

Designing healthcare systems with an emphasis on relational quality and peace of mind

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Abstract. In this paper we explore the challenges and opportunities of designing information systems in healthcare with an emphasis on informational needs of family caregivers and work practices of professionals. We focus particularly on the context of Nursing Homes (NH), where family members and care professionals are often faced with challenging situations that can affect their ability to communicate and collaborate effectively, and thus, leading to the episodes of conflicts or mismatch of expectations. We report on two sets of user studies with staff and residents' family members in four nursing homes, studying current information practices, factors that influence them, and explore design alternatives that could target identified issues.

Keywords: information sharing · health & wellbeing · information architecture · nursing homes.

1 Introduction

Shifting from *in-home* to *nursing home (NH)* care is a stressful transition for both older adults and their family members (FMs), with challenges ranging from the adaptation to a new environment to feelings of guilt and mistrust towards the NH staff [1, 8, 9]. In such situations, the NH staff plays not only the role of caregiver for the new resident, but has to carefully manage the interaction with the FMs as well and to some extent even coordinate care, as FMs often act as informal caregivers [2, 11].

Several studies [7, 10] investigated the communication between professional and family caregivers showing that *families need more information* and a greater involvement into the care process [3, 12]. Thus, the staff-family interaction and the kind of exchanged (or not) information is important for the wellbeing of the FMs. The way professionals communicate residents' health related information to their family may also significantly affect the work routine of the staff, increasing or reducing their (often very high) workload [15].

In this paper we study if and how technology can facilitate the staff-family interaction and information exchange, and which are the opportunities, critical aspects, and design considerations for doing so. Mediating and semi-automating the staff-family interaction via technology has a lot of potential in improving

the information exchange, increasing its transparency, and, therefore, providing increased sense of trust and control and reducing the care related workload of the staff. On the other hand, the personal interaction is often essential, and technology may worsen it, for example, by generating unnecessary worry and doubts in FMs when information is given without the proper context or explanation for the specific recipient.

Not surprisingly, discovering the most effective ways of mediating such relations and communications using ICT is recognized as a prominent research direction [6]. However, only few studies have explored how technology can support family caregivers and staff-family interactions [4,13], so there is a little knowledge on the actual *design* of technologically mediated communication [5,14].

In the following we investigate the information seeking behavior, information expectations of FMs, and factors that define them. We also explore professional communication practices and the rationale behind them to identify if and how technology can provide a contribution. An area of specific interest, as pointed to us by NH management, was the opportunity to selectively communicate information taken from the NH information system to the FMs, possibly endowed with explanations to make information easy to understand by non professional. Specifically, we aimed at answering the following research questions:

- RQ1: What are the communication practices, perceived satisfaction and mutual attitudes regarding information sharing in NHs?
- RQ2: What are the main design considerations in technology-supported information sharing between NH staff and FMs?

We proceed by designing a set of studies, first to understand the space of problem and opportunities and then to focus on specific cases and designs. We run the studies in several NHs throughout Italy, to also capture the different NH policies and attitudes related to staff-family interactions. As we will see, the results show us that there is a space for the introduction of technology but it is rather narrow: most of the initial beliefs, not only by non-professional like us but by NH management as well and even by family members, turned out to be wrong, although there are specific situations where technology can help.

2 Methods

After the preliminary phase of informal exploratory visits in 12 Italian nursing homes (NHs), two sets of user studies were conducted in four of them, which were approved by the University of Trento Committee on Research Involving Human Beings (Application N. 2017-003). All of the NHs use the information system that stores various health and wellbeing (HWB) information updated daily for each resident. Each staff member has a defined role and information access according to it within the system and in terms of interaction with relatives but only specific personnel is allowed to report on medical information to family members.

2.1 Study 1. Communication practices and relational attitudes

Focusing on emerging NH communication practices from the perspectives of the staff and family members, with this study we investigated information sharing and seeking strategies, how staff and family members deal with potentially sensitive information, and the role of technology in shaping interactions between them. Participants were recruited through the NH contacts, as to get a representative sample of family caregivers and NH staff. We conducted a total of 26 semi-structured interviews with relatives (17, 65.5 mean age and 59% of females) and professionals (9, 48.9 mean age and 55.6% of females) who volunteered to participate. Prior to the start of each interview, participants were briefed on the objective of the study and signed an informed consent.

