Need for Telecare for Home Residents with Dementia: Potential Solutions - Based on the Experiences of Close Relatives and Healthcare Professionals

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Abstract

Elderly people would ideally live in their home as long as possible, even in situations with cognitive deficits, such as with an early stage of dementia. Their close relatives will often try to assist and support with problems in daily care and normal living situations, which can last for a long period of time before the home health care services get involved.

In a qualitative study carried out in a Norwegian municipality, we have focused on how close relatives of elderly home-living people with dementia experience their situation, and how they would like to collaborate with the municipality home health care services. During a series of group interviews with representatives from home nurse services, we highlighted the experience of a collaborative dementia care.

In order to evaluate potential technology solutions that might be favorable for both the elderly person and their close relatives, we investigated relationships between the experienced daily problems and how technology could be used to compensate the lack of cognitive functions, presenting some examples of current Telecare solutions.

Keywords:

Dementia care, family caregivers, welfare technology, eHealth, safety, confidence, coping

Introduction

Many national care plans and research projects have promoted active involvement of informal networks in elderly care. This strategy has been presented as a crucial step for future home care services because of tremendous growth in elderly populations as a consequence of the global trend in demographic changes. The importance of technology tools in home health care in order to deliver more cost-efficient services have been highlighted [1]; however, little is known of possibilities and effects for close relatives to introduce technology tools in an early stage of dementia. Often, close relatives will lack of enough time for an optimal care, having to take care of both young children and elderly parents, combined with a full-time professional job and the travelled distances related. The burden for family caregivers can be perceived as high [2], and the use of technology to support people with dementia seems to be underestimated because of the assumption that they are no longer able to benefit from technology [3]. Few studies are reporting on the family caregivers about people with dementia and the benefits from Information and Communication Technologies (ICT) use. These studies revealed the gap in literature between technology-driven interventions and the reported outcome [4]. However, interventions for care givers to people with dementia that were delivered through the Internet can have positive effects, especially if the services provided include guidance by a coach and contact with other caregivers [5].

Carers of frail elderly and disabled children living at home reported benefits from using web-based discussion forums, which resulted in better services and had a positive impact in facilitating sharing emotions and reflections with fellow carers [6]. Even if technology that can improve the lives of people with dementia and their careers are available, carers want the solutions to be complementary and not a substitute for existing provisions, and research should be focused on how ICT can meet the carer's needs, attitudes and beliefs [7].

Pilotto et al. reported that relatives/informal caregivers found ICT to be useful for patients with Alzheimer's disease, to improve quality of life and achieve a more independent lifestyle [8]. Results from a two-year case study indicates ICT systems can have a positive impact for family caregivers, but it needs to be constantly supported from formal caregiving services in the municipality [9].

In a review paper of ICT-based services for people with dementia, Lauriks et al. found that they can benefit from such technologies and thus indirectly reduce the burden for the family caregiver [10]. Currently different technologies exist on the market, but despite their proven positive impact, they are not widely used [11]. Based on a selected literature review, Vogt et al. proposed a framework for technology design and development of context-aware assistive applications for patients with dementia and their caregivers, and gave some recommendations for the design process [12]. The solutions would require a user-friendly design [13]. ICT solutions can be useful in topics such as safety and security for patients with dementia, when they provide the needed functionality and are introduced at the right time, but there should be a reciprocity between the relatives and the dementia patient in the decisions of ICT use [14]. Use of technology can also have a potential to significantly support other people, but they will need information of actual solutions and be able to incorporate that use into the existing habit of the dementia patient [15]. Technology for home healthcare can be defined by different terms. In this study, we will use *Telecare* as the solution for remote monitoring to manage risks, thereby assisting the individual to live independently [16].

