



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

Journal:	<i>Aging and Mental Health</i>
Manuscript ID	CAMH-2020-0110.R1
Manuscript Type:	Review
Keywords:	Alzheimer-s Disease < Dementia and Cognitive Disorders, Dementia and Cognitive Disorders, Advocacy, Activism, Campaign

SCHOLARONE™
Manuscripts

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 (Schick Tanz, 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?

1
2
3 What impact does their involvement have upon them as individuals, their wider
4
5 community and society?
6

7
8 What are the policy and future research implications?
9
10
11
12
13
14

15 **Methods**

16
17 This systematic narrative review consisted of a systematic search, and a narrative synthesis of
18
19 results based upon thematic analysis. This approach has more rigor than a narrative review, as
20
21 studies were identified in a systematic manner (Hagan, Manktelow, Taylor, & Mallett, 2014).
22
23 Studies were evaluated using Consolidated Criteria for Reporting Qualitative Research
24
25 (COREQ) (Tong, Sainsbury, & Craig, 2007).
26
27
28
29

30 ***Inclusion Criteria***

31
32 This Prospero-registered review focused upon people with dementia involved in advocacy.
33
34 Studies of case advocacy, where a third party worked to ensure that a person with dementia's
35
36 voice was heard, were excluded, as were studies of large advocacy organisations
37
38 representing people with dementia, unless the involvement of people with dementia was
39
40 researched as part of a wider study and reported separately. Where this arose, results included
41
42 only those elements specifically focused upon people with dementia. The review covered
43
44 original research appearing in peer reviewed publications. Grey literature was excluded as not
45
46 meeting the standard of peer review (Pappas & Williams, 2011). There were no restrictions
47
48 based upon study design or date. Language was limited to English for practical reasons.
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 transplantation (Walker et al., 2019) to advance care-planning (Sellars et al., 2019). COREQ
4 was employed in this review, reported under the three domains of research team and
5
6 reflexivity, study design, and analysis and finding (Tong et al., 2007).
7
8
9

10 Thematic analysis was used to analyse the results, being considered an appropriate
11 tool for analysis of themes across studies (Centre for Reviews and Dissemination, 2009).
12
13

14 **Line-by-line** open-coding was completed by the first two authors, coding only researchers'
15 words, rather than quotes from advocates. This was followed by in-depth analysis of open-
16 codes, which were interpreted as four themes. Reflexivity was at the heart of the process and
17 interpretations were discussed by the first two authors. It is acknowledged that the first
18 author's experience of working in Older Persons' Mental Health Teams will have influenced
19 the interpretations. As the third author of the current review was co-author of two included
20 studies (Clare et al., 2008; Hillman et al., 2018), she did not contribute to coding/theme
21 development.
22
23
24
25
26
27
28
29
30
31
32
33

34 **Results**

35
36 The earliest paper was an exploratory study of the experiences of members of
37 Dementia Advocacy and Support Network International (DASNI) (Clare et al., 2008). This
38 was followed by two studies from the same two-year project investigating the experiences of
39 people with dementia campaigning for change (Bartlett, 2012, 2014) and one of advocates
40 supporting higher education (Russell, 2016). A realist evaluation of an empowerment service
41 (McConnell et al., 2018) and a series of interviews with individuals "speaking as and for"
42 people with dementia (Hillman et al., 2018) followed. The final paper analysed the
43 aims/purposes of POs representing people with dementia (Schicktanz et al., 2018) and for the
44 purpose of this review should be treated with caution as only three people with dementia
45 were included as part of a much larger sample.
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 None of the papers detailed who conducted interviews, although Bartlett (2012) identifies the
4 field researcher. Clare et al (2008) contacted participants by email, whereas Schicktanz et al
5 (2018) used more than one interviewer, reflecting their international scope. All studies
6 outlined researchers' affiliations, but three added credentials, occupation, experience and
7 training (Clare et al., 2008; McConnell et al., 2018; Russell, 2016). In their reflexive IPA
8 approach, Clare et al (2008) addressed their own pre-conceptions through discussion within
9 the research team.

10
11
12
13
14
15
16
17
18
19 Only Schicktanz et al (2018) mention prior participant knowledge of researchers (two
20 participants through professional workshops). Three studies involved repeated observations
21 (Bartlett, 2012, 2014; McConnell et al., 2018), suggesting that participants may have come to
22 know researchers.

