



Collective strength

The impact of developing a shared social identity in early-stage dementia

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Abstract Current theories of social power suggest that development of a shared social identity can create the possibility of bringing about political and attitudinal change as well as benefiting individual psychological well-being. This exploratory, qualitative, internet-based study extending over two years explored the impact of developing a shared social identity among a group of people with early-stage dementia. We investigated the experience of belonging to the self-help network Dementia Advocacy and Support International (DASNI), and its effect on self-concept and adjustment, from the perspective of DASNI members in order to understand more about the factors that promote self-help, and the effects of engaging in self-help, mutual support and advocacy in this context. Seven active members of DASNI with a dementia diagnosis volunteered to participate. Interviews were conducted via email, and Interpretative Phenomenological Analysis (IPA) was used to develop a thematic account. The challenges engendered by the onset of dementia were reflected in descriptions of loss, struggle and uncertainty. Participating in DASNI, in contrast, engendered a sense of collective strength and having something valuable to contribute, and made it possible to discover that there can be life after diagnosis. Belonging to DASNI helped to counteract the challenges to self and identity posed by developing dementia, thus significantly affecting the experience of living with dementia, and creating the possibility of effecting social change. Gradually, people in the mild to moderate stages of dementia are developing a 'voice' and rejecting the passive patient role. One important element in this process is the way in which people with dementia band together to help themselves and one another, and influence social attitudes, through mutual support and collaborative advocacy. The development of DASNI, consistent with recent theoretical developments in conceptualizing processes of social power and influence, offers significant potential for change.

Keywords Dementia Advocacy and Support International; interpretative phenomenological analysis; self-concept; self-help; social power; support groups

The trend to earlier identification and diagnosis of dementia has been accompanied by a developing focus on the perspective of the person with early-stage dementia, and the importance of supporting people in 'living with' and 'managing' the condition is increasingly acknowledged (Clare, 2002). The development of support groups (Snyder, Quayhagen, Shepherd, & Bower, 1995; Yale, 1995, 1999) has been one important response. Support groups appear to provide positive benefits for individuals in the early stages of Alzheimer's disease. Evaluations based on analysis of session transcripts and interviews with participants (Morhardt & Menne, 2001; Yale, 1995) have suggested that support groups are generally appreciated by participants, and that the main benefits relate to the opportunity for social contact and for sharing of information and concerns. However, Mason, Clare and Pistrang (2005) found that while participants perceived the group as generally supportive and beneficial, most interactions involved a facilitator and there was little evidence of mutually supportive helping exchanges between members.

This is consistent with what is known in general about the impact of professional facilitation on group dynamics and interactions. Professionally facilitated groups are typically more structured and hierarchical than peer-led groups, with participants taking on a more passive role and often becoming dependent on the facilitators (Borkman, 1999; Toro et al., 1988). Evidence from other domains suggests that professional facilitation is not necessary in order for support groups to produce benefits (Lieberman & Bliwise, 1985; Toseland, Rossiter, & Labrecque, 1989). It has been argued that professional facilitation is essential in groups for people with early-stage dementia because of the challenges posed by members' cognitive and behavioural difficulties (Jones, Cheston, & Gilliard, 2002; LaBarge & Trtanj, 1995; Yale, 1995). Paradoxically, however, these very difficulties could in certain circumstances lead to an increased risk that the facilitated support group might tend to foster passivity and dependence, with facilitators adopting a 'dependency-support script' when in fact members have the potential to respond differently (Baltes, Neumann, & Zank, 1994; Small, Geldart, Gutman, & Clarke Scott, 1998). Clearly, there is a role for professional facilitation, and the question of how best to offer useful facilitation remains an important area to be explored. However, it is also important to consider the possibility that people with early-stage dementia can organize themselves and engage in self-help and mutual support under certain circumstances without professional facilitation, and that for some individuals this may bring even greater benefits.

Self-help groups are likely to encourage an active search for meaning, emphasize empowerment through maximizing choice and control, and engage in advocacy and collective action aimed at changing social representations and attitudes (Gray, 2001; Harvey, Mishler, Koenen, & Harney, 2000; Rootes & Aanes, 1992). In this sense, shared values and norms within self-help groups can provide a basis for collective self-realization (Reicher & Haslam, 2006a). Turner (2006) argues that it is through developing shared social identities that people who have limited resources, power or status may group together to create the social and political power that allows them to exert influence and bring about social change through collective action.

This process is facilitated by the growing possibility of adopting more flexible communication formats. Face-to-face meeting is not always essential in order for participants to derive benefit (e.g. Aleim et al., 1996). Use of the internet as an additional vehicle to promote mental health and as an adjunct or independent treatment is becoming increasingly accepted (Christensen, Griffiths, & Korten, 2002; Lange et al., 2003; Luce, Winzelberg, Zabinski, & Osborne, 2003; White et al., 2002), and this can apply equally to older people (Gustafson, 1999) and people with early-stage dementia (Freeman et al., 2005). Since cognitive changes can lead to difficulties with participation in a group discussion based on a group therapy format, alternative communication formats might offer a more positive experience for some.

The feasibility and value of self-help and mutual support has been established in relation to many challenged or socially excluded groups. A useful example is provided by the development of self-help in the mental health context, which has been likened to a 'new social movement' (Crossley & Crossley, 2001; Rogers, Pilgrim, & Lacey, 1993). It is likely that the struggle for empowerment may be even greater in the case of people with early-stage dementia, since they must challenge the widespread assumption that cognitive impairment precludes effective self-advocacy (and the frequently heard corollary that if a person can engage in this then the diagnosis of dementia must be incorrect) along with societal ignorance about the nature and impact of the early stages of dementia and the possibility of living, managing or coping with dementia in this context. Nevertheless, a self-help movement is now beginning to emerge among people with dementia.

