

Evaluation of an electronic calendar as helping aid for persons suffering from memory problems or cognitive impairment.

by
Torhild Holthe 1, Inger Hagen 2 & Sidsel Bjørneby 3
1 Norwegian Centre for Dementia Research,
INFO-banken
Box 64
N-3170 Sem

2Rugdeveien 6
N-0386 Oslo

3Human Factors Solutions
Øvre Vollgate 7
N-0158 Oslo

The present evaluation is part of the EU project Technology, Ethics and Dementia (TED) under the EU programme Biomedicine and Health.

Summary

Confusion about day and date is frequently observed among persons in the early phases of dementia. Most calendars available require either the ability of logical reasoning or the habit of tearing off a page every day. In cases where such functions are reduced, these calendars are of limited use. In the present study, an electronic calendar where day and date are shown automatically on a small display has been evaluated among 21 persons with memory problems. In order to avoid possible confusion by introducing a new device the design of the calendar was as similar as possible to the type of calendars used in most homes. It consists of a plastic frame with a picture and a display where day and date are shown. The purpose of the study was to examine whether persons who are confused about day and date and frequently ask questions about it would benefit from using the electronic calendar. 19 women and 2 men, age between 60 and 90 years took part in the study. All of them had to be reminded upon appointments, and half of them asked frequently which day it was. The calendar was placed in the user's home for 3 weeks. Registration of the extent of usefulness, usability and acceptability were addressed in a semi-structured interview at the end of the test period.

15 of the respondents used the calendar daily or more often, whereas 3 used it less than once a day, and 2 did not use it. Many of the respondents found it difficult to express effects of using the calendar, e.g. whether they felt less uncertain about day and date, improved confidence by being able to manage daily routines and remember appointments. The usability was found satisfactory by most of the users, but some wanted bigger letters and a more stable foot. 11 of the persons chose to keep the calendar at a reduced price.

It is concluded that the calendar can be useful for persons who are confused about day and date, in particular persons who remember that they have the calendar, who appreciate it when they see it and are not afraid of using a new product. In contrast, it was not useful for persons with poor eyesight, or persons suffering from passivity and lack of interest about day and

date. Ethical aspects as well as methodological challenges in the evaluation of aiding devices for persons with reduced cognitive performance are discussed.

1. Introduction

Description of the problem

Confusion about day and date is a major problem for people in the early phases of dementia. According to Sweep (1), informal carers rated disorientation in time, not knowing how to structure the day, “being lost in the day” as a very big and burdening problem. Also formal carers acknowledged this as a big problem, and mentioned this as 5th priority. Consequences of the disorientation can be e.g. unrest or repeatedly asking questions about the time. Other authors too have found that spouses and family-members experienced repeated questions as a common problem, and this was experienced as burdening next to difficult behaviour and sleep disturbances (2) (3). In particular, persons who still live at home encounter problems due to reduced time orientation, but also some persons in nursing homes or day care frequently ask questions about day and time.

Not knowing which day it is, may have dramatical consequences for a person – it is a fundamental basis of structuring ones life. Not knowing which day it is today may result in the feeling of confusion, uncertainty and lack of self-confidence. Appointments forgotten, be it with the hairdresser, health centre, friends or family, occurs invariably, and induces a negative spiral in function and ability to cope with the daily life.

The different types of calendars available today requires some abilities from the user, either logical reasoning, or systematic habits like tearing off or turning a page, which persons with mental impairment like memory-problems no longer possess. There is thus a need for a calendar which shows the day and date automatically. One such product has now been developed in Norway, based on a micro-processor and an electronic display. The concept was that the calendar should be similar to a calendar with which the elderly already would be familiar.

Purpose of study

The purpose of this study was to evaluate whether persons suffering from confusion about day and date would benefit from an electronic calendar which switches day and date automatically, and to examine if this helping aid could improve disorientation for day and date and help the elderly to feel more safe and comfortable. Also, effects on informal carers/family-members were recorded, e.g. whether they experienced less questions about day and date, the usefulness of the notepad and whether the calendar could be improved in any way to better satisfy the needs of the respondents.

Background

The present evaluation is a part of the EU project “Technology, Ethics and Dementia” (TED) which is a so-called concerted action under the Biomedicine and Health programme.

