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Stigma and GPs' Perceptions of Dementia.

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Declaration of contribution of authors

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Stigma and GPs' Perceptions of Dementia

Abstract

Objectives

General Practitioners (GPs) are crucial to improving timely diagnosis but little is reported about how they perceive dementia, and if their perceptions display any elements of stigma. The aim of this study was to explore how GPs' perceptions of dementia map onto current conceptualizations of stigma and whether GPs feel stigma affects timely diagnosis.

Methods

Twenty-three GPs from England were interviewed by telephone. Data were analysed by means of content analysis. This involved open coding followed by the application of a coding framework derived from the literature to explore how and to what extent their perceptions relate to stigma as well as the unique nature of their perceptions.

Results

Three themes emerged from the analysis: 1. "making sense of dementia", 2. "relating perceptions of dementia to oneself" and 3. "considering the consequences of dementia". GPs' perceptions of dementia mapped onto current conceptualizations of stigma. Perceptions about dementia that were linked to their own existential anxiety and to a perceived similarity between people with dementia and themselves were particularly salient. GPs perceived dementia as a stigma which was gradually being overcome but that stigma still hindered timely diagnosis. They provided examples of structural discrimination within the health service, including lack of time for patients and shortcomings in training that were to the detriment of people with dementia.

Conclusion

Measures to involve GPs in tackling stigma should include training and opportunities to explore how they perceive dementia, as well as support to address structural discrimination.

Keywords: Dementia; General Practitioners; stigma; timely diagnosis

Introduction

Perceptions of the Origin and Nature of Dementia

The origin and nature of dementia is perceived in different ways. It is sometimes perceived as a natural part of ageing (Berchtold and Cotman, 1998; Corner and Bond, 2004; Karenberg and Förstl, 2006), this perception is evident to a greater degree in some cultural groups (Ayalon and Areán, 2004; Braun and Browne, 1998; La Fontaine et al., 2007, Roberts et al., 2003; Werner, 2004). It is also commonly perceived as a mental disorder (Alzheimer's Society, 2008; American Psychiatric Association, 2012; Rimmer et al., 2005). Other perceptions include dementia as like a second childhood (Cayton, 2001; Ngatcha-Ribert, 2004), a contagious condition (Ayalon and Areán, 2004; Purandare et al., 2007) and as linked to fate, evil spirits, the evil eye, lack of faith in or punishment from God (Blay and Peluso, 2010; Downs et al., 2006; Elliot et al., 1996; Hussain, 2001; MacKenzie, 2006; Uwakwe, 2000; Yeo et al., 2007).

Perception of Dementia as Stigma

Increasing attention has also been given to perceptions of dementia as a stigma: by the general public (Blay and Peluso, 2010), carers (Blum, 1991; Devlin, MacAskill and Stead, 2007; Liu, 2008; Nolan et al., 2006; Werner, Goldstein and Buchbinder, 2010; Werner and Heinik, 2008), older people (Corner and Bond, 2004), people with dementia (Burgener and Berger, 2008; Devlin, MacAskill and Stead, 2007; Nolan et al., 2006) and health and social care professionals (Nolan et al., 2006). Several studies suggest that GPs also consider dementia a stigma (Cahill et al., 2008; Husband, 2000; Iliffe, Manthorpe and Eden, 2003; Kaduszkiewicz, Bachmann, and van der Bussche, 2008; Moore and Cahill, 2013; Pentzek, Fuchs and Abholz, 2005; Van Hout et al., 2000; Vernooij-Dassen et al., 2005).

Stigma as Reason to Delay Diagnosis

Stigma has been identified as one of the most important factors contributing to delays in the diagnosis of dementia (Vernooij-Dassen et al., 2005). The need to reduce stigma is internationally recognized (Batsch, Mittelman and Alzheimer's Disease International, 2012) and stigma is mentioned in national dementia strategies in Norway, Finland, England and Scotland (Alzheimer Europe, 2012). GPs are often the first health professionals approached when people have concerns about signs and symptoms that might be associated with dementia. They play a

key role in its identification and subsequent management (Downs, 1996) but little is known about their perceptions of dementia and how these relate to stigma. Moreover, there are indications that differences in cultural and ethnic backgrounds might result in an emphasis on different key factors in stigma (Cohen, Werner and Azaiza, 2009; Mackenzie, 2006). It is therefore important to consider how GPs, including those from different cultural and ethnic backgrounds, perceive dementia.

