Enabling Technologies for People with Dementia

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1 Foreword

The overall objective of ENABLE is to investigate whether it is possible to facilitate independent living of people with dementia and to promote their wellbeing through access to enabling technological systems and products.

This report is based on the results from the Norwegian assessment trial, which took place from June 2002 till December 2003. Data are collected from 25 persons with dementia and 25 family carers. Persons with dementia, living in their own home, tested each one of the six ENABLE products for up till one year.

In Norway respondents were recruited from the city of Oslo and the county of Vestfold. Memory clinics in these districts were asked to recruit respondents to the project. Because of geographic distances, four research assistants have been trained to do the interviews and collect data. The research assistants have had regular meetings with the WP 4 leader, in order to be as consistent as possible in the data collection. Many thanks to the research assistants; Elisabeth Raastad, Anne-Grethe Solhaug, Jennie Arenlind and Ragna Ingeborg Gjone, who contributed in data collection and in transcribing the qualitative data.

Acknowledgements: I will address a few words of thanks to Øyvind Kirkevold and Per Kristian Haugen for support in handling the spss-data, and to Aase-Marit Nygård for peer reviewing the qualitative data. Special thanks to Knut Engedal, who has contributed greatly to this report.

Tønsberg, March 2004

Torhild Holthe, OTR

Project manager for the assessment trial in Norway, wp 4.3

2   Introduction

2.1   Prevalence and incidence of dementia

Norway has a small population of 4.5 millions. Except in the major cities and their surroundings, the population tends to be sparse. The retirement age is 67 years. Between 1930 and 1980 the population of people aged 60 years and over has doubled (Sosialt Utsyn 1998). Today (2004), 600 000 people are above 67 years of age (67 -79 years: 400 000 and 80 years + : 200 000).

By 2030, the population of people aged 80 years and above is expected to have increased by more than 50 %. Mean life expectancy (based on 1996 data) is 75.4 years for men and 81.1 years for women.

The prevalence of dementia is estimated to 4,5 % in the age group 65 - 79 years old, and 20 % in the age group 80 years and older. This means that there are about 65.000 people suffering from dementia in Norway today (Ott et al., The Rotterdam study)

2.2   The health care system in Norway

Until recently, the public health-care system has been the only professional health care services on offer in Norway, ideally provided according to need and independent of economic status and place of residence. These objectives have not been completely fulfilled. The private market for health and social care services is growing, and there is an ongoing public debate about the future organisation of the public health care-system in general.

The total national budget for public care for people in the municipalities was in 2001, NOK 43 billion. In all 90 000 professional carers provided care for 200 000 clients.

There are some particular services for people with dementia in Norway. In general there are three types of services: 1) Memory clinics for assessment and diagnosis, 2) day care centres (a rather low number), and 3) a number of specially designed wards in nursing homes. The health services, in general, are quite well developed when it comes to nursing homes and institutional facilities, however, not sufficient to meet the future needs.

In the recent years, there has been a refocus on priorities in the Norwegian care of the elderly, from institutional care to helping the elderly to live at home for as long as possible. Therefore, group homes or service housings have been built to facilitate nursing and health care, intending to assist old people to live outside an institution for longer than before. Nursing homes are reserved for old people with serious disabilities and in a considerable need of nursing. Approximately 75% of the residents in nursing homes suffer from dementia. In addition, the plan is to give priority to solutions that take account of people with dementia in old age and their special needs, e.g. special care units or community residences (group livings).

Approximately 75 % of the municipalities offer home care 24 hours a day. However the number of persons still living in their homes and in need of almost full-time care is increasing. The accessibility of this particular type of service varies markedly across the country. According to the "Action Plan for the Care of the Elderly", operating grants (total NOK 2.1 bn) are allocated to the local authorities to achieve this objective.

The core objectives of the action plan are listed as:

- To provide nursing and care services that ensure the elderly a secure and, to the maximum possible extent, worthy and independent life.

- To ensure elderly people's ability to live in their own home as long as possible.

- To provide sufficient capacity to ensure that services are available when and where needed

2.3 The present treatment and care service for people with dementia

A service that is suitable for people with dementia must be based on the fact that most dementia diseases develop and progress slowly. The need for assistance will depend on the person's functional capacity and social situation at the various stages of the disease. It is therefore not possible to talk about one single service for this group of patients. The model on which professionals generally agree is a series of measures: early diagnosis, support and advice to both the patient and his or her relatives at an early stage of the disease; various forms of day care and respite services for patients living at home; and a variety of institutional accommodation when living at home becomes impossible. According to the Municipal Health Care Act, local authorities are responsible for providing necessary social and health care for everyone living either permanently or temporarily in the municipality. The local health authority must be able to provide a wide range of services, consisting of prophylactic services, treatment, rehabilitation, nursing and care. General practitioners in the local health service have responsibility for referring patients to the specialist health services when necessary. The local health authority has responsibility for following up patients who have had specialist treatment and need further care at home. The health and social care services for the elderly are fully integrated into the national public health-care system.

Home helpers and district nurses are often supporting persons with dementia in their homes. Persons with dementia, needing help quite frequently, are particularly vulnerable having several formal carers come to support them. It is also a problem that few of the staff in the home based services is trained dementia workers.

It is estimated that more than half (60%) of the persons suffering from dementia live at home, of whom many with support from family caregivers only. The typical family caregiver is a spouse, or a daughter or son of the patient. More seldom siblings or nieces and nephews are in the picture. If the person with dementia is not cohabiting with the spouse, he or she usually lives alone in a house or a flat, only occasionally he/she would cohabit with a child.

2.4 Assistive Technology (AT) Services

The municipalities are responsible for health and rehabilitation for all citizens. Providing assistive technology is a part of this responsibility. If the municipality needs further assistance in this aspect, the Regional Centre for assistive technology can be contacted.

Each of the 19 counties in Norway has a Regional Centre for assistive technology. Persons that have lasting (more than 2 years) and considerable limited abilities because of illness, injuries or defects, can be supported from the National Insurance Agency (Folketrygden).

Individuals, when entitled to it, can apply for assistive devices and borrow this/these for as long as required. Often occupational therapists or nurses help the client writing the applications after doing a user needs assessment. However, anybody can send an application. The Regional Centres for assistive technology are funded by the state, and AT are reimbursed by the National Insurance Agency. According to the employees in the Regional Centres there is less use of technology in dementia care than in other areas, and this is probably due to lack of awareness of the potential of technology to assist persons with dementia (Marshall 2000, Bjørneby et al. 1999)

So far, very few studies have included persons with dementia in studying the usefulness of assistive technology.

Norway has participated in two earlier EU-projects on dementia and technology. The TED- project (Technology, Ethics and Dementia,1996 – 1999) and the ASTRID-project (A Social & Technological Response to meeting the needs of Individuals with Dementia and their carers 1998-2000) The conclusions from these projects were that there is a need to address the issue of technology and dementia further. It is important to raise the awareness of the potential of new technology among the health professionals. However, it is even more critical to gain knowledge on which type of technology the persons with dementia could benefit from and how to address the individual user needs and to do a

successful implementation. The Norwegian Centre for Dementia Research joined the ENABLE project to gain knowledge on these topics, in order to maintain a leading position on the topic in Norway.

3 Aim

The overall objective of ENABLE is to investigate whether it is possible to facilitate independent living of people with dementia and to promote their wellbeing through access to enabling technological systems and products.

Key scientific and technological objectives are to:
- Develop prototypes and provide a test series of products that aim to enable the person to keep him/herself occupied with activities which give pleasure, support memory or facilitate communication, and to adapt and validate products that are commercially available
- Develop a methodology for assessment and analysis of effects of products aimed to enable people with dementia living in their own home.
- Develop an approach towards cost/benefit analysis and make preliminary estimations based on the experience of users and carers.
- Examine whether such products can enable people with dementia and support their wellbeing by giving positive experiences, reducing worries and unrest, and reducing the burden on carers.
- Disseminate knowledge to people with dementia, their carers and organisations as well as to health and social care service systems and industry about the potential of enabling products.
- Make an overview of the problems and needs which each of the products aim to solve or reduce, both for the person with dementia, for their carers and for the society.

The expected achievements of the project include:
- Test series of new technological products with documented effects and commercial possibilities
- New insight about how to involve users with dementia and their carers in product development and assessment, in line with ethical principles to maintain their dignity and respect.
- New knowledge about effects on users and carers of specific technologies that aim to further enable people with dementia. This includes knowledge about factors which facilitate and promote positive effects, as well as the opposite.
- New knowledge of costs and benefits of enabling technologies for people with dementia both at micro and macro level based on empirical evidence.
- Raised awareness among different actors in the society about dementia and the potential of enabling technology
- Commercial possibilities created for products developed which are found to be useful and cost/effective.

The explicit aims for work the study described in this report were as follows:
- To examine whether the products provided can mitigate or solve certain practical problems in carrying out daily tasks for persons with dementia living in their own home
- To examine whether the mitigation or solving of these practical problems may have further impact on supporting independent living on the wellbeing of the persons, and reduce the burden on their carers.
- To examine whether the products provided yield socio-economic costs and benefits.

4 Methodology

4.1 The hypothesis which directed the work

Our hypothesis is whether the person with dementia uses the product or not can be explained by factors related to the person with dementia, the carer, the environment, the product or the researcher, as illustrated below.

Figure 1: Factors related to use and usefulness
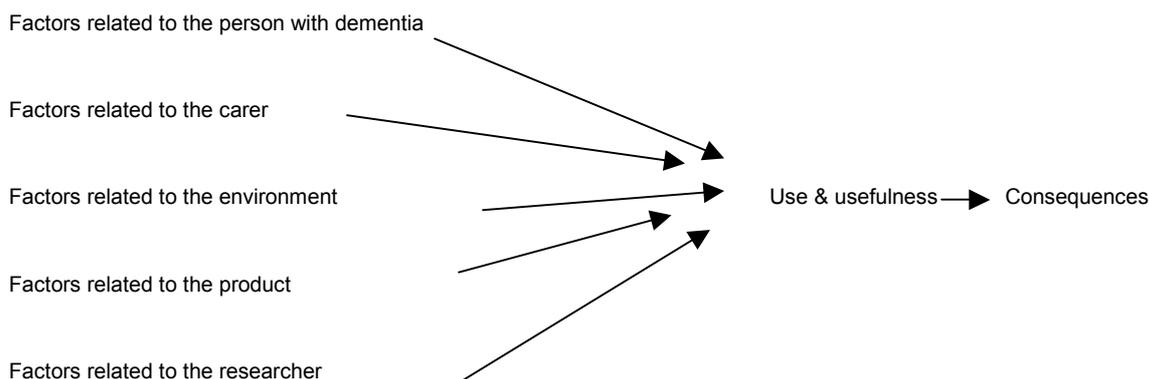
Use & usefulness are the primary outcome measures. Use of the devices may have further consequences for the patient, the carer and the community. These will depend on the character of the problem (falls at night, forget to turn off cooker, time orientation), the importance of the problem for the patient, the carer and the society and how it affects them, respectively. These are secondary outcome parameters. Outcome parameters marked with * are used as outcome parameter categories also for the primary carer.

Categories of secondary outcome measures (consequences) are:

- Support independent living
- Support feeling of coping
- *Create pleasure, activity
- *Reduce general emotional burden due to worries, anxiety, stress or irritation
- *Prevent unwanted incidents or accidents
- Support memory
- *Prevent situations creating unwanted negative feelings between the patient and the carer due to stress in connection with e.g. not finding lost objects, repeated questions, passivity

4.2 Recruitment

The protocol was submitted to the Ethical Committee for Medical Research, Region South, and to the Norwegian Science Data Services in December 2001, and approval was obtained early February 2002.

Persons with dementia and their families were recruited to the project via Memory Clinics in Oslo and in Vestfold County. The staffs at the clinics were requested to identify potential subjects satisfying the project's inclusion criteria and to invite them to participate in the study. A standard information letter was given to potential participants. The patients and the family caregivers were asked for consent by the staff, and the consent was signed by both and sent to the research team. Thereafter, the research worker called the family carer for an appointment for the first meeting (T0) and user needs analysis in order to determine which ENABLE product to implement.

4.3 Inclusion and exclusion criteria

Problems with daily tasks, that could be solved or mitigated with use of the ENABLE products, represented a preliminary inclusion criterion.

The inclusion criteria were:

- People who live in their own home with a diagnosis of mild or moderate dementia according to ICD-10, preferably Alzheimer's disease, vascular dementia or mixed Alzheimer's/vascular types. Patients with sub-cortical dementia may be included, but must be described carefully.

- Age > 50

- MMSE score > 12

- Reasonably good nutritional status and general health; i.e. able to move on their own both within the house and outside

- A primary caregiver who is able and willing to participate. A primary caregiver is defined as that persons or persons who have responsibility for the day to day care needs of a cognitively impaired person. The definition does not exclude carers living apart form their dependent, or those who have additional care/work responsibilities (Stone et al 1987)

- The primary caregiver can either live with the person with dementia or have frequent contact with him/her. Frequent contact means telephone call or visit at least once a week.