Torhild Holthe, Norwegian Dementia Research Centre (project leader), Sidsel Bjørneby, Human Factors Solutions and Inger Hagen constituted the Norwegian project group.

Informal carers: Britt Bruaas, Gunn-Helene Larsen. They have assisted in filling out the questionnaires and implemented the calendar by their relatives. They also have given their opinions on the product.

Formal carers: Tove Lepperød, Ragna Fossvold, Unn Lima, Charlotte Eiksjø, Sissel Sandvik, Janne Aker Thorkildsen og Yngvild Zachrisen.

These formal carers have participated in this project by locating respondents and being

responsible for implementation of the calendar, and filling out the questionnaire of the first interview. They were also asked to give their opinion on how they assessed the respondents problems knowing day and date, and about their opinion of the product. Therefore – their opinions are represented in these results.

2. Description of the product

Description of calendar

A picture of the calendar is shown in figure 1. It consists of two plates (15 x 23 cm), a white polystyrene back and a transparent plexi glass front. A picture or notepad support is placed between the plates. One can choose personal photos, pictures of the season or any other picture according to the user's wish. Day, date and month are shown automatically on the display, 2x10 cm, at the lower part of the calendar. The display is controlled by a microprocessor. In programming the processor, consideration has been taken to secure the correct number of days in each month, including leap year. No problems will appear in connection with the year 2000. The text can be in any language. The display is equipped with back-light which improves the contrast and facilitates the reading. A battery eliminator is needed to ensure sufficient power. In case of power failure, e.g. disconnection of the battery eliminator, a small battery will provide power supply to the microprocessor so that the correct day and date will be shown on the display when the battery eliminator is reconnected. The calendar can be placed on a table or hung on a wall. In standing position the calendar rests in a wooden base.

Design

The first prototype was designed by Paul Bencze, engineer and student of industrial design, IDELAB, Oslo, Norway. The prototype was presented to user groups, carers, health personnel, dementia experts and experts on product testing to get feed-back and suggestions for improvement (4). A second model was produced and used in the present study.

Producer of calendar

The producer of the product is Inger Hagen, Oslo, Norway. The electronic part was developed by Per Schjølberg-Henriksen and manufactured by Totenprodukter AS, Gjøvik. The plastic frames were made by Idéplast AS, Oslo, Norway. The development was supported by the programme Centre for Innovation in the Health Sector which is administered by SINTEF, and by SND (The Norwegian Industrial and Regional Development Fund).

Methodological considerations

The evaluation aimed to examine the usefulness, usability and acceptability of the calendar among elderly people suffering from memory problems and/or mental impairment. The concept was that the user would be able to find information about day and date himself, and thereby be less confused about day and date. The calendar might eliminate or reduce the need to ask formal and informal carers. In many cases, such questions are asked so frequently that it may disturb and cause irritation, and thus have negative effects on the relation. Effects on informal and formal carers were therefore also considered. This is further in line with the concept of the social triangle and effects of technology as outlined by Bjørneby and van Berlo

(5). However, the person with memory problems was the main focus.

Evaluation of effects is often connected with methodological challenges, and especially so when the cognitive abilities of the major target group is reduced. One essential question is how to obtain “correct” information from the respondents. Their answers may be biased by e.g. reduced memory, a wish to satisfy the interviewer (too positive reaction) or denial of the problem (too negative reaction). In this study, we aimed to meet these challenges by personal interviews with the user, and by information obtained from formal and informal carers. Taken together, this should give a more nuanced picture of the effects. Since individual differences were expected, it was decided to present the results both at aggregated level and by three case reports.

The interviews were based on three questionnaires. The interviews were semi-structured, and included both closed and open questions. The data from the open questions were later structured after tendency (positive or negative). The questionnaires contained questions to informal carers as well as formal carers.

At the start, the carers filled in questionnaire A – information about the respondent, gender, age, whether she/he lived at home or at a nursing home, kind of help received, and an estimation of how big the problem of not knowing day and date happened to be. (appendix 1) Both a MMSE (Mini Mental Score Examination) and a CDR (Clinical Dementia Rating) assessment were performed, if the respondents had not recently undergone one. Further, it was registered what kind of calendar they were used to, and if the candidate was asking for the time, or managed to keep appointments. The formal carer were asked to do an overall assessment of the problem.

