

Perceptions of stigma among people affected by early and late-onset Alzheimer's disease

Abstract

An exploration of perceptions of stigma among people with early and late-onset Alzheimer's disease and those who support them; using questionnaires (n=44) and semi-structured interviews (n=14). Perceived stigma reporting was low in the questionnaires; whereas interviews revealed higher levels of perceived stigma in the form of unpredictable reactions to diagnosis, feeling stupid, and ignorance of the condition among the public. Perceived stigma was managed in similar ways across age groups; focusing on 'being the lucky ones'. Results support the need to further tackle stigma and challenge expectations, particularly given the drive to diagnose people and thereby expose them to stigma.

Key words

'Dementia' 'Alzheimer's' 'Stigma' 'Early-onset' 'Late-onset' 'Socioemotional Selectivity Theory'

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Introduction

An estimated 46 million people are diagnosed with dementia globally (Prince et al., 2015). Dementia is an umbrella term encompassing a range of progressive neurodegenerative diseases, which by their nature get worse over time and are currently without a cure (Mielke et al., 2014). Alzheimer's disease is the most common type of dementia for older and younger people (Rossor et al., 2010; Ulfacker & Doraiswamy, 2017) affecting over half of those diagnosed, including around 500, 000 people in the UK and 40, 000 people living in Scotland (Prince et al., 2014; Wilson & Fearnley, 2007). An accumulation of 'tangles' and 'plaques' result in the most common symptoms of Alzheimer's disease including memory loss, language difficulties, problems with planning and organising, and orientation (Alzheimer's Society, 2015).

Increasing incidence has resulted in a heightened drive towards early diagnosis (Aminzadeh et al., 2012), to allow people as much time as possible to plan their future (Dubois et al., 2016). Importantly, diagnosis of Alzheimer's disease exposes people to negative attitudes and beliefs (Garand et al., 2009), known as stigma (Goffman, 1963). Stigma is a commonly cited reason for avoiding diagnosis and taking on the identity of a 'person with Alzheimer's disease' (Bunn et al., 2012). Therefore, understanding more about people's perceptions of stigma could provide valuable insights to policy and practice (O'Sullivan et al., 2014). Scotland's national dementia strategy supports the increased focus on diagnosis, whilst recognising the prevalence of stigma and need actively address the consequences (Scottish Government, 2017). People diagnosed with dementia in Scotland are currently offered one-year of post diagnostic support, which may serve to reduce experiences of stigma (Miller & Kaiser, 2001; Alzheimer's Disease International, 2012) relative to those living in other areas although more research is needed to see whether this is happening in practice.

Stigma and Alzheimer's disease

A range of stigma in the form of negative attitudes and inaccurate beliefs has been reported in the literature towards people affected by Alzheimer's disease. Examples of myths include that dementia is an inevitable part of ageing; and that people with dementia cannot have insight into their condition (Mendez & Cummings, 2003). McParland et al. (2012) also provide examples of myths such as: once someone has dementia the person you knew will eventually disappear; and people with dementia are like children and should be cared for as such. These myths have been seen within the public (Devlin et al., 2007), as well as amongst healthcare professionals (Baste & Ghate, 2015) despite a wealth of evidence demonstrating their inaccuracy (Nelson et al., 2011; Markova et al., 2014; Clare et al., 2012; Peel et al., 2014; George, 2014).

The myths highlight that the stigma is not just attached to the diagnostic label, but to the assumed experiences people will have post-diagnosis. They present an image of dementia as being something that cannot be lived with, fuelling the catastrophizing image of dementia as a 'living death' (Sweeting & Gilhooly, 1997) that continues to prevail in current social discourse (Peel, 2014). As Behuniak (2011) argues, the stigma attached to Alzheimer's disease is dehumanising and based on fear, describing how the socially constructed image of the condition has alarming parallels to that of zombies. The stigma-driven assumptions which focus on social death therefore do not recognise the continuing futures of people living with Alzheimer's disease.

Close family and friends can also be exposed to stigma relating to their association with Alzheimer's disease, known as 'courtesy stigma' (Goffman, 1963). Supporters¹ have been documented as experiencing stigma based on their association with the person with dementia (Phelan, 2005), as well as stigma attached to their role (Werner et al., 2010). The extent of this stigma is unclear; Werner and Heinik (2008) reported that courtesy stigma has been largely unexplored in relation to supporters of people with Alzheimer's disease. Therefore, more research is needed which explores stigma for both people with Alzheimer's disease and their supporters.

Age-related experiences of stigma and Alzheimer's disease

A key feature of Alzheimer's disease is the increased risk of the condition as people age. However, the condition is distinct from 'normal' cognitive ageing (Sonnen et al., 2011) and can be experienced by younger and older people (van der Flier et al., 2011). From a biological perspective, people's experiences of the condition should be similar, yet when considered in relation to stigma a complex picture emerges.

