TECHNOLOGY FOR PEOPLE WITH DEMENTIA:

USER REQUIREMENTS

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Eindhoven, September 1998
IGT/98.319
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This research is part of the European project Technology, Ethics and Dementia (TED).

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SUMMARY

This report explores the user requirements of technology for people with dementia in home care situations. Central are questions on utility and usability: Utility: which are the main problems and needs of people with dementia and their caregivers to support with technology? Usability: How must technology be designed in order to be user friendly for people with dementia and their caregivers?

These questions were asked at professional caregivers, in questionnaires and structured interviews. The study resulted in a selection of twelve most important problem areas, and in general guidelines for the development of technology for people with dementia.
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GENERAL INTRODUCTION

This research is part of the European research project Technology, Ethics and Dementia (TED). Overall goal of the TED research project is to support people with dementia to live with dignity, comfort and safety in ordinary housing in the community and to support the informal and formal carers, with help from technological solutions. The aim is to implement integrated technological solutions in ordinary housing and to assess ethical issues inherent in the use of technology.

The work for TED has been divided into different work packages. All participating countries carry out the work in the different work packages. For each work package one country is responsible for the plan, framework, collection of information and report. The Institute for Gerontechnology of the Eindhoven University of Technology is responsible for the second work package: User Requirements.

The framework for user requirements is derived from an empirical study carried out in the Netherlands and comments from the other TED-partners. Basic to the study is workpackage 1: the user analysis and the description of user needs.

There is much research available on age-related changes and the impact on (the use of) technology (Bouma and Graafmans (eds) 1992, Graafmans, et al, 1998). Research has been done into designing for elderly people. Pirkl and Babic (1988) formulated general guidelines for designing for elderly, based on age related physical changes. There is also literature available on designing environments for people with dementia. Cohen and Weisman (1991) e.g. have published on institutional living and architectural answers on problems and needs resulting from the dementia syndrome. There is at the moment much awareness on the fact that the environment and architecture of institutional care has great impact on the well being of people with dementia and can be stimulating and compensating.

This awareness is not yet found in the home-care situation of people with dementia although the majority of the people with dementia live at home. At the moment there is neither much technology (nor research) available to support the independent living people with dementia and their caregivers.

The aim of this part of the TED-project, the User Requirements, is to explore the possibilities of technology in the home care and to identify user requirements of technology for people with dementia and their caregivers, based upon the results of work package 1, the User Needs. The identification of user requirements is an essential step in ensuring that the design and development of technology will meet the needs of people with dementia and their caregivers. Basic dimensions of user requirements are utility, usability and acceptability.

The acceptability of technological solutions depends partly on the utility and the usability. For another part the acceptability of technology depends on bigger ethical questions and dilemmas that are involved, e.g. the dilemma between beneficence and autonomy, the possible conflicts of interests, decision processes. These questions are described in work package 1 and were discussed in the TED-workshop on ethical issues in use of technology for dementia care (Björneby and van Berlo (eds), 1997).

Central in this report are questions on utility and usability:
A. Utility: which are the main problems and needs of people with dementia and their caregivers to support with technology?
B. Usability: how must technology be designed in order to be user friendly for people with dementia and their caregivers?
In part A the results on utility aspects are described. This part of the user requirements study has been based on user needs analysis, which were carried out among primary caregivers (Sweep, 1997). The results are summarised in a top 12 of problems according to informal and formal caregivers of people with dementia. Subsequently, this top 12 list was used to choose for 5 products, which were further worked out in the reinforced action. (In the reinforced action new products are developed, adapted and/or purchased, and implemented and evaluated in home care situations).

In part B the results of inquiries for usability aspects are given. These inquiries have led to a first set of general guidelines for designing technology for people with dementia and their caregivers.
Part A. UTILITY

FROM NEEDS/PROBLEMS OF PRIMARY CAREGIVERS TO A SELECTION OF TECHNOLOGIES TO ASSIST PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS.

1 INTRODUCTION

Part A gives the results of research into the utility of technological solutions: the needs and problems of people with dementia and their primary caregivers, the priorities for technological solutions and the arguments given for the priority. Basic material for the research is an earlier study carried out by us into needs and problems of primary caregivers (Sweep, 1997). The practical aim of the present study is to support the reinforced action of TED: the development or adjustment, implementation and evaluation of technological solutions to assist independent living people with dementia. Technology is to be adjusted to the special needs of the target group. The choice for the needs/problems and technological solutions that will be the subject of the sub-project, will be bottom up. That means that the choice will be based on the needs and problems of the target group, the priority that is given on the various needs to be met with technology and the arguments given for the priority. Possible technological solutions are taken into account in the selection process.

Questions in this study are:
- Which problems of people with dementia and their caregivers have priority in the search for and evaluation of technological solutions?
- Which arguments are used for making a selection?
- What kind of technological solutions is one thinking of?

In the following paragraph you will find results of an earlier study into needs and problems of primary caregivers and the priority they make. The results of this study will be the basic material for the present study. In the third paragraph you will find the research questions, the methods and materials. In the fourth paragraph you will find the results. In paragraph five, you will find conclusions and discussion.

2 NEEDS AND PROBLEMS OF PEOPLE WITH DEMENTIA AND THEIR INFORMAL CAREGIVERS

A first step in the process to describe the utility dimension of user requirements is to determine the needs and problems of people with dementia and their informal caregivers. In research carried out by Sweep (1997) a total of 10 primary caregivers were thoroughly interviewed on the care they give at their dementing relative and the problems they meet. The aim of this study was to identify possibilities for relief of burden on the caregiver and indicate areas for implementation of existing and new technologies. One of the results of this study was an inventory of (practical) problems and needs of people with dementia and their informal caregivers.

The problems were classified in the following categories:
1. Acting of the demented person, subdivided into:
   a. Activities of daily living (ADL)
b. Instrumental activities of daily living (IADL)
c. Time spending
d. Communication

2. Memory and orientation of the demented person, subdivided into:
a. Memory
b. Orientation in time
c. Orientation in space
d. Orientation of person

3. Safety of the demented person and his environment

4. Problems with supervision

(The complete inventory can be found in the annex.)

The first question to be answered for the TED sub-project is: which problems have priority in the search for and evaluating of technological solutions, according to primary caregivers? The ten primary caregivers in our research mentioned a large amount of problems. In the inventory the frequency in which the problem is mentioned is given. The burden resulting from the problem is however different for each interviewed person. When talking about burden, one has to make a distinction between objective burden and subjective burden. The objective burden involves a number of factual aspects about the care-giving situation. The subjective burden involves the way the caregiver perceives and gives significance to these objective aspects (Duijnstee, 1992). In other words, we do not only have to look at the frequency of the problem, but specially to the experienced burden as a result of the problems.

Closer analysis of the data of the in depth-interviews revealed a number of problems that are not only more often mentioned, but also meant a high amount of overload on the primary caregiver. Those problems are found in the table below.

Table 1. Priority according primary caregivers, according to frequency and burden (not in order of appearance)

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL/safety</td>
<td>5 (3a,2p)</td>
<td>disequilibrium/risk of falling/mobility</td>
</tr>
<tr>
<td>IADL/safety</td>
<td>7 (5a,2p)</td>
<td>domestic equipment too complex to handle</td>
</tr>
<tr>
<td>Time-spending</td>
<td>6 (1a,5p)</td>
<td>loss of usual ways of time-spending/keeping dementing person busy, activated/</td>
</tr>
<tr>
<td>Communication</td>
<td>6 (5a,1p)</td>
<td>handling the telephone</td>
</tr>
<tr>
<td>Communication/safety</td>
<td>6 (4a,2p)</td>
<td>alarm-system/control from a distance</td>
</tr>
<tr>
<td>Memory</td>
<td>4 (3a,1p)</td>
<td>loosing money, keys, administration</td>
</tr>
<tr>
<td>Memory/safety</td>
<td>6 (5a,1p)</td>
<td>failing to switch off domestic equipment</td>
</tr>
<tr>
<td>Orientation in place/safety</td>
<td>6 (5a,1p)</td>
<td>wandering</td>
</tr>
<tr>
<td>Orientation in place/safety</td>
<td>4 (2a,2p)</td>
<td>no understanding of the traffic</td>
</tr>
<tr>
<td>Orientation in time</td>
<td>8 (5a,3p)</td>
<td>structure the day, unrest over appointments and dates, inability to tell the time</td>
</tr>
<tr>
<td>Safety</td>
<td>4 (4a)</td>
<td>fear for criminality against dementing person</td>
</tr>
<tr>
<td>Supervision</td>
<td>8 (4a,4p)</td>
<td>24 hours supervision of dementing person</td>
</tr>
<tr>
<td>Supervision</td>
<td>8 (4a,4p)</td>
<td>having no time for oneself</td>
</tr>
<tr>
<td>Supervision</td>
<td>9 (4a,5p)</td>
<td>continuous fear for unsafe or problematic situations (e.g. fire, criminality, malnutrition, poisoning by medicines, water damage, falls, panic of dementing person)</td>
</tr>
</tbody>
</table>

Note: a: caregiver of independent and alone living dementing person, p: caregiver who shares a household with the dementing person, partner
The above mentioned problems give a first answer to the question which problems have to be selected for the TED sub-project. The arguments for these problems are: frequency of the problem and the extent of the burden as a result of the problem. It appeared to be very difficult for primary caregivers to think in terms of technological solutions. They were not able to come with ideas. Reasons can be the emotional impact of the in depth interview and the fact that all respondents were in the middle of the care-situation.

