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GPS, STIGMA AND THE TIMELY DIAGNOSIS OF DEMENTIA:

A QUALITATIVE EXPLORATION

The implications of general practitioners' perceptions of dementia as a stigma for timely diagnosis.

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Abstract

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GPs, stigma and the timely diagnosis of dementia: a qualitative exploration

Key words: general practitioners, lay people, perceptions, dementia, stigma, conceptualization, contributing factors and timely diagnosis.

Background

The focus of this study is on how far GPs' perceptions of dementia map onto the components and contributing factors to stigma as described by Link and Phelan (2001; 2006) and Jones et al. (1984).

Aim

The study explores GPs' perceptions of dementia as a stigma, develops a specific conceptualization of the stigma of dementia and considers implications for timely diagnosis.

Methods

Data from twenty-three GPs in northern England were collected by semi-structured telephone interviews. Within the context of a qualitative design, a combined process of grounded theory and framework analysis was adopted to collect and analyse data.

Results

The findings reveal that GPs' perceptions of dementia map onto Link and Phelan and Jones' identification of contributing factors and components of stigma and may hinder timely diagnosis. Three themes emerged reflecting a dynamic process of making sense of dementia, relating perceptions to oneself and considering the consequences of dementia. Within those themes, certain categories had particular salience for GPs, namely the characteristics of the attribute, existential anxiety and discrimination. The themes and categories are inter-related and can be considered as parts of a system. Perceived lack of reciprocity could be detected in most categories which suggests that it is influential in the social construction of the stigma of dementia.

Conclusion

The data suggest that current conceptualizations of stigma are insufficient to fully account for the stigma of dementia. A specific conceptualization of the stigma of dementia is proposed and the implications of GPs' perceptions for timely diagnosis are discussed.

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1. Introduction

1.1 Background to the report

This document is an account of research carried out in the field of dementia for the purpose of submitting an application for a PhD. It explores GPs' perceptions of dementia and how they relate to stigma within the context of timely diagnosis.

The topic was chosen in 2008 when a gap in the literature on timely diagnosis and stigma was detected and my curiosity awakened. However, the design of the study gradually developed throughout the duration of the PhD study. The final result is a qualitative study involving telephone interviews which explores GPs' perceptions of dementia.

1.2 Personal statement

This study was carried out after several years working in the field of dementia on a range of projects covering legal, ethical, social and care issues within a European umbrella organization of national Alzheimer associations based in Luxembourg. The selected topic reflects, in addition to a perceived gap in the literature, an interest in all forms of social injustice towards individuals and groups. Such issues had been the focus of prior study into eating disorders, gender and disability within the context of education and psychoanalysis. Direct and frequent contact with people with dementia, carers, researchers and a range of healthcare professionals has been possible through joint work on various projects. Nevertheless, contact with GPs has been fairly limited.

I have had no personal experience of dementia despite having had several relatives who lived well into their 80s and one to 109. I may have approached the research question and findings from a White/British female perspective (as well as other aspects of my background and biography). However, living out of England for many years has given me a certain distance and perhaps objectivity combined with an experience of being in an “out group” and experiencing cultural diversity.

1.3 Contribution to the field

This study contributes towards the field of research into the stigma of dementia in five ways. Firstly, it is the first study, to explore GPs’ perceptions of dementia within a broad framework of stigma theory with a sample of GPs from the UK. There is a growing awareness of the need to overcome stigma and thereby improve the timely diagnosis of dementia, and of the important role that GPs play in achieving this. However, whilst there has been considerable research into how lay people perceive dementia as a stigma, only one study has explored GPs’ perceptions of dementia insofar as they relate to stigma. It was a quantitative study, set in Israel and guided by attribution theory, which is quite limited in scope.

Secondly, this study contributes to understanding the diversity of meanings associated with dementia by GPs in the UK. GPs are difficult to recruit for research and, in addition, few studies have involved many GPs from minority ethnic groups. However, there is a high percentage of GPs in the UK who identify with ethnic minority groups. In seeking to be inclusive and to cover a diverse range of perceptions of dementia held by GPs, this is one of the few studies to have explored the perceptions of dementia of GPs from ethnic minority groups.

Thirdly, this study contributes to the development of a specific conceptualization of the stigma of dementia. Studies and debates about stigma have focused on generic conceptualizations of stigma and considered them as applicable to dementia. This study uses such conceptualizations as a starting point and framework for exploration. However, it is the first study to go one step further in testing the appropriateness of current conceptualizations of stigma for dementia and determining what is specific about the stigma of dementia.

Fourthly, this is the first study to systematically explore the perceptions of dementia of GPs in their professional capacity but also as fellow citizens who may eventually develop dementia. In some studies, it is not clear whether GPs' perceptions of dementia as a stigma reflect their own thoughts and feelings or merely describe those they believe other people to have. This study goes beyond discussions about how stigma is perceived as a societal problem and how other people's perception of dementia as a stigma might interfere with timely diagnosis. It brings the issue much closer to home. This study explored GPs' perceptions of dementia from the perspective of a healthcare professional with medical knowledge and a certain professional distance from the subject but also as someone who can imagine one day having dementia and sitting at the other side of the table in the patient's chair. This was in addition to exploring their understanding of stigma within society.

Finally, this study is unique in that it explores how GPs' perceptions of dementia as a stigma lead to delays in timely diagnosis. Previous studies have neglected how GPs' perceptions of dementia relate to stigma and there is therefore a lack of detailed information about how perceiving dementia as a stigma interferes with timely diagnosis.

1.4 Dementia

1.4.1 Definition and types of dementia

"Dementia" is the term used to describe a syndrome or set of symptoms with multiple aetiology, typically involving loss of memory, mood changes and problems with problems with thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (Crutch and McCulloch, 2012). It is an umbrella term which describes the symptoms, usually of a chronic or progressive nature, which occur when the brain is damaged as a result of one or more illnesses (World Health Organization, 2012). The ICD-10[1] definition of dementia is one of the two most commonly used classifications systems for diagnosing dementia (the other being the DSM-IV[2]). According to the ICD-10, for a diagnosis of dementia to be made, the memory and intellectual impairments must be sufficient in nature to cause significant social and occupational impairment and not occur solely during a state of delirium (Grabowski and Damasio, 2004).

The term dementia stems from the Latin word "demens" which means "out of one's mind" or "without mind". It is likely that the term dementia will soon be replaced by "major neurodegenerative disorder" in the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric

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[1] The International Statistical Classification of Diseases and Health Related Problems (10th revision) of the World Health Organization.

[2] The fourth version of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association.

Association (2012). There are over one hundred specific forms of dementia, the most common being Alzheimer’s disease (AD), which accounts for approximately a half of all people diagnosed (Longley and Warner, 2002, Milne, 2010, Naue and Kroll, 2008), followed by vascular dementia (with or without Alzheimer features) and dementia with Lewy bodies (Iliffe et al., 2009).

1.4.2 How people are affected by dementia

People do not all experience dementia in the same way. Physical as well as behavioural and psychological difficulties may occur. Difficulties carrying out everyday tasks may result in people with dementia becoming increasingly dependent on others. However, the symptoms and the way that a person is affected by dementia are also influenced by personal factors, coping skills, the way that society is organized and the way people with dementia are treated, in addition to neurological impairment (Brody et al., 1971; Kitwood, 1993). This reflects the biopsychosocial definition of disability of the World Health Organization (WHO) which emphasizes the interaction between health conditions and contextual dimensions (which include environmental and personal factors) (WHO, 2002).

WHO uses the umbrella term disabilities to refer to impairments, activity limitations and participation restrictions. They specify, “An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations” (WHO, 2011). Whilst this might be typically associated with physical impairments and learning difficulties (which are frequently stigmatized conditions), many people experience dementia as a disability. On a more personal level, dementia can also be considered a communication disability which has consequences for care, social interaction and quality of life (Hubbard, Downs and Tester, 2003; Murphy et al., 2005).

1.4.3 Number of people affected

Recent estimates of the number of people with dementia in the world are 35.6 million in 2010, which is set to rise to 65.7 million by 2030 and to 115.4 million by 2050 (Prince and Jackson, 2009; WHO, 2012). Approximately 7.3 million people in Europe (EU-27) are estimated to have dementia and the number of people with dementia in Western Europe is expected to double by 2040 (European Commission, 2009; Ferri et al., 2005). The incidence of dementia is expected to rise from 9.9 million to 13.95 million by 2030 which represents an increase of 40% (Pinto Atunes, 2011).

Dementia will affect a growing number of people as the population ages and is now considered as a major public health issue (WHO, 2012). Life expectancy for women in Europe was 82.1 in 2008 and it is estimated that it will increase to 89 by 2060. The figures for men are 70 and 84.5 respectively (Pinto Antunes, 2011). The number of people over the age of 80 is set to rise dramatically (Knapp et al., 2007). It is estimated, for example, that in OECD countries the population aged over 80 will at least double, representing an increase from 4% to 10% of the total population (Colombo and Mercier, 2011). The ageing population has implications for the number of people with dementia. Younger people can have dementia but this is comparatively rare (Knapp and Prince, 2007; WHO, 2012) as age is the most significant risk factor for dementia (Frölich, 2008).

1.4.4 The cost of dementia

The total world-wide cost of dementia has been estimated at USD 604 billion (WHO, 2012). The total cost of dementia in 2008 in the EU-27 was estimated at EUR 160 billion (EUR 22,194 per person with dementia). 56% of this cost was attributed to informal care (Wimo et al., 2009). In the United Kingdom, the number of people with dementia is estimated to be 683,597 and the cost of care and support to be GBP 17.03 billion per year, with an average cost of GBP 25,472 per person with late onset dementia per year (Knapp and Prince, 2007). This is expected to increase to 1.4 million people and three times the cost within the next 30 years (Goodchild, 2009).

Dementia is amongst the top six disorders constituting 13% of the global burden of disease in the world (more than cardiovascular disease and cancer) (WHO, 2004). In high income countries, it ranks second to the top for disability adjusted life years (DALY) (Collins et al., 2011).

1.5 Government response to dementia

Governments across the world have responded to the challenge posed by the growing number of people with dementia in different ways, for example by changing the long-term care insurance system in Korea, defining service priorities in Canada, challenging the normalization of dementia as part of ageing in Hong Kong and China and raising awareness of the care environment in Japan (Burns, 2010). Countries with national dementia strategies and plans, such as England, Scotland, Wales, the Netherlands, Denmark, Finland and Norway have covered a wide range of issues such as research, social support, training and timely diagnosis. Others such as Cyprus, the Czech Republic, Jersey, Portugal and Malta are currently negotiating such plans (Alzheimer Europe, 2012a). Many of these plans emphasize early diagnosis as a top priority.

1.6 Timely diagnosis and the possible role of stigma

Nevertheless, despite the graying of the population and with it, an ever increasing number of people with dementia, diagnosis rates remain low. It is estimated that only about one third of people with dementia receive a diagnosis (Banerjee et al., 2007). In the foreword to the Prime Minister's challenge on dementia, David Cameron states that as many as half of all people with dementia in England are unaware that they have dementia (Department of Health, 2012). Dementia is increasingly being recognised as a stigma at the policy level (Alzheimer's Society, 2008; Department of Health, 2009; European Commission, 2009). The European Commission has highlighted a lack of awareness of the importance of prevention and early intervention throughout the EU and acknowledged that the stigma associated with dementia could influence the health of people with dementia (European Commission, 2009). The European Commission (2009) identified the above-mentioned issues as being amongst those that Community action should help address through joint action between the European Commission and the Member States within the Second Health Programme (2008-2013).

At the national level, it is stated in the English National Dementia Strategy that dementia-related stigma must be addressed in order to reduce social exclusion and discrimination, increase public awareness of the benefits of timely diagnosis and encourage appropriate help-seeking behaviour (Department of Health, 2009). Throughout Europe, national governments agree on the need to tackle the stigma of dementia and to improve timely diagnosis. Furthermore, a multi-disciplinary group consisting of 23 healthcare professionals from 8 countries concluded:

> *"The hesitancy and delay surrounding timely recognition is prominent in all EU states and specialist services in themselves are not enough to overcome this. Stigma associated with dementia by professionals seems to be the most powerful influential factor." (Vernooij-Dassen et al., 2005, p.384)*

Additional research is needed in order to determine in what way stigma influences timely diagnosis but first, a greater depth of understanding is needed into whether and if so how healthcare professionals perceive dementia as a stigma. GPs play a key role in the timely identification and subsequent management of dementia (Downs, 1996) and are often the first port of call when people have concerns about dementia. Yet we know little about their perceptions of dementia and how they relate to stigma. They should be the starting point for such an investigation and have been chosen as the focus of this research. In the next two sections of chapter 1, the structure of the thesis will be explained and brief details about the literature review provided. The procedure for the literature review is described in detail in section 2.2.

1.7 Structure of the thesis

The thesis is organized into the following chapters:

Chapter 1 has provided initial background information about the importance of timely diagnosis and recognition by governments of how stigma interferes with timely diagnosis and of the need to address the perceptions of stigma held by healthcare professionals.

Chapter 2 provides an overview of what stigma is (covering components and contributing factors, theories and empirical studies), with examples of long-term health conditions used as illustration.

Chapter 3 describes how people perceive dementia and it is argued that the perceptions that lay people and healthcare professionals (including GPs) have of dementia relate to the components of, and contributing factors to, stigma.

Chapter 4 explores barriers perceived by GPs as interfering with the timeliness of the diagnosis of dementia. Gaps in the literature are then discussed. The key argument of this chapter is that whilst it has been found that stigma may be a barrier to timely diagnosis, very little research has explored how GPs' perceptions of dementia relate to stigma, their understanding of stigma amongst their patients and their views on how stigma might affect timely diagnosis. Chapter 4 concludes by arguing that there is a need for an exploratory study on this topic.

Chapter 5 contains the epistemological paradigm and the methodology.

Chapter 6 provides a detailed explanation of the study's methods and procedure, including details of the sampling procedure. The sample, the recruitment process, data collection, data analysis, and the trustworthiness of the data are considered.

Chapter 7 presents the key results of the study. The findings are presented in the context of the research questions and the aims of the study. The chapter has four parts. Quotations from the participants are used to illustrate the points being made.

Chapter 8 provides a summary of the key findings and discusses the relevance of the findings, reflecting on how they relate to existing literature and theory, and the relevance and implications of the findings for practice, policy and future research.

Figure 1 below shows the topics covered and the relationship between them. This is an overview of the organization of the thesis and not of the research process. Starting at the top left, the reader progresses from the identification of the problem (i.e. Chapter 1) to an explanation of what stigma is (chapter 2). Chapter 3 follows on from this general explanation, covering the perceptions of lay people, including family carers and healthcare professionals, as well as those of GPs. Chapter 4 addresses the issue of barriers to diagnosis and the role of stigma in delaying timely diagnosis, whereas chapters 5 and 6 on methodology and methods explain how this study can fill the gap in knowledge identified through the literature review and the resulting research questions. The findings are presented in chapter 7. These are then related to the literature and to the original questions in chapter 8, concluding with a presentation of the practical, policy and research implications for strategies to address stigma and improve timely diagnosis, as well as two concluding hypotheses which summarize these implications and point towards possible future research.

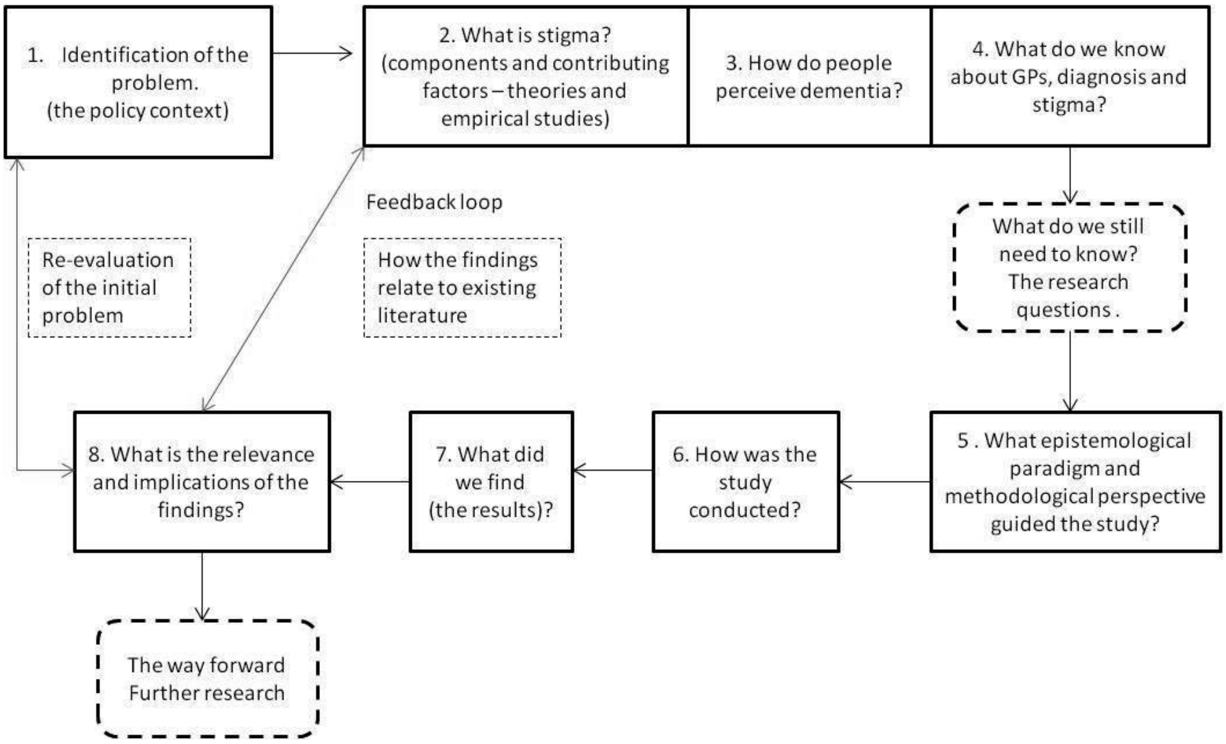

Figure 1: Overview of the thesis

1.8 The literature review adopted

An integrative method was used to review the literature on stigma in general and on the stigma of dementia (Whittemore and Knafl, 2005). An integrative review is comprised of a general literature review and a systematic review of empirical research. Integrative reviews involve more than one method and have the advantage of covering both theoretical and empirical literature, as well as a wide range of purposes such as the definition of concepts, a review of theories and a review of supporting evidence (Whittemore and Knafl, 2005). According to Broome (1993), this can lead to a more comprehensive understanding of a particular phenomenon.

A two-pronged approach was used to review the literature. This consisted of a first general exploration of the topic in order to find out how stigma has been conceptualized and measured in other long-term health conditions, thereby contributing towards the choice of an appropriate theoretical framework for the study. The scope of the literature review was then narrowed down in order to review literature on the specific topic of perceptions of dementia as a stigma and barriers to timely diagnosis, as this is the focus of this study.

The aims of the literature review were:

1. to present an overview of the development and current state of thinking on stigma in general, and in relation to the main components of, and contributing factors to, stigma, supported by examples of literature from a range of long-term conditions (box 2 in Figure 1);
2. to examine the literature on perceptions of dementia amongst lay people and healthcare professionals insofar as it relates to the components and contributing factors of stigma examined in the previous sub-section (box 3 in Figure 1);
3. to examine the literature on practice, barriers and the attitudes of GPs to the timely diagnosis of dementia (box 4 in Figure 1).

The term “lay people” is used in this thesis to refer to people who have no specialized knowledge of dementia and other medical conditions, in the sense of medical training. This term is preferred to “general public” as healthcare professionals could be considered as a sub-group of the general public. The use of the term lay people and healthcare professionals enables two distinct categories to be made, which is reflected in the structure of chapter 3. However, depending on the studies described in the review, a variety of terms may be used as different researchers have different ways of describing the participants in their studies. Researchers may also differ in the terms they use to describe their sample. People having taken part in a study will nevertheless be referred to as participants throughout the thesis.

1.9 Summary

Dementia has become a key priority for governments across Europe, particularly with regard to the need for timely diagnosis. The graying of the population will bring with it a considerable increase in the number of people with dementia. There is international agreement about the need to provide support and treatment and it is universally acknowledged that diagnosis is the first step towards treatment. Dementia must be diagnosed in a timely manner and stigma is believed to interfere with timely diagnosis.

1.10 Conclusion

Timely diagnosis is increasingly being recognized as important to quality of life. Now more than ever, governments are committed to tackling stigma and improving timely diagnosis. Data is available which suggests that the stigma of dementia may lead to delays in people presenting for diagnosis. However, little is known about GPs' perceptions of dementia and how they might relate to stigma. GPs play a vital role in the detection and diagnosis of dementia and measures to improve detection and diagnosis are often focused on them without taking into account their perceptions of dementia. In addition, stigma is a complex social phenomenon and it is possible that different people are using the term “stigma” in different ways. If stigma is to be tackled as part of the measures to improve timely diagnosis, it is important to be clear about what we mean by “stigma” and to understand how GPs' perceptions of dementia relate to stigma. These issues are addressed in this study.

2 Stigma

This chapter will provide a brief overview of the development and current meaning of the term stigma (and its derivatives and associated terms). This will be followed by a description of how the integrative literature review was carried out and how this led to the adoption of the theoretical framework for this study. The theoretical framework, which is divided into two parts (namely, components and contributing factors), will then be described and examples of studies provided to support the points being made.

2.1 Background to stigma

The term “stigma” has been used to refer to a mark imposed by various means (e.g. by cutting, burning, pricking or tattooing) to signify something bad or unusual about the person bearing the mark (Falk, 2001; Goffman, 1963). In ancient Greece, for example, the mark was imposed on slaves and prisoners by means of a tattoo which was obtained by pricking the skin with a sharp instrument (“stig” being the ancient Greek word for “to prick”) (Falk, 2001). Goffman (1963, p.11) states that this sign “advertised that the bearer was a slave, a criminal or a traitor - a blemished person, ritually polluted, to be avoided especially in public places”.

Weiss and Ramakrishna (2004) claim that branding was also a common punishment in the seventeenth century aimed at disgracing the individuals concerned. They further suggest that stigma was not considered a social problem but rather, a legitimate form of social control.

Early psychological and sociological work on stigma concentrated on visible marks such as physical deformities and disfigurement which had occurred naturally (e.g. hereditary or as a result of an accident or medical condition) rather than which had been deliberately imposed. Goffman (1963) moved the study of stigma to a wider range of attributes, including a range of visible and non-visible medical conditions that a person may be born with or acquire in the course of his/her life. He also introduced the concept of people being discredited (having a differentness which is already known about or visible) or discreditable (having a stigma which is not immediately apparent).

Researchers in the field of HIV/AIDS further emphasized the role of power, domination and subordination (Parker and Aggleton, 2003), as well as "structural violence", based on social forces such as racism, sexism and poverty, which may exacerbate stigmatizing conditions (Mahajan et al., 2008).

The work of Jones et al. (1984) and of Link and Phelan (2001; 2006) was also influential in highlighting factors which contribute towards stigma and which are necessary components of stigma. These are discussed in detail in sections 2.3 and 2.4.

Stigma is a <u>complex social phenomenon</u>. It is complex in that it occurs at every level of society. It is a collective, intergroup and cultural phenomenon with affective, cognitive and behavioural dimensions (i.e. covering feelings, thoughts and actions) (Dovidio et al., 2003).

Stigma is also a <u>social process</u>, whether public or private, which is part of this complex social phenomenon. Public stigma is a social process involving the identification of people sharing a socially salient group difference who are subsequently devalued and discriminated against, either overtly or covertly

(Farina et al., 1966; Link, 2009). Private stigma, on the other hand, is the process by which the stigmatized person or group internalizes the perceived stigmatizing attitudes of others and experiences or anticipates discrimination (Rüsch et al., 2005; Thornicroft et al., 2009). The latter is not addressed in this thesis as it is closely linked to how people with dementia experience stigma and not on the perceptions of dementia that lay people and healthcare professionals might have, which might interfere with timely diagnosis. Stigmatization involves an interaction between cognitive, affective and behavioural components, with the primacy of any of the three being dependent on the situation, the nature of the stigma and the people involved (Dovidio et al., 2003). This suggests the need to explore each with regard to specific stigmas rather than to stigma in general and to be attentive to possible cultural differences.

Stigma is also the term used to refer to the attribute which is deeply discrediting in that it reduces someone in other people's minds from a "whole and usual person to a tainted, discounted one" (Goffman, 1963, p12). The attribute is not stigmatizing in itself but may become so depending on the meanings people attach to it (i.e. it is socially constructed). Jones et al. (1984) preferred the term "mark" to that of "attribute".

> *"Mark is thus our generic term for perceived or inferred conditions of deviation from a prototype or norm that might initiate the stigmatizing process."* (Jones et al., 1984, p.8)

Stigma is socially constructed by all members of society and, as such, is culturally determined. Different people in different situations, geographical areas and eras are influenced by different factors in constructing the attribute (or mark) as a stigma. These include political, economic, cultural, religious and educational factors, amongst others. Consequently, not all shared attributes will become stigmas and the same attribute may become a stigma in one country or culture and not in another depending on the meanings attached to it. When trying to understand stigma, it is therefore important to consider the meanings that people attach to attributes and not to focus on the attributes *per se*.

In order to understand how stigma applies to dementia, it is necessary to consider in more detail how stigma has been conceptualized and then to determine in what way this conceptualization can be usefully applied to the stigma of dementia. This contributes towards the process of choosing a theoretical framework to guide this study, which necessitated a broad literature review in order to determine what is already known about stigma and which theories might be most relevant to this study. This was achieved by means of an integrative review of the literature on stigma which is described below.

2.2 The procedure for the integrative review

KEY SEARCH TERMS USED:

- Stigma, discrimination, labelling, stereotype, social distance, prejudice and attitude.
- Schizophrenia, leprosy, mental disorder and AIDS

The first phase of the integrative review of stigma focuses on the concept of stigma and on stigma in long-term health conditions (including mental health conditions) other than dementia. Schizophrenia, leprosy and AIDS (Acquired Immune Deficiency Syndrome) were selected as key search terms as they represent long-term conditions with different aetiologies, which are manifested in different ways. The first two have a long history of being considered as stigmas. In the case of leprosy, references to the social alienation of people with leprosy date back thousands of years (Gillen, 2007; Harrison, 1986; Jones et al., 1984). AIDS, on the other hand, is more recent. Research was also considered involving groups of related conditions such as “mental disorder” which covered bipolar disorder and depression in addition to schizophrenia, and pandemics such as Severe Acute Respiratory Syndrome (SARS) and tuberculosis (TB) in addition to AIDS. The integrative review will examine what is already known about stigma and how it has been explored and measured in other conditions.

This general review necessitated a search for documents from a wide range of sources including reviews of empirical research, reports from the government and from non-governmental organizations, books, articles and conference proceedings. One of the features of the integrative method is that it allows for the qualitative analysis of findings from several sources. For this review, this was achieved by means of holistic coding which can be used for a variety of texts ranging from half a page to a full study (Dey, 1993; Saldaña, 2009). Holistic coding typically involves the chunking of text “into broad topic areas, as a first step to seeing what is there” (Bazeley, 2007, p. 67).

Starting from a broad overview of the literature on stigma (from the sources mentioned above) and by means of holistic coding, key issues related to stigma began to emerge. A note was made of these emerging issues and summaries drafted of the main topics such as discrimination, social distancing, the attribution of responsibility, labeling, cognitive separation and stereotyping.

A combined search was made of selected electronic research databases in order to find scientific articles on stigma in general, to follow up on certain issues and to look for empirical research which might confirm but also challenge the picture that was emerging. Those which were particularly illustrative of a particular point were retained for future use as examples.

The databases used were PsycINFO (which provides extensive international coverage of the literature on psychology and allied fields), PsycARTICLES (a database of full-text articles from 56 journals published by the American Psychological Association, the APA Educational Publishing Foundation, the Canadian Psychological Association, and Hogrefe & Huber) and CINAHL (Cumulative Index to Nursing and Allied Health Literature). MEDLINE, which focuses on biomedical literature from around the world, was not used at this stage but was adopted for the later search for literature linked to dementia.

By means of holistic coding, several categories and two overriding themes were identified. The two themes which emerged from the review closely reflected the conceptualization of stigma of Link and Phelan (2001 and 2006) and the description of contributing factors of Jones et al. (1984). These were adopted as the guiding theoretical framework for this study and are examined in sections 2.3 and 2.4 below.

2.3 The key components of stigma

2.3.1 Definition and value of studying components

In order to understand the stigma of dementia, it is necessary to consider *what* the components of stigma are and *how* the various components of stigma are manifested in relation to dementia. Components are the elements which when combined make up the complex social phenomenon that has come to be known as stigma. According to Link and Phelan (2001; 2006) and Link et al. (2004), stigma occurs when the following components converge:

1. Labelling
2. Stereotyping
3. Separating “us” from “them”
4. Status loss and discrimination
5. The exercise of power
6. Emotional reactions

Link and Phelan describe the above components as dynamically related. They do not explicitly state that all components must be present for an attribute to be considered a stigma. However, in collaboration with Yang and Collins, they specify, in an article on mental illness stigma, that stigma is a “matter of degree”. For example, depending on the condition, labels may be more or less socially salient, stereotypes may be fairly strong or rather weak and emotional reactions may vary between those which are trivial and those which are overwhelming (Link et al., 2004).

Link and Phelan’s conceptualization of stigma (2001; 2006) has been used as a guiding framework for a number of empirical studies on stigma (e.g. Angermeyer and Matschinger, 2004 & 2005; Mahajan et al., 2008; Green, 2009). This conceptualization is theoretical but based on extensive experience in the field of mental health and stigma and there is empirical evidence to support its various components. The components of stigma can also be detected in several other theories of stigma. Consequently, the components described in the following sub-sections are structured around the conceptualization of stigma of Link and Phelan (which forms part of the theoretical framework for this study) with the additional theoretical contributions being incorporated into the relevant sub-sections of that structure.

2.3.2 Labelling

Labelling is the first component described by Link and Phelan but it actually covers two processes, namely the identification and subsequent labelling of human differences which are deemed “relevant and consequential” (Link and Phelan, 2006, p.528). Such differences are often described as being socially salient. This means that a particular attribute is socially meaningful (i.e. it matters socially) and has social implications. Salient social differences are believed to affect the social status of those concerned resulting in them being considered “flawed”, “blemished”, “spoiled” and “a lesser person” (Goffman, 1963, Jones et al., 1984) and ultimately in them being discriminated against (Link and Phelan, 2001; 2006).

The creation of groups based on salient differences involves substantial over-simplification and may vary between cultural groups although many are common to most cultural groups (Link and Phelan, 2001). For example, knowing that someone has had their tonsils removed or has hay fever is of no significance to most people, whereas knowing that someone has schizophrenia, tuberculosis or a criminal record often is. People from different cultures may be more divided on the social significance of certain attributes such as being cross-eyed, which was valued in ancient Mayan culture (Link and Phelan, 2001), or having a tattoo which was for centuries a respected tradition and admired in numerous cultures including those of the Egyptians, the Maoris, the Celts and the Polynesians (“Designboom”, 2009).

According to Goffman (1963), people form normative expectations about other people they encounter and there may be a discrepancy between a person’s “virtual social identity” (i.e. how they are characterized by society or how members of society think they ought to be) and a person’s “actual social identity” (i.e. the attributes that the person could eventually be “proved to possess”). This represents an undesired differentness from what was anticipated which is subsequently labelled. Goffman summarized this as follows:

> *“Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories”* (Goffman, 1963, p.11)*.*

Taking the example of the tattoo, this attribute is fairly common in New Zealand. Consequently, there would be no difference between the virtual social identity and the actual identity of people with tattoos in that particular community, whereas there might be in a European country like Sweden or Luxembourg.

Labelling may also serve a purpose. Parker and Aggleton (2003) suggest that the marking of difference plays an important role in establishing social order in that defining unnatural is essential for the definition of natural, as is abnormal for the definition of normal and thus reflects power relations.

Labelling is part of a social process in which people try to make sense of perceived differences. It is therefore important to consider the meanings associated with various labels as these rather than the simple fact of being labelled or having a particular attribute lead to the bearer being stigmatized (Goffman, 1963; Jones et al., 1984), hence the importance of perceptions.

Conflicting findings have been reported regarding the impact of labels in terms of attitudes towards people with the same stigma. A study involving 113 undergraduates and 77 non-undergraduate adults from the surrounding area of Louisiana State University (USA) compared responses to a questionnaire about attitudes and intended behaviour towards a hypothetical person with schizophrenia, described using one of four terms. The term “consumer of mental health services”, which was considered by the researchers as being the most politically correct, resulted in less negative reactions such as perceived danger, greater hopes for recovery but greater responsibility, compared to the term “schizophrenic” which was considered the least politically correct (Penn and Nowlin-Drummond, 2001). A similar study found no significant difference in attitudes linked to the use of different terms for people with schizophrenia (Chung and Chan, 2004).

A qualitative study by Rose, Thornicroft, Pinfold and Kassam (2007) involved asking 472 fourteen-year-old schoolchildren at the start of a lesson “What sort of words or phrases might you use to describe someone who experiences mental health problems?” 400 of these children provided 250 words and terms which were analysed by means of grounded theory. Five themes were identified. Popular derogatory terms, such as “crazy”, “nuts” and “ga ga”, accounted for almost half of all the responses given and, combined with labels reflecting negative emotions, accounted for 70.8% of responses.

The above studies suggest that the potentially negative consequences of labelling may be due to the meanings associated with the conditions which can be detected in the labels used. They also suggest that labels are more than a means of identification as they may be negatively charged and linked to other factors, such as perceived responsibility and stereotyping.

2.3.3 Stereotyping

Once labelled, the human difference is linked to undesirable characteristics (Link and Phelan, 2006) that form stereotypes. Stereotyping is integral to the initial identification and labelling of difference in the sense that the labelled difference represents a departure from the anticipated norm which is itself a stereotype:

> *"Note too that not all undesirable attributes are at issue, but only those which are incongruous with our stereotype of what a given individual should be."* (Goffman, 1963, p. 13)

Stereotyping is an information processing strategy which serves to rapidly categorize "superficially similar stimuli into a set of ideas or "schemas" which then serve to organize our experiences, memory, expectations and assumptions" (Levey and Howells, 1994, p.320). This is often at the expense of accuracy and typically involves comparison. As Corrigan, Watson and Ottan (2003) point out, the belief that "schizophrenics are dangerous" implies that they are more dangerous than people who do not have schizophrenia. Differences between groups are exaggerated in order to obscure differences within groups (Levey and Howells, 1994; Townsend, 1979 in Byrne, 2000), thereby facilitating social distancing by the stigmatizers (Byrne, 2000).

Stereotypes differ from one condition to the next and reflect the different perceptions that people have of various conditions. People with obesity, for example, are typically stereotyped as lazy, undisciplined, unmotivated, less competent and non-compliant (Crandall, 1994; Hebl and Mannix, 2003; Puhl and Brownell, 2001; Wang et al., 2004). Tuberculosis (TB), on the other hand, is often associated with poverty and being dirty (Long, Johansson, Diwan and Winkvist, 2001; Yamada et al., 1999). People with mental illnesses are frequently considered by the general public as being recognizably different, dangerous and unpredictable (Angermeyer and Matschinger, 2004; Lauber and Sartorius, 2007; Pescosolido et al. 1999). Various methods were used in the above studies to uncover stereotypes such as focus groups, surveys and face-to-face interviews.

2.3.4 Separating “us” from “them”

In-groups and out-groups are formed in which those considered as “them” are perceived as being very different from “us”. This process, which is often called “cognitive separation” combines the identification of difference, labelling, adding negative attributes and demarcating barriers, thereby creating a separation in one’s mind between oneself and people with the stigma. This involves more than a mere recognition that one is not a member of that group but, in addition, that the members of that group are fundamentally different to oneself (Link and Phelan, 2001). This facilitates stereotyping and in the extreme may even lead to the perception that members of that group are not quite human.

> *“By definition, we believe the person with a stigma is not quite human.” (Goffman, 1963, p.15)*

This demonstrates the dynamic interplay between the components of stigma. Perceived similarity to stigmatized people can be threatening. Cognitive separation may therefore also serve as a means to ward off perceived threat (e.g. to survival, morality, social order etc.) by creating a clear separation in one's mind and thus a safe distance between "us" and "them". However, boundaries are not always clear and this may lead to ambivalence (Sontag, 1991). People with long-term illnesses, for example, may be considered by close friends or relatives, as one of "us" but at the same time, one of "them". For acquired stigmas, people are initially part of the ingroup before joining the outgroup and are therefore familiar with how their differentness is perceived. However, according to Goffman, irrespective of the origin of the stigma, people with a stigma are faced with an "unaccepting world".

> *"Such an individual has thoroughly learned about the normal and the stigmatized long before he must see himself as deficient." (Goffman, 1963, p.48)*

This emphasizes the importance of current calls for a dementia-friendly society such as that made by the current Prime Minister, David Cameron (Department of Health, 2012). Separating "us" from "them" has been demonstrated in connection with mental illness (Lauber et al., 2006; Levey and Howells, 1994; Mahatane & Johnston, 1989; Servais and Saunders, 2007). A random survey of 306 clinical psychologists' perceptions of people with mental illness reported an association between "disidentification" (considering oneself as being different to people with mental illness) and prejudicial attitudes (Servais and Saunders, 2007). Participants were asked to compare themselves with a member of the public, a person with moderate depression, a person with borderline features and a person with schizophrenia. Nearly half of the participants considered people with borderline features very undesirable (followed by those with schizophrenia) and almost three quarters considered people with schizophrenia as very dissimilar to themselves (followed by people with borderline features). This suggests the existence of different levels of the components of stigma. Less than a quarter of participants considered people with moderate depression as being very dissimilar to themselves. This study revealed that levels of perceived difference varied from one mental disorder to another (i.e. stigma is condition-specific), which highlights the importance of studying each separately rather than relying solely on studies which group different mental disorders together.

2.3.5 Status loss and discrimination

According to Link and Phelan (2001; 2006), the low status that people with a stigma acquire forms the basis for discrimination. They may be devalued, rejected and excluded (Link and Phelan, 2006). Unfair treatment may actually occur or simply be feared or expected; both of which can be damaging to people with stigmas (Rethink et al., 2008). Reference is sometimes made to stigma and discrimination as if the two were unrelated but in Link and Phelan's conceptualization (2001; 2006), discrimination is one of the components of stigma. It is also prominent in attribution, evolutionary and cognitive-affective-behavioural theories of stigma (Corrigan et al., 2003; Dovidio et al., 2003; Kurzban and Leary, 2001; Weiner et al., 1988).

Discrimination may occur at the interpersonal level (i.e. between individuals) by being refused a job, for example, or through social distancing.

Discrimination can also be structural in that it is expressed though imbalances and injustices which are inherent in social structures, legal and political regulations (Schulze and Angermeyer, 2003) and practices and procedures within society that work against stigmatized groups (Link et al., 2004; Mahajan et al., 2008). Based on a review of 123 studies measuring mental illness stigma, Link et al. (2004) suggest that there has been an overemphasis on abstract measures of discrimination based on attitudes, beliefs and behavioural intentions rather than as measures of actual behaviour.

A combination of self-reports, historical accounts and statistics (e.g. from government sources and advocacy groups) nevertheless attest to discrimination against people with various conditions. It is reported, for example, that in the past, people with leprosy were banished to “leper colonies” (Jones et al., 1984) and many people with leprosy are still ostracised, rejected, insulted, divorced, barred from education and deprived of employment for example (DANLEP, 2003; Scott, 2000; Stigter et al., 2000). In the case of HIV/AIDS, people have reportedly suffered health care, employment and social discrimination (Crandall and Coleman, 1992; Herek, 1999; Herek and Glunt, 1988). People with mental disorders and their families have reported similar discrimination to that experienced by people with HIV/AIDS, as well as in the domain of education (Crowther et al., 2001; Mataityte-Dirziene and Sumskiene, 2009; Wahl, 1999). They have also suffered the systematic withdrawal of fundamental rights (Hemmens et al., 2002; Mental Disability Advocacy Centre, 2005) and been subjected to inhumane treatment in some societies (Diatri and Minas, 2009; Doloksaribu, 2009).

The above-mentioned studies suggest that people with a variety of conditions suffer discrimination in similar areas of life. They also reveal that certain forms of discrimination (e.g. banishment and inhumane treatment) are more common for some conditions (e.g. leprosy and mental disorders respectively) than for others, and that this may vary according to the cultural context. This emphasizes the need to determine how the various components of stigma are manifested in different stigmatized health conditions (such as dementia) and within specific cultures.

2.3.6 The exercise of power

Link and Phelan (2001) state that stigma is entirely dependent on social, economic and political power in that it takes power to stigmatize. Power can be detected behind every component of stigma. Power is needed to impose stigma or defend oneself against it. This separates power from the other components of stigma. Power is associated with and expressed through every component of stigma rather than a component in its own right. In their initial conceptualization of stigma, Link and Phelan did not include power as a component but merely highlighted the dependence of stigma on power.

Without the social, political and/or economic power of the people who stigmatize, there would be no stigmatization (Link and Phelan, 2006; Mahajan et al., 2008; Parker and Aggleton, 2003). Stigmatization also serves to produce and maintain relations of power and control (Castro and Farmer, 2005 in Mahajan et al., 2008; Kelly, 2006). Scrambler (2009) questions whether those who stigmatize actually possess sufficient power to ensure that the other components of stigma occur. It is unlikely that individuals do but at the level of society this seems plausible.

Parker and Aggleton (2003) claim that establishing both the norm and deviance from the norm requires established regimes of knowledge and power. They point out that whilst Goffman made little reference to power and Foucault made little reference to stigma, “their two bodies of work make a compelling case for the role of a culturally constituted stigmatization as central to the establishment and maintenance of the social order” (2003, p. 17). Drawing on the work of Bourdieu, they further suggest that stigmatization is part of a complex struggle for power in which words, images and practices serve to promote the interests of the dominant group and convince those who are stigmatized to accept their lot in life through the processes of hegemony.

Power provides an alternative explanation for the driving force behind the social construction of stigma to the one proposed by Stangor and Crandall (2003), which was perceived threat. However, the two approaches are not necessarily contradictory as the possible loss of power could be construed as a permanent threat and the group must have the power to enforce the “social reality” which serves as a protection against such perceived threat.

Power was not directly addressed in a review of 123 empirical studies measuring mental illness stigma (Link, Yang, Phelan and Collins 2004). Mahajan et al. (2008) highlight an overemphasis on cognitive processes (e.g. of labelling and stereotyping) in research into HIV/AIDS stigma and the lack of attention paid to power and socio-cultural processes.

2.3.7 Emotional reactions

Perceived, and subsequently labelled, differences may result in emotional reactions. In Link and Phelan's initial conceptualization, there is no direct reference to emotional reactions linked to stigma. However, in an intermediary paper on the measurement of mental illness stigma, Link, Yang, Phelan and Collins (2004) state their opinion that a broad conceptualization of stigma should include emotional reactions as these can be detected by the stigmatized person and may shape subsequent behaviour. Often, an emotional reaction is also a perception of people or the condition itself. For example, a person who feels disgusted or pities people with a particular stigma is likely to perceive those people as disgusting or pitiful.

Many studies measuring emotional reactions to stigmas have focused on fear, anger and pity in the theoretical framework of attribution theory (Corrigan et al., 2003; Weiner et al., 1988). Angermeyer and Matschinger (2003) measured these three emotional responses to a person described, but not labelled, as having schizophrenia or major depression in a vignette-based, face-to-face questionnaire study involving a representative sample of 5,025 German adults. They found that particular emotional reactions were associated with perceptions of possible causes for the condition as well as in relation to perceived prognoses. For both conditions, women responded with significantly more fear and pity and less anger.

Other researchers have also recognized the association between emotional reactions and various perceptions. In a study which measured the emotional reactions of 200 Jewish Israeli undergraduates (aged between 18 and 49) towards people with disabilities, it was found that emotional reactions were influenced by the level of death-related emotions and cognitions (Hirschberger et al., 2005). These studies suggest that emotional reactions may be dependent on a range of perceptions which may be both individual and culturally determined.

An exploration of the components of stigma contributes towards an understanding of what stigma is and how it is expressed in different conditions. It does not explain why particular attributes become stigmas (e.g. what makes them socially salient or which particular features people find discrediting). The next section of this chapter focuses on specific aspects (or dimensions) of various attributes which may increase the likelihood of such attributes becoming stigmas.

