



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

"We're all thrown in the same boat..."

Citation for published version:

Keyes, S, Clarke, C, Wilkinson, H, Alexjuk, J, Wilcockson, J, Robinson, L, Reynolds, J, McClelland, S, Corner, L & Cattan, M 2014, "We're all thrown in the same boat...": A qualitative analysis of peer support in dementia care ' Dementia., 10.1177/1471301214529575

Digital Object Identifier (DOI):

[10.1177/1471301214529575](https://doi.org/10.1177/1471301214529575)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Author final version (often known as postprint)

Published In:

Dementia

Publisher Rights Statement:

© Keyes, S. E., Clarke, C. L., Wilkinson, H., Alexjuk, E. J., Wilcockson, J., Robinson, L., Reynolds, R., McClelland, S., Corner, L., and Cattan, M. (2014). "We're all thrown in the same boat...": A qualitative analysis of peer support in dementia care. *Dementia*, first published on April 17, 2014 doi:10.1177/1471301214529575/

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



“We’re all thrown in the same boat.....”: a qualitative analysis of peer support in dementia care

Authors

1. Dr Sarah E. Keyes (corresponding author), School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG. sarah.keyes@ed.ac.uk
2. Professor Charlotte Clarke , School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG. charlotte.clarke@ed.ac.uk
3. Dr Heather Wilkinson, School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG. h.wilkinson@ed.ac.uk
4. Eva Joanna Alexjuk J. School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG. jo.alexjuk@ed.ac.uk
5. Dr Jane Wilcockson jane.wilcockson@googlemail.com 07545271330
6. Professor Louise Robinson, Institute of Health and Ageing, Newcastle University, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL
a.l.robinson@newcastle.ac.uk
7. Dr Joanna Reynolds, Faculty of Health and Life Sciences, University of Northumbria, Coach Lane Campus, Benton, Newcastle upon Tyne, NE7 7XA.
joanna2.reynolds@northumbria.ac.uk
8. Professor Siobhan McClelland, Health Economics Research Unit, University of Glamorgan, siobhan.mcclelland@btinternet.com
9. Dr Lynne Corner, Institute of Health and Ageing, Newcastle University, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL. l.s.corner@newcastle.ac.uk

10. Professor Mima Cattan, Faculty of Health and Life Sciences, University of Northumbria, Coach Lane Campus, Benton, Newcastle upon Tyne, NE7 7XA.

mima.cattan@northumbria.ac.uk

The Healthbridge Evaluation was funded by the Department of Health Policy Research Programme (England) Ref: 025/0058). The views expressed in this paper are the views of the authors and not necessarily the views of the Department of Health.

Abstract

Peer support is well established in fields such as the disability movement and mental health and is increasingly recognised as one way of enabling support by and for people with a diagnosis of dementia and their immediate carers. It was central to the implementation of the National Dementia Strategy (NDS) for England (DH 2009), where 40 demonstration sites were established. This mixed methods study included in-depth qualitative interviews with people living with dementia (n=101) and staff/stakeholders (n=82) at eight of the 40 sites. Data analysis was a five-stage process: coding framework developed (using 25 transcripts); further development of the framework (using a further 70 transcripts); development of emerging themes; modelling of themes and verification of models based on the entire data set.

Peer support had positive emotional and social impact that was rooted in identification with others, a commonality of experience and reciprocity of support. There was also a contrast between the quality of peer support and support from professionals. This emphasises the significance of lived experience and promoting a strengths-based approach to interpersonal support that is enabling and challenges a deficit approach to understanding dementia.

Background

The global challenges of meeting the needs of increasing numbers of people living with dementia (Alzheimer Disease International 2012) mean that attention is being given to a wider range of service provision (Nakanishi & Nakashima in press), including those that are more socially orientated and seen as low intensity, low cost forms of support. In planning the implementation of the National Dementia Strategy for England (DH 2009), the case for introducing forms of peer support was that *'one clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people with dementia and their carers, to exchange practical advice and emotional support'* (p41). Peer support was promoted in the implementation of the National Dementia Strategy through the introduction of 40 demonstration sites: 18 Peer Support Network (PSN) sites where people with dementia and carers were supported by network facilitators to engage in a range of forms of peer support, and 22 Dementia Adviser (DA) sites where peer support was encouraged (alongside other forms of support) through signposting to peer support groups and/or development of user-led groups.

This paper explores qualitative data collected as part of Healthbridge (Clarke et al 2013), a larger mixed-methods study of the PSN and DA demonstration sites. Our analysis of peer support within this paper has synthesised data relating to peer support, shedding light on support by and for people with dementia and carers within initiatives which prioritise peer support as well as peer support that occurred as a result of or alongside services which prioritise advice and information provision. The focus of our exploration of peer support, therefore, is the role and impact of peer support and not the role and impact of the services.

We begin by defining our understanding of "peer support" based on existing literature on peer support. We then outline previous research on peer support by and for people with a diagnosis of dementia and immediate/ family carers, before outlining the Healthbridge study, including its relationship to the implementation of the National Dementia Strategy. The methods section

focuses on our approach to recruitment, consent, interviews and data analysis, thus defining the parameters of the claims we are making about peer support by and for people living with dementia. Our findings focus on describing peer support (aspects), providing insight into the processes (mechanisms) and the outcomes of peer support (benefits). We also return to theoretical and practical underpinnings of peer support introduced in the literature review and identify barriers and challenges to peer support. Our discussion explores both the scope and the limitations of this work.

