The involvement of people with dementia in advocacy: a systematic narrative review.

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The involvement of people with dementia in advocacy: a systematic narrative review

Objectives: This Prospero-registered review sought to answer three questions concerning people with dementia involved in speaking out on behalf of themselves and others as dementia advocates. First, what are the views and motivations of the people involved? Second, what impact does this have upon them and others? Third, what are the future policy and research implications?

Methods: A systematic search and narrative synthesis of original research was conducted. Searches in Pubmed, Web of Science, PsychINFO and CINAHL followed PRISMA Guidelines. The review focused on people with dementia involved in advocacy. There were no restrictions based on study design or date. Language was limited to English.

Results: Seven papers were identified, with predominantly qualitative methodologies. Four overarching themes were identified: threats, fighting back, evolving identities and making a difference. Threats ranged from those arising from dementia as an illness, to exposure to stigma. Fighting back represented advocates’ response to these threats, often described using martial metaphors. Evolving identities captured advocates’ journeys through diagnosis to involvement in advocacy and subsequent impact upon identity. Making a difference represented the impact of dementia advocacy at an individual, community and societal level.

Conclusions: This review confirms that the threats associated with dementia extend beyond the symptoms of illness. Dementia advocacy offers potential improvements in well-being for those involved, through the activity itself and via extended social networks. There is little research on broader aspects of advocates’ identity, including ethnicity, gender, and age. There has been little attempt to quantify the impact of dementia advocacy.
Introduction

Globally, around fifty million people live with dementia, with ten million new cases annually (World Health Organisation, 2019). A consensus has emerged around the benefits of early diagnosis, including timely advice on treatment and support (Alzheimer's Society, 2020), and an increased potential for self-advocacy (Bartlett, 2014). Despite these advantages, the threat to identity remains (Caddell & Clare, 2011). Diagnosis may lead to fear, frustration and uncertainty (Bunn et al., 2012), and changes in how a person is treated by others (MacRae, 2011).

One such change is through exposure to stigma, fuelled partially by media portrayals of dementia (Thomas & Milligan, 2017). People with dementia have been stereotyped as a drain on resources (Beard, 2017) and public understanding often draws upon worst-case scenarios (Herrmann et al., 2018), with people with advanced dementia seen to represent all (Gove, Downs, Vernooij-Dassen, & Small, 2016). People with dementia are aware of this stigma, which may amplify distress (Milne, 2010) and increase social isolation (Scholl & Sabat, 2008). Stigma constitutes a barrier to seeking support (Piver et al., 2013), leading to delays in seeking help (Phillipson, Magee, Jones, Reis, & Skladzien, 2015) which impacts upon quality of life (Alzheimer's Society, 2010).

This review focuses on cause advocacy by people with dementia. This may be defined as “the process by which one or a number of people seek justice or social change in relation to a specific issue” (Dixon, Laing, & Valentine, 2018). This differs from case advocacy, where a third party, often professional or family, supports a person with dementia, to ensure their rights are maintained (Dixon et al., 2018).

Advocacy may be either “for” or “of” people with dementia (Schicktanz, Rimon-Zarfaty, Raz, & Jongsma, 2018) and self-advocacy by people with dementia is a relatively recent phenomenon (Bartlett, 2012). Historically, dementia advocacy has been carer-led.
(Schicktanz et al., 2018) and reliant on proxy views, partly due to perceived incompetence in people with dementia (Beard, 2004). UK advocacy organisation, Alzheimer’s Society, was initially carer-led, innovatively involving people with dementia in governance from the early 2000s (Moreira, 2015). A recent study of Israeli and German patient organisations (POs), described mixed views on advocacy by people with dementia, with a reluctance in some organisations to embrace self-advocacy (Schicktanz et al., 2018).

People with dementia have become involved in diverse advocacy, including fundraising, campaigning (Bartlett, 2014; McConnell et al., 2018), consultation (McConnell et al., 2018), awareness-raising (Schicktanz et al., 2018), lobbying (Bartlett, 2012), public-speaking (Bartlett, 2014), and supporting learning (Russell, 2016). Advocates also communicate online, through blogs (Kannaley, Mehta, Yelton, & Friedman, 2018), Twitter (Talbot, O'Dwyer, Clare, Heaton, & Anderson, 2018) and Facebook (Craig & Strivens, 2016).

Telling one’s story can connect a person’s past and present identities (Hillman, Jones, Quinn, Nelis, & Clare, 2018) and advocacy helps people maintain a sense of self (Bartlett, 2012; Clare, Rowlands, & Quin, 2008), offers meaning (Knauss & Moyer, 2006) and holds the prospect of societal change (Clare et al., 2008). It has been described as life affirming (Bartlett, 2014) work that improves self-respect (Bartlett, 2012) and reinforce citizen rights (Brown, Standen, & Khilji, 2013).

