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# **General Practitioners' perceptions of the stigma of dementia and the role of reciprocity.**

## **Abstract**

A qualitative exploration of the stigma of dementia reported that GPs described lack of reciprocity as one way in which people with dementia are perceived within society. This was closely linked to their perception of dementia as a stigma. In this paper, we explore whether GPs perceive people with dementia as lacking reciprocity and, so, if this is linked with societal opinions about dementia as a stigma. The implications of both perceptions of people with dementia failing to reciprocate and of stigma for timely diagnosis are explored.

GPs' perceptions of societal views of people with dementia included a perception of a lack of reciprocity. Specifically, an absence of reciprocity was linked with; failing to respond to human contact, the absence of an appropriate return on social investment and failing to contribute to, or being a burden to, society. GPs reported a link between societal perceptions of lack of reciprocity and stereotypes about advanced dementia, difficulties communicating with people with dementia and lack of opportunities for people with dementia to reciprocate.

GPs occupy a key position, they can challenge stereotypes and, with support and targeted training about communicating with people living with dementia, can emphasise the ways in which people with dementia can communicate, thereby enhancing their potential to reciprocate. Such changes have implications for improved care and quality of life through the continued maintenance of social inclusion and perceptions of personhood.

**Key words:** dementia, reciprocity, stigma, general practitioners and perceptions

## **Introduction**

Dementia is a syndrome which typically involves memory loss, difficulties with problem solving, thinking and language and in most cases is caused by damage to the brain resulting from diseases (the most common being Alzheimer's disease) or a series of strokes (Alzheimer's Society, 2014; Kalaria, 2002; National Institute on Aging, 2015). However, dementia is perceived in different ways: as predominantly a biomedical condition (Cummings, 2007; Gaines and Whitehouse, 2006; Katzman et al., 1978), as a natural part of ageing (Ayalon and Aréan, 2004; Lee, Lee and Diwan, 2010; Purandare et al., 2007) or as a mental disorder or "insanity" (Corner and Bond, 2004; Devlin et al., 2007; Forbat, 2002; Langdon, Eagle and Warner, 2007; Lee, Lee and Diwan, 2010; Morgan et al., 2002; Sahin et al., 2006). Examples of less common perceptions include dementia as being linked to fate, retribution and lack of faith (Ayalon, 2009; Blay and Peluso, 2010; Elliott et al., 1996; Mackenzie, 2006) and dementia being contagious (Ayalon and Aréan, 2004; Purandare et al., 2007). A comprehensive overview of the many different ways that dementia is perceived and portrayed has been published elsewhere (Alzheimer Europe, 2013).

Attention to the rights, dignity and wellbeing of people with dementia has increased in recent years. There has been an increased interest in developing dementia-friendly communities and other initiatives (Alzheimer's Disease International, 2015; Alzheimer Europe, in print; Alzheimer's Society, in press), the development of national dementia strategies throughout Europe and the Glasgow Declaration (Alzheimer Europe, 2015) which calls on the European Commission to develop a European dementia strategy. However, dementia is still often perceived as a stigma (Brooker et al., 2014; Burgener and Berger, 2008; Cahill et al., 2008; Jolley and Benbow, 2000; Mukadam, Cooper and Livingston, 2011; Nolan et al., 2006; Vernooij-Dassen et al., 2005).

Stigma is a complex social phenomenon involving a process whereby people sharing a socially salient group difference are identified and subsequently devalued and discriminated against, either overtly or covertly. This may be accompanied by a private process whereby the stigmatized person or group internalizes the perceived stigmatizing attitudes of others (Rüsch et al., 2005; Thornicroft et al., 2009). Stigma is also the term used to refer to the attribute which is 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). Consequently, whilst there is general agreement about the need to challenge the stigma of dementia, we need to understand better the meanings associated with dementia which contribute towards it being perceived as a stigma and to the stigmatization of those who have dementia, which in some cases extends to their family and friends (Batsch, Mittelman and ADI, 2012; Nolan et al., 2006; Werner and Heinik, 2008).