Peer Support: theoretical and practical underpinnings

Peer support is increasingly recognised as a means of accessing and providing practical, social and emotional interpersonal support (DH 2010; HM Government 2012), reflecting a conscious shift in emphasis from “*advice from on high to support from next door*” (DH 2004 p103). In defining what is meant by “peer support”, it is important to consider what we mean by “peers” as well as the nature of support given and received. An exploration of the theoretical and practical basis of peer support in a range of groups and settings provides evidence for our understanding of peer support as having five aspects:

- It is an interpersonal interaction grounded in a commonality of experience,
- It is (often) based on a reciprocity of support
- It may have a positive social and emotional impact,
- It includes learning based on direct experience,
- It challenges a medical/ deficit model of disability

We now explore each of those five aspects within the context of peer support within a range of settings.

Firstly, peer support amongst people who have the same or a similar diagnosis or life situation is rooted in a commonality of experience: in diagnosis or life experience and the challenges faced as a

consequence. Other work highlights peer support amongst people with cancer (Ussher, Kirsten, Butow and Sandoval 2006) or diabetes (Fisher et al 2012) and carers of people with mental health issues (Chien and Norman 2009). In these instances, “peers” are defined as people who identify with one another on the basis of experiences surrounding a specific diagnosis, which may or may not be the only aspect of their lives in which there is a commonality of experience.

Secondly, peer support is often (though not always) rooted in a reciprocity of support within a relationship where support is both given and received, with some people who have benefited from such relationships referring to friendship. There are also examples of peer support roles being more formalised, for example Peer Support Workers in mental health (Repper and Carter 2011) and within in-depth peer counselling programs (for example, Ho 2007).

Thirdly, there is some evidence of peer support relationships having positive impacts socially and emotionally. For some, peer support enables a re-gaining of social interaction which has been lost or diminished. Examples include people facing marginalisation, such as older people who are isolated (MaCKean and Abbott-Chapman 2012). Peer support can also be effective in preventing potential crises, for example amongst women at a high risk of postnatal depression (Dennis et al 2009).

Fourthly, there is an aspect of learning from peers within peer support (Hartley-Brewer 2002). Peer support can focus on the sharing of information, coping strategies and advice based on solutions that have been effective for others in similar circumstances, for example in the field of addiction recovery (Boisvert, Martin, Grosek and Claire 2008) and in supporting specific behaviour (Thomson, Crossland and Dykes 2012; Klatt, Berg and Thomas 2008). There is a contrast between the quality and content of this sharing of advice and information (which are rooted in the impact of sharing on a practical and emotional level with people whose knowledge and advice is based on lived experience) and professional support (which is rooted in expertise and experience of the disorder) (Bassett, Faulkner, Repper and Stamou, 2010).

Fifthly, peer support shifts the focus away from medical model understandings of 'what is wrong' with an individual, towards a social model understanding of the physical, environmental, cultural, psycho-emotional and attitudinal barriers to inclusion faced by people with impairments and ways in which people with a commonality of experience can support one another to overcome those barriers. A significant theoretical underpinning of peer support is illustrated by its role in the development of the Disabled People's Movement, in particular within the development of user-led disability services (Barnes and Mercer 2006). As such, peer support can also lead to self or group advocacy as people with a commonality of experience come together to challenge stigma and discrimination ([first author] and Brandon 2012).

Peer Support and people living with dementia

Previous research-based, peer-reviewed literature which specifically focussed on the impact of peer support amongst people with dementia or amongst carers of people with dementia was identified through comprehensive searches on variants of 'peer support' 'dementia' 'people with dementia' and 'carers' within the following databases: EBSCO Discovery Service, ProQuest, BIOSIS, Ovid, PubMed, SCIE and The Cochrane library. From a content analysis of papers, six international studies (published in seven peer-reviewed journal articles) were identified as relevant.

A previous study on peer support by and for people with a diagnosis of dementia focussed on the impact of peer support in enabling re-engagement with life in the context of loneliness, isolation, loss and struggle, providing a sense of belonging, friendship and understanding within a reciprocity of support (Clare, Rowlands and Quin, 2008). Clare et al (2008) also highlight the role of peer support in enabling people with dementia to find new and valued roles, reject a "passive patient" role and form new communities. Clare et al (2008) outline the impact of new collective identity in enabling people with dementia to re-gain control, for example through sharing of coping strategies (Clare et

al 2008 p20). In exploring peer support in the context of friendships and people with dementia, Ward, Howorth, Wilkinson, Campbell and Keady (2011) highlight the role of a peer support group in reducing social isolation and sharing of information leading to the group being:

“a space for collaborative meaning making away about dementia away from the imposition of medicalized definition of the condition characterized by an emphasis on deficit” (Ward et al, 2011 pp. 299-300).

International studies that have focussed on peer support and carers of people with dementia provide similar evidence around positive impact on social networks and increased confidence through sharing of coping strategies (Fung and Chien 2002) as well as an increase in perceived quality of life (Wang, Chein and Lee 2012) with evidence of carers feeling more in control (Chien 2011). Greenwood, Habibi, Mackenzie, Drennan and Easton (2013 pp 619-622) outline the benefits for carers and volunteers engaged in one-to-one peer support between carers and volunteer peer-supporters who were people with previous caring experiences (n=13). Benefits of peer support, for carers and volunteers, included: the impact of identifying with and subsequently engaging with someone in a similar position (including realising that their responses to their situation were “normal”); reduced isolation; emotional support and release; the significance of *enjoying* engaging in peer support; learning strategies for managing situations and mutual problem solving. Greenwood et al (2013 p621-622) also refer to the significance *genuine understanding* in the context of *experiential similarity*.

