowed the coupling of juridical law and mass population norms, producing importance and dominance of the coupling of alliance (e.g. marriage, kinship ties, transmission of names and possessions). The affective intensification of the family space through biopower, gave the family a modern form, while opening it up to an endless plethora of experts (e.g. doctors, educators, psychiatrists, priests and pastors) who would listen complaints of sexual suffering (Foucault, 1998).

Individualisation & Industrialisation. Fitting with this, Beck and Beck-Gernsheim, (2002) describe that after industrialisation, discourse around investing in relationships was as much as about material resources, as conjugal love. For instance, women, particularly the very elderly, single, or widowed women, were most likely to be poor (Hewitt, 1974; as cited in Philipson, 1982, p.12). Figures have presented that there was a gender imbalance in almshouses, including two thirds of women; whereas married couples were more likely to live above the poverty line (Philipson, 1982). Also, legal rights ensured an obligation between spouses, their children and their in-laws to care for family members. Namely, a condition poor law act was: “public aid is denied to aid individuals with parents, grandparents, spouses, adult children, or grandchildren who are able to take them into their homes” (Katz, 1996, pp. 13–14). This presents how the conventional family came to be a political control and an economic regulation.

Donzelot and Hurley (1997) report individuals were tormented by the family, through various forms of abuse, and at the same time, individuals were unable to live without family, through a structural dependency. The “psy specialist furnishes a natural terrain for the resolution of difference in the regime through management of bodies and management of populations” (Donzelot & Hurley, 1980; p.229). The family like other mechanisms of power ensured heterogeneous and contradictory elements of liberal governing presented themselves as coherent and natural (Denzelot & Hurley, 1980). Torrent’s point about ideologies of love and sentiment, which mask the political infrastructures of family and marriage, is fitting here. For example, until the Divorce Reform Act (1969), many couples were likely to have lived in the context of domestic abuse – after 1969 divorce rates rose considerably. Likewise, until 1973, it was very

difficult for women to gain child custody when leaving unsustainable marriages (Thane & Filby, 2010).

Counter discourses relating to marriage and family. Although not much discussion is designated to counter-discourses on the family unit in this subsection, these have been apparent and influential⁷. A fundamental example is discourses surrounding World War Two (WW2) regarding women's rights movements, indicating a questioning of the nuclear family roles, alongside the requisite for women to continue working (Panu, 2009)⁸. Due to large number of men who died at war, structurally supporting forces upheld a resistance to a patriarchal society. Yet throughout the 1950s, governmental family agenda's and a series of scientific research studies presented truth statements on 'discoveries' that broken families were consequential to the social failure of children. The accusation against liberal mothering over-shadowed the complex mechanisms of social determinism and poverty while sustaining a neutral ideology of the family (Panu, 2009). Correspondingly, at this time, women's masculine behaviour was problematized and considered to lead to frustration, hostility, destructiveness, frigidity and mental illness. Likewise, men engaging in homosexual acts were pathologised (see, DSM I published in 1952, American Psychiatric Association et al., 2008).

In the 1980s and 1990s Silva, Roseneil and Mann, (1996) describe how there were increasing numbers of never married parents and single parents resisting heteronormative family formations, which created a 'moral panic.' Various governmental policies and initiatives were developed to strengthen the family, in the form of crisis intervention programmes (e.g. counselling, substance misuse treatments, foster-care, adoption, child support enforcements). A discourse about unmarried mothers in which delinquent children, juvenile crime, masculinity crises, and social and educational failure were blamed upon them, effectively diverted attention from governmental responsibility. Foucault's (1997) conceptualization of power may be thought of here where he states that power comes from different sources and relates in complex ways. It does not work in a hierarchal sense, it works through a net power including different, connected channels – apt when considering change around the discourses relating to marriage and family over time.

1.13 Dementia and Marriage

Qualitative research on dementia and marriage. In the last ten years, possibly linked to post-structuralist research movements and the emphasis on the value of qualitative methodologies, there have been a large body of qualitative studies on carers of people diagnosed with dementia. Bamford and colleagues (2004) completed a systematic review finding those with dementia's perspective were largely absent from the literature. Daniels and colleagues (2007) reported this was due to the assumption persons with dementia are unable to contribute due to their condition; also the social constructions of mental capacity is deemed to limit PWDD from providing informed consent to participate in research. There have been some studies relating to the PWDD's experience from a humanist perspective (see methodology 1.02): Steeman and colleagues (2006) completed a review of qualitative findings on the subjective accounts of PWDD and presented multiple challenges (i.e. loss of thinking ability, problem solving difficulties, getting lost, forgetting names, and feelings of shame, guilt, uselessness and worthlessness). Nevertheless, samples tend to include individuals with early stages of dementia again relating to barriers such as strict research ethics requirement centred upon mental capacity.

Few qualitative studies have examined dementia within the marital relationship (Beard, Sakhtah, Imse, & Galvin, 2012; Daniels et al., 2007; Hellstrom, 2005; Hellstrom, Nolan, & Lundh, 2007; Svanstrom, 2004). Amongst this data participant's portrayed marriage was pertinent to managing dementia, and that spouses would actively try to maintain the continuity of their marriage through sharing joint perspectives and reminiscing on past times. Daniels et al (2007) uniquely adopted a narrative approach, presenting findings of spouse's tendency to talk over the person with dementia and dominate the discussion, whereas, more commonly amongst these studies, Svanström and Dahlberg (2004) adopted a phenomenological method describing spousal 'experience' (e.g. futility, hopelessness and homelessness).

As common to most qualitative research, objectivity/applicability and scientific rigor are often used to evaluate the usefulness of studies; this may be argued that as an attempt to fit the method toward the dominant scientific paradigm. Nonetheless, limitations of research on dementia in couplehood described is that studies had limited applicability of data. Two were self-selective case studies (Hellstom et al., 2005; Daniels et al., 2007) and in Svanström and Dahlberg's study (2004) only five out of fourteen people participated. Apart from Hellstom, Nolan, Lundh (2007; 2005) all studies

conducted one interview with spouses jointly, where talk in front of the spouse may be censored.

Discourse Analysis (DA) is distinguished from other forms of analysis due to its central focus on power and knowledge, and the way these reciprocally influence social thought, action, organisations, systems and ideologies. Although the discursive approach has been used to investigate interactions in residential homes this has not been applied to the persons with dementia and their spouses or the marital sphere (Dijkstra et al., 2002). This qualitative interview study will be guided by a discourse analysis, which emphasizes the importance of recognizing the shaping effects of dominant discourses; in this case how people with dementia and their spouses are frequently subject to discourse, with or without awareness and how this may accord them certain ‘speaking positions’ or ways of speaking, thinking and acting. At the same time, a discourse enquiry may focus upon times when dominant discourses or speaking positions are conflicted, replaced, resisted, co-existing or disappearing from spouses talk. Using an example from discussions in the chapter, the informal carer may replace the speaking position of the marital partner, or the older adult with the person with dementia. The PCM may substitute talk on biomedical notions of dementia, or as argued work together to hegemonize the latter dominant and historically located scientific discourse. In table 2, the specific research aims based on this methodology are listed.

Table 2. *Study research aims*

1. To consider the regularities and discursive patterns that can be discerned from the data, as well as discontinuity and deviances, giving significance to resistance and bi-directionality.
 2. To explore power and knowledge implications of dementia discourses for participants (e.g. ‘disciplinary technologies’, ‘zones of power’ ‘soul effects’ and ‘the other’, ‘regimes of truth’).
 3. To decipher the various ‘speaking positions’ or ways of acting and thinking that are available for participants - in particular the positions that do not support the dominant way of thinking and conceptualising.
 4. At the same time, to explore the appearance, disappearance, replacement and co-existence of subjects (e.g. the marital role vs. carer role).
-

1.14 Chapter Summary

This chapter discussed the political basis of the concept and practise around dementia and the social and historical conditions that have enabled dementia discourse to emerge in a more dominant and stable form. It discussed, current ‘treatment pathways’, such as person centred care, and the informal carer including implications this may have on the marital sphere. The following chapter explores the research methodology.

2. Methodology

2.01 Chapter Overview

This chapter begins with an exploration of the epistemological stance and theoretical orientation of this study, as these both influence the methodology. To support the discussion of complex notions and theory, examples from other chapters are embedded throughout the text to augment descriptions. This methodology details the research procedure, including ethical considerations, recruitment, the collection of data and the analysis.

2.02 Research Paradigm

Rationale for research methodology. This study has utilised a constructivist epistemology, which Parker (2014) explains represents a critical reflexive movement away from objective measurement, and an effort towards a socially mediated and historically situated study of action and experience. This research explores the dominant construction of dementia. It considered how this concept may be taken for granted or assumed to be ‘something we know’, plus the way that dementia is typically construed as a ‘truth’ through the human sciences and other industries sustaining certain power and knowledge relations. As well as exploring historical processes, this study explores present language systems and practices in relation to dementia. Firstly, through the analysis of professionally produced leaflets from memory assessment clinics as well as professional guidelines and policy relating to dementia, and secondly through analysis of interviews completed with PWDD and spouses, to consider wider political processes but also the impact of discourse within the marital sphere. The study applies a critical orientation to understand the complex relationships surrounding dementia and the way dementia’s meaning is produced, considered further throughout this chapter.

Epistemology. Epistemology has primarily been concerned with the assumptions that we make about what knowledge is, how we generate knowledge, what we know, and how we know what we know (Breakwell, Smith, & Wright, 2012). Within social sciences, amongst other fields, these questions have been debated; according to some epistemological positions these answers remain unclear (Gergen, 1985). In order to explain the rationale for a social constructivist position used in this study, three epistemological positions are considered: constructivism, humanism and objectivism⁹. It should be noted that categorising in such a way risks over-simplifying the nature and

scope of knowledge; there are overlaps between the positions in research; and there are other positions which are not mentioned.

Burr (2003) has explained that amongst the social sciences we have seen a gradual emergence of the constructivist approach to knowledge. This approach appears under a variety of rubrics, such as critical psychology, discourse analysis and post-structuralism, which all may be thought of as having social constructionism in common. According to Burr (2003) social constructionism can be seen as a theoretical orientation that brings about radical and critical research methodologies, which this study embraces.

Constructivism proposes truth is not obtainable or measurable as it is created within the subjects' interactions with the world. For instance, Gergen (1985) states that "constructivism views discourse about the world not as a reflective map of the world, but as an artefact of communal interchange" (p.266)¹⁰. In viewing traditional understandings of dementia as an artefact of communal interchange, research studies that claim that there is an epidemic of dementia, and measurement tools that are used to diagnose dementia may be challenged; both are constructed in scientific communities.

Researchers from a humanist epistemological position may describe social reality as a creation of individual consciousness (i.e. it is 'personal' and 'subjective'). As reality is an aspect of our minds, it is inevitably affected by our minds, therefore our attempts to understand any form of social reality must be grounded in people's social experiences of that reality (Gray, 2014). They also propose that such understandings can be achieved through qualitative, rather than quantitative methodologies. This leads to the view: "we must lay aside our prevailing understanding of phenomena... social reality is too complex to be understood through the process of observation alone. We must interpret in order to achieve deeper levels of knowledge and self-understanding" (Gray, 2014, emphasis added, pp.21-23).

Nonetheless, some humanist researchers argue that observational data alone *is* valuable within the humanist epistemology, particularly within dementia research. Clare et al. (2008) claim that a number of ethnographic, observational studies provide rich subjective insights into the life of people with dementia, for instance in residential care homes or hospital units. Also, most constructivist researchers would emphasise the point that we cannot understand phenomena (or the mind) except *through* discourse, rather than phenomena not existing. One example is the many research studies that attempt to understand the emotional experiences of PWDD and/or their spouses; these may be thought of as ways of constituting knowledge, together with social practices, forms of

subjectivity and power relations which are maintained and produced through this way of understanding knowledge. The researcher's "individual consciousness" is very much embedded within the dominant historical and cultural discursive frame, which inevitably affects interpretations drawn. Therefore, studying dementia discourse is a way of understanding power and knowledge, making apparent wider political processes that may otherwise be hard to notice.

Although there has been a remarkable increase in the amount of published qualitative research in the field of dementia research – mostly from a humanist rather than constructivist epistemological stance – the objectivist position is still central in many respects. The objectivist epistemology assumes that through focusing our efforts on the method, a set of general laws and principles can be established to enable a close alignment with an objective truth or reality. Kerlinger (1973) explores four general ways knowledge is developed: through common sense or lay beliefs, expert opinion, priori testing, or through reasoned knowledge developed using scientific methods. The scientific method has been esteemed and is seen to subjugate other methods of knowing. It bases itself upon the assumption that through repetitive testing of hypotheses and controlled systematic processes, there is a 'survival of the fittest' hypothesis.

As discussed in the introduction, psychology, as a social science, has been affiliated to this understanding of knowledge, truth and reality. Part of this study has been to investigate psychology's relationship to dementia, and to examine how it has and may utilise experimental methods to solidify dementia as a distinct disease entity, overpowering alternative explanations. One clinical example is the commonly held assumption that through using the DSM-V criteria, a psychologically administered 'cognitive screening battery' (multiple pen and paper tests), and informant reports (a spouse or family member's account), a clinical psychologist can accurately detect and diagnose dementia. Problems with this are explored further in a discussion directly below regarding social constructionism as a theory.

Social constructionism. Craib (1997) highlights variations between basic assumptions of social constructionism, partly due to the separation of the disciplines of sociology and psychology in the twentieth century. Although there is no one clear definition to capture the multiplicity of social constructionist ideas, Burr (2003) states we may think of social constructionism as having four tenets:

1) *A critical stance toward taken for granted knowledge and understandings of the world.* Here, the idea of objective unbiased observations, and the categories and concepts that we use, are seen as being dependent on social and economic arrangements. For instance, the rise in those diagnosed with dementia could be seen as related to the societal structures in place (e.g. the current neuro, biomedical, psychological, charity and pharmaceutical industries that uphold dementia as a distinguishable and treatable entity, while maintaining their disciplinary and/or marketing foundations). In relation to psychology, supporting diagnostic understandings of dementia maintains the need for a clinical psychologist's knowledge in society. Diagnostic procedures may be seen to remediate, correct, or restore, as per economic arrangements, ensuring an ordered population.

2) *A historical and cultural specificity in the ways we understand the world.* For instance, this study has explored the political movement where the mind and body were considered to be separate yet representative systems. This became a catalyst for medical practices to identify the physical manifestation of internal disturbances e.g. where doctors used certain disciplinary apparatuses to make inferences about internal structures or mind/body diseases. To relate this to dementia, this concept came to represent substantial forgetting and the diminution of brain cells. Dementia had previously been clustered under the terms 'demens', and 'delirium', yet changed over time, according to the prevailing cultural understandings of the world (Berrios, 1987) – refer to genealogy for further detail.

3) *Knowledge is not gained from nature of the world as it really is; rather it is constructed socially between people.* For instance, Alzheimer's disease was a newly coined term added to Kraepelin's taxonomy of disease classifications in the early 1900s, after his colleague Alzheimer produced two case studies combining new laboratory technologies (i.e. Nissl staining of cells, microscope) with clinical observations. The two constructed a non-age specific, abnormally progressive decline, labelled at the time as Alzheimer's disease (Dillman, 1990). Rather than a discovery of dementia, protected hierarchical positions, tools and vocabularies constructed this 'discovery' (see genealogy). Bearing this in mind, when using social constructionism, specific attention is paid to social interactions of all kinds, and in particular language. For instance, *how may language be produced between marital partners when one spouse has a diagnosis of dementia?*

Lastly, 4) *knowledge and social action are assumed to go together.*

Understandings are negotiated, and these could take a wide range of forms. Each construction can invite a different kind of action from human beings. To illustrate this, currently there are countless media descriptions of dementia being increasingly prevalent in old age. As one example, “850,000 people are currently suffering from dementia in the UK, with Alzheimer's disease being the most common type. The disease kills at least 60,000 people each year” . This invites a vigilance toward indicators of disease in old age to survive or resist the fate of “death”, and diverse reactions from politicians, professionals, researchers, families, older adults and so forth. Descriptions and constructions in the world sustain some patterns of action (e.g. diagnosis) and exclude others (e.g. possibly a movement towards a non-medical approach). This is entangled in the self-interests of power groups leading to some groups in society having power and knowledge, and others who are subjugated. One example of this is where PWDD and spouses perhaps not able to question easily due to the sophisticated languages and professional tools these groups use. In other words practise of “language formation”, meaning the constraints and enabling functions of “speaking, writing and thinking” (Hook, 2010; p. 102).

One aspect of this study has been to consider the way psychiatry is implicated; for instance, psychiatrists continue to prescribe pharmaceutical interventions for dementia, for which they receive various incentives (i.e. contracts from pharma, and a more privileged position within mental health care). Yet it is important not to position those with dementia and their spouses as *inevitably* oppressed – some people with dementia and their spouses would also view diagnosis and medication as important, here seen as illustrating how knowledge can produce multiple realities that stabilise power relations. Nonetheless, the premise that there are many different realities constructed within different historical and cultural contexts can be seen as problematic, as we have no way of judging between them (Burr, 1998). This leads to the position of relativism, where different constructions of the world can only be judged in relation to one another and not by comparison to an ultimate standard or truth.

Ideology. Burr (1998) proposes a way of thinking about social constructionism and relativism is to draw upon the sociological notion of ideology. Ideology refers to a single or a dominant discourse with relative stages of formation, and multiple complex discursive relations that produce divisions and mutually exclusive categories Dolar

(1999). One ideology may relate to scientifically produced truth. Burr (1993) deconstructs this by arguing that rather than truth, we may instead think about ideology as “knowledge deployed in the service of power” (p. 82). A version of events may be true or false, but it is only ideological to the extent that it is used by relatively powerful groups in society to sustain their position (Burr, 1998). In addition, Billig and colleagues (1988) discuss ideology explaining that our thought and its content are provided by wider, socially shared concepts and issues. We tend to think about these as dilemmas, which, implicitly, always have two sides. For instance, *who is to blame for poverty, the individual or society?* Billig and colleagues (1988) name these ‘ideological dilemmas’, referring to how one’s thinking is shaped by prevailing ideologies in society. Ideologies therefore cannot be seen as logical and coherent or unified systems of ideas; rather, they are inherently dilemmatic. This is important regarding the point made about relativism, and standards or truth. Here truth is an ideology, a political formation that shapes how people relate or are socially positioned.

In this study, although it was hypothesised that the person diagnosed with dementia or their spouse may exercise some degree of choice and resistance amongst the systems of ideas relating to dementia discourse that they use, it was also considered that there are discursively produced categories and divisions (‘dementia’ and ‘non-dementia’) upheld as truths. The PWDD and spouses may find it difficult, though not impossible to step outside the prevailing ideologies. Given this, the researcher of this study, who may also be, influenced by inherently dilemmatic meaning systems, contemplated the multifaceted outcomes of discourses employed by PWDD and their spouses, abstaining from claiming right or wrong standards or truths, in line with the epistemological approach taken.

2.03 Methodological Framework

This research is utilising Foucauldian Discourse Analysis (FDA), an approach to research that draws heavily upon Foucault’s multiple works. Social constructionist ideas themselves may be thought of as being influenced by Foucault and other post structuralist thinkers, like Derrida and Saussure, discussed further.

Discourse Analysis. This methodological framework has broad and varying applications, across a range of disciplines. A general definition of discourse may be “the investigation of language in use, with particular attention being paid to talk and texts, in

their original contexts” (van Dijk, (1997, p.33). More specifically, those in the field of linguistics and semiotics have described discourse as a shared and changing system of signs, symbols and codes, which allow various social practices (e.g. expressing one’s ideas, the following of dress codes) (Saussure, 1986; Strauss, 1968). Marxist theorists may depict discourse as a much wider set of social practices and phenomena that have an economic basis and a political suprastructure; this leads to the differing positions of privilege and oppression within society (Howarth, 2000). The work of Foucault, Derrida, Zizek, Laclau and Mouffe, although varied and nuanced approaches, may be thought of as having in common post-marxist and post-structuralist approaches to discourse. This is the emphasis on how social structures are inherently ambiguous, incomplete and contingent systems of meaning. Foucault, in particular, was concerned with the way discourses ‘are shaped’ by social practices and the way that social practices ‘shape’ relationships and institutions (Howarth, 2000).

Contemporary discourse theorists, such as Fairclough and others, developed an approach termed ‘critical discourse analysis’ thought of as studying discourse on a macro level. This includes the analysis of power in, for instance, political speeches – in order to show the repressive function of discourses towards minority groups (British Association for Applied Linguistics & Clark, 1990). This differs from Foucault who avoided seeing power as something repressive or possessed by another, although notably, it has been argued that Foucault considered micro and macro levels of discourse (e.g. Miller & Rose, 2013; Hook, 2007). Foucault regarded power and/or micro and macro levels as ‘relational’, enacted between the subject and institutions, which could be, on varying levels, inventive and generative as well as adversative and unfavourable (Hook, 2010). Foucault stressed that we should assess everyday processes and rules through direct observations of talk and analyses of writing to draw conclusions about wider processes. This fits with the study rationale to examine professionally produced dementia leaflets and to interview people accessing memory clinics. Foucault also emphasised how we should examine systematized vehicles of thought, hereby accounting for more macro level analyses intertwined with micro. One example is the biomedical construct of dementia. From a Foucauldian perspective, the biomedical construction of dementia may be thought of as over determined and complimentary to producing and generating power-effects for organisational, commercial, government, and medico-therapeutic systems. This influenced the study design to focus the way people with dementia and their spouses talk about their diagnoses, post diagnosis.

Although discourse theorists, Potter and Wetherall (1987) have studied discourse on a micro level, this should be distinguished from Foucault's work. Potter and Wetherall (1987) wrote a text, particularly influential in social psychology, that studied language and the way individuals use language in a performative and action orientated way. One of Potter and colleagues analytical resources was termed *interpretative repertoires* where a central metaphor is used to represent a cluster of terms (Potter & Wetherell, 1987). They also utilised the term *subject positions* to consider how individuals are 'positioned' through the act of discourse as a particular kind of person with different rights and prerogatives. This can be a helpful theoretical construct in discourse analysis and has been considered in this enquiry, *how are PWDD and spouses positioned within dementia discourse?*

Nonetheless, Potter and colleagues approach also explored language minutely, as an entity for accessing individuals 'mental entities' (Potter and Wiggins, 1996). Foucault used a vocabulary and understanding in his work that was 'anti-psychological' (Hook, 2010). Part of this included avoiding the idea of 'individual agent'. Foucault saw the individual as something that had been advantageously created and maintained through disciplines such as psychology and law to facilitate types of control, action and normalisation. For example, when PWDD access psychology services embedded within memory clinics, they are interpreted through psychological explanations, through which subject-orientated descriptions are made. These descriptions may be thought of as a type of control that is constitutive of certain actions for the person diagnosed and others around them. Despite the individualising knowledge about PWDD concerning their human qualities and traits, in effect they are being homogeneously grouped within a domain of power and knowledge that assumes all individuals can be observed and influenced. This enhances the remit of control psychology, and other aforementioned organisations, structures and systems have. This calls for caution concerning individualised notions – discussed further below.

Foucauldian Discourse Analysis (FDA). Using FDA, this research project will explore the different discourses that PWDD and their spouses draw upon and how each interviewee is positioned in relation to dominant or alternative discourses. FDA is an approach that has been developed using Foucault's various writing and lectures to extrapolate his unique means of analysing and understanding discourse. His techniques and concepts are particularly useful for the critical orientation to dementia taken in this

study. Rawlinson (1987) has developed a FDA model to analyse the discursive processes within medicine and psychiatry. As dementia is considered a psychiatric construct, this may be thought of as a useful model for this research. Hook (2010) also provides a model for the application of FDA, highlighting some of the misconceptions in current research using this approach. Examples of this have been discussed in relation to Foucault's complex understandings of power, discourse and the individual. Another example may be the genealogical method Foucault developed, depicted below. Hook (2010) clarifies that this method of analysis is not a complete and historical tracing of a discourse, instead, it is a body of text constructing an argument to advance a different view of 'how the world is' by isolating a some principal scenes and roles, whilst being sensitive to the fact that there are a multiplicity of events upholding and maintaining a discourse that will not be accounted for in the genealogical analysis (Hook, 2007, p.257).

Genealogy. Foucault described genealogy as "a form of history which can account for the constitution of knowledge, discourses, domains of object, which run their empty sameness throughout history" (Foucault, Burchell, Gordon, & Miller, 1991, p.117). A genealogy may challenge the common sense view that 'dementia' has always existed and that it is a 'truth'. Foucault (1981) explained how the ideal of 'truth' is a discourse in its self, developed through the philosophical and scientific disciplines. For instance, the ethic of knowledge that promises to give truth, which enforces that "speech should appear simply as thought made visible by words" (Foucault, 1981; p.65). In creating a genealogy, Foucault aimed to bring together notions of the past and the forgotten, along with the deliberately excluded (Hook, 2010). He aimed to present the divisions, fragmentations and contradicting knowledge, which functional and systematic organisations are designed to mask.¹¹ Also, this method of analysis enables us to consider what knowledge may we resist (Dreyfus et al., 1983).

To develop a genealogy, Foucault (1991) emphasised the need for an accumulation of source materials, as a way of critically assessing the complex circumstances that allow for discourse to emerge. For example, Behuniak (2011) used films featuring zombies to discuss biomedical perceptions of dementia and to argue that societal constructions of dementia have a political function¹².

Secondly, in forming a genealogy Foucault argued that attention should be applied to discourse, such as the process of concepts forming and fading (Dreyfus et al., 1983). Hook (2010) explains how exploring the different meanings or clusters in a discourse can

present a 'network of elements' that become fixed to enable an object of knowledge to attain its coherence. Powers (2013) describes elements smaller subparts of the discourse which are replaceable and always subject to shift/change. For dementia, elements may include the biomedical origins of disease, i.e. plaques, neuro fibular tangles, excessive degeneration and so on, that have obtained coherence yet remain at risk of being altered. Marriage may be thought of as having had elements that perhaps have altered or faded in some respects, particularly when considering the westernised dominance of marriage discourses fifty years ago (see introduction, 1.09-1.10).

A third premise of a genealogy is a focus on events in a non-linear ahistorical process. The term ahistorical refers to Foucault's distrust of originary explanations that propose linear and successive discoveries. Instead, he proposed attention should be directed to the *surfaces of emergence*, referring to the particular complex events and circumstances that locate a discourse in a time and place (Hook, 2010). Rabinow (1986) also describes emergence as forces and struggles that wage against one another to gain strength and form, whilst struggling against external or internal elements that may act as oppressor's to the dominant discourse. In accordance with this, this study has considered some of the contingent moments and struggles that surrounded the emergence of biomedical discourse of dementia and to a lesser extent the contingent moments surrounding family and marriage discourses, to show how they are upheld by political events, circumstances and forces.

At the time of writing this thesis, there have been few genealogical enquiries within the field of ageing, these are limited to Alzheimer's disease alone (Dillmann, 1990; Robertson, 1990) or old ageing generally (e.g. Biggs & Powell, 2001; Katz, 1996).

Disciplinary technologies. In Foucault's (1991) *Discipline and Punish: The Birth of The Prison*, disciplinary technologies are portrayed to have emerged after the sovereign era, in what he terms as the humanist era. He explains that between these time periods there was shift in the way that crime was perceived in society and the way that a punishment was carried out (e.g. torture and execution to imprisonment). Humanist reformists argued against inhumane treatment, supporting a more curative model of punishment that goes only so far as to preventing a person recommitting a crime. Foucault views this as the beginning of psychological knowledge being tied intimately to power – proto-psychological concepts of will, tendencies and dispositions were used to structure penalties (Hook, 2010). There was a dynamic co-investment of new forms of

control, such as psychology and the law. Dreyfus & Rabinow (1982) add that disciplinary technologies and the notion of the problematic subject became powerful means of control where punishment remained ‘out of sight’, while exposing subjects to permanent surveillance. Disciplinary technologies involve technical skills, analytical procedures and professional vocabularies as means of codification and control, often mounted as ‘change’ and ‘betterment’ (Hook, 2010).

Here we may consider the PCM of dementia that emphasises personality, life experiences and individualised approaches to dementia (see introduction). Within this, both professional vocabularies (e.g. ‘dementia’, ‘relationship-centred care’) and disciplinary technologies (e.g. the vocabularies and procedures of service managers, nurses, occupational therapists, psychologists, commissioners that codify and control dementia) can be seen as structuring the discourse and meaning of dementia as found in the PCM at the same time as guarding and reifying disciplinary technologies.

Subjectification and objectification. Foucault’s notion of subjectification is defined by Hook (2010) as a thoroughly individualising set of knowledge about a single person or subject. Foucault (1991) emphasised a flourishing of the disciplinary technologies (e.g. the practices of researchers, psy professionals, cell biologists and pharma, among many other structures and systems in a dynamic web of power), which account for the successful rise of an individualistic society. Objectification is the objectifying of the individualised ‘subjects’ through means of watching, measuring and coding behaviour tendencies (Hook, 2010). Objectification increases the need for disciplinary technologies, and this increases ‘subjectification’ processes to capture the deviant subjects and apply modes of modification and rehabilitation (e.g. cognitive stimulation therapy groups, cognitive enhancement drugs). The tools used to measure dementia effects may exemplify objectification: for example obtaining personal histories to judge the extent of behavioural abnormalities may illustrate subjectification. Both processes are considered to be areas of expertise, there is no other means of accessing ‘truth’, whether the person has dementia or not, without a reliance on, and a need for experts.

Subjectivisation. Where an individual experiences himself or herself in terms of the individualising set of knowledge or subjectification constructed, this may be understood as subjectivisation. Hook (2010) states “the speaking subject is subject to

their speaking, and the subject of what is spoken” demonstrating the reflexive loop of discourse (p.37). Rose (1996) explains subjectification is the process of becoming subject to a narrative, which becomes attached to the work of constructing an identity. This is bound to both language norms and psychological expertise. Thus, a person with dementia may only experience themselves within the realms of language norms and psychological expertise (i.e. memory impaired, dementing, deteriorating).