People with late-onset Alzheimer's disease have been suggested to experience greater amounts of stigma due to the 'double stigma' of being an older adult and having Alzheimer's disease (Nolan et al., 2006). There is a wealth of research evidence to illustrate discrimination of people based on their age, with particularly acute stigma attached to older people (Richeson & Shelton, 2006). Older adults have been stereotyped as being frail, ill, and dependent (Thornton, 2002); with Erber and Szuchman (2015) attesting to minimal change in

¹ 'Supporter' has been chosen instead of terms such as 'carer' or 'caregiver' (Molyneaux et al., 2011), to reflect preferences of supporters (O'Connor, 2007) and their role (Carers and Confidentiality, 2013).

stereotypes over time, stressing how ingrained they are in western society. Stereotyping older people as poor drivers, and fully reliant on others (Erber & Szuchman, 2015) portrays loss of skills and abilities resulting in inferiority. Of interest is how such assumptions impact society and the person, particularly when these stereotypes can then accumulate with the stereotypes of Alzheimer's disease (Jolley & Moniz-Cook, 2009). As such, Scodellaro and Pin (2013) proposed that people affected by early-onset Alzheimer's disease experience less stigma than people affected by late-onset Alzheimer's disease, as they do not have the additional stigma of being an older adult.

Alternatively, Chaston (2010) argued that people with early-onset Alzheimer's disease may experience more stigma than people with late-onset Alzheimer's disease. Having a condition associated with older adults (Van der Flier & Scheltens, 2005) is suggested to lead to 'inverse ageism' (Chaston, 2010). This hypothesis is supported by theorist such as Neugarten (1976), who suggests that people will experience more adverse reactions to situations which take place 'off time' to their age-expected trajectory (Heckhausen et al., 1989), based on age-based norms (Ferraro, 2013). Therefore, the theory expects people with early-onset Alzheimer's disease to be more affected by their diagnosis than older adults due to the 'untimely' nature of the condition. Boerner and Wang (2010) provide support for this hypothesis, finding that vision loss had more negative consequences for younger adults than older adults, explained through the 'untimely' nature of the condition.

The conflicting hypotheses around age-based stigma allude to differences in public expectations; however, of key importance to the perception of stigma is how the individual interprets such reactions. In this regard, 'double stigma' (Scodellaro & Pin, 2013) and 'inverse ageism' (Chaston, 2010) may be present yet the way stigma is perceived by the person with Alzheimer's disease needs further exploration. Socioemotional selectivity theory

(Carstensen, 1991) proposes that there would not be significant age-based differences between perceived stigma for people with early and late-onset Alzheimer's disease; due to them facing a 'life-limiting' condition (Carstensen & Fredrickson, 1998; Sullivan-Singh et al., 2015). Per the theory, when people are living with a condition which limits their time, they are motivated to focus on positive experiences and actively withdraw from negative interactions. Recent research supports this 'positivity bias' in people with Alzheimer's disease (Bohn et al., 2016). Similar methods for managing experiences are expected irrespective of age; thereby suggesting that age is not the causal factor (Fung & Carstensen, 2004; Lockenhoff & Carstensen, 2004). Collectively, the research evidence depicts a complex relationship between Alzheimer's disease, ageing, and experiences of stigma. Therefore, the inclusion of both younger and older people within research is promoted to allow for more direct age-based comparisons.

Consequences of Stigma

The rationale for understanding more about stigma can be seen through its possible consequences. Stigma can decrease well-being of people with dementia (Milne, 2010), including loss of confidence and subsequent withdrawal from activities (O'Sullivan et al., 2014). Importantly, stigma relating to Alzheimer's disease and other dementias can increase the physical and psychological symptoms of the condition for people affected (Bamford et al., 2014). Further, people affected by dementia have discussed fears of disclosing their condition due to fear of stigma (Reed & Bluethmann, 2008), which could increase social isolation (Nolan et al., 2006).

Supporters of people with Alzheimer's disease have also been reported to experience various consequences of stigma including anticipatory grief, based on the belief that the person with Alzheimer's disease will be subsumed by their illness (Garand et al., 2012). Feelings of loss and anticipatory grief have been shown to affect all family members, not just the primary supporter (Allen et al., 2009). Additionally, supporters may experience shame and guilt (Werner et al., 2010), highlighting the similarities in consequences for the person with Alzheimer's disease and their supporter. Feelings of shame and embarrassment have also been reported by older people with forgetfulness due to fear of dementia (Ballard, 2010). Taken together, the findings highlight the breadth of stigma attached to dementia and the importance of understanding its consequences.

Aim

The aim of this research was to explore people's experiences of living with Alzheimer's disease focusing on perceptions of stigma and whether age may influence these experiences. Specifically, based on responses to the Stigma Impact Scale (Burgener & Berger, 2008) and semi-structured interviews, do people with Alzheimer's disease and their supporters perceive stigma? Additionally, are there differences in perceived stigma, for people experiencing early-onset Alzheimer's disease and late-onset Alzheimer's disease?

Methods

Ethical approval for this study was granted by NHS Research Ethics Committee (West of Scotland, REC 5). This was followed by site-specific approval across five NHS health boards (Forth Valley, Tayside, Grampian, Lothian, and Greater Glasgow and Clyde).

Participants

People with Alzheimer's disease and their supporters were sampled using purposive sequential sampling from the Neuroprogressive and Dementia Network (NDN, formally known as the Scottish Dementia Clinical Research Network) research register, supplemented by two NHS referrals. All participants lived in Scotland and spoke English. People with Alzheimer's disease were categorised as having mild-moderate symptoms on the NDN register, and all had capacity to consent with the model of process consent (Dewing, 2007) applied throughout the study. All participants needed to have a study partner due to the research aim including both people with Alzheimer's disease and their supporters.

