

I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study

Fiona E. Pison-Young

Sussex Partnership NHS Foundation Trust, UK

Kristina M. Lee

Sussex Partnership NHS Foundation Trust, UK

Fergal Jones

Canterbury Christ Church University, UK

Reinhard Guss

Kent and Medway NHS and Social Care Partnership Trust, UK

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Abstract

In this study we explored the experiences of younger people with dementia (age 60–67 years) using an action research methodology across three phases. Phase One involved interviews with participants ($n=8$). Phases Two ($n=5$) and Three ($n=4$) consisted of two action research groups. Thematic analysis highlighted few difficulties commonly associated with younger people with dementia (e.g. loss of employment). Participants highlighted a need for social support from a variety of sources as well as the opportunity to develop a shared social identity and a focus on remaining strengths. The 'action' (Phase Three) comprised a leaflet written by participants for other people with dementia. The findings suggest there is a need for people with dementia to receive information from people who have experienced dementia and for that information to foster a sense of hope and resilience. Furthermore, the findings support the use of action research methodologies with people with dementia.

Keywords

action research, resilience, subjective experiences, younger people with dementia

Corresponding author:

Fiona E. Pison-Young, Sussex Partnership NHS Foundation Trust, Older People's Mental Health Services, Pepperville House, Littlehampton, West Sussex, UK

Email: Fiona.Pison-Young@sussexpartnership.nhs.uk

Introduction

Younger people with dementia are those diagnosed with dementia before the age of 65 (Ferran et al., 1996). There are around 15 000 younger people with dementia in the UK (Bentham & La Fontaine, 2005).

It is recognized there can be key life stage developmental differences between younger and older people with dementia. For example, younger people with dementia are likely to be experiencing midlife changes. Midlife has been defined as occurring between the ages of 40 and 65 and is associated with periods of peak functioning in many domains including some aspects of cognitive functioning, and the ability to deal with multiple roles and stressors (e.g. employee, partner, parent and financial provider) (Lachman, 2004). Furthermore, younger people with dementia are more likely to be diagnosed with rarer forms of dementia (e.g. frontotemporal dementia, alcohol-related dementia) and, coupled with their young age, this often results in delays in diagnosis or misdiagnosis due to the rarity of cases (Bentham & LaFontaine, 2005; McMurtray, Clark, Christine, & Mendez, 2006).

The experiences of people with dementia

Until the 1990s dementia was largely described from a medical perspective. However, Kitwood (1997) argued for psychological models of dementia in order to challenge the 'malignant social psychology' (p. 45) surrounding people with dementia. He defined malignant social psychology as those processes that undermine the person with dementia through a variety of cultural behaviours including infantilization, stigmatization, disempowerment and mockery.

Currently, there are a number of models to explain the experience of dementia for older people. Psychosocial explanations (e.g. Pratt & Wilkinson, 2003) bring together the psychological challenges that may be present (e.g. feelings evoked by the diagnosis) alongside the personal context of the individual (e.g. their life experiences). These models suggest an interaction between psychological and social context that predict how a person adjusts to their diagnosis.

Similarly, social constructionist approaches (Clare, 2003a; Sabat, 2002) describe a number of different self concepts within which dementia must be incorporated. Again there is an emphasis on the perception and attitudes of those around the person with dementia in determining whether or not these new identities will be positive (e.g. a focus on the remaining healthy attributes) or negative (e.g. being perceived as burdensome) (Sabat, 2002).

The experiences of younger people with dementia

Limited research has been conducted with younger people with dementia exploring their lived experiences (Beattie, Daker-White, Gilliard, & Means, 2002). The majority of studies have focused on younger people's experiences of services, with the predominant outcome to provide written guidelines for services based on these findings (Alzheimer's Australia, 2007; Braudy Harris, 2004; Whiting, 2002). There have also been mixed results with regard to the need and desire for age-specific services and many of the recommendations made could be of benefit to all people with dementia, not just those diagnosed before the age of 65 (Beattie, Daker-White, Gilliard, & Means, 2004; Reed, Cantley, Clarke, & Stanley, 2002).

Owing to the narrow focus of these studies there is also a gap in understanding the experiences of younger people with dementia in a variety of areas, including how people adjust to a diagnosis of dementia at their stage in the lifecycle and an understanding of what is meaningful and helpful for them on a daily basis in order for them to manage their illness and maintain quality of life (Logsdon, 2002).