Despite a growing body of research documenting dementia advocacy, to date there has been no synthesis. In order to examine similarities and differences in study findings, explore the gaps, and identify directions for future research, practice, and policy, a systematic narrative review was indicated.

The aim was to answer three questions:

What are the views/motivations of people with dementia involved in advocacy?
What impact does their involvement have upon them as individuals, their wider community and society?

What are the policy and future research implications?

Methods

This systematic narrative review consisted of a systematic search, and a narrative synthesis of results based upon thematic analysis. This approach has more rigor than a narrative review, as studies were identified in a systematic manner (Hagan, Manktelow, Taylor, & Mallett, 2014). Studies were evaluated using Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007).

Inclusion Criteria

This Prospero-registered review focused upon people with dementia involved in advocacy. Studies of case advocacy, where a third party worked to ensure that a person with dementia’s voice was heard, were excluded, as were studies of large advocacy organisations representing people with dementia, unless the involvement of people with dementia was researched as part of a wider study and reported separately. Where this arose, results included only those elements specifically focused upon people with dementia. The review covered original research appearing in peer reviewed publications. Grey literature was excluded as not meeting the standard of peer review (Pappas & Williams, 2011). There were no restrictions based upon study design or date. Language was limited to English for practical reasons.
**Search Strategy**

The search strategy was implemented on 12/04/19 in accordance with PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & Group, 2009), with the following searches conducted in Pubmed, Web of Science, PsychINFO, and CINAHL.

(1) **Dement* OR Alzheimer* OR Lewy OR Fronto**

    AND

(2) **2 advocac* OR activis* OR citizenship OR campaign* OR ‘social movement’ OR ‘peer support group*’ OR ‘self-help group**

The searches identified 938 papers, reduced to 375 by removing duplicates. Two researchers, including the first author, independently screened titles/abstracts extracted against the predefined inclusion criteria. Papers not meeting these criteria were excluded. Full text of remaining articles was screened against the criteria by both researchers and differences were resolved through discussion. The second author was involved where a difference of opinion remained over one paper, which was subsequently included. The relatively high number of exclusions partially reflects the wide and varied use of the term “advocacy”. The number of papers screened, included, and excluded may be found in Figure 1.

**Data extraction and synthesis**

Seven studies met the inclusion criteria. Six were exclusively qualitative and presented results in a narrative form, usually as themes. One realist evaluation incorporated quantitative elements, reporting data under the headings of Dementia Northern Ireland’s intervention strategies (McConnell et al., 2018).

Although there is little consensus on the evaluation of qualitative studies (Centre for Reviews and Dissemination, 2009), the 32 item COREQ (Tong et al., 2007) has been widely employed in systematic reviews of qualitative studies, addressing issues from attitudes to
transplantation (Walker et al., 2019) to advance care-planning (Sellars et al., 2019). COREQ was employed in this review, reported under the three domains of research team and reflexivity, study design, and analysis and finding (Tong et al., 2007).

Thematic analysis was used to analyse the results, being considered an appropriate tool for analysis of themes across studies (Centre for Reviews and Dissemination, 2009). Line-by-line open-coding was completed by the first two authors, coding only researchers’ words, rather than quotes from advocates. This was followed by in-depth analysis of open-codes, which were interpreted as four themes. Reflexivity was at the heart of the process and interpretations were discussed by the first two authors. It is acknowledged that the first author’s experience of working in Older Persons’ Mental Health Teams will have influenced the interpretations. As the third author of the current review was co-author of two included studies (Clare et al., 2008; Hillman et al., 2018), she did not contribute to coding/theme development.

Results

The earliest paper was an exploratory study of the experiences of members of Dementia Advocacy and Support Network International (DASNI) (Clare et al., 2008). This was followed by two studies from the same two-year project investigating the experiences of people with dementia campaigning for change (Bartlett, 2012, 2014) and one of advocates supporting higher education (Russell, 2016). A realist evaluation of an empowerment service (McConnell et al., 2018) and a series of interviews with individuals “speaking as and for” people with dementia (Hillman et al., 2018) followed. The final paper analysed the aims/purposes of POs representing people with dementia (Schicktanz et al., 2018) and for the purpose of this review should be treated with caution as only three people with dementia were included as part of a much larger sample.
Study Design

The methodological orientations and theoretical frameworks of the studies were diverse. A comparison is provided (Table 1), so the information is only summarised here. Both Bartlett studies used the diary/interview method, supplemented by participant observation (Bartlett, 2012, 2014). These studies drew upon social movement theory and Goffman’s (1963) dramaturgical ideas respectively, employing a combination of content and thematic analysis. Hillman et al (2018) adopted the theory of narrative economies in their study of people with dementia and caregivers, whilst Schicktanz et al (2018) presented a comparative analysis of Israeli and German dementia POs based upon grounded theory. Clare et al (2008) interviewed DASNI members via email, using interpretative phenomenological analysis (IPA). The McConnell et al (2018) study was theory driven and included elements of ethnographic observation. Russell’s (2016) brief study described a qualitative approach, incorporating thematic analysis.