23 24 25 26 27 28 29 30 *Analysis and Findings*

31
32 Most studies described their coding process and numbers of researchers involved. Russell
33 (2016) was less specific, but noted that thematic analysis was employed. Schicktanz et al
34 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,
35 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,
36 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,
37 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,
38 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,
39 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,
40 (2018) translated some transcripts. Two studies used analysis-software (McConnell et al.,

41 Clare et al (2008) derived themes from participants' own words where possible,
42 whereas Bartlett (2012; 2014) viewed data through the prism of social movement theory and
43 Goffman's ideas respectively. The McConnell et al (2018) themes were theory driven, but
44 used participants' words, whereas Russell's (2016) major themes were developed in advance.
45 All study themes were consistent with and supported by quotations. For the purpose of this
46 review, the Schicktanz et al. (2018) findings should be treated with caution as only two
47 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

1
2
3 was also implied by loss of future plans (Clare et al., 2008) and in advocates' desire to see
4 rapid change (Bartlett, 2012).
5
6

7
8 The threat from stigma recurred across studies and acts as a barrier to people joining
9 empowerment (McConnell et al., 2018) or support groups (Schick Tanz et al., 2018).
10
11 Advocates are acutely aware of this stigma (Bartlett, 2012), and how it affects the value
12 attributed to people with dementia (Hillman et al., 2018). Furthermore, fear can reduce the
13 likelihood of others interacting with people with dementia (Hillman et al., 2018), perhaps
14 accounting for advocates' expressions of profound loneliness after diagnosis, when others
15 could not understand their experiences (Clare et al., 2008). Hillman et al (2018) highlighted
16 the threat posed by societal views of dementia, and advocates were motivated to challenge
17 these ideas (Clare et al., 2008). Paradoxically, advocates felt uncomfortable when performing
18 well, caught between their desire to be an effective citizen and societal conceptions of
19 dementia (Bartlett, 2014).
20
21
22
23
24
25
26
27
28
29
30
31
32
33

34 *Fighting Back*

35
36 Most studies drew attention to the martial metaphors used by advocates. For instance, Clare
37 et al (2008) noted how DASNI members "battle to compensate" the effects of illness,
38 whereas Schick Tanz et al (2018) talked of fighting, and McConnell et al (2018) battling
39 stigma. Even where martial metaphors were not adopted, the language was adversarial;
40 advocates "confront their dementia" (Clare et al., 2008) or adopt narratives as "forms of
41 resistance" (Hillman et al., 2018).
42
43
44
45
46
47
48
49

50
51 Fighting stigma was a priority for all POs, including members with dementia
52 (Schick Tanz et al., 2018). Advocates had a sense of owning the challenge of addressing
53 stigma (Clare et al., 2008), and fighting stigma was motivation for many (Bartlett, 2012;
54 McConnell et al., 2018). Advocates were driven by a desire to challenge injustice, to achieve
55 structural change (Bartlett, 2012), and to alter how **people with dementia** are viewed (Hillman
56
57
58
59
60

1
2
3 et al., 2018). Advocates did not wish to be perceived as passive (McConnell et al., 2018), but
4
5 to regain their sense of purpose through continued contribution to society (Clare et al., 2008).
6
7 In this way, advocates sought to regain respect, both for themselves and others (Bartlett,
8
9 2012).
10
11

12 Advocates also ‘fought back’ against the effects of illness. The day-to-day experience
13
14 of living with dementia was described as “an ongoing battle to compensate” (Clare et al.,
15
16 2008) and Hillman et al (2018) documented one participant’s “battle plan” to hold back the
17
18 symptoms of dementia. This battle plan extended beyond the medical to include enjoying art
19
20 and music (Hillman et al., 2018). Likewise, advocacy was seen as beneficial in the protection
21
22 of self, with many believing their involvement slowed their decline (Bartlett, 2012).
23
24
25

26 Advocates did not fight back alone, but drew inspiration, knowledge and strength
27
28 from each other (Bartlett, 2012; Clare et al., 2008), sometimes described as ‘working off each
29
30 other’ (Bartlett, 2012). Advocates also drew upon other sources, notably their families. For
31
32 instance, one participant’s ‘battle plan’ was devised in conjunction with his wife (Hillman et
33
34 al., 2018). Advocates can feel exploited by powerful organisations (Bartlett, 2014) and
35
36 groups were often contacted by external organisations looking to improve their own services
37
38 (McConnell et al., 2018). Here advocates involved another ally. Facilitators helped guard
39
40 against tokenism, by supporting the group to ensure that action followed any consultation
41
42 (McConnell et al., 2018).
43
44
45
46
47
48
49
50

51 *Evolving Identities*

52 Advocacy has the potential to alter a person’s identity, helping facilitate adjustment to
53
54 diagnosis (Clare et al., 2008). Participation leads to contact with other advocates, shaping a
55
56 wider collective identity (McConnell et al., 2018) with its attendant sense of collective
57
58 strength (Clare et al., 2008; McConnell et al., 2018). This in turn helps influence wider
59
60

1
2
3 societal views of dementia, re-framing the story of deterioration to one of adaptation
4
5 (Hillman et al., 2018).
6