Different Approaches to Stigma

There is a voluminous literature that seeks to understand the nature of stigma, and how it is manifest in relation to a wide range of groups in society. Goffman (1963), drawing on research on physical deformity and disfigurement, understandings of crime and the social impact of psychiatric hospitalization, identified a wide range of attributes, or characteristics, of stigma. He emphasized the role of perceived deviation from the norm and introduced the concept of people being discredited or discreditable. Others have drawn attention to the role of perceived threat in the social construction of stigma (Stangor and Crandall, 2003), the role of stigma in reinforcing group cohesion within the dominant social group (Corrigan, Watson and Ottan, 2003) and of the role stigma plays in the survival of the species (Kurzban and Leary, 2001). The importance of attributions of responsibility and dangerousness has been highlighted (Corrigan et al., 2003; Weiner et al., 1988) as has the role of power and social structures in the social construction of stigma (Link and Phelan, 2006; Mahajan et al., 2008; Parker and Aggleton, 2003; Scambler, 2009). Link and Phelan (2006), as well as Weiss and Ramakrishna (2004), have considered public health implications of stigma.

Certain theories seem to provide a better explanation for some kinds of stigma than others and some better explain the depth of hostility towards certain groups. In order to explore dementia as a stigma, a conceptualization is needed which is sufficiently flexible to permit an examination of various aspects of stigma such as the nature of the attribute, the social process, factors which might contribute towards or perpetuate the stigma and the experience of the actors involved. The conceptualization and theories of Link and Phelan (2001; 2006) and Jones et al. (1984) have been used extensively in the health domain. They cover a series of components and contributing factors, respectively (see methods section for details) including some of the factors addressed in other theories (e.g. perceived threat, the process of social exclusion, the attribution of blame and

visibility). Consequently, they provide a useful framework within which to explore GPs' perceptions of dementia and their implications for timely diagnosis.

Purpose of This Study

The aims of this study were to explore how GPs' perceptions of dementia map onto current conceptualizations of stigma, how GPs understand the role of stigma in delaying timely diagnosis and to consider the implications of these findings for the involvement of GPs in attempts to tackle the stigma of dementia.

Methods

Study Sites and Sampling Strategy

The sampling frame consisted of all practicing GPs in two health districts in the north of England. This was an expedient choice influenced by ease of access for the researcher and extant contacts with health care providers in these areas by members of the study team. An initial phase of recruitment involved individual GPs being randomly selected from contact details on NHS websites followed by purposeful selection aimed at ensuring participants with a broad range of characteristics (e.g. age, years of practice and location). Table 1 provides an overview of the different characteristics of the participants.

< Insert Table 1 about here >

Ethical Considerations

Approval for this study was obtained from the regional NHS ethics committee and the NHS Primary Care Trusts in the recruitment areas. Informed consent was given by all participants. Transcripts were returned to the participants for verification and to provide an opportunity to raise any issues or concerns which might have resulted from the interview. Once approved, the audio recordings were destroyed.

Data Collection

Data were collected by means of semi-structured telephone interviews. This approach permits in-depth exploration of a particular topic in a private and safe environment. A semi-structured interview schedule (available from the author on request) reflecting the key components of stigma as described by Link and Phelan (2001; 2006) and the contributing factors as identified by Jones et al. (1984) was used. In addition, there was a direct question about whether, and if so

in what way, GPs considered dementia a stigma and whether they felt that this affected diagnosis. Data collection ceased when the point of saturation was reached (i.e. when continued data collection did not result in new evidence and when all concepts were well defined and explained) (Corbin and Strauss, 2008; Ritchie, Lewis and Elam, 2003). Interviews were recorded and transcribed verbatim.

