

Maintaining social connections in dementia: a qualitative synthesis

Linda Birt, Rebecca Griffiths, Georgina Charlesworth, Paul Higgs, Martin Orrell, Phuong Leung, Fiona Poland

Abstract

The clinical symptoms of dementia include difficulty with speech, poor short-term memory and changes in behavior. These symptoms can affect how the person with dementia understands and performs in social interactions. This qualitative review investigated how people with mild to moderate dementia managed social connections. A systematic search of social science databases retrieved 13 articles; data were synthesized using thematic analysis. Results established the work undertaken by people with dementia to maintain and present a social persona seen as socially acceptable. Interpretations are contextualized within Goffman and Sabat's theories on 'self'. People with dementia were agentic in impression management: undertaking work to maintain recognized social roles, while being aware of when their illness led to others discrediting them. Wider recognition of strategies used to maintain a social self could inform interventions designed to increase capability and confidence in co-managing social connections following dementia diagnosis.

Key words Agency, dementia, sociology, self, stigma, social construction, Goffman, Sabat

Introduction

The stigma associated with the label of dementia may limit opportunities for people to retain and build their social connections. Social connections are shaped by verbal and non-verbal performances that co-construct the meanings of such interactions. Consequently, language that situates the person with dementia as a victim or as suffering ‘a living death’ creates metaphorical and sometimes physical gulfs between ‘them’ and ‘us’ (Alzheimer Society, 2013; Zeilig, 2014). Such narratives of despair and deficit position the person with dementia as one who might not be able to ‘perform’ in social situations in culturally expected ways.

Stigmatizing attitudes and behaviors may be reinforced when cognitive symptoms of dementia become evident in social interactions. Symptoms such as memory loss, difficulties in recalling names and recent events, or appearing apathetic and behaving in challenging ways, can mark a person out as different making them more likely to be excluded from social roles and activities (Batsch & Mittelman, 2012). Fear of making mistakes in public can lead to the person with dementia withdrawing from social activities (Roland & Chappell, 2015).

Although stigma continues to pervade dementia narratives (Herrman et al., 2017), narratives of living with dementia are shifting from inevitable despair and decline to some which encompass living well (Rahman, 2015; Wolverson, Clarke, & Moniz-Cook, 2016). People living with dementia often report wanting opportunities to participate in meaningful activities: to keep connected within their communities (Mountain & Craig, 2012). Understanding how people with dementia take part in, and make meaning from, social connections with family, friends and the wider community is important as positive social connections are essential for quality of life and maintaining cognitive health in older people (Bennett, Schneider, Arnold, & Wilson, 2006; Fractiglioni, Paillard-Borg, & Winblad, 2004; Kuiper et al., 2015; Pillai & Verghese, 2009). Sustaining or gaining positive social connections appears to reduce risk of cognitive decline, although it is quality rather than the number of interactions that appears to mediate the cognitive protective benefit (Khondoker, Rafnsson, Morris, & Orrell, 2017). Studies reporting the experience of living with dementia identify that people with dementia and, more often, their carers report social isolation (Harris & Keady, 2004; Kane & Cook, 2013). However, other studies suggest that those living with dementia are contented with their relationships (Wolverson et al, 2016). Differences in experiences of social interactions may be related to severity of dementia, previous social relationships, or the strategies used by the person with dementia to maintain social connections. This review explores ways in which people with dementia manage their social connections.

Making and maintaining positive social connections involves ‘work’ by people, who, if they are to be socially active and connected to others, need to perform and to fulfil responsibilities (Brannelly,

2011). Here the ‘work’ of a social connection entails presenting one’s ‘self’ to others. However, people diagnosed with dementia often report a change in their sense of self, introducing uncertainty about what ‘self’ to present and how (Caddell & Clare, 2010). Some people attempt to normalize events to try to maintain a prior sense of self (Clare, 2003). Whereas others make adaptations; for example moving from ‘being valued for *what they do*’ [our italics], to ‘being valued for *who they are*’ (Steeman, et al. 2013). The process of adapting can also mean gaining new skills (Hedman, Hansebo, Ternstedt, Hellstrom, & Norberg, 2012). Beard (2004) drew on Goffman’s work on stigma to understand how people may undertake the work of ‘identity preservation’ by constructing narratives that helped them manage public impressions. All actions to normalize or preserve ‘self’ take place within socially constructed interactions and the lens of symbolic interactionist can illuminate the work of the individual and their responses to others’ actions.

Within the domain of sociology, the ‘self’ does not have independent substance, rather it is a metaphysical concept in which both identity and time can be integrated (Higgs & Gilleard, 2016). The ‘self’ is constructed, initially through adopting a set of perspectives about who one is, then reinforced through interactions with others and patterned by larger social structures (Gergen, 1971; Stets & Burke, 2003). Symbolic interactionist theorists such as Cooley (1902) and Mead (1934) identified that the way in which a person sees himself or herself is shaped by how they perceive others as seeing them.

Goffman’s work on stigma, grounded within a symbolic interactional position (Scheff, 2005), reinforces the notion of the constructed nature of self. He argues that when, due to mental or physical capabilities, people do not perform as others anticipate and expect they risk being stigmatized and having their identity ‘spoiled’ (Goffman, 1963). A spoiled identity may reduce the range of social connections a person can maintain or develop. Goffman distinguishes a discredited identity where stigmatizing marks such as age, ethnicity or physical disability may be visible, from discreditable conditions such as mental illness where stigmatizing attributes may be hidden (Chaudoir, Earnshaw, & Andel, 2013). It may be that in trying to maintain a ‘prior sense of self’, people in the early stages of dementia, are working agentically to hide potentially stigmatizing symptoms.

From a psychological perspective, Sabat’s (2002) work also acknowledges the importance of others in the construction of ‘self’. He posits that of three possible constructions of self, at least one will rely in part on others’ cooperation in reflecting and reinforcing an attribute. In ‘Self 1’ the use of pronouns indicates the responsibility people take for their actions, feelings and experiences. ‘Self 1’ often remains intact in dementia. In ‘Self 2’ mental and physical attributes and personal beliefs about these attributes come to the fore. People often take pride in such attributes as ‘having a good memory’ or ‘being the organizer’ and experiencing dementia symptoms may change the sense of ‘self 2’. In Sabat’s conceptualization of ‘Self 3’, people are seen to construct different social

personae when fulfilling different social roles. The ‘Self 3’ may be threatened if the visible symptoms of dementia lead others to discredit the person with dementia by calling into question personal attributes and stigmatizing their behaviors (Sabat, 2002, 2008).

Remaining socially connected with family, friends and the wider community is key to living well and sustaining quality of life. Some evidence indicates that people’s ability to be agentic in social interactions may be constrained both by the symptoms of dementia and by the actions of others (Birt, Poland, Csipke, & Charlesworth, 2017). This highlights the importance of exploring the distinct ways in which people with dementia experience social relationships in community settings. Specifically do they report being agentic in social connections and, if so, in what way? This article synthesizes qualitative studies that reported the experiences of people living with dementia in the community as they negotiated their agentic place in social interactions. The focus of this paper is on the work people with dementia undertook to present an acceptable, not a discredited self, to others

Methods

The selected design of the review enabled synthesis of evidence through techniques to compare, translate, analyze and make new interpretations from the original studies (Zimmer, 2006). The method draws on the principles of thematic synthesis (Thomas & Harden, 2008). The approach enables a translation from descriptive to analytical themes. The method entailed four steps: 1) purposive search of literature; 2) assessing quality and relevance of evidence; 3) extracting data; 4) data synthesis. The process was iterative: during the preliminary synthesis, we inductively extracted data related to social interaction and social participation. However, discussion in multidisciplinary analytical meetings indicated that then deductively applying theoretical perspectives on how ‘self’ might be constructed in and through connections with others could provide new understanding of the work done by people with dementia in social interactions.