The problems in table 1 are derived from 10 in depth interviews. The correct question arises whether those 10 primary caregivers represent a realistic picture of the situation and problems of primary caregivers in general. For this reason is decided to do further research in order to make a selection of technology to be adjusted and evaluated in the project. An other reason to do further research is the restricted number of arguments that is used (frequency and burden). There are more arguments possible on which a choice can be based, e.g. expected effects on well being, ethical acceptance, technological possibilities, effectiveness.

3 METHODS

We decided not to extend the research to informal caregivers, but to experts in the field of dementia care: professionals in the care for people with dementia and for their informal caregivers. The following main arguments play a part in the choice for extending the research to professional caregivers:
- the wide experience of professional caregivers in many different care-situations and the overview they have
- the emotional distance by which professionals can refer to care-situations, this makes the research less burdening for them then for informal caregivers
- professionals can be approached with by questionnaires, what will take less time

Extending the research to professionals has the disadvantage that a certain degree of depth and the personal experience that informal caregivers have, can get lost. Professionals need a big doses of empathy to assess the needs and problems of people with dementia and their caring relatives. It is possible that the meaning of problems and needs are not always comprehended by professionals. For this reason and to do justify the contribution of informal caregivers as much as possible, we decided to take the inventory of problems and needs from the in depth interviews of informal caregivers as starting point and base for our research under professionals.

Data were collected by questionnaires and structured interviews, based on the questionnaires. Names and addresses of respondents were obtained from existing networks, approaching organisations in dementia care and via the snowball method: people were asked to spread the questionnaires under other professionals known to them.

A total of 39 questionnaires have been sent, together with an accompanying letter. There were 21 responses. A total of 16 questionnaires were taken along in the analysis; four persons returned the questionnaire blank and gave a reason for not filling it in (lack of time: 3, too abstract: 1); one questionnaire was not taken along in the analysis because it was filled in by a person who did not belong to the target group. Via the snowball method another 16 questionnaires were returned by care workers. These questionnaires were spread by managers in a home help, a home care and a respite care organisation.
A number of 13 persons were approached on the telephone. To increase the chance on response we gave the choice to fill in a questionnaire or being interviewed. All 13 wanted to co-operate with our research. There were 3 questionnaires sent and returned; 10 persons preferred an interview.

The total number of respondents taken along in the analysis is 47. The greater part of the respondents is working in the region’s ‘s-Hertogenbosch en Eindhoven (in the South of the Netherlands).

Most of the respondents are working in professional care organisations (29) and advisory- and support organisations (15). These respondents are coming from various levels within organisations. Both professionals from the executive staff (31) and (middle) management (13) are represented. However, the bigger part of the respondents belongs to the executive staff, and is working direct with people with dementia and/or their informal caregivers. A number of 3 respondents are working as a researcher in the field of dementia and informal care.

Table 2 shows the field of work of the respondents.

Table 2. Background/field of work of respondents

<table>
<thead>
<tr>
<th>Field of work</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home help</td>
<td>11</td>
</tr>
<tr>
<td>Home care</td>
<td>6</td>
</tr>
<tr>
<td>Respite care</td>
<td>5</td>
</tr>
<tr>
<td>Day care</td>
<td>3</td>
</tr>
<tr>
<td>Therapy (occupational/activity)</td>
<td>4 (1/3)</td>
</tr>
<tr>
<td>Out patient mental health advisory service</td>
<td>6</td>
</tr>
<tr>
<td>Social work/informal care support project</td>
<td>7 (5/2)</td>
</tr>
<tr>
<td>Advisory organisation</td>
<td>2</td>
</tr>
<tr>
<td>Scientist in field of dementia/informal care</td>
<td>3</td>
</tr>
</tbody>
</table>

The first question in this study was: which problems of people with dementia and their caregivers have priority in the search for and evaluation of technological solutions?

To answer this question, two questions were asked in the questionnaire:

A: Which problems of people with dementia and their informal caregivers have according to your opinion priority in the search for technological solutions?

B: Which five problems would you tackle first?

For answering question “A” respondents got a list with 47 items, derived from the inventory of problems and needs from the depth interview with primary caregivers. They were asked to give priority on a five-point scale: very low priority, low priority, mediate priority, high priority and very high priority.

A disadvantage of use of the inventory, resulting from the in depth interviews, is that some items are overlapping each other. An other disadvantage is that the items vary in weight. Some items are very specific, other items contain a bigger problem-area.

For this reason we adapted the inventory to the list with 47 items. The disadvantages of the inventory however were only partly taken away. Also for this reason question “B” was incorporated in the research. The complete inventory as well as the list with 47 items can be found in the annex.

There were more reasons to incorporate question “B”. The question is open, it gives the respondents the opportunity to use their own words to indicate problems. Furthermore, it forces the respondents to make a selection for a limited amount of problems (five). A last reason is that question “B” makes part of a sequence of questions that are leading to
arguments and technology, namely:
B: Which five problems would you tackle first?
C: Why do you choose for each of these five problems?
D: What type/sort of technology are thinking of to solve each of these 5 problems?

4 RESULTS

4.1 PRIORITIES ACCORDING TO 47 ITEMS

Respondents gave a priority to the 47 items on a five-point scale. For each item a total score is calculated. In table 3 you find the first 20 items in sequence of priority given by respondents.

Table 3. Priority according to 47 items
Total score of the first 20 items, in sequence of priority according 47 professionals and experts.

<table>
<thead>
<tr>
<th>priority</th>
<th>score experts/ professionals</th>
<th>score informal caregivers</th>
<th>item/problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>232</td>
<td>6*</td>
<td>Failing to switch off domestic equipment</td>
</tr>
<tr>
<td>2</td>
<td>227</td>
<td>8*</td>
<td>Fire-risk</td>
</tr>
<tr>
<td>3</td>
<td>221</td>
<td>9*</td>
<td>Continuous fear for unsafe or problematic situations</td>
</tr>
<tr>
<td>4</td>
<td>220</td>
<td>8*</td>
<td>24 hours supervision of dementing person</td>
</tr>
<tr>
<td>5</td>
<td>217</td>
<td>6*</td>
<td>Not enough possibilities to control the situation from a distance, no remotely control whether everything is secure</td>
</tr>
<tr>
<td>6</td>
<td>212</td>
<td>4*</td>
<td>Loosing money, keys, administration, etc.</td>
</tr>
<tr>
<td>7</td>
<td>212</td>
<td>5*</td>
<td>Wandering</td>
</tr>
<tr>
<td>8</td>
<td>209</td>
<td>3</td>
<td>Not being able to call for help by safety alarm system</td>
</tr>
<tr>
<td>9</td>
<td>205</td>
<td>4*</td>
<td>No understanding of the traffic</td>
</tr>
<tr>
<td>10</td>
<td>205</td>
<td>5*</td>
<td>Domestic equipment too complex to handle</td>
</tr>
<tr>
<td>11</td>
<td>204</td>
<td>2</td>
<td>Disruption of day-night rhythm</td>
</tr>
<tr>
<td>12</td>
<td>203</td>
<td>3</td>
<td>Storing or eating perishable or bad food</td>
</tr>
<tr>
<td>13</td>
<td>202</td>
<td>3</td>
<td>Not finding the way outside the house</td>
</tr>
<tr>
<td>14</td>
<td>201</td>
<td>1</td>
<td>Control by telephone gives not enough information</td>
</tr>
<tr>
<td>15</td>
<td>200</td>
<td>6*</td>
<td>Dementing person can not keep himself busy independent</td>
</tr>
<tr>
<td>16</td>
<td>198</td>
<td>3</td>
<td>Failing to lock doors</td>
</tr>
<tr>
<td>17</td>
<td>198</td>
<td>4*</td>
<td>Handling the telephone</td>
</tr>
<tr>
<td>18</td>
<td>196</td>
<td>1</td>
<td>Failing to switch off taps</td>
</tr>
<tr>
<td>19</td>
<td>196</td>
<td>3</td>
<td>Forgetting to eat or eat too often</td>
</tr>
<tr>
<td>20</td>
<td>195</td>
<td>5*</td>
<td>Disequilibrium/risk of falling</td>
</tr>
<tr>
<td>21</td>
<td>194</td>
<td>7*</td>
<td>Caregiver has no time for himself</td>
</tr>
<tr>
<td>22</td>
<td>194</td>
<td>5*</td>
<td>Unable to structure the day</td>
</tr>
<tr>
<td>23</td>
<td>182</td>
<td>5*</td>
<td>Fear for criminality against dementing person</td>
</tr>
<tr>
<td>24</td>
<td>182</td>
<td>4*</td>
<td>Unrest over appointments and dates/ inability to tell the time</td>
</tr>
</tbody>
</table>