2.4 Factors which contribute towards stigma

2.4.1 The value of identifying factors contributing towards specific stigmas

Considering which factors might result in a particular medical condition being considered a stigma may contribute towards the identification and development of effective measures to overcome stigma. Understanding *why* an attribute is considered as a stigma (i.e. which aspects of it and based on which meanings) has implications for tackling stigma. The work of Jones et al. (1984) draws attention to factors which may increase the likelihood of attributes becoming stigmas. These factors are not “facts” but social constructions. The contributing factors are closely linked to the identification and labelling of difference, which involves the identification of socially salient differences as they provide insight into what makes certain attributes socially salient. The work of Jones et al. (1984) provides a useful framework in which to explore the stigma of dementia in addition to that of Link and Phelan (2001; 2006).

Jones et al. (1984) analysed eleven empirically grounded studies carried out between 1957 and 1970. These were quite varied and had adopted diverse methods. Some were based on single distinguishing marks (i.e. potential stigmas) and others on groups of different marks. Nevertheless, there was a considerable degree of consistency in the dimensions of discrediting marks detected in the studies. A total of fifty factors were identified of which 72% were the same as one of the six dimensions identified by Jones et al. Amongst the 28% which differed, some were limited to a particular mark (e.g. “attitudes towards mental hospitals”) and some specifically to long-term relationships between those with the stigma and those without (e.g. “capacity for normal life”). The six dimensions are as follows:

1. Concealability
2. Course of the mark
3. Disruptiveness
4. Aesthetic qualities
5. Origin
6. Peril

These dimensions are described as being important in determining how distinguishing marks influence interpersonal relationships. Some are interrelated and it is therefore not surprising that the median number of dimensions detected by Jones et al. (1984) in the eleven studies was four.

Subsequent researchers have incorporated some of the factors into further theories and research (Corrigan et al., 2003; Kurzban and Leary, 2001;

Stangor and Crandall, 2003; Weiner et al., 1988). Hinshaw (2007) suggests that perceptions of the factors identified by Jones et al. may be linked to further “metaphoric associations” and that focusing on people’s perceptions of specific mental conditions and on the associations they make with the contributing factors can make research on attitudes more precise and conceptually rigorous. In the remainder of this section, each factor will be briefly described and its relevance illustrated with examples. Details about other relevant theories will also be provided.

2.4.2 Concealability

Concealability refers to the characteristics of an attribute which render it visible or “known about” to other people or, on the contrary, concealable and hence, undetected (Jones et al., 1984). This can vary according to the situation, context and time and corresponds to Goffman’s concept of people being discredited or discreditable. The issue of concealability (which covers visibility too) can also be detected in the evolutionary theory of stigma of Kurzban and Leary (2001) as judgements about exclusion from the social group, based on signs of poor health, are dependent on the ability to detect them. Certain other contributing factors, such as evaluations about aesthetics, disruptiveness, course of the mark and peril, are also influenced by concealability.

A tendency to avoid people with visible or known about stigmas and to display negative arousal, feel awkward and desire social distance in the presence of disabled people has been reported (Cacciapaglia, Beauchamps and Howells, 2004; Kleck and Strenta, 1980). The issue of visibility is also a key factor in the stigmatization of people with leprosy (Berreman, 1984; Rao, 1992; Valencia, 1989), which, if left untreated, may result in severe visible deformities. However, this must be put into the context of a range of possible associations, particularly those related to contagiousness, supernatural beliefs, poverty and immorality (Wong, 2004). Also, for some conditions, increased visibility coincides with an increased level of severity, disruptiveness and aesthetics.

2.4.3 Course of the mark

"Course of the mark" refers to the extent to which a condition is believed to or actually does become more debilitating and socially alienating over time as opposed to remaining stable or being reparable. Jones et al. (1984) highlighted three main possibilities for the progression of a particular condition: 1. It becomes less stigmatizing and may disappear over time 2. It remains stable (e.g. blindness or dwarfism) and 3. It progressively deteriorates becoming increasingly debilitating and socially alienating (e.g. some cases of multiple sclerosis and leprosy if left untreated). Sometimes, reactions to the progressive nature of a condition depend on its visibility and perceived origin which has implications for attributions of responsibility and again, highlights the inter-connected nature of the contributing factors. Jones et al. (1984) also distinguish between the actual progression of the condition and beliefs about its progression, noting that this affects how people with such attributes react towards others and vice versa. Studies focusing solely on the course of the mark were not found.

2.4.4 Disruptiveness

Disruptiveness refers to the property of an attribute that hinders, strains and adds to the difficulty of interpersonal relationships, especially if visible and aesthetically unpleasant. Jones et al. stated,

> *"The more visible, dangerous, and aesthetically displeasing the mark is, the more disruptive of smooth, interpersonal interactions it will be" (Jones et al., 1984, p.46).*

However, there is perhaps more to this factor than just feeling uncomfortable. According to Kurzban and Leary's evolutionary theory of stigma (2001), people cooperate with others who are maybe less fortunate than they are in the hope that they will reciprocate such behaviour later (reciprocal altruism). They also associate with people with complementary/supplementary skills (mutual enhancement). This practice, which has relevance for the survival of the species, requires certain abilities or resources. Whilst there is a certain degree of tolerance for those who cannot reciprocate, people with unpredictable behaviour and minimal social or economic resources may nevertheless be considered a wasted investment in social terms and may lead to a loss of social status.

The disruption of interpersonal communication caused by specific attributes has been demonstrated in relation to stuttering, being deaf and having a harelip (Shears and Jensema, 1969), visible marks such as facial disfigurement (Houston and Bull, 1994; Kleck and Strenta., 1980; Langer et al., 1976) and mental disorders (Hinshaw, 2007; Thornicroft, 2006). These examples suggest that such disruptiveness may be physical or behavioural and not necessarily visible.

2.4.5 Aesthetics

The term aesthetics was used by Jones et al. (1984) to describe the extent to which the mark makes the possessor "repellent, ugly or upsetting". They drew attention to various attributes which tend to be considered unattractive such as missing limbs, dwarfism or having a cleft palate. Aesthetics can also be detected in Goffman's (1963) category "abominations of the body" which included physical deformities.

Again, Kurzban and Leary (2001) provide an evolutionary and biological perspective on aesthetics. They theorize that in the absence of an effective means of identifying people with parasites, there is a tendency to look for bodily signs such as a "lack of symmetry", "excessive grooming", "discoloration", "coughing and sneezing", but also at "unusual behaviour". Parasites are described as "viruses, bacteria, or more complex organisms, such as insects or worms" (Kurzban and Leary, 2001, p.197). They claim that deviation from the physical norm tends to be considered ugly or unattractive and there is a human capacity to detect symmetry and a preference for it which might be linked to parasitic avoidance.

Other evolutionary biologists suggest a possible association between perceptions of symmetry and good health (Palmer & Strobeck, 1986; Parsons, 1990; Thornhill & Møller, 1997 – cited in Rhodes et al., 1998). Affective reactions linked to an unpleasant aesthetic are often almost instantaneous (commonly referred to as a "gut reaction") with the cognitive response only coming later (Jones et al., 1984). Evolutionary theories take Goffman's theory of deviations from the socially defined norm to an internal and biological level which nevertheless has implications for social exclusion and status loss.

Research involving newborns and infants suggests that perceptions linked to aesthetics might not be entirely socially constructed (Johnson et al. 1991; Langlois et al., 1987; Rumsey et al. 1986). Other studies highlight physiological responses to physical disability suggesting anxiety and a reaction to threat even in the absence of any awareness of feeling uncomfortable (Blascovich et al., 2003; Kleck et al., 1966). Some emphasize the importance of awkwardness based on socialization (Lerner et al., 1976, Gray, 1982) although this does not necessarily imply that derogation (i.e. disparaging or belittling a person) can be ruled out (Newell, 1996).

Responses to physically disturbing images are often accompanied by strong emotions such as disgust and revulsion (Jones et al., 1984) and may lead to people physically distancing themselves from a person with a disturbing physique. An example would be not sitting next to them on a train (Houston and Bull, 1994). This creates a link to “emotional reactions” and “discrimination”.

2.4.6 Origin

The term “origin” describes how the attribute originated, whether it is congenital or non-congenital, whether its onset was rapid or slow and, most importantly according to Jones et al. (1984), a person’s role in engendering it. Perceptions of responsibility may result in blame and affect how the person with the attribute is treated. Weiner et al. (1988) claim that people tend to make three attributions about stigmas (i.e. the discrediting attributes): 1. whether the condition or situation is controllable, 2. whether the person could be considered responsible for having it or its occurrence and 3. whether s/he could have prevented it. This cognitive-emotional-behavioural process can work in someone’s favour (e.g. eliciting pity and leading to help or a positive response) or against them (e.g. provoking anger and a lack of help). In addition to making an attribution of responsibility for the onset of a condition, people may also be held responsible for failure to control the symptoms.

Weiner et al. (1988) measured the attribution of responsibility and blame for ten different stigmatized conditions having either a “physical genesis” (e.g. Alzheimer’s disease and paraplegia) or a “mental-behavioural origin” (e.g. AIDS and obesity). A vignette-based questionnaire was administered to convenience samples of 59 and 320 American and Canadian psychology students. They were asked to rate the attribution of responsibility, blame and controllability, their affective reactions and their attitudes regarding the provision of help. The results supported the hypothesis that there would be an association between the attribution of responsibility, emotional reactions and behaviour.

More recently, Mak et al. (2006) measured the link between the stigma of HIV/AIDS, SARS and TB, and three attributional factors (i.e. controllability, responsibility and blame) by means of a telephone survey involving 3,011 adults. Their results showed that the effects of controllability and blame were equivalent across all diseases. However, the mean score for stigma and the attribution of responsibility were greatest for AIDS, followed by TB and then SARS. This suggests that there are different degrees of blame for different conditions. This is perhaps linked to different meanings and stereotypes associated with the three conditions and suggests the socially constructed nature of stigma.

2.4.7 Peril

Jones et al. (1984) described peril as the danger posed by the mark to physical, psychological and social well-being. Examples include physical threat to life and limb (e.g. through contagion or aggression) but also the threat to social order, to systems of shared meanings and to taken-for-granted, shared views of the world (Berger and Luckmann, 1966), which partly serve to protect people from existential fears provoked by people who are “deformed, disabled, irrational, disfigured or deviant in other ways” (Jones et al., 1984, p. 89) .

Jones et al., (1984, p.66) suggest that “danger, in its many forms, is the most fundamental characteristic of stigmatizing interactions”. Stangor and Crandall (2003) claim that there is a universally held motivation to avoid danger. Starting with an initial perception of a tangible or symbolic threat, perceptions are distorted, thereby amplifying group differences. The consensual sharing of threats and perceptions results in stigma. However, attributes are not inherently threatening. Their threatening aspects are dependent on the meanings attributed to them.

There are two theories associated with existential fear of particular relevance to an understanding of stigma. The first is Terror Management Theory (TMT), which was inspired by the work of Ernest Becker. According to TMT, people develop and rely on a cultural conception of reality which provides meaning and secures self-esteem in order to deal with awareness of the inevitability of death (Solomon et al., 1991, Hinshaw, 2007). Mortality salience increases stereotypical thinking and the derogation, avoidance or punishment of people who threaten that cultural conception of reality (Florian and Mikulincer, 1997; Greenberg et al., 1990; McGregor et al., 1998; Rosenblatt et al., 1989). Fear of death not only relates to one’s own death but also to that of others, leading to “interactional strain”, the rejection of intimacy and feelings of personal vulnerability (Livneh, 1985).

The second is the “belief in a just world theory” which also makes a possible link between feelings of vulnerability and stigma. According to this theory, people are motivated to believe in the existence of a just world (i.e. one that is stable and orderly) and that there is a relationship between a person’s character or actions and what happens to him/her (Lerner, 1980). This makes them feel that they have some control over their lives. When that just world is called into question (e.g. through disability or mental disorder), they may make unjustifiably negative evaluations of the people concerned so as to convince themselves that they deserve what has happened to them. Perceived similarity with people who challenge the belief in a just world may heighten fears that something could happen to anyone (i.e. to oneself) which is too threatening and may lead to cognitive separation (Levey and Howells, 1994).

The threat posed by people with mental disorders has been linked to perceived dangerousness and to subsequent social distancing (Corrigan et al., 2000). This has already been discussed in the context of stereotypes. In the case of AIDS and leprosy, fear of infection is the most obvious fear. However, in the case of AIDS, there may be homophobia (Bouton et al., 1989; Pryor et al. 1989 in Rozin et al., 1994) which perhaps represents a threat to the established social order. The actual risk of contagious conditions is sometimes exaggerated, not always linked to physical contact and even irrational (Bishop, 1991; Klaczynski, 2008; Rozin et al., 1994). In both AIDS and leprosy, perceived threats based on supernatural forces have also been reported (Berreman, 1984, Maughan-Brown, 2009). These studies demonstrate that different fears are associated with different conditions and that even the same fear (e.g. of contagion) may be associated with different meanings.

2.5 Summary

The concept of stigma has been around for thousands of years and there is a rich theoretical tradition focusing on the key components of, and contributing factors to, stigma. Chapter 2 described how stigma has evolved from a social means of control to a socially constructed phenomenon which has a negative impact on the lives of people with a perceived stigma.

Two main conceptualizations of stigma were described based on the work of Link and Phelan (2001; 2006), Link et al. (2004) and Jones et al. (1984). It was demonstrated that this theoretical framework was sufficiently broad to permit a consideration of empirical data reflecting other theories of stigma, particularly those based on evolution, threat and attribution (Corrigan et al., 2003; Kurzban and Leary, 2001; Stangor and Crandall, 2003; Weiner et al., 1988).

The degree of overlap and the interrelationship between the various components and contributing factors addressed in the various studies described in Chapter 2 lent support to Link and Phelan’s (2001; 2006) claim that stigma occurs when a range of components converge. The examples of research also illustrated how components are expressed differently depending on the groups studied, typical features of the disease and cultural factors. This highlights the socially constructed nature of stigma and the need to examine each medical condition separately.

Studies of stigma in different medical conditions suggest that there are similarities and differences in the factors which contribute towards them being perceived as stigmas. For example, the fear of contagiousness is important in the stigma of leprosy, morality in the stigma of AIDS and aesthetics in the stigma of both physical disability and leprosy. Again, this can be attributed to the fact that stigma is socially constructed and that in addition to differences between conditions, the history, traditions, beliefs and fears surrounding one condition are not the same as those surrounding another condition. The components and contributing factors were demonstrated to have varying degrees of importance depending on the condition, thus reflecting the claim of Link et al. (2004) that stigma is a matter of degree.

2.6 Conclusion

It was argued in Chapter 2 that stigma is the result of socially constructed meanings and is a social problem. To understand the stigma of dementia, it is therefore important to understand the meanings attached to dementia. Knowledge gained from research into the stigma of different conditions, as well as possible solutions, may contribute towards an understanding of that of dementia and be usefully applied to tackling the stigma of dementia. However, studies described in this and the previous section have revealed that the components and factors are not only interrelated but also that the extent and manner in which they are expressed differ from one condition to the next. This highlights the importance of exploring conditions separately, rather than relying solely on knowledge gained in the context of other conditions. Some studies suggest that different groups within society perceive the same condition differently. This suggests the need to explore how dementia is perceived by different groups and to determine the common and distinctive features of the stigma associated with dementia.

The literature on stigma theory and the supporting empirical studies considered in Chapter 2 confirm the appropriateness of adopting the theories of Link and Phelan (2001; 2006) and Jones et al. (1984) as a guiding theoretical framework for this exploration. The next chapter will use this theoretical framework to examine how the perceptions of dementia of lay people and healthcare professionals relate to stigma.

3 Perceptions of dementia of lay people and healthcare professionals

In this chapter, literature relating to the perceptions of dementia of lay people (including family carers) and healthcare professionals (including GPs) will be presented. The perceptions of lay people are important as they may affect their willingness to seek a diagnosis which, in turn, will affect their access to timely medication and support. Family carers are included in this category as they are generally considered a sub-group of the lay population although healthcare professionals may also be family carers. Healthcare professionals' perceptions are also important as they reflect their own relationship to dementia which may be reflected back to patients and may, in addition, affect the way that they detect, manage and in some cases diagnose dementia. The aim of this chapter is to present an overview of the way in which the perceptions of these different groups relate to the various components of, and contributing factors to, stigma.

3.1 Literature search

A combined literature search for this section of the thesis was carried out using the research databases PsycINFO, CINAHL Plus with Full Text, PsycARTICLES and MEDLINE. A search for the following terms was carried out:

- dement* OR Alzheimer* AND
- lay OR “general public” OR care OR “general practitioner” OR “professional carer” OR psychiatry* AND
- stigma OR perceptions OR attitudes OR beliefs OR knowledge

The aim, in including the search term “knowledge”, was not to discover how well educated people are about “the facts” of dementia but rather to understand what people “know” as “reality” in their everyday lives, which Berger and Luckmann (1966, p.27) describe as “this knowledge which constitutes the fabric of meanings”.

The combined search of the four databases produced 215 records. This was reduced to 198 after the removal of duplicates. A review question was formulated in line with the systematic review procedure of health interventions developed by the University of York (Centre for Reviews and Dissemination, 2008). As the purpose of this review was to obtain a broad overview of perceptions of dementia and did not involve the review of a specific health intervention, a review question was simply used to guide the selection of relevant and appropriate articles. The review question was:

- How is dementia and how are people with dementia perceived by lay people and healthcare professionals?

The title and abstract of the studies were examined in order to determine whether the corresponding article answered the review question. If it did, the full document was obtained and again compared against the review question, if not, it was discarded. In this way, 167 records were discarded as the studies did not provide a response to the review question, because the participants included people who already had dementia or because they were not in English. The perceptions that people with dementia have about dementia were not included as accounts of such perceptions tend to be based on diagnosed cases. This does not fit in with the focus of this study which is about how perceptions of dementia as a stigma might be linked to delays in diagnosis. Numerous studies involving family carers focused on care-related issues such as burden, stress, service use and coping and not on perceptions of dementia *per se*. Most were therefore also excluded as it was difficult to disentangle carers' perceptions of dementia from their experience as a carer, which might also involve the experience of courtesy stigma (Batsch, Mittelman & ADI, 2012; Blum, 1991; MacRae, 1999; Nolan et al., 2006; Werner & Heinik, 2008).

The remaining 31 studies were sorted into three categories, namely lay people (including family carers and "live-in" paid carers), healthcare professionals (other than GPs) and GPs. The findings of the review are presented in that order.

3.2 Lay people's perceptions of dementia

The first set of studies described in section 3.2 focuses on how lay people perceive dementia as a disease in terms of its characteristics (e.g. what kind of a disease it is, whether it is a disease at all, and whether it is contagious or curable). This is accompanied by several studies which describe a wide range of factors believed to cause dementia and some which address the issue of blame. Perceptions of relevance to stigma in this section mainly include peril, labelling, course of the mark and origin.

This is followed by an overview of studies relating to lay people's perception of people with dementia (i.e. what do they look like and how do they act and react to others?). These studies reflect perceptions which are related to aesthetics, stereotyping, peril, power, separating "us" from "them", loss of status, disruptiveness and course of the mark.

The third section describes the emotional and behavioural factors linked to lay people's perceptions of dementia. Studies in this section focus on fear of dementia and other related emotional reactions, as well as discriminatory attitudes. As this review covers perceptions of dementia rather than behaviour towards people with dementia, the emphasis is on discriminatory attitudes (i.e. suggesting a desire to discriminate in the form of social distancing or through acceptance of structural discrimination) and not on discriminatory behaviour. The main factors addressed in the third sub-section of relevance to stigma are emotional attitudes and discrimination.

3.2.1 How dementia is perceived in terms of a disease

The characteristics of dementia

Several studies have examined lay people's knowledge about dementia and this has been found to be fairly accurate but with some variation and significant differences between ethnic and cultural groups with regard to certain types of knowledge (Ayalon and Areán, 2004; Lee, Lee and Diwan, 2010; Pin-le-Corre and Cantegreil, 2009; Purandare et al., 2007; Sahin et al., 2006; Werner, 2003; Werner and Davidson, 2004) and between men and women (Arai, Arai and Zarit, 2008).

For example, in a self-completed questionnaire-based study involving 191 South Asians and 55 Caucasians in the UK, a significantly higher percentage of South Asians perceived dementia as a contagious but curable condition (Purandare et al., 2007). High scores were also recorded for Asians and Latinos on these two measures in a quantitative survey of four ethnic groups in America (Ayalon and Aréan, 2004). However, in the same study, the lowest scores for the belief that AD is generally fatal were recorded for

Asians and African Americans, but with less than 50% of the Latino and Anglo groups responding correctly. By contrast, 91.3% of 209 Korean American immigrants responded in a self-administered questionnaire that AD is not contagious and 67.9% that AD is usually fatal. These studies suggest that different ethnic groups differ with regard to certain perceptions and not others. They also suggest that dementia represents a peril for some ethnic groups based on contagiousness but that that for some, the peril is not associated with dementia being fatal.

Differences in the perception of dementia either as a medical condition or part of normal ageing have been detected between lay people from different cultural groups in several quantitative studies (Ayalon, 2009; Ayalon and Aréan, 2004; Gray et al., 2009; Lee et al., 2010; Puradare et al., 2008). Differences have also been detected between the “same” cultural group in different countries (Ayalon and Aréan, 2004; Purandare et al., 2008).

The labels people use may also reflect how people perceive dementia. Studies using both qualitative and quantitative methods have revealed mixed perceptions of dementia as being either part of normal ageing or a brain disorder, often described in terms of mental illness or insanity and associated with the stigma of mental disorders (Corner and Bond, 2004; Devlin et al., 2007; Forbat, 2002; Langdon, Eagle and Warner; 2007; Lee et al., 2010; Morgan et al., 2002; Sahin et al., 2006).

In a series of focus groups conducted in Scotland, lay people were found to use the terms dementia and Alzheimer’s disease interchangeably (Devlin et al., 2007). However, in the Facing Dementia Survey, 19% of the 600 lay people interviewed associated dementia with being crazy or insane compared to just 4% for AD, which suggests that dementia and AD have different meanings (Rimmer et al., 2005). Nevertheless, some cultural groups perceive AD as a form of insanity but also part of normal ageing (Ayalon and Aréan, 2004; Lee et al., 2009).

Origin and blame

Perceptions of dementia as being a mental illness and/or part of normal ageing reflect beliefs about the origin of dementia. However, a wide range of different possible causes of dementia can be found in the literature. Some spiritual beliefs linked to fate, the evil eye, punishment for past deeds, lack of faith in God and lack of self-love have been associated with dementia by lay people (Ayalon, 2009; Blay and Peluso, 2010; Elliott et al., 1996; Mackenzie, 2006) and in Nigeria by religious ministers (Uwakwe, 2000).

In face-to-face qualitative interviews with ten older people without dementia attending day centres in the UK, above-average education, stress, inactivity and anxiety were cited as risk factors (Corner and Bond, 2004). Similar interviews were carried out with 18 carers from Hong Kong (six male and six female spouses as well as five daughters and one daughter-in-law) from Alzheimer associations and community-based centres. The participants linked dementia to the side effects of anesthesia or pain killers, critical life events such as mourning, lack of stimulation and supernatural beliefs such as “feng shui” (Chung, 2000).

According to Gaines (1988), black southerners in America describe AD as something that is caused by “worrration” (i.e. thinking too much, over-use of the brain) and “high blood” (i.e. stagnation of thicker or sweeter blood which builds up and eventually bursts blood vessels). Gaines warns against considering people who seem to be from the same ethnic group as homogenous as this is often not the case.

Where an element of blame has been detected, this has been associated with beliefs that dementia is caused by social, physical and emotional factors (La Fontaine et al., 2007) and “laziness” and “weakness of character” (Low and Anstey, 2009). Otherwise, perceived responsibility of people with AD has been found to be low or moderate in several quantitative studies (Cohen et al., 2009; Crisp, 2004; Werner, 2005; Werner, 2008).

The above-mentioned studies reveal that lay people have different perceptions about the nature and origin of dementia and AD. This is partly reflected in the labels they use. Low levels of perceived responsibility have been recorded and some degree of blame in some cultures depending on the perceived origin of dementia.

3.2.2 Lay people’s perceptions of people with dementia

Stereotypes and peril

In two small qualitative studies, people with dementia have been described as having “no quality of life”, being “passive”, having “little unawareness”, and having lost their “control, identity and dignity” (Corner and Bond, 2004; Devlin et al., 2007). Some studies have found that carers perceive the quality of life of people with dementia as being lower than people with dementia perceive it themselves (Conde-Sala et al., 2009; Sands et al., 2004; Thorngrimsen et al., 2003). In the context of a qualitative study involving semi-structured face-to-face interviews with 48 older people and 48 family members attending a memory clinic (prior to diagnosis), dementia has been described as involving a loss of mind and bodily functions such as continence and mobility (Moniz-

Cook et al., 2006). Participants also felt that dementia would cause upset within the family, negatively affect personal relationships and pleasure, and result in the placement of the person with dementia in a care home. The perceptions described in the above studies may represent stereotypes. It is also possible that these perceptions are not attributed to all people with dementia or that they simply represent people's worst fears.

Common sense might suggest that assuming incapacity would be a stereotype of dementia. However, the findings of one study suggest that this is not the case as lay people distinguished between different types and levels of capacity of people with AD, ranging from making a cup of tea to making financial decisions (Werner, 2006). On the other hand, 82.6% of Filipino live-in home care workers in Israel believed that people with AD need constant supervision, which suggests a possible stereotype of people with AD lacking capacity or being a danger to themselves (Ayalon, 2009). However, it must be borne in mind that such live-in carers are only authorized in Israel for elderly people with significant impairments of daily living. Consequently, these carers might only come into contact with people who need constant supervision and many are expected to provide almost round-the-clock care. This may have resulted in participants believing that this was the desired response.

In a study designed to measure the impact of a training course promoting the bio-psycho-social model of dementia, 15 first year college students were asked to write down up to 10 "descriptors/ideas/characteristics" that came to mind when they thought about AD (Sabat, 2011). Whilst all fairly negative attributes, the responses mainly reflected a series of possible symptoms and scenarios. With the exception of “burdensome”, they did not reflect the kind of derogatory judgements or hostile generalizations (e.g. “weird”, “bedraggled”, “stupid” etc.) found in studies into certain other stigmas (Lauber et al., 2006).

Low or moderate levels of perceived dangerousness of people with AD have been reported in several studies (Cohen et al., 2009; Crisp, 2004; Werner, 2005; Werner, 2008). This suggests that people with AD are not stereotyped as being dangerousness in the same way that people with other mental disorders, particularly schizophrenia, are. A fairly high score for dangerousness (i.e. 41.6%) was nevertheless recorded by means of structured face-to-face interviews with a random sample of 500 lay people in Brazil (Blay and Peluso, 2010). However, the opinion was based on a vignette which did not specify that the person had dementia. Also, the question asked was “In your opinion, could a person like John (or Mary) commit a violent act against other people?” This could be interpreted as a question about the capacity to commit a violent act. If so, a positive response would not imply that the person was any more likely to be violent than somebody else.

Aesthetics, loss of status and personhood, and power

Whereas stereotypes are cognitive representatives, people often have visual representations of people with dementia. Disturbing images of dementia were highlighted in a study involving in-depth, semi-structured face-to face interviews with a purposive sample of ten adult children caring for a parent with dementia in Israel (Werner, Goldstein and Buchbinder, 2010). The participants (8 female and 2 male) drew attention to the disturbing appearance of the person with dementia (e.g. “messy”, “filthy”, “soiled”, “neglected”, “badly groomed” and “badly dressed”). They associated this with feelings of disgust and the desire for social distance, an association which creates a link between aesthetics, emotional reactions and discrimination. The participants believed that other people perceived people with dementia the same way. This is one of the only studies to emphasize the importance of aesthetics with regard to perceptions of dementia as a stigma.

In focus group discussions with older people living in Scotland, people with dementia were described as “sitting there like vegetables”, not wanting “to see anything, do anything” and not wanting “to get involved in anything” (Devlin et al., 2007). This is a negative image of advanced dementia in which the person lacks social status, being likened to something that is not human based on his/her visible appearance and behaviour. This also reflects disruptiveness in the form of a perceived lack of reciprocity. Categorizing people in this way therefore also reflects separating “us” from “them”. The lack of human or social status, particularly in connection with separating “us” from “them”, is reminiscent of Kitwood’s definition of personhood:

> *“It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.” (Kitwood, 1997, p.8)*

Similar observations about personhood were revealed in another small-scale qualitative study into power relations involving face-to-face qualitative interviews with 26 female carers (6 spouses, 15 daughters, 3 daughters-in-law and 2 granddaughters) (Dunham and Cannon, 2008). These carers described people with dementia as “not being there”, the person just being “a body" and that they felt they were "not dealing with a human being". At the same time, they expressed the desire to continue perceiving the dignity of the person with dementia despite his/her apparent loss of status, which suggests an element of respect based on their relationship to the person with dementia. Dunham and Cannon (2008) suggest that this conflicts with the official discourse about role reversal, with its focus on unequal power relations. Apart from this study, perceptions of power in connection with dementia are not directly addressed in the literature. How far things can be concealed has not been directly addressed either but the above studies emphasize the negative impact of dementia based on its visible aspects which are increasingly difficult to conceal in the advanced stage.

Course of the mark and disruptiveness

A study using grounded theory and involving interviews with 15 Canadian carers (five daughters, five wives, three husbands, one son and one sister), situates perceptions of gradual deterioration and of loss of reciprocity within a process of emotional and physical alienation which has implications for separating "us" from "them" and disruptiveness (Wuest et al., 1994). The researchers describe this process in terms of "dimensions of becoming strangers". Such perceptions also reflect an awareness of the progression of dementia accompanied by increasing levels of debilitation which is relevant to both "course of the mark" and "disruptiveness".

Powell, Hale and Bayer (1995) also describe perceptions of the disruptiveness of dementia. They compared the perceptions of communication of 79 family carers of a relative with dementia to those of 76 family and close friends of a control group of people without dementia.

Perceptions of 32 symptoms which might contribute towards a breakdown in communication were measured. The carers of people with dementia reported significantly greater communication difficulties in the form of repeated questioning, difficulty following group conversations, difficulties keeping the conversation going and difficulties remembering people's names and places.

The above studies suggest possible stereotypes of dementia and people with dementia, disturbing images, loss of status and personhood and disruptiveness. Some of the findings suggest possible emotional reactions and might logically contribute towards certain behaviour. The next section considers studies which have addressed these two issues directly.

3.2.3 Lay people's emotional and behavioural responses to dementia

Emotional responses to dementia

The most frequently addressed emotional reaction in the literature is the fear of developing dementia. Several studies confirm high levels of fear amongst lay people (Blendon et al., 2012; Cutler and Hodgson, 2001; Pin-le-Corre and Cantegreil, 2009; Tsolaki et al., 2009, Werner, 2002; Werner and Davidson, 2004; Wortmann et al., 2010). Significantly higher levels of concern about developing dementia have been found to be associated with personal experience of the disease as well as being female (Cutler and Hodgson, 2001; Low and Anstey, 2009; Rimmer et al., 2005; Wortman et al., 2010). However, a telephone, questionnaire-based survey involving 2,678 randomly selected adults in four European countries and the United States of America found an association between fear and having experience of dementia but not in two of the European countries (Blendon et al., 2012). Differences were also detected between two cultural groups in America in that white

Americans reported higher levels of fear than African Americans (Roberts et al., 2003). Some studies have nevertheless indicated complacency about developing dementia (Lee et al., 2010; Low and Anstey, 2009; Sahin et al., 2006; Yeo et al., 2007).

There has been less interest in other emotional responses to dementia. Exceptions include two Israeli studies involving face-to-face interviews with convenience samples of 170 Israeli Arab adults (Cohen, Werner and Azaiza, 2009) and 150 Jewish Israeli adults (Werner and Davidson, 2004). Participants were asked to rate on a Likert scale 16 emotional reactions towards a person depicted in one of two vignettes of a person as having either advanced or moderate dementia. Four factors emerged, namely rejection, anxiety, “prosocial” (i.e. sympathy, desire to help and compassion) and aggressive. In both studies, high levels of prosocial emotions were reported. In the Jewish-based study, scores on the rejection factor were significantly higher for men. However, the expression of prosocial emotions was higher in the Arab population compared to the Jewish population. Cohen et al. (2009) suggest that this may be related to higher levels of religiosity amongst the Arab population. Positive emotions were also recorded by 221 female undergraduates in America towards a person in a vignette labelled as having AD. However, greater anger was directed towards the person in the vignette if described as a father rather than a mother (Wadley and Haley, 2001).

A self-completed questionnaire study involving a convenience sample of 71 female and 28 male undergraduate students in the United States of America revealed relatively high scores for empathy towards people with dementia irrespective of the amount of previous contact with people with dementia (Lundquist and Ready, 2008).

Discriminatory attitudes

Discriminatory attitudes towards people with AD have been measured in quantitative, survey-based studies and found to range from fairly low/moderate in the United States, Canada and Israel (Weiner et al., 1988; Werner, 2005) to high in Germany (Schomerus, Matschinger and Angermeyer, 2006). However, the severity of AD as well as feelings of rejection towards people with AD are associated with an increased desire for social distance, whereas prosocial feelings or familiarity with the disease or close contact with people with dementia are associated with a decreased desire for social distance (Werner, 2005) or a greater willingness to make sacrifices for them (Lundquist and Ready, 2008). Lay people’s perceptions about competence have also been found to affect the desire for social distance (Werner, 2006).

The possible link between the perceived severity of AD and discrimination was further explored by Werner (2008) in an exploration of discriminatory behaviour towards people with AD in nursing homes This was based on the realization that most studies measuring low levels of discrimination had focused on vignettes of community dwelling people with dementia who might be presumed to have less severe dementia. The study involved telephone interviews with a representative sample of 501 lay people in Israel. Discrimination was operationalized by means of a scale covering coercion, segregation and avoidance. Two vignettes were used describing a person with AD either living in the community or in a nursing home. Werner (2008) found no significant difference in respondents' reported likelihood of avoidance of people with AD in the two groups. However, scores for segregation (i.e. separating people from society) were significantly higher and scores for coercive treatment (i.e. treatment without consent) significantly lower in relation to the people described as being in a nursing home. The study did not support the hypothesis that being in a care home increases discrimination but rather that it is associated with less anger and discrimination. The findings from this and the above-mentioned studies highlight the possibility that people with dementia are not perceived as a homogenous group and that differences between them may affect people's desire for social distancing.

Attitudes towards structural discrimination have been measured in two large-scale telephone surveys involving random samples of Canadian and German adults. The findings suggest that lay people are not in favour of structural discrimination with regard to the allocation of resources for dementia (Oremus et al., 2009; Schomerus, Matschinger and Angermeyer, 2006).

The above-studies suggest that emotional reactions and behavioural attitudes of lay people associated with perceptions of dementia focus on fear, prosocial emotions and limited desire for social distancing or structural discrimination.

3.3 Healthcare professionals' perceptions of dementia

A small number of studies using both qualitative and quantitative methods provide some insight into the perceptions that healthcare professionals (other than GPs) have of the nature and impact of dementia and their attitudes towards people with dementia. These studies were set in Sweden (Åstrom et al., 1990; Björkman, Angelman and Jönsson, 2008), Norway (Kada et al., 2009) and the UK (Keightley and Mitchell, 2004). The participants in these studies, with the exception of two clinical psychologists, were all nurses working in mental health and geriatric care. The studies have implications for an understanding of labelling, stereotyping, emotional responses and course of the mark and, indirectly, to status loss and discrimination. In addition, the Norwegian study addresses perceived disruptiveness, dangerousness and responsibility. Perceptions described in the four studies do not address aesthetics, concealability, separating "us" from "them" or power.

3.3.1 Perceptions about the nature and impact of dementia

The UK study involved qualitative face-to-face, semi-structured interviews with two male and three female community psychiatric nurses (CPNs) and two male clinical psychologists about factors affecting disclosure of a diagnosis of dementia (Keightley and Mitchell, 2004). The study provides information about their perceptions of dementia but also about how they think lay people perceive dementia. The transcripts of the interviews were analysed by means of grounded theory.

The participants described "degrees of telling" in which diagnostic labels were often avoided in favour of simpler, more descriptive terms. Some stated that this was based on their belief that the term "dementia" was stigmatizing. This highlights their awareness of the possible negative impact of the diagnostic label. The participants believed that people with dementia were portrayed in the media as being out of control. Their reluctance to use the label dementia was also linked to how they perceived dementia. People with dementia were described as being "in a different, awful reality" with the awfulness being linked to “loss of self, power and cognitive functions”. The participants made frequent reference to the issue of loss of insight by people with dementia although this was not described in terms of a stereotype. With regard to the course of the mark, the participants reportedly spoke in terms of dementia being something “worse than death” and of it having an inevitable course and a prognosis so distressing that patients might become depressed or commit suicide, and that they themselves felt hopeless and helpless (Keightley and Mitchell, 2004).

Kada et al. (2009) measured the attitudes of 291 nursing staff towards institutionalized people with dementia in 14 Norwegian nursing homes and 1 hospital. The instrument used was the Approach to Dementia Questionnaire. This focused on attitudes towards care rather than perceptions of dementia. However, one of the two factors measured was hope and the items making up this factor reflected a combination of “emotional reactions” and “course of the mark”. For example, 8.2% of participants considered that there was no hope for people with dementia, 6.5% felt that nothing could be done for people with dementia except for keeping them clean and comfortable and 31.3% felt that once dementia develops, it was inevitable that the person would go downhill. Staff over the age of 50 showed significantly less hope. This may be explained by Terror Management Theory and “just world” theories (as described in section 2.4.7) in that being older may reduce the safe distance between oneself and people with dementia. In both studies, hopelessness might reflect a stereotype of dementia being a condition for which there is no hope.

3.3.2 Attitudes towards people with dementia

The second factor measured in the study by Kada et al. (2009) was person-centred attitudes. Overall, high levels of person-centred attitudes were recorded with significantly higher scores being obtained by nurses with higher levels of education but significantly lower scores by those over the age of 50. Whilst person-centredness does not have an obvious link to perceptions of dementia or stigma, the items in the scale reflect a desire to treat people with dementia with respect and as equals. This is the opposite of “status loss and discrimination”. In a Swedish study involving 358 nursing staff empathy, burden and attitudes towards people with dementia were measured by means of a self-completed, non-anonymous questionnaire. Moderately positive attitudes were recorded but no details were provided of the nature of the positive attitudes (Åstrom et al. 1990).

3.3.3 Perceptions of disruptiveness, responsibility and dangerousness

Perceptions of disruptiveness, responsibility and dangerousness were explored in another Swedish study involving structured interviews with 120 nurses (including both registered and assistant nurses) about their attitudes towards people with seven types of mental illnesses, including dementia (Björkman et al., 2008). The interviews were based on adapted questionnaires, namely the Level of Familiarity Questionnaire and the Attitudes to Persons with Mental Illness Questionnaire. Scores for the item “hard to talk to” were almost the same for dementia as for schizophrenia (e.g. 54.2% and 55.5% respectively) but with the exception of severe depression, were well below 50% for all other conditions (Björkman et al., 2008).

Dementia received the second to the lowest score (i.e. 2.5%) for blame compared to five other mental disorders (Björkman et al., 2008). Only schizophrenia scored less (0.8%). None of the participants believed that people with dementia could just “pull themselves together” compared to 28% and 44.9% respectively for eating disorders and drug addiction, which also suggests a perception of people with dementia not being responsible for their condition. Scores for perceived dangerousness were also low with only 21% of student or assistant nurses considering people with dementia a danger to others but 56.3% considering them as unpredictable (which might also represent a stereotype).

The above studies suggest that some healthcare professionals have a fairly negative perception of dementia linked to their understanding of the experience of dementia, the course of the disease and its perceived impact. The main emotional reaction explored was hope, for which different levels were expressed. People with dementia are not generally considered responsible for their condition or considered dangerous. The positive attitudes towards people with dementia suggest an absence of perceived loss of status, of unequal power relations or of the desire to discriminate. However, such issues were not directly addressed so this can only be inferred.

3.4 GPs’ perceptions of dementia

Three qualitative studies provide limited information about how GPs perceive dementia and people with dementia, namely about the nature of dementia, the impact of labels, the course of the mark, concealability, emotional reactions and possible stereotypes (Cahill et al., 2006; 2008; Hansen et al., 2008; Kaduszkiewicz et al., 2008). These studies, which focus on issues related to diagnosis, were set in Ireland, Australia and Germany respectively.

Only one study to-date has explored GPs' perceptions of AD in the context of stigma theory. This was a study conducted in Israel which measured GPs' emotional reactions, their attitudes towards discrimination and their attributions of responsibility and dangerousness (Werner and Giveon, 2008). Perceptions linked to aesthetics, separating "us" from "them", status loss and discrimination may be implicit in some of the reported findings but were not addressed directly.

References to studies which merely suggest that GPs perceive dementia as a stigma but without providing details about those perceptions are not included in this section. They are, however, mentioned in section 4.5 in the section on stigma as a barrier to timely diagnosis.

3.4.1 The nature of dementia and how it is described

Kaduszkiewicz et al. (2008) carried out in-depth face-to-face interviews with a random selection of 30 GPs in Germany about their attitudes towards revealing the diagnosis. Some of the data reflects their perceptions of dementia. One quote, for example, reveals a GP's perception of what dementia involves and the belief that this perception "must remain in the head and the heart of the doctor". The perception that the GP decided not to share with a patient was that that person's existing personality would at some point be eradicated. This could be considered as a stereotype of dementia but also a reflection about the course of the mark involving progressive degeneration and debilitation. Some of the GPs expressed the belief that even people diagnosed early would not understand the diagnosis. This seems to reflect a stereotype of people with dementia lacking the capacity to understand. This contradicts the perceptions of 422 GPs in Missouri, 40% of whom responded in a postal survey on practice-related attitudes that people with moderate dementia were capable of making informed decisions about their medical treatment and care (Meuser, Boise and Morris, 2004).

Cahill et al. (2008) used a mixed methods design involving a random sample of 300 GPs in Ireland, selected from a national database of registered GPs, who took part in a postal survey and a focus group consisting of seven GPs. Again, whilst the main topic of the study was attitudes and practices regarding diagnosis, the focus group provided some information about GPs' perceptions of dementia. The GPs in the focus group discussion expressed concerns about not wanting to label patients or put them in a category of high dependency and only pursuing a diagnosis once it has become inevitable. With reference to the same study, Cahill and Clark (undated) report that GPs used words like “devastating”, “terrifying” and “fatal” to describe dementia. The GPs expressed a desire to avoid diagnostic labels and the terms they used to describe dementia were emotive, summing up fear and, as with the German GPs, an awareness of the course of the disease.

The Australian study involved 3 focus groups and semi-structured interviews with 13 GPs. Several GPs described the discrediting nature of dementia which reflects the component “status loss” (Hansen et al., 2008). This term is central to Goffman's (1963) definition of stigma but it is not known whether this is the terminology of the researchers or that of the GPs.

3.4.2 Discrimination, emotional reactions, origin and peril

Werner and Giveon (2008) investigated discriminatory behaviour of GPs towards people with AD within the theoretical framework of attribution theory in the context of stigma. This was a vignette-based study involving computer-assisted telephone interviews with a representative sample of 501 GPs. The study provides insight into GPs' emotional reactions towards people with AD and their attributions of responsibility and dangerousness. It did not measure behaviour but rather the reported desire for or agreement with discriminatory behaviour.

GPs scored high on the dimensions of avoidance and coercion (e.g. items linked to forced treatment and care) and somewhat lower on that for segregation (e.g. items linked to willingness to place the patient in a nursing home). This suggests a perception of people with AD not inspiring the desire for contact and needing controlling but not necessarily segregating. The severity of the disease was found to increase desired social avoidance and female GPs were found to have higher scores for avoidance.

Factor analysis produced two factors: pity and anger-fear. Significantly higher levels of pity (items included pity, sympathy and concern) were reported than of emotions linked to anger-fear (items included anger, irritation, aggravation, terrify, scared and fright). Pity was associated with less avoidance which supports attribution theory. One of the items from the anger-fear factor was “terrify”. The word “terrify” suggests a high level of fear but it is not known what the GPs found terrifying about the person in the vignette (i.e. whether such emotional reactions were linked to perceived physical dangerousness or to fears of a more psychological or existential nature). The methodology adopted was not compatible with the further exploration of these issues.

