http://ebooks.iospress.nl/bookseries/assistive-technology-research-series,
Volume 29: Everyday Technology for Independence and Care. Page3-9, 2011
DOI 10.3233/978-1-60750-814-4-3

Memory aid to structure and support daily activities for people with dementia

Yvonne Kerkhof[1a], Fatemeh Rabiee[b] and Charles G.Willems[a].
[a]*Saxion University of Applied Science The Netherlands.* [b]*Birmingham City University United Kingdom.*

Abstract:
*Objective***:** Use of technology to structure and support the daily activities of the residents in a small scale group accommodation (SSGA) for dementia is a new innovation in the Netherlands. This paper presents: a) the process of development of this new way of structuring activities by describing the making of digital planning boards, b) the findings of a pilot study looking at the experiences of using this device in people with dementia living in a small-scale group accommodation as well as experiences of informal carers and members of staff and c) the process of organizing day structure using this device from the user's perspectives.
Main content of paper: To develop the memory aid a user centered development process was used. After the first development cycle was completed the resulting digital planning boards were placed in the living room of a small scale living group for people with dementia and in private rooms of the residents. The main task of the aid is to support the memory of the residents by structuring the daily activities during the day. This paper provides the experiences of the users including the residents, informal carers and members of staff, issues around implementation and further development..
Method & findings: A qualitative method was chosen, data was collected using semi structured individual interviews with the residents (n=6) and focus groups interviews with informal carers (n=5) and members of staff (n=6). The framework analysis by Ritchie & Spencer (1994) was used to analyse the data. The following steps were applied: familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation. This resulted in the description of the findings based on the following three general themes; the state of affairs regarding the implementation, the needs for further development and the learning experiences acquired during the development.
The occurrence of installation errors, inefficient use, limited ease of use and a lack of knowledge regarding the function and use of the memory aid are highlighted as the most important issues that prevented a successful implementation. However, the majority of the residents were happy with the use and function of the memory aid when it worked. The informal carers were not very positive but indicated opportunities for improvement. This was echoed by the staff, although they saw an added value for the current use of the device. The findings highlighted shared views about ways of improving through adaptation of the software programme and additional technological applications such as Internet connectivity, improving its accessibility by using a remote control, adding videos and photos.
Conclusions: A number of lessons are learned about the use and transferability of this innovation in general health care setting as well as in people with dementia. The process of user centered design and development will be followed to obtain solutions that can be effectively implemented in their living environment.

Key words: memory-aid, dementia, small-scale group accommodation, user centered design and development

[1] Corresponding author: Yvonne Kerkhof Saxion University of Applied Science P.O.Box 70.000 7500 KB Enschede the Netherlands. E-mail: y.j.f.kerkhof@saxion.nl

Introduction

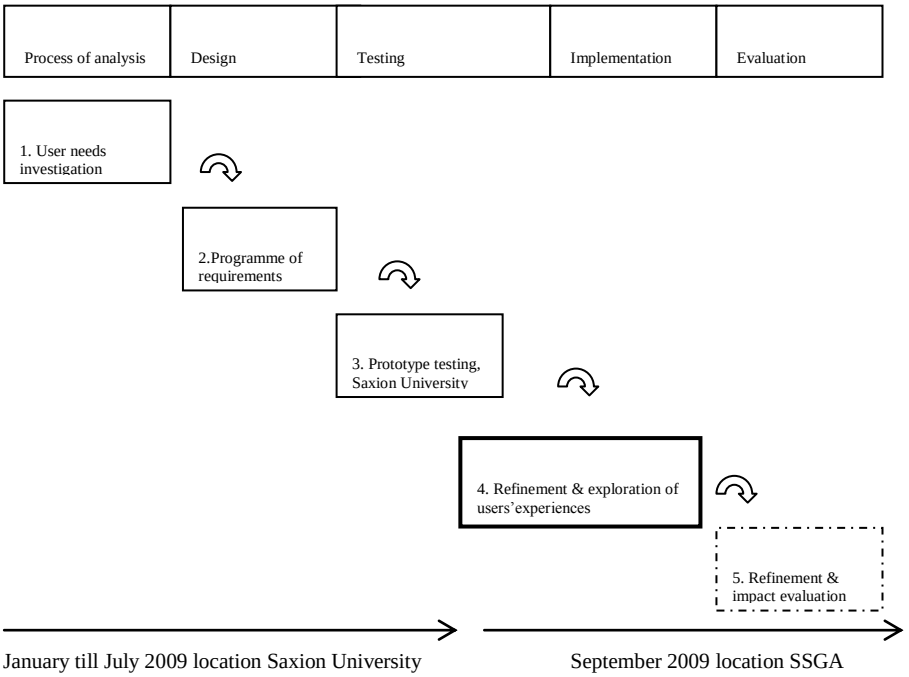
Lucy van de Berg has lived in a small-scale group accommodation (SSGA) for people with dementia for a few years. Because the group is small, she knows her fellow-residents and care providers well and feels at home there. Due to her health condition, Lucy has some difficulty remembering appointments and the fixed activities that take place every day, such as eating, drinking coffee, cooking, etc. She is very annoyed when she forgets an appointment or is late for an appointment. In order to prevent this from happening, she often appeals to the care providers or fellow-residents, but this also makes her uncomfortable. A memory aid in the form of a digital planning board was recently installed in the group accommodation, which states all of the fixed activities of the day and other appointments, including times. She also has her own digital planning board in her bedroom, which displays her personal appointments. This is the ideal solution for her to not forget appointments or to be late. She still occasionally asks a care provider what time she has an appointment, but her care provider points out that she should check her digital planning board. This is a good thing, because eventually, she will manage it herself…