Whilst policy interest in peer support is high, there is, however, little research on peer support which explores views and experiences of people with first-hand experience of living with dementia. Hornillos and Crespo (2012 p155) state that “support groups for family caregivers are an intervention frequently used.....but their extensive use does not correspond to the current scientific interest in them”. Wakui, Saito, Agree and Kai (2012 p505) similarly state that “qualitative research will help further our understanding of the benefits of structured peer activity programmes for

caregivers". Clare et al (2008 cited previously) explored through interview the experiences of seven "exceptional individuals" who were "at the forefront of the emergence of a new voice for people with dementia". The positioning of these people, several of whom had leadership positions within an international advocacy network (DANSI), raises questions as to the representativeness of their experiences and therefore the transferability of their findings to people with dementia as a wider group. Through drawing upon qualitative evidence within a research process which captures views and experiences of people with dementia and carers across a range of settings, our work addresses these previously identified gaps. The significance of the work outlined in this paper is the evidence that it provides for the role and impact of peer support among people with dementia and carers on an unprecedented scale and within a range of settings and contexts.

The Healthbridge Study

The Healthbridge study, commissioned by the Department of Health Policy Research Programme, ran alongside the implementation of 40 demonstration sites (22 DA sites and 18 PSN sites). Although each site differed from others, DA sites were established on a model of an individual adviser or group of advisers providing information and guidance to people with dementia and their family / supporters, with a focus on signposting to appropriate support (which could include peer support groups). PSN sites were established on a model of one or more facilitator developing one-to-one and group support by and for people with dementia and carers. The sites were established across England within a wide range of health, social care and voluntary sector organisations, often involving partnerships between all three sectors.

In evaluating the impact of the 40 sites, the aims of the Healthbridge Evaluation were:

- To describe the range of DA and PSN services, their evolution, establishment, delivery and governance characteristics

- To assess these models of service design and delivery in relation to influence on wellbeing, contribution to the objectives of the NDS for England and influence on the wider health and social care landscape
- To identify ways in which PSN and DA services contribute to the wellbeing and resilience of people with dementia and carers.

Methods

Healthbridge adopted a mixed methods approach (Johnson and Onwuegbuzie 2004) to gathering evidence on both the breadth and depth of activity across the 40 demonstration sites (see co-author et al 2013). This approach allowed for strength of evidence to be gathered within the research process through convergence and collaboration of findings from a range of data sources. There were three main strands to the research process: activity and outcome monitoring; organisational surveys and collaborative discussions; and in-depth case studies. Full ethical and governance approval was obtained for the study (SCREC Ref: 10/IEC08/13; ADASS Ref: Rg 10-009).

Sampling and Recruitment

The data presented within this paper focuses on qualitative interviews within the in-depth case study sites. The eight sites (four DA sites and four PSN sites) were selected through a process in which all 40 sites were asked by questionnaire to identify their organisational position and structure; specific target groups; situational demographics of sites and scope and purposes of services (e.g. whether the service focussed on specific or 'harder to reach' communities, including BME communities, and a range of geographical locations (e.g. rural, borough, county). These criteria informed identification of eight sites that were representative of the range of services being

provided across all 40 sites. 80% of the sites, n=32, replied to the questionnaire. The organisational context of the sites included:

- Four were located in the voluntary sector (one a local Mind Association, two within branches of the Alzheimer’s Society and another within a County-wide Memory Café network);
- One was located in the NHS (NHS Foundation Trust);
- One was located in an Older Adults Community Mental Health Team and delivered in partnership with a local council;
- One was located within a local council;
- Two crossed all three sectors, for example one site was hosted by an Alzheimer’s Society branch and supported by local council, NHS and Age UK.

Within each case study site, matrix sampling allowed staff local to the service to identify a pool of potential participants who represented a range of roles within, and opinions of, the service (see Table 1). From this pool, the research team made final selections of participants, continuing to seek diversity of perspective. Continuity within each case study site was maintained by one researcher taking responsibility for the entire process of sampling, recruitment and data collection within each of the sites (see Figure 1).

Core staff and stakeholders	People with dementia and carers	Other stakeholders/people with interest or insight in services
Core staff and volunteers: their role, including whether employed or a volunteer, employer details and length of time they had worked in dementia care	Ten people with dementia: details about these people including whether or not they considered the person to have capacity to consent and if they had a carer living with them; how they had accessed the demonstrator site service; any reasons why it might be inappropriate to contact the person at that particular time and details of any communication challenges (including if an interpreter was needed in the interview process)	Five professional/volunteer staff who had accessed the services: the reason for accessing and the organisation they work in

	Five carers of people with dementia, and details about how they had accessed the service, and other personal information as above for people with dementia	Five people who work in other dementia services locally: their role and how their organisation(s) interact with the demonstrator site
		People who commission services for people with dementia or develop policy that influences services in the locality
		Any local evaluators of the service
		Three people with an opinion about the service (even if the key staff didn't agree with it)

Table 1. Sampling matrix within each case study site.