A key element in this development has been the establishment of Dementia Advocacy and Support Network International (DASNI), an internet-based self-help and mutual support network for people with a dementia diagnosis. Detailed information about DASNI can be viewed at the organization's website.¹ DASNI is a non-profit organization founded in

2000 that aims to promote respect and dignity for persons with dementia, provide a forum for information exchange, encourage support mechanisms, advocate for services for people with dementia, and assist people in linking to local Alzheimer's groups. About one-third of members have a dementia diagnosis, with the remainder being made up of supporters who endorse the goals and values of the group. DASNI espouses an accepting and positive view of what it means to live with dementia. The organization has the goal of empowering people with dementia to participate actively in their own care and treatment, and encouraging them to improve the quality of their own life by advocating for others. Members with dementia have given plenary addresses, led groups and organized exhibitions at national and international conferences around the world, published books and articles, and appeared on TV and radio. One member with dementia is on the board of Alzheimer's Disease International and another served for a time on the executive body of the UK Alzheimer's Society.

The effects of belonging to this innovative self-help movement have not yet been empirically investigated. Clearly, effects may be evident at a number of levels, but from a psychological point of view the impact on subjective experience and well-being is of particular interest. In this study, we explore the experience of belonging to DASNI, and the impact this has on self-concept and adjustment in the early stages of dementia, from the perspective of DASNI members. We aim to understand more about the factors that promote self-help, and the effects of engaging in self-help, mutual support and advocacy in this context, in order to consider the possibilities for genuine empowerment of people experiencing early-stage dementia.

Method

Design

This was an exploratory, qualitative, longitudinal, internet-based study. Data were collected through semi-structured interviews conducted by email. Responses were subjected to Interpretative Phenomenological Analysis (IPA; Smith, Jarman, & Osborn, 1999). The protocol envisaged data collection occurring over a period of up to five years. This article focuses on the first study phase comprising Year 1 and Year 2 data.

Background and ethical considerations

The study was initiated as a result of contact between an active member of DASNI, who suggested that it would be valuable to research the effects of participation, and one of the researchers, who was exploring aspects of the subjective experience of developing dementia and ways of supporting

functioning and well-being. The study design and protocol were developed in collaboration with, and subsequently approved by, the Board of Directors of DASNI. The study was reviewed by the research ethics committees of University College London and the School of Psychology, Bangor University. A steering group consisting of three active DASNI members who were also participants in the study, one DASNI professional supporter with the role of research liaison officer and one external professional researcher with relevant interests and expertise reviewed and supported the study on an ongoing basis, communicating via email.

One key ethical issue was that of confidentiality. Participants were likely to be known to each other, and gathering data via email would imply an electronic record. Participants were asked for their views about confidentiality and in fact indicated that they were willing to be individually identified in connection with the findings, reflecting the collaborative nature of the research and the importance of the DASNI members 'owning' the findings. Additionally, some participants offered extra material to supplement their interview responses that was already in the public domain, such as web logs, records of articles or speeches posted on the internet and a published book. Nevertheless, in accordance with usual confidentiality requirements, for purposes of data analysis the research team assigned pseudonyms to contributors and removed all reference to real names from the stored and printed data records, dissociating these from the email communications with participants. Participants have not been individually identified in the account that follows here.

Participants

We aimed to recruit active members of DASNI who had been given a medical diagnosis of dementia. Details of the study were advertised on the DASNI website and interested members were invited to contact the researcher for further information. Eight members made contact and subsequently provided informed consent for participation. One of these did not respond to further contact. The final participant group therefore consisted of seven individuals, two men and five women. They ranged in age from 48 to 66 at the start of the study (mean 60.22 years, SD 5.83), and estimated the approximate length of time since their diagnosis at between four and nine years (mean 6.43 years, SD 1.99). All participants were retired: five from professional or managerial positions and two from caring occupations. Four were resident in the USA, two in Canada, and one in New Zealand. Participants' roles and contributions within DASNI included involvement in the posting board, hosting chats, writing papers, public speaking, and participation in fundraising and public relations, and some held prominent roles within the organization.

Data collection

The account presented here is based on interviews conducted in Year 1 and Year 2 of the study. In each case, a brief list of topics for discussion was sent as an email attachment to the participants, who sent written responses by the same means. Participants responded promptly and enthusiastically, and some provided additional information either in the form of email attachments or by directing the researchers to their own websites or to material posted on the DASNI website. Year 1 interviews were conducted between April and September 2003. Once participants had responded, the researcher followed up their responses individually with further questions or comments. Year 2 interviews were conducted in October and November 2004, and an individualized set of follow-up points based on reading of responses was sent to all participants in February 2005.

At each contact, participants were invited to give written responses to the interview topics as briefly or extensively as they wished, and to take as much time as they felt they needed before responding. At the initial contact, the researcher asked participants about:

- their background;
- what led up to the diagnosis;
- their experience of living with a diagnosis of dementia;
- how they first accessed DASNI;
- how they made use of DASNI and what involvement they had;
- how they perceived the benefits of involvement in DASNI, and any associated difficulties;
- what impact they felt DASNI had on their well-being, quality of life, ability to function, and relationships;
- how they were finding life at that time.