Note: Column 1: Sequence of priority given by professionals and experts. Column 2: Total score. Calculated by giving grades to the priorities: very low: 1, low: 2, mediate: 3, high: 4, very high: 5; the sum of amount of times an item is given a certain grade, multiplied with the value of the grade itself. Column 3: The number of times the item was mentioned by informal caregivers (out of 10). The added asterisk (*) means that the item is both more often mentioned as well as experienced as very burdening. The four last items were taken in, because they are both more often mentioned as well as experienced as very burdening by primary caregivers.
The problems derived from the in depth interviews with primary caregivers are very much recognised and acknowledged by the respondents. Professionals and experts appear to give great importance at the search for technological solutions. This is shown by the high priorities that were given. More than 28% of the items are given a very high priority and over 42% are given a very high priority. Respondents gave on average on the 47 items 0.5 times a very low priority, 3 times a low priority, 10 times a mediate, 13.5 times a high and 20 times a very high priority. Many items that are more often mentioned by primary caregivers and are experienced as very burdening were also given a high priority by the respondents. Some items however were given a lower score, e.g. caregiver ‘has no time for himself’, ‘fear for criminality’, ‘unrest over appointments and dates/unable to tell the time’.

Making a selection on base of this outcome is somewhat risky. Because of the high priorities that are given, the difference between the item with the highest score and the 20th item is not very large.

4.2 SELECTION OF FIVE PROBLEMS

All respondents mentioned problems they would tackle the first, however not everybody came to a number of five problems. The question to make the selection for five problems was formulated as an open question, respondents formulated problems on their own way. Therefore the answers to this question were categorised not as problems but as problem areas. In table 4 you find all problem areas that were mentioned.

<table>
<thead>
<tr>
<th>Priority</th>
<th>Score experts/ professionals</th>
<th>Score informal caregivers</th>
<th>Problem area</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>36</td>
<td>6 (5a,1p)</td>
<td>Safety (failing to switch off domestic equipment, fire-risk)</td>
</tr>
<tr>
<td>2</td>
<td>16</td>
<td>6 (4a,2p)</td>
<td>Remotely control</td>
</tr>
<tr>
<td>3</td>
<td>16</td>
<td>6 (5a,1p)</td>
<td>Wandering, way-finding</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>6 (1a,5p)</td>
<td>Time spending</td>
</tr>
<tr>
<td>5</td>
<td>14</td>
<td>8 (5a,3p)</td>
<td>Disorientation in time</td>
</tr>
<tr>
<td>6</td>
<td>13</td>
<td>7 (5a,2p)</td>
<td>Problems with handling domestic equipment</td>
</tr>
<tr>
<td>7</td>
<td>9</td>
<td>5 (3a,2p)</td>
<td>Disequilibrium/risk of falling</td>
</tr>
<tr>
<td>8</td>
<td>8</td>
<td>6 (5a,1p)</td>
<td>Problems with handling the telephone,</td>
</tr>
<tr>
<td>9</td>
<td>8</td>
<td></td>
<td>Not being able to call for help</td>
</tr>
<tr>
<td>10</td>
<td>6</td>
<td></td>
<td>Problems around meals</td>
</tr>
<tr>
<td>11</td>
<td>5</td>
<td></td>
<td>Incontinence, problems with handling diapers</td>
</tr>
<tr>
<td>12</td>
<td>5</td>
<td></td>
<td>Problems with taking medication</td>
</tr>
<tr>
<td>13</td>
<td>2</td>
<td></td>
<td>Handling taps</td>
</tr>
<tr>
<td>14</td>
<td>2</td>
<td>4 (4a)</td>
<td>Fear for criminality against dementing person</td>
</tr>
<tr>
<td>15</td>
<td>2</td>
<td></td>
<td>Not recognising persons</td>
</tr>
<tr>
<td>16</td>
<td>2</td>
<td></td>
<td>Hygiene</td>
</tr>
<tr>
<td>17</td>
<td>1</td>
<td></td>
<td>Mobility</td>
</tr>
<tr>
<td>18</td>
<td>1</td>
<td></td>
<td>Forgetting to lock doors</td>
</tr>
<tr>
<td>19</td>
<td>1</td>
<td>4 (3a,1p)</td>
<td>Loosing keys, money, administration</td>
</tr>
<tr>
<td>20</td>
<td>1</td>
<td></td>
<td>Obstructing sink and drain</td>
</tr>
<tr>
<td>21</td>
<td>1</td>
<td></td>
<td>Switching lights on and off, handling central heating</td>
</tr>
</tbody>
</table>

Note. Column 1: sequence of priority. Column 2: number of times the problem area is selected as one of five products. Column 3: number of times primary caregivers mentioned the problem area and experienced it as very burdening. a: caregiver of independent and alone living dementing person; p: caregiver who shares a household with the dementing person, partner. Column 4: problem areas.
Making a selection of five problems turned out to be an useful question, when looked at
the small differences in the results of the former question (A) and the much bigger differ­
ences in the results from question “B”. The results of question “B” are making a much
stronger selection of problems with high priority to be solved, possible. It is very obvious
that respondents give the highest priority to solve safety problems, especially problems
caued by failing to switch off domestic equipment that stands on a lonely high score of
36. The next five problem areas have more comparable scores, between 16 and 13 times
mentioned.
Apart from the fact that a stronger selection is made, there are more differences between
the results of questions “A” and “B”. Some problems with a high score in question “A” do
not come back as a problem area in question “B”. Other problem areas are in “B” much
given a much high priority then in “A”. Reasons for these differences can be:
- Formulation in problem areas in stead of problems. Because of the formulation the
overlap between items disappears: the first five items from question “A” are
brought back to two items in question “B”.
Other differences as a result of the way of formulating things is that e.g. the items
’inability to tell the time’ and ‘unable to structure the day’ are given less priority
then the problem area ‘disorientation in time’ in question “B”.
- The sequence of questions (B-C-D) leads to ideas for technology, therefore items
that are formulated more vague, broad and not very concrete, fall away, e.g. 24
hours supervision of dementing person’. It is also possible that items are not
selected in “B”, because respondents can not imagine any technology that can solve
the problem, e.g. loosing money, key, administration’.

When we look at the first six problem areas and compare them with the number of times
primary caregivers mentioned this problem area and experienced it as very burdening, we
find that all six problem areas are also frequently indicated by primary caregivers as very
burdening.
At a closer look at the responses of primary caregivers, five of the six problems are more
often mentioned by primary caregivers from an independent and single living demented
person than by primary caregivers that share a household with their dementing partner. In
the in depth interviews was found that partners care for the dementing person for 24
hours a day, are continuously aware of the where-abouts of their partner and prevent all
sorts of risks by taking over actions. Partners do not mention e.g. ‘failing to switch of
domestic equipment’, because they prevent the dementing person to come even near the
equipment. Partners mentioned more often overall problems with supervision (see table 1).
A major problem for partners is time spending. The problem of time spending can be more
visible for partners because of their continuous awareness and nearness. An other reason
is that they prevent problems by taking over actions from the dementing person. This can
have as an unintended effect that there is not much left to do for the dementing person
and problems with time spending arise.