- Informed consent given

- Living in a reasonable distance from the researchers

The exclusion criteria were:

- People participating in other intervention studies

- Any major psychiatric disorder

- Active malignancy

- People with fronto-temporal dementia

- Patients without a reliable caregiver

- Nursing home patients

- People on a waiting list for nursing home

Additionally to the general criteria for inclusion and exclusion specific inclusion and exclusion criteria for each of the products to be tested were defined. The following present the criteria for the products tested in Norway:

Criteria for being provided with the night and day calendar:

- Problem with day-time/night-time orientation and worry about it

- Ability to read the text on the display

- Ask about time of day and/or telephone calls to primary carer at night, or wander at night

Criteria for being provided with an automatic lamp

- Often out of bed at night

- Previous falls?

- Previous disorientation

Criteria for being provided with an item locator

- Problem with finding keys, purse etc. and worry about loosing objects

- Ability to hear the sound and understand the use of the locator

- Ability to learn new routines or is co-habiting

It was imperative in the user needs analysis to identify the most important need. Often a person might need several devices, however, only one ENABLE product was provided per person. The respondent was offered to keep the product for free for as long as it is used and useful to the person. When it is no linger I n use, the product is given back to the provider (NCDR) at the provider's expense. A sticker will be placed under each device with name, address and telephone number to the person to contact in case of questions or problems. The researcher was provided with some spare units in order to do a quick swap in case of technical problems, and return the faulty device for repair. A statement was made: " the products are not commercially available yet, but they have nevertheless been developed to the same safety standards that apply to the product."

The selection of products procedure was discussed at one partner meeting. It was decided that all partner countries should test the same products, as far as it was culturally appropriate. Gas cooker monitors were not culturally for Norway and were excluded from the Norwegian selection. Some optional products that were commercially available were suggested to be included in the assessment trial. In Norway following products were selected, and these criteria were written post assessment.

Criteria for being provided with medicine reminder

- Problems in taking correct medication in correct time because of memory problems

- Ability to hear the sound

- Ability to learn to use a new device or co-habiting

Criteria for being provided with picture phone:

- Problems with remembering and dialling a row of numbers in correct order

- Ability to read the text or identify persons on the keys

- Wish for being able to get in touch with family and friends

Criteria for being provided a remote day planner:

Problems with remembering future appointments and events

Agreement upon installing ISDN telephone line if not already installed

Ability to learn new routines (to look at the screen)

Participants, who participated three months (finished T3) in the project, were regarded as completers. They would still be followed up for the next nine months, in order to get more information about use and usefulness of the products over time.

Participants who dropped out of the study before three months were classified as drop-outs, and reasons for dropping out are of particular interest according to the hypothesis. Thus, the analysis of drop-outs will be presented.

4.4 Time schedule for following up the trial assessment

The first home visit (T0) took place with both the respondent and family carer present. The enable product was demonstrated and implemented by the person with dementia. Further the fieldwork involved the first follow-up telephone call after one week (T1), then a home visit after three weeks (T2), and then at three monthly intervals (T3, T4 and T5), up to one year to assess the continued use and usefulness of the product.

The frequency of interviews/contacts can be summarized as follow:

T0	Baseline interview and implementation of product
T1	Telephone call to carer 1 week post implementation
T2	Home visit and interview with patient and carer 3 weeks post implementation
T3	Home visit and interview with patient and carer 3 months post implementation
T4	Home visit and interview with patient and carer 6 months post implementation
T5	Telephone call to carer 12 months post implementation

Developing the methodology

Reviews were made of methods and tools used in the trial. The work comprised desk research, literature studies and consultation with researchers and experts in dementia care, including:

- a. Processes to secure compliance with ethical principles
- b. Diagnosis of dementia and severity of dementia
- c. Evaluating Quality of Life for persons with dementia
- d. Evaluating Burden of care/carers' stress

A unified methodology for assessing impacts of enabling products for persons with dementia was developed, based on these reviews and the user requirements. The methodology developed served as basis for designing the protocol for the assessment study. A single instrument to gather quantitative and qualitative data was constructed which incorporates factors pertinent to effects on functional abilities, wellbeing and socio-economic parameters. Some questionnaires on use and usefulness were created in the project, in order to be able to measure the outcomes of use and usefulness, which were the dependent variables.

The work with selecting and putting together scales for the questionnaires was characterised by thorough discussions and some of the scales had to be interpreted into Norwegian.

4.5 Presentation of the scales used in ENABLE

To develop a new methodology has been time consuming, and the presented selection of scales has provided us with new knowledge on the topic – dementia and technology. Scales used at the different stages of ENABLE assessment study - an overview

Table 1: A: Scales for interviewing patients (time 1 –11/2 hours maximum)

Scales	*T0* *Baseline*	*T1* *Post 1 week*	*T2* *Post 3 weeks*	*T3* *Post 3 months*	*T4* *Post 6 months*	*T5* *Post 12 months*
MMSE (Mini Mental State Examination) if not available from the memory clinic	(X)					
Socio-demographic data (if possible)	(X)					
Quality of life of the person with dementia (Brod)	X		X	X		
Experience with product/overall impression Questions to patient			X	X	X	

Table 1B. Scales for interviewing the family caregiver (carer may fill out some forms by themselves)

Scales	*T0* *Baseline*	*T1* *Post 1 week*	*T2* *Post 3 weeks*	*T3* *Post 3 months*	*T4* *Post 6 months*	*T5* *Post 12 months*
Socio-demographic data on patient	X		X	X	X	
Form (User need analysis)	X					

Form I (on expectations to product)	X					
Form II (on actual outcomes of use of product)			X			
Form II.i Willingness to pay			X	X	X	
RUD (on health economics) Interview with carer A1.1, A1,2, A1.3	X					
RUD (on health economics) Follow up questionnaire B1.1, B1.2			X	X	X	
Relative's Stress Scale (Greene)	X		X	X		
Experiences on the product			X	X	X	
Telephone-call Is everything OK?		X				
Telephone-call Is product still in use?						X

The Mini-Mental-State Examination – MMSE (Folstein et al)
The MMSE is a short cognitive test used worldwide to screen for dementia and to assess the degree of dementia. It consists of 20 questions to the patient, measuring short-term memory, orientation in time and place, speech praxis and general cognitive and motor functions.

The Dementia Quality of Life Instrument - DQoL (Brod et al)
The DQoL is a 29-item scale developed on the basis of domains identified as important to people with dementia. These domains are: (i) physical functioning, (ii) daily activities, (iii) discretionary activities, (iv) mobility, (v) social interaction, (vi) interaction capacity, (vii) bodily well-being, (viii) sense of well-being, (ix) sense of aesthetics and (x) overall perceptions of quality of life. Responses are given on a 5-point Likert scale ranging from "never" to "very often". The items are scored under 5 sub-scales namely (i) *self-esteem*- the frequency a person feels confident, satisfied with self, accomplished something, makes own decisions, (ii) *positive affect,* the frequency a person feels happy, cheerful, content, hopeful, finds something that makes him/her laugh, jokes and laughs with others), (iii) *negative affect,* the frequency a person feels afraid, lonely, frustrated, embarrassed, angry, worried, depressed, nervous, sad, irritated and anxious, (iv) *feeling of belonging* , the frequency a person feels useful, liked and loveable and (v) *sense of aesthetics*, the extent to which a person obtains pleasure from sensory awareness, appreciation of beauty - enjoys listening to music, listening to nature, watching animals and birds, looking at colourful things and watching the sky or clouds. The scale (DQoL) includes three sample questions to ascertain if the person with dementia understands the scale and the question and answer format. The scale can only proceed if two of the three sample questions are answered correctly. The scale has proven to be reliable and valid when tested in the United States but does not include the perspective of the family caregiver.

The Relative's Stress Scale (Greene et al)

The Relative's stress scale is a 15 item questionnaire to the primary caregiver. The scale aims to measure the stress experienced by the family carer, for the time being. The scores are summarized and higher scores indicate that more stress is experienced.

The RUD scale

The RUD questionnaire is a quite extensive questionnaire on health economics, and aims to measure carer's time spent for looking after and caring for the patient, the carer's work situation, the patient's

use of public health services, medication, accommodation facilities and reasons for change of such, additionally to more general data on the socio-demographics. The questionnaires are two-fold, part A for basic data collection and part B for follow up questions.

Cost-benefit questions

The cost-benefit questionnaires were developed in the project and aimed to measure the expectations of the carers and their perception of the importance of the problems for both themselves and the patients. The follow-up questionnaires aimed to investigate the consequences of the use of the product.

Questions for use and usefulness

These questionnaires were developed in the project to measure the experienced use and usefulness by the patients and the carers. The questionnaires differed partially from each other, because the questions were related to the specific products being tested.

Questions on emerging themes

Additionally to the DQoL questionnaire (page 14) the partners agreed to include three questions about how the person with dementia assessed his/her situation; i.e. what their concerns and worries were and what made them happy. This was decided, in order to grasp "the voice of the person with dementia" and to have more qualitative data that could enlighten their quality of life.

4.6 User needs analysis

Six ENABLE products were selected for the assessment trial. Each respondent was to test one product each, and the product provided should meet the patient's most urgent need, if possible, in order to be able to assess the feasibility. The number and types of products were decided in one partner meeting, and because the availability was limited, the first patients to join the project had most products to choose in. This meant that if a patient's most urgent need was to have a telephone, and the four telephones already were lent out; the patient could either be excluded from the project or we could find the second urgent need to be met. Sometimes a patient might need more than one device. This raises ethical questions which will be further discussed in the end of this report. The number of persons who tried out a specific product depended thus upon the identified individual user need. In Norway the user need analysis usually took place during the first telephone conversation with the family carer. Only twice the research assistant brought with her more than one device for deciding which of them to test.

Examples of parameters which were registered included:
- - aspects connected to the use of the device, including the need for follow-up by family or professional caregivers
- - whether use of the device can mitigate the problems it is aimed to reduce
- - reactions to having a new device in one's home
- - concerns about the device and opinion about its advantages and disadvantages
- - whether the device should be removed

Experienced researchers and care workers were involved to ensure sensitivity to the ways in which people with dementia express their needs and views.

5 Presentation of baseline data

5.1 The persons with dementia

In total 25 respondents and 25 family carers were consenting to participate in the study, eighteen women and seven men. Their average age was 80,4 years with a range from 65 to 92 years old. This means that the average age is high, even for persons with dementia living at home.
Sixteen of the Norwegian patients was blue collar workers, and nine were white collars. According to the UK's Office of National Statistics the Socio-economic classification for occupations (NS-Sec) are as following:

- Higher managerial and professional occupation
- Lower managerial and professional occupation
- Intermediate occupation
- Small employers and account workers
- Lower supervisory and technical occupations,
- Semi-routine occupations
- Routine occupations

In Norway we usually do not operate with such a detailed classification, however, it is quite customary to divide into clericals and workers. Clericals have education of a higher degree. In the Norwegian selection professions like workers, farmers and housewives are classified as blue collars, and daily managers and academics etc. are classified as white collars.
The level of income was divided into five categories, from < €14.999, € 15.000 – 24.999, € 25.000 – 29.999, € 30.000 – 39.999 and lastly > € 40.000. In the Norwegian selection, eighteen of the respondents had gross household income lower than € 25.000.

The respondents MMSE score was 21.1 by average, ranging from 12 to 28. Their diagnosis was divided into four categories: nine had Alzheimer's disease, one vascular dementia, while six had a mixture of both Alzheimer's and vascular dementia. Nine had an unspecified dementia.

According to the MMSE score, fifteen had dementia in a mild stage (>18), and ten had dementia in a moderate stage (12<18). Fourteen of the twenty-five respondents used prescribed medications for their conditions of dementia (Aricept, Exelon, Reminyl).

Thirteen of the respondents were living alone in their own house or apartment; ten were living together with their spouse or co-habitant, while two were living with other family, a niece and a son. Eleven of the respondents reported to have family caregivers, with a range of weekly hours from 1 to 15. Only two patients received care from other relatives, time ranged from 1 to 16 hours weekly. Nobody confirmed having help from public health services, however, ten respondents had support from public health nurses, range 0,15 to 10 hours a week, and eight had home help coming from 0,30 to 3 hours weekly.

Assessment of perception of own quality of life showed that 15 of 25 persons with dementia rated their quality of life as good, very good or excellent. Only 3 of 25 rated their quality of life to be bad. The distributions of respondents in the five domains using the Brod's Quality of Life Scale are presented in bar charts. The five domains were:

-
    Self Esteem (included 4 variables)
- Positive Affect/Humour (included 6 variables)
- Negative Affect (included 11 variables)
- Feelings of Belonging (included 3 variables)
- Sense of Aesthetics (included 5 variables)

Table 2 shows the socio-demographic characteristics of the Norwegian persons with dementia. The completers stayed in the project for three months (T3). The five drop-outs, dropped out before three weeks (T2).

