Chapter 24

Involving People with Dementia in the Development of a Discussion Forum: A Community-centred Approach

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24.1 Introduction

Dementia has been defined as a syndrome characterised by the development of multiple cognitive deficits including at least one of the following: aphasia, apraxia, agnosia or a disturbance of executive functioning (Cummings and Khachaturian, 1999). There are an estimated 18 million people world-wide with dementia. Dementia primarily affects older people. The chance of having the condition rises with age to 1 person in 20 over the age of 65, and 1 person in 5 over the age of 80 (ADI, 2004). There are many causes of dementia including Alzheimer's disease, vascular dementia and dementia with Lewy bodies (Alzheimer's Society, 2005).

24.1.1 Symptoms of Dementia

The distinction between severe dementia and normal ageing is obvious but establishing the difference between early, mild Alzheimer's disease and age-related cognitive loss can be more difficult (Jones and Ferris, 1999).

The cognitive domain which is impaired first and foremost in Alzheimer's disease is memory (Kertesz and Mohs, 1999). Working memory is often lost in dementia, but the patchy progression of dementia means that even people in the later stages may retain early learning and access to long laid down memories (McIntosh, 1999). Perhaps the most substantial deficits in people with Alzheimer's disease are found in short-term memory tasks that require divided attention (Morris, 1994). Alzheimer's disease is also associated with deficits in various aspects of semantic memory functioning, *e.g.* categorical organisation (Backman, 1998). However, procedural memories are relatively spared (Zanetti, 2001).

Subtle language impairment is usually detectable early in the course of Alzheimer's disease (Kertesz and Mohs, 1999). People with Alzheimer's disease have been shown to be impaired in their appreciation of the relationship between a word and its attributes (Grossman *et al.*, 1996).

Topographical disorientation, *i.e.* difficulty in orienting to, navigating through and feeling familiar with one's surroundings has also been identified as a problem for people with Alzheimer's disease (Pai and Jacobs, 2004).

The symptoms of dementia are not uniform. People with Alzheimer's disease may experience different symptoms at different times. The type and severity of cognition impairment vary from person to person, especially in the early stages (Kertesz and Mohs, 1999).

24.1.2 Involving People with Dementia in Research

Involving people with dementia in research as participants rather than research subjects is a relatively new concept. Once people have a diagnosis of dementia, assumptions are often made that they do not have views about their care and are unable to express their own history (Allen *et al.*, 2003).

However, there is growing recognition that people in the early stages of dementia are able to provide accurate and valid reports of the experience of services provided for them, such as community care (Bamford and Bruce, 2000).

When asked, people with dementia have expressed a willingness to participate in research as they perceive it to be doing something worthwhile (Robinson, 2002). There may also be a feeling of being taken seriously as a capable person again (Dewing, 2002).

Many researchers believe that a collaborative style is appropriate when carrying out research with this population. In such research the person with dementia, carers and researchers explore difficulties and options for their resolution together (Blackman *et al.*, 2003).

24.1.3 Focus Groups and People with Dementia

Because focus groups have been found to be appropriate for research with people with limited power and influence (Morgan and Kreuger, 1993), this method of research has also been used with people with dementia. Group discussions may have a number of potential advantages over individual interview including enhanced quality of interaction, reduced pressure on individuals to respond, mutual support and the opportunity for shared experiences to trigger memory (Bamford and Bruce, 2000).

Bamford and Bruce (2002) have described a study with fifteen older people with dementia where formal focus group discussions took place with four to nine people with dementia. They concluded that focus groups are only suitable for researching certain topics and only with certain groups of people with dementia. For example, focus groups will be more useful for people in the earlier stages of

dementia and to discuss specific issues rather than broad experiences. It was therefore thought that focus groups may be a suitable research methodology for developing a web-site for this user group.

Focus groups have proved a useful tool for finding out about the views of people with dementia about their own day centre. For example, Heiser (2002) describes how a group of people with dementia quickly grasped what the session was about and were forthcoming with their views.