A care organisation in the eastern part of the Netherlands offers care to elderly people, both externally and internally. An auxiliary branch of this care organisation started a SSGA in the spring of 2008 for eight residents, aged between 60-80, with a mild to moderate form of dementia. Characteristic for this group is the diversity of the different forms of dementia in combination with psychiatric problems. The most common form is Korsakov. Despite the diversity, the group was composed in this way due to a number of common characteristics such as functioning independently under the supervision of care providers, by offering a fixed structure with unit rules and trusted people. Due to this memory problems are less in the foreground; however they cannot be left alone.

In this SSGA, the care organisation intends to use technological applications to support the problems involved coping with dementia and to support efficiency of providing care by an effective deployment of people and means. Therefore a joint project was started in collaboration with the Saxion University. An extensive phase of data gathering took place in which the staff of the SSGA was intensively involved in order to get a clear picture of the technological applications. Eventually, the development of a memory aid resulting in digital planning boards for the living room of the SSGA and for the bedrooms of the residents was opted for, which are interconnected via a wireless network. It was agreed that the digital planning boards will focus initially on the support of the resident's memory with regard to the day structure. The daily fixed structure is presented on the planning board in the living room under the photographs of all of the SSGA's residents, such as breakfast, lunch and dinner, etc. It also provides an overview of the specific personal activities, which are not private, such as cycling with the volunteer and housekeeping activities. The planning boards have a touch screen, by tapping on a resident's picture: the plan and activities of the resident concerned becomes more visible. The planning boards in the bedrooms display both private activities, such as taking a shower, a visit to the hospital and other specific personal activities. All planning boards are equipped with a digital clock and a display of the day and date. When it is time for a certain activity, this is

supported by a sound in the living room, and the activity concerned also lights up. The intention is that residents - with help from the staff - can indicate which information they want to share with the other residents and which information can only be viewed on their individual planning board. Staff members have to use a computer to introduce the activities of the residents, which are subsequently displayed on the digital planning boards. Students of the Saxion University carried out the research with regard to the desired design of the digital planning boards. Findings of the research were submitted to and tested by the residents of the SSGA. A definitive programme of requirements came into being on the basis of the following aspects: design, safety, environmental factors, comfort and use. This was piloted by another group of students to ensure the digital planning boards meet its requirements. The digital planning boards were installed in the SSGA in the summer of 2009. In the development of this memory aid, it was pursued that the users were involved optimally by making an inventory of the users' needs and processing the information. This is also called a 'user-driven' or 'user-centered design' [1-3]. Figure 1 gives a diagrammatical overview of the steps in the developmental and implementation of this device. This paper focuses on a pilot study looking at the users' experiences with the memory aid (step 4).

Figure 1 Process of development & implementation of the memory aid.



This study was planned to find out whether an optimal user involvement was carried out during the development of the memory aid, what consequences this has on the implementation and adoption of the memory aid and which learning experiences are relevant to the continuation of this project and its development in the future.