Other theorists have adapted Foucault’s notion of subjectification as the differing ‘subject-positions’ which individuals are accorded (Potter & Wetherell, 1987). Hook (2010) has argued that a closer ‘fit’ to Foucault’s notion of subjectification may be illuminated by the psychoanalytic and anti-humanist notion of ‘the other’ devised by Lacan. The ‘other’ is the sum-total of the symbolic domain (i.e. the laws, language and social structure etc.) which can provide a reference for how we are structured in the complex social relations that we are part of (Dolar, 1999). ‘The other’ is crucial for accounting for the mechanisms of power and reflexivity. We ask: *how am I seen by ‘the other’? What does ‘the other’ want from me? What are the social values it holds most dear?* Here we may consider the role of the marital partner without a dementia diagnosis, who may have had contact with professionals through their spouses/the PWDD diagnosis and treatment. The marital partner may be interpreted as confirming with ‘the other’ (i.e. what do these professionals want from me? How am I seen?) and may shape themselves according to professional expectations and wider discourses around care.

Soul effects. Not dissimilar to subjectification, the soul as an evaluative and self-regulatory process - a pre-emptive intervention, occurring prior to the act of any disobedience. Foucault’s (1991) study of an architectural design of the Bentham prison led him to examine modern power (in an abstract and a concrete sense) and how the corrective involvement of various institutions produces soul effects, or docility and aptitude:

“...An annular building; at the centre, a tower; ...[it] is divided into cells...they have [windows] on the outside, which allow the light to cross the cell from one end to the other. ... Place a supervisor in a central tower... in each cell a madman, a patient, a condemned man, a worker or a schoolboy. By the effect of backlighting... each actor is alone, perfectly individualized and constantly visible” (Foucault 1991, p. 200).

The prisons circular shape and lighting, was understood to prevent prisoners from being watched and so they behave as if they are being watched continuously. Foucault (1991) explained this as the process of ‘inscribing’ the self, resulting in our own subjectivity being ‘disciplinary’, as a permanent means of control. Although different disciplinary technologies are dissimilar and the zones where they are centred/enacted are not homogenous (e.g. prisons are different from classrooms) they work together to form disciplinary power. For example, Kitwood (1997) provided numerous case studies to show how subjects with dementia often monitor and check themselves in social situations (e.g. for repetition of speech, word errors) whereby the ‘subject’ with a diagnosis of dementia may be thought to have ‘inscribed’ the disciplinary gaze upon themselves, effectively maintaining order and control.

Power and resistance. Foucault cautioned against stereotypical notions of power as something held, possessed, exchanged or governed, such as the Marxist repressive model of power (Foucault & Hurley, 1998). Foucault’s notion of power is a relational force which has various complex manoeuvres and manifestations. It is seen as an invisible unity that is produced from one moment to the next, with the potential to be extended and perpetuated (Powers, 2013). However, within the discursive horizon there may be alternative discourses that can create a means of resistance and alternative speaking positions. An alternative discourse to the dominant biomedical discourse of dementia may replace perceived symptoms of dementia as part of a continuum of ageing effects that can occur in later life, while avoiding biomedical understandings of dementia. Resistance may also involve contesting the diagnosis or the pertained ‘truth’ methods used to diagnose dementia. Resistance in its self may be thought of as a counter-power, challenging authority and subverting apparatuses of knowledge and power. This demonstrates the flow of power which Foucault explained using the term ‘bi-directionality’ - the opportunities for response and answering back. What this means is individuals do not control power, nor are they merely anonymous points of its application. Power is transmitted by and through those whom it comes to invest (Foucault 1980; as cited in Hook, 2010).

In terms of dementia, it may be important to avoid notions of people with dementia as being ‘victims’ or ‘repressed’ by others, most significantly avoiding the claim that spouses without dementia diagnoses repress their spouse with diagnoses. In Kitwood’s (1997) work, he depicted how spouses without dementia could dominate the

talk with the person with dementia, and out-pace them making it difficult for them to join the conversation. His work has encouraged efforts toward empowering people with dementia to align with a person-centred rather than biomedical identity. In relation to this, Foucault emphasised how notions of individuals breaking free of power, may be seen as liberalist notions enhancing the veil of the machinery (Hook, 2010). He claimed that in order to understand power, there is a need to attend to the interfaces between subjects and institutions or the day-to-day appearances of the apparatuses of knowledge and power, whilst avoiding notions of the individual agent – such as the spouse repressing or dominating the spouse with dementia (an individual level perspective).

In this study, one of the chosen interfaces was memory assessment clinics in a host NHS trust. From here, professionally produced leaflets were selected and used as part of the analysis, in combination with professional guidelines (NICE, 2006). Another chosen interface was the marital dyad; marital couples, where one spouse has a diagnosis of dementia were recruited from the abovementioned host NHS trust. This substantiated to a two-part analysis. From this data, close attention was paid to how discourse (relating to dementia) was interdependent on macro level processes (i.e. the organisational, epistemological, technological, economic forces).

Summary of FDA framework. In using this methodological approach, the ‘relational’ aspects of power and knowledge can be assessed, which is a novel line of enquiry within the field of dementia research. FDA can examine how dementia is constituted through disciplinary technologies and apparatuses and how this in return constitutes the need for disciplines. The use of this method scrutinises how diagnostic practise around dementia perpetuates dominant discourses, whilst disqualifying others (e.g. as discussed the dominant biomedical model (BMM) of dementia may prevent alternative conceptualisations of dementia). It also considers the outcomes of these discourses in terms of action (e.g. soul effects, and subjectification). This research method views power not as something held or possessed, but instead uses notions of bio-directionality to assess the flow of power in discourses. It enables an explanation of the historical and social circumstances surrounding dementia discourses and how these have altered and consolidated over time.

2.04 Method of Analysis

Reflexivity. Theoretical reflexivity is often seen to be an important aspect of qualitative methodologies. It is a process by which researchers acknowledge the different ways in which their beliefs, assumptions and knowledge might influence the research process (Breakwell et al., 2012). Qualitative approaches to research have received criticism for unsystematic and subjective observations that cannot be replicated and reflexivity is often considered a way of facilitating more reliable findings. There are various frameworks that are developed in order to assess the quality of qualitative pieces of research (see Greenhalgh, 1997). However, these may be thought of as trying to emulate the quantitative exactness of natural sciences. Within Discourse Analysis there is often far less emphasis on qualitative techniques in relation to underlying assumptions about knowledge. Discourse is depicted as something that enables us to communicate with the world rather than to accurately represent it.

Nonetheless, Willig (2013) has argued that how researchers engage with research material is influenced by their own experiences, and so there is a need to be reflexive in research. A reflective journal is one means to consider issues around reflexivity (appendix A), as well as combining data from different contexts known as triangulation. This study triangulated findings from four joint and six individual interview transcripts which encouraged a variation of talk between couples and individuals (Appendices B & C). It also used professionally produced dementia leaflets (Leaflet 1-13), and NICE (2006) professional guidance for dementia care. Research supervisors checked the analysis and verbatim quotes from interviews were included in the results chapter to illustrate the discourses.

Researcher's historical location. Historical location refers to the researchers positioning in the history of their knowledge. In terms of Foucault's position on one's relation to knowledge, he seemed less concerned with critical reflexivity although argued that researchers are in effect, looking through a 'modern day lens' leaving the risk of misinterpreting historical moments and events, and misinterpreting current relations. One example is where society is dominated by psychological knowledge and individualised understandings, the researcher could psychologise the data and find it difficult to think beyond the individual agent. Secondly, it is possible that the researcher may find it difficult to separate the study research findings from mainstream, universalising, internal and politicising trends, for instance, the lay understandings of empowering people with

dementia discussed (Parker & Gordo-López, 1999). In consideration of his own research location Foucault adopted the genealogical method to attempt to dismantle the ‘individual subject’ as the primary vehicle of explanation (Hook, 2007; p.171). Genealogies by Rose (2007, 1985) have examined various types of psychologies to engage in a critical psychology, within a broader web of social power. Tamboukou and Ball (2003) argue that the researcher should shatter norms and certainties about what can and should be researched; interrogate how we define accounts of knowledge, truth and scientificity; recover silenced discourses; restore political dimensions by highlighting the centrality of power; and guard against the temptation to recognise oneself in the data analysed (Tamboukou & Ball, 2003). These methods have been used to guide the researcher throughout the data analysis, discussed further in chapter four.

Ethical considerations. There are various guidelines to support the researcher to attend to ethical issues raised by their study (e.g. British Psychological Society, 2009, 2014). Particularly in relation to one of the spouses having a diagnosis of dementia consent to the research was carefully considered, as well as aspects of risk. This study also adhered to guidelines when: advising participants of the study aims through participant information sheet (Appendix I); seeking consent to contact them (Appendix J); obtaining informed consent (Appendix K); notifying the right to withdraw from the study; maintaining confidentiality and anonymity; and debriefing participants (appendix L).

Ethics. This research received approval from the University of Essex Ethics Committee, received on 13th October 2015 (Appendix M), a National Research Ethics Committee, on the 14th July 2015 (Appendix N) and the host NHS Research and Development Department on the 2nd September 2015 (Appendix O). The research project had a co-sponsorship arrangement for legal and professional indemnity between the University of Essex and the host NHS trust (Appendix P).

Participants for this study were recruited from one host NHS trust as patients who had received a diagnosis of dementia and their spouses. PWDD were recruited whilst attending Cognitive Stimulation Therapy, post-diagnosis. This meant that clinicians were involved to support with any risks that may have arisen (e.g. disclosure of suicidal thoughts and so forth). Potential suitable participants attending this group who met the inclusion and exclusion criteria (Appendix L) were sent an information letter (Appendix I) from their clinician inviting them and their partner to take part in the research. The

researcher did not have access to any of the potential participant's personal data without prior consent, in line with the NHS data protection policy (NHS England, 2014). Participant information letters included the co-sponsorship organisations logo's, the researcher's and research supervisors contact details and information on complaint procedures. Information on the purpose and nature of the research, benefits, risks/burdens, confidentiality and right to withdraw were also detailed in the letters. The language used was intended to be accessible and invitational.

The information letter was discussed verbally prior to any interviewing and participants were asked to provide informed consent (Appendix K). Participants indicated they had read and understood the information letter, had been given a chance to ask any questions and were aware of withdrawal procedures. Although there were no cases where participants were unable to understand the information sheet, the researcher drew upon NHS capacity assessment tools to support the consideration of this. While mental capacity may be considered a social construction, the National Research Ethics Committee and ethical guidance frameworks listed endorse full mental capacity is fundamental for the participant to understand what they were committing to in participating in research (dementia and marriage are both potentially sensitive topics). If a case had arisen where the participant with dementia did not have mental capacity to consent, the researcher would have offered to rearrange the interview, or reinstated the participant's right to withdraw from the study.

As interview questions included the possibility of disclosures and safeguarding risks, participants were informed of confidentiality limits and whistle blowing procedures prior to providing their consent. They were aware that if a risk did become apparent, the researcher would encourage them to speak to their clinician, or alternatively, the researcher may contact a member of staff in line with confidentiality agreements. The British Psychological Society Code of Conduct (2009), and host NHS trust Prevention and Management of Violence and Aggression Work Policy were used as guidance frameworks in the research procedure.

At the end of the interview participants had the opportunity to ask any questions and reflect on the interview process. All participants were offered a summary of the results or access to any published peer reviewed article; those interested in this offer were asked to sign a consent form agreeing for the researcher to store their preferred contact details at the University of Essex. Each participant was offered a voucher for the value of ten pounds funded by the researcher for their participation and as a thank you gesture.

Data management. Interviews were audio recorded and transcribed; these were stored on an encrypted, password protected memory stick. Transcripts were edited and contained no personally identifiable data to protect participant's identities (Appendices B & C). Participants were made aware that the researcher was the only one with access to the recordings. The researcher used her personal laptop to analyse the data once it had been anonymised. These files were double password protected by a laptop password and an electronic file password. Participants' consent forms were stored at the University of Essex in a locked filing cabinet. Once anonymised transcripts had been written, audio recordings were discarded. Prior to consent, participants were aware that quotations would be used in the write up of this thesis and possibly in a peer reviewed article. Where quotations were used from professionally produced dementia leaflets from GP/memory clinics (Leaflets 1-13), these were also anonymised to protect participants' identities (e.g. XXX NHS Partnership Foundation Trust).

McCosker, Barnard, & Gerber's (2001) interview protocol for sensitive interview topics was used to guide interview discussion, such as how to manage circumstances when the participant showed negative emotion. The researcher kept details of professional support services to give to participants if necessary. In one case, the researcher was informed of a PWDD having fleeting suicidal thoughts and low mood - this was openly discussed and no immediate risk concerns were identified, yet with the participant's permission it was agreed that the interviewer would contact their lead clinician, after which the lead clinician contacted this PWDD to offer support.

2.4 Procedure

Fourteen leaflets were collected from four memory clinics in a host NHS trust, to combine with NICE (2006) professional guidelines for dementia. In addition, participants with a diagnosis of dementia (PWDD) and their marital partners, recruited from the same host NHS trust, were interviewed. Out of seven marital dyads, four were interviewed together and three were interviewed separately meaning ten interviews were completed in total.

Participants. Data was collected from seven PWDD and their partners, equating to a sample of fourteen. Participant's ages ranged between seventy-three and eighty-eight,

and the mean age was eighty. All participants described their ethnicities as White British and spoke fluent English. All the marital dyads in this sample were cohabiting; they married between the ages of nineteen and twenty-eight (with a mean of age twenty-three). The length of time together ranged from fifty-two to sixty-three years (with a mean of fifty-seven years of marriage).

Five PWDD taking part in this study were female and two were male; the time since PWDD received their diagnosis ranged from five to thirty-six months, with an average of fourteen months. No one in this study had what would be characterised as severe stage dementia in relation to the inclusion/exclusion criteria (Appendix L). Three participants had a diagnosis of Alzheimer's disease; two had a diagnosis of Vascular Dementia; one, Parkinson's disease; and one, Lewy Bodies dementia. Table 3 provides a summary of these details, including fictitious participant names allocated by the researcher. The length of time since diagnosis is indicated as this presents how recently PWDD and their partners have been in contact with professionals.

Table 3. *Participant's demographic data.*

Allocated Name	Gender**	Current Age	Years of Education	Length Married (Age Married)	Diagnosis (Time Since Diagnosis)
Sebastian	m	86	9	63 (23)	-
Olive	f	84	16	63 (21)	Alzheimer's (12 months)
William	m	88	9	60 (28)	-
Marie	f	81	11	60 (21)	Vascular (36 months)
*Emma	f	74	11	54 (19)	-
*Henry	m	75	16	54 (20)	Vascular (14 months)
*Florence	f	84	12	58 (26)	-
*Les	m	84	16	58 (26)	Alzheimer's (8 months)
*Thomas	m	80	18	52 (28)	-
*Betty	f	73	11	52 (21)	Parkinson's (5 months)
*James	m	80	10	56 (24)	-
*Norah	f	76	10	56 (20)	Lewy Body's (9 months)
Jack	m	77	13	54 (23)	-
Ruby	f	77	12	54 (23)	Alzheimer's (12 months)

* Interviewed as a dyad ** m: male and f: female

Data collection. Leaflets were selected based on their availability and relevance to this research project. In terms of the form of documents chosen, leaflets, it was

considered that this data may allow access to fairly lay talk in relation to dementia and ageing; leaflets were analysed alongside NICE (2006) professional guidelines for dementia to see how sources matched or differed. Original copies of the leaflets are included in appendices (Leaflet 1-13). NICE (2006) professional guidance for dementia are referenced and obtainable online.

Concerning the interviews, for those who contacted the researcher and were willing to participate, a face-to-face interview was arranged. Interviews were all completed at an NHS base on working days to ensure other professionals were in the building. Telephone interviews were not an option. Both of these factors were related to the possibility of potential risk.

In terms of the conducting the interview, four dyads were interviewed together and three were interviewed separately. This was to gain potential variations in talk on dementia, which may differ within and outside of the relationship. Generally, participants did not have a preference as to which type of interview they completed and choices were made around logistics such as time they had available (separate interviews tended to take longer partly because each participant waited whilst the other was being interviewed). Only one participant presented a strong preference to a joint interview due to concern about their communication.

A semi structured interview guide (Appendix M) was used to facilitate the interview. During interviews, the researcher followed an approach of devil's advocate whereby debate was promoted and the researcher offered opposite opinions to participant's points coinciding with the complex formation of discourse and incomplete fragmented language systems (advised by Tanggaard, 2007). Tanggaard (2007) states that discourse studies using interviews can have a 'humanist frosting' with a focus on experience; introducing alternative questioning and controversy, is a means to promote meaning making and offers a way of avoiding reciprocal or harmonious dialogue between the interviewee's and interviewer. Research questions were designed to be broad and to provide opportunity for varying discussions.

Interviews were conducted between December 2015 and January 2016. The longest interview lasted one hour and fifty-six minutes and the shortest, forty-two minutes.

Transcriptions. Interviews were audio recorded using a Dictaphone and transcribed using a transcription guide (Appendix N). In writing transcriptions,

participant's exact words, pauses and stresses were included; words were added to provide further clarification, or omitted to protect identities (see transcription guide for details).

Process of analysis. FDA is a methodological approach to research that is based upon Foucault's various lectures and analyses (Hook, 2010). Foucault did not distinguish a clear procedure for his approach linked to his attempt to disassemble the discourse of 'truth'. Howarth (2000) describes Foucault's work as consisting of an early and later phase; the researcher adopted methods from both to answer the research questions¹³. Powers (2013) has described a genealogy as the first step in research using FDA, followed by an analysis of how the discourse functions presently. Similarly, Rawlinson (1987) makes an important distinction stating that *how* a discourse has *arisen* is the task of the genealogy in the first stage of analysis, and *why* it *functions* should be encompassed in a second stage.

The first stage of this research aimed to complete a genealogy to explain the historical and social circumstances of dementia discourse broadly. This used primary and secondary data to present fragments and divisions in the concept and practice surrounding dementia, while paying attention to disciplinary systems that uphold dementia discourse (see 1.1). The genealogy studied dementia as an umbrella term (previous researchers have completed genealogies focused on Alzheimer's specifically, e.g. Robertson, 1990; Dillman, 1990). It began with a conceptual analysis of dementia in the 1500s and shifts to various key time points such as the 1900s and then the 1980s, by way of dismantling dementia's seamless truth that runs through history. It also modestly considered family and marriage as part of the enquiry 'dementia in the marital sphere'. This was to a lesser extent due to limited space and capacity. On the following page, table 4 presents questions used to guide the researcher in the genealogy.

 Table 4. Questions to support the researcher in developing a genealogy

1. What discourses, models or ideas influenced the functioning of dementia discourse? For example, were there any discourses that were used as models for the discourse of dementia in political, institutional, or academic settings?
 2. What is the historical context influencing the development of the discourse? How had dementia been conceptualised and described at earlier time points?
 3. What are the physical and bodily spaces being created by the discursive practices of the discourse? (E.g. subjectification and soul effects)
 4. By what processes did the dementia discourse construct the right to pronounce truth? How did the first instance of dementia discourse come about? Who performed the action, and why? What were some of the immediate consequences?
 5. What other discourses were affected and how?
 6. How did the development of discourse around dementia affect media representations of dementia?
 7. Who may be benefiting from the discourse of dementia; what are the interests, implications and bio-directionality involved?
-

(Adapted from Rawlinson, 1987)

The second phase of the analysis, presented in chapter 3, aimed to study the way dementia discourse *functioned* within professional leaflets and guidelines, and following this interview data. Interviews were with spouse dyads when one spouse has a diagnosis of dementia. Similar to the genealogy, there were a series of questions used to guide the researcher in the analysis of these sources, depicted in table 5 on the following page.

Data analysis began with fourteen leaflets from memory clinics and NICE (2006) professional guidelines for dementia. Similar to other qualitative approaches, this data was read repeatedly, annotated and coded (Breakwell et al., 2012). Document titles, slogans, bodies of text, and images were used in the analysis. Appendix B presents the researchers notes and initial coding of three of the leaflets studied. For each leaflet, particular attention was paid to discursive patterns and themes, when the discursive pattern may be seen to deviate, or when talk was seen to resist a more dominant discursive pattern. Appendix C presents some of the patterns derived across the sources examined. Leaflets and NICE (2006) guidelines were chiefly considered together, though, how they contrasted or differed was also of interest.

As this document analysis was smaller than the successive interview analysis, it was more tentative; discursive patterns were considered, rather than inferring discourses. This analysis however, was used to corroborate the findings from interview data, and as such, more interpretations were made about the discourses functioning. This presents the inductive process of the analysis.

Data analysis of interviews began during transcription phase. Here, the researcher wrote down interesting patterns such as the speaking positions that participants appeared to enact, or how data linked to broader political, cultural and social trends. As mentioned there were ten transcripts in total. Similar to leaflets, each transcript was read repeatedly, annotated and coded (appendix E & F). The researcher developed a colour co-ordinated key to support coding (Appendix D). This highlighted the researcher's attention to topics such as what triggered involvement with institutional settings in the context of dementia, and how did talk construct the marital relationship. It also focused upon absences, resistances, subject positions, and other related discourse theory concepts. Analysis proceeded by distinguishing the way that power and knowledge may interact between subjects – how separate and joint interviews contrasted was of particular interest. The researcher examined relationships between discourses, counter-discourses, as well as the context in which discourse was situated (e.g. see, Figure 1. *Main discourses and their relationships toward one another*, page 69).

Qualitative data analysis software, NVivo, was initially used, though was found to be unhelpful given that it pools data together and reduces the distinction between joint and separate interviews, and participants generally. This diverges from the analytic approach where one considers divergences and irregularities closely. Therefore, data extracts copied into a word document and organised in a way that allowed for these distinctions (e.g. appendix G). Where Powers (2013) places emphasis on 'grids of specification' (i.e. a systematic taxonomy of concepts constructed within a discourse which is used to place discourse elements into an ordered hierarchy) various discourse elements were mapped (appendices G & F) and diagrammatic presentations of these are illustrated in the results for each discourse (e.g. p.71).

Table 5. Questions to support data analysis

1. What are the objects and subjects of the discourse? What strategies were people with dementia and their spouses using given the dominance of discourses surrounding the medical model and person-centred model?
 2. What regularities and discursive patterns can be discerned from the data?
 3. What are the assumed truths of the discourses?
 4. How is discourse organised to create a particular effect and what are the implications for subjects?
 5. What are the discourse elements or subparts, how are these organised?
 6. Where do deviations and resistances arise?
 7. What are the zones of disciplines that exist?
 8. What governs the appearance, disappearance, replacement and co-existence of the subjects, objects, styles of statements within discourse?
 9. What are the alternative 'speaking positions' or ways of acting and thinking that do not support the dominant way of thinking and of conceptualising subjects? (Consider 'bi-directionality')
 10. How does discourse justify technologies of power it constructs for its purposes? How do researchers, academics justify this?
-

(Adapted from Rawlinson, 1987).

To the researcher's knowledge this was the first FDA enquiry in this field combine such data. This study is also novel owing to the analysis leaflets and professional guidelines of relating to dementia, used to corroborate the interview analysis.

2.06 Chapter Summary

As discussed, this study has taken a social constructionist epistemological position and has drawn upon Foucault's work. This chapter has not focused on the limitations of Foucault's work, although the researcher acknowledges there are various critiques¹⁴. It has considered the reasons for taking a Foucauldian discourse approach, plus recruitment and ethical considerations. The following chapter presents the study results.

3. Results

3.01 Chapter Overview

This section describes the findings of a two-part analysis: firstly, the discursive themes, patterns, irregularities and deviances within, leaflets obtained from memory clinics, and NICE (2006) guidelines for dementia are discussed; secondly, the examination of discourse within ten transcripts from joint and separate interviews with spouse dyads where one spouse has a diagnosis of dementia. Here, the dominant and alternative discourses in relation to dementia are formulated, as well as forms of resistance, bidirectionality, and subject positions. Eight main discourses are described in total. Diagrams present the relationships between discourses and the interlinking elements or subparts within a given discourse. Throughout this chapter, theoretical interpretations are made drawing upon Foucault's work and discourse theory.

3.02 Part One: Document Analysis

Summary of the findings. The findings from an analysis of leaflets from memory clinics and NICE (2006) guidelines for dementia presented various discursive patterns and deviances in relation to dementia talk (See appendices; Leaflets 1-14). To summarise, one discursive theme amongst the sources was listings of *statistics and symptoms* commonly associated with dementia; here, dementia was often depicted as a biomedical disease. In addition, a subject position of a person with dementia *at risk to themselves or others* was a theme indicated in the data. These two discursive patterns appeared to produce fear, influencing people to *seek professional support*. Seeking professional support was rationalised by experts holding specialist knowledge and skills concerning dementia.

Although a less apparent, across the documents, a pattern of resistance was an *avoidance of professional care*, and also, a *minimising of dementia* through grouping it as a physical condition alike to diabetes – this suggests a more treatable physical health condition with less cause for concern. Similarly, a discursive pattern was talk around *PWDD independence, individuality and activity*. The active and independent subject position constructed here may be seen to align with person-centred and community care discourses upheld by service-user, charity and liberation movements, and government policy – discussed further below.

A discursive theme *professional tools*, constructed GP's and spouses as supportive for people at risk of dementia, particularly in assisting them to access professionalism, expertise, and knowledge from more specialist professionals. Where there was no description on what *treatments* substantiated to in leaflets, there was detail in NICE guidelines. This may depict the way languages and tools professionals use are confined to scientific and professional communities. This upholds expertise and power in dementia systems or organisations, while limiting potential resistance from those with dementia diagnoses and others.

A final finding was the objectification (i.e. assessment, monitoring, coding) of the *Carer or marital partner* by an array of disciplinary technologies. *For instance*, the Carer was bound to an authoritative position to make legal decisions for the PWDD, and monitored in their ability to do so. The relation of the Carer was unspecified in the text – the lack of specification may imply how the Carer is open to new constructions and representations according to socio-political needs.

The discursive patterns recognized in document analysis are described in more detail below including extracts from sources. The analysis process is described in more detail between pages 56-59. Analytical coding for the document analysis can be seen in appendices B and C.

Statistics and symptoms. This theme partly relates to listings of statistics and symptoms associated with dementia. It was apparent in most of the documents studied. Numbers were used to signify the extent of people affected by the progressive condition dementia, alerting the reader. Sources also highlighted how research/science was credible, progressive, and working towards cure and prevention for dementia. The following extracts exemplify this:

“There are currently 850,000 people living with dementia in the UK; there are around 6.5 million carers in the UK” (Leaflet 14 – [omitted] County Council, 2015).

“...based on innovative medical and progressive social research into the cure and prevention of dementia” (Leaflet 11 – Alzheimer's Society, 2016a).

This discursive theme relates to a discourse drawing upon the ideology of truth in science and medical practice, upholding dementia as a tangible and observable entity.

Fitting with this, there was a promotion of the need for individual and cultural awareness of the symptoms or signs associated with developing dementia. Enhanced risks of developing dementia in old age were portrayed, such as through images of older adults on the front of leaflets paired with the word dementia. Also, in several leaflets notable memory loss distinguished from the odd case of forgetfulness. As discussed in the introduction chapter, this discourse, constructing a biomedical characterization of memory loss, is upheld by social, ethical, scientific, commercial and professional forces, which work together in differing ways.

Subject positions: inactive/active. In the documents analysed, subject positions were implied. For instance, supposed dementia symptoms “aggression” and “disinhibited sexual behaviour” in the excerpt below construct an active subject who may place others at some level of risk. This was similar in another leaflet that referred to “admission” to hospital.

“Many people with dementia... experience difficulties with activities of daily living, self-neglect, psychiatric symptoms (for example, apathy, depression or psychosis) and out-of-character behaviour (for example, aggression, sleep disturbance or disinhibited sexual behaviour)” (NICE, 2006).

“Admission for patients removed by police under court warrant under Section 135 of the Mental Health Act 1983. Why am I in Hospital? It is believed you have a mental disorder and you need treatment and care. A magistrate has issued a warrant which says you can be kept here, even if you do not want to come” (Leaflet 10 – XXX Borough Council, 2016b).

In opposition, listed signs of “self neglect” and “difficulties with daily living” construct a more absent and vulnerable subject who is potentially at risk to their self. In conjunction, a further leaflet promoted “planning end of life care” soon after diagnosis as mental functioning and capacity deteriorates (Leaflet 14 – XXX Partnership NHS Foundation Trust et al. 2015).

Despite the incongruence of the two subject positions regarding active risk or inactivity, it may be interpreted that both positions work together to produce fear and coordinate action towards/within professional sites and organisations. This is arguably a political incentive to manage behaviours deemed as disruptive or unproductive within a westernised culture. Rabinow (1983) states how political problems, the need to maintain societal order plus manage limited resources, are often turned in to technical problems for the concentration of specialists. Specialists may be thought of as a whole coalition of primary investigators, including hospital settings, community agencies, legal professionals, charitable support networks, implicating directing and operating PWDD's care.

Seeking professional support. Correspondingly, a clear discursive pattern from sources was continuous encouragements for those suspected of having dementia symptoms to seek professional advice early. This was constructed around warnings on the risk of memory loss increasing in later life illustrated in the excerpts below.

“If you are worried about your memory... it is important to seek advice... because, in some cases, memory problems are an early sign of a medical condition such as dementia” (Leaflet 2 –Alzheimer’s Society, 2016b).

“Should I be concerned about my memory? It’s happened to all of us at some time or another. You can’t put a name to a face. You forget where you put your keys...your car... Most of the time such slips are a nuisance, rather than a sign of something more serious.... But it’s worth seeking advice.” (Leaflet 2 – Alzheimer’s Society, 2013).

This may be seen to relate to Foucault’s (1991) depiction of power, where media, government, professional, and charitable organisations depict the dementing mind, more and more people are constituted and constitute themselves as having dementia.