The summary characteristics of people who took part in this study are shown in table 1 including number of participants, age, time since diagnosis, gender, and socioeconomic status measured using Scottish Index of Multiple Deprivation Decile scores from postcode data (Scottish Government, 2013). Early-onset is defined as people who are diagnosed under the age of 65 years old; Late-onset is defined as people diagnosed over the age of 65 years old, in-keeping with clinical parameters (Koedam et al., 2010). Despite the prevalence of supporters being adult-children of people with dementia (Brodaty & Donkin, 2009), only 3 of the 22 supporters in this study were, all other supporters were spouses.

[Insert Table 1 Summary table for sample characteristics of people with Alzheimer's disease and their supporters included in the study]

Overall 22 people with Alzheimer's disease (7 early-onset: 15 late-onset) and 22 supporters were recruited (7 early-onset: 15 late-onset). Of these participants, 12 people with Alzheimer's disease (5 early-onset: 7 late-onset) and 14 supporters (6 early-onset: 8 late-onset) took part in interviews. Twelve were joint interviews, and two were supporter only. The retention of people across the study was high, with all but one pair of participants invited to interview agreeing, giving a retention rate of 93%. Due to the difficulty recruiting younger people with Alzheimer's disease, all those with early-onset Alzheimer's disease included in the questionnaires were invited to interview. For people with late-onset Alzheimer's disease cases were chosen based on 'extreme and deviant scores' (Patton, 1990) and discrepancy between the person with Alzheimer's disease and their supporter with the aim of covering a range of experiences.

Design and Protocol

A mixed method design was chosen to include the most appropriate measures to address the research questions. People with Alzheimer's disease and their supporters completed questionnaires which looked at perceived stigma (Stigma Impact Scale, Burgener & Berger, 2008). Additional questionnaires explored variables which may influence stigma, including quality of life (Dementia Quality of Life scale, DEMQOL, Smith et al., 2005; Zarit Burden Interview Short Form, Bedard et al., 2001), insight (Memory Awareness Rating Scale-Memory Functioning Scale, MARS-MFS, Clare et al., 2002), and activities of daily living (Bristol Activities of Daily Living, BADLs, Bucks et al., 1996).

Perceived stigma was measured using the Stigma Impact Scale (Burgener & Berger, 2008), and thematic analysis of interview data. The scale was development by Fife and Wright (2000) before Burgener and Berger (2008) adapted its use for people with Alzheimer's

disease (Burgener et al., 2013; Chapman, 2011; Liu, 2008; Riley, 2012). The scale is made up of four subcategories: social rejection, financial instability, internalised shame, and social isolation. Examples of subcategory questions include: ‘Some family members have rejected me because of my condition’, which represents social rejection, and ‘I have experienced financial hardship that has affected how I feel about myself’, which represents financial instability. Questions were the same for the supporter’s questionnaire with wording changed to reflect their role, for example, ‘I do not feel I can be open with others about my family member’s condition’, which represents internalised shame, and ‘Changes in the appearance of my family member with Alzheimer’s disease have affected my social relationships’, which represents social isolation.

Quality of life measures were included as a possible covariate to perceived stigma. Research literature suggests that people who report increased stigma are more likely to experience poor quality of life in comparison to people who report lower levels of stigma (Mashiach-Eizenberg et al., 2013; Burgener et al., 2013). The DEM-QOL (Smith et al., 2005) was used to assess quality of life and how it may affect stigma scores for people with Alzheimer’s disease. The DEM-QOL focuses on a person’s experiences over the past week in terms of emotions, memory, and everyday life. Example questions include, ‘In the last week how worried have you been about your physical health?’ The Zarit Burden Interview- short form (Bedard et al., 2001) measured a proxy of quality of life for supporters (Isaac et al., 2011; Rha et al., 2015; Santos et al., 2014), to see if it influenced their perceived stigma scores. Example questions include ‘Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?’

Evidence from mental health literature indicates that lower ‘insight’ or ‘awareness’ could reduce the negative consequences of stigma (Boyer et al., 2012); however, there is not sufficient evidence within the field of dementia to support this. Insight was therefore measured using

the MARS-MFS for people with Alzheimer's disease and their supporters separately (Clare et al., 2002). Examples include: 'You have (your family member has) an appointment and need to remember to go along'. How frequently would you (they) be able to manage this situation? Response cards were given to participants with 5 possible answers, 'never', 'rarely', 'sometimes', 'often', and 'always'.

Cognitive assessments such as the Mini Mental State Examination (MMSE, Folstein et al., 1975) were deliberately excluded from the research as cognitive ability was not a primary outcome in the research and even in circumstances where people's awareness is relatively low, cognitive assessments can still be distressing (Mograbi et al., 2012). Therefore, the Bristol Activities of Daily Living (BADL, Bucks et al., 1996) was chosen to reflect the focus on people's daily experiences moving beyond cognitive ability. The BADL was completed by supporters with example questions including: "Thinking of the last two weeks, which statement indicates your relative's/friend's average ability. Preparing Food: a) selects and prepares food as required; b) able to prepare food if ingredients set out; c) can prepare food if prompted step by step; d) unable to prepare food even with prompting and supervision; and e) not applicable.

All questionnaires were paper-based; supporters self-completed, with the researcher in the same room to provide any additional clarity. The questionnaires for people with Alzheimer's disease were read out loud by the researcher, and participants were given a response card to facilitate answering.

A subsample of participants took part in semi-structured interviews exploring experiences of stigma in more depth; including questions such as 'How do you feel about others' reactions to yourself and/or your diagnosis of Alzheimer's disease?' and "Have your relationships changed?" Interview visits took place between 3 and 6 months later than the questionnaire data collection, following a sequential exploratory design (Creswell, 2003). All study visits

took place in people's homes, and included additional time for sharing a cup of tea (Ashworth, 2014) and informal conversation to build relationship and encourage the indirect benefits of research (Higgins, 2013).