Table 2: Characteristics of the Norwegian patients

	Included N= 25	Completers N= 20	Drop-outs N= 5
Male	7	5	2
Female	18	13	3
Age, X , (range)	80.4 (65-92)	79.3 (65-92)	80.0 (65-89)
Profession			
Blue-collar	16	13	3
White collar	9	7	2
Income level gross household (2 missing)			
< € 14.999	9	7	2
€ 15.000 – 24.999	9	7	2
€ 25.000 – 29.999	2	2	-
€ 35.000-39.999	2	2	-
> € 40.000	1	1	-
MMSE, X, (range)	21.1 (12-28)	21.8 (12-28)	18.6 (16-21)
Diagnosis (4 missing)			
AD	9	7	2
VaD	1	1	0
Mixed AD/VaD	6	6	0
Unspecified	9	6	3
Mild dementia (MMSE >18)	15	12	3
Moderate dementia (MMSE 12 -18)	10	8	2
Using "anti-dementia drugs"			
Yes	14	12	2
No	11	8	3
Living arrangement			
Living alone	13	10	3
Living with spouse	10	8	2
Living with others	2	2	0
Own house/flat	19	17	2
Other accommodation	6	3	3

Go out alone			
Yes	18	14	4
No	7	6	1

5.1.1 Dementia Quality of Life (DQoL)

Table 3 is presenting the experienced quality of life in the patients at three different stages; at baseline and implementation date (T0), post three weeks (T2) and post three months (T3). The idea by presenting the experienced quality of life over the three month's period was to determine whether the ENABLE product may influence the patient's well-being.

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Table 3: DQoL – overall quality of life

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Overall Quality of life at	T0 (n=25)	T2 (n=20)	T3 (n= 20)
Excellent	2	4	2
Very good	11	9	10
Good	4	5	5
Fair	2	0	0
Bad	1	1	0
Missing	5	1	3

It is of interest to investigate how the patients assess their quality of life and which domains are representing the highest grade of well-being. The profiles of the Norwegian patients regarding the five domains are presented in bar charts below. The positive side of the bar chart is to the right. Not all the patients were able to answer the DQoL, therefore all the bar charts below will have missing data.

5.1.1.1 The distribution of respondents after domains on DQoL:

Figure 2.1 presents the profile on the patients' experienced self esteem. The bars are showing that 17 of the patients rated their self esteem as good sometimes or often. Five stated that their self esteem seldom was good and only one rated his or her self esteem to never be good.
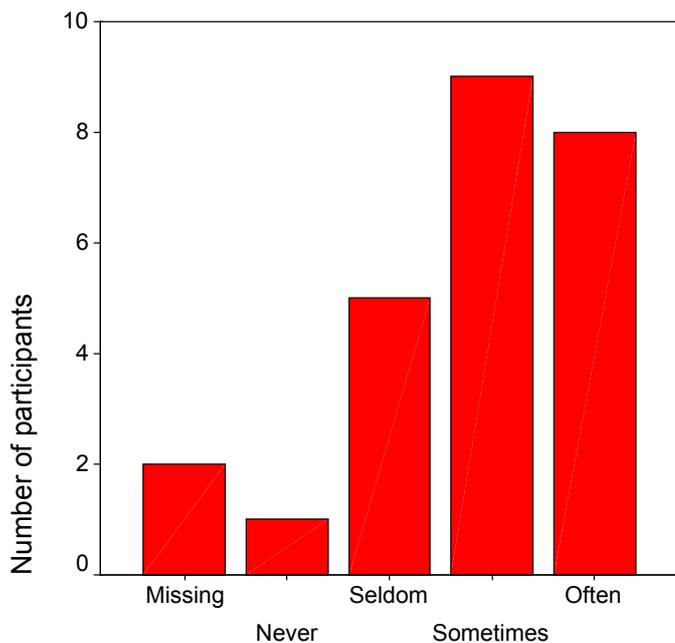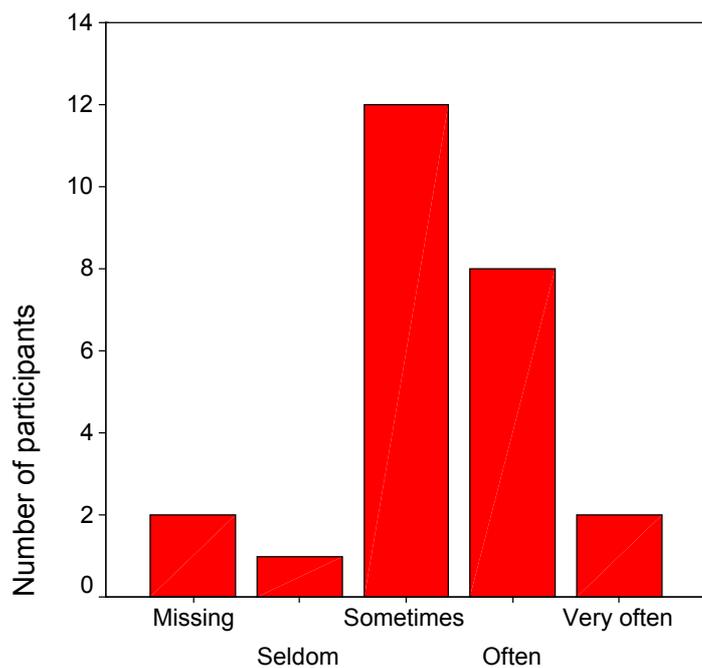
Self Esteem T0

Figure 2.2 on positive affects is showing that 10 patients stated they experienced positive affect often or very often, while 12 stated they experienced positive affect sometimes. Only one stated that he or she seldom experienced positive affect. Positive affect included feeling of happiness and cheerfulness, feeling of content and hope, and things that made them laugh or whether they enjoyed joking and laughing.
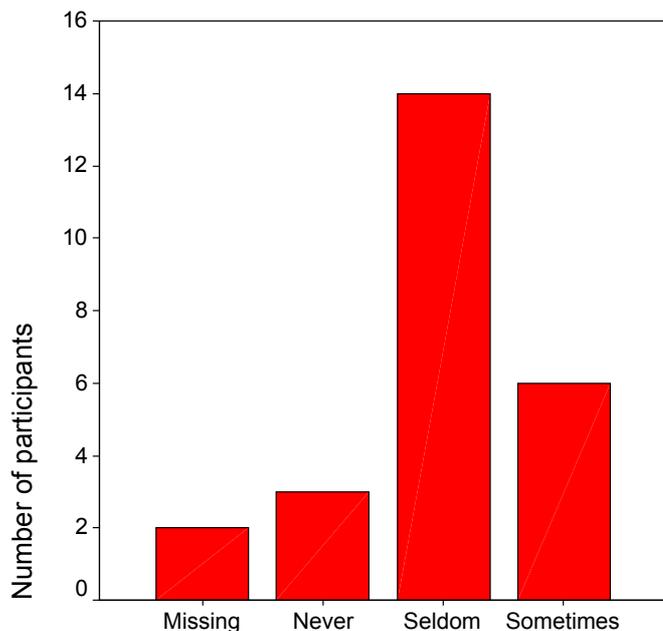
Positive Affect T0

Negative affect T0

Figure 2.3 on negative affect shows that 6 of the patients sometimes experienced negative affect, while 17 seldom or never experienced negative affect.

Negative affect included feelings of embarrassment, loneliness, fear, frustration, anger, worries, depression, nervousness, sadness, irritation and anxiousness.
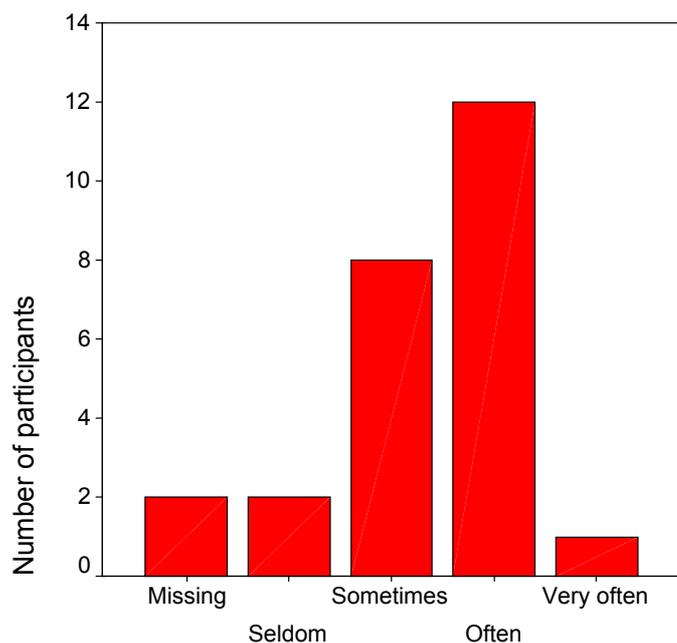
Feelings of belonging T0

Fig. 2.4 is showing the patients feelings of belonging. Thirteen of the patients stated that they often or very often had positive feelings of belonging, while eight said sometimes. Only two stated that they seldom felt to belong. The variables included in the feelings of belonging were feelings of being useful, loveable and that people like you.

Sense of Aestetics (T0)
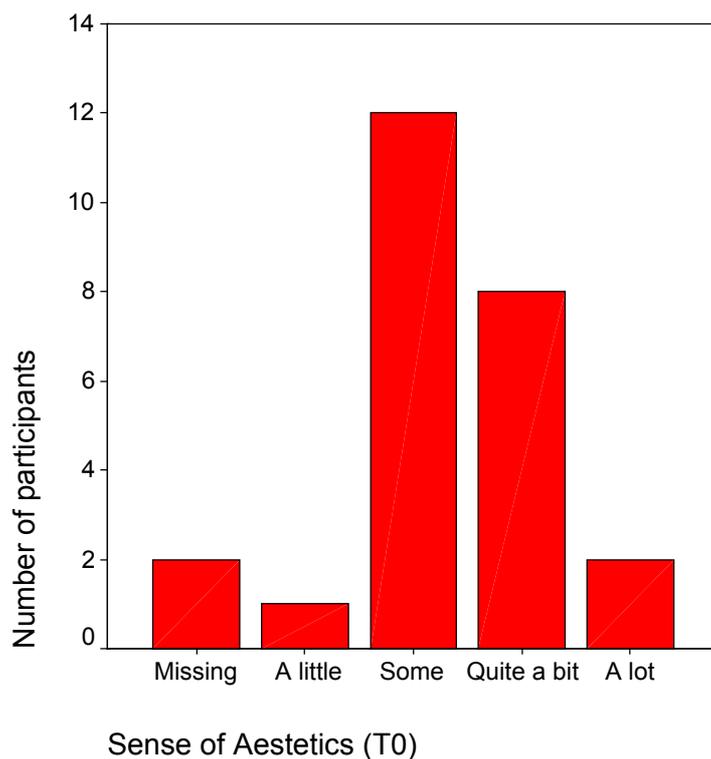
Figure 2.5 shows the patients' sense of aesthetics.

Twenty-two of the patients stated that they enjoyed aesthetics to some degree, quite a bit or a lot. Only one stated that he or she enjoyed aesthetics a little.

Aesthetics contained questions about how often people enjoyed music, sounds of nature, bird or animals, colourful things and the weather.

The family carers

Of the twenty-five family carers 13 were women and 12 were men. Their age ranged from 39 to 83. Nine of the family carers were spouses to the respondent, fourteen were children or children-in-law, and two had another relation (co-habitant and nephew).

Ten of the twenty-five family carers were working (having paid work) and these were children of the respondents. Fourteen were not working, because of retirement or unemployment.

Thirteen of the family carers lived in the same house as the respondent or the neighbour house. Three lived within a distance of 1 kilometre and three in a distance of up to 10 kilometres away from the respondent. Five family carers lived more than 10 kilometres away from the respondent. (one missing).

Regarding the Relative's Stress Scale, the sum score ranged from 2 to 41, with a mean score of 18,4. It was a tendency that spouses experienced more stress than children of the patients. Table 4 shows the characteristics of the Norwegian family carers

Table 4. Characteristics of the Norwegian family carers

	Included N = 25	Completers N = 20	Drop-outs N = 5	
Male	12	11	1	
Female	13	9	4	
Age, range	39-83	39-78	43-83	
Relation to carer				
Spouse	9	7	2	
Children	14	11	2	
Others*	2	2	0	* cohabitant and nephew
Working situation				
Working	10	7	3	
Not working	14	12	2	
No answer	1	1	0	
Distance from patient				
0	13	11	2	
< 1 km	3	2	1	
1-9,99 km	3	3	0	
>10 km	5	3	2	
No answer	1			
Relatives' stress				
Green scale, X (s.d)	18.4 (11.2)	16.6 (10.4)	25.6 (12.2)	N.S.*

* N.S. = not significant using Mann-Whitney U-test

5.2 Care provision at baseline

Eleven of the respondents received help and support from a family carer, and two received addition-ally help form other relatives. Ten persons (eight women and two men) received help From public home nurses, and eight persons (six women and two men) received support from home helpers. When correlating these persons with MMSE score it was obvious that the persons with the lowest scores had most weekly hours from public services.