7
8 A diagnosis of dementia is characterised by an initial sense of loss (Clare et al., 2008),
9
10 but as this subsides there is a time when activism may develop (Bartlett, 2012). Advocacy
11
12 constitutes a journey (Clare et al., 2008) with the potential to change the experience of illness
13
14 (Bartlett, 2012), and by “anchoring” the advocate in the present helps them maintain a sense
15
16 of well-being (Bartlett, 2012). When participants’ accounts moved from diagnosis to
17
18 advocacy, they began to describe a potentially fulfilling life (Clare et al., 2008).
19
20

21
22 Advocates’ stories act as the glue to unite past and present identities, to make sense of
23
24 their experiences and to convey a sense of biographical stability in spite of cognitive
25
26 deterioration (Hillman et al., 2018). In outlining their circumstances, advocates demonstrated
27
28 acceptance and adaptation (Clare et al., 2008), influencing wider discussion by reclaiming
29
30 what it might mean to live well, with dementia reframed as manageable disability (Hillman et
31
32 al., 2018). The status of citizen patient was used to facilitate change, with advocates
33
34 embracing the category of dementia (Bartlett, 2012), reinforcing a sense of self and
35
36 acceptance of self (Clare et al., 2008). Fundamentally, there is a status in being an advocate
37
38 (Bartlett, 2012), a “pioneer” in a new endeavour (Clare et al., 2008), or citizen patient
39
40 (Bartlett, 2012), who remains a valuable and contributing member of society (Clare et al.,
41
42 2008).
43
44
45

46
47 Advocates described their solidarity and collective will (Hillman et al., 2018), best
48
49 illustrated by the use of the terms ‘we and us’ rather than ‘I and me’ (Bartlett, 2012).
50
51 Schicktanz et al (2018) suggested that the individual voice gives way to the collective,
52
53 although paradoxically DASNI members talked of regaining their individual voice through
54
55 their involvement in a large organisation (Clare et al., 2008). Most simply, advocates felt
56
57 more powerful as a whole (Clare et al., 2008; McConnell et al., 2018).
58
59
60

1
2
3 Group membership can create a sense of belonging (McConnell et al., 2018),
4 particularly as members understood each other's experience (Clare et al., 2008). Bartlett
5 (2012) found that advocates tended to know each other and meeting other advocates was
6 valuable in itself (Bartlett, 2012), to the extent that they were considered as like family
7 (Bartlett, 2012; Clare et al., 2008). The advocacy role enabled meeting with those in power,
8 and whilst this afforded status and allowed people to seek rapid change (Bartlett, 2012),
9 advocates sometimes gained an unwelcome celebrity (Bartlett, 2014), a regrettable loss of
10 anonymity, as their personal and collective identities merged (Bartlett, 2014).
11
12
13
14
15
16
17
18
19
20
21
22

23 *Making a Difference*

24 The motivation for advocacy can relate to both protection of self and a desire for structural
25 change (Bartlett, 2012). This theme examines the differences, both positive and negative, that
26 advocacy makes in relation to the individual, their wider community and society.
27
28
29
30
31

32 McConnell et al (2018) argues that empowerment groups without consultation or
33 awareness raising are just support groups, hence advocates sought to influence others, to
34 make a valuable contribution (Clare et al., 2008; Russell, 2016) at a community and societal
35 level (McConnell et al., 2018), regaining respect for themselves and others (Bartlett, 2012).
36 Advocacy might range from encouraging healthy living (Hillman et al., 2018) to community
37 awareness raising (McConnell et al., 2018), challenging decision makers (McConnell et al.,
38 2018) and societal stigma (Clare et al., 2008). Through consultation work, empowerment
39 group members were well placed to make a difference, with both policymakers and other
40 organisations becoming more aware of the needs of **people with dementia** (McConnell et al.,
41 2018).
42
43
44
45
46
47
48
49
50
51
52
53

54 Advocacy can also make a difference at an individual level. The role of activist holds
55 status in social movement theory (Bartlett, 2012) and advocates understood their contribution
56 as work, which has civic value (Bartlett, 2014). Advocates described the energising quality
57
58
59
60

1
2
3 of their work (Bartlett, 2012), which for some was part of a range of measures to “live well”
4 and stave off the progression of dementia (Hillman et al., 2018). Others questioned the
5
6 concept, saying that it should be acceptable not to live well (Hillman et al., 2018).
7
8
9

10 Although many advocates regard advocacy as work, some preferred not to be paid,
11 citing the potential for harming their relationships with professionals (Bartlett, 2014). Others
12 found the idea of working unpaid to be demeaning and damaging to their well-being (Bartlett,
13 2014). Regardless, the rewards of advocacy extend beyond monetary payment and the
14 knowledge of having made a difference was important. (McConnell et al., 2018). Advocates
15 supporting learning found this to be intrinsically rewarding (Russell, 2016), and sometimes
16 advocacy was more rewarding than previous working roles (Bartlett, 2014). The awareness of
17 having made a contribution improved advocates’ confidence (Russell, 2016) leading to pride,
18 both in their own achievements, and in those of their organisation (Clare et al., 2008). This
19 was particularly true for group members. Group membership led to an activist mentality,
20 building advocates’ confidence to take part in media campaigns, which they could not have
21 considered without peer-support (McConnell et al., 2018). Advocacy involvement brought
22 some strains, with the effort involved in maintaining a social front going unseen, and being
23 characterised by exhaustion (Bartlett, 2014), leaving some with dementia fatigue (Hillman et
24 al., 2018). Advocates were also burdened by their perception of others’ expectations about
25 how **a person with dementia** should behave (Bartlett, 2014), leaving some advocates feeling
26 awkward when performing well (Bartlett, 2014).
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49