Involving people with dementia in research

In the UK there has been increasing emphasis on the importance of involving the views of service users when planning and developing services (Department of Health, 1999, 2000). However, the inclusion of the views of people with dementia has been lacking in service development (Cantley, Woodhouse, & Smith, 2005). Studies have instead tended to focus on the views of families and carers as it was believed people with dementia were unable to express their opinions (Freyne, Kidd, Coen, & Lawlor, 1999). However, by not including the views of people with dementia our language for understanding their experiences remains impoverished (Phinney, 2002). Consequently, over the past 5 years, in the UK a number of documents have been produced to support and encourage professionals to include the views of people with dementia in research and service development (Cantley et al., 2005; Care Services Improvement Partnership, 2007a, 2007b; Department of Health, 2005).

Action research

Action research is a research method that assumes knowledge is rooted in social relations and most powerful when produced collaboratively through action (Fine et al., 2003). It is a problem-focused, participant-generated and collaborative approach to investigation that provides people with the means to take action to resolve specific problems (Kilgour & Fleming, 2000; Lax & Galvin, 2002). Younger people with dementia have typically been excluded from research. The majority of recommendations regarding the needs and unique difficulties for younger people with dementia have come from research based on the opinions of professionals and carers (Beattie et al., 2002). The action research methodology is a participatory and action-orientated approach in which participants are fully engaged. It is an emancipatory method that benefits people normally excluded from research, with all participants equally involved in the conclusions of the work (Tee & Lathlean, 2004).

Stringer (1996) describes action research as involving three stages: looking, thinking and acting. This process is cyclical in nature involving a process of looking, then reviewing (looking again), reflecting (reanalysing) and modifying actions based on the findings. It involves the full collaboration of participants at every stage (Ditrano & Silverstein, 2006).

The present study aimed to explore the experiences of younger people with dementia, utilizing an action research design. The hope was that this would allow deeper understandings of not only the challenges of the illness, but also the more positive aspects including what might be helpful and how to maintain a sense of well-being and independence. Collaboration with the participants was hoped to facilitate the development of an action that was both meaningful and useful for this client group (Cantley et al., 2005; Department of Health, 2000, 2005, 2009). Finally, no action research studies involving groups of people with dementia have been described previously. As such,

the study aimed to demonstrate the possibilities of this methodology with people with dementia.

Methods

Study aims

The main aims of the study were to:

- (1) develop a broader understanding of the experiences of younger people with dementia, including what it was like to receive their diagnosis and what particular concerns or difficulties they encountered (including work, finances, social relationships);
- (2) to develop an understanding of the support that has been beneficial, including support from services, family and friends;
- (3) to identify areas in need of change (e.g. lack of appropriate services, information about dementia);
- (4) to draw out the key problem areas with the aim of developing an action based on a problem or problems identified.

Recruitment and participants

The participants were recruited via clinicians within a local National Health Service (NHS) Trust. The following inclusion criteria were applied:

- participants were diagnosed with dementia before their 65th birthday;
- it had been at least 6 months since this diagnosis;
- they had received a brief overview of the research;
- they were deemed to have the capacity to consent (Department of Constitutional Affairs, Department of Health, Public Guardianship Office & Welsh Assembly Government, 2005).

Once participants had been identified, the 'process consent method' (Dewing, 2007, p. 15) was used to establish informed consent. Owing to the progressive nature of dementia, consent was monitored throughout the project and separate consent sheets were completed at each phase of the project.

Eight younger people with dementia agreed to take part in the project. Participants' ages ranged from 60 to 67 years. Participants' demographic information are displayed in Table 1.

Participants came from both urban and rural England. All attended NHS secondary care mental health services and seven were in receipt of specialist services for younger people with dementia. The other participant lived abroad most of year.

Design and procedure

The research utilized the look, think and act approach (Stringer, 1996) across three phases. The following is a brief description of each phase:

- **Phase One** - Looking: participants took part in individual interviews to describe their experiences of dementia.

Table 1. Participants' demographic information

Sex	Pseudonym	Age	Diagnosis	Age at diagnosis	Living arrangements	Ethnicity
F	Amy	63	Mixed dementia	61	With partner	White British
F	Susan	62	Alzheimer's disease	58	With son	Black other
F	Trish	67	Alzheimer's disease	62	Alone (at home)	White/Asian
F	Penny	64	Alzheimer's disease	63	With partner	White British
M	John	63	Alzheimer's disease	61	With partner	White British
F	Alice	63	Alzheimer's disease	62	With partner	White British
F	Bette	63	Alzheimer's disease	62	With partner	White British
F	Julie	60	Alzheimer's disease	58	With partner	White British

- **Phase Two** - Thinking: action research group one, predominantly focused on a discussion of the information collected during Phase One.
- **Phase Three** - Acting: action research group two, predominantly focused on identifying a problem area and developing an action plan.