The calendars were placed with the respondents for 3 weeks.

Questionnaire B was a follow-up after 10 days, to check if there were any problems regarding the calendar. It was natural to talk about the calendar and ask if the respondents liked it and used it. Both questionnaire A and B were filled out by formal carers except for 2 cases, where this was done by informal carers.

The final interview, questionnaire C was carried out by the project-leader except for the same 2 cases. In order to get answers that were not influenced by acquaintances, we chose the project-leader (unknown person for the elderly) to do the final interviews. She visited the elderly after having made an appointment.

The final interview had focus on the elderly, informal and formal carers opinions about the usability, usefulness and acceptability of the calendar. And further on what could be done to improve the calendar.

In addition to the meetings with the expert group, we also called the formal carers to a meeting announcing the results. The meeting was planned to take place the 26th of October, and further comments from the carers would be included in the final version of this report.

Costs

The cost of producing 30 calendars for this project was about NOK 1000 a piece. The respondents were offered to buy the calendar for NOK 300 after the evaluation period. Estimated price for one calendar would be about NOK 700.

Study-design

The study design was outlined by Bjørneby and Hagen (6) as illustrated below:

1. Expected benefits in relation to the social triangle:

- persons with dementia
- informal carers/caregivers
- formal carers

2. Expected problems

- persons with dementia
- informal carers/caregivers
- formal carers

3. Pilot study

4. Inclusion and exclusion criteria

5. Ethical questions and implementation

6. Evaluation tools

7. Evaluation results

These points are further described in the following paragraphs.

Expected benefits

The calendar is aimed at providing memory support in the daily life of persons with memory problems when they need to know the day or date. It is expected that this may reduce confusion and promote independence, which further would improve their feeling of being in control of their life. It is further expected that use of the calendar would relieve some of the burden from informal as well as formal carers who have to deal with the frequent questions.

Expected problems

The main problem foreseen would be that the calendar is neglected or forgotten by the user, either because he/she is unaccustomed to it or not interested. The robustness needs to be tested, and the price may be too high.

Pilot study

The first prototype was presented to user groups, formal and informal carers from the carer society in Oslo (PADIO), dementia experts and experts on product development and testing (4). Their feed-back and suggestions for improvement were taken into consideration in connection with the production of the test series.

The dementia experts also commented upon the project outline and were invited to give their comments to the results of the evaluation.

Inclusion and exclusion criteria

Inclusion criteria:

elderly persons suffering from mild to moderate memory problems/ cognitive decline and who frequently ask which day it is
elderly persons living at home and who desire to cope with day and date
elderly persons living at nursing home and who are worried about their memory related to day and date

Exclusion criteria:

Persons with severe mental impairment, if day and date are of no relevance.
Severely visually impaired persons who cannot read the calendar or see the pictures.
Persons that tend to destroy products by picking them apart.

The persons were selected through occupational therapists and nurses working with elderly in the municipality of Tønsberg, Norway. The elderly who were asked to participate were already clients of the home service. In addition, two persons from other regions, Oslo and Telemark, were recruited through earlier contact with their respective informal carers.

MMSE and CDR – assessment tools

A possible correlation between usefulness of the calendar and mental functioning would also be of potential value both for future selection of users and further studies of cognitive aids. From other partners in TED-project it was recommended to use a kind of a screening test for mental impairment.

Mini-Mental State Examination (MMSE) and Clinical Dementia Rating (CDR) were chosen as tests. MMSE is probably the most used examination in the world to assess cognitive functioning in the elderly. MMSE measures memory, orientation, concentration and construction. MMSE however is not sufficient as a diagnostic tool in order to decide whether a person suffers from dementia diseases (7).

CDR is a combined scale which measures several conditions regarding mental impairment. It evaluates memory, orientation, judgement, problem-solving, community affairs, home and hobbies and personal care (8).

MMSE and CDR are common questionnaires in Norwegian health services and these scales were a part of the ordinary tasks for some of the occupational therapists and nurses.

The formal carers interviewed the elderly to get an MMSE-score, and they also made an CDR-evaluation. However, in the material we lack three MMSE-examinations and one CDR-assessment.

