

Cooperating to build and manage patients' trajectories

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Abstract. The medical activities generate a huge amount of data that healthcare actors need to make sense of. Moreover, healthcare actors cooperate with the different participants in a patient's journey to offer coherent care. In this paper, we focus on the way healthcare actors request information, and how they use it for delivering care. We discuss the visualization of patients' trajectories as an effective way to deliver information about practitioners surrounding the patients and events happening in the care journey.

Keywords: visualization, patient trajectory, time-based data, cooperation

1 Introduction

The increase in the elderly and the vulnerable population called for multidisciplinary collaboration between the health actors [1]. The dispersed activities of those actors across the different organizations raised the interest in inter-organizational collaboration to organize the patients' care journey through the different settings [2]. The flow of information between the healthcare stakeholders presents the crucial element permitting the coordination of activities [3]. This circulation of information about the patients prevents cross boundaries breakdowns and helps create a solid base for an efficient communication and joint problem-solving [4].

To carry out their care activities, healthcare actors need to be constantly aware, both socially and temporally, of their cooperators and the activities they are holding [5]. Moreover, to identify the action to undertake, the healthcare actors need to preview the current and the past treatments and antecedents [6].

Health information systems facilitate storing and accessing patients' data on demand [7]. However, the medical activity generates a tremendous amount of data [3, 8–11] which is generally split through the silo systems used across the organizations [12]. Therefore, the effort to seek information and to get a sense of it escalated. Moreover, errors in the interpretation of data and diagnosis may derive from the burden caused by the analysis of this amount of information that may be redundant, peripheral, or unstructured [9]. At the same time, healthcare actors are generally obliged to make decisions based on the analysis of the compound patients' histories due to the different pathologies treated [13].

Researchers argue that data visualization is an effective technique to enable users to gain a quick insight into data from a simple glance [8, 10]. Indeed, presenting medical data in time-based representation is touted as a way to spot clinical progress, to support interpretation, and to better expose details [14, 15]. Therefore, in this paper, we discuss

the notion of patient's trajectory [4, 6, 15] as the best presentation of the medical data that may help healthcare actors following a patient's situation and act upon it.

Existing research shows that the effort to seek information and get a sense of it is a cooperative effort [16]. Also, a large core of researchers called for the consideration of those practices before designing information systems that promote cooperation [17, 18]. Following this position that urges considering the work practices before designing systems supporting cooperation [17–19], we claim that we need to shift the focus from creating health information systems (HIS) that enable the storage and access to data to designing systems that allow users to follow the temporal flow of information [3].

Our proposition to ensure cooperation between inter-organizational healthcare actors, is to offer them a system enabling them to identify who are their evolving collaborators in the care journey of a patient. Indeed, it would allow them to reach all the care actors around of their patient in order to get further information and to work collectively to make sense of the data that are collected. This kind of system could promote their cooperation by allowing them to build collectively the patient's trajectory in a timeline format (instead of filling in a form for instance). In this way, all the participants can add the piece of information they have, allow collective awareness, and then contribute to the care journey. To put our proposition in practice, we are currently following the deployment of a regional project aiming at implementing a system supporting cooperation among healthcare professionals.

The remaining parts of this article are structured as follow: We first present the ongoing project launched in ACOUNTRY to promote cooperation among healthcare actors. We then summarize the existing work on cooperation and data visualization in healthcare. Finally, we present our method and we build upon existing work to offer design implications for a visualization that enables cooperation.

2 CARE-O: a system supporting cooperative work

To develop the healthcare system and give citizens a better access to healthcare, the government of ACOUNTRY has launched a strategic health plan. The essential pillar of this plan is to promote cooperation among healthcare professionals working in hospitals, and the ones having private practices. This healthcare transformation program aims at increasing equal access to healthcare services for all citizens, reducing the costs by fostering prevention, and guaranteeing the quality, safety, and relevance of care [Anonymized for review]. To reach the objectives of this strategic plan, the government called for relying on digital tools to encourage cooperation and communication around patients to improve the care journey.

In this context, we are following the deployment and use of CARE-O, a system launched by a regional organization in ACOUNTRY. The system aims to provide healthcare professionals exercising around patients with chronic conditions a way to facilitate their acquaintance and communication.