Overall, ratings for the perceived dangerousness and responsibility of people with AD were quite low. Higher levels of perceived dangerousness and higher levels of anger-fear toward the person with AD described in the vignette did, however, lead to a greater desire for segregation and avoidance. Higher levels of perceived responsibility were associated with less desire for avoidance. This does not support the attribution model but as the measure was based on perceived responsibility for *behaviour*, not for having AD, it does fit in with the extended model of attribution (Corrigan et al., 2000).

The study by Werner and Giveon (2008) is the only study to date, which has explored GPs' perceptions of people with dementia within the context of an exploration into stigma. As such, it represents a valuable contribution to knowledge. Unfortunately, as a vignette-based study, the scores only apply to the vignette used and not to people with AD as a group. Also, different results might be obtained with a non Israeli population and the authors admit relatively weak internal validity of some of the indices.

3.5 Summary

Research into the perceptions that lay people and healthcare professionals have of dementia has been piecemeal in that it consists of several studies which have studied different populations and revealed perceptions of dementia which reflect different components of, and contributing factors to, stigma. However, the findings of the various studies can be likened to pieces of a jigsaw pieces, it is possible to join them together and construct an overall picture of how dementia is perceived. Chapter 3 revealed that lay people and healthcare professionals are generally sympathetic towards people with dementia and do not blame them for having dementia. They are afraid of this disease and feel threatened by the prospect of developing it but not by the people who have it. Dementia is perceived as a negative experience and as involving progressive degeneration which affects quality of life and interaction with others. This is sometimes described in terms which suggest a perceived loss of personhood. Different terms are used for dementia which reveal different perceptions of the origin of dementia, for which there are several theories. Several studies suggest that there is confusion amongst lay people as to whether dementia is a disease or part of normal ageing.

The review of the literature has also revealed that dementia is perceived differently by different groups of people. Differences have also been found between the perceptions of men and women, in relation to different stages of dementia and connected to where the person with dementia lives. Reactions towards people with dementia may be affected by the age of the perceivers and by the degree of contact they have had with people with dementia.

Chapter 3 has demonstrated how the perceptions of dementia of different groups relate to the various components of, and contributing factors to, stigma. However, most of these have been addressed by a limited number of studies or can only be inferred from the findings of the studies involving lay people. The range of components and contributing factors covered in the studies involving healthcare professionals is much narrower and few studies have been set in the UK.

3.6 Conclusion

Literature on the perceptions of healthcare professionals is closely linked to their perceptions of caring for people with dementia, making or disclosing the diagnosis and making decisions related to treatment. This has resulted in limited knowledge about how they perceive dementia and how this relates to stigma. Literature relating to lay people’s perceptions is much broader and has therefore covered a wider range of perceptions. It has therefore been easier to form an impression of how lay people's perceptions relate to stigma.

Attempts to understand how stigma interferes with timely diagnosis need to move away from a rigid focus on GPs solely as medical professionals. The focus needs to be broadened in order to allow them to express their perceptions from the perspective of a person with an equal likelihood of developing dementia. An exploration of GPs' perceptions of dementia should therefore focus on their perceptions of dementia and their understanding of how dementia is perceived within society. Additional data about GPs' understanding of stigma as a societal issue and about issues related to timely diagnosis may be helpful and contribute to an understanding of how perceptions of dementia as a stigma relate to timely diagnosis. However, there should be a clear distinction between the two so that the issues related to GPs' professional role do not limit data collection.

In keeping with the need to clearly differentiate between GPs' perceptions of dementia and their understanding of timely diagnosis and stigma, the next chapter will now briefly examine the latter. This will further clarify the context of this study and provide a justification for this study.

4 Timely diagnosis of dementia, GPs and stigma

4.1 Introduction

This chapter starts with an overview of studies which have addressed the importance of diagnosis and how well GPs are at fulfilling their role in this respect. This is followed by a summary of the findings from studies which addressed GPs' perceptions of barriers to timely diagnosis, including stigma. Gaps in the literature, which have been identified in the course of the literature review, will be highlighted and the chapter will conclude with details of the aims of the study and the research questions.

4.2 Literature search

For the literature on barriers to the timely diagnosis of dementia, a search was carried out on the databases PsycINFO, CINAHL Plus with Full Text, PsycARTICLES and Medline using the keywords:

- dementia (and related terms);
- general practitioner (and related terms);
- diagnosis and
- barrier OR timely diagnosis OR early diagnosis

For the term dementia 209,924 records were retrieved, for general practitioner 161,358 records and for diagnosis 2,926,553 records. A search for the records combining all three key terms plus barrier or timely or early diagnosis resulted in 80 records (with duplicates removed). The review question used to guide the selection of relevant articles was:

- What do studies involving GPs reveal about the perceived importance of timely diagnosis, how well GPs are fulfilling it and the barriers to timely diagnosis which they perceive?

The titles and abstracts of all records were read and 16 relevant full articles obtained. Additional articles were obtained by a hand search through indexes.

4.3 The importance/benefit of the timely diagnosis of dementia and the difference between timely and early diagnosis

Timely diagnosis is considered a prerequisite to people with dementia receiving the services, treatment and support they need (Department of Health, 2009), yet universally acknowledged as not happening in a timely manner (Boustani et al., 2008; Department of Health, 2001; European Commission, 2007; Werner, 2003, Wilkinson et al., 2004). Very often, a timely diagnosis is one that is made early on in the course of disease. However, whereas an early diagnosis may be beneficial for many people, for others the disadvantages may outweigh the advantages. The diagnosis must therefore be made at the right time, rather than simply early.

Disadvantages to early diagnosis might include unwelcome interference with coping strategies such as denial and psychological defences, exposure of personal failure, perceived threat and, if the person has been brought in by a relative, a feeling of betrayal (Woods et al., 2003). Moreover, if the diagnosis comes too early, the potential advantage of being able to make plans may be countered by the fact that the symptoms might never actually become all that severe.

Timely diagnosis, on the other hand, is considered helpful in preventing premature deterioration of the condition and in improving the quality of life of people with dementia (Banerjee et al., 2007) and their carers (Mittelman et al., 2007). Access to timely pharmacological treatment has been recognized as important (DeKosky, 2003; Petersen et al., 2005; Winblad et al., 2006). Combined with psycho-social support and case management, this may even delay premature entry into long-term residential care and time to dependency (Challis et al., 2002; Geldmacher et al., 2003; Neumann et al., 1999; Spijker et al., 2008), one of the direct costs of dementia care which are higher than informal care costs in northern and western Europe (Leon et al., 1998; Wimo, 2009). In practical terms, timely diagnosis enables people to plan their future support and care (Woods and Pratt, 2005) and take care of legal and financial matters, perhaps making an advance directive (Milne and Wilkinson, 2002). Psychological benefits have also been highlighted such as reducing uncertainty, coming to terms with the disease, understanding what is happening and preventing crises (Elson, 2006; Iliffe et al., 2003).

Diagnoses should therefore be considered as timely for people with dementia “at the point when the cognitive and other changes they are experiencing begin to affect their lives and the lives of people close to them” (Nuffield Council on Bioethics, 2009, p. xix) or to prevent crises, facilitate adjustment and provide access to treatment and support (Woods et al., 2003).

4.4 The role of GPs in early diagnosis and how well they are fulfilling it

GPs are usually the first port of call for people who suspect that they or one of their relatives might have dementia (Brodaty et al., 1994; Downs et al., 2002; Tsolaki et al., 2009; van Hout et al., 2000) and are also in a position to notice dementia when people come to them for other conditions but show "early pointers" to dementia such as forgetting appointments or to take medication, social withdrawal and a decline in self-care (Hansen et al., 2008). However, GPs do not always pursue a diagnosis (Downs et al., 2000) or wait until doing so becomes inevitable due to the patient's inability to manage on their own (Cahill et al., 2008; Hansen et al., 2008).

We have a long history demonstrating that many GPs do not diagnose in a timely fashion (Audit Commission, 2000; Downs, 1996; Iliffe et al., 1999; Werner, 2003, Wilkinson et al., 2004). Delays from 10 months in Germany to 32 months in the UK have been reported (Wilkinson et al., 2005) and in some cases delays of up to 4 years (Bamford et al., 2007). There have also been reports of underdiagnosis (i.e. of people with dementia not merely being diagnosed late, but not being diagnosed at all) (Boise et al., 1999; Connolly et al., 2011; Iliffe et al., 1990). A recent review of 30 studies covering 15,277 people consulting for cognitve disorders (including 7,109 assessed for dementia) in primary care revealed that whilst 80% of cases of moderate to severe dementia were identified, only 45% of people with mild dementia or mild cognitive impairment were identified (Mitchell, Meader and Pentzek, 2011). They estimate that about 1 out of 4 cases of dementia are missed. The results of a postal survey, to which 153 GPs in Sweden responded, suggest that GPs underestimate the number of cases of dementia and therefore probably also underdiagnose (Ólasdóttir et al., 2001). In Norway, diagnosis is estimated to occur in 50% of cases of dementia irrespective of its degree of severity (Lystrup et al., 2006). Timely diagnosis can therefore not be considered as having been achieved on a wide-scale basis in Europe.

Timely diagnosis is perhaps to a certain extent a subjective matter but one which can be located on the continuum of too early to too late. In England, for example, death rates between 1990 and 2007 were more than three times higher for people with dementia who had been diagnosed by a GP in the previous year than for people who did not have dementia (Rait et al., 2010). One possible explanation for this is that dementia was only diagnosed in the later stage or when it had resulted in a crisis for the person with dementia or his/her family (Sachrajda, 2011) and was already too late. There are also delays in disclosing the diagnosis, with this sometimes occurring late, not to the person with dementia or not at all (Bamford et al., 2004).

4.5 Barriers to GPs providing or engaging in timely diagnosis

Several possible barriers to timely diagnosis have been identified in the literature. These reflect a lack of knowledge, structural factors, attitudes, psychological issues and stigma.

A different type of barrier, namely the lack of a definitive test, was described as the top barrier to timely diagnosis (followed by insufficient information from patients and carers) by a total of 996 physicians who were surveyed in the United States, the United Kingdom, France, Italy and Japan. However, only an unspecified proporotion of the participants were GPs and details of the methodology are lacking (Lilly, 2012).

Lack of knowledge about dementia

One possible contributing factor that has been identified is that of a knowledge gap (Bowers et al., 1992; Downs, 1996; Iliffe and Wilcock, 2005; Koch and Iliffe, 2010; Olafsdottir et al., 2001; Tsolaki et al., 2009; Turner et al., 2004). In a systematic review of barriers to diagnosis based on eleven studies, GPs highlighted their lack of knowledge about community services and resources, making the diagnosis, the ability to distinguish between dementia and normal ageing (and subsequent fear of misdiagnosing) and how to disclose the diagnosis (Koch and Iliffe, 2010). In a survey-based study involving 75 general practitioners in Greece none of the GPs were aware that people as young as 50 could have AD (Tsolaki et al., 2009).

The results of a self-administered questionnaire completed by 268 Scottish GPs revealed that 48% had difficulty establishing a diagnosis, 41% in disclosing the diagnosis to the patient and 21% in disclosing the diagnosis to a family member (Downs et al., 2000). Significantly more female GPs reported difficulty disclosing the diagnosis to the patient and of the 55% of GPs who experienced difficulty accessing information on support, there was a significantly higher number of younger GPs. This suggests that difficulties linked to diagnosis are fairly common but that specific aspects of diagnosing and disclosing the diagnosis of dementia are more problematic to some sub-groups of GPs than others.

A lack of knowledge amongst GPs about dementia may affect their confidence in diagnosing and their ability to detect dementia at an early stage (Audit Commission, 2000; Cahill et al., 2006; Ólafsdóttir et al., 2001; van Hout et al., 2000). It has also been found that many GPs fail to differentiate between different types of dementia, which may, in addition, have implications for the provision of appropriate treatment and support (Rait et al., 2010). Whether this lack of differential diagnosis is due to a lack of knowledge or failure to accord importance to it is not known.

Lack of knowledge might be logically linked to a lack of training. Perceived lack of adequate training was recorded in a study in which only 31% of GPs in London believed that they had received sufficient basic and post-qualification training in the diagnosis and management of dementia (Commissioning Support for London, 2009). On the other hand, some GPs have reported a fair degree of confidence in their ability to diagnose dementia. Out of a total of 127 GPs, 64% declared that they were confident about their ability to make a diagnosis (Turner et al., 2004). In Germany, the mean score on a self-completed assessment of competency to diagnose dementia by 211 GPs was 4.31 out of 6 and the mode score 5 (Kaduszkiewicz et al., 2008b). Similarly, Brodaty et al. (1994) concluded on the basis of a postal questionnaire completed by 1,474 GPs in Australia, that GPs were able to recognize the clinical features of dementia which are helpful in making a diagnosis. However, it is not known whether this actually translated into practice. A Swedish postal survey revealed that GPs had a fairly good knowledge of dementia but nevertheless felt that they would benefit from more training (Ólafsdóttir et al., 2001).

Koch, Iliffe and the EVIDEM-ED project (2010) make a distinction between GPs' perceptions of their knowledge and their actual knowledge or training. They also highlight the difficulties which GPs may have to learn from experience due to the low number of new patients with dementia or possible dementia they are likely to encounter each year (1 to 2 patients on average per GP in Britain) (Koch et al., 2010). They conclude that training in dementia should not be limited to the augmentation of clinical knowledge (e.g. as typically imparted by formal, didactic methods) but should focus more on an experiential learning approach (e.g. employing educational interventions which also address GPs' attitudes and their perceptions of their suitability and ability to make diagnoses).

Structural barriers

Each GP is personally responsible for ensuring that s/he has sufficient knowledge to detect and diagnose dementia but there must be an appropriate system in place to provide this. The absence of such a system therefore also represents a structural barrier to the timely diagnosis of dementia. A system is needed to facilitate the acquisition not only of medical knowledge but also of familiarity with people with dementia and issues related to dementia, which many GPs lack due to the limited number of people with dementia in their portfolios.

Other structural barriers include lack of time and lack of specialized dementia services.

Time

A study of 190 GPs and 3,674 patients in six European countries involving videotaped consultations and self-completed questionnaires revealed an average consultation time of 10.7 minutes, ranging from 7.6 minutes in Germany to 15.6 in Switzerland (Deveugele et al., 2002). Consultations in the United Kingdom were 9.4 minutes on average. This is ill-suited to the complex task of diagnosing (Boise et al., 1999; Cahill et al., 2006; 2008; van Hout et al., 2000) or managing dementia (Ólafsdóttir et al., 2001). Based on the findings from a focus group of 28 GPs who also filled out a questionnaire, Van Hout et al. (2000) conclude that the eight minute consultation limits the appropriate assessment of both cognitive impairment and the care needs especially of older people. One GP is quoted as saying that to diagnose dementia properly, it takes more than the available time. This was also the case in the study by Boise et al. (1999), who in addition found that lack of time was more frequently cited as a key factor hindering timely diagnosis by GPs in urban compared to rural practices.

Lack of specialized dementia services

Bowers et al. (1992) draw attention to a lack of appropriate testing procedures and Cahill et al. (2006; 2008) to the lack of specialist diagnostic services, particularly in rural areas. The latter was based on a mixed methods design involving a random sample of 300 GPs (selected from a national database of registered GPs) from Ireland who took part in a postal survey. This included one open-ended question on reasons for late presentation for diagnosis. It also involved a focus group of seven GPs (a convenience sample of seven people). In the postal survey, 55% of GPs who responded declared having had to wait a minimum of 3 months for geriatric service consultations, whereas access to neuropsychological services was even worse. In the focus group discussion, the GPs drew attention to geographical differences in access to CT scans and MRIs although the authors were uncertain as to whether this disadvantage was real or perceived.

Attitudes towards timely diagnosis and treatment

Many GPs remain unconvinced about the usefulness of a diagnosis of dementia and this is often linked to therapeutic nihilism. They feel that they have nothing to offer people who are diagnosed with dementia and/or that existing medication is of limited benefit to patients with Alzheimer’s disease.

It is therefore considered pointless to carry out a thorough investigation (Audit Commission, 2000; Boise et al., 1999; Brodaty et al., 1994; Hansen et al., 2008; Iiffe et al., 2006; Renshaw et al., 2001; Vernooij-Dassen et al., 2005; Wolff, et al., 1995). The results of focus group discussions involving 78 primary care physicians in the United States of America reveal that many had fatalistic attitudes about dementia, linking it to normal ageing rather than a treatable medical condition (Boise et al., 1999). On the other hand, in the study by Cahill et al. (2008), almost a decade later, only a small percentage of GPs considered early diagnosis as being of no value. In a small scale qualitative study carried out by De Lepeleire et al. (1994), 9 out of 10 GPs interviewed felt that diagnosis was important but it should be noted that these were all GP trainers which limits the transferability of the findings.

Psychological barriers

Embarrassment has been expressed by GPs linked to discussing memory loss and possible dementia with patients, particularly those with whom they have built up a relationship over the years (Cahill et al., 2008; Iliffe et al., 2005; van Hout et al., 2000). Concerns about the psychological impact of the diagnosis on the patients have been found (e.g. resulting in shame, anxiety and isolation for patients) (Cahill et al., 2008; Iliffe et al., 2003). The nihilistic attitudes described in the previous sub-section also suggest possible feelings of hopelessness or helplessness (as described by Keightley and Mitchel in 2004 relation to nursing staff and clinical psychologists). Downs et al. (2000) found that disclosure was a key challenge for many GPs. This was linked with a recognition of their limited communication skills.

Van Hout et al. (2000) highlighted the problem whereby GPs refer patients to specialists to follow, when they have a suspicion of dementia but the patients do not always comply perhaps because they are in denial. The issue of denial by patients was also highlighted by Cahill et al. (2006; 2008), whereas De Lepeleire et al. (1994) detected denial also on the part of the GPs who, like the families, did not want to be confronted with the facts.

Stigma

Stigma has been specifically highlighted as a factor which may interfere with timely diagnosis (Cahill et al., 2008; Husband, 2000; Iliffe et al., 2003; Kaduszkiewicz et al., 2008; Pentzek et al., 2005; and Van Hout et al., 2000; Vernooij-Dassen et al., 2005). Stigma is also believed to interfere with the disclosure of the diagnosis which is part of the diagnostic process (Bamford et al., 2004; Boise et al., 1999; Brodaty et al., 1994; Cahill et al., 2008; Iliffe et al., 2005). There may be cultural differences as Boise et al. (1999) found that GPs in the US feared the impact of stigma in relation to the disclosure of a diagnosis of AD but not of dementia.

GPs have, for example, expressed concern about the impact of the diagnosis because of the associated stigma (Brodaty et al. 1994; Cahill et al., 2006; 2008). A postal survey of 1473 GPs in Australia revealed that 7.2% felt that GPs had to be quite sure about the diagnosis of dementia before disclosing it due to the stigma attached to dementia (Brodaty et al., 1994). In the qualitative Australian study mentioned earlier, GPs expressed the belief that dementia was not a diagnosis people wanted to receive (Hansen et al., 2008).

Kaduszkiewicz et al. (2008) provide insight into GPs' perception of possible reasons lay people may have for not wanting such a diagnosis. They describe the belief of some GPs that lay people perceive dementia as something which leads to dependency on others (which is feared), as something that is shameful and as a condition which might result in people being stigmatized as "crazy". Some GPs mentioned the possibility that bringing up the topic of dementia might ruin the doctor-patient relationship, suggesting that patients could feel angry and offended. The study by Cahill et al. (2008) also indicated GPs' perception that some patients find dementia embarrassing, consider it a stigma, mistake it for normal ageing and have nihilistic attitudes regarding treatment, with some being in denial.

On the basis of a five-country qualitative study into factors affecting the timely recognition and diagnosis of dementia, involving multi-disciplinary focus groups (comprised of 23 experts in dementia from a range of disciplines including general practice), Vernooij-Dassen et al. (2005) concluded that stigma is the most powerful obstacle to timely diagnosis.

4.6 Gaps in the literature

The focus of this chapter, so far, has been on what is currently known about GPs' practices and perceptions with regard to timely diagnosis. The literature suggests that early diagnosis is considered important provided that it is timely but that this is far from being achieved. GPs are aware of several barriers to timely diagnosis, some of which are structural rather than based on individual knowledge, attitudes and behaviour. The literature also suggests that GPs believe that stigma is a significant barrier to timely diagnosis. There are, however, several important gaps in the literature which hinder a comprehensive understanding of the role of stigma in delaying the timely diagnosis of dementia. These are discussed in the remainder of this chapter.

4.6.1 Focus and depth of investigation into stigma

With the exception of the study by Werner and Giveon (2008), none of the studies on GPs’ perceptions of dementia involved an in-depth analysis of perceptions of dementia and their possible relationship to stigma. They were not set within a clear framework of stigma theory. The studies provide little detail about dementia-related stigma and of the nature of GPs' perceptions of the possible stigmatizing impact of diagnosis. Moreover, these studies did not set out to address stigma but rather stigma emerged from the findings. Consequently, they do not provide the depth of understanding about dementia-related stigma that a thorough exploration into that topic would bring.

Moreover, as it is often taken for granted that the meaning of stigma is clear, it is possible that participants understood the concept of stigma in different ways. Perhaps some had in mind discrimination and others negative labelling, whereas some may have been referring to stigma in its entirety.

The literature on stigma in other conditions is much richer. It has placed particular emphasis on identifying the components of, and contributing factors to, stigma as well as exploring how these components and contributing factors are manifested in the case of specific stigmas. This has resulted in greater insight into the stigma of specific conditions such as schizophrenia, leprosy and AIDS.

A study is needed which explores the components of, and contributing factors to, stigma whilst also giving participants the opportunity to talk about stigma as they understand it in relation to dementia and timely diagnosis.

4.6.2 Insufficient information about GPs' perceptions of dementia

Insufficient information is available to determine whether and if so in what way GPs' perceptions of dementia relate to stigma (e.g. whether GPs consider dementia discrediting, have stereotypes about it, believe that people with dementia experience loss of status and will suffer discrimination). Information about how GPs feel about dementia is also lacking. This means that we do not know how GPs feel when around people with dementia (e.g. anger, frustration or pity) or what kinds of fears dementia might arouse in them (e.g. fear of developing dementia themselves, of becoming dependent and ultimately, of death), some of which may represent latent ontological insecurities. Similarly, we do not know which aspects of dementia GPs think that lay people, most importantly their patients and the carers of those patients, find stigmatizing. This is important in the light of their concerns about the possible impact of a diagnosis and whether it would offset (at least in part) any possible benefits of diagnosis.

A study by Downs et al. (2002) into what GPs tell people with dementia and carers described a tendency to describe deficits and dysfunctions and emphasized the need for GPs to provide a more balanced picture of dementia. However, it is not known to what extent GPs themselves have such a balanced picture and if they do not, they cannot convincingly portray it to their patients.

Even if GPs are aware of stigma and believe that diagnosis is important, their personal perceptions of dementia may affect the way that they portray dementia to their patients, how they react when symptoms of dementia are detected or when their patients speak about related concerns, how they broach the issue with patients, the terms they use and issues linked to referral and disclosure of the diagnosis. All these factors may affect GPs' readiness to address the issue of dementia during consultations and to refer patients to specialists for diagnosis, which may result in late diagnosis, no diagnosis or failure to disclose the diagnosis.

4.6.3 Disentangling GPs' perceptions of dementia and those they believe lay people to have

GPs may be knowledgeable about dementia as a medical condition but they are also members of society in which other meanings associated with dementia have been socially constructed through interaction within a specific cultural context. Berger and Luckmann (1966) describe the existence of a kind of common-sense knowledge that is shared with others and taken for granted as reality. It is based on an ongoing correspondence between one person's meanings and those of other people and involves constant negotiation and adaptation through past and current conversations which reaffirm reality against the background of a world that is simply taken for granted. However, such knowledge does not always totally correspond.

> *"My "here" is their "there". My now does not fully overlap with theirs. (…/…) All the same, I know that I live with them in a common world" (Berger and Luckmann, 1966, p. 37).*

Or as Blummer put it, “people may be living side by side yet be living in different worlds” (Blumer, 1986, p.11 cited in Pregernig, 2002). We do not know enough about the common sense, taken-for granted knowledge that GPs have about dementia which may, in addition to their professional and scientific knowledge, affect the way they deal with the issue of dementia (i.e. managing diagnosis and dealing with patients) in the specific cultural context of England. We do not know in what way their perceptions of dementia overlap with those of lay people and in what way they are different.

Healthcare professionals need to be aware of their own beliefs, emotional reactions and perceptions of their patients as they have the potential to both stigmatize and de-stigmatize (Sartorius, 1998; Schulze, 2007). In addition to examining their own attitudes, it is important that they challenge professional behaviours that may stigmatize others (e.g. by refuting fatalistic notions about prognosis and treatment, shifting the focus from curing to caring and avoiding the tendency towards cynicism or paternalism) (Sartorius, 1998). Servais and Saunders (2007) point out (with reference to psychologists) that attitudes of professionals towards patients may be motivated by their humanitarian and professional interests as well as by their training and experience but they are also influenced by sociocultural and psychological factors that may give rise to negative perceptions, distancing and “disidentification” (i.e. not considering themselves as similar).

The dementia studies do not permit GPs’ personal perceptions to be disentangled from those attributed to their patients (because as already explained, data is lacking on the former). When trying to tackle the stigma of dementia, an understanding of both is necessary. It cannot be presumed that

GPs' perceptions of dementia differ from those of lay people or, on the contrary, that they are the same.

Lauber et al. (2004) draw attention to the fact that psychiatrists are sometimes used as role models or opinion leaders in anti-stigma campaigns but that they must be aware that their attitudes do not differ from those of the general public and consequently, they may need to improve their knowledge about stigma and discrimination towards people with mental illnesses. This observation may well also apply to GPs with regard to their perceptions of dementia but there is, as yet, insufficient information on this issue.

Information about GPs' perceptions of dementia and about their understanding of those of lay people is important as such perceptions may well affect their own behaviour. We do not have sufficient knowledge about GPs' perceptions of the impact that a diagnosis of dementia may have on their patients. The expected impact of diagnosing somebody with dementia depends to some extent on how one thinks that that person perceives dementia. Lay people's perceptions of dementia may be important in determining how they approach the issue of diagnosis and some insight into such perceptions was provided in Chapter 3. However, GPs' understanding of those perceptions may equally affect how they (the GPs) approach the issue of dementia with them (irrespective of whether they correspond to lay people's actual perceptions or not). More information is needed about GPs' perceptions of dementia and their understanding of lay people's perceptions, and the distinction between the two must be clear.

4.7 Summary

Timely diagnosis is essential to early intervention and support. GPs play a key role in timely diagnosis but are not fulfilling it due to a range of barriers such as a knowledge gap, therapeutic nihilism and time constraints. Stigma has also been implicated in delays to timely diagnosis. There is an increasing awareness of dementia as a stigma but little empirical research about GPs' perceptions of dementia as a stigma, how they think it is perceived by lay people and what it is about dementia which makes is a stigma. The emphasis of the studies has been on GPs' awareness of how dementia interferes with timely diagnosis. In most studies, the GPs seem to have been considered mainly as medical experts (i.e. in the context of their professional function) with less attention being paid to how they perceive dementia and how these perceptions relate to stigma.

The studies described in this chapter reveal a considerable awareness of the potential stigma of dementia and its possible impact on diagnosis. Much less is known about GPs' perceptions of dementia as a possible stigma and about their sensitivity to the perceptions of dementia that lay people may have (other than in relation to fear).

4.8 Conclusion

We know that dementia is perceived as a stigma by lay people. However, this is just one side of the coin – the other side being GPs. As stigma is socially constructed, everyone in society, including GPs, contributes towards the construction and perpetuation of dementia-related stigma. These two groups separately, together and in the wider social context contribute towards the construction and perpetuation of dementia-related stigma and each can contribute towards overcoming stigma. Consequently, there is a need to address this topic in the GP population as well.

GPs cannot simply be considered as neutral professionals. They are the main gatekeepers to a diagnosis of dementia and therefore have a pivotal role to play in ensuring timely diagnosis (Downs, 1996) as well as in helping overcome stigma. GPs are expected to have or develop attitudes which enable them to deal with patients competently and with impartiality (Lauber et al., 2006). Perceiving dementia as a stigma could jeopardize this or interfere with their ability to help patients to deal with perceptions of dementia as a stigma.

A study is needed which specifically explores the stigma of dementia from the perspective of GPs. Such information is needed if we are to effectively tackle the stigma of dementia and its interference with timely diagnosis through the development of targeted measures. This PhD proposes to fill this gap. Such a study should specifically focus on GPs' perceptions of dementia as a stigma and of the impact of such stigma on timely diagnosis. It should be based on a social constructivist understanding of stigma and cover the main components of, and contributing factors to, stigma as identified by key theorists. This exploration should also provide data about GPs' perceptions of dementia as a stigma amongst lay people (which would include their patients and potential or future patients), taking care to distinguish between their own perceptions of dementia as a possible stigma and those of lay people.

4.8.1 The aim of the study

The aim of this study is to explore how GPs' perceptions of dementia relate to stigma, to propose a first step towards developing a conceptualization of the stigma of dementia and to consider the possible impact of stigma on timely diagnosis.

4.8.2 The research questions

The objectives of this exploratory, qualitative study translate into the following three research questions:

1. In what way do GPs' perceptions of dementia reflect the various components of, and contributing factors to, stigma?
2. How do GPs' perceptions of dementia contribute towards the development of a conceptualization of the stigma of dementia?
3. What do GPs' perceptions of dementia, stigma and diagnosis reveal about the role of stigma in delaying timely diagnosis?

In chapters 2 to 4, the literature pertaining to stigma, perceptions of dementia and barriers to timely diagnosis was considered. This revealed that stigma is a complex social phenomenon which applies to dementia and can be detected in the perceptions of dementia held by lay people and healthcare professionals. This, combined with the perceived gaps in the literature, led to the formulation of the above research questions. In order to find responses to these questions, an appropriate methodology and suitable methods of data collection and analysis are required. This will be addressed in the Chapters 5 and 6.

5 Research methodology

The section on research methodology will address the choice of methodology covering issues such as the appropriate research paradigm in which to situate the study and the most suitable approach to data collection and analysis. In order to justify the various choices made, alternatives will be discussed.

5.1 General methodological considerations

5.1.1 Research paradigm and overall theoretical lens

Paradigms are world views or belief systems which influence the way that researchers approach and carry out their studies (Guba and Lincoln, 1994). This study is set within the paradigm of interpretivism (sometimes referred to as constructivism). This emphasizes the social construction of reality, the importance of meaning, the impossibility of obtaining value-free knowledge, an emphasis on inductive logic and an awareness that methods of inquiry used in the natural sciences are not wholly appropriate for the study of social phenomena because the social world is mediated through meanings and human agency (Ritchie, 2003; Tashakkori and Teddlie, 1998). Qualitative research methods are generally associated with the interpretivist paradigm.

5.1.2 Research methodology, approach and tradition

A qualitative research methodology was adopted for this study. This is appropriate for studies which delve into complexities and processes, and focus on little-known phenomena (Marshall and Rossman, 1995). As highlighted in the literature review, numerous studies have examined the stigma of a wide range of medical conditions by means of quantitative and qualitative measures but with an emphasis on the former. The literature review revealed several studies which addressed a range of issues relevant to lay people's perceptions of dementia as a stigma. However, GPs have been largely excluded from research into the stigma of dementia, other than in their expert capacity as medical professionals commenting on this social phenomenon, either directly or in connection with other topics such as diagnosis.

Examining their own perceptions of dementia and how these relate to stigma is a new area of investigation. Consequently, an exploratory approach is most suitable and in keeping with a qualitative methodology. Exploratory approaches are particularly suited to studies which aim to investigate little understood phenomena, identify important variables and generate hypotheses for further research (Marshall and Rossman, 1995). A qualitative approach should provide deeper insight into GPs' perceptions of dementia and may lead to the discovery of paradoxes, contradictions and ambiguities. As this study is based on perceptions of dementia as a stigma and not on the actual stigmatization of people with dementia, neither dementia studies based on attribution theory nor studies into stigma in other conditions based on quantitative measure of stigmatization or the experience of stigma were used to guide this study (i.e. they did not form part of the theoretical framework). However, in providing a clearer understanding and better definition of the subject matter (Ritchie, 2003), this study could serve as a prelude to a quantitative inquiry aimed at measuring GPs' perceptions of dementia as a stigma or of the extent to which they stigmatize people with dementia. Data were therefore collected, analysed and interpreted using methods typically associated with qualitative research (which will be described in the following sub-sections).

An interactive approach to qualitative research was used to guide the development of the study (Maxwell, 2005). This is based on a model, mainly comprised of five components, namely goals, conceptual framework, research questions, methods and validity. These components are common to the majority of research designs, but this approach is described as interactive because the components of the model are interactive rather than linear/one-directional. This allows the researcher to be able to make changes to the design in the course of the study in response to circumstances under which the study is being conducted. The interactive nature of the research design applies to all the components. This was important in this study in which the research questions were continually refined as the research process unfolded, the methods of recruitment were adapted in response to circumstances. The methods of data collection and analysis also underwent some changes.

Within the context of the broader function of social research, this study could be broadly defined as contextual as it involves mapping a range of dimensions within a social phenomenon, displaying the features of that phenomenon, describing the meanings that people attach to that phenomenon and identifying or defining typologies (Ritchie, 2003). There are also explanatory and generative elements to the study.

Certain research traditions are generally associated with qualitative research methods. These include, amongst others, ethnography, phenomenology, symbolic interactionism, critical theory and constructivism. The research tradition and guiding theoretical lens for this study were constructivism, the aim of which is to display “multiple constructed realities through the shared investigation (by researchers and participants) of meanings and explanations” (Snape and Spencer, 2003, p.12). Further details of the influence of constructivism (and also of symbolic interactionism) can be found in the sub-sections on the ontological and epistemological positions (two of the main axioms of research paradigms) taken in this study.

5.1.3 Ontological position

Ontology is concerned with the nature of reality. The position adopted in this study is that of ontological relativism (Guba and Lincoln, 1994). This is based on the belief that there is not one social reality but rather multiple social realities which are created by people through interacting and reflecting within the world in which they live. This construction of reality takes place in a particular social context and is therefore influenced by a range of factors such as the economy, politics, history, education, the media and so on. “Subtle idealism” is also appropriate to this study. This is an ontological stance which reflects the belief that (social) reality is only knowable through socially constructed meanings (Ritchie, 2003).

The process whereby society, reality and the self are socially constructed (i.e. through interaction and communication) within a dynamic process in which meanings are created, refined, challenged and transformed, has been described as symbolic interactionism (Blumer, 1969, Mead, 1934). Berger and Luckmann (1966) add that the social construction of reality is not limited to the people with whom one interacts in person but includes predecessors, successors, people you briefly encounter and those you simply know of (such as members of the royal family, film stars and well-known criminals).

They also claim that people apprehend and deal with others by means of typificatory schemes (e.g. as a woman, a worried person, a potential buyer etc.). These typificatory schemes may, unless challenged by the person thus typified, hold until further notice and determine actions in a given situation (Berger and Luckman, 1966). It is therefore important to try to understand the realities of different people and groups, which in this study are the realities of GPs and those they understand lay people to have.

5.1.4 Epistemological position

Epistemology is concerned with the manner by which knowledge is constructed and the relationship of the knower to the known (Tashakkori and Teddlie, 1998). This study is guided by a constructivist epistemology which is considered particularly suitable for qualitative research (Creswell, 2003).

The knowledge obtained in this study consists of GPs' perceptions of dementia (including those they believe lay people to have). Such knowledge does not consist merely of the words themselves but rather what is meant by those words and how this is interpreted by the researcher. Knowledge was therefore not out there waiting to be discovered but rather recreated in the course of the study. Knowledge is never complete or finished but constantly being recreated by the participants and through interaction between the participants and researchers.

This corresponds to Kvale and Brinkmann's metaphor of the researcher as a traveller, who explores the many domains of a country, roaming freely on unknown terrain, and walking along with the local inhabitants whilst asking them questions and encouraging them to tell their own stories of their lived world. The implications, metaphorically speaking, are that the traveller interprets the stories told, may uncover new knowledge, may change during the journey and may uncover previously taken-for-granted values of his/her own (Kvale and Brinkmann, 2009). This does not mean that knowledge cannot be recorded and becomes contaminated or distorted by researchers but rather that it is constantly being created and recreated with some features remaining fairly constant and others being modified or rejected along the way.

This study could be seen as a snapshot of a group of GPs' perceptions of dementia at a particular moment in time. One might question the value of having such a snapshot which as soon as it has been taken reflects knowledge about "realities" of the past. According to Stacey's theory of complex responsive processes of relating (which draws on the work of Mead and Elias), human interaction is an iterative process (Stacey, 2003). Interaction, which takes place in a specific location (e.g. between a GP and a lay person), is influenced by the past and at the same time implicitly or explicitly based on expectations about the future. By means of "self-organizing patterns of meaning and relating" (SOPMR), there is a continuous re-enactment or recreation of meaning and the possibility for novel or stable patterns of meanings to emerge from human interaction (Suchman, 2006). Consequently, greater insight into GPs' perceptions of dementia and how they relate to stigma may contribute towards the development of strategies to influence in a positive manner the ongoing, dynamic construction of perceptions of dementia.

5.2 Reasons for choosing an approach based on framework analysis and the N-C-T approach to qualitative data analysis using Atlas.ti

5.2.1 Introduction

The collection and analysis of data involved the combined use of two approaches, namely framework analysis and computerized NCT analysis. Framework analysis was chosen as a method of managing and analyzing the data as it is a very structured approach, incorporating a conceptual framework, which can be easily combined with computerized NCT analysis by means of Atlas.ti, which facilitates the handling of large amounts of qualitative data. The latter is an approach devised by Friese (2012), based on over 20 years' experience working with and developing Atlas.ti, which is a CAQDAS (Computer-Aided Qualitative Data Analysis Software) programme. Before deciding on this combined approach to the collection and analysis of data, several candidate approaches were considered. These are described below.

5.2.2 A grounded theory approach

This study is firmly anchored within a framework of stigma theory, with two theories serving as a guiding structure and forming the basis for the predetermined categories as well as the development of the semi-structured interview guide. This could be considered as being in direct opposition to grounded theory in which researchers generally approach the research topic without fixed assumptions and let the findings emerge from the data. Charmaz (2006) describes this as not forcing preconceived ideas and theories directly onto the data. Corbin and Strauss, on the other hand, state:

> *"Qualitative research begins with a broad question and often no preidentified concepts. Concepts are identified in and constructed from the data." (Corbin and Strauss, 2008, p. 21)*

However, Corbin and Strauss (2008) do acknowledge that researchers bring to the study considerable background knowledge of relevant literature. They also accept the possible usefulness of a theoretical framework as a conceptual guide to the choice of concepts to be addressed, the development of research questions and the framing of the results of the study. The following quote is an example of one way in which a theoretical framework can be helpful.

> *"…..a previously identified theoretical framework can provide insight, direction, and a useful list of initial concepts. However, a researcher should remain open to new ideas and concepts and be willing to let go if he or she discovers that certain "imported" concepts do not fit the data." (Corbin and Strauss, 2008, p.40)*

Moreover, Corbin and Strauss claim that the use of a theoretical framework can contribute toward the exploration of a core concept across different groups which in turn can lead to greater depth, breadth and level of abstraction of the guiding theory. This fits in with the overall aim of this study which is to study GPs' perceptions of stigma and to consider what the findings suggest about the concept of stigma and also with the use of directed content analysis.

With grounded theory, the findings are grounded in the data and this is an inductive approach which leads to the development of theory. This study involves a combination of deductive and inductive logic but the main aim of the study is not to generate theory. Nevertheless, one of the aims is to test the applicability of existing conceptualizations of stigma which are being used to ensure that it is really stigma that is being explored in its entirety. This may lead to tentative conclusions about necessary refinements of existing theory or about the specific nature of the stigma of dementia which would in a way involve the development of theory and is therefore in keeping with the grounded theory approach. Furthermore, Miles and Huberman (1994) claim that some degree of theory construction is required in all qualitative research and Strauss (1987) suggests that both induction and deduction (as well as verification) are essential parts of grounded theory.

Consequently, whilst this study does not attempt to adopt a pure grounded theory approach, it is undeniably influenced by the grounded theory philosophy in that whilst the researcher has pre-determined categories, she is open to new concepts and is partly interested in the generation of theory. As will be described later, the analysis of the data is also influenced by techniques which originate from grounded theory such as constant comparison, the search for negative cases and the use of memos and diagrams. The main reason for not claiming that the study adopts a grounded theory approach is that the generation of theory is not the main goal as an important aspect of this study is to test the appropriateness of current stigma theory for an understanding of the specific stigma of dementia based on the perceptions of a relatively unexplored group of people. Nevertheless, this study does not stand in opposition to grounded theory. As Charmaz (2006) suggests, the grounded theory approach can complement other approaches to the analysis of qualitative data.

5.2.3 An ethnographical approach

Ethnographic studies typically involve the in-depth study of a culture in which researchers immerse themselves within people’s lived realities in a natural setting, within a particular cultural context and over a prolonged period of time (Creswell, 2003; Newell and Burnard, 2006). The method of data collection tends to be observation but may also include interviews and the aim is to produce a detailed account of a particular culture and social structure of a particular group. This includes the way people live and behave, and what they think, feel and believe. In the past, this tended to be a totally different culture to the one in which the researcher lived but nowadays it may include the researcher's own culture or a sub-culture within it.

Apart from the fact that it would be difficult if not impossible, as a lay person, to become totally immersed in the sub-culture of GPs, observing and interacting with them in their daily lives, this approach was not suited to this study as the focus was on their perceptions of dementia and people with dementia and not in understanding the whole sub-culture of GPs. Nevertheless, this study is contextualized by the subculture of such practitioners, which informs their views.

5.2.4 A phenomenological approach

The phenomenological approach is closer to the research aims of this study in that it is suited to studies in which the researcher is interested in how participants make sense of the world (which would include their perceptions of various aspects of that world) but more in the sense of their perceptions of their own experiences. It is about how they view their lives and how they live their lives from *inside* (Newell and Burnard, 2006).

This study was aimed at exploring the diverse and multiple meanings that GPs attach to dementia within the context of stigma theory. Whilst searching for a wide range of perceptions, there was an interest in some degree of commonality. This is not the aim of phenomenological research which focuses on the lived experience of individual people and is much more about their inner worlds. In this study, some GPs spoke about how they were affected by interaction with people with dementia, of their existential fears and of their personal experience of caring for a relative with dementia and this took the interview to a deeper level. The focus of this study was on GPs' socially constructed meanings and how they make sense of dementia, which was more turned towards the external world than to their deep, inner experience.

5.2.5 An approach based on content analysis

Hsieh and Shannon (2005) describe conventional content analysis in a way that seems, on the surface, to be quite similar to grounded theory. They state, for example, that preconceived categories and theoretical perspectives are avoided and that the categories and the names of the categories should flow from the text. As stated above with regard to grounded theory, this does not fully correspond to the aims and design of this study.

Content analysis is often described as manifest or latent. The former addresses the surface meaning and is generally associated with quantitative methods, and the latter assesses the underlying meaning and is generally associated with qualitative methods of analysis. However, Hsieh and Shannon (2005) point out that both can be used for qualitative research as it depends on what the researcher wants to do with the data. They describe summative content analysis as a method which starts with the identification and quantification of words in a given text. The researcher may then look at the context in which the words are used, by whom and how that differs to less frequently used words. For example, the researcher might consider whether women use a certain term more than men do. Alternatively, the researcher might notice that participants only use a certain term when expressing uncertainty or anger, and a different set of words when speaking in a more neutral manner about the topic.

The aim of conventional content analysis is described as being at most to develop concepts or build models. Directed content analysis, on the other hand, is an approach which can be used to validate or extend conceptually a theoretical framework or theory. It is particularly suited to topics for which there is already a theory or prior research but which are incomplete or would benefit from further investigation (Hsieh and Shannon, 2005). This corresponds more to this study, which involved the use of pre-determined categories and the testing and possible refinement of existing conceptualizations of stigma.

On the other hand, the aim of this study was wider, seeking to understand GPs' perceptions of dementia, and the main reason for having a conceptual framework was in order to ensure that stigma in its entirety was addressed and not just one aspect of it, not principally to test that conceptualization. For this reason, it was important to be open to all GPs' perceptions, not just those covered by the pre-determined categories. It is still possible to code non-related data using the directed content analysis approach but this is not the emphasis or the starting point of that particular approach.