The purpose of the calendar was to create a product that would be of benefit for persons having memory-problems, especially for persons suffering from dementia diseases. At first we wished to try out the calendar by respondents suffering from dementia. However selecting respondents having such a diagnosis became impossible, because very few in fact are diagnosed. We therefore had to expand the inclusion criteria to include persons suffering from cognitive problems/mental impairment based on observed and reported symptoms rather than a diagnosis.

Cognitive decline and mental impairment are synonyms and means: "impaired memory and disorientation in an extent that affects the persons ability to take care of him/herself in order to maintain a sufficiently every-day life."(9)

Using MMSE and CDR was also a way to ensure that our selection fulfilled the inclusion criterias.

Ethical questions and implementation

Ethical considerations are of particular concern. It was considered that use of the calendar was unproblematic regarding monitoring or unwanted effects on the user since calendars are a common items in most homes, and the use is fully up to the persons living there. No messages are logged or sent from the calendar used in this study. The ethical considerations are rather connected to the involvement of a person with memory problems or dementia in a research project. The recruitment of persons, the way information is provided and how the calendar is introduced to the user are important issues in this respect.

In addressing ethical aspects of the study, emphasis was laid on providing information to the elderly and his/her carers. It was necessary to ensure that they understood the idea of the project and that they agreed to participate. We claimed a signed informed consent. The ethical issues are connected to have persons with mental impairment joining a project, especially in which way they are introduced to the project and to the product. It is important that the elderly understand what the project means and that they are willing to participate. They must know that the calendar is borrowed for some weeks and that their opinions regarding the product will be included in a broader evaluation. It was emphasised to make the interview situation in a safe and confident atmosphere, and to avoid any feeling of pressure to express positive or negative views. It is also important to pay attention to the question of removing the calendar after 3 weeks if they did not want to buy it.

In order to recruit possible users occupational therapists were invited to an information meeting. In addition, the leaders of two care homes for people suffering from dementia were asked if they had residents that might benefit from the calendar. The project-leader visited the housings, demonstrated the calendar and explained the project plan. All expressed a positive interest. A protocol was written in order to ensure that the implementation process would take place under as standardised conditions as possible.

An application was sent to the Norwegian Social Science Data Services in order to get permission to carry out the study.

We thought it would be important that the implementation was done by a person known to the users. The implementation was therefore taken care of by the formal carers, except for two cases where this was done by informal carers. Relatives were informed, and signed informed consent was obtained from the users.

4. Results

19 women and 2 men, age between 60 and 90 years, took part in the study. 9 of the users lived in their own home, whereas 4 and 8 lived in institution and care home (housings adapted to persons suffering from dementia), respectively. Most of them normally used the page-a-month type of calendar, but newspapers and tear-off calendars were also used by some. All of them were able to read the text on the display when showing it to them. According to the carers, all 21 had to be reminded about appointments, 11 of them asked daily or several times a day about day or date. This caused some problems or was a big problem for 13 of the users. The formal carers thought the calendar would be very or somewhat useful for 19 of the 21 respondents.

The results concerning usefulness, usability and acceptability are given below together with three different case descriptions.

The questionnaires with aggregated results are given in appendix 1,2 and 3.

Usefulness

To evaluate the usefulness of the calendar both actual use as well as the effects of use was examined. 15 of the respondents used the calendar daily or more often, whereas 3 used it less than once a day and 2 did not use it. Of possible reasons for not using it 4 of the carers thought it was because the user forgot about it, whereas 1 respondent felt it was nothing for

her.

Many of the respondents felt that this was a difficult question and hesitated or expressed confusion by asking “what do you mean by that”. Often it was necessary to reformulate the question to “Do you feel more confident having this calendar?” or “Do you feel that the calendar help you to find out which day and date it is?”

Concerning effects of using the calendar, the interviewer`s impression was that positive effects were expressed by 8 users, whereas 6 of the users expressed no effects.

Usability

The usability was found to be satisfactory by most of the users. However, 3 meant that the contrast of the display was poor, and 4 would preferred bigger letters and a bigger display. These persons suffered from visual impairment.

Everybody liked the picture (no answer in 2 of the cases), and one would like to change the picture according to the season. Nobody had tried the note-pad, but one person expressed a wish to try it.