Data Analysis

Content analysis was used to analyse the data. Open coding was carried out to identify GPs´ perceptions of dementia and to explore their awareness of stigma and of the role of stigma with regard to timely diagnosis. The codes reflecting GPs' perceptions of dementia were initially categorised based on an existing framework derived from the literature. This was an iterative process aimed at determining whether GPs' perceptions of dementia reflected the components and contributing factors of stigma (Link and Phelan, 2001; 2006; Jones et al., 1984). The use of a coding framework comprised of pre-determined categories served as a guiding theoretical framework to ensure that stigma was explored in its entirety and as a means to validate, or extend conceptually, the theoretical framework guiding the study. As the analysis progressed, codes were compared, differences discussed, modifications to the coding framework made and themes, categories and codes reviewed by the co-authors. This led to agreement on the final conceptual framework. See Figure 1 for the initial and final conceptual framework. Data analysis was enhanced by the use of ATLAS.ti version 6.

INSERT FIGURE 1 ABOUT HERE

Establishing Trustworthiness of the Data

Measures taken to ensure the trustworthiness of the data (Guba and Lincoln, 1985) included: triangulation of data analysis, searching for negative cases, utilizing inter-rater reliability, self-reflection on the researcher's own background and perceptions, and maintaining a non-judgmental and open approach towards both the participants and the emerging data. Member checking was carried out *in situ* by the researcher restating or summarizing information and then questioning the GPs to determine the accuracy of her understanding and interpretation. GPs were given the opportunity to comment on the transcripts. Peer validation of codes, categories and themes was provided by co-authors and two independent researchers. Feedback on the relevance, implications and meaningfulness of emerging findings was provided by representatives of Alzheimer associations, a retired GP and a person with dementia following presentation of preliminary results at conferences.

Results

GPs' perceptions of dementia mapped onto the components and contributing factors of stigma. Almost all GPs felt that dementia was a stigma, that this perception did not affect timely diagnosis and that there were other factors which did.

GPs' Perceptions of Dementia and how they relate to Stigma

Analysing whether, and if so in what way, GPs' perceptions of dementia as a stigma reflected the components and contributing factors to stigma revealed three key themes: 1) Making sense of dementia; 2) Relating perceptions of dementia to oneself; 3) Considering the consequences of dementia.

INSERT FIGURE 2 ABOUT HERE

As is evident from Figure 2, which depicts the initial conceptualization of stigma and the conceptualization which resulted from this study, the way that dementia is perceived by GPs is similar in several respects to the way stigma is perceived across a range of conditions. However, the precise nature of those perceptions and the interrelationship between the components of the final conceptualization is specific to GPs' perceptions of the stigma of dementia. Details of the three themes and categories are provided below.

Theme 1. Making Sense of Dementia

The first theme focuses on what GPs believe it means to have dementia, not simply in medical terms but as a condition which affects people "personally, mentally and socially" (I:8). GPs' perceptions of dementia can be detected in their use of dementia-related terminology with their patients (i.e. through *labelling*). Some described a progressive introduction of the topic, starting with a general explanation of what was going on in the body and gradually moving towards the use of medical terms as the diagnosis became more certain. Most GPs favoured the term dementia over Alzheimer's disease. GPs' preference for certain terms was linked, in part, to their beliefs about their patients' perceptions of dementia and of patients' and their families' comfort with particular words.

> *'Yes, and that's why people don't really like to blurt the word out "Alzheimer's". They like to talk about... 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... it's really quite painful at times.' (I:11)*

GPs highlighted the *characteristics of the attribute* in that they were aware of the progressive nature of dementia making its effects increasingly visible over time and, in most cases, resulting in disturbing mental images of people with dementia.

'I think some of the very advanced stages... 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.' (I:18)

GPs were aware of *stereotyping* amongst lay people and in some cases healthcare professionals. They were aware that the disturbing images that they themselves had, which often included immobility, difficulties eating, loss of contact, suffering, incontinence and little quality of life, were of people with advanced dementia whom they had personally encountered in nursing homes. However, several GPs were concerned that for many lay people, such perceptions were not considered as being of the advanced stage but were of dementia *per se*.

'When you start talking about dementia, that's the image people have. They kind of miss out the years before that.'(5/39).