Search and inclusion Strategy

The search strategy developed over several months, alongside authors’ developing interest in the agentic behaviors of people with dementia. The primary focus of the review was to explore engagement and social participation in response to a wider research aim of understanding social discourses around dementia within The PRIDE study (Promoting Independence in Dementia). Searches were carried out by Birt in November 2014 and due to the time between the search and the focused analysis, repeated by Griffiths in September 2016. Three databases were searched: Web of Science SSCI, PubMed and ASSIA. Each database was searched from inception to September 2016 for articles reporting the experience of social participation in family and community settings, for people with dementia. We used combinations of the following search terms: ‘Dement*’ or

‘Alzheimer*’ or ‘cognitive impairment’ combined with ‘agency’, or ‘engagement’, or ‘social identity’, or ‘constrain*’, or ‘empower*’, or ‘lived experience*’, or ‘relationship*’, or ‘independence*’.

Inclusion criteria were selected to ensure empirical data relevant to the research aim was available:

- 1) Articles were from peer reviewed journals
- 2) Data from people with dementia
- 3) People with dementia living in the community
- 4) Results include data on how people with dementia engaged with others
- 5) Results refer to experience of people with dementia being members of a community (physical or online).

We were not able to include any article not written in English. We did not exclude on research methodology as mixed method studies may contain participant quotes.

Assessing the quality and relevance of evidence

The Weight of Evidence framework [WoE] (Gough, 2007), was used to assess retrieved articles for quality and relevance. The WoE framework appraises the research quality of a study and the relevance of the study’s design and results to the review question across three domains. Domain A relates to the soundness of study i.e. is the research reported in the article of high, medium, or lower quality. We assessed the research quality of each article using the Critical Appraisal Skills Programme (CASP, 2017). Domain B considers if the design of the study is appropriate to the review question (i.e. randomized controlled trials are unlikely to provide information on lived experiences). Domain C appraises the relevance of the study to the review question (i.e. if results can be generalized, or in qualitative reviews transferable). No articles were rejected on quality or relevance.

Data extraction

In the data extraction phase, details of the research methodology, sample characteristics and reported analytical interpretations were tabulated. Participants’ illustrative quotes were retrieved, coded and tabulated using a word processing package. Coding was predominantly undertaken by Birt with regular consultation with members of the research team.

Due to the diversity of theoretical themes presented in the articles, an analytical decision was made not to code findings that did not relate to social participation. For example in Vikstrom, Josephsson, Stigsdotter-Neely, and Nygard, L(2008) the theme ‘Caregivers management approaches to handle changes’ did not contain data relevant to the review questions, however the theme ‘Perceived changes in activity engagements’ was relevant. This method of selective data extraction ensured evidence selected was relevant to the review question (Noyes & Lewin, 2011). It could be argued that this might limit the likelihood of disconfirmatory examples being noted and reported. However

an iterative process of returning to the articles, reflecting on developing themes and questioning the place of the themes within each retrieved article highlighted examples where people were not so agentic in their social interactions and we acknowledge this in our results and discussion.

Data synthesis

Data synthesis was guided by the principles of thematic synthesis that draws on analytical processes commonly used in primary qualitative research to develop analytical themes (Thomas & Harden, 2008). Drawing on practices within meta-ethnography (Britten et al., 2002) interpretations from the original authors (i.e. second order constructs) were retrieved as well as the participants' illustrative quotes (i.e. first order constructs).

Initial inductive coding identified facilitators and barriers to social participation including: accepting diagnosis, being objectified, treated in a childlike way, maintaining purposeful occupation, strategies to promote communication, friendships, citizenship activities. During this inductive coding the participants' language, in the illustrative quotes, demonstrated the agency people were enacting in managing their interactions with other. In research team discussions, and influenced by the academic interests of the predominantly sociological team's wider research interests, the analytical focus was refined to explore the data by drawing on the theories of symbolic interactionism. Rather than 'closing down' the analysis this more deductive approach enabled new insights into studies that had predominantly focused on adaptation to dementia diagnosis and the construction of identity. As actual or perceived stigma can affect social participation (Batsch & Mittelman, 2012)) there was value in deductively exploring the data through Goffman's work on stigma and presentation of 'self' (Goffman 1959, 1963). Including Sabat's work on 'self' in dementia provided further context to the actions of people with dementia (Sabat, 2002, 2008). First and second order constructs were group under four interpretive themes (third order constructs). The analytical interpretations were reviewed and agreed by all authors. Participants' quotes and original authors' interpretations are used to illustrate four themes.

Results

Summary of studies

The database search resulted in identification of 7918 records (Figure 1). After duplicates were removed, 3403 articles were screened and reviewed by titles or abstracts to check for relevance to the research question. 3331 articles were excluded for the following reasons: non-empirical research, not reporting on dementia, study of dementia in long-term or residential care settings, aspect of dementia not relevant to research question, and reports of pharmaceutical treatment and drug trials. Following this 72 full-text articles were assessed for relevance and 59 were excluded for not meeting one or

more of the inclusion criteria Birt and Griffiths. Reference lists of relevant articles were used to identify two additional sources. Figure 1 demonstrates the search process.

The heterogeneity of articles between research design, aim, sample and data collection methods had sufficient resonance to enable a synthesis of qualitative evidence from each article. Thirteen articles are included in this review, all reporting qualitative results. Table 1 reports details of articles.

Quality of articles

The majority of articles had sound study design with clear reporting of sample and methods (W0E criteria A, see table 1). All studies had an appropriate qualitative research design (WoE criteria B). There was variety in the relevance of the study to the review question with only eight articles scoring medium to high on this criteria (WoE criteria C). However, those articles scoring low in criteria C were still included as discrete segments of data in the results were particularly pertinent to our review question. Twelve of the articles scored medium or high on overall judgement (WOE criterion D) predominantly due to the research quality and relevance of the findings to the review question.

Summary of studies

While the research aims of the studies differed: with some exploring ‘self’ and ‘identity’ and others exploring ‘engagement in activities’ they all included data on how people living in the community with dementia engaged in social interactions. Therefore, it was possible to undertake a qualitative synthesis. Seven studies were undertaken in the UK, two in the USA, one in Sweden and two in Canada (MacRae has published twice from the same study). The number of participants in each study was small, with sample sizes ranging from seven to 52. The experiences of more men (n=98) than women (n=59) are reported. In the majority of studies, the mean age of participants was over 70 years; only two studies had a sample predominantly younger than 65 years (Clare, Rowlands, & Quinn, 2008; Clemerson, Walsh, & Isaac, 2014). Participants were mostly of white ethnic origin.

Qualitative synthesis

Four analytic themes define the agentic ‘work’ undertaken to manage presentation of ‘self’ by people with dementia. The four themes are: impression management in social connections; performing recognized roles in social connections; maintaining an acceptable presentation of self; recognizing the spoiled identity. In each theme, we draw on the work of Goffman and Sabat to locate conceptually the active ‘work’ that people with dementia are found to undertake in managing social connections. Table 2 contains detailed examples of data within each theme.

Impression management in social connections

The person with dementia was often agentic in the social connection, managing how others might perceive them. Goffman's dramaturgical theories refer to impression management and implies a performance or deception. Eight studies had data indicating that people with dementia managed interactions so as to present themselves in particular ways. They constructed personal narratives about the work they needed to do to interact successfully with others; much of this was about managing the impression they presented. Clare et al., (2008) described how participants '*had a sense of owning the challenge of addressing the stigma attached to the dementia label*' (2008:19).