Analysis

Analysis of questionnaires included discriminant analysis, analysis of covariance and multiple regression analysis, supported by SPSS 21 software. Interview data were analysed using thematic analysis following the guidelines set out by Braun and Clarke (2006), supported by NVivo [version 10] software. Audio-recordings were transcribed by the researcher. An initial code book made up of 11 codes was developed based on the literature review and research questions. Transcripts were read through multiple times and separated by age for exploration of possible age differences. New codes were added throughout. Data with multiple codes was either allocated a singular code upon further revision, or kept across multiple codes. Potential themes were considered based on the collation of codes, as discussed by Braun and Clarke (2006). The themes were then reviewed to reflect both the chunks of data and the entire data set. Once themes had been identified and refined, they were named and prepared for reporting (Braun & Clarke, 2006). Finally, the data collected at interview was compared to the questionnaire scores to look for patterns of responding and discrepancies, as well as develop a more in-depth picture for the participants who completed both interview and questionnaires.

Results

Table 2 provides a summary of Stigma Impact Scale scores for people with Alzheimer's disease and their supporters. Scores are presented alongside mean scores and standard deviations for the covariates used in the subsequent analysis. Measures explored perceived stigma (Stigma Impact Scale, Burgener & Berger, 2008), quality of life (DEM-QOL, Smith 2005; Zarit Burden Interview short form, Bedard et al., 2001), insight (MARS-MFS, Clare et al., 2002), and activities of daily living (Bucks et al., 1996).

[Insert Table 2: Summary scores for people with Alzheimer's disease and their supporters used for multiple regression analysis of Stigma Impact Scale scores]

An independent-samples t-test, $t(42) = 2.46, p = .007, d = 0.74$, with an observed power of 0.37 suggests a significant difference between the amount of stigma reported on the Stigma Impact Scale by people with Alzheimer's disease and their supporters. Covariance analysis (ANCOVA) explored whether the significant difference observed in the t-tests remained when possible covariates (age, socioeconomic status, and gender) were included. ANCOVA produced significant results, $F(1, 39) = 2.90, p = .034, \eta_p^2 = 0.23$, with an observed power of 0.73; people with Alzheimer's disease reported higher levels of stigma than their supporters, and this difference was not explained by age, socioeconomic status or gender.

Subcategories of Stigma Impact Scale

The Stigma Impact Scale is made up of 4 subcategories (Fife & Wright, 2000). Participant's scores within these categories were explored to understand more about the key areas of stigma. Table 3 presents a summary of scores by subcategories, with the number of items and score ranges presented to illustrate the unequal weighting of mean scores.

[Insert Table 3: Summary scores by subcategory for people with early and late-onset Alzheimer's disease and their supporters]

A multiple analysis of variance (MANOVA) was computed to compare people with Alzheimer's disease and their supporters across the four subcategories. Significant differences between people with Alzheimer's disease and their supporters were highlighted across subcategories, $F(4, 39) = 3.61, p = .014, \text{Wilk's } \Lambda = 0.73, \eta_p^2 = 0.27$ with an observed power of 0.83.

Significant differences were found between people with Alzheimer's disease and their supporters for social rejection, $F(1,42) = 9.25, p = .004, \eta_p^2 = 0.18$ with an observed power of 0.84 and internalised shame, $F(1,42) = 8.95, p = .005, \eta_p^2 = 0.18$ with an observed power of 0.83. This suggests that people with Alzheimer's disease report higher levels of stigma than their supporters, in relation to social rejection and internalised shame, but not social isolation ($F(1,42) = 2.67, p = .11, \eta_p^2 = 0.06$ with an observed power of 0.36) and financial instability ($F(1,42) = 0.53, p = .47, \eta_p^2 = 0.01$ with an observed power of 0.11). Across subcategories, social isolation was highest for people with Alzheimer's disease and supporters of people with Alzheimer's disease.

Age of onset

A regression model was used to explore possible age differences in perceived stigma measured by Stigma Impact Scale mean score, with insight scores (self-report and discrepancy), quality of life, socioeconomic status, gender, time since diagnosis in years, age, and activities of daily living included as variables. A significant association was found for socioeconomic status measured by Scottish Index of Multiple Deprivation (SIMD) decile,

and quality of life measured by DEMQOL score, $F(8,13) = 3.15$, $p = .033$, $R^2 = 0.66$, observed power of 0.94. The direction of the coefficients in the regression model suggests that as socioeconomic status decreases, indicating increased levels of deprivation, perceived stigma reporting increases ($\beta = -0.51$, $p = .03$). Similarly, as quality of life decreased, perceived stigma reporting increased ($\beta = -0.53$, $p = .04$). The multiple regression analysis for people with Alzheimer's disease suggests that perceived stigma is associated with socioeconomic status and quality of life. Further, age was not significantly associated with stigma reporting in this model ($\beta = 0.05$, $p = .80$). Overall the findings suggest that the difference in perceived stigma reporting on the Stigma Impact Scale for people with Alzheimer's disease is associated with quality of life and socioeconomic status.