Theme 2. Relating Perceptions of Dementia to Oneself
The second theme reflects a process of GPs relating perceptions to themselves (i.e. how are, or might, they be affected by dementia?). They also reflected on the personal significance of dementia to lay people. *Existential anxiety* was particularly salient within this theme. The term is used here to denote a perceived threat, specifically the prospect of an unbearable existence prior to death. Components of this unbearable existence included fears about dependency, the loss of their uniqueness or essence as a person and of their awareness of themselves and others, as well as a loss of their own personal history and intellect.

'The fear's about "am I going to be like this?" Am I going to end up like this? (.../...)They need help doing this, that and the other and eventually they don't recognize somebody. It's living death.' (I:18)

'I would desperately not like to have dementia because I wouldn't like to lose myself.' (I:5)

GPs' perceptions reflected an awareness of processes of *separating us from them*. They felt that some people considered people with dementia as being "just like you or me" (except that they happen to have dementia) whilst others considered them as fundamentally different, a group apart. This distinction was explicitly linked to the fear of developing dementia.

'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.' (I: 6)

'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.' (I:18)

It was suggested that a person with advanced dementia may, at times, seem to be a non-person.

'You know the advanced dementia case becomes a non-person so there is very much a separation in that sense.' (I:18)

Separation between us and them was linked to GPs' understanding of personhood.

'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.' (I:4)

Emotional reactions to perceived difference were not predominantly negative. Some GPs stated that they occasionally found people with dementia frustrating and irritating. However, they mainly described feelings of empathy, sympathy, concern and protectiveness, as well as sadness and a sense of injustice based on the perception that dementia is "cruel". Such emotional reactions often seemed to take on a personal significance. It was as if the person with dementia was perceived as a reflection of a possible future self.

'I remember 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.' (I:16)

Theme 3. Considering the Consequences of Dementia

The third theme focuses on GPs' perceptions of the consequences of dementia for other people and for society. Interviews highlighted the negative *impact of the attribute* on relationships, particularly in terms of communication, changes in personality and emotional distancing.

'So I think the kind of changing personality is disturbing and I think one thing that's very frustrating is when you seem to be going over and over the same thing with people because they just haven't taken it in.' (I:22)

'They sort of lose the essence of their being. And I think that can be very distressing because you love somebody and slowly you can see more frustration and things like that kicking in for relatives and then they feel guilty that they don't maybe love the person in the same way anymore.' (I:15)

Dementia was also described as having a practical, economic, ethical and emotional impact on the organization and functioning of society, sometimes with radical implications for people with dementia.

'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 hence a massive rise in dementias and hence a smaller number of people who are paying the pension and care for all these older people. You could almost imagine, God help us, that it could be like George Orwell saying that you need euthanasia by a certain age.' (I:19)

The data suggests that GPs gave people with dementia the same kind of respect and value as that accorded to other patients. However, GPs highlighted their awareness of *devaluation* through their perception of people with dementia not being particularly valued by society and not being considered valuable partners for social interaction. They associated this with ageism, or with societal beliefs about mental disorder. They recounted how the devaluation of people with dementia might take the form of derision, including gestures such as rolling the eyes and tapping the head.

Several GPs were concerned about healthcare *discrimination*. They linked this to stereotypes within the healthcare profession of people with dementia having little quality of life.

'I mean if you are referring somebody with a prostate cancer just based on the blood test, (…/…), they would send a letter back saying, "Well why are you sending this 89 year old with dementia to us? You know his quality of life and things just don't justify having this particular treatment. It's very expensive".' (I:12)

Perceptions of healthcare discrimination were linked to the *exercise of power*. GPs perceived people with dementia as lacking power and some GPs described themselves as being powerless to protect them.

'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 regard to Alzheimer drugs but to treatment for other conditions.'
(I:3)

GPs did not feel that lay people were aware of healthcare discrimination but some provided examples of the occurrence of "social distancing" by lay people (e.g. excluding people with dementia from social events, not visiting them or ignoring them). However, this was not generally considered as discrimination due to a perceived lack of malicious intent.