The purpose of this study was to investigate the experiences

by close relatives and home healthcare services to identify the main obstacles for the user to stay longer in his/her own home. We have highlighted possible challenges of Telecare solutions for elderly people with dementia and their close relatives. In addition, we will combine their expressed challenges with an overview of technical solutions and comparison of available products on the Norwegian market

Materials and Methods

To carry out an open study, we used a descriptive and explorative design with a qualitative approach based on focus group interviews, according to recommendations given by Graneheim & Lundman [17]. The study was carried out in the period from May to June 2011, in a typical medium size municipality in Southern Norway (ca. 21.000 inhabitants). Evaluation of actual technology solutions was conducted in the period from August 2013 to January 2014.

Participants

The criteria for participation in the study where close relatives of a person with dementia living at home, and personnel in the home nurse services at the local municipality level. In total eight relatives and nine health care professionals were interviewed. The relatives were daughters or sons who had taken care of their mother or father for the last years, combined with regular visits from the caregiving services in the municipality. Four semi-structured focus group interviews were conducted, two with family members and two with health care professionals.

Procedure

Local government professionals responsible for the caregiving services identified relatives of people with dementia, and health care professionals, who showed interest to participate in the study. Department nurse with a special responsibility for dementia care services contacted the participants and gave them written and oral information about the study´s aim and procedure, as well as the written consent form. Subsequently she scheduled an interview appointment at a place and time preferable to the relative**s.** The nurse also contacted her colleagues for arranging time and place for the interviews.

The interviews were conducted separately between the two groups. Between four and five informants participated in each focus group, and the two of the authors (MMF and ET) carried out the interviews. A small focus group was easier to recruit, and was more manageable and more comfortable for the participants (18).

The interviews took place at the local health center in the municipality. It was used a semi-structured interview guide based on the research questions. One of the authors behaved as a moderator and was responsible for leading the interviews. The other one behaved as assistant moderator responsible for observation of the group dynamics, and to summarize the contents regularly, trying to focus the discussion around the significant issues in questions according to the interview guide. She was also responsible for the final group summary.

Data collection

The interviews started with a short presentation of the reason for carrying out the study and the focus on their experiences of the elderly dementia person's ability to carry out the normal daily activities. Questions were about concentrating on what is functioning satisfactorily, what seems to be problematic and which factors can be of importance to be able for them to continue living in their own home.

Each interview began with open questions about: "*How have the current situation for resident individuals with dementia and their family been perceived*", "*What are the main obstacles for the user to stay longer in his/her own home*", and "*How can it be possible to improve the elderly's ability to manage living alone at home?*" Follow up questions were used for clarification and elaboration, such as: "*Can you tell us more about this?", "What did you mean?", "What did that means to you?", "How can use of technology contribute to improve the ability of independent living?"* The interviews lasted about 90 minutes, and were digitally recorded. Two of the authors (MMF and ET) were responsible for transcribing two interviews each, and they collaborated on the data analysis in order to obtain a broad understanding and defining meaning units.

Data analysis

Data were analyzed by using qualitative content analysis as specified by Graneheim and Lundman [17]. Firstly, the entire text was read several times to obtain a general understanding of the content. Then, the text was demarked into meaning units corresponding to the focus in this study. The meaning units were condensed in a way that the text became compressed and abstracted. By defining groups by condensed meaning units, sub-categories were extracted as invariant themes. The last step in the analyses was to create common overarching themes by an interpretation of the content in the invariants themes.

Literature review/state of the art of technology solutions

Based on the user inputs of ideas for actual technology solutions that could be helpful both to the close relatives and to the home health care services, we clarified actual challenges to technology use during the data analysis.

Different technology solutions were investigated by search in scientific literature, and in EU-project reports, as well as search for actual products available on the Norwegian market, in order to compare different technology solutions and evaluate possible use.

Ethical considerations

The study was conducted according to ethical guidelines used validated and used in other studies [18, 19]. Participation in the focus group interviews was based on written, informed and voluntary consent. It was assured that the collected data were confidently treated and that the informants had an opportunity to withdraw without declaring their reasons. Consent forms were securely stored in locked rooms and lockers. Since no questions were asked about informants own health, there was no obligation in Norway to get approval from an ethical committee. The study was reported to the Norwegian Social Science Data Services (NSD) (Ref 26918).