5.2.6 The approach finally adopted

A combined approach to the collection and analysis of the content of the data, involving framework analysis and Atlas.ti was best suited to the type of data being collected and to the research questions.

Framework analysis can be used at all stages of the analytic process to analyse data irrespective of the tool used to aid that process (Spencer, Ritchie and O'Connor, 2003). In this study, it provided a clear structure within which to organize and manage the data and to progress from description to the interpretation of data and the possible generation of theory. With a slight adaptation to involve the use of pre-determined categories as a guiding framework, it can, like directed content analysis, also serve as a method to validate or extend conceptually the theoretical framework guiding the study. In this study, framework analysis involves the use of theory to guide the collection and analysis of data. Whilst theory may also develop out of the data, the generation of theory is not the main aim of the study or of the choice of this approach.

The use of directed content analysis and grounded theory techniques within the context of N-C-T and framework analysis (as described in section 5.3) results in the testing and validation of the guiding theoretical framework (Hsieh and Shannon, 2005) and the development of theory (Corbin and Strauss, 2008). Directed content analysis tests by qualitative means whether general conceptualizations of stigma are relevant and meaningful to the stigma of dementia. This does not involve testing the relationship between independent and dependent variables by statistical means. It involves closely examining GPs' perceptions to determine whether and in what way they reflect current theory and new hypotheses can be developed.

The generation of theory, on the other hand, reflects the philosophy of the grounded theory approach to qualitative research. The aim of grounded theory is to generate hypotheses after and not before the collection of data, based on questioning and theoretical coding, which in this study, allows the hypothesis to be grounded in what the GPs say and not in the literature. Whereas the categories and themes emerge from the data, the hypotheses are created based on the researcher’s interpretation of the data (Corbin and Strauss, 2008). The hypotheses, thus generated, can be tested in further studies.

5.3 The major characteristics of the N-C-T approach to qualitative data analysis with Atlas.ti and to the framework analysis approach

5.3.1 N-C-T approach to qualitative data analysis with Atlas.ti

The N-C-T approach to qualitative data analysis is an approach to the analysis of qualitative data by means of the Atlas.ti computer programme as developed by Susanne Friese (2012), based on an original idea of Seidel (1998). The three main components of this approach are noticing things, collecting things and thinking about things.

Noticing things involves finding interesting details in the data (e.g. whilst interviewing the GP, whilst transcribing the document and eventually when coding the transcript). It is not considered important at this stage whether the researcher is using an inductive or deductive approach nor whether the data coded is descriptive or conceptual. It is simply important to notice what is in the data, give it a name (i.e. code it) and where appropriate write memos or comments for further reflection.

Collecting things is likened to working on a jigsaw. It involves collecting and sorting the data by identifying similarities and differences between the various pieces of data. People look for things which resemble each other and separate those which are different. Some pieces may be different in some respects and the same in others. As Friese (2012) points out, failure to recognize similarities can lead to hundreds if not thousands of codes depending on the size and nature of the project. By means of constant comparison (as described by Strauss and Corbin, 1998), things that are conceptually similar can be grouped together and those which are different separated, thus reducing the number of codes and contributing towards the development of higher levels of conceptualization.

Continuing with the analogy of the jigsaw, in some studies, the picture on the jigsaw box cover, which provides some guidance to the collecting process, may be the literature or the research questions. In other studies, the "wasgij" (jigsaw backwards) may be a more appropriate analogy in that the picture on the box cover is not what the completed jigsaw will look like. Rather it portrays a character and the completed picture will resemble that character's perception of something (which the person doing the wasjig must find). This study could be considered as a combination of both approaches as the theoretical framework and research questions offer certain clues as to what to look for but the end result must be the perceptions of the characters on the cover (i.e. the perceptions of the GPs as understood by the researcher). This may be quite different to what the researcher expected to find.

Thinking about things involves examining the things which have been noticed and collected, further comparison of how the various pieces fit together or differ, but also looking for patterns, sequences and higher order concepts represented by the emerging data. The close examination of the data involves asking questions about the data and about the phenomenon being studied (Corbin and Strauss, 2008). This is an iterative process in that these components are interrelated and do not generally operate in a linear manner.

Moreover, whilst these are described as separate steps in the process, Seidel (1998) points out that the process is holographic as noticing things tends to already involve mentally collecting and thinking about them. Similarly, at the collecting and thinking about things stages, a new light may be cast on the phenomenon leading to a re-reading and coding of the raw data.

This computerized approach to data analysis gives the researcher considerable freedom to move about data, rename, merge and split codes, and try out different ways of organizing the data into higher and lower levels of conceptualization. The query tool and the graphic display of data, which includes the possibility to record relationships within the data, permit the easy handling and management of large amounts of qualitative data and ways to explore the data collected which would be difficult to achieve manually. The supporting description of the processes of noticing, collecting and thinking represents a very general description of what goes on during any coding process of qualitative data. It is not a specific procedure to follow.

5.3.2 Framework analysis

Framework analysis provides a useful means to analyze cross-sectional, descriptive data through a series of inter-connected stages, which guide the systematic analysis of data from its initial management through to the development of a coherent explanation of the phenomenon (Smith and Firth, 2011). Spencer, Ritchie and O'Connor (2003) describe framework analysis as an analytic hierarchy made up of a series of "viewing platforms", each of which involves an analytical task which enables the researcher to make sense of his/her data. This is, however, an iterative process in that the researcher can go backwards and forwards between the various platforms looking for new clues, checking assumptions and seeking underlying factors.

The different stages within this overall process also represent different levels of abstraction of the data. The term “framework” refers to a matrix-based method for ordering and synthesizing data. Their model of analysis consists of nine stages which are further divided into three overall phases: data management, descriptive and explanatory.

Data management:

In the first phase, the researcher familiarizes him/herself with the topic and the data in order to develop a conceptual framework or “index” consisting of a set of concepts or themes according to which the data can be labeled, sorted and synthesized. Using the analogy of “conceptual scaffolding”, Spencer, Ritchie and O’Connor (2003) liken the process of familiarization to the construction of the foundation of a structure. To build this foundation, which covers the range and depth of the data, researchers should familiarize themselves with the data (not necessarily all of it) and also consider any other relevant factors such as the diversity of the sample, the research questions and the issues addressed in the interview guide. The terms used in the index should ideally reflect terms which are found in the data but may be more abstract depending on the requirements of the study.

Fragments of data (i.e. selected quotations) can then be labelled or tagged. Ritchie et al. (2003) describe this as indexing as it involves indicating which category is being referred to or is reflected in a particular quotation. As will be described later, this process was slightly different in this study, as the indexing was carried out after an initial open coding process whereby fragments of data were first coded and only later associated with a particular category.

When qualitative analysis is carried out manually, the data must sorted so that those corresponding to the same category in the conceptual framework are located together. This can be done by creating physical piles of quotes which have been labelled, photocopied and cut out. Nowadays, this is usually done by CAQDAS packages such as Atlas.ti by making a visual distinction within the computer system between codes and categories, and by printing out lists of selected codes (e.g. those having been attributed to a particular category) accompanied by all the quotations belonging to those codes.

Another option, which is also a distinguishing feature of framework analysis, is the development of thematic matrices or charts with a separate chart for each topic with its sub-topics. On each chart, the relevant points from each piece of data and from each participant in relation to a particular topic are summarized. This helps clarify differences and similarities between each GP's perceptions with regard to a particular component or contributing factor. In addition, it facilitates the identification and comparison of positive and negative cases for each code as well as of the differences and similarities between GPs' perceptions and those they believe lay people to have. This process may lead to new hunches to be followed and also to reflect on missing data which might reflect differences between participants or factors linked to interviewing style to be addressed by the interviewer. The production of such tables is greatly facilitated by the various functions of Atlas.ti such as the generation of lists of codes based on certain criteria (i.e. negative cases and type of perception). Consequently, the production of such matrices is no longer necessary but it can be helpful to synthesize the data in this way in order to engage with the data and consider the meaning behind what was said.

Descriptive accounts:

Once the data has been coded on the basis of this index, descriptive accounts are prepared, key dimensions are identified and the range and diversity of each code mapped out. This involves looking at the words used and the meanings of what was said. The development of abstract concepts gradually moves towards the identification of core concepts or themes, which Spencer et al. (2003) call typologies. These are “specific forms of classification that help to describe and explain the segmentation of the social world or the way that phenomena can be characterized or differentiated” (Spencer et al., 2003, p. 214).

Explanatory accounts:

This represents a higher stage of analysis and usually occurs later in the analytic process. It involves moving from description to explanation of the data by looking for patterns of association and trying to understand why those patterns occur. Such patterns might include frequently occurring links, contradictions and associations between perceptions and certain characteristics of the participants. Spencer, Ritchie and O’Connor (2003) point out that whilst human behaviour is not law-like with clear causal relationships, neither is it chaotic. Again, Atlas.ti provides the means to interrogate the data (e.g. through the query tool, the node network function and the co-occurrence table).

5.3.3 Terms and definitions – analysis, coding and categorizing

Qualitative research involves the collection and analysis of qualitative data. Different issues linked to the collection of data were described earlier in terms of what constitutes knowledge (insofar as it is derived from research data) and how can or should it be obtained. The analysis of such data has been described as being:

> *"... the act of giving meaning to data. (.../...) taking data apart, conceptualizing it, and developing those concepts in terms of their properties and dimensions in order to determine what the parts tells us about the whole" (Corbin and Strauss, 2008, p.64)*

There are different levels of analysis and different terms are used to describe the data at each level. In this thesis, the terms code, category and theme will be used. Please see Figure 2.

The lowest, most basic level is that of the code, which is also the closest to the raw data and the least abstract. This is often "a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data" (Saldaña, 2009, p.33). Categories are higher-level concepts, which explain what the lower-level concepts have in common, are broader and more explanatory but lack the specificity and power of description that the codes have (Corbin and Strauss, 2008). These are the categories. Themes are the highest level of abstraction, describing more subtle and tacit processes, which lead to the construction of theory (Rossman and Rallis, 2003; Saldaña, 2009).

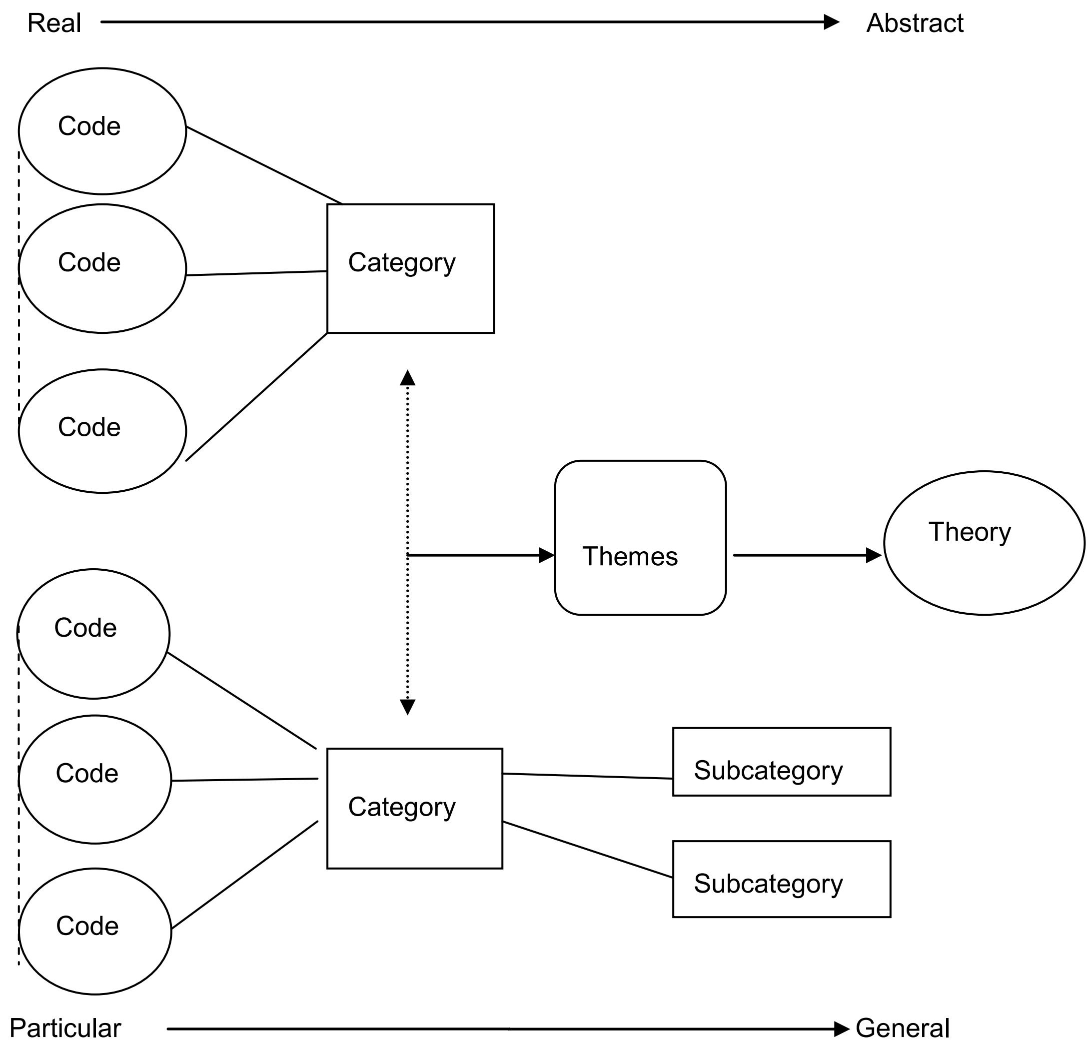

Figure 2: From codes to theory (Saldaña, 2009)

The above table shows the various terms used to describe the different stages or levels of coding. It is too simplified to serve as a depiction of the actual coding process. Moreover, it does not correspond to the combined inductive and deductive coding procedure adopted in this study.

5.4 Summary

In this chapter, arguments for and against the adoption of a range of research methodologies were presented. The strengths and weaknesses of different approaches to data collection and analysis were also discussed. A qualitative, exploratory approach was adopted for this study based on its suitability to the research questions and the type of data required. With regard to data collection and analysis, it was decided to use the N-C-T approach as a means to manage, structure and interrogate the data, combined with framework analysis as a means to focus the exploration on current conceptualizations without this being restrictive. The relevance of a grounded theory was recognised and certain elements of that approach incorporated into the study design.

5.5 Conclusion

The methodology chosen for this study is best suited to the research questions which reflect the gaps in the current state of knowledge. It is not the only possibility but should maximize the possibility of obtaining suitable data. Careful consideration must also be given to the way that the study is carried out within the overall design and the precise way in which the methods of data collection and analysis are applied to this specific study. This involves looking at additional issues such as how the participants are recruited and what measures can be taken to ensure the trustworthiness of the findings. This will be covered in the next chapter on methods.

6 Methods

In this chapter, details are provided of the procedure or methods to find and contact participants (including details of that sample), collect and analyse data and maximize the likelihood that such data will be considered trustworthy. This includes details of the justification for the use of various methods as well as details of the ethical and governance approval obtained for the study.

6.1 General issues

6.1.1 Overall design

This is a qualitative study involving qualitative methods of data collection and analysis. The reasons for adopting a qualitative approach have been explained in the previous section of this chapter.

6.1.2 Method of data collection

The semi-structured, in-depth telephone interview was the method of data collection used. This approach permits in-depth exploration of a particular topic with each individual in the context of a safe environment. Self-disclosure may be facilitated by the existence of a non-threatening environment and perhaps in some cases the fact that the participant is talking to a relative stranger rather than a personal acquaintance (Krueger and Casey, 2009).

Semi-structured rather than unstructured interviews help limit the amount of potentially unusable data and help the researcher to stay focused (Miles and Huberman, 1994). A structured approach, whilst ensuring that every GP provides information about every relevant theme, would have been too restrictive and risked being too focused and creating tunnel vision, which could have led to important issues being overlooked (Maxwell, 2005; Miles and Huberman, 1994). An unstructured approach might have resulted in too much information, not all of which would be relevant or useful to the study. The semi-structured interview was the “happy medium” which enabled a range of topics to be introduced whilst remaining sufficiently open to enable GPs to address other relevant issues (e.g. the influence of religion, financial issues and the ability to reciprocate). However, it does run the risk that participants may give far less attention to a particular question than the researcher might wish but this may be an indication that the question is not meaningful to them or relevant to their perception of the topic (which would be information in itself).

Telephone interviewing allows a greater degree of anonymity and less social desirability than is the case with face-to-face interviewing. According to Marshall and Rossman (1995), the use of interviewing as the sole method of data collection is appropriate if the aim of the study is to uncover and describe the perspective of participants (i.e. when the main focus is on their subjective views). Nevertheless, the influence of the researcher on the subjects (known as reactivity) cannot be completely overcome and must be acknowledged. Moreover, trying to minimize its effects is not generally regarded as important in the context of qualitative research (Hammersley and Atkinson, 1995).

6.1.3 Reasons for not using other methods of data collection

In addition to interviewing (including different forms of interviewing such as focus groups and phenomenological interviewing), there are three other primary forms of data collection in qualitative research, namely participant observation, direct observation and document review (Marshall and

Rossman, 1995). These alternative approaches to data collection (including different forms of interviewing) were considered but eventually ruled out. Participant or direct observation, for example, would have necessitated the observation of GPs with lay people or amongst themselves, neither of which were feasible due to ethical considerations linked to privacy, dignity and confidentiality and concerns about the authenticity of the observed behaviour. Moreover, it may have been difficult to infer perceptions from the professional dialogue and behaviour observed.

Face-to-face interviews would have permitted confidential and in-depth discussion about GPs perceptions but this approach is time consuming and requires advance commitment from GPs. Consequently, it was not considered compatible with GPs' professional routines.

The review of documents was not considered an appropriate means to explore GPs' perceptions due to the absence of appropriate documents which would be ethically and practically accessible to the researcher and which would cover the range of issues of relevance to the topic.

An anonymous questionnaire would have permitted a relatively large number of people to be reached at a relatively low cost and for a great number of issues to be addressed (Rea and Parker, 2005). However, this is incompatible with the task of obtaining rich, meaningful data from a targeted group of people. Whilst this approach has the advantage that people can fit it into their busy schedules, if sent by post many recipients would not be sufficiently motivated to respond. Questionnaires also tend to be much less flexible in that they lack the possibility for further clarification of responses, refinement of questions and the further development of the topic under exploration (Dane, 1990; Rea and Parker, 2005).

It was decided not to base the exploration of GPs' perceptions of dementia on one or more vignettes of a particular person with dementia as this might unnecessarily restrict GPs' responses to one or more hypothetical people with dementia. Also, it was felt that the use of vignettes constitutes, to a certain extent, the imposition of the researcher's perception of dementia onto the participants and it was their perception which was being sought. Furthermore, the use of vignettes in the form of case studies was not considered an appropriate method for telephone interviewing. The participants would have had to remember all the details in order to respond and might have eventually become overloaded and mixed up the different details of each vignette.

6.1.4 Offer of focus group not taken up by GPs

Focus groups have been successfully used in several studies in which GPs' opinions about diagnosis were sought (Cahill et al., 2008; Iliffe et al., 2005; Vernooij-Dassen et al., 2005) and which touched on the issue of stigma. Focus groups use the group interaction to generate data. It has been suggested that such groups generate more information and are more productive than one to one interviews (Fern, 1982; Stewart et al., 2007) and that people tend to disclose more about themselves to people who resemble them in various ways than to people who differ from them (Jourard, 1964). The focus group approach also makes it possible to compare and contrast information obtained from the different groups and in this way identify trends and patterns of understanding. Drawbacks include possible hesitancy about sharing controversial views or revealing personal thoughts and feelings (which would not occur in a one-to-one interaction) and some people dominating discussions.

Due to the possible advantages to the approach and the possible benefits of having a triangulation of methods, GPs were initially offered the opportunity to participate in a focus group and/or to be interviewed by telephone. Insufficient interest from GPs ruled out the possibility of organising one or more focus groups. Please see the section describing the recruitment process for further details.

6.2 Participants

6.2.1 Inclusion and exclusion criteria

The inclusion criterion was to be a practicing general practitioner. Four types of GP were considered acceptable:

- GPs who have trained and practiced solely in the field of general medicine.
- GPs who have undertaken specialized training in various areas of healthcare but continue to work as a GP.
- GPs who have worked as specialists in a particular field and then trained to become a GP.
- GP Registrars who have completed their theoretical training and are in the process of obtaining a couple of years' experience in general practice before being granted the full title of general practitioner.

GP Registrars were included in the list of possible participants as it was felt that this would increase the overall age span covered and involve GPs having been trained more recently and with less experience.

The exclusion criteria excluded those who were unable to take part in a telephone interview due to:

- physical impairments such as impaired hearing or difficulties articulating,
- the inability to communicate effectively in English,
- cognitive impairments.

The justification for this was that it would render the telephone interview ineffective and make it necessary to carry out a face-to-face interview or adopt another method of data collection for which ethical approval had not been obtained. Another solution would have been to involve another person as translator or facilitator but this would have involved extra costs (which were not budgeted) and change the nature of the interaction.

6.2.2 Method of sampling

As it was not the aim of this study to produce generalizable data, probability sampling procedures were not used. Instead, purposive sampling techniques were used. Purposive sampling involves the deliberate, non-randomized selection of participants based on specific purposes linked to answering the research questions (Teddlie and Yu, 2007). An important aim in qualitative research is to make sense of the meanings people associate with the phenomenon being studied. In purposive sampling, a sample is therefore sought which will provide rich information about those meanings and insight into the phenomenon studied (Denzin and Lincoln, 2008; Maxwell, 1997; Onwuegbuzie and Leech, 2007).

There are several purposive sampling strategies. Patton (1990) identified 16 strategies and other researchers have described a few more (Onwuegbuzie and Leech, 2007). Sampling strategies can also be combined (Onwuegbuzie and Leech, 2007; Teddlie and Yu, 2007) and sampling criteria can be changed as the research unfolds (Tuckett, 2004). In this study, the following purposive sampling strategies were adopted: maximum variation sampling, stratified purposive sampling, theoretical sampling and snowball sampling.

Through maximum variation sampling, participants were purposively selected with a wide range of characteristics in order to obtain data covering a diverse range of meanings. This approach also helped ensure symbolical representativeness which means that the range of characteristics of the participants were considered typical of that group (but not necessarily representative of the wider population in the statistical sense).

As will be explained in the section on the recruitment process, two samples were selected for this study, one from the Preston area and one from the Bradford area. For the Preston sample, stratified purposive sampling was used. This involved identifying key characteristics of GPs within the sampling frame and then taking measures to ensure that various sub-groups of GPs were involved in the study but not necessarily in the exact proportions that they exist in the population. Even within those sub-groups, as much diversity as possible was sought with regard to characteristics (e.g. GPs from second or third generation ethnic minority groups, those employed on a part-time and full-time basis, GPs from different religious backgrounds and covering a broad span of ages, male and female GPs, and so on). This sampling approach makes it possible to make group comparisons of the data (Miles and Huberman, 1994).

Theoretical sampling was used as a means to contribute toward evolving theory by clarifying and refining emerging concepts (Bradley, Curry and Devers, 2007; Glaser and Strauss, 1967). This was linked to the process of constant comparison in that GPs were continually sought in order to provide unique information of relevance to the research questions and to clarify conceptual gaps. For example, if a different perspective was heard which contradicted the perspectives of previously interviewed GPs or resulted in a hunch, additional GPs were sought to clarify the issue. In this way, sampling was driven by emerging theory.

Finally, some degree of snowball sampling occurred in which a few GPs who were enthusiastic about the study spontaneously offered to ask their colleagues to take part. Two GPs from Bradford acted as “buddies” (i.e. sharing their experience and inside knowledge of how to access GPs as friends might do). They opened up the possibility of contacting GPs by email and electronic newsletter. Please see the sub-section on recruitment for further details.

6.2.3 Sample size

As this is an exploratory study involving the use of qualitative methods of data collection and analysis, the number of participants was not set in advance. Sample sizes for qualitative studies (e.g. involving depth interviewing and focus groups) are usually quite small, typically ranging from a single case to about 30 people (Newell and Burnard, 2006). For single studies involving individual interviews, Ritchie, Lewis and Elam (2003) propose a rule of thumb of not more than 50 participants as beyond that amount it may become difficult to ensure the quality of the data collection and analysis processes. The collection and analysis of rich, detailed information requires a great deal of time and effort.

In qualitative research, there is no need to ensure a sufficient number of participants to determine statistical significance of discriminatory variables, and the participants do not need to have been randomly selected for statistical purposes or in order to ensure that the results of the study can be generalized to the wider population. However, irrespective of the size of the sample for a qualitative study, it is important to aim for sufficient symbolic representation (as mentioned earlier) and diversity within the sample. The number of selection criteria is also likely to increase the number of participants needed (Ritchie, Lewis and Elam, 2003).

In this study, the only selection criterion was for the participant to be a practicing GP. However, in view of the large number of GPs of South East Asian descent practicing in the geographical areas in which the study was carried out, it was deemed necessary to ensure that a sufficient number was included in the study to make the exploration of any emerging differences in perception possible. The same applied to female GPs as it seemed important to be able to explore any possible differences between the perceptions of male and female GPs.

An important criterion for justifying sample size and knowing when to stop collecting data is that of saturation. This has been described as the point of diminishing return when continuing to collect data does not result in new evidence and when all concepts are well defined and explained (Corbin and Strauss, 2008; Ritchie, Lewis and Elam, 2003). Interviewing therefore continued until this point of saturation had been reached (i.e. when no significantly new ideas and thoughts were being generated and the information being received was not sufficiently different to warrant continuation).

6.2.4 Sampling issues

The inclusion and exclusion criteria were influential in the selection of the sample but the symbolic representativeness of the sample and the diversity within the sample occurred naturally. Numerous ideas to increase diversity and increase sample size were hampered by the necessity to obtain governance approval. For example, in order to ensure that GPs were reached who had less understanding of or interest in either dementia or people with dementia, it might have been possible to contact them through their attendance at non-related training courses (e.g. on management issues, surgical interventions or children's health). However, this was not possible due to the need to obtain governance approval for every venue outside Bradford or Preston and for every GP attending such a training course but practicing in another region. This would have been too time-consuming and could not be planned in advance as their place of professional activity would not have been known in advance.

It proved impossible to cover diversity within the GP population in terms of lifestyle factors and different experiences in life. For example, it would have been interesting to have interviewed GPs with physical impairments, with different sexual identities, those having had mental health problems or addictions, those having children and those not and those identifying themselves with stigmatized groups of any kind etc. It was unfortunately unrealistic and perhaps for some issues even unethical to try to access such details. Nevertheless, certain other details came out during the interviews or initial contact or could be found on local GP websites for individual surgeries. These included spiritual beliefs, hobbies, voluntary activities, time spent abroad, foreign languages spoken and past professional activities and current interests.

6.2.5 Socio-demographic details of the final sample

Despite tremendous difficulty recruiting GPs for this study (see sub-sections 6.3.4 to 6.3.6), the aim of obtaining a group of participants with a wide range of different characteristics was achieved. To monitor the emerging diversity of the sample, socio-demographic details were recorded at the end of each interview. Table 1 below provides the socio-demographic details of the 23 GPs who participated in this study. A breakdown per participant of these details can be found at the end of this section.

Total sample	**23**
Male	13
Female	10
British/white	13
British/Asian	7
International	2
Ethnic identity not stated	1
Urban or semi-urban practice	19
Rural or semi-rural practice	4
Age	29-62
Years´ practice	1-32
Group practice	21
Single practice or partnership	2
Preston area	14
Bradford area	9
Relative with dementia	15
No relative with dementia	8

Table 1: Summary of socio-demographic details of the sample

The mean number of years' practice of the GPs was 12 and the number of years' practice ranged from 1 to 32. Eleven GPs had between one and five years' experience, four had between six and fifteen years' experience and eight had between 16 and 32 years' experience. Whilst several GPs did not give their age, the age range of those who did is from 28 to 62.

Ten of the GPs (43.5%) were women and the other thirteen were men. In England, women represent 45% of GPs (NHS, 2012). Fifteen GPs had a relative with dementia of which five were first degree relatives and the others a more distant relation. None of the GPs had a partner with dementia.

Just over one third of the GPs interviewed identified with the Asian Community. Specific ethnic categories were not proposed. Five GPs described themselves as being British/Asian or South East Asian, one as being Indian and another as being Chinese. One GP did not provide this information. In England, 12.8% of GPs obtained their primary medical qualification in South Asia (NHS, 2012) but there are perhaps others who identify with that community but who qualified in the UK. It is possible that there is a higher percentage of South Asian GPs in the Bradford and Preston areas than in other parts of England. Two GPs identified themselves as being international. In both cases, one parent was of Asian origin and the other parent was either White/British or Scandinavian. However, having both lived in other countries as well as in England, the GPs did not identify with a specific ethnic minority group or consider themselves as White/British.

In England, single handed GP practices are not very common but this varies considerably throughout the country. For example, in the Central Lancashire Primary Care Trust (PCT), they account for 36% of practices (with a further

20% of practices having just 2 GPs), whereas in the North Tyneside PCT, there are no practices with less than 3 GPs (NHS, 2012). For the purpose of diversity, it was considered important to have a couple of participants from such small practices. Fifteen practices were in urban areas. Just one practice served a rural community. The remaining GPs described their practice and catchment area as coving both urban and rural areas.

ID	Gender	Age	Years' Practice	Location of practice	Type of practice	Self-assigned cultural identification
P1	Female	50	15	Urban	Group	White/British
P2	Female	29	1	Urban	Group	White/British
P3	Male	50	21	Semi-urban	Group	Ethnic Minority
P4	Female	44	20	Urban	Group	White/British
P5	Male	31	2	Urban	Group	Ethnic Minority
P6	Male	56	22	Urban	Group	Ethnic Minority
P7	Male	33	1	Urban	Group	Ethnic Minority
P8	Male	NS	32	Urban	Partner	Not stated
P9	Male	35	3	Urban	Group	Ethnic Minority
P10	Male	33	3	Urban	Group	International
P11	Male	NS	10	Rural	Partner	White/British
P12	Male	NS	11	Urban	Group	Ethnic Minority
P13	Male	37	8	Urban	Group	Ethnic Minority
P14	Male	54	27	Urban	Group	White/British
P15	Female	NS	16	Urban	Group	White/British
P16	Female	NS	5	Semi-urban	Group	White/British
P17	Female	NS	5	Urban	Group	White/British
P18	Female	62	30	Semi-urban	Group	White/British
P19	Male	57	29	Semi-urban	Group	White/British
P20	Male	40	12	Urban	Group	White/British
P21	Female	28	1	Semi-rural	Group	White/British
P22	Female	32	2	Semi-rural	Group	White/British
P23	Female	37	1	Semi-rural	Group	International

Table 2: Socio-demographic details of the GPs interviewed

6.2.6 Ethnic diversity with the sample

The final sample was diverse, especially in terms of gender, years of practice (which generally coincided with age) and, above all, personal ethnic identification. Very few studies have focused on the perceptions of GPs from ethnic groups. Having been able to involve GPs from a range of different cultural backgrounds in this study, this was an ideal opportunity to explore possible cultural differences within the data.

Presuming that there would be differences linked to ethnic group identification might reflect racial stereotyping but ignoring the possibility of differences could be construed as failing to acknowledge cultural diversity. In some Asian languages, for example, there is no word for dementia and as highlighted in the literature review, there may be differences in knowledge and beliefs about dementia compared to White/British lay people. However, GPs are highly educated, have a medical perspective of disease aetiology and understand what dementia is. They have the terms with which to talk about dementia. Their ethnicity is just one part of their identity and the Asian community is an integral part of British society. Nevertheless, GPs may be in a different social class (if class divisions still exist) and move in different social circles than the majority of other people sharing the same ethnic identity. With regard to their understanding of the perceptions of lay people from ethnic groups, they were not asked to differentiate between patients on that basis. Moreover, British/white GPs probably have similar numbers of Asian patients.

So as not to overlook any possible differences based on the socio-demographic characteristics of the sample, such potential differences were actively sought. Once the data had been coded and analysed on the basis of all participants, it was filtered according to socio-demographic criteria. This enabled a comparison of the data from different sub-groups of GPs. As will be revealed in the results section, no such differences were detected even in cases where there was a notable difference of perspective amongst GPs.

6.3 Procedure prior to data collection

6.3.1 Ethics and research approval

Approval for this study was obtained from the North West 12 Research Ethics Committee – Lancaster on 16 April 2010. Approval for a substantial amendment was obtained from the same committee on 25 August 2010. This consisted of offering GPs the sum of GBP 50 in recognition of their time and effort. Governance approval was obtained from the NHS Primary Care Trusts Preston and Bradford and Airedale on 17 April 2010 and 24 March 2011 respectively.

6.3.2 Ethical issues

This study involved a fairly low level of risk to the participants and the researcher. A couple of potential risks were nevertheless identified such as the possibility that participants might be upset by reflecting on their attitudes to dementia and that they might reveal inappropriate practices by themselves or others. It was decided that should the researcher detect signs of distress from a GP during an interview, she would prioritize the GP's wellbeing by showing empathy, allowing the GP to express his/her emotions and if necessary stopping the interview. If this was not sufficient, she would tactfully suggest that the GP contact an Alzheimer association for support or information. In the case of the revelation of inappropriate practices, the researcher would not take action as confidentiality had been promised. If a legal offense had been revealed, she would have discussed the issue with her supervisors after the interview in order to determine the best way to respond. This was nevertheless unlikely as the topic of research was perceptions and not practices.

As this was a sensitive topic, it was essential to ensure anonymity and confidentiality. Documents identifying the GPs (i.e. consent forms) were therefore stored in a secure place, separate from printed transcripts (which had been anonymised). Once transcripts had been anonymised and approved by the GPs, the digital recordings were deleted from the recorder as some contained details of names and places.

6.3.3 Recruitment of participants

The recruitment of participants was carried out in two phases. Based on the initial governance approval from the Central Lancashire National Health Service (NHS) Primary Care Trust (PCT), the first phase involved recruitment in Preston and the surrounding area. When it proved impossible to advance any further in the recruitment process but saturation had not yet been reached, governance approval was sought and obtained from the Bradford and Airedale NHS PCT. This not only involved two entirely different areas (one in Lancashire and one in Yorkshire) but the recruitment methods were also slightly different. For this reason, the two phases of recruitment and the initial problems with the first are described below separately.

6.3.4 First phase of recruitment in the Preston area

Details of GPs with practices in Preston and the surrounding areas were obtained from the public PCT website for Central Lancashire. This website contains a postal address, surgery telephone number and fax number, details of languages spoken by the GPs and details of their various qualifications. Neither email addresses nor direct telephone numbers were available. Some entries on the website provided links to websites where it was possible to obtain further information about the GPs including professional and to a lesser extent personal backgrounds, as well as photos.

200 GPs were contacted by mail and invited to take part in this study. They all had the possibility of responding by mail, email, fax or telephone. Faxes could be sent to the University of Bradford, phone calls could be made to an English mobile which had been obtained for that purpose alone and mail could be sent to Bradford University or the researcher’s UK home address in order to minimize costs to GPs (i.e. rather than asking them to phone or send letters abroad). They were all offered the possibility of participating in a focus group or a telephone interview. Only two GPs were open to either. 40 GPs were then contacted by mail offering half the possibility of a focus group and the other half the possibility of a telephone interview. This resulted in a couple of telephone interviews.

As there was never a sufficient number of GPs interested in a focus group, the offer was dropped in subsequent dispatches of letters and the two who were open to both were interviewed by telephone. Waiting for a sufficient response to form a focus group would have involved contacting some of the GPs 6 to 8 months later, at which time they would have perhaps lost interest in participating or no longer have the time to do so. It may have been confusing to offer two different possibilities in the same letter. A total of 400 GPs were contacted by mail. Each received a cover letter, a participation information sheet and a consent form. This resulted in 14 GPs being interviewed by telephone between May 2010 and April 2011. Once additional ethical approval had been obtained to offer financial remuneration for the GPs’ time and effort, this was mentioned in the cover letter and participant information sheet. The payment was made by a UK cheque posted from England at the latest two days after the telephone interview.

6.3.5 Strategies adopted to try to increase participation rate

In view of the difficulties encountered recruiting GPs, advice was sought from supervisors and a couple of GPs, and the literature on this topic consulted. Possible barriers to participation in research identified in the literature included lack of interest in the topic, lack of financial incentive and above all, lack of time (Bell-Syer et al., 2008; The Royal Australian College of General Practitioners, 2008). The main reason for the low participation rate may well have been time, but the possibility that GPs were reticent in talking about their personal perceptions of dementia in the context of a fairly sensitive topic such as stigma could not be ruled out. Numerous attempts to increase the participation rate were made and fell into the following three categories:

- Speaking to relevant people (e.g. managers of training colleges for GPs and training practices, course organizers, practice managers, administrative staff at the surgeries, the Royal College of General Practitioners and the local Alzheimer Society branch).
- Varying the presentation of the documents (e.g. format, style, condensed text, recto-verso printing, hand-written or typed envelopes, and including additional contact details of supervisor).
- Varying the method of delivering the invitation (e.g. posting letters in England, using 1st class stamps and including a response coupon).

Observing the time take to obtain one positive response compared to the number of letters sent in each dispatch, the most effective way to recruit GPs seems to have been to send just the cover letter mentioning payment with a response coupon in a stamped addressed envelope posted from England with a first class stamp. Nevertheless, one year later and after 400 letters, only 14 GPs had been interviewed. After a lengthy process, additional approval was obtained from the NHS Primary Care Trust covering the Bradford area.

6.3.6 Second phase of recruitment in the Bradford area

Once governance approval had been obtained from the NHS PCT for Bradford and Airedale, Prof. Murna Downs (one of the academic supervisors of this study) wrote to two contacts from the NHS in Bradford for advice. They responded with concrete offers of help consisting of:

1. The provision of a group email address for GPs linked to memory clinics,
2. Personally forwarding an email to GPs in the Bradford and Airedale PCT region,
3. Mentioning the study at local training events,
4. Being interviewed themselves.

After a few email exchanges, it was agreed that an adapted version of the cover letter would be sent to the two contacts, which they would forward to all GPs linked to the memory clinics and have inserted in the weekly electronic newsletter which all GPs receive. This meant that the GPs received this information directly by email rather than through their administrative support staff. It also meant that those who responded did so by email which in most cases made it easier to correspond as trying to get through to a GP when s/he is either giving consultations or is not at the surgery is very difficult. This process was extremely cost efficient, enabled access to a large number of GPs and resulted in an additional eight interviews in the space of one month and another invitation three months later. Some of the 23 GPs were recruited by means of snowballing whereby GPs who were enthusiastic about the study spontaneously talked about it to their colleagues who then offered to participate.

6.3.7 Procedure for obtaining consent

Participants all received a Participant Information Sheet and a Consent Form prior to the telephone interview (please see Appendix 1 and 2). When a GP responded and stated that he or she was willing to consider participating, his/her understanding of what participation would involve was checked and additional information provided if required.

Later, when response coupons were included with the invitation to the GPs in the Preston area, the Participant Information Sheet and Consent Form were sent after the initial contact. The return of the consent form and agreement on a date for the interview were then arranged by email or telephone. During the second phase of recruitment in the Bradford area, GPs were also sent the Participant Information Sheet and Consent Form after their initial interest.

GPs had as much time as they needed to think about participating before deciding. The signed consent forms were returned by fax, normal mail or as scanned attachments to emails prior to the interview. The consent form also covered consent to the interview being recorded and to quotes being included in possible future publications as well as whether the GP would like to receive a copy of the transcript and/or to comment on the results.

A few GPs asked for confirmation that the results would be anonymous. This was stated in the Participant Information Sheet and seems to have been sufficiently clear, as the GPs mentioned having read it but they wanted confirmation of this. None were concerned about being recorded. One asked to see the interview guide before being interviewed. It seemed to be very important to him and with hindsight it does not seem to have had an adverse effect on the outcome of the interview.

6.4 Data collection – conducting telephone interviews

6.4.1 The development of an interview guide

The semi-structured interview schedule was drawn up to reflect the key components of stigma as detailed by Link and Phelan (2001; 2006) and the contributing factors as identified by Jones (1984) (please see Appendix 3). It contains questions aimed at exploring GPs' perceptions about dementia and others aimed at exploring their understanding of lay people's perceptions of dementia. It did not contain questions aimed at exploring GPs' understanding of health care professionals' perceptions of dementia but as will be seen in the results section, some did mention these. Such information nevertheless reflects part of GPs' perceptions of dementia and was equally valuable data.

As can be seen from Appendix 3, the questions on the interview schedule sought to identify whether and if so, how, GPs' perceptions of dementia reflected the components and contributing factors of stigma as identified by Link and Phelan (2001; 2006) and Jones et al. (1984) respectively.

Throughout the data collection procedure the interview guide was constantly being amended and improved. In addition to the questions on components and those on contributing factors, it was decided after the first 14 interviews to be much more explicit about the possible impact of GPs' perceptions of dementia, their possible perception of dementia as a stigma and their readiness to diagnose dementia in the light of the those two factors. Towards the end of the interviews, GPs were asked whether they felt that their perceptions of dementia would affect the likelihood of them pursuing a diagnosis of dementia. This question was intended to introduce the topic of possible factors affecting timely diagnosis and whether these included stigma. The changes made to the interview guide were also reflected in changes made to the research aim, objectives and questions. These additional questions can be found in section 10 of the interview guide (in Appendix 3).

A question was inserted at the beginning of the interview to set the scene and let GPs talk a little about their contact or experience with dementia so far. The aim was to let GPs talk a little about themselves and start talking about dementia in a general way before been asked specific questions in order to reduce the effect of an interrogation or test, and to give them the opportunity to confirm and obtain reassurance about their value as a participant in the study.

During supervision meetings, the wording of the questions was analysed and subsequently changed so as to limit the use of closed questions. A couple of closed questions were retained but it was agreed that they should be followed up with second questions such as “Oh, could you perhaps tell me more about that” or “in what way?”

6.4.2 The development of interviewing skills

A mock interview was conducted with Prof. Murna Downs, who first took the role of interviewer and then that of a hypothetical GP. This provided valuable feedback on interviewing skills and insight into what it might be like to be on the receiving end of an interview (i.e. to be the interviewee). This resulted in greater attention being paid to how GPs might be feeling about their performance as a research participant. At a later date, Prof. Murna Downs and Prof. Myrra Vernooij-Dassen listened to one of the interviews for the purpose of comparing coding and this also led to feedback about interviewing style. Two very useful pieces of advice were given:

1. to be careful not to become so enmeshed with the GP that the researcher role is cast aside and the interview becomes a mutual conversation,
2. to avoid asking leading questions.

The issue of leading questions was discussed in subsequent supervision meetings - why they should be avoided (namely that they lead to poor data) and how to avoid them whilst still testing out hunches and following through a particular thread.

6.4.3 Procedure for conducting the telephone interview

Once the consent form had been signed and returned, interviews were conducted at a time of the GP's choosing. Telephone interviews were audio-taped. The semi-structured interview schedule was used to guide the discussion. Consistent with best practice in conducting semi-structured interviews, the order and exact manner of asking the questions was flexible, thereby making it possible to stop and explore some issues in more depth, refer back to issues discussed earlier and follow hunches (Charmaz, 2006). Indeed, sometimes it was not necessary to ask a question as the interviewee had already addressed the issue when answering an earlier question.

As the data collection process unfolded and interviewing skills were developed, the interviews became longer (generally about 45 minutes) and the depth of data collected improved, in that GPs questioned their own perceptions and developed their ideas as they went along.

6.5 Procedure for the analysis of the data

The telephone interviews were recorded by means of a digital recorder connected to a landline via a telephone recording adapter. Recordings were transferred from the digital recorder to a computer and coded using the Atlas.ti software. Verbatim transcripts were made of the interviews. Once transcribed, the recordings were deleted from both the digital recording device and computer. The transcripts were sent to the GPs for approval and possible comment (if they had indicated interest in receiving a copy on the consent form or expressed the wish during the interview).

6.5.1 The framework being used in this study

The following conceptual framework (or “index”) was created.