4.3 ARGUMENTS FOR THE SELECTION OF THE PROBLEM AREAS AND IDEAS FOR
TECHNOLOGY

Respondents were asked to give arguments for their selection of five problems and also
mention the technology they are thinking of to tackle the problem. The bigger part of the
respondents gave arguments for their selection. The arguments given by respondents
were formulated in two ways:
The arguments that were mentioned the most by respondents are:

- The frequency of occurring of the problem area
- The burden resulting from the problem area on people with dementia and their caregivers
- The safety of people with dementia and their environment
- The need to reassure carers and take away fear/worries
- Prevention of (premature) admission into a nursing home
- The (expected) therapeutic effects of technology on people with dementia

The question 'what kind of technological solutions is one thinking of?' is asked in this research to gather ideas on possible technological solutions and to give professionals and experts the chance to ventilate their ideas. Part of the respondents did not or only partly answer this question. Assumed is that they had for some problem areas no technology in mind.

In the next section the arguments and ideas for technology given by the respondents, are presented for each problem area. The problem areas are given in sequence of priority. Only the problem areas that are mentioned five times or more are represented in the overview.

The arguments given by respondents are formulated in two ways:
- as problems that can occur as a result of the present situation, in the overview they are marked with the sign '0'
- as expected effects of new or adjusted technology, in the overview they are marked with the sign '+'

### 1. Safety, failing to switch off domestic equipment and fire risk.

Cookers (on gas) and coffee machines are the main concerns.

**Arguments:**

- frequent occurring problem
- big chance on accidents: individual and societal danger
- reason for (premature) admission to a nursing home
- much fear and feelings of powerlessness with primary and formal caregivers
- major burden on primary caregivers
- allows people with dementia to live in their own homes longer
- safe environment creates rest and prevents damage to people and environments
- independence and autonomy of dementing persons will be maintained longer
- gives feelings of self-respect to dementing persons

**Technology:**

- automatic switch off
- timers
- reminders
- possibility to pre-set domestic equipment according preferences
- smoke and fire alarms
- control panel on a distance
- fire proof materials
2. Remote control
Arguments:
- burden of 24 hours supervision
- continuous fear for unsafe or problematic situations
- incidents are often a reason for admission into a nursing home
+ primary caregiver gets more time for own time spending
+ taking away fear and worries
+ gives space for emotional coping and dealing with grief
+ prevents (premature) admission to nursing homes
+ can give a false sense of safety and can chain the primary caregiver to the control device

Technology:
- monitoring, video cameras
- picture telephone
- system to detect and alarm

3. Wandering, way-finding
Arguments:
- gives panic and distress with dementing person
- gives panic and distress and fear with caregivers: when will the dementing person be missed and in what condition, where and when will he be found?
- is a reason for admission into a nursing home, although the dementing person without the wandering, would still be able to live in his own home
- dementing persons are less or not able to get a comprehensive view of the traffic, this gives a bigger chance on accidents
+ knowing where one is and how one can come somewhere increases the mobility of the dementing person

Technology:
- address and telephone numbers in pockets, handbag of dementing person
- signal that goes off when the dementing person leaves the house
- alarm that goes off when the dementing person takes an other route as usual
- device that can trace someone
- pictures, symbols, arrows

4. Time spending. Keeping the dementing person active.
Arguments:
- is a major problem and gives much distress for dementing persons and their primary caregivers
- it is very difficult and burdening for primary caregivers to keep someone busy and activated
+ activities to help spending the time give structure to the day
+ keeps body and mind in shape, prevents further deterioration, maintains abilities
+ gives positive feelings: interest, pleasure, feeling useful, gives meaning, self esteem and satisfaction
+ spending time can distract the dementing person from dangerous or problematic activities e.g. wandering
+ gives primary caregiver more time for own activities
+ simple intervention, can have much effect on the burden on primary caregivers
Technology:
- games from the old days, or games that refer to earlier times
- easy to operate television, radio, c.d.-player and remote controls
- video tapes with slow and recognisable programmes in the native language
- books with big letters and many illustrations

5. Orientation in time. Structuring the day, day and night rhythm, reminders for appointments.
Arguments:
+ prevents other problems, e.g. unrest, wandering
+ makes it possible to live longer in one's own house
+ sense of time gives structure at the day and by that grip on life itself

Technology:
- clock with indicators (not digital)
- clock that indicates the day and the daily period
- speaking clock or watch
- day calendar
- instructions by intercom
- planbord
- agenda with pictograms
- diary

6. Operating domestic equipment, today's equipment is often too complex to handle
Arguments:
0 inadequate use can cause dangerous situations
0 is very frustrating for dementing persons and gives insecurity, it can lead to behavioural problems and/or passivity
0 complex equipment causes many practical, irritating and daily recurring problems
+ increases or maintains the autonomy and independence of dementing persons
+ being able to operate equipment in the house, means an entrance, access into ....
+ social roles of dementing persons (e.g. caring for oneself and others) can be preserved

Technology:
- stick operation instructions at equipment, put notes
- simplification of operating technology: few, big switches; built-in safety measurements
- pre-set tuning

7. Falling risks, disequilibrium
Arguments:
0 chance on fractures (hip, arm, wrist), admission into a hospital can be a disaster, hospitals are most of the time not equipped for people with dementia
0 dementing person can not call for help after a fall
0 there is very much concern with informal caregivers for falling
Technology:
- protection in the clothes, so one falls softer
- (stair)handrails on both sides
- bracelet by which an alarm can be given

8. Problems with handling the telephone
Arguments:
0 communication is basic for solving other problems
0 gives insecurity, can cause unrest and panic with dementing persons
0 causes more social isolation:
+ being able to handle the telephone is essential in personal contacts and contacts with the world outside
+ for the primary caregiver the telephone is a means of communication and control on a distance
+ being able to use the telephone increases safety of dementing persons

Technology:
- pre-set telephone numbers with pictures
- picture telephone
- intercom
- microphone and speakers in rooms
- transmitting equipment

9. Not being able to call for help or use the active alarm system
Arguments:
0 causes panic with dementing person
0 dementing person is often handed over to the coincidence of being found/helped
+ increases security of dementing person and his environment
+ is reassuring for primary caregivers

Technology:
- passive alarm system
- big alarm knob, very well visible and placed in every room
- whistle around the neck

10. Problems around meals
Arguments:
0 is especially a problem for dementing persons who live alone
0 danger for undernourishment, dehydration, lack of vitamins
0 eating bad food causes health risks (food poisoning, diarrhoea, obstipation)
+ is a fundamental human activity, gives even in an extreme situation a feeling of self-control and identity

Technology: -

11. Incontinence
Arguments:
Dementing persons have difficulties or are unable with handling the incontinence material by themselves.

Incontinence material is not logical for dementing persons.

Problems with hygiene: using the material more often, obstruction of drains.

Often very burdening for primary caregivers: taboos, shame to help the dementing person.

Is sometimes a reason for admission into a nursing home.

**Technology:**
- Elastic in upper-side of incontinence material
- Design incontinence material as usual underwear: disposable underwear with the quality of incontinence material

### 12. Problems with taking medication

**Arguments:**
- Wrong use can lead to health risks, poisoning.
- Professional care to help taking medicines is often given 1-3 times a day and is very expensive.

**Technology:**
- Medicine box with an alarm

### 5 DISCUSSION AND CONCLUSION

The problems derived from the in depth interviews with primary caregivers are very much recognised and acknowledged by the respondents. Professionals and experts appear to give great importance at the search for technological solutions. This is shown by the high priorities that were given to the 47 items derived from the in depth interviews: more than 70% of the items were given a high or very high priority.

Making a selection of needs and problems to be solved in the TED project on base of this question appeared to be somewhat difficult because of the high scores and the little differences between the item scores as a result of that. The question: 'Which five problems would you tackle first?' appeared to be a better entrance to make a selection. Firstly, because the question was an open question. The problems were formulated in problem areas, by which overlapping items disappeared. Secondly, the question restricted respondents: they had to choose the five most important problems.

The twelve most important problem areas according to professional carers and experts in the field of dementia are, in sequence of priority:

1. Safety (failing to switch off domestic equipment, fire-risk)
2. Remote control
3. Wandering, way-finding
4. Time spending
5. Disorientation in time
6. Problems with handling domestic equipment
7. Disequilibrium/risk of falling
8. Problems with handling the telephone,
9. Not being able to call for help
Problems around meals
Incontinence, problems with handling diapers
Problems with taking medication

The first eight problem areas of this list were also more often mentioned as very burdening by primary caregivers. This indicates that selecting problem areas from the first eight on the list above, is according the wish of both the interviewed primary caregivers and the professional caregivers in our research.