Results

The findings will be presented by describing the three categories "Obstacles for people with dementia living in their own

home", "Relatives' experience of having responsibility for the elderly with dementia living at home" and "Challenges related to living in own homes", and then the overall theme **"**Use of technology to promote the sense of safety, confidence and coping".

Obstacles for people with dementia living in their own home

Both relatives and health professionals were asked to describe the typical characteristics of a person becoming demented. They talked about gradual changes in behavior, changes that may be difficult to detect because they can be mixed with normal age-related changes and personality traits of the person. They also told how they, in the beginning, rationalized the signs and symptoms of early cognitive decline.

Development of cognitive decline makes the person gradually becoming more passive and indifferent/apathetic. The person often stops with activities and hobbies and is unconcerned with their appearance and cleaning their house. The home is becoming dirty and messy. Many people are suspicious, show a lack of insight, and have periods of confusion. Gradually, the person develops disabilities, and will become further pacified. At the beginning, the person often manages to hide his failure by withdrawing from difficult situations. As the disease progresses, many develop apraxia and sensory impairments. Consequences of sensory impairment may be that they throw diapers in the toilet, they may use the trash-bin as a toilet, or the person falls because they do not see stairs or doorsteps. Both the relatives and the health care professionals explained that the person gradually developed increased resistance to interference and help from others, which makes it problematic to implement actions to improve the situation. In spite of these entire symptoms, the relatives expressed that it was important for their mother or father to be able to live in their own residents: *"I would like to say that for my mother at this time, it is important to continue to live at home. It is what keeps her in a good mood and makes sure that she would like to continue to do the things that she is looking forward to doing ".*

Relatives' experience of having responsibility for the elderly living at home with dementia

Relatives described their situation as very difficult, characterized by uncertainty, insecurity, unpredictability, suspiciousness, and they used a lot of time following up their mother or father. They also spent a lot of time to be available, or to check the daily conditions in the elderly´s home.

Relatives find that personality changes generate uncertainty and insecurity. They are insecure because they feel that a person that they think they know well, gradually change personality. The changes also make it difficult to approach the person in the normal way, which contributes to uncertainty. Many close relatives have little knowledge about dementia and is therefore uncertain how to deal with their relatives, and they have little knowledge about what kind of services the municipality can offer.

Consequences related to living in own homes

During the data analysis, areas where it might be problematic for the elderly to continue living in own homes where identified and summarized in Table 1 into six characteristics.

The obstacles are reflecting the relatives and home care services experiences related to what they found to be challenging for the elderly.

Use of technology to promote the sense of safety, confidence and coping

Technology solutions were evaluated to reflect what the patients could currently need and in the future. The faithful support from close relatives has been very beneficial for the elderly in the phase of initial dementia, which makes it very necessary to be continued even when the public health care services gradually undertake the daily support for the elderly person. In Fig. 1, this collaborative approach is visualized where arrows indicate types of necessary support, showing the gap between the actual cognitive impairment and the ideal level of independence. In the early phase of a dementia situation, support from close relatives will normally be the important effort. The close relatives and home health care nurses anticipated that use of technology could have important impact. Gradually, the public health care service will increase their influence. However, both informants groups expressed difficulties in the ability of being able to exchange necessary information to be able to act as a coordinated supportive team.