A paradox of living with dementia is that often there are no visible physical signs to mark one out as different and people may mask their disability. There were a few examples of participants speaking about being 'exhausted' by the work they did to maintain social interactions (e.g. Bartlett, 2014). This resonates with the front and back stage work identified in Goffman's dramaturgical approach (Goffman, 1959). In 'front stage' activities, actors perform visible roles meeting expectations of the 'normal' behaviors and appearances in a setting. An actor will conduct 'back stage' work in private spaces so as to enable the credible appearance of a front stage performance. Bartlett's (2014) work reports the efforts people with dementia make backstage, often at home, so as to be able to take part in the 'front stage' public campaigning events. MacQuarrie (2005) interprets this as '*their facade*'.

The front stage work is represented through the language people used, which reflects the language of theatre actors, thereby reinforcing our interpretation of a performance: '*this is a false face*' (MacQuarrie, 2005:435); '*do it with a smile on your face*' (Bartlett, 2014:1299). Our interpretation here that people may be undertaking impression management was reinforced in Langdon, Eagle and Warner's (2007) study when a participant asked for feedback on his performance: '*Do you think I am fumbling*' (2007:994). People with dementia showed they were aware of the work they were doing and its outcomes, some stating that their performance as a 'normal' person has convinced the audience: '*the men don't even notice there is anything wrong with me*' (MacRae, 2011:451). This suggested that people were striving to hide a discreditable condition. A few people reported the physical effort involved in managing impressions: '*my biggest challenge really is keeping effective without total exhaustion*' (Bartlett, 2014: 1298).

Goffman (1959) suggests that in doing impression management, people use strategies or props to shape and control others' impressions of them. A dementia diagnosis can be a prop as it provides context for the actor's actions and perhaps changes the audiences' expectations of the actor. Some participants could disclose their dementia diagnosis as doing this enabled them to be agentic in structuring the interactions in ways that supported their effective communication (Beard & Fox, 2008; MacQuarrie, 2005; Preston, Marshall, & Bucks, 2007). Two studies reported participants' embraced the social persona of a person with dementia and performed as experts, happy to be on the

‘dementia stage’. This could be in person or through online communities (Beard, Knauss, & Moyer, 2009; Clare et al., 2008).

Furthermore, in Langdon’s study (2007) participants were not sure that others would understand the term dementia; although since the time of that research there has been an increase in public understanding of medical terms and symptoms associate with dementia. We suggest people were managing the impressions they produced to avoid others making judgements on their performance in social connections.

Performing recognized roles in social connections

Eight studies reported people with dementia maintaining and developing new social roles within their in-person or virtual communities (see Table 2). These roles provided new social status reinforcing the ‘self’ as a person of importance. However there was recognition of the ‘*changing social status*’ and ‘*increased difficulty in carrying out roles that had previously given them a sense of self-worth and social standing*’ (Langdon et al., 2007: 996). Such change was reported as a devastating loss (Clare et al., 2008:170) and there was a ‘fear of embarrassing’ themselves in social activities (Caddell & Clare, 2011:390). However, involvement in alternative social roles, here an online support and advocacy community, enabled ‘*feelings of being a valuable and contributing member of society*’ (Clare et al., 2008: 18).

In both studies where people with dementia contributed to an online community, they reported experiencing this as a positive social role with opportunities for giving and receiving support (Beard et al., 2009; Clare et al., 2008). It is noted that an online community may require less instant co-operations and feedback than in-person community-based activities.

Some articles reported the person with dementia acknowledged changes in the personal attributes and values held about oneself (Clare et al., 2008; Langdon et al., 2007). This suggests a change in ‘self’², namely the personal attributes of who one is (Sabat, 2002). People strived to believe in their own continuing abilities to perform in valued and valuable ways. Reasons for reducing social activities were as fear of making a fool of oneself and loss of confidence (Caddell & Clare, 2011; Clemerson et al., 2014; Vikstrom, et al., 2008). Actions of family and friends could also reduce opportunities to engage in social activities (Beard & Fox, 2008; Clarke, et al., 2010). Yet social roles were reported as providing a ‘sense of continuity’ and ‘enriching lives’ (Beard, et al., 2009: 233) and for some roles were linked with duty (Bartlett, 2014). The actions of others were generally undertaken with good intentions to protect the person with dementia, but they could result in reduced agency for the person with dementia. Fewer social connections led people with dementia to describe being ‘*isolated and disconnected*’ (Clemerson et al., 2014:460). The absence of opportunities for

social connections was reported as leading to a life that is *'very, very shallow ...my lifestyle is so limited and narrow'* (Caddell & Clare, 2011:391).

Maintaining an acceptable presentation of self

Sabat (2002) notes that the construction of self relies on the cooperation of others to reflect and reinforce an attribute. His 'Self 3', the social persona that people construct can be threatened if others discredit the person's attributes and stigmatize the person as an infant, or as having no valuable attributes: it is hard to present a particular front stage self if the audience disputes the portrayal. Seven studies had data which demonstrated the interactional nature of social connections and the ways participants were working to maintain an acceptable 'self'. MacQuarrie's subtheme 'Constructing the agentic self in the face of loss' (2005:432) captures the tension participants, in many studies, expressed over the wish to share the diagnosis against the fear that in sharing a diagnosis people might then enable others to objectify them (Langdon et al., 2007; MacRae, 2010).

There was evidence of people protecting their social persona by avoiding those who sought to discredit them *'I just avoid people I don't like who are being negative towards me'* (Clemerson et al., 2014:460) or by distancing themselves from others with dementia. Describing a participant at a support group, Clemerson describes his sitting near the door as he explains *'it is too warm in there'* (2014:459). Some people with dementia may be agentic in distancing themselves from discredited groups, be that others with dementia or older people. Decisions were made about who to tell *'...I won't tell them anything...I think they may yap, yap, yap with everyone that I have dementia'* (Langdon et al., 2007: 995). Some people were very directive in challenging expectations of others indicating the interaction could be controlled by the person with dementia *'I practice saying no'* (Beard et al., 2009:231).

People worked to maintain an acceptable presentation of self. Humor was frequently used to diffuse tension in a social interaction and to become self-effacing (Beard & Fox, 2008; MacRae, 2010). This differs for impression management as humor only works if others accept and acknowledge the behavior.

Accepting their dementia diagnosis seemed to enable people to reconcile their changing abilities and assimilate the attribute of having dementia as *'part and parcel of who I am now'* indicating a change to Self 2 (Clemerson et al., 2014; MacQuarrie, 2005; MacRae, 2011; Preston et al., 2007). However, others feared that sharing a diagnosis would enable 'normal' people to discredit and stigmatize them *'I almost bit my tongue after saying it [his diagnosis] as I looked around because I wasn't sure what that meant to them'* ([brackets added] MacRae, 2011:450). This was compounded when they perceived that others held negative views about their abilities, *'...people might not want to talk to me because they might think I am thick but I am not'* (Clemerson et al., 2014:458).

Participants expressed concern that if the 'front stage' performance was not flawless, others would notice, and this could create a situation where others discredit the person, '*the worst part is when I lose my chain train of thoughts and you stand there like an idiot*' (MacQuarrie, 2005:434). Others recognized ways in which changes in their cognitive ability affected their performance in social interactions: '*to me it feels like I am insulting them not remembering their name... I don't like that at all*' (Caddell & Clare, 2011:386). This resonates with Sabat's 'self' 2 where personal characteristics such as knowing people by name are essential to one's identity. In MacRae's study where the participant explained that he was concerned that others perceptions of him as a '*pretty smart man*' might change and he would miss the '*accolades*' (2011:449). This example mirrors the applause that comes at the end of a successful theatre performance, indicating the need for positive feedback in performance of self in order to judge and retain an acceptable persona.