The latter four points were repeated in the Year 2 interviews. Further follow-up questions in Year 2 expanded upon some of these points, for example asking about participants' views of DASNI and whether these, or their motivations for participating, had changed over time, and about their communications and relationships with other group members. Participants' willingness to continue to be involved was checked by the researcher at every contact, and it was made clear that participants were free to withdraw at any time.

Data analysis

Interview transcripts were analysed using IPA, which aims at understanding aspects of lived experience and the subjective meanings that this experience holds for participants (Smith, 2004). IPA is phenomenological in that

it is concerned with individual, subjective accounts and beliefs, and interpretative in that it acknowledges the role played by the researchers' beliefs in the interpretation of data. Thus, it draws on both descriptive and hermeneutic phenomenology, synthesizing these two elements to provide a descriptive and interpretative account (Smith, Flowers, & Osborn, 1997). IPA has been identified as particularly relevant for research that aims to understand subjective reactions to illness, including early-stage dementia (Quinn & Clare, in press).

The analytic process using IPA was carried out as described in Quinn and Clare (in press). First, all three researchers read each transcript a number of times in order to become familiar with the content. This led to an early decision to consider the Year 1 and Year 2 data together, as participants' accounts were highly consistent across these time-points. We also read all the associated material participants had sent, which provided valuable background and context. The three researchers completed this phase independently before discussing initial thoughts and impressions. The second stage involved working with each participant's transcripts in turn, conducting an analysis at the individual level. Two researchers each worked independently and then came together for detailed discussion with the third researcher. For each transcript, key points were noted in the margin, remaining as close as possible to the words of the interviewee, and a summary list of these key points was compiled. This formed the basis for identifying themes emerging in the transcript, as key points were grouped together. Wherever possible, theme titles were drawn directly from the words of the participants, to assist in maintaining a focus on their experience rather than imposing pre-conceived ideas and constructs. The resulting emergent themes were then coded on the transcript, and a list of themes was compiled for each participant. The third stage involved reviewing this list of themes in order to explore areas of similarity and difference between participants and identify the emerging overarching themes that were evident in all transcripts. Again, this stage was completed by two researchers working independently and coming together for detailed discussion with the third researcher. The result was a single coherent list of themes representing the psychological experiences described by participants in the interviews. All transcripts were recoded accordingly. Finally, a full list of themes including all relevant extracts under each theme heading was compiled. This was shared with participants and with the steering group and their comments and views were sought. Feedback was received from four participants and one professional member of the steering group, and some minor amendments were made accordingly. The final full list of themes and associated extracts forms the basis for the account presented below.

Credibility and trustworthiness

The systematic nature of the analytic procedure in IPA highlights the methodological rigour of this approach and contributes to the provision of a credible and trustworthy set of findings. We sought to maximize credibility and trustworthiness throughout by adopting a number of the validity checks proposed by Elliott, Fischer, and Rennie (1999). As noted above, participants were engaged as collaborators in the research, and were invited to respond to the emerging findings and comment on any ideas or recommendations that they considered to arise as a result of the research. The steering group was similarly engaged. Comments were also sought from other researchers working in the dementia field. In presenting the findings, the participant group has been clearly described, and the thematic account is fully supported by examples drawn from the transcripts. The collaborative nature of the study supported the process of reflection that lies at the heart of the IPA approach, and helped the researchers to identify any preconceived ideas and beliefs that they brought to the study and to address the impact of this through discussion.

Results

Four themes emerged from the analysis: *Dementia Land*; *collective strength*; *a valuable contributing member of society*; and *there is life after the diagnosis of dementia*. The theme *Dementia Land* represented the context within which joining and belonging to DASNI was experienced, and reflected the challenges engendered by living with dementia. Participating in DASNI, in contrast, created a sense of collective strength and having something valuable to contribute, and made it possible to discover that there can be life after diagnosis. This had significant implications for participants' perceptions of their own subjective experience and well-being. Here, we will explore each of these four themes in turn and then draw them together to provide an integrated account of the experience and impact of participating in this innovative self-help initiative in the context of developing and living with dementia.

Dementia Land

This theme incorporated the range of emotions that were experienced pre-diagnosis, those endured when receiving and in reaction to the diagnosis, and those that prevail and are lived through on a day-to-day basis. The words 'Dementia Land', used by one participant to describe this experience, neatly encapsulate the sense that, with the onset of dementia, one moves into an unfamiliar and very different territory.

The process of obtaining a diagnosis was portrayed as *riding the diagnostic merry-go-round* and communicated as being charged with feelings of

frustration as a result of struggling not only to be heard but also to receive a diagnosis. This was followed by a sense of shock once the diagnosis was given:

I got nowhere with my appeals . . . I didn't have the language to describe my problems.

Although I was expecting it by then, the words were still devastating to hear.

Participants' experiences of isolation and loneliness emerged through statements indicating that others fail to understand what they are going through, as they do not encounter the same problems and challenges:

No one really understands how hard it is to live life like this, so people tend to trivialize how you feel, patronize you, and make out they feel the same way. They unwittingly say things like: 'I always forget things like that too!' or 'That happens to me too'.

Life in *Dementia Land* was further characterized by feelings of loss. There was a sense that part of the self had been lost, especially as a result of having to give up work, and participants compared their present sense of self with the identity they had enjoyed before the onset of dementia:

I had to give up my job, this was a devastating loss. It was essentially how I had defined myself.

Loss could also mean a loss of value, self-worth, or voice, and a loss of future plans and possibilities:

Written off as being devoid of feelings and needs . . . It was clear to me that my dementia negated the things that I said. It was very painful.

What has affected it (sense of self) is losing some self esteem because I can feel myself losing me . . . I do not want to live a life that is going to happen . . . that my disease(s) have mapped out for me.