An avoidance of professional care and a minimising of dementia. In contrast to the above finding, one leaflet (extract below) appeared to represent alternative discourse that downplayed or resisted cultural seriousness associated with dementia and

old age mentioned above, alongside the need for contact with medical professionals. This was an irregular pattern in the documents studied.

“Your free NHS health check: helping you prevent heart disease, stroke, diabetes, kidney disease, and dementia... The check helps to identify risks early. It is part of a national scheme to prevent the onset of these health problems. Why do I need this check? I feel fine! ... I know what I’m doing. How can the doctor help me?” (Leaflet 8 – Public Health England, 2013).

This extract implied an opposing discursive theme minimising the distinct boundaries between what is normal and pathological, while challenging the usefulness of contact with professionals (e.g. “how can the doctor help me?”). Where this particular leaflet grouped dementia as being alike to kidney disease or diabetes, it suggests a discourse that avoids the construction of an age related mind disease, dissimilar to abovementioned themes.

The material in the above quoted leaflet highlights the health check does not cost anything and it is not old age specific (e.g. “this is a free health check to improve health in adults aged 40 to 75”). The front cover image of a body with mechanic cogs inside presents a working body; text emphasises the purely precautionary aspect of the check and “part of national scheme”. In opposition to this, another leaflet presented cogs falling outside the mind and the word dementia, representing a broken mind (e.g. Leaflet 14 - XXX Partnership NHS Foundation Trust et al. 2015). The latter appears to reflect the more dominant discursive pattern across the analysed sources.

Independence, individuality and activity. A further discursive pattern within documents was the need to maintain PWDD independence. Both Life Story work, a book about life events using memorabilia or photos, and Cognitive Stimulation Therapy, a group with various activities argued to keep the mind active, were talked about in leaflets and professional guidelines (NICE, 2006), for those with dementia diagnoses. As discussed in the introduction chapter, these may be thought to interact with person centred discourse; a movement promoting individuality and engagement in activities proliferated psychological therapies, service-user movements and large charity organisations. Recent policy and service initiatives aim to reduce health and social care

costs and support community based care, often aligning with the person centred model of care in dementia (e.g. Department of Health, 2016a).

One leaflet listed a multiplicity of products including stair lifts, walk in baths/showers, personal alarms, and travel insurance (Leaflet 9 - Age UK, 2016). Another stated, “maintain your independence your families piece of mind” by “subscribing to monitoring and response services, less than £6 a week”: for “young and old alike” (Leaflet 5 – Helpline B, 2016). This included two images of elderly people with younger relatives/grandchildren, perhaps symbolising an active role in the family and resistance to the dementia subject positions discussed, i.e. at risk/a risk (Leaflet 6 – Helpline A, 2016). Nevertheless, a divergence from talk on independence surrounded lack of safety, incapability and potential familial burden. For instance:

“Care Cameras – secure and private... Has dad left the hob on? Worried about mum falling down the stairs? Caring for an elderly relative? Check they are safe. Just £1 per day” (Leaflet 3 - Care Cameras, 2016).

Professional tools. This document analysis found that the GP was constructed as an important gatekeeper who could refer for assessment and management from dementia. The spouse/relative was also accorded a subject position facilitating the professional decipher whether dementia signs are present, a quasi-professional role:

“If you are concerned about the memory of someone close to you, encourage them to visit their GP” (Leaflet 2 –Alzheimer’s Society, 2016b).

“You might start the conversation by gently asking the person if they are feeling any different or struggling with anything” (Leaflet 2 –Alzheimer’s Society, 2016b).

The documents included information on how GP’s would refer to array of professional specialisms and this could involve taking medication. For instance:

“...the anti-dementia drug memantine may be an effective treatment for behavioural and psychological symptoms... [it] may reduce the severity of some

behavioural and psychological symptoms in dementia and help delay their onset” (Leaflet 1 –Alzheimer’s Society, 2016a).

A discursive pattern was the specification that interventions were based on evidence, expert knowledge and “high quality coordinated care” as illustrated in the following extracts.

“Memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia” (NICE, 2006).

“GPs, community nurses and specialists ensure high quality coordinated care ” (Leaflet 14 - XXX NHS Partnership Foundation Trust, 2016).

Where specialist’s specific tools (e.g. MRI and neuropsychological tests) were absent in the leaflets and only present in NICE (2006) professional guidelines, this may indicate *the will to know* (Foucault & Hurley, 1998). This is where certain social actors are deemed to have limited ability to speak on procedures, systems and discursive practices, such as biomedical tests and treatments constructed in scientific communities. Katz (1996) has labelled this as a ‘gray industry’, where commercial and industrial forces come to circulate and benefit from the biomedical discourse of dementia based on changes in the gray matter of the brain. This industry maintains scientific discourses amongst psy-professionals justifying their expert status, while ensuring practice around those suspected of dementia.

Informal Carer or marital partner? Despite frequent mentioning of the Carer in analysed documents, the relational connection of the Carer to the PWDD was not specified. Generational statistics present that older adults within this generation are likely to be married¹⁵ - it may be inferred that a significant proportion of unpaid Carers are likely to be marital partners. Nonetheless, it was implied that all Carers have shared characteristics and activities, resulting in a collective grouping of those in the caring role. As demonstrated on the following page.

“Your carer is the person who provides regular unpaid help to support you to manage your daily life” (Leaflet 7: [omitted] NHS Partnership Trust, 2016a).

Within documents, promotion of Carer's wellbeing, quality of life and so on (see below) was apparent. One example was the pledge to protect carers through carer assessments (NICE, 2006). This perhaps materializes as 'protective' system around Carers, *and* those cared for, which may be traced to discourse on the management of risk, abuse or neglect within familial contexts amongst older adults:

“All caregivers are entitled to an assessment of their needs while they are supporting and looking after you. This is known as a carer's assessment.” (Leaflet 7: [omitted] NHS Partnership Foundation Trust, 2016a)

“All carers... are welcome to attend Inpatient Carers Group; a safe and confidential space to receive mutual support, a chance to reflect and receive guidance and advice” (Leaflet: [omitted] NHS Foundation Partnership Trust, 2016b).

NICE (2006) guidelines set out responsibilities that a Carer must make when taking a decision on behalf of another, such as ensuring the decision is the person's best interests. The document states that at the point of diagnosis the PWDD and their carer [or marital partner] should:

“...seek a Lasting Power of Attorney... a legal document that allows people to state in writing who they want to make certain decisions for them if they cannot make them for themselves, including decisions about personal health and welfare” (NICE, 2006).

This document legally ties the carer to make decisions on the person's behalf and binds them to a subject position of authority, expertise and responsibility¹⁶. This corresponds with (leaflet 6 - Power of Attorney, 2016).

In relation to these findings, Foucault (1997) argues that there is a complex interplay between presence (what you see, the visible) and absence (what you cannot see, what has displaced it within the frame) – this in turn, produces how the representation and a subject work. Thus, despite the absence of talk on the relation of the Carer or the marital partner, what you cannot see or what is not specified, works to produce the

subject position of the Carer. Interventions directed towards the Carer exemplifies their objectification (e.g. their behavioural tendencies are watched, coded and measured), justifying the need for expert bodies to correct or influence any deviances, such as in the case of safeguarding concerns. As such, spouses as informal Carer's, are subjected to processes of objectification, alike to PWDD.

3.03 Results Part 2: Interview Analysis with Spouses and PWDD

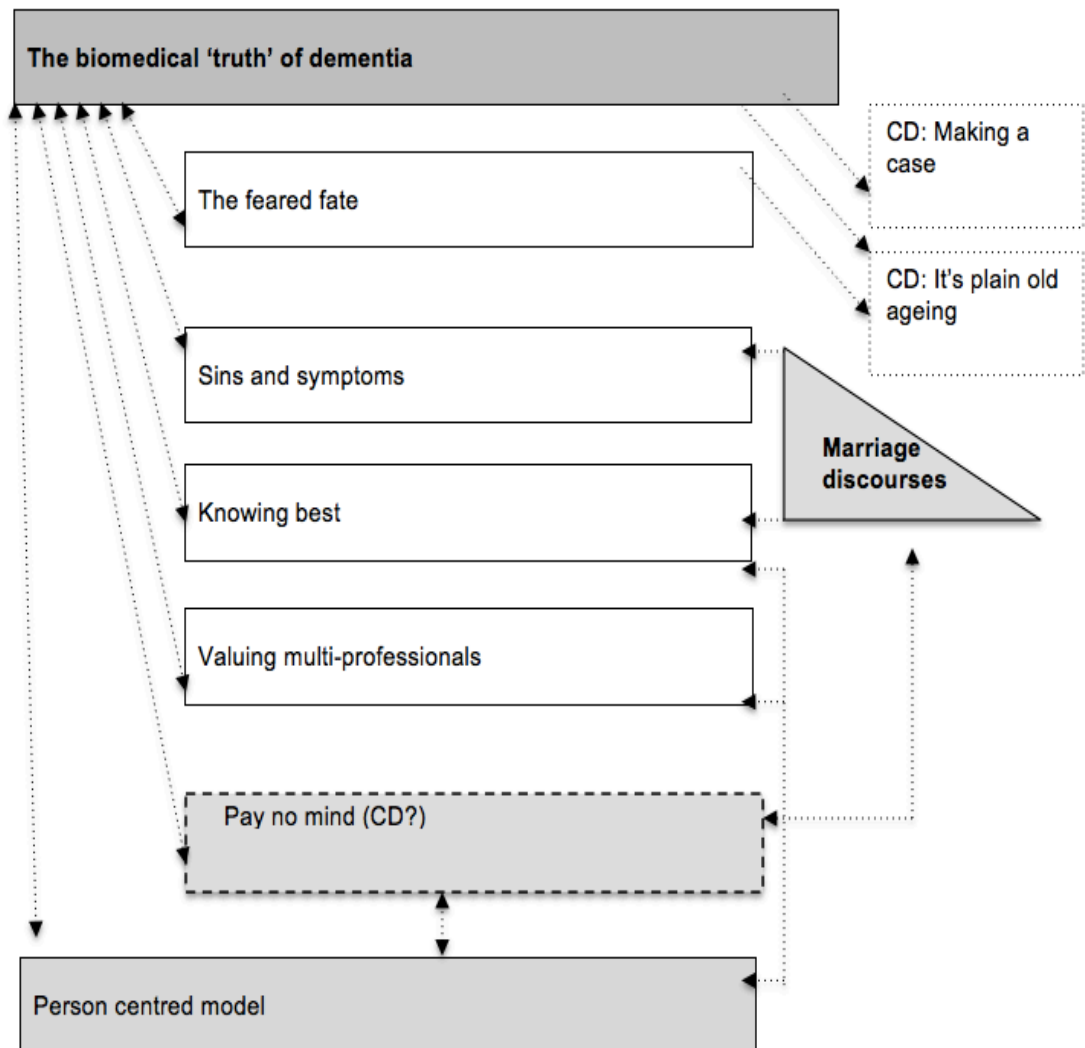
Summary of the findings. Here, the findings from ten transcripts (after separate and joint interviews with spouse dyads when one spouse has a diagnosis of dementia) are examined. The analysis of transcripts led to the recognition of eight main discourses in relation to dementia. The document analysis, where discursive themes and irregularities in relation to dementia talk were discussed, can be used to corroborate findings from the second phase of analysis. The discourses derived in the analysis were, 1) 'The feared fate' constructing the inescapability of dementia in old age relating to facts and figures. 2) 'Pay no mind' constructing PWDD individuality, through paying little attention to dementia. 3) 'Making a case', an intellectual discourse that problematises the diagnostic construct of dementia. 4) The 'biomedical truth of dementia' referring to the technologies (e.g. doctors, tests and medications) that allow the uncovering of 'truths', in this case the biomedical basis of dementia. The aforementioned two discourses were chiefly adopted by PWDD in interviews. In contrast, spouses primarily adopted the discourses in interviews: 5) 'sins and symptoms' and 6) 'knowing best'. Within these discourses the medical construction of dementia resulted in spouses monitoring, but also preventing and correcting changes in the PWDD behaviour in interviews in a quasi professional role. In addition, 7) 'valuing professionals' constructed the importance of the *expert body* in dealing with dementia effects, as well as the branching out of multi-professional disciplines. 8) Marriage discourses related to the significance of marriage, in which trials and tribulations are overcome. Also, conflicting discourses, such as the counter-discourse 'its plain old ageing', where dementia was viewed as a normal part of growing old, were considered. Subject positions included 'the informal carer' and 'the marital partner'.

These discourses are described individually between 3.04 and 3.11, with excerpts from participant interviews. Figure 1, illustrates relationships between discourses and Figures 2 to 12 present the sub-parts/elements within discourses. Appendices B present H series of documents to illustrate the inductive process of the analysis; the method, page 56 outlines this process in further detail.

Relationships Between the Discourses

Figure 1 is intended to guide the reader to consider how the eight discourses identified relate, connect or deviate from one another when reading this second part of analysis. It allows for a visual summary of the findings.

Figure 1. *Main discourses and their relationships toward one another*



Within the analysis, ‘the biomedical truth of dementia’ was found to be a dominant overarching discourse in the data, thus, in Figure 1, this discourse is shown in a box shaded dark grey, positioned at the top of the diagram. As demonstrated in the introduction chapter, this discourse is based upon complex, historically and socially located forces. ‘The biomedical truth of dementia’ was a central element in several other discourses. For instance, the white square boxes labelled ‘the feared fate’, ‘sins and symptoms’, ‘knowing best’ and ‘valuing multi-professionals’ represent main discourses

in the data which were understood to be established through ‘the biomedical truth of dementia’. In turn, these discourses fed back to maintain the discourse, ‘the biomedical truth of dementia’, upholding its dominance as discourse. Double-headed arrows in the figure represent the circular relationship between aforementioned discourses.

Within figure 1, the light-grey shaded boxes, labelled ‘person centred model’ and ‘pay no mind’ present discourses that were questionably overriding discourses to ‘the biomedical truth of dementia’. As discussed in the introduction chapter, person centred care is often depicted as a movement away from biomedical characterisations of dementia. The discourse ‘person centred model’ and ‘pay no mind’ were strongly associated. The dotted outline around ‘pay no mind’ and “CD?” is used to illustrate the researchers questioning over whether ‘pay no mind’ may be a counter-discourse. In particular, the uptake of this discourse amongst participants resembled opposition to ‘the feared fate’.

On the other hand, this analysis also contended the possibility that ‘the person centred model’ and ‘pay no mind’ may be coordinated by ‘the biomedical truth of dementia,’ while perpetuating dementia’s construction as a biomedical disease. This is discussed further below. These discourses may include subtle modes of differentiating and categorising a person diagnosed with dementia – the double-headed arrow linking to ‘the biomedical truth of dementia’ indicates this.

The discourses ‘making a case’ and ‘its plan old ageing’, were presented in boxes with dotted outlines, and arrows pointing away from *the biomedical truth of dementia*, as they were deemed to be clear counter-discourses (e.g. “CD”) which challenge alternative discourses constructed from a biomedical viewpoint.

The triangle shape in figure 1 demonstrates how marriage discourses/elements were not necessarily one coherent discourse. This may relate to how marriage discourse *was* dominant or unified at a point in time, including elements monogamy, romance, privacy, and so forth, however, that it is less cohesive at present. Nonetheless, the continued importance of marriage discourses/elements for the participants interviewed is symbolised by the grey shading of the triangle. In particular, spouses assumed marital obligation enacting the discourses ‘knowing best’ and ‘sins and symptoms’ in the data – arrows from ‘marriage discourses’ to ‘knowing best’ and ‘sins and symptoms’ characterize the interactions between these discourses.

‘The person centred model’ was deemed to have a circular relationship with ‘knowing best’, plus ‘valuing professionals’, as demonstrated by double-headed arrows in

the diagram - each discourse sustained the others dominance or influence. These discourses were associated with corrective processes, such as preventing and supporting the PWDD abilities and their continuation in activity. This required spouses and professionals intervening.

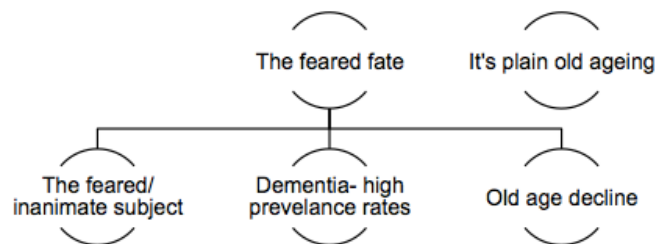
Although there were additional overlaps between ‘the feared fate’, ‘sins and symptoms’, ‘knowing best’ and ‘valuing professionals’, not all links are represented in Figure 1, which was in attempt to maintain straightforwardness. Figures 2 to 11 depict more detail concerning the interconnections amongst discourses.

It is notable that order of presented discourses in Figure 1 is not representative of the order of the following discussion on each discourse.

3.04 The Feared Fate

Figure 2 represents the construction of the discourse ‘the feared fate’. Figure 2 is described in more detail below and may be generalized to interpret subsequent figures (figures 2-11).

Figure 2. The discourse ‘the feared fate,’ associated elements & a counter discourse



In Figure 2, the circle labeled ‘the feared fate’ on the top of the diagram refers to the discourse in discussion. Connected directly below this, the chain of elements that construct the discourse ‘the feared fate’ can be seen. In the methodology, it was considered how a discourse is made of a net of different clusters/meanings, referred to as elements (see method 2.2 & discussion 4.3). In this case, ‘the feared fate’ was considered to include three main elements or subparts: ‘the feared/inanimate subject’, ‘high prevalence rates in dementia’, and ‘old age decline’. Other discourses and their representative figures include more or less elements.

Elements have varying but connected meanings upholding the discourse. In ‘the feared fate’ for example, ‘high prevalence rates in dementia’ incorporates facts and figures on the prevalence of dementia, and ‘the feared/inanimate subject’ represents

historical and cultural representations of dementia and madness, such as one becoming dangerous or lifeless when diagnosed with dementia. The third element, *old age and decline* relates to how ageing and disease were constructed as occurring hand in hand in the data. This cluster of elements all similarly hold predictions or likelihoods regarding dementia and evoke fear or alarm.

In figure 2, aside to circle labeled ‘the feared fate’, there is a circle labeled, ‘its plain old ageing’. This circle has no connecting lines in order to show that it is a counter discourse (i.e. ‘its plain ageing’ is directly separable and oppositional to discourse ‘the feared fate’ whereby it challenges or changes the meaning of elements in the discourse to construct an alternative discourse). Drawing upon discourse theory, the competing discourse, *its plain old ageing*, may be more or less dominant at a particular point in time, and the chains of elements which form a discourse, such as ‘the feared fate’ are frequently open to new representations and meanings.

Although ‘the feared fate’ was more prominent amongst spouse’s interview data, both spouses and PWDD demonstrated the use of this discourse. The elements within this discourse are described individually, in further depth below.

Old age decline and dementia. The following extracts, amongst others, indicated that all older adults face physical and mental decline. With the extract from William, the question asked could be seen as a rhetorical question to illustrate a point rather than to elicit a direct answer – plus, the temporal reference to “one day” indicates that all mankind are faced with the fate of dementia when they reach a certain age. This discourse is contingent upon the element of dementia, without this it lacks the same severity – it is either a physical problem alone, or ‘plain old ageing’ discussed further. The ‘feared’ aspect of the discourse perhaps resonates with the unpredictability of when one *will* develop “memory problems” and how this unknown, yet publicised, fate will manifest. To illustrate this discourse further, participants were asked to elaborate on their various references to “I should be like this,” depicted below.

Florence (Spouse): *What is it that they say... old age doesn't come alone! It brings problems. Physical problems...and Les he's developed these memory problems haven't you?*

William (Spouse): *Yes, but how do you feel in dealing with these people like this? It must be disheartening to see people like this and to think that one-day I should be like this?*

The feared/inanimate dementia subject. The feared fate was possibly based on the cultural postulation that certain behaviours, thoughts and actions, associated with dementia, are dangerous, or unwholesome to the constitution of the individual subject, as illustrated:

Sebastian (Spouse): *I mean I've got a very close friend ... she used to come to [a psychiatric unit] (quietens voice) she was in a semi. They sent her at the bottom end of the ward...a secure ward.*

William (Spouse): *I've got a sister in law, she's dead now, she had this dementia, so I know what's coming ... A cabbage! A vegetable!*

Jack (Spouse): *I picture a dribblin' old fella' sitting in the corner of a nursing home! Unable to converse, read, or communicate. Enjoy life! That's what I think of dementia!*

Betty (PWDD): *I think they're frightened in a way, I suppose we all are, that erm, that what is the unknown, I mean I know there is a lot of sort of things around now, literature, well more about dementia really erm*

Thomas (Spouse): *It's the word dementia that frightens people if you wanna come down to the basics!*

Drawing upon the genealogical analysis, people within dementia are appearing in public in new ways, as opposed to formerly being hidden from the public eye in asylums, private institutions and family or nursing homes. One argument is that this was before the science and biomedical industry became interested in dementia, and it was construed as senescence or old age. Although the subject who is “unknown” or dangerous, “sent to the bottom end of a... secure ward” was present in the discourse of ‘the feared fate’, perhaps

this also operates with a more contemporary and public dementia subject: someone lacking capability to think or act. This was illustrated with the use of inanimate objects (vegetables) and the imagery of dribbling. It also coincides with the document analysis concerning inactivity alongside activity.

Moreover, in the following extract it was suggested dementia is something close to wickedness. There was ambiguity in the meaning here. It may concern the PWDD being subjected *to* wickedness, witchery or spell craft exercised by an individual or a group through secret knowledge. Alternatively, it may have indicated the individual with dementia as having potential to *be* “wicked” through their ‘condition’, associated with sinfulness and criminality. From this angle, the discourse ‘the feared fate’ constructed the absence of what it is to be a both a moral, and a participating, citizen in contemporary society.

Henry (PWDD): *...I won't say it's [dementia] wicked or anything like that but its erm, it very serious. Say having vascular dementia or something, which is terrible really isn't it.*

In these extracts, it may be construed that through labeling or confining ‘the inanimate/dangerous dementia subject’, there was a process of convincing, communicating and recognising one’s own absence of dementia and so sanity, constitutive of action (discussed in further discourses).

The prevalence of dementia. This element in the discourse ‘the feared fate’ appeared to be mobilised by many population-based studies that emphasise the problematised case discussed in the introduction chapter, i.e. the growing population, plus people living longer, increases the prevalence of dementia. The requirement for action, policy, health care and progressive medical research were also built into the discourse of the feared fate, as a justification for *serious* concern. The following spouse dyad, Les and Florence, demonstrate this:

Les (PWDD): *I mean Alzheimer's and whatever er, it's been mentioned in the paper in the last six weeks more than I've ever heard it before... it's a growing disease of the elderly population you know and they are trying to do something about it*

Florence (Spouse): *Yes I think it's because more and more people are living longer aren't they, so you hear more and more about it don't you?*

Also, as seen in the quotations below, the BMM and its associated knowledge and power positions (e.g. neurobiologists, researchers, psychiatrists and so forth), also uphold the discourse of 'the feared fate' whereby it constructs dementia as a 'brain disease' to be investigated and understood – comparable to the findings in part one of the chapter. This aspect of 'the feared fate' overlaps with other discourses, and is elaborated in more depth in the 'biological truth of dementia' (see, 3.05).

Les (PWDD): *Some of these things showing up in people being investigated which may, probably, bring about some enzyme that can make to erm I haven't put it very well-*

Florence (Spouse): *Oh yes! Medical research, yes.*

What we can briefly see here is the professional vocabularies and the idea of scientific progress (i.e. future developments) protect the professions. Any gaps in the discourses relating to the biomedical basis of dementia were overlooked or smoothed over, as participants lacked access to this meaning system, "some enzyme... I haven't put it very well." This corresponds with the analysis of documents, regarding the discrepancy of talk between NICE (2006) guidelines and leaflets regarding treatment.

Counter-discourse: It's plain old ageing. This discourse symbolised resistance to 'the feared fate'. As shown below by Jack (spouse), the cultural pairings of dementia with insanity or a lack of intelligibility are present in his talk, though rejected. An alternative discourse was drawn upon, where the signs and symptoms of dementia are everyday blunders occurring more frequently in old age. This offered different subject position for those with diagnoses – 'the aged adult'. Similarly, as portrayed by Betty (PWDD), through the discourse of senility, the boundaries between 'the aged adult' and 'the dementia subject' became blurred. Others also drew upon this alternative discourse which is at odds with the dominant conceptualisation of dementia; illustrating individuals are not merely anonymous points of the application of power. This alternative discourse was indicated in the analysis of documents, though was apparent in only one of the

sources which paired dementia and diabetes, constructing dementia less concerning physical health condition.

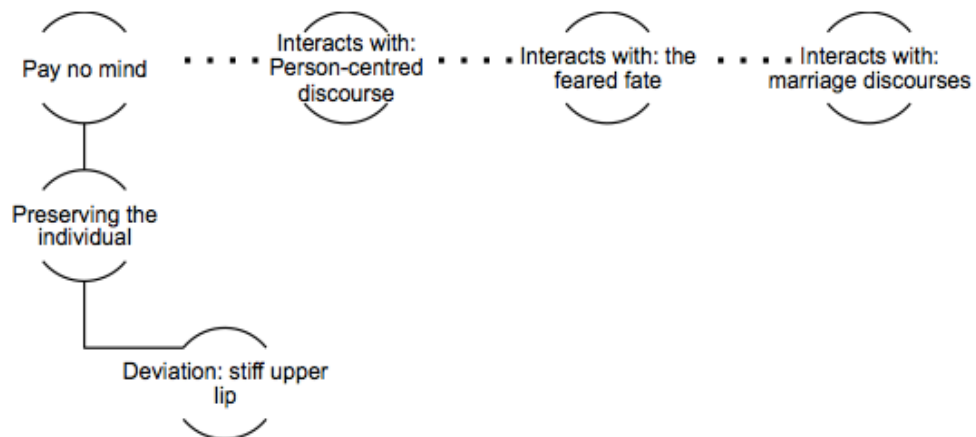
Jack (Spouse): *...their mother has got dementia but she's a perfectly intelligent women! But I did notice last year that she told me the same thing twice, but so did I! I've probably told you several stories twice already! But I don't attach any importance to that (.) I've got an school friend who comes to see me every other week and I've heard his stories over and over again! ... it doesn't mean you're a loony, only so many things you can talk about!*

Betty (PWDD): *When you say Parkinson's it sounds much like old age! We've always said that with old age, you always say old age, but why should we have to say its Parkinson's when it might mean that its old age? You expect to have old age anyway!*

3.05 Pay No Mind

This discourse 'pay no mind' symbolised that one should pay little attention, or give little concern, to dementia. It was enacted when participants described their interests, past and current roles, and experiences, thus preserving their individuality. It resembles with the discursive theme in part one of the results, *Independence, Individuality, and Activity*.

Figure 3. 'Pay no mind,' associated elements & complimentary discourses.



Although it was not included in description regarding Figure 2, in Figure 3 and some of the succeeding figures, the discourse in discussion is shown to interact with other discourses in the data using a dotted line. The circle plus the label/title of the discourse this connects has some significance to the meaning of the discourse in discussion. In addition, deviations from the discourse are characterised by a protruding line, such as with *it's a stiff upper lip* above.

As portrayed in the following extracts, 'pay no mind' was drawn upon principally by PWDD and interestingly, female participants. One argument is that 'Pay no mind' is a counter discourse to 'the feared fate', similar to 'its plain old ageing'. However, through further analysis it is inferred that 'pay no mind' may be intertwined with subtle modes of differentiating and categorising, controlling 'the inanimate/dangerous dementia subject', discussed further below.

Preserving the individual. "Preserving the individual' is considered to be an important element in the discourse 'pay no mind'. With the discourse 'the feared fate', an inactive, unresponsive, yet precarious, subject position was presented. In contrast, the following extracts, representing only a modest range of the obtainable excerpts, demonstrate how the discourse 'pay no mind' incorporated talk on 'the self' to preserve the individual, which ensued a move away from 'the inanimate/dangerous dementia subject'.

Norah (PWDD): *I'm a NNEB [national nursery education nurse]*

Marie (PWDD): *I'm a great gardener! I love the way I have designed and laid out my garden, which I think is very nice, and in the past I have done designs for other people. Yes! I am very interested in gardening! Planning, laying it out, and anything to do with it.*

Ruby (PWDD): *I quite like cooking! What I do is...*

Olive (PWDD): *I used to foster babies. New babies. I fostered straight from them leaving the hospitals, until they had family with them...*

Here, Norah (PWDD) talked about herself in the present tense as a nursery nurse, although retired; Marie (PWDD) shared her existing knowledge of gardening and Latin names of plants; Ruby, described her current skills in cooking and organisation; and Olive (PWDD) shared her past experiences of fostering babies. This discourse rested upon notions of competency, ability, and individuality, which surpassed dementia talk. It also brought familiar or former positions to the forefront: Henry (PWDD) and Marie (PWDD) typify this where they presented the subject position of the rational, active or supportive family member:

Marie (PWDD): *... and all the things we do with the schools and everything with my grandchildren's schools, its love- its lovely! When I got to know the teachers at the schools they go to, that's lovely.*

Henry (PWDD): *Our grandson actually lives with us at the moment... I think when you get older, um, you recognise difficulties along the way that youngsters don't necessarily do. And you know it does create a certain worry in your mind you know.*

The person-centred discourse. As discussed in part one of the results, one explanation for the permanence of the discourse 'pay no mind' is that it is influenced by, or interacts with, the person-centred discourse of dementia. The person-centred discourse is proliferated through various disciplinary technologies, including psychological therapies, service-user movements and large charity organisations – the discourse has become increasingly dominant. In the introduction chapter, it was presented that although the person-centred model is usually proliferated as separate from the BMM, it was argued both may be understood as discourses that coincide and work in complimentary ways. The PCM posits that we should see the person with dementia as an individual, liberating them from their illness or abilities they may have 'lost'. It argues that if the mind is stimulated it can have the positive effects on the brain, slowing down the disease progression of dementia.