As with all focus groups, interaction may not necessarily be positive. Bamford and Bruce (2002) found that participants with dementia sometimes showed a lack of respect to one another. They feared that negative responses of other participants could undermine a speaker's confidence and feelings of self-worth. Bamford and Bruce have also found that there may be more potential for a dominant participant to exert a significant effect on the findings in group discussions and found problems with parallel conversations independent of group size (Bamford and Bruce, 2002).

Using skilled dementia specialists to facilitate the group has been found to be important, especially in giving prompts to move people on to the next question without leading anyone with answers (Heiser, 2002).

Time is a big issue in focus group discussions. People with dementia often need time to communicate their thoughts, but it has been found difficult to give them this time in focus group settings (Bamford and Bruce, 2002). Researchers advise against trying to tackle lots of topics in one session (Heiser, 2002). Each person's abilities such as speech and thought response time need to be considered so that all contributions are valued and acknowledged. Care should be taken to make sure that people feel included even if not playing an active verbal part or if they do not fully understand. For such a person to feel at ease with a sense of belonging is important (Moyes, 2002).

24.2 A Community-centred Approach to Developing an Online Community for People with Dementia

One of the most significant developments in the field of dementia care has been the focus on personhood (Kitwood, 1997) and people with dementia are increasingly becoming involved in the work of the voluntary organisations such as Alzheimer's Society (Litherland, 2004). Developing communities of people with dementia is seen by the Alzheimer's Society as being very important.

24.2.1 Alzheimer's Forum

Alzheimer's Forum is a web-site that is run by people with dementia for people with dementia. It was established and is run by a small group of people with dementia at the West Kent branch of the Alzheimer's Society. The aim of

Alzheimer's Forum is to 'communicate with people with dementia across the world'. The site features 'contributions from friends' and a 'predicament of the month'. Both features encourage contributions from people with dementia across the country (Alzheimer's Forum, 2005).

The people with dementia at Alzheimer's Forum expressed the wish to have a discussion forum on the web-site. They had contributed to the Alzheimer's Society's main discussion forum (Alzheimer's Talking Point, 2005) but had found it too complicated to use. A preliminary needs analysis has been carried out with this group of people and we decided that people with dementia should be involved at every stage in the development of the Alzheimer's Forum discussion board.

24.2.2 A Community-centred Approach

We have decided to use a community-centred development approach with the goal of actively involving people with dementia in the design of a prototype of the community, and also with the goal of making sure that our design fits with the needs and expectations of our target population.

Community-centred development is participatory. Right from the start, members of the community work with developers to build the community (Preece, 2001).

This paper describes how a focus group of people with dementia was successfully used in a community-centred development approach to inform designers in the first stage of developing prototype discussion forum software for people with dementia. The paper describes the issues surrounding the use of this methodology and the ways in which they were overcome in this study.

24.3 Methods

24.3.1 Participants

Nine people were invited to attend a focus group meeting. The participants were all involved with the Alzheimer's Society either through local support groups for people with memory problems and dementia, or through other services. Therefore they would be expected to be part of any future Alzheimer's Forum online community. One of the participants did not have a diagnosis of dementia. However she attends a support group for people with dementia run by a local branch of the Alzheimer's Society and has memory problems.

One participant was unable to attend the focus group and one participant withdrew on the morning of study.

The final group of seven participants consisted of two women and five men. The age range was from 57 to 82. Educational achievement also varied from leaving school at 15 to postgraduate level. Most of the participants had access to computers at home, but varied in the extent to which they themselves used the computer.

Table 24.1. Details of participants

Participant	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Age	60	67	75	60	57	66	82
Sex	M	M	F	M	M	M	F
Approximate years of education post 15	9	0	8	3	0	5	5
Happy using computers	Nearly	Yes	No	No	Yes	Yes	Yes
Computer at home	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Frequency of computer use	Daily	2 x week	Less than once a week	2 x week	Daily	Daily	2 x week
Use of discussion board	Once	Never	Once	Once	Often	Often	Never

24.3.2 Composition of Focus Groups

The participants were divided into three groups based where possible on their stated ability and ease with using computers. It was decided to group them in this way to ensure that all participants would feel confident about expressing their views. It was felt that bringing together people with similar experience, for example of online discussion forums, would be productive (Kitzinger and Barbour, 2001). It should also be noted that some of the participants already knew each other and some did not.