In addition to the social and emotional impact of the perception of dementia as a stigma, there are also implications for health in that the stigma of dementia has been linked to delays in 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). Little is known about the meanings that medical professionals associate with dementia or what they believe the general public associate with dementia but the opinions and perceptions of healthcare professionals may be similar in some ways to those of the general public (Lauber et al., 2004). If GPs' understanding of the way that dementia is perceived as a stigma in society was similar to that of the general public, and this overshadowed their medical knowledge, training and expertise, they would be ill-placed to play a role in helping tackle such stigma.

In a previous study (XXXX, 2015), we reported how GPs' perceptions of dementia reflected components of and contributing factors to stigma (according to the conceptualizations of Link and Phelan (2001 and 2006) and Jones et al. (1984)) and how they shared similar fears about the experience of having dementia to those they believed were current in society. When asked directly, all but one felt dementia was a stigma despite some optimism that this was gradually changing (XXX et al., 2015). An additional finding was that GPs perceived people with dementia as failing to reciprocate in some situations and/or believed that this was how they are perceived in society. Perceived lack of reciprocity may therefore be central to an understanding of what is socially salient about dementia and what contributes towards it becoming a stigma.

Reciprocity has been described as a basic human need and as a universal norm forming the basis for all human contractual relationships (Gouldner, 1960; Simmel, 1950; Vernooij-Dassen et al., 2011). This norm contributes towards preventing exploitation and sustaining cooperation (Alexander, 1987; Halali, Bereby-Meyer and Meiran, 2014). A distinction can be made between different types of reciprocity. For example, positive reciprocity will see a person respond with "niceness" to a nice action whereas in the case of negative reciprocity, a person may respond meanly to a "mean" action (Guala, 2012). Reciprocity can therefore involve both benevolent and harmful responses (Adams and Sharp, 2013), including proportionate retribution for wrongdoing (Folbre, 2009). Folbre and Weisskopf (1998 cited in Adams and Sharp, 2013) also mention generalized reciprocity involving helping someone who will in turn help someone else. According to Adams and Sharp (2013), in the context of paid and unpaid caring work, positive and generalized forms of reciprocity potentially increase the quality of care provided.

In addition to possible implications for the provision of care and support, a perceived lack of reciprocity has been linked to a negative assessment of social value whereby a group is

considered unworthy of membership in the community if unwilling or unable to reciprocate acts of kindness (Kurzban and Leary, 2001; Reidpath et al., 2005). Perceived lack of reciprocity is closely linked to the process of stigmatization which includes discrimination, often in the form of social exclusion or distancing. It has been argued that groups of people, the example given being people with Alzheimer's disease, who lack the capacity to reciprocate, would not be penalized for failing to reciprocate (Kurzban and Leary, 2001). Weiner et al. (1988) further report that negative emotional and behavioural reactions towards people with shared socially salient attributes are less likely if those people are not deemed responsible for having them. However, in our previous study, people with dementia were not perceived as being responsible for having dementia but were perceived, in some instances, as failing to reciprocate and dementia was nevertheless perceived as a stigma, albeit less so than in the past.

To date, there have been no studies focusing solely on the perception of reciprocity in relation to the stigma of dementia. There have, however, been limited references to people with dementia being perceived as lacking reciprocity (Graham and Bassett, 2006; Nolan et al., 2006). In interpersonal interactions, for example, they are perceived as sometimes failing to demonstrate recognition of others, to acknowledge or show interest in others or to respond to verbal or non-verbal invitations to social contact. Such perceptions are reflected in references to people with dementia as vegetables, plants, an empty shell and as being "just a body" (Corner and Bond, 2005; Dunham and Cannon, 2008, Nolan et al., 2006, Ngatcha-Ribert, 2004, Van Gorp and Vercruyse, 2011). Some carers have emphasised the importance of reciprocity, explaining that they feel that they receive something in return for the care they give, namely being appreciated by the person with dementia, feeling needed and wanted and feeling that if the situation were reversed, the person with dementia would have cared for them (Andrén and Elmståhl, 2005; Walmsley and McCormack, 2014). However, reciprocal

behaviour by people with dementia, such as attempts to show attention and affection, is not always recognized or valued (Vernooij-Dassen et al., 2011; Clare, Woods, Whitaker, Wilson and Downs, 2010). Graham and Bassett (2006) found in their analysis of reciprocal relations in the co-construction of care that give and take is often less straightforward. It may be richer and less uni-directional than it seems. Their findings also suggest that the behaviour of people with dementia is often interpreted in the light of normative expectations based on the person with dementia's "old self" and that this may lead to subtle signs of reciprocity being overlooked.