The day-to-day experience of living with dementia was expressed as an *exhausting struggle*, an ongoing battle to compensate. Feelings of lethargy could exacerbate the difficulties:

Tomorrow I'll have little memory of today – makes living today like pushing the rock up the hill knowing it will roll back.

Inertia is a serious problem with me, and sometimes I seem glued to my chair. Likely it's just that it's so much effort to get myself organized to do things, that I'm mentally exhausted before I even start!

Life in *Dementia Land* was full of uncertainty. This uncertainty, about what *challenges should I expect and when*, was described retrospectively, prior to diagnosis, but was also evident when the future was considered:

It is a really frightening thing when no one can tell you how fast you will deteriorate. It is hard to get across how that feels, but it gnaws at you continually and each day you wonder what faculty might be lost next.

The experience of developing and living with dementia evoked many challenges for the participants, with a predominant emotional tone of loss, struggle and uncertainty. However, once participants began to describe their involvement in DASNI, the tone of their accounts changed. Themes expressing the impact of belonging to DASNI emphasized a feeling of *collective strength*, a sense of being a *valuable contributing member of society*, and the discovery that *there is life after the diagnosis of dementia*.

Collective strength

The experience of DASNI membership engendered a sense of *collective strength*, encapsulating what the participants had gained thus far, and continued to gain, as a result of belonging to DASNI. In short, it illustrates that DASNI membership entails key elements that appear to counteract the effects of some of the challenges of living with dementia.

A strong sense of belonging helped to mitigate the feeling of being alone that was evident in describing *Dementia Land*. It was expressed through comfort in the knowledge that others are in the same situation:

The internet group can provide a feeling of belonging to a very large network of people with dementia, and that can help further to reduce fear and isolation ('You are not alone! There are people around the world just like you!')

This sense of belonging was reinforced by the way individuals embraced and regarded their fellow members as *special new family and friends*:

I could not do what I do or feel as I feel or lecture or even have accepted the disease if it were not for my DASNI family.

Collective strength also manifested through participants feeling understood, and knowing that their DASNI family really do understand their situation:

It is that bit of extra that you know these people are having the same problems and really understand.

There was a culture of reciprocal support within the DASNI group whereby individuals both gave and received support from their fellow members:

I have gotten real down two times in the last four months. At that time it seems as though my failure in things I do is exaggerated many times. I feel as though my power has been lost to do anything about it. I feel helpless and hopeless. Thank God for my chat group DASNI sticking with me and helping me to crawl out.

It was also clear that participants felt DASNI had furnished them with knowledge about the condition and what to expect.

DASNI emails have also helped me develop the language to be able to talk about some of the 'weird' experiences that happen inside my head. The most frightening ones often involve agnosia. Not only have I gotten lost, but I often 'lose' things that I know I put somewhere, and then search all over for them, only to find hours later that they were where I had put them all along. I was just unable to perceive them for a period of time.

In the beginning, I hung on to every email and attended every chat session. Every day I learned something new about dementia, its treatment, management, diagnostic tests and coping skills.

DASNI membership was depicted as offering a sense of belonging, friendship, understanding and support. Reciprocity was a key element that emerged within *collective strength*, with participants not only receiving support from the group but also giving support to others. Most importantly, DASNI membership operated to counteract the loneliness expressed in *Dementia Land*.

A valuable contributing member of society

Feelings of pride emanated from the transcripts. Participants took pride, not only in their own achievements, but also in DASNI as an organization. As part of DASNI, participants found that they had a purpose after diagnosis, were able to help others and acted as pioneers. Hence, they felt valued.

Participants indicated that they were proud of DASNI, its resources and the impact that its existence has on individuals with dementia:

I am very proud to be a member.

The world is more informed because of DASNI and our principles.

They had a sense of owning the challenge of addressing the stigma attached to the dementia label, and it is through facing up to this challenge that they developed a sense of *purpose after diagnosis*:

I do it in hopes that people with dementia will begin to be treated with more respect and dignity and to help others recognize how much coping we must do to accomplish even simple things throughout a normal day.

Through belonging to DASNI, they were able to regain a voice and express their views:

DASNI gives me entrée in a variety of places where I want to participate.

There was a great sense of pride in relation to the advocacy work that participants undertook. This came not only from the knowledge that they

were partaking in advocacy work but that they were *helping others who are in the same situation*, and furthering the dementia cause as a whole:

I know that I am helping other people to improve their difficult lives.

I have always been a person who has wanted to make a difference in the world and through DASNI I feel that I have been able to change a small part of the way some people think about early-stage dementia.

Engaging in advocacy constituted a *journey for early-stage awareness* as participants actively worked to challenge the stigma associated with dementia and help make the changes they believed necessary to improve the experience of living with dementia. They felt good to be associated with the achievements of DASNI:

This is not a personal achievement for me personally but a DASNI achievement – and as I am a founding member of DASNI I feel good about what happened: Because of DASNI speaking out in 2001 to ADI, this year at the ADI conference in Kyoto Japan, Japanese people with dementia spoke out in public about their disease. This was such a big step for Japan in trying to decrease the stigma and myths that go along with dementia. It feels good to have been a part of this international achievement.

Further expressing this sentiment, participants mentioned what individuals with dementia need and what can help them to function better in society, and called for help in their journey to transform the current situation:

Let's work together to change paradigms about what persons with dementia can and can't do. Don't limit us – help us push the envelopes of our new abilities.