All the users preferred to place the calendar on a table and not on the wall. 3 of them found that the wooden base was not good enough. The calendar sometimes loosened from the base, it was unstable and they thought it might break when pressing the calendar into it.

Acceptability

In order to examine the acceptability of the calendar, the users were asked how much the calendar should cost, both in comparison to some other products as well as actual price in Norwegian kroner. Most of the respondents did not know whether the calendar should cost the same as an alarm-clock or a coffee machine, and felt that 600 NOK would be unacceptable. However, family members and formal carers thought this price was acceptable. 11 of the users bought the calendar at a reduced price (300 NOK) after termination of the test period.

Overall assessment

The overall assessment was positive for 13 of the users, whereas 8 found the calendar less useful and 1 did not answer. The overall assessment was in most of the cases done by the project-leader, after the final interview. The respondents opinion of the calendar led her to assess whether they accepted the product and if it was useful to him/her. In one case the respondent thought the information on the display to be incorrect, and this showed that the calendar was of no benefit for this person.

Case reports

Case 1:

Man, between 60 and 64 years old, living in his own home together with his spouse. CDR: 2. MMSE 24. Informed consent was obtained through the occupational therapist who already knew this client. The calendar was placed on the kitchen-table. His spouse encouraged him to use the calendar. He read the text on the display when using glasses. His first reaction on the calendar was that the text was hard to read. He often forgot appointments and must always be reminded of them. The formal carer maintained that not knowing day and date is a big problem to the man, and that the calendar would be of somewhat use. After 10 days he found the calendar good. He needed glasses to see text and numbers. He looked at the calendar several times a day, and this lead to a feeling of more confidence about day and date. His self-esteem was bettered because he was now able to follow the time better. It was easier for him to be orientated about day and date on his own. Sometimes he forgot the calendar, but his spouse reminded him of it every time he asked for day and date. He found it hard to tell if he

would recommend the calendar to others.

He preferred a picture on the calendar and in his opinion one picture was enough. Further he wished bigger letters – to be able to see the text without finding his glasses first. He found the contrast not good enough.

He has not used the wall hanging device, and he found the foot too unstable and not big enough.

He thought the calendar should be free for persons who needed it. He thought NOK 600,- is far too much to pay for this calendar.

His spouse commented that the calendar was fine, and that it was of help to her husband, and that it was ok to pay for something they could benefit from. She thought that changing pictures was a good idea.

This man hesitated, but with support from his wife he decided to keep the calendar.

Case 2:

Woman, age between 85 and 90 years old, lives in a housing adapted for persons suffering from dementia diseases. CDR: 2, MMSE: 20. Informed consent was obtained through daily manager and nurse at the housing, who also participating as formal carer in this project. The respondent asked for day and date every day, and sometimes forgot appointments – she must have reminders to remember appointments. The formal carer has not decided whether this was a big or minor problem for the woman, but maintained she might have some benefit from the calendar. At the final interview the respondent meant that the calendar was better for every day – she had learned to use it and appreciated it. It made her feel more secure about day and date, and she knew that if in doubt, she could just take a look on the top of the television, where the calendar was placed. She was able to read the calendar at the distance of 2 meters, maybe more. She would certainly recommend the calendar to others. She found the calendar easy to use and of great benefit to her. “Whenever in doubt – I go and check” she said. Family-members expressed that the calendar was fine and practical. The staff made no comments. Why not, is not investigated, but maybe they did not believe this was expected from them, or maybe they simply forgot. This underlines the necessity of giving information and have routines for following up.

This woman wanted to keep the calendar.

Case 3:

Woman, age between 85 – 90 years old. Living at housing adapted for persons suffering from dementia diseases. CDR: 2, MMSE: 20. Informed consent was obtained through daily manager/nurse at the housing. The woman asked several times a day about day and date, and asking the staff was her only way to get that information. She must always be reminded of appointments. The formal carer anticipated that the woman could benefit somewhat from the calendar, but had not decided how big the problem was for her. The calendar was placed by the bedside. She was only able to see the text in the dark, never at daytime, except when holding it in front of her. At the final interview she stated that the calendar was nothing for her. She did not use the calendar and ignored it completely at daytime. She would not recommend the calendar to others, because she was not able to use it herself. She found the display too small and could only read the text at night-time. The size and outlook of the calendar she found fine. She found the price too high and preferred to save her money for her children. She had the local paper delivered at her door every morning, and preferred to read the day and date in the paper. She did not want to keep the calendar.