GPs are often the first to be contacted when people have concerns about dementia. They both recognize societal perceptions of dementia as a stigma and accept that they have a role in helping challenge stigma (XXX et al., 2015). But as we have argued, GPs are members of society and are likely to share, or at least be influenced by, prevailing views and reciprocity is a complex construct. In consequence, it is important to examine in more depth their understanding of lack of reciprocity and of societal perceptions of people with dementia lacking reciprocity. This would contribute towards a more nuanced understanding of the stigma of dementia and towards the development of appropriate support for GPs to tackle this. We therefore decided to follow through this thread of reciprocity by means of a secondary analysis of the data from our previous study. The purpose of this study was to determine whether, and if so how, GPs perceive people with dementia as failing to reciprocate, and whether they consider the general public/wider society as perceiving people with dementia as failing to reciprocate.

## **Methods**

This study builds on an analysis of GPs' perceptions of dementia and how they relate to stigma. The initial study, conducted by the authors of this follow-up study, involved semi-structured telephone interviews with 23 GPs from England for which appropriate ethical

approval and informed consent were obtained (see XXX et al., 2015 for full details). Purposive sampling of male and female GPs was carried out, covering a range of ages, ethnic backgrounds, years of experience and locations of practice to contribute towards obtaining a diverse range of perceptions and to ensure that any differences in perspectives between participants with different characteristics were explored.

Please insert Table 1 about here.

As theoretical sampling was also adopted, participants were contacted and interviewed until the researchers felt that the point of saturation had been reached at which no further insights would be obtained by interviewing additional participants (Ritchie, Lewis and Elam, 2003). This decision was based on agreement by all researchers that the last three interviews did not result in the need for additional codes or contribute towards the further refinement of existing codes. Framework analysis was used with the frame for the initial study being influenced by the conceptualization of stigma developed by Link and Phelan (2001; 2006) and the theory of contributing factors to stigma described by Jones et al. (1984). These were chosen as they permitted the incorporation of a broad range of issues relevant to an understanding of stigma.

Lack of reciprocity emerged through the open coding process which was carried out alongside the application of the framework (so as to minimize the risk of trying to force data into inappropriate categories). It was found that perceptions reflecting lack of reciprocity frequently reflected other aspects of stigma (based on the pre-determined categories in the coding framework) such as labelling, loss of social status and discrimination, but were in addition coded separately in order to reflect specifically “lack of reciprocity”.

Triggered by this finding, we (the authors of this article; all researchers involved in the study) followed up on this “thread” by further analysis to determine in what way the concept of lack of reciprocity was reflected in GPs’ perceptions of dementia as a stigma. “Following a



thread” is a research approach (Moran-Ellis et al., 2004 and 2006) whereby an analytic question or theme in one dataset is selected and followed across another (the thread) “to create a constellation of findings which can be used to generate a multi-faceted picture of the phenomenon” (Moran-Ellis et al., 2006, p.54). Moran-Ellis and colleagues (2006) describe the integration of findings derived from qualitative and quantitative elements of a study and from different data sets. In this study, a sub-set of qualitative data was used which comprised all data which had been coded in the initial study (XXXX, 2015) as reflecting an aspect of stigma (based on the predetermined categories derived from the literature). The analytic question serving as the thread was “in what way do GPs perceive people with dementia as failing to reciprocate and/or consider such perceptions to be present amongst the general public/wider society?”

In order to follow this thread, a coding framework (See Figure 1) was constructed by the authors based on prior familiarization with perceived lack of reciprocity as described in the literature (Graham and Bassett, 2006; Nolan et al., 2006; Vernooij-Dassen et al., 2011) and on the verbatim transcripts of the data which had been coded as reflecting lack of reciprocity in the initial study (XXX, 2015). A brief overview was made of recurring themes with the aim of producing a small number of broader, higher-order categories, which were not too abstract but rather grounded in the data (Spencer, Ritchie and O’Connor, 2003). This process was carried out by the four authors and resulted in categories reflecting failure to give something back / in return at three different levels, namely one-to-one basic human contact, more meaningful interpersonal or social interaction and at the level of broader society.