Conceptual framework for the study into GPs’ perceptions of dementia and how they relate to stigma

Components of stigma

- Labelling
- Stereotyping
- Separating “us” from “them”
- Status loss and discrimination
- The exercise of power
- Emotional reactions

Factors contributing towards stigma

- Concealability
- Course of the mark
- Disruptiveness
- Aesthetics
- Origin
- Peril

Figure 3: Conceptual framework for this study

It was deemed important to situate the exploration of GPs' perceptions within a clear framework of stigma theory. For this reason, the initial framework resembles the components of, and contributing factors to, stigma outlined by Link and Phelan (2001 and 2006) and Jones et al. (1984) respectively. The same terms were adopted as those used by the above-mentioned theorists because at this point there was no justification for changing them.

Ritchie et al. (2003) warn against imposing concepts based on existing literature when constructing the framework, stating that this distracts analytical thinking and may result in the analytical process not being grounded in the data. However, this study is not based solely on grounded theory and the framework draws on the research questions, which are themselves closely related to existing theory. In addition, as explained in section 6.5.2, a coding procedure was adopted to help ensure that the codes truly emerge from the data and are not unduly influenced by the theoretical concepts reflected in the pre-determined categories which make up the conceptual framework. Moreover, as Spencer et al. (2003) point out, the framework serves merely to provide conceptual clarity and is just a starting point. It can be changed later by refining and adding categories to the conceptual framework being developed.

In the initial conceptual framework (i.e. before it was developed in the course of the analysis of the data), the predetermined categories representing the various components of stigma could be described as follows:

- Labelling

  Human differences which are deemed socially relevant and consequential (i.e. dementia or people with dementia) are identified and labelled.

- Stereotyping

  Labelled human differences (i.e. dementia or people with dementia) are linked to undesirable characteristics that form stereotypes.

- Separating “us” from “them”

  In-groups and out-groups are formed in which those considered as “them” (i.e. people with dementia) are perceived as being very different from “us”.

- Status loss and discrimination

  The low status that people with a stigma (i.e. dementia) acquire forms the basis for discrimination. They may be devalued, rejected and excluded.

- The exercise of power

  Stigma is entirely dependent on social, economic and political power in that it takes power to stigmatize.

- Emotional reactions

  Perceived, and subsequently labelled, differences (i.e. dementia) result in an emotional reaction.

Emotional reactions and discrimination are somewhat different to the other predetermined categories as they represent the affective and behavioural components of stigma in the conceptualization of Link and Phelan (2001) and cannot be as easily explored as perceptions. However, emotional reactions are linked to how dementia is perceived. For example, GPs who report feeling protective may perceive people with dementia as being vulnerable. Those who feel frustrated or irritated may perceive people with dementia as being frustrating or irritating (even if there are other factors contributing towards them being so). In the case of discrimination, data can be obtained on whether, and if so how, GPs perceive dementia as a condition leading to discrimination and examples of the discrimination they perceive can be recorded.

The predetermined categories representing the contributing factors of stigma, as in the initial conceptual framework, could be described as follows:

- Concealability

  Related to the characteristics of an attribute (i.e. dementia) which render it visible or "known about" to other people or, on the contrary, concealable and hence, undetected.

- Course of the mark

  The extent to which a condition (i.e. dementia) is believed to or actually does become more debilitating and socially alienating over time, as opposed to remaining stable or being reparable.

- Disruptiveness

  Relates to the property of an attribute (i.e. dementia) that hinders, strains and adds to the difficulty of interpersonal relationships (e.g. making it difficult for people to interact or less willing to do so, or making people feel awkward when interacting), especially if visible and aesthetically unpleasant .

- Aesthetics

  The extent to which the mark (i.e. dementia) makes the possessor repellent, ugly or upsetting.

- Origin

  How and when the attribute (i.e. dementia) originated, whether it is congenital, whether its onset was rapid or slow and, most importantly, the person's role in engendering it which may result in blame.

- Peril

  The danger posed by the mark (i.e. dementia) to our physical, psychological and social well-being.

6.5.2 The coding procedure

<u>6.5.2.1 Introduction</u>

The content of the data was coded by means of open coding and through the application of a conceptual framework, which was prepared prior to the initial open coding of the data and constantly refined throughout the coding process. This is depicted in Figure 4 below.

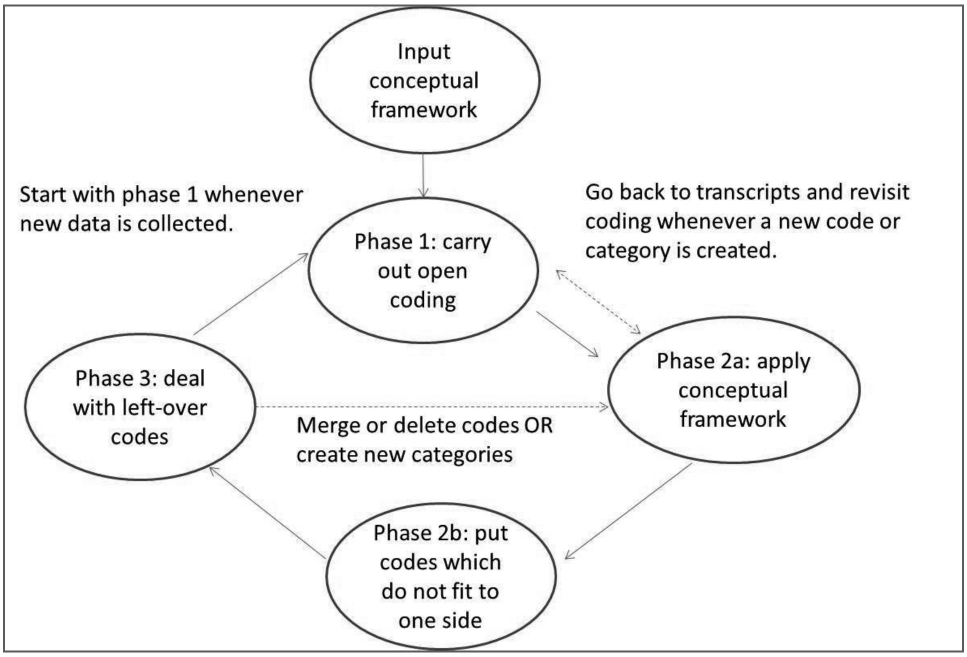

Figure 4: The coding process

Starting the coding of each transcript or set of transcripts with Phase 1 helped ensure that codes were not forced into becoming preconceived results (Glaser, 1992). Phase 2 involved the application of a framework which had been developed prior to data collection. This reflected a deductive approach to coding and provided a means to benefit from previous insight into the topic of the study (Miles and Huberman, 1994). However, the complete process was iterative in that it was not carried out in a strict linear fashion but involved moving backwards and forwards within the coding process and repeating the various phases. This is in keeping with Marshall and Rossman’s description of qualitative data analysis:

> *“Data analysis is the process of bringing order, structure, and meaning to the mass of collected data. It is a messy, ambiguous, time consuming, creative, and fascinating process. It does not proceed in a linear fashion; it is not neat.” (Marshall and Rossman, 1995, p.111).*

6.5.2.2 Preparatory phase – The conceptual framework

As mentioned earlier, a conceptual framework comprised of pre-determined categories, based on the work of Link and Phelan 82001; 2006) and Jones et al. (1984), was developed. Unfortunately, there is no distinct function in Atlas.ti to create a recognizable category. The “families” function provides the opportunity to group together several codes under one heading but the same code can be assigned to several families, whereas usually a code is only assigned to one category. However, categories can be created in the form of empty codes (Friese, 2012). They do not serve the function of a code as they do not contain any coded data. Their status as a category can be made visible by the use of capital letters. The twelve initial predetermined categories, which together make up the conceptual framework for this study, were therefore input as follows:

LP_LABELLING
LP_STEREOTYPING
LP_COGNITIVE SEPARATION
LP_LOSS OF STATUS AND DISCRIMINATION
LP_EMOTION REACTIONS
LP_POWER

J_VISIBILITY AND CONCEALABILITY
J_COURSE
J_DISRUPTIVENESS
J_AESTHETICS
J_RESPONSIBILITY
J_PERIL

Once input, the predetermined categories forming the conceptual framework could be temporarily put to one side in order to carry out the open coding of the initial data. It could be argued that the predetermined categories would be in the back of the researcher's mind and that this might have an impact on coding. The researcher might be inclined to code material likely to eventually fit into those pre-determined categories and either overlook other data or, alternatively, interpret its meaning in such a way that the resulting code would fit into a pre-determined category.

It would not have been possible to block out all knowledge of the pre-determined categories and to simply refer back to them when needed. Bryant (2003) criticizes the claim made by some researchers that "cognitive reservoirs of previous experience and knowledge can be dammed, blocked or diverted". A few techniques from psychoanalysis, although used for an entirely different purpose, were helpful such as trying not to attend to some details more than others, trying to maintain evenly-suspended attention with regard to everything that had been said and refraining from censorship.

6.5.2.3 Phase 1 – Carrying out open coding

Initial coding

Open coding was carried out. This involves “breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss and Corbin, 1990, p.61). Each transcript was carefully read and each segment of text (i.e. a word, phrase, sentence or paragraph) was given a code. For example, for a segment of data which seemed to reflect stereotyping, a code was created called “stereotype” and attributed to the quotation. When a second quotation reflecting a stereotype was detected, this newly created code entitled “stereotype” was attributed to it and so on. For each quotation for which a code did not already exist, a new code was created.

Following this process, the number of codes and the number of quotations associated with each code gradually increased. The following list shows the first seven of seventy codes (in alphabetical order) which were created during the coding of the first 14 interviews.

Aesthetics
Ageism
Analogy to cancer
Attribution of dangerousness
Attribution of responsibility
Avoidance of labels
Avoiding or delaying diagnosis or disclosure

This initial coding process was deliberately free. Little attention was paid to the number of codes being generated and possible new codes were not prematurely censored or ruled out. Emerging codes, even if unlikely to fit into any of the predetermined categories, were not questioned. Such codes could turn out to be unimportant or, on the contrary, lead to the development of new categories or lead to changes in predetermined categories.

Splitting and merging codes

Some codes housed a large number of quotations. It was not immediately clear how the various quotations differed. The use of thematic charts facilitated an exploration and subsequent organization of such codes (Ritchie and Lewis, 2003). In keeping with the first step of data management, described in the section on framework analysis, each quotation coded for each participant was synthesized (i.e. summarized in a few words whilst maintaining the essence of each quotation). This highlighted similarities and differences and led to some codes being split into more than one. The quantity of quotations linked to a particular code was not a strict criterion for the splitting of the code but it did suggest the need to look more closely at the content and meaning of the quotations (Friese, 2012). Where it was found that a few codes were actually different expressions of the same issue, those codes were merged.

Constant comparison

Constant comparison is commonly used in the analysis of narrative and textual data and involves a rigorous and iterative scrutiny of the differences and similarities in the data at all stages of the analysis (Chamaz, 2006; Glaser and, Strauss, 1967, Leech and Onwuegbuzie, 2008). This contributed towards decisions to allocate one code rather than another code to a particular piece of data. Within-code comparisons were also made in order to discover the different properties and dimensions of each code, which in turn contributed towards the refinement of categories. In order to facilitate such decisions, a code book was created which contained a couple of sentences describing each code. This information was input in the form of a memo attached to each code which could be easily adapted during the coding process and printed out if needed.

Comparison of data based on different GP characteristics

Ritchie et al. (2003) include socio-demographic details of the participants in the initial conceptual framework. However, with Atlas.ti it was possible to compare the responses of GPs with different characteristics during the coding process, and at any moment in time to print out a list of all quotations linked to a particular code for GPs with particular characteristics. This necessitated the renaming of the primary documents according to a list of meaningful abbreviations reflecting the characteristics of each GP. Primary document families were then created based on selected characteristics for the purposes of filtering and comparing the data from GPs with different characteristics (e.g. based on gender, identification with an ethnic minority group, having a relative with dementia etc.).

Comparison of data based on attribution of the perception

Both GPs' perceptions of dementia and those they believe lay people to have were sought. In order to distinguish between the two, quotations were double coded – first on the basis of meaning and second on the basis of the attribution of the perception. The second code attributed to each quotation was not a code in its own right but rather a dimension of the first code and will therefore be called a code label. It was then possible to sort quotations by code and by attribution of the perception by means of a “supercode”. This is also not a code but a search function, which can be saved and automatically updated to incorporate new quotations corresponding to the search criteria.

Search for negative cases

Negative cases are examples of data which do not fit or actually contradict the emerging patterns of meaning (Corbin and Strauss, 2008). They differ from the main body of emerging evidence. It is important to search for such cases when coding qualitative data as a means to refine the emerging concepts and to challenge or even disconfirm certain findings, thereby resulting in a greater confidence in the trustworthiness of the results. Explaining or accounting for negative cases, may strengthen the general explanation of the “typical” case.

In order to ensure that all data was considered in terms of whether it fitted into or contradicted emerging meanings, another “code label” was created called “opposite of”. Each quotation could, if deemed appropriate, be double coded with the “opposite of” code label. As with the codes labels for the GP, lay person or health care professional’s perspective, this code label had a special status in that it was meaningless on its own. It only served to add information to a coded quotation. These four code labels were therefore preceded by a symbol (! or #) in order to separate them from the “real” codes and to make them easy to find during the coding process.

6.5.2.4 Phase 2 – Applying and developing the conceptual framework

Sorting the codes into categories

Following the initial process of open coding which involved the attribution of specific codes to quotations, the coding framework was applied. This involved deciding whether any of the codes corresponded to the items in the conceptual framework and if so, to which ones. The codes which did not fit in to any of the pre-determined categories were allocated to a new category labelled “ZZZ”. The latter served as a provisional container for the newly emerging codes which might eventually be merged, split, renamed or discarded. Below, a predetermined category from the conceptual framework containing three codes and the special provisional container category containing six codes can be seen as an example.

LP_ COGNITIVE SEPARATION
LP_ Cognitive separation - a group apart
LP_ Cognitive separation - no longer a person
LP_ Cognitive separation - no longer the same person

ZZZ
Z_Abuse
Z_Being put in a home
Z_Class differences and ethnicity
Z_Depends who it is
Z_Familiarity/exposure
Z_Famous people
Z_Religion or spirituality

In order to ensure that the codes belonging to a particular category can be easily seen as belonging to that category, the code name is preceded by a prefix similar to the category name (i.e. an abbreviation and/or truncated segment of the title). This ensures geographical proximity in the Atlas.ti system. Abbreviations were used to identify and keep together codes which might later be merged.

The components of stigma described by Link and Phelan are considered as being interrelated. Each component, whilst separate, has implications for the other components and this makes the process of organizing the codes into the various predetermined categories difficult as it is necessary to try to understand the dominant issue being addressed in each quotation. It is therefore important to look for common underlying dimensions within the data.

This can be likened to factor analysis which is sometimes used in the analysis of quantitative data. Factor analysis involves the search for common variance as a means to reduce a large number of variables to a smaller number of factors. There are different types of variance including that which is specific to a particular variable (unique or specific variance) and that which is due to fluctuations (error variance) but what is most important is that which is shared by different variables (common variance). With quantitative data, this process is facilitated by statistical analysis such as Kaiser's criteria but this is not possible with qualitative data. With qualitative data, this is achieved by means of constant comparison which involves the search for internal convergence and external divergence (Guba, 1978) but also by means of peer checking. Peer checking involves checking inter-rater reliability and discussing any differences of opinion. As such, it also contributes towards establishing the trustworthiness of the findings and is therefore described in the section on confirmability.

Deciding whether to retain or discard predetermined categories

As the predetermined categories were derived from theory rather than from the initial data, it was clear that the GPs' perceptions might not actually correspond to them all. Discovering this was of equal importance compared to the aim of finding supporting evidence for the pre-determined categories.

The codes were not forced into the pre-determined categories. If the diversity in the data provided by the GPs was insufficient to warrant the creation of more than one relevant code which would fit that category, the category was eventually discarded. The reason for the decision not to retain the predetermined category was based on meaning in that it did not seem to be a higher order concept giving meaning to more than one lower order concepts. It was not a higher level of abstraction.

Creating new categories

Just as some of the pre-determined categories could be eventually discarded, new ones could also be created if necessary and meaningful. This was part of the ongoing development of the conceptual framework.

Creating themes

Having used predetermined categories based on components of, and contributing factors to, stigma, it was, at first, difficult to move away from the origins of the predetermined categories and to avoid the adoption of predetermined themes. This was finally achieved as part of the process of constant comparison.

6.5.2.5 Phase 3 - Dealing with left over codes and those linked to diagnosis and stigma

The codes, which had been identified in the first phase of coding and put to one side as they did not fit into pre-determined categories making up the initial conceptual framework, were eventually considered. Through the process of constant comparison, a decision was made whether to discard the code (as it was not relevant to the topic), merge it into another code or keep it as a separate code and consider the possible creation of a meaningful category to house that code along with others that did not fit into the existing coding framework. As explained in the introduction to this sub-section, coding was an iterative process and consequently, any of the three phases could influence the other phases and from the first bout of ongoing coding onwards, the coding framework was constantly changing. Consequently, a code which did not initially fit in, might do so later. However, the development and placement of these outsider codes in the coding framework could also call for a reconsideration of previously coded quotations. It was therefore necessary to regularly go back over the transcripts and re-examine the attribution of codes.

6.5.2.6 Ending the process of data collection and analysis

As the collection and analysis of data progressed, the data gradually became less diverse and less novel with similar ideas and meanings being expressed as had already been expressed by GPs interviewed previously. This coincided with the realization that the categories were well defined and that outstanding questions or the need for clarification had been successfully addressed. This was interpreted as a sign that the point of saturation (described in sub-section 6.2.3) had been reached.

6.6 Trustworthiness

6.6.1 Trustworthiness of the findings

The findings of this study are based on an interpretation of the perceptions of a group of GPs, which are, in turn, also interpretations of a range of social realities (e.g. what it is or would be like to have dementia, what stigma is, how people feel about dementia, what kind of treatment and support is available etc.). It makes little sense to ask questions about their truth or falsity as perceptions are neither true nor false. It is much more meaningful to ask questions about the trustworthiness of the findings. The notion of trustworthiness has been described as providing an answer to the question, “How can an inquirer persuade his or her audiences (including self) that the research findings of an inquiry are worth paying attention to, worth taking account of?” (Guba and Lincoln, 1985, p.290). From the perspective of audiences (or reviewers), Eisner (1991) further suggests that the findings should reflect coherence (i.e. they should make sense), consensus (i.e. they should be consistent with the reviewer’s own experience or with the evidence presented) and instrumental validity (i.e. they should provide an explanation for an otherwise enigmatic or confusing situation or phenomenon) (Hoepfl, 1997). Guba and Lincoln (1985) proposed four criteria to evaluate the trustworthiness of qualitative research, namely credibility, transferability, dependability and confirmability.

6.6.2 Credibility

The concept of credibility is the means by which it can be established that the findings of a particular study are believable. This study set out to explore GPs’ perceptions of dementia and how they relate to stigma. It must therefore be credible that the findings which are reported reflect the perceptions of GPs insofar as they do or do not relate to stigma. Presuming that there are multiple realities, such multiple realities must also be accurately reported.

Credibility was enhanced by ensuring informational adequacy (Zelditch, 1962). This was achieved by choosing a research design which maximized the possibility of being able to respond to the research questions thoroughly and thoughtfully (Marshall and Rossman, 1995). As explained in Chapter 5 on methodology, this was a qualitative, interactive design.

As the findings are described by the researcher but through the GPs' eyes, the GPs have an important role to play in helping ensure the credibility of the results. It was therefore important to determine whether the information that they were providing was being interpreted in a way which reflected what they meant by what they said. The credibility of the data obtained was increased *in situ* by carefully attending to what was being said, questioning the meaning of what was said, feeding back to the participants for verification of the interpretations and following up on inconsistencies where necessary (Kvale and Brinkmann, 2009). Doing this made it possible to determine whether apparent contradictions were due to a misunderstanding or a genuine reflection of ambiguity held by the GPs interviewed.

With regard to multiple realities, attention was also paid to data which ran counter to the findings that were generally emerging. Negative cases of particular concepts (e.g. the opposite of cognitive separation or stereotyping) were double coded to indicate their departure from the emerging norm. In some cases, GPs made statements which they seemed to find slightly unorthodox or unconventional. Such statements were received in an equally matter-of-fact but interested way to so as not to convey any kind of judgement as this could have limited the further expression of such views. This was not difficult as such statements were of equal interest and value to the study. This was also facilitated by the researcher's former training in analytical Gestalt psychotherapy.

A communicative approach was adopted to test the validity of the knowledge claims, incorporating member checking (by some of the GPs involved in the study) and peer validation (mainly involving the supervisors) (Kvale and

Brinkmann, 2009). Member checking is also mentioned in the sub-section on confirmability.

Another method of establishing credibility is through triangulation. This can contribute towards increased confidence in the conclusions that are drawn (Patton, 2002). It was initially intended to include triangulation of sources by comparing the data generated by focus groups with that generated by telephone interviews. However, as explained earlier, this was not feasible. The study involved a certain degree of theory triangulation as apart from the fact that the theoretical framework was based on the work of both Link and Phelan (2001; 2006) and Jones et al. (1984), the findings were interpreted with reference to wider stigma theory. A small degree of triangulation through multiple analysis was achieved by involving other individuals in the process of coding and interpreting incoming data (Lewis and Ritchie, 2003).

An important aspect of credibility is ensuring that it is the entity or phenomenon under investigation (rather than something else) which emerges from the results of the study (Newell and Burnard, 2006). If not, the results of the analysis would have no relevance and would lack credibility. For this study, it was necessary to ensure that GPs were sharing their perceptions of dementia (i.e. and not of older people or of people with mental disorders in general which might or might not include people with dementia). Similarly, the study is also about whether and if so how their perceptions relate to stigmatization (and not simply to discrimination or taboos, which may be linked to stigma but are not stigma on their own). In order to ensure that GPs', perceptions of dementia and how they relate to stigma were being explored, an interview schedule was drawn up with questions covering each component of, and contributing factor to, stigma. Using a conceptual framework of stigma based on the literature helped ensure that the questions in the semi-structured interview focused on stigma. However, it was also necessary to ensure that GPs could share any perceptions of dementia which did not reflect stigma. The questions were therefore carefully worded so as to enable GPs to provide data which might support or disconfirm a relationship to stigma.

In qualitative research, the researcher him/herself is the main instrument for data collection and analysis and must therefore also be credible. It must be demonstrated that the researcher’s approach to data collection and analysis, as well as his/her interaction with the participants, would be likely to result in data of relevance to the research questions. The interview schedule was therefore constantly reviewed by the researcher together with the supervisors, the transcripts were reviewed with the aim of improving the researcher’s interviewing skills, and training in the form of role playing was provided.

The sampling approach may also contribute towards credibility (Newell and Burnard, 2006). In adopting purposive strategies to sampling, emphasis was placed on reaching an adequate number of GPs with a sufficiently broad range of characteristics to be able to provide relevant data to answer the research questions.

Finally, it was considered important to consider any factors in the research situation which might affect the quality of the data or its relevance to the topic. One possible factor was time. It was considered necessary to try to ensure that GPs all had ample opportunity to think about the issues being discussed. The researcher was therefore extremely flexible about the time of the interview (i.e. it could be at any time of the day or evening, on any day of the week and could be changed at extremely short notice). Another possible factor was that the researcher works for a European NGO in the domain of dementia. The researcher wanted to ensure that GPs responded authentically and were not influenced, either positively or negatively, by her background. At the same time, it was important to be transparent. Consequently, details of employment status were included in the participant information sheet. For other correspondence and contact, the researcher's status as a PhD student at the University of Bradford was emphasized.

6.6.3 Transferability

The question remains as to whether the findings of this study can be generalized beyond the sample and context involved (i.e. issues of representational and inferential generalization). As this was a purely qualitative study, generalization cannot be claimed on a statistical basis. Assertions cannot be made that are context free on the basis of this study and which would enable prediction in a law-like manner (Lewis and Ritchie, 2003). However, according to Lewis and Ritchie (2003) representational generalization is not automatically ruled out in qualitative research. The robustness and credibility of the data, which are aspects of trustworthiness, determine whether and if so in what form, wider inference can be drawn from a particular study. The use of Atlas-ti, a computerized data analysis package, helped guarantee a certain degree of scientific rigour in the thematic coding process.

Inferential generalization may also be possible. Lincoln and Guba (1985) claim that it might be possible to apply the findings of qualitative research to other similar situations provided that there is a certain degree of similarity between the “sending context” and the “receiving context”. This necessitates the provision of thick description which means sufficient detail about the original statements made and the environment or context in which they were made. It is not possible to know in advance the contexts in which the results of this study might be transferable.

The researcher was able to present the emerging findings of the study at the 2011 Alzheimer Europe conference in Warsaw and at the 2012 Alzheimer’s disease international conference in London. This resulted in feedback from some members of the audience from the UK, Denmark (a retired GP), Iceland and Malta which suggested that the emerging findings were at least meaningful to them at that point.

Whilst claims concerning the generalization of the findings of this study cannot be made, attention has been paid to increasing the likelihood of future researchers and readers considering this feasible by providing rich descriptions and measures taken to enhance the trustworthiness of the data.

6.6.4 Dependability

As interviewing takes place within a particular context and can be seen as a mutually accomplished story based on collaboration and the unique interaction between the researcher and the participant (Gubrium and Holstein, 2002), it is unlikely if not impossible that the same data and dynamic process could ever be replicated. Especially when studying social phenomena, repeating the same study cannot be considered as measuring the same thing twice but rather as measuring two different things. However, qualitative researchers can try to ensure dependability, which involves providing evidence that they have tried to account for ongoing changes within the research context which affect the consistency of the findings (i.e. their stable, unchanging and continuous qualities).

Lincoln and Guba suggest that as there can be no credibility without dependability, “a demonstration of the former is sufficient to establish the latter” (1985, p.316). They nevertheless propose an inquiry audit which involves reviewing the process and the project of the research for consistency. Other approaches proposed by Silverman (2006) include:

- ensuring that the research process is transparent,
- ensuring that the theoretical stance through which the data are interpreted is transparent
- being consistent in the way that interviews are recorded and transcribed
- transcribing the interviews oneself to ensure that that the criteria for reliable analysis are fulfilled
- presenting long extracts of data in the research report (including details of the context and of the question that was asked)
- comparing the analysis of the same data by several researchers

The above criteria were adhered to in the conduct of this study.

In order to limit the risk of researcher bias, four people were involving in the coding process, feedback about the findings was sought from the participants themselves and findings were discussed with all three supervisors as well as some healthcare professionals who were board members of Alzheimer Europe. This is also relevant to the following sub-section.

6.6.5 Confirmability

Confirmability is another factor which contributes towards the overall trustworthiness of the results. This involves demonstrating neutrality and taking measures to ensure that the findings can be corroborated by others.

Each researcher brings something unique to the research situation and this is not a problem provided that the researcher is aware of this and strives for neutrality (i.e. avoids being biased). Patton (1990) suggests that there are two aspects of neutrality. One is linked to the participants and the other to the findings. Patton (1990) recommends that researchers strive for “empathic neutrality” which consists of an empathic stance towards participants and a neutral stance towards the findings. The empathic stance also reflects neutrality because having empathy for somebody means being able to identify with them and thus not being judgemental. This should not be confused with sympathy which may involve sharing a person’s feelings and beliefs. Empathic neutrality therefore contributes towards a balanced reporting of the findings. The researcher adopted a non-judgemental approach in which all perceptions were considered with equal interest and strove to present the findings in a balanced way.

Reflexivity and sensitivity are important in qualitative research in order to ensure that researchers remain focused on the data, do not force their own experience, knowledge, theories and world view onto the data and are able to present and understand the views of the participants through immersion in the data (Corbin and Strauss, 2008).

Reflexivity has been described as “no longer pretending to be a faceless respondent and invisible researcher” (Fontana and Frey, 2008, p. 141). Sensitivity, on the other hand, involves the researcher trying to become aware of him/herself (e.g. knowledge, experience and theories) and bringing this to the research process (Corbin and Strauss, 2008). The aim is not to approach the study with an empty head but rather with an open mind which includes the possibility of drawing on accumulated knowledge and experience to enhance sensitivity, avoid drawing false conclusions and understand the significance of what is being said (Corbin and Strauss, 2008; Dey, 1993)

It is not possible to rule out researcher reactivity (i.e. the possibility that the researcher might influence the research situation or the participants) or achieve objectivity (in the sense of freedom from bias) completely. It was therefore important to reflect on this and attempt to gain insight into it (a process which Kvale and Brinkmann call "reflexive objectivity") thereby enhancing sensitivity. This involves reflecting on one's own background, history and other relevant factors as well as regularly writing memos of one's thoughts and observations about the data collection and analysis.

A personal statement can be found in section 1.2 in which the most relevant details about personal background are stated which may have had a global impact on the overall research process and especially on the choice of topic.

An analysis of inter-rater reliability was also carried out in order to enhance confirmability. This involved asking other people to code or to comment on the results of the coding process. Two research supervisors (Prof. Murna Downs and Prof. Rob Newell) contributed towards the development and definition of the coding categories for the initial conceptual framework, and applied that framework to a small selection of transcripts. This was followed by a discussion and the decision to code data reflecting worries about developing dementia as existential anxiety and not under emotional reactions. A third research supervisor (Prof. Myrra Vernooij-Dassen) provided feedback on the final conceptual framework by considering how the data had been organized into themes, concepts, categories and codes, and also by reflecting on the appropriateness of the quotations provided as examples for the codes. This therefore also provided another perspective on the open coding process.

It was considered equally important to involve people who had no direct link to the study or to the topic of stigma. Two people were found who were willing to code ten transcripts. These were Ms Julie Fraser who is a colleague with experience in dementia and a background in law, and Dr Jürgen Staadt who is a friend having recently obtained a PhD in Strategic Programme and Project Management which involved the qualitative analysis of data from interviews. Both were asked to code the transcripts and were given details from the code book of the various codes which had emerged so far through the open coding process and which had been incorporated into the initial conceptual framework. This made it possible to compare the attribution of codes to specific fragments of data. A high level of agreement was obtained in both cases but the task proved useful in drawing the researcher’s attention to several fragments of data which had been overlooked and to a certain number of patterns within the data.

Measures were also taken to ensure that the data obtained constituted a trail of evidence through which it would be possible to justify how conclusions were arrived at (Krueger and Casey, 2009). This can be achieved by means of a “confirmability audit” (Lincoln and Guba, 1985), which necessitates the careful recording and storage of data and details of the process in a systematic manner.

6.7 Hypothesis generation

A process of integration was adopted in order to arrive at the concluding hypotheses of this study (Corbin and Strauss, 2008). This process involved a gradual move from description to conceptualization. More specifically, it involved sorting through the data, looking at different ways that the categories might fit together, making visual representations of possible links by means of diagrams and node networks (a function of Atlas.ti), discussing tentative conclusions with the supervisors of this study and with other interested parties and plain thinking.

6.8 Summary

This chapter provided a detailed description and justification for the choice of telephone interviews as the means of data collection and of how the data obtained from the GPs would be coded and analysed. It was suggested that telephone interviews were particularly suited to the sensitive topic and to the professional demands (especially time constraints) of the participants. Difficulties with recruitment were highlighted but it was explained that this did not eventually have a negative impact on the study as saturation was nevertheless achieved. The steps taken to maximize trustworthiness (which can be divided into those related to credibility, transferability, dependability and confirmability) were also outlined. In the next chapter, the results of the coding and analytic process are presented, which result from the application of the methods and procedures described in this chapter.

6.9 Conclusion

In keeping with the interactive approach to qualitative research described in chapter 5 (Maxwell. 2005), it was necessary to make changes to the methods used in the course of the study in response to circumstances and knowledge gained throughout the research process. Chapter 6 described some of these circumstances and the relevant changes made to the methods used in this study. As these methods were considered as being appropriate and suited to the research problem and research questions, they were subsequently applied to the study. In the next chapter, the findings, which resulted from the application of these methods, are presented.

7 Results

This chapter reports the outcome of the process of deconstructing stigma into its components and contributing factors (based on the work of Link and Phelan, and Jones et al.), relating GPs' perceptions to that deconstruction and then reassembling the data into a conceptualization specific to the stigma of dementia which raises important questions about timely diagnosis. This process is reflected in the structure of this chapter which is divided into four parts.

The first part of this chapter consists of a presentation of the data relating to each of the components and contributing factors described by Link and Phelan (2001: 2006), Link et al. (2004) and Jones et al. (1984). The aim in the first part is to demonstrate whether and, if so, in what way GPs' perceptions relate to each of these components and contributing factors. The results of Part 1 answer the first research question which was:

- ➢ In what way do GPs' perceptions of dementia reflect the components of, and contributing factors to, stigma?

The key finding in relation to the above question is:

- GPs' perceptions of dementia map on to all the components of, and contributing factors to, stigma albeit with refinements.

Part 1 is structured around the components and contributing factors which made up the initial conceptual framework and not according to the categories which resulted from the data analysis. Consequently, the sub-titles in bold (e.g. **7.1.1 Labelling**) reflect the components and contributing factors of Link and Phelan and of Jones et al. This facilitates the mapping process of GPs' perceptions on to that initial framework.

Part 2 of this chapter focuses on the reconstruction of a holistic conceptualization of the stigma of dementia. The deconstruction of the original general conceptualizations of stigma and their reconstruction into a specific conceptualization of the stigma of dementia can be likened to the demolition of a building and its reconstruction into a new purpose-built one. The categories which emerge from this study are like the bricks of the new building. They are similar to the old ones (i.e. to the initial conceptual framework which was used in Part 1 for the mapping purpose) but have been reshaped/reformed and are unique to the new purpose built construction (i.e. the conceptualization of the stigma of dementia).

This process of rebuilding involved a combination of two approaches. First, it consisted of looking at how the categories resulting from the analysis fit together, interact, overlap and reflect common themes. Some categories, which were more dominant or meaningful to GPs, were also highlighted. These were particularly salient to the stigma of dementia. Second, it involved examining GPs' perceptions of the stigma of dementia as a concept that might be different to that used by Link and Phelan (2001; 2006) and Jones et al. (1984). GPs might, for example, consider dementia a stigma based solely on perceived fear, derogatory remarks or taboo. Combining the two approaches contributed towards establishing the trustworthiness of the data and helped establish whether the data had ecological validity (i.e. reflected the stigma of dementia not only based on theoretical conceptualizations but also on GPs' everyday definition of that stigma). The results of part two answer the second research question which was:

- How do GPs' perceptions of dementia contribute towards the development of a conceptualization of the stigma of dementia?

The key findings in relation to the above question are:

- There are unique categories which emerge from the data and the dynamics of the interaction between them reflect what is unique about the stigma of dementia as perceived by GPs.
- Three themes emerge from the data and are particularly salient to the stigma of dementia: 1. making sense of dementia, 2. relating perceptions to oneself and 3. considering the consequences of dementia.
- There is some overlap between the categories and between the themes.
- Within each theme, there is one key category which is particularly salient. Within making sense of dementia it is the characteristics of the attribute, within relating perceptions to oneself it is existential anxiety and with considering the consequences of dementia it is healthcare discrimination.
- Some degree of existential anxiety and the perceived failure of people with dementia to reciprocate can be detected in many of GPs' reported perceptions.

Part 3 provides findings re the link between perceptions of dementia as a stigma and possible delays in timely diagnosis. GPs' responses fell into two category, namely “the value of diagnosis” and “barriers to diagnosis” and provide a response to the third research questions which was:

- ➢ What do GPs’ perceptions of dementia, stigma and diagnosis reveal about the role of stigma in delaying timely diagnosis?

The key findings in relation to the above question are:

- GPs believe in the importance of diagnosis despite, and in some cases because of, stigma.
- Delays in timely diagnosis are due to GPs’ perception of dementia as a social stigma, their perceptions of dementia resembling those they believe lay people to have and their sensitivity towards these.
- The characteristics of the attribute, existential anxiety and healthcare discrimination are directly linked, in GPs’ eyes, to delays in timely diagnosis. These three categories are linked to all other categories either directly or indirectly.
- Manifestations of stigma at the level of state structures and practices, as reported by GPs, also hinder timely diagnosis.

Part 4 is linked to the new conceptualization of the stigma of dementia (presented in Part 2) but also reflects the way that stigma interferes with timely diagnosis (presented in Part 3) through its interaction with other systems within society. The key findings, which emerge from the response to the second research question and which provide an additional response to the third research question, are:

- Stigma functions like a system.
- Stigma is a system within other systems in society.

7.1 Part 1: The key findings based on a deconstruction of stigma

GPs' perceptions of dementia as they relate to the various components and contributing factors are presented in this section. First, the extent and way in which GPs' perceptions do or do not relate to the categories in the initial conceptual framework of stigma (based on the work of Link and Phelan, and Jones et al.) is considered. This helps clarify whether GPs' perceptions of dementia fully or only partly reflect stigma. The extent of any differences from the initial conceptualization can also be considered in order to determine whether they sufficiently reflect the former to be considered as the same component or contributing factor. Brief details are provided of any amendments made to the categories during open coding (see sub-section 6.5.2.3), such as renaming, splitting, merging or deleting. Notable similarities and differences to the findings of previous studies are also mentioned. Finally, a detailed description is provided of the nature of GPs' perceptions of dementia as a stigma. Quotes are used to illustrate the points being made. Tables providing an overview of the themes, categories and codes resulting from the analysis can be found in Appendix 4a. The order of presentation follows that of the initial conceptual framework which was:

Components of stigma (based on Link and Phelan, 2001; 2006)

Labelling
Stereotyping
Separating "us" from "them"
Status loss and discrimination
The exercise of power
Emotional reactions

Factors contributing towards stigma (based on Jones et al., 1984)

Concealability
Course of the mark
Disruptiveness
Aesthetics
Origin
Peril

Components of stigma:

7.1.1 Labelling

According to Link and Phelan (2001; 2006), labelling involves the identification and labelling of human differences which are deemed to be socially relevant and consequential.

As it is a GP's professional responsibility to identify and categorize medical conditions such as dementia, the practice of labelling *per se* is therefore not necessarily pejorative. It may simply reflect the recognition of a medical condition. Nevertheless, the terms used by GPs and their reasons for using or not using specific terms suggest that they recognize dementia to have social consequences.

The terms for dementia used by GPs can be divided into three main groups, namely: 1. medical terms; 2. non-medical terms; and 3. colloquial expressions. Their choice of medical and non-medical terms was partly influenced by their understanding of the way that lay people interpret those terms. Overall, the terms used by GPs when referring to dementia and people with dementia reflect their understanding of dementia as both a medical condition and a societal phenomenon.

Medical terms

Practically all GPs stated that they used medical terms when discussing dementia with their patients. Most had a preference for using the term “dementia” and some had specific reasons for doing so. Very few referred to specific forms of dementia. Reasons for this included a lack of certainty based on where they were in the diagnostic procedure (e.g. they perhaps merely suspected dementia or had not yet received the results of diagnostic tests), insufficient knowledge to differentiate between different forms of dementia and the fact that specialists were responsible for making a differential diagnosis. The use of the term dementia was therefore linked to levels of understanding of this syndrome but also to GPs’ role in the diagnostic process.

> *“I think as a GP you don’t tend to diagnose with that [Alzheimer’s disease]. You just diagnose with dementia.”* **Interview 7, line 29**

GPs use of medical terms also reflected an awareness of stigma. Their use of medical terms was linked to their understanding of the way that dementia is perceived within society and the perceived consequences of dementia, as well as their understanding of and sensitivity to their patients’ perceptions of dementia as a stigma. Dementia and Alzheimer’s disease were perceived by GPs as terms which bore negative connotations (i.e. stigmatizing) and could be emotionally laden. Practically all GPs felt that dementia was the term with which lay people were most comfortable. One GP spoke of the perceived impact of the term Alzheimer’s disease.

> *“Yes, and that’s why people don’t really like to blurt the word out “Alzheimer’s”. They’re quite comfortable talking about short-term*

> *memory problems but once you start, when you come out with the word Alzheimer, it’s really quite painful at times.”* **Interview 19, line 86**

Others explained the careful choice of medical terms used, influenced by the stage of diagnosis and the particular needs and understanding of each patient.

> *“I suppose in my personal practice I would use memory....memory function, memory problems. And I think probably if I were to grade the wording of different labels I would put dementia as probably the word I would use the least, and then I would put Alzheimer’s because I think people do have an understanding. I think they perhaps still think that I and they feel more comfortable with that. And then I’d put memory disturbance or function problems earlier...”* **Interview 13, line 28**

Non-medical terms

Some GPs had an overall preference for non-medical terms. One of the reasons given was that medical terms are not very meaningful or understandable to patients. One GP described dementia as a “fancy Latin name”. GPs were aware that terms could be deeply disturbing or perceived as stigmatizing (e.g. due to negative connotations and fear). Some GPs preferred to talk to patients about memory problems, to describe what patients were experiencing and to link this to familiar health issues.

> *“So sometimes I talk about quite a few things in ways that people will understand rather than names that initially they might not understand.*

> *It's more meaningful. (../..)*[3] *It then becomes a bit more of a natural process. ….. nothing to do with stigma - well yes, there is a bit to do with stigma. Yes, as I said, cos that word dementia has that connotation. (…/…). I tend not to use the word dementia because it doesn't mean anything."* **Interview 18, line 208:219**

Colloquial terms

Over two thirds of the GPs at some point during the interview used the term "demented". Although still sometimes used in the medical domain, this term is considered derogatory as it has connotations with mental disorder (Rose et al., 2007). Comparable terms would be "mad" or "crazy". One GP highlighted his awareness of the possible association between the term "demented" and insanity as opposed to a memory disorder.

> *"it's got the old connotation of "demented" and when somebody is…. sort of like in the old movies, you know, almost em a mad woman locked in the tower, then the word demented is used. Or people say, "I'm going demented" and I don't mean elderly. I mean I might talk colloquially like "Oh it's driving me demented this." You know, well actually that doesn't mean that's driving me forgetfully."* **Interview 19, line 94**

GPs referred to several colloquial expressions for dementia such as "lights on but no-one at home", "completely gone" and "losing it", including some which are generally considered as being derogatory such as "ga ga", "batty" and "not right in the head". The derogatory terms often have a link to insanity.

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[3] Within quotations, (…/…) indicates that part of the quotation has been omitted (as not considered relevant to the point being made). A row of dots within a quotation (e.g. …….) indicates that the person paused or left a phrase unfinished.

Some GPs occasionally used colloquial terms themselves such as people with dementia being “off with the fairies”, “losing their mind” or “losing their marbles”. “Losing your marbles” is a common colloquial expression typically associated with a perceived loss of sanity (Chantrell, 2004). “Off with the fairies”, on the other hand, seems to reflect a perception of people with dementia lacking insight, or as some GPs put it, being “blissfully unaware” and “just living in their own little world”. This fits in with the uncertainty expressed by several GPs as to whether people with advanced dementia have insight. GPs’ awareness, and in some cases use, of colloquial terms and euphemisms provides insight into their perception of dementia.

7.1.2 Stereotyping

Stereotypes are socially salient human differences, which have been identified and labelled, that tend to be associated with undesirable characteristics (Link and Phelan, 2001; 2006). The terms “undesirable characteristics” and “stereotypes” are often used interchangeably in the literature on stigma. However, stereotyping only occurs when the undesirable characteristics are applied to everyone with that specific label.

GPs provided numerous examples of undesirable characteristics but these cannot be considered as stereotypes as they did not generalize them to all people with dementia. However, GPs did identify stereotypes that they believed lay people and some healthcare professionals had of dementia. It is therefore GPs’ perceptions of stereotyping within society rather than their own perceptions of dementia which relate to the component “stereotyping”. The component “stereotyping” can be detected in the undesirable characteristics that GPs perceive and in the stereotypes they believe other groups to hold.

Undesirable characteristics

Undesirable characteristics of dementia were frequently described by GPs. Examples include the loss of self-control and dignity, dependency, doing embarrassing things, agitation and incontinence. These descriptions did not seem to reflect derogatory judgements or hostility which is consistent with the findings of Sabat's (2011) study involving college students' perceptions of dementia. GPs recognized dementia to be heterogeneous, including different stages and individual differences such that dementia could be experienced in different ways by different people. Negative, age-related stereotypes such as "decrepit", "diseased", "dysfunctional" and "incompetent", mentioned by Scholl and Sabat (2008) in their reflections on stereotype threat, were also absent. Other terms mentioned in that study such as "dependent", "confused" and "dying" were used by GPs but not in the form of stereotypes as GPs seemed to be aware of the heterogeneous nature of dementia.