Both health care providers and relatives were interested in using technology solutions for communication with each other to achieve improved cooperation and coordination of actions to the elderly. It was suggested a system where nurses and caregivers could give each other messages when they had been visiting the old, or use a *Facebook* feature that allowed for communication between patients, their families and the health care personnel and possibly volunteers. Son (1): *"I do not know if they have been with my mom now or if they come later in the day, so it would be very nice to have had control that seems to work today".* Daughter (1): *"... one of those "beeps" that they might touch, something and that on my phone, that "now we have been there".*

It was expressed a need for e-mail contact between health care personnel and relatives. This could make it easier to communicate and to give information about changes in the situation from both sides. Home nurse (7): *"... we have no opportunity to communicate by mail, but if we only could receive short messages, it would be a great way to communicate".*

Both relatives and health care personnel went through a high degree of uncertainty and unpredictability in how people with cognitive impairments managed their daily living at home. A need for good technological solutions that could provide security and predictability in the home setting was expressed. Door alarms, fall alarms, fire and flood alarms, web camera, use of GPS for outdoor activities, and social security alarms were some of the solutions specifically mentioned as appropriate in order to create a safe situation.

Several relatives told about episodes with fall accidents because of physical impairment and subsequent cognitive decline. They had experienced that their mother or father had fallen several times because of many elderlies are shaky and that the risk of fall accidents is an imminent danger. Some believed that a fall alarm could contribute to improve security if one could be sure that it was triggered by a fall accident. Other types of alarm that relatives and health personnel mentioned were door-alarm. Daughter (2): "*So he is confused at night, he wakes up and thinks he is going to work. Then he goes out and he falls often and .. We will try a door alarm."*

Table 1 Operationalization of the findings from the content analyzes

Obstacles	Experiences	Consequences
Orientation	Loss of orientation related to time, place and space/room - Problems in maintaining the circadian rhythm - Use a lot of energy to organize appointments	Confusion/delirium Get lost Risk of fall Forget appointments Risk of medication error Risk of disturbances in eating times
Personal hygiene	Loss of ability and initiative to perform personal hygiene - Loss of dignity - Loss of well-being	Social isolation "dirt and spills" Personal decay
Medication	Medication errors - Incorrect treatment of disease(s) - Forget or taking medication at wrong time - Obliviousness related to changes in the circadian rhythm	Risk of fall Risk of delirium Mess Difficult to detect errors in medication because of memory loss
Nutrition	Loss of ability and initiative to make food Routines gradually slipping Forget to eat and make purchases Forget meals	Malnutrition Confusion Stale food Clutter and mess Poor hygiene
Communication	Loss of language (aphasia) - Loss of insight - Reduced interaction - Reduced collaboration	Lack of confidence Suspiciousness /paranoia Loss of interests
Social isolation	Reduced social contact - Loneliness - Lack of stimulation	Withdrawal Reduced activity

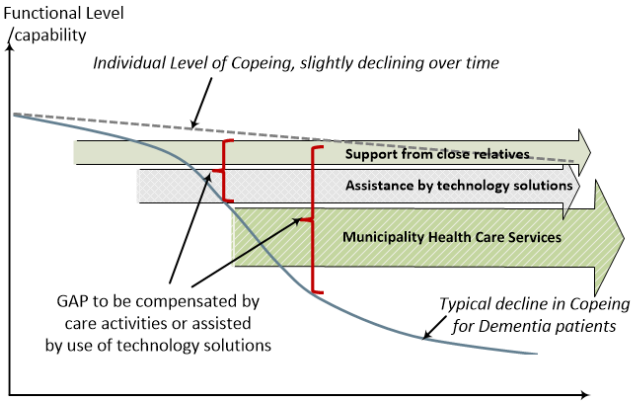

Figure 1*Gap in cognitive impairment and supportive influence from close relatives in addition to assistance by technology solutions and public health care services.*

Home nurse (5): *"Some of the patients are going out walking in the middle of the night, and some of them have a door-alarm which alerts us, but in other cases the personnel have put on tape at the patients front door and check it out whether the door has been opened during the night".*

The needs of GPS alarm were also mentioned. Home nurse (4*):" ...when they go out and not find their way back home, then it is difficult to be taken care of in their own homes".*

Table 2. *Technology to promote the sense of safety, confidence and coping. By defining problems related to being demented, general needs related to technical aids and some technology solutions, focusing on challengers related to technical solutions are summarized.*

