Development of an Online Platform to Support the Network of Caregivers of People with Dementia

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Abstract. In the Netherlands, care technology is used insufficiently to support people with dementia, their family and professional caregivers. In this project we integrate a range of services and applications into an online platform, with the aim to strengthen these networks and to support communication between their members. The prototype of the platform was made in an iterative user centered way. Semi structured (group) interviews were conducted to specify the requirements. The platform consists of 'cubes' with information about dementia (care), video communication options, a calendar and a care plan. The first prototype of the platform was valued by the participants, but privacy matters and registration issues were pointed out when using a shared care plan. Additional applications to monitor health and safety will be integrated in the second prototype. This prototype will be tested on its usability, feasibility and desirability during a pilot study in spring 2016.

Keywords. Assistive technology, dementia care, family care, online platform

1. Introduction

Worldwide, 47.5 million people have dementia [1] of which 260.000 live in the Netherlands. The number of people with dementia (PWD) is expected to rise significantly in the near future. According to Dutch government healthcare policy, people in need of care have to live at home for as long as possible. Seventy percent of the PWD live at home; 60% with and 40% without a partner or other family members [2]. Without a partner, PWD are dependent of children, friends and neighbors, but not everyone has such a social network [3]. As a result of the increase in the complexity of requests for help and at the same time a decrease in available healthcare professionals, care for PWD shifts from the formal towards the informal network. What are the implications of this transition? Based on research into the quality of care in the networks of community-dwelling PWD, the Dutch Health Care Inspectorate is seriously concerned about the neglect of PWD without a social network, the overload of family caregivers, the problems related to care planning, medication intake and

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continuity of care [4]. Therefore, it is a major challenge to strengthen these networks and the collaboration between formal and informal caregivers.

Online platforms to improve information exchange between healthcare professionals, PWD and their family caregivers as well as other forms of care technology can play an important role in helping PWD and their caregivers to maintain autonomy and continuity in their lives [5-8]. Therefore in this Network Support Dementia project we aim to integrate a range of services and applications into one platform, assuming that such integration will be beneficial.

Three care organizations and four companies were willing to integrate their services via one specific platform, which was already in use in the region to promote cohesion between citizens [9]. The available services of the companies were specifically related to providing information about dementia [10], information exchange between informal caregivers [11] and between family caregivers and healthcare professionals through web collaboration [12]. The design challenge was to provide a flexible platform and to realize custom solutions for different users with different needs and expectations in different settings. Therefore the following research questions were posed:

- Which problems encounter members of the (in) formal network while caring for PWD at home and which type of care technology could be supportive in reducing or eliminating these problems?
- What are the user requirements regarding the online platform; which services and applications should be included in this platform and how should they be presented?

2. Methods

2.1. Design

The two-year Network Support Dementia project started in March 2015. An iterative user-centered design method was used to integrate the services into the platform [13]. Semi-structured (group) interviews with family and professional caregivers were conducted, to specify the user requirements. The study was approved by the medical ethical committee of Zuyderland-Zuyd (15-N-122).

2.2. Participants

Two groups of participants were interviewed, family caregivers of PWD and professional caregivers representing different disciplines. Family caregivers were found through the network of the researchers and via 'dementia case managers', in two municipalities in Limburg, the Netherlands. We selected informal caregivers with different characteristics: different relationships to the PWD (partners, siblings, children or neighbors), caregivers of people with different stages of dementia, whether or not resident with the PWD, and living closely or far away. Besides the care professionals, who were selected based on different disciplines and experience, we also interviewed two people with a coordinating role regarding informal care.

2.3. Data collection

In the first step nine semi-structured interviews with family caregivers and 15 with professional caregivers were conducted. The topic lists were based on former research into needs of family and professional caregivers of PWD (table 1) [14-16]. At the end of each interview, interviewees were asked to read a "use case" and give comments.

In the 'use case' the imaginary platform consisted of an overview of websites with relevant information about dementia (care) and community health and welfare services; video communication between different members of the network; a calendar and scheduling option for family caregivers and volunteers; a shared care plan to be used by both family and professional caregivers; opportunities for support of peers and volunteers; sensors, cameras and GPS surveillance; and a list of recommended apps for entertainment especially for people with cognitive disabilities.