The interactional nature of maintaining an acceptable presentation of self was evident in several studies (Caddell & Clare, 2011; Clarke et al., 2010; Langdon et al., 2007; MacRae, 2010). This is particularly illustrated in Clarke's findings where the participant stated '*I make them laugh*' (2010: 106). This could be seen as a positive agentic behavior but the participant follows up with a potentially derogatory statement '*I come out with some daft things.*' (Clarke et al. 2010: 106).

Recognizing a spoiled identity

Ten studies reported the insight people with dementia had into the potential for having a stigmatized identity. There was evidence that people with dementia internalized aspects of a spoiled identity. For example, they were sensitive about whether other people were concealing negative thoughts about them (Langdon et al., (2007: 994), being '*aware of disjuncture between theirs and others perceptions*' (MacQuarrie, 2005:432). People had insight into how others perceived them, '*I can tell when someone is getting frustrated with me*' (Beard et al., 2009). .

There were a few accounts where a discredited self was internalized without the participants recalling direct actions being enacted by another person. For example in Langdon's study a participant states her daughter thinks she is 'crackers', however the participant states that her daughter has never said so (Langdon et al., 2007: 994). Caddell and Clare report that participants '*believed others must have noticed*' (2011:392). This demonstrates the insight people with dementia have into the social connections and behaviors of others, yet MacRae (2010) found that most participants in her study did not feel they were treated differently.

The diagnosis of dementia could 'negated' the person's opportunity to contribute in social interactions (Clare et al., 2008; Langdon et al., 2007). If the person with dementia perceived themselves as discredited, and identified as belonging to a stigmatized group, then the social interaction lead to perceptions of being 'socially demoted' (Beard and Fox, 2008: 1517). People

spoke of being treated like a child (Clemerson et al., 2014; Preston et al., 2007) or of being controlled by others, '*wheeled out when needed*' (Bartlett, 2014:1300). This suggests a stifling of agency and a reliance on others, an insight seen in many of these articles (Beard & Fox, 2008; Beard et al., 2009; Clarke et al., 2010, MacQuarrie, 2005).

Discussion

By synthesizing multiple studies using the theoretical lens of symbolic interactionism, and then drawing on the works of Goffman and Sabat, we provide detailed insights into the agentic work people with dementia undertake in co-constructing social connections. In establishing theories of stigma and presentation of 'self' Goffman provided a macro-lens on society that enabled us to identify and characterize the performance requirements for maintaining 'certain social characteristics' following a dementia diagnosis (Goffman, 1963). Social characteristics such as attentiveness and reciprocal responses in communication with others confer a moral right to be treated as citizens. Living with the symptoms of dementia might change how people perform communications with others, perhaps leading to their performance being seen as discrediting, and constraining their participation in their communities. Drawing on Sabat's micro-lens of relationality and the requirement of others' to positively confirm one's desirable characteristics was key in maintaining the person's 'self 3' and often 'self 2' (Sabat, 2008). . This helps make explicit the role of various others in supporting the actions and performance of a person with dementia.

Goffman's work explicitly informed three studies in this review (Beard and Fox, 2008; MacRae, 2010, 2011; Bartlett, 2014)). However, our synthesis builds on these single studies by demonstrating the utility of this sociological lens in a wider range of studies. Each had disparate research aims including: the impact of diagnosis on identity, the impact of belonging to support groups on self-concept and adjustment, the experience of campaigning, adjusting and managing risk, and how dementia affects engagement in social activities. Synthesizing data from diverse studies makes it possible to see the ways in which narratives of agentic presentation of 'self' are being constructed in different interactions, thereby providing a more comprehensive understanding of the agentic work undertaken by people with dementia. Earlier reviews reported that people can live positively with dementia, maintaining identity and achieving growth (Wolverson et al., 2016). People may use coping strategies to maintain identity, however the (re) formulated self may still be put under threat (Gorska, Forsyth & Maciver, 2018). As social beings, we must constantly manage our front-facing social personae, to react and pre-empt loss of 'self'; specifically if we see others as perceiving a discrediting attribute which may stigmatize us. Our findings specify the nature of agentic work people with dementia do to manage threats to self so as to remain positively, socially connected, indicating that people living with mild to moderate dementia continue to be alert to and undertake this interactional work.

Goffman (1959), in discussing impression management, draws on dramaturgical ideas to explore in detail the ways in which an individual's actions are given meaning by others and what tensions can develop when the performance does not unroll as anticipated. Our review findings identified that people with dementia present themselves in social interactions by actively managing their 'front stage' performance through the use of humor, reflecting on and adapting their performance and being alert to how others perceived them (Bartlett, 2014; Beard & Fox, 2008; Beard et al., 2009; Langdon et al., 2007; MacRae, 2010). While some people referred to their dementia diagnosis as a prop to 'explain' any changes in performance during social interactions, others chose to mask their symptoms. This enabled them to put on a 'passable' 'front stage' performance in public places. Studies reporting on the experience of other stigmatized groups also report that people actively adapt appearance and actions to appear 'normal' in public, thereby reducing the risk of being stigmatized (O'Connell, 2016; Whitley & Campbell, 2014). If others reinforced an acceptable performance in social interactions, this enabled the person with dementia to sustain their personal attributes grounded in 'Self 2'. This resonates with work by Harmon and Clare (2006) who reported that people with dementia recognized when the attitude and behavior of others changed towards them. It builds on findings of Clare's (2003) research that reported on how people tried to confront difficulties by 'self-adjusting'. Our synthesis reinforces that people are agentic in compensating for social changes inherent in dementia.

People with dementia were here seen to be agentic in making and managing their social connections: being the producer as well as the product of the interaction. Bandura (1989) describes the interactional causal nature of agency as actions shaped by cognitive, motivational and affective processes. We found that people with dementia had cognitive abilities to enact social performances in an agentic way and they were motivated to do so. However, where people perceived themselves to be stigmatized or even at risk of being stigmatized, this affective factor could lead to their withdrawing from social interactions. Remaining engaged in social relationships and activities has the potential to enhance quality of life and reduce cognitive decline.

Our findings suggested that people tried to take steps to normalize events to maintain their continuity of self. Doing such work within a social interaction may be a way of maintaining 'normality' within connections as relationships fluctuate. Seeing positive connections as based on trust can follow if 'situational normality' can be established and maintained (Misztal, 2001). When there is order, predictability and regularity in events, trust can be generated. However, the symptoms of dementia may threaten the predictability and regularity of an interaction. Therefore, both the person with dementia and others with whom they engage may need to make adaptations in what they expect within interactions to ensure that a sense of the normal can continue. For example, that it is *'safe and sound to continue with the activity at hand with only peripheral attention given to checking up on the stability of the environment'* (Goffman, 1971:239).

Methodological reflections

This review was undertaken to increase understanding of the nature of the social participation for people with dementia. The literature search was run twice to increase likelihood of capturing recent publications. The term social connections was not used to direct the search as it was only through the analysis process that the theme of maintaining social connections emerged as relevant to the later discussion, and subsequently 'social connection' has not been found to be a term commonly used in published related research.