Sampling was predominantly purposive, with some convenience samples and snowball techniques. Samples ranged from n=3 to n=16 people with dementia. Four studies (Bartlett, 2012, 2014; Clare et al., 2008; Russell, 2016) were of people with dementia exclusively, whilst the remainder included combinations of people with dementia, caregivers, and professionals. Limited demographic data were available, although most studies included younger advocates.

None of the researchers returned transcripts to participants, but McConnell et al. (2018) refined findings in feedback sessions and interpretations were agreed with participants in both Bartlett studies (Bartlett, 2012, 2014).

Research Team Reflexivity
None of the papers detailed who conducted interviews, although Bartlett (2012) identifies the field researcher. Clare et al (2008) contacted participants by email, whereas Schicktanz et al (2018) used more than one interviewer, reflecting their international scope. All studies outlined researchers’ affiliations, but three added credentials, occupation, experience and training (Clare et al., 2008; McConnell et al., 2018; Russell, 2016). In their reflexive IPA approach, Clare et al (2008) addressed their own pre-conceptions through discussion within the research team.

Only Schicktanz et al (2018) mention prior participant knowledge of researchers (two participants through professional workshops). Three studies involved repeated observations (Bartlett, 2012, 2014; McConnell et al., 2018), suggesting that participants may have come to know researchers.

**Analysis and Findings**

Most studies described their coding process and numbers of researchers involved. Russell (2016) was less specific, but noted that thematic analysis was employed. Schicktanz et al (2018) translated some transcripts. Two studies used analysis-software (McConnell et al., 2018; Schicktanz et al., 2018), whereas two were hand-coded (Bartlett, 2012, 2014).

Clare et al (2008) derived themes from participants’ own words where possible, whereas Bartlett (2012; 2014) viewed data through the prism of social movement theory and Goffman’s ideas respectively. The McConnell et al (2018) themes were theory driven, but used participants’ words, whereas Russell’s (2016) major themes were developed in advance. All study themes were consistent with and supported by quotations. For the purpose of this review, the Schicktanz et al. (2018) findings should be treated with caution as only two themes were supported by quotation from people with dementia.
Interpretations and Themes

Four main themes were identified in data. These were: threats, fighting back, evolving identities and making a difference. Threats ranged from those arising from dementia as an illness, to exposure to stigma. Fighting back represents advocates’ responses to these threats, often described using martial metaphors. Evolving identities traces advocates’ journeys from diagnosis to advocacy and how this led to changes in identity. Making a difference represents the impact of dementia advocacy at an individual, community and societal level. Inevitably, these themes overlap somewhat, being framed by broader cultural ideas about dementia.

Threats

The multiple threats posed by dementia were evident across studies. These ranged from the “disordering effects of illness” (Hillman et al., 2018) to the experience of inequities (Bartlett, 2012) and stigma (McConnell et al., 2018). Indeed, challenging stigma (Bartlett, 2012; McConnell et al., 2018; Schicktanz et al., 2018) and injustice (Bartlett, 2012) was often a significant motivation for advocacy.

Advocates recognised the difficulties associated with dementia as an illness. In receiving a diagnosis, people moved into unfamiliar territory, accompanied by loss of self-esteem, future plans, and voice (Clare et al., 2008), leading to disruption in the person’s life-story (Hillman et al., 2018). The often unseen impact of illness (Bartlett, 2014) affected people’s experience of advocacy and ranged from difficulties with administration processes (Bartlett, 2014) to the exhaustion evident in photo diaries (Bartlett, 2014), that sometimes interrupted campaigning (Bartlett, 2012).

The passage of time presented a threat that was often explicit, but sometimes implied. In general, advocates were aware that their cognitive abilities would diminish (Bartlett, 2012) and that this may affect their future ability to contribute (Russell, 2016). Bartlett (2012) goes furthest, suggesting that time overarches all aspects of dementia advocacy. The threat of time
was also implied by loss of future plans (Clare et al., 2008) and in advocates’ desire to see rapid change (Bartlett, 2012).