50 **Discussion**

51 To our knowledge, this is the first systematic **narrative** review to synthesise the research
52 documenting dementia advocacy. The review identified four themes: threats, fighting back,
53 evolving identities, and making a difference. It highlights how the threats perceived by
54 advocates extend beyond the symptoms of dementia. Advocates’ frequent use of martial
55
56
57
58
59
60

1
2
3 metaphors suggests the strength of feeling towards these threats and the need to overcome
4
5 them. The struggle to fight back and make a difference leads to an evolution in the person's
6
7 identity as the status of advocate and member of a broader movement is incorporated into the
8
9 person's story. The stigma associated with dementia remains powerful and the concept
10
11 permeates the themes in this review.
12
13

14
15 Biomedical explanations of illness are influential (Haslam, Jetten, Cruwys, Dingle, &
16
17 Haslam, 2018) and this is true for dementia. However, it can be problematic if complexities
18
19 are understood exclusively through this lens. For example, Schicktanz et al (2018) noted that
20
21 POs sometimes attributed complex intra-family conflicts to poor insight in people with
22
23 dementia. Kitwood (1997) provided an early warning of how narrow biomedical approaches
24
25 could lead to a malignant social psychology, and this review highlights how the threats
26
27 perceived by advocates extended beyond the symptoms of dementia. Consequently,
28
29 advocates promote a wider view of dementia than some organisations that have traditionally
30
31 represented people with dementia. Furthermore, first-hand stories carry an emotional
32
33 resonance that increases their persuasive impact (Burchardt, 2016), highlighting the
34
35 importance of involving people with dementia in policy and service development.
36
37
38

39
40 This review suggests that both diagnosis and participation in advocacy impact upon a
41
42 person's social network. This is important because a person's sense of self may be linked to
43
44 connectedness with a social network (Van Dijkhuizen, Clare, & Pearce, 2016). Furthermore,
45
46 social withdrawal is a predictor of depression (Förster et al., 2018), which is under-
47
48 recognised in dementia (Chang, Edwards, & Lach, 2011). Moreover, the impact of reduced
49
50 networks extends beyond the psychological (Haslam et al., 2018) and "frequent social contact
51
52 tends to be associated with greater longevity" (Shor & Roelfs, 2015).
53
54

55
56 Social identity theorists suggest that leaving a stigmatised group can help individuals
57
58 maintain positive identities (Tajfel & Turner, 1979), but where there is no opportunity to do
59
60

1
2
3 so, the key to reducing stigma impact lies within the group itself, possibly by restoring a
4 positive identity through campaigning (Haslam et al., 2018). The benefits of advocacy on
5 wellbeing are demonstrated in studies of people with mental health difficulties (Eiroa-Orosa
6 & Lomascolo, 2018) and HIV (Earnshaw, Rosenthal, & Lang, 2016). Likewise, this review
7 suggests that advocacy facilitated positive collective identities, and a sense of collective
8 strength, empowering advocates to counter negative views of dementia.
9

10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 stigma acts as a barrier to people engaging in groups (McConnell et al., 2018; Schicktanz et
4 al., 2018). This is problematic, as people are excluded from the personal benefits of
5 membership and because these groups need sufficient numbers to operate. The threat of
6 stigma might also deter people from seeking help (Phillipson et al., 2015) and here the unique
7 perspectives of advocates may be of greatest value to policymakers, as the review
8 demonstrates that advocates are well placed to advise on a variety of issues, including
9 diagnosis and challenging stigma.

10
11
12
13
14
15
16
17
18
19 It has been suggested that many dementia advocates are unrepresentative, tending to
20 be younger with atypical and perhaps insecure diagnoses (Howard, 2017). Consistent with
21 this, of the four studies that commented on age, all included younger advocates, some in their
22 late 40s or early 50s (Bartlett, 2012, 2014; Clare et al., 2008). Most studies provide limited
23 information on diagnosis. Participants were generally recruited via existing groups and the
24 focus was often upon individual experiences rather than group advocacy. Consequently, the
25 findings may not generalise to all people with dementia.