The interviews with family caregivers focused on i) information seeking strategies, and ii) expectations and attitudes towards sharing of information by the NH staff. The interviews with the NH staff followed similar themes, with an emphasis on information communication practices and factors that shape them. Each interview lasted from 20 to 30 minutes and was carried out in full anonymity without the involvement of third parties.

2.2 Study 2. Design considerations for HWB information sharing

Building on the findings from the previous interviews, we explore the specific dimensions of information exchange by navigating NH staff through low-fidelity prototypes. Overall, 9 semi-structured anonymous interviews that lasted from 20 to 40 minutes were conducted with NH staff members (50.6 mean age and 66.7% of females). They were asked about relevance, importance, and views on preferred ways of communicating examples of NH routine events to the FMs using ICT tools. Events included medical (sodium and glucose levels and blood pressure), daily routine events (meals, sleep, and social events), and change of therapy. Questions and surveys were specifically focused around the implications of different *design alternatives* of medical and non medical events, granularity (single events and trends) and presentation (raw events, and enriched). Regarding each screen, staff members were asked to express their informed opinion on expected reactions of the FMs upon receiving information in a given way, as well as the readiness of staff to share using given design alternative.

3 Results

3.1 Study 1. Communication practices and relational attitudes

The qualitative analysis revealed specific communication practices and attitudes depending, primarily, on the type of HWB information, the role of the NH staff member, and the characteristics of the family member involved.

Communication practices of NH staff Critical events are communicated proactively by the NH, for instance, a fall is always communicated *immediately* by phone but not alarms for specific health parameters like high blood pressure. Instead, upon necessary therapy changes doctor reaches family members if approval is necessary. Information is usually provided by doctors face-to-face via fixed appointment and NH staff members calling based on their competence area, and test results and daily events are communicated mostly during the visits and by request based on the resident’s condition. Overall, staff communicates “trends” but not specific events, e.g., not if a person did not sleep last night but if he or she skipped several nights in a row, which is first medically evaluated. In general, for non-critical events professional judgment plays the key role in deciding what information to share.

Information seeking by family caregivers. We observed three distinct types of family caregivers based on their organisation and involvement: individuals (5), care teams (6), and proxies (2). *Individuals* are family members playing the role of primary contact with little to no involvement from other relatives. *Care teams* are groups of FMs sharing care responsibility and involvement. *Proxies* are persons hired by the family to visit the resident on their behalf and deliver them HWB information.

All participants reported interactions during NH visits as a primary mode of information exchange and phone calls as another common channel, which aligns with the communication practices reported by the NH staff. However, these communications were mostly initiated by NH staff, and in two cases daily visiting participants reported not even having that. No other modes of information exchange with the NH were reported. The importance of human contact was explicitly raised by three participants from the relational perspective, while those with the loved one in a critical condition stressed the importance of the appointments with the doctor.

Phone calls were reported as the dominating mode of information exchange and coordination among family caregivers, while individual carers reported little communication with the relatives who are not involved. Proxies mentioned updating family members via phone and email. All participants reported interacting with doctors and the responsible nurses for information exchange and, interestingly, four participants also indicated the resident as their main source of information. Family information needs were determined by the resident’s health condition and the level of trust on the NH. Family caregivers of residents in a non-critical condition showed either a more passive approach to information exchange, expecting the NH staff to inform them of relevant updates (e.g., “*I do not ask but if there is something [wrong], I guess they will tell me*”, F11, daughter) or contacting them when they observe an issue. Two participants with relatives in a more critical conditions preferred having access to all available information, but also reported negative past experiences with the NH staff.

General updates about the resident’s situation was the dominant theme in FMs information requests (“*What is good, what is bad. Information about the*

day”, F10, son), while two participants (F5, proxy; F11, daughter) explicitly mention social and relational information as the most important one. Some participants were interested in general medical information relying on what the NH could communicate and deemed relevant. This aligns with the NH staff interviews, where they reported that family members rarely asked or did not even know about specific medical tests.