The threat from stigma recurred across studies and acts as a barrier to people joining empowerment (McConnell et al., 2018) or support groups (Schicktanz et al., 2018). Advocates are acutely aware of this stigma (Bartlett, 2012), and how it affects the value attributed to people with dementia (Hillman et al., 2018). Furthermore, fear can reduce the likelihood of others interacting with people with dementia (Hillman et al., 2018), perhaps accounting for advocates’ expressions of profound loneliness after diagnosis, when others could not understand their experiences (Clare et al., 2008). Hillman et al (2018) highlighted the threat posed by societal views of dementia, and advocates were motivated to challenge these ideas (Clare et al., 2008). Paradoxically, advocates felt uncomfortable when performing well, caught between their desire to be an effective citizen and societal conceptions of dementia (Bartlett, 2014).

**Fighting Back**

Most studies drew attention to the martial metaphors used by advocates. For instance, Clare et al (2008) noted how DASNI members “battle to compensate” the effects of illness, whereas Schicktanz et al (2018) talked of fighting, and McConnell et al (2018) battling stigma. Even where martial metaphors were not adopted, the language was adversarial; advocates “confront their dementia” (Clare et al., 2008) or adopt narratives as “forms of resistance” (Hillman et al., 2018).

Fighting stigma was a priority for all POs, including members with dementia (Schicktanz et al., 2018). Advocates had a sense of owning the challenge of addressing stigma (Clare et al., 2008), and fighting stigma was motivation for many (Bartlett, 2012; McConnell et al., 2018). Advocates were driven by a desire to challenge injustice, to achieve structural change (Bartlett, 2012), and to alter how people with dementia are viewed (Hillman...
et al., 2018). Advocates did not wish to be perceived as passive (McConnell et al., 2018), but to regain their sense of purpose through continued contribution to society (Clare et al., 2008). In this way, advocates sought to regain respect, both for themselves and others (Bartlett, 2012).

Advocates also ‘fought back’ against the effects of illness. The day-to-day experience of living with dementia was described as “an ongoing battle to compensate” (Clare et al., 2008) and Hillman et al (2018) documented one participant’s “battle plan” to hold back the symptoms of dementia. This battle plan extended beyond the medical to include enjoying art and music (Hillman et al., 2018). Likewise, advocacy was seen as beneficial in the protection of self, with many believing their involvement slowed their decline (Bartlett, 2012).

Advocates did not fight back alone, but drew inspiration, knowledge and strength from each other (Bartlett, 2012; Clare et al., 2008), sometimes described as ‘working off each other’ (Bartlett, 2012). Advocates also drew upon other sources, notably their families. For instance, one participant’s ‘battle plan’ was devised in conjunction with his wife (Hillman et al., 2018). Advocates can feel exploited by powerful organisations (Bartlett, 2014) and groups were often contacted by external organisations looking to improve their own services (McConnell et al., 2018). Here advocates involved another ally. Facilitators helped guard against tokenism, by supporting the group to ensure that action followed any consultation (McConnell et al., 2018).

Evolving Identities

Advocacy has the potential to alter a person’s identity, helping facilitate adjustment to diagnosis (Clare et al., 2008). Participation leads to contact with other advocates, shaping a wider collective identity (McConnell et al., 2018) with its attendant sense of collective strength (Clare et al., 2008; McConnell et al., 2018). This in turn helps influence wider
societal views of dementia, re-framing the story of deterioration to one of adaptation (Hillman et al., 2018).

A diagnosis of dementia is characterised by an initial sense of loss (Clare et al., 2008), but as this subsides there is a time when activism may develop (Bartlett, 2012). Advocacy constitutes a journey (Clare et al., 2008) with the potential to change the experience of illness (Bartlett, 2012), and by “anchoring” the advocate in the present helps them maintain a sense of well-being (Bartlett, 2012). When participants’ accounts moved from diagnosis to advocacy, they began to describe a potentially fulfilling life (Clare et al., 2008).

Advocates’ stories act as the glue to unite past and present identities, to make sense of their experiences and to convey a sense of biographical stability in spite of cognitive deterioration (Hillman et al., 2018). In outlining their circumstances, advocates demonstrated acceptance and adaptation (Clare et al., 2008), influencing wider discussion by reclaiming what it might mean to live well, with dementia reframed as manageable disability (Hillman et al., 2018). The status of citizen patient was used to facilitate change, with advocates embracing the category of dementia (Bartlett, 2012), reinforcing a sense of self and acceptance of self (Clare et al., 2008). Fundamentally, there is a status in being an advocate (Bartlett, 2012), a “pioneer” in a new endeavour (Clare et al., 2008), or citizen patient (Bartlett, 2012), who remains a valuable and contributing member of society (Clare et al., 2008).