Data collection

Phase One. A semi-structured interview schedule was constructed following guidelines by Smith (1995) and Patton (1990) consisting of open-ended questions with prompts. The literature on the experiences of people with dementia was used to develop the interview schedule. Two participants were invited to make comments on the face validity and relevance of the questionnaire following their interview. No changes were requested.

Interviews lasted between 20 and 70 minutes (average 44 minutes) and were conducted in participants' homes. Each interview was recorded on a digital voice recorder and transcribed for analysis.

Phases Two and Three. For both groups a brief protocol was devised following guidelines by Greenbaum (1998). However, the information discussed in these groups was largely at the discretion of the participants. The main areas of discussion included:

- exploration of results from Phase One;
- reactions to these results;
- areas for change.

Both groups were held in a local NHS older adult setting and were audio and video recorded for transcription.

Analytic procedure

Phase One. Transcripts were manually analysed using thematic analysis techniques (Boyatzis, 1998; Corbin & Strauss, 2008). These methods consisted of inductive strategies for analysing data starting with individual experiences and developing progressively to more abstract conceptual categories (Charmaz, 1995). Table 2 outlines this procedure.

Phases Two and Three. The action research group data was analysed in two ways. First, transcripts were analysed using focused coding techniques described by Charmaz (1995) and Boyatzis (1998). Analytic codes produced in Phase One provided a framework for analysis. If a new code did emerge this was dealt with using the same inductive techniques as in Phase One.

Second, transcripts and field notes were analysed using the action research interpretative method of concept mapping to monitor the process of looking, thinking and acting through conversation (McNiff & Whitehead, 2006).

Credibility checks

Guidelines for publication of qualitative research were followed throughout (Elliott, Fischer, & Rennie, 1999). To ensure themes generated were a fair reflection of participants' experiences, credibility checks and measures of inter-rater agreement were conducted (Elliott et al., 1999; Howell, 2002). One transcript from Phase One was independently analysed by a co-author (FJ) using the code book of themes. The percentage of agreement between the authors (FP-Y and FJ) was measured using Cohen's kappa (Cohen, 1960). Agreement between raters was 81%. A satisfactory level of agreement is any above 70%, indicating a satisfactory level (Howell, 2002).

Respondent validation (Silverman, 2005) was gained during Phases Two and Three of the project. During Phase Two, themes generated from Phase One were fed back to participants. Participants were invited to comment on the themes identified, with all of those attending the action research groups describing them as fair. During Phases Two and Three, concept maps were used to monitor discussions during the groups. Participants were invited to both take part in this process as well as comment on the representativeness of these maps in describing the conversation between research participants.

Table 2. Analytic procedure for individual interview transcribes

Text	Margin Code	Code	Category	Theme
[Describing the young onset dementia (YOD) group] 'Nice, we all know that we're all in the same boat you know. We've all got something the matter'.	She's describing it as nice that within the YOD group they all share the same experiences. That everyone has similar problems.	Values being with others who share similar experiences	Value of knowing others people with dementia	Sharing a social identity
'We [YOD group members] make a joke about it [dementia] (laughs). Aghh, it's alright, it's alright. Cause everybody jokes'.	She and the group share jokes about dementia. It's alright cause everybody jokes.	Sharing a sense of humour with others with dementia.	Able to share a sense of humour with other people with dementia	

Finally, an audit trail to ensure quality of the analysis and to document the decision-making process was kept by the lead researcher throughout the project (Corbin & Strauss, 2008).

Findings

The research set out to explore the broader experiences of younger people with dementia, including the beneficial support received by younger people with dementia as well as areas in need of change. The research aimed to bring about an action based on the findings. The analysis of the data gathered during Phase One, Phase Two and Phase Three generated 11 themes (Table 3). These themes are discussed in relation to research aims of the project. The action is then discussed separately.

Aim 1: Exploring the experience of younger people with dementia

Theme 1: Age-related difficulties. Overall, there was little discussion regarding the particular difficulties raised with regards to employment, children and other financial concerns. What did surprise people was their age at diagnosis, with the general assumption that dementia was something affecting older people:

‘I think [for] younger people it’s more coming to terms that they’re not managing so well and that they’ve got the diagnosis at such a young age...if I’d been 80 as I said, then that wouldn’t be a problem. I’d say right I’m entering old age, but not at 60 plus.’ (Pam, Phase One)

During Phase Two the lack of discussion regarding specific issues relating to their stage in the lifecycle were raised with the group. Discussion highlighted the ambiguity of the term younger people with dementia:

‘I don’t think I thought of myself as younger.’ (Penny, Phase Two)

Table 3. Themes emerging from the data

Research Aim	Theme
<i>Exploring the experience of younger people with dementia</i>	Age-related difficulties* Reactions to diagnosis* Acknowledging change* Thoughts about the future* Others’ reactions to dementia* Maintaining a sense of self* Saving face*
<i>What has been helpful?</i>	Keeping active and involved* Sharing a social identity* General areas of support*
<i>Developing areas for change</i>	Resilience**

*Themes emerging during Phase 1.

