CARE, an Application to Support the Collective Management of Patients at Home

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Abstract— To perform quality home care work, care actors (formal and informal) have to collaborate and coordinate their practices. In this article, we present the prototype of the “CARE” application that we are developing to help care actors collectively manage patients’ conditions at home. This application facilitates the collaboration among care actors by providing a global vision of the patients’ trajectory, a discussion-based documentation, and an open indexation of the documented information. The first feedback confirmed the prototype pertinence for collaboration among a variety of self-employed health and care actors providing home care services.

Keywords— home care; collaborative practices; teamwork; groupware.

I. INTRODUCTION

As in many developed countries, France has an increasing number of elderly people suffering from chronic conditions. This demographic shift, associated with growing health care needs, challenge the re-organization of long-term care [1]. Facing this challenge, the health and social care sector for the elderly and disabled fosters the policy of “maintaining patients at home”, which encourages home care services.

In France, self-employed health professionals are the main providers of home care services [2]. Usually, patients can choose their health professionals and might keep the same health partners for many years (e.g. family doctor). This situation helps to personalize the care because the health partners know their patients. However, self-employed health and care professionals do not have a shared information system to assist them in their collaborative practices, which are essential for maintaining patient safety at home [3]. In fact, the electronic patient record (EPR) does not correspond to the needs of all the actors involved in the home care provision (e.g. professional caregivers and family members do not have access to EPR) [4].

In an attempt to develop a system aligned with current collaboration practices of self-employed health and care actors, we worked with an association of self-employed health and care professionals. The E-Maison Médicale association has eighty members from both health and care professions and promotes collaboration among the different actors providing care for the same patient.

In the following report, we will first describe our fieldwork and our approach, before specifying the design implications of technologies supporting self-employed care actors working collectively to manage patients at home. Then we present a mock-up of the “CARE” ¹ application, in which we implemented our design principles. Finally, we report on the first feedback from care actors about our proposed system, and we conclude with future work.

II. FIELD WORK AND APPROACH

A. The E-Maison Médicale Case

The "E-Maison Médicale" association gathers self-employed health and care professionals from several cities of the Troyes agglomeration (in the northeast of France). They aim at enhancing the quality of home care by creating inter-professional care teams. This team-based initiative is one of the few successful examples of collaboration among different self-employed health and care professionals for home care in France.

The association started in 2011 when a general practitioner and a nurse were faced with a terminally ill patient with complex health issues who wanted to spend his last moments at home. To deal with the situation, the family doctor and the nurse invited ten of their self-employed colleagues and put in place a care team. The team members coordinated their work and shared information in a paper-based notebook. This collaboration enabled the patient to stay at home and comforted his family. The association was then created to facilitate the interaction between local care professionals and thus combine their different skills to fulfill the wishes of patients who want to stay at home.

A patient (and his/her family) enters the association through one care professional who is a member of the association. The patient and his/her entourage then become part of a care team where composition depends on the patient's needs: the care team may include nurses, dieticians,

¹ CARE: In French, Classeur pour une Approche en Réseau Efficace, which means binder for an efficient networking approach

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pharmacists, specialist doctors, mental health services, and home care. Altogether, the members of the team participate in creating a "care plan" for each patient that captures the patient's personal goals and becomes a guide for all team members.

B. Data collection

To understand the collaborative practices performed by E-Maison Médicale, we applied ethnographic methods [5], combining discussion sessions, and observation. We followed a participatory design approach [6] to involve different kinds of care actors in the design process of the CARE application and used mock-ups to assess the implications for design that emerged from our field work.

The field study that we conducted lasted nine months. We focused on the collaborative practices and artifacts implemented by the care actors. We started by organizing a discussion session with five members of the association that lasted three hours. Participants included a general practitioner, a registered nurse (both are founders of the E-Maison Médicale), a physiotherapist, and two home helpers. Next, we followed the registered nurse over three days (15 hours total) while he was visiting 20 patients (at their homes) per day on average. During and after each visit, we posed questions to the various care actors (primarily home helpers and family caregivers). We also collected a sample of notebooks that are used by the care actors to document the patients' situations and to interact asynchronously.