Awareness of stereotyping

GPs were aware of society's stereotyping in the form of people with dementia not being considered as having any quality of life, especially by hospital staff and professionals. In addition, they provided graphic descriptions of what they believed to be lay people's stereotype of dementia as consisting solely of the advanced stage and often linked to people with dementia in nursing homes.

> *"Yes, I think people see older people with sort of lack of expression, who sit around in chairs and don't respond to the world around them. Em, I think they think about people who are incontinent and who don't…who drool food and things like that. I think they see the image*

> *of the sort of vacant, loss of sort of a physical exterior but without anything inside. Maybe that's about nursing homes, that's how people see nursing homes. Then I suppose that's how people see/think that that's what happens to people with dementia."* **Interview 15, line 58**

7.1.3 Separating "us" from "them"

According to Link and Phelan (2001; 2006), separating "us" from "them" involves perceiving people who have been labelled and stereotyped as being an out-group. Once separated in this way, they claim that it is easier to devalue and discriminate against people in that out-group. GPs' perceptions reflected this process of separating based on the label and stereotype and they also considered this separation as having consequences in terms of devaluation and discrimination.

GPs' perceptions of separating "us" from "them" with regard to people with dementia were closely related to the philosophical understanding of what it means to be a person. They perceived people with dementia as being: 1. just like anyone else; 2. as having become a different person; or 3. as hardly recognizable as a person. Most GPs considered people with dementia as just like them. Some GPs suggested that separateness could differed/was more or less evident alonng a continuum of mild to advanced dementia.

Just like me/anyone else

Many GPs perceived people with dementia as being just like themselves or anyone else, except that they have dementia and others do not, just as someone might have diabetes, a heart condition or asthma and others not. One GP used the term "complex elderly" to describe people with multiple health problems of which one such problem was dementia. Another described dementia as part of an “illness package”. These GPs focused on people with dementia being an integral part of a much larger group and not an out-group. Perceived similarity was not necessarily considered as being positive as some GPs felt that it contributed towards fear amongst lay people.

> *“No, not fundamentally different. That’s where the fear comes in. They know they are people like them. (…/…) I think they…… most people are aware that this could happen to them. So I don’t think they do see them as fundamentally different.”* **Interview 18, line 224-230**

Whilst people with dementia were described as being just like anyone else, they were also seen as being a separate group as they had specific needs. Dementia was seen to affect every aspect of a person’s life. Some also thought that lay people perceived people with dementia as being different (i.e. not just like them) and linked this to possible fear. As with perceived similarity, the fear was felt to be of developing dementia themselves. The following quotation brings to mind the proverb “There but for the grace of God go I”.

> *“You know, they pity them, think what a shame and I guess probably it’s often “thank god, it’s not me” and the sense that they are in a different group and you know, I’m not, thankfully.”* **Interview 6, line 54**

No longer the same person

Becoming a different person was considered by some GPs as contributing towards a separation between “us” and “them”. Some described the way that people with dementia start to respond differently, becoming almost like a stranger and failing to reciprocate in the usual way or even at all. Separation was also described as occurring because the person no longer has value, has lost what made him/her significant to others and is not able to recognize significant others.

> *"…it would be their essence maybe that might have changed and they don't respond to you as they would have before, they don't interact with you as they would have before. So I guess the essence of that person has changed to a certain extent. OK, yes that person, you know, is my mum, is my dad, is my brother but they don't actually recognize me, they don't recognize where they are. So I guess from my point of view, I would probably find the person different, yes."* **Interview 23, line 69**

Almost a non-person

The perception of people with dementia not being human reflects the highest level of perceived difference to oneself. Some GPs considered the possibility of a special status of being "almost a non-person".

> *"I think when you are talking about advanced cases then in a sense they almost become a non-person and so that very much makes it "them and us" because it's separate from me and all my friends and family."* **Interview 14, line 33**

Some GPs considered it possible for a person with dementia to be a living body with no mind. This does not necessarily imply that people with dementia are non-human. The GPs who mentioned this possibility described "a little spark of something" that is always possible. Others referred to the possession of a spirit or soul. Such beliefs make it possible to perceive a person as having no mind and yet remaining a person.

> *"It's still them but their brain's so scrambled that mentally…. mentally it's not them. I'm a Christian so I think the soul of the person is still there. But the mind, the mind isn't there."* **Interview 4, line 54**

One GP stated that people could not become non-persons as that implied animal status but that they could eventually become depersonalized and this might result in them being treated as if there were an object. Another suggested that depersonalization occurs when people are treated as just a system of organs, especially in the advanced stage of dementia. The following quote suggests the temporary disregard of somebody as a valued person rather than the belief that s/he is no longer human.

> *"I think they become a system of organs, especially when it comes to calling the GP out and things. Even the nursing staff…. You just go and listen to the chest. You don't go and speak to them. Not because they can't but because hey they've got dementia so what does it matter?"* **Interview 12, line 179**

The progression from not separate to very separate

People with severe dementia were described as becoming an "entity with dementia" and dementia as affecting "every aspect of a person's life", thus accentuating their difference.

> *"In the later stages, I suppose it's so all pervasive so that it's rather….well that's the same sort of question as saying is somebody with cancer the same as anybody else. Well, once they are terminal,*

> *they are not because that's all they are (…/…) So in the mild stages, they are but once that's the pervasive thing, then they are "somebody with dementia" rather than "somebody with dementia and blood pressure just like anybody else". It's really the dementia isn't it?"* **Interview 19, line 140**

7.1.4 Status loss and discrimination

Link and Phelan´s component "status loss and discrimination" (2001; 2006) includes elements of devaluation, rejection and exclusion. It is the undesirable characteristics that reduce a person's social status and form the basis for discrimination. Devaluation and loss of status are not discrimination per se but increase the likelihood of it occurring.

Not all GPs' perceptions of discrimination were based on the low status acquired by people with dementia. Similarly, not all undesirable characteristics were linked to status loss. Sometimes the main issue was fear of having such symptoms one day oneself and pity for the person concerned. As GPs' perceptions reflecting "status loss and discrimination" reflected two different concepts, this component was divided into two categories which were named devaluation and discrimination. These are discussed separately below.

Devaluation

GPs perceived people with dementia to lack value (rather than having lost it) and social roles. Some GPs reported occasional derision of people with dementia by lay people but their own perceptions did not reflect animosity or hostility towards people with dementia.

GPs demonstrated a great deal of respect for people with dementia. However, some felt that one of the consequences of dementia is that people are considered within society as having less value. One GP reflected on whether there was anything in dementia that could be valued. He concluded that there was not. This was not a negative judgement of people with dementia but of dementia as a condition. Talking about Margaret Thatcher, he stated:

> *"Anyway, past achievements do bring something to other people. I mean, as an example in her case, she has been a prime minister so she has done a lot of things for the country. So that will bring value, but dementia itself will not bring any value."* **Interview 8, line 42**

Another GP felt that status within the community was not easily maintained in that people lose sight of what a person was. They only see what the person is now and that is not valued. Perceived devaluation within society was sometimes linked to ageism and lack of productivity. A perceived failure to reciprocate and a sense of people with dementia being a burden was also reported.

> *"But you know, if you take the generality of what one senses is the general mores of this country, I think people value production. They value people who produce things or people who make you feel good, people who serve you. And those are kinds of things that the elderly in general and the demented in particular don't do."* **Interview 14, line 51**

> *"…it's like a group of people waiting to die, who no longer contribute. I mean we all expect older people when they are retired not to be*

> *working but they still give a lot back in other aspects of life but I think that starts to, even that goes, you know, in people with dementia and I suspect that people do see them as a burden."* **Interview 15, line 158**

GPs highlighted the difficulty people with dementia have in maintaining social roles and retaining a valued position within the family. Some felt that people with dementia were sometimes the object of black humour and derogatory remarks. One GP provided examples of non-verbal devaluation used by lay people in the form of signs and gestures such as tapping the head with one finger and rolling the eyes to insult or mock people with dementia.

Discrimination

GPs' perceptions of discrimination focus on its occurrence: 1. at the level of the individual (interpersonal discrimination); 2. through various practices and systems (structural discrimination); and 3. within the healthcare system (healthcare discrimination). Healthcare discrimination comprises elements of the two other types of discrimination.

Interpersonal discrimination:

GPs provided several examples of interpersonal discrimination. This was mostly in the form of social distancing, which is a common measure of discrimination in stigma research (Link et al., 2004). Not all GPs considered social distancing as discrimination due to the perceived absence of malicious intent. Consequently, it was sometimes described as occurring and at the same time the perpetrators were exonerated from blame. The first extract below provides an example of discrimination not being linked to devaluation but to perceived functional and interactional difficulties on the part of the person with dementia.

> *"They might not pay attention to him. It's not a deliberate sort of thing that they are going to discriminate against him, you know, in the sense, "you're not a part of society" but because he is less able to socialize and take part in activities…..."* **Interview 8, line 64**

> *"…. they just said quite outright, "Oh you know, there's no point talking to your mum any more. She can't really answer the questions" and so they just sat at the table and didn't try to speak to her."* **Interview 6, line 48**

Some GPs attributed social distancing not only to difficulty interacting but to failure to reciprocate in an appropriate manner within the social exchange. They felt that people expect something in return for their social investment and that people with dementia do not always provide this.

> *"I suspect, you know, that when you invite somebody socially, you sort of want a good interaction and if you think that somebody gives nothing back or they are likely to behave in a way that you find unacceptable, then you are probably less likely to invite them so probably their social world drops off as time goes on."* **Interview 15, line 186**

Structural discrimination:

GPs reported that the way that society is organized results in the unequal or unfair treatment of people with dementia. Such discrimination was perceived particularly in relation to technological advances and practices which are ill-suited to the needs and capacities of people with dementia.

> *"I think that the more we move on with technology, the more people*

> *with learning difficulties and with dementia are kind of left behind in a way with things like the abolition of cheque books and having to use PIN numbers everywhere. That's all going to mean a struggle earlier on I feel for people who have memory problems."* **Interview 16, line 139**

Healthcare discrimination:

Most GPs believed that people with dementia were discriminated against in the health service. One GP suggested that although it might sometimes seem like discrimination, decisions were sometimes made on the basis of comorbid conditions such as hypertension or diabetes. Most, however, were convinced that healthcare discrimination did occur and that it was often quite subtle. Examples included barriers to obtaining certain operations such as hip replacements and other treatment such as dialysis or chemotherapy, inadequate or inappropriate care and treatment and failure to consult people with dementia. Not getting a diagnosis of dementia was not mentioned by any of the GPs as a form of discrimination. Healthcare discrimination was often attributed to healthcare professionals holding stereotypes of people with dementia as having no quality of life and not being valued by society.

> *"We don't give people choice, we assume they don't want an operation or we'll assume that because they've got that disease, they may not want their cancer treated. (…/…) I don't think…… they [healthcare professionals] don't systematically say they don't need to have an operation. I think it's probably a little bit more subtle than that."* **Interview 15, line 78**

Healthcare discrimination was the most dominant feature of GPs’ perceptions relating to Link and Phelan’s component “loss of status and discrimination” and a salient feature of their perceptions of dementia in general. As mentioned earlier, it contains elements of interpersonal as well as structural discrimination. Healthcare discrimination was an issue of great concern to several GPs who nevertheless did not feel that lay people were particularly aware of it.

7.1.5 The exercise of power

Link and Phelan (2001) claim that stigma is entirely dependent on social, economic and political power in that it takes power to stigmatize. GPs made explicit reference to power and were particularly aware of the relationship between power and discrimination. Their perceptions therefore reflect Link and Phelan’s component “the exercise of power”.

GPs’ references to power include two key areas of focus: 1. The changing nature of power in relationships; and 2. The powerlessness and vulnerability of people with dementia as well as their own powerlessness. They emphasize changing power relations between people with dementia and their relatives as well as between healthcare professionals such that people with dementia become disempowered. This perception also reflects an awareness of the vulnerability of people with dementia to discrimination and abuse. GPs reflected on the powerlessness of both people with dementia and themselves.

Changing power relations

GPs described changes in power relations, including a transition to a parent-child relationship or to a more paternalistic doctor-patient relationship. These changes in power relations lead to disempowerment such that the voice of people with dementia is either ignored or deemed to be unreliable. In their view, over time changes occur in the balance of power with people with dementia losing power and relatives and healthcare professionals gaining power.

GPs' powerlessness

Some GPs regretted their role in the process of disempowerment. They explained it was often the result of a lack of time, a factor over which they felt powerless. The problem of time constraints was linked by GPs to the way that appointments are organized within the current healthcare system rather than solely to a heavy workload. The GPs did not mention a possible link between the organization and financial remuneration of consultations, which may nevertheless influence GPs' decisions regarding the use of their available time for consultations. Payment per consultation is probably not conducive to promoting lengthy consultations and in some previous studies GPs have cited inadequate financial remuneration as a barrier to timely diagnosis (Cahill et al., 2008; Iliffe et al., 2005; Turner et al., 2004).

Some GPs recognized their own lack of power. In the following quote, the GP describes his awareness of the vulnerability of people with dementia and how he often feels that he struggles in vain to protect them from discrimination.

> *"And you just have to hear the comments and discussions around the ward which make you a bit worried about what happens to patients when they get labelled and discriminated in that sense. And often, we end up fighting in the corner because we often find people once again labelled and people like that will get discriminated in terms of*

> *investigations and resources not just with regards to Alzheimer drugs but to treatment for other conditions.”* **Interview 3, line 72**

Vulnerability to discrimination

GPs felt that people with dementia lacked the power to protect themselves from such discrimination. In addition,

The failure of people with dementia to protect themselves or stand up for their rights was sometimes described in terms of vulnerability. This was based on people with dementia’s lack of awareness or of the ability to take action.

> *“It’s easy to cut costs and reduce the number of carers because you can do. This group can’t fight back in the same way that cancer patients will fight back or heart patients will fight back if their services are cut.”* **Interview 15, line 174**

> *“People are always going to see it as the “oh well what’s this person going to complain about”. You know, how are they gonna prove it or how are they going to realize that there is something going on?”* **Interview 10, line 195**

7.1.6 Emotional reactions

According to Link et al. (2004), labelled differences may evoke emotional reactions in others which can be detected by stigmatized people and may shape subsequent behaviour towards them. When asked directly whether dementia resulted in any emotional reactions, most GPs said that it did not or at least, they were not aware of any. As the interviews progressed, they nevertheless described in detail, and often with feeling, their emotional reactions towards dementia and people with dementia. Their perceptions did therefore reflect the component “emotional reactions”.

Emotional reactions were described by GPs mainly in terms of: 1. emotional reactions towards people with dementia; 2. emotional reactions to the disease; and 3. the perceived emotional impact of having dementia.

Emotional reactions towards people with dementia

GPs reported experiencing a range of emotional reactions linked to their contact with people with dementia (i.e. either provoked by or targeted at people with dementia). Examples include hopelessness, helplessness, sympathy, empathy, heartsink, sadness, concern paternalism, protectiveness, frustration and irritation.

> *“Em, I guess you know sort of sadness. Em I think it’s…. I remember (actually maybe I’m digressing now) kind of going to a nursing home and seeing someone who was demented and looking at a picture on the wall of a beautiful woman in her twenties and it was her. So I think it’s sort of sadness that perhaps that’s what’s awaiting us all.”* **Interview 12, line 86**

> *“I suppose I maybe tend to compensate and to be a bit, em I don’t know really, paternal perhaps. Do you know what I mean? Em, a bit over touchy-feely, “don’t let that worry you Sir”, “we’ll sort you out”, that sort of thing.”* **Interview 20, line 80**

Emotional reaction to the disease

Emotional reactions towards dementia were also described. One GP, for example, spoke passionately about the cruelty and unfairness of dementia, stating that people would not put an animal through such suffering and expressing the wish that people “could just drift away”.

> *“I wouldn’t treat my dog…..I mean you would put your dog down if they were like this. You know that kind of… they shouldn’t have to suffer like this.”* **Interview 19, line 122**

Emotional reaction to the prospect of having dementia

Emotional reactions were also related to beliefs about the experience of dementia. Some GPs stated that there were certain aspects of dementia which they would find disturbing to experience. These included loss of dignity, loss of independence and control over one’s life, personality changes, becoming disinhibited, becoming totally dependent on others and becoming an embarrassment or burden to others.

> *“But with things linked to dementia, you might dread aspects of your personality coming up to the fore that you hold well in check. (…/…) We have demented patients, you know, who become a nightmare to manage because they become sexually dis-inhibited, for example. And I think, you know, if I was thinking myself that I got that kind of illness, that’s the kind of thing that I think would potentially be very shameful.”* **Interview 14, line 159:163**

Perceived emotional impact of dementia on people with dementia

GPs reflected on the emotional impact of dementia on people who have it. Some described their perception of people with dementia sometimes being embarrassed and frustrated or feeling lonely, isolated and sad.

Factors contributing towards stigma:

7.1.7 Concealability

Jones et al. (1984) considered that the extent to which an attribute was visible or could be hidden contributed towards whether it was likely to become a stigma. GPs' perceptions of dementia reflected issues related to its visibility and its potential concealability. However, they tended to focus on lack of visibility in terms of this being an obstacle to diagnosis rather than in relation to stigma. Their perceptions of visibility and concealability were closely linked to their perceptions of aesthetics and the course of the mark (i.e. the progressive deterioration and debilitation associated with dementia). For example, the visible aspects of dementia are perceived as unpleasant and worrying and become more difficult to conceal as the disease progresses.

The close relationship between these three factors (i.e. concealability, aesthetics and course of the mark), which all contribute towards stigma, resulted in the creation of a new category called "characteristics of the attribute" into which they were placed. Whereas in the initial conceptual framework each was a category, when the data was coded they remained at the level of a code. Each is described separately here as Part 1 of the Results is structured around the predetermined categories from the initial conceptual framework rather than the categories which emerged from the coding.

GPs' perceptions of the concealability of dementia reflect two key issues. Firstly, they reveal a perception of the visibility of dementia being problematic for them as GPs with responsibility to recognize and diagnose dementia.

Secondly, they reveal a perception of people with dementia and their carers seeking to conceal dementia.

Visibility of dementia

Some GPs felt that it was difficult to recognize dementia as it is not particularly visible. One suggested that this is because dementia is “a mental rather than physical condition”. Others emphasized the possibility to observe dementia through behaviour. Some felt that more time was needed than GPs generally had to detect dementia in patients who were not presenting with dementia as a concern. There was also awareness that dementia becomes more visible over time.

> *“Unless I am able to talk to the person, it won’t be noticeable just like that because it’s not a physical sign anyway. It’s a mental illness. (…/…) Yes, in the early stages even if you see the person and talk to him, you will never notice but as the time progresses you will be able to notice that. (…/…) So I think you can see from actions, not from physical signs.”* **Interview 8, line 72:85**

GPs suggest that dementia is sometimes more visible to relatives as they have more exposure to the person with dementia. Moreover, relatives know what is normal for that person and what represents a change in his/her abilities, mood or behaviour.

Concealing dementia

Some GPs commented that people with dementia often try to conceal their dementia and that partners sometimes help them to do so, whether unwittingly or deliberately.

> *"…. you wouldn't know the difference unless it's picked up by say a relative who then says "well, you know, Mum's been very forgetful" because they know the person from before."* **Interview 10, line 277**

The above quote also demonstrates how relatives sometimes "out" the person with dementia by revealing what the latter is trying to conceal.

7.1.8 Course of the mark

Jones et al. (1984) described the course of the mark as the awareness of a condition which progressively deteriorates and becomes more debilitating and socially alienating over time. GPs' perceptions of the progression of dementia reflect this component. "Course of the mark" is one of the issues covered in the newly created category "characteristics of the attribute" mentioned earlier.

Progressive deterioration

All GPs commented on the progressive nature of dementia, not only when directly asked but often when discussing other issues.

> *"Well I think it depends on the type. I mean, there's obviously different types of dementia. And it depends on, you know, the extent or the degree of their illness. Em so it's hard to really give you a black and white answer. You know, there's mild, there's moderate, there's severe."* **Interview 12, line 36**

Increasing debilitation and social alienation

GPs' descriptions of dementia and of how they thought lay people perceived dementia emphasized increasing social alienation and debilitation in line with the progression of the disease resulting in people with dementia becoming totally isolated and dependent on others.

> *"…..and you do the dementia screening test and they are just mildly forgetful and you think I hope they drop dead of something else. Otherwise they are going to go down the slippery road. But you also have the vision that I think most people, most lay people, have of severe dementia, where people are in a home, where they don't know who they are, they don't recognize anybody, they are dependent for their needs on other folk."* **Interview 19, line 82**

7.1.9 Disruptiveness

Disruptiveness was described by Jones et al. (1984) as the property of an attribute which hinders, strains and adds to the difficulty of interpersonal relationships. GPs described dementia as a condition which disrupts interpersonal relationships.

GPs' perceptions of the negative impact of dementia extended beyond interpersonal relationships to the broader context of the perceived impact of dementia on society. GPs' perceive dementia to disrupt interpersonal interaction and to be considered a burden to society.

Consequently, the pre-determined category "disruptiveness" was renamed "impact of the attribute" in the final conceptual framework of GPs' perceptions of dementia as a stigma and covers: 1. the impact on relationships; and 2. the impact on society. This new category reflects the factor "disruptiveness" proposed by Jones et al. (1984) and adds another dimension to it which is relevant to the stigma of dementia.

Impact of dementia on relationships

GPs attributed the impact of dementia on relationships to difficulties with memory, emotions and communication. They highlighted the difficulties people with dementia have remembering what they and others have said, what they have done and can talk about, losing “the thread of what you’re saying” and “losing the train of thoughts”. Emotional factors interfering with interaction include people with dementia being embarrassed, confused and no longer recognizing people. Communication issues included failing to initiate conversation, not being able to explain or understand something and not being able to communicate who they are or their hopes and fears. These difficulties were perceived as interfering with the ability of people with dementia to reciprocate which, in turn, resulted in them not being valued as partners for social interaction.

However, GPs perceived the disruption to interpersonal interaction as being two-sided. Some felt that lay people experienced difficulties communicating with people with dementia, not knowing how to respond or what to say or do. This caused feelings of embarrassment, awkwardness and fear. Such disruptiveness was also linked by GPs to social distancing.

> *“I think they feel awful and guilty about it because these people are close to them, they might be people they’ve known all their lives and they have been quite happy chatting about this and that and then all of a sudden, they go into a nursing home and visit two or three times a week and they are running out of things to say. I guess because the conversation is a lot more one sided and they are not getting the sort of responses back. And with my partner, when his granddad had that dementia, he just hated himself for going to the hospital and not….., you know, running out of things to say within ten minutes and not*

> *knowing what to say and what to do. That's very distressing for people I think."* **Interview 21, line 55**

Some GPs felt that dementia was sometimes more disturbing to relatives than to the people who have dementia. They pointed out that relatives often witness gradual changes of personality, loss of awareness and even "nastiness".

> *"When you realize that I think it's almost in the end stages when they've lost that awareness, from what you can gather, it's probably more the people around you that it upsets most because they see the change in the person."* **Interview 22, line 21**

> *"…..he gets <u>really</u> angry and <u>really</u> vocal and he shouts in her face and she talks about his eyes popping out. There's nothing she can do about it. I think she's quite disturbed by it."* **Interview 20, line 31**

Changes in personality were perceived as putting a strain on relationships and changing the nature and quality of relationships, especially when the person seemed to have become a different person. Some GPs perceived dementia as a condition which can lead to people becoming a psychological, physical and financial burden to their families. This was sometimes accompanied by concern about one day themselves being that burden.

> *"I mean in the later stage of dementia, do they know that things have gone so badly wrong and that they are such a burden? Or are they not aware?"* **Interview 4, line 41**

> *"Yes, I guess for myself being a burden on the family would be one of the big fears, I think - having seen my mother and she's been fairly*

> *blissfully unaware of herself, of how it’s affecting her, …… but thinking if I were her and having the family look after me, I would find that one of the most difficult things I think.”* **Interview 6, line 28**

Impact on society

Some GPs emphasized the impact of dementia on society in terms of financial burden, the greying of the population leading to more people with dementia, fewer people to bear the cost of their care and changes in the pattern of inheritance. This represents a disruption of a tradition which is closely linked to economic issues and may contribute towards resentment against people with dementia by other members of society.

> “*Because in the past when people didn’t live so long with dementia, there was wealth to be handed down and now there’s not going to be wealth handed down. That allied with the population getting older and not as many people working so there’s less contributions and pensions cos as you know, there’s no pension pot in existence anywhere. It’s really the people working today who pay for the people tomorrow. So there’s going to be some understandable move to say kill them all off.”* **Interview 19, line 156**

7.1.10 Aesthetics

Jones et al. (1984) described aesthetics as the extent to which the mark renders the person “repellent, ugly or upsetting” (p.24). GPs perceived dementia, especially in the advanced stage, as presenting a disturbing mental image. However, the mental images they described emphasize the emotional impact of the image rather than suggest that people with dementia are inherently repellent or ugly. Perceptions reflecting “aesthetics” were dependent on dementia being visible and on the course of the mark (i.e. negative images being mainly of advanced dementia). This further justifies grouping aesthetics, concealability and course of the mark under the new category “characteristics of the attribute”.

GPs’ perceptions of dementia relating to aesthetics focused almost entirely on disturbing mental images. The term “mental image” denotes the images that GPs had in their mind of people with dementia in general and not necessarily accurate representations of specific people with dementia. The term “image” will be used hereafter for the sake of simplicity. These can be divided into: 1. GPs’ images of people with dementia; and 2. those GPs believed lay people to have. Whilst the two were almost identical, GPs suggested that the meaning of the negative images for each group was different.

GPs’ images of people with dementia

GPs’ images of people with dementia were focused on the advanced and end-stage of dementia. They described advanced symptoms in a way which suggested that they had been moved by the people they had seen in that condition.

> *“You know, when you see someone in a very pitiful state, perhaps curled up in a deformed position in a bed, unable to have any kind of meaningful interaction, just crying or screaming or…… you know, that’s a sad kind of image.”* **Interview 14, line 117**

Images of people with dementia with incontinence, poor hygiene and in a passive state were also mentioned. However, GPs recognized that there was no one image of dementia (e.g. “sometimes they are unkempt, sometimes they are not”). Moreover, they were aware that the images they had were probably somewhat biased due to dementia being very visible “in the later stages”. Some said that they did not have a image of mild dementia. Exceptionally, one GP described an image which is perhaps more characteristic of mild dementia. This consisted of “a vacant look in somebody’s eyes” which was believed to signify that the person could not follow in the way s/he once could.

The images believed to be held by lay people

The mental images that GPs felt lay people had of dementia were also focused on the advanced or end stage. These were of people “meuling and puking”, “emaciated”, “mumbling incoherently”, “looking gormless” and “shrivelled up”. GPs also described people with dementia suffering from incontinence, unaware of their surroundings, unable to recognize people, and needing full-time nursing care. For GPs, the image of advanced dementia that lay people had was not due to dementia being more visible in the more advanced stage. It was linked to the stereotype of dementia only consisting of the advanced stage. This may explain their caution when discussing dementia with lay people. They felt that it was important to consider not what they as GPs know dementia to be but what lay people think it is.

7.1.11 Origin

The term “origin” describes under what circumstances the condition originated (i.e. how it was started or what caused it), whether it is congenital or non-congenital, whether its onset was rapid or slow and, most importantly according to Jones et al. (1984), whether the person is responsible for it. Perceived responsibility for the attribute was further linked to negative attitudes and behaviour towards the person bearing it.

GPs' perceptions of responsibility were linked to their perceptions of the origin of the mark and considered in relation to possible blame. As responsibility was central to GPs' perceptions on this issue, the category was renamed "responsibility". GPs' perceptions of responsibility covered actual and hypothetical responsibility. Perceptions of actual responsibility did not support the contributing factor "origin" described by Jones et al. (1984). Perceptions of hypothetical responsibility did but not with regard to blame. The renamed category (i.e. "responsibility") was therefore retained in the final conceptual framework.

As mentioned above, GPs' perceptions covered three main topics. These were: 1. origin/cause; 2. responsibility; and 3. hypothetical responsibility.

Origin/cause

GPs' perceptions relating to the origin of dementia are mainly medically orientated. They attribute dementia to the existence of a mental disorder or disability and to the biological impact of lifestyle. GPs' descriptions of the origin of dementia reflect theories of neuro-degeneration and destruction of brain cells leading to various cognitive deficiencies. Perceptions of the progression, typical age of onset and irreversibility of dementia were also reflected in such descriptions. Whilst several GPs made statements to the effect that dementia was more common in older people, some specifically stated that they did not consider dementia a natural consequence of ageing.

> *"Yes, they have got a mental illness and they need help or treatment if available or possible… just like any other person."* **Interview 8, line 30**

> *"I see it as more common in the elderly population. I wouldn't see it as a normal part of ageing. I would see it as a separate condition."* **Interview 2, line 14**

Actual responsibility

None of the GPs considered people with dementia responsible for having the condition. They did not feel that lay people did either. GPs felt strongly that people were not and should not be blamed for having dementia with responses such as "absolutely not!", "no, no, no!", "no, not at all!"

> *"No, no, no! I think that would be unfair really. Er, I think that would be most unfair….. awful really, aye."* **Interview 11, line 119**

Hypothetical responsibility

Several GPs reflected on a hypothetical situation in which people might be considered responsible for having dementia. One GP also considered this in terms of people's tendency to blame themselves. Possible blame was based on lifestyle factors such as smoking, drinking alcohol and being obese, particularly in relation to alcohol-related and vascular dementia. GPs nevertheless concluded that even if, technically speaking, some people were responsible for having dementia, they should not be blamed for it.

> *"No, people can't be blamed for having dementia. Well, actually, it's a bit of a contentious issue, isn't it? I mean, it's a bit like with cigarette smoke and lung cancer. Can you really be sure that the smoking has led to the cancer? With dementia, it is not known what causes it. With alcohol-related dementia, can we say that they have done it to*

> *themselves? And even if we could, does that mean that we should blame them for it. No, I don't think so."* **Interview 12, line 145**

The reluctance of GPs to attribute blame seems to be partly due to their belief that dementia has multiple causes, that lay people are not necessarily aware of risk factors and that there is a lack of conclusive scientific evidence of cause and effect relationships. One GP added that where cause and effect might be fairly well established (e.g. in alcohol-related dementia), the effect occurs so long afterwards that people may fail to see the link. Some GPs could, however, foresee an element of blame arising in the future if knowledge and awareness about risk factors were to increase. This demonstrates how perceptions of dementia are constructed within a particular period of time and are susceptible to change.

7.1.12 Peril

"Peril" was described by Jones et al. (1984) as the danger posed by an attribute to a person's physical, psychological and social well-being. GPs perceived dementia as a condition which people, including themselves, find very threatening in terms of physical danger and existential anxiety (consisting mainly of a threat to psychological and social wellbeing). Whilst danger in the form of physical violence was perceived as possible, the main threat perceived was existential, linked to the prospect of an unbearable existence. GPs' perception of dementia as engendering existential anxiety is linked to almost all other perceptions. Existential anxiety is one of the most salient aspects of GPs' perceptions of dementia in that GPs accord it a high level of social significance.

The name of the pre-determined category, peril, was therefore renamed as existential anxiety in order to more accurately reflect the data. Details of GPs' perceptions of physical danger are nevertheless also described below in order to demonstrate how these relate to Jones et al.'s (1984) contributing factor of "peril".

Physical dangerousness

People with dementia were not generally considered as being physically dangerous. Some GPs commented that people with dementia are not physically threatening as they are often old and frail. Isolated incidents were nevertheless considered possible and understandable.

> *"I mean I'm not saying that people aren't, in the same way as any other person can be, violent if that's part of their personality but as a group of people I don't see them as any more violent or disturbed than anybody else. (../…) If you move somebody ultimately round the ward in a hospital multiple times and confuse them and don't explain what you're doing, then it's no wonder they get frightened and potentially lash out."* **Interview 15, line 68**

Exceptionally, one GP felt that violence was quite common. Another stated that people with dementia "can sometimes be a bit violent and scratch and thump". Others described violent incidents as being largely restricted to nursing homes and involving "nipping and biting" and verbal aggression. Aggressive behaviour was also believed to occur in situations where people with dementia living alone perceive visitors as unwelcome intruders. GPs did not hold stereotypes of violence often attributed by lay people to people with other mental disorders.

> *"….they can become moderately violent, often violent towards other patients, but in the way of sort of lashing out rather than a deluded idea that somebody needs killing now with this knife cos otherwise they will become possessed and that kind of thing."* **Interview 19, line 100**

> *"I mean not dangerous in the sense that they are going to go out and wield axes and things like a psychopathic 20 year old might do."* **Interview 14, line 141**

Existential anxiety

The term "existential anxiety" is not used to denote a physiological state of anxiety or dread linked to the inevitability of death, reflection about freedom, isolation and meaning as is common in existential psychology (Yalom, 1980). It is used in the context of this study to indicate a perceived threat to one's own existence. Examples of existential anxiety were common and quite varied but generally reflected a kind of existence that GPs did not wish to experience. Some GPs specified that they would not want an existence with a "lack of insight", "loss of control", "loss of dignity" and "total dependency" on others. Some described dementia as cruel and involving a "slow process…. to a certain extent maybe a bit undignified". Dementia was linked to fears about the loss of one's uniqueness or essence as a person (whilst alive) and of one's awareness of oneself, as well as of one's own personal history and intellect.

> *"I would desperately not like to have dementia because I wouldn't like to lose myself really."* **Interview 5, line 22**

> *"…. but somehow it seems an inhuman way - compared to having a quick MI* [myocardial infarction/coronary] *or even having cancer, which is very unpleasant and painful but actually to take away what is essentially the human being by the mind…. I think that just seems cruel."* **Interview 19, line 110**

> *"If I had a choice, I'd prefer not to go that way. Cos I think it's quite a slow process and I think to a certain extent maybe undignified. And I think if it was me and you know I could choose, I'd sort of choose something a lot quicker personally."* **Interview 23, line 13**

GPs were aware that dementia was "a terminal condition". Nevertheless, as also demonstrated in the above quotes, it was not death that GPs feared but an unbearable existence prior to death which they associated with dementia. As we have seen in the section separating "us" from "them", GPs made a connection between the existential fear of dementia and people's tendency to reflect on their own possible "fate".

> *"The fear's about "am I going to be like this?" Am I going to end up like this? (…/…) The "like this" is someone confused who can't cope, who can't manage their own affairs. They need help doing this, that and the other and eventually they don't recognize somebody. It's living death. It's a living death and I think a lot of people fear it as much as cancer and some people think it's worse".* **Interview 18, line 118**

The breakdown of stigma into identifiable parts (components and contributing factors) made it possible to check whether GPs' perceptions reflected stigma in its entirety (i.e. as a whole concept) rather than just certain aspects of it. In the case of separating “us” from “them”, stereotyping and origin, GPs’ perceptions differed slightly from the description of each component and contributing factor provided by Link and Phelan (2001; 2006) and Jones et al. (1984). However, they corresponded sufficiently to these conceptualizations to be considered as reflecting the same components and contributing factors. This approach also made it possible to compare GPs’ perceptions with those they believe lay people to have, of which there were several. In Part 2, the way in which GPs’ meanings associated with dementia and their understanding of how stigma is perceived in society contributes towards the construction of a specific conceptualization of the stigma of dementia, will be addressed.

7.2 Part 2: Rebuilding the data into a coherent conceptualization of stigma which is unique to the stigma of dementia

This section starts with a presentation of GPs’ views about stigma in order to determine whether they correspond to the conceptualization of stigma which guided this study and was presented in Part 1. This is followed by an explanation of how the findings from the interviews represent a transformation from a general conceptualization of stigma, which could be applied to any condition, to one which is specific to dementia. The main themes, which provide the structure for this new conceptualization are presented. The last two sections of Part 2 describe the dynamic relationships between the categories and themes within that conceptualization and highlight the most salient features of it.

7.2.1 GPs’ views on stigma and how these relate to their perceptions of dementia

GPs were asked specifically about the stigma of dementia. This direct question about stigma, which was introduced after the eighth interview, consisted of asking GPs a closed question as to whether they thought that dementia was a stigma. This was followed by a discussion about the way in which it was or was not a stigma. The issues that GPs associate with stigma are similar to those which have been presented in Part 1 of this results chapter. Of the 15 GPs who were asked, 13 felt that dementia was to some extent a stigma.

For the two GPs who did not consider dementia a stigma, this perception was consistent with their other responses which did not greatly reflect stigma. For example, they did not believe that people with dementia were considered as a separate group, or were stereotyped or discriminated against. They did feel that lay people feared getting dementia but had no such concerns themselves.

With regard to the GPs who considered dementia a stigma, for some, this was based on their perception that lay people considered it shameful and a taboo in the sense that it is “still not talked about in more positive or open way”. GPs perceived lay people as being sympathetic towards people with dementia but as speaking about dementia in a “downbeat sort of way”, using the kind of colloquial terms described earlier which reflect the loss of one’s mind.

> *“Em, I think there is still some stigma with it. It’s difficult to quantify but you know you hear people say “oh, it’s such a shame but so and so,*

> *you know, they are losing it" and I think there is an element of stigma linked to that."* **Interview 14, line 173**

Colloquial terms, mentioned earlier in connection with labelling, which suggested a perceived association between dementia and mental illness, were confirmed by statements directly linking dementia to the stigma of mental conditions.

> *"A lot of people view dementia as a stigma. It's kind of like with all things that are linked to the mind, there is a lot of stigma whereas with other conditions, for example, linked to the heart or with diabetes, there's not. You know, there is stigma linked to depression, bipoloar and dementia. It is the stigma linked to mental health issues."* **Interview 12, line 148**

However, the opposite view was also the reason given by one of the two GPs as to why dementia was not a stigma.

> *"I don't think I would say it was a stigma. I don't think it's got the same stigma as other psychiatric, mental health conditions etc."* **Interview 22, line 71**

One GP who felt that dementia was still a stigma stated:

> *"This stems from the fact that it's a progressive, debilitating illness that robs people of their, well of themselves really."* **Interview 21, line 82**

This links the stigma of dementia to the course of the mark, separating "us" from "them" and existential anxiety. The latter is also reflected in the following quote.

> *"I think it's still got a huge stigma. It's what mainly elderly people are scared of. From what I have seen in my personal and professional life, it's the one thing that relatives and friends will often bring up about being forgetful about things. (…/…) And I think a lot of people want to avoid thinking about it really."* **Interview 4, line 32**

Some GPs compared the stigma of dementia to that of cancer some twenty years ago when cancer was much feared, not openly discussed and often concealed. This is in keeping with GPs' perceptions of dementia linked to existential anxiety and concealability. Existential fear was linked by one GP to the stereotype of dementia consisting just of the advanced stage. He described this in terms of a misconception which results in people even in the early stages of dementia being stigmatized.

An analogy was also made to ageism (i.e. the stigma of age). Some GPs felt that the stigma of dementia and that of age were almost inseparable because most people with dementia are older. This fits in with some of their comments about people with dementia being considered as giving nothing back, being a financial burden and not being productive. As such it also corresponds to perceptions of the devaluation of people with dementia by society.

The way that people speak about dementia was also cited as a reason for not considering dementia a stigma. Some GPs felt that dementia was less of a stigma nowadays because people with dementia and their relatives tend to be quite open about it. Celebrities such as Terry Pratchett were praised for speaking out about their experience of dementia and helping to remove stigma. One GP was nevertheless skeptical about claims that dementia was no longer a stigma.

> *"I think actually it still is. I think people who say it isn't, are actually wanting to believe it isn't because it shouldn't be. It makes you feel uncomfortable if you think that it is stigma there because you don't want it to be. It shouldn't be so I think there is a kind of move to say it isn't."* **Interview 19, line 178**

Some GPs felt that perceptions about the stigma of dementia were gradually changing. They felt that dementia was still a stigma but that it was gradually becoming less so. A better understanding of dementia nowadays was associated with a greater acceptance of it. One GP suggested that the older generation might be more inclined to consider dementia a stigma than the younger generation. Others reflected on the way that dementia is gradually becoming less of a stigma. Such perceptions reflect the socially constructed nature of stigma within a particular historical period. The link between stigma and diagnosis is also addressed in section 7.3.1.

7.2.2 Proposing a unique conceptualization of the stigma of dementia

The initial conceptual framework, which was applied at the start of the coding process after the initial open coding (see section 6.5.2) was gradually developed and eventually replaced by the final conceptual framework of GPs' perceptions of dementia as a stigma. Figure 5 below provides a comparison of these two conceptual frameworks.

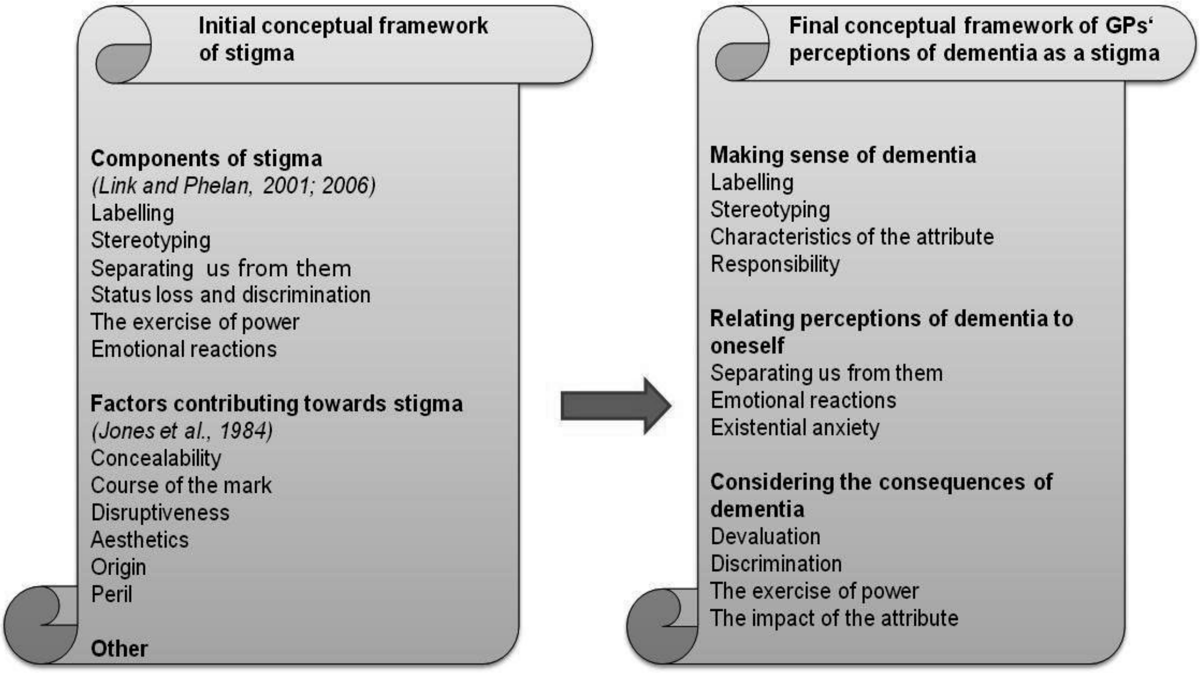


Figure 5: The initial and final conceptual frameworks

The categories which emerged from the study (and are represented in the right-hand scroll in the above diagram) represent GPs' perceptions of dementia for which the distinction between component and contributing factor is no longer meaningful. Moreover, the manner and extent to which GPs' perceptions of dementia reflect the components and contributing factors in the initial conceptual framework has already been established (see section 7.1). Consequently, such a distinction was not retained in the final conceptual framework.

The initial conceptual framework consists of a general conceptualization of stigma which is applicable to a wide range of medical conditions and other attributes. The final conceptual framework, on the other hand, represents a specific conceptualization of the perceived stigma of dementia according to the GPs interviewed. It is thus unique. Several categories are present in both the initial and the final conceptualization. However, as has already been demonstrated, it is the way that they are expressed that is important as well as how they interact in order to form meaningful themes. In the remainder of this chapter, the themes will be described followed by the salient features of the stigma of dementia and finally, the relationship between categories and across themes. This will clarify what is unique about the stigma of dementia.

7.2.2.1 The three themes of the perceived stigma of dementia

The following three themes will now be discussed.

1. Making sense of dementia
2. Relating perceptions of dementia to oneself
3. Considering the consequences of dementia

Making sense of dementia

The theme "making sense of dementia" covers perceptions of dementia which reflect the way that dementia is understood (i.e. what dementia and people with dementia are like). There are four categories within this theme: labelling, stereotyping, characteristics of the attribute and origin.