The family carers were asked how much time they spent in assisting their relative with dementia in PADL (Physical activities of daily living), IADL (Instrumental activities of daily living) and in supervising during everyday living, at baseline, after three weeks and after three months. The table shows the number of persons receiving visits from public nurses and home helps, and how many receiving family care. In parenthesis are the ranges of hours for each "service". Ten of twenty-five patients received care from public nurses. The time spent by the nurses ranged from a quarter of an hour to 10 hours a week. Only eight of the twenty-five patients received support from a home help, and the time provided ranged from half an hour to 3 hours per week. Eleven of the patients had family carers support them in IADL , i.e. shopping, economics, house work, cooking etc. and in supervision i.e. reminding of ap-pointments, tasks to be done, to avoid harmful situations and support memory difficulties in the pa-tient. The family caregivers spent between one and fifteen hours weekly to support their relative with dementia. This table do not display whether it is the same patients receiving both public nurse and home help and family care giving. Interestingly only eleven family carer's have stated that they provide support for the relative with dementia.

Table 5: Care provision at baseline

	Included	Completers	Drop-outs
	N= 25	N= 20	N= 5
Care provision (weekly hrs at T0)			
Public health nurses (0,15-10 hrs)	10	9	1
Home help (0,30 – 3 hrs)	8	7	1
Family caregiver (1-15 hrs)	11	10	1
Other relatives (1 – 16 hrs)	2	2	-
Family care hours/week (n=11)	M 5.9 (s.d. 3,8)	Range 1-15 hours	
Other relatives care hours/week (n=2)	M 8,5 (s.d. 10,6)	Range 1- 16 hours	
Home help, hours/week (n=8)	M 1.2 (s.d. 0.8)	Range 0,30 – 3 hours	
Public health nurse, hours/week (n=10)	M 3.2 (s.d. 3.7)	Range 0,15 – 10 hours	

Table 6 is presenting how the family caregiver situation develops over three months from baseline to T3. It seems evident that most family caregivers provide help in instrumental activities of daily living (laundry, shopping, cleaning, economics, transport) and in supervision.

Table 6: Care provision by family carer during three months

Family carer assisting in	T0 (n= 25)	T2 (n=20)	T3 (n=20)
	Baseline and implementation	3 weeks post implementation	3 months post implementation
PADL(hrs/week)	7 (range 1-2hrs)	5 (range 1-3hrs)	7 (range 1-3hrs)
IADL(hrs/week)	21 (range 0,15-8hrs)	19 (range 0,10-8hrs)	19 (range 0,20-8hrs)
Supervision (hrs/week))	24 (range 0,10-24hrs)	19 (range 0,1 -24hrs)	18 (range 0,10-24hrs)

5.3 Presentation of the devices assessed

There were a certain amount of products available, due to the decision made on a partner meeting:

Products selected to be tested in Norway	Description of product	Expected effects
10 Night and day calendars	As a calendar, day and date is always correctly displayed, together with the time of day (morning, day, evening and night)	Facilitates orientation, prevents people from going out during the night and disturbing others
10 Automatic lamps	Automatically turns on and off the light when a person gets in and out of bed	Prevents falls at night, reduces anxiety and facilitates orientation back to bed
10 Item locators for lost objects	Pressing the picture of the item on a wall display panel causes the lost item to emit a warbling sound, stops when item is picked up	Finds frequently lost objects such as keys, purse etc. Reduces worries and time spent looking for lost objects
4 Picture phones	A fully functional telephone that displays the pictures of nine contacts whose numbers are stored in the phone, it also has larger buttons	Reduces anxiety surrounding the use of telephones, supports memory
5 Careousel medicine reminders	A battery driven medicine reminder that alarms at pre-set times. It both reminds the person on taking the drugs and provides the correct drugs in correct doses.	Reduces anxiety for not taking the correct drugs to the right time. Avoids overmedication. Support independent living
1 Remote day planner	A screen on the wall connected to a telephone-line. Displays messages for the current day. Messages can be sent by e-mail from a carer outside the house	Support memory, and remind the person on the day's appointments and events
1 Picture gramophone	A computer with touch screen and loudspeakers, showing pictures to be touched. When touching the picture, music will start to play and lyrics are shown on the screen. The content of the programme can be tailored after the person's preferences in music.	Represent a possibility for entertainment and stimulation. To be used in a smaller group or individually.

Products

Products aimed to support memory, facilitate communication, or to provide pleasure and comfort, as had been identified prior to the start of the project. Prototypes and test series of seven new products were developed during the first year of the project. The partners selected five products to be tested in each country from a list of twelve different products described in Technical Annex. In addition, testing of one or more of remaining seven products was optional.

It was decided to test the following products in Norway:

- locator for lost objects (keys, purse etc), developed by ENABLE partner

- automatic night lamp to prevent falls at night, developed by ENABLE partner

- electronic "Night and Day" calendar to enable time orientation, developed by ENABLE partner

- multimedia "Do-it-yourself" Picture Gramophone for entertainment and enjoyment of favourite music*, developed by ENABLE partner

*The trial of the Picture gramophone was conducted in a day centre for persons with dementia in Oslo. The study with results will be presented in a separate report.

In addition, two existing products were selected for optional testing:

- medicine reminder "Careousel", which gives a sound when it is time for medication, commercially available

- picture telephone "PicturePhone", with big buttons which can be pre-programmed and show names or pictures of the persons one would like to call, commercially available

Product selection and rationale

The ENABLE consortium decided which products to test in the assessment study. Possible cultural adaptations on the equipment were discussed. For example, a gas cooker monitor with an automatic shut-off device was to be tested. In Norway, gas cookers are seldom used, and the device was therefore not relevant to test. Another product, the sensor controlled water tap device, which was interesting and expected to meet a need, had to be adapted to Norwegian standards regarding water pipes and taps. To select the sensor controlled water tap device would challenge culturally adaptations, way over the standards in Norway, need plumbers to be included as subcontractors and possible need approval from insurance companies and other authorities.

The rationale for selecting products to the Norwegian assessment trial was first of all to test some of the products developed in the ENABLE project. Of optional products, medicine reminder was selected, a product that is well acquainted in Sweden, but hardly used in Norway, and the Picture Phone which also is commercially available.

It was planned to test one remote day planner, which would need more advanced telephone line and that the family carer had access to PC and internet. However, the product required a "tablet" PC screen, and the provider of this was not able to deliver in time and later went bankrupt.

5.3.1 Presentation of the ENABLE-products in Norway

LOCATOR

Basic functioning

The locator device is aimed at enabling people who have mislaid objects in their homes to locate them. The device has a series of touch panels on the front onto which can be stuck pictures of objects to be located. When the user touches the picture the tag attached to the lost object will beep so the object can be found.

Technical details

The device can be placed on a horizontal surface or be wall-mounted, and requires plugging into the mains. It has space for five objects to be pictured on the front panel together with a cancel button. The touch panels simply need to be touched by the user to initiate a search, and a light appears within the panel to indicate that it is signalling. Each object to be found has a tag connected to it or inserted in it. The tag detects that it is being called by the panel unit and initiates the sound. If it is picked up it will stop. Users can

cancel the sound on the panel if they wish by touching the cancel sign, and it will stop anyway after 5 minutes. The unit generates a coded radio signal that is picked up by the tags. The tags check every two seconds to see if they are being called but go into sleep mode in between to conserve their batteries. The unit has a range that is suitable for a domestic dwelling. Battery life is about 5 months. The tags can be mounted on key rings, pension books etc, or put inside purses, glasses cases etc. The sound has been developed to be two-toned. A pure tone is provided at the resonant frequency of the sounder to maximise output. In addition a brief burst of pseudo white noise is provided as this has been shown by other workers to be easier to locate.

NIGHT LIGHT

Basic functioning

The night light is aimed at providing light, particularly in a bedroom, when the user gets up at night. A sensor under a bed leg detects bed occupancy and an ambient light sensor detects whether it is dark or not. If it is dark and the user gets out of bed the bedside light is faded on. If they leave the light on when they get back to bed it will fade the light off again.

Technical details

The bedside light comes with all the electronics packaged within the lamp base, and two cables attached, one with a mains plug on the end and the other with a small plug on the end. To set it up the lamp needs to be placed in a convenient position and plugged into the mains. The bed-leg sensor needs to be placed under a leg and the other cable from the lamp plugged into it. It only operates when it is dark and will automatically fade on if someone gets out of bed after they have been in it. It will automatically fade off again about 5 minutes after the user has returned to bed. The lamp can be turned on and off through the normal switch at any time. To demonstrate it in daylight the small ambient light sensor that is fitted on the very top of the lamp base needs to be covered up to simulate darkness. The sensor unit comes with a series of ringed inserts. The inserts allow the sensor to be configured to the size of the bed leg. The lamp will automatically adjust itself according to the weight of the user. It generates a running average of the load that the sensor is seeing and looks for any changes from this that indicate that someone has got out of bed. So it should not be sensitive to someone turning over in bed for example. It is recommended that the sensor is put under a bed leg at the head end of the bed. If two people share the bed it is best to put the sensor under the leg on the side used by the person with dementia. If the other person gets up the light may sometimes come on as well. The sensor unit is quite insensitive to water being spilled on it and will function properly again once it is dry. The light level achieved after it has faded up can be adjusted by means of a small adjuster under the base of the lamp.

NIGHT AND DAY CALENDAR

Basic functioning

Disorientation for time is common among people with dementia. Also, some people mistake night for day and *vice versa*. The aim of the Night-and-Day calendar is to:

- Enable people with dementia to find out whether it is day or night

- Reduce the risk that the people with dementia go out in the middle of the night and get lost

- Avoid that people with dementia call family members or others in the middle of the night and wake them up - unless they need help.

- Help people with dementia with time orientation

The Night-and-Day calendar consists of an LCD display which shows day, date and "Morning", "Afternoon", "Evening" or "Night", as appropriate. At midnight, day and date shifts automatically, and similarly, the time of the day shifts from Night to Morning at 7 a.m., to Afternoon at 12 noon, to Evening at 6 p.m. and to Night at 11 p.m. It is connected to the mains. The text will disappear in case of power failure, but will reappear when the current is turned on.

Technical details

Development of the Night and Day calendar is based on the software of the Forget-me-not™ calendar which has been on the market since 1998. A new microprocessor (PIC16 627) has been used, and the software modified according to the new functions specified. A revised circuit card has been designed. Day, date and time of the day (Morning, Afternoon, Evening and Night) are shown in the respective language on a LCD display of 4x20 characters, according to the specifications given by the leaders of the WP4.1- 4.4. The Night and Day calendar prototypes were fit into a commercially available picture frame, except for the use of a specially constructed encapsulation on the back side. It can be placed on the wall, on a table etc. where it easily attracts the user's attention. A picture, personal or other can be put into the frame.

CAREOUSEL MEDICINE REMINDER

The medicine reminder is loaded with medicine once a week – or less frequent, usually by a public nurse or a relative. It is not necessary to commit the medication schedule to memory: the medicine reminder takes care of that.

The Careousel medicine reminder is an asset to anybody who takes medicine regularly. An acoustic signal reminds you when it is time to take your medicine, and if you don't, the Careousel keeps on reminding you once a minute for 30 minutes. Medicine is rendered readily available - an advantage for the disabled, elderly and visually handicapped. It is convenient to take along on journeys. You can keep it handy on the table, and it may reduce the risk of forgetting to take the medicine. The lid can be locked, a necessary requisite for mentally handicapped patients and substance abusers. It is also possible to check back and see whether any medication has been skipped - vital information should the patient suffer an acute attack. The Careousel comes ready for immediate use. In normal use, the small 1,5 volt batteries will last about a year, and the unit gives automatic warning when the batteries need replacing.

PICTURE PHONE

Picture Phone is a telephone with big buttons (3x4 cm) for placing photos. Up till nine numbers can be pre-programmed and stored in the telephone. The telephone is suitable for children, elderly and persons who have problems remembering telephone numbers. To use the phone, one has to pick up the phone and press the photo button and wait for answer.

Summary

The ENABLE products which were tested in Norway

Table 7: ENABLE products among Norwegian respondents

	Included	Completers	Drop-outs
Calendar	11	8	3
Lamp*	0	0	
Locator	4	3	1
Picture Phone	4	4	
Medicine reminder	6	5	1

* since the lamp was not tested in Norway, the device will not be presented in the results

5.4 Drop-outs

In Norway, five out of twenty-five persons with dementia dropped out of the assessment trial before three months (T3). Actually they dropped out before the three weeks assessment (T2). The persons who dropped out were two men and three women, age between 65 and 89. Two of the respondents lived alone; the other three lived with someone, two with their spouse and one with her child. Four of the respondents were provided with a night and day calendar and one with a locator for lost objects.