26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
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, Crameri, Lambourne, 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

1
2
3 encounter barriers to service access (Advocacy Plus, 2010). The role of ethnicity in dementia
4
5 advocacy remains to be explored. There may also be value in researching the experiences of
6
7 older advocates, perhaps through cross-sectional surveys or maximum variation sampling for
8
9 qualitative research. The studies in this review cast considerable light on advocates'
10
11 experiences, but further qualitative research and initial quantitative studies measuring the
12
13 impact of advocacy would enrich our understanding.
14
15

16
17 This review suggests that the threats associated with dementia diagnosis extend
18
19 beyond the symptoms of illness to include exposure to stigma and altered social networks.
20
21 Advocates are motivated by both a desire to challenge perceived injustice and to make a
22
23 continued contribution. Advocacy offers the potential for societal change and improvements
24
25 in the well-being of those involved, both through the activity itself and via extended social
26
27 networks. For this reason, dementia advocacy should be of interest to researchers,
28
29 policymakers and health providers alike.
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1. Study Design.

Figure 1. Flowchart of Search Strategy.

- Advocacy Plus. (2010). Bringing Dementia out of the shadow –A report on the ethnic minority advocacy project. *Working with Older People*, 14(1), 12-15.
- 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
- Alzheimer's Society. (2020). Why have an assessment for dementia? Retrieved from <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-assessment>
- Barrett, C., Cramer, P., Lambourne, S., Latham, J. R., & Whyte, C. (2015). Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia, and their partners. *Australas J Ageing*, 34 Suppl 2, 34-38. doi:10.1111/ajag.12271
- Bartlett, R. (2012). The emergent modes of dementia activism. *Ageing and Society*, 34(04), 623-644. doi:10.1017/s0144686x12001158
- Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, 29(8), 1291-1304. doi:10.1080/09687599.2014.924905
- Beard, R. L. (2004). Advocating voice: organisational, historical and social milieu of the Alzheimer's disease movement. *Sociology of Health and Illness*, 26(6), 797-819.
- Beard, R. L. (2017). Dementia and the privilege of growing old. *Dementia (London)*, 16(6), 685-688. doi:10.1177/1471301217709661
- Brown, G., Standen, N., & Khilji, K. (2013). Dementia advocacy in a time of austerity. *Working with Older People*, 17(2), 58-64. doi:10.1108/13663661311325472
- Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., . . . Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Med*, 9(10), e1001331. doi:10.1371/journal.pmed.1001331
- Burchardt, M. (2016). The self as capital in the narrative economy: how biographical testimonies move activism in the Global South. *Sociol Health Illn*, 38(4), 592-609. doi:10.1111/1467-9566.12381
- 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
- Centre for Reviews and Dissemination. (2009). *Systematic Reviews: CRD's Guidance on Delivering Reviews in Healthcare*. Retrieved from York:
- Chang, Y. P., Edwards, D. F., & Lach, H. W. (2011). The Collateral Source version of the Geriatric Depression Scale: evaluation of psychometric properties and discrepancy between collateral sources and patients with dementia in reporting depression. *Int Psychogeriatr*, 23(6), 961-968. doi:10.1017/S1041610211000147
- Clare, L., Rowlands, J. M., & Quin, R. (2008). Collective strength. *Dementia*, 7(1), 9-30. doi:10.1177/1471301207085365