C. The Collective Management of Patients at Home by E-Maison Médicale – Towards a better quality of life

Our field study shows that focusing on patients' quality of life drives the care actors of E-Maison Médicale to deal with issues beyond the medical scope. In the following, we present the synthetic case of John, a "patient" that we built upon different patients' situations that we have observed. The case of John illustrates the multiple dimensions of home care, and the emerging issues that lead the care actors to adapt constantly. We describe how the care actors coordinate to deal with these changes.

John suffers from the Alzheimer's disease for more than ten years. The disease has evolved, and John is occasionally facing behavior disorders (he becomes aggressive) and is sometimes lost. Otherwise, concerning the pathology, there is no significant concern. However, he suffers from an inflammatory rheumatic disease that evolves in spurts, and the pain justifies a cortisone-based treatment.

John lives together with his wife, Alice (his main informal caregiver). A home helper comes twice a week to help Alice in caring activities, and a registered nurse visits John when needed, especially when he needs an injection of cortisone. John's general practitioner also visits home when needed, especially when he needs an injection of cortisone. The general practitioner, like instructions (e.g. a medication that must be taken at least 1 hour before or 2 hours after a meal).

1) Dealing with Unexpected Medical Issues

John suddenly suffered from severe diabetes episodes caused by the cortisone treatment; the general practitioner then asked the nurse to start diabetic surveillance and insulin treatment. The nurse and John's wife cooperated to implement the diabetic surveillance and to stabilize John's situation. The nurse taught the wife how to make the necessary measurements and, together with the general practitioner, they discussed how they should document necessary information in the notebook. Here, an unexpected medical issue (diabetes) caused care actors to organize a meeting and adapt their work practices, including the documentation style, to share the needed information and ensure efficient coordination.

2) Dealing with Unexpected Social Issues

Alice (patient's wife) injured her wrist while gardening. The home helper called the general practitioner without success, so she called the nurse who managed to arrive promptly. The nurse examined Alice's wrist and recommended that Alice make an appointment for a radio image to confirm a suspected fracture. Later on, the nurse called the general practitioner to inform him about the situation, and the latter suggested sending Alice directly to his clinic, instead of going to the emergency department of the local hospital. Once Alice arrived at the clinic, the general practitioner managed to see her between his scheduled appointments. He confirmed the nurse's diagnosis and contacted the x-ray clinic to make sure that Alice would have the x-ray taken as soon as possible. After the x-ray, and according to the request of the general practitioner, the radiologist contacted the hand surgeon so Alice had her hand plastered and could come back home later in the afternoon. The intervention of the general practitioner and the involvement of all the care actors allowed a fast management of the situation (Alice's broken wrist). If not, she would have gone to the emergency and would have waited for hours before she got her radio image. Shortening this process was vital for her role as John's main caregiver; as the nurse explained to us.

JSS (nurse) "John is unable to stand alone, to wash, or to feed himself. Most importantly, he would panic without his wife. If his wife goes to the grocery shop and does not come back in two hours, he goes down the street, and you would find him on the opposite side of the town, screaming."

3) Dealing with Unexpected Logistical Issues

Alice's had her hand in a cast, which hindered her ability to do day-to-day patient's care. The wife’s injury will affect the management of John's situation, so care actors (the general practitioner, the nurse, home helper and Alice) needed to come together to find a solution. They chose to increase the number of hours the home helper spends to assist Alice, instead of deciding to place John in a care setting while Alice is recovering. When making this decision, the care actors take into account the impact that the second option would have on John's situation, as the general practitioner expressed:
DS (general practitioner) "This is a case that will have consequences for the management of her husband because the lady will be more or less disabled, and so we have set up the needed help [...] as for the husband, he is very attached, as an Alzheimer's person, to his routine. You change the routine of this gentleman he will be like an atomic bomb."