Participants asserted, and evidenced, that they do still have things to offer; they can and are making a valuable contribution. They described feeling *valued and appreciated for the things (they) still have to offer*, and how in turn they have gained both the respect of others and self-respect:

The benefits to me personally are so important, as I can still feel that I am a valuable contributing member of society, even though I am 'cognitively disabled'.

After six years of struggle my life has a new respect.

As with any group, participation was not always entirely without its difficulties. Part of being a valuable contributing member involved dealing with these issues and trying to find a way forward. A number of *upsets in the email community* were mentioned, concerning both DASNI as an organization and individual members. Some of these revolved around differing opinions on difficult or controversial issues, and the way in which these should be dealt with:

I do have a couple of problems with our site and the main one is death and dying. We are open about everything except for the support of all to have their own platform for death. The moment someone who wants assisted dying at the end is labelled and lectured to. The poor few who admit it and want to talk about it are least swept under the rug and being the reason for people wanting to eliminate the thought.

In response to these difficulties, participants identified changes that might be made to the organization and described ways in which they felt DASNI could be developed in order to ensure that it benefits all members:

We have a voting process but I would prefer the whole group vote and not just the directors. I believe we need better job descriptions for the Board of Directors that are not executive. We are working on this.

This adds emphasis to their role as *valuable contributing members of society* who are still in a position to have their say and express their opinions.

The theme *a valuable contributing member of society* captured what participants were able to gain as a result of DASNI membership: the direct impact of belonging to DASNI. They experienced increased feelings of pride, purpose and value, and these gains enabled them to enhance their contribution in terms of helping others, participating in pioneering work, and having the confidence to voice their opinions. The loss expressed through *Dementia Land* appeared to be mitigated by the impact of DASNI. Participants' reciprocal relationship with DASNI enabled them to help others with dementia, both within and outside of DASNI. This process then facilitated the development of their sense of pride, purpose and value and hence their contributions were able to flourish to the point where they had the confidence to work to improve both DASNI and the situation of people with dementia as a whole. In this way, DASNI allowed them to use their skills in a new context.

There is life after the diagnosis of dementia

The final theme illustrates the personal consequences of belonging to DASNI. It describes how, as a result of being *a valuable contributing member of society*, participants felt able to regain control over their lives and accept and adapt to the changes and challenges brought about by their dementia.

The first step in the journey to regain a clear sense of self following onset and diagnosis of dementia was expressed as *staring down the throat of the dragon*. Participants took control by confronting their dementia and the associated fears:

I think it is alright to allow yourself a bit of time to focus on the pain and fear that is only human; but it is important to move away from that sad focus and not let it consume you.

Through involvement in DASNI participants became more *engaged in life*, experiencing the feeling that life was still good and that they had much to be thankful for. Participants presented examples and arguments that challenged the current myth surrounding the dementia label:

It has been proven by thousands of early stage PWIDs [people with dementia] to be capable and intelligent beings just moving a little slower.

Further, by adapting their lives to accept their dementia, participants developed *the confidence to stand up for themselves*. When depicting their current situation, it was apparent that participants felt a strong sense of self, and acceptance of that self. Some had also been able to regain, to a degree, their previous abilities and standing within society, which made life seem more worthwhile:

The world doesn't seem grey, life doesn't seem pointless, I don't usually feel down on myself.

Having gone through this process of confrontation and adjustment, participants found that *everything is a little easier, not normal but easier*. It was apparent that participants were able to adapt and come to accept the reality of their new life, life with dementia. They knew that they still had to deal with dementia, but now felt better equipped to do so:

These days the words 'mistakes' and 'wrong' aren't an important part of my vocabulary.

This theme illustrates what participants felt they had gained as a consequence of their involvement with DASNI: the ability to take control and confront their dementia and the associated fears; the ability to deal with life with dementia; and an acceptance of who they are. Through their acceptance, participants recognized that some of the challenges expressed in *Dementia Land* were ongoing, requiring them to continually adapt to their ever-changing levels of functioning. While these challenges were not removed by belonging to DASNI, the experience of mutual support and collaborative engagement in an important and ground-breaking endeavour contributed significantly towards altering their impact.

Synthesis and proposed model

Participants' accounts tell the story of what it is like to live with dementia within the special and unique context provided by membership of DASNI. Entry into, and life in, the strange territory of *Dementia Land* challenged sense of identity and well-being, and created a need to re-establish and maintain an effective sense of self. DASNI membership provided a context through which this could be achieved, by experiencing a sense of *collective strength*

and knowing that one was a valuable contributing member of society. This created an opposing force that could help to counteract the effects of living in *Dementia Land*. *Dementia* challenges, and DASNI helps to renew and rebuild, a sense of self and well-being. The struggle to find a balance between these two opposing forces emerges in the experience of life after the diagnosis of dementia as an ongoing process of adjustment and re-evaluation, with DASNI continuing to provide a context that facilitates empowerment and well-being, supports resilience and allows members to contribute to changing attitudes and practice in a wider context.

Discussion

In this qualitative study of the experience of seven members of DASNI, we explored the subjective impact of living with dementia in the context of belonging to this innovative self-help organization. The findings indicated that participating in DASNI provided a sense of mutual strength and personal worth that could help to counteract the challenges to self and identity posed by developing dementia, thus significantly affecting the experience of life after diagnosis and creating the possibility of effecting social change. This process is reminiscent of the 'virtuous circle of social identification' described by Reicher and Haslam (2006b), in which development of a shared social identity leads to mutual support and thence to effective organization, as a result of which group members are able to assume new roles and work together to turn their goals into social realities in a process of collective self-realization. The outcome is increased group identification and enhanced well-being for the individual members. Shared social identity creates social power, conferring influence and access to resources, and allowing members to achieve group and individual goals, and bring about political and attitudinal change (Bruins, 1999; Turner, 2005, 2006).