Table 1. Interview topics

Family caregivers	Professional caregivers
Screening / general / personalized information	Overview of the network
Support for symptoms of dementia	Communication
Social contact / company / activities	Uniformity in work processes
Monitoring health and safety	Knowledge and expertise
Sharing information / communication/ therapy	Monitoring and evaluation

In the second step focus groups with nine family caregivers and seven professional caregivers were held. First, the results from the interviews were discussed briefly to confirm and complement the findings and then the first prototype of the platform was demonstrated. The platform consists of different 'cubes'. Per cube participants were asked to answer the following questions on a feedback form: would you use this cube (yes/maybe/no, please explain), what do you like about this cube, what not and provide a 'valuable tip'.

2.4. Data analyses

The interviews were transcribed verbatim and the data were analyzed following a directed content analysis method. The notes of focus groups together with the feedback forms were combined into one summary. General themes emerged and these themes were used as input for the user requirements document.

3. Results

3.1. The needs of the network of caregivers of PWD

Family caregivers - All nine family caregivers who were interviewed were female, with a mean age of 61 year (range 27 to 77). Four of them were daughters of the PWD; three were partners; one sister in law; and one neighbor. All interviewees indicated that good information provision is very important to fulfill their role of family caregiver. They specifically asked for information about how to deal with difficult behavior of the PWD. They also indicated that they could not find a clear and up-to-date overview of

locally available care facilities. Furthermore, several interviewees expressed their interest in contacts with fellow family caregivers. In many cases, day-care was seen as a good solution to relieve the family caregiver. Some interviewees were looking for suitable volunteers to support them. Besides finding appropriate activities for the PWD, creating a safe environment also proved a recurring theme for most interviewees. Finally, almost all interviewees mentioned the fact that different professional caregivers often ask the same questions and do not know what was previously agreed upon.

Professional caregivers - From the fifteen professional caregivers who were interviewed, twelve were female and three were male with a mean age of 48 year (range 22 to 69). They represented a variety of disciplines with eleven different functions: two General Practitioners (GP's), a home mentor, a counsellor specialized in care for the elderly, three coordinating nurses, two case managers dementia, a domestic assistant, two community nurses, a day activities coach, an employee of a care farm, a care and support consultant and a coordinator of volunteers. Interviewees indicated that because of this large diversity of professional caregivers involved in the care for PWD and the overlap in roles and responsibilities, in many cases they don't know who exactly is involved in a case. As a result, every professional separately identifies the health needs and establishes a care plan. Furthermore, most participants indicated that there is a shortage of information about current changes regarding medications, weight and hospitalization of the PWD, due to the use of different record systems. Most interviewees confirmed the key role of the GP in the care for PWD, but they indicated that it often proved difficult to involve the GP in multidisciplinary consultation because of time constraints and planning problems.

Most professional caregivers indicated that it would be a substantial improvement if they could access a database with information about dementia and treatment options, how to assess care needs of PWD and their family caregivers, assistive technology and a clear and up-to-date overview of locally available care facilities.

3.2. From use case to prototype

The feedback on the use case was positive; family and professional caregivers indicated that such a platform would facilitate communication in the network. There were doubts about the use of one shared care plan because of privacy issues and most professional caregivers were critical about the extra registration time, because they also use the record system of their care organization. Furthermore, some family caregivers thought that clear instructions would be essential for those users with limited computer experience.

Subsequently, the first prototype of the platform was built. In the focus groups the following cubes in the prototype were presented: 'Dementia info', 'Contacts/Clients', 'Messages' and 'Forums', 'Calendar/Share Care', 'We Care', registration of health and care through 'My measurements', 'Medication' and 'Care notebook'. The first impressions of the prototype were also positive. Participants indicated that use of the platform would promote co-operation with other members of the network, this could improve the quality and efficiency of care. Remarks were made about the considerable overlap between the cubes. All participants stressed the importance of simplicity and several tips for improvement were given. All these user requirements were listed in a use requirements document, which was used during further development of the prototype.

4. Discussion

This paper reports about the ongoing process of the user centered development of an online platform to support family and professional caregivers of PWD. Based on the results of the interviews and focus groups a prototype was built, which will be tested on its usability, feasibility and desirability during a pilot study in spring 2016. Participants were positive about the prototype, but there are still some barriers to overcome. Some services, such as providing information about local health and welfare services and monitoring of health and safety through the use of video cameras and sensor technology have not yet been realized within the platform. For a successful implementation, there are issues to be solved concerning privacy and integration with record systems of the different professional caregivers' organizations.

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