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Making Person-Centred Health Care Beneficial for People with Mild Cognitive Impairment (MCI) or Mild Dementia – Results of Interviews with Patients and Their Informal Caregivers

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Abstract. In the health care sector, person-centred treatment approaches have shown the potential to improve treatment outcomes and quality of life of patients. In particular, this applies where patients are living with complex conditions like multimorbid older patients with Mild Cognitive Impairment (MCI) or mild dementia. Such treatment approaches quite often include input from modern health technologies like health/home monitoring platforms which also offer services to patients for self-management of their conditions. This approach is also followed in the research project CAREPATH (An Integrated Solution for Sustainable Care for Multimorbid Patients with Dementia). To achieve acceptance of such complex health technologies, their services must be beneficial in the eyes of target end users which included in the case of CAREPATH, the patient's informal caregivers.

Therefore, understanding the user requirements of patients and their informal caregivers is of utmost importance which was achieved in CAREPATH by interviews. These revealed that patients' preferences in regard to what services and information shall be provided to them shall be limited to what they deem necessary which is highly personal. Informal caregivers as opposed to patients, are much interested in receiving most possible information about their care-dependent's health status. Thus, provision of services and information for these user groups need to be highly customizable to their personal preferences and needs.

Keywords: Person-centred care · Health technologies · Home monitoring · Human-centred design · Usability · User requirements engineering

1 Introduction

In the health care sector, person-centred treatment is understood nowadays as a very promising approach to improve the treatment and quality of life, also for patients with complex conditions such as multimorbid older patients suffering from multiple chronic conditions as well as Mild Cognitive Impairment (MCI) or mild dementia. To reach best results, such treatment approaches quite often include input from modern health technologies such as health data collected by a health/home monitoring platform and self-reports from patients. Self-reports are most of the time gathered on platforms where patients are presented their care plan with tasks to complete in order to manage their health situation, such as measure their weight, take their medication, make an appointment with a health professional or fill out a health questionnaire - Patient-Reported Outcome Measures (PROMs). In this way, implementation of such technologies bears the potential to support patients in the self-management of their diseases. Informal caregivers may also benefit from such technologies because it will ease their care tasks, if they have access to, e.g., the care plan of their care-dependent and know about the status of tasks to-do. However, such technologies are often complex and require collaboration with the patient. Thus, to take advantage of their potential, it is of utmost importance to understand thoroughly the requirements of target end users, so they will be perceived as useful and offer a good user experience (UX) both known as key factors for acceptance.

Therefore, in the EU-funded research project CAREPATH (An Integrated Solution for Sustainable Care for Multimorbid Patients with Dementia) a process was established to elicit, document, update and follow-up on user requirements. It is the focus of CAREPATH to accomplish an ICT-based solution for optimising the clinical practice in the treatment and management of multimorbid older adults with MCI or mild dementia (see Fig. 1). In order to achieve this, CAREPATH will elaborate on a methodology for computer interpretable clinical guidelines and computationally derived best clinical practice for best suitable treatment of this patient group. Thereby, a multidisciplinary care approach is considered, with a focus on the very individual needs of patients in this group to be translated into personalized care plans. The project utilizes a health/home monitoring platform to receive health data analysed by artificial intelligence (AI) algorithms for clinical decision support and provides an integrated care platform for creating personalized care plans for the patients based on a patient's most recent context received from

the health/home monitoring platform, AI algorithms as well as Electronic Healthcare Records.