Descriptions of entering, and living in, the territory of *Dementia Land* emphasized fear, frustration, struggle, loss, isolation and uncertainty, leading to a sense of being 'written off' as having no worth or value. These accounts draw out in particular some of the issues most pertinent to younger people who develop dementia (Harris, 2004), including the lengthy and difficult process of obtaining a clear diagnosis, the struggle to continue working and to make sense of failures at work that are inconsistent with earlier performance, and ultimately the loss of employment and professional role. Faced with the challenges of *Dementia Land*, a range of reactions and responses can result (Harris & Sterin, 1999), and these can be seen as lying on a continuum from 'self-maintaining' to 'self-adjusting' (Clare, 2002, 2003). Participants in this study were responding at the self-adjusting end of the continuum,

with a preference for confronting their fears and taking action accordingly. It may be that it is primarily those individuals who tend to respond in this self-adjusting way who are drawn to DASNI, but it is also possible that participation in DASNI facilitates this approach to the challenge of living with dementia. While a self-adjusting coping style offers the potential for development of a fighting spirit, usually the context offers few opportunities to develop this in the direction of collective action or of self-help and mutual support, and professionally facilitated support groups are more likely to focus on individual experience than on collective action or self-advocacy. Here, however, we see the emergence of a different voice. Participation brings a sense of community and shared responsibility. People with dementia are standing up and advocating for themselves and others, finding ways to deal with difficult and sensitive issues, acknowledging but not dwelling on their losses and difficulties, and taking pride in having something to offer. In so doing, they contribute to altering public perceptions as well as the nature of their own subjective experience, and call on others to work together with them to bring about change.

These members of DASNI are at the forefront of the emergence of a new voice for people with dementia. In this sense they are, by definition, exceptional individuals. They tend to be well-educated, and have often been high achievers in their previous occupations. They are also a relatively young group of people with early-stage dementia, for whom the onset of dementia has impacted sharply on working life and future expectations. Therefore, it is important to acknowledge that the current findings are based on the experience of a small and possibly distinctive group of people. Even within DASNI, these individuals may be exceptional, as they tend to be significant contributors and to hold leadership positions. Nevertheless, the experience of exceptional individuals is of particular interest, since by studying the factors that contribute to a more positive experience for these individuals it may be possible to identify ways in which this positive potential could be more widely harnessed for the benefit of a wider range of people with dementia.

In another sense, however, the participants may not be so very different from many other individuals who develop dementia. Their experience of life in *Dementia Land* resonates with existing accounts. They are coping by confronting their difficulties and trying to adjust accordingly. As noted above, this self-adjusting coping style is evident among a proportion of participants in other studies as well. What is different, though, is that here a number of contextual elements have come together to enable these participants to harness the full potential afforded by their approach to dealing with what is happening to them. The past decade has seen a trend to earlier diagnosis and an acknowledgement of the need to consider the

perspective of the person with dementia, and consequently perhaps there is a little more readiness to listen on the part of policy makers and service providers. In this context a grass-roots movement such as DASNI, which brings together people with dementia and draws in additional supporters who espouse its aims, is able to flourish and to exert a significant impact. Individual members of DASNI are able to experience a sense of community and to contribute in ways that help to restore some of their sense of self-worth. In taking up this opportunity and capitalizing on it, they also alter the nature of their own individual struggle with dementia. It is interesting to note that this group with early-stage dementia had been diagnosed on average six and a half years previously, which is quite a considerable period; certainly the participants themselves tend to the view that their social engagement and self-advocacy work may to some extent counteract or delay progression of the dementia or its effects. This is in line with growing evidence suggesting that having larger social networks, or a factor associated with this, can reduce the effect of underlying Alzheimer's disease pathology on cognitive abilities (Bennett, Schneider, Tang, Arnold, & Wilson, 2006). Maybe our participants would have done something exceptional in any case, but DASNI has provided a channel for their abilities and strengths, enabling them to take pride in the resulting collective achievements.

DASNI, like the facilitated support group, provides a context for interactions through which selfhood can be constructed and maintained, but it goes further than this. While support groups appear to offer limited opportunities for developing mutually supportive interactions and hence, perhaps, for developing a real sense of community, these features are, or can be, part of the DASNI experience. This context allows people to reconnect with and adjust their sense of self, to create a more positive narrative of what it means to live with dementia, and to take action based on that new narrative. Through DASNI membership, participants have the opportunity to enhance key aspects of self, including their sense of self-efficacy and self-esteem (George, 1998). As a result, they can engage in action that transcends individual experience and contributes to a wider process of social change. DASNI has been in the forefront of new developments, and many local initiatives are already building on this starting-point and identifying new approaches (e.g. McKillop, 2005).

The effectiveness of DASNI is facilitated by the social changes resulting from technological developments. The internet offers the possibility of engaging and connecting individuals in diverse locations and promotes equality and accessibility in communication. In many ways email communication advantages people with early-stage dementia, as it maintains electronic records that can serve as a substitute memory, allows them

to respond at their own pace with time for reflection and tends to be relatively brief and to-the-point (Freeman et al., 2005). This particular group of people with dementia is very proficient in using the internet, being a relatively young group. Although in this regard the participants may not be entirely representative of the full spectrum of people with dementia, it is likely that in the future more and more people with early-stage dementia will have these skills.