Mutual views in relation to information exchange. Most family caregivers were satisfied with the NH communication, especially in case of stable or non-critical condition of the resident (“*My mother takes just one medicine, there is nothing much to discuss*”, F11). In two particular cases however, participants expressed dissatisfaction, which raised a series of communication exchange problems. One family caregiver from a care team highlighted episodes of confrontation where they considered the NH did not take the appropriate actions in a case of emergency. This participant indicated that they would like to see all the test results with the exact numbers: “*I would like to see the exact numbers. Because now, for example, my mother has diabetes. [Early this year] we had a meeting with a diabetologist in [a nearby city] to see the state of the diabetes. Back then, she was under control... And now, [NH staff] controls [the progress of diabetes] just once a day. It’s not enough. We asked the coordinator, how [my mother] is doing, and [the coordinator] told fine. What does it mean ‘fine’? At home we measured 3 times a day and now here nothing.*” The quote encapsulates several themes: the feeling that family was taking a better care of the resident at home; an apparent lack of trust in the NH practices shaped by the participant previous experiences; the involvement of third parties (experts) to verify the care practices; and issues related to expectations and understanding of the information provided by the NH staff.

Another participant expressed dissatisfaction with the doctor in particular, but for different reasons: “*He doesn’t update me [on my mother health condition] if I don’t ask, even if there are things to be communicated.*” This participant showed different expectations on the way information should be communicated by the NH staff, more proactively. As a way to manage the situation and uncertainty, the participant wish was to be informed if only things were fine (“*If they’d [keep me informed], it’s always good. It’s also good to know that everything is going well*”). On that last point, all participants were aware that calls from the NH have a sort of negative connotation as the “bearer of bad news”.

The **interviews with the NH staff** gave us a rich perspective into different dimensions they use to categorise and describe family members or “personas”:

- Reactions to updates based on level of worry, anxiety, and irrational requests;
- Care involvement or time spent with a relative at the NH;
- Views on the NH as a facility and services it has to provide;
- Care related knowledge and experience;
- Trust on practices adopted by the NH professionals;
- Feeling of guilt towards moving their relative to the NH influenced by cultural context and society stigma;

- Expectations towards amount and quality of work from the staff members;
- Amount of questions family members ask the staff;
- Health condition of the resident.

Personal relations are very important, how comfortable staff feels to communicate certain events directly or in a less detailed fashion. However, the knowledge of the “personas” is implicit and different communication strategies scattered through the NH staff.

3.2 Study 2. Design considerations for HWB information sharing

While participants agreed that introducing the technology-mediated information exchange with FMs could improve the communication, most of them were concerned of workload increase if information would have to be logged manually: *“Well, it could be nice and probably reassuring for the family members. I am asking you if a nurse who takes care of 102 residents during the night also has time to do this. I have doubts”* (P1, doctor).

Presentation of HWB information Discussing *raw* singular events, NH staff emphasized the importance of reference values or explanations, since family members may not know how to interpret them. However, they also noted that each case is unique and it is difficult to provide a generic explanation of the values: they depend on the specific health situation.

When shown the concept of event enrichment and explanation, which included smileys as a way to facilitate the interpretation of the event (negative, neutral, or positive), most of the professionals approved such summaries: *“If the program will let me [add]... also just a smiley, sad or red, green, anyway these are the signals that make relatives understand that there is more explanation, that it says that everything is going well”* (P4, nurse coordinator). However, one participant assumed that a smiley can also miscommunicate information: *“The family members know the resident, they can see things we do not see, if they see the red smiley and instead they know that it is not critical... [may be stressful]”* (P6, nurse coordinator).

Events communicated directly without translation by the professionals and presented only graphically could be perceived as “cold and distant”: *“This one [raw event without translation] is more technical, colder, more detached. Instead this one [raw event with translation], even more visually, it makes you immediately understand the situation”* (P8, social worker).

Reports over a period of time (trends) were seen as helpful both for family and staff members, for example, to detect deviations or verify past activities and monitor overall wellbeing or therapy. *“[On the trend of having meals] I think that a graph like this would nice to have for us too. To understand better”* (P6, nurse coordinator). Regarding the time periods for such reports, most of the staff members (5 out of 9) expressed the preference towards the weekly reports.