There is however a difference between primary caregivers from single living dementing persons and primary caregivers who share a household with the dementing person. These differences were clearly in the in depth interviews, but did not came forward in the questionnaires for professionals and experts. Because primary caregivers that share a household with the dementing persons mention more overall problems with supervision and fewer concrete problems, it is possible that the effects of technology on both types of primary caregivers are different. This can be examined in further research and in the evaluation of technology.

The arguments for giving priority to solve a certain problem, were formulated in two way's:
- as problems that can occur as a result of the present situation
- as expected effects of new or adjusted technology

When we take a closer look at the expected effects of technology, we see that respondents expect a great deal of technology. Almost all effects are described as positive effects. Further research will show whether these expectations are realistic and how we can improve our efforts to realise the expectations.

The type of arguments given, can be reformulated in aims of technology for people with dementia, namely:
1. Prevention
2. Supervision:
   - monitoring
   - detection
   - control
3. Enabling (rehabilitation):
   - manage behaviour or practical coping
   - stimulation and relax
   - reminders
   - orientation

Both prevention and supervision are aimed at the safety of people with dementia and their environment and on reassuring carers. Enabling or rehabilitation technology however is aimed at compensation of the loss of abilities of the dementing person as a result of the dementia syndrome; it is aimed at maintaining or increasing the independence and self-confidence of the dementing person.

The inventory of arguments used to give a high priority to solve the problem revealed various types of arguments:
- The frequency of occurring of the problem area
- The burden resulting from the problem area on people with dementia and their caregivers
- The safety of people with dementia and their environment
The need to reassure carers and take away fear/worries
- Prevention of (premature) admission into a nursing home
- The (expected) therapeutic effects of technology on people with dementia

The types of arguments given, reflect the background/field of work of the respondents: the arguments stay very close with the needs of people with dementia and their caregivers, hardly any economical or technological arguments were given. Our way of questioning however, e.g. starting with the impressive list of problems and needs of dementing persons and their caregivers, did not exactly lead respondents to the direction of giving answers from an economical or technological point of view. When making a definitive choice for products to be adjusted, implemented, tested and evaluated, also economical and technological arguments should be taken into account.

The user needs analysis among informal caregivers and the utility aspects of the user requirements, studied among professionals in the field of dementia, have delivered similar results. Highly ranked is the safety problem: failing to switch off the domestic appliances. The top 12 list of problems/needs among persons with dementia further gives very concrete product ideas.

Within the TED-project, the results of this study have led to a choice of five problem areas for which technological solutions are being developed, adapted or purchased, and implemented and evaluated in home care situations. The problem areas are: failing to switch of the cooker, wandering, time spending, disorientation in time and problems with handling the telephone. The product ideas are: a system that automatically switches off the cooker in specific situations, a tagging device, an entertainer program on a personal computer with touch screen, a day calendar and a telephone with photographs to select the telephone number.
Part B. USABILITY

GUIDELINES FOR THE DEVELOPMENT OF TECHNOLOGY FOR PEOPLE WITH DEMENTIA

1 INTRODUCTION

Persons suffering from the dementia syndrome lose more and more the ability to cope with situations in normal life. Most people with dementia need in the course of the disease support from others. In many cases people with dementia need 24 hours supervision. The burden on informal caregivers is often very high and a reason for admission of the demented person into a nursing home.

We assume that technology is an additional way to support people with dementia to cope. Technology could compensate for the losses resulting from the disease, and in the same time help people with dementia to keep their self-esteem, dignity and autonomy. Technology could also support informal caregivers in caring for their demented relative. To design technologies for people with dementia and their caregivers, we have to be aware that technological solutions have to be adapted to the specific needs of the target group.

2 METHODS

One of the problems with technology for people with dementia is that people with dementia have difficulties to express their needs clearly. We therefore decided to ask professional caregivers to give their opinion on usability.

The (open ended) questions we asked were:
Developing technology or aids for people with dementia asks special attention to usability aspects. Taken into account the experience and knowledge you have of the nature of the dementia syndrome, and the effects on the person suffering from the dementia syndrome and their informal caregivers,
A: ... what usability aspects are to your opinion important for the person with dementia?
B: ... what usability aspects are to your opinion important for their informal caregivers?

Data are collected by questionnaires and structured interviews, based on the questionnaires. (See part A, methods). Names and addresses of respondents were obtained from existing networks, approaching organisations in dementia care and via the snowball method: people were asked to spread the questionnaires under other professionals known to them.
A total of 39 questionnaires have been sent, together with an accompanying letter. There were 21 responses. A total of 16 questionnaires were taken along in the analysis; four persons returned the questionnaire blank and gave a reason for not filling it in (lack of time: 3, too abstract: 1); one questionnaire was not taken along in the analysis because it was filled in by a person who did not belong to the target group.
Via the snowball method another 16 questionnaires were returned by care workers. These questionnaires were spread by managers in a home help, a home care and a respite care organisation.
A number of 13 persons were approached on the telephone. To increase the chance on response we gave the choice to fill in a questionnaire or being interviewed. All 13 wanted to co-operate with our research. There were 3 questionnaires sent and returned; 10 persons preferred an interview.
The total number of respondents taken along in the analysis is 47. The greater part of the respondents is working in the region’s 's-Hertogenbosch en Eindhoven (in the South of the Netherlands).

Most of the respondents are working in professional care organisations (29) and advisory- and support organisations (15). These respondents are coming from various levels within organisations. Both professionals from the executive staff (31) and (middle) management (13) are represented. However, the bigger part of the respondents belongs to the executive staff, and is working direct with people with dementia and/or their informal caregivers. A number of 3 respondents are working as a researcher in the field of dementia and informal care.

Table 1 shows the field of work of the respondents.

<table>
<thead>
<tr>
<th>Field of work</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home help</td>
<td>11</td>
</tr>
<tr>
<td>Home care</td>
<td>6</td>
</tr>
<tr>
<td>Respite care</td>
<td>5</td>
</tr>
<tr>
<td>Day care</td>
<td>3</td>
</tr>
<tr>
<td>Therapy (occupational/activity)</td>
<td>4 (1/3)</td>
</tr>
<tr>
<td>Out patient mental health advisory service</td>
<td>6</td>
</tr>
<tr>
<td>Social work/informal care support project</td>
<td>7 (5/2)</td>
</tr>
<tr>
<td>Advisory organisation</td>
<td>2</td>
</tr>
<tr>
<td>Scientist in field of dementia/informal care</td>
<td>3</td>
</tr>
</tbody>
</table>

### RESULTS

The answers of the respondents were analysed by ordering and categorising the answers by recurring themes.

The user requirements are categorised according to the following characteristics:

1. Age
2. Dementia syndrome
   - Symptoms of the dementia syndrome
   - Safety problems
   - Dementia as a progressive process
   - Dementia as a threat to self-esteem, autonomy and dignity
   - Uniqueness of each individual with dementia: personality and circumstances
3. System around person with dementia: delicate balance
4. Social position of elderly

In the following section you will find the inventory of user requirements based on the opinions of the respondents.

Note: Because the next is an inventory, the user requirements can be contradictory.
3.1 REQUIREMENTS RELATED TO AGE

• Technology for people with dementia and their caregivers must meet the guidelines for designing for elderly

The respondents mentioned several requirements related to ageing, especially requirements in connection with changes in vision and changes in mobility. The prevalence of the dementia syndrome increases with age. The bigger part of the people with dementia is elderly. A big part of the informal caregivers belongs also to the elderly. That means that technology for people with dementia and their caregivers must meet the guidelines for designing for elderly. Design guidelines for designing for elderly according to Pirkl and Babic (1988) can be found in annex III.

3.2 REQUIREMENTS RELATED TO THE DEMENTIA SYNDROME

Symptoms of the dementia syndrome are: cognitive problems, difficulties with reasoning and judgement; difficulties with memory and recollecting information, especially for recent events; difficulties with learning new things; difficulties with orientation, often resulting in confusion and behavioural problems; the possibility of hallucinations and delusions; the possibility of agnosia and apraxia. These symptoms demand various requirements for technology to be used by dementing people.

COGNITIVE PROBLEMS

• Intrinsic logic: function and operation must be recognisable, each time, again and again
• Ease of operation

Technology for people with dementia must be very easy to use and to operate. This is a result of cognitive problems of people with dementia, such as: the progressive loss of memory, agnosia, apraxia, problems with sequences and with concentration. Technology must have a sort of 'intrinsic logic'. The function and operation of the technology must be clear for the dementing person. Because of the loss of the short term memory, learning to operate new technology will be very difficult for people with dementia. The dementing person is not able to recollect information about the technology from his memory. That means that he will experience the technology each time as new. Therefore it is important that function and operation of a certain technology is recognisable or self-evident, each time, again and again.