The inclusion criteria for our review located experiences of social interaction within accounts from those people, predominantly living in the community, with mild to moderate dementia, who were competent to give consent and engage with qualitative interviews. It was beyond the scope of this review to explore how people with more severe dementia or living in nursing homes manage their presentation of self. However, research in residential care settings has also drawn on Goffman's theories to identify that people living with severe dementia have reduced opportunities for agentic presentation of self and such opportunities they do have will be provided or restricted by others (Cromwell & Philips, 1995; Ericsson, Hellstrom, & Kjellstrom, 2011; Naess, Fjaer, & Vabo, 2016).

Data synthesis was undertaken on studies of varying quality and relevance to our review questions, nonetheless, there were robust examples of agentic positive social connections in each article as well as examples where participants had begun to withdraw from social connections. The degree of interpretation required when developing third order constructs leads to the findings being several steps removed from the lived experience of people with dementia. We appreciate a team of predominantly sociological researchers developed these interpretations and that people from other specialties might have differing interpretations and data groupings.

The transferability of findings is affected by the relatively narrow demographic of participants in the retrieved articles. The experiences of comparatively few female participants are reported.

Underrepresentation of female participants has been seen in other reviews, which is important to acknowledge as gender may have distinct impact on experiences of dementia (Bartlett, Gjenes, Lotherington, & Obstfelder, 2018). Participants were predominantly drawn from white ethnic backgrounds and it is well reported that the meanings given to dementia, as well as normative roles in communities, are highly culturally situated (Cipriani & Borin, 2015). People with Young Onset dementia may face distinct challenges in settings in which social connections occur such as work placements. However, the data reported in our selected studies did not focus on employment.

This review reports only one side of a social connection, that of the person with dementia, but in co-constructing meanings a more nuanced understanding would be gained by studying the impression and actions of all partners in social interactions. This might contextualize how others such as health

professional, family, and friends support or obstruct the work people with dementia undertake to mask 'discreditable' attributes (as seen in Clarke et al. (2010) and Vikstrom et al., 2008).

Acknowledging the actions of others beside those of people with dementia in co-constructing meaning is essential, as a robust 'Self 3' may be threatened if stigmatizing actions or words come to be internalized. A review by Steeman, de Casterle, Godderis and Grypdonck, (2007) on living with early stage dementia reported that being a 'meaningful member' of society can be threatened when the person is '*accused, restricted, ignored, or patronized by others*' (2007:735).

Social connections for people with dementia may be predominantly found within personal interactions. However, the growth of online support groups may provide distinctly different ways for people with dementia to present their selves. Online communities can provide alternative social connections and communities where front and back stage work are managed in different ways (Rodriquez, 2013).

Implications

Self-awareness and the capability to enact agentic decisions may recede overtime for those living with dementia. While acknowledging the challenge of Simm, Jamieson, Ong, Garner and Kinsella (2017) to the concept of self-awareness in dementia, we would counter that in the early stages of dementia people continue to be self-aware. Clare, Markova, Verhey and Kenny (2005) reported on the complexity of assessing awareness in dementia, drawing the conclusion that an important outcome of researching awareness should be to understand the subjective experience of the person with dementia in order to inform care practice. More recently, they concluded that self-concept is '*generally stable over a 20-month period*' (Clare, et al., 2013:500). More consistent reporting of length of time since diagnosis in studies may increase transferability of results. Research is now needed to specify how far on the dementia journey people may retain the ability to manage performance and present their 'self' in specific ways for specific purposes. Longitudinal study findings would help improve empirical understanding of what specifically enables some people to retain capabilities to undertake impression management so as to maintain positive social connections, while others experience internal or external stigma and lack active presence in social situations. Such knowledge may inform interventions that recognize the person with dementia as an agentic actor.

Kitwood's seminal work on personhood started the movement towards recognizing the individual with dementia; however his theories were grounded within social psychology with the emphasis being on '*the standing or social status that is bestowed upon one human being, by others*' (Kitwood, 1997:8). There is now a growing discourse that people with dementia should be recognized through the lens of citizenship: acknowledged as self-acting agentic social citizens with rights, responsibilities and opportunities to remain connected in their social worlds (Bartlett, 2016; Bartlett & O'Conner, 2010; Birt et al., 2017; Boyle, 2014). This promotes research that may expand theory

and practice that in turn can help identify opportunities to support the agentic actions of those living with dementia, rather than inappropriately narrowing choice and opportunity for social connections.

We suggest that others living with potentially stigmatizing illness such as mental illness and those living with physically stigmatizing conditions, may undertake similar work to maintain an 'acceptable self' in social interactions. Understanding the nature of such work may enable health and social care practitioners to develop ways to recognize and support such work that might amplify opportunities for social inclusion.

Conclusion

Establishing and managing social connections is complex and dynamic; often the person with dementia requires support from family or friends to access social opportunities and to manage their presentation of self. This review of 13 studies reporting qualitative aspects of living with dementia in the community indicates that many people with dementia continue to have significant self-awareness and agency and so can undertake performances that enable them to position themselves as competent actors on the social scene. However, this work can come with costs to them of fatigue and social burden (Bartlett, 2014; MacRae, 2010). Understanding this can help health practitioners and researchers to be alert to, and appropriately support, the agentic individual living with dementia, so as to challenge and not reproduce stigmatizing stereotypes of dementia as leading to a deficit in the social interactions of those who live with this condition.

References

- Alzheimer's Society. (2013). *The hidden voice of loneliness*. Retrieved from https://www.alzheimers.org.uk/download/downloads/id/1677/dementia_2013_the_hidden_voice_of_loneliness.pdf. (accessed 04.01.2018).
- Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist*, 44, 1175-1184. doi: 0003-066X/89/\$00.75
- Bartlett, R., & O'Conner, D. (2010). *Broadening the dementia debate: towards social citizenship*. Bristol: Policy Press.
- Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability and Society*, 29(8), 1291-1304. doi: 10.1080/09687599.2014.924905
- Bartlett, R. (2016). Scanning the conceptual horizon of citizenship. *Dementia*, 15(3), 453-461. doi: 10.1177/1471301216644114
- Bartlett, R., Gjernes, T., Lotherington, A., & Obstfelder, A. (2018). Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research. *Health and Social Care in the Community*, 26(1), 14-26. doi: 10.1111/hsc.12340
- Batsch, N.L., & Mittelman, M.S. (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia*. London: Alzheimer's Disease International.
- Beard, R.L. (2004). In their voices: identity preservation and the experiences of Alzheimer's disease. *Journal of Ageing Studies*, 18(4), 415-428. doi: 10.1016/j.jaging.2004.06.005
- Beard, R.L., & Fox, P.J. (2008). Resisting social disenfranchisement: negotiating collective identities and everyday life with memory loss. *Social Science and Medicine*, 66(7), 1509-1520. doi: 10.1016/j.socscimed.2007.12.024
- Beard, R.L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: how we reframe dementia through personal narratives. *Journal of Aging Studies*, 23(4), 227-235. doi: 10.1016/j.jaging.2008.01.002
- Bennett, D.A., Schneider, J.A., Arnold, S.E., & Wilson, R.S. (2006). The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: a longitudinal cohort study. *Lancet Neurology*, 5(5), 406-412. doi: [https://doi.org/10.1016/S1474-4422\(06\)70417-3](https://doi.org/10.1016/S1474-4422(06)70417-3)