Problems related to being demented	General needs related to technical aids	General solutions	Technical solutions	Challenges related to technical solutions
Circadian rhythm	Memorial/ functional	Electronic/Digital calendar/ PC with reminder functions	Web-access to the patient's calendar to fill in reminders and remote programming of electronic pill boxes	Ethical- and legal restrictions Computer security, data storage, authentication and access control issues
Medication		Electronic pill box		
Personal hygiene		Visual Communication program/ solutions		
Meals and nutrition		Reminders and instructions		
Fall accident	Safety and security	Fall alarm/ Safety- alarm	Home health-care alarm systems with internet gateway and Cellphone with integrated GPS	Interoperability issues, standardization in technology solutions based on international recommendations
Not finding their way home		GPS systems		
Going out in the middle of the night		Door alarm		
Not understanding what may be flammable		Fire alarm		
Throwing objects into the toilette		Water-flooding-alarm		
Loneliness Isolation Lack of stimuli	Social isolation Activity and stimulation	Skype Telephone/cellphone Games- or training program	Use of social media and gaming technologies, /web camera/ Skype/ videophone	Ethical- and legal restrictions Usability Consent form
Difficult to get in touch and give and receive information	Collaboration Coordination Interaction		New collaborative web-based portals	Data security Legal restrictions Confidentiality

Table 3 *Comparison of some current products available in the Norwegian market, according to the defined user needs and functions.*

	Technological solutions/actual products								
Defined functions	Memoplanner *	FlexiBlink *	Cognitass *	Numa trygghetsalarm *	Dignio trygghetspakke	Altibox alarm	Common social alarms	Common building alarms	Building automation *
Medicine reminder	X	X	X		X				
Fire alarm					X	X		X	X
Manual alarm button	X	X		X	X		X		
Stove alarm	X	X							X
Voice messages	X	X	X						
External alarm call	O	X		X	X		X	X	
Automatic speech conversation				X			X		
Calendar reminders	X		X						
Remote control function	X		X						
Controlling light & heat						X			X
Surveillance camera								X	
SMS alarm messages	O	X		X	X			X	
Skype- video functions	X								
Mail functions			X						
APP-based functions						X			X

** Actual products tested in a lab environment*

Some of the relatives had experienced that their mother or father could not find their way back home. One of them had perceived use of GPS. Son (1):*" ... I feel quite more secure now and I don´t need to contact my mother quite so often, and in addition to health personnel, they have to visit her two times a week to charge the GPS alarm".*

Base on the content analysis findings, we have summarized in Table 2 some of the current problems related to being demented. Those problems have been expressed as important factors affecting the situation for home living elderly patients, and it has been evaluated technology aids, which can help in compensating the functional impairment. Several technical solutions might be relevant for the actual elderly person to address those problems.

There will be several general solutions available and ready to be used by elderly at an early stage of dementia. In order to evaluate actual solutions targeting user's needs, we have compared some of the products available in the Norwegian market, summarized in Table 3. Functions marked with an X indicate what the actual products support, while O indicates optional functions. The products investigated are Memoplanner[1], Flexiblink[2], Cognitass[3], Numa[4], Dignio[5], Altibox[6], as well as a general overview of common social alarm systems, building control with home alarm systems and systems for building automation as for instance KNX-systems.

Of those nine different systems/solutions, we have evaluated five in a lab environment at University of Agder, those products are marked with an * in the table.

Several different types of technologies can be implemented with important functions; however, it might be challenging to find an actual product containing all functions needed, as the extent of functions shows a plurality of combinations. Being able to use the technologies within the legal and security regulations for health care solutions, there are several important challenges to be taken into consideration upon implementation. Especially, legal requirements for privacy and secure access to medical information can be challenging for providers of new technology solutions. In addition, the need of standardization may in the future give recommendations for interoperability between different products, which can give new possibilities of plug-and-play functions for different types of sensors and alarm functions.