For supporters, multiple regression analysis of perceived stigma scores produced significant results for the quality of life measured by Zarit Burden Interview, but not for the additional covariate questionnaires (MARS-MFS, BADL, Age, Gender, SIMD, and time since diagnosis), $F(8,13) = 2.71$, $p = 0.05$, $R^2 = 0.63$, observed power 0.93. As with people with Alzheimer's disease, data collected from supporters were explored across the subcategories of the Stigma Impact Scale. Supporters' quality of life, as measured using Zarit Burden Interview was found to be a significant predictor of scores for mean subcategory scores for Social Rejection ($F = 6.04$, $p = .01$), Internalised Shame ($F = 17.2$, $p = .01$), and Social Isolation ($F = 4.60$, $p = .03$). Decreased quality of life was associated with greater stigma reporting across the three subcategories.

Age of onset- Subcategories of Stigma Impact Scale

Analysis of variance between groups produced a significant difference in scores for people with early and late-onset Alzheimer's disease for financial instability and internalised shame.

People with early-onset Alzheimer's disease scored significantly higher than people with late-onset Alzheimer's disease for financial instability, as shown by a significant analysis of variance, $F(1,20) = 16.9, p = .001$. People with late-onset Alzheimer's disease scored significantly higher than people with early-onset Alzheimer's disease for internalised shame, $F(1,20) = 5.12, p = .035$.

Supporters of people with late Alzheimer's disease scored lower across the 4 subcategories than supporters of people with early-onset Alzheimer's disease, as seen in table 3. As with people with Alzheimer's disease, scores for financial instability were significantly different between supporters, with scores for supporters of people with late-onset Alzheimer's disease scoring significantly lower ($F(1,20) = 5.03, p = .036$).

Comparisons between people affected by early and late-onset Alzheimer's disease should be taken with caution as there was not sufficient power to minimise the risk of a type I or II error. To address concerns about lack of power, possible age differences were explored in more depth through qualitative data collection.

Interview Data – Perceptions of Stigma

In order to explore the findings of the questionnaire data in more depth, semi-structured interviews with people affected by early and late-onset Alzheimer's disease were conducted. These interviews sought to expand on participant's questionnaire answers as well as capture experiences not measured on the Stigma Impact Scale. Initial quantitative analysis, including descriptive statistics and Stigma Impact Scale scores was carried out before the interviews. The data from interviews and questions were considered together in the final stage of analysis, looking at individual differences, and group similarities and differences. Table 4 provides the identifier key and pseudonyms of interviewed participants.

[Insert Table 4: Interviewed participant's identification key]

Thematic analysis of the semi-structured interview generated five overarching themes in relation to people's perceptions of stigma: 'Unpredictable reactions of others', 'Feeling 'stupid'/self-stigma', 'Public expectations', 'Age-related differences' and 'Being the 'lucky ones'' These themes will be discussed in turn.

'Unpredictable reactions of others'

One of the strongest messages throughout the interviews was that people with Alzheimer's disease and their supporters were experiencing a mixture of positive and negative reactions towards the diagnosis of Alzheimer's disease, and importantly this reaction was difficult to predict. This reaction is exemplified in Jennie (SE6) and Matthew's (PE6) conversation,

'The people that we expected to offer support...disappeared off the face of the earth, and the people that we had, I would say we weren't close friends with but we were friends, they are the people that I've...' (Jennie) 'They've come through and we see a lot more of' (Matthew).

Similar experiences of friends 'falling away' were shared by Katie (SE3) and Toby (PE3), and Michael (SL2) and Grace (PL2),

'She just stays very close [lives nearby], within walking distance, and I thought right well I've been along a couple of times, I've phoned every day nearly, I've text, right I'll just see what happens, I've never heard from her since.' (Katie)

‘Our bridesmaid who was on the phone maybe 3, 4, 5 times in the year, umm she hasn’t phoned at all, the same with the people who [identifier removed] used to come and stay with us here, they’ve gone, I’ve had to phone them three times in a row over a period of 4, 5, months, but there’s no coming, no phone call back to us.’ (Michael).

The stigma surrounding Alzheimer’s disease is often considered in the context of public understanding, however, the experiences of these participants illustrates that stigma can impact on relationships with close family and friends, which is likely to be more distressing to people affected (Benbow & Jolley, 2012). Of course, it remains important to consider public understandings of Alzheimer’s disease as it is from this point that many of the assumptions and stereotypes begin to seep through into closer networks and relationships.

Public expectations

The way Alzheimer’s disease is viewed by the general public was discussed by participants, although less poignant than expectations of closer social networks. Matthew (PE7) talked about how the public hold misconceptions and assumptions about people with Alzheimer’s disease,

‘They expect you to be all... [Imitates vegetative state]’ (Matthew)

Further, Jennie (SE7) highlights that this may be linked to a lack of accurate knowledge about the condition among the general public,

‘...I think it’s just been left in the dark too long, and now suddenly there’s all this rush, it’s splashed over the telly and the papers...there’s very few facts, sadly, but there’s plenty of speculation.’ (Jennie)

The lack of facts is argued to lead to ignorance, which the majority of participants cite as the underlying cause of stigma, as indicated by Eva (SE1) who points out that Alzheimer’s disease is an ‘invisible illness’ which makes it harder for people to recognise and understand. Alternatively, increased visibility of the condition may increase people’s exposure to stigma (Goffman, 1963). Therefore, increasing accurate understanding of the condition may be of most benefit.