Discussion

Who might benefit from using the calendar?

One hypothesis was that elderly with high score on MMSE would benefit most from the calendar. We thought that they better would cope having a new product in their house, and also be more able to make use of the calendar. If so, it would mean that it is very important to install this helping aid as early as possible. The results do not confirm that persons with a high MMSE-score benefit more compared to those with a lower score.

Another possible hypothesis was that persons assessed to have a big problem regarding disorientation of time, would benefit most from using the calendar. The formal carers assessed the size of the problems for each of the respondents and disorientation of time was evaluated to be a big problem for 6 of the respondents, caused some problems for 7 and was a small problem for 5. Regarding expected usefulness, 4 were assessed as very useful, 15 quite useful, and 2 do not know. In other words, the calendar was expected by the formal carers to be useful for 19 of the 21 respondents. Why not for the last 2, is not investigated. It could be that candidates were selected to fulfil the quote, and/ or that the formal carer did not know the respondent well enough to assess usefulness to the person.

It seemed that the formal carers were more reluctant than informal carers in assessing the extent of the problem and the expected usefulness. However, the informal carers were more enthusiastic about the calendar's ability to solve problems regarding confusion about day and date. This might reflect the informal carers' perspective on the problem, as a family-member, due to the theory about the social triangle.

However, it is impossible to confirm this hypothesis from the present information.

The material shows that 13 of the 21 elderly evaluated the calendar to be "useful to me", 6 evaluated it to be "not useful to me", 1 says "a little useful" and 2 did not answer the question. In other words the formal carers estimated that 19 persons would find the calendar useful, but at the end of the project 13 of the respondents confirmed the benefit and also wanted to keep the calendar.

The project leader's impression from interviewing 19 of the 21 respondents is that the elderly's personality was of importance. A person who seemed open-minded and not suspicious were more likely to accept the product. It could be that these persons were more likely to accept their memory problems too. Such acceptance may be correlated with age as well. The oldest people may show greater acceptance of memory problems than the younger ones. In fact, there is a tendency towards a higher degree of usefulness in the age-groups 80 years +, - out of 17 persons over 80 years, 11 found the calendar useful to themselves. In other words; age do not exclude benefit! However, since the old group (84 – 90 years) constituted by far the largest number of users in this study, it is not possible to conclude on this question from the present information.

Factors promoting use and usefulness

Everybody liked the picture of the calendar. And the picture indeed had a function as a visual reminder. This is important, because an aid has to attract attention to be of benefit. Only one of the elderly, but most of the informal and formal carers preferred to change pictures according to the season. Normally, it is believed that old information is getting boring, and that new information is necessary to keep the interest. In other words, persons suffering from inattention might ignore old information, but respond positive to a new item. However, regarding persons suffering from poor memory, it would be better to keep the one and only

picture or photo, because this would give the opportunity to recognise and recall on behalf of a reminder. Experiences show that recognition is easier than recalling, and this is a strategy that we try to exploit in the dementia care. For instance to use signs and labels in homes for persons suffering from dementia, gives them the opportunity to get a clue about what is hidden behind a door, before opening it. In that way they do not have to recall what is behind the door, but use the label or sign as a reminder, in order to remember by recognising an item.

The results showed some inconsistency. For example one person meant that the calendar was of great use to her, while she according to the staff in fact ignored it. Furthermore 4 persons told that the calendar was of no use to them, even if they used it once or several times a day. The reason for this inconsistency, in the first case, could be that the person ignored the calendar unless she was reminded of it. During the final interview she was reminded of the calendar, and at that moment it was of benefit for her.

Looking at the “4 false negative” respondents, one explanation could be that they were reluctant to admit the benefit of the calendar in case they might have to buy the product or in some way be responsible for something. Especially in this study we must expect unlogic answers due to the memory-problems. Examples: One of the women did not want to use her money to buy something for herself. She was very eager to convince the project-leader that she managed to know day and date reading in the paper that was delivered at her door every morning. She used the calendar during the test period, but did not admit that it was of any use. Another thought she got the calendar as a present, and did benefit from it. But when realising that she had to pay for it, she did not want to keep it. “I’ll rather manage without” she said.