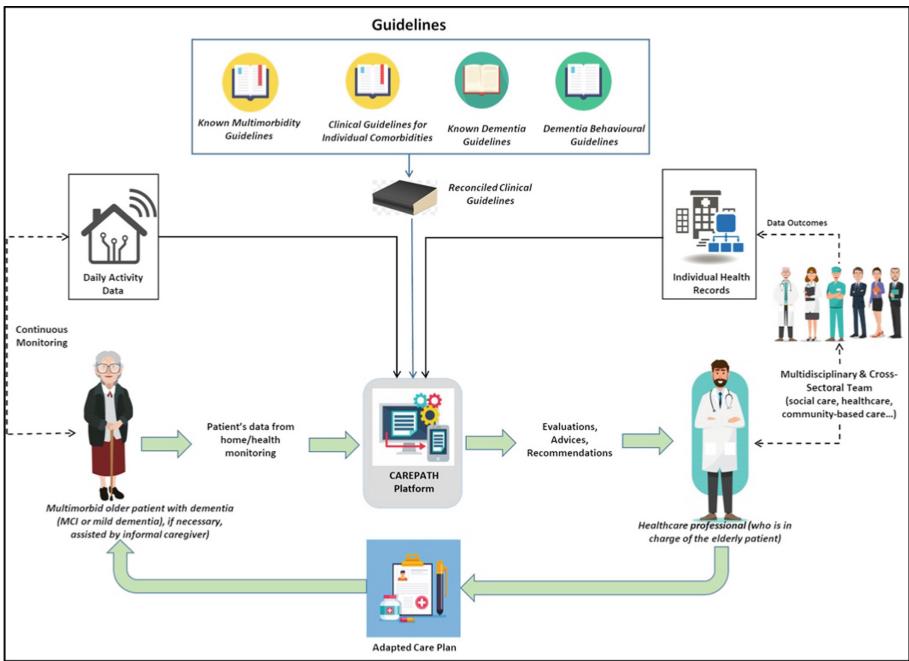


Fig. 1. The CAREPATH ecosystem

The CAREPATH approach will be validated in a clinical study with 208 multimorbid older patients with MCI or mild dementia (104 patients intervention group/104 patients control group) at pilot sites in Spain, UK, Romania, and Germany. In the project a strict human-centred design approach is followed according to ISO 9241–210:2019 [1] and thus target end user groups were involved in the design of the CAREPATH platform from the beginning of the project. As first activity user requirements were collected from in total 16 health professionals of various disciplines, 16 patients and 16 informal caregivers at the 4 pilot sites by interviews. In the course of the project, these will be updated and missing ones added by group-based expert walkthroughs with prototypes and a usability evaluation before the clinical study starts. In the following sections, the methodology for elicitation of first user requirements by interviews with patients and informal caregivers will be presented.

2 Methodology

It was considered most appropriate to involve patients and their informal caregivers in the elicitation of user requirements by conducting interviews, first, due to the pandemic situation not favouring group formats and second, because interviews are assumed to

offer a situation where patients will feel most comfortable and safe. Interviews are an acknowledged method for gathering valid in-depth information suitable particularly in early design stages where issues to be considered for technical development are rather large [2]. They also offer a valuable means to gather information about opinions and attitudes of target end user towards IT-based environments such as CAREPATH and necessary pre-conditions for user acceptance. In the following a description of the test sample, the interview guidelines and interview results where user requirements were derived and documented for technical realization.

2.1 Test Sample

Since the project was at its beginning and ethics approvals and data protection agreement were not finalized yet, the interviews needed to be conducted under ‘Patient and Public Involvement (PPI)’ or similar regulations at each country involved which means no personal data of interviewees could be recorded. However, inclusion criteria were agreed on with pilot sites to ensure that the group of interviewees represents crucial characteristics of the CAREPATH target end user groups and that interview results are comparable. Each pilot site conducted interviews with 4 patients and 4 informal caregivers. For patients the inclusion criteria specified that they are of age 65 or older, are clinically diagnosed as living with MCI or mild dementia and are affected by at least one of the morbidities in focus of the project, e.g., diabetes, heart failure, hypertension, and chronic obstructive pulmonary disease (COPD). Beyond this, they should be using at least one electronic device such as a mobile phone. It had to be ensured that at each pilot site, two females and two males were interviewed and that two patients lived together with their informal caregivers whereas two lived alone and the informal caregiver somewhere else. Following this approach, inclusion criteria for informal caregivers determined that two are female and two are male, two live with their care-dependent and two do not live in the same household.

2.2 Interview Guidelines

As mentioned above, interviews were conducted at the 4 pilot sites of the CAREPATH project by health professionals with patients and informal caregivers they were familiar with. In order to ensure that in the interviews key themes were addressed that the project consortium aims to investigate and that interview results can be somehow related, an interview guideline was developed that included questions with a range of possible response options describing in more detail what information is sought for. For example, in case it was asked how patients are managing medication intake, possible responses included that either the informal or a professional caregiver helps them, they use a pill box, a calendar, an app etc. However, interviewers were always free on how to follow-up on a question, what issues to explore and even encouraged to elicit information not covered by the provided response options to learn best about users’ requirements. In order to keep the effort for pilot sites within reasonable limits to document results of the interviews, the response options could also be used for documentation purposes and new information recorded in a dedicated section. According to the feedback from pilot sites, this approach was suitable to help them conduct and document results of the

interviews. Since new preferences and needs of interviewees were recorded, it can be assumed that the structure of the interview guidelines did not seem to have narrowed down the investigation of issues.

The goal of patient interviews was to gain a better understanding of how the organization of everyday life is affected by their health conditions, what they would like help with and what specific tasks they need to fulfil in order to manage their conditions. The consortium is aware that people with cognitive impairments are a vulnerable user group and that interview questions need to be very concrete and concise. Therefore, key themes to investigate were broken down into bits of information, so they are easy to answer, for instance 'Do you need help with taking your medication' was one of the questions to find out about care management at home and if the interviewee responded with 'Yes', they were asked what help is needed.