- Birt L., Poland, F., Csipke, E., & Charlesworth, G. (2017) Shifting dementia discourses from deficit to active citizenship. *Sociology Health and Illness*, 39(2), 199-211. doi: 0.1111/1467-9566.12530
- Boyle, G. (2014). Recognising the agency of people with dementia. *Disability and Society*, 29, 1130-1144. doi: 10.1080/09687599.2014.910108
- Brannelly, T. (2011). Sustaining citizenship people with dementia and the phenomenon of social death. *Nursing Ethics*, 18(5), 662-71. doi: 10.1177/0969733011408049
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesis qualitative research: a worked example. *Journal of Health Services Research & Policy*, 7(4): 209-215. doi: 0.1258/135581902320432732
- Caddell, L.S., & Clare, L. (2010). The impact of dementia on self and identity: a systematic review. *Clinical Psychology Review*, 30(1), 113-126. doi: 10.1016/j.cpr.2009.10.003
- Caddell, L.S., & Clare, L. (2011). I'm still the same person: the impact of early-stage dementia on identity. *Dementia*, 10(3), 379-398. doi: 10.1177/1471301211408255
- Chaudoir, S.R., Earnshaw, V.A. & Andel, S. (2013). "Discredited" versus "discreditable": Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic Applied Social Psychology*, 35(1), 75-87. doi: 10.1080/01973533.2012.746612
- Cipriani, G., & Borin, G. (2015). Understanding dementia in the sociocultural context: A review. *International Journal of Social Psychiatry*, 61(2), 198-204. doi:10.1177/0020764014560357
- Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57(6), 1017-1029. doi: 10.1016/s0277-9536(02)00476-8
- Clare, L., Markova, I., Verhey, F., & Kenny, G. (2005). Awareness in dementia: a review of assessment methods and measures. *Aging and Mental Health*, 9(5), 394-413. doi: 10.1080/13607860500142903
- Clare, L., Rowlands, J.M., & Quin, R. (2008). Collective strength: the impact of developing a shared social identity in early-stage dementia. *Dementia*, 7(1), 9-30. doi: 10.1177/1471301207085365
- Clare, L., Whitaker, C.J., Nelis, S.M., Martyr, A., Markova, I.S., Roth, I., Woods, R.T., & Morris, R.G. (2013). Self-concept in early stage dementia: profile, course, correlates, predictors and implications for quality of life. *International Journal of Geriatric Psychiatry*, 28(5), 494-503. doi: 10.1002/gps.3852.

Clarke, C.L., Keady, J., Wilkinson, H., Gibb, C.E., Luce, A., Cook, A., & Williams, L. (2010). Dementia risk: contested territories of everyday life. *Journal of Nursing and Healthcare of Chronic Illness*, 2, 102-112. doi: 10.1111/j.1752-9824.2010.01040.x

Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: an exploration of coping from the perspective of those diagnosed. *Dementia*, 13(4), 451-66. doi: 10.1177/1471301212474149

Cooley, C.H. (1902). *Human nature and the social order*. New York: Charles Scribner and son. Retrieved from <https://ia802707.us.archive.org/35/items/humannaturesocia00cooluoft/humannaturesocia00cooluoft.pdf>

Critical Appraisal Skills Programme. (2017). CASP. *Qualitative Research Checklist*. retrieved from http://docs.wixstatic.com/ugd/dded87_25658615020e427da194a325e7773d42.pdf.

Cromwell, S.L., & Phillips, I.R. (1995). Forgetfulness in elders: strategies for protective caregiving. *Geriatric Nursing*, 16, 55-59.

Ericsson, I., Hellström, I., & Kjellström, E. (2011). Sliding interactions: an ethnography about how dementia interacts in housing with care for the elderly. *Dementia*, 10, 523-538. doi: 10.1177/1471301211409376

Fratiglioni, L., Paillard-Borg, S., & Winblad, B. (2004). An active and socially integrated lifestyle in late life might protect against dementia. *Lancet Neurology*, 3(6), 345-353. doi: 10.1016/S1474-4422(04)00767-7

Gergen, K.J. (1971). *The concept of self*. New York: Holt, Rinehart and Winston Inc.

Goffman, E. (1959). *The presentation of self in everyday life*. London: The Penguin Press.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.

Goffman, E. (1971) *Relations in public: microstudies of public order*. New York: Basic Books.

GÓrska, S., Forsyth, K., & Maciver, D. (2018). Living with dementia: a meta-synthesis of qualitative research on the lived experience. *The Gerontologist*, May 8;58(3):e180-e196. doi: 10.1093/geront/gnw195

Gough, D. (2007). Weight of Evidence: a framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, 22, 213-228. doi: 10.1080/02671520701296189

- Harman, G., & Clare, L. (2006). Illness representation and lived experience in early-stage dementia. *Qualitative Health Research*, 16(4), 484-502. doi: 10.1177/1049732306286851
- Hedman, R., Hansebo, G., Ternstedt, B., Hellstrom, I., & Norberg, A. (2012). How people with dementia express their sense of self: analysis using Ron Harré's theory of selfhood. *Dementia*, 12(6), 713-733. doi: 10.1177/1471301212444053
- Herrmann, L.K., Welter, E., Leverenz, J., Lerner, A.J., Udelson, N., Kaneetsky, C., & Sajatovic, M. (2017). A systematic review of dementia-related stigma research: can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, 26(3), 316-331. doi: 10.1016/j.jagp.2017.09.006
- Higgs, P., & Gilleard, C. (2016). *Personhood, identity and care in advanced old age*. Bristol: Policy Press.
- Kane, M. & Cook, L. (2013). *Dementia 2013: The hidden voice of loneliness*. London: Alzheimer's Society.
- Khondoker, M., Rafnsson, S.B., Morris, S., & Orrell, M. (2017). Positive and negative experiences of social support and risk of dementia in later life: an investigation using English Longitudinal Study of Ageing. *Journal of Alzheimer's Disease*, 58(1), 99-108. doi: 10.3233/JAD-16116
- Kitwood, T. (1997). *Dementia reconsidered: the person comes first*. Buckingham: Open University Press.
- Kuiper, J.S., Zuidersma, M., Oude Voshaar, R.C., Zuidema, S.U., van den Heuvel, E.R., Stolk, R.P., & Smidt, N. (2015). Social relationships and the risk of dementia: a systematic review and meta-analysis of longitudinal cohort studies. *Ageing Research Reviews*, 22, 39-57. doi: 10.1016/j.arr.2015.04.006
- Langdon, S.A., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world, a qualitative study. *Social Science and Medicine*, 64(4), 989-1000. doi: 10.1016/j.socscimed.2006.10.029
- MacQuarrie, C.R. (2005). Experiences in early stage Alzheimer's disease: understanding the paradox of acceptance and denial. *Aging and Mental Health*, 9(5), 430-41. doi: 10.1080/13607860500142853
- MacRae, H. (2010). Managing identity while living with Alzheimer's disease, *Qualitative Health Research*, 20(3), 293-305. doi: 10.1177/1049732309354280
- MacRae, H. (2011). Self and other: the importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies*, 25(4), 445-456. doi: 10.1016/j.jaging.2011.06.001