Feeling ‘stupid’/self-stigma

The pervasiveness of public understandings of Alzheimer’s disease can be internalised by people who develop the condition. For instance, Holly (SL12) discussed how Millie’s (PL12) fear of dementia made it very difficult to use the term Alzheimer’s disease around her for fear of the self-stigmatisation it would cause,

‘She used to say if I go like that, shoot me. It was always her worst nightmare.’ (Holly)

Similarly, the fear of Alzheimer’s disease and what it may mean can lead to people avoiding their diagnosis or hiding their difficulties, as exemplified by Isobel (SL5),

‘I think at the start Dad [Hamish, PL5] tried to cover up and hide it, and he was very stressed about it...I think it was affecting his pride, and he was trying to cover up.’ (Isobel)

A combination of the symptoms of the condition, and the surrounding stigma, can result in people internalising negative assumptions as illustrated by Katie's experiences with Toby (SE3 and PE3), and Hamish and Isla (SL4 and PL4),

‘...something that Toby kept saying to me at the beginning was, he kept saying I'm, I feel so stupid, I'm stupid, I wish I wasn't stupid.’ (Katie)

‘She [Isla] feels a failure, that I think is one of the main trigger points for the frustration.’ (Hamish).

Several people spoke about feeling stupid and a failure. Others said they were not bothered by their difficulties, however, supporters reported significant physiological and psychological stress at the time. For example, Emma (SE4) and Charlie (PE4) discussed memory testing and its impact,

‘You said to her right away, I know I'm going to be no use at this.’ (Emma). ‘I just tell them that I can't do it and that's it, not worried about it.’ (Charlie). ‘Yeah, but deep down you are...although he was smiling and saying I can't do it, and it's not bothering me, I could see’ (Emma).

Overall people with Alzheimer's disease and their supporters noted several examples of times where beliefs about Alzheimer's disease have shaped how the person feels about themselves. Further, examples of participants hiding symptoms or delaying diagnosis suggest that self-stigma may be one of the earliest experiences relating to stigma and Alzheimer's disease.

'Age-related differences'

Possible age-related differences emerged in relation to identifying with the label of 'Alzheimer's disease' and expectations of the condition; these two aspects are likely to influence each other due to the way people learn to explain their condition. Interviews with younger participants illustrate more use of the 'Alzheimer's disease label'. By taking on the 'illness identity' (Beard & Fox, 2008) people with early-onset Alzheimer's disease could explain their unexpected symptoms to others and were arguably able to see the condition as outside of their control. For example, Jack's (PE6) managed public reactions by embracing the identity of 'someone with Alzheimer's disease' carrying around business cards with the following statement for when he met strangers,

'My name is Jack, I have an illness called dementia. I would appreciate your help and understanding...I like to be independent, but sometimes I need help. Here's how you can help: Be patient and try to understand me. Ask how you can help me. If I seem very confused or distressed, contact Olivia.' (Jack)

Comparatively, older participants were more likely to think about the condition in terms of 'normal ageing' as a way of managing their experiences and their fears of dementia as discussed by Holly (SL12),

'... she [Millie, PL12] thinks oh I'm in my 80s I'm bound to have a bad memory and that's ok, and I think that goes with a lot of them [people with dementia], and because they've got dementia they don't remember, so each time you mention them having dementia, it's like you're hitting them straight again.' (Holly)

Similarly, Isobel (SL5) discusses avoiding identifying Oliver (PL5) as someone with Alzheimer's disease,

‘It was the one thing he feared and didn't want.’ (Isobel).

Finally, in relation to age-related differences, experiences of supporters are important to note; in particular for younger supporters. As Jennie's (SE7) conversation illustrates, people do not expect younger people to have the condition,

‘Although quite honestly quite a lot of people expect, you know, they say ‘what does your husband do?’ I say oh he's retired, he, he has Alzheimer's disease, ‘oh, he's much older than you?’’ (Jennie)

Olivia (SE6) shares similar experiences to Jennie (SE7),

‘It's for older people, people don't realise that people as young as Jack can get that.’
(Olivia)

Although these experiences suggest that a diagnosis of Alzheimer's disease may be more difficult for younger participants, as the condition is more unexpected and potentially requires greater explanation; the idea that ‘it's for older people’ also reinforces misunderstandings about Alzheimer's disease and ‘normal ageing’.

‘Being the lucky ones’

The final theme to discuss from the interviews is how people with Alzheimer’s disease and their supporters learned to manage stigma and the experiences shared across the other four themes. Participants chose to avoid situations where they might face stigma and focused on ‘being the lucky ones’.

Poppy (SL1) was one of several supporters who avoided going to support groups to avoid facing some of the potential realities of Alzheimer’s disease; in doing so she was able to focus on her own situation with her husband and not worry about stereotypical symptoms.

‘I just feel that groups, I feel personally that that would depress me... I can see the benefit for some ...but I also feel too that people are obviously going to be at different stages... I think I could start to panic, and really worry about the future, about things that might never happen.’

(Poppy)

Similarly, Murray (PE5) avoided going to his usual social groups following diagnosis but as he began to adapt to the condition he began to participate, as Lucy (SE5) describes,

‘I mean first you missed it [occupational/social group] for a few months, once you got the diagnosis you didn’t want to go, you thought it was the end of all of that sort of thing, and then gradually your colleagues were saying why don’t you come back Murray?’ (Lucy)

The ability to adapt and see that the condition does not necessarily follow the path suggested by a lot of the stigmatised assumptions of dementia has also helped people manage, as exemplified by Isobel (SL5),

‘We’ve been really pleasantly surprised that dad after all these years... you expect when you get the diagnosis that they’re going to go downhill very quickly, but that hasn’t been the case with dad at all, dad’s still very active and very, just memory problems.’ (Isobel).