Advocates described their solidarity and collective will (Hillman et al., 2018), best illustrated by the use of the terms ‘we and us’ rather than ‘I and me’ (Bartlett, 2012). Schicktanz et al (2018) suggested that the individual voice gives way to the collective, although paradoxically DASNI members talked of regaining their individual voice through their involvement in a large organisation (Clare et al., 2008). Most simply, advocates felt more powerful as a whole (Clare et al., 2008; McConnell et al., 2018).
Group membership can create a sense of belonging (McConnell et al., 2018), particularly as members understood each other’s experience (Clare et al., 2008). Bartlett (2012) found that advocates tended to know each other and meeting other advocates was valuable in itself (Bartlett, 2012), to the extent that they were considered as like family (Bartlett, 2012; Clare et al., 2008). The advocacy role enabled meeting with those in power, and whilst this afforded status and allowed people to seek rapid change (Bartlett, 2012), advocates sometimes gained an unwelcome celebrity (Bartlett, 2014), a regrettable loss of anonymity, as their personal and collective identities merged (Bartlett, 2014).

Making a Difference

The motivation for advocacy can relate to both protection of self and a desire for structural change (Bartlett, 2012). This theme examines the differences, both positive and negative, that advocacy makes in relation to the individual, their wider community and society.

McConnell et al (2018) argues that empowerment groups without consultation or awareness raising are just support groups, hence advocates sought to influence others, to make a valuable contribution (Clare et al., 2008; Russell, 2016) at a community and societal level (McConnell et al., 2018), regaining respect for themselves and others (Bartlett, 2012). Advocacy might range from encouraging healthy living (Hillman et al., 2018) to community awareness raising (McConnell et al., 2018), challenging decision makers (McConnell et al., 2018) and societal stigma (Clare et al., 2008). Through consultation work, empowerment group members were well placed to make a difference, with both policymakers and other organisations becoming more aware of the needs of people with dementia (McConnell et al., 2018).

Advocacy can also make a difference at an individual level. The role of activist holds status in social movement theory (Bartlett, 2012) and advocates understood their contribution as work, which has civic value (Bartlett, 2014). Advocates described the energising quality
of their work (Bartlett, 2012), which for some was part of a range of measures to “live well” and stave off the progression of dementia (Hillman et al., 2018). Others questioned the concept, saying that it should be acceptable not to live well (Hillman et al., 2018).

Although many advocates regard advocacy as work, some preferred not to be paid, citing the potential for harming their relationships with professionals (Bartlett, 2014). Others found the idea of working unpaid to be demeaning and damaging to their well-being (Bartlett, 2014). Regardless, the rewards of advocacy extend beyond monetary payment and the knowledge of having made a difference was important. (McConnell et al., 2018). Advocates supporting learning found this to be intrinsically rewarding (Russell, 2016), and sometimes advocacy was more rewarding than previous working roles (Bartlett, 2014). The awareness of having made a contribution improved advocates’ confidence (Russell, 2016) leading to pride, both in their own achievements, and in those of their organisation (Clare et al., 2008). This was particularly true for group members. Group membership led to an activist mentality, building advocates’ confidence to take part in media campaigns, which they could not have considered without peer-support (McConnell et al., 2018). Advocacy involvement brought some strains, with the effort involved in maintaining a social front going unseen, and being characterised by exhaustion (Bartlett, 2014), leaving some with dementia fatigue (Hillman et al., 2018). Advocates were also burdened by their perception of others’ expectations about how a person with dementia should behave (Bartlett, 2014), leaving some advocates feeling awkward when performing well (Bartlett, 2014).

Discussion

To our knowledge, this is the first systematic narrative review to synthesise the research documenting dementia advocacy. The review identified four themes: threats, fighting back, evolving identities, and making a difference. It highlights how the threats perceived by advocates extend beyond the symptoms of dementia. Advocates’ frequent use of martial
metaphors suggests the strength of feeling towards these threats and the need to overcome them. The struggle to fight back and make a difference leads to an evolution in the person’s identity as the status of advocate and member of a broader movement is incorporated into the person’s story. The stigma associated with dementia remains powerful and the concept permeates the themes in this review.

Biomedical explanations of illness are influential (Haslam, Jetten, Cruwys, Dingle, & Haslam, 2018) and this is true for dementia. However, it can be problematic if complexities are understood exclusively through this lens. For example, Schicktanz et al (2018) noted that POs sometimes attributed complex intra-family conflicts to poor insight in people with dementia. Kitwood (1997) provided an early warning of how narrow biomedical approaches could lead to a malignant social psychology, and this review highlights how the threats perceived by advocates extended beyond the symptoms of dementia. Consequently, advocates promote a wider view of dementia than some organisations that have traditionally represented people with dementia. Furthermore, first-hand stories carry an emotional resonance that increases their persuasive impact (Burchardt, 2016), highlighting the importance of involving people with dementia in policy and service development.