In addition to the three themes, a perceived lack of reciprocity by people with dementia was detected through the process of open coding, underlying many of the GPs' perceptions

> *'You know, in social settings, broader society kind of looks for a return almost, don't they, on engaging with people? And if you don't get that something back or are likely to, then you're less likely to engage and people don't get invited to things as much.' (I:18)*

> *'...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.'* (I:15)

These findings are in keeping with the evolutionary theory of stigma (Kurzban and Leary, 2001) but are also reflections of the contributing factor "disruptiveness" and "loss of status and discrimination" described by Jones et al. (1984) and Link and Phelan (2001; 2006) respectively.

GPs' Perceptions of Stigma in Relation to Timely Diagnosis

In addition to GPs' perceptions of dementia described in relation to the above-mentioned themes, the majority of GPs explicitly stated that dementia was perceived as a stigma within society even though several felt that this was gradually changing for the better. GPs stressed the importance of diagnosis despite dementia being perceived as a stigma. Some felt that diagnosis might even serve as a means to overcome such stigma.

> *'I think that although there is the stigma associated with it to both healthcare professionals, individuals and society I think we have moved a great deal. But I think there's still a huge, huge way to go really and I think unless we use it and label people and treat people appropriately, that's never going to change.'* (I:13)

Some GPs mentioned lack of training, knowledge and support as possible reasons for delays in diagnosis, but also difficulty broaching and colluding to avoid the topic. Limited consultation times, confounded with dementia not being very visible and patients trying to hide it, was considered as a major factor delaying timely diagnosis.

> *'You actually need to be with somebody. Five to ten minutes sometimes isn't going to tell you whether someone has dementia.' (I:18)*

> *'People do a very good job of covering it up often.' (I:21)*

At the same time, GPs emphasized the need for considerable caution when addressing the topic of dementia with patients and had concerns both about the impact of the label (emotionally and in terms of discrimination) and not having anything useful to offer the patient . The issue of patients not wanting to face the possible prospect of dementia and hence not wanting to pursue a diagnosis was also raised. This suggests that whilst GPs' perception of dementia as a stigma may not prevent diagnosis, it may delay diagnosis as GPs seek to reconcile sensitivity to their patients' fears and their concerns about the impact of diagnosis with the benefits they believe accrue from disclosing the diagnosis in a timely and appropriate manner.

Discussion

GPs' perceptions of dementia mapped onto current conceptualizations of stigma (i.e. the components and contributing factors proposed by Link and Phelan (2001; 2006) and Jones et al. (1984) in ways which are specific to dementia in some respects and similar to other conditions in other respects. GPs' understanding of stigma reflected an awareness of how it might contribute towards hesitancy in seeking a diagnosis. They demonstrated less awareness of how it might affect their own practice but highlighted issues related to structural discrimination as hindering timely diagnosis.

Recognition of the Specificity of the perceived Stigma of Dementia

Similarities between GPs' perceptions of dementia and those we find in the literature in relation to other conditions include an awareness of the impact of labels and the occurrence of stereotyping, discrimination, disruptiveness and peril. Here, the perceived nature of dementia means that these components and contributing factors are presented with different emphases. Discrimination in terms of access to marriage, employment and education has been found in relation to many stigmatizing conditions (Van Brakel, 2006). With dementia, while the process

might be the same, discrimination is enacted in terms of a lack of equity in healthcare and some degree of social distancing. Across a range of conditions peril (i.e. perceived threat), has been linked to a sense of challenge to established morality, the stability and cohesion of the dominant social group, contagiousness or even behaviour which risks violating personal space or physical integrity (Hinshaw, 2007). In the case of dementia, the threat is more existential than in other conditions. That is, it is perceived as a threat to a prevailing sense of the self. Disruptiveness was also found in relation to dementia but it also has a broader impact, extending to disruption to society. Finally, perceptions related to aesthetic qualities, concealability and the course of the condition were present but so closely inter-related in relation to dementia that they form a unique category (characteristics of the attribute) in the final conceptualization.

The specific nature of the stigma of dementia, as highlighted by GPs, calls for further reflection about theories focusing on perceived responsibility, separating us from them and fear in relation to stigma. For example, none of the GPs in this study considered people with dementia responsible for having dementia and felt that even if they were (i.e. indirectly or partially through lifestyle habits), this should not affect how they are treated. This suggests that the association between perceived blame and negative behavioural outcomes, seen in other conditions, might not be applicable to this group. That is, the absence of blame is not a strong protective factor. With dementia, people are stigmatised even if they are not blamed for their condition.