The carers consisted of four women and one man. The Greene's scale on relative's stress ranged from 13 to 41, with a mean on 25,6. This score is considered to be high, and higher than the scores of the cases who completed three months follow-up, however the difference was not of statistical significance.

Table 8 below summarizes the characteristics of the drop-outs.

_____

Table 8: Characteristics of the drop-outs (N=5)

_____

Gender	2 male and 3 female
Age	Range 65 – 89 M = 80,6 Md = 85
Marital status	2 lived with spouse, 2 lived alone, 1 lived by child
MMSE	16 – 21, M = 18,6
Products	3 calendars, 1 medicine reminder and 1 locator
Carer's stress	Range 13 – 41 M = 25,6 Md = 21
Carer gender and stress	Female: M=26 (n=4), Male: =21 (n=1)
Public health services	1 had home nurses, 1 had home help
Drop-out time	Between one week and three weeks post implementation

The reasons for dropping out were:

- Impaired eye-sight – could not read the display of the calendar

- Neglected the calendar - did not benefit from the information

- Found the locator fro lost objects not useful for the time being

- Refused to continue/wish from patient to withdraw (medicine reminder)

- Moved to a nursing home (calendar)

5.4.1 Case story

One woman lived with her spouse in a quite new flat. She suffered from Alzheimer's disease and was asking repeatedly about day and time of day. She was provided with a night and day calendar, on request from a home care nurse who often visited the couple and who had learnt about the enable-project.

When implementing the calendar, it was tested that she was able to read and understand the information on the display. Together with the spouse it was decided to place the calendar at a table in the living room, but apparently the woman neglected the calendar. Later the calendar was moved to her bedside, because she tended to wake up at night waking her husband asking what time it was. After a couple of days it was obvious that the woman did not benefit from the calendar. She had problems reading the text, and she waked her husband to ask what the light in the display was.

The calendar was not useful to the woman and she dropped out of the assessment study after one week.

6 Results three months post-implementation

6.1 Recruitment of participants

The aim was to enroll forty persons and forty carers in the project from each country participating in the ENABLE project. The patients should mainly be recruited from memory clinics in Oslo and in the county of Vestfold. These recruitment bases were chosen in order to ensure the inclusion criteria about having a dementia diagnosis. In addition, we decided to include another recruitment base, as one municipality in Vestfold, which had a "dementia team" and expertise in diagnostic work-up, was interested and able to locate several possible respondents to the ENABLE.

Before starting enrolling patients and family carers in the project, we visited the recruitment bases and presented the purpose and the aim of the ENABLE project. The products were presented as well. Each hospital was provided with a poster displaying and explaining about the ENABLE products, in order to create awareness of the project and curiosity for participation. The project was announced for all staff in the memory clinics and in the municipality a couple of times. It turned out to be difficult to recruit participants, more difficult than expected.

We enrolled only 25 couples. The issue was discussed in the Norwegian project group and we outlined some hypothesis about possible reasons:

- Several projects were ongoing in the memory clinics – and there was a competition of enrolling patients

- When staff in the memory clinic submitted a potential patient, they did not always fit to the inclusion criteria, i.e. it is easy to forget all details in a project that is outside your daily business

Three of the ENABLE research assistants worked in memory clinics and had access to files and meetings. They frequently asked for possible ENABLE respondents during the enrolment period, and in that way found some respondents. The dementia team in the municipality, which aimed to support elderly having a dementia disease living in their own homes, knew of possible potential respondents, and recruited some to the project. During the winter 2003 we had an advertisement in an Alzheimer's carer journal, and one patient was enrolled as a result of this. Lastly, one person called the researcher for participation. She was recently diagnosed with Alzheimer's and wanted to prepare herself for the future.

The enrolment period lasted from March 2002 till July 2003. It was prolonged with 6 months due to having a new ENABLE partner in the project, Lithuania. After closing the enrolment at July 1, 2003, a couple of possible respondents were reported, and they were included.

6.2 Data collection

Data were collected from the persons with dementia under face-to-face interviews on home visits four times during twelve months; by implementation and first interview, three weeks after implementation, three months after implementation and lastly six months after implementation. The family carers were interviewed following the same schedule. They usually were present at the home visits. Sometimes, if the carer was a daughter or a son, they were called in the evening and interviewed by phone.

We called the family carers one week after implementation to check that the product functioned as it should, and twelve moths after implementation to hear if they still used the product and wanted to keep it. All respondents could keep the product as long as they benefited from it, without being charged.

To ensure interviewer's reliability the Norwegian research assistants regularly met to prepare and uniform the data collection method. They used role plays to train themselves in using for example the Brod's DQoL scale (Dementia Quality of life). One of the hypotheses was that the consequences for use and usefulness may be influenced by the researcher. All research assistants had to fill in a questionnaire regarding their own attitudes towards the devices. These were collected and ultimately compared to the results in the cross-country analysis and report (in preparation).

6.2.1 Quantitative data

The quantitative data contained data on use and usefulness of the ENABLE product, Carer's stress and Quality of Life in the patients. Further, data on health economics were recorded (RUD). These data were collected both at three weeks and three months post implementation. However, the results presented below are mainly results from three months post implementation.

6.2.2 Qualitative data

At each interview comments from the patient and the carer were collected and recorded.

Three questions on quality of life (in addition to DQoL) seek explicitly to explore the voice of the person with dementia, exploring what their thoughts are for the time being, whether they have any worries and what make them happy or make them feel well. The themes emerging in Norway were categorised into the following domains: family, health and health related issues, living situation and well-being.

Further, qualitative data were collected on suggestions for improvements of the products. These data were collected in a separate file on product specific data. Both patients and carers were asked to contribute with suggestions for improvements.

Only a few times, family carers added qualitative data after being or having filled in the Greene's Relative's Stress scale. Therefore, the qualitative data from family carers regarding burden of care is scarce, and not sufficient to be used as case stories.

The researcher's comments after conducting an interview were also recorded, but would not be included in the analysis of the qualitative data from patient and carer.

6.2.3 Data analysis

The quantitative data collected with the DQoL questionnaire were analysed after recommendation from Brod. (Brod et al, 1999). We followed her instructions regarding missing data; which was to exclude patients with more than two missing answers on each domain, and to include patients with one item missing on self esteem, feelings of belonging and sense of aesthetics and two missing items on positive and negative affect. For the missing items a mean score was calculated for each domain and put in. This made us able to present bar charts of the answers regarding each domain at baseline. We also did some t-tests and Wilcoxons test to identify any significant results.

All answers regarding the cost-benefit questionnaires were punched into a separate file. These data were to be analysed by the Irish partner of ENABLE.

All quantitative data from all T stages were put into the spss-files. The qualitative data was analysed to identify categories and themes. Colour coding was used to highlight positive, negative and neutral experiences with the products.

The emerging themes which were of interest in order to picture the "voice of the person with dementia" were also categorized after line-by-line colour coding (Bogdan and Bicklen) in order to gain knowledge on actual themes. One theme, i.e. family could represent both positive and negative aspects. The themes were counted in order to identify a tendency on the current emerging themes in the patients.

6.3 Use and usefulness rated by the persons with dementia and their carers

Fifteen of the twenty persons with dementia, who completed the trial, stated that they used the ENABLE product at T3, while seventeen of the carers said that the person with dementia used the device. Fifteen of the twenty persons with dementia rated the product they tried to be useful to them at T3, and four said the product was not useful. Sixteen of the family carers stated that the product was useful to their relative, and four assessed the device not to be useful.

Table 9: Use and usefulness

Persons with dementia:					
I have used the product	15	I find it useful to me	16	Not useful	4
Family carer:					
Pwd has used the					
product	16	I find it useful to him/her	16	Not useful	4

The use and usefulness will be presented per device in the following. Not all respondents have answered the questions; therefore the number of answers will differ throughout the presentation.

6.3.1 Night and day calendar (8 completers)

Twelve person with dementia tested the night and day calendar. Six of eight patients expressed that they used the calendar, and seven found it useful, and one not useful. Seven of the family carers stated that the persons with dementia used the product. Seven of the family carers assessed the calendar to be useful, and one said not useful.

It seems that both the persons with dementia and the carers agree upon use and usefulness of the calendar.

One of the completers' deteriorated rapidly during the three months trial, and was at the T3 interview not aware of the calendar at all. She had recently come back from a stay in the hospital, and was probably unaware of her situation, and was not able to recall any calendar.

Only one complained about technical problems with the night and day calendars, and that concerned a show of strange squares instead of letters. This calendar was replaced with a new, and did not cause drop-out.

Case stories

A. The woman who went to visit her neighbours at night

This story is about one widowed lady, 85 year old. She had newly moved into a service house for senior citizens, and when she was enrolled into the ENABLE-project, she had not yet habituated herself to this new accommodation. When she woke up in the middle of the night, she usually called her daughters, and sometimes she left her flat to visit other residents in the senior centre. Her daughters were working and they were tired of having their sleep interrupted several nights a week. The nurses at the senior centre stated that the woman did not really fit in, they thought she was confused and rather should have moved to a nursing home. The woman had impaired hearing, and appreciated social contacts and hand-crafts.

The woman user needs were analysed and the conclusion was that she needed a night and day calendar to remind her of night and day.

The calendar was demonstrated at the first home visit (T0) and together with the woman and her family; we agreed to put the calendar upon a drawer by her bedside. The calendar was placed next to the telephone. And one of her daughters told her in a strict tone that as long as the calendar showed night, she must not call anybody!

Results: From the first day the woman got the calendar, she stopped walking out of her flat and to call her children at night. If she woke up at night, she used to look at the calendar, and if the calendar showed night, she told me, she only turned her head to sleep. She used the calendar both day and night. In daytime, after having a nap, she oriented herself by looking at the calendar. The nurses were happy, and the children were happy. The woman was not forced to move to a nursing home. She could benefit from the calendar and fitted into the senior centre, in where she enjoyed staying after a while.

B. The woman who always asked for what time of day it was

This woman was widowed and 88 years old. She suffered from vascular dementia and lived alone in a house, near her daughters, to which she recently moved. She felt safe and content because the house was nice and her daughter was looking well after her. To me she did not seem happy. She felt lonesome, missing her acquaintances at her old place. She often felt tired. She became exhausted even after dressing herself. It was a problem that the woman often missed what time of day it was. She had lost her sense of day and night structure and asked frequently about the time of day.

The woman was provided with a night and day calendar. On the first home visit, she appreciated the calendar very much and asked for one in her bed room as well. And, she was provided with a second calendar by her bed.

Results: The woman read the text on the display and understood how to use it. She had one calendar on a table in the sitting room, and another by her bed. Her daughter told that she stopped asking for which day and date and time of day it was after she was provided with the calendar. Once, the daughter came late at night to see to the woman, she discovered that the mother was not yet in bed. "The calendar still says evening," the woman explained. The calendar was a relief to the daughter, because she was relieved for repeated questions about day or time of day.

A couple of times the calendar only showed squares instead of text. The daughter unplugged and re-plugged the calendar and then everything worked OK. However, the calendar was replaced with one which worked properly. Both the woman and the family carer assessed the calendar to be very useful, and the calendars were used several times a day and night.

Later during the trial, the woman's dementia deteriorated, she had poor balance and the needs for care increased dramatically. The respondent was admitted to a nursing home between T2 and T3. I offered her to bring the calendar, because she obviously benefited from it. The daughter rejected this offer, and insisted on leaving the study.

Suggestions for improvements on the night and day calendar

The table demonstrates what the persons with dementia (pwd) and the family carers suggested for improving the night and day calendar:

Night and day calendar (11 trials) 8 completers

Comments from pwd	Comments from carer
The letters should be easier to read	Improved contrast between letters and background, more bold letters and reduced reflection of the screen. Difficult to read in daylight. Could be useful to include a clock as well.
None	Better letters and contrast.
It is OK as it is	More sharp and darker letters compared to the background. The contrast should be better. Also a clock should be included.
The letters are hard to read…. They are too modern…. At T3: they are modern, but now I am getting used to them…	The text is difficult to read, a bigger display would have been a solution. The possibility to include a clock…The text should be in a style, which old people recognise and are used to
Sometimes it is difficult to see and to read the text. The contrast is dim… darker letters and bigger letters would have been better for me..	A bigger display would have been easier to read, for example would it be good to use red letters on a black background. Also, avoid reflections in the screen!
None	Better text and better contrast. Sometimes she reads V as U. Night should be shown from 10 pm, morning from 7 am, day from 10 and evening from 6 pm.
Satisfied the way it is	No suggestions – satisfied !
I find it good, it's simple and easy to use – Can't think of anything…	Fine as it is.. maybe a clock..?.
It is OK – both text and contrast	Missing T3
	Wishes a more detailed description of the day (pre-noon, afternoon etc) Avoid reflections in the screen Bigger text and display and include a clock.
No suggestions –	It is simple and good as it is

Comments from research assistants: The text should be in block-letters, and then it would be easier to read. To include a clock would in my opinion make the calendar more difficult to use and not be beneficial to the persons with dementia.