One question is whether the calendar was placed at the most appropriate place in the respondents` home. None of the respondents had preferred to hang it on the wall despite the fact that this is common in Norwegian homes. Some had the calendar placed by the bed, some by the telephone or TV, and others at the kitchen table depending on the respondents habits and level of functioning. In 2 cases the place of the calendar did not seem optimal, and should have been changed. However, in order to clarify such problems earlier, this question should have been specified more clearly in the mid-term questionnaire (appendix 2), by asking whether several placements had been tried.

Example: When the project-leader came for the final interview, one of the respondents asked “which calendar?” When entering her room at the nursing home, and showing her the calendar she did not show any interest or sign of recognition. The calendar was placed on a little table together with many other objects. The table was in front of the window with curtains and plants, and partly hidden by a chair. The calendar was obviously hardly visible between all the objects and colours, and the respondent was not able to select and pay her attention to this one object.

Some questions concerning methods

Length of test period

In one case we discussed whether the period should be prolonged, because the formal carer expected the respondent to benefit from the calendar after keeping it for a longer period. It maybe asked whether the period should be longer than 3 weeks. During this project we had an unexpected delay because of a strike. When we started, the test period was squeezed in before the start of the holidays. However, looking back, we find 3 weeks to be an optimal time. The calendar was regarded as recently installed, it was a new product, lent them for some weeks. Most of the formal carers did not forget to complete the questionnaire B. And when the project-leader came for the final interviews, the calendar still had the attention as a new installation. We think 3 weeks to try out the calendars were sufficient.

Selection of users

In our material 11 of 21 persons belonged to the oldest age-group from 85 – 90 years old. This skewed age distribution may affect the results. We know that dementia diseases increases with the age, and that the prevalence in the group 80 years and more is 20%. It is assumed today that elderly easier accept their poor memory and complain and talk about their problems. It is also known that persons in the old age-group, 85 – 90 years in particular, are the most common customer of health services in the municipalities today. Daatland states that more than every fourth elderly (above 67 years old), and about 60% of the population above 80 years old are consumers of the health services for the elderly(10). In our study some respondents were not able to cope: one of them did not understand how the calendar worked and removed the plug. Another did not believe the information on the display to be correct.

Questionnaires

Another aspect concerns the use of a questionnaire. Many persons suffering from mental/cognitive impairment have lost their ability to abstract thinking. The questions therefore have to be carefully planned in order to be sufficiently concrete. It seems important to avoid technical words like “effect” and “acceptability” a to minimise the number of questions. We recommend to create an atmosphere that allows a dialogue about the product amongst other things. If the researcher is too eager to have all the questions answered quickly, the respondent may feel confronted beyond her/his abilities and reactions may be aggressive or very anxious. This happened for 3 – 4 of the respondents in our project. For future research this issue should be emphasised. Maybe we have to involve informal carers to a greater extent than we did this time.

Ethical aspects

Some of the respondents did not remember the calendar and were afraid that they had lost the object. (lost another persons property).

One person had totally forgot that she had the calendar. She got very confused, upset and got heartache when she could not find what the project-leader asked for: the calendar. Later we discovered that the calendar had been removed from her flat, because she always unplugged it, - she neither understood the use of it, nor recognised it as a calendar.

It is important to ensure that the respondent not suffer any inconvenience, and we underline the importance of giving information to project-members to avoid situations like this.

Some thought that family-members already had paid for the calendar, or that the calendar was a birthday-present, and did not understand that they had to pay or return the calendar. This happened to be difficult situations; one person insisted that he had paid for it and the interviewer said he had not. How solve a issue like this, when not knowing relatives or formal carers should be discussed in advance.

Do we get the right information? A few (2 persons) found it was difficult make assessment, and compensated by being over-enthusiastic. This can be a problem because their wish to keep the calendar is in conflict with family-members/staffs opinions based upon observations of the situation.

This can be a dilemma because one has to take the persons wish seriously. Maybe one solution could be to ask the carers first and the elderly afterwards, and in this way avoid giving the elderly the decision of buying the calendar or not.