**Themes emerging during Phase 2.

Pam suggested dementia might be a very different experience for someone in their 40s in comparison with someone in their 60s:

‘We’re looking at it from the perspective of our age group of 60, around the 60 age group obviously, but 40 to 50 age group is much, much worse and much harder.’ (Pam, Phase Two)

However, Pam still felt strongly that there were significant differences for all people below the age of 65:

‘The needs of younger people are totally different...They’ve lost jobs, they’ve stopped driving, their income is stopping and the stress factors are completely different...you’re responsible for children, you’ve got a mortgage, you’ve got a business to run.’ (Pam, Phase Two)

Theme 2: Reactions to diagnosis. All participants spoke about their experiences of receiving a diagnosis. Many spoke of the psychological impact including shock and the ongoing impact of this on their lives. As John described, within this was a sense of loss regarding previously held abilities:

‘Just thinking about it, I’m not doing this and I’m not doing that and I can’t remember this and I can’t remember that. It does just get a bit depressing sometimes.’ (John, Phase One)

The shock experienced was, for some, in relation to their age and perception of dementia as an illness affecting much older people:

‘I just took it, it’s dementia, yeah. But then I think I thought, well that’s, old ladies get that, I’m not that old.’ (Bette, Phase One)

Theme 3: Acknowledging change. Descriptions of the experience of dementia often related to changes people experienced, particularly in relation to what they could no longer do, a loss of independence or how their life had changed. This included a loss in social status and an inability to carry out everyday tasks:

‘You know I cook as much as I can, but I can’t, I can’t umm co-ordinate that, whereas normal people can put the potatoes on, put the vegetables on at a certain time, if I’m not told or it’s not put somewhere I can’t do it. I forget about it.’ (Bette, Phase One)

Theme 4: Thoughts about the future. All participants referred to their concerns of what may happen as their dementia progresses. This concern arose in response to meeting others with more advanced dementia:

‘When you see all the other people like in the wheelchairs you know just sitting there, now that worries me because I sat there and I’m thinking “oh gosh, I’m going to get like that”.’ (Alice, Phase One)

It was also frightening for people to imagine a time when they may not realize their memory was deteriorating:

‘The only one [concern about the future] is obviously “will I remember that I’m going dolally?”...sometimes it hits me if I’m sort of walking around doing something and I can’t

remember what I'm doing. And I suddenly think, oh my god, I'm going to be like this all the time soon, I get frightened.' (Bette, Phase One)

Theme 5: Others' reactions to dementia. Often raised was the negative impact of others' perceptions. Typically described were the negative perceptions of the word 'dementia', resulting in a lack of understanding about dementia and a loss as to how to be with people with dementia:

'Some people are absolutely don't understand any of it [dementia] (*sic*). They, it's just like they don't know what to do with it, or you with it (*sic*).' (Julie, Phase One)

Penny described the loss of how to be around people with dementia as a fear of the unknown:

'My grandmother obviously had it and it was laughed about in the family. You know it was kind of she's gone poeey, that was the word that was used, she's gone poeey.... Sad, sad isn't it. People don't like anybody who's outside of their perception of life that's it somehow; I don't know what it is because they're scared of it I suppose.' (Penny, Phase 1)

There also seemed to be a lack of understanding of what was meant by term dementia. Bette described friends not wanting to believe the diagnosis or seeing it as just memory problems:

'Most of them [friends] say "oh no, you haven't got that", you know "I forget things, I do this, I do that" "no you're alright", that's what they say.' (Bette, Phase One)

Bette felt people wanted to avoid her difficulties, particularly her daughter who she felt was afraid of the reality of the illness:

'I think she's [daughter] afraid probably she's more afraid than the eldest [daughter] one. And it comes out that she wants me to keep going.' (Bette, Phase One)

At the other extreme were those who perceived it as what happens in the final stages of dementia:

'I think that probably they would look at dementia as more what happens at the end stages. I think that's what most people's perception of what dementia is.' (Pam, Phase One)

A number of misconceptions were described regarding others' understanding of dementia. There seemed to be a sense that there was an avoidance of a true understanding in order to prevent painful truths.