When talking about dementia with patients, GPs' careful choice of words suggests that they are not just fulfilling their obligation as a GP to inform patients about a disease they may have. On the contrary, their choice of terms, manner of addressing the topic and avoidance of certain terms go beyond a medical understanding of dementia and reveal their attempts to make sense of dementia as a complex social phenomenon.

The term "making sense of dementia" implies an ongoing, dynamic process which is socially constructed with others rather than the simple acquisition of facts. GPs have already acquired facts in their medical training although this may be quite limited according to their own estimations (see section 7.3.2).

GPs' perceptions of dementia may therefore be influenced by their medical training as well as by their attempt to make sense of dementia in the context of people's lives. Their perceptions of concealability and aesthetics revealed reflection about how people live and cope with dementia. They were linked to people's experiences, past lives, hopes, fears and suffering. The GPs were not merely citing symptoms and the typical progression of the disease. They were reflecting on what it must mean to have dementia. Even when asked about possible responsibility for having dementia, they first answered in human terms, almost with indignation at the idea that someone might be blamed for having dementia. Only later did they respond in terms of possible cause and effect relationships.

GPs' recognition of dementia as a complex social phenomenon which people make sense of in different ways is reflected in their awareness of stereotypes held by lay people and some healthcare professionals. They did not share those stereotypes and they may have even wrongly interpreted other people's perceptions of dementia. However, their perception of the existence of stereotypes within society influenced some of their perceptions. For example, the stereotype believed to be held by lay people of dementia being uniquely advanced dementia influenced GPs' perceptions of the possible impact of using terms such as "dementia" or "Alzheimer's disease". This stereotype was also linked by GPs to lay people's existential fear of dementia. Stereotypes that GPs believed healthcare professionals held about people with dementia having no quality of life were prominent in GPs' perceptions of healthcare discrimination.

GPs highlighted the complexity of dementia as a medical condition and the way that it affects people in different ways. One GP described it as affecting people emotionally, cognitively, physically and socially. Some commented on limited training in dementia and difficulties differentiating between types of dementia. Others expressed their uncertainty as to whether, and if so at what point, people with dementia lose insight. These factors all emphasise a dynamic process of making sense of dementia.

The tendency to go beyond a factual description of dementia is perhaps linked to the fact that dementia is one of the only medical conditions which a high percentage of people are likely to develop if they survive into old age. Although many people will also develop cancer, there is perhaps more optimism about the possibility of active treatment and even cure. The likelihood of developing dementia is therefore relevant to us all and may lead not only to attempts to make sense of it but also to relate perceptions of dementia to oneself, which is the second theme.

Relating perceptions of dementia to oneself

The categories linked to the second theme suggest that perceptions of dementia are not merely about other people but take on a personal significance, perhaps based on the understanding that anybody can develop dementia. The categories in this theme reflect a process of GPs relating perceptions to themselves (i.e. how are, would or might they be affected by what they understand dementia to be?). This process is also extended in some cases to lay people in that GPs believe that lay people also reflect on the significance of dementia for themselves.

An example of relating perceptions to oneself can be found in the category “existential anxiety”. Many of the perceptions of dementia which GPs feared or said they would find extremely disturbing, including negative mental images of advanced dementia, were particularly meaningful as GPs realized that they might be like that one day. They could put this feared possible existence into the context of the overall progression of dementia of which advanced dementia is just one part. They were concerned that lay people in general could not appreciate this context. This may partly explain their sensitivity towards patients when discussing dementia.

Similarly, GPs’ perceptions about separating “us” from “them” did not reflect a straightforward technical or philosophical issue about whether people with dementia were the same, different or even non-human. On the contrary, perceptions were closely linked to existential anxiety, either allaying fears or amplifying them based on the creation, or not, of a safe psychological distance. This is further discussed in section 8.1.2. With regard to emotional reactions towards and aroused by dementia, GPs demonstrated great empathy and prosocial emotions in that they seemed able to put themselves in the shoes of people with dementia. This provides a good basis for empathy but perhaps goes deeper if the person with dementia is perceived as a reflection of one’s own future self. Metaphorically speaking, it was as though GPs imagined wearing those shoes one day. Consequently, the emotional reactions attributed by GPs to people with dementia (such as loneliness, unhappiness and emotional pain) might also reflect how GPs think they would feel if they had dementia.

Relating perceptions to oneself would probably not emerge as a theme in the case of other conditions for which the likelihood of ever having the perceived stigma oneself would be less. The expression of peril and separating “us” from “them” would be based on different characteristics such as fear of infection or moral outrage. This might result in other themes such as self-preservation or protection of the moral order. Not all GPs’ perceptions reflected an attempt to make sense of dementia or relate perceptions to themselves. Some perceptions were more wide reaching in that they went beyond the disease, the person with dementia and the relevance to oneself to a reflection on the consequences of dementia on relationships and wider society. This is the topic of the third theme.

Considering the consequences of dementia

The categories linked to the third theme reflected perceptions of what dementia means to society and how people with dementia are treated or considered within society. The categories in this theme (devaluation, discrimination, the exercise of power and the impact of the attribute) suggest that GPs perceive dementia as having practical, economic, ethical and emotional consequences for the organization and functioning of society as well as for individuals and their relationships to others.

The perceived consequences imply that dementia is not a strictly personal matter but one which has implications for society and for interpersonal relationships and service provision. GPs were aware that the way that dementia and people with dementia are understood, perceived and portrayed within society has implications for their wellbeing, their personal relationships, their place in society and in some cases, their very existence. GPs recognized that healthcare and structural discrimination not only affects people with dementia but also the way that resources are distributed (e.g. for support, services and research). This has implications for everyone and reflects unequal power relations of which GPs were aware.

The categories in the third theme highlight GPs' understanding of the complexity of dementia. They also demonstrate how various perceptions of dementia interact with each other and both influence, and are influenced by, factors in wider society such as productivity, ageism, the distribution of wealth, the organisation and provision of healthcare services, medical training and politics. The categories in the third theme suggest an awareness of dementia and the stigma surrounding it as being part of a system. This suggests the need to take a systemic approach in which it is necessary to recognize that categories and themes are interrelated and to look beyond them to the wider social context in which those perceptions and the associated meanings are constructed.

Whilst the three themes are all equally important to an understanding of the stigma of dementia, some of the categories within them are more dominant than others. This reflects the perceptions which are particularly salient to the stigma of dementia.

7.2.2.2 The salient features of the perceived stigma of dementia

The semi-structured nature of the interviews meant that GPs were asked about any components of, or contributing factors to, stigma if they did not cover them spontaneously. As reflected in the presentation of the results, some perceptions were discussed at length and in great detail suggesting that GPs had already thought about them or that they were in some way meaningful and socially salient. Others were addressed in a more factual or expedient manner suggesting the opposite, or that they were not issues which GPs particularly associated with dementia.

The most salient aspects of GPs' perceptions were those related to existential anxiety, aesthetics, healthcare discrimination, labelling and impact of dementia on relationships as well as society. The perceived stereotyping of dementia as being just advanced dementia was also particularly salient. Emotional reactions were present and linked to other features of dementia. Separating "us" from "them" was particularly salient for GPs through its perceived implications for existential anxiety, the impact on relationships and discrimination. Perceptions reflecting responsibility, physical danger, the exercise of power and devaluation were present but not particularly salient. GPs did not give a great deal of attention to the course of the mark and concealability but these were central to other perceptions (especially existential anxiety) and relevant to the issue of timely diagnosis. Perceptions about the course of the mark were inseparable from almost all GPs' perceptions related to dementia.

Based on a broad consideration of the literature on stigma, examples of which were presented in Chapter 2, the results suggest that the salient features of GPs' perceptions of dementia differ in some ways to those commonly associated with other conditions and are similar in other ways. GPs' perceptions which relate to peril, for example, focus on existential anxiety whereas perceptions of peril in relation to leprosy, AIDS and schizophrenia tend to focus on contagion, morality or physical danger. The characteristics of the attribute (i.e. visibility, aesthetics and course of the mark), on the other hand, are particularly salient in leprosy and central to other perceptions in dementia. Devaluation, negative stereotypes and negative emotional reactions are more salient in relation to schizophrenia than dementia. The way that GPs' perceptions reflected the various components of, and contributing factors to, stigma revealed a few deviations from current theoretical explanations and the way that those components and factors are typically expressed. This was particularly notable in the case of separating "us" from "them" and responsibility. The data also suggests the need to expand the concept of disruptiveness.

7.2.2.3 The relationships between categories across themes

The way in which the various categories identified in this study come together in a dynamic process of making sense of dementia, relating perceptions of dementia to oneself and considering the consequences of dementia, make this conceptualization of the stigma of dementia unique. Parts of this process may well be applicable to certain other stigmas. However, it is based on an analysis of the content and interaction between the various categories identified in this study which reflect perceptions of dementia. Often, the relationship between categories was explicitly stated by GPs as can be seen in the following extract which links the categories separating "us" from "them" and existential fear.

> *"No, not fundamentally different. That's where the fear comes in. They know they are people like them. (../…) Most people are aware that this could happen to them. So I don't think they do see them as fundamentally different.* **Interview 18, line 226**

Relationships can be detected within and across themes. For example, within the first theme, labelling is closely related to the stereotypes that GPs believe lay people to have which in turn were based on the perceived characteristics of dementia. There is also a relationship between GPs' perceptions in the first two themes in that the perceptions of the characteristics of the attribute are linked to existential fear. Some perceptions linked to separating "us" from "them" (i.e. in the second theme) were linked to devaluation and discrimination (i.e. in the third theme). Perceptions of the impact of the attribute (in the third theme) were linked to devaluation and in turn can be detected in perceptions linked to separating "us" from "them" (i.e. in the second theme). The relationships between various categories and across themes is relevant to an understanding of the role of stigma in delaying timely diagnosis.

Making sense of dementia takes on particular significance when what is understood to be dementia is considered in the light of one's own possible future self. It is also connected to reflection about the possible consequences of dementia on relationship and society (i.e. one's own relationships and how one will be perceived and treated by other people). Even if considered solely in relation to other people, the meanings associated with dementia and the perceived consequences of it will not disappear. If the person (or his/her family or close friends) eventually develops dementia, at that time s/he will apply those perceptions to him/herself, thus leading to self-stigmatization.

The results presented in Part 2 of this chapter demonstrate how GPs' perceptions of dementia contribute towards the development of a conceptualization of the stigma of dementia with specific salient features and relationships between and within the three dynamic themes. Such information is valuable for an understanding of the stigma of dementia and provides the basis for a consideration of how this stigma might interfere with timely diagnosis, which is the topic of Part 3 of this chapter.

7.3 Part 3: Relating GPs´ findings concerning the stigma of dementia to the issue of timely diagnosis

Having established how GPs' perceptions of dementia relate to stigma and having described the specific features of the stigma of dementia, this section will present the findings from the two categories which make up the theme "timely diagnosis". This theme is not part of the conceptualization of GPs' perceptions of dementia as a stigma. It emerged from the open coding process and was retained as it was particularly relevant to the topic of the study.

The first category focuses on GPs' perception of the value of diagnosis and the second focuses on their perception of factors which affect timely diagnosis. The interview schedule contained a question about the possible importance of diagnosis whereas data relating to factors affecting diagnosis emerged spontaneously.

7.3.1 The value of diagnosis

GPs' perceptions about the value of diagnosis are linked mainly to their doubts about the efficacy of AD drugs and their belief in the importance of diagnosis. The latter is linked to their beliefs about the relationship between stigma and diagnosis.

GPs' perceptions about the efficacy of drug treatment

Some GPs emphasized the importance of early diagnosis so that people could benefit as soon as possible from appropriate medication, which slows down the progression of Alzheimer's disease for a certain time. Some felt that although there was no cure, progress had been made in the development of drug treatment and were optimistic about future drug developments. Nevertheless, most views about the efficacy of drug treatment were fairly negative. Drug treatment was described as being “of dubious value”, “marginal in benefit” and simply putting people back to where there were a few years ago, but with the condition inevitably progressing. Some stated that they had not seen much evidence of the benefits of drug treatment.

> *“I mean there’s only the Aricept that’s started on people and even that’s sort of, well generally, you see such a decline anyway. I’ve never actually seen somebody sort of diagnosed with dementia, eh, and then get better from it cos they’re on Aricept. Or, well it might slow things down but I don’t think it does much.”* **Interview 10, line 321**

Some GPs were critical of the publicity surrounding Alzheimer drugs. They believed it led to some lay people thinking that there was a miracle treatment which would result in “the return of the pre-morbid person” and that this treatment was effective for all types of dementia.

GPs’ perceptions about the advantages to diagnosis

Despite a predominant lack of enthusiasm about the effectiveness of Alzheimer drugs, most GPs nevertheless had a fairly positive perception of the value of diagnosis. Advantages were described as being to help people to make decisions about their future whilst they have sufficient capacity to do so, to appoint a power of attorney, to benefit from medication, if appropriate, and to give relatives the opportunity to try to be more understanding. However, some GPs were doubtful that diagnosis was beneficial to everybody and suggested that for some people, it wouldn't change anything.

> *"Probably we suspect it in lots of people but I don't know that actually making a diagnosis is helpful in every patient."* ***Interview*** **22, line 75**

Some questioned for whom the diagnosis was beneficial. One GP pointed out that relatives often push for a diagnosis and then have difficulty dealing with it.

> *"Family members! The thing is you do get family members wanting a diagnosis. "Is it Alzheimer's?" "Is there something going on?" But then, the difficulty is dealing with it if it does turn out to be Alzheimer's for instance. Although they push to get a diagnosis, once the diagnosis has been confirmed, they are sort of like "Oh! Now what?""* ***Interview*** **23, line 111**

Some of the GPs who saw the value of diagnosis reflected on the attitudes of their fellow GPs. One stated that GPs have different thresholds for referring. He suggested that GPs may have a tendency to think that dementia is so common in the over-80 age group that there is no need to involve other people, especially in the case of mild dementia. Some suspected that their colleagues did not always make a diagnosis. Some said that GPs often ask "what's the point?" They felt that such GPs should understand that diagnosis is not only about treatment but about giving people a choice about their future. It could be presumed that the generally positive attitude of the GPs to diagnosis was in contradiction with their perceptions of dementia and of the way that they reflect stigma. However, this seems not to be the case as GPs' understanding of the stigma of dementia and of how to tackle it highlights the necessity to diagnose dementia despite possible stigma.

GPs' perceptions about the relationship between stigma and diagnosis

*S*ome GPs used the stigma of cancer as an example of the way to move forward and overcome the stigma of dementia. Most felt that cancer was much less stigmatizing nowadays than in the past when it was a taboo subject and that dementia is now where cancer was 20 to 30 years ago.

> *"And I suppose it's not different from cancers. People talk about cancer…..Some people find it quite easy to talk about the word cancer and I suppose now, you know, in the last 20 to 30 years, cancer, the word cancer has actually become much, much more acceptable as it's much more in society. We talk about beating cancer. (.../...) And I suppose the analogy with dementia is probably maybe we're on the path of being more open about it. But I think we're at the early stage like we were 20 or 30 years ago with cancer."* **Interview 13, line 38**

The GP quoted above emphasized the importance of using the appropriate diagnostic terms as a means of changing people's perceptions of dementia as a stigma. He felt that such perceptions were held by healthcare professionals, individuals and society.

GPs considered diagnosis important despite the belief of most in the persistence of stigma as well as a general lack of enthusiasm about the efficacy of current treatment. None believed that lay people's possible perception of dementia as a stigma was a reason not to diagnose dementia. Some felt that systematically diagnosing dementia was even an important and necessary means to help overcome such stigma.

However, the following quote suggests that GPs may be caught between their professional and personal perceptions of dementia and beliefs about the importance of diagnosis. The GP considers a possible difference between what he thinks he would do in the private context and what he would do in the professional context.

> *"But you know, personally as a doctor, we are still very encouraged, very much, to diagnose it earlier, and I know that's what I try to do in my professional life…. but in my personal life, if I thought an elderly relative was developing dementia but they were coping well and they didn't want to discuss it, then I wouldn't. I'd be reluctant to bring it up, I think. Although professionally I would do, but maybe not… This is all anonymous isn't it?"* **Interview 4, line 32**

The data in this section and that presented in section 7.2.1 demonstrates GPs' understanding of the key features of the stigma of dementia and their theories about the way to tackle the stigma of dementia, their role in this process and the importance they attribute to diagnosis. Most GPs consider diagnosis important but are aware of several barriers to diagnosis.

7.3.2 Factors affecting timely diagnosis

GPs' perceptions of factors which might hinder or in some cases facilitate diagnosis can be divided into those reflecting human factors and those reflecting structural factors although the two are often related. These reflect the barriers identified in a number of previous studies (see section 4.5).

Human factors

Human factors consisted mainly of emotional reactions, perceived readiness for diagnosis, power relations, GPs' difficulties broaching the topic and the perceived impact of diagnosis.

GPs believed that timely diagnosis might be affected by emotional reactions of lay people such as shame, embarrassment and denial, as well as a lack of insight of some people with dementia into their condition. This corresponds to "emotional reactions" and "existential fear". One GP felt that people were not as embarrassed nowadays as in the past about admitting that they had dementia. Nevertheless, fear of dementia and denial were commonly associated with avoiding consultation.

> *"I think people spend a lot of time worrying about developing it or their partner might develop it and they will be left caring for them. And I think a lot of people want to avoid thinking about it really. You know they worry about it and don't want to go and find out and get a diagnosis."* **Interview 4, line 32**

A couple of GPs felt that lay people could be divided into two main groups. The first group consisted of people who would consult at the first sign in order to benefit from services and treatment. The second group consisted of people who would not consult or would wait until their dementia could no longer be concealed. This creates a link to "concealment". Some GPs felt that people with dementia were not always interested in obtaining a diagnosis but that their relatives were. One GP pointed out that it may sometimes seem as though GPs are not diagnosing dementia but that they cannot force a diagnosis, support or treatment on somebody who does not want it. Another felt that he, and other GPs, sometimes colluded with patients in ignoring the signs when it seemed that the person did not want to address the issue.

> *"..... because you don't force the diagnosis if they are not kind of seeking it so in some ways I think we are kind of colluding. [Kind of playing it by ear then?] Yes, a nice way is to say we're being flexible and playing by what the patients want. The prejudicial words would be we're "colluding" with them."* **Interview 19, line 196**

GPs also reported that when diagnosed, people with dementia sometimes keep the diagnosis secret, do not comply with medication and do not use services or support offered. One GP complained that this was typical in cases where relatives brought someone for diagnosis, as one might bring a child to the doctor, and added that the relatives then complain that the GP did nothing. This reveals a link to "the exercise of power", particularly in the context of personal relationships, as well as to "emotional reactions" and "existential anxiety".

Difficulties broaching the topic were also mentioned. For some GPs, this was linked to their awareness that it is a sensitive and emotionally laden issue. Others linked the difficulty to feelings of powerlessness and helplessness in the sense of not feeling able to offer patients anything, which combines both human and structural factors.

> *"It's certainly under-diagnosed but I think it has more to do with the fact that the process of diagnosis is laborious, long and difficult sometimes and yes, yes, it's a very negative label and, like I said, a GP can't diagnose it and do nothing."* **Interview 20, line 123**

GPs were also concerned about the possible negative impact of the diagnostic label, particularly in terms of healthcare discrimination. When asked directly whether they thought that their perception of labelling and discrimination might affect their readiness to diagnose dementia, they stated that they did not feel that it would. However, as described in section 7.2.2, GPs' perceptions were interrelated. Consequently, although GPs stated that their perceptions of dementia did not affect their readiness to diagnose, they frequently associated those perceptions with the need to be cautious and to tread carefully. Such sensitivity was also based on their understanding of lay people's perceptions of dementia, especially with regard to negative mental images, the stereotype of advanced dementia and existential anxiety. These factors might contribute towards GPs' desire to protect their patients or to "fusing" with them (i.e. their own perceptions and feelings becoming enmeshed with those of their patients), thus indirectly contributing towards delays in diagnosis.

Structural factors

Structural factors were mainly linked to the availability of support for GPs and patients, insufficient training and limited time. In some cases, these were related to human factors in that GPs were concerned about the impact on diagnosis and how it affected their responsibility as a GP. One GP suggested that it is not just an issue of there being no effective treatment or cure but of GPs' desire to offer patients some kind of post-diagnostic support. Where this was available, it was perceived as beneficial to the diagnostic process, both for patients and GPs.

> *"Well yes, I think that things have improved a lot for us because we've*

> *got like a community nurse practitioner who spends the day visiting people in their homes and so they've got more continuity and she can spend more time with them and she's got much kind of deeper knowledge of what's available in terms of resources and services. Em, so I feel that we as a practice and me as a GP can offer a much more comprehensive service now that meets the needs of people with dementia a lot better."* **Interview 16, line 32**

A perceived lack of diagnostic support services for GPs was mentioned. As with post-diagnostic support, the few GPs who benefited from diagnostic support services spoke very favourably about it and about its positive impact on timely diagnosis. Lack of such support may be an important barrier as some GPs admitted that they lacked confidence in identifying and talking about specific forms of dementia. Some felt that this might lead to GPs mistaking dementia for normal ageing and failing to pursue a diagnosis. These difficulties were attributed to lack of knowledge which was perceived as a consequence of having received insufficient training in dementia.

> *"I don't have an in-depth knowledge of dementia. It's just what I've read and picked up but nothing particularly focused."* **Interview 23, line 19**
>
> *Interviewer: And if it is an established diagnosis and it happens to be Alzheimer's disease, would you say Alzheimer's disease or still dementia? GP: I'd probably say still dementia, just out of ignorance more than anything else.* **Interview 5, line 13**

Inadequate training and diagnostic support services could be interpreted as structural discrimination in that it amounts to inequity in the provision of healthcare to people with dementia.

GPs identified lack of time as a structural barrier to diagnosis in the form of a professional constraint making it difficult to dedicate the necessary time to diagnosis. It was not considered a deliberate disregard for people with dementia. One GP compared a series of ten minute consultations to a much more effective whole morning spent at a memory clinic. This again highlights an awareness of the benefits of having access to good diagnostic support. The problem of limited time was linked to the belief that lay people often conceal possible signs of dementia which represents a combined human and structural barrier. One GP added that dementia is sometimes only detected when a crisis occurs which renders concealment more difficult. With regard to concealability, the barrier to timely diagnosis was described as being mainly based on the relative invisibility of dementia rather than on stigma caused by it being visible.

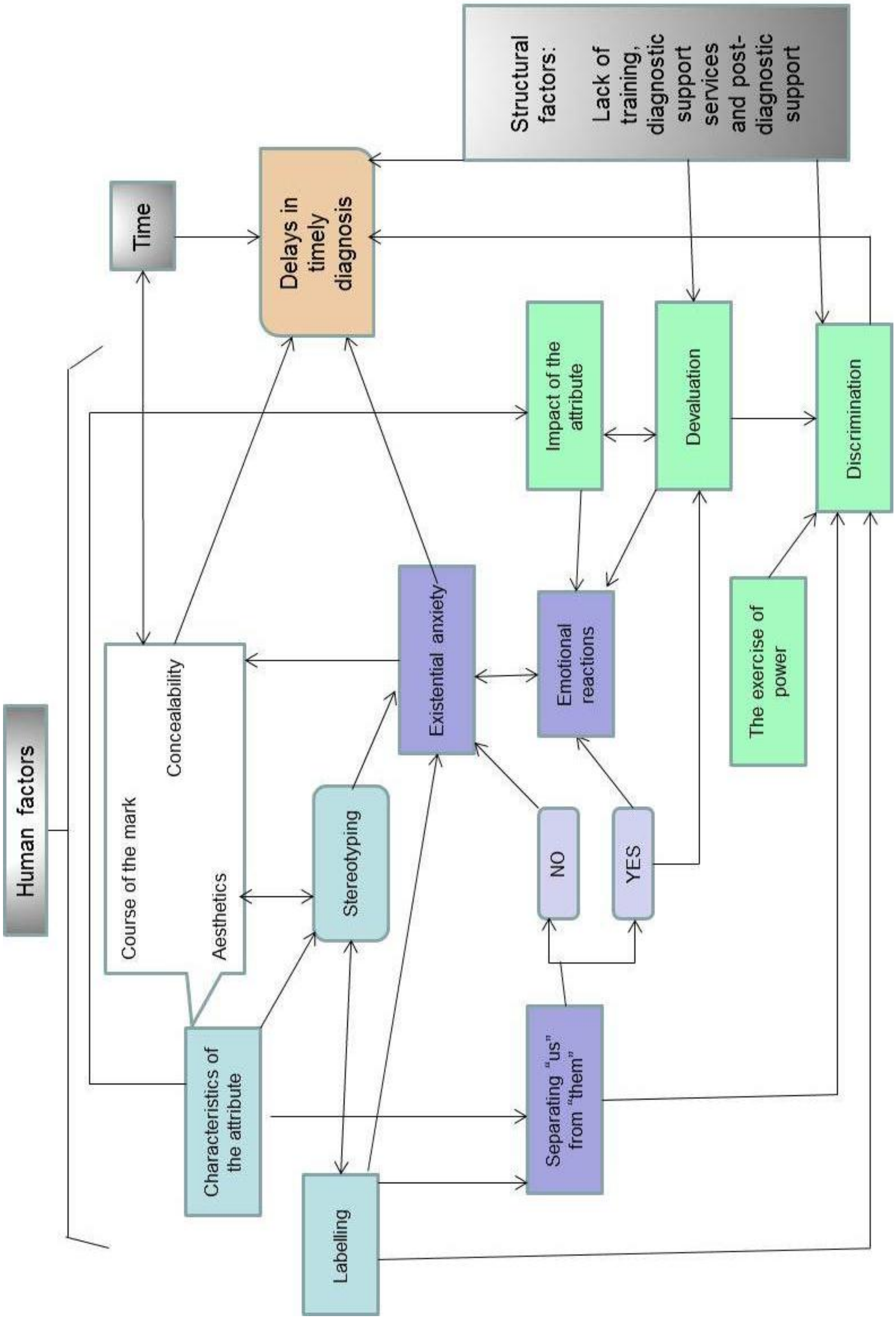
> *"I think people conceal it all the time and that's why you notice when they come into hospital. (../…) Its only when something happens to one half of the couple that it becomes apparent or you take them out of a setting that they know really well, from their own homes, that it becomes obvious."* **Interview 15, line 194**
>
> *"You actually need to be with somebody. Five to ten minutes sometimes isn't going to tell you whether someone has dementia."* **Interview 18, line 88**

The structural barriers to timely diagnosis reflect discrimination and suggest that people with dementia are not valued in the same way that other groups in society are. These represent indirect links to stigma and also suggest that the stigma of dementia is related to wider issues within society.

7.4 Part 4: Considering stigma as a system within other systems

The relationship and dynamics between the different categories and themes which make up the conceptualization of stigma, and their relationship to GPs' perceptions of timely diagnosis and barriers to it, suggest that stigma operates like a system within other systems in wider society. Figure 6 provides a graphic overview of the unique dynamics of the stigma of dementia, as described in Part 2, and of how these directly and indirectly affect timely diagnosis. It also suggests that stigma operates like a system whereby the parts not only converge but are dependent on or influenced by each other.

Figure 6 demonstrates that the most direct links to the issue of timely diagnosis can be traced to a single category in each of the three themes, namely the characteristics of the attribute, existential anxiety and discrimination (in themes 1, 2 and 3 respectively). Several other categories, between and within themes, represent indirect links to the issue of timely diagnosis. Existential anxiety is literally placed in the centre of the diagram because, having the most links to other aspects of stigma, this was necessary in order to graphically display the links. However, this also reflects its central position with regard to GPs' perceptions of dementia and is the most salient aspect of the stigma of dementia.



Key to diagram 6: Pale blue boxes = categories in theme 1: Purple boxes = categories in theme 2: Green boxes = categories in theme 3: Grey boxes = categories reflecting factors affecting timely diagnosis.

Figure 6: Direct and indirect links between the stigma of dementia and delays to timely diagnosis

The human factors described by GPs as interfering with timely diagnosis are also indirectly linked to various categories reflecting stigma (e.g. based on the characteristic of dementia, emotional reactions to it and concerns about labelling). Time is closely linked to the issue of concealability, which in turn hinders timely diagnosis. The other structural factors, such as lack of training, diagnostic support services and post-diagnostic support, also affect timely diagnosis and can be linked to devaluation and discrimination. Perceptions of the limited value of drug treatment are not included in the diagram as affecting timely diagnosis due to the emphasis placed by most GPs on the importance of diagnosis for other reasons, such as to access support, make plans for the future and understand changes being experienced.

The links to external factors demonstrate how stigma functions within other systems. GPs mainly linked their perceptions of dementia, stigma and barriers to timely diagnosis to issues within the healthcare system. However, some revealed their awareness of links to other systems such as the education system, the economy, capitalism, systems of inheritance and the legal system. The following quote provides an example of the association made by one GP between the devaluation of people with dementia, demographic changes and the pension system, which in turn is part of the welfare system and the economy.

> *"I think that's going to play itself out that there's going to be less and less patience with the fact that we're going to have a massive rise in over 85-year olds and consequently a massive rise in dementias and a smaller number of people who are paying the pension and care for all these older people. You could almost image, God help us, that it could be like*

> *George Orwell saying that you need euthanasia by a certain age.* **(Interview 19, line 39)**

7.5 Summary

This chapter has demonstrated how the information obtained from the deconstruction of stigma contributed towards the reconstruction of a conceptualization of the stigma of dementia and how this, combined with information about GPs' perceptions of timely diagnosis, led to an understanding of the role of stigma in delaying timely diagnosis. The findings suggest that GPs perceived dementia as a stigma and felt that this might interfere with lay people seeking a diagnosis. However, they did not perceive stigma as the only or even main barrier to diagnosis and were aware of factors within wider society affecting stigma. GPs did not feel that their perception of dementia as stigma affected their readiness to diagnose dementia. On the other hand, data in section 7.1 suggest that their perception of dementia as a stigma was likely to contribute to great caution and sensitivity when addressing the issue of dementia. Despite limited enthusiasm about the benefits of dementia drugs and concerns about lay people's and healthcare professional's perceptions of dementia as a stigma, most GPs were convinced of the importance of diagnosis. The stigma of dementia was described as undergoing a transition similar to that of cancer a few decades ago. This was not described as an easy transition but one in which they had an important role to play particularly in the domain of diagnosis and about which they seemed quite optimistic. Ironically, whilst GPs' perceptions of dementia suggest that stigma interferes with diagnosis, some GPs described diagnosis as key to helping overcome the stigma of dementia.

7.6 Conclusion

This study represents a journey from the initial contemplation of a collection of individual components which converge to form stigma and a series of factors which contribute towards the likelihood of a particular attribute becoming a stigma, to the recognition of a complex and dynamic action-oriented process. This process is one in which people are continuously trying to make sense of dementia, relating their perceptions to themselves and considering the consequences of dementia for the person with dementia, for themselves and for society at large.

GPs' perceptions reveal a complex relationship between dementia, stigma and timely diagnosis. They suggest that stigma cannot be tackled as if it were something that is separate from the rest of society. Their perceptions reveal that the stigma of dementia affects people's hopes and fears about their lives, and that it occurs and is maintained by societal attitudes, values, and practices which almost everyone contributes towards in some way even as a passive member of that society. This suggests the need to consider the issue of stigma and timely diagnosis from different angles taking into account the individual and society and the dynamic nature of the interaction between them. It also suggests the need to avoid simplistic solutions based on an isolated factor such as changing the official terms for dementia and Alzheimer's disease or increasing knowledge but rather to aim for a co-ordinated approach which recognises the complexity of stigma.

The next chapter will focus on how this conceptualization of GPs' perceptions of dementia as a stigma relates to the general literature on stigma and to what is already known about stigma in the context of dementia. The possible implications of the findings of this study for practice, policy and further research with regard to timely diagnosis will also be considered.

8 Discussion

8.1 Introduction

This final chapter of the thesis summarises the key findings of the research, describes how the findings relate and add to previous research and considers the unique contribution of this study to the literature. It considers the implications of the findings for policy, practice and future research and discusses the limitations to this study. In keeping with the grounded theory approach adopted, the chapter ends with two hypotheses which sum up the main findings insofar as they relate to timely diagnosis and the stigma of dementia.

The themes which emerged from this study are helpful in understanding how dementia comes to be considered a stigma and in understanding how the various elements of stigma fit together and relate to each other. They are an essential part of the “big picture” which emerges from this study and provide a global framework in which to make sense of the specific stigma of dementia. They are also important in understanding the stigma of dementia as a dynamic process and as such lend support to the theoretical lens guiding this study, which was social constructivism. However, the categories within these themes are perhaps more helpful in shedding light on the specific relationship between stigma and delays in timely diagnosis. Consequently, the emphasis in Chapter 8 will be mainly on the categories with occasional reference to the themes, where necessary, to demonstrate how the findings relate to the global concept of the stigma of dementia.

8.2 How the findings relate to previous literature

This study lends support to the body of research into lay people's perceptions of dementia which was described in the literature review and suggests that lay people perceive dementia as a stigma. The findings also support previous research which revealed that GPs were aware of such perceptions and concerned that they might interfere with timely diagnosis (Brodaty et al., 1994; Cahill et al., 2008; Kaduszkiewicz et al., 2008; Vernooij-Dassen et al., 2005).

As with previous research, stigma was not the only factor linked to delays in timely diagnosis. The GPs in this study emphasized lack of time as a key barrier to timely diagnosis as did Boise et al. (1999) and van Hout et al. (2000), as well as lack of diagnostic support (Bowers et al., 1992; Cahill et al., 2006 & 2008) and psychological factors such as denial (also on the part of GPs), embarrassment and concerns about the doctor-patient relationship (Cahill et al., 2008; De Lepeleire et al., 1994; Iliffe et al., 2005; van Hout et al., 2000).

Some GPs expressed a feeling of powerlessness and helplessness which is similar to that described by Keightley and Mitchell in relation to healthcare professionals (2004). However, the kind of therapeutic nihilism highlighted in several studies (Audit Commission, 2000; Boise et al., 1999; Brodaty et al., 1994; Hansen et al., 2008; Iiffe et al., 2006; Renshaw et al., 2001; Vernooij-Dassen et al., 2005; Wolff, et al., 1995) was not reflected in this study. The GPs were almost all positive about the potential benefits of diagnosis despite limited enthusiasm about the efficacy of drug treatments.

With reference to the components and contributing factors from the initial conceptual framework, GPs' perceptions of dementia lend support to the findings of previous studies involving GPs. Low levels of perceived dangerousness and responsibility for the condition, perceived loss of status and desire for social distance, as well as prosocial emotions such as pity, sympathy and concern (as described by Hansen, 2008; Werner and Giveon, 2008) were also reported by GPs. The use by GPs of emotionally-laden terms as well as concerns about the use of medical terms for dementia and concerns about the perceived impact of diagnosis were also recorded (Cahill et al., 2006; 2008; Kaduszkiewicz et al., 2008; Werner and Giveon, 2008). However, possible stereotypes about loss of personality and capacity, such as those described by Kaduszkiewicz et al. (2008), were not found. Some of the findings relating to contributing factors, which were covered in studies involving healthcare professionals other than GPs, such as the awareness of the course of dementia (Kada et al., 2009) and the disruptiveness of dementia (Björkman et al., 2008) were also supported. The findings of this study therefore largely support prior research but provide deeper insight and a more textured, nuanced and rich description of GPs' perceptions of dementia and of how these relate to stigma.

The distinction made in this study between GPs' perceptions of dementia and their understanding of how lay people perceive dementia has not been systematically explored in previous studies. Moreover, previous studies have provided very little information about how GPs perceive dementia. Consequently, findings cannot be realistically compared.

In adopting a qualitative, exploratory design for this study rather than a more rigid quantitative design, this study made it possible to uncover the unique features of the stigma of dementia. Werner and Giveon (2008), for example, measured the extent to which certain aspects of stigma were present but restricted the GPs to the items included in the various predetermined tools they chose to use. These were more suited to schizophrenia than to dementia. Werner and Giveon (2008) merely measured perceived responsibility and found it to be low. The results of this study confirm this finding as there was an absence of perceived responsibility. However, the open, exploratory approach of this study revealed that GPs did not feel that perceived responsibility would lead to blame or a negative behavioural response.

The findings of this study lend support to the recommendation by Vernooij-Dassen et al. (2011) to recognize the need to reciprocate and to enable frail older people and people who are physically or mentally impaired to do so. Numerous examples were provided in this study of the different ways in which people with dementia are perceived as failing to reciprocate and of how this is related to stigma. The importance of reciprocity, the dilemma of perceived similarity and the link between blame and negative behavioural outcomes all have theoretical implications for an understanding of the stigma of dementia which are addressed in more detail in the following section.

8.3 The key findings and unique contribution of this study to the literature

Numerous findings emerged from this study of relevance to the concept of the stigma of dementia and the relationship between GPs' perceptions of dementia as a stigma and timely diagnosis. These have been described in detail in Chapter 7 and will not be repeated here. However, the key findings of relevance to the research questions and which represent a unique contribution to the literature, are summarized below:

1. GPs perceive dementia as a stigma.
2. The stigma of dementia is unique.
    a. The conceptualization of the stigma of dementia consists of unique themes, unique categories and a unique dynamics between them.
    b. The relevance of perceived lack of reciprocity for an understanding of the stigma of dementia.
    c. The dilemma of perceived similarity or difference and its relationship to existential anxiety.
    d. The absence of a relationship between perceived responsibility and negative behavioural responses.
3. Stigma acts as a barrier to timely diagnosis.
4. The stigma of dementia is like a system within other systems.

1. GPs perceive dementia as a stigma

The first key finding from this study is that GPs do perceive dementia as a stigma. This is a unique contribution to the literature as it is based on an analysis of how GPs' perceptions of dementia map on to the components of, and contributing factors to, stigma as described by Link and Phelan (2001; 2006) and Jones et al. (1984). Other studies have not provided the necessary detail to support such a claim, although as this is a qualitative study, further research is needed in order to determine whether the findings can be generalized to the wider GP population.

This finding is further confirmed by GPs' direct references to dementia in terms of it being a stigma and when comparing the stigma of dementia to that of cancer some twenty years ago. It is also reflected in the three themes which reveal how GPs make sense of dementia, relate perceptions of dementia to themselves and consider the consequences of dementia. The finding that GPs perceive dementia as a stigma is not based solely on their reported perceptions but also on their understanding of how dementia is perceived within society (i.e. their understanding of lay people's perceptions of dementia and, to a lesser extent, of those of other healthcare professionals).

2. The stigma of dementia is unique

a. The stigma of dementia has unique themes and categories and a unique dynamics

The second key finding and unique contribution to the literature is that the stigma of dementia has its own unique dynamics and expression, which are not identical to those of other conditions including other mental disorders. Whilst many of the categories which emerged from the data resemble the contributing factors and components from the two theories guiding this study (Link and Phelan, 2001; 2006; Jones et al., 1984), those conceptualizations of stigma are inadequate to describe fully the stigma of dementia. The final conceptual framework of the stigma of dementia suggests that, in some respects, it is fundamentally different from that of other conditions. It has unique categories, unique themes and a unique dynamic of interaction between them.

The second theme (relating perceptions of dementia to oneself), for example, is particularly meaningful in the context of a condition like dementia but is likely to be less meaningful or not meaningful at all, in relation to other conditions such as strabismus or leprosy. Peril, which is often expressed in terms of physical threat in the case of schizophrenia, was associated with existential anxiety in the case of dementia. Moreover, the perceived existential threat was not a threat to life (as with other life-threatening conditions) but a fear of a certain kind of existence prior to death. This is very specific to dementia.

GPs' perceptions of perceived responsibility and separating “us” from “them” reveal differences, compared to other conditions, in that perceived responsibility was not linked to a negative emotional or behavioural response, and perceived similarity was not the only factor linked to fear and subsequent stigma. The uniqueness of the stigma of dementia is also related to the importance of perceived lack of reciprocity which receives very little mention in relation to the stigma of other conditions. Consequently, even the categories which seem identical to those in the initial conceptual framework are unique in the way that they are manifested in relation to dementia, in the dynamics between them and in their saliency. These factors emphasize the unique nature of the stigma of dementia and have implications for theory.

Existential anxiety linked to dementia was the most salient element of GPs' perceptions of dementia and this also contributes to the uniqueness of the stigma of dementia. Drawing on the work of Habermas (1987), existential anxiety would be characteristic of the lifeworld, which is the medium of the symbolic and cultural reproduction of society (Finlayson, 2005). It is a repository of shared meanings, assumptions, background knowledge and understandings which are negotiated and open to revision and change. GPs and lay people all participate in this process and contribute towards a common understanding of dementia which takes the form of a kind of “taken for granted reality”.

The system emerges from the values and meanings which are created and shared within the lifeworld based on communicative exchanges. The two may eventually uncouple due to the increasingly complex requirements of the system. In that case, the system, which is characterized by rules, regulations and procedures (which have become detached from language and values), takes on a life of its own as it were. The system, which is comprised of two sub-systems, namely power and money, may colonize the lifeworld, systematically distorting communicative patterns and subjecting it to outside control which no longer reflects the values of the lifeworld.

The GPs in this study frequently expressed their frustration with the system of which they were a part but which did not reflect their values and beliefs with regard to dementia. Their position is fairly unique in that they are caught between the lifeworld and the system. In terms of the three themes which emerged from this study, GPs are largely influenced by their professional background (which reflects the system) insofar as their perceptions relate to making sense of dementia and considering the implications of dementia. However, with regard to the theme “relating perceptions to oneself”, it seems that it is the self as a man or woman in the street rather than the self as a healthcare professional to which their perceptions relate. The emphasis is therefore on the values and beliefs which are part of the lifeworld). This may create a dilemma and hinder their ability to tackle stigma but their unique position also represents an opportunity which has implications for practice.

A further contribution to the literature is the finding that perceived lack of reciprocity, existential anxiety and perceived responsibility do not relate to the stigma of dementia in the same way as they might to other stigmatized medical conditions. This is discussed below.

b. *The relevance of perceived reciprocity for an understanding of the stigma of dementia*

The findings of this study suggest the need to consider perceived lack of reciprocity by people with dementia as underlying most of the elements of stigma. Failure to reciprocate is an important element in the evolutionary theory of stigma (Kurzban and Leary, 2001) and can be detected in the contributing factor “disruptiveness” (Jones et al., 1984). It was not directly addressed in the conceptualization of stigma of Link and Phelan (2001; 2006). However, in this study, it was often reflected in GPs’ perceptions of dementia, including those relating to the components of Link and Phelan. Gouldner (1960) and Kurzban and Leary (2001) suggest that people who are not able to reciprocate cannot be considered as obliged to fulfil the societal expectation or obligation to do so. Kurzban and Leary (2001) recognised that dementia may interfere with the ability to reciprocate. They suggest that people with dementia who fail to reciprocate would not be excluded from the social group or punished, unlike others who have that ability but do not reciprocate. People with dementia, may nevertheless pay the price for their perceived failure to reciprocate in more subtle ways. Figure 7 below depicts a possible relationship between a perceived lack of reciprocity, how this is interpreted and negative outcomes which reflect various elements of stigma such as labelling, separating “us” from “them”, devaluation, discrimination, power and the impact of dementia on relationships and society.