Betty (PWDD): *Well I have to be organised obviously, it's it's, it's not easy for me to kind of do things kind of on the spare-[spare of the moment?]. But we do do lots of things you know! It's so we're we're busy all*

of the time... I dunno which is worse, er, or better, to be, we don't wanna be idle but perhaps we don't wanna be as er as busy as we are, because you can't tell if it's working which way or the other

In the quote on the previous page, Betty demonstrated how the discourse 'pay no mind' may indicate a form of self-discipline and self-monitoring, to ensure one is performing enough activities and, as shown by other participants, that one's identity is unwavering. As discussed in the methodology, 'the other' may also account for such mechanisms of power and reflexivity: the PWDD may ask '*how am I seen by the other? What does the other want from me? What are the social values they hold most dear?*'

In sum, the talk on identity and individual differences, proliferated by disciplinary technologies, may also be construed as a form of subjugation and a way of exercising power that may prevent PWDD from moving from outside the fixed boundaries of individualisation, power and knowledge.

Marriage discourses. 'Pay no mind' mostly being enacted by females but also PWDD is a puzzling issue. To attempt an explanation may move theoretically into a different territory. One idea was that 'preserving the individual' links to marriage discourses and gender relations, through a historical phenomenon. As depicted in the introduction chapter, in the 1900s, and for a significant period afterwards, many women had limited education and status within society. The sample reflected an education difference between men and women (see table 3 in the methodology for demographic details). Most of the study sample reflected the dichotomy where the women were formerly positioned in the home, rearing children, whereas the man was formerly positioned in the field of work. According to Foucault, this would not relate to a true distinction between gender per se but a means of controlling sexual activity, conduct and the economy. Various political infrastructures influenced these arrangements (see introduction chapter) where the human body became constituted by 'experts'. It was considered that the pattern in the data seen in the discourse element 'preserving the individual,' may be where women and PWDD have been silenced, or their experiences perhaps set aside – 'pay no mind' then acts as a strategy to confront this situation/context. Dementia and femininity, correspondingly, could be associated with a subject position of feeble-mindedness, resisted through a promotion of individual skill sets and attributes. It

may represent a rejection of dominant discourses relating to gender, marriage and dementia. This will be considered further in the discussion.

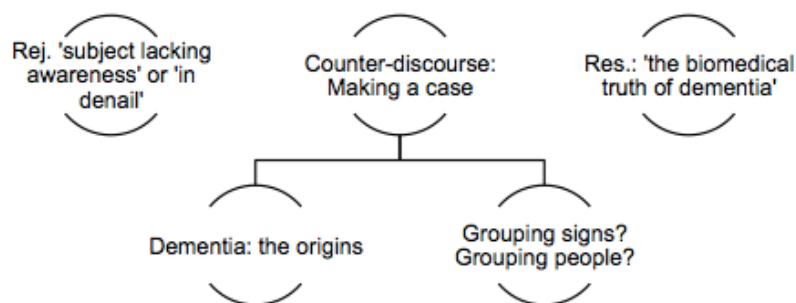
The discourse ‘the feared fate’. One final conjecture regarding the discourse ‘pay no mind’ is that it engages with the feared fate; if one does not preserve the individual, the feared fate will happen and the ‘inanimate/dangerous’ subject position will prevail.

Deviation: A stiff upper lip. One deviation from the discourse ‘pay no mind’ was the discourse the ‘stiff upper lip’, which constructed that one should remain firm to a purpose and continue with life’s happenings. For instance, Marie (PWDD) stated, “It was a shock! Yes! (pause– 3 seconds) I just, yes (laughs) carry on and get on with life as it is and I erm carry on”. This discourse was not necessarily concerned with identity or the PCM, though did still resemble a form of self-discipline. Such stoicism is perhaps associated with post Second World War culture, as part of a public response to national events and moral indignation, as well as late Victorian values of sentiment and self-control.

3.06 Making a Case

This discourse emphasised that dementia has not always been known as dementia (the element: dementia the origins). It also underlined that dementia is not always fitting as a diagnostic construct (the element: grouping signs: grouping people). ‘Making a case’ is arguably an intellectual, or academic, counter-discourse resisting the BMM of dementia and contests ‘the will to speak’ on dementia if one is not an expert. ‘Making a case’ was confronted with opposing discourses concerning the PWDD’s lack of awareness or the spouse’s or PWDD denial. This discourse was less common in the data, and again, it had more permanence amongst PWDD. One particular participant using this discourse was formerly a university lecturer, Henry (PWDD). Another participant, Ruby (PWDD), was a legal secretary while child rearing, and Jack (spouse) worked in journalism. This is not to draw upon Marxist notions of a suprastructure of privilege and oppression, but to indicate that this may have permitted access to contest or understand dementia discourse in a different way. Figure 4, on the following page, presents the elements in making a case, discussed further.

Figure 4. 'Making a case', associated elements, rejections & resistances.



Dementia: the origins. Part of the discourse 'making a case' was the element where the origins of dementia were questioned, in effect disassembling the discourse that presents dementia is a 'truth' that has always been. This was demonstrated in the excerpt below from Henry (PWDD) – the time frame of a decade was used to construct the novelty of dementia. The participant enquired whether there was (or is) "even such a thing" as a brain disease affecting cognition. The phrase before speaking, "well I have to say", signified that this argument is not often placed, or it faces resistance. Similarly, Ruby (PWDD) also exemplified 'dementia: the origins' where she discussed a time when a different frame of thought focused on the practicalities in life. Although the extract below does not give weight to the full conversation, Ruby was exploring this as if to elicit information from the researcher; she was questioning dementia.

Henry (PWDD): *Well I have to say, I feel that perhaps ten years ago there wasn't even such a thing as dementia!*

Ruby (PWDD): *I don't know because when I was young, you didn't come across dementia really. It wasn't something that I heard of or it wasn't something that was talked about, no, I think we were too engrossed in the practical things, we were doing er... I don't remember anyone having memory problems really!*

The element 'dementia: the origins' was uncommon in the data. It was seen to relate to the discursive pattern a minimising of dementia discussed in part one of the chapter, which also had limited prevalence amongst sources.

Grouping signs? Grouping people? The second aspect of this discourse was the problematising of the diagnostic construct and its validity. As explored in the introduction, there is a theory that psychiatric knowledge and practice is able to distinguish ‘groups of signs’ and draw a line between distinct diseases, such as sub-types of dementia. In contrast, through this discourse existing knowledge was brought to bear on people yielding a diverse group of subjects into one homogenous group. As demonstrated by Henry (PWDD), the diagnostic signs of dementia and the participant’s signs were claimed to have a considerable gap. He questioned, the applicability of Vascular dementia defined by reduction in brain capacity, awareness, understanding and decline, in relation to himself e.g. “I don’t feel I am not aware”. Through the discourse ‘making a case’ Henry claimed that his presentation or influent speech was a weak distinguishing factor to accord this diagnosis.

Henry (PWDD): *Well, particularly vascular dementia is a reduction in your brain, ability, whereas I can read something and understand what it I and listen to something and understand what that is, erm so I’m not, erm in my view, I haven’t taken it and gone backwards... but it seems to me that that’s not the case, I don’t feel that I’m not aware, I get frustrated when I cant speak fluently but I’m not-*

The dementia subject lacking awareness/insight. Other participants disputed this alternative discourse ‘making a case’ impeded by the construction of the ‘feeble minded dementia subject’ as depicted in previously discussed discourses. This subject position included a lack of awareness or judgement, and was restricted by the protected domain of scientific knowledge. Norah (PWDD) demonstrates this ‘ontological bind’. Ontology refers to ways of thinking and understanding according to what is around us, as well as a site for experimenting with explanations of reality which continually limit and define everyday existence. Norah pointed out that if she refutes the ‘truth’ of dementia, this would be deemed by others as part of the signs and symptoms of dementia; she is experimenting with the spaces available for her to think about dementia, though seemingly finding herself in a bind through the limits of ‘reality’. In the extract presented on the previous page, Henry (PWDD), while drawing upon ‘making a case’, insinuates that it might only be *his* view. It appeared that he has limited authority to fully challenge

scientific knowledge all together, but he is able to draw upon an individualised discourse based on his own position on the matter.

Norah (PWDD): *I mean I I I wouldn't say full blown dementia. I can't say that. I couldn't believe it! I can't be possible! Which is the way I would be expected to think! Yup!*

In contrast, below, Henry (PWDD) presented bidirectionality to the above conflict; he appears to draw upon a discourse critiquing the expansion of the diagnostic system, resulting in positive outcomes for those in the 'privileged domain' to diagnose. This may be thought of as being linked to critical academic arguments against the biomedical and human science disciplines, and diagnostic categorising:

Henry (PWDD): *I'm not being unkind but, if if if you're a doctor that erm, specialises in dementia, erm, it can become erm erm, a bigger area, because its been added....if you want to inform something that you want to do and that then in my eyes it can only be a good thing for doctors. Now I think you'll understand what I'm saying here! My view is that its not always useful to have someone who can be physically ill with Parkinson's and someone else resident with their speech... all manifested together. I don't like that policy.*

Resistances: in denial. In spouse dyads, where one spouse was seen to take up this discourse, the other spouse was seen to resist it. As shown in the following excerpts, Ruby (PWDD) constructed Jack (spouse) as not accepting her diagnosis of dementia, owing to denial. Jack was rejecting of this, he draws upon a psychological discourse of personality traits that are stable over time to construct a case against his wife having dementia. Although the two interviews are separate, this overlap of talk may represent the ebbs and flows of power and resistance that take effect within a marital sphere.

Jack (spouse): *I mean, I don't, you will say I'm in denial! But I don't see any change in her at all! She's always been looo loopy! I mean she's got a better memory than I have er ...I mean I'm desperately trying to think of something that has changed in the last year – ... but I am*

honestly not in denial I have seen no noticeable change in her abilities or personality!

Ruby (PWDD): *Unfortunately my dear husband, he wouldn't accept it! He said, "you've always always been dizzy, absent minded" and all the rest of it and he said "of course there's nothing wrong!" ... but I don't know if he will accept it now, now that it is for real, mmm.*

Within the extracts from Henry (PWDD) and Emma (spouse) shown below, the reverse pattern was presented: here, Emma constructed Henry as being in denial and lacking sensibility, whereas Henry drew upon 'making a case'.

Henry (PWDD): *(long sigh) well I don't think we want to bring vascular dementia into it do we?*

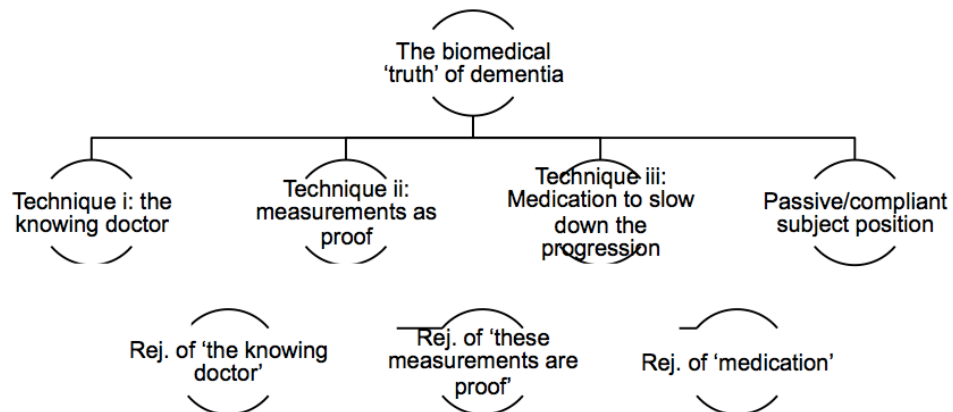
Emma (spouse): *[You mean that you don't want to! ... You've got to realise that that is what it is and it could get worse couldn't it?*

Nonetheless, through 'making a case', rather than dementia being an unproblematic field, silent behaviours, habits and practices encompassing dementia are questioned.

3.07 The Biomedical Truth of Dementia

This discourse concerned three elements labelled truth techniques: 'the knowing doctor', 'measurements as proof' and 'medication to slow down the progression' in dementia. In this discourse science and doctors' unique tools, languages and medical treatments upheld dementia, as a BMM disease. This relates strongly to discursive theme *professional tools*, as well as others discussed in part one. Figure 5, on the following page, presents the elements within 'the biomedical truth of dementia'.

Figure 5: 'The biomedical truth of dementia,' elements & rejections.



'The biomedical truth of dementia' overlapped with many other discourses, and it was considered to be the unifying element for the discourses discussed in this results chapter (also see figure 1, 3.0). Through the process of analysis, the researcher drew upon Post Structuralist Discourse Theory (PSDT) to understand this – explored further in the discussion chapter. In brief, some schools of PSDT argue that there can be a privileged element around which other elements are centered, organised or clustered. This arrangement of elements may be seen to be contingent upon the privileged element, 'the biomedical truth of dementia'. The cluster of elements secures a dominant ideology that science and doctor's 'truth techniques' discover and treat the biomedical basis of dementia. Some participants rejected the elements or 'truth techniques', reviewed below.

Truth technique (I): the knowing doctor. Here, there was the construction of 'the knowing doctor' – an educated, privileged and wise subject. The doctor, situated within a frame of legitimate knowledge, is entitled, and able, to gain capacity to truth, upheld by institutions, social structures and practice. This limited the free flow of discourse, such as what participants could and cannot say or understand. The 'knowing doctor' may be seen, at times, to have replaced other systems of knowledge, such as 'making a case' (3.03). This arrangement reinforced and renewed 'the BMM of dementia' as central.

Sebastian (spouse): *we gr- we gradually got to a point where ... you really ought to go and see a GP' ya'know... I mean if I couldn't understand half of what he said anyway, he [the doctor had all the information, a vast wad of it! I was quite impressed actually! Obviously very very bright ... I said, 'have you the faintest idea what he's talking about?'] Nothing was comprehensible at all!*

In the above extract, Sebastian (spouse) presented how it 'got to the point' where he and his wife required the speaking subject of the doctor "educated", "very bright" and so on. They sought 'the knowing doctor' to draw upon their legitimate knowledge to decipher if dementia was present or not. This was a discourse that supported the constraining, restraining and restrictive functions of 'the biomedical truth of dementia' and the subject positions available for others. For example, participants appeared to enact the 'active patient' subject position seeking a doctor's advice yet portrayed a 'passive/compliant patient' subject position concerning the knowledge of the disciplinary technologies. To exemplify this further:

Emma (spouse): *But you've got to take what the doctors are saying Henry haven't you?*

Henry (PWDD): *Well I've seen doctor [omitted] two or three times and once or twice he said I've lost two or three points but erm, you know that my my, for example, my oh what do you call it? My counselling assessment.*

As shown above, many participants discussed two or more doctors, multiple times, who 'assessed' whether the PWDD had dementia or not. This did not appear to lead to deviations from the discourse or its embedded element 'the knowing doctor'. For instance, it could be that the doctor is not capable of a clear or concise judgement, and devalued, but this was rarely the case in the data. One explanation is that the construction of the doctor is someone who seeks to uncover the 'objective truth' through practises of 'rigor'. An exception, in the excerpt below, is where Betty (PWDD) and Thomas (spouse) talk about multiple doctors being unclear, and they conclude that they are not ultimately convinced of the diagnosis made. This was partially resolved through the Consultant's status and credibility that grounds the veracity of his/her statements, as opposed to the GP

who offers “just an opinion”. This appeared to replicate the dichotomy between participants and doctors too, the former offering lay or more “personal” opinions and the latter offering credible and informed opinions.

Betty (PWDD): *But it took a long time to receive a diagnosis and, I don't really think they know what it is!*

Thomas (spouse): *There was three er, there was three separate opinions Hhh (laughs) Betty's doctor was not convinced she had Parkinson's and she's a very caring doctor isn't she? The Consultant thinks she's got Parkinson's Lewy Body's the the er Hhh (laugh) Consultant here in this unit thinks she's got, Parkinson's with dementia, so we asked the co-ordinator to sort it out so that we knew, forgetting the personal doctor [the GP] as that was just an opinion. This is just between the two Consultants.*

Betty (PWDD): *We're still no absolutely convinced that it is Parkinson's.*

Rejection of ‘the knowing doctor’. As seen below Jack (spouse) rejected ‘the knowing doctor’, similar to Marie (PWDD). This is alike to the analysis of documents and the rejection indicated in one source (e.g. “how can the doctor help me?” in Leaflet 8 – Public Health England, 2013). However, with the constraining and restrictive functions of ‘the biomedical truth of dementia’ Marie, as an example, deemed herself unable to question doctors knowledge (though, this is presented as “laziness”). Despite her disagreement, she enacted a ‘passive/compliant patient subject position’, and drew upon the formerly mentioned discourse ‘the stiff upper lip’ (“[you] turn your back on it”).

Jack (spouse): *Well they said Alzheimer's! I mean everybody calls it Alzheimer's but I don't know! But that is what she says. She came back and she said oh I've got Alzheimer's but as I said I don't believe that. Its certainly not critical yet if it ever will be I don't know.*

Marie (PWDD): *I haven't really said to the professionals ‘I don't agree with it’ erm, I suppose I just accepted it and its just as time goes on, you suddenly think, “Oh! Well why do I agree with it?” // I: Mmm and why do you think that is? // Marie: I think its laziness... I haven't*

really brought it up with my GP and, really, I tend to stay away from hospitals as much as possible! (Laughs) sighs... yes if its something that you don't agree with you turn your back on it.

Truth techniques (II): measurements as proof. The tools and measurements that doctors, psychiatrists and psychologists used also secured the discourse ‘the biomedical truth of dementia.’ These measurements are situated in a matrix of socio-political arrangements, discussed in the introduction chapter. For example, psychology as a discipline was seen to proliferate experimental and observational methods and tests through epistemological positivism. Despite ambiguities in these measurements, they became a logical means to diagnose and treat dementia, plus became leverages for funding and professional status surrounding dementia. All participants mentioned various biomedical tools and tests, as demonstrated in the extracts below:

Ruby (PWDD): *I had to you kno just, recognise things and answer questions or fill in the questions, on the, they were really easy questions, ...but yes there were things like that x-rays and things, well not x-rays but scans! And that was erm, definite, that there was you know, problems, and anyway at the end of it all they said you’ve got, Alzheimer’s dementia...yes I must say I was a bit taken a back when we had actual you know proof... yes it had sort of shrunken, is that what it looks like? ...Mmm. I had got it.*

Florence (spouse): *He had a scan. Doctor [omitted] showed us the brain. You could see the scan yes, he showed us where there were changes. He had dementia.*

Similarly, Ruby (PWDD) constructed cognitive testing and the MRI scan as measurements proving dementia. These tools rely on the binary division between true and false, and normal and abnormal. Florence (spouse) demonstrated the limits in which people can speak, whereby the MRI is definitive, a representative map of reality that could not be questioned.

Rejection of ‘these measurements are proof’. In contrast, a few participants rejected the construction that measurements were definitive. Jack (spouse) drew upon the discourse ‘its plain old ageing’ discussed formerly, blurring the binary of normality and abnormality. William (spouse) and Henry (PWDD) also rejected cognitive testing – it became a “crude” tool lacking objectivity.

Jack (spouse): *These scans they took, I can’t comment at all (!) there must be some diminutat dimunuation no what’s the word basically reduction in brain cells (.) what is the word (?) dimin- ution no that's not the word is it, but I mean what do you call normal signs of old ageing?*

William (spouse): *We saw the GP and it got, crude! [He got a] thingy paper out [hand gesture of throwing a piece of paper on the side] ... I mean it was very crude! I mean at least I thought it was. And then we saw another GP, and he did the same thing!*

Henry (PWDD): *Okay so it might be twenty-six or something [test score] and he’ll say “well it used to be twenty seven”, and I think “yeah okay!” (Laughs)*

Truth technique (III): medication to slow down the progression. One further element to the discourse ‘the biomedical truth of dementia’ was medication. Knowledge of medication was limited to those who are skilled to understand types/names of medication, dosages and biochemistry. In line with this, participants implicitly conveyed that they did not fully understand how these worked or what they were (i.e. “if that's the way to put it,” “...donesarapol or something”). This constituted the need for expert bodies and pharmaceuticals, and was constitutive of the ‘passive-compliant’ subject position, a recurrent pattern throughout this discourse.

Sebastian (spouse): *...[its] a very very good drug for slowing down the progression, you know, the processes in the brain that gradually deteriorate if that's the way to put it*

William (spouse): *... it was very mild dementia and she recommended demepretzol, the drug, which I'm sure you're very familiar with and she said ten milligrams*

Florence (spouse): *Yes! but when he was when we saw doctor [omitted], and we got the results, he put him on a new drug, donesarapol or something?*

Rejection of 'medication to slow down the progression'. Nonetheless, resistance was shown towards medication regarding side effects (e.g. below Olive, PWDD, states, "I couldn't take the stronger one. No way!"). Pharmaceuticals became problematic in this resistance; Norah (PWDD) presented a dilemma involved in taking medication. She expressed that she did not know the rate of decline she may experience with the absence of medication, so her only option was to adhere to taking it.

Olive (PWDD): *They gave me drugs, I can't remember the names, I had to take a drug for three weeks and then they were going to make it strong, and I couldn't take the stronger one. No way! ... Well I was walking around all day with a bucket feeling sick, honestly! I felt so bad.*

Florence (spouse): *He was put on five milligrams to start with and he had a course of that... but he had some awful nightmares didn't you?*

Norah (PWDD): *I mean what good are these tablets! why should I take them and them! ...you got nothin' that says when you wake up in the mornin' that tablet will make you better! But there's nothing wrong with me, that's the vicious circle ... even the doctor came and said to me you know "you must take your tablet!" Everybody's been very nice but –*

Dominant discourse. As follows, Thomas, a spouse, indicated that he would have resisted the 'biomedical truth of dementia' had it not have been for the element of 'medication to slow down the progression' in this discourse. This presented how the clustering of the discourses in the 'biomedical truth of dementia' is key. As portrayed, one element or truth technique being contested (e.g. 'measurement tools') is often

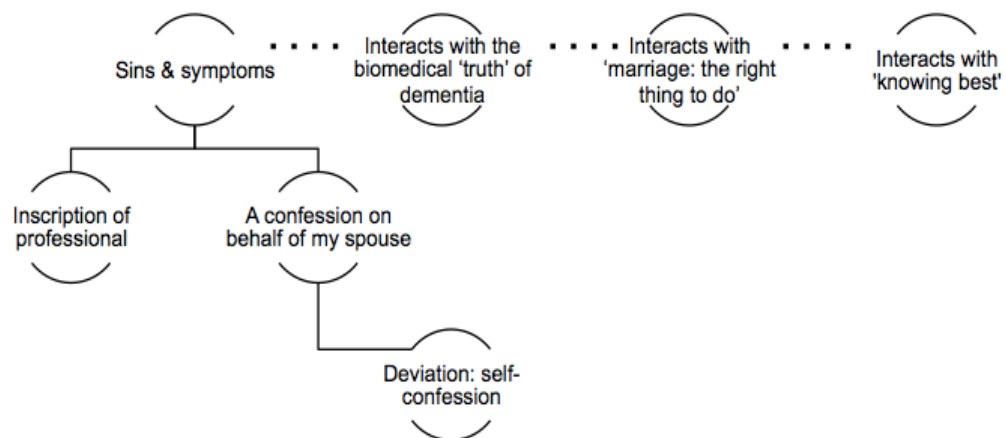
counteracted by another closely positioned element (e.g. ‘medication’ or ‘the knowing doctor’), re-securing the dominance of this discourse and its power and knowledge relations. Although this was apparent amongst PWDD, it was more evident amongst spouses: the next discourse, ‘sins and symptoms’ discussed, shows how spouse’s inscription of a biomedical discourse gave power to other discourses in the data.

Thomas (spouse): *as we knew that the medication treated either condition it didn't really matter to us, whereas if they'd have been “right well we have to do that particular medication for that particular symptom and its different to that one” that would be more concerning!*

3.08 Sins and Symptoms

‘Sins and symptoms’ was a discourse primarily enacted by spouses, in which they provided significant lists of the PWDD’s mistakes and diagnostic symptoms –both subjectifying and objectifying. As discussed in the methodology, subjectification involves individualising sets of knowledge about a subject as a means to regulate them as a single unit, whereas objectification is the watching, measuring and coding of subjects. As indicated ‘sins and symptoms’ may be seen as one of the discourses in the data that was unified through the discourse ‘the biomedical truth of dementia’.

Figure 6. ‘Sins and symptoms,’ associated elements & complementary discourses.



Sebastian (spouse): *She got totally wound up today about this one thing and she has this great confusion! ...And the other thing I don't know if this is normal, I mean she's not, by any matter of means a, racist, or anything of the sort! But I know that remark she made on the phone to you about [a professional], which, I absolutely nearly died over! To you about, the big fat lady! I was sitting in the other room and I th I thought ... "what are you saying!" ... I mean this is the sort of thing our son said to the neighbours when he was about two "cor aren't you fat!" ... it's things like that. I mean whether its all part and parce- ... we were going to the shop and seeing something [and my wife says] "oow much is it?" and then "HOW MUCH!" then there's this sort of explosion of disgust (laughs).*

Representative of this discourse, Sebastian (spouse) provided several 'sins' in a short space of time, and the acts are constructed as if especially extreme, "what are you saying!", yet he denoted these as "part and parc[el]" of dementia. Also in the extract below from Florence (spouse), Les's symptoms were also catalogued as dementia effects. In this extract, as typical of other joint interviews, the spouse without dementia questioned, "haven't you?" as if making a micro-level exchange to negotiate how much subjectification and objectification could be made in the PWDD's presence:

Florence (spouse): *One minute you can have something and the next minute you have lost it haven't you?*

Les (PWDD): *Yeah yeah*

Florence (spouse): *You'll put something down somewhere and then you can't remember where it is.*

Les (PWDD): *(Sighs and laughs) there was something that happened this morning*

Florence (spouse): *What have you lost this morning?*

Les (PWDD): *I don't know we laugh after but at the time*

Interviewer: *Yeah at the tim-]*

Florence (spouse): *[and he can't cope with paperwork!*

Les (PWDD): *I go down the bank don't I?*

Florence (spouse): *Oh you go down the bank yes... you don't get cash out though do you, with your card. He writes a cheque out and goes in and they'll give him the money*

Les (PWDD): *Oh yes its gradually got worse hasn't it?*

Florence (spouse): *Yes.*

Thomas (spouse): *Part of the symptoms is that Betty has a great fascination with time... erm, what time is it, what day, what have I got to do today? Are very much part of her life, would you agree [Betty, PWDD]?... And that's one of the main manifestations of Parkinson's.*

The inscription of disciplinary technologies. The discourse 'sins and symptoms' appeared to be contingent upon the spouse's inscription of disciplinary technologies or the professional's techniques. The element 'the inscription of disciplinary technologies' meant that the spouse acted as if under surveillance to oversee the PWDD. As indicated in the analysis of documents, the *informal carer or marital partner*, was objectified and subjectivised similar to the PWDD in their ability to perform as quasi-professional role. As one example, regarding their ability to make decisions on the PWDD behalf through a legal framework, Power of Attorney. In addition, where the spouse without the diagnosis of dementia had individualising knowledge of their spouse's character (what is normal or abnormal) this appeared to facilitate them to recognise errors that others, or professionals, may not see:

James (spouse): *If you look at it logically it's self-explaining, to a greater extent, but if you've got Dementia, you haven't got the capability of seeing it, and everybody just treats her as if she is a normal person.*

The spouse's inscription of disciplinary power led to them seeing pathology within the PWDD presentation continuously; their talk was saturated by 'sins and symptoms.' This focus replaced talk on the PWDD's individual attributes or abilities, a possible outcome of objectification processes. One enactment of this was where Sebastian, a spouse, focused heavily on 'sins and symptoms' and then forgot his wife's former occupation. Other examples were spouse's reference to PWDD's interests or

attributes in the past tense, as if through objectifying the person becomes a dormant ‘inanimate object’.

Sebastian (spouse): *... oh my goodness me! She used to run a playgroup that's what she did! (Surprised) I'd forgotten that she had in fact for several years been a guider a brown owl!*

Thomas (spouse): *Betty [PWDD] was (tuts) was! Is a very good cook. Has always been a very good cook!*

A confession on behalf of ‘the subject’. A further illumination on this discourse ‘sins and symptoms’ is that it is a form of confession. The confession is a western tradition or ritual assuming some production of ‘truth’, used in medicine, justice, family and marital relationships, and everyday life. Interestingly, this confession was from the spouse without dementia, on the PWDD’s behalf; thus, alongside the inscription of the disciplinary power, there was the inscription of ‘the dementia subject’. The PWDD did not typically confess *their own* ‘sins and symptoms’ or draw upon this discourse. However, the enactment of this discourse ‘sins and symptoms’ was not necessarily a top down process. It was not the spouse having power over the PWDD neither the professional having power over the spouse, rather it seemed to be an attempt to reveal the hidden essence of dementia, as an object of science (other explanations are explored in more depth in the discussion chapter).

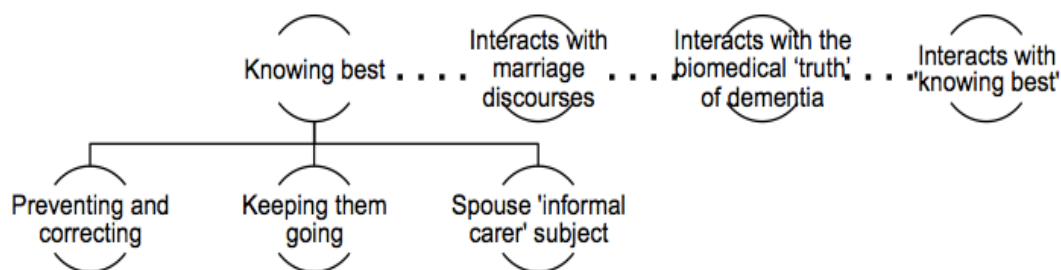
A deviation from ‘a confession on behalf of the PWDD’ was when spouses confessed themselves. Nonetheless, the more common pattern in the data was ‘a confession on behalf of the PWDD’. Both forms of confession may have been influenced by the construction of a confession as being something that elicits a sense of unburdening the ‘sinning’ PWDD and themselves too.