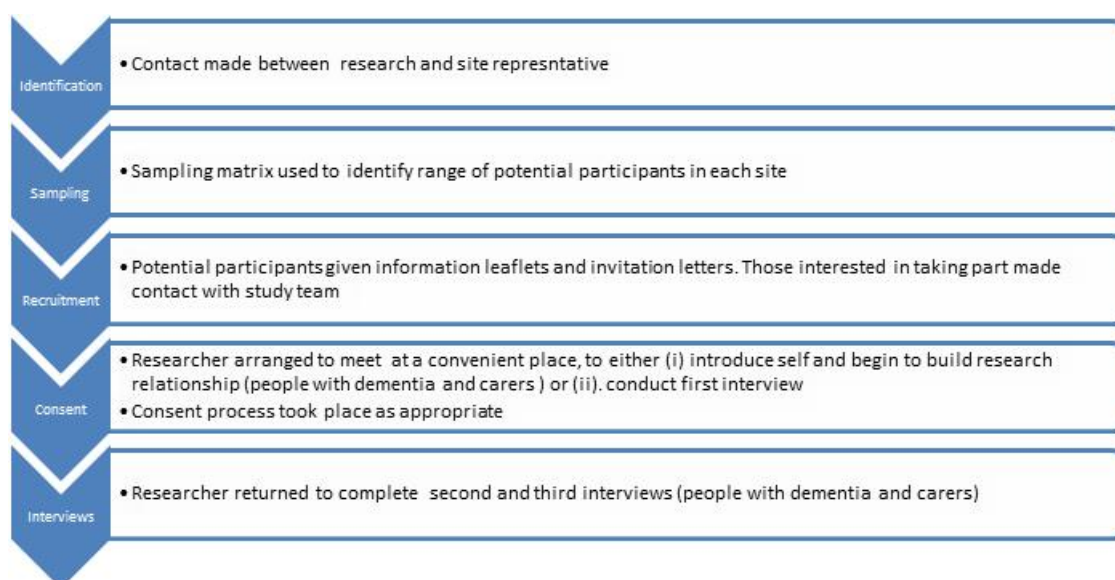


Figure one: process for identification, sampling, recruitment, consent and interviews.

Table 2 indicates the number of interviews in the case studies. Most of the people with dementia taking part in interviews were in the early-mid stages, and all were living at home. The carers who took part were representative of people at all stages of dementia, from pre-diagnosis through to people whose family member was in a care home and carers who had been bereaved.

	Interviews with people	Interviews with carers	Joint interviews	Interviews with staff/volunteers/other
--	------------------------	------------------------	------------------	--

	with dementia on their own	on their own	(people with dementia and carers)	stakeholders
Dementia Adviser sites	17	36	26	40
Peer Support Network sites	29	32	17	42
Total number of interviews	46	68	43	82

Table 2. People interviewed in in-depth case study site interviews.

Interviews

Informed consent with people with dementia was viewed as a process (Dewing 2007) that was grounded within the principles of the Mental Capacity Act (DH 2005), with active involvement from people who knew them well. The emphasis on involvement of people with dementia in the study as a whole, and in particular in the in-depth case studies, was based on the importance of research which actively listens to the views and experiences of people living with dementia (Cheston, Bender, and Byatt 2000; Reid, Ryan and Enderby 2001). Criteria identified by Clarke and Keady (2002) were applied to ensuring that people with dementia were able to articulate and express their perspective as well as ensuring researcher confidence in the data.

Interviews with 101 people with dementia and carers were spread over two or three occasions, allowing time for a research relationship to develop. Eighty-two staff, volunteers, stakeholders and others with a significant opinion of the services mostly taking part in one interview which lasted around an hour. The In-depth interviews were audio-recorded and took place in a variety of settings, as preferred by those being interviewed, including people's homes, venues already used by the demonstration site services, or another public place. Interview topics of significance to this exploration of peer support included: experiences of support within services; ways in which DA and

PSN services had contributed to wellbeing and resilience; accessibility of services, involvement and information and support for making choices and independence. Service staff and other stakeholders also discussed their views and experiences of the day to day running of sites as well as their governance and strategic direction.

Data Analysis

Qualitative data were analysed using the storage and retrieval functions of NVivo9, a computer assisted qualitative data analysis software tool (Lewins and Silver 2007). There were five main stages to the analysis: the creation of initial coding framework using raw data from 25 transcripts; further development of coding framework through process of coding a further 70 transcripts; development of emerging themes with input from the wider evaluation team; visual modelling of themes (an example of which can be found in figure 2, below) and, finally, verification of models and emerging themes using the entire data set. All data that had previously been coded as thematically relevant to peer support were interrogated further to identify what peer support had taken place (aspects); how peer support was enabled (mechanisms); and the impact of peer support described by participants (benefits). Whilst our analysis of data remained sensitive to the two types of sites (DA and PSN), we did not separate the data. This means that data coded at nodes relating to peer support included data from people who had accessed both types of site.

The aspects, mechanisms and benefits of peer support and their interrelationships that were identified in this analysis are illustrated in Figure 2.