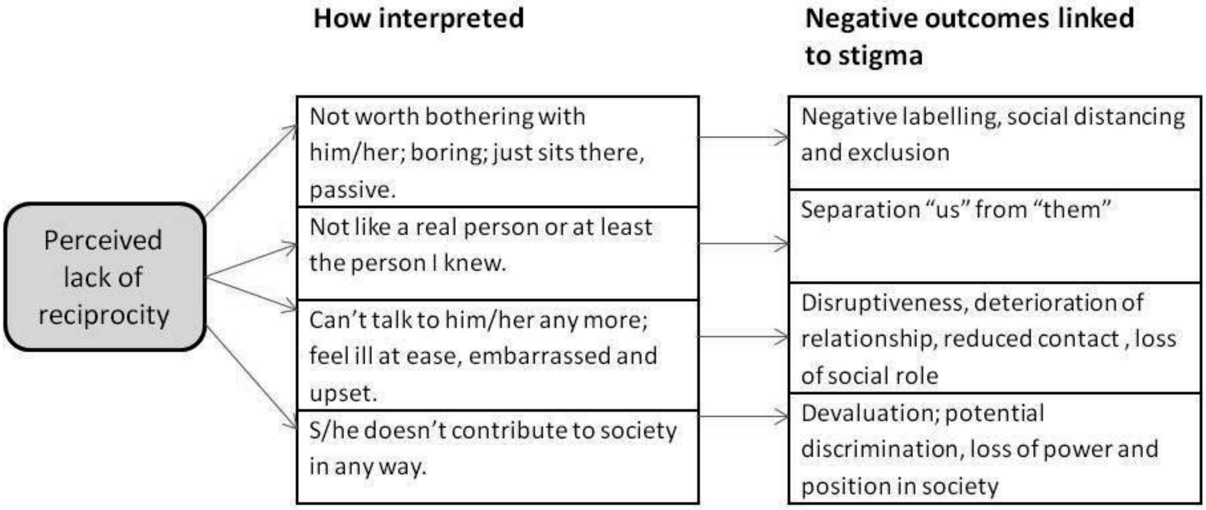


Figure 7: The possible consequences of lack of reciprocity

Perceived failure to reciprocate, as revealed in this study, could be detected within all three themes. It reflects what people think dementia is and, relating this perception to themselves, what they think they might be like one day. It also reflects the perceived consequences of dementia in terms of the impact on other people and on society. This study therefore lends support to the evolutionary theory of stigma which emphasizes the importance of reciprocity. It also suggests the need to take into consideration the indirect consequences of failure to reciprocate. On the surface, there may be understanding for people with dementia and no desire to exclude or punish them. At a deeper level, their inability to reciprocate may fuel the process of stigmatization, particularly with regard to separating “us” from “them”, devaluation and discrimination. This has implications for practice.

c. *The dilemma of perceived similarity or difference and its relationship to existential anxiety*

Also linked to the uniqueness of the stigma of dementia is the observation that perceived similarity to people with dementia might also contribute towards stigma through existential anxiety. In Link and Phelan’s conceptualization of stigma (2001; 2006), separating “us” from “them” is believed to make it easier to devalue and discriminate against people with a stigma and is facilitated by the process of stereotyping. The focus is therefore on perceived difference. The consequences of perceived similarity, which are particularly relevant to dementia, are not adequately addressed in theories of stigma.

Perceived similarity to people with dementia was linked by GPs to fear. As mentioned in section 2.4.7, this could be explained using terror management theory and the belief in a just world. Fear has also been described as playing a major role in the social construction of stigma (Stangor and Crandall 2003). This means that there may be an understandable tendency to consider oneself different to people who have a stigma and that failure to make such a distinction may indirectly also contribute towards stigma. Stereotypes and negative mental representations of advanced dementia may therefore serve a useful function in amplifying the perceived difference. Failure to create a separation between “us” and “them” may leave people exposed to the existential fears against which those who have made that separation feel protected. This seems to reflect a "catch 22 situation"[4] whereby separating and failing to separate can both contribute towards stigma.

The boundaries between "us" and "them" may also be blurred (e.g. in the mild to moderate stage of dementia) due to uncertainty about the difference between dementia and normal ageing which GPs perceived amongst lay people. The three types of perception are depicted in Figure 8 below.

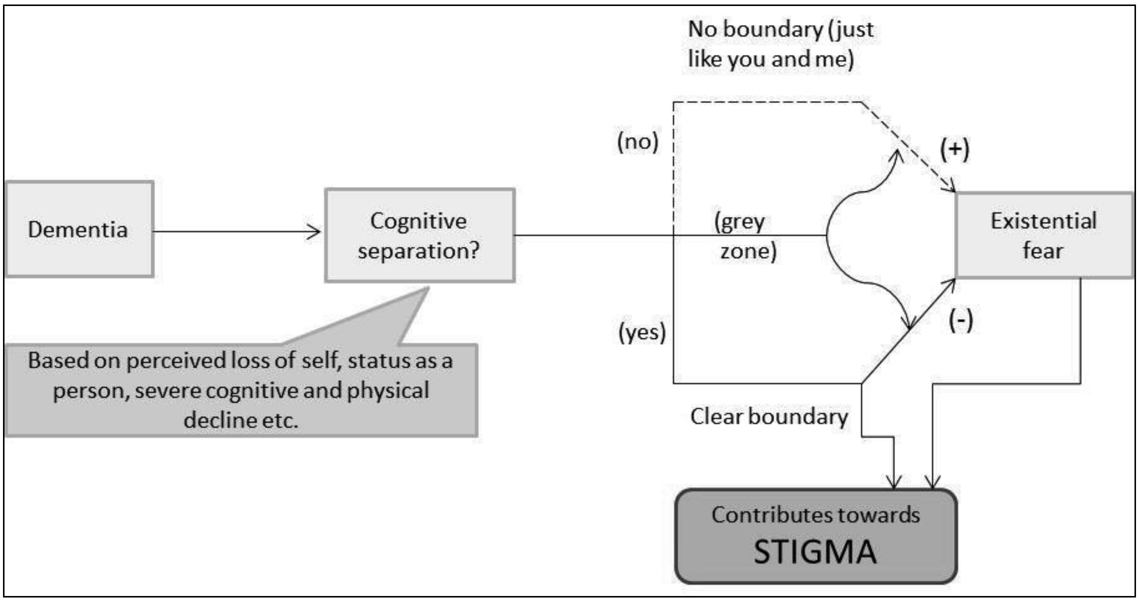


Figure 8: Possible consequences of cognitive separation on existential fear

Separating "us" from "them" is therefore important with regard to the stigma of dementia but unlike with other conditions, the implications of both separating and not separating must be equally considered. Attempts to tackle stigma which emphasize similarity may backfire by creating fear which also leads to stigma.

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[4] This phrase is taken from the book "Catch 22" by Joseph Heller. The term is now generally used to describe a certain type of vicious circle whereby doing one thing may be mutually dependent on doing another thing but for some reason this is illogical, impossible or creates a dilemma.

d. The absence of a relationship between perceived responsibility and negative behavioural responses

In keeping with the second key finding that the stigma of dementia is unique, the findings of this study challenge the universality of the claim that perceived responsibility for a condition results in a negative response towards the person concerned (Weiner et al., 1988). The origin of a condition was also believed by Jones et al. (1984) to increase the likelihood of that condition becoming a stigma. As explained earlier, GPs did not consider people with dementia as responsible for their condition and felt that even if they were, this should not affect how they were treated. Some felt that blame might lead to other people having negative attitudes or behaviour towards people with dementia but that they would not. As the participants of this study were different in many respects and apparently similar only in their capacity as a GP, it is possible that GPs share a common attitude or approach to the issue of responsibility for health. This adds more precision to the theory which associates perceived responsibility with blame and negative reactions towards people with a stigma.

3. The stigma of dementia acts as a barrier to timely diagnosis

The third key finding of this study is that the stigma of dementia may interfere with timely diagnosis in ways which are not immediately apparent. This is a unique contribution to the literature. An element of stigma may hinder timely diagnosis through its relationship to other elements. For example, the visibility of dementia in the later stage may contribute to the stereotype that dementia consists solely of advanced dementia and to an emphasis on negative images of dementia leading to fear, which may lead to delays in consulting a doctor. Similarly, barriers to timely diagnosis described by GPs, other than stigma *per se,* represent structural discrimination and are therefore manifestations of stigma. Such forms of discrimination are described by GPs as being inherent in the healthcare system. This creates a link to the fourth key finding which focuses on the stigma of dementia as part of systems in wider society.

GPs in this study were not always aware of possible links between stigma and barriers to timely diagnosis. They described lack of time and inadequate training and diagnostic support as potential barriers but did not seem to consider these factors as being in any way related to stigma. On the other hand, when they discussed practices within the healthcare system which might limit access to certain services or treatment, they clearly linked this to discrimination, based on perceived devaluation and stereotypes (e.g. of people with dementia having no quality of life). However, all of the barriers to timely diagnosis can be understood in terms of discrimination.

Practices and procedures, which are inherent in, and tolerated by, society, result in people with dementia not benefiting from the same level of support and treatment as other groups. The principle of reasonable accommodation, enshrined in article 2 of the United Nations Convention on the Rights of Persons with Disabilities (2006), states that:

> *"…necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms."*

Such rights and freedoms are further defined in article 2 as being linked to “political, economic, social, cultural, civil or any other field”. An equal right to be diagnosed and to receive appropriate support and treatment is hindered by practices and procedures, which are not suited to achieving this aim. Failure to provide reasonable accommodation, in order to facilitate the timely diagnosis of dementia, is a form of structural discrimination. GPs’ understanding of the way that dementia is perceived within society suggests that such discrimination which interferes with timely diagnosis is due to dementia being perceived as a stigma.

4. The relevance of a systems perspective in understanding stigma and delays to timely diagnosis.

The fourth key finding and contribution to the literature is that stigma is a dynamic system of interrelated elements within other systems. It cannot be considered as a neat, separate entity. It is embedded in the culture, traditions, practices, procedures and policies of the society in which it is constructed. Some of these factors are the means through which stigma is manifested.

The theories of stigma proposed by Link and Phelan (2001; 2006) and Jones et al. (1984) recognize possible relationships between various elements of stigma but this is not sufficiently emphasized or framed in terms of systems. Consequently, proposed solutions tend to focus on stigma as an entity or on single cause and effect relationships (e.g. lack of knowledge, awareness or training leading to stigma and hindering timely diagnosis). Such approaches are inadequate for complex societal problems such as stigma.

This study emphasizes that each element of stigma is important in its own right and collectively as a system. This reflects the claim of Ackoff (1973, p.664) that “The elements of a system may themselves be systems, and every system may be a part of a larger system.” The healthcare system provides the context in which dementia is defined and diagnosed as a medical condition and in which GPs exercise their profession and develop their professional identity. The healthcare system is, in turn, part of the wider system covering the economy, politics, productivity, employment, education and the media as influenced by culture, demographics and history. GPs’ perceptions were related to these wider societal issues. This highlights the complex nature of stigma and has implications for policy.

The general system theory of von Bertalanffy (1968) can be meaningfully applied to the findings of this study. This theory focuses on the relationships between the parts of a system and the way that they are connected to the whole. It does not merely reduce the system to the properties of its constituent parts. The deconstruction of the elements of stigma and subsequent reconstruction into a coherent concept of the stigma of dementia carried out in this study confirm the importance of considering the elements, the whole concept and the dynamic relationship between them all. For example, the three themes and eleven categories which make up the conceptualization of the stigma of dementia represent two levels of abstraction within the same system. The thematic level provides a useful structure in which to consider the dynamic processes behind stigma, in that it highlights what people are actually doing (i.e. making sense of dementia, relating perceptions of dementia to themselves and considering the consequences of dementia). Zooming in to the level of the category within each theme provides the level of detail needed to understand how stigma may be interfering with timely diagnosis. However, each element of stigma (i.e. a theme or category in the conceptualization which emerged from this study) is meaningful in its own right, is influenced by other elements and has an impact on other elements. This emphasizes the complexity of stigma as a societal phenomenon.

8.4 Implications of the findings

The key findings also have implications for practice, policy and research, which are discussed in this section of Chapter 8. The implications for practice are linked to the professional and private lives of GPs and laypeople (i.e. to addressing stigma and timely diagnosis in everyday life). The implications for policy are more directed at the level of government and policymakers, although the two are related as such policies have an impact on the daily lives of GPs and laypeople, and some changes in people's daily lives necessitate policy changes. The implications for research focus on the possible future exploration of some of the key findings.

8.4.1 Implications of GPs perceiving dementia as a stigma

The key finding that GPs perceive dementia as a stigma has implications for further research, namely that:

- *An appropriate quantitative measure of perceptions of dementia as a stigma should be developed*

As this was a qualitative study, findings are based on an interpretation of the in-depth data provided by a non-representative sample of GPs using qualitative methods of data collection and analysis. This was appropriate for the research questions and the objectives of the study. Although the findings may be transferable to other populations with similar characteristics, it would nevertheless be interesting to determine whether they are reproduced in a larger, representative sample of GPs. The findings of this study could therefore be used as a basis for the development of a quantitative instrument to measure perceptions of dementia of a stigma. Once developed, this instrument could be used to test the impact and efficacy of measures designed to tackle stigma and improve timely diagnosis.

It is important to develop appropriate tools and to avoid measuring the stigma of dementia with quantitative instruments which were developed for other conditions or other groups or which are based on concepts which are not particularly relevant to the stigma of dementia. Examples include social distancing scales with items which are not meaningful in the context of dementia and measures of perceived dangerousness and responsibility which are not very appropriate in the context of dementia (as used in some of the studies carried out by Werner and her colleagues in Israel).

8.4.2 Implications of the stigma of dementia being unique

There are two implications for practice and two implications for future research based on the second key finding which was that the stigma of dementia unique. These are discussed below.

- *People with dementia must be provided with opportunities to reciprocate*

Measures are needed to reframe perceived lack of reciprocity as an unmet need and to address that need. People with dementia must be provided with the means to reciprocate so that they cease to be perceived as failing to do so. Reframing and meeting this unmet need should gradually result in perceived lack of reciprocity ceasing to contribute towards the social construction of dementia as a stigma. This would be an important step towards overcoming the stigma of dementia.

The focus should be on enabling people with dementia to reciprocate rather than on trying to change perceptions. For example, GPs reported mental images they had of people with advanced dementia being immobile, passive, uncommunicative and socially withdrawn, not responding to stimulation or acknowledging the contribution of or interest in the other person, and not giving back or helping maintain social interaction. These perceptions were based on their personal experience of what they had seen in nursing homes. It would be unrealistic to try to change GPs' perceptions as they reflect their "reality". It is therefore necessary to address perceived lack of reciprocity as an unmet need and to facilitate such reciprocity. A change in perceptions should follow.

At the interpersonal level, people without dementia must recognize the role they play in this process and adapt their behaviour and expectations to the needs of people with dementia. Providing people with dementia with the opportunity to reciprocate involves meeting them where they are in an authentic interaction, providing the right level of support at the right time and avoiding the kind of malignant social psychology described by Kitwood (1990) such as infantilizing, devaluing, objectifying and ignoring. This diminishes personhood and leads to a downward spiral of social isolation and exclusion which is not compatible with the ability to reciprocate.

Measures must also be taken by the government to change the experience of dementia (e.g. through social support, procedures, drug development, professional training and infrastructure) in such a way as to maximize the potential and opportunities that people with dementia have to contribute towards society and to retain their ability to interact with others. This might include measures to educate lay people and healthcare professionals, including GPs, in how to communicate more effectively and facilitate interaction, thus empowering people with dementia. Timely diagnosis and appropriate medication may also contribute towards people with dementia maintaining a more active role in the community and being better able to reciprocate. Improvements in social support and psycho-social interventions may also provide an opportunity to maintain the social and cognitive skills necessary for reciprocation. Better conditions in long-term care including trained and motivated staff, appropriate activities and stimulation, and a higher staff-resident ratio should all facilitate social interaction and opportunities for people with dementia to reciprocate.

- *Providing GPs with the necessary support and means to deal with their existential anxiety*

GPs should be provided with an opportunity to address their existential fear and disturbing perceptions of dementia. They should also be provided with support from within the healthcare system to enable them to focus on their professional role and on what they can offer patients in their professional capacity.

A lack of awareness or suppression of existential fear and perceptions of dementia could perhaps lead to over-identification with patients' fears and cognitive separation. Servais and Saunders (2007) highlighted the possible negative impact of cognitive separation from mental patients by clinical psychologists and suggested that it might inhibit their ability to display empathy and genuine concern, contribute towards excessive pessimism about therapeutic outcome and affect their willingness to engage patients in treatment. This might also be the case with GPs in relation to dementia.

A two-pronged approach is needed. First, support should be provided in the form of longer consultations combined with increased payment, diagnostic support services, dementia-friendly procedures and environments, and appropriate and adequate post-diagnostic support for people with dementia and carers. This is not an unrealistic “wish list” as much of this has already been initiated and piloted in Scotland due to the perseverance of Alzheimer Scotland and the Scottish Dementia Working Group and with the support of the current Scottish government (Simmons, 2012). Such measures would place diagnosis in a more positive context for patients and enable GPs to focus on the professional aspects of what they can offer.

Second, GPs must be provided with the means to address their existential fear and gain awareness of their perceptions of dementia so as to be able to consider dementia objectively. Measures must also be taken to enable GPs to feel more confident in recognizing and managing dementia. Workshops and educational materials should therefore be developed to help GPs develop the necessary skills to broach the topic of dementia and address stereotypes held by patients about advanced dementia, as well as possible confusion about the distinction between normal ageing and dementia (Audit Commission, 2000). However, the focus of such measures should be on small group experiential learning rather than traditional didactic learning. They should provide opportunities for reflective and creative problem solving based on inquiry and the acquisition of new experience.

Kolb (1984) described a four stage experiential learning cycle involving the acquisition of new experience, reflection on that experience, the construction of theoretical constructs resulting from such reflection and active experimentation involving problem solving activities (Kolb, 1984). Such an approach might involve multi-disciplinary working groups working on problem solving tasks, the use of case studies and direct contact with people with possible or actual dementia (Iliffe et al., 2000) and the use of technology such as immersive online environments and tools to replicate aspects of the “real world” (Cruickshank and Frame, 2012). Workshops could also provide GPs with an opportunity to explore their feelings, their taken-for-granted assumptions about dementia and the meanings and values linked to dementia.

According to Innes (2001), adult learning theories such as experiential learning place the learner and their experience at the centre of the learning process. This is essential for GPs for whom learning must be suited to their individual experience and perception of dementia and at the same time provide them with opportunities to reflect on that experience and acquire direct experience which many are unlikely to encounter in their everyday practice and lives.

Finally, according to Habermas (1987), it is important to harmonize the lifeworld and the system world. GPs are well placed to influence the communicative actions which might enable the values and meanings of the lifeworld to influence in a positive manner the ongoing development of the healthcare system and counteract the negative impact of colonization by the healthcare system. This is not something that can be achieved in isolation but as a concerted effort involving many networks of social actors such as people with dementia, carers, researchers, Alzheimer societies, healthcare professionals and dedicated policy makers. Issues related to training, sufficient time for consultations and diagnostic support for GPs, as well as post-diagnostic support, which they can offer to their patients, must be addressed. This would enable GPs, in the context of their consultations, to focus on their professional identity (within the system) and to avoid focusing on the existential fear, typical of the lifeworld, which may interfere with effectively addressing stigma and timely diagnosis. This would also enable GPs to use their unique position to influence, within the context of consultations, the social construction of more positive meanings and values around dementia, which should help reduce stigma.

- *Possible relationships between perceived reciprocity, similarity, existential anxiety and other elements of stigma should be explored.*

It would be helpful to test by means of statistical analysis possible relationships between various elements of stigma which were identified in this study (e.g. between separating “us” from “them”, existential anxiety or perceived lack of reciprocity). This would test the accuracy of the conceptualization of stigma which emerged from this study. It would also be meaningful to test whether perceptions of lack of reciprocity, for example, correlate with other established stigma-related concepts. This would help determine whether it should actually be considered as an element of stigma in its own right as opposed to an underlying thread running through most other elements of stigma.

- *Additional methods of data collection should be considered to explore the stigma of dementia*

In connection with the second key finding that the stigma of dementia is unique but also based on experience gained during the study, an implication for research is that the possible usefulness of vignettes should be explored. Some GPs, who felt that discrimination probably occurred but were not sure in what way, asked for examples. Two scenarios were described based on data previously provided by other GPs. The first involved an older person with advanced dementia who needed an unrelated operation and the question was whether s/he should or probably would receive it. The second was whether people with dementia tend to be included in social events and celebrations and whether they should be. Having been provided with an example, the GPs concerned could instantly describe how they felt about those situations and what they thought typically happens.

The experience gained from this study suggests that vignettes could be used within semi-structured telephone interviews as prompts or to enable the comparison of perceptions about concrete situations. In order to avoid imposing the perceptions of the researcher onto the participants, such vignettes could be developed out of the emerging data and also serve as a means to challenge emerging findings. The way the scenarios, which were used in this study and which originated from GPs, provoked reflection and generated data from other GPs, also suggests that focus groups might be a useful method to collect qualitative data on stigma.

8.4.3 Implications of stigma acting as a barrier to timely diagnosis

The third key finding was that stigma acts as a barrier to timely diagnosis although, as mentioned earlier, this is not always immediately apparent.

- *Structural barriers to timely diagnosis should be addressed*

Measures should be taken at various levels to overcome structural discrimination against people with dementia which has an impact on timely diagnosis and on their lives, particularly, but not limited to, that which occurs in the healthcare system. Whereas some measures may necessitate policy and even legislative changes, others can be achieved with goodwill and involve a broad range of actors within society. One goal could be to ensure that the principle of reasonable accommodation is respected.

8.4.4 Implications of the stigma of dementia being like a system within other systems

There are two implications of the fourth key finding, namely that the stigma of dementia is like a system within other system. The first is linked to the need to tackle stigma from a systems theory perspective and the second to the need to also change what is perceived, as opposed to focusing entirely on perceptions.

- *The stigma of dementia should be tackled from a systems perspective*

The government should address the stigma of dementia in its entirety (i.e. as a complex societal problem) and in relation to the elements of which it is constituted. The need for such an approach became clear in the course of this study. An intervention in one area may have repercussions in another or at a different level, and perceptions are unlikely to change if the context in which they are constructed remains the same.

This fits in with general system theory described earlier which focuses on the relationships between the parts of an open system (i.e. one which can be influenced from outside) and the way that they are connected to the whole (von Bertalanffy, 1968). This perspective is helpful when dealing with complex problems such as the stigma of dementia which has persisted for centuries and is resistant to changes in society. Link and Phelan (2001) describe stigma as a "persistent predicament". According to Staadt (2012), resistant problems require holistic[5] and problem-structuring approaches which draw on system theory. Problem-structuring approaches emphasize the necessity to understand interdependencies and their possible causalities as opposed to focusing on simple cause and effect relationships (Staadt, 2012). They recognize that complex problems are based on complex relationships. Stigma can and should be tackled at many levels. It may sometimes be useful to focus on certain elements of stigma and at others on the global concept of stigma. However, it is important to avoid thinking of stigma as an entity which is separate from society and can be "wiped out", as if it had an existence of its own, independent of the people who construct and

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[5] "something that is simultaneously a whole and a part" (Staadt, 2012, p.17)

maintain it. The aim is to wipe out stigma but to do so, it is necessary to address stigma as a whole concept, as a system within other systems and in addition, in relation to the many issues within society which are directly or indirectly linked to it.

The stigma of dementia and delays to timely diagnosis must therefore be approached from various angles. An intervention in one area may have repercussions in another or at a different level. For example, attempts to reduce separation between “them” and “us” which emphasize similarity to people with dementia may, based on the findings of this study, lead to existential anxiety. Similarly, tackling discrimination without addressing other factors such as existential anxiety, labelling and separation would not eliminate stigma as they are all inextricably bound. They must all be considered when attempts are made to tackle stigma.

When devising policies to tackle the stigma of dementia, governments must therefore consider the possible impact of various measures on other factors or elements likely to maintain or increase stigma. Measures must be carried out as part of a concerted, multi-faceted campaign to overcome stigma in which the possible negative impact of actions in one area is foreseen and measures taken in other areas to counteract this. One way to do this is to consider not only perceptions but what is actually perceived which is addressed in the next subsection.

- *Addressing practices as well as perceptions*

A belief in the importance of perceptions motivated this study. However, as stigma is a system within other systems, practices and procedures within society also contribute to the perception of dementia as a stigma. In keeping with the concept of stigma being an open system, the findings suggest the need for policymakers to address factors which influence what people perceive as dementia and to avoid focusing solely on changing perceptions.

People fear what they perceive dementia to be. Whether their future experience of dementia corresponds to that perception is another matter. Solutions based on changing perceptions (e.g. through awareness raising or tackling the way dementia is portrayed in the media) are common and fail to validate some people’s real, lived experience of dementia. They reflect an underlying assumption that perceptions are inaccurate and need changing. This is not necessarily the case. Some are, some are not.

Stereotypes, for example, should be challenged as they are, by definition, inaccurate generalizations. In the case of stereotypes about quality of life, this might involve measures to promote social inclusion, emphasize personhood and work towards a greater acceptance of changes in the manner of communicating with and relating to people with dementia. People with dementia are already playing a key role in providing a different image of dementia meeting healthcare professionals, service providers, students and politicians in order to share their experience and challenge negative stereotypes. Examples include the Scottish Dementia Working Group, EDUCATE and the newly created European Working Group of People with Dementia (Alzheimer’s Society, 2012; Alzheimer Europe, 2012b).

The extent to which dementia is visible and aesthetically unpleasant or disturbing also depends on a number of independent factors such as the kind of care, stimulation, therapy and treatment that people with dementia receive, how others relate to them and the extent to which they are valued. Such perceptions do not reflect an inevitable “reality” as better standards of care and support may result in people having a different perception of dementia. Practices and procedures which influence perceptions should therefore also be addressed. These represent predisposing factors which may foster certain attitudes and beliefs about dementia, thus maintaining and perpetuating perceptions of dementia as a stigma, as well as actual discrimination. Consequently, whilst changing perceptions is important, perceptions do not occur in a vacuum and it is equally important to change what people perceive. This requires commitment from the government as well as from individual members of society to improve the care, support and social inclusion of people with dementia.

8.5 Limitations of this study

When considering the implications of the findings, it is important to bear in mind four possible limitations to this study, namely:

1. The absence of female GPs identifying with ethnic minority groups.
2. The absence of triangulation of data collection methods.
3. That the researcher was not a GP.
4. That the GPs interviewed may have been giving socially desirable responses or shared a common characteristic.

1. The absence of female GPs identifying with ethnic minority groups

The first possible limitation is that despite a good balance having been obtained between male and female GPs, all the female GPs in the study described themselves as white/British (and just one as half white/British-half Arabic). Although no significant difference was found between the responses of the British/Asian and white/British GPs or between male and female GPs, there may have been a difference between those of British/Asian female GPs and other sub-groups of GPs. The fact that none were willing to take part despite targeted attempts to reach them may be an indication of some kind of difference which might have been reflected in the data had they taken part. On the other hand, it was difficult in general to recruit GPs and consequently perhaps coincidental that there were not many female British/Asian GPs. Moreover, statistics for the number of GPs identifying with ethnic groups were lacking so it is not possible to know whether or not there were in fact simply fewer female British/Asian GPs.

2. The absence of triangulation of data collection methods

A second possible limitation is that there was no triangulation of data collection methods. It would have been interesting to triangulate the data using a combination of data collection methods (e.g. including focus groups) but this was not feasible (please see section 6.3.5). It is not clear whether this would have been successful as some of the GPs were quite concerned about anonymity and would have been unlikely to express personal views on such a sensitive topic within a group context. Others might have been more open to this and it is not known whether the lack of interest by GPs in a focus group was based on the sensitive nature of the topic, the increased time including travel to the venue, the need to commit themselves in advance to a particular time or another issue.

3. The researcher was not a GP

The third possible limitation is that the researcher was not a GP. In qualitative research based on interviews, the neutrality of the researcher is not sought as the collection of data in this way is considered a collaborative approach between the researcher and the participants (Fontana and Frey, 2008). Consequently, it is not problematic *per se* that details about the researcher are known to the participants and has even been described as a *quid pro quo* of good faith on the part of the researcher (Douglas, 1985). However, in this study a distinction was made between GPs' perceptions of dementia and how GPs understood lay people to perceive dementia. This may have resulted in some of the GPs situating the researcher (i.e. myself) in the role of lay person and this may have affected the way they spoke about dementia. On the other hand, the name of the employer of the researcher (a European Alzheimer Association) was stated in the Participant Information Sheet. This may have given the impression that the researcher nevertheless had some knowledge about dementia which not all lay people have. This may have had a negative impact during the interview, and perhaps even on the recruitment of participants, as some GPs were not confident about their knowledge of dementia.

4. The GPs interviewed may have been giving socially desirable responses or shared a common characteristic.

The fourth possible limitation to this study is that some of the GPs may have given socially desirable responses. Even though most GPs considered dementia to be a stigma, all spoke about people with dementia with respect, empathy and consideration. None used derogatory terms or gave any indication that they did not value people with dementia at least as much as their other patients. It is therefore possible that GPs were providing socially acceptable responses but this seems unlikely based on their apparent openness and willingness to call into question their own behaviour and attitudes. Another possibility is that despite the diversity observed in the sample (e.g. different ages, gender, cultural background and experience), the GPs shared a common characteristic such as “niceness”, a positive attitude towards dementia, a particular interest in dementia or feeling at ease with the topic. This is quite subjective and difficult to ascertain. Nevertheless, it is unfortunate that it was not possible to recruit GPs in different circumstances such as at training courses or at conferences on totally unrelated health conditions, through acquaintances or in different regions. However, this was not possible mainly due to issues related to PCT approval.

8.6 Summary

In this chapter, it was demonstrated that the findings from this study generally support those from previous studies about GPs’ perceptions of dementia but provide a greater depth of understanding. They provide much needed detail about GPs’ perceptions, which were missing in previous studies (e.g. about separating “us” from “them”, aesthetics, hypothetical responsibility and the impact of dementia on society) and confirm that GPs perceive dementia as a stigma. The data also support previous findings about barriers to timely diagnosis and demonstrate in what way they hinder diagnosis (i.e. through human and structural factors) and how they relate to perceptions of dementia as a stigma (i.e. through the perceived characteristics of the attribute, existential anxiety and perceived healthcare discrimination).

GPs’ perceptions highlight the importance of existential anxiety and link this to the process of separating “us” from “them”. This lends support to a range of theories of relevance to stigma such as the evolutionary theory, the role of fear in the social construction of stigma, terror management theory and the belief in a just world theory, which further confirm both guiding theories to this study. It was also revealed that reciprocity is an underlying factor to most perceptions of dementia. Implications for policy and practice include the need to support GPs in focusing on their professional role as a means to bypass their existential anxiety and to take measures to enable people with dementia to reciprocate.

The findings suggest the need to consider the stigma of dementia from different angles and at different levels, considering the global concept and its components, which together form a system and are part of a wider system. Practices and influences from wider society, which were highlighted by GPs, contribute towards the way that dementia is perceived which means that these must also be challenged in addition to challenging perceptions.

The implications for research included the need to build on the findings of this study with a larger sample and with different populations, perhaps incorporating the use of vignettes and focusing on the use of appropriate stigma-related concepts when developing instruments for the quantitative measurement of stigmatization or of perceptions of dementia as a stigma.

8.7 Conclusion

Stigma interferes with timely diagnosis though the perceptions that GPs, other healthcare professionals and lay people have of dementia, as well as through GPs’ understanding of lay people’s perception of dementia as a stigma. Such perceptions, which include existential anxiety, affect the willingness and ability of all concerned to address the issue and are associated with avoidance, denial and collusion. This study has provided detail which was lacking about how GPs perceive dementia as a stigma. It has also revealed links between perceptions of dementia as a stigma and both barriers and delays to timely diagnosis. Understanding the way that GPs perceive dementia and how they think it is perceived by patients provides a solid basis for addressing their concerns about balancing the need to diagnose dementia with the desire to protect their patients from the perceived impact of stigma.

In addition to knowledge based on studies involving lay people, the GPs in this study provided additional insight into lay people’s perceptions, based on their unique and confidential relationship with patients. They witness lay people’s reaction to discussions about dementia, hear how they talk about it and in some cases directly discuss their concerns and fears. This provides another perspective on the perceptions of lay people.

One of the central issues identified in this study was existential anxiety. It was already known from previous research that people fear dementia. However, the detailed information about the nature of that fear (i.e. a specific kind of existential anxiety), the fact that it is also experienced by GPs and the way that it is directly or indirectly linked to other aspects of stigma enhances the possibility of addressing those fears. Knowledge about the interrelationships between different aspects of stigma and about the themes, which contribute towards an understanding of what people are doing and do with their perceptions of dementia, provides a basis to tackle the stigma of dementia. GPs’ perceptions of dementia closely reflect issues in wider society, which are not easily recognisable as being linked to stigma (such as the availability of Alzheimer drugs and the conditions in nursing homes which affect the perceptions linked to concealability and aesthetics). This emphasises the need to tackle perceptions of dementia as a stigma but also to broaden the approach to wider society, identifying and challenging current practices and policies, which cause, maintain or perpetuate the stigma of dementia through stigmatization or by contributing towards perceptions of dementia as a stigma.

8.8 Concluding hypothesis

In keeping with the grounded theory approach and by means of the process of integration described in section 6.7, the following two hypotheses are also proposed as a conclusion to this study and as possible topics for further research:

- The timely diagnosis of dementia is hindered by the combined impact of GPs' perceptions of dementia and their understanding of lay people's perceptions of dementia as a stigma, as well as by factors within wider society, which serve to maintain and perpetuate the stigma of dementia.
- Meeting the unmet need of people with dementia to reciprocate reduces separation between "us" and "them" as well as existential anxiety.

4. Appendix 1: Participation information sheet

Bradford Dementia Group
Division of Dementia Studies
School of Health Studies
www.bradford.ac.uk/acad/health/dementi

PARTICIPANT INFORMATION SHEET

(Version 2 of 29 July 2010)

Title of study

General practitioners' perceptions of dementia and how stigma is related to these perceptions.

Purpose of this Participation Information Sheet

You are invited to take part in the above-mentioned study, which is part of my PhD in Dementia Studies. Before deciding whether or not you wish to participate, please read the following information about the study and what participation would involve.

What is the study about?

Some studies have suggested that delays in diagnoses of dementia may be due to the stigma associated with dementia. This includes a growing awareness amongst general practitioners (GPs) of dementia-related stigma and consequently, of the possible implications of a diagnosis for patients. This is a topic which requires further investigation as GPs have a vital role to play in helping tackle stigma. The conceptualization of dementia-related stigma is relatively undeveloped and there is very little research involving GPs on this specific topic.

Why have I been chosen?

You are being asked to participate in the study because you are a practicing GP and have a crucial role to play in the management of dementia.

Do I have to take part?

It is entirely up to you to decide whether or not to take part and your decision will remain confidential (i.e. between you and me).

Will there be any financial compensation for participating in this study?

Participants will be offered the sum of £ 50 for their participation in a 20 to 40 minute telephone interview in recognition of the time and effort that this would involve.

What will happen to me if I take part?

You will be interviewed by telephone. This will take between 20 and 40 minutes. I will contact you in order to agree on a date and convenient time and will then interview you by telephone at the agreed time. The interview will be tape recorded provided that you consent to this. Questions will be focused on your perceptions of dementia and how stigma is related to these perceptions. I will follow an interview guide covering topics such as terms used when referring to or addressing people with dementia, perceptions of capacity, personhood, dignity, loss of status and discrimination linked to dementia etc.

What are the possible benefits of taking part?

There are no direct benefits to you taking part, although it may prove useful to clarify your own perceptions about dementia and its possible link to stigma. Nevertheless, your participation and expertise would be greatly appreciated and go some way towards clarifying certain aspects of dementia-related stigma and contribute towards the growing body of knowledge about the possible relationship between dementia-related stigma and timely diagnosis.

Are there any risks to taking part?

I do not foresee any risk associated with participation in this study although there is a slight possibility that the questions may lead to personal reflection and personal concerns about dementia. You are of course under no obligation to answer all the questions and you would be very welcome to discuss with me any distress which might arise from the topic of discussion.

Will my taking part in the study be kept confidential?

Any details taken from you will be treated in strictest confidence. Your identity will not be disclosed to any unauthorised person and will not appear in any reports or other publications. During the process of transcription, anything which might identify you (such as your name or the location of your practice) will be removed. The tape recordings will be destroyed after transcription.

What will happen to the study results?

The information from this study will be analysed and summarised in a research report which will be submitted to Bradford University for consideration for the granting of a PhD in Dementia Studies. This is the first part of a two part study in that the findings will also contribute towards the development of questionnaire for a large sample of GPs, thereby ensuring that the relevant and important topics are covered. Separate REC approval will be sought for the follow-up study which is also part of the PhD.

The findings from the combined study may later be published and used to inform clinical practice but all data will have be anonymised which means that you will not be identifiable in any way in any report or published material. As part of the process of analysis, you will be invited to comment on the findings of the interviews. You are free to decide whether or not to do so.

Study organisation and funding

The study will be supervised by the School of Health Studies, University of Bradford. My course fees and travel costs are being paid by my employer, Alzheimer Europe, which does not have any influence on the content or direction of the study. I will personally cover the financial remuneration of GPs for their time and effort (i.e. the sum of £ 50 for each telephone interview).

What if I have concerns or complaints about the conduct of the study?

If you have any concerns or complaints about the way the interview or focus group is conducted, please contact my supervisor, Professor Murna Downs at 01274 233 996.

Who has reviewed the study?

This proposal for this study has been reviewed and approved by my supervisor. It was also examined for ethical appropriateness and subsequently approved by the Lancaster Research Ethics Committee. Separate REC approval will be sought for the follow-up study.

What should I do if I am interested in participating or have further questions?

Having read the above information, if you are interested in participating, please return the signed consent form to Bradford University for the attention of Professor Murna Downs or send it to me directly as a scanned and signed document: D.Gove@bradford.ac.uk.

If you have any questions about the study or about participating, please contact me by email or telephone (at 07969 352233) or Prof. Murna Downs by telephone (at 01274 233 996) and we will get in touch as soon as possible.

Thank you for having taken the time to read through this sheet.

Dianne Gove, PhD student at Bradford University

5. Appendix 2: Consent form

Bradford Dementia Group
Division of Dementia Studies
School of Health Studies
www.bradford.ac.uk/acad/health/dementi

CONSENT FORM

Title and reference number of study: An exploration of GPs' perceptions of dementia and how stigma is related to these perceptions.

Name of researcher: Dianne Gove

Please tick or initial box if in agreement

1 I confirm that I have read and understood the Participant Information Sheet (version 2 of 26 July 2010) for the above study and have had the opportunity to consider the information and ask questions. Any questions I may have asked have been answered satisfactorily. ☐

2 I understand that, should I agree to participate, such participation would be voluntary, I would be free to withdraw at any time and my identity would remain anonymous. ☐

3 I understand that direct quotes from the interviews may be used in the publication of the findings from the study. I give consent for these quotes to be published. ☐

4 I consent to being interviewed by telephone for the proposed study. ☐

5 I consent to the telephone interview being tape recorded. ☐

6 I would like to receive a copy of the transcript or summary and have the opportunity to comment on the findings. ☐

Numbers of statements **not** ticked or initialed: ______________________________

Name of GP: _____________ Surgery/practice: _______________________

Date: __________ Signature: _____________________________

6. Appendix 3: Telephone interview schedule

Telephone interview schedule

Points to cover in the introduction

Thank you very much for having agreed to be interviewed today. I very much appreciate it

I have an interview schedule with questions on 9 main topics but we don't have to cover them all and I'd like you to feel free to take your time answering. I'll let you know where we are as we go along.

What I am really seeking to understand is:

1. your perceptions of dementia
2. how you think the general public perceives dementia
3. and how this might possibly relate to an awareness of dementia as a stigma

One thing I would like to stress at the outset is that in this kind of an interview there are no right and wrong answers.

Every so often I may feedback to you what I understand you to have said so as to avoid my making any assumptions.

And at the end I will ask you for a few background details so that I can describe the age, type of practice and so on of GPs I've spoken to

1. Your perception of (characteristics of) people with dementia

1a. Which characteristics come into *your* mind when you think about people with dementia?

A: ______________________ B: __________________

C: ______________________ D: __________________

Which, if any, of these do you think people would find disturbing?

Thank you very much. That's very helpful.

2. The general public's perception of (characteristics of) people with dementia

2a. and which characteristics do you think the general public associates with people with dementia?

(or how do you think the general public perceives people with dementia?)

A: ______________________ B: __________________

C: ______________________ D: __________________

Which, if any, of these do you think the general public would find disturbing?

2b. What kind of visual image do you think the general public has of dementia/people with dementia?

[Find out if the GP thinks the general public find that kind of image disturbing and whether it is accurate]

2c. In what way do you think people with dementia are perceived as being dangerous or violent by the general public?

And do you personally think that is an accurate perception?

3. Terms used when referring to dementia and people with dementia

3a. Which terms do you generally use when talking about dementia with your patients?

[If not mentioned] Do you ever avoid using particular terms.

3b. Which terms do they generally use?

[If not mentioned] do they sometimes use more colloquial terms?

4. Fear of developing dementia

4a. What kind of fears do you think people have about developing dementia?

4b. If you were to imagine that one day in the future you were to develop dementia which aspects, if any, would you most fear or find disturbing?

5. Feelings towards people with dementia

5a. What kind of feelings do you have towards people with dementia?

5b. What kind of feelings do you think the general public has towards people with dementia?

6. Perceived difference of people with dementia

6a. If you think of the phrase “them and us”, do you think that people with dementia are perceived by the general public as being “them” (in the sense of not at all like us)?

Could you tell me a bit more about that please?

7. Value of people with dementia

7a. How do you think people with dementia are valued (or not as the case may be) within society? [Prompts if needed: status, social roles, considered worthy, respected, valued as an individual and as a human being etc.]

8. Discrimination against people with dementia

8a. In what way, if any, are people with dementia discriminated against within society?

[Ask the following question only if discrimination at the level of everyday, interpersonal interaction has not been addressed.]

8b. How do you think people with dementia are treated by fellow members of society?

9. What dementia is like

Question if the topic has not already been covered	**Don't ask/ already covered**
9a. Can you tell when someone has dementia? I mean, is it visible? Please tell me more about that	
9b. Do you think it is possible for people with dementia to hide it? Please tell me more about that	
9c. Does dementia become more debilitating as time goes on? Please tell me more about that	
9d. In what way does dementia interfere with communication and interpersonal interaction?	
9e. Could people with dementia be blamed in any way for their condition? If so, in what way?	

10. Stigma and diagnosis

10a. Some people say that dementia is a stigma and some say that it is not (that that is a thing of the past). What is your opinion?

10b. What are your views on the usefulness of a diagnosis of dementia? (Prompt if needed: I mean whether it is helpful or maybe does more harm than good.)

10c. In what way do you think that your awareness of the way that dementia is generally perceived and of possible discrimination might affect the likelihood of you diagnosing someone with dementia?

11. Background information for the study

Male/female ______ Date of birth: _______ OR Years' experience as a GP: _______

Single or group practice: ________________ Urban or rural location: _________

Personal identification with ethnic group:

Asian / black / white / other: ________________________

Close relative with dementia: _______________________

12. End of the interview

Thank you very much. I have covered all the topics I had. Is there anything else you would like to add?

Give GP the chance to comment.

13. Next steps

Well thank you again. You have been a great help and it was very interesting hearing your perspective on this issue.

I'll be looking for themes across the various interviews and writing it up for publication and for my dissertation. I'm hoping to have the initial analysis finished by about May or June 2011. If you would like a lay summary of the findings I would be very happy to provide it. If for any reason you would like to reach me in connection with this study or about anything we have spoken about, please feel free to email (or ring) me again.

Give GP the chance to comment, repeat thanks and say goodbye.

I already have information form the consent form on whether s/he would like to receive a transcript and be consulted about the results.

7. Appendix 4: Themes, categories and codes

Themes	Categories	Codes
1. MAKING SENSE OF DEMENTIA	**Labelling**	Medical terms Non-medical terms Colloquial terms
	Stereotyping	Undesirable characteristics Awareness of stereotyping
	Characteristics of the attribute	Course Aesthetics Visibility and concealability
	Responsibility	Origin/cause Actual responsibility Hypothetical responsibility
2. RELATING PERCEPTIONS OF DEMENTIA TO ONESELF	**Separating "us" from "them"**	Just like me/anyone else No longer the same person Almost a non-person
	Emotional reactions	To the disease To the prospect of having the disease Perceived emotional impact on people with dementia
	Existential anxiety	Physical dangerousness Existential anxiety
3. CONSIDERING THE CONSEQUENCES OF DEMENTIA	**Devaluation**	Lack of perceived value Loss of social roles and position in society
	Discrimination	Interpersonal discrimination Structural discrimination Healthcare discrimination
	The exercise of power	Changing power relations GPs' powerlessness Vulnerability to discrimination
	The impact of the attribute	Impact on relationships Impact on society

Overview of results of analysis of GPs' perceptions of dementia

Theme	Categories	Codes
4. TIMELY DIAGNOSIS	**Factors affecting diagnosis**	Human factors Structural factors
	The value of diagnosis	Efficacy of drug treatment Advantages to diagnosis Relationship between stigma and dementia

Overview of results of analysis of GPs' perceptions of diagnosis and stigma

8. Appendix 5: References

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