Theme 6: Maintaining a sense of self. Nearly all participants raised the importance of acknowledging that although they have dementia, there were many aspects of their lives that remained the same:

'To be quite honest I don't really dwell on it [the dementia] too much. Umm, as I say when I go out I happily do what I do and I go places and do this and that and I have no problems.' (John, Phase One)

This was in contrast to how they believed others viewed their circumstances:

'It's only the people who are outside looking in that tend not to actually realise a lot of these people [with dementia] still lead their lives in a reasonable manner.' (Julie, Phase one)

Theme 7: Saving face. Many participants described ways in which they covered up their dementia. Reasons for this surrounded the uncertainty of others' reactions and perceptions of them. Participants described wishing others would keep seeing them as the person they always were and 'normal':

'I haven't said anything to anybody . . . I wouldn't because they see me as I was before.' (Susan, Phase One)

'I just want to be normal, until it's obvious that I'm not.' (Penny, Phase One)

Others saw it as better to tell others that they had dementia, so they could understand their difficulties:

'If it's somebody that we haven't seen for a while then it's, you know, I feel more at ease to say what the problem is than to ramble on not making any sense.' (Alice, Phase One)

Aim 2: Beneficial support

Participants identified two specific areas of support (themes 8 and 9), as well as other general areas of support (theme 10).

Theme 8: Keeping active and involved. Participants spoke of the importance of remaining independent. This could be achieved by finding a reason to keep fighting and not only focusing on deficits:

'Try and do everything that you can, for as long as you can. Don't just sort of sit there and say "ahh I've got dementia and I can't do this and I can't do that".' (Bette, Phase One)

Often related was a need to find ways of keeping busy with things that were enjoyable to the person:

'I'm a painter and a poet and pianist and I type [husband's] letters and I do all sorts of and (*sic*) I do also make cards, paint and make cards.' (Penny, Phase One)

Theme 9: Sharing a social identity. Many participants spoke of the importance of knowing other people with dementia. Related was the importance of being able to share understandings through similar experiences. The following conversation during Phase Two illustrated this:

John: 'It's good to be able to go and talk to people with the same sorts of problems and we have quite a good laugh don't we?'

Penny: 'Yes, it's been lovely to be with other people who are, I mean we've got our own group haven't we?'

Pam: 'That is lovely, yes. To be accepted as you are.'

Furthermore, through knowing others there was a sense people were not facing their difficulties alone:

‘Well it is because they sort of say something and you say “yeah, that’s happened to me”. It’s nice to know that you’re not on your own.’ (Bette, Phase One)

Theme 10: General areas of support. Participants identified a number of general areas of support following their diagnosis, including support from partners, friends and family:

‘The one who lives at home [her next door neighbour] . . . although I don’t want to go in there and say hello, hello, every five minutes . . . I do know he’s there . . . So if I’m in any trouble I can just pop over.’ (Penny, Phase One)

‘Well knowing that I’ve got support and my family support is there for me as well. They all understand what’s going on. That helps.’ (Alice, Phase One)

support through faith and spirituality:

‘I have a very strong faith . . . my faith will keep me strong.’ (Pam, Phase One)

and support from services and professionals:

‘The support I’m getting now is brilliant it really is. Cause you can go to any of them [psychologists] and sort of talk (*sic*).’ (Bette, Phase One)

Alongside this, participants described a number of specific strategies that were helpful:

‘I write things down that I want to get done in the day.’ (Penny, Phase One)

‘I make shopping lists.’ (Pam, Phase Three)

However, these strategies were not always helpful:

‘I’ve never been good at writing things down . . . I’ve never been that way inclined in here [points to head].’ (John, Phase Three)

Aim 3: Developing areas for change

Theme 11: Resilience. The following theme emerged during Phase 2 and formed the basis of the action. There was a sense from participants that being diagnosed with dementia was not a helpless situation. There were still things they could do for themselves. The following are summaries from the group’s discussions.

Participants spoke of the ease in giving up following the diagnosis:

‘It’s very easy, for a condition like this to, if you allow it to, especially when you’re on your own and you play on it, you can let it get to you and it will destroy you very easily.’ (Pam, Phase Three)

Instead there was a need to find ways of focusing on the positives and using intact skills:

‘You’ve got to keep you’re independence for as long as you can . . . If you’ve got an ounce of ability, mentally and physically then I think you must use it to the fullest.’ (Pam, Phase Two)

One way of maintaining this was through managing the illness and maintaining a sense of worth and control. Penny and Pam's conversation highlighted this:

Penny: 'Having somebody ring you and share their problems with you. A friend of mine did that yesterday and that was really good you know because it's like she's forgotten [Penny has dementia], and I'm still Penny.'