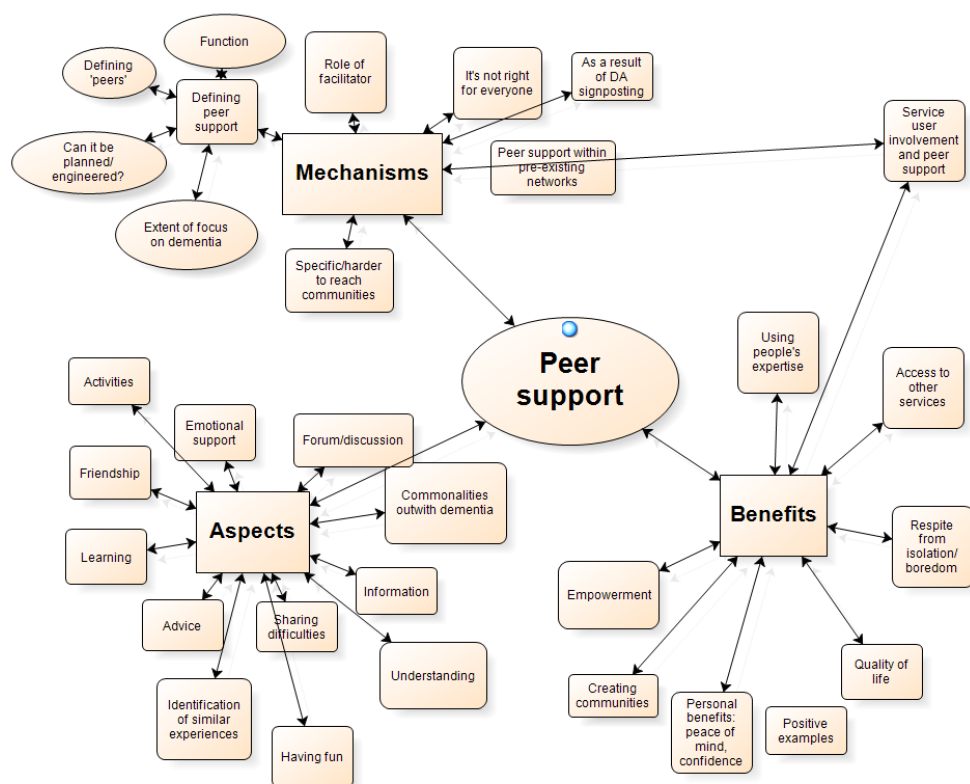


Figure 2. Aspects, Mechanisms and Benefits of Peer Support. Nvivo model created in stage four of data analysis.

In order to contextualise the findings discussed in this paper, the following information is included and was obtained through other aspects of the Healthbridge study (see co-author et al. 2013). We did not have access to detailed demographic information about people who accessed the services, or know of people who were not accessing the services, including service refusals and drop-out rates. This impacts on what we can claim in relation to peer support. What we do know from the data collected within the activity and outcome monitoring is that, of the average of 16 people accessing any one site during any one week, 23% were people living alone and 49.4% were female. Of those in contact with DA services, 37% were people with a diagnosis of dementia. Of those in contact with PSN services, 56% were people with a diagnosis of dementia. Overall, 11.9% of those in contact were people who staff identified as having a BME background, with this being much higher for those sites with a specific focus on BME communities (two such services were case study sites).

Findings

There was considerable diversity in the way in which peer support was undertaken. Some PSN groups focussed on socialising or activities such as gardening and Tai Chi. Other groups focussed more on discussion of dementia related issues. In some instances, all of these were included such that dementia fluctuated in being central or marginal to the support. Some groups involved people with dementia or carers on their own, others were joint, and there were examples of more structured one-to-one support (for example, in one of the case study sites, people were paired with others who were at an earlier stage in the dementia journey). People with dementia and carers who had accessed support from DA services also referred to peer support groups and giving and receiving from others on a one-to-one basis. The supportive atmosphere within the groups was referred to by many, and positive impacts included reduced isolation, sharing of information and advice leading to increased support in maintaining or improving memory.

In the following section, key inter-related aspects of peer support are explored, albeit necessarily briefly, in presenting the perspectives that participants had on how and why, for them, peer support was of positive benefit.

Commonality of experience

People with dementia and carers spoke about support emerging from identification with others who were in a similar position. Suzanne's reference below to people from 'all walks of life' highlights a breadth of previous life experiences of people within the group that she and her husband Jim (who had a diagnosis of dementia) were attending (as a result of signposting from a DA), at the same time as highlighting the significance in commonality of present circumstance:

Suzanne (wife and carer of person with dementia who had accessed a DA service): A huge group of people and, you know, we're both friendly with people that are suffering and obviously their carers as well. So it's quite nice.

Jim: Oh, it is.

Suzanne: And they understand, don't they? Because, you know, it has no...

Jim: Nobody argues with anybody or anything like that. Everything is the same – they're just one happy bunch.

Suzanne: You know, there's people with Alzheimer's from all walks of life, you know. We're all thrown in on the same boat and, you know, you sink or swim.

Jim: That's it.

Reciprocity

The data also contained examples of reciprocity within supportive relationships. The following quote from Jen, a carer who had accessed a carer support group within a PSN site, outlines a journey from feeling alone, through to knowing that she wasn't alone because there were others who had similar experiences, through to hearing about how others have coped with difficulties and learning from their experiences. Jen also suggested ways in which peer support might be extended to people "down the road ahead of us", thus reflecting a reciprocity of support:

Jen, daughter/ carer who had accessed PSN site: First of all the thing of the peer support is know you're not alone. I think the second thing about it is hearing from them how they have dealt with various problems they have come across. What has been happening in their scenario. What might be even better was if... If you like, people down the road ahead of us – like, people who

have relatives who are at a further advanced stage – that they would, sort of, say how they got to the point where they are.

There were examples of both practical and emotional support, often within interactions that encompassed both:

Debbie, daughter/carer who had accessed support from a DA: Lots of different things of meeting different people in the same situation....To talk to people in the same situation, really.

Rae, person with dementia (Debbie's mother): Yeah, it's nice to know you're not the only one.

Debbie: I think it's.....having done some of the courses and things – and you suddenly realise that, you know, mum is always forgetting her keys, or where she's put her keys. And there are people in the same situations that say "oh, my husband does that" or ".....my wife does that" and you think "Oh, good".