Please insert Figure 1 here

This new coding framework (Figure 1) was applied to the sub-set of data from the previous study, which was scrutinized for both latent and manifest content reflecting lack of reciprocity. Latent content included cases where GPs had not made explicit reference to lack

of reciprocity but perceptions relating to this concept could be detected in their statements. Latent meaning may also include that which is not necessarily explicitly conscious for the participant (Kvale and Brinkman, 2009).

## **Results**

The findings suggest that most GPs (19 out of 23) perceive people with dementia as failing to reciprocate and/or consider such perceptions to be present amongst the general public/wider society. The following sections demonstrate three ways in which GPs' perceived a lack of reciprocity by people with dementia or considered such perceptions to be present amongst the general public/wider society, namely: failure or inability to respond to human contact, absence of appropriate return on social investment and lack of contribution to or being a burden to society.

### *1. Failure or inability to respond to human contact*

Several GPs described people with dementia as failing to reciprocate based on a perceived absence of meaningful presence (e.g. appearing disconnected, unresponsive and "absent"). A few highlighted a perception of people with dementia failing to interact with or respond to other people through analogies which suggest an existence within a parallel, imaginary world, of being "empty", or of having turned their attention inwards, away from the current world. For example in the context of a reflection about insight at various stages of dementia and in relation to her own father, one GP stated:

"They do have insight to start with. In some ways, I think it must be particularly nice when it's completely gone. To use modern parlance, non-technical, I mean when you are "away with the fairies" and you've got no idea." (P1, 55-56)

The GP is using the term "away with the fairies" to explain how she perceives her father as not being aware of his condition. However, looking at the possible latent content, the term is also generally understood to mean "out of touch with reality" (Collins Online Dictionary,

2015) and has its origins in the Scots/Irish Gaelic tradition in stories about a parallel world in which people are spirited away by fairies/little people and thus lose contact with people in the “real world” (The Phrase Finder, 2015). Following on from a statement about loss of dignity, another GP stated:

“The other thing is “the lights are on but there’s no one at home” sort of thing. I think people do view that and relatives will sort of say: it’s not the person that I married and that it’s not the person I know for the last two years - that that person has gone. Yes there is that and that’s what people voice in those kinds of terms.” (P6, 36)

Examining the latent content, this statement reflects not only a perceived loss of the person as they knew him/her but also an absence of a person at all (i.e. the reference is to a house which looks inhabited as the lights are on but there is *no one* inside). Building on this analogy, if someone were to knock on the door, no one would answer. Both examples suggest that whilst there are signs that the person is physically there, a meaningful return on any contact offered is unlikely.

Some GPs made specific reference to the difficulties of connecting with the “real person”, sometimes with doubts about whether the person with dementia is still a person. In terms of lack of reciprocity, there is an underlying assumption that people are not communicating with the real or whole person and hence a meaningful return is not anticipated.

The following statement, which was made in the context of a discussion about the persistence of personhood, reflects an awareness that perceived failure to reciprocate may be accompanied by the inability of other people to reach the person with dementia (i.e. not solely on a lack of willingness of the person with dementia). As the perceived vacant look seems to be the main indication that the person has difficulties understanding, it is likely that this observation relates to a person in the early stages of dementia.

“There tends to be almost a sort of vacant look in somebody’s eyes that tells you perhaps they are trying to hide from me that their brain isn’t sort of working as well as it used to. That tends to be the thing that hits you when you’re talking about something that’s completely unrelated in a consultation. It’s hard to explain but there’s a sort of look in the eyes that says they’re not fully following what they use to be able to.” (P17: 58-60)

This inability to reach the person with dementia is further emphasized in the following quote which occurred in the context of a question about lay perceptions of personhood and seems to be linked to a much later stage of dementia. Here, perceived lack of reciprocity can be detected in the reference to people with dementia being immobile, unable to speak, move or communicate (i.e. unable to react to attempts to communicate) and therefore dependent on other people’s ability to communicate with people with dementia.