Method

In order to explore the experiences of the memory aids, a qualitative method was chosen and data was collected through individual and focus group interviews. Individual semi-structured interviews with the residents were chosen to get an impression of the personal experiences with the memory aids. All the residents were invited to participate in the interviews to gain maximum information, but it was recognised some residents would not be willing to or able to participate. Despite the fact that 8 residents (and 8 most important carers) gave their consent, only 7 individual interviews took place.

Focus group interviews among staff members and informal carers were appropriate for stimulating interaction and a joint discussion [4] about the effectiveness of the implementation and the ways in which the memory aids need to be developed further. For the focus group interview among informal carers, 8 most important carers were invited to participate. If the most important carer was unable or not willing to participate, this carer was asked to appoint another informal carer from the resident's social network who could replace this carer. Despite the fact that 5 most important carers and 1 informal carer gave their consent only 5 participated in the focus group interview. In a staff meeting, during which the researcher explained the study, all staff members were invited and asked if they were willing to participate in the focus group interview. The plan was if more than 8 participants agreed, the group would be divided into two focus groups. However, in the end only 6 members of staff agreed and were able to participate in one focus group.

The framework analysis by Ritchie & Spencer [5] was used to analyse the data and the following steps were applied: familiarisation, identifying a thematic framework, indexing, charting & mapping and interpretation. The steps ensure a transparent analysis so that policy-makers and practitioners can see that decisions and actions were based on the findings obtained from qualitative methods [5]. The Medical Ethics Committe (MREC) and the Regional Ethics Committee were consulted before this study was performed.

Findings & discussion

The findings indicate a number of issues regarding the experience and use of the memory aid. In summary, the findings on the basis of the three perspectives: residents, informal carers and staff, highlighted:

1. the state of affairs regarding the implementation of the memory aid,
2. the needs for further development and,
3. the learning experiences acquired during the development process.

<u>The state of affairs regarding the implementation of the memory aid</u>

It appears from the findings that the majority of the residents use the planning board, when it worked, although the degree of usage and the degree of support experience differs among the residents. Advantages that are indirectly mentioned include: confidence, peace of mind and convenience.

'Yes, it can say what I have to do at certain times. For example, when I have to eat again. If we eat around quarter past twelve. And that I know that I can have another cigarette at half past two. And when I can have a cup of coffee. This makes things easy'.

Some of the staff also indicates that they see an added value already, for example, that residents respond about activities that have to take place by communicating about these.

'In my opinion, it is not perfect yet. But it already has an added value. I can safely say that. An added value, yes. This mainly concerns the event, showing that there is an activity. Coffee time, dinner time. The tune that can be heard. You are often early or late. And then there is a resident, saying: Hello, the coffee, or dinner, should already be here. Or, we are already having coffee. Just the fact that something is happening up there. I consider that a positive thing'.

This is confirmed by some informal carers, who also mention the advantage that the planning board keeps repeating activities, which increases the recognisability of the activities that take place in a day.

The disadvantages experienced most strongly from the three perspectives are installation errors that often occur, inefficient use, limited ease of use and a lack of knowledge regarding the fuction and use of the memory aid. One resident indicates feeling uncertain when the planning board is not functioning or is not working. As only a few members of staff know what they have to do to solve these installation errors, the planning board is not used by the majority of the staff when these errors occur. When the planning board is working, both informal carers and staff think it is not used efficiently. Residents indicate that there are other ways that help them with memory support, for example, that staff draws their attention to the activities that are taking place and the use of other aids, for example, a personal agenda or medication alarm.

The efficiency can be improved by using the planning board more effectively, making it possible for other aids to be replaced by the planning board. Informal carers suggest that the activities have to be presented to the residents in another way, by adjusting them better to the needs of each resident's individuality, for example, by introducing the times for medication and smoking, introducing activities of housekeeping, which are normally carried out by certain residents, etc.

'For example, if you indicate via the planning board when resident X has to have his/her medication, you have a certain direction in it, a goal for which it is on the wall. Now it just hangs on the wall as an aquarium and nothing else is done with it'.

Overviews like these are of benefit to both the residents' memory support and the effectiveness of care, because the residents' independence is stimulated by this. Orpwood [6] states, that it is better to remind people with dementia than to take their memory from them.