Social and emotional impacts

There were also references to the positive impact and quality of relationships that emerged within peer support groups:

Ron, person with dementia who had attended a Peer Support Network group: I have started this one at the cafe, where we... There's... What? 2, 4 – there's 6. 6 of us. That's... [Peer Support Coordinator] takes that one. And we sit there and most of the time we just have a really good giggle, you know. Now I've been there early this morning and it was the first time it's came up about dementia. One of the lads fetched it up, you know. And it was nice to... Nice to actually see. Or rather listen to.

There was an aspect of humour within some of the peer-peer relationships:

Denise, person with dementia who had accessed PSN site: *I think it's mostly because they're other people in the same situation as yourself.....and you can laugh about it and realise that other people are exactly the same. And I think that's really important.*

For many, the social impact of peer support was significant too:

Lillian, person with dementia who had accessed PSN site: *For like 18 months, 2 years, maybe 2½ years, I was just sat in the house every day, doing nothing, really. I mean, my family came to see me and that, but other than that I take my dog for a walk. I... I didn't really know it [peer support group] was there. I knew there would be something out there, but I didn't think I would qualify for being part of it.*

Direct experience

Giving and receiving of information, based on the pooling of resources that had been useful to others in similar positions, enabled a sharing of what had and had not worked for others. People also spoke about a sharing of advice and coping strategies:

Judy, wife/carer who had accessed PSN site: *you get to know other people's you know, little mishaps..... and you seem to settle things up together, you know. And I think that's what it's all about. It's getting to know each other and helping each other.*

Enabling

There were examples of peer support as an enabling mechanism, challenging a medical deficit understanding of dementia:

Denise, Person with Dementia: *Yes. And I've found, since I've been to the [PSN group] and got more confidence, I tend to chat to people more. You know, people on the bus or people you see I town. Whereas I wouldn't do that before. So I think it's helped me a lot. Yeah.....*

.....Definitely. And even my daughter has noticed that.

Interviewer: *Really? Oh, what has she said to that?*

Denise, Person with Dementia: *Well, just different things. "Oh, you wouldn't have done that before" or... You know.*

Quality of peer relationships

Data also provides evidence around the unique quality within relationships between peers, contrasting this with support from professionals. For this particular carer, the distinctiveness lies in people being in the same position:

Gill, daughter and carer who had accessed PSN site: *I mean, talking to [PSN Group Facilitator] I mean she's lovely and she comes up with all the right ideas and everything, but she's not actually in the same position as you. Although she's got everything at her fingertips....she's still, sort of like, you know, a nurse and not a person who's in the same position as you.*

Staff and stakeholders also acknowledged the difference and quality in relationships between peers:

Moazzam, PSN facilitator: *If you're caring for someone, it's all very well talking to professionals, but professionals come and go, I am conscious of that in my own life, my own working life, which is as a nurse up to this point. And I've had a lot of individual case work with people, but then I have moved on to other jobs.....you leave people stranded, but with*

peer support, that real experience that people have is shared.....there's a recognition of each other's' needs.....on an emotional as well as a practical level.

Discussion

Peer support within the services evaluated by the Healthbridge study enabled those engaging with others in a similar position to realise that *“there is life after a diagnosis of dementia”* (Clare et al 2008 pp21-22). The focus was on the realisation that there were others in a similar position, which could lead to friendship, a sense of belonging and re-engagement with life in the context of loneliness, isolation, loss and struggle (as highlighted within work by Clare et al 2008 and Fung and Chein 2002). In addition to reduced isolation, and in keeping with work by Ward et al (2011), peer support amongst people with dementia and carers brought a sense of belonging and social acceptance. Evidence from Healthbridge adds both a breadth and depth of evidence to work which has identified ‘new friendships’ within both formal and informal group environments (Snyder, Quayhagen, Shepherd and Bower 2001). This study also adds to recent literature which has challenged assumptions around capabilities of people with dementia in engaging in meaningful interpersonal interaction (Harris 2012; Sabat and Lee 2012), highlighting the importance of social interaction (MacRae 2011).

This study also demonstrates that exchange of information, advice and coping strategies amongst peers was significant, as was being in a setting where dementia could be discussed without stigma, creating that *“space for collaborative meaning making about dementia away from the imposition of medicalized definitions of the condition, characterised by an emphasis on deficit”* (Ward et al 2011 pp 299-300). Peer support amongst people with dementia and carers which is conceptualised in this way similarly challenges a medical, deficit understanding of dementia. Thus, the evidence on peer

support within Healthbridge promotes a strengths-based approach to interpersonal support. The experiences captured within the data also demonstrates peer support as enabling the development of services which are rooted in direct experience, with all of the benefits associated with 'bottom-up' service design and provision (Mental Health Foundation 2012).

This, in turn, has implications for how we think about dementia and the experiences of people living with dementia. A medical model understanding of dementia would focus on physiological differences in individuals, leading to interventions which seek to treat those differences, leaving people with dementia as unable to do much out-with medical treatment to improve their situation (Gilliard, Means, Beattie and Daker-White 2005). A consideration of what people with dementia and carers spoke about in relation to peer support in this study constructs a different model of intervention in supporting people with dementia and carers - one which focuses on enabling people to live well with dementia (as aspired to by national policy e.g. DH 2009). This includes: overcoming social isolation; learning new ways of coping based on what has worked for others; giving and receiving advice from others; access to services and support as a result of information from others; and the increase in confidence and belief in ability to cope.