“I have seen people with very advanced dementia who were immobile in a nursing home, unable to speak, unable to move and they do seem like a shell because we don’t feel there is any way of communicating with them but I think people at all stages of dementia, there is still a personality there and I think that people who are looking after them all the time will say that they can communicate and there is something of the person there. So I don’t think that I agree that people with dementia sort of become a shell.” (P2, 40)

Another GP, talking about how she felt that people with dementia were generally perceived, especially in the later stages, suggests an absence of minimum contact (which is necessary for reciprocal relations).

“They don’t do anything and they don’t engage with anyone. Yes, I have certainly heard of people having that concept of them as just eating..... or as Shakespeare said “meuling and puking”.” (P1, 29).

Some GPs felt that lay people hold stereotypes about advanced dementia and the above quote is an example of how such stereotypes also incorporate aspects of perceived lack of reciprocity.

## *2. Absence of appropriate return on social investment*

In addition to the minimum response to other people linked to acknowledging their presence and offer of contact, some GPs described situations in which they felt people with dementia were unable (or were perceived to be unable) to recognize those with whom they have social and family ties and to respond appropriately and sufficiently to the efforts of the latter to maintain those ties.

“They don’t respond to you as they would have before, they don’t interact with you as they would have before. (.../...) OK, yes that person, you know is my mum, is my dad, is my brother but they don’t actually recognize me.” (P23, 69)

“They go into a nursing home and visit two or three times a week and they are running out of things to say because it's, I guess because the conversation is a lot more one sided and they are not getting the sort of responses back.” (P21, 55)

In the first quote above, the GP highlights the importance of reciprocal exchanges being perceived as relevant and appropriate (as compared to previous interactions with the person with dementia) and it is not clear if such interaction would be perceived as reciprocity at all. The second quote seems to describe awareness of a perceived imbalance in terms of quantity (i.e. how much is invested in the interaction compared to how much is received in return).

In response to a question about social inclusion and exclusion, a few GPs described their perception of the possible impact of people with dementia being deemed as failing to reciprocate socially.

“I suspect that, you know, when you invite someone 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.” (P15, 186)

However, a few GPs demonstrated an understanding that it becomes difficult for people with dementia to give something back in the context of social exchanges and activities (i.e. to continue to occupy social roles and to contribute to social interactions) as the severity of dementia increases. One linked this to a lack of understanding by friends.

“You can’t hold down the jobs, even the little jobs. You know, I mean.... I saw one yesterday. He was the treasurer of a small bowling association. He’s just having some investigations. It’s just a little job in a little club but he is no longer able to hold that job down. So, you just start to withdraw from life, don’t you? And that’s difficult because at that time of life, it’s those kinds of things that keep life going and keep you active. And it’s often difficult to replace things at that time of life.” (P4, 48-50)

“...and I talk about my mum quite a lot - but I just know that her old friends, when I was out socially with them all, 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.” (P6, 48)

In the first example above, the patient described is in the process of undergoing tests. Whilst it is not stated that s/he is suspected of being in the early stage of dementia, the GP suggests

that lack of reciprocity is a very gradual process which starts with apparently minor issues but has an important impact on social inclusion.

### *3. Lack of contribution to or being a burden to society*

GPs perceived people with dementia as eventually (as the disease progresses) being unable to contribute towards society and consequently as being perceived as a burden. They described an imbalance between what people with dementia appear to give to society compared to what they receive from society, which represents a division between “us” (we contribute/give back) and “them” (they don’t).

“Oddly enough, you know, I think that because society values people for their utility value, unfortunately, then, I think society values the elderly, but particularly the demented, less.” (P19, 174)

“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 dementia in particular don’t do.” (P14, 51)

“I suppose one of the things we don’t want to get is dementia, mainly because of our how we might be seen, being in those situations and being a burden to others.” (P13, 9)

One GP highlighted people with dementia using up family resources and potential heritages and thus failing to give something back after their death. This was described in terms of an actual rather than perceived failure to reciprocate in financial terms but a criticism of the system can also be detected which suggests a lack of blame on the part of people with dementia.