The interview guideline for patients covered the following key themes (number of questions is in parentheses): technical expertise and accessibility issues (3), care organisation at home (10), coping with cognitive impairment and management of everyday life (4), exercise and diet control (9), improvement of personal management (5). The interview guideline for informal caregivers included questions on: technical expertise and accessibility issues (3), care management (3), design of devices and sensors (1).

3 Results of Interviews

The interviews allowed the consortium to collect a plenitude of information in regard to how patients manage their health conditions, what informal caregivers seek help with and what are the preferences of both user groups. In the following some results will be highlighted. The majority of patients used a smartphone ($n = 15$), one a tablet. They used it mainly for making calls and chatting with the family by messaging services. Accessibility issues mentioned referred to problems with gestures such as swiping or pinching and design issues like too small buttons and cluttered screens. Fear of fraudsters and being observed were also mentioned. If asked what makes an application easy to use, main characteristic mentioned was that they are used to it. This hints at that when delivering a new application to this patient group, the first hurdle will be to support them while using it until they feel totally comfortable with handling it.

When presented with an example of a daily care plan, that could be shown to patients on a tablet to support them in achieving their daily care tasks, 6 patients responded that this could be of help to them, 10 stated that they do not think so. Reasons provided were that they do not have many tasks to do, that it is everyday routine for them and 4 patients would feel supervised. However, 8 informal caregivers were interested in receiving such a plan for them as well their care-dependent to be aware of the to-dos and their status, 5 said this could be helpful in a later stage.

About half of the patients ($n = 9$) measure vital parameters mainly in case they do not feel well. However, they do not document results and take this information along when visiting physicians. 7 patients admitted though that this could be useful. Along this line, in the opinion of 7 patients utilizing technology could help to receive better overview on the personal health condition by, e.g., checking results of blood pressure measurements ($n = 7$), weight ($n = 4$), sleep ($n = 3$) and pain ($n = 3$). 11 informal

caregivers stated that they would be much interested in being presented results from their care-dependents' health measurements.

8 patients stated that they would like to remind themselves of doctor's appointments and the medication list. They also would like to document symptoms such as how they feel on a day, when they have health problems such as headaches, constipation issues etc. It was also mentioned by 8 patients that they need support with everyday activities such as shopping or preparation of meals. 9 patients said that they forget things they wanted to do, e.g., call a friend or a family member or listen to a concert on the radio, 5 of these patients would like to be reminded of such activities.

The majority of informal caregivers ($n = 10$) stated that they need help with their care tasks, 5 said that for now they can handle the situation. Main issues mentioned were keeping track of appointments with health professionals ($n = 4$) as well as taking to and picking up their care-dependent from appointments with therapists, friends, social activities etc. ($n = 4$). Furthermore, they were worried to leave the house, because they do not know what is happening when they are away ($n = 4$). They are mainly afraid that the care-dependent might fall, starts wandering in the house or leaves the house ($n = 4$) and that accidents may happen with using the kitchen and water spilling over ($n = 3$).

When asking informal caregivers whether they feel sometimes unsure about their care-dependent's health situation, 7 stated that they do not feel unsure, but 9 felt unsure though in regard to a risk of fall ($n = 7$), deterioration of cognitive status they do not notice ($n = 5$) and unnoticed worsening of the physical conditions ($n = 3$).

Finally, informal caregivers together with their care-dependent were asked about design requirements for sensors and devices used by a health/home monitoring platform. Requirements most often mentioned were the following: Be comfortable to wear ($n = 11$), easy to handle ($n = 10$) and provision of means to find the device in case it is misplaced ($n = 9$).

4 Conclusion

Results from the interviews revealed that the preferences and needs of patients vary in regard to what information they are interested in, what they would like to be reminded of and in their perception of health technology providing potentially a powerful tool to support them in self-management of their health conditions. The latter might be due to some reluctance to give up established routines, even though sometimes perceived as suboptimal.

Another relevant finding of the interviews was that much care needs to be taken to avoid that patients will feel overwhelmed by too many tasks and new situations they may easily experience as obstructive. Besides this, patients aim to lead a self-determined life as much as possible and, therefore, seek support only where deemed necessary. The view of informal caregivers differed a bit sometimes in regard to where help is needed, however, a major issue for both target groups was management of appointments with health professionals.

So, from the interviews it became apparent that services and information presented on the CAREPATH platform for patients and informal caregivers need to be highly customizable to their personal needs to make them beneficial.

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