Respondents gave very much attention to the recognisability of the function and operation of technology.

The recognisability of the function of a product can be encouraged by:
• Intrinsic logic of the design. This logic of design must clarify the function of the product, in the same way as a handrail invites to grip it and a rollator invites to walk.
• Design the way that people are used to. In many cases that will be 'old fashioned design', design from the past. The ability to learn decreases, the long term memory however lasts longer. Another reason for old fashioned design is emotions and feelings that are connected to certain products. These emotions and feelings can give an other
entrance for memory and re-collection.

- Give the product only one function. More functions in one product can be confusing for people with dementia, because then choices have to be made. Making the wrong choice can be very demotivating and can cause unrest or apathy. Much technology nowadays is characterised by the great number of functions and choices that can be made.
- Form, colour and materials must support the recognisability of the function of a product.
- Put the product on a striking and logical place, because it is very well possible that the dementing person forgets he has the product or aid. The logic of the place depends on the habits and preferences of the dementing person.

Requirements to accomplish the recognisability of the operation and therefore the ease of operation of a certain technology:

- Restrict the number of necessary actions, preferable to only one action to set going a product. If more actions are necessary, then the next steps must be logical, visual and temptative. Apraxia and problems with sequences are symptoms of dementia. A frequent occurring problem with sequences is dressing: not knowing what to put where. A solution is to put the clothes in the right sequence on top of each other on a chair, so what the dementing person takes the first has to be put on the first. To let this work however, you have to know a person’s personal sequence: first socks or bra or pants? A sequence that the dementing person is not used to, can only become more confusing.
- Reduce the number of knobs as much as possible. Knobs must be very visible: big and in a signalling colour (or, when you do not want to attract the attention to the knob, put it in a not contrasting colour). Pre-set choices when no or little variation is made, according to individual preferences and wishes. The possibility to pre-set must not be visible for the dementing person.
- Information must be clearly visible, in simple, plain words, in an understandable language. Give analogue information in stead of digital information. Use pictograms to support the operation. Use letters, not symbols: symbols are often not clear, not recognisable for older persons. Use more signals to attract the attention to the same function, for example: image, sound and colour.
- Avoid superfluous parts of information (including decoration), because people with dementia can have problems to distinguish between sorts of information.
- An action must give immediate feedback. The product must work immediately and fast, no waiting time, because of low concentration ability. Operation and product must be close together. No remote control. Even the switch of a lamp on a distance of the lamp itself, can cause problems. Use a touch screen. Use a switch or a knob that gives traditional feedback by feeling the knob turns or by a 'click-sound'.

DISORIENTATION AND CONFUSION

- Link with long term memory

An effect of the memory problems of dementing people is disorientation and confusion. Every new technology is a change in the situation of the demented person and may cause extra disorientation and confusion. For instance replacing the washing machine can have as an unintended effect that the dementing person is not able any more to operate the
new washing machine, while there were no problems with operating the old machine. To avoid these problems as much as possible respondents mention the following requirements:

- Maintain the situation the demented person is used to as much as possible. This can be done by, for example, installing safety-measures on the already used domestic machines, preferably not visible.
- Add aids to existing and used technology, for example, place next to the clock an aid that gives the date and the daily periods.
- Use one type of operation for the whole machine, do not mix different types such as turning, pressing or pushing. Use the same type of operation in different machines as well.
- Aids must fit between other used products: they must not be very out of the ordinary.

**BEHAVIOURAL PROBLEMS**

- **Not causing suspicion or unrest**

  Behavioural problems such as unrest, aggressiveness, hallucination and suspicion arise frequently with dementia syndrome. Technology can have as an unintended effect that it causes behavioural problems.

  - Technology must not be threatening, or must not be perceived this way by people with dementia. This could be the case with all kinds of ‘automatically’ happening things, i.e. an automatic lock on doors, curtains that open and close automatically at a certain time, a warning voice or signal as reminder. We must bear in mind that the dementing person, can not become used to those things because of the loss of the short term memory, and experience them each time as new.

**SAFETY PROBLEMS**

- **Safe in all ways**

  Safety problems can be the consequence of memory problems, disorientation, confusion, low concentration ability, problems with judging situations of the dementing person, apraxia, agnosia, sensor deficits, etc. Because of these problems the dementing person can endanger the safety of one self and his environment. Respondents mention the following requirements to prevent safety-problems for people with dementia:

  - People with dementia forget frequently that domestic appliances are switched on. For that reason especially electric appliances must be able to switch themselves off, for example after a certain time-period, a certain time, after reaching a certain temperature. Examples are: electric blanket, lights, iron, cooker, coffee-maker.
  - No possibilities to injure one’s self: make rounded corners, no sharp edges, no loose parts, technology must be safe to put in one’s mouth, must be colourfast, must not contain hazardous materials, must be fire proof, avoid plugs and electric flexes
  - Products must be durable and of good quality: not breakable, solid, stable, products must be washable, easy to clean, products must be urine resistant
  - Use signalling colours: red is danger, green is safe
DEMENTIA AS A PROGRESSIVE PROCESS

- **Maintain capacities, therapeutic goals**
- **Possibilities for early introduction**

The process of dementia is progressive: the person with dementia will lose more and more abilities to perform in a way that is acceptable for the people around him. Respondents emphasise the possibilities to slow down this process and propose therapeutic goals or requirements, in order to maintain capacities:

- Technology must give a healthy incentive/stimulus, e.g. actual situations, social contacts, structuring the day, societal manners
- Technology or aids must emphasise the good in one’s self
- Technology must encourage the ability to do things independently, the ability to cope
- Technology must increase the freedom of people with dementia
- A technology is user-friendly if the product is useful for the dementing person. The product must make an appeal to the abilities and capacities of the dementing person

Technology for people with dementia must be introduced preferable in an early stage of the dementia process. At this moment the chance that the dementing person becomes used to the product and learns to handle it, is the greatest. People (in general) wait often too long with calling for help and the use of aids. An early introduction can be improved by:

- Good publicity and information around the disease, the products and the aids
- Service around the products and aids
- Technology must be quickly available, no long waiting lists
- Possibility to borrow and try out technology can increase the acceptance and possibilities of early introduction

DEMENTIA AS A THREAT TO SELF-ESTEEM, AUTONOMY AND DIGNITY

- **Enabling, stimulant and self-confidence**
- **Increase acceptance of technology by people with dementia**

The complexity of the technology around us plays an extra part in the loss of abilities to perform in an acceptable way. Respondents emphasised the disabling role of contemporary technology. Technology can be very frustrating for people with dementia. When the technology does not 'co-operates', it can cause, unrest, anger, distrust and also apathy, because of the fear of doing wrong. Respondents mentioned the following requirements to enable people with dementia to perform in an acceptable and pleasant way, to stimulate them and to give them self-confidence:

- Technology for people with dementia has to connect with their capacities and abilities, in stead of the other way around. Technology must appeal to existing knowledge, experiences and abilities of a person with dementia. Technology must not be alienating and must be fun to work with.
- Products must be touchable, must feel pleasant (soft, not too cold, not too hot). The design must match with the emotions
- Design must be such that the product attracts the attention of the person with dementia, it must be visible constantly and attract him or her to use it. Products must be attractive to use, call on initiative
• Products must be a more or less natural solution for problems
• Technology must give a feeling of security. Products must be reliable

As a result of the problems with reasoning and judging, the need for aids can often not be discussed with the demented person with rational arguments. This can cause problems with the acceptance of technology by people with dementia. An extra disturbing factor, that can cause problems with acceptance of technology, is that in many cases the diagnosis dementia is not clearly expressed to the person with dementia. Respondents mention the following requirements to increase the acceptance of technology:
• Technology must not be stigmatising, neither in the perception of the person with dementia nor in the perception of informal caregivers. Aids must be inconspicuous, small in size and not refer to disease and infirmity.
• Avoid the association with childish things, especially in an early stage of dementia
• The demented person must experience an aid as a solution. The product must be useful, meaningful and functional

UNIQUENESS OF EACH INDIVIDUAL WITH DEMENTIA: PERSONALITY AND CIRCUMSTANCES

• Adaptable to individual person and situation

Respondents mention the uniqueness of each individual with dementia. The unique personality and the unique circumstances make it difficult to give general statements on user requirements. The difficulties are caused by the many individual differences there are in the progress of the process of dementia, the phase of dementia, the manifestations of the disease, the pre-morbid personalities involved, the pre-morbid and current social relations. Respondents mention the following user requirement:
• Adaptability. Technology must be adaptable to individual persons and individual circumstances and also to changes in the needs and situation of individuals. Because of the progressive character of the dementia syndrome, there is a real chance that products can only be used temporarily by the demented person. The period of time can be longer, but can also be very short. To accomplish that products are of use for a longer period of time, products should be adaptable as much as possible to changes in the demented person’s situation, the problem or needs.