“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, as you know, there’s no pension pot in existence anywhere. It’s really the people working today who pay for the people tomorrow.”  
(P19, 158)

Quotations which reflected a lack of meaningful response and being considered as a burden to families and society were also linked to concerns about the negative impact for people with dementia of being perceived as failing to reciprocate. The following quote describes a GP’s belief that a diagnosis of dementia may evoke fears which effectively represent concerns about lack of reciprocity in terms of receiving a lot of care and not being able to give back socially.

“People are aware that potentially you can suffer from severe dementia for many, many years and that sounds quite bleak really (.../...) with people sort of being full time carers for you for such a long time. (.../...) I think people tend to focus on the people that they have even seen or imagined almost slumped in homes on chairs in a lounge with everybody in that same state without much social interaction, almost cut off from society really. I think that’s what’s most fearful and so that’s what sticks in people’s minds you know about a diagnosis of dementia.” (P17, 132-136)

A lot of the statements made by GPs were associated with fairly advanced dementia. Whereas all the GPs interviewed displayed an understanding of the progressive nature of dementia, some were concerned that lay people and even other healthcare professionals did not all have such an understanding and tended to perceive dementia in a way which only reflects the advanced stage. A consequence could be that their perceptions of lack of reciprocity might be extended to all people with dementia.



“When you say the word dementia people think of the end stage and actually if you are... if you have dementia in sort of all its forms, then you could sort of miss out on all the early and moderately affected people and deny them treatment just by the label. Certainly, healthcare professionals do that.” (P13, 46)

“A typical stereotype is someone in a rest home, just not doing anything, sat there, looking gormless. When you start talking about dementia, that’s the image people have. They kind of miss out the years before that.” (P4, 101-104)

## **Discussion**

Following the thread of lack of reciprocity across the data reflecting perceptions of dementia as a stigma confirmed that GPs perceive people with dementia to some extent failing to reciprocate and believe that they are perceived as failing to reciprocate by the general public/wider society. This analysis also provided a more complete picture of the stigma of dementia, namely that perceived lack of reciprocity is not merely something that exists alongside the stigma of dementia but is an integral part of GPs’ perceptions of dementia as a stigma. This has implications for our understanding of the stigma of dementia, for timely diagnosis and for how people with dementia are treated in society.

### *Reciprocity and the stigma of dementia*

Lack of reciprocity is not merely one way in which dementia is perceived; it is an integral part of a number of components which, when combined, result in stigma. Consequently, whilst it has been established that people with dementia are not generally considered responsible for their condition (Cohen et al., 2009; Crisp, 2004; Kurzban and Leary, 2001; Werner, 2005; Werner, 2008) and thus should not be blamed or socially excluded for failing to reciprocate (Kurzban and Leary, 2001), they may still be stigmatized. For example, the perceived failure to give something back in the context of social interactions may be met with understanding but is nevertheless reflected in negative labelling and separation between “us”

and “them”. Similarly, people with dementia are perhaps excused for not playing a more active role in society (as many are unable to do so) but such failure (or perceived failure) to do so denies them the value attributed to others who do and may lead to discrimination. The impact of perceived failure to reciprocate on perceived value is further linked to the process of stigmatization through “loss of social status/discrimination” (Link and Phelan, 2001/2006), “peril” (Jones et al., 1984) and the role of threat (Stangor and Crandall, 2003). To summarise, on the surface, there may be understanding for people with dementia and no desire to exclude or punish them, but at a deeper level, their perceived inability to reciprocate may fuel the process of stigmatization of which social exclusion is just one part. It may be helpful to consider the role of non-reciprocity not as potentially leading to stigma but rather as underlying the various components of stigma as well as the factors contributing towards stigma.

#### *Implications for timely diagnosis*

There is an indirect link between timely diagnosis and perceived lack of reciprocity insofar as stigma has been associated with delays in the timely diagnosis of dementia and in this study perceptions of lack of reciprocity were reflected in practically all GPs’ perceptions of dementia as a stigma in society (their perceptions and their understanding of how lay people perceive dementia). Such perceptions were closely intertwined and consequently, attempts to tackle delays in timely diagnosis should address lack of reciprocity and stigma together, not as unrelated concepts or phenomena.