Discussion

In this study, we have investigated the experiences by close relatives and home healthcare services, to identify the main obstacles for the user to stay longer in their own home. We have highlighted possible challenges of Telecare solutions for elderly people with dementia and their close relatives. In addition, we combined their expressed challenges with an overview of technical solutions and comparison of available products on the Norwegian market.

Close relatives expressed that their situation were characterized by uncertainty and insecurity for their mother or father. They stressed that it was important to find good solutions to minimize the obstacles. Both close relatives and health care providers showed a positive attitude to use Telecare if this could maintain the activity of daily life, safety and security, in a way that the dementia patient could still be able to live in their own residence. It is important to involve patients with dementia in discussion of technology, being also an ethical issue. These findings are according to what has been described by Olsson et al. [14]

Both family caregivers and health care services mentioned the need of early implementation of ICT devices in the dementia disease, while the person is still competent to make use of the device and take advanced of ICT devices. In addition, the actual solutions need to be user-friendly, as pinpointed by Vogt et al. [12] and Hanson et al. [13].

[1] http://www.abilia.no/produkter/produkt.aspx?productgroup=313780&product=343546

[2] http://www.vestfoldaudio.no/produkter/flexiblink

[3] http://www.cognita.no/produkt/580

[4] http://www.numa.no/produkt/trygghetsalarm/numa-ta10-trygghetsalarm

[5] http://www.dignio.no/trygghetspakken/

[6] http://www.altibox.no/privat/alarm/sikkert-hjem

Another challenge is to motivate the patient with dementia to make use of ICT devices. It is important to adapt the ICT device to the person's needs, so the device does not remain unused. On the contrary, it could be a false sense of security for both family caregivers and the health providers. As described by Hanson et al.[13], this will require sufficient support in the implementation phase.

It is also important that the professionals have knowledge and awareness about different ICT devices so they could give advice and support in training both the patient with dementia and the family caregivers. It has to be a close collaboration between family caregivers and the health providers. Use of ICT devices could also release family caregivers form daily tasks, and give them more time to social meetings, activity outside, etc.

Statements from close relatives showed that there also was a need of systems for daily communication, such as e-mail for feedback from the municipality health care services. It was relevant for relatives to know the visit agenda of careers regarding their mother or father to not to be worried or afraid about anything that could have happened. Health care personnel supported this view, and they wished to find good solutions for these challenges. Close communication and easy access with each other could provide security and predictability in home setting, but because of a strict legislation, such routines could be difficult to implement.

For evaluation of technology according to meet the challenges described in six main categories, there will be relevant products available on the market. However, it can be difficult to find optimal solutions combining several of the challenges, as there is a lack of standardization and interoperability for Telecare solutions, as described by Gerdes et al. [20]. In addition, several challenges in technology use that should be taken into consideration before implementing desired solutions have been listed in Table 2. For close relatives, it can be difficult to gain knowledge of alternative solutions, as stated by Rosenberg et al. [15], and information of useful technologies should be easily available. This can be an important issue for home healthcare services.

Recommendations for future research

Future research should initiate development of a web-based system for sharing information between the dementia patient's informal care team consisting of close relatives, and the formal home healthcare services. Such solutions need to be user-friendly and as simple to use as *Facebook*, but with necessary data security in order to share medical information of care. Our project indicates that there is a need of supportive teamwork accordingly to the importance of close support from health care services as described by Torp et al. [6]., where the importance of a secured virtual private network was highlighted.

Increased research efforts should be concentrated on investigating dementia patients, and close relatives outcome from use of Telecare and smart home solutions with sensor technology, including alarm systems. Interoperability and standardization of system design is challenging, but there might be opportunities for better follow-up in the near future, and with fewer burdens to the family members. Especially smooth transitions from support by close relatives to gradually compensate from deficits by introducing technology, and to progressively influence home healthcare services should be in the agenda. Nevertheless, those types of integrated care can be of importance for managing the expected growth in elderly populations with increased number of people suffering from dementia.

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