The aim of this qualitative study has been to present a descriptive and interpretative account of participants' experience and consider the wider implications, rather than producing generalizable conclusions. A number of measures were adopted to try to ensure that the resulting account was credible and trustworthy (Elliott et al., 1999), with careful and thorough checks on both the analytic process itself and the thematic account derived from the data. In line with the collaborative approach to the study, the findings are, of course, based entirely on self-report, which has both strengths and limitations in any context. Initially, we considered whether to interview a care partner or other nominated informant as well, but DASNI members with dementia felt strongly that they should be allowed to speak for themselves and that their own 'insider' perspective should be privileged in this context. As the primary aim was to explore subjective experience in a collaborative manner, this was considered to be entirely reasonable. Equally, the participants were engaged collaboratively in considering the findings as an important means of checking validity. Participants were invited to comment on the emerging thematic account, and all those who responded fully endorsed the validity of the account, as the following comments indicate:

Each of the themes is right on target.

I think that they reflect my experience well.

As a Board Member of DASNI I feel it reflects views of our members and topics we discuss on our chat and in our emails.

One participant questioned whether we had under-emphasized the importance of members educating and informing one another. A review of the data suggested that this aspect was evident but had been under-represented in the discussion of the theme *collective strength*, and the account was amended to redress this. Two participants suggested minor changes of wording, which were implemented. Participants also responded with suggestions about dissemination of the findings and future research, which will be the subject of further discussion among the participants, steering group and researchers. Participants' feedback was incorporated into the presentation of the findings. Subsequently, the participants were invited to comment on

a draft of this article prior to submission, and thus to consider the practical and theoretical frameworks used to situate the findings and the interpretations placed on the data. Two participants responded, endorsing the focus of the article. One commented:

Good job . . . I appreciate your stressing the dangers of passivity and dependence in professionally-facilitated groups.

While IPA has generally been associated with the analysis of data obtained in face-to-face semi-structured interviews, it has also been effectively applied to data obtained in other ways, including interviewing participants via email (Murray, 2004). Reflecting on the research process and findings, the use of email for data collection had some notable benefits, particularly in terms of immediacy and the provision of a clear written record that was shared between participant and researcher. We attempted to emulate the process of verbal conversation in our exchanges with participants by first identifying broad topics for discussion to which they could respond as extensively as they wished and subsequently following up on their responses with further comments, questions or topics for discussion. We also indicated from the outset that we were open to receiving, or being directed to, any additional material such as web logs that participants wished to share. Any concerns that data obtained via email might lack the richness required for qualitative analysis were quickly allayed because the accounts that participants gave were rich in detail and conveyed with great intensity the nature of their emotional and subjective experience. While the thematic account presents a general synthesis of themes emerging in the data, and addresses the identified research questions, it may not always do full justice to the individual narratives provided by the participants. Further work might usefully seek to view these deeply engaging personal stories in a narrative context.

The study presented here is a first attempt to capture the essence of the psychological resilience and resourcefulness of these highly effective individuals, to identify the important features of the community they have helped to create and to explore the impact of this for the individuals concerned, for the group and for wider awareness of the issues faced by people with early-stage dementia. Gradually, people in the mild to moderate stages of dementia are developing a 'voice' and rejecting the passive patient role. One important element in this process is the way in which people with dementia band together to help themselves and one another, and influence social attitudes, through mutual support and collaborative advocacy. It is through this kind of collective response that the 'voice' of people with dementia will have a real influence at the social and policy level as well as at a more individual and local level. The development of DASNI, consistent

with recent theoretical developments in conceptualizing processes of social power and influence (Turner, 2005, 2006), offers significant potential for change. The experience and achievements of the exceptional individuals who are highly active members of DASNI are important because they open the possibility of a new model for 'living with' dementia.

Note

1. DASNI website: www.dasninternational.org, accessed 20 January 2005.

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References

- Aleim, F., Mosavel, M., Stephens, R., Ghadiri, A., Krishnaswamy, J., & Thakkar, H. (1996). Electronic self-help and support groups. *Medical Care*, 34(10), Supplement, 32–44.
- Baltes, M.M., Neumann, E.-M., & Zank, S. (1994). Maintenance and rehabilitation of independence in old age: An intervention program for staff. *Psychology and Aging*, 9, 179–188.
- Bennett, D.A., Schneider, J.A., Tang, Y., Arnold, S.E., & Wilson, R.S. (2006). The effect of social networks on the relation between Alzheimer's pathology and level of cognitive function in old people: A longitudinal cohort study. *Lancet Neurology*, 5, 406–412.
- Borkman, T. (1999). *Understanding self-help/mutual aid: Experiential learning in the commons*. New Brunswick, NJ: Rutgers University Press.
- Bruins, J. (1999). Social power and influence tactics: A theoretical introduction. *Journal of Social Issues*, 55, 7–14.
- Christensen, H., Griffiths, K.M., & Korten, A.E. (2002). Web-based cognitive behaviour therapy (CBT): Analysis of site usage and changes in depression and anxiety scores. *Journal of Medical Internet Research*, 4, e3.
- Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Aging and Mental Health*, 6, 139–148.
- Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, 1017–1029.
- Crossley, M.L., & Crossley, N. (2001). 'Patient' voices, social movements and the habitus: How psychiatric survivors 'speak out'. *Social Science and Medicine*, 52, 1477–1489.
- Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215–229.
- Freeman, E., Clare, L., Savitch, N., Royan, L., Litherland, R., & Lindsay, M. (2005). Improving the accessibility of internet-based information resources for people with dementia: A collaborative approach. *Aging and Mental Health*, 9, 442–448.
- George, L. (1998). Self and identity in later life: Protecting and enhancing the self. *Journal of Aging and Identity*, 3, 133–152.