Pam: 'And it makes you feel like you've still got a purpose.'

Penny: 'That's right, exactly, exactly.'

Pam: 'Well I think it's very important that we try to keep up our hobbies and interests and if possible, find someone interested to do it with.'

Pam and Penny spoke of the need to find ways of staying engaged with the world. Ideas as to how this could be achieved included finding ways of compensating for the difficulties experienced:

FP-Y: 'Well, has anyone tried anything or found anything helpful when they want to remember something that is important?'

Pam: 'Well I just write it down.'

Penny: 'It's me that's got to remember it. It's the answer I get I can't remember. Perhaps I should carry some bits of paper and write it down.'

Susan: 'I write it down, I always write it down.'

Other suggestions included finding ways to keep the brain stimulated:

'Something like the brain exercises, anything that stimulates your thought processes, crossword puzzles, multiplication, sums.' (Pam, Phase Three)

'I play the piano So that would be a good way of . . . stimulating the brain, so I have to read the music, play at that same time (*sic*), so yeah.' (Penny, Phase Three)

There was a further sense that feeling in control of the dementia was important in accepting the diagnosis:

'I think it's very important to have a positive attitude towards the condition, that you can manage it.' (Pam, Phase One)

In summary, finding ways of staying engaged with the world and maintaining activities, hobbies and relationships were ways in which people could retain enjoyment and meaning in their lives with a sense that giving up would be giving in to dementia.

Action: Producing information for other people with dementia

Participants decided to share their experiences and ideas with other people with dementia through a leaflet. The leaflet aimed to provide support to those recently diagnosed with dementia through personal experience, advice and ways of managing or coping with the illness. The leaflet used personal experiences covering the following areas:

- diagnosis and coming to terms with dementia;
- ways of coping with dementia;
- maintaining a sense of humour;
- the benefit of attending groups and meeting others with dementia;
- keeping the brain stimulated (e.g. crosswords).

Participants agreed the leaflet should be laid out making sure it was:

- easy to read;
- short and sharp;
- built on personal experiences and anecdotes.

The group hoped the leaflet would be available for people attending memory services in the local NHS trust.

Discussion

This study aimed to explore the experiences of younger people with dementia and establish areas for change. An action research design was employed to look at the experience of dementia for younger people, to think about the issues arising and identify areas for change. Areas of change centred on providing information and support to other people with dementia, something the participants felt was lacking during their own experiences. In particular, there was a need to change the perception that life was over following a diagnosis of dementia, and an emphasis was placed on finding ways of maintaining a meaningful life in spite of the dementia. This resulted in the action addressing this through the production of a leaflet to provide information and support to others diagnosed with dementia which specifically included ways of maintaining a sense of meaning.

Being a younger person with dementia

The findings suggest age at diagnosis was a particular area of concern, with participants describing the shock of receiving a diagnosis in their 60s. This is in agreement with previous studies looking at the experience of younger people with dementia, describing the incongruence of receiving a diagnosis often associated with those in their 80s (Braudy Harris, 2004).

Interestingly, the results demonstrated few issues arising as a result of work, financial and retirement difficulties. These areas are often cited in other studies as specific issues for younger people with dementia (Braudy Harris, 2004; Whiting, 2002). None of the participants in the current study described these difficulties personally. One of the reasons for this may have been the age of the participants included here, all of whom were aged between 60 and 67 years. Furthermore, of those who were diagnosed during their 50s, all had already stopped working due to other physical health complaints (e.g. cancer, work injuries).

Relating to their experiences of services, participants did not suggest a need for more services or indeed services for people their own age. Previous reports often describe a lack of age-appropriate services as an area of concern for younger people with dementia (Guss, Hawkins, Lough, & Allen, 2006). However, all participants in the current study were either using or had been offered age-specific services meaning this was unlikely to be an area of concern. Participant accounts also suggested confusion over the term younger people with dementia and queried the meaning of this for people in their 60s. This finding supported previous studies whereby few distinct characteristics typically associated with younger people with dementia had been found, suggesting cut-off points based on age are unlikely to be related to individual needs (Reed et al., 2002).

Difficulties described resulted from the psychological impact of coming to terms with dementia (e.g. shock, fear) alongside the importance of contextual factors (support from friends/family, perceptions of others); including the multiple losses incurred, change in roles within the family and a sense of autonomy and status. This was a consistent finding from previous studies with younger people with dementia but also older adult models describing the experiences of dementia (Braudy Harris, 2004; Pratt & Wilkinson, 2003).