- Mead, G. H. (1934). *Mind, Self, and Society*. Chicago: University of Chicago Press.
- Misztal, B.A. (2001). Normality and trust in Goffman's Theory of Interaction Order. *Sociological Theory*, 19(3), 312-324. doi: 10.1111/0735-2751.00143
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G., The PRISMA Group. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med*, 6,(7) e1000097. doi: 10.1371/journal.pmed.1000097
- Mountain, G., & Craig, C.L. (2012). What should be in a self-management programme for people with early dementia? *Ageing and Mental Health*, 16(5), 576-583. doi:10.1080/13607863.2011.651430.
- Naess, A., Fjaer E.G., & VabØ, M. (2016). The assisted presentations of self in nursing home life. *Social Science and Medicine*, 150, 153-159. doi: 10.1016/j.socscimed.2015.12.027
- Noyes J & Lewin S. (2011). Chapter 5: Extracting qualitative evidence. In: Noyes J, Booth A, Hannes K, Harden A, Harris J, Lewin S, Lockwood C (editors), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Version 1 (updated August 2011). Cochrane Collaboration Qualitative Methods Group. Available from <http://cqrng.cochrane.org/supplemental-handbook-guidance>
- O'Connell, N.P. (2016). "Passing as normal": living and coping with the stigma of deafness. *Qualitative Inquiry*, 22, 651-661. doi:10.1177/1077800416634729
- Pillai, J.A., & Verghese, J. (2009). Social networks and their role in preventing dementia. *Indian Journal of Psychiatry*, 51(supp11), S22-S28.
- Preston, I., Marshall, A., & Bucks, R.S. (2007). Investigating the ways older people cope with dementia: a qualitative study. *Ageing and Mental Health*, 11, 131-143. doi:10.1080/13607860600844572
- Rahman, S. (2015). *Living better with dementia: good practice and innovation for the future*. London: Jessica Kingsley Publishers.
- Rodriquez, J. (2013). Narrating dementia: self and community in an online forum. *Qualitative Health Research*, 23(9), 1215-1227. doi:10.1177/1049732313501725
- Roland, K.P., & Chappell, N.L. (2015). Meaningful activity for persons with dementia: family caregiver perspectives. *American Journal of Alzheimer's Disease and Other Dementias*, 30(6), 559-568. doi: 10.1177/1533317515576389

Sabat, S.R. (2002). Surviving manifestations of selfhood in Alzheimer's disease: a case study. *Dementia*, 14, 11-19. doi: 10.1177/147130120200100101

Sabat, S.R. (2008). A bio-psycho-social approach to dementia. In M Downes & B Bowers (Eds.) *Excellence in dementia care: research into practice* (pp.70-84). Open University Press, Maidenhead.

Scheff, T.J. (2005). Looking-Glass Self: Goffman as Symbolic Interactionist. *Symbolic Interaction*, 28, 147-166. doi:10.1525/si.2005.28.2.147

Simm, L.A., Jamieson, R.D. Ong, B., Garner M.W.J., & Kinsella, G.J. (2017). Making sense of self in Alzheimer's disease: reflective function and memory. *Aging and Mental Health*, 21(5), 501-508. doi:10.1080/13607863.2015.1120706

Steeman, E., de Casterle, B.D., Godderis, J., & Grypdonck, M. (2007). Living with early stage dementia: a review of qualitative studies. *Journal of Advanced Nursing*, 54(6), 722-738. doi:10.1111/j.1365-2648.2006.03874.x

Steeman, E., Tournoy, J., Godderis, J., Grypdonck, M., Godderis, J., & Dierckx de Casterle, B. (2013). Managing identity in early-stage dementia: maintaining a sense of being valued, *Aging and Society*, 33(2) 216-242. doi:017/S0144686X11001115

Stets, J. A., & Burke, P.J. (2003). A sociological approach to self and identity. In Mark R. Leary & June Price Tangney (eds.), *Handbook of Self and Identity*. New York: Guildford Press. (pp. 128—152).

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 42. doi:10.1186/1471-2288/8/45.

Vikstrom, S., Josephsson, S., Stigsdotter-Neely, A., & Nygard, L. (2008). Engagement in activities: experiences of persons with dementia and their caregiving spouses. *Dementia*, 7, 251-270. doi.org/10.1177/1471301208091164

Whitley, R., & Campbell, R.D. (2014). Stigma, agency and recovery amongst people with severe mental illness. *Social Science and Medicine*, 107, 1-8. doi: 10.1016/j.socscimed.2014.02.010

Wolverson, E.L., Clarke, C., & Moniz-Cook, E.D. (2016). Living positively with dementia: a systematic review and synthesis of the qualitative literature, *Aging and Mental Health*, 20(7):676-99. doi: 10.1080/13607863.2015.1052777.

Zeilig, H. (2014). Dementia as a cultural metaphor. *Gerontologist*, 54, 258-67 doi:10.1093/geront/gns203

Zimmer, I. (2006). Qualitative meta-synthesis: a question of dialoguing with texts. *Journal of Advanced Nursing*, 53(3): 311-318.

Figure 1 PRISMA Chart (Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. From Moher, et al., 2009).

Table 1 Summary of retrieved articles

Table 2 Experiencing and constructing social connections when living with dementia.

Data sharing is not applicable to this article as no new data were created in this study

Maintaining social connections in dementia: a qualitative synthesis – supplementary file

Table 2 Experiencing and constructing social connections when living with dementia.

Author and date	First order constructs (participant quotes)	Second order constructs (author interpretations)	Third order constructs (Interpretation of first and second constructs)
Bartlett (2014)	<p><i>‘We look okay, but nobody sees beyond what it takes to get up in the morning, what effort it takes’ (1287)</i></p> <p><i>‘I am performing in whatever way I need to perform and I come back on the train and I am exhausted for the next couple of days’ (1298)</i></p> <p><i>‘My biggest challenge really is keeping effective without total exhaustion’ (1298)</i></p>	<p>‘Taking action was conceptualized by most participants as work’ (1296)</p> <p>‘Challenges in being an effective citizen’ (1296)</p> <p>‘The effort required to be effective citizen often goes unseen by professionals’ (1297)</p> <p>‘Having to campaign with dementia fatigue was mentioned by several participants’ (1298)</p>	Impression management
	<p><i>‘It’s a sense of self-satisfaction...it’s nice to be able to do things and people say to you, “you’ve done well”’. (1296)</i></p>	<p>‘Participants were influenced by a duty-bound notion of citizenship’ (1299)</p>	Performing recognized roles in social connections

	<i>'I feel that like others that we are 'wheeled out' when needed' (1300)</i>	'Campaigning can create a sense of loss of one's former self' (1300) '	Recognizing spoiled identity
Beard and Fox (2008)	<i>'I won't always remember and you will have to tell me again. I find being direct is usually the best way to handle things like that' (1513)</i>	'Respondents subsequently employed various methods of management, or ways of adjusting to changes, to minimize the rupture of their existing identities' (1512)	Impression management
	-	'Participation in support groups and research studies is arguably an attempt to maintain self-hood through the development of new social roles' (1515)	Performing recognized roles in social connections
	<i>'I still have the intelligence to be treated as a person, not just someone you pat on the head as you go by...It's devastating and it takes away your sense of self' (1516)</i> <i>'My family members' relationships [with me] changed as soon as they found out I was 'no longer competent' (1516)</i>	-	Recognizing spoiled identity

	<i>'You have to adjust your schedule to someone else's. I guess the best word for it is that it is somewhat humiliating to be in that position' (1513)</i>		
Beard et al. (2009)	<i>'I ask people not to expect me to remember things' (231)</i> <i>'I ask for help I ask people to go slower' (231)</i>	<p>‘...efforts to make life with memory loss more manageable. They allowed individuals to maintain active involvement and focus on what they could do rather than their losses’ (231)</p> <p>‘Respondents attempted to manage their circumstances through concrete cognitive aids as well as conscious decisions to modify their activities, request assistance from others, and accept changes as they arose ‘ (232)</p>	Impression management
	<i>'I also do volunteer work for our local Alzheimer's Association' (233)</i> <i>'I love coaching, it is my passion and I am not going to give up my dream' (233)</i> <i>'Our choir sings at nursing homes and does shows at our club house' (2009: 233)</i>	‘Maintaining a sense of continuity to past interests, social roles and relationships enriched their lives’ (233)	Performing recognized roles in social connections