6.3.2 The locator for lost objects (3 completers)

Four persons with dementia tested the locator for lost objects. According to the persons with dementia, two of them used the locator, and one found it useful. The family carers told it was used by two of the respondents and they found useful. One was not used and it was not useful to the respondent. In one of the locators technical problems with the tags were reported and this was the reason for not using or not found useful. The suggestions for improvements mainly concerned the sound and the size of the tags.

Case stories

A. The woman who put her wallet in the freezer

The woman was married; she was 69 years old and lived together with her husband in their own house on the countryside. The main problem was an eternal search for her belongings. She forgot her purse, her wallet, her keys and this lead to searching operations that could take hours. The husband was tired of the searching, which became and extra burden.

The locator was demonstrated and placed in the kitchen. During the test procedure, the wallet was hidden in the sitting room. The woman heard the sound and managed to locate the object because she got several reminders on searching after the sound. The husband had impaired hearing and could not hear the sound form the tags.

Result: After implementation of the locator it seemed that the woman "pulled herself together". The problem was not as critical as before. However, when the locator was used, the husband had to follow her around in the house and constantly encourage her to keep searching for the sound. Then she managed to locate the object. The locator was used occasionally and they found it useful. It was the husband who administered the use of the locator.

B. The man who prepared himself for the future

This is a story about a man; he was 65 years old and married. The couple lived together in a flat in a middle-size village. He was diagnosed with Alzheimer's disease, and complained about forgetfulness, and problems in putting events together in a bigger picture. He tried to prepare himself for an uncertain future. In his search for assistive technology, he was eager to test the locator. He often searched for his glasses. However, the keys and his wallet were placed in a separate place, and represented no problem for the time being. The locator was placed in the entrance hall.

Result: After one week, the man told that he had no use for the locator now and he wanted return the device and drop out of the study.

The researchers commented that testing the product for one week was too short, and that the man definitely should have kept the product for a longer period of time.

Suggestions for improvements of the locator for lost objects considered mainly smaller tags and louder sound.

Locator for lost objects (4 trials) 3 completers

Comments from pwd	Comments from carer
Louder sound from the tags	Louder sound on the tags, because one will not continue searching if one cannot hear the sound properly. Can be difficult to hear the sound when the TV is on. Smaller tags.
None	Smaller tags
Smaller tags – The size of the tag make it impossible to put on my wallet or my glasses. Improve the panel so you can feel that the button is pushed	None

It is fine as it is..	Louder, more sharp sound

6.3.3 Medicine reminder (5 completers)

Six respondents tested the medicine reminder (Careousel). Five persons with dementia used the medicine reminder and four assessed it as useful. One dropped out by T1. Another person with dementia used the medicine reminder more than six months. Thereafter, her husband said it was not useful because of his wife's hearing deficits.

Four of the six family carers assessed the medicine reminder to be used; they found it useful even though the persons with dementia did not manage to use the medicine reminder independently, and needed support from the family carers.

Case stories

A. One woman needed a medicine reminder

The respondent lived in her own apartment in the first floor. She had good contact with her neighbours and her children, who called every day or visited several times a week. She enjoys watching TV and knitting. She prays to God every night – "please let it go me well.." She has had two heart attacks and sometimes she feels afraid, when she is not feeling well.

Her main problem was to remember to take medication twice a day. She forgot about the pill in the evening. Home nurses gave her medication every night. The woman felt this was a waste of time and she really wanted to manage to take the pills herself. The woman suffered from impaired hearing. The medicine reminder was placed in the kitchen, and the alarm was set at the time she usually had her breakfast and her supper. Then she would be in the kitchen and be able to hear the alarm and get reminded of taking the medication.

Result: The respondent manages to take the drugs by herself when using the medicine reminder. She found the product nice, and she was impressed and fascinated how she can be helped by it. The respondent was very happy managing to take the pills on her own, she complained that before she got this box, she had to rush to get ready to welcome the home nurses, and she was happy she didn't need to do that anymore. The family found the medicine reminder very useful, they trusted that their mother would have the right pills at the right time, and this was a relief for all of them

Negative:

Sometimes when she watched TV in the other room she was not able to hear the alarm, and the alarm may beep for a long period of time. This is power consuming and the batteries need to be changed more frequently.
Twice the batteries ran out and the alarm was ringing all the time. The product had to be sent back to the producer because of a fault, but it was replaced shortly after.
The home nurses did not appreciate the pill-box, they didn't know how to open it or how to change batteries.

Comments from the researcher:

The medicine reminder was very useful for the respondent. She managed to take the medication independently. Her children felt secure that mother is taking the pills at the right time. The respondent is positive and very impressed by the product. She is happy to have it, and content that she is able to manage taking the pills on her own. The collaboration with the public health nurses should be improved.

B   "Together we are dynamite"

This is about a married couple. The woman suffered from dementia and needed medication three times a day. Both husband and wife found it difficult to remember to take the medication, especially at lunch time. A medicine reminder was provided and implemented in the kitchen.

Result: When the alarm sounded, the woman shouted to her husband that something noisy was happening. (The husband had impaired hearing). The woman could not identify the alarm, and was therefore not able to use the medicine reminder independently. In spite of this, both husband and wife assessed the medicine reminder to be useful to them.

Automatic medicine reminder (6 trials) 5 completers

Comments from pwd	Comments from carer
Don't know	Should be easier to open
	Too small hole, she doesn't understand that she has to turn the box upside down, and she doesn't manage to pick up the pills from the small hole
It should have been in a smaller size… it is too big to put in my handbag or to bring with me on travels.	The sound/alarm could have been improved, she doesn't hear the alarm when she is watching the TV with a hearing aid cable (teleslynge). The alarm should be louder. How to put in new batteries should be clearly explained, and idiot-proof. Could have had one on/off button to use when we were on holidays to save the battery power, without ruining the pre-programmed times for medication. Other colours could be available, - and it could have been smaller.
Don't know what could be improved – it it easy to use the way it is.	A blinking light additionally to the alarm would give one with impaired hearing a visual reminding. A user's guide in Norwegian would be fine - a simple one!
No suggestions	No, I cannot say what that would be....
	It should be easier to switch between summer and wintertime.
I think it is OK the way it is	The sound could be louder. And it should have an indicator for it is time for changing the batteries, so it won't happen in the middle of the holidays when all the shops are closed… It could also have reloadable batteries.
	It should be easier to change the time. An on/off button would make us save the batteries power, when we're not at home.

6.3.4 Picture Phone (4 completers)

Four patients tested the Picture Phone, and all completed the participation in the project. All of the respondents had reported difficulties in using an ordinary telephone, which usually was caused by difficulties in remembering the correct row of numbers.

Case stories

A. One man needed to be able to call his family and friends

Man, 79 years old, living together with his wife. The wife was actively engaged in several associations and clubs, and she often attended meetings in the evenings. The husband was alone at home and it was imperative to him to be able to call people, his children and friends or even his wife. He had big problems in dialling the correct row of numbers and the telephone bills tended to be huge, because of dialling wrong persons. A picture phone was tested to meet his needs for dialling. In the beginning of the trial, he managed to dial by pressing the picture buttons, but later in the trial his health deteriorated and he was not able to dial independently anymore. It was suggested to remove the telephone, but the

wife told that even if he could not dial independently, he managed to dial after her instructions. He was not able to dial from the "old" telephone after her instructions. The picture phone was assessed to be useful to both persons with dementia and the family carer due to its simplicity and because it was easy to use and needed simple instructions to be used.

B. One woman did not approve the phone

One woman was living alone in a flat. She had collected lots of memos with telephone numbers to friends and family, which she had put on the kitchen wall. The problem was that when she wanted to dial someone, she had problems in identifying the correct sticker. Her son thought she might benefit from the picture phone.

Result: the woman was not very happy for the picture phone. She maintained that there were too few picture buttons and if she was to dial on the "normal" buttons, she would not be able to see the numbers very well. The research assistant tried to make a better contrast on the numbers, still information with letters additionally to the numbers on the keys were confusing. In a way she could benefit from the phone, but it did not meet her needs properly. She quit the trial assessment, but after three months participation.

Suggestions for improvements

Picture telephone (4 trials) 4 completers

Comments from pwd	Comments from carer
Better numbers on the keys	The keys should be clearer – everything is grey. More keys should be able to pre-program – 9 are a bit too few!
None	Don't think it is possible to improve it – it is fine as it is..
Satisfied with the telephone the way it is	Wants more picture keys Wants bigger keys, maybe…easier to fit in the photos
Diffuse / non-recognisable photos	Small photos are not clear enough – wants bigger keys. How to get more numbers to the same person?

6.4 The patients' and carers' opinions on usefulness of the product at T3 (three months trial)

All patients were asked about their motivation for testing a product free of charge. All 25 patients answered yes, they were motivated. The carers were asked the same, and they were more reluctant, and not everybody thought their family members would be motivated for such a trial. It is imperative to note that all the drop-outs were considered to be motivated for receiving a product.

Table 10 shows the respondents and carers expectations and opinions of usefulness. The calendar was assessed to be potentially very useful by 4 of the carers and less useful by 3, and not useful by 1. The locator was assessed to be potentially very useful by one and less useful by 2 of the carers. The medicine reminder was assessed to be potentially very useful by 3 of the carers and less useful by 1. And finally, the picture phone was assessed to be potentially very useful by 1 and less useful by 3 carers. These figures are summarized under the * and ** in the table (n= 17) below.

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Table 10: Expectation of Norwegian respondents and carers

	Included N = 25		Completers N = 20		Drop-outs N = 5	
	Pos	Neg.	Pos	Neg.	Pos	Neg.
Patient's motivation	25	0	20	0	5	0
Carers opinion of patient's motivation	17	1	12	1	5	0
Carer's expectation of usefulness of device	18	4	17	3	4	1
very useful (n=17)*			8			
less useful (n=17)**			9			
Importance of problem for the carer	18	5	11	4	4	1
Carer's opinion of importance of problem for the patient	20	4	14	1	3	1

Table 11: An overview of participants characteristics and use and usefulness by devices:

Age	Gender	MMSE	product	status	use pwd	useful pwd	use carer	useful carer	
85	F	23	telephone	T3*	yes	yes	yes	yes	
73	F	12	telephone	T5*	yes	yes	yes	yes	
79	M	20	telephone	T5*	with help	yes	yes	yes	
79	M	22	telephone	T5*	yes	yes	yes	yes	
77	F	26	med.rem.	T3*	no	no	no	yes	
65	M	25	med.rem.	T5*	yes	yes	yes	yes	
79	F	20	med.rem.	T5*	yes	yes	yes	yes	
79	M	25	med.rem.	T5*	yes	yes	yes	yes	
85	F	19	med.rem	**T1***	no	no	no	no	**drop out**
77	F	25	med.rem.	T5*	no	yes	yes	yes	
74	F	26	locator	T3*	yes	yes little	yes	yes	
89	F	18	locator	T5*	no answ	no	no answ	no	
65	M	26	locator	**T1***	yes	no	no answ	no answ	**drop-out**
69	F	16	locator	T3*	yes	yes	yes	yes	
88	F	23	calendar	T3*	yes	yes	yes	yes	
76	F	16	calendar	**T1***	no	no	no	no	**drop out**
82	F	22	calendar	T4*	yes	yes	yes	yes	
82	F	19	calendar	T3*	yes	yes	yes	yes	
89	F	12	calendar	**T2***	yes	yes	yes	yes	**drop out**
87	F	18	calendar	T5*	yes	yes	yes	yes	
91	F	25	calendar	T4	yes	yes	yes	yes	
79	M	25	calendar	T4	yes	yes	yes?	yes?	
79	F	16	calendar	T3*	?	?	no	no	
84	M	28	calendar	T3*	yes	yes	yes	yes	
88	M	21	calendar	T1*	no	no	no	no	**drop out**

7 Other findings

7.1 Quality of life

To gain knowledge about how persons with dementia feel about their quality of life, Brod's Dementia Quality of Life scale was used. Findings demonstrate that people with dementia appear to have a more positive appraisal of their lives, roles and relationships than family caregivers and professionals tend to expect. The persons reported their subjective quality of life as follow:

By T0 17 of the respondents assessed their quality of life to be good, very good or excellent. Three persons assessed the quality of life to be bad or fair. Three weeks later (T2) only one persons assessed the quality of life to be bad, while 18 reported it to be good, very good or excellent. Three months after implementation (T3) 17 persons assessed the quality of life to be good, very good or excellent. The main weight is on the positive side of the scale for all stages. (See table 2, page 14)

The DQoL categorizes the variables into the categories of Self Esteem, Positive Affect/humour, Negative Affect, Feelings of Belonging, Sense of Aesthetics, which all demonstrate the quantitative data collected. Figures 1.1 to 1.5 show bar charts on the profiles at baseline (page 14 – 15).