In summary, the findings suggest salient issues concerned age at diagnosis, with the belief that dementia was a disease affecting much older people. Few difficulties usually described as unique to younger people emerged (Roach & Keady, 2008). Reasons for this may have been the age of participants, the fact that the majority had retired before diagnosis and the availability of age appropriate services in the locality.

Coping with dementia at a younger age

Participants described a number of areas helpful to them. In particular, the support and understanding of friends and family was important in allowing people to stay optimistic. This finding supports Pratt and Wilkinson's (2003) psychosocial model of dementia, which suggests social support correlates with more successful adjustment to dementia.

Similarly, others' reactions had a negative impact. Participants described covering up their difficulties to still be seen as 'normal'. They also described others as generally not understanding what a diagnosis of dementia meant. Langton, Eagle, and Warner (2007) describe the sense of isolation and marginalization experienced by people with dementia, resulting from others treating them as different. Participants in the current study were keen to right the wrong perceptions held by people who do not have an accurate understanding of dementia through describing the skills and abilities they maintained.

Key to maintaining abilities were the importance of finding things to hold on to in order to maintain a positive self identity. This included activities, hobbies and finding ways of compensating for and delaying the progression of the illness. In relation to this was the proposed idea that dementia should be seen as a disability with a focus on remaining strengths and abilities (Dorenlot, 2005; Gilliard, Means, Beattie, & Daker-White, 2005).

The action

The action centred on finding meaningful activities and social identities to allow people to retain a sense of identity beyond the dementia. This resonated with principles of recovery. The four elements of which have been defined as: finding and maintaining hope; re-establishing positive self identities; building a meaningful life; and taking responsibility and control (Andersen, Oades, & Caputi, 2003). Likewise participants in the current study spoke of a need to retain hope, find meaningful activities and hobbies, retain a sense of identity and find ways of compensating for their difficulties or slowing them down through particular activities (e.g. puzzles, sums). Whether or not this finding is unique to this age group is unclear. However, recently within the literature there has been increasing recognition of the positive images of dementia, suggesting such concepts would benefit all age groups (Braudy Harris & Keady, 2008).

A further significant emphasis was the need to share experiences and knowledge with others with dementia in order to develop positive social identities (Bond, Corner, & Graham, 2005). This mirrors findings by Clare, Rowlands and Quin (2008) who have described the

benefits of sharing a sense of identity with others as key; not only in developing a sense of well-being in people with dementia, but also in bringing about political and attitudinal change. Their study outlined the development of a shared social identity for people with dementia through a self-help organization. The findings suggested that when people with dementia develop a shared social identity they also develop mutual support, this in turn, allows people to assume new roles and group identification. The participants in this study valued support from others and wanted to reach out to others with dementia in order to offer support.

Methodological limitations

A significant limitation of the study was the small number of participants consulted. Participants ranged between 60 and 67 years of age, were predominantly White-British, female, partnered and in receipt of age-specific services. This lack of variation could mean findings do not represent the broad range of experiences of younger people with dementia.

It should also be highlighted that variations in experiences of dementia at a younger age are often defined by employment status and child rearing responsibilities (Sperlinger & Furst, 1994). None of the participants in the current study were in full-time employment when diagnosed, neither did they have dependent children. Ideally, a greater age spread might have led to a wider variety of difficulties including some of the more typical issues associated with younger people with dementia.

Furthermore, all of the participants had been offered services specifically designed to meet the need of younger people with dementia. The lack of variation in ethnicity and living circumstances may mean that these findings do not generalize to people in other family contexts or from different backgrounds. Future studies would benefit from providing a more diverse view of the experiences of younger people with dementia.

As a final point, this was the first attempt at using action research with people with dementia. Action research methodology requires researchers to be committed to the full participation of participants. Often action research researchers train participants in the skills and understandings necessary to become equal researchers (e.g. Fine et al., 2003). Owing to the cognitive difficulties experienced by people with dementia, the authors decided not to train participants in thematic analysis techniques and thus could be accused of creating artificial collaboration (Fraser, 1990). One way of examining this is to look at the contribution of each group member on the decisions made. From the group transcripts it was clear that this was not evenly spread. Reasons for this may be multiple and include the personalities of participants (Greenbaum, 1998), differing levels of cognitive ability and the lead researcher's position within the group. This raises some interesting dilemmas in conducting action research with people with dementia. In particular, what level of collaboration is acceptable and what strategies can be employed to facilitate more equal collaboration (e.g. matching people for level of cognitive abilities).

However, to respond to difficulties in reaching authentic collaboration with the exclusion of people with dementia from further action research would result in the further silencing of their voices. The present study aimed to find a balance between providing information about the methodology and analysis that was at an acceptable level for participants. Future research would benefit from identifying what is the appropriate level of collaboration when conducting action research with people experiencing a range of cognitive impairments.