3.09 Knowing Best

This discourse included the construction that the spouse knows what is best for the PWDD. As with the examined discourse above (‘sins and symptoms’) ‘knowing best’ also relied on a biomedical construction of dementia, and supported subjectification and objectification processes. While the former discourse was focused upon capturing or recognising deviances, ‘knowing best’ focused upon applying modes of correction on the

PWDD (e.g. including the elements 'preventing and correcting' and 'keeping them going').

Figure 7. 'Knowing best,' elements & complimentary discourses.



Preventing and correcting. Part of 'knowing best' was the construction that the spouse may notice things the PWDD may not; an enactment of this was where the spouse took measures to correct or scaffold the spouse. Amongst many examples to illustrate this, the following three are provided:

- Les (PWDD): *What about [...] (?)*
 Florence (spouse): *Well [...]’s your daughter dear (!)*
 Interviewer: *Don't worry*
 Les (PWDD): *Yes (laughs, embarrassed?)*
 Florence (spouse): *You get muddled up don't you dear, with names and generations.*
- Les (PWDD): *Saves traffic*
 Florence (spouse): *(Correction) saves driving*
 Les (PWDD): *you know saves driving[*
- Henry (PWDD): *I was talking to, oh god who was I talking to? My very good friend*
 Emma (spouse): *[provides name]?*
 Henry (PWDD): *Yes [...], and erm, after I'd spoke to him...*

In the above excerpt, Henry (PWDD) may have been asking his wife to support him in the task of remembering a name. Alternatively, he may have been asking a rhetorical question to allow him a moment to think of the name. Nonetheless, Emma

(spouse) enacted the discourse ‘knowing best’. Similarly, this is shown between Florence (spouse) and Les (PWDD), in the extracts previous to this. These examples present that ‘knowing best’ could result in the position of ‘the dementia subject’ where talk is obstructed, or rather ‘the capable, communicative, rational subject’, where talk is enabled. Thus, the discourse may generate an array of different outcomes: micro reactions between spouses, influenced by this discourse, may be more or less supportive to the PWDD at different times.

As well as ‘knowing best’ being demonstrated in joint interviews, in a separate interview, William (spouse) recalled a time when he prevented his wife, Marie (PWDD) from making a mistake in a supermarket:

William (spouse): *Well now, it gets gradually worse, now as the time goes on. Well its I mean, when were shopping, she put some things on the list, she got some shampoo or something, er er I said, ‘we got another bottle of shampoo cos’ we bought ...’*

Taking caution to infer too much from the data, it did seem evident there was conflict with the discourse ‘knowing best’. One example of this was provided by Emma, a spouse: “...being able to give him to word or to give him what he’s trying to say or can’t remember and I don’t know what he can’t remember!” This hints that the subject position the spouse finds himself or herself in, through preventing and correcting, was not necessarily a wanted one - parallel to the dementia related subject positions that PWDD were shown to resist. Where dominant discourses can politically organise day-to-day conduct and subject positions, these can be difficult to negate. The extract on the following page demonstrates this further:

Interviewer: *Are you okay?*
 Les (PWDD): *Oh yes I’m just thinking about tomorrow*
 Interviewer: *Okay*
 Florence (spouse): *We’re best at doing it one day at a time erm.*
 Interviewer: *Do you tend to get a bit worried about things that are coming up then Les in the future?*
 Florence (spouse): *Yes! Yeah very*
 Les (PWDD): *Yeah I go off a bit*

Interviewer: *Well I guess its quite an adaptive thing to do if you know you might forget them then your brain is telling you that you need to remember it and is keeping it in mind so[*

Florence (spouse): *[And keeps looking at the calendar over and over again*

Les (PWDD): *Well I have to*

In the extract shown, despite the interviewer's reframing of Les's (PWDD) behaviour as "adaptive", it was overlooked. Les's behaviour was ostensibly fixed as being 'maladaptive' – "and he keeps looking at the calendar over and over again".

Keeping them going. Correspondingly, 'keeping them going' (an element in the discourse 'knowing best') engendered similar fixed subject positions. 'Keeping them going' constructed PWDD's continuation of activities as significant; it incorporated the idea that if a person with dementia did not use their current capacity, they may worsen, or lose their ability altogether, conjoining with 'the feared fate'.

Thomas (spouse): *...so I'm the flower arranging chauffeur and bridge. Betty still places bridge every week, which is excellent I think for the memory, with the cards*

Betty (PWDD): *Yeah I'm having trouble though*

Thomas (spouse): *No! You're doing well you really are!*

Betty (PWDD): *Hhh (sighs)*

William (spouse): *I don't think she's at all a hundred per cent but er I, I try and keep her going as much as I can ... I mean I gotta big vegetable garden I have, I still dig this vegetable garden and, we have vegetables and I think you've got to keep doing something to keep interests and this why I try and try and I don't know how long it will last, to keep my wife going.*

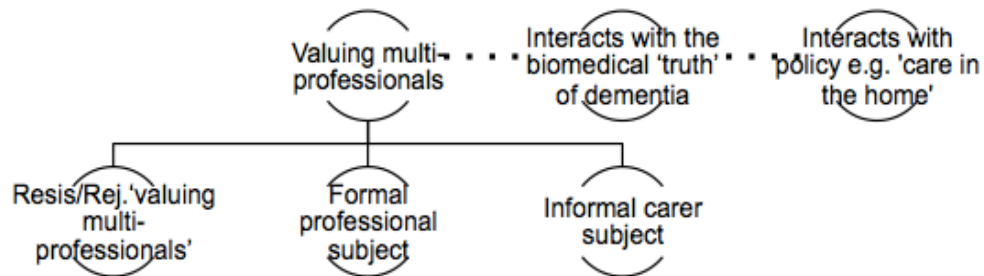
As discussed in the introduction and part one of the results, currently, contextually and politically, there is, a requirement and responsibility for the spouse without dementia to adopt a more expert and intervening stance, or the role of an informal professional. Professional organisations, government policy and family arrangements are presently

supporting this. Nonetheless, with the excerpts provided, one does question the outcomes of this discourse ‘knowing best’ and whether they are the most conducive for the PWDD or spouse. The PWDD’s opportunity to resist an activity seems limited, alongside the spouse’s opportunity to resist ‘knowing best’. One also questions, *how former subject positions embedded within marital discourse then manifest?* ‘Knowing best’ presumably has some link to the point where PWDD was first coded, observed or diagnosed. The conflict between the informal carer and the marital partner are discussed further in 3.10.

3.09 Valuing Multi-Professionals

This discourse surrounded multi-professionals and their expertise. It embodied an adherence to their advice and a respect of their knowledge. It corresponds with document analysis concerning *professional tools*, where professionals were constructed as having specialist knowledge and skills to support and ‘treat’ individuals with diagnoses of dementia; this was valued and advocated by spouses, GP’s and others.

Figure 8. ‘Valuing multi-professionals,’ elements & complimentary discourses.



To distinguish this from the previous discourse ‘knowing best’, ‘valuing multi-professionals’ included the construction that there are some things *only* multi-professionals can do. This interacted with ‘the biomedical truth of dementia’. ‘Valuing multi-professionals’ related to ‘treatments’ after diagnosis, and was not limited to ‘the knowing doctor’ or ‘medications to slow down the progression’. This discourse may be seen to relate to the Enlightenment, which glorified the clinical gaze and exaggerated trust in the wisdom of the professional, at the same time justifying the expansion and branching out of disciplines. Within interview data, ‘valuing multi-professionals’ was mostly enacted by spouses. One interpretation of this was ‘formal’ knowledge was required to support spouses in their more ‘informal’ professional role.

- Thomas (spouse): *You haven't mentioned to [the interviewer] about Parkinson's physiotherapy! ...*
- Betty (PWDD): *Oh yeah we gotta' physiotherapist through somebody. It's not part of anything here it's our own physio and she's done some, some maps, not maps, some papers, with exercises...*
- Thomas (spouse): *Well we try and do it two or three times every week, and then we er, she comes and see's Betty every three or four months to see how she's getting on ... next time she'll come to Betty and say now do it twelve times.*
- Sebastian (spouse): *There seems to be a lot of back up in this area for the mentally impaired! A great deal of back up! And this has become very apparent since we left the clinic and she was first diagnosed... so there's been a lot of actual contact if you know what I mean.*
- Ruby (PWDD): *Yes! It is very good! [Cognitive Stimulation Therapy]. Yes it is! Its good fun and helpful....mmm and you can see how the memory lets you down mmm.*
- James (spouse): *Yeah but we're waiting to see the psychiatrist because you have people talking in your head... you have to shut the doors don't you?*

Amongst the many multi-professionals mentioned in the data, the discourse 'valuing professionals' showed a demand for, and a supply of, institutions to work with PWDD, beyond the spouse's remit portrayed in 'knowing best' and the doctor at diagnosis phase.

Resistance to 'valuing professionals'. The following extracts presented how spouses enacted the discourse 'valuing professionals' when PWDD resisted it - bidirectionality was demonstrated by Betty, a PWDD and Thomas, a spouse. Likewise, in the following extract Florence, a spouse, encouraged Les's attendance at the CST therapy group after he questioned its credibility. The emphasis on "boost[ing]" memory shows how professionals are constructed as counteracting the effects of dementia.

- Interviewer: *... what kind of recommendations did the nurse give you?*
- Betty (PWDD): *I think that she was so busy that erm she couldn't really.*
- Thomas (spouse): *No! She was fine Betty! She was good on information on Parkinson's in a very practical way.*
- Betty (PWDD): *Oh yes she was good but I was just thinking she could you know, there were things she could have told us.*
- Thomas (spouse): *She was a very very practical lady and she was very very well informed we learnt a lot from her... because she is dealing with it on a day-to- day basis with people and she is very enthusiastic.*
- Les (PWDD): *Well... there's the first half hour of talking and there's a cup of tea and I think that's a waste of space! I thought I was going to learn something! They give you a card from a pack of cards and then they ask you what did you do when you were eight years old or 'summin' like that! ... I'm thinking something's going wrong here!*
- Florence (spouse): *[I think there are fourteen classes he's only been to two! And I said they're starting right at the beginning and they'll do different things each time and they try and boost your memory.*

The spouses apparent dismissing of the PWDD views connects with the point made earlier in 3.06; the contrast between participants, offering lay or more “personal” opinions, and the professional, offering credible and informed opinions. The PWDD’s resistance is undermined perhaps through their positioning as a ‘feebleminded subject’ – they, unlike the spouse lack the ability for insight into the supposedly true value of professionals.

Correspondingly, a pattern of resistance discussed in part one of the results, ‘*avoidance of professional care*’ presented bidirectionality regarding uselessness/usefulness of seeking professional support. Although this related to seeking professional advice for the first time, it still indicated resistance regarding professional input. In the analysis of documents, spouses were accorded a role of encouraging PWDD to ‘*seek advice*’ from professionals, counteracting resistance, concurrent with aforementioned findings.

Rejecting ‘valuing multi-professionals’. At other times both spouses and PWDD unmistakably rejected the discourse, ‘valuing professionals’, indicating the contestability of this discourse, in contrast to the ‘biomedical truth of dementia’. Multi-professionals’ practice, not including doctors, appeared to be more open to scrutiny and questioning from participants.

Thomas (spouse): *She came home [from CST] last time and said ‘oh I spent the afternoon throwing a ball! (Laughs loudly)*

Olive (PWDD): *Oh we had nametags that’s right [in CST]. I mean we couldn’t remember their names anyway [with or without nametags]! I mean our memories have gone a bit! And then we had to throw a ball at each other! God! (laughs) I mean I could be at home doing ma knitting!*

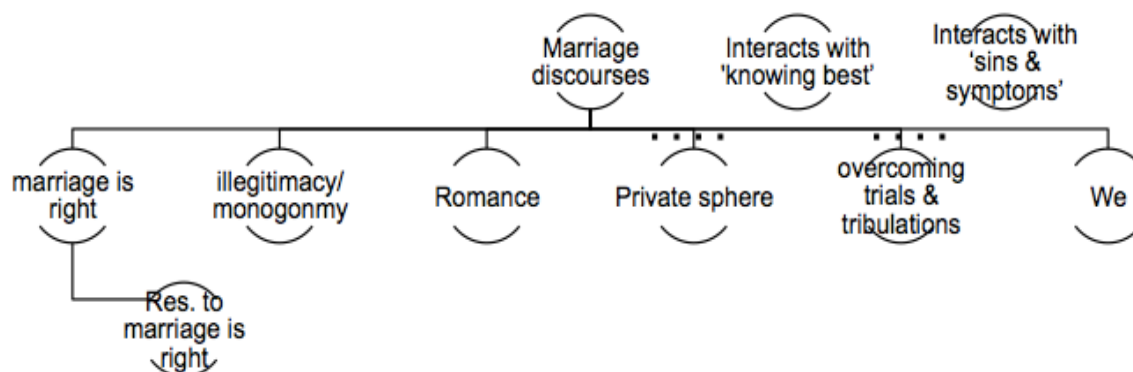
Norah (PWDD): *[CST] was like being at playgroup! The children love it so why shouldn’t we (laughs). // I: what do you make of it James? // James (spouse): What playgroup? (Laughs)*

Comparable to the discourse ‘making a case’, power and knowledge relations were being criticised within the resistance and rejection of the discourse, ‘valuing multi-professionals’ – dementia practises were problematised.

3.11 Marriage Discourses

Marriage discourses are presented separately here, although, they may be seen as elements that are no longer linked, as they did not appear to connect as one or more unified discourses. This is possibly owing to elements moving and changing fluidly with no clear beginning or end, yet through a historical process where they no longer have the same permanency in peoples’ meaning systems. Nevertheless, the presence of these marriage elements in participant’s talk, as well as comparisons between *then* and *now*, suggested that they have influenced, and do influence, certain social bodies, discussed further.

Figure 10. Marriage discourses & complimentary discourses.



Marriage is the right thing to do. This discourse constructed getting married as the right and expected thing to do and not getting married as being wrong or unexpected.

Jack (spouse): *I think a lot of people who did in fact get married because they thought it was what they should do. That was the right thing to do.*

Sebastian (spouse): *It was a question of marriage and children and it got to the point one day where I said to the vicar one day, 'oh there's a marriage queue'. I mean in our time, you were either in your late teens or early twenties, you were expected to get married and if you didn't... then something was wrong!*

As mentioned in the introduction to this chapter, in the nineteenth century the family was construed as a means to form a satisfying and mutually enhancing relationship between men and women, to create an environment fit to nurture children. Women and men were designated separate spheres, the male provider and the female nurturer. This was evident in 'marriage is right' – demonstrated as follows:

James (spouse): *The little lady always stayed at home and the man, earns and er, and that's what it amounted to but I guess thirty years ago or more women became more, imensified if that's the right word, and they*

wanted their own life, and if you go back in story books there wasn't many people like you [interviewer]! It was men! It was a man's world!

Emma (spouse): *Henry has always been the provider.*

The above excerpts present how power is exercised within discourses in the ways it constitutes and governs subjects. For instance, it shows how influential and political apparatuses, religious, economic and so on, governed the doctrine of marriage and separate spheres, as being morally acceptable. Reconsidering the gendered discourse of 'pay no mind' (3.03), this adds weight to the explanation that the mainly female enacted discourse, where individuality was overtly promoted, was connected to social structures perhaps preventing scope for 'originality' and female independence – similar to the relationship/pattern those with diagnoses of dementia.

Forbidden sex outside of wedlock. A further element was sexual intercourse is an act permitted through wedlock, which differed from dominant contemporary notions. As discussed in the introduction chapter, historically, sexual acts outside of the marital sphere were condemned and punished, as Jack demonstrated below. This was once upheld strongly by moral and legal frameworks. Also, William, a spouse, demonstrated how this discourse, forbidding sex outside of the marital dyad, ensures loyalty and trust.

Jack (spouse): *I mean it [sex out of wedlock] was unthinkable! Funny enough another girl... she got into the pudding club as we called it and she went away to a convent to have the child and never saw the child again and that's what you did in those days...because of this child the family disowned her. You know the attitudes were totally different!*

William (spouse): *I mean I've never gone out with another women or been with another women. She is my life!*

Romance, loyalty and love. Coinciding with the above, and ideologies of love and sentiment, several participants recalled how they first met, and depicted their current

loyalty towards their spouse. They would contrast this against the modern day absence of romance and marriage longevity. In the genealogy, ideologies of love and sentiment were argued to mask the political infrastructures and power within the marital sphere.

Although several extracts exemplify this, two are presented:

Jack (spouse): *I was walking back and it was the only time in my life I had a posh suit on...um...anyway, I met this girl. She had the most enchanting smile. I met her next in church and chatted her up! I was then allowed to empty the barrows for her because it was very creepy in the woodlands. I went up because I just wanted to get to know her! So on my horse I went... it was a long time before we actually even pecked! We just clicked and somehow we knew it was going to be permanent.*

William (spouse): *I said about going to the doctors... she says "am I losing my memory" I says "I don't know"... I said "look I'll look after you... don't worry about that I am here and I'll look after you"... but I'd do anything I could to help her because I told her I said "you've been a very good friend to me and if I can look after you, now, I will do everything I can".*

Overcoming trials and tribulations. Demonstrated through this discourse was the normalisation of hardship, endurance and suffering, at certain times in the marital relationships. As mentioned in the introduction chapter, it was particularly difficult for people to seek a valid ground for divorce until the Divorce Reform Act (1969) presenting the structural influences once supporting this discourse. Sebastian typified this.

Sebastian (spouse): *I think whatever trials and tribulations you've had through the years you solider on through them, and eventually, it's just discretion and stickability really. It seems the generation now days that stickability doesn't exist really. There are too many get outs.*

Marriage problems: a private sphere. One participant explicitly stated the privacy of marriage, when asked how he and his spouse had found talking about difficulties in the interview it was explained: “it is very much an individual private situation”.

We. All participants referred to one another as ‘we’ at least one point in their interview, though commonly many times. They also conjointly told stories and answered for one another. Even concerning dementia ‘treatments’ spouses referred to ‘we’ as if they were both going through the treatment. This is fitting with marriage vows (religious, political and legal structures) that two bodies become united as one. ‘We’ may be thought of as interacting on some level with ‘sins and symptoms’. The spouse’s confession and inscription of disciplinary technologies is a product of their united body with the PWDD, where they both have dementia.

Resisting ‘marriage: the right thing to do’. ‘Trials and tribulations’ and ‘the private sphere’ worked effectively in regulating resistance to ‘marriage discourse’. Slight indications of resistance were shown, such as in the extracts below. Concerning the first extract, Thomas, spouse, explained that Betty, PWDD, tends to think of negative rather than positive outcomes relating to marriage. Interestingly he says, she will tell you what she thinks, although Betty did not then comment further on this, nor did many female participants take up the discourse ‘marriage; the right thing to do.’ What is not said was possibly a rejection of the discourse in itself.

Thomas (spouse): *Fifty-two years ago we got married... I’ll say it quickly as this is where Betty will tell you the glass is half empty as marriage is not.*
er –// Betty (PWDD): (laughs) // I: (laughs) oh really. In what way? // Thomas: Nah she’ll tell you what she thinks anyway, but yes over fifty years ago

In addition, marital difficulties tended to be avoided by female participants, conceivably through the governing effects of the discourse ‘marriage the right thing to do’. This is shown in the excerpt on the following page.

Marie (PWDD): *We've never really... I suppose it's sad really but we've never really, how do we put it (hesitation) (#3) talked too much. It's just something that goes just goes along over the years... I have sometimes thought (laughs) I don't think about it much otherwise-
//I: do you think that you might like to talk a bit more then? //
Marie: Ohhh, I don't know. I don't really know. I don't know.*

In wedding vows, the groom promises to 'love, cherish, and worship', and the bride to 'love, cherish, and obey'. The women's silence was ambiguous: it could be seen as having been constituted through 'the obeying subject', or through resisting this.

3.12 Conflicting or Complimentary Discourses?

One reoccurring conflict amongst the discourses was between marital discourses, 'sins and symptoms' and 'knowing best.' As discussed the latter two were united by the 'biomedical truth of dementia' and marital discourses. With 'sins and symptoms' spouses monitored PWDD's 'symptoms': with 'knowing best' the spouses would scaffold and support the PWDD to 'keep them going'. Where at times the spouse acted as if under surveillance to oversee the PWDD this could be problematic. Firstly, the PWDD is not necessarily compliant to the spouses shift in subject position from a marital partner to an 'informal professional.' Neither is the PWDD necessarily compliant to the subject position of the 'informal patient'. The same could be said for spouses without dementia diagnoses. The following extract illustrates one example of how this resulted in pronounced tension and disagreement amongst marital partners, as well as bidirectionality. One example is presented below.

Florence (spouse): *you get upset sometimes when you've got things wrong*

Les (PWDD): *well when you get on to me*

Florence (spouse): *you don't like it when I put you right do you. I try and do it nicely but –*

Les (PWDD): *well you're never wrong are you!*

Florence (spouse): *I am sometimes wrong and I admit it you never admit it (!)...
Well I suppose you know when you get in a muddle with things and lose things and things like that, it does get very, does get a bit*

stressful at times. It does. I have to say. If I do put you straight in any way you say I'm causing an argument. It's not easy.

As discussed, the subject position the spouse or PWDD finds himself or herself in, through 'sins and symptoms' and 'knowing best', was not necessarily a desired one, however, dominant discourses politically organise day-to-day conduct, through the state or established institutions making resistance to certain subject positions difficult.

Secondly, within the marital discourses, males and females had been assigned gender specific roles. In these extracts, through 'knowing best' there was a requirement to scaffold the partner in their day-to-day tasks. At times this was constructed as an all-encompassing role, yet also an important and required one. William's rejection of the task ("no you do it") suggested some unwillingness to take on a more domesticated or typically female orientated role, alongside a will to keep his wife going. Other male participants presented this conflict, though mostly performed within the fixed boundaries of 'knowing best', which could be seen to supersede marital discourses.

William (spouse): *And I try and get her involved, she says 'noo noooo you do it, you can do it' and I say 'no, you're the expert, I'm lear- I'm the trainee, but I realise that it's all going to fall on me! Completely! In a few years time...she's still got all this stuff in the machine and I hang it out and dry it and all this sort of thing ... and I help her. Sometimes I'll do the ironing while she does the cooking and things like that ... I never used to years ago but as I say ...I do more now*

Thirdly, with the marital discourses the spouse's relationship is enacted as a 'private matter'. With an array of professional bodies that surround the marital dyad, further conflict between discourse elements is shown – marriage is no longer private but viewed by professionals and confessed. In particular, several male spouses gave reference to getting angry or "exploding"; *perhaps acceptable in the remits of a marital relationship though not an informally professional relationship?* Despite these contradictory discourses, the spouse seemingly inscribed the professional gaze and ethical and moral codes/rules. This is shown in the following extract where the interviewer, seemingly related to as a professional, was assured by the spouse that he had not been

“violent” to the PWDD. This is an effective political regime, whereby, without any direct professional intervention, the spouse constitutes him or herself as the moral subject of his or her own actions and transforms themselves accordingly (e.g. “I don't rage as much now”).

Sebastian (spouse): *...it passes you see as long as you don't start shouting and saying women for goodness sake what the hell do you think you're doing! 'OH FOR GOODNESS SAKE WOMEN!' you know, 'lift the lid up any have a look inside!' ... I don't explode or anything like that, I'm not violent.*

James (spouse): *Well I don't rage as much now. It's changed. // I: Rage? // James: Oh yeah you'd be surprised, I 'ave no patience. I really don't and it's one thing you need more than anything else is patience.*

Although in some cases discourses did conflict, in others they were seen to complement one and other, particularly through constructions of loyalty and love, participants constructed that they were dedicated to doing all they possibly could for the PWDD – the ‘informal professional subject’ is then enacted as a choice. Similarly, where many participants referred to ‘we’ throughout their interviews, as if encompassing one body through marriage, one spouse’s problem (i.e. dementia effects) was the other spouse’s problem. The marital discourse at times worked alongside the construction of the spouses’ requirement and responsibility for the PWDD, or the intervening stance.

3.13 Chapter Overview

This chapter has presented an initial analysis of NICE (2006) guidelines for dementia and professionally produced leaflets from memory clinics, and it discussed the discursive themes, patterns and deviances in relation to this data. Also, from the analysis of ten interview transcripts from spouse dyads when one spouse has a diagnosis of dementia, eight main discourses have been explored– as presented these are corroborated by the analysis of documents. The following chapter will, discuss findings further and revisit the rationale for this study in relation to the research aims. It will consider further research and clinical and service implications.

4. Discussion & Review

4.01 Chapter Summary

This chapter includes an appraisal of the research aims and summarises the study findings. Given that the results chapter considered each discourse separately drawing upon Foucauldian Discourse Analysis, this section gives less consideration to reviewing discourses in this way. The discussion has been structured based on a series of questions generated by the researcher that may be asked of the data, whilst drawing upon alternative theoretical models. The questions referenced here are embedded throughout the chapter, between sections 4.02 and 4.07. The chapter also offers clinical and research implications, and a critique on this study.

4.02 Study Summary & Appraisal of the Research Aims

At the time of writing this thesis, there are few genealogical enquiries within the field of ageing. The first study aim was to provide a genealogical enquiry concerning dementia, and not limited to Alzheimer's disease alone (Dillmann, 1990; Robertson, 1990) or old ageing generally (e.g. Biggs & Powell, 2001; Katz, 1992), as other authors have done. Given the relevance of marriage in relation to dementia and informal care, kinship and family were also explored in this thesis, albeit modestly.

A second aim was to explore currently functioning discourse surrounding dementia. Corresponding with the second aim, critical enquiries in the field of dementia and recent political developments, as opposed to a more historical perspective, have been completed by Moser (2008) and Bender (2013).

The first and second aims were based on the guidance given by Hook (2010), Powers (2013) and Rawlinson (1987): a discourse analysis should comprise of two platforms, how discourse has arisen, and how it functions. In both cases, a discourse analysis perspective was supportive of a critical engagement with the historical and/or political nature of dementia, i.e. how dementia has been a set as category with fixed boundaries which shape particular outcomes and actions.

As discussed in the introduction chapter, there is a very limited body of qualitative research including interviews with PWDD and spouses— available studies have been from a humanist epistemological position describing individual experience and selfhood (Beard et al., 2012; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Hellstrom, 2005; Svanstrom, 2004). As argued, a humanist epistemology, whereby assumptions are made

regarding agency and freewill, neglects the complex discursive inter-relationships that construct and organise knowledge and meaning, such as ‘the individual viewpoint’ (see, 4.08).

To the researcher’s knowledge, this is the first discourse analysis study dementia study to analyse documents (leaflets and professional guidelines) and interviews (with spouse dyads when one spouse has a diagnosis of dementia). The study aimed to consider the discursive patterns and deviances in the different data sources. Where an analysis of documents is more common is discourse analysis, the lack of interview studies relates to this type of data collection being unusual to discourse analysis (interviews are often associated with hermeneutic, descriptive and naturalistic methods).

This research utilised the concepts of resistance and bi-directionality, power and knowledge implications, zones of disciplinary power, the other, soul effects and so forth, as lenses to support the analysis (Hook, 2010). The various ‘speaking positions’ enacted and rejected by participants in the data were also attended to. Appraisals of the research aim is discussed as follows:

Research aim one. Addressing the first aim, this study explored dementia in the pre-nineteenth century when the psychiatric classification was yet to emerge. Amongst a modest array of broadly defined concepts common to this time, delirium, psychosis and lethargie were commonly used to describe what would now be considered dementia. The conditions that determined the proliferation of medical knowledge were contemplated, such as the Poor Law Act, almshouses, and the social survey. It was argued that populations were made into a material process of biopolitics, and that the state came to increasingly rely upon the scientific community, meaning disciplinary interests were asserted. Kraepelin’s proliferation of a disease classification system, and Alzheimer’s case study in 1906, where ‘Alzheimer’s disease,’ a pathological disease of accelerated mental decline was categorized, was considered. At this time, dementia and its biomedical origins were ‘patchy.’ This contrasts with the mainstream description of the moment when dementia was discovered. It was not until the flourishing of the industries and organisations including psychology and psychiatry, relating to the proliferation of intelligence theory/measurement and the DSM-V, that ‘dementia’ became a more dominant discourse.

To date, controversy has continued to be smoothed over and dementia is constructed as a separate and distinguishable condition from old age, in line with what is

argued to be the growing ageing population. As mentioned, a growing population is hard to dispute, yet certain arguments have been placed against the apocalyptic case of hoards of elderly depleting social resources (see 1.02). Also, this study in effect fragments the ‘epidemic’ of dementia repeatedly portrayed. Instead it places the view that the structuring of systems and organisations increasingly generate people diagnosed with dementia and dementia discourse constitutes those diagnosed. Moreover, a briefer review of marriage and family was considered. In particular, focusing on discourses constructing marriage as a means to regulate sexual activity, social conduct and to support economic arrangements. At times, the mainstream discourse on the importance of marriage and the traditional family unit have been contested – contingent moments where this occurred were briefly reviewed (e.g. in the 1950’s, 1970’s and 1990’s). In addition, the introduction chapter questioned the portrayed ‘progressive’ shift within the last decade towards the PCM and group therapy treatments. It was argued that the PCM works alongside the BMM to control older adults and the marital sphere in particular ways, elaborated further in the next section, 4.03.

Research aim two. Regarding the second aim, this study reviewed NICE (2016) guidelines for PWDD, as well as professionally produced dementia leaflets from GP and memory clinics to distinguish the discursive patterns concerning dementia talk. In sum, statistics and warnings of a disease in older age, alongside health checks, just to be on the safe side, were seen to be directing people and their spouses toward professional sites concerning memory difficulties. The professionals, who were constructed to have sophisticated apparatuses and specialist knowledge, were seen as able to resolve the question of dementia. Support post diagnosis was more descriptive in NICE (2006) guideline as opposed to leaflets – this perhaps limited resistance from people without professional status concerning expertise. Subject positions constructed the PWDD as being active (e.g. “aggressive”, “sexually disinhibited”) and contrastingly, resembled their inactivity (e.g. “end of life care”). The informal carer or marital was constructed as having a quasi-professional role, such as encouraging specialist professional involvement or making legal decisions on the PWDD’s behalf.