- 1
2
3 Craig, D., & Strivens, E. (2016). Facing the times: A young onset dementia support
4 group: Facebook style. *Australas J Ageing*, 35(1), 48-53.
5 doi:10.1111/ajag.12264
6
7 Cruwys, T., Haslam, S. A., Dingle, G. A., Haslam, C., & Jetten, J. (2014). Depression
8 and Social Identity: An Integrative Review. *Pers Soc Psychol Rev*, 18(3), 215-
9 238. doi:10.1177/1088868314523839
10
11 Devlin, E., MacAskill, S., & Stead, M. (2007). 'We're still the same people': developing
12 a mass media campaign to raise awareness and challenge the stigma of
13 dementia. *International Journal of Nonprofit and Voluntary Sector Marketing*,
14 12(1), 47-58. doi:10.1002/nvsm.273
15
16 Dixon, J., Laing, J., & Valentine, C. (2018). A human rights approach to advocacy for
17 people with dementia: A review of current provision in England and Wales.
18 *Dementia (London)*, 1471301218770478. doi:10.1177/1471301218770478
19
20 Earnshaw, V. A., Rosenthal, L., & Lang, S. M. (2016). Stigma, activism, and well-being
21 among people living with HIV. *AIDS Care*, 28(6), 717-721.
22 doi:10.1080/09540121.2015.1124978
23
24 Eiroa-Orosa, F. J., & Lomascolo, M. (2018). Training mental health activists increases
25 the well-being of participants with high baseline levels of self-stigma: Results of
26 the Obertament training evaluation. *Am J Orthopsychiatry*, 88(6), 617-625.
27 doi:10.1037/ort0000376
28
29 Förster, F., Stein, J., Löbner, M., Pabst, A., Angermeyer, M. C., König, H.-H., &
30 Riedel-Heller, S. G. (2018). Loss experiences in old age and their impact on the
31 social network and depression— results of the Leipzig Longitudinal Study of the
32 Aged (LEILA 75+). *Journal of Affective Disorders*, 241, 94-102.
33 doi:10.1016/j.jad.2018.07.070
34
35 Gove, D., Downs, M., Vernooij-Dassen, M., & Small, N. (2016). Stigma and GPs'
36 perceptions of dementia. *Aging Ment Health*, 20(4), 391-400.
37 doi:10.1080/13607863.2015.1015962
38
39 Hagan, R., Manktelow, R., Taylor, B. J., & Mallett, J. (2014). Reducing loneliness
40 amongst older people: a systematic search and narrative review. *Aging Ment*
41 *Health*, 18(6), 683-693. doi:10.1080/13607863.2013.875122
42
43 Haslam, C., Jetten, J., Cruwys, T., Dingle, G. A., & Haslam, S. A. (2018). *The New*
44 *Psychology of Health Unlocking the Social Cure*. London and New York:
45 Routledge Taylor and Francis Group.
46
47 Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., &
48 Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma
49 Research: Can We Move the Stigma Dial? *Am J Geriatr Psychiatry*, 26(3), 316-
50 331. doi:10.1016/j.jagp.2017.09.006
51
52 Hillman, A., Jones, I. R., Quinn, C., Nelis, S. M., & Clare, L. (2018). Dualities of
53 dementia illness narratives and their role in a narrative economy. *Sociol Health*
54 *Illn*, 40(5), 874-891. doi:10.1111/1467-9566.12729
55
56 Howard, R. (2017). Doubts about dementia diagnoses. *The Lancet Psychiatry*, 4(8),
57 580-581. doi:10.1016/s2215-0366(17)30150-5
58
59 Kannaley, K., Mehta, S., Yelton, B., & Friedman, D. B. (2018). Thematic analysis of
60 blog narratives written by people with Alzheimer's disease and other dementias
and care partners. *Dementia (London)*, 1471301218768162.
doi:10.1177/1471301218768162
Knauss, J., & Moyer, D. (2006). The role of advocacy in our adventure with
Alzheimer's. *Dementia*, 5(1), 67-71. doi:10.1177/1471301206059755

- 1
2
3 MacRae, H. (2011). Self and other: The importance of social interaction and social
4 relationships in shaping the experience of early-stage Alzheimer's disease.
5 *Journal of Aging Studies*, 25(4), 445-456. doi:10.1016/j.jaging.2011.06.001
6
7 McConnell, T., Best, P., Sturm, T., Stevenson, M., Donnelly, M., Taylor, B. J., &
8 McCorry, N. (2018). A translational case study of empowerment into practice: A
9 realist evaluation of a member-led dementia empowerment service. *Dementia*
10 (*London*), 1471301218814393. doi:10.1177/1471301218814393
11
12 Milne, A. (2010). The 'D' word: Reflections on the relationship between stigma,
13 discrimination and dementia. *J Ment Health*, 19(3), 227-233.
14 doi:10.3109/09638231003728166
15
16 Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, P. (2009). Preferred
17 reporting items for systematic reviews and meta-analyses: the PRISMA
18 statement. *BMJ*, 339, b2535. doi:10.1136/bmj.b2535
19
20 Moreira, T. (2015). Understanding the role of patient organizations in health technology
21 assessment. *Health Expect*, 18(6), 3349-3357. doi:10.1111/hex.12325
22
23 Pappas, C., & Williams, I. (2011). Grey Literature: Its Emerging Importance. *Journal of*
24 *Hospital Librarianship*, 11(3), 228-234. doi:10.1080/15323269.2011.587100
25
26 Phillipson, L., Magee, C., Jones, S., Reis, S., & Skladzien, E. (2015). Dementia
27 attitudes and help-seeking intentions: an investigation of responses to two
28 scenarios of an experience of the early signs of dementia. *Aging Ment Health*,
29 19(11), 968-977. doi:10.1080/13607863.2014.995588
30
31 Piver, L. C., Nubukpo, P., Faure, A., Dumoitier, N., Couratier, P., & Clement, J. P.
32 (2013). Describing perceived stigma against Alzheimer's disease in a general
33 population in France: the STIG-MA survey. *Int J Geriatr Psychiatry*, 28(9),
34 933-938. doi:10.1002/gps.3903
35
36 Russell, C. W. (2016). People with dementia, contributing to learning and teaching in
37 higher education: Innovative practice. *Dementia (London)*, 1471301216685460.
38 doi:10.1177/1471301216685460
39
40 Sandberg, L. J. (2018). Dementia and the gender trouble?: Theorising dementia,
41 gendered subjectivity and embodiment. *Journal of Aging Studies*, 45, 25-31.
42 doi:10.1016/j.jaging.2018.01.004
43
44 Schicktanz, S., Rimon-Zarfaty, N., Raz, A., & Jongsma, K. (2018). Patient
45 Representation and Advocacy for Alzheimer Disease in Germany and Israel. *J*
46 *Bioeth Inq*, 15(3), 369-380. doi:10.1007/s11673-018-9871-8
47
48 Scholl, J. M., & Sabat, S. R. (2008). Stereotypes, stereotype threat and ageing:
49 implications for the understanding and treatment of people with Alzheimer's
50 disease. *Ageing and Society*, 28(01), 103-130. doi:10.1017/s0144686x07006241
51
52 Sellars, M., Chung, O., Nolte, L., Tong, A., Pond, D., Fetherstonhaugh, D., . . .
53 Detering, K. M. (2019). Perspectives of people with dementia and carers on
54 advance care planning and end-of-life care: A systematic review and thematic
55 synthesis of qualitative studies. *Palliat Med*, 33(3), 274-290.
56 doi:10.1177/0269216318809571
57
58 Shor, E., & Roelfs, D. J. (2015). Social contact frequency and all-cause mortality: a
59 meta-analysis and meta-regression. *Soc Sci Med*, 128, 76-86.
60 doi:10.1016/j.socscimed.2015.01.010
61
62 Tajfel, H., & Turner, J. (1979). An Integrative Theory of Intergroup Conflict. In W. G.
63 Austin & S. Worchel (Eds.), *The Social Psychology of Intergroup Relations* (pp.
64 33-47). Monterey, California: Brooks/Cole Pub. Co.