Comparing the three perspectives it can be concluded that the planning board has not yet been sufficiently integrated in the care process, which is why it is experienced as 'extra'. The ease of use of the memory aid is experienced as too complex by informal carers and staff. The members of staff who actively use the planning board indicate that introducing the activities takes too much time and that there is no room for personal creativity. However, the ease of use is strongly influenced by the installation errors and problems mentioned above and problems that occur in the control of the planning board. The planning board automatically turns to a screen saver, showing an aquarium, if it is not touched. Apart from the fact that it is desirable that the planning board is activated automatically as soon as it is time for an activity, the residents, informal carers and staff indicate that the planning board is not frequently touched/operated by the residents, which was the intention originally. For some residents, this is not possible due to physical impairments and another solution will have to be considered. This also applies to other residents who may need more support

and instruction with regard to the use of touch screen or operating the device before concluding that a touch screen is not feasible for this target group. Finally, comparing the three perspectives it can be concluded that the possibilities of trying out were limited to the 'early adopters' [7] and that the use of the digital planning board was hardly experimented by all of the members of staff.

The needs for further development

The findings from the three perspectives show specified needs for improving the use of the memory aid; such as adjusting more to the residents' personal needs with regard to the types of activities and how these should be displayed. However, the needs here differ from the perspectives of the residents themselves and the informal carers; this is often related to the severity of the memory problems (type of dementia). Some residents need a display of the activities in the short term (one day), whereas other residents indicate needing a display of the activities in the longer term (several days). An informal carer indicates:

'For example, they're playing shuffle board tomorrow evening; put that on the planning board. Then they have something to look forward to, but it is just coffee and dinner. And some are fairly clever, for resident X already knows what he/she has to do, and does not need it. So he/she does not check it'.

The same applies to the display of fixed activities that take place every day and the specific person-oriented activities versus the sole display of the specific person-oriented activities, because some residents can remember the fixed activities that take place daily themselves.

In contrast with the residents and informal carers, the members of staff point out the needs much more from the perspective of the residents as a group. For example, that the fixed daily activities should be presented per day on the planning board in the living room and that the more special, person-oriented activities should be presented on the planning boards in the residents' bedrooms.

The informal carers introduced plenty of ideas about all sorts of desirable other applications that should be added to the planning board; the residents and staff were a little more modest. Some residents would like it if the planning boards in the bedrooms were also used for displaying photographs of their children and grandchildren; another resident indicated that there are photo frames for this. The staff would like it if a connection with the Internet were attained, because this would enable the informal carers to introduce personal appointments/activities for the residents by means of an account. The informal carers indicate that an Internet connection would make displaying pictures and images from nowadays and from the old days possible on the planning board, for example, about their place of residence. Actual information can also be retrieved and displayed, for example, the weather forecasts for that day. It was mentioned earlier that the operation of the planning board can be improved. According to the informal carers, this would be possible by activating the planning board by means of a big red button in a central location in the living room.

Other applications mentioned by the informal carers include: contact with family members via a webcam, playing a DVD on the planning board and making an image in an image possible. An example that is mentioned with regard to this is that by placing a camera in the SSGA's chicken coop, the chickens become visible on the digital planning board. This – in its turn – connects to the residents' wish to make the planning board more natural.

The findings show that the needs between residents and their carers (informal carers and staff) can differ. The fact that there is no correlation between these different groups is also shown in various other studies [8-10]. These studies show that responding to the needs of people with dementia outlined solely from the perspectives of the informal carers and staffs is not sensible. It appears from the findings of this study as well as of other studies that people with dementia are capable of participating in research and making their needs clear [8-10].

The learning experiences acquired during the development process

Although the development of the memory aid took place in a user-centered way, this is not always in conformity with the experiences of the users. Both the residents and informal carers indicated that they received insufficient information and instructions regarding the function and use of the memory aid during the development of this project. Most of the members of staff also experienced a lack of knowledge. The findings also show that the informal carers and staff had other expectations regarding the function and use of the memory aid.

'Well, I expected that it would be connected to the Internet and that information from the world outside could be put on it. News paper articles or so'.

The staffs think that the pre-conditions failed to implement the planning board adequately. They experienced a lack of time with regard to giving colleagues good instructions, hence the knowledge regarding the function and use of the planning board is limited to the 'early adopters'.