Following on from the data analysis described above, eight main discourses were identified in transcripts from interviews from seven PWDD and seven spouses. In total there were four joint, and six separate, interview transcripts. Discourses formulated were ‘the feared fate’, ‘pay no mind’, ‘making a case’, ‘the biomedical truth of dementia’, ‘sins

and symptoms', 'knowing best', and 'valuing professionals'. Marriage discourses or elements were also explored, e.g. 'we', 'romance', 'trials and tribulations', and counter-discourses, such as 'its plain old ageing'. Substantial differences were found between the discourses PWDD and spouses constructed and enacted, plus, between discourses when spouses were interviewed together rather than separately. In particular, spouses drew upon the dominant discourse 'the biomedical truth of dementia'. This was far less common amongst PWDD. This influenced subject positions encountered and enacted.

Discourses in the interview analysis were largely collaborated in the document analysis. As one example, the use of statistics, signs and symptoms regarding dementia, which generated fear directing people to memory clinics, was strongly identified in leaflets and interview data.

In the analysis of interview data, it was indicated that there was a two-fold socialisation to a group that one does not chose to be a member of (i.e. dementia and female gender type), linked to the enactment of the discourse 'pay no mind'. The outcome of this arrangement may be to ensure that a certain version of the 'self' is constructed, explored more in 4.05. One example is how female participants were very active in talk concerning their interests, experiences and skills (i.e. an enactment of 'pay no mind'). The person centred discourse proliferating 'pay no mind' was also seen to generate acts of self-discipline upon the PWDD; whereas, the BMM heavily influenced spouse's acts, particularly in their monitoring and confessing of their partners dementia effects.

Following the discussion on research aims, new theoretical insights will be considered to enrich understandings of the most noteworthy findings.

4.03 How were discourses adopted complementary to the apparatus of power and the expansion of the neuro-hybrid?

PWDD and spouses drew upon relatively different discourses and dissimilar subject positions, and this would be expected from a discourse perspective where participants draw upon a multiplicity of discourses (Burman & Parker, 1993). However, it was unforeseen that there would be such a division between spouses and PWDD. As mentioned, spouses tended to use dementia discourses united through the 'the biomedical truth of dementia' and they inscribed the subject position of the informal carer (e.g. 'sins and symptoms', 'knowing best', 'valuing professionals'). Yet, PWDD enacted the discourse 'pay no mind' to the disease, promoting their individuality and capability

associated with the PCM. It may seem that these discourses and subject positions are conflicting; *does one not embody the PWDD's independence and the other their dependence?* However, these discourses may be understood as complementary power/knowledge arrangements – governing and disciplining the PWDD and their spouse.

In a similar vein, ‘marriage discourses’, ‘sins and symptoms’ and ‘knowing best’ were also considered to be unified discourses – particularly, the elements of ‘romance’ or ‘we’, combined with the spouses monitoring to see things the PWDD cannot. These were argued to be productive and social-economic techniques of power.

To explain these complicated arrangements further, the researcher refers to the Panopticon depicted in the introduction and method chapter (see 2.05 & 3.05). The Panopticon is an architectural description of the prison designed by Bentham. In its abstract sense, the Panopticon refers to the design of political institutions (e.g. medical, psy, religious, marital, legal, moral) that facilitate a discrete, affordable, dispersed and effective surveillance and control over ‘individuals.’ Individuals are proposed to detect observation, even though it is impermanent, and they begin to govern themselves as if the observation is permanent.

“He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection” (Foucault, 1991, p.203).

A further understanding that enriches Foucault’s description of the Panopticon is ‘neo-liberal governmentality’ (Rose, 1998). This is a specific mode of reasoning and governing ‘bodies’ in a social system. This regime firstly brings about order through a self-monitoring, responsible, optimising and maximising subject. This holds the ideology of the ‘free agent’ who speaks and acts ‘liberally’ which works to ‘mask’ the apparatus of power (i.e. made of groups, institutions, organisations, the state). Secondly, it is a political-economic rationality that strives to extend the ethic of the market logic to ever-broadening spheres of life (Rose, 1998).

“[Neo-liberal governmentality is] an emergent pattern or order of a social system, arising out of complex negotiations and exchanges between intermediate social actors, groups, forces, organizations, public and semi-public institutions in which state organisation, amongst many others seeking to steer or manage these relations” (Rose, 1999, p.21)

Lastly, concerning the Panopticon, Hook (2010) has discussed the notion of ‘the other’ (linked to Lacanian theory). Hook (2010) explains ‘the other’ is crucial for accounting for the mechanisms of power and reflexivity. We ask: *how does ‘the other’ see me; what does ‘the other’ want from me; what are the social values it holds most dear?*¹⁷

Considering these theoretical stances in relation to the present findings, it may be conceived that spouses self-govern and monitor themselves as an informal care-giver refraining from non-professionally coded reactions (e.g. potentially abusive reactions ‘anger’ and ‘rage’) to perhaps prevent the attraction of the observer he/she imagines to be there. Marriage (e.g. through ‘love & loyalty’, ‘we’ & ‘the right thing to do’) becomes a ‘natural terrain’ for informal acts of caring, and through the ideology of the free agent, they are ‘chosen’ acts. With this, and the spouse ‘keeping [their spouse] going,’ not all PWDD and spouses require direct state intervention, a political-economic rationality. Similarly, spouses with diagnoses of dementia self-discipline, ensuring their capability and ‘preserving their individuality’ – through the person centred discourse. In doing so, they steer away from the potential confinement of “a psychiatric unit” or other more direct modes of care (see 3.02), potentially draining societal resources (1.01). These operations, on some level, remain opaque to the PWDD and spouses, which is why they perhaps work effectively.

Within the frame of the Panopticon, the spouses confessing on behalf of the PWDD and inscribing ‘the professional’ is a perplexing finding (3.06). One potential explanation using these models of thought is that despite the voluntary appearance of conformity, it is dependent upon ‘lighter self discipline’ (e.g. the spouses inscription of professional to govern the self and the PWDD) to avoid ‘heavier professional-disciplining’. In order to do this, spouses must understand the rules and recognise signs from ‘supervisors’ or professionals through the mechanism of ‘the other’. The Panopticon requires rational actors, thus *perhaps in this case spouses are seen to be more suited?* As shown in the results, PWDD were inter-changeably positioned as dangerous and

inanimate, or in denial and lacking-awareness. The branching out of professionals, organisations, institutions, depicted in ‘valuing professionals’ (see 3.07) perhaps enhances the field of conformity, self-discipline, and the sharing of knowledge between spouses and professionals, beyond the remits of the state alone.

Consistent with this, the introduction chapter presented the hybrid of neuro-industries centred on dementia. In order for this to survive it must expand and open up new industries. Where dementia rates have expanded, alongside awareness and a dementia hyper vigilance (e.g. indicated in leaflets within the document analysis), this necessitates intervention from the professionals, whether directly or indirectly. Examples are the increasing use of medication, neurocognitive and MRI testing, charity support, and therapy groups pertaining cognitive improvement. What we are led to believe is that it is *not* that the supply of neuro-industries around dementia that creates their demand, rather the opposite – it is *dementia itself*.

Similarly, the recent addition to *the Diagnostic Statistical Manual- Fifth Edition* (DSM-IV) of Mild Neuro-Cognitive Impairment (MNCI) expands the boundaries of diagnosis in relation to dementia (American Psychiatric Association, 2013)¹⁸. As illustrated in the extract below, MCNI is proposed to be a pre-condition that needs identifying. It is centred on psy-industries and the provision of their ‘therapies’, as well as relatives’ inscription of the professional to ‘detect’ signs. This accords with the above reading of the data. Additionally, it clearly differentiates the pathological disorder from ‘normal old age’, through the dominant biomedical discourse.

“The diagnosis of MCNI in the DSM-5 provides an opportunity for early detection and treatment of cognitive decline before patients’ deficits become more pronounced and progress to the major neurocognitive disorder, dementia. Its inclusion in the manual will help clinicians develop effective treatment plans as well as encourage researchers to evaluate diagnostic criteria and potential therapies. Mild neurocognitive disorder *goes beyond normal issues of aging*. It describes a level of cognitive decline that requires compensatory strategies and accommodations to help maintain independence and perform activities of daily living. To be diagnosed with this disorder, there must be changes that impact cognitive functioning. These symptoms are usually observed by the individual, *a close relative*, or other knowledgeable informant, such as a friend, colleague, or

clinician, or they are detected through objective testing” (American Psychiatric Association, 2003; italics added to give emphasis).

Recently, a large amount of media attention has been given to research reporting a “significant reduction in overall UK prevalence” of diagnosed with dementia over the age of sixty five (Wu et al., 2016). This was a longitudinal study between two time periods – 1989-94 and 2008-11, where the prevalence rates of dementia is argued to have dropped from twenty to sixteen per cent in the UK. The researchers of the study conclude that “fears” of increasing dementia rates among may be “wrong” and claim this is a unique finding (Wu et al., 2016). However, this may reflect the expanding and ever-changing boundaries of the classification system. In the 1990s, clinicians may have been diagnosing probable mild stages of dementia which may now be seen as MCNI. The outcome is more people are accessing memory clinics.

Furthermore, to broaden discussion regarding the above mentioned subject positions of inanimate or lacking-awareness, Robertson (1990) argues that dementia holds an ontological position of increasing helplessness, dependency and mental deficiency. Robertson (1990) supports this case with empirical studies on elderly, which present accelerated learned helplessness, mindlessness, disability and death after institutionalisation. She also argues there is so much ‘talk’ and media publicity on people with dementia being victims, patients, depressed and in despair that the inevitable outcome is the self-inscription of this role (Robertson, 1990).

Contra to Robertson’s (1990) point on self-inscription, one argument relating to this thesis, is that through ‘pay no mind’ PWDD were self-disciplining to steer away from mentioned subject positions, and thus were resisting self-inscription to this end. This is perhaps a power arrangement more fitting to a proposed time of austerity and budget cuts, plus policies regarding care in the home for longer (NICE, 2016; The Care Act, 2014). *Some* level of independence and capability for PWDD is required to avoid ‘heavier’ professional intervention. Fitting with this, Cloud (2001) claims the rise of the psy-disciplines is such an effective political strategy of capitalism, as descent is claimed in a discourse of individual responsibility.

Nonetheless, as shown with the discourse ‘making a case’ (see 3.05) PWDD adopted discourses that attempted to resist professional tools and interventions (‘lighter intervention’ such as a diagnosis). This problematises the view of people as empty, passive vessels subject to the omniscient powers of the psy and biomedical industry.

However, where some participants attempted to resist the political apparatus of power, there was a rejection from their marital partners and a reframing of the PWDD resistance as a form of ‘mental deficiency’ inherent with dementia effects. In one case, the spouse without dementia who resisted professional tools and interventions towards his wife, the discourse of a psychologised grieving process was used instead. Difficulty with the discourse ‘making a case’ may be reflective of policy (Mental Capacity Act, 2005; Lasting Power of Attorney, 2015) reviewed in the introduction. The PWDD and their spouse is implicitly or explicitly advised of the potential for fluctuating mental awareness in dementia and the need to be aware and proactive around this. In this case, the spouses are perhaps ‘proactively’ reacting to the PWDD through the discourse of their limited capacity, with the legal obligation to ensure their decisions are ‘in their best interests’ (MCA; 2005). That is, adhering to professional tools and interventions, and not deconstructing them as within ‘making a case’. Also shown in the genealogy, through the emergence of modernity, it has *typified* modes of ‘ordering’ of the living being through science and its material processes. This too, results in the control of resistances or deviations relating to dementia.

4.04 ‘The biomedical truth of dementia’ – how may our understandings be improved by poststructuralist discourse theory?

The biomedical truth of dementia was an important discourse through which participants took doctor’s statements and practises surrounding dementia to be a ‘fixed’ truth (refer to 3.04). It was argued that this discourse worked to operate a range of other discourses, e.g. ‘pay no mind’, ‘sins and symptoms’, ‘knowing best’ and ‘valuing multi-professionals’. ‘The biomedical truth of dementia’ also included the speaking positions, some already discussed (e.g. the knowledgeable and wise doctor, the compliant relative, and the person with dementia lacking insight). These categorisations appear natural, rather than contingent upon discursive practices.

Although Foucault’s genealogical approach enables us to scrutinise how particular discourses and objects, are scientifically, societally, and economically prioritised over others (see introduction chapter), certain schools of post-structuralist discourse theory (PSDT) may be seen to add another dimension. PSDT is centred on understanding the semantic-material structure of a discourse. A drawback within the Foucauldian frame relates to describing the jigsaw puzzle arrangement of discourses in any given analysis. At times, aspects of PSDT were drawn upon to complement the exploration of dementia

discourses in the latter stages. For instance, where the discourses consisted of sub-parts, these were labelled elements in the results chapter, more fitting with PSTD.

Laclau and Mouffe (2014) discuss how it is ultimately impossible for a discourse to fix a web of meanings or signs into set positions, however, there are processes in which they can appear as if they are 'fixed' through the constitution of nodal points. Nodal points organise the discourse around a central privileged signifier or reference point (Lacan & Sheridan, 2001). They bind together particular systems of meanings or 'chains of signification', assigning meanings to other signifiers within that discourse. For instance, Žižek (2008) provides the example of communism being the nodal point around democracy, state, freedom, which rearticulates them into a new meaning, different from those used in competing discourses. For Žižek, (2008) the nodal point or the word communism unifies the given field, and constitutes its identity. It is structured through articulatory practises, whereas, on its own, it lacks density. It acquires its meaning from the arrangement of other signs. In this theory, while nodal points are the elements that crystallise a discourse, other signs can be 'floating signifiers' meaning discourses are potentially 'open' to different ascriptions.

In this case, the nodal point may be seen to be 'the biomedical medical truth of dementia', arranged with other signs: doctor, education, tests, MRI, medication, plaques, tangles, amyloid, memory. Through repeated articulation this discourse has established an *apparent* closure or a structured totality. The floating elements around this nodal point can be seen to function in 'pay no mind' (which is centred upon the person centred treatment of dementia), for instance, individuality, personhood are introduced and have the potential to restructure meaning. In a further discourse, 'valuing multi-professionals', the sign 'doctor', may become 'multi-professional' accounting for nurse, physiotherapist, psychiatrist, etc. Though fundamentally, these discourses may be considered as centred upon, and crystallised through, the nodal point the 'biomedical model truth of dementia'. The practices of articulation through which a given order is created and the meaning of social institutions is fixed are conceptualised as 'hegemonic'. This is where discourses reach the level of 'common sense', in that their origins and intrinsic contingency are forgotten (Laclau & Mouffe, 2014): "What is at a given moment accepted as the 'natural order', jointly with the common sense that accompanies it, is the result of sedimented hegemonic practices" (Mouffe, 2008, p. 4).

Some schools of PSDT are perhaps more linked with structuralist language theories, contrasting with the relativist position Foucault, at times, aligned with. Foucault

avoided reductionism, and inferences of causality or truth, the very political practices he critiqued. He states, “if interpretation can never be completed, this is quite simply because there is nothing to be interpreted, for after all everything is already an interpretation” (Foucault: as cited in Said, 1974 , p.28). In addition, “discourses are not to be treated as groups of signs but as practices that systematically form the objects of which we speak” (Foucault & Smith, 2002, p. 42). Nonetheless, and notably an oversimplification, the use of PSDT, as depicted above, is in a way breaking down ‘signs’ to understand the way regimes of practices are held together, as well as to ‘uncover’ the rules that inform this regime. In a purely relativist bind, this perhaps limits the potential of discourse to destabilise or stabilise particular discourses, by seeking to find *which obstacles are able to be overcome? Or, how might links and formations within a discourse, re-emerge?* This frame of thought is explored further in relation to the PCM of dementia in 4.08, and its potential to re-emerge.

4.05 ‘Pay no mind’ – a two-fold collectivization of gender & dementia?

Perceptions from post-structuralist feminism & identity politics

Unexpectedly, this study presented the finding that there were almost wholly gendered discourses, ‘pay no mind’ and marriage discourses: ‘the right thing to do’, ‘sex before wedlock’, ‘romance, loyalty and trust’, and ‘trials and tribulations’. One interpretation was that within ‘pay no mind,’ the preoccupation with interests, experiences and ‘the self’ was a product of a two-fold experience of marginalisation and oppression, through the identity of 1) the dementia subject and 2) the women. The female participant’s silence towards marriage discourses was understood to resemble resistance – speculations being, *marriage is not the right thing to do*, it was not a choice they had or it is not a topic they felt able to speak freely on. The spouse’s dismissal of the PWDD’s rejection in ‘valuing the professional’ and ‘making a case’ was linked to a dismissal of the PWDD voice, credibility and insight. As mentioned in the analysis, the researcher was faced with a quandary, *how does one describe this without falling in to the positivist binary of male and female, and marxist and feminist notions of identity oppression colluding in the very process of identity oppression?* Yet, to disregard the permanence of the resistance from both female’s and PWDD would contest the ethics of research and the uniqueness of the findings. Other ways of discerning this finding are now offered: firstly, exploring Foucault’s notion of biopolitics, and secondly, feminist post-structuralist identity politics.

To begin with, biopolitics, Foucault's (1998) *The History of Sexuality* highlights the contextually specific apparatus of power, tied to a host of disciplinary technologies and numerous and diverse techniques that control the 'bodies' of the population¹⁹. Cotoi (2011) also explains, biopolitics is a machine for reinforcing and expanding the exercise of bureaucratic state power; it is an intervention of control on an exceptionally wide level, relating to governmental concerns about the characteristics of species. Linked to this is the development and reliance on the social survey, and the turn towards scientific communities to regulate bodies, such as through categorisations of dementia and sex, as depicted in the genealogy.

To consider this complex notion further, in *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth Century Hermaphrodite* Foucault (1980) wrote about a person raised in a convent as a 'her', later found to have male and female sexual organs. Professionally rationalised, Herculine was a 'he' owing to Herculine's sexual preference of other 'women' and the ability to procreate through male genitalia. Similar to *The Order of Things*, Foucault (1994) presents how in different times and different spaces, particular to the emergence of modernity, human beings became a source of meaning and ordering, their essence to be discovered scientifically or through life sciences. From this angle, the taxonomy of living beings, applies to not only gender, but dementia too. Participant's bodies are 'biopolitically' ordered through the life sciences, according to state power. The significance of this is that participants are ordered through a much wider, and complex political process that limits the subject positions available. This helpfully reframes the overgeneralized oppressed notion mentioned earlier. The need to assert the self as being 'capable', 'important' and 'individual' counteracts homogenous and politically governed groups.

In accordance with this, over the past decade, many influential feminist thinkers have expressed the idea that feminism needs to move beyond a politics of identity, concerning dismantling the essentialist binary of gender towards a post-identity politics. These arguments have been expressed in different ways but the apprehension is that "the focus on identity reifies social difference resulting in a parochial politics of recognition that hinders participation in wider democratic debates" (Burman, 1998, p. 513). Arguably, by relinquishing the preoccupation with gender identity, a space would be created for feminist theory and practice to attend to a wider politics of diversity where difference is understood as a resource rather than as an end in itself.

Correspondingly, an instrumental critique has been made by Brown (1994) who argues that identity politics all too often attributes an incontestable moral legitimacy to the idea of personal suffering where it is taken as irrefutable evidence of oppression and injustice. Not only is suffering far from being an automatic guarantor of social injustice but the persistent focus upon injury sets up a negative psychic dynamic that binds individuals and groups to their own subjugation and ultimately impasses the political imagination. In this case, through the above mentioned interpretation (a two-fold collectivization of marginalization and oppression), the researcher is potentially falling into the remits of the dementia subject and women as suffering, while binding them to the subjection and preventing alternative political movements.

Zerilli argues that the relentless focus upon ‘the subject question’ has obstructed thought regarding ‘freedom’ and ‘action’ beyond the assertion of identity (as cited in Burman, 1998). It focuses on ‘I can’ rather than ‘I will’ – a vicious circle of agency. Linking to Foucault’s (1991) understanding of power (see methodology, 2.*) there is the assertion is that political actors do not know what they do, thus, it is not an effective regime to direct anger or action towards those ‘oppressors’ or characterised enemies, who are potentially unaware. Instead, Zerilli encourages political action to be a future oriented, world-building practice that seeks to appoint unanticipated modes of being. Then, as a world-building practice, it should base itself not on the assertion of pre-given differences (gender or perhaps non-age associated decline), the ‘what’ of identity, but a pursuit to establish the newly thinkable in terms of dementia and gender (the ‘who’ of politics). She states “that which cannot be proved like a truth or possessed like a substance, can only be practiced or enacted by present and future generations” (Zerilli; as cited in Burman, 1998). In sum, notions of biopolitics and post-identity politics may be seen as complementary theoretical notions, to support avoiding the binds of agency.

4.06 The feared fate & ‘inanimate/dangerous dementia subject’ – scope for exploring emotions?

The feared fate was one of the most prominent discourses across both PWDD and spouses accounts, and across the document and interview analysis. It shaped dementia as a great concern, ensuing and justifying the biomedicalisation and differentiation of dementia. It was also embedded with epidemiological research studies or ‘media talk’ on the apocalyptic case for older adults (e.g. “its been mentioned in the paper... it's a growing disease of the elderly population).

In relation to the analysis of professional leaflets, sources listed symptoms of biomedical ‘dementia’ symptoms supporting the uptake of memory assessment clinics. One leaflet stated, “contact your GP, if you seek help sooner, you can get information, advice and support”. The leaflet also constructed how spouses and families should monitor and assess people’s possible symptoms owing to the “risks” of developing dementia in late adulthood. The introduction to this thesis discussed Foucault’s (1991) notion of the *regime of truth* where these facts are believed to coincide with a certain criteria and rigor, through the privilege means of science and research, or ‘technologies of truth’.

To build upon this understanding, Moser (2007) states that ‘*facts matter – they are of concern or of importance*’ and ‘*they are value loaded and charged matters*’ (p.98). Feminist writers such as Haraway (1997) have presented the way that facts have built in ‘normatives’ and justify certain objectifying practises (e.g. defining, controlling and monitoring dementia). Butler (1990) has also offered that ‘natural realities’, alike to dementia in this discourse, are ‘mattering’ and produce particular power effects. Neither given stable nor closed, they rely on the continued enactment and re-enactment of situated practices (e.g. science, politics, technology, research and medicine). Using these descriptions then, ‘the feared fate’ is a discourse that can be understood as hegemonised through materially and socially productive practices constitutive of spouses being hyper-vigilant to any signs of change.

Another understanding of ‘the feared fate’ is that today society is no longer concerned with attaining something good but with preventing the worst (Beck, 1992). This has been coined by Beck (1992) as the “not yet event as stimulus for action” (p.34) or what Sontag (1989) has termed as “the apocalypse from now on” (p.53). In other words, it is an anticipation of the worst possible outcome and a production of the individual as an object, powerless to omnipresent forces. Sontag relates this to the AIDS movement in the 1980s and claims that this is a symptom of cultural and political malaise. She identifies the striking relevance of so many to envisage a far-reaching catastrophe.

In leaflets, there was the advertisement of “care-cameras” understood here as surveillance techniques. This is consistent with the ‘catastrophe’ embedded in the ‘the feared fate’, and the potential for the participant to be “dangerous”, where they need to be watched.

Moreover, Robertson (1990), in her genealogical analysis, argues that the construction of dementia as biomedical disease is reassuring as it envisages ‘armies of professionals’ making visible and eliminating the ‘real’ foundations of this disease. The alternative normalising of dementia, such as the discourse ‘its plain old aging’ in this study, which was less apparent across participant data, leaves little hope of a cure. ‘The feared fate’, on a societal level, moves away from the possibility that the aged adult is collectively problematised and a burden on society, and upholds the organised task to combat dementia.

Moreover, Behuniak (2011) states all too often negative perceptions of dementia are reduced to biomedical understandings as the enemy, and emotional responses to dementia are not given enough attention. He argues that these also have a political function. In this study, this gap is perhaps relevant to a Foucauldian approach that evades talk on emotions as a manufacture of individualising and psychologising procedures. Where Foucault gave significance to the micro, this avoids individual emotional reactions and experience.

To widen the discussion in consideration of this critique, Behuniak (2011) explores scholarly and popular literature on dementia, and skilfully portrays how the problematic ‘zombie dementia subject’ is a strongly embedded social construction of dementia. This exists through the ‘emotions’ of fear and revulsion it evokes in people, motivating power relations, marginalisation and labelling. The zombie dementia subject is both a victim and a dehumanised monster. It also has links with other feared conditions such as cancer, tuberculosis, AIDS, leprosy because it “commands fear before sympathy” (Behuniak, 2011, p.71). Similarly, Fox (1989) describes that dementia ‘conjures up images of a hideous, debilitating condition... it is the disease of the century’ and ‘the mind robber’ (p.58). Because the disdain is aimed at all individuals who share the specific feature, they become unwilling members of a stigmatised group (Schneider, 2005, p. 474)– as relevant in ‘pay no mind’ and ‘making a case’.

Congruently, as constructed through the ‘feared fate’ — one does not have to go very far to find “the dangerous/inanimate dementia subject”, or to think hard about how this may generate fear and despair, whilst upholding the subject position or the defining and refining of dementia:

“Up to 75% of people with dementia may be affected by non-cognitive symptoms/behaviour that challenges. They are a leading cause of distress to carers

and often lead to the institutionalisation of the person with dementia. Several studies have shown that acetylcholinesterase inhibitors may improve non-cognitive symptoms ... cost-effectiveness has not been established” (NICE, 2006).

Similar to Behuniak’s (2011) critique, Parker 2014 draws attention to how psychoanalytic theory is generally ‘screened out’ from some discourse enquiries owing to concerns that it is based on the same ideological that structures as medicine, psychology, and psychiatry. Parker (2014) also states that psychoanalysis and discourse theory do not align when related to psychoanalysis’ political conservatism, and mainstream understandings of a particular time. However, one potentially intriguing notion from psychoanalysis to make sense of ‘the feared fate’ is that it resembles a ‘defense mechanism’ (or a strategy) used to protect participants from psychic pain, or from thoughts and memories that evoke pain (Parker, 2014). In this case, the constructed *fact* they that the PWDD or the spouse may face the inevitable fate of dementia, motivates the construction of the ‘inanimate/dangerous dementia subject,’ as it produces dementia outside of themselves or their partner. This defense may be understood by certain schools of psychoanalytic thought as a projective identification, where the person expels unpleasant objects from their own minds into the minds of others (Parker, 2014).

Consistent with this, among participants the inanimate and dangerous subject may be seen as a projection of their own [imagined or real] mental decline or potential to be pathologically destructive – in a sense then the feared fate is a self-protecting discourse. Enquiries regarding racism (e.g. Fanon, 2008; Lowe, 2007) have had a very strong political grounding using psychoanalytic processes. While bearing in mind ideological ties it offers an understanding of internally motivated processes and how they may constitute community, managerial and economic agendas. In the case of dementia, there are deep political implications from the fear evoked by the inanimate dementia subject, such as the spouses’ responsibility to self-discipline, confess, monitor, correct and keep the PWDD going.

Considering this, Foucault makes a statement about the need to problematise normalised yet problematic societal divisions of man of reason and man of madness, or in this case, man (or woman) with dementia.

“[people], through sovereign reason, act to confine their neighbors and communicate and recognize each other through. We must renounce the convenience of these terminal truths and never let ourselves be guided by what we may know of [dementia], even implicitly, it can play and organising role” (1965, p. xi/preface).

4.07 Sins & symptoms, knowing best & pay no mind – what other theoretical understandings are there regarding the finding of ‘the confession’?

Following on from the above discussion regarding the absence of emotional discussions from a FDA perspective, the researcher returns to the discourse ‘sins and symptoms’ and the confession.

To review discussions up until now, ‘sins and symptoms’ may be thought of as centred upon ‘the biological truth of dementia’ (nodal point), by which, it is crystallised through the belief that there are visible and tangible signs of dementia that ought to be uncovered by others. This resulted in a process where spouses worked to ‘discover’ the PWDD’s dementia effects, exhibiting objectifying and subjectifying practices. An alternative account is to consider how the spouses confess not only their own ‘sins’, but also the PWDD’s.

Firstly, disparate to ‘the biological truth of dementia’, ‘sins and symptoms’ is perhaps linked with ‘elements’ of religious discourse, plus, popularised psychological and psychoanalytic discourses on the ‘self’. This is an historical discursive arrangement that produces the need for spouses to confess the ‘truth’ (or dementia signs) to those in authority (e.g. the priest, GP, psychiatrist, psychologist, researcher). This is illustrated as follows:

“Medical metaphors have borrowed a lot from the religious metaphors of past centuries, where the 'sinner was described as a sick man' and the 'onset of illness stirred up anxiety, self doubt and guilt' within the individual afflicted with illness by observers around him or her. The sufferers of long-term illness were seen to be in a perpetual state of 'gracelessness’” (Millen & Walker, 2001).

Guilt and doubt afflicted with dementia, and the ‘graceless’ state associated with dementia, perhaps encourages spouses to ‘confess’ PWDD’s as well as their own. Sontag (1989) adds, this is even more fitting where illnesses, like dementia, are constructed as a

mysterious or higher order force. In the results, a participant referred to dementia as if wickedness inflicted upon people by a higher power, supporting this stance. Likewise, Turner (1987) adds illness metaphors of the body have reflected a process of inwards looking, placing the individual and his/her illness on centre stage for others to 'see'.