- 1
2
3 Talbot, C., O'Dwyer, S., Clare, L., Heaton, J., & Anderson, J. (2018). Identifying people
4 with dementia on Twitter. *Dementia (London)*, 1471301218792122.
5 doi:10.1177/1471301218792122
6
7 Thomas, C., & Milligan, C. (2017). Dementia, disability rights and disablism:
8 understanding the social position of people living with dementia. *Disability &*
9 *Society*, 33(1), 115-131. doi:10.1080/09687599.2017.1379952
10
11 Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting
12 qualitative research (COREQ): a 32-item checklist for interviews and focus
13 groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
14
15 Van Dijkhuizen, M., Clare, L., & Pearce, A. (2016). Striving for connection. *Dementia*,
16 5(1), 73-94. doi:10.1177/1471301206059756
17
18 Wahl, O. F. (1999). Mental Health Consumers' Experience of Stigma *Schizophrenia*
19 *Bulletin*, 25(3), 467-478.
20
21 Walker, R. C., Abel, S., Reynolds, A., Palmer, S. C., Walker, C., & Tipene-Leach, D. C.
22 (2019). Experiences, perspectives and values of Indigenous peoples regarding
23 kidney transplantation: systematic review and thematic synthesis of qualitative
24 studies. *Int J Equity Health*, 18(1), 204. doi:10.1186/s12939-019-1115-y
25
26 Westwood, S. (2016). Dementia, women and sexuality: How the intersection of ageing,
27 gender and sexuality magnify dementia concerns among lesbian and bisexual
28 women. *Dementia*, 15(6), 1494-1514. doi:10.1177/1471301214564446
29
30 World Health Organisation. (2019, 19/09/2019). Dementia. Retrieved from
31 <https://www.who.int/news-room/fact-sheets/detail/dementia>
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1

	Bartlett (2014)	Bartlett (2012)	Clare et al (2008)	Hillman et al (2018)	McConnell et al (2018)	Russell (2016)	Schicktzanz et al (2018)
Theoretical Framework							
Methodological orientation & theory	Goffman’s ideas concerning impression management inform interpretations. Discussion linked to critical disability debates. 2 year qualitative study. Diary/interview method. Combines content & thematic analysis.	Adopts social movement theory. Explores individual motives, organisational tactics & collective identity, framed by the passage of time. Diary/interview method. Combines content & thematic analysis.	Interpretative Phenomenological Analysis. Originally, a longitudinal Study conducted by email, but year 1 & 2 data were analysed together. Design developed with Dementia Advocacy and Support Network International (DASNI) involvement.	Draws upon Burchardt’s Narrative Economies theory. 18 qualitative interviews. Part of the IDEAL cohort study.	Realist evaluation, with ethnographic observation. Qualitative & quantitative methods including interviews & documentary analysis. Data collection-theory driven, with generation, testing & refining.	Qualitative study using thematic analysis. A two part study. Interviews in 2014 & 2015.	Grounded theory. A comparative analysis of organisations "for" & "of" people with dementia. 26 semi-structured interviews with members, service users & board representatives in Germany & Israel. Background analysis of documents & policy.
Participant Selection							
Sampling	Purposive- people with dementia identified as campaigning.	Purposive-people with dementia involved in campaigning.	Purposive-recruited “active DASNI members”	Opportunistic sample of existing advocacy group.	All current users of an empowerment group in Northern Ireland.	Convenience sample.	Purposive- used snowball to reach extra people.
Method of Approach	Unclear, how approached, although 4 came from the same campaign group.	Recruited via Alzheimer’s Society (9) (advert), & Scottish Dementia Working Group (SDWG) (2) (Newsletter & talk). People Rely on People Group (5) (Newsletter & talk.)	Advert on DASNI website.	Approached through the group-unclear how.	All contacted via email.	Peer selection from existing Dementia Engagement and Empowerment Project & Alzheimer’s .Society groups.	Association members approached via office holders.
Sample Size	16 people with dementia involved in campaigning	16 people with dementia involved in campaigning	7 members of DASNI.	5 people with dementia & 4 care partners.	15 people with dementia , 3 staff, 5 board members.	4 people with dementia from existing groups.	3 directors, 2 chairs, 5 board members, 3 other office holders, 10 carers/service recipients