3.3. REQUIREMENTS RELATED TO THE SYSTEM AROUND PERSONS WITH DEMENTIA: DELICATE BALANCE

• Support and fit in family/care-system

In many cases there is a delicate balance between the needs of the independent living dementing person and the care that informal and/or formal caregivers can give. The needs for care of dementing persons increase in the course of the disease, whilst the burden on informal caregivers is often already very high. For this reason it is important that technology does not disrupt the balance negatively, but supports and fits in the family/care-system. Respondents mention the following requirements:
• Technology must fit all parties: the person with dementia, the informal and formal caregivers. An aid for a person with dementia must also be user-friendly for the people
around the demented person, especially for informal caregivers. Technology should not cause complexity in the perception of informal caregivers. It must not mean extra work or an extra burden on informal caregivers.

- Technology must give a relief of burden on informal caregivers: it must be effective, efficient and take away fear and worries.
- Technology must be easy to operate and easy to learn. This knowledge must be easy to transfer to other caregivers.
- Caregivers must be able to have attention for the person with dementia during the use of aids. Caregivers must be able to use aids that are specially meant for them almost blindly, with only one hand (so the other hand can comfort the demented person) and without overloading him or herself.
- Technology must be integratable in daily activities.
- An aid must have a clear intermediate function between the dementing person and caregivers

3.4 SOCIAL POSITION OF ELDERLY IN GENERAL AND OF PEOPLE WITH DEMENTIA

- Accessibility and availability of technology
- Information and instruction around technology

Respondents mention the diversity of the social position of elderly. Approximately one third of the elderly has a low income, one third a middle and one third higher income. Most elderly have a low education level. The following requirements are mentioned:

- The price must be good, many elderly have a low income.
- Aids must be accessible and available for many people, that means that technology must not be too expensive and not too specific.
- Technology must fit in existing houses and in the sometimes small senior houses.
- There must be good information on existence and functionality, instruction and service around products.
The result of this study is a list of general guidelines for designing technology for people with dementia and their caregivers. The next gives an overview of the main user requirements for people with dementia and their caregivers.

### General guidelines for designing for people with dementia

<table>
<thead>
<tr>
<th>Area</th>
<th>Problems</th>
<th>Requirements in general (guidelines)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>age-related changes:</td>
<td>adjust technology to physical changes related to age</td>
</tr>
<tr>
<td></td>
<td>- sensory (vision, hearing, touch)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- mobility (large, small, intermediate and combination movements)</td>
<td></td>
</tr>
<tr>
<td><strong>Dementia-syndrome</strong></td>
<td>cognitive problems</td>
<td>'intrinsic logic': function and operation must be recognisable each time, again and again</td>
</tr>
<tr>
<td></td>
<td>disorientation and confusion</td>
<td>ease of operation</td>
</tr>
<tr>
<td></td>
<td>behavioural problems</td>
<td>link with long term memory</td>
</tr>
<tr>
<td></td>
<td>safety problems</td>
<td>not causing or generating suspicion or unrest</td>
</tr>
<tr>
<td></td>
<td>progressive process</td>
<td>safe in all ways</td>
</tr>
<tr>
<td></td>
<td>progressive process</td>
<td>maintain capacities, therapeutic goals</td>
</tr>
<tr>
<td></td>
<td>threat to self-esteem, autonomy and dignity</td>
<td>possibilities for early introduction</td>
</tr>
<tr>
<td></td>
<td>uniqueness of each individual</td>
<td>enabling, stimulant and self-confidence</td>
</tr>
<tr>
<td><strong>System around person with dementia</strong></td>
<td>delicate balance</td>
<td>increase acceptance</td>
</tr>
<tr>
<td><strong>Social position of elderly</strong></td>
<td>low income, low education level, houses</td>
<td>adaptable to individual person and situation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>support and fit in family/care-system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>accessibility and availability of technology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>education and instruction around technology</td>
</tr>
</tbody>
</table>
We asked our respondents to mention user requirements for people with dementia and for informal caregivers. During the analysis it appeared that the respondents gave many user requirements for people with dementia and gave much less user requirements for informal caregivers. Most of the user requirements given for informal caregivers were also already mentioned as user requirements for demented persons. The reason for this can be that respondents actually mentioned as most important user requirement for informal caregivers that technology must fit their demented relative. If it fits them, it fits the informal caregiver. This was especially the case with the items safety and acceptance.

Sometimes similar user requirements were given, but the reasons were different. An example is ‘ease of operation’, what was often mentioned for both groups. It was mentioned for people with dementia because of the problems resulting from the disease. The reason it was mentioned for informal caregivers was the already stressful position of informal caregivers, and the supposition that (complicated) technology can cause more stress.

In some cases there was no difference in the reasons why the same user requirements were given for both groups. An example is the theme age-related changes. Both people with dementia and their caregivers belong in most cases to the elderly population.

In order to avoid repetition, we decided to combine the results of the two questions.

The guidelines for development of technology for people with dementia, are formulated according the opinion of 47 professional caregivers, which have (practical) experience with people with dementia and/or primary caregivers on different levels. Starting point and central are the point of view, the needs, possibilities and the context of the user, both person with dementia and informal caregiver. This is different from many other cases, where technological possibilities are starting point for the development of products, and where users are not or very late involved in the design process.

In previous research (Sweep, 1997) we found that in the home situation of people with dementia, not much technology adapted to the needs of people with dementia is used. A substantial part of the technology that is used, consists of measurements that restrict the independence and autonomy of people with dementia. Many ‘normal/regular’ technology that is used becomes too complicated during the dementia process. Examples are cookers, iron’s, the remote control for the television, the telephone. Because the demented person cannot handle the technology any more, problematic or dangerous situations can occur. A result can be that the technology is been taken away by informal or formal caregivers to avoid safety risks. An other result is that the demented person stops using the technology. The technology becomes in fact disabling.

A very important goal for this research is to accomplish the development of technology that is enabling, that makes things possible for demented people and that supports (informal) caregivers.

A set of design guidelines have been achieved through a process of interviewing a large number of professional caregivers. These design guidelines will serve as a very practical instrument in translating the user requirements for a chosen product idea into technical requirements and technical specifications.

The design guidelines give information to designers that can help them to design products that are enabling and supportive. The guidelines can be translated in specific technical
requirements for certain products. By keeping the user (that is: both person with dementia and informal caregiver) involved during the process of designing products, the user requirements become more sophisticated/sharpened and the technology will meet the needs of users better. In this way technology can contribute to a higher quality of life.
LITERATURE:


ANNEX I

PROBLEMS/NEEDS

In this study we made an inventory of problems/needs that are mentioned by the primary caregiver of a dementing person. Interviewed were 10 primary caregivers. Five of them are partners (three female, two male) who share the a household with the dementing person. The other five are all female caregivers of a dementing person who lives alone: four daughters (in law) and one neighbour.

1. ACTIONS OF THE DEMENTED PERSON
   a. Activities of daily living
      The respondents mention the following ADL-problems of the demented persons, for which supervision is necessary:
      Eating and drinking: - using cutlery
                          - making a mess
                          - eating plants
      Incontinence:       - inability to use a diaper without help
      Dressing and undressing: - taking over
                              - giving instructions
                              - assisting in putting on socks
      Wash:              - fatigue and keeping balance
                          - taking over
                          - giving instructions
      Walking and moving: - falls
                           - balance with walking
                           - balance with coming out of bed/chair
                           - climbing stairs
                           - wheelchair too heavy
                           - inability to handle a cane
                           - moving chair to the table

   b. Instrumental activities of daily living
      Eating and drinking - preparing meals
                           - using the gas cooker or electric cooker
                           - using the coffee machine
                           - using the microwave
                           - forgetting to switch off the cooker
                           - forgetting to switch off the coffee machine
                           - storing or eating perishable or bad food
      Cleaning the house - obstructing sink and drain
                           - clearing away used incontinence pads
      Other             - switching on and off the lights
                          - using the taps
                          - watering the plants
                          - manipulating the thermostat knob
c. **Spending time**
- keep the demented person busy/activated, particularly in winter time
- demanding behaviour of the demented person with respect to the time of the primary carer
- operating the T.V., remote control
- understanding what’s on T.V., too fast moving pictures
- reading the subtitles
- falling down off the home trainer
- riding a bicycle independently
- writing
- reading

d. **Communication**
- having a conversation
- expressing oneself verbally
- speaking through the telephone
- handling telephone numbers
- inability of the primary carer to phone in presence of demented person
- use of an active safety-alarm system
- remotely control if everything is secure

e. **Disturbing or deviating behaviour**
- removes ones pair of trousers on the street
- violent
- swear
- threatens violence
- licks the plate

2. **MEMORY AND ORIENTATION OF THE DEMENTED PERSON**

Memory
- failing to lock the doors
- loosing money, keys, administration, etc.