This review suggests that both diagnosis and participation in advocacy impact upon a person’s social network. This is important because a person’s sense of self may be linked to connectedness with a social network (Van Dijkhuizen, Clare, & Pearce, 2016). Furthermore, social withdrawal is a predictor of depression (Förster et al., 2018), which is under-recognised in dementia (Chang, Edwards, & Lach, 2011). Moreover, the impact of reduced networks extends beyond the psychological (Haslam et al., 2018) and “frequent social contact tends to be associated with greater longevity” (Shor & Roelfs, 2015).

Social identity theorists suggest that leaving a stigmatised group can help individuals maintain positive identities (Tajfel & Turner, 1979), but where there is no opportunity to do
so, the key to reducing stigma impact lies within the group itself, possibly by restoring a positive identity through campaigning (Haslam et al., 2018). The benefits of advocacy on wellbeing are demonstrated in studies of people with mental health difficulties (Eiroa-Orosa & Lomascolo, 2018) and HIV (Earnshaw, Rosenthal, & Lang, 2016). Likewise, this review suggests that advocacy facilitated positive collective identities, and a sense of collective strength, empowering advocates to counter negative views of dementia.

Alongside the development of collective identities, advocacy enabled participants to regain their own voices and redefine their personal identities. This is consistent with the notion that individuals define themselves in terms of groups they identify with (Tajfel & Turner, 1979), highlighting how individual identity consists of both personal and social aspects (Cruwys, Haslam, Dingle, Haslam, & Jetten, 2014). In this sense, the adoption of a collective identity involves redefinition rather than loss of personal identity (Haslam et al., 2018).

Despite the benefits of advocacy, this review suggests that participation is not a universally positive experience. This has been reported elsewhere, including people with HIV for whom advocacy involvement has been linked with higher rates of depression, despite extended social networks (Earnshaw et al., 2016). Consequently, it is important to take a nuanced approach to evaluating the impact of advocacy (Earnshaw et al., 2016). The implications for service development are also complex. Service providers may encourage involvement in advocacy in an effort to bolster positive identities, but not to the extent of imposing an unwanted identity (Haslam et al., 2018).

Stigma around dementia may be seen as part of a wider fear of mental illness (Devlin, MacAskill, & Stead, 2007) and historically people with mental illnesses have tried to hide their conditions (Wahl, 1999), echoing Goffman (1963) who suggested that revealing a discredited condition invites exposure to stigma. Two of the included studies highlight how
stigma acts as a barrier to people engaging in groups (McConnell et al., 2018; Schicktanz et al., 2018). This is problematic, as people are excluded from the personal benefits of membership and because these groups need sufficient numbers to operate. The threat of stigma might also deter people from seeking help (Phillipson et al., 2015) and here the unique perspectives of advocates may be of greatest value to policymakers, as the review demonstrates that advocates are well placed to advise on a variety of issues, including diagnosis and challenging stigma.

It has been suggested that many dementia advocates are unrepresentative, tending to be younger with atypical and perhaps insecure diagnoses (Howard, 2017). Consistent with this, of the four studies that commented on age, all included younger advocates, some in their late 40s or early 50s (Bartlett, 2012, 2014; Clare et al., 2008). Most studies provide limited information on diagnosis. Participants were generally recruited via existing groups and the focus was often upon individual experiences rather than group advocacy. Consequently, the findings may not generalise to all people with dementia.

The broader identities of advocates are likely to influence their engagement in and experience of advocacy. While most studies touched upon wider aspects of identity, such as gender, ethnicity and occupational background, these were not always explored in detail, and sexuality and religious identity were not addressed at all. This is an important gap, which Bartlett (2014) acknowledges. For instance, the impact of gender on the experience of dementia is little studied (Sandberg, 2018). People with dementia can be de-gendered (Barrett, Cramer, Lamberth, Latham, & Whyte, 2015) with an attendant risk to self (Sandberg, 2018). Furthermore, attitudes to age, gender and sexuality coalesce to marginalise lesbian and bisexual women with dementia in particular (Westwood, 2016).

Ethnicity can affect quality of life for people with dementia (Alzheimer's Society, 2010), not least because people from black and ethnic minority groups are more likely to
encounter barriers to service access (Advocacy Plus, 2010). The role of ethnicity in dementia advocacy remains to be explored. There may also be value in researching the experiences of older advocates, perhaps through cross-sectional surveys or maximum variation sampling for qualitative research. The studies in this review cast considerable light on advocates’ experiences, but further qualitative research and initial quantitative studies measuring the impact of advocacy would enrich our understanding.