	-	‘Condescension and paternalism based on stereotypes and assumptions about “life with dementia” hampered their efforts’ (232)	Recognizing spoiled identity
Caddell & Clare (2011)	<i>‘I converse with all of them and they converse with me and I don’t feel I am being treated differently because I have got a memory problem’ (391)</i>	‘Participants were able to identify numerous aspects of themselves that had remained constant over a long period of time’ (385)	Maintaining an acceptable presentation of self
Clare et al. (2008)	<i>‘DASNI gives me entrée in a variety of places I want to participate’ (19)</i>	‘They had a sense of owning the challenge of addressing the stigma attached to the dementia label’ (19)	Impression management
	<i>‘The internet group can provide a feeling of belonging to a very large network of people with dementia and that can help further to reduce the fear and isolation’ (18)</i> <i>‘I have always been a person who has wanted to make a difference in the world’ (20)</i> <i>‘I had to give up my job it was a devastating loss. It was essentially how I defined myself’ (17)</i>	‘There was a sense that part of the self had been lost, especially as a result of having to give up work’ (17) ‘they described feeling <i>valued and appreciated for the things (they) still have to offer</i> ’ (20) [italics author’s own]	Performing recognized roles in social connections

	<p><i>'It was clear to me my dementia negated the things I said' (17)</i></p> <p><i>'No one really understands how hard it is to live life like this, so people tend to trivialize how you feel, patronise you' (17)</i></p>	'Participants' experiences of isolation and loneliness emerged' (17)	Recognizing spoiled identity
Clarke et al. (2010)	<p><i>'I still see my friends and I enjoy going out with them , I feel human after that' (105)</i></p> <p><i>'Sometimes I make them laugh. I come out with some daft things' (106)</i></p>	-	Maintaining an acceptable presentation of self
Clemerson et al. (2013)	<i>'I think people might not want to talk to me because they might think I am thick but I am not' (458)</i>	<p>'A reduced sense of self-worth also contributed to the threat to self' (458)</p> <p>'redefining self...to move towards identifying with their diagnosis and achieving a potentially more robust sense of self (459)</p>	Maintaining an acceptable presentation of self
	<i>'There's a couple, a couple of doors away who seem to treat me, I don't know, maybe a little bit childlike perhaps' (457)</i>	'Loss of adult competency. This emerged through people's experience of either feeling more 'childlike' due to loss of skill or being treated this way by others' (457)	Recognizing spoiled identity

	<i>'I'm trying to get my coat on and then my wife is trying to get it on for me and I feel like a baby'</i> (457)	'The struggle to define their identity was strongly linked to responses of others and the way in which they believed others viewed them' (458)	
Langdon et al (2007)	<i>'I'd rather they just talked to me as though I was normal and just picked me up when I'm wrong if you like to put it that way without being unkind about it...I might feel a bit silly but no more than that...it would be better to be told'</i> (993)	'Participants were concerned about how others people perceived dementia and were acutely sensitive to how people reacted to them' (993) 'There seemed to be a general desire for others to respond authentically and honestly about memory difficulties' (993)	Impression management
	<i>'...but I take a back seat now'</i> (996)	'Many participants were aware of their changing social status in the world and their increased difficulty carrying out roles that had previously given them a sense of self-worth and self-standing' (996) 'A number of participants expressed enthusiasm about helping those who were researching dementia in order to help others affected by the condition' (996)	Performing recognized roles in social connections

	<p><i>'You are someone, and to me, he's obviously given me that impression, and that's why I like him' (994)</i></p> <p><i>'I've got into the habit of making a joke of it, ...otherwise it will take over your life' (995)</i></p>	<p>'Outside this familiar inner circle there appeared to be some caution with who it was helpful to share their diagnosis with' (994)</p> <p>'Sometimes, even in social situations when the memory problem became apparent to others, participants chose not to reveal their diagnosis and used other strategies to cope instead.' (995)</p>	Maintaining an acceptable presentation of self
	<p><i>'Everybody puts me down...I wish to discuss something...they will turn around and say "oh well, it's no good discussing it with him because he wouldn't know the first thing about it"' (995)</i></p>	<p>'Participants were sensitive to possible concealment by others of their true thoughts' (994)</p>	Recognizing spoiled identity
MacQuarrie (2005)	<p><i>'I have to have somebody ask me questions, cause then it's easier for me to say' (432)</i></p> <p><i>'Eventually you just have to tell your friends, "sorry I've been having some memory problems lately"' (432)</i></p> <p><i>'This is a false face. A lot of it is false. Here this laughing or anything like that a lot of it is false.'</i> (434)</p>	<p>'Participants spoke about their facades when dealing with others' (433)</p> <p>'Encouraging others to give them a structure was a strategy used by participants to keep their interactions going' (434)</p> <p>'Openness may have been a way to continue enjoyment of interactions with friends' (435)</p>	Impression management

		‘Resistance pushed against an undermining of their agency in a disease process’ (436)	
	<i>‘I have volunteered myself to these particular things (drug and research trials) that may run out on me but it may help somebody else someday’ (435)</i>	‘...thinking about leaving a legacy’ (435)	Performing recognized roles in social connections
	<i>‘I stand up for myself more’ (433).</i>	-	Maintaining an acceptable presentation of self
	<i>‘A tough thing to live with is the overly protective’ (432)</i> <i>‘This is the worst part is when I lose my chain train of thoughts and you stand there like an idiot’ (434)</i>	‘Participants were aware of the disjuncture between theirs and other’s perceptions (432) ‘...feelings of humiliation in front of others’ (434)	Recognizing spoiled identity
MacRae (2010)	<i>‘I keep this (diary and appointment book) so that I can trying to take charge of my own life’ (452)</i>	‘They had told me a great deal about who they were, not always in response to questions about identity...but more often in a personal story they had chosen to tell’ (296)	Impression management
	<i>‘Interested in doing things for other people’ (296)</i>	‘... involved in numerous volunteer activities, maintaining what has been a lifelong commitment’ (296)	Performing recognized roles in social connections

	<i>'I like to help people if I can, I've been doing it all my life' (301)</i>		
	<i>'Got to appreciate you've got some assets it's not all negative' (229)</i>	<p>'Showing resilience and resourcefulness, participants used various means to negotiate identity' (298)</p> <p>'Constructing new dimensions of self' (298)</p> <p>'Focusing on intact abilities was another means of managing to normalize and preserve a positive sense of self' (299)</p>	Maintaining an acceptable presentation of self
MacRae (2011)	<i>'Don't even notice that there is anything wrong with me' (451)</i>	'Can chose as a point of reference others whose reactions are positive and self-affirming' (450)	Maintaining an acceptable presentation of self
	<i>'If I say I've got Alzheimer's, some people will sort of step back but that's very few, you know and, nobody I really care about' (450)</i>	-	Recognizing spoiled identity
Preston et al. (2007)	<i>'So I had to bluff a lot' (136)</i>	'Avoidance and covering up' (136)	Impression management

	-	‘Self as able/valued...they asserted identities as “helpers” and were eager to aid others by taking part in research’ (133)	Performing recognized roles in social connections
	<i>‘She treated me like I was a little girl’ (134)</i>	<p>‘Their abilities were masked by dementia and wanted to argue against being negatively positioned by those around them’ (133)</p> <p>‘Some spoke of the negative identities ascribed to them as a result of dementia, such as being disabled, a child, stupid or frightening’ (134)</p>	Recognizing spoiled identity
Vikstrom et al. (2008)	<i>‘Since I am the way I am it is too tough to meet people, it is difficult; (257) ‘Who shall I call, what say I say and who will answer. Actually I don’t have that many acquaintances any more’ (258)</i>	‘Occasionally the persons with dementia also told of negative social consequencesthey themselves started to question if they were interesting enough as friends’ (258)	Recognizing spoiled identity