'*It's all plus this and plus that. You hardly have time to transfer information about the patients. Transferring information about the residents is important, and you do not feel like explaining the planning board on top of that'.*

Issues raised by some members of staff indicate that an experimental phase is necessary to be able to identify the needs for further development adequately.

'And, you know, they see a text. But they do not remember a text. They remember pictures better. But you learn this during the process. We were not aware of that before, this is gradually growing on us. I think the planning board has no disadvantages, we only need to get a great deal more out of it'.

The findings do not only give a clear direction with regard to the further development of the digital planning board, but also provide valuable input for development projects in the future.

Conclusions

The occurrence of installation errors, inefficient use, limited ease of use and a lack of knowledge regarding the function and use of the memory aid are the most important findings that get in the way of a successful implementation. These findings can roughly be reduced to the innovation characteristics by Rogers [7] that need to be developed further to influence the users' attitude towards the planning board in a positive way. In this study, needs and ideas were introduced from three perspectives that can contribute to this. By including the needs from three perspectives, a more complete picture emerges and, moreover, it prevents the needs from the residents themselves to be snowed under. The memory aid offers many possibilities of supporting residents better in the future with their memory function, on the one hand, by meeting the individual needs regarding the display of the activities on the planning board. On the other hand, choices have to be made with regard to this so that the planning board in the living

room is also suitable for the total group. It is important that a new inventory is made on the basis of three perspectives by means of specific examples, with regard to the desired design (the display of the activities, introducing the activities, etc.) as well as other desirable applications (Internet, contact at a distance, remote control, showing photographs, etc.). Lessons were learnt that can have an impact to development processes in the future. Additionally, the findings also provide clear insight into which actions need to be taken to stimulate the further development of the memory aid in this SSGA. Long-term and intensive cooperation is necessary between the care organisation, a software company and the Saxion University. Also in these steps input by users will be organized to improve the use of the resulting applications. The results presented in this paper indicate that also other target groups may benefit from the development of the memory aid provided that their input is also organized during the development.

References

1. Kinzie, M.B., Cohn, W.F., Julian, M.F. & Knaus, W.A. (2002). A User-centered Model for Web Site Design. *Journal of the American Medical Informatics Association.* Volume 9, number 4, pages 320-330.
2. Orpwood, R., Gibbs, C., Adlam, T., Faulkner R., Meegahawatte, D. (2005), The design of smart homes for people with dementia, user-interface aspects. *Universal Access Information Society*. Volume 4, pages 156–164.
3. Sixsmith, A.J., Gibson, G., Orpwood, R.D. & Torrington, J. M. (2007). Developing a technology 'wish-list' to enhance the quality of life of people with dementia. *Gerontechnology.* Volume 6, number 1. Pages 2-19.
4. Bryman, A. (2008). *Social Research Methods.* Oxford: University Press.
5. Ritchie, J. and Spencer, E. (1994) Qualitative data analysis for applied policy research. In, Bryman, A. and Burgess, R.G. (eds.) *Analyzing Qualitative Data*. London: Routledge.
6. Orpwood, R. (2009). Involving People with Dementia in the Design Process-Examples of Iterative Design (pages 79-95). In Topo, P. & Östlund, B. (2009). *Dementia, design and technology, time to get involved.* Assistive technology series, volume 24. Amsterdam: IOS Press.
7. Rogers, E.M. (1995). *Diffusion of innovations.* London: The Free Press.
8. Dröes, R.M., Boelens van der Knoop, E.C.C., Bos, J., Meihuizen, L., Ettema, T.P., Gerritsen, D.L., Hoogeveen, F., De Lange, J. & Schölzel-Dorenbos, C.J.M. (2006). Quality of life in dementia in perspective: An explorative study of variations in opinions among people people with dementia and their professional caregivers, and in literature. *Dementia*. 5, pages 533-558.
9. Orrell, M., Hancock, G.A., Galboda Liyanage, K.C., Woods, R., Challis, D. & Hoe, J. (2008). The needs of people with dementia in care homes: the persectives of users, staff and informal carers. *International Psychogeriatrics.* 20:5, pages 941-951.

10. Roest, van de, H.G., Meiland, F.J.M., Comijns, H.C., Derksen, E., Jansen, A.P.D., van Hout, H.P.J., Jonker, C. & Dröes, R. (2009). What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *International Psychogeriatrics.* 21:5. Pages 949-965.