CARE-O is a digital service platform that enables healthcare actors to communicate and cooperate with different colleagues working in different organizations to create a

coordinated care plan. Each functionality is represented in a different tab. The main features of the system are:

- The liaison notebook that permits users to write down all the information about what they have done with the patients.
- The directory of professionals that encompass the information about the different professionals taking care of the patient.
- An instant messaging service enabling users to exchange about the patient or professional subjects.
- A shared calendar that allows users to visualize the booked appointments.
- A lifeline view that enables to visualize the booked events and the reports added by the professionals after each appointment.

Through those functionalities, the system aims at enabling the creation of “care circles” around patients in which the different actors can initiate and participate in exchanges, sharing information and discussing cases to make collective decisions.

3 Related Work

3.1 Cooperation in healthcare

The healthcare system requires a consolidation between different actors and specialties to deliver the care [20]. This service delivery depends on the communication between those actors to discuss values, goals, preferences, and motivation and the linking between their interactions [21].

Moreover, to participate in the treatment, healthcare practitioners constantly collect medical information in their day-to-day activities [22]. Also, they are constantly seeking information to achieve a self-awareness of the different aspects of the patient's health and the different activities held by their co-actors [5, 6]. At the same time, they collectively work to assemble the small pieces of data they are achieving, each on their side, to create a big picture of the situation [4, 22]. This collective effort enables the healthcare professionals to build a common ground that engages them in a collective understanding of the cases and prevents breakdowns and conflicts [23].

However, healthcare actors work through different organizations and settings in public and private practices [2]. The geographical spread of actors raises interdependencies between the different organizations [4]. Indeed, this dispersion escalates the efforts to identify the availability of correspondents and to seek information.

Moreover, researchers debated the emergence of new organizations in healthcare where the cooperation occurs in an episodic format and where actors involved in the care work change constantly [22, 24]. In this work setting, known as knotworking [25], the challenge to launch conversations and request information is even more difficult to face. Also, the lack of a shared overview and common base to negotiate the goals and agreements present a steady stump [26–28] to attain the needed cooperation to deliver care.

Therefore, researchers argued for the necessity to design a flexible digital system that enables users to identify collaborators and launch communication both synchronously and asynchronously [24]. In their study, Bossen and Grönvall [22] presented a prototype with a timeline-based visualization that allows the members of a care hotel to see the different participants intervening around a patient and to reach out to them while following the care activities. In our case, we focus on supporting the cooperation among the different healthcare professionals belonging to a multitude of organizations. Our aim is to permit those different professionals to contribute to the building of the patient's medical trajectory. We argue that the time-based visualization of this trajectory will enable the care actors to identify the other actors, the different pieces of information to have a clear and general overview of the patient's case, and the information they need to add in order to ensure a collective awareness of the patient's situation.

3.2 Data visualization in healthcare

Computer-based visualization systems are tools that supply users with visual pictures of their data in order to help them making sense of it and make decisions accordingly [10].

However, illustrating the temporal information in healthcare is a challenging task [29]. Indeed, the medical system is known for its time-critical event, the pace shift in the action's priority, and the hardness to follow the drifts as time moves [29]. Moreover, there is a huge amount of information to consider, such as the treatments' steps, timing, duration, and frequency [30]. Also, designers have to consider how to present the flow of the patient record data according to each practitioner [7]. Therefore, visualization techniques are generally used to offer physicians a tool to merge all their medical data, to provide administrative staff an instrument that facilitates decision-making, and to support researchers in understanding populations' cases and medicine outcome [9, 31].

Much work proposed guidelines for the creation of visualization systems. Shneiderman proposed the mantra saying that the system needs to enable the user to see the "Overview first, zoom and filter, then details on-demand" [32]. Researchers also proposed the user intent model [33] that calls to supply users with a visualization that allows them to obtain the data they are looking for, in the context of their activity. Therefore, a list of principles was proposed to design useful visualizations, in particular the ability to choose the data to be included in a visualization, the possibility to reconfigure the visuals and change the representation of its items, as well as the ability to filter and connect the data [33].

Researchers also worked to define the most appropriate representation of the temporal data. They found that the appropriate visualizations combine numeric scales and color-coded and height-coded timelines. Indeed, this kind of representations help the users making senses of the data [34].