Statistical tests were run to control for any significances and correlations in the material. (T-tests, Mann-Whitney Test, Pearson, Spearman and Wilcoxon tests.) In the Norwegian material there was a tendency that the variables categorised under Negative Affect developed to be more negative during the three months from T0 to T3. This might be explained by deterioration of the disease, or it might be seen as a result of becoming familiar to the researcher (third visit), or both.

When we compared the completers and the dropouts, it seemed that they differed most in Positive Affect, otherwise they were quite similar, as the following graph will illustrate (fig. 3) It may be discussed whether the most positive persons stayed in the project, and it would have been interesting to compare the two groups by T4 (6 months).

Figure 3: Differences in DQoL after three months, completers vs drop-outs
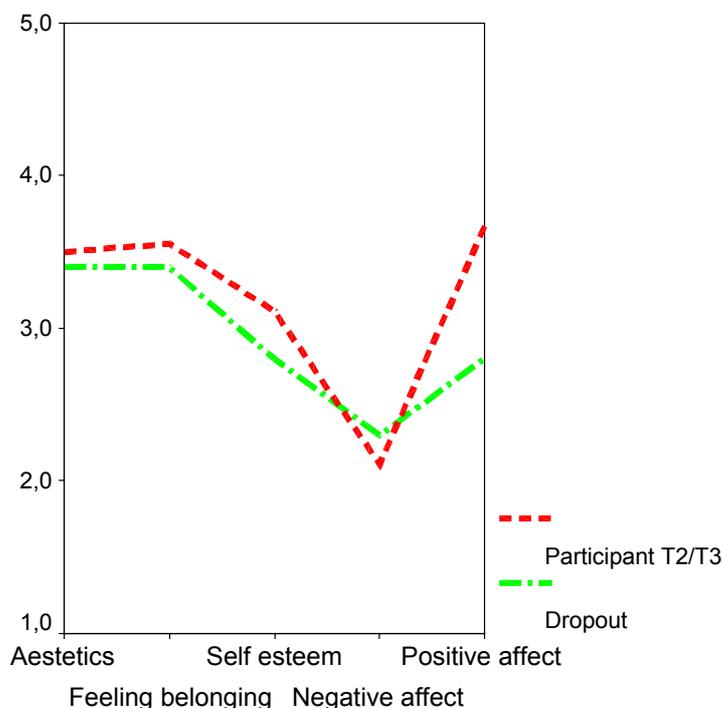
7.2 Emerging themes related to quality of life

The emerging themes presented by the persons with dementia was coded line by line and later categorized. Data on emerging themes are answered by 19 of the 25 respondents. Three additional questions were included in the questionnaire in order to be able to "hear the voice of the persons with dementia". The questions were concerning 1) how they assessed their own quality of life, 2) things they worried about and 3) what made them happy and made them feel well.

1. Family and social relations

It was mentioned by sixteen of nineteen that family and/or social relations to friends and neighbours were important for well-being and for having a good life. However, family and friends could also be a reason for worrying; eight persons mentioned that they worried about family members. Some had problems in their marriage, some worried about children of grandchildren being unemployed. Also loss of family members and friends was a reason for worrying and lead for some to a feeling of loneliness.

2. Health – sickness and symptoms

Six of nineteen respondents mentioned that having good health (meaning being physically fit and without pain) was positive, and they felt both happy and grateful for this.

Thirteen of nineteen persons mentioned health and health related issues as worries; they worry about loss of health, about how the disease will progress, and how the future will be like.

3. Living situation

Living situation concerns accommodation facilities, well-being and a feeling of being safe and secure, i.e. having regularly visits form the home nursing services. Seven of nineteen respondents mentioned these things as important to have a good life.

4. Celebrating events – adventures

Four of the respondents talked about celebrating anniversaries and events as positive experiences. Also going on holidays, or visiting the old cottage seemed to be of importance to enjoy life and have quality of life.

7.3 Burden of Care

To describe the family carer's experienced burden of care, Relative's Stress scale was used (Greene). Looking at the sum scores at T0, it seemed that the family carer's of the drop outs had the highest scores and experienced most stress. However, looking into these five cases, one family carer had extremely high sum score and skewed the result. In spite of this, the mean sum score of the completers are lower than for the whole population and for the drop-outs.

Table 12: Relative's Stress Scale – sum scores at T0, T2 and T3

	T0 (N=25)	T2 (N=20)	T3 (N=18)
Mean sum score	18,4	19,8	17,8
Range	2 – 41	3 – 47	4 – 36
Std Deviation	11,2	12,0	9,7

If we exclude the drop outs and those who did not answer completely, we have 17 family carers left, and the sum scores now are:

Table 13: Relative's Stress Scale – sum scores for completers at T0, T2 and T3

	T0 (n=17)	T2 (n=17)	T3 (n=17)
Mean sum score	15,1	17,7	18,0
Range	2 – 40	3 – 47	4 – 36

The tendency is that the carer burden was increased in general over this period of three months, and the carer burden was found to be most burdensome for women. This is a significant finding. The distribution of sum scores is illustrated in the table below. The range in sum scores may partially be explained by one very high sum score on 40 at T0.

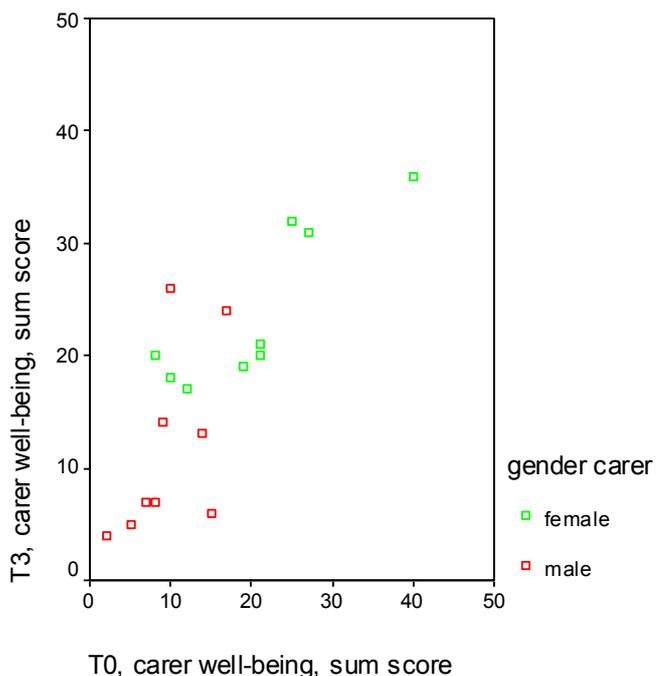Figure 4.1: Relatives' stress, distribution by gender

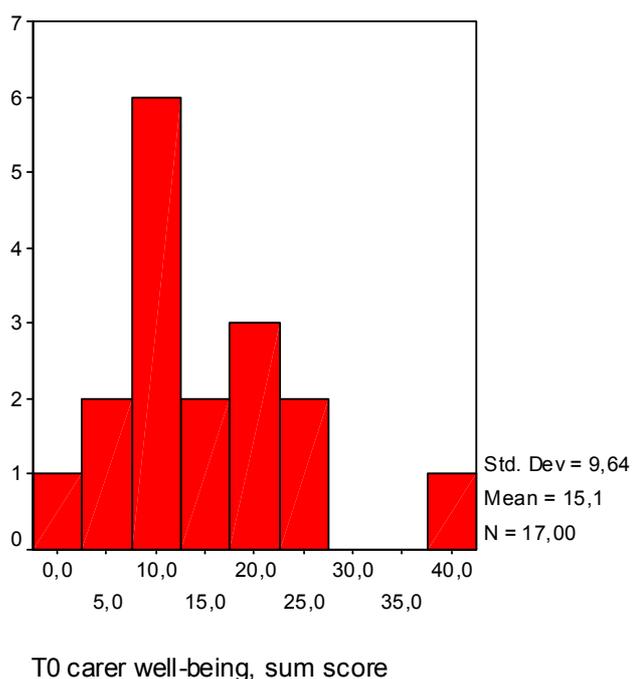Figure 4.2: Bar chart on distribution of relatives stress in completers

Table14: Paired samples test on Relatives stress scale (Carer well-being) at 3 months and 3 weeks

Paired Samples Test

		Paired Differ-ences			95% Confi-dence Inter-val of the Difference		t	df	Sig. (2-tailed)
		Mean	Std. Devia-tion	Std. Error Mean					
					Lower	Upper			
Pair 1	carer well-being, sum score - T3, carer well-being, sum-score	-3,00	6,010	1,458	-6,09	,09	-2,058	16	,056
Pair 2	carer well-being, sum score - T2, carer well-being, sum score	-2,65	5,744	1,393	-5,60	,31	-1,900	16	,076

7.4 What happened from T3 – T5?

At T3, three months way in the project, twenty persons with dementia continued to use the device. Three months later, at T4, only 12 stayed within the project. Eight persons stayed for six more months till T5, and then they had participated for one year. Two respondents who were enrolled in June 2003 have not yet finished T5, one year participation.

The reasons for dropping out after the first three months were mainly admission to nursing homes, and deterioration in of health status which led to no longer beneficence from the product. In the cases with admission to a nursing home, inattention of the product was recorded, and this may be regarded as one consequence of the progression of dementia diseases.

7.5 Experiences from the assessment trial

7.5.1 Experiences of using the different questionnaires and scales

The Dementia Quality of Life Instrument (DQol)
In Norway we were four research assistants who frequently met to prepare for the data collection and to emphasize the way of doing this in a most possible uniform way. Amongst others we trained ourselves conducting the DQoL interview. The opinions of the research assistants were that they felt not polite asking questions that were very similar; i.e. asking "how often have you felt anxious lately?" and "how often have you felt afraid lately ?" This might be a bigger problem to the interviewer than to the interviewee. The research assistants felt rude asking the same questions over and over again.
The directions told us to include the questions in a conversation. This turned up to be difficult, and the risk for having approximate answers was absolutely present. Using the gliding scales from 1 – 5, showed to be very useful, and if we suggested one particular number, the respondent knew at once whether this was a correct score for them or not. Looking at the answers, during the analysis, it was striking how consistent the respondents had assessed their feelings. Also the profiles that turned up in the bar charts on domains gave an overview of their everyday living: Self esteem was more positive

than negative for the group, positive affect were on the positive side (sometimes and often) and the negative affect were on the negative side (sometimes and seldom), feelings of belonging was on the positive side and also sense of aesthetics. Regarding the aesthetics – the respondents in Norway scored highest on the variable concerning clouds and the sky – In other words; Norwegians are interested in the weather!

The Relative's Stress scale
This scale was easy to fill in. Sometimes the family carer was asked to do this in a separate room, when the researcher interviewed the respondent. If the carer was unable to read and note on the scale themselves, we interviewed them by telephone the next day or so.

The RUD-questions
These were used to collect data that could be used for a cost-benefit analysis. There were reactions from the carers regarding asking about their medication, and working conditions. Mostly, people were polite and answered, but some complained about being too detailed and nosy; like one who said: " My father is testing this calendar, what the XXX has that to do with me and if I take any medication?"

Cost benefit questions on expectations and results
Some questionnaires on expectations of trying the product and results from testing the product were developed in the project. Any questionnaire will reflect the pre-understanding of the author(s). In some cases it seemed of little relevance to ask for an expectation or result on a community level, as the respondents actually did not receive any public services.

Questions on use and usefulness of the enable-product
These questionnaires were developed to map the opinions of the persons with dementia and the family carer. The questions were in other words asked to both the respondents with dementia and her/his family carer. During the analysis it became clear that the opinions of use and usefulness not always corresponded between the two interviewees. This could both reflect the everlasting questions of the reliability of involving a person with dementia as an informant. However, the frequency of the family carers' visits will also influence the awareness and knowledge about use and usefulness. In other words, these measures must not be taken to be representative due to the small selection in this trial.

7.5.2 Experiences on user needs analysis

The user needs analysis was important. In Norway, after being recruited from one of the memory clinics, names and telephone numbers were sent to the research assistants, who phoned the family carer to discuss what the main need for support was for the person with dementia. Often, several of the patients had more needs and certainly could need more than one of the ENABLE-products. It was urgent to collaborate with the family carers to find the product most needed for the time being. The research assistant would bring this product to the first home visit, also conducting the T0 interview and the implementation.

In one case, a health worker outside the group of research assistant's reported one patient needed a specific product. The research assistant took the information for granted. However, by implementation at T0, it became clear that the product turned out to be useless because of poor eye-sight.

One of the research assistants did the T0 visit without having concluded which device to select. She brought two of the ENABLE products and tested which of them the patient could benefit mostly from, and implemented this. In three cases, the patient turned out not to fit with the inclusion criteria, or to have problems that the ENABLE product not could solve, after all.