Similarly, the importance of relating perceptions of dementia to oneself, as revealed by this study, differs to the general focus within stigma research on perceived difference. The process of separating us from them has been described as making it easier to devalue and discriminate against people, and is further facilitated by stereotyping (Link and Phelan, 2001; 2006). People who have made a separation, such that they see people who have dementia as completely different to those who have not (including themselves), may feel protected. Stereotypes and negative images of advanced dementia may thus serve a "useful" function in amplifying perceived difference and providing a sense of security, but also contributing towards stigma.

However, perceived similarity can be threatening as it may heighten fears that something bad could happen to anyone, including oneself (Lerner, 1980). GPs' perceived a degree of uncertainty amongst lay people about the difference between dementia and normal ageing, combined with an awareness that the risk of dementia increases with age and a blurring of the boundaries between "us" and "them". Perceived threat plays a key role in the social construction

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of stigma (Stangor and Crandall, 2003) and leads to a tendency to emphasize difference (Levey and Howells, 1994). Consequently, focusing on similarity, and failing to create a separation between "us" and "them" (the latter being a component of stigma), may leave people exposed to existential fears (a factor which contributes towards stigma). Existential anxiety linked to dementia was central to GPs' perceptions of dementia as a stigma, in relation to themselves and their patients. GPs' awareness of a relationship between perceived similarity to people with dementia and existential fear/threat therefore seems to reflect a situation whereby separating, and failing to separate, can both contribute towards stigma. This needs to be recognised when developing anti-stigma campaigns.

Issues surrounding the Role of Stigma in delaying Timely Diagnosis.
The findings suggest that GPs perceive dementia as a stigmatizing condition which may result in a certain hesitancy amongst lay people to seek diagnosis but that they do not feel that stigma interferes with their readiness to diagnose dementia. The perception of dementia as a stigma was firmly rooted in existential anxiety surrounding dementia (i.e. a fear not of dying from dementia but of living with advanced dementia). Consequently, despite an overriding dedication to diagnose dementia in a timely manner, GPs emphasised great sensitivity and a need for extreme caution when broaching the topic and this may delay the diagnostic process.

Lauber et al. (2004) have drawn attention to the need for psychiatrists to be aware that their attitudes towards people with mental disorders do not differ from those of the general public. The same could be said with regard to GPs and existential anxiety. Their perceptions were similar in many respects to those they believed lay people to have and it is therefore unclear to what extent their caution might have been influenced by their own existential fear and even inadvertently communicated to patients.

GPs mentioned insufficient time rather than stigma as a major factor affecting their ability to make a timely diagnosis, as well as lack of training and support, further hampered by dementia often being concealed (i.e. sufficient time is needed to detect it). However, these factors could be considered as examples of structural discrimination as lack of time, training and support may be a reflection of societal attitudes towards people with dementia which reflect stereotyping and devaluation and lead to inequity. Such structural discrimination needs to be addressed and GPs should be empowered to tackle it.

In addition, GPs need opportunities to address their perceptions of dementia as a stigma and to develop skills to address this sensitive topic with their patients. An experiential learning approach, as described by Iliffe, Walters and Rait (2000), would perhaps be suited to this task. Such an approach would consider how their perceptions might affect their approach to diagnosis. There is a need to give an opportunity for GPs (and other healthcare professionals) to voice and explore their fears about the possibility of developing dementia themselves. This would increase their confidence in separating the needs of their patients from their own fears of dementia.

Strengths and Limitations of the Study

This study is unique in providing insight into the perceptions of dementia of male GPs from South Asian ethnic groups as well as from "British" or "British/White" male and female GPs (as self defined). However, we were not successful in recruiting female GPs from South Asian ethnic groups. Although observed differences in perceptions of dementia could not be attributed to ethnic group status, possible differences amongst female GPs of South Asian identification cannot be ruled out. Secondly, the participants were to some extent self-selected as only a small percentage of those contacted took part in the study. It is possible that they shared a common characteristic, which may have been reflected in the results. Whilst the sample was diverse, in future studies it would be beneficial to reach GPs in a manner which reduces the element of self-selection in relation to the topic (e.g. through GP training events in topics not related to the study).