The flow-chart algorithms also named clinical algorithm's maps, are the most used techniques to create medical data visualization as they are judged familiar by the healthcare actors [30]. LifeLines [14] and PlanningLines [35] (see Fig. 1) are the most common visualizations to present medical data [30]. The first one allows the visualization of temporal intervals hierarchically by grouping the horizontal bars, representing

events and their duration, inside facets to facilitate the reading and the navigation [14]. The second one presents the potential doubts in the medical data through glyph representation that consists of two wrapped bars [35].

From a more general perspective, many recommendations have been established to ensure those visualizations are usable. First, the visualization needs to be intuitive so the user can get a sense of it even if they are new to the representation technique [36]. Also, the visualization must permit a flexible shift from a general view to a more elaborated view [6, 36]. Simultaneously, it needs to allow the user to merge different types of data to get a sense of their dependencies [36].

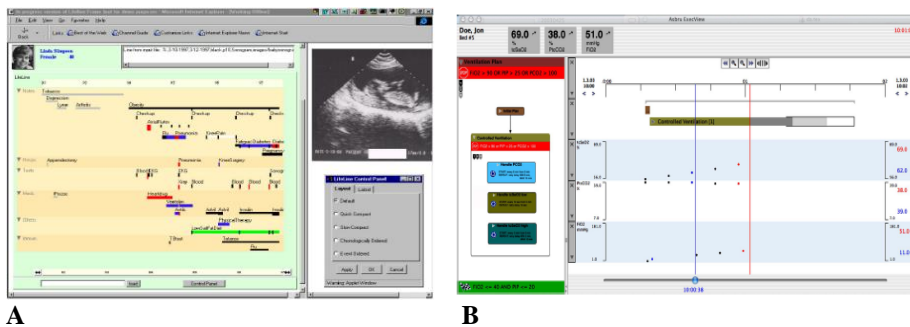


Fig. 1. A) LifeLines illustration of the patient record timelines [37]. B) PlanningLines used to modelize the execution of a controlled ventilation plan [30]

Through this literature review, we were interested to examine the different efforts made to create visualization systems in the healthcare domain. From our understanding, few studies focus on the use of visualization for a collective, as a way to support cooperation among actors working in different organizations. We aim to shed light on the power of the visualization of patients' trajectories for supporting cooperation among healthcare actors. We argue for its strength to enable users to build a collective awareness of the care journey participants and their activities. .

4 Method

The deployment of the CARE-O system provides a case for us to investigate how technology can support the cooperation between the different healthcare actors participating in the patient's journey. Therefore, we endeavor to observe how the system fits the work practices and to analyze the different feedback by the users, in order to design an effective visualization tool that aligns with the work practices and promotes cooperation by giving users an understanding of the patient's timeline.

To carry out our study, we attended three meetings in which CARE-O was presented by members of the regional grouping responsible for its customization and deployment to the team of the local hospital. During these meetings, we were able to get an idea of the features offered as well as the first users' groups solicited to test the system. They

decided in particular to start deploying CARE-O to healthcare professionals managing diabetic patients.

Following this identification of actors, we started scheduling and organizing semi-structured interviews with the different types of users participating in the care treatment of diabetic patients (diabetologist, endocrinologist, dietitian, nurses ...). These actors work across different settings in private practices and in the hospital.

The recruitment criteria were based on a list of actors who participated in the presentation meetings of CARE-O. We also solicited other actors who belong to the territorial professional health communities, because they have a long experience of cooperative work.

The different participants were contacted by phone and email. The interviews were held both in the hospital and private practices. Due to the covid-19 pandemic, many interviews were held through videoconference tools. In total, we conducted seventeen interviews, with three nurses, three dietitians, four general practitioners, and seven specialist doctors.

5 Patients' trajectories: visualizing for cooperating

From our first analysis of CARE-O, we identified some problems.

The first ambiguity that we came to identify is the inclusion of the users. Diabetics, and patients in general, are surrounded by different healthcare professionals, social and medico-social actors that contribute - each one according to their role - in the care journey. However, when a professional wants to create an account in CARE-O, the system verifies their identity based on the regional directory of healthcare professionals, which is not necessarily updated. Consequently, many actors who participate in taking care of the patient are left behind.