- Group 1 consisted of three people (2 male and one female aged 57, 66 and 82). These participants stated that they were happy using computers. Both the male participants had extensive experience of computer use, used a computer daily and had used online discussion forums extensively.
- Group 2 consisted of two men (aged 60 and 67) who were fairly happy with computers but had little or no experience of using discussion forums.
- Group 3 consisted of one man and one woman (aged 60 and 75) who were not happy using computers.

24.3.3 Focus Group Discussions

Three different designs were presented for comment.

- Design 1 was a text only design
- Design 2 used a frameset design
- Design 3 used a rich media (Flash) design.

Each design was presented to the participants by a member of the design team. The designs were presented with limited functionality as Flash animations projected onto a screen. Flash animations were used rather than paper prototypes for two reasons. Firstly, design 3 (rich media) would be difficult to represent on paper. Secondly, each design would have been represented by a different number of sheets. It was felt that if this were done it might give to our participants an incorrect impression of the complexity of the different designs.

Each group had a facilitator. The facilitator ensured that each member of the group was able to express his or her views and that members were given sufficient time to understand the concept of each design and to collect and express their thoughts. This is particularly important when asking the views of people with dementia who might have language and cognitive problems. All views of each of the participants were noted.

The facilitator also acted as note-taker. Each discussion session was completely open with no pre-set questions. Participants were asked to imagine using each system and to comment on what they liked or disliked. They were also encouraged to discuss general issues as defined by Preece and Maloney-Krichmar (2003), such as:

- Dialogue and social support – how easy if would be to perform actions such as reading or sending messages
- Information display – how the information is designed and structured
- Navigation – how they would find their way around the system

24.4 Results

24.4.1 Design Assumptions Prior to the Focus Group

24.4.1.1 Design Group

The three designs were developed before the focus group was established. Following a preliminary needs analysis with the people with dementia responsible for Alzheimer's Forum, a small design group was set up. The group consisted of a technical web designer, a HCI research student and someone involved in providing care and support for people with dementia. Following discussions of the literature review, the perceived needs of people with dementia and the technical constraints, this group decided on the three design options.

24.4.1.2 Design Options

Design 1: The text-only design was based on the idea that people with dementia might prefer a design that was very simple. The cognitive load was reduced by only offering a limited choice of options. However, it was thought that people with dementia might have problems with such a design because of the limited availability of cues to establish where in the system the person was and what actions were available.

Therefore the trade-off in this design was between the problems associated with divided attention and the issues associated with 'getting lost'.

Design 2: Design two was based on a frameset design. Although usability guidelines (Preece, 2001a) warn against using such designs, it was felt that such a design might be appropriate for people with dementia. It was felt that the ability to have all options available on the screen at the same time might avoid a feeling of being lost.

Design 3: Design three was an innovative design using Flash. It was felt that a more graphical display might be able to represent better the complexities of the discussion forum.

24.4.2 Results from Focus Group Discussions

The notes of each discussion were analysed and trends and consensus within the groups identified. As the groups were quite small, there was a lot of consensus in opinions within them.

The following tables represent broad categories of comments and indicate which groups voiced each opinion.

Table 24.2. Design 1: text only

Category of comment	Groups voicing this opinion
Clear, simple design but possibly too unfriendly	group 2, group 3, group 1
Liked being able to see message while replying	group 2, group 1
Text boxes too small – need to see whole message	group 2, group 3
Too much scrolling	group 1, group 2, group 3
Unclear where new message and first message would appear	group 1, group 2, group 3
Problems with terminology and where fields should be filled in automatically – comments, reply to message, author/username	group 2, group 1
Difficulty with knowing where you are	group 2, group 1
Unclear how to start new thread	group 2
Relies on meaningful message subjects	group 1
Blank space not explained until reply button clicked	group 3

There was consensus across the whole focus group about the need to eliminate scrolling. It was perhaps interesting that even the more advanced computer users (group 1) found this necessary. The comment about needing meaningful message subjects only came from group 1. This could reflect their experience in using discussion forums. The confusion around the blank space in the design shown by group 3 may reflect their relative inexperience of using computer systems.