This review suggests that the threats associated with dementia diagnosis extend beyond the symptoms of illness to include exposure to stigma and altered social networks. Advocates are motivated by both a desire to challenge perceived injustice and to make a continued contribution. Advocacy offers the potential for societal change and improvements in the well-being of those involved, both through the activity itself and via extended social networks. For this reason, dementia advocacy should be of interest to researchers, policymakers and health providers alike.
Table 1. Study Design.

Figure 1. Flowchart of Search Strategy.


Alzheimer's Society. (2010). My Name is not Dementia People with Dementia Discuss Quality of Life Indicators. Retrieved from London: http://www.cardi.ie/userfiles/My_name_is_not_dementia_report%5B1%5D.pdf


URL: http://mc.manuscriptcentral.com/camh


Table 1

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<tr>
<th>Theoretical Framework</th>
<th>Methodological orientation &amp; theory</th>
<th>Participant Selection</th>
<th>Sampling</th>
<th>Method of Approach</th>
<th>Sample Size</th>
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<td>Bartlett (2014)</td>
<td>Goffman’s ideas concerning impression management inform interpretations. Discussion linked to critical disability debates. 2 year qualitative study. Diary/interview method. Combines content &amp; thematic analysis.</td>
<td>Purposive- people with dementia identified as campaigning.</td>
<td>Unclear, how approached, although 4 came from the same campaign group.</td>
<td>16 people with dementia involved in campaigning</td>
<td>16 people with dementia involved in campaigning</td>
</tr>
<tr>
<td>Clare et al (2008)</td>
<td>Interpretative Phenomenological Analysis. Originally, a longitudinal Study conducted by email, but year 1 &amp; 2 data were analysed together. Design developed with Dementia Advocacy and Support Network International (DASNI) involvement.</td>
<td>Purposive-recruited “active DASNI members”</td>
<td>Advert on DASNI website.</td>
<td>7 members of DASNI.</td>
<td>7 members of DASNI.</td>
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<td>Hillman et al (2018)</td>
<td>Draws upon Burchardt’s Narrative Economies theory. 18 qualitative interviews. Part of the IDEAL cohort study.</td>
<td>Opportunistic sample of existing advocacy group.</td>
<td>Approached through the group-unclear how.</td>
<td>5 people with dementia &amp; 4 care partners.</td>
<td>5 people with dementia &amp; 4 care partners.</td>
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<tr>
<td>McConnell et al (2018)</td>
<td>Realist evaluation, with ethnographic observation. Qualitative &amp; quantitative methods including interviews &amp; documentary analysis. Data collection-theory driven, with generation, testing &amp; refining.</td>
<td>All current users of an empowerment group in Northern Ireland.</td>
<td>All contacted via email.</td>
<td>15 people with dementia, 3 staff, 5 board members.</td>
<td>15 people with dementia, 3 staff, 5 board members.</td>
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<td>Russell (2016)</td>
<td>Qualitative study using thematic analysis. A two part study. Interviews in 2014 &amp; 2015.</td>
<td>Convenience sample.</td>
<td>Peer selection from existing Dementia Engagement and Empowerment Project &amp; Alzheimer’s Society groups.</td>
<td>4 people with dementia from existing groups.</td>
<td>4 people with dementia from existing groups.</td>
</tr>
<tr>
<td>Schicktanz et al (2018)</td>
<td>Grounded theory. A comparative analysis of organisations “for” &amp; “of” people with dementia. 26 semi-structured interviews with members, service users &amp; board representatives in Germany &amp; Israel. Background analysis of documents &amp; policy.</td>
<td>Purposive- used snowball to reach extra people.</td>
<td>Association members approached via office holders.</td>
<td>3 directors, 2 chairs, 5 board members, 3 other office holders, 10 carers/service recipients</td>
<td>3 directors, 2 chairs, 5 board members, 3 other office holders, 10 carers/service recipients</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non Participation</strong></td>
</tr>
<tr>
<td><strong>Setting</strong></td>
</tr>
<tr>
<td><strong>Presence of non-participants</strong></td>
</tr>
<tr>
<td><strong>Description of sample</strong></td>
</tr>
</tbody>
</table>
Table 1