- Gray, D.E. (2001). Accommodation, resistance and transcendence: Three narratives of autism. *Social Science and Medicine*, 53, 1247–1257.
- Gustafson, D.H. (1999). The impact of a patient-centred, computer-based health information/support system. *American Journal of Preventative Medicine*, 16, 1–9.
- Harris, P.B. (2004). The perspective of younger people with dementia: Still an overlooked population. *Social Work in Mental Health*, 2(4), 17–36.
- Harris, P.B., & Sterin, G. (1999). Insider's perspective: Defining and preserving the self of dementia. *Journal of Mental Health and Aging*, 5, 241–256.
- Harvey, M.R., Mishler, E.G., Koenen, K., & Harney, P.A. (2000). In the aftermath of sexual abuse: Making and remaking meaning in narratives of trauma and recovery. *Narrative Enquiry*, 10, 291–311.
- Jones, K., Cheston, R., & Gilliard, J. (2002). Sharing problems through group psychotherapy. *Journal of Dementia Care*, 10(3), 26–27.
- LaBarge, E., & Trtanj, F. (1995). A support group for people in the early stages of dementia of the Alzheimer's type. *Journal of Applied Gerontology*, 14, 289–301.
- Lange, A., Rietdijk, D., Hudcovicova, M., van de Ven, J., Schrieken, B., & Emmelkamp, P. (2003). Interapy: A controlled randomized trial of the standardized treatment of posttraumatic stress through the internet. *Journal of Consulting and Clinical Psychology*, 71, 901–909.
- Lieberman, M., & Bliwise, N. (1985). Comparisons among peer and professionally directed groups for the elderly: Implications for the development of self-help groups. *International Journal of Group Psychotherapy*, 35, 155–175.
- Luce, K.H., Winzelberg, A.J., Zabinski, M.F., & Osborne, M.I. (2003). Internet-delivered psychological interventions for body image dissatisfaction and disordered eating. *Psychotherapy: Theory, Research, Practice, Training*, 40, 148–154.
- Mason, E., Clare, L., & Pistrang, N. (2005). Processes and experiences of mutual support in professionally-led support groups for people with early-stage dementia. *Dementia*, 4, 87–112.
- McKillop, J. (2005). Turning the corner when someone's there to help. *Journal of Dementia Care*, 13(2), 17–18.
- Morhardt, D., & Menne, H.L. (2001). The experience of early stage dementia support groups on the individual and their family: A qualitative analysis. *The Gerontologist*, 41(Special Issue 1), 73–74.
- Murray, C.D. (2004). An interpretative phenomenological analysis of the embodiment of artificial limbs. *Disability and Rehabilitation*, 26, 307–316.
- Quinn, C., & Clare, L. (in press). Interpretative phenomenological Analysis. In R. Watson, H. McKenna, S. Cowman, & J. Keady (Eds.), *Nursing research: Designs and methods*. Edinburgh: Elsevier.
- Reicher, S., & Haslam, S.A. (2006a). Rethinking the psychology of tyranny: The BBC prison study. *British Journal of Social Psychology*, 45, 1–40.
- Reicher, S., & Haslam, S.A. (2006b). Groups, psychological well-being and the health of societies. *The Psychologist*, 19, 146–150.
- Rogers, A., Pilgrim, D., & Lacey, R. (1993). *Experiencing psychiatry: Users' views of services*. Basingstoke: Macmillan.
- Rootes, L.E., & Aanes, D.L. (1992). A conceptual framework for understanding self-help groups. *Hospital and Community Psychiatry*, 43, 379–381.
- Small, J.A., Geldart, K., Gutman, G., & Clarke Scott, M.A. (1998). The discourse of self in dementia. *Ageing and Society*, 18, 291–316.
- Smith, J.A. (2004). Reflecting on the development of interpretative

- phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39–54.
- Smith, J.A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material discourses of health and illness*. London: Routledge.
- Smith, J.A., Jarman, M., & Osbourn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray and K Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 218–240). London: Sage.
- Snyder, L., Quayhagen, M.P., Shepherd, S., & Bower, D. (1995). Supportive seminar groups: An intervention for early stage dementia patients. *The Gerontologist*, 35, 691–695.
- Toro, P.A., Reischl, T.M., Zimmerman, M.A., Rappaport, J., Seidman, E., Luke, D.A., et al. (1988). Professionals in mutual help groups: Impact on social climate and members' behaviour. *Journal of Consulting and Clinical Psychology*, 56, 631–632.
- Toseland, R.W., Rossiter, C.M., & Labrecque, M.S. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. *The Gerontologist*, 29, 465–471.
- Turner, J.C. (2005). Explaining the nature of power: A three-process theory. *European Journal of Social Psychology*, 35, 1–22.
- Turner, J.C. (2006). Tyranny, freedom and social structure: Escaping our theoretical prisons. *British Journal of Social Psychology*, 45, 41–46.
- White, H, McConnell, E., Clipp, E., Branch, G., Sloane, R., Pieper, C., et al. (2002). A randomized controlled trial of the psychosocial impact of providing internet training and access to older adults. *Aging and Mental Health*, 6, 213–221.
- Yale, R. (1995). *Developing support groups for individuals with early stage Alzheimer's disease: Planning, implementation and evaluation*. Baltimore, MD: Health Professions Press.
- Yale, R. (1999). Support groups and other services for individuals with early-stage Alzheimer's disease. *Generations*, 23(3), 57–61.

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