Table 24.3. Design 2: frameset

Category of comment	Groups voicing this opinion
Too many complex – too much information and choices on one screen	group 2, group 3
Too much scrolling	group 1, group 3
Problems with printing	group 1

The comments of the experienced users revolved around their knowledge of the problems associated with frameset designs. However, the relatively inexperienced groups found the design confusing.

Table 24.4. Design 3: rich media (Flash)

Category of comment	Groups voicing this opinion
Attractive. Simple – graphics rather than text	group 2, group 1
Can see where you are/takes you through the logic of what's going on	group 2, group 1
Scrolling problem	group 2, group 3
Problem with subject and author tags	group 2
Might need online help	group 2, group 1, group 3
Problem with scalability	group 1

Although this design was thought attractive, all participants were worried about their ability (or the ability of others) to use such an innovative design.

24.5 Discussion and Conclusions

24.5.1 Advantages of Using Focus Groups

Focus groups are used not to get usability information but rather to explore general attitudes on a given topic (Kunaiavsky, 2003). This study has demonstrated that the

focus groups are a useful tool for finding out views and opinions of people with dementia about computer interfaces, but that researchers running such groups need to be aware of the issues involved.

In fact, focus group methodology can be particularly suitable for this group of people. Often people with dementia feel isolated. Bringing this group of people with dementia together was a rewarding experience both for the participants and for the facilitators. This physical coming together will perhaps be particularly useful if this group of people are to become the core community for the development of an online community.

Although the three groups varied considerably in their experience of using online discussion forums, there was quite high agreement in their opinions about the three design options. Grouping people by perceived skills was found to be useful as the groups were able to contribute to the discussion on a level at which they felt comfortable. The female participant in group 1 expressed a feeling that her views were not as important as those of the other members of her group. It would probably have been better to have asked her to join Group 2.

24.5.2 Issues When Using Focus Groups with People with Dementia

Focus groups are often used in this sort of study with people from the general population. Problems associated with using focus groups for user needs analysis in the general population include ensuring that everyone participates and that there is interaction within the group. A quiet location without distractions is important and the mix of people within the group needs to be considered (Brink *et al.*, 2002).

However, this study has shown that traditional human computer interaction focus group methodologies need to be adapted and altered to be an effective methodology for use with people with dementia. The group facilitators in this study came across some of the issues highlighted by researchers in the dementia field (Bamford and Bruce, 2002). These include parallel conversations, where participants talk simultaneously, or domination of the group by individuals. People with dementia were also found to be easily distracted and spent considerable time telling stories about the past or their condition rather than concentrating on the designs. Some participants could not remember discussions about other designs earlier in the day.

24.5.3 The Importance of Involving People with Dementia

Very little is known about the computer-interface design needs of people with dementia (Savitch and Zaphiris, 2005). It is therefore important to find out as much about user needs as possible.

Preece and Maloney-Krichmar (2003) have identified the link between social interaction in an online discussion forum (sociability) and usability. The community-centred approach involves software design, deciding on initial social

policies and development of the community over time (Preece, 2001). Involving people with dementia at an early stage in the development of an innovative discussion forum for people like themselves is vitally important. It is only if a group of people with dementia feel ownership and responsibility for the discussion forum that it will succeed.

From this study it is clear that making assumptions about the needs of potential online community groups is not sufficient, even when these assumptions are being made by people with experience of working with the group in question. The only way to know if the software is suitable is to ask the users.

The clear message for the next phase of the development is that the frameset solution is not a suitable design for a discussion board for people with dementia. This finding is in line with general usability guidelines (Preece, 2001a).

A working prototype will now be developed . It is likely that this prototype will use the graphical interface display but also have text-based alternatives. The prototype will undergo extensive and iterative user testing with people with dementia. The methods used to conduct user testing will be developed taking into account the needs of people with dementia.

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24.6 References

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