To Nietzsche a confession is an act of 'slavery' and 'self-punishment': "man could never do without blood, self-torture and sacrifice" (Nietzsche, as quoted in Grosz, 1994, p. 131). Concerning the findings in this thesis, where spouses focus on PWDD's pathological changes, it may also be conceived of as an act of self-torture, through the discourse of loss and change in dementia, and thus, their spouse. In a sense they are mourning their spouse while their spouse is still alive. This perhaps links with the discourse 'the feared fate' and the construction of the subject as no longer participating in life. Although the person may have a physical presence they are seen to have no presence in 'mind' (e.g. a person with a diagnosis of dementia is constructed as "a vegetable"). Aquilina and Hughes (2006) add, "people with dementia can be treated as already dead and as walking corpses to be both pitied and feared, despite their obvious signs of life" (p.143). Likewise, Lushin (1990) has referred to people with dementia as "ghouls" and Cohen and Eisorfer (1986) describe dementia as "death before death" (as cited in Behuniak, 2011).

A further speculation is that through self-abnegation, embracing moral codes, and professional understandings, the spouse is produced as a heroic and admired figure; the carer is often honored and pitied.

Intriguingly, Nietzsche also depicts the confession as a product of memory, or as a refusal to forget from the confessor (Grosz, 1994; p.131) – this may be the case with regards to PWDD and their enactment of 'pay no mind'. To elaborate further, Nietzsche explains memory works through the body to give meaning to reality, truth, and history; it enables social organisations and systems of law, so, in order for this to function, forgetfulness must be rejected (Grosz, 1994; p.131). Based on this conclusion, through 'pay no mind', where self-hood or individuality featured so heavily, PWDD may be constructing their memory and a certain version of their person, that sets dementia aside. It could be that PWDD are in effect providing a confession that manifests in a different way to spouses– 'I am'. Drawing upon psychoanalysis, as referenced to earlier in the discussion (Parker, 2004), this mode of confessing may also be considered as a defense mechanism from PWDD, where they dispel the 'I cannot' aspect of themselves.

4.08 An unhelpful alignment of the person-centred model with biomedical model?

Policy, research and clinical implications

The PCM is often seen as a movement away from the medicalisation of dementia towards apolitical subjectivity. Nonetheless, it is argued in the genealogy, the PCM has been crafted alongside the medical model – in effect hegenomising and expanding upon ‘the biomedical truth of dementia’. The ‘biomedical truth of dementia’ is seemingly what Laclau and Mouffe have described as ‘*the dominant horizon of social orientation and actions*’. This arrangement of elements and nodal points, in a particular context, yields substantially effectual outcomes and webs of power relations. From this approach then the following question arises: *did the PCM begin with legitimate potential to counteract the dominant biomedical paradigm? Has it somehow lost its ‘original’ radical prospective, by being consumed through the political infrastructure and various social actors establishing PCM and so called treatments?*

If using PSDT then, a signifier is allocated a certain meaning in one discourse and may be given another meaning in a different discourse, and since signs derive their meaning from their relation to one another, with the PCM and its uniting element as ‘the biomedical truth of dementia,’ there is potentially scope for intervention. “Any discourse is constituted as an attempt to dominate the field of discursivity, to arrest the flow of differences, to construct a centre” (Laclau & Mouffe, 1985: p.112). “Every hegemonic order is susceptible of being challenged by counter-hegemonic practices which attempt to disarticulate it in order to install another form of hegemony”. (Mouffe, 2008: p.4).

When two or more antagonistic discourses (in other words two *potentially* opposing discourses that could come into conflict) compete for hegemony, conflicting demands are made upon social identities, relationships and systems of knowledge and beliefs. Antagonisms may be visible through the presence of elements that are articulated in different ways by opposing political projects. *This may potentially be ‘the biomedical truth of dementia’ and the PCM of dementia as one articulation – the picture as it seems currently. The alternative could hypothetically be where the PCM of dementia is supplemented with elements from ‘making a case’ and/or ‘its plain old ageing’, or a more deconstructive understanding of dementia, while biomedical elements are placed outside of this discursive arrangement of elements – here, the PCM is no longer inter-dependent on the ‘biomedical’.*

The PCM model of dementia may be determined, albeit temporarily, through hegemonic interventions or concerted efforts to re-articulate discourses and achieve the

dominance of one particular perspective, thus reconstituting unambiguity (Laclau, 1993). To do this, hegemonic projects will need to construct and stabilise the nodal points that structure social orders by articulating elements into one unambiguous set of meanings (Laclau & Mouffe, 1985). A further research project may give more of a focused opportunity to study the potential for the re-articulation and stabilising of the PCM of dementia with a different nodal point, or to consider the potential to supersede the dominant discourse of the 'biomedical truth of dementia'. This project however, indicates the potential for innovative critical thinking around developing new or alternative meaning systems and social positions for PWDD and their spouses.

Nonetheless, one cannot help but think that the above discussion and point is perhaps ambitious and detached from the historical material structures within the political context of dementia where there are vast political interests. Fitting with this inclination, Chouliaraki and Fairclough (2007), have argued that, in emphasising the contingent nature of discourses, Laclau and Mouffe overestimate the ability of social groups to bring about change through the rearticulation of elements into new social orders.

What is brought to mind as a topical example that may be difficult to change is Cognitive Stimulation Therapy (CST), a 'treatment' stimulating the mind and emphasising the individual that is repeatedly evidenced to be slowing down the magnitude of disease in dementia (see Spector et al., 2003). In the NHS trust this study has recruited from alone, the number of CST groups offered to participants has increased fourfold in the last two years. In 'valuing professionals', the participants certainly were not valuing CST (five quotations from separate participants: "it's a waste of space"; "oh I spent the afternoon throwing a ball (laughs)"; "I mean god, I could be at home doing ma' knitting"; "CST was like being at playgroup, the children love it so why shouldn't we"). Sabat & Harré (1993), Cheston & Bender, (1999) and Parker (1995) have argued the PCM has dominated the minds of service providers and health and social contexts. The idea that cognitive improvement can occur through person centred rehabilitation programmes is founded on the argument that dementia is linked to complex structures in the brain, built upon a whole episteme of promoting science and the humans sciences. As we have seen alternative social actors to PCM are often restrained by 'the will to speak'.

Nonetheless, Glynos, Speed & West, (2015) from a post-structuralist discourse perspective, discuss the radical reform of the NHS between 2010 and 2013. This reform is highly relevant here, as Cognitive Stimulation Therapy groups and early identification and thus management of dementia may be seen as 'cost effective' products of

organisational and economic restructuring, replacing individual therapy or institutionalisation with substitute ways to regulate PWDD and their spouses, amongst other groups. The NHS reform was Politically proposed to be related to pragmatic concerns about the market logic and the need for competition and profit to avoid fragmentation of the NHS (Glynos, Speed & West, 2015). Many opposing arguments about the threat to welfarism and democratic values, among others, were marginalised and the reform continued with its objectives intact. To very roughly summarise, the current coalition were able to use the idea of integration to accelerate privatization, competition and market based principles in the NHS (Glynos, Speed & West, 2015). This discourse study is helpful in relation to Dementia practice which may be thought of as based on Political interests, pragmatic concerns and social actor's positions, contingent upon discourses. It is a way of enabling research, policy and political movements that challenge this.

In addition, as depicted in the introduction, the biomedical discourse on dementia was shown to not really take presence until the 1970s, when differentiated subtypes of dementia were increasingly proliferated and tools of measurement became more established. This shows that dementia has not always been a hegemonic discourse and is open to 'reshaping' once again. Particularly in 'making a case', several participants drew upon aspects of this argument, recalling how dementia had not always been construed as a 'truth' and/or a social problem in their lifetime. This is fitting with the conceptual analysis in the genealogy where dementia was perhaps conceptualised medically as delirium, or in almshouses as 'infirmness'. Foucault (1980) indicated that resistance and freedom can be more effective from those groups of people, 'dementia subjects' who have encountered power relations associated with dementia. "There are no relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised; resistance...exists all the more by being in the same place as power" (Foucault, 1980; p.142). Thus, not only research and political movements may challenge dominant dementia discourses, people with dementia and their spouses may also do this.

In the discourse 'making a case' participants questioned the behavioural symptoms of the diagnostic construct and the few/limited symptoms they had, juxtaposed with the very broad group of dementia patients they fell amongst through labelling. In the extract below, regarding counter discourses, Foucault (1991) discusses how rules are essentially empty signifiers, and their meaning/representation can be reshaped. For

PWDD enacting the discourse 'making a case' they reversed the meaning of the DSM/dementia diagnoses, reformed this, and used this to reject the ideology of science and the BMM of dementia.

“Rules are empty in themselves, violent and unfinalised; they are impersonal and can be bent to any purpose. The successes of history belong to those who are capable of seizing those rules, to replace those who had used them, to disguise themselves so as to pervert them, invert their meaning, and redirect them against those who had initially imposed them so as to overcome the rules” (Foucault, 1991; p.151).

The arguments made may be considered as an exchange of knowledge too, through streams of psychiatry, social workers, doctors, researchers, who have also problematised dementia. The discourse 'making a case' appears to be a re-articulation of academic arguments, through privileged points of intersection, one being the university:

“The university and the academic emerge, if not as principal elements, at least as 'exchangers,' privileged points of intersection... the multiplication and reinforcement of [universities] power effects as centres in a polymorphous ensemble of intellectuals who virtually all pass through and relate themselves to the academic system” (Foucault, 1977; as cited in Tallack, 2014, p.74).

On a final note, returning to hegemony, given that when discourses successfully become hegemonic, the social practices they structure can appear so natural that members of a society fail to see that they are the result of political hegemonic practices; one intervention may then be to make this more apparent to the social groups. One example here is perhaps non-medically organized peer groups for PWDD/spouses (as opposed to biomedical based CST groups). Counter-hegemonic practices may occur naturally through every day talk and practices working to challenge and transform existing discourses, or they may be deliberate and strategic through interest groups as a struggle for discursive dominance (Grant et al, 1998). In peer groups, many participants may critique their diagnosis regarding their own or their spouse's case (e.g. “he was put on drugs, five miligrams to start with, but her had some awful nightmares”). In medically structured therapeutic interventions, one can imagine there is little scope to share and

convene these adversities produced via the biomedical and psy disciplines, whereas in a peer based interest group outside of these setting, alternative social actors may deliberate wider issues such as the pharmaceutical industry and fear evoked by dementia working to dismantle the discourse. This may be organized by community-based projects and drivers as opposed to clinic based drivers. It may be centered on a critical movement away from the dominant and politically governed biomedical paradigm of dementia.

In terms of policy, Robertson (1990) argues, we need to be moving away from individualised solutions, national policies ought to be addressing structural factors, fragmented often diagnostic (though not much beyond this point) service measures. The main thrust of these interventions has been to create and fund professional agencies and organisations to monitor and manage older adults, literally and figuratively making ‘dementia’ everyone’s business (as we have seen with spouses without dementia). Robertson (1990) also states so much goes in to talking about the needs of older adults through professionals, that money does not go on older adult’s needs. Professionals, are benefiting from and proliferating these individualised notions, “colluding in the wittingly or unwittingly creation of this structural dependence” (Robertson, 1990; p.439).

Perhaps there is room for targeting this at a professional level too? Bender (2013), publishing in the Division of Clinical Psychology, may be one example of this and this may facilitate those at the site of power professionally to question their engagement with mainstream practices. *Is it helpful to be encouraging masses of older adults through memory clinics and testing them? What are the benefits of early diagnosis if ‘treatments’ are so absent? Has psychology been caught up in the will to know themselves in not fully comprehending pharmacological workings? Can we think more creatively, outside of the clinic or CST groups?*

This research highlights a complex network of groups and relations, and considers ways of offering opportunities for resistance. For instance, applying post structuralist discourse theory and discourse theory to present the discursive fields of formation and their potential for change and contestation, as well as exploring the scope for influencing policy, professionals and community non-medical projects that may shape critical stance towards dementia discourse and allow for more flexible and varying speaking positions. It also illustrates how power is not negative it can also be a necessary and productive force in society (Gaventa, 2003):

“The interventions are going on, and power seeps through various crisscrossing capillaries in the social body: heterogeneous networks of actors and technologies; new fields of knowledge like social sciences, economy, management or the sociology of governance; old micro-fields of power and expertise that are being connected in new ways” (Catoï, 2011, p.111).

4.09 Conclusion & Critical Reflections

This research has contributed to a generally under-researched field. It began by problematising dementia as an increasingly prevalent disease that may result in societal catastrophe and a depletion of its resources. Beginning with a genealogical enquiry, some of the contingent moments where certain dementia related discourses were examined. In this process, caution was taken regarding ‘empowerment’ movements towards people with dementia and informal carers as these could implicitly control and regulate them. Analysis of NICE (2006) guidelines for people with dementia, their carers and professionals, and dementia-focused leaflets from memory assessment clinics supported the analysis of currently functioning dementia talk; as well as fourteen interviews with PWDD and spouses (separate and joint). Data was analysed from a FDA perspective and related discourse theory, revealing competing and conflicting discourses, as well as deviances and resistances.

Among the most thought-provoking findings, marriage was seen to compliment the political apparatus of the BMM of dementia; it was deemed to be a natural sphere for care acts and constructed dependency in dementia. Similarly, spouses and PWDD were found to perform certain acts, enacting dominant discourses, ensuing self-governance and/or professional inscription. This was argued to be a political economic rationality of neo-liberal governmentality. One example of this was where spouses controlled acts of aggression; this was construed as an alignment with professional codes of relating.

This enquiry attended to marital friction/bidirectionality that may be consequential of subject positions spouses and PWDD enacted and rejected. To illustrate, where spouses were seen to monitor and correct PWDD, PWDD were understood to ‘answer back,’ and vice versa. It was discussed that seemingly fixed subject positions (informal carer) were not the most conducive for PWDD and their spouses.

Also, this thesis explored different theoretical orientations to complement and contest the Foucauldian perspective taken to analyse the results: in particular, theory concerning gender and dementia ‘identities.’ The appraisal of theory, plus the difficulty

of how we may support new discursive horizons and acts concerning dementia has been considered.

Critical reflections are embedded throughout this thesis, though particularly in the discussion chapter. What has not yet been mentioned is the consideration over the inclusion/exclusion in the genealogy, and the decision to account for breadth rather than depth (e.g. BMM, PCM, carers and marriage are each critical enquiries in their own rights). It is proposed that a more focused enquiry, with a smaller time frame (e.g. 1990's-2016) and fewer topics (e.g. carer's, dementia) would be valuable to the field. In the genealogy, little attention was given to the separate subcategories of dementia; arguably this is an important distinction to make. The first rationale was to avoid the positivist frame of categorisations: second, where most genealogical enquiries have focused on Alzheimer's disease, this enquiry offered something novel.

Given limited space and time, it is acknowledged that perhaps not enough attention was given to the nuances of politics influencing discourses (e.g. political movements such as Thatcherism and the turn to marketisation, Blair and the turn to communitarianism and social inclusion). Originally ambitions were to include recent house of parliament discussions, and party speeches on dementia, which, during the 2015 general election, unsurprisingly was a topical issue. This would have offered interesting discussion and insights, particularly applying PSDT. This is perhaps another opportunity for a discourse analysis.

An interesting Foucauldian enquiry to old age by Biggs and Powell (2001) lends itself to some discussion on Politics concerning social welfare, and rather than the hybrid of industries, it focuses specifically on social work. Nonetheless, it is argued that the researchers background in clinical psychology has facilitated discussions on the tools and treatments deployed relating to this discipline too.

Problems with the methodology, as indicated previously were that at times Foucault's work ensues a relativist standpoint to understanding discourse²⁰. In the complete rejection of realism there is no way of knowing whether something has any level of truth or not. As such, the researcher did choose to interpret and speculate concerning the meaning of discourses and the arrangement of signs within them through an inductive and two-part process of analysis; recommendations were also made.

At times the methodological approach created points of tension, for example in how best to describe sub-discourses (later explained as elements using PSDT). Where the researcher did draw upon PSDT, this was with limited acquaintance to the different

schools of thought of more contemporary discourse theories and so their complexity may have been overlooked. The researcher engaged with critiques that Foucauldian study of discourse, from some angles, can be seen to belong more to a meso or macro-level than to a micro-level (Jaeger, 2007). As such, in the discussion new theoretical insights were deliberated (e.g. regarding emotions and psychoanalytic theory).

A common ‘buzz term’ used in the field of qualitative research is objectivity/applicability and scientific rigor, yet this is argued that these terms are social constructions and applying them is discernibly an attempt to fit the method toward the dominant scientific paradigm. Nonetheless, the use of original sources of data in the genealogy, the sample size, the mixed method (joint/separate interviews), excerpts from documents and interviews in the results chapter, on some level align with these constructions of quality. In addition, the researcher made efforts to ensure critical reflexivity (i.e. keeping a field diary, developing an audit trail, having supervision when deriving the discourses) and undertook a comprehensive course on discourse theory to support the method. The study findings are not necessarily repeatable and do not make claims to be, but they are applicable to people accessing memory assessment clinics currently.

This research was conducted through the NHS as opposed to a community-based sample. This was in order to seek people who had encountered the psy’s, who had a probable diagnosis of dementia. It was also to support ethical research (e.g. the interviews to be conducted in a clinical environment with a sound risk protocol to support the likelihood for emotive responses or disclosure of risks). Nonetheless, PWDD and spouses outside of this setting may have presented very different findings, with potentially more or less resistance to mainstream practices surrounding dementia; the analysis of documents, although modest, perhaps supports applicability of finding to other groups/contexts.

On the occasions where potential participants who had not wanted to partake in the study contacted the researcher, they were asked why this was. The reasons were health difficulties, being a private person and adverse experiences of the NHS in the diagnosis phase. The researcher may conclude that these findings have applicability to the people accessing ‘treatment’ in the trust the study recruited from – some indication of scope for service provisions and policy that has been mentioned. Efforts will be made to circulate these findings to the NHS trust and participants who have specifically requested publications.

Where this study has made interpretations, it is acknowledged that another researcher, with different cultural experiences and theoretical assumptions would have no doubt made different interpretations (Burman & Parker, 1993). This study recognises that it is a construction in itself and is not an absolute truth. The critique of ‘neutrality’ and ‘unbiased’ research within the field of qualitative research has been a source of influence here.

One reason interview analyses from a Foucauldian perspective are absent in the field of dementia, although some genealogical analysis *have* been completed, is perhaps interview analyses can be reproached for being artificial or co-produced with the researcher. Fixed positions maybe co-produced through the context of a research interview, discussed further below.

Where interview analysis has been adopted by other discourse related methods this may be critiqued for psychologising (e.g. Potter & Wetherell, 1987). Willig (2013) has informed against analysing very personal accounts from a discourse perspective for ethical reasons, claiming that accounts from, in this case PWDD and their spouses, were provided in good faith and the interviewer, is not necessarily interested in the spouses’ experiences as it is not focal to the analysis. Foucault’s approach however arguably focuses on discursive resources available to participants while viewing them as potentially ‘powerful’ subjects constructed and constituted through discourse.

Critical Reflexivity. Throughout this thesis, the researcher has engaged reflexively. For instance, how the researcher’s beliefs, assumptions and knowledge, might influence the research findings have been studied. The researcher was aware of the circular processes in research involving power and knowledge, whereby the questions, interpretations and conclusions drawn within research can define and sculpt patterns of interaction and further research. Regarding the latter, Biggs and Powell (2001) discuss an example regarding ‘quality of life’ particularly apt concerning dementia research: research studies on ‘quality of life’ have had a spiralling effect, generating more and more research on this topic, alongside power for professionals, while reinforcing the importance concept ‘quality of life’. This demonstrates how the questions researchers ask have a direct link to the data they collect.

One example of reflexive practise in this research was concerning gender identity – this has become a highly politicised issue (Burman, 1998). In the data, the pattern of silence regarding marriage discourse amongst female participants was deemed to be

interesting by the researcher. It was deliberated whether this may relate to subject positions female participants had previously enacted and/or continued to enact. For instance, participants had discussed that in the past females had tended to reside at home with the children whilst males went to work. Here, the researcher considered how interpretations drawn regarding this could reify predefined gender roles. By emphasising or problematizing how women were silent in the interview, it might further abstract or sculpt the position of 'the silent female'. The researcher also considered the modern cultural viewpoint perhaps influencing her interpretations of the findings; that is, supporting the liberation of females, while inherently assuming marginalisation or oppression. Similarly, where the inclusion/exclusion criteria were used to recruit marital partners, the researcher considered her role in pre-constructing gendered subject positions prior to the interviews commencing, again predefining or influencing findings.

Working with these issues, the researcher listed the research findings (i.e. the pattern of silence amongst female participants), though, was also open with the reader about the dilemmas, questions and potential pitfalls encountered (e.g. on page 119 the researcher questions, "how does one describe this without feminist notions of identity oppression?" and discussed this accordingly). Additionally, to guide the researcher, new theoretical understandings, such as post-structuralist feminist theory, were introduced into the discussion. This supported some written debate regarding gender identity, and allowed the researcher to consider this topic carefully. Although only one example is illustrated here, other examples requiring critical reflexive practice could equally be discussed here.

To assist reflexive practice more generally, the researcher attempted to maintain a social-historical view regarding, the use of social categories, and understandings emerging and changing, rather than an essentialist viewpoint. The researcher also considered language and interaction within wider social and political contexts and systems, rather than on individual level. A field diary was kept to support a critical engagement concerning the researchers assumptions (appendix A). Lastly, regular supervision with supervisors invited other viewpoints when developing findings.

Personal Reflections. In this thesis, the ethics of the analysis and the write up of the results was an obstacle I faced. Hearing the emotional grapples and experiences of participants (e.g. thoughts of suicide in one case, see method) I naturally wanted to both support and honor these personal experiences. One example of this is shown in the results

chapter (3.06 ‘knowing best’) where I reframe a participant’s difficulty forgetting short term issues, though not long term, as potentially adaptive, on a rare occasion stepping outside of the research frame as faced with this personal tension. Many participants asked my advice about their condition during interviews, I was often positioned as an ‘expert’ with ‘the will to speak’ depicted in the data (e.g. ‘the biomedical truth of dementia’ and ‘valuing professionals’). My attempts to resist this position in line with research guidance (e.g. BPS, 2009) at times felt as if I was being unfair to participants. Reluctance was also taken in writing this thesis concerning issues relating to spouses as the informal carer: I would question ‘*can I really say this?*’ I was aware the potential to dismiss spouse’s efforts and kinship; as well as physical and cognitive changes involved in dementia. Given that my grandmother and grandfather are also faced with dementia in their marriage, in which I hold huge regard and admiration for them, as well as my role as a clinical psychologist in training, where I have worked closely with adults of an older age, and professionals and organisation’s who make genuine efforts to support PWDD/spouses, this pressure was exacerbated. On the other hand, this position has motivated and determined me to ‘step outside’ of the data towards a meso/macro level approach. I deliberated over the possibility of completing a project critiquing psychological and psychiatric regulating practices towards this client group. As such, I made use of my training, my reading and supervision to contribute a potentially useful and controversial study to the field of dementia. As Foucault (1965) states:

‘My role, and that is too empathic a word, is to show people that they are much freer than they feel, that people accept as truth, as evidence, some themes that have been built up at a certain moment during history, and this so called evidence can be criticized and destroyed’ (p.10).

Through the process of conducting this research I have been cautiously critical of the ‘healing’ discipline I am associated with and its power/knowledge relations. I will continue to question ‘taken for granted assumptions’ and endeavor to contribute further critical discourse research to the field.

References

- Acierno, R., Hernandez, M. A., Amstadter, A. B., Resnick, H. S., Steve, K., Muzzy, W., & Kilpatrick, D. G. (2010). Prevalence and Correlates of Emotional, Physical, Sexual, and Financial Abuse and Potential Neglect in the United States: The National Elder Mistreatment Study. *American Journal of Public Health, 100*(2), 292–297. <http://doi.org/10.2105/AJPH.2009.163089>
- Aguirre, E., Spector, A., Streater, A., Burnell, K., & Orrell, M. (2011). Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia, 10*(4), 459–473. <http://doi.org/10.1177/1471301211417170>
- Alexandra Hernandez-Tejada, M., Amstadter, A., Muzzy, W., & Acierno, R. (2013). The National Elder Mistreatment Study: Race and Ethnicity Findings. *Journal of Elder Abuse & Neglect, 25*(4), 281–293. <http://doi.org/10.1080/08946566.2013.770305>
- Alzheimer, A., Förstl, H., & Levy, R. (1991). On certain peculiar diseases of old age. *History of Psychiatry, 2*(5 Pt 1), 71–101.
- Alzheimer's Society. (2013). Worried about your memory? "I remember that day as clear as can be... but it's a struggle to recall what I did in the morning." *Alzheimer's Society*.
- Alzheimer's Society. (2014). Dementia UK: Second Edition Update. Retrieved May 22, 2016, from https://www.researchgate.net/publication/270904426_Dementia_UK_up
- Alzheimer's Society. (2016a). Affected by dementia? We're here to help: If you're affected by dementia or worried about your memory call the Alzheimer's Society. *Alzheimer's Society*.

- Alzheimer's Society. (2016b). Drugs used to relieve psychological and behavioural symptoms in dementia. *Alzheimers Society*.
- American Psychiatric Association. (2003). Mild Neurocognitive Disorder. Retrieved January 1, 2016, from <http://www.dsm5.org/Documents/Mild%20Neurocognitive%20Disorder%20Fact%20Sheet.pdf>
- American Psychiatric Association (Ed.). (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5. ed). Washington, DC: American Psychiatric Publ.
- American Psychiatric Association, & Committee on Nomenclature and Statistics. (2008). *Diagnostic and statistical manual, mental disorders*.
- Aquilina, C., & Hughs, J. (2006). The return of the living dead: agency lost and found? In J. C. Hughes, S. J. Louw, & S. R. Sabat (Eds.), *Dementia: mind, meaning, and the person*. Oxford ; New York: Oxford University Press.
- Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry, 19*(2), 151–169. <http://doi.org/10.1002/gps.1050>
- Barbin, H. (1980). *Herculine Barbin: being the recently discovered memoirs of a nineteenth-century French hermaphrodite*. New York, NY: Pantheon Books.
- Barer, M. L., Evans, R. G., Hertzman, C., & Lomas, J. (1987). Aging and health care utilization: New evidence on old fallacies. *Social Science & Medicine, 24*(10), 851–862. [http://doi.org/10.1016/0277-9536\(87\)90186-9](http://doi.org/10.1016/0277-9536(87)90186-9)
- Beard, R. L. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies, 18*(4), 415–428. <http://doi.org/10.1016/j.jaging.2004.06.005>

- Beard, R. L., Sakhtah, S., Imse, V., & Galvin, J. E. (2012). Negotiating the Joint Career: Couples Adapting to Alzheimer's and Aging in Place. *Journal of Aging Research*, 2012, 1–12. <http://doi.org/10.1155/2012/797023>
- Beck, U. (1992). Risk society: towards new modernity (trans. Mark Ritter). In *Theory, culture and society* (p. 271). London: Sage Publications.
- Beck, U., & Beck-Gernsheim, E. (2002). *Individualization: institutionalized individualism and its social and political consequences*. London ; Thousand Oaks, Calif: SAGE.
- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31(01), 70–92. <http://doi.org/10.1017/S0144686X10000693>
- Bender, M. (2014, January). [Review of *The ethics of complicity?: clinical psychologists and the contemporary "dementia" narrative*, by Division of Clinical Psychology], *Ethics Column*(253), 52–56.
- Berrios, G. E. (1981a). Delirium and confusion in the 19th century: a conceptual history. *The British Journal of Psychiatry*, 139(5), 439–449. <http://doi.org/10.1192/bjp.139.5.439>
- Berrios, G. E. (1981b). Stupor: a conceptual history. *Psychological Medicine*, 11(04), 677. <http://doi.org/10.1017/S0033291700041179>
- Berrios, G. E. (1987). Dementia during the seventeenth and eighteenth centuries: a conceptual history. *Psychological Medicine*, 17(04), 829. <http://doi.org/10.1017/S0033291700000623>
- Berrios, G. E. (1992). V.A. Kral and senescent forgetfulness: an affair to remember. *European Neuropsychopharmacology*, 2(3), 253. [http://doi.org/10.1016/0924-977X\(92\)90095-P](http://doi.org/10.1016/0924-977X(92)90095-P)

- Berrios, G. E., & Hauser, R. (1988). The early development of Kraepelin's ideas on classification: a conceptual history. *Psychological Medicine, 18*(04), 813.
<http://doi.org/10.1017/S0033291700009740>
- Berrios, G. E., & Porter, R. (1998). *A history of clinical psychiatry: The origin and history of psychiatric disorders*. (Vol. 31). London: Athlone Press.
- Biggs, S., & Powell, J. L. (2001). A Foucauldian Analysis of Old Age and the Power of Social Welfare. *Journal of Aging & Social Policy, 12*(2), 93–112.
http://doi.org/10.1300/J031v12n02_06
- Billig, M., Condor, S., Edwards, D., Gane, M., Middleton, D., & Radley, A. (Eds.). (1988). *Ideological dilemmas: a social psychology of everyday thinking*. London ; Newbury Park: Sage Publications.
- Breakwell, G., Smith, J. A., & Wright, D. B. (2012). *Research Methods in Psychology*. Retrieved from https://nls.ldls.org.uk/welcome.html?ark:/81055/vdc_100025509529.0x000001
- British Association for Applied Linguistics, & Clark, R. (Eds.). (1990). *Language and power: papers from the Twenty-Second Annual Meeting of the British Association for Applied Linguistics, held at Lancaster University, September 1989*. London: Centre for Information on Language Teaching and Research for British Association for Applied Linguistics.
- British Psychological Society. (2009). Code of ethics and conduct. Retrieved January 1, 2016, from http://www.bps.org.uk/system/files/documents/code_of_ethics_and_conduct.pdf
- British Psychological Society. (2014). Code of human research ethics. Retrieved January 1, 2016, from

http://www.bps.org.uk/system/files/Public%20files/code_of_human_research_ethics_dec_2014_inf180_web.pdf

Brown, L. (1994). *Subversive Dialogues: Theory in Feminist Therapy* (First). London: Basic Books.