NH staff believe that retrospective information is less stressful for family members. However, in cases when family members were not informed about some negative events or certain dynamics in their loved one’s health, discovering

it later in trends may raise additional questions. “*They would also ask [the NH] if they were not informed in advance. In the sense that, if things are not going well and they did not know, seeing the trend like this, they would ask “How come?”. They would call immediately if they were not informed*” (P6, nurse coordinator).

Staff members were concerned that unlike trends, sending singular events would overload family members with excessive information: “*Rather than bombarding a [family member] with SMS everyday to say “today he went to the bathroom, today she walked, today he ate a beef steak”... [trend] is less invasive*” (P7, physiotherapist).

Expected preference and reactions Beside the qualitative evaluation of the design alternatives, participants were asked to assess each of the randomly selected screens in relation to two main factors: preference based on efficiency and simplification of communicating events, and expected reactions and stress level of FMs upon receiving information in a given way.

Efficiency. While talking to the staff members about their views that sending *translated events* to family members could make the communication more efficient, in 75% of responses participants agreed or strongly agreed that it could, while only 12.5% did not. As for direct communication of not translated events, 58.4% of responses were positive about increasing the efficiency of such communication and 37.5% were negative.

Simplicity. For the simplicity of communication with family members, 66.7% of all comments on the design alternatives were positive that translated events could indeed simplify information the interaction. Just 8.4% disagreed. As for the design alternatives of not translated events, in more than half of their responses, staff members stated that they would share the events in this way to simplify the communication, while in 37.5% of comments they did not think so.

Anticipated reactions by family members. As the response to receiving medical events, staff members would expect relatives to call the nursing home for the clarifications (occurred in 44% of responses), while the most expected reaction on daily routine updates would be asking during the visit, which was mentioned in the 38.5% of the responses.

Medical events were seen as more stressful for the FMs than daily events. In 29.2% of responses, staff would expect extreme stress in family members after receiving medical updates, while for the daily information it is just 4.2% and the most common – no stress at all (45.9%). Translation of events was considered as less stressful comparing to the direct communication. Expectations of light stress or no stress at all occurred in 79.2% of comments on translated events, while for the alternative it was 45.9%.

4 Discussion and Limitations

The results can be translated into design considerations to be taken into account when designing technology-mediated HWB information:

- **Tailor information sharing** to the “hidden” needs of the family members. Personalisation is known to increase user satisfaction but these needs are

not always evident to the FMs, which can be tackled by the NH staff by mapping the relative classification (from a communication perspective) into the technology to allow for this personalization.

- **Allow for family to staff communication**, to let staff know the care preferences and habits of the resident that the family member wants to be respected if possible.
- **Consider the modalities of information sharing**, in terms of proper granularity, contextual information, and explanations. Information on trends is considered useful by both staff and family as it avoids information overload. Contextual information such as condition of the resident and historical data can help understand the data, while explanations or “translation” provide useful narrative to properly interpret information, and give an additional human touch.
- **Provide scaffolded and contextual information presentation**, from summaries from the resident’s general condition to specific health parameters, giving family members the possibility to understand the situation at a glance and navigate it at their desired level of detail. Provide relevant information to the time and context, which implies thinking in terms of what information can be delivered through synchronous and asynchronous channels.
- **Provide tools to allow for coordination and information exchange** in family care teams, as well as tools to update the larger family within the limits of GDPR and related regulations.
- **Provide wellbeing and relational information**: while the interest in medical information varied, for basic questions it was overwhelming, such as how the resident slept or ate. Family members want to have the same information collected only partially by the NH today, and technology can help us gather it semi-automatically.

Overall, this work strengthens the idea that it is critical to consider both preferences of family caregivers and work practices of the NH staff in designing information services such as e-health systems. The studies have also reshaped the initial belief in communication of medical information from staff to family to the focus on i) bidirectional interaction, ii) social and wellbeing events, and iii) attention to personas and personalized explanations and contextualizations.

The study has several limitations and the most frustrating one was the difficulty in approaching FMs who visit rarely due to a variety of factors including the recruitment through NH contacts. However, this means that the results are only applicable to “frequent visitors”.

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