Secondly, ad-hoc conversations about patients are accessible only in the "professional social network", and are therefore not visible in the timeline representing the patient's trajectory. Therefore, as the actors evolve around a patient, a newcomer will not be able to identify the critical events when conversations occurred. Moreover, if an expertise is provided only once during a critical event, not being able to identify this conversation will lead to the ignorance of an expertise.

We have also identified an issue related to the high number of tabs used to navigate the different features. Time is a very critical aspect of medical activity [5, 38], therefore, we judge at first glance that navigating the different tabs to visualize and enter data is too time-consuming.

We also found that the presentation of documents in the lifeline requires a lot of efforts to navigate through it. For instance, one can identify when a report was shared, but not the kind of report. The interviewees mentioned this issue and suggested to gather documents according to a medical specialty.

Moreover, the main promoted feature of CARE-O is the professional social network that allows the exchanges among healthcare actors around each patient, and in general.

However, for more than thirty years, it has been raised by the computer-supported cooperative work (CSCW) community that computer-mediated communication is not sufficient to support cooperative work [39]. Systems supporting cooperative work need to offer features allowing to build social and activity awareness, and to be flexible enough to cope with the evolution of the situations [40].

Therefore, we argue that supplying the users with a time-based representation collectively created by those engaged users, will allow them to track the different participants and get in touch with them. Also, it will lend a hand to healthcare actors to follow the flow of information about the patients' care trajectories. Therefore, we suggest modeling a patient's trajectory in a visualization format. However, creating such a visualization raises challenges related to the access permission to the different levels of the visualization, and to the customization of items according to each practitioner.

Based on the needs to support cooperation, and the design principles that we have identified in the literature, enriched by our interviews with the care actors and our analysis of CARE-O, we have identified how the visualization of a patient's trajectory should complete a healthcare information system. It will:

- Allow each user, according to their specialty (physicians, pharmacist, social worker...) to access the visualization and bring along their experience and knowledge about the patient's case.
- Enable users to stay aware of the events occurring in the patient's treatment path, and the different documents shared by the care actors. Therefore, healthcare professionals will be able to get a "historical and here-and-now" overview of the situation [6].
- Enable users to stay socially aware of the other stakeholders participating in the care journey by allowing them to identify their names, profiles, their contact information, and their status (available or absent). This feature should allow establishing a trustful cooperation.
- Enable users to launch communication channels (both synchronous and asynchronous according to the collaborator status) to get in touch and seek the needed information. This exchange of information will be visualized through the patient's trajectory to allow users to follow the patient's evolution throughout the care journey.
- Enable the user to control the level of information that the other actors can visualize. This option will guarantee to each user the medical data confidentiality.
- Allow a user to request an access to a specific piece of data that may help them to make a diagnosis. This option will allow the evolution of access to medical information for each user according to the evolution of their participation in the care journey.
- Enable users to get a general overview or to focus on a specific event or document. This feature will enable users to pass from a thorough vision to a detailed one.
- Enable users to spot important events by highlighting them and sending notifications.

Through our proposal, we do not aim to substitute the electronic medical records that are already in use, but rather to design a system that fits them and can be added upon. We argue that using this solution will enable connecting the geographically dispersed users and support their cooperation across the boundaries of their organizations. Indeed, it should enable the collective building of the patients' trajectories that allow all the stakeholders to stay aware of the patients' management.

6 Conclusion

In this paper, we discussed the necessity to design visualization systems that fit with practices and help healthcare actors to collectively build a patient trajectory. We listed design principle for a visualization tool aiming at facilitating the identification of the evolving actors taking care of a patient and enabling the user to reach them out to get more information or make a collective decision. We presented CARE-O, a novel system deployed in ACOUNTRY to ensure cooperation among healthcare professionals. We reviewed the existing work on cooperation in healthcare and the techniques used to establish visualization for actors in this field. We then presented our preliminary work to understand how CARE-O is introduced to the users and the first issues that we observed that may hinder its appropriation and therefore the cooperation. Based on existing work and these issues, we finally presented the headlines of our proposal aiming to enable the healthcare actors to engage in a permanent effort to create the patients' trajectories in an intuitive format that allows the different actors to gain insight into the different cases.

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