Orientation in time
- forgetting to eat or eating too often
- forgetting to take medicines
- disruption of day-night rhythm
- inability to tell the time
- amorphous structure of the day
- difficulty using the calendar

Orientation in space
- wandering
- finding the way in house
- finding things in house
- finding the light switches
- finding the way outside the house
- dealing with the traffic
- shopping
- lying between bedclothes

Personal orientation
- recognising the primary carer
3. SAFETY OF THE DEMENTED PERSON AND HIS ENVIRONMENT

Because of the dementia and the related problems, mentioned in the previous sections, the safety of the demented person and his or her environment may suffer. In the next section the problems with safety, such as those mentioned by the respondents, are categorized, although most of them have been mentioned in previous sections already.

<table>
<thead>
<tr>
<th>ADL</th>
<th>IADL</th>
</tr>
</thead>
<tbody>
<tr>
<td>- fear of falling</td>
<td>- malnutrition</td>
</tr>
<tr>
<td>- eating plants</td>
<td>- use of domestic appliances</td>
</tr>
<tr>
<td>- abuse of medicine</td>
<td>- use of taps</td>
</tr>
<tr>
<td></td>
<td>- switching lights</td>
</tr>
<tr>
<td></td>
<td>- matches</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication</th>
<th>Memory and orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>- use of active safety-alarm systems</td>
<td>- wandering</td>
</tr>
<tr>
<td></td>
<td>- remote control at non-partners location</td>
</tr>
<tr>
<td></td>
<td>- understanding the traffic</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>- plugging the wrong things in a socket</td>
</tr>
<tr>
<td>- fear of criminality (i.e. not locking the doors)</td>
</tr>
<tr>
<td>- not able to open doors because of bolts</td>
</tr>
<tr>
<td>- interrupted sleep because of supervision at night</td>
</tr>
</tbody>
</table>
ANNEX II

PRIORITIES

*Note:* First column: the total score on each of the items. Second column: number of primary caregivers that mentioned the item (of a total number of 10 respondents). Column 3: Items.

Items that are mentioned in the second column and not mentioned in the first column, were mentioned by primary caregivers, but not incorporated in the questionnaire. If neither the first nor the second column is filled in, then the item was not incorporated in the questionnaire, nor mentioned by primary caregivers. The item was mentioned by professional caregivers.

1. **ACTIONS OF THE DEMENTED PERSON**
   a. **Activities of daily living**
      158 7 Disequilibrium
      184 5 Fear of caregiver that dementing person falls
      141 5 Making a mess with eating and drinking
      187 1 Inability to use a diaper without help
      186 2 Inability to handle walking aids
      ... 4 .......(taking medicines)
      ... 10 .......(dressing and undressing)
   b. **Instrumental activities of daily living**
      204 5 Domestic equipment is too complex to handle
      203 3 Storing or eating perishable or bad food
      154 1 Obstructing sink and drain
      186 1 Manipulating the thermostat knob
      169 2 Using the taps
      145 2 Switching on and off the lights
   c. **Spending time**
      200 6 Dementing person can not keep himself busy independent
      178 6 Dementing person does not take initiatives
      164 4 Understanding what’s on T.V., too fast moving pictures
      155 2 Dementing person can not read the subtitles
      156 5 Dementing person can not read
   d. **Communication**
      198 4 Handling the telephone
      216 2 No remotely control if everything is secure
      206 3 Inability of use of an active safety-alarm system
      201 1 Control by telephone gives not enough information
      ... - ....., Problems with hearing aid
      ... 2 ....., Communication between professionals
2 Memory and orientation of the demented person

a. Memory

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>232</td>
<td>6</td>
<td>Failing to switch off domestic equipment (e.g. coffee machine, cooker, iron)</td>
</tr>
<tr>
<td>196</td>
<td>1</td>
<td>Failing to switch off taps</td>
</tr>
<tr>
<td>198</td>
<td>3</td>
<td>Failing to lock the doors</td>
</tr>
<tr>
<td>212</td>
<td>4</td>
<td>Loosing money, keys, administration, etc.</td>
</tr>
</tbody>
</table>

b. Orientation in time

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>204</td>
<td>2</td>
<td>Disruption of day-night rhythm</td>
</tr>
<tr>
<td>165</td>
<td>4</td>
<td>Inability to tell the time</td>
</tr>
<tr>
<td>192</td>
<td>5</td>
<td>Unable to structure the day</td>
</tr>
<tr>
<td>196</td>
<td>3</td>
<td>Forgetting to eat or eating too often</td>
</tr>
<tr>
<td>186</td>
<td>2</td>
<td>Unrest over appointments and dates</td>
</tr>
</tbody>
</table>

c. Orientation in space

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>179</td>
<td>1</td>
<td>Finding the way in house</td>
</tr>
<tr>
<td>194</td>
<td>1</td>
<td>Finding things in house</td>
</tr>
<tr>
<td>161</td>
<td>2</td>
<td>Finding the light switches</td>
</tr>
<tr>
<td>202</td>
<td>3</td>
<td>Finding the way outside the house</td>
</tr>
<tr>
<td>214</td>
<td>5</td>
<td>Wandering</td>
</tr>
</tbody>
</table>

d. Personal orientation

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>188</td>
<td>2</td>
<td>Recognising the primary carer</td>
</tr>
</tbody>
</table>

3 Safety of the demented person and his environment

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>227</td>
<td>8</td>
<td>Fire risk</td>
</tr>
<tr>
<td>186</td>
<td>1</td>
<td>Damage caused by water</td>
</tr>
<tr>
<td>182</td>
<td>4</td>
<td>Fear of criminality (i.e. not locking the doors)</td>
</tr>
<tr>
<td>211</td>
<td>3</td>
<td>Not being able to call for help by the safety-alarm system</td>
</tr>
<tr>
<td>195</td>
<td>5</td>
<td>Risk of falling</td>
</tr>
<tr>
<td>209</td>
<td>5</td>
<td>Wandering</td>
</tr>
<tr>
<td>205</td>
<td>4</td>
<td>No understanding of the traffic</td>
</tr>
</tbody>
</table>

4. Major problems for informal caregivers with supervision

<table>
<thead>
<tr>
<th>Code</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>220</td>
<td>8</td>
<td>24 hours supervision of dementing person</td>
</tr>
<tr>
<td>217</td>
<td>6</td>
<td>Not enough possibilities to control the situation from a distance</td>
</tr>
<tr>
<td>200</td>
<td>6</td>
<td>Keeping the dementing person busy, activated</td>
</tr>
<tr>
<td>194</td>
<td>7</td>
<td>Having no time for oneself</td>
</tr>
<tr>
<td>221</td>
<td>9</td>
<td>Continuous fear for unsafe or problematic situations (e.g. fire, criminality, malnutrition, poisoning by medicines, water damage, falls, panic of dementing person)</td>
</tr>
</tbody>
</table>
ANNEX III

Guidelines for designing for elderly people according to Pirkl and Babic (1988).

Pirkl and Babic mention as most important physiological changes: changes in sensor (vision, hearing, touch) and in mobility (small, large, intermediate and combination movements). They translated these changes in design guidelines. Main design guidelines related to physical changes are:

Design guidelines resulting from changes in vision:
• Provide appropriate product illumination and contrast
• Consider the object’s environment
• Minimise the need for typography, if typography is necessary: make it legible
• Eliminate glare

Design guidelines resulting from changes in hearing:
• Use adaptive volume controls
• Provide midrange and/or modulated sound indicators
• Minimise use of problem consonants
• Filter out background noise
• Reduce the speed of voice messages

Design guidelines resulting from changes in touch:
• Minimise the need for tactile differentiation
• Provide definitive pressure “feed-back” cues
• Prevent possible thermal injury

Design guidelines resulting from changes in mobility/movement:
• Minimise the need to rotate, twist and grasp
• Provide appropriately sized components
• Minimise effort required for each task