Table 1

							& 3 people with dementia.
Non Participation	No-one appeared to drop out. Where doubt existed on capacity, the person was excluded.	4 participants excluded. 2 did not have dementia. 1 in poor health & 1 lived outside UK.	8 volunteered, but 1 made no further contact.	Not specified whether anyone refused.	Not specified-but more people with dementia participated over time. Phase 1=3, phase 2 = 5 & phase 3 = 8.	Not specified.	Not specified.
Setting							
Setting of data collection	Pre-diary-Person's home. 4 attended focus group in group's meeting room. Participant's diaries (photo, written, audio or combination). Post diary interviews 1 to 1 in or near home/base. 1 by phone due to time issues. 30 hours of participant observations,	Pre diary person's home. 1 to 1 apart from SDWG met as a 4 in a meeting room. Post diary interviews were all at home, except 1 by phone due to time constraints. 30 hours of participant observation, with 116 photos taken.	Data collected via Email.	Participants' own home	Private space convenient to participants.	Not specified.	Own home /own office/ or telephone-interviewees preference.
Presence of non-participants	No, except focus group.	No, apart from SDWG focus group.	Not knowable. Response by email.	Not specified whether people with dementia & partners were interviewed together.	No-not for interviews or observations.	Partners were present by request.	Not specified.
Description of sample	Gender, age, ethnicity & time since diagnosis given. Previous working role & experience of taking action recorded.	Gender, age, ethnicity, time since diagnosis & whether living with spouse given. Previous working roles & campaigning experience recorded.	Gender, age, nationality & previous working role reported, but not ethnicity. Role in DASNI described;	Ages & gender reported, but ethnicity was not. Authors did not give occupation to preserve anonymity.	Little demographic detail supplied, but there was a clear description of participants' role in organisation.	No demographic detail, other than as group members.	Organisation & role reported.

Table 1

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

some held high
profile positions.

For Peer Review Only

Table 1

Data Collection

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

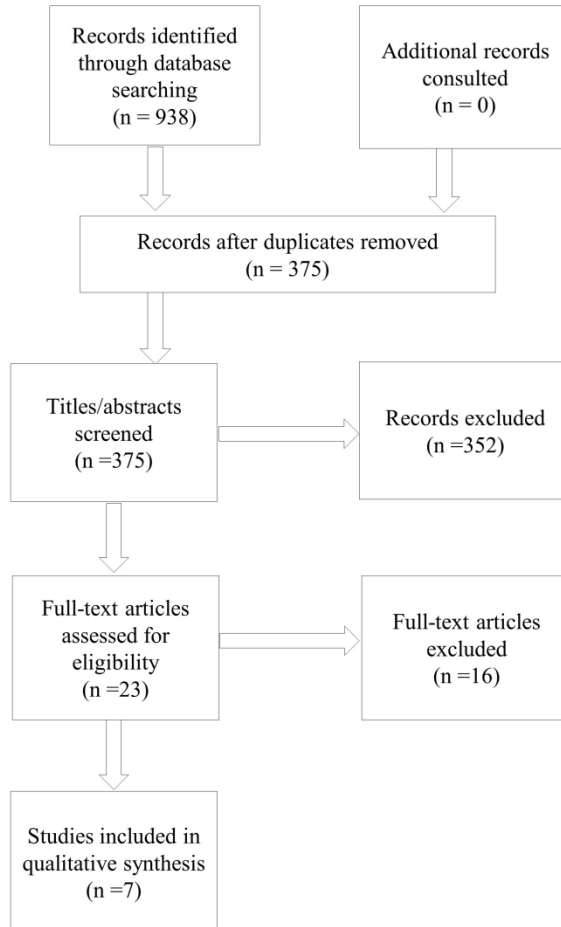
Table 1

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

agreements with
modes.

For Peer Review Only

Figure 1 Flowchart of Search Strategy



740x900mm (96 x 96 DPI)