Implications for services

The findings suggest a number of practical ways clinicians can provide support to people with dementia. Important for these participants was the value of social support (e.g. family, friends, services and faith groups) whilst also being allowed to develop new shared identities with other people with dementia. Support groups seemed helpful in assisting people in adjusting to new social identities with both participants in this study and previous literature suggesting the importance in providing groups which match participants for both age and disease progression (Yale & Synder, 2002). Clinicians may therefore wish to enable younger people with dementia to meet other people experiencing similar situations through the provision of supportive groups led by professionals (Mason, Clare, & Pistrang, 2005). Where this is unavailable other similar access routes should be explored such as the online Dementia Advocacy and Support International (DASNI) and the wealth of published personal accounts available (e.g. McGowin, 1993; Synder, 1999).

Participants also regarded the strategies and techniques taught to them to help with memory as important, although they highlighted a 'one size fits all' approach as unhelpful. They further suggested the importance of compensatory strategies such as crossword puzzles. Alongside this was a need to find meaningful activities that were engaging for people, and enabled a sense of identity capable of transcending the label of dementia. Braudy Harris and Durkin (2002) suggest a variety of ways in which this can be achieved including pagers, mobile phones and voice recorders.

The action initiated by participants further suggested there was a need for accurate and honest information about dementia from those with direct experience. The messages they wished to convey included the need to find something to hold on to and to remain hopeful for the time they had left. Therefore, alongside person-centred approaches there may also be the need to begin to think about dementia and the person with dementia within a recovery framework (Shepherd, Boardman, & Slade, 2007). That is, to begin to focus on providing services that engender hope, encourage the establishment of positive self identities (focusing on retained skills), promote activities that are meaningful to the person (employment, hobbies) and allow people to take control and responsibility for their own lives for as long as possible whilst also acknowledging the losses associated with dementia and its progression.

Conclusion

The current project suggested a need to begin to draw links with principles of recovery in dementia care. Over the last 20 years person-centred care has become essential in guiding care and services for people with dementia (Kitwood, 1997). Results of the present study suggest people with dementia may benefit from interventions and services that focus on remaining strengths and foster individual resiliencies. That is, services focused on retained abilities that promote independence and a sense of positive self identity alongside a shared social identity with other people with dementia. Future research in this area is necessary to determine how such principles could be integrated within person-centred care as well as exploring whether older adults would also benefit from a similar approach.

The study further raised questions concerning the usefulness of the term younger people with dementia with adults over the age of 60. Questioning further the appropriateness of defining need and experience based on chronological age when many

people the same age are at different life phases with regard to their social, family and work contexts (Lachman, 2004). Future research may shed further light on this question. In particular, it may be helpful to look at a person's stage in the family lifecycle (e.g. child rearing responsibilities) rather than age at diagnosis (Rolland, 1999). A study that includes comparative data looking at the experiences of older adults may also help to separate any variations in experience.

Finally, few studies exist with younger people with dementia and none have taken an action research approach. The current study was a preliminary attempt to conduct action research with this client group. The results demonstrate that people with dementia can and should be included in participatory methodologies, due to the valuable contributions they can offer to the research process (Clare, 2003b; Goldsmith, 1996). Furthermore, through the use of an action-orientated approach participants demonstrated the value in sharing their thoughts with others and were able to use their own experiences to provide support for others which they felt they themselves had lacked. Future research would benefit from more extensive inclusion of people with dementia in this process.

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Fiona Pipon-Young is a Highly Specialist Clinical Psychologist with Sussex Partnership NHS Foundation Trust working in Older People's Mental Health Services.

Kristina Lee is a Consultant Lead Clinical Psychologist for West Sussex Older People's Services in Sussex Partnership NHS Foundation Trust.

Fergal Jones, MA, PhD, PsychD is a Senior Lecturer in the Department of Applied Psychology at Canterbury Christ Church University, where his main role is to teach and supervise research on the clinical psychology training programme. He also works as a clinical psychologist in a Primary Care Mental Health Team in Sussex Partnership NHS Foundation Trust.

Reinhard Guss qualified in Clinical Psychology and Gerontology, Heidelberg University 1989 and has practiced in the NHS since 1991, initially in Salford, and since 1993 in Kent. He is a consultant clinical psychologist with specialist interests in dementia and dementia care from the outset and increasingly in diagnostic pathways, care and support services for younger people with dementia, and is the lead clinician for young onset dementia with Kent and Medway NHS Social Care and Partnership Trust.