some held high
profile positions.
# Table 1

**Data Collection**

<table>
<thead>
<tr>
<th>Method</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interview guide</strong></td>
<td>Post diary interviews explored diary entries. Pre diary interview questions are less clear. Not piloted.</td>
</tr>
<tr>
<td><strong>Post diary interviews</strong></td>
<td>Post diary interviews explored diary entries. Example questions were given. Not piloted.</td>
</tr>
<tr>
<td><strong>Researchers</strong></td>
<td>Researchers sent list of 8 topics, then followed up with secondary questions. Not piloted.</td>
</tr>
<tr>
<td><strong>Semi-structured</strong></td>
<td>The focus was identified, some of the specific questions are highlighted in findings.</td>
</tr>
<tr>
<td><strong>Phase 1</strong></td>
<td>Phase 1 guided by theory. Phase 2 &amp; 3 testing/refining theory. Specific questions not described but theoretical backdrop was. A topic guide used. Not piloted.</td>
</tr>
<tr>
<td><strong>Not piloted</strong></td>
<td>The questions were provided in supplementary materials &amp; were similar in both countries. Not piloted.</td>
</tr>
<tr>
<td><strong>Repeat interviews</strong></td>
<td>Pre &amp; post diary interviews conducted.</td>
</tr>
<tr>
<td><strong>Topics revisited</strong></td>
<td>Topics 5–8 were revisited in second year email exchanges.</td>
</tr>
<tr>
<td><strong>2 interviews held</strong></td>
<td>2 interviews held a few months apart.</td>
</tr>
<tr>
<td><strong>The study was in three phases</strong></td>
<td>The study was in three phases—theory generation, testing &amp; refining.</td>
</tr>
<tr>
<td><strong>Before &amp; after</strong></td>
<td>Before &amp; after 2014-15 academic year.</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>No</td>
</tr>
<tr>
<td><strong>Audio visual recording</strong></td>
<td>Not specified whether interviews recorded, but participants recorded their own diaries.</td>
</tr>
<tr>
<td><strong>Interviews</strong></td>
<td>Interviews were &quot;tape recorded&quot; There were also diary recordings by participants.</td>
</tr>
<tr>
<td><strong>Audio recorded</strong></td>
<td>Audio recorded.</td>
</tr>
<tr>
<td><strong>Audio recorded</strong></td>
<td>Audio recorded.</td>
</tr>
<tr>
<td><strong>Digitally recorded</strong></td>
<td>Digitally recorded.</td>
</tr>
<tr>
<td><strong>Field notes</strong></td>
<td>Not specified, but researchers spent 30 hours plus observing &amp; participating in events.</td>
</tr>
<tr>
<td><strong>30 hours of participant observation supported by field notes &amp; photographs.</strong></td>
<td>None. Study via Email.</td>
</tr>
<tr>
<td><strong>None</strong></td>
<td>Audio recorded interviews.</td>
</tr>
<tr>
<td><strong>Notes were jotted. Records were made after event if subject discussed was sensitive.</strong></td>
<td>Audio recorded.</td>
</tr>
<tr>
<td><strong>No.</strong></td>
<td>No.</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>Not specified</td>
</tr>
<tr>
<td><strong>Initial interviews</strong></td>
<td>Initial interviews 45-120 minutes.</td>
</tr>
<tr>
<td><strong>Not applicable.</strong></td>
<td>Not applicable.</td>
</tr>
<tr>
<td><strong>Not specified.</strong></td>
<td>40-60 minutes.</td>
</tr>
<tr>
<td><strong>15-40 minutes.</strong></td>
<td>15-40 minutes.</td>
</tr>
<tr>
<td><strong>30-90 minutes.</strong></td>
<td>30-90 minutes.</td>
</tr>
<tr>
<td><strong>Data Saturation</strong></td>
<td>Not specified</td>
</tr>
<tr>
<td><strong>Authors record that year 1 &amp; 2 data was highly consistent.</strong></td>
<td>Not specified.</td>
</tr>
<tr>
<td><strong>Not specified.</strong></td>
<td>Not specified.</td>
</tr>
<tr>
<td><strong>Not specified-but only 4 participants.</strong></td>
<td>Authors specify that they agreed that saturation reached.</td>
</tr>
<tr>
<td><strong>Transcripts Returned to Participants</strong></td>
<td>No but diary entries &amp; interpretations discussed with participants,</td>
</tr>
<tr>
<td><strong>No but reports provided &amp; discussion suggested broad</strong></td>
<td>Not applicable email</td>
</tr>
<tr>
<td><strong>No specified.</strong></td>
<td>No, but findings refined via &quot;interview &amp; feedback sessions&quot;.</td>
</tr>
<tr>
<td><strong>No specified.</strong></td>
<td>No specified.</td>
</tr>
<tr>
<td><strong>No specified.</strong></td>
<td>No specified.</td>
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Table 1

agreements with modes.
Figure 1 Flowchart of Search Strategy

Records identified through database searching (n = 938)

Additional records consulted (n = 0)

Records after duplicates removed (n = 375)

Titles/abstracts screened (n = 375) → Records excluded (n = 352)

Full-text articles assessed for eligibility (n = 23) → Full-text articles excluded (n = 16)

Studies included in qualitative synthesis (n = 7)