Brunet. (2013). Screening and early diagnosis., *21*(3), 22–24.

Bulmer, M., Bales, K., & Sklar, K. K. (Eds.). (1991). *The Social survey in historical perspective, 1880-1940*. Cambridge ; New York: Cambridge University Press.

Burman, E. (1998). *Deconstructing Feminist Psychology* (first). London: Sage Publications.

Burman, E., & Parker, I. (1993). *Discourse analytic research: repertoires and readings of texts in action*. London; New York: Routledge.

Burr, V. (2003). *Social constructionism*. London; New York: Routledge.

Canguilhem, G. (1988). *Ideology and rationality in the history of the life sciences*. Cambridge, Mass: MIT Press.

Carabine, J. (2001). Constituting sexuality through social policy: the case of lone motherhood 1834 and today, *10*(3), 291–314.

Cheston, R., & Bender, M. (1999). *Understanding dementia: the man with the worried eyes*. London ; Philadelphia: J. Kingsley Publishers.

Chouliaraki, L., & Fairclough, N. (2007). *Discourse in late modernity: rethinking critical discourse analysis* (Transferred to digital printing). Edinburgh: Edinburgh Univ. Press.

Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The Experience of Living With Dementia in Residential Care: An Interpretative Phenomenological Analysis. *The Gerontologist*, *48*(6), 711–720.

<http://doi.org/10.1093/geront/48.6.711>

- Cloud, D. L. (2001). Laboring under the Sign of the New: Cultural Studies, Organizational Communication, and the Fallacy of the New Economy. *Management Communication Quarterly*, *15*(2), 268–278.
<http://doi.org/10.1177/0893318901152006>
- Cotoi, C. (2011). Neoliberalism: a Foucauldian perspective, *1*(2), 109–124.
- Craib, I. (1997). Social Constructionism as a Social Psychosis. *Sociology*, *31*(1), 1–15.
<http://doi.org/10.1177/0038038597031001002>
- D’Amico, F., Rehill, A., Knapp, M., Aguirre, E., Donovan, H., Hoare, Z., ... Orrell, M. (2015). Maintenance Cognitive Stimulation Therapy: An Economic Evaluation Within a Randomized Controlled Trial. *Journal of the American Medical Directors Association*, *16*(1), 63–70. <http://doi.org/10.1016/j.jamda.2014.10.020>
- Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and Alzheimer’s disease: One couple’s story. *Families, Systems, & Health*, *25*(2), 162–177. <http://doi.org/10.1037/1091-7527.25.2.162>
- Davis, D. H. . (2004). Dementia: sociological and philosophical constructions. *Social Science & Medicine*, *58*(2), 369–378. [http://doi.org/10.1016/S0277-9536\(03\)00202-8](http://doi.org/10.1016/S0277-9536(03)00202-8)
- Department for Constitutional Affairs (Ed.). (2007). *Mental Capacity Act 2005: Code of Practice* (2007 final ed.). London: TSO.
- Department of Health (2007). *Putting People First: A shared vision and commitment to the transformation of adult social care*. Retrieved March 3, 2016, from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

Department of Health (2008). *High quality care for all – NHS next stage review*.

Retrieved March 3, 2016, from

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf

Department of Health (2009a). *Dignity in Care Campaign*. Retrieved March 3, 2016,

from

http://www.dignityincare.org.uk/_library/Opinion_Leader_Final_Report_to_DH.doc.pdf

Department of Health. (2009b). *Living well with dementia: A National Dementia Strategy*

(Social Care/Partnership Working No. 11198). Retrieved from

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

Department of Health. (2016a). The Prime Minister's challenge on dementia 2020.

Retrieved April 20, 2016, from

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf

Department of Health. (2016b, January). Policy paper: Joint declaration on post-

diagnostic dementia care and support. Retrieved March 3, 2016, from

<https://www.gov.uk/government/publications/dementia-post-diagnostic-care-and-support/dementia-post-diagnostic-care-and-support>

Dolar, D. (1999). Where does power come from? *New Formations*, (35), 79-92.

Donzelot, J., & Hurley, R. (1997). *The policing of families* (John Hopkins paperbacks ed).

Baltimore: Johns Hopkins University Press.

- Drachman, D. A. (1974). Human Memory and the Cholinergic System: A Relationship to Aging? *Archives of Neurology*, 30(2), 113.
<http://doi.org/10.1001/archneur.1974.00490320001001>
- Dreyfus, H. L., Rabinow, P., & Foucault, M. (1983). *Michel Foucault, beyond structuralism and hermeneutics* (2nd ed). Chicago: University of Chicago Press.
- Fanon, F. (2008). *Black skin, white masks* (New ed). London: Pluto-Press.
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., ... Scazufca, M. (2005). Global prevalence of dementia: a Delphi consensus study. *The Lancet*, 366(9503), 2112–2117. [http://doi.org/10.1016/S0140-6736\(05\)67889-0](http://doi.org/10.1016/S0140-6736(05)67889-0)
- Foucault, M. (1965). *Madness and Civilization: A history of insanity through the age of reason* (first). London ; New York: Pantheon Books.
- Foucault, M. (1991). *Discipline and punish: the birth of the prison* (Reprint). London: Penguin Books.
- Foucault, M. (2010). *The birth of the clinic: an archaeology of medical perception* (1. publ., reprinted). London: Routledge.
- Foucault, M., Burchell, G., Gordon, C., & Miller, P. (Eds.). (1991). *The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault*. Chicago: University of Chicago Press.
- Foucault, M., & Hurley, R. (1998). *The will to knowledge* (Amended reprint). London: Penguin Books.
- Foucault, M., Martin, L. H., Gutman, H., & Hutton, P. H. (Eds.). (1988). *Technologies of the self: a seminar with Michel Foucault*. Amherst: University of Massachusetts Press.

- Foucault, M., Rabinow, P., & Hurley, R. (1997). *The essential works of Michel Foucault, 1954-1984*. London: Allen Lane.
- Foucault, M., & Smith, A. M. S. (2002). *Archaeology of knowledge*. London: Routledge.
- Fox, P. (1989). From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement. *The Milbank Quarterly*, 67(1), 58.
<http://doi.org/10.2307/3350070>
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266–275. <http://doi.org/10.1037/0003-066X.40.3.266>
- Glendinning, S. (2011). *Derrida: a very short introduction*. Oxford ; New York: Oxford University Press.
- Glynos, J., Speed, E., & West, K. (2015). Logics of marginalisation in health and social care reform: Integration, choice, and provider-blind provision. *Critical Social Policy*, 35(1), 45–68. <http://doi.org/10.1177/0261018314545599>
- Greenhalgh, T. (1997). How to read a paper. Papers that report diagnostic or screening tests. *BMJ (Clinical Research Ed.)*, 315(7107), 540–543.
- Grosz, E. A. (1994). *Volatile bodies: toward a corporeal feminism*. St. Leonards, NSW: Allen & Unwin.
- Hacking, I. (1996). Memory sciences, memory politics. In P. Antze & M. Lambek (Eds.), *Tense past: cultural essays in trauma and memory* (pp. 67–85). New York: Routledge.
- Harper, S., & Speed, E. (2012). Uncovering Recovery: The Resistible Rise of Recovery and Resilience, 6(1), 9–25.
- Haraway, D. J. (1997). *Modest witness: Feminism and technoscience*. London: Psychology Press.

- Harwood, R. H. (2012). Dementia for hospital physicians. *Clinical Medicine*, 12(1), 35–39. <http://doi.org/10.7861/clinmedicine.12-1-35>
- Hellstrom, I. (2005). “We do things together”: A case study of “couplehood” in dementia. *Dementia*, 4(1), 7–22. <http://doi.org/10.1177/1471301205049188>
- Hellstrom, I., Nolan, M., & Lundh, U. (2007). Sustaining ‘couplehood’: Spouses’ strategies for living positively with dementia. *Dementia*, 6(3), 383–409. <http://doi.org/10.1177/1471301207081571>
- Hook, D. (2010). *Foucault, psychology and the analytics of power*. Basingstoke: Palgrave Macmillan.
- House of Parliament. (2010). The ageing population: Key issues for the 2010 Parliament. Retrieved May 22, 2016, from <http://www.parliament.uk/business/publications/research/key-issues-for-the-new-parliament/value-for-money-in-public-services/the-ageing-population/>
- House of Parliament. (2015). Key issues for the new Parliament 2015. Retrieved May 22, 2016, from <http://www.parliament.uk/business/publications/research/key-issues-parliament-2015/>
- Howarth, D. R. (2000). *Discourse*. Buckingham [England] ; Philadelphia, PA: Open University Press.
- Huppert, F. A., Brayne, C., & O’Connor, D. W. (Eds.). (1994). *Dementia and normal aging*. Cambridge ; New York, NY, USA: Cambridge University Press.
- Ishizaki, J., Meguro, K., Ohe, K., Kimura, E., Tsuchiya, E., Ishii, H., ... Yamadori, A. (2002). Therapeutic Psychosocial Intervention for Elderly Subjects With Very Mild Alzheimer Disease in a Community: The Tajiri Project: *Alzheimer Disease & Associated Disorders*, 16(4), 261–269. <http://doi.org/10.1097/00002093-200210000-00008>

Jaeger, H.-M. (2007). "Global Civil Society" and the Political Depoliticization of Global Governance. *International Political Sociology*, 1(3), 257–277.

<http://doi.org/10.1111/j.1749-5687.2007.00017.x>

Jaspers, K. (1910). Eifersuchtswahn: Ein Beitrag zur Frage: Entwicklung einer Persönlichkeit oder Prozeß? *Zeitschrift für die gesamte Neurologie und Psychiatrie*, 1(1), 567–637. <http://doi.org/10.1007/BF02895947>

Jewson, N. D. (2009). The disappearance of the sick-man from medical cosmology, 1770-1870. *International Journal of Epidemiology*, 38(3), 622–633.

<http://doi.org/10.1093/ije/dyp180>

Katz, S. (1996). *Disciplining old age: the formation of gerontological knowledge*. Charlottesville: University Press of Virginia.

Katz, S. (2012). Embodied memory: aging, neuroculture, and the genealogy of mind., (4(31)), 1–14.

Kerlinger, F. N. (1973). *Foundations of behavioral research* (2d ed). New York: Holt, Rinehart and Winston.

Kitwood, T. M. (1997). *Dementia reconsidered: the person comes first*. Buckingham [England] ; Philadelphia: Open University Press.

Klein, A., Tobin, T., Salomon, A., & Dubois, J. (2008). *A Statewide Profile of Abuse of Older Women and the Criminal Justice Response* (The National Institute of Justice (NIJ) funded No. 222459) (p. 93). US: Department of Justice. Retrieved from <https://www.ncjrs.gov/pdffiles1/nij/grants/222459.pdf>

Kraepelin, E. (2002). *Clinical psychiatry : a textbook for students and physicians, abstracted and adapted from the 7th German edition of Kraepelin's Lehrbuch der Psychiatrie, (electronic resource)*. EBSCOhost & Diefendorf, A. R. 1871-1943.

Lacan, J., & Sheridan, A. (2001). *Écrits: a selection*. London: Routledge.

- Laclau, E., & Mouffe, C. (2014). *Hegemony and socialist strategy: towards a radical democratic politics*. London; New York: Verso.
- Locke, J. (1995). *An essay concerning human understanding*. Amherst, N.Y: Prometheus Books.
- Lowe, F. (2007). Colonial Object Relations: Going Underground Black-White Relationships. *British Journal of Psychotherapy*, 24(1), 20–33.
<http://doi.org/10.1111/j.1752-0118.2007.00061.x>
- Maurer, K., & Maurer, U. (2003). *Alzheimer: the life of a physician and the career of a disease*. New York: Columbia University Press.
- McCosker, H., Barnard, A., & Gerber, R. (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All Participants, 2(1).
- Mid Staffordshire NHS Foundation Trust, Great Britain, Parliament, & House of Commons. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London: Stationery Office.
- Millen, N., & Walker, C. (2001). Overcoming the stigma of chronic illness: strategies for normalisation of a “spoiled identity.” *Health Sociology Review*, 10(2), 89–97.
<http://doi.org/10.5172/hesr.2001.10.2.89>
- Miller, P., & Rose, N. S. (2013). *Governing the present: administering economic, social and personal life* (Nachdr.). Cambridge: Polity Press.
- Moser, I. (2008). Making Alzheimer’s disease matter. Enacting, interfering and doing politics of nature. *Geoforum*, 39(1), 98–110.
<http://doi.org/10.1016/j.geoforum.2006.12.007>
- Mouffe, C. (Ed.). (2008). *Art as a public issue: how art and its institutions reinvent the public dimension*. Rotterdam: NAI Publ. [u.a.].

- Myles, J. F. (1983). Conflict, Crisis, and the Future of Old Age Security. *The Milbank Memorial Fund Quarterly. Health and Society*, 61(3), 462.
<http://doi.org/10.2307/3349868>
- National Dignity Council. (2016). Dignity in Care Campaign. Retrieved March 3, 2016, from http://www.dignityincare.org.uk/About/Dignity_in_Care_campaign/
- Neno, R., & Neno, M. (2005). Identifying abuse in older people. *Nursing Standard*, 20(3), 43–47. <http://doi.org/10.7748/ns2005.09.20.3.43.c3964>
- NHS England. (2014). *Data Protection Policy* (pp. 1–12). NHS England. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2013/06/dpa-policy-1.pdf>
- NICE. (2006). Dementia: supporting people with dementia and their carers in health and social care. Retrieved January 4, 2016, from <https://www.nice.org.uk/guidance/cg42/chapter/Introduction>
- Office of the Public Guardian. (2013, June). Lasting Power of Attorney. Retrieved January 1, 2016, from <https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney>
- O’Keeffe, M. (2007). *UK study of abuse and neglect of older people: prevalence survey report* (Government Publication). UK: London : National Centre for Social Research.
- Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., ... Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *The British Journal of Psychiatry*, 204(6), 454–461. <http://doi.org/10.1192/bjp.bp.113.137414>
- Panu, M. (2009). *Contextualizing family planning: truth, subject, and the other in the U.S. government*. New York, NY: Palgrave Macmillan.

- Parker, I. (2014). *Discourse dynamics: critical analysis for social and individual psychology*. Retrieved from <http://alltitles.ebrary.com/Doc?id=10832506>
- Parker, I., & Gordo-López, Á. J. (Eds.). (1999). *Cyberpsychology*. New York: Routledge.
- Parker, J. (2005). Constructing Dementia and Dementia Care: Daily Practices in a Day Care Setting. *Journal of Social Work, 5*(3), 261–278.
<http://doi.org/10.1177/1468017305058935>
- Parker, R. G., & Aggleton, P. (Eds.). (2007). *Culture, society and sexuality: a reader* (Second Edition). London ; New York: Routledge, Taylor & Francis Group.
- Poole NHS Foundation Trust. (2013). Hospital price list 2013/2014. Retrieved April 3, 2016, from
https://www.poole.nhs.uk/pdf/Poole%20Hospital%20Private%20Patient%20Prices%202013_14%20IS.pdf
- Porter, R. (2010). *Madness: a brief history* (Nachdr.). Oxford: Univ. Press.
- Poster, M., & Laclau, E. (Eds.). (1993). Power and representation. In *Politics, theory, and contemporary culture*. New York: Columbia University Press.
- Potter, J., & Wetherell, M. (1987). Rawlinson's Three Axes of Structural Analysis: A useful framework for a Foucauldian Discourse Analysis. *Aporia, 5*(1), 6-12.
- Powers, P. (2013). *Discourse and social psychology: beyond attitudes and behaviour*. London ; Newbury Park, Calif: Sage Publications.
- Public Health England. (2013). Free NHS health check: helping you prevent heart disease, stroke, diabetes, kidney disease, and dementia. *Public Health England Publications*.
- Rawlinson, M. C. (1987). Foucault's Strategy: Knowledge, Power, and the Specificity of Truth. *Journal of Medicine and Philosophy, 12*(4), 371–395.
<http://doi.org/10.1093/jmp/12.4.371>

- Richardson, J. T. E., Richardson, J. T. E., Potter, J., & Wiggins, S. (1996). Discursive psychology. In *Handbook of qualitative research methods for psychology and the social sciences* (pp. 73–90). Leicester: British Psychological Society.
- Riggins, S. H., & Van Dijk, T. A. (Eds.). (1997). Political discourse and racism. In *The language and politics of exclusion: others in discourse* (pp. 33–64). Thousand Oaks, Calif: Sage Publications.
- Rinker, A. G. (2009). Recognition and perception of elder abuse by prehospital and hospital-based care providers. *Archives of Gerontology and Geriatrics*, 48(1), 110–115. <http://doi.org/10.1016/j.archger.2007.11.002>
- Robertson, A. (1990). The Policies of Alzheimer's Disease: A Case Study in Apocalyptic Demography. *International Journal of Health Services*, 20(3), 429–442. <http://doi.org/10.2190/C8AE-NYC1-2R98-MHP1>
- Roos, N. P., & Shapiro, E. (1981). The Manitoba longitudinal study on aging: Preliminary findings on health care utilization by the elderly., 644–657.
- Rose. (2007). Psychology as a social science. Presented at the BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society, Department of Sociology: London School of Economics and Political Science.
- Rose, N. (1985). *The psychological complex: psychology, politics and society in England ; 1869 - 1939*. London: Routledge & Paul.
- Rose, N. (1998). *Inventing our selves: psychology, power and personhood* (1. paperback ed). Cambridge: Cambridge Univ. Press.
- Sabat, S. R., & Harré, R. (Eds.). (1993). The construction and deconstruction of self in Alzheimer's Disease. *The British Journal of Social Work*, 23(4), 416–418.
- Said, E., & Foucault, M. (1974). An Ethics of Language. *Diacritics*, 4(2), 28. <http://doi.org/10.2307/464989>

- Saussure, F. de, Bally, C., Sechehaye, A., & Riedlinger, A. (1986). *Course in general linguistics*. LaSalle, Ill: Open Court.
- Schneider, D. J. (2005). *The psychology of stereotyping* (Paperback ed). New York: Guilford Press.
- Scoville, W., & Milner, B. (1957). Loss of recent memory after bilateral hippocampal lesions, (20 (1)), 11–21.
- Silva, E. B., Roseneil, S., & Mann, K. (Eds.). (1996). Unpalatable Choices and Inadequate Families: Lone Mothers and the Underclass Debate. In *Good enough mothering?: feminist perspectives on lone motherhood* (pp. 191–210). London ; New York: Routledge.
- Sontag, S. (1989). *AIDS and its metaphors*. London: Penguin Books.
- Spector, A., Davies, S., Woods, B., & Orrell, M. (2000). Reality orientation for dementia: a systematic review of the evidence of effectiveness from randomized controlled trials. *The Gerontologist*, 40(2), 206–212.
- Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *The British Journal of Psychiatry*, 183(3), 248–254. <http://doi.org/10.1192/bjp.183.3.248>
- Steeman, E., de Casterle, B. D., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: a review of qualitative studies. *Journal of Advanced Nursing*, 54(6), 722–738. <http://doi.org/10.1111/j.1365-2648.2006.03874.x>
- Strauss, G. (1968). Human Relations—1968 Style. *Industrial Relations*, 7(3), 262–276. <http://doi.org/10.1111/j.1468-232X.1968.tb01080.x>
- Streater, A., Spector, A., Aguirre, E., Hoe, J., Hoare, Z., Woods, R., ... Orrell, M. (2012). Maintenance Cognitive Stimulation Therapy (CST) in practice: study protocol for

- a randomized controlled trial. *Trials*, 13(1), 91. <http://doi.org/10.1186/1745-6215-13-91>
- Svanstrom, R. (2004). Living with Dementia Yields a Heteronomous and Lost Existence. *Western Journal of Nursing Research*, 26(6), 671–687. <http://doi.org/10.1177/0193945904265920>
- Tamboukou, M., & Ball, S. J. (2003). Genealogy and ethnography: Fruitful encounters or dangerous liaisons. *Dangerous encounters.*, (17), 1–36.
- Tanggaard, L. (2007). The Research Interview as Discourses Crossing Swords: The Researcher and Apprentice on Crossing Roads. *Qualitative Inquiry*, 13(1), 160–176. <http://doi.org/10.1177/1077800406294948>
- Thane, P., & Filby, L. (Eds.). (2010). *Unequal Britain: equalities in Britain since 1945*. London ; New York: Continuum.
- The Guardian, a. (2016, February 18). Unpaid carers can't keep on plugging gaps in the NHS and social care: More people need care than get it, and the gap is growing. Support for family carers is vital. *The Guardian*. Retrieved from <http://www.theguardian.com/social-care-network/2016/feb/18/unpaid-carers-gaps-nhs-social-care-act>
- The Stationary Office. (2014). The Care Act: Chapter 23. Retrieved January 1, 2016, from <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>
- The World Health Organisation. (2012). WHO member states disease and injury regional mortality estimates, 2000–2012. Retrieved May 22, 2016, from http://www.who.int/healthinfo/global_burden_disease/estimates/en/index1.html
- Torfiing, J. (1999). *New theories of discourse: Laclau, Mouffe, and Žižek*. Oxford, UK ; Malden, Mass: Blackwell Publishers.

- Tarrant, J. P. (2011). The Contemporary Family and its Representations. In J. P. Tarrant (Ed.), *The Material Family* (pp. 1–32). Rotterdam: SensePublishers. Retrieved from http://www.springerlink.com/index/10.1007/978-94-6091-630-4_1
- Turner, B. S. (1987). *Medical power and social knowledge*. London ; Beverly Hills: Sage Publications.
- Van der Flier, W. M. (2005). Epidemiology and risk factors of dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 76(suppl_5), v2–v7.
<http://doi.org/10.1136/jnnp.2005.082867>
- Willig, C. (2013). *Introducing qualitative research in psychology* (3. ed). Maidenhead: Open Univ. Press.
- World Health Organisation. (2006). Neurological disorders: a public health approach. Retrieved May 22, 2016, from http://www.who.int/mental_health/neurology/chapter_3_a_neuro_disorders_public_h_challenges.pdf
- Wu, Y.-T., Fratiglioni, L., Matthews, F. E., Lobo, A., Breteler, M. M. B., Skoog, I., & Brayne, C. (2016). Dementia in western Europe: epidemiological evidence and implications for policy making. *The Lancet Neurology*, 15(1), 116–124.
[http://doi.org/10.1016/S1474-4422\(15\)00092-7](http://doi.org/10.1016/S1474-4422(15)00092-7)
- Young, R., & Foucault, M. (Eds.). (1981). Part One. The Order of Discourse (Chapter 3). In *Untying the text: a post-structuralist reader* (pp. 48–79). Boston: Routledge & Kegan Paul.
- Žižek, S. (2008). *The sublime object of ideology* (Nachdr.). London: Verso.

End Notes

- ¹ To elaborate on discourse, Foucault's definition and study of discourse may be thought of as an attempt to restore materiality and power to what "...has remained the largely linguistic concept of discourse" (Hook, 2001; p.522). For instance, Foucault (1981) states "in every society the production of discourse is at once controlled, selected, organised and redistributed by a...number of procedures" (p. 52). Foucault's definition of discourse may be thought of as containing a micro and macro level which interact relationally to one another. The micro concerns, "the finest capillary levels of power" that is "at more precise localised levels, usually institutional interfaces" e.g. memory assessment clinics may be a good example (Hook, 2007; pp. 63-64). The macro, "systematized vehicles of thought" or knowledge, which are "over determined" and complimentary to producing and generating power-effects for organisational, commercial, government, and medico-therapeutic settings (Hook, 2007, p. 65-67).
- ² For those aged sixty-five, one in fourteen are diagnosed with dementia; for those aged eighty, one in six are diagnosed with dementia. See, Alzheimer's Society. Dementia UK: Update (PDF Download Available). (2014). Retrieved May 22, 2016, from https://www.researchgate.net/publication/270904426_Dementia_UK_up
- ³ The analysis in this thesis has in no way intended to ignore distress experienced by people with diagnoses of dementia (from here onwards referred to as PWDD) or their marital partners; or to dismiss professional or social organisations efforts to alleviate distress; it is a contribution towards supporting these efforts from an alternative angle.
- ⁴ Berrios (1981a; 1981b; 1987; 1992) work is not written or understood from Foucauldian discourse perspective, and is adapted for this genealogy/thesis. His works are argued to be particularly useful and thorough given the multiple translations from different languages and sources, which would go far and beyond the scope of this thesis with time restraints. Berrios (1981a; 1981b; 1987; 1992) does not account for the power and knowledge relations involved in psychiatry as a political discipline. He also argues demence is a stable concept that readily maps onto

contemporary understandings of dementia, whereas, the opposite has been argued in this thesis (Berrios, 1987).

- ⁵ A description and a critique of ontology can be found in Levinas's (1998) essay, *Is Ontology Fundamental?* Levinas described the philosophical foundations of ontology, which have given the notion a fundamental place in revealing the disclosedness or opening of being in relation to dominant horizons of being (e.g. Heidegger). Nonetheless, Levinas (1998) epistemologically critiques how understanding 'being' is a way of being at the same time, which has become dominant in certain schools of thinking, perception, knowledge and language.
- ⁶ Other policies not mentioned in relation to the role of the informal carer applicable to the context of dementia, may include: *Putting People First: A shared vision and commitment to the transformation of adult social care* (Department of Health, 2007). *High quality care for all – NHS next stage review*, (Department of Health, 2008). *Dignity in Care Campaign* (Department of Health, 2009a).
- ⁶ The concept of the 'baby boom' has been used to describe a boost in birth rate after the Second World War in predominantly western countries and the America. This was between the 1940s and 1960s. This is also sometimes understood as a time when there was a rejection of more traditional family values (e.g. Panu, 2009). Those diagnosed with dementia in 2016 between ages sixty and eighty may be born within or around this time frame, and may be described as baby boomers.
- ⁷ It is important to note that this is not to present counter-discourses as being more or less correct than other, whereby falling into a liberal frame of freedom, choice and progression, it is rather to highlight that there is complex web of competing discourses that have been taken up by subjects in a particular social contexts.
- ⁸ Divorce rates rose dramatically from the 1960s to a peak of 14.2 per 1,000 married people but declined slightly to 12.9 per 1,000 in 1998 (Office for National Statistics, 2000).
- ⁹ The use of the term constructivism and constructionism can be seen to be used interchangeably by different researchers in the field; where some people may define constructivism as being separate from social constructionism, the former being more interested in how human beings make sense of social phenomena and thus, create social phenomena (it incorporates more of the individual level), for others like Burr (2003) the terms are more tightly linked.

-
- ¹⁰ Discourse, as defined by Foucault, refers to: ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations which inhere in such knowledge's and relations between them (Hook, 2010). Discourses are more than ways of thinking and producing meaning.
- ¹¹ Rawlinson (1987) also helpfully clarifies a genealogy: “[It] reveals that the epistemological and the political, knowledge and power, are ineluctably intertwined, so that truth is not so much discovered – as if it lay ready made in an objective reality patiently awaiting to articulate the voice of science – as produced according to regular and identifiable procedures that determine in any given historical situation what it is possible to say, who is authorised to speak, what can become of an object of scientific enquiry, and how knowledge is to be tested, accumulated and dispersed” (p.372).
- ¹² Behuniak (2011) uses films is analysed from a discourse perspective however is not strictly a genealogical analysis. The illustration is to highlight that genealogies do not just include policies or written forms of data.
- ¹³ Although an oversimplification, Foucault's early work focused on how historical, cultural, organizational factors are interrelated with dominant or prevailing discourses (e.g. exploring madness and medicine). He illustrates ‘the episteme’ referring to particular periods of thought. For instance, after the Enlightenment, there became a ‘category of man’ and an arrangement of disciplinary technologies as discussed that was a shift in thought. Foucault's later work may be thought of as a more intricate problematizing of the complex relationship between of power and knowledge, as well as a turn towards individual subjectivity ability for resistance (see Howarth, 2000; Hook, 2007). Nonetheless, some authors contest this and state Foucault was always concerned with subjectivity and there is not such a distinct divide as often depicted (e.g. see, Cook, 1993).
- ¹⁴ For a concise overview of critiques on Foucault's work see Kelly, M. G. (2010). *The political philosophy of Michel Foucault*. Routledge (pp. 124-148).
- ¹⁵ Matrimony may be thought of as being strongest for a particular generation. Figures (Office for National Statistics, 2012) present marriage was highest amongst adults above the age of sixtyfive. Where people are living longer, the rate of those married over aged sixty-five increased by approximately 25% between 2011-12.

Divorce was more common in those aged 20-40 years. Age UK presented that in 2012 among men in their late 60s, 3,520 remarried and among women 1,990 remarried (in relation to widowing of a prior spouse though in few cases divorce). This presents the tradition and discourse surrounding marriage is important for this generation of older adults.

- ¹⁷ Simon (2005) depicts a similar account relating to the other: “Not only does the panoptic machine make one visible but it also hides the operations (the motives, practices and ethics) of the supposed viewer, to know one is being seen without being able to see carries with it an uncertainty that becomes a source of anxiety, discomfort and terror... Who is watching? Why are they watching? What will they do?” (p.5)
- ¹⁸ The expansion of the diagnostic criteria (e.g. between 1952 and 1994 respectively the *Diagnostic Statistical Manual (DSM)* grew from 130 to 886 pages, and diagnostic categories tripled (Blashenfield & Fuller, 1996).
- ¹⁹ ‘The Birth of Biopolitics’, a course delivered by Foucault on this subject, was translated in English only in 2008. This is probably one of the reasons why two of the most powerful contemporary accounts of neoliberalism are more recently formulated (e.g. Rose, 2006). Prior to this work Harvey (*) discussed the 1970s and Fordism – the pact among nation state, corporate capitalism based on mass production, consumption and democracy – and post-Fordism, characterized the emergence of entirely new sectors of production, new ways of providing financial services, new markets, and, above all, intensified commercial, technological, and organizational innovation, giving rise to a vast surge in employment and entirely new industrial groups.
- ²⁰ Foucault does direct clear critique towards medicine, human sciences and psychiatry.