Anyway, a thorough user needs analysis, made prior to the first home visit could save both time and shelter the patient from confusion or intervention without any results. In the future, emphasis must be on developing a proper use needs analysis.

7.5.3 Experiences on the implementation process and maintenance

The implementation of the ENABLE product happened at T0. Usually, the interview started by showing the product, and then demonstrating it. Also the product was tested by the person with dementia in order to ensure that he or she understood how to operate the product. All the patients in the Norwegian selection were motivated to receive a free product for testing.

Case story

One woman, age 74, was living alone in a big house, and her son expressed a need for a locator for lost objects. She was motivated to use it. The product was demonstrated in the sitting room. After testing, time had come to decide where in the house the locator should be placed. Both the patient and the family carer agreed that the locator should be placed in the kitchen. After doing the interview, the patient was asked how to use the locator, and then she went straight to the sitting room, where the locator hade been demonstrated in the beginning.

It seems that it is important to think about how to present and demonstrate the products. Early in the conversation, the placement of the product should be decided, and the demonstration should take place from this spot.

7.5.4 Experiences on collaboration with family carers and public health services

Family carers were positive to participate in the project. In general, spouses seemed more positive than children.

In some cases, especially if the persons with dementia lived alone, it was necessary to collaborate with the home nurse service. This was not an easy thing to do, because there were often new nurses in the home, and some of the nurses did not know how to open the medicine reminder or even how to change batteries. The project workers offered to come and demonstrate the products for the nurses, but they did not accept this offer.

It seems that the products should be very user-friendly, i.e. that all people can understand how to use it without reading the user's guide.

7.5.5 Experiences on technical problems

Some of the ENABLE products were easy to demonstrate and implement, for example the night and day calendar. Others were more difficult. An example of a device that was challenging to demonstrate was the locator for lost objects. The reason was that this device demanded ability to remember and to learn the instructions. Also, the locator consisted of more items: the panel and five small tags. It seemed difficult for the person with dementia to concentrate on the panel only, and if they started to think about the tags, or started to locate the tags, this complicated the whole operation. Often the locator turned out to be an aid for the family carer rather than to support the person with dementia.

Sometimes, when demonstrating the locator the tags did not always beep. In one demonstration setting, the alarms were set continuously, which led to a kind of power exhaustion. The only solution was to sit and wait for the product to regain power. This demonstrated that the product might be less reliable, or had to be operated in a particular way to function. The product easily appeared less reliable.

The lamp was not tested in the assessment in Norway. Prior to the assessment trial the research assistants tested all the products at home, in order to be familiar with them. The lamp was found unreliable in several ways. It was difficult to calibrate properly. In a twin bed it could start to blink when as of the persons turned their head or by other movements in the bed. The implementation procedure, having the patient going in and out of bed to calibrate it properly, was a procedure which discouraged the implementation. Also, in the recruitment phase and during the user need analysis, other needs were found to be more important than having an automatic lamp at night.

8 Discussion

8.1 Use and usefulness

Our hypothesis was that use, usefulness and possible consequences thereof would be dependent on factors related to the respondents, the carers, the products, the environment and/or the researcher could have an impact on the consequences for use and usefulness.

Factors related to the person with dementia

Related to the persons with dementia, the tendency showed that the MMSE score had impact on use and usefulness. Persons with lower scores on MMSE tended to use the product less, and found it less useful. It seems that the persons cognitive functioning influences the use and usefulness of the product. In the TED study (Holthe, Hagen, Bjørneby, 2001) we found no correlation between MMSE score and use and usefulness of the product. The conclusion in that study was that the individual attitude towards the product was the main predictor for acceptance, use and usefulness.

Another personal characteristic, namely attitude towards the product, was also of importance. All respondents were motivated to test a new product. However, their situation probably changed over the next six months, in the way that the deterioration of the disease made them neglect the device and they could neither use it nor find it useful any longer. After six months twelve of the twenty-five patients had left the assessment trial. This indicates that persons with dementia should be provided with assistive technology in an early stage of the disease. Establishing good every day routines and familiarity to assistive devices are crucial.

Factors related to the carers

The family carers seemed to be enthusiastic about the products, and this attitude easily transmitted to the respondents. In general, the family carers were happy to have some kind of support. Family carers who had high scores on Relative's stress scale seemed less positive to the product. Only one of the family carers said that the only negative thing by being participating in the project was the excessive questioning only to assess one small device!

Factors related to the product

It is striking that there seemed to be a general agreement about use and usefulness of the devices between the persons with dementia and their family carers. Table 10 shows the agreement between patients and family carers about use and usefulness of the different products. In general eighteen of the products were used and found useful. This is a positive result, after testing twenty-five products with persons with dementia and their carers. An explanation for this successful result, may be the thorough user needs analysis conducted by the research assistants

The different products were selected after a careful user needs analysis. It was imperative to identify the person's "hottest" need. Only in that way, we would be able to tell if the product might have an influence on the person's experienced quality of life, or whether it would relief the family carer from a burden of care and possibly diminish stress. Even if the respondent might be in need of several aids, only one was given.

The first request to a product was that it must work properly! The product must be reliable! In the ENABLE project, test-series were tried out and the quality of the products was as good as possible at the time the assessment trials were to start. There were some technical problems with the tags to the locators and one of the night and day calendars. Also the night lamp was discovered to be demanding to calibrate properly and might lead to uncertainty and stress for the respondent, who would have to get into and out of bed until the lamp was calibrated. The locator for lost objects had five tags connected. They did not always work as they should. It was difficult to know for how long the small battery would work, and assure that they were changed when needed. Also the sound was low, and for several impossible to hear if for example the TV was on. When the products failed during the demonstration and implementation process, people easily lost their faith in the product, and it would be easier for them to drop out of the study.

Also, there were some problems with the medicine reminder. All three cases concerned changing batteries. In one case the family carer put the batteries in wrongly, which lead to short-circuit. In the

other case, the batteries went out during the holidays, and new batteries were bought some days later. Then the clock had to be adjusted, and this was too complicated for the family carer, so they had the alarm to wrong times of day for one week, until the researcher came for a new interview. The third case concerned a woman who had support from the public health nurses. The nurses did not know how to change the batteries, and they claimed that they did not have any money to buy them either (!), and left the whole problem to the family carer. In spite of these problems, which were not insignificant, all the users found the medicine reminder useful and they used it, and they wanted to keep it after the project's end.

One explanation: It could be assumed that the medicine reminder worked well the first months, and that the family got used to being reminded and found that very useful. Therefore they tolerated the problems they experienced. Or they simply understood the reason for why the problem occurred in the first place, and did not think of that as a serious failure.

To find a successful solution:

1) The product has to be reliable and function as promised.

2) The user analysis must carefully evaluate all the persons needs, i.e. assess functional abilities and record limitations and resources in order to provide the best aid and tailor the implementation process. This includes recording all sensory function to ensure that the persons not only see and hear in optimal situations or under testing the product.

3) In order to strengthen the health worker in the implementation process, she/he should be familiar to the product, have tested it thoroughly and be able to present the product without confusion, hesitation and mistakes.

4) The smaller changes in a persons daily living the chosen product requires, the better. To learn new routines is difficult.

Factors related to the environment

Where to place the product was expected to play an important role. If the night and day calendar was placed on a table with a lot of other items; it could turn "invisible", and was at risk of being easily neglected. The placement of the product was an important issue in the implementation process, and the carer's opinion on this was very much put to ground for the final solution. The placement of the locator was special, because it should hang centrally in the house or flat, and it should hang close to an wall outlet. The medicine reminder was in most cases placed in the kitchen, and also often brought with for travels and visits in the evening. It seemed to be a general attitude that the product should have a particular and permanent place in the Another example, is about the night and day calendar: One of the respondents claimed, after seeing it demonstrated, that she would need one by her bedside as well as one in the sitting room. This was also the case with another respondent, and they were both provided with two night and day calendars, which turned up to be most helpful.

Factors related to the researcher

In Norway, all the research assistants were occupational therapists by profession. This could influence the way the user needs analysis was done and how the data were collected. Furthermore, the research assistants visited the patient and carer regularly during six months for a face-to-face interview and this may influence the result. The respondent might feel a pressure to be positive or to please the researcher.

The researcher was to write comments after each visit to clarify own thoughts and reactions, and to note down her impression of the interviews and the situation of the respondents. These comments could also reflect the persons' professional state.

Before the assessment study, the research assistants had to fill in a questionnaire about how they valued the products that were to be tested. This was done in order to investigate whether the opinion of the researcher might influence in any way. One of the research assistants maintained that it was difficult for her to recommend a product that she had tested and which turned out to be unreliable, like the automatic night lamps. That might have influenced why no lamps have been tested in Norway.

8.2 Selection of persons with dementia and their carers

The respondents

The respondents' distribution of gender and ages was representative for the elderly population. The distribution of gender reflects the normal appearance of gender in this age group in the Norwegian society. Their age ranged from 65 to 92 years old, with a mean age at 80 years. Half of the respondents lived alone, which also seem to reflect the situation for elderly in general.

The respondents and their carers were recruited from memory clinics, and the diagnosis was made before the time for enrolment. The selected participants had a positive attitude towards the project and towards receiving a technological device, which influenced the assessment in the way that in fact all persons with dementia were motivated to try a new product free of charge.

The mean sum score of MMSE was 21, ranging from 12 to 28. An interesting to hypothesis was that people with a mild degree of dementia is more likely to benefit from new technology/new devices. In our selection it was a tendency that people with lowest score on MMSE, rated use and usefulness of the product somewhat lower.

More than half of the respondents in the Norwegian assessment trial were using anti-dementia drugs (14 of 25). Two of the five drop-outs used such medication.

Rather few, only 10 of 25, respondents stayed within the projects for one year. After three months respondents quit the project, often because of admittance to a nursing home. This might lead us to think that persons with dementia are diagnosed rather late. After 6 months only twelve of twenty-five respondents participated, i.e. from T0 till T5, half of the respondents were out of the project. This might indicate that the respondents as a group were too fragile to benefit from interventions of assistive technology for a longer period of time.

The carers

Half of the family carers were female and half male. Traditionally women have had the role as the primary supportive relative, but in this selection it is evident that men also contribute as primary care-givers. It seemed that spouses and co-habitants experienced more stress than children of the respondents, as they are having higher scored on "The Relative's stress scale". The mean score for carer's stress in the group of completers was 13,5 for male family carers and 20 for female family carers, ranged from 2 to 40. One interpretation could be that women experience more stress than men.

Regarding the assessment trial some carers were more positive than the respondents. They wanted the person with dementia to accept the ENABLE device. Also discrepancies in perception of use and usefulness occasionally differed between the respondents and the carers. This has been further out-lines in the chapter of use and usefulness.

Drop-outs

Five of twenty-five respondents dropped out of the study. They dropped out quite early in the study, all before three weeks participation (T2). This could mean that the user analysis and the implementation process were not well done. The drop-outs had a lower mean score on MMSE than the mean MMSE score of the participants, 18.6 against 21.1. They had little support from public services; only one had home nursing and another had home help.

Also, it seemed that the carers with the most experienced stress dropped out of the study. The sum scores on Relative's stress scale ranged from 13 to 41 with a mean score on 25.6 in the drop outs, while the completers ranged from 2 to 40 with a mean score on 16.6.

Ethical considerations

Involving persons with dementia in research raises several ethical issues. The experiences from the ENABLE-project show that persons with dementia are both willing to and able to tell about their own experiences and perceptions. The ENABLE-products tested in Norway were unobtrusive and easy to implement and remove. The user needs analysis was discussed with the family carer in order to protect the patient from confusion and claiming a decision, but rather present a suitable solution to be accepted or rejected. Sometimes, a person might need more than one product. The research assistants gave on request from carers information about how to get other technical aids. Only a few (2 -3) of the respondents had other equipment in the house during the assessment trial.

9 Conclusions

Out of twenty-five respondents, eighteen benefited from one or another product for a period of three months. The results from the Norwegian trial are mainly descriptive, as the numbers of respondents are low, and the number of persons testing each product is even smaller, representativeness will not be possible in a small selection like this.

Approximately half of the respondents and their carers quit the project after six months. This indicates that persons with dementia should have access to technology early in their disease, to be able to benefit longer from the products. A careful user needs analysis is crucial to identify the most important needs. Also the products selected must be adapted to the person's situation to meet the needs optimally. Information and collaboration with family carers and professionals are important to ensure quality and responsibility for follow-up.

Assistive technology should be one of the possible interventions in order to provide an everyday life compensating for impairments like memory and orientation problems, and having the potential to facilitate well-being in the persons with dementia, decrease stress in the family carers and relief burden of care.

Further research is needed on development of new products that aims to facilitate living with a dementia. Also, a guide for user needs analysis should be made in order to support health professionals in their daily work.

Technology has come to stay! It is better to collaborate multi-professionally to find the best solutions for persons with dementia, than to pretend technology does not exist. Also health workers have a responsibility in this matter.

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