A few thought the calendar was too expensive, and felt they had to buy something they

thought they could not afford. Others said no thanks to a product they really could benefit from, because of the price. Both these examples describe the problems of not knowing the situation regarding prices and costs. People who suffer from dementia will often be able to remember old times, while what they had for dinner today can be impossible to recall. “Living in another time” is a saying, and regarding their opinion of the prices we must expect this to be a difficult question for many of them. Because of that the question was reformulated to “as much as a clock” and “as much as a coffee-machine” instead of prices. In spite of this it was hard to get any answers.

A respondent early in the interview said that she did not want to keep the calendar, and it was hard to get any information about how she liked it, or what she found positive and negative. The person is not interested in the product and further questions can seem like a sales-trick or an attempt to persuade the person.

This can be a difficult situation – as an interviewer you will be eager to have the respondents opinion of the product, and might overlook the persons reluctance to answer the questions.

At the final interviews the project-leader realised that some of the respondents believed she was a salesperson. This was a surprise. She was neither prepared for questions about where to repair the calendar, nor about the conditions for guarantee. If the calendar had been free for the respondents participating in the project, it might have given unrealistic answers, because some might feel they had to speak well about a product given to them. We decided that the calendar should cost something, in order to assess whether the respondents were willing to pay for a benefit, or just as a opinion of the value of the product. However, many of the respondents needed advice from their relatives in order to buy the calendar.

Conclusions

The calendar can be useful for persons who are confused about day and date. The tendencies in our study was that persons that particularly found the calendar useful and easy to use were: the elderly who can remember that they have the calendar – are able to learn new routines
the elderly who do not remember the calendar, but appreciate it once looking at it – are able to recognise an object and appreciate the reminder
the elderly not afraid to use new things/products
The calendar can for these persons mean safety and security in every-day life and be of good help as an aid for orientation of day and date.

The reasons observed for not being useful were:

poor eye-sight/visual problems

lack of interest or passivity towards the environment – do not care which day it is

confusion and lack of understanding, or complete ignorance.

The hypothesis that people with a high score on MMSE would benefit most from the calendar is not confirmed. It seems like other factors also are involved. Regarding the other hypothesis about age and benefit, the results confirm a tendency that persons in the age-group 80 years and more meant that the calendar was useful to them.

Furthermore the placement of the calendar was of great importance. It must be placed a common and spectacular place, not hidden among other things.

Regarding the test, it is important and necessary to collaborate with the informal carers and relatives about the implementation-process and the final assessment. In this way the information about the calendar can be repeated and understood by all. This would also give an opportunity to plan the final interview together with the carers, in order to make this situation as safe and convenient as possible for the respondent.

References:

(1) Sweep Marij: "Technology for people with dementia: User Requirements". (TED Workpackage 2) 1998, Eindhoven University of Technology

(2) Haugen, Per-Kristian: "Aldersdemente i hjemmemiljø. Familieinnsats og offentlige tiltak" NGI-rapport 9/85, Oslo ISSN 0332-9593

(3) Zarit, S. H.: "Behaviour disturbances of dementia and caregiver issues", Int. Psychogeriatrics, 1996, 8 Suppl 3; 263-8; discussion 26-72

(4) Hagen, Inger: "Evaluation of the electronic calendar. Report from a pilot study", 1998, Human Factors Solution

(5) Bjørneby, Sidsel & van Berlo, Ad: "Ethical Issues in the Use of Technology for Dementia Care" The Akon Series "Ageing in the Contemporary Society" vol 13, 1997, Akontes Publishing, Kneqsel

(6) Bjørneby & Hagen: "Evaluation Protocol for evaluation of calendar "Forget-me-not", 1998,

(7) (8) Kjeldsberg, Anne-Britt: "Håndbok for skalaer i klinisk alderspsykiatri". INFO-banken 1996, ISBN 82-91054-40-1

(9) Brækhus Anne: "Demens og bilkjøring". INFO-bankens temabøker 1998, ISBN 82-91054-51-7

(10) Daatland, Svein Olav: "Søkelys på eldreomsorgen. Tilgang til tjenester og bruk av ressurser – før, nå og framover" NGI-rapport 4, 1990, Oslo, ISSN 0332 9593