The work on peer support also adds to an increasing body of work which shifts the focus away from people with dementia as passive recipients of care towards people with dementia as *'equal partners in the context of dementia care, support and formal services'* (Dupuis, Gilies, Carson and Whyte 2011) with opinions that need to be heard by policy makers as well as by others living with dementia (Weaks, Wilkinson, Houston and McKillop 2012). The significance of peer support in contrast to support from professionals - what Hornillos and Crespo (2012) refer to as *"first-hand knowledge"* - within Healthbridge also adds to the evidence around the unique quality of peer support.

Within their observations and interviews with people with dementia who had attended a peer support group, Ward et al (2011 p300) highlight the role of facilitators in *"behind the scenes work"*, consequently questioning the differences between peer support and 'facilitated friendship'.

Similarly, in exploring the processes and experiences of peer support amongst people with early-stage dementia within the context of professionally led support groups, Mason, Clare and Pistrang, (2005) highlight the significant role of facilitators in enabling support within groups at the same time as ensuring that members do not return to a '*patient role*' (Mason et al 2005 p 107). The role of facilitators within the demonstration sites studies in Healthbridge was clear and needs to be acknowledged, in particular when prioritising peer support amongst people with dementia and carers. However, what this paper demonstrates is that people with dementia and carers rated highly the quality of peer-to-peer relationships which were rooted within *direct experience* of living with dementia, strengthening evidence from previous work (including Fung and Chein 2002; Wang et al 2012; Wang and Chien 2011).

Limitations

There are, of course, limitations to this work. The lack of personal information about participants that was available in the context of the Healthbridge study (e.g. ethnicity, socio-economic class and sexual orientation) means that we are unable to comment on commonality of experience out-with a diagnosis of dementia. Additionally, unless referred to by individual participants, our work does not explore other impairments or illnesses that people with dementia and carers may have been experiencing. Participants were recruited because they engaged with the demonstration site services, and consequently we are unable to comment on the perspective of people with dementia and carers who chose not to engage with these services.

All of the data on peer support presented in this paper provides positive examples of the impact of peer support by and for people with dementia and their carers. However, it must also be acknowledged that there are limitations to peer support (Greenwood et al 2013 pp622-633) and that whilst the arguments in this paper represents a wide-spread support for the impact of peer support from the perspective of a range of people with dementia and carers, peer support cannot and should not be seen as a replacement for the development of other forms of service provision.

The approach to sampling in this study meant that all of the participants were actively engaging with peer support and one can assume therefore, that they found it beneficial. Those who chose not to use the services may of course have held a different perspective which was not accessed in this study. Similarly, it is also important to acknowledge that many people with dementia and carers who were engaging with the demonstration sites were concurrently accessing other services and support (Pillemer and Suitor 2002). Whilst this was the case for most people who took part in Healthbridge, the thematic framework which emerged from the data analysis process (see co-author et al 2013) enabled peer support to be considered as part of a complex framework that encompassed service provision, factors effecting service delivery, insight into mechanisms of enabling, personal experience and mediating factors. Thus, the framework upon which the argument within this paper is based does consider peer support within the complexities posed by the many interacting aspects of people's lives and experiences.

Conclusion

Peer support was appreciated by people with dementia and carers who participated in this study as a meaningful and enriching form of support. Staff and stakeholders at the demonstration sites also recognised the unique potential and nature of peer-to-peer relationships. The data reveals ways in which peer support enabled social interaction, often in the face of previous loneliness and/or social isolation. It was through identification with others in a similar position that peer support enabled people to learn new strategies for coping, sharing information and advice. This learning of new ways of coping, in contrast with support from most professionals, was rooted in the positive impact of interacting with people who had shared the same or similar experiences. In addition to the positive impact of emotional and practical support and understanding, people with dementia spoke about feelings of increased confidence and empowerment.

The work presented in this paper places peer support by and for people with dementia and carers alongside the theoretical and practical underpinnings of peer support among other groups. The work

adds to understandings of dementia, challenging assumptions around interventions which are focussed more on medical and 'therapeutic' intervention and adding to growing work around the capacity of people with dementia to engage in interpersonal interactions. Peer support had a significant role in enabling people to live well with dementia (as promoted by the NDS for England, DH 2009) and should be encouraged and nurtured by all seeking to improve support for people living with dementia.

References

Alzheimer's Disease International (2012) *World Alzheimer Report 2012: Overcoming the stigma of dementia*. London: ADI.

Barnes, C. & Mercer, G. (2006) *Independent Futures: Creating user-led disability services in a disabling society*. Bristol: Policy Press.

Bassett, T., Faulkner, A., Repper, J. & Stamou, E. (2010) *Lived Experience Leading the Way. Peer Support in Mental Health*. Nottingham: Together.

Boisvert, R., Martin, L., Grosek, M., & Clarie, A. (2008). Effectiveness of a peer-support community in addiction recovery: participation as intervention. *Occupational Therapy International*, 15, 205-220.

Cheston, R. R., Bender, M. M., & Byatt, S. S. (2000). Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health*, 9, 471-480.

Chien, W., & Norman, I. (2009). Review: The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: A literature review. *International Journal of Nursing Studies*, 46, 1604-1623.

Clare, L., Rowlands, J., & Quin, R. (2008). Collective strength: the impact of developing a shared social identity in early-stage dementia. *Dementia*, 7, 9-30.

Clarke C.L. & Keady J (2002) Getting down to brass tacks: a discussion of data collection with people with dementia. In: Wilkinson H (ed) *The Perspectives of People with Dementia*. London: Jessica Kingsley.

[co-author et al] (2013) *Healthbridge: The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England*. A Department of Health Policy Research Programme Project (Ref:025/058).