In the initial study (XXXX, 2015), several GPs expressed concern that dementia is often stereotyped as being solely the advanced stage. The follow-up study has demonstrated that perceptions of people with dementia failing to reciprocate (or appearing to fail to do so) are often an integral part of perceptions of advanced dementia. Consequently, when GPs broach the topic of dementia in the context of diagnosis, their understanding of the way people with

dementia are perceived as failing to reciprocate is of equal importance as their understanding of societal perceptions of dementia as a stigma. GPs would benefit from support materials to use with their patients to facilitate dialogue, especially in the context of detecting and diagnosing dementia, and to challenge perceptions of dementia as a stigma and of people with dementia lacking reciprocity.

#### *Addressing practices and perceptions*

GPs had concerns about stereotypes of advanced dementia associated with perceptions of lack of reciprocity, about difficulties many lay people have communicating or “reaching” people with dementia, resulting in the belief that people with dementia were not reciprocating, and about people with dementia eventually lacking opportunities to reciprocate. This lends support to the findings of Graham and Basset (2006) and Clare et al. (2010) which suggest that the perceived lack of reciprocity does not necessarily mean that the person with dementia is not reciprocating. For frail older people (including those with dementia), opportunities to reciprocate may represent an unmet need (Vernooij-Dassen et al., 2011). Similarly, Reidpath et al. (2005) argue that infrastructure which serves to prevent loss of social value by enabling people to continue to engage in reciprocal exchange may help prevent stigmatization. Measures must be taken not only to change perceptions but also to maximize the capacity and opportunities that people with dementia have to reciprocate.

#### *Implications for care, relationships and social inclusion*

Statements which suggested a perceived absence of the person, a feeling that it is pointless talking to the person with dementia and the belief that this is no longer the person s/he used to be as s/he doesn't respond in the same way affect the maintenance of meaningful relationships social inclusion and the motivation to provide care (see Adams and Sharp, 2013).

There is a need to carefully examine the way that the costs of care and treatment of people with dementia are portrayed at societal level (e.g. in media reports, official documents and research papers). Terms which are negatively biased such as “burden” and sensationalist terms such as the rising tide, silent tsunami or silent epidemic (Zeilig, 2014; Gubrium, 1986) may heighten fears and thus reinforce stigma. As GPs are key stakeholders in the provision of care, the development of appropriate support to tackle such stigma should include training in the appropriate language to be used when talking about dementia and people with dementia.

A limitation of this study is that perceptions of non-reciprocity were obtained by means of a secondary analysis of data which had already been collected and consequently certain aspects of this concept could not be explored in greater depth. A further study on this topic involving lay people, people living with dementia as well as other healthcare professionals would therefore be beneficial in clarifying the awareness of different groups in society of their own role and responsibility in facilitating reciprocity by people with dementia.

## **Conclusion**

The GPs in this study perceived people with dementia as sometimes failing to reciprocate, as being considered within society as failing to reciprocate but also as often lacking the skills and opportunities to do so. Despite the absence of blame, this may have implications for the stigma of dementia as these perceptions of lack of reciprocity were associated with those reflecting stigma. Providing opportunities for people with dementia to reciprocate and challenging the way that they are perceived as failing to do so may contribute towards reducing the stigma of dementia. Greater awareness is therefore needed of ways to foster the ability of people with dementia to reciprocate, to recognise and value any attempts they make

to do so and to promote a better understanding within society of the progressive nature of dementia and of how to foster communication with people with dementia.

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## Tables

Table 1: Characteristics of the participants and setting

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

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## Figures

Figure 1: The pre-determined categories forming the coding framework for further analysis

<b>Pre-determined categories for further analysis of the data</b>
1. Failure or inability to respond to human contact
2. Absence of appropriate return on social investment
3. Lack of a contribution to or being a burden to society

## Miscellaneous

### **Declaration of contribution of authors**

All named authors have made a substantial contribution to the conception and design, or analysis and interpretation of the data, and the drafting and revision of the article for important intellectual content. They have also approved the version to be published.

### **Statement of conflict of interests**

None declared.

### **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.

### **Underlying research materials**

Underlying research materials are available from the researchers.