Being lucky relative to other supporters or people with other health conditions helped people manage their everyday lives as the following two examples from a supporter (Sophie, SL15) and person with Alzheimer’s disease (Matthew, PE7):

‘...Neighbour says life is not what it was like when his wife could do it [referring to activities neighbour’s wife was able to do before she became unwell] ...she has an awful lot of health problems...I think, I don’t have that to contend with...He’s had two heart attacks and also had prostate cancer, so I think we’re lucky, when I compare myself, I think we’re ok.’
(Sophie)

‘At the end of the day it’s something that happens, it’s not, I’m not the only person that’s got it, there’s an awful lot of other people out there that have it as well, you know, and there’s a lot of things a lot worse than Alzheimer’s, so you know, if you’ve got to have something, I don’t mind because you can forget things, it’s convenient you know?!’ (Matthew)

Finally, by focusing on being the ‘lucky ones’ participants showed a general preference for separating themselves from negativity as Jennie’s (SE7) quote exemplifies,

‘It’s their problem; I mean if they can’t deal with it, quite honestly I’d rather they stayed away.’ (Jennie)

The interviews demonstrate that across participants, feeling lucky relative to others was a way of managing a difficult diagnosis and the associated stigma.

Questionnaire and Interview Findings

The findings above highlight an interesting discrepancy between the extent of stigma reporting in questionnaires and during interviews. The questionnaire scores alone would suggest that perceived stigma is low, with people with Alzheimer’s disease agreeing or strongly agreeing to 9.3% of statements on the Stigma Impact Scale, and supporters agreeing or strongly agreeing 11.1% of the statements. However, interview data show multiple examples of stigma being experienced, including public expectations, unpredictable reactions of family and friends’ and feeling ‘stupid’/self-stigma.

Some of the discrepancy between methods can be attributed to the use of mean scores of the Stigma Impact Scale. When subcategory responses were considered in relation to individual interview data the discrepancy between methods reduced. For instance, Jack (PE6) and Olivia (SE6) discussed financial difficulties because of people not recognising Jack’s condition as a younger person living with Alzheimer’s disease. Consistently with this, they were also the lowest scoring in the ‘financial instability’ subcategory of the Stigma Impact Scale. Similarly, ‘internalised shame’ was higher for older adults, which is supported by examples of Isla (PL5) and Hamish (PL3) who were very fearful of the ‘label’ relative to younger participants such as Matthew (PE7) and Jack (PE6). Considering interview data along with the Stigma Impact Scale scores allowed for the more complex picture of stigma to be captured, with

responses between subcategories reflecting the experiences of participants more accurately than the mean score and quantitative data alone.

Discussion

Using quantitative and qualitative data collection, this study explored the experiences of people with early and late-onset Alzheimer's disease and their supporters. The aim was to consider people's perceptions of stigma, including the possible age differences previously unexplored in the research literature. By adopting a mixed-method approach, the study was able to build on questionnaire responses to show the complex nature of stigma, and demonstrate how the methods chosen will shape the answers participants give.

Previous research has focused more on public understanding of Alzheimer's disease, leading to considerable drives to challenge the stigma attached to the condition internationally (Batsch & Mittleman, 2012). The findings support the conclusion that the development of Alzheimer's disease can expose both people with the condition and their supporters to stigma, the source of which can range from negative public perceptions through to family, friends, and self-stigmatisation. Despite low agreement with the Stigma Impact Scale, the pattern of responses in the subcategories and the more in-depth interview data supports the conclusions that people with Alzheimer's disease and their supporters experience stigma. The extent of this stigma varies across participants, as well as within individual circumstances.

Statistical analysis evidenced a higher reporting of stigma overall by people with Alzheimer's disease compared to their supporters. Further, these differences were particularly evident in feelings of internalised shame and social rejection which may be linked to the impact of Alzheimer's disease symptoms on social reactions and self-stigma, compared to everyday experiences which may affect people with Alzheimer's disease and their supporter together

such as financial concerns, and mutual isolation. These findings mirror the direction of difference in previous research (Batsch & Mittleman, 2012; Werner & Heinik, 2008). The presence of stigma challenges the stigma-driven assumption that people with Alzheimer's disease will not have insight into their circumstances (Bond et al., 2002). Further, the findings support the limited research currently available into insight and perceptions of people with Alzheimer's disease, with a focus on stigma (Burgener & Berger, 2008; Riley, 2012).

For supporters, stigma reporting was associated with quality of life and 'caregiver burden', with decreased quality of life associated with higher perceived stigma. As supported by previous research literature, higher stigma has been associated with increased 'caregiver burden' (Werner et al., 2012), which has been used as a proxy for quality of life in this study (Isaac et al., 2011; Rha et al., 2015; Santos et al., 2014).