Dennis, C., Hodnett, E., Reisman, H. Kenton, L. Weston, J., Zupinac, J., Stewart, D. Love, L. & Kiss, A. (2009) Effect of peer support on prevention of postnatal depression among high risk women: multisite randomised controlled trial: *BMJ*, 338 (7689), 280-284.

Department of Health (2004) *Choosing Health: Making healthy choices easier*. London: The Stationery Office.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. London:

Department of Health (2005) *Mental Capacity Act*. London: Department of Health.

Department of Health (2010). *Putting People First: Planning Together – peer support and self-directed support*. London: Department of Health.

Dewing J (2007) Participatory research: a method for process consent with persons who have dementia. *Dementia*, 6, 11–25.

Dupuis, S. Gillies, J. Carson, J. & Whyte, C. (2011) Moving beyond patient and client approaches: mobilizing ‘authentic partnerships’ in dementia care, support and services. *Dementia*, 11, 427-452.

Fisher, E. B., Boothroyd, R. I., Coufal, M., Baumann, L. C., Mbanya, J., Rotheram-Borus, M., & ... Tanasugarn, C. (2012). Peer Support For Self-Management Of Diabetes Improved Outcomes In International Settings. *Health Affairs, 31*, 130-139.

Fung, W. & Chien, W. (2002) The effectiveness of a mutual support group for family caregivers of a relative with dementia. *Archives of Psychiatric Nursing, 16*, 134-144.

Gilliard, J., Means, R., Beattie, A. & Daker-White, G. (2005) Dementia care in England and the social model of disability. *Dementia, 4*, 571-586.

Greenwood, N., Habibi, R., Mackenzie, A., Drennan, V., & Easton, N. (2013). Peer Support for Carers A Qualitative Investigation of the Experiences of Carers and Peer Volunteers. *American journal of Alzheimer's disease and other dementias, 28*(6), 617-626.

Hartley Brewer, E. (2002) *Stepping Forward: Working Together through Peer Support*. London: National Children's Bureau Enterprises Ltd.

HM Government (2012) *Caring for our future: vision for 2015*. London: TSO.

Harris, P. (2012). Maintaining friendships in early stage dementia: Factors to consider. *Dementia, 11*, 305-314.

Ho, A. (2007) A peer counselling program for the elderly with depression living in the community. *Aging and Mental Health, 11*, 69-74.

Hornillos, C. & Crespo, M. (2012) Support groups for caregivers of Alzheimer patients: A historical overview. *Dementia*, 11, 155-169.

Johnson, R. & Onwuegbuzie, A. (2004) Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher*, 13, 14-26.

[first author] & Brandon, T. (2012) Mutual Support: a model of participatory support by and for people with learning difficulties. *British Journal of Learning Disabilities*, 40, 222-228.

Klatt, C., Berg, C. & Thomas, J. (2008) The role of peer e-mail support as part of a college smoking-cessation website. *American Journal of Preventative Medicine*, 35 (6S), S471-S478.

Lewins A. & Silver C. (2007) *Using software in qualitative research: a step by step guide*. Los Angeles and London, Sage Publications.

MacKean, R. & Abbott-Chapman, J. (2012) Older people's perceived health and wellbeing: the contribution of peer-run community-based organisations. *Health Sociology Review*, 21, 47-57.

MacRae, H. (2011) Self and other: The importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies*, 25, 445-456

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.

Mental Health Foundation (2012) *Peer Support in mental health and learning disability*. Need2know. London: Mental Health Foundation.

Nakanishi, M. Nakashima, T. (2013) Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health- and social-care systems? *Alzheimer's & Dementia* 1–11

Pillemer, K. & Suitor, J. (2002) Peer Support for Alzheimer's Caregivers: is it enough to make a difference. *Research on Aging*, 24, 171-192.

Reid, D. Ryan, T. & Enderby, P. (2001) What Does it Mean to Listen to People with Dementia? *Disability and Society*, 16, 377-392.

Repper, J. & Carter, T. (2011) A review of the literature on peer support in mental health Services. *Journal of Mental Health*, 20, 392-411.

Sabat, S. & Lee, J. (2012) Relatedness among people diagnosed with dementia: social cognition and the possibility of friendship. *Dementia*, 11, 315-327.

Snyder, L., Quayhagen, M. P., Shepherd S. and Bower D. (1995) Supportive seminar groups: An intervention for early stage dementia patients. *The Gerontologist* 35: 691–695.

Thomson, G., Crossland, N. & Dykes, F. (2012) Giving me hope: women's reflections on a breastfeeding peer support service. *Maternal and child nutrition*. 8, 340-353.

Ussher, J., Kirsten, L., Butow, P. & Sandoval, M. (2006) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine*. 62, 2565-2576.

Wakui, T., Saito, T., Agree, E. M., & Kai, I. (2012). Effects of home, outside leisure, social, and peer activity on psychological health among Japanese family caregivers. *Aging & Mental Health, 16*, 500-506.

Wang, L. & Chien, W. (2011) Randomised controlled trial of a family-led mutual support group programme for people with dementia. *Journal of Clinical Nursing 20*, 2362-2366.

Wang, L., Chein, W. & Ym Lee, I. (2012) An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China. *Contemporary Nurse 40*, 210-224. Retrieved from: Academic Search Elite.

Ward, R., Howorth, M., Wilkinson, H., Campbell, S., & Keady, J. (2011). Supporting the friendships of people with dementia. *Dementia (14713012), 11*, 287-303.

Weeks, D. Wilkinson, H. Houston, A. & McKillop, J. (2012) *Perspectives on ageing with dementia*.

York: JRF.