Conclusion

This study provides rich description of GPs' perceptions of dementia and how they map onto the key components and contributing factors from stigma theory (Link and Phelan, 2001 and 2006; Jones et al., 1984). However, the stigma of dementia has particular dimensions and emphases which means it differs significantly from stigma related to other conditions. Specifically, existential anxiety and perceived similarity are central to the perception of dementia as a stigma. The combined impact of GPs' perceptions of dementia and their understanding of lay people's perceptions of dementia as a stigma and of structural discrimination may serve to maintain and

perpetuate the stigma of dementia and in turn hinder timely diagnosis. The findings from this study, if replicated on a larger scale, might suggest the need for experiential training and support to enable GPs to reflect on how they perceive dementia and to be better equipped to address their patients' fears, and for measures to ensure that GPs have adequate time to recognise and explore early signs of dementia during consultations. Underlying our findings is a compelling need to separate our own fears from the judgements we make about care and to root out discrimination in the health and social care of people with dementia.

Notes

Note 1: The letter I followed by a number in brackets after each quote denotes the number of the interview (e.g. I:22 indicates that the quote is from the 22nd GP interviewed).

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Table 1: Characteristics of the participants and setting

	(N = 23)
Gender:	
Male	13
Female	10
Ethnic self-identification:	
British/White	13
British/Asian	7
International	2
Not revealed	1
Location of practice:	
Urban or semi-urban	19
Rural or semi-rural	4
Type of practice:	
Group	21
Single or partnership	2
Relation with dementia:	
Yes	15
No	8
Age:	
Minimum	29
Maximum	62
Years of experience:	
Minimum	1
Maximum	32

Figure 1: The coding framework

Coding framework	Description of pre-determined category
Components of stigma (Link and Phelan, 2001; 2006)	
Labelling	Identification and subsequent labelling of attributes which are deemed "relevant and consequential"
Stereotyping	Linking the observed difference to undesirable characteristics
Separating us from them	Making a distinction between those with and without the attribute (i.e. an in and an out-group)
Status loss and discrimination	Acquisition of low social status forming the basis for discrimination
The exercise of power	As expressed through various components.
Emotional reactions	Range of emotional reactions towards and perhaps detected by the person with the attribute.
Contributing factors (Jones et al., 1984)	
Concealability (and visibility):	Extent to which the attribute is detectable or visible
Course/progression:	Extent to which the attribute is likely to become more salient and debilitating over time
Disruptiveness:	Extent to which the attribute hinders, strains and ads to the difficulty of interpersonal relationships.
Aesthetic qualities:	Subjective reactions to the unattractiveness of the attribute
Origin:	The origin of the attribute and the extent to which the person is considered responsible for having it
Peril:	Danger/threat posed by people with the attribute which might be of a physical or existential nature

Figure 2: Coding framework and the themes and categories resulting from analysis

Coding framework	GPs' perception of dementia as a stigma
Components of stigma (Link and Phelan, 2001; 2006; Link et al., 2004)	*Theme 1: Making sense of dementia*
Labelling	Labelling
Stereotyping	Stereotyping
Separating us from them	Characteristics of the attribute
Status loss and discrimination	*Theme 2: Relating perceptions of dementia to oneself*
The exercise of power	
Emotional reactions	Existential anxiety
Contributing factors (Jones et al., 1984)	Separating us from them
Concealability (and visibility)	Emotional reactions
Course/progression	*Theme 3: Considering the consequences of dementia*
Disruptiveness	Impact of the attribute
Aesthetic qualities	Devaluation
Origin (and perceived responsibility)	Discrimination
Peril	The exercise of power

Ethical approval

Approval for this study was obtained from the North West 12 Research Ethics Committee - Lancaster (United Kingdom) [reference number 10/H1015/29] and the Central Lancashire and the Bradford and Airedale Primary Care Trusts on 17 April 2010 and 24 March 2011 respectively.