This decision had a cost, and again the care actors discussed whether the couple could afford it. The couple did not get any financial support for John's situation, and they paid the home helper from their money. However, John was eligible for receiving financial help, and Alice was not aware of that. After a discussion with the general practitioner the wife started the procedure to receive the financial help. However, the procedure takes a long time to yield, so the general practitioner asked Alice to see if her insurance could cover the extra hours of the home helper, as it is an injury that caused the need for the need for these hours.

Care actors go beyond their prescribed roles to ensure the quality of life of the patient. To address the emerging issues collectively, care actors currently use the paper-based notebook to write their observations, telephone conversations to address emergencies, and meetings are organized to discuss complex issues. Based on these findings, we defined some design guidelines for supporting the collaboration of self-employed care actors caring for a patient at home.

III. DESIGN PRINCIPLES FOR SUPPORTING THE COLLECTIVE MANAGEMENT OF PATIENTS AT HOME

The collective management of the patient's condition is satisfactory, in the sense that the patient and their entourage are happy about the way the situation is being handled. However, care actors are encountering some challenging issues that we could help them to overcome by using information and communication technologies (ICT).

The first issue is the integration of new care actors (e.g. new people entering the association or a specialist doctor who intervenes to handle a specific situation). Indeed, when reading the notebook of a patient for the first time, it takes a lot of time to identify the most important information.

Another issue concerns the participation of a wide range of care actors coming from different work traditions (practitioners, nurses, home workers, psychologists, dieticians, etc.). This variety is needed to deliver a quality home care, but these care actors normally do not work together, and some of them don't even have an idea of what the work of others is about. However, their mutual understanding of their practices is needed for them to be able to work together.

To address these challenges, a system supporting these collaborative practices should be open enough so that any professional could feel comfortable leaving information or could be able to make use of information left by another care actor. For instance, if a nurse is only documenting physiological values, they may have no sense for the home helper of the patient. It is then important to provide a system that is flexible enough so that the nurse can comment on information and "translate" it to other professions (e.g. "the patient has to cut down the salt in his diet").

We have also seen during our field study that care actors need to discuss with each other about the patient's condition. However, they rarely meet due to their overloaded schedules. Thus, we have to support their continuous discussions without disturbing their current workload. Exchanging messages around the patient could enable care actors to address complex issues by discussing problems in an asynchronous way.

Finally, as the home of the patient is the place where the care takes place, we suggest that the application should be made available at the patient's home.

Following the above-mentioned considerations, the CARE application implements three main principles to support collaborative practices of care actors for care at home:

First, allowing tracing the challenging issues in patients' trajectory, to facilitate the integration of new care actors by giving them the necessary information about the patient.

Second, enabling a discussion-based documentation to provide a flexible way of documenting patients' information and by then to be aligned with the current way of solving problems and adjusting practices.

Third, offering an open indexation of documented information to facilitate highlighting the most important information for each care actors.

These implications for design guided our definition of use scenarios and mockups.

IV. DESIGN WORKSHOP

We organized a design workshop with six participants: three home helpers, a registered nurse, a physiotherapist and general practitioner. We used mock-ups and scenarios to illustrate our interaction design options.

A. Scenarios

We used three scenarios to address the collaboration of regular actors and the participation of one-time actors in the collective management of patients at home:

- The first scenario described the intervention of a nurse to illustrate how the care actors could access the application, add a new message, and read old messages and reply to each other's questions.
- The second scenario described a consultation at the general practitioner's clinic to illustrate the utility of grouping information for the care actors who intervene when needed and not on regular bases.
- The third scenario described the situation of a patient who travels to spend a week with his family. Here we wanted to illustrate how the application can help entirely new care actors to easily get an idea about the patient's situation.

These scenarios were accompanied with mock-ups to illustrate the application features.
B. Mock-up

The care actors access the application via a tablet that stays with the patient. The patients are asked to take their tablets with them when going for a consultation or when traveling. Regular care actors will have profiles that include details such as name, address, and contact information and all care actors will have their own password to access the application (Fig. 1).