Possible age-based differences emerged relating to financial instability, and internalised shame. People affected by early-onset Alzheimer's disease reported greater stigma in relation to financial instability, reflecting previous literature on financial concerns among younger people with dementia (Chaston, 2010). Younger people with Alzheimer's disease may have more financial obligations and be more likely to have to leave work early, and therefore be in a more financial ambiguous situation in relation to employment and pensions (Roach et al., 2008). People affected by late-onset Alzheimer's disease reported higher internalised shame which would support a 'double stigma' of ageing and Alzheimer's disease (Scodellaro & Pin, 2011). The comparatively reduced internalised shame for younger people may be indicative of improved awareness of dementia in more recent years particularly around 'normal ageing'. For supporters, less perceived stigma was reported by supporters of people with late-onset Alzheimer's disease than early-onset Alzheimer's disease. Feelings of financial instability were higher for younger supporters, in line with previous literature on age based differences (Chaston, 2010). The findings show support for both sides of previous age-related evidence

(Chaston, 2010; Scodellaro & Pin, 2011), demonstrating the complexity of the topic area. They also help to illustrate the multifaceted nature of stigma, and suggest it cannot be considered as a unitary concept. Instead, perceptions of stigma could be explored through people's different contacts and social networks.

Despite the differences reported on the assessment scales, interview data highlighted that there were overarching similarities in the way people managed exposure to stigma and its consequences. Both older and younger participants were motivated to focus on positive aspects of their experiences. For instance, people focused on considering the friends and family who remained supportive, and felt that they were lucky relative to others. The findings provide support for socioemotional selectivity theory in a population of people with Alzheimer's disease (Mark, 2012). The underlying premise of the theory being that as we age our motivational goals change from seeking knowledge-focused experiences, to more emotion-led experiences (Carstensen et al., 1991), essentially 'making the most of the time we have'. In the presence of 'time-limiting' conditions people of any age are equally likely to actively focus on positive experiences as a way of managing (Lockenhoff & Carstensen, 2004); therefore, the presence of Alzheimer's disease as a 'time-limiting' condition can be seen to override the potential age-based differences between participants.

The findings suggest that greater efforts are needed to improve public understanding as well as individual's beliefs about the condition to minimise internalised stigma and feelings of 'stupidity'. By focusing on positive experiences, people are better able to manage stigma and therefore finding ways to support this may lead to better outcomes overall for people living with Alzheimer's disease and their supporters.

Limitations

In terms of study limitations, the low agreement towards statements on the Stigma Impact Scale in contrast to the experiences reported at interview suggests the scale may not be a viable tool for capturing stigma for this population. In practice this means that people with Alzheimer's disease may be reporting low levels of stigma when in fact they are experiencing much higher levels. Therefore, further research could develop a new scale which is better able to measure perceived stigma efficiently and consistently with qualitative methods.

The sample size was also relatively low, particularly for people with early-onset Alzheimer's disease and their supporters. As a result, the sample size reduced the overall power of quantitative measures, meaning that valid statistical comparisons could only be calculated between people with Alzheimer's disease and their supporters (n=22 per group). There was not sufficient power to compare people with early and late-onset Alzheimer's disease as separate groups within the quantitative analysis; instead the age of participants was included in analysis as a continuous rather than categorical variable. This is not to say that the results would be invalid for age-based comparisons, rather that they should be interpreted cautiously. The reduced sample size and its impact on internal validity is in part counteracted by the inclusion of semi-structured interviews which contextualise and expand on the questionnaire data. An initial direction of future research would be to replicate the study with a more diverse, larger sample size. If more potential participants were available, stratified sampling could be used for a more proportionate representation of characteristics such as gender, age and socioeconomic status (Knapp & Prince, 2007; Teddlie & Yu, 2007). Despite the challenges of recruitment, the retention rate for the study was high at 93%, this particularly positive given the difficulty in recruiting and retaining participants in health-related research (Provencher et al., 2014).

The research only included the experiences of people with mild-moderate Alzheimer's disease, due to the increased likelihood of having insight in their experiences (Rankin et al., 2005) as well as the validity of measures for this sample (Burgener & Berger, 2008). It would be of great interest to explore whether similar perceptions of stigma are reported in people experiencing more 'advanced' symptoms of Alzheimer's disease, particularly given the increased visibility of symptoms and potential 'intrusiveness' (Chaudoir et al., 2013; Hellstrom & Torres, 2013). Further, it would provide useful insights into whether people with more 'advanced' symptoms of Alzheimer's disease are able to employ the same positivity biases to cope with experiences as participants in this research (Mark, 2012; Reed & Carstensen, 2012).

Finally, the population sample was entirely based in Scotland where there is a national strategy guaranteeing people diagnosed with dementia access to one year of post-diagnostic support (Scottish Government, 2013). Research suggests that increased support may influence perceptions of stigma, as well as potentially increased diagnosis rates and future planning strategies (Miller & Kaiser, 2001; Alzheimer's Disease International, 2012; MacLeod & Conway, 2005; Prenda & Lachman, 2001). Therefore, replication of this study in countries without such support may produce different findings, although the pattern of results found in this study has mirrored similar literature in other countries such as America (Burgener & Burger, 2008; Burgener et al., 2013).

Conclusions

The key finding of this study was that people living with the condition experience stigma and this impacts on their relationship with others as well as their views about themselves. The findings support the exploration of perceived stigma through a mixed-method approach rather

than using the currently available questionnaires alone, as interview data allowed for the complexities and similarities between the groups to emerge. The findings bridge the conflicting hypothesises in the age-related literature by demonstrating that despite their differences, there is a shared coping style across age groups resulting from having a ‘time-limiting condition’. Further, the study includes the experiences of both younger and older people together, rather than drawing conclusions from the groups separately. As well as continued efforts to reduce stigma of Alzheimer’s disease internationally, there is a need for more focus on the person’s perceptions of themselves; identifying people who may not have the ‘positivity bias’ and are therefore more exposed to the consequences of stigma

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