Fig. 1. Care actors can select their profile or write their name and profession

To access the application, care actors can select their profile or enter their name and profession if they are not regular care actors. We organized the functionalities of the application into four tabs: 1) "day-to-day" follow-up, 2) discussions, 3) contacts, and 4) patient care profile.

In the day-to-day follow-up tab, all the posts of the care actors are displayed in chronological order. These posts can be basic information or starting point of discussions (e.g. questions, suggestions). The care actors can read and search existing posts, create a new post, or comment on an existing one. To support the discussion between the care actors, a link to answers/comments is displayed at the bottom of the original post. In Fig. 2 for instance, we can see that Mark (the physiotherapist) has answered or commented the message from Tomas (the nurse). When creating a new post, care actors can attach an image (Fig. 3). They can also tag a message as important by checking the box "important message". Care actors might use this function when they need another care actor to be aware of the situation and to handle it. For example, if a question needs to be answered or if an action has to be done. When a message is identified as important, it will be the first to appear in the message list regardless of its date of creation, until a care actor handles the issue.

Fig. 2. Day to day tab

In the "Discussion" tab, we can see grouped together all the messages that belong to the same thread in the day-to-day follow-up. Thus, care actors can be aware of issues discussed recently. A discussion is labeled with the title of the first message and the number of exchanged messages (Fig. 4). The care actor can then decide to click on a discussion title to browse all the messages in chronological order.
In the Contact tab, we find a list of all the current care actors for the patient (Fig. 5). The users can see the contact information.

When clicking on the picture of a care actor, we can get more details like the list of recent messages written by him/her and the history of visits (Fig. 6).

In the patient tab (Fig. 7), we find patient's contact information and a list of the patient medical antecedents. A calendar is showing a trace of the different care actors visits represented by colored rectangles (this information is generated automatically when the care actor accesses the application).

Care actors can also see a list of information that they highlighted in the follow-up messages. For example, if one of the actors highlighted the temperature and blood pressure, the information is automatically added to the patient profile.

In this tab, care actors can read and edit the medical history of the patient. The content of the patient's information is not predefined to allow care actors to add what they think is important for each particular patient.
C. First Feedback

When we presented the different design options to the care actors, they acknowledged that they correspond to their documentation practices. Also, they declared that an automatic synthesis would be very helpful during emergency situations or when a new care actor is entering the network.

During the workshop, the care actors discussed giving access to the application to one-time care actors (like specialist doctors). They all agreed that a one-time care actor should have access to the patient's synthesized record, the contact information of the regular care actors, and the day-to-day follow-up. They should also be able to post messages. The care actors discussed the role of this application in anticipating emergencies. The participants believe that a phone call is the best way to handle an emergency when it takes place. However, they see the potential of the application in alerting a degradation of the situation that might lead to an emergency.

This workshop confirmed our first design options and emphasized the importance of opening the management of patients at home to include all potential care actors. However, a discussion arose about privacy and security issues. Indeed, the information shared among the care actors is considered as a "shared secret" in a professional context. This situation is not totally conform to the privacy rules of the healthcare system but is tolerated by the patients and/or their entourage because it is easing the collective management of their case. This discussion highlighted the gap between privacy rules protecting patient data and the practical needs to integrate all care actors in the home care management of patients.

V. Conclusion and Further Work

We report how a study of a collaborative approach to home care provision in France led us to identify a potential to support this approach with ICT. The implications for designing a system supporting the collective management of patients at home are 1) providing a global vision of patients’ "trajectory", 2) enabling a discussion-based documentation, and 3) offering open indexation of documented information. These implications guided us to define three use scenarios and to build mock-ups, which were discussed with six care actors during a design workshop. First feedback from care actors confirmed the potential of the "CARE" application in enhancing collaboration among self-employed care actors. We are currently rolling out the first version of the CARE application, which will respect the current collaborative practices of the self-employed care actors and enable them to focus on maintaining the patient's quality of life at home. In the following months, we will observe how its use impacts the daily management of patient issues.

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