Designing Interactive Systems to Mediate Communication Between Formal and Informal Caregivers in Aged Care

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ABSTRACT Previous work has focused on designing and evaluating information communication technology (ICT) tools for improving the coordination, organization of care practices, and to a less extent, the mediation of care communication among various involved actors. Our work contributes to addressing this gap with a specific emphasis on aged care, exploring communication practices, related challenges and design principles that should guide the design of technology-mediated information sharing. We do this by conducting three sets of user studies iterating on design mockups of increasing fidelity, through semi-structured interviews and workshops with nursing home (NH) staff and residents' family members in four Italian nursing homes. The qualitative and quantitative results point to the potential of computer-mediated information sharing in this context, and to the importance (and challenges) of tailoring information and presentation to people's needs and traits, and assisting care professionals in managing the information flow and proper communication.

INDEX TERMS E-health, aged care, sharing, information architectures, information design, human computer interaction.

I. INTRODUCTION

Shifting from *in-home* to *nursing home (NH)* care is a stressful transition for both older adults and their family members, with challenges ranging from the adaptation to a new environment and lifestyle to feelings of guilt and even failure by family members, often combined with a lack of trust in how the NH staff will care for the loved ones [1]–[5]. In such situations, the NH staff not only plays the role of caregiver for the new resident but has also to manage the interaction - and coordinate care - with the family members, as these often act as informal caregivers [4], [6].

Several studies [7], [8] investigated the communication between professional and family caregivers, showing that *families need more information* about their loved ones and a greater involvement in the care process [9], [10]. Thus,

the staff-family interaction and the kind of information that is or is not exchanged is important for the involvement of the family members in the care process and their peace of mind. The specific way in which professionals communicate residents' health-related information to their family may also affect the work routine of the staff, increasing or reducing their (often very high) workload [11].

Previous studies have shown that mediating and semi-automating aspects of the staff-family interaction via technology can improve the quality, quantity, timeliness, and consistency of the information exchanged, and can increase transparency, thereby providing a greater sense of trust and control in the family member and reduce the staff workload in this specific aspect of their daily routine [12]–[14]. However, technology-mediated interaction may also generate unnecessary worry (for example when information is given without the proper context), which in turn results in *more* interactions and workload for the staff. Furthermore, in-person interaction

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is often considered important or essential by family members [15], [16]. In general, it is crucial to analyze what information about a resident is relayed to family members and how it may affect the caregiving context and influence how various stakeholders behave, "both in relation to the technology itself and co-located people" [17].

Not surprisingly, discovering the most effective ways of mediating such relations and communications using ICT is recognized as a prominent research direction [18]. A simple indicator that interactions could be improved in this domain is that only about 50% of all information recalled from consultations is in fact remembered correctly [17]. As Williamson et al. highlight, a significant part of out-of-home caregivers already use health IT in their caregiving activities, and there is a big interest among "technology nonusers" in using it in their caregiving responsibilities [19], which however does not always result in their adoption. This mismatch may be explained by barriers such as "perceived cost, potential resistance by the care recipient, and a lack of user-centered focus in the design and implementation of current long distance caregivers (LDCs) systems" [19, p.1961].

However, only a few studies have explored how technology can support family caregivers and NH staff-family interactions in residential aged care scenarios [17], [20]. As a result, we know very little about the *design dimensions* of technologically mediated communication that targets the different types of family caregivers [21], [22], both from information architectures and interactive or visual points of view.

The essential starting point in coming up with the information architecture of such mediation is to study the preferences of the actors involved in the care process, their sharing strategies, adopted communication channels, their values, priorities, skills, and resources. These factors dictate whether the information could and should be communicated and the types and the attributes of information to be shared.

On a more practical level, the goal of information visualization is to support information exchange through the use of external visual aids, which becomes particularly useful in the contexts of sensitive and complex information exchange such as aged care context [18]. Tools can act as visual cognitive aids to enhance understanding and communication of complex health cases and large or frequent amounts of health related data [23], [24]. Although technology and visualizations are already used in aged care contexts, the opinions of involved actors on the design and the effect of such tools on users' care related behaviour and emotional state need to be investigated.

In this paper, we investigate the information practices of formal and informal caregivers, information expectations and reactions of family members, as well as the factors that define them, to then derive a set of design challenges and recommendations that should guide the design of information sharing and communication in aged care. We focus particularly on relevant aspects of health and wellbeing information (HWBI) in this context, such as information management, information flow and presentation, and how the sharing of this information

can affect formal and informal caregivers. An area of specific interest, as repeatedly pointed to us by NH management, was the opportunity to selectively communicate information taken from the NH information system (storing all sort of information, also related to health and wellbeing of guests at a high level of detail) to the family members, possibly endowed with explanations to make information easy to understand by a non professional.

Specifically, in our research we aim at answering the following research questions:

- **RQ1: What are the main design challenges in enabling computer-mediated information sharing of HWBI in aged care?** With this RQ we focus on understanding the information practices and relational attitudes of formal and informal caregivers, the existing and new challenges in moving those interactions to a digital channel.
- **RQ2: What design choices and principles should guide the design of HWBI sharing in aged care?** With this RQ we aim at identifying sensible design choices - spanning information architecture, information flow as well as presentation aspects - that should guide the design process, while also contributing with a set of concrete design recommendation.

Answering these questions is tricky: as we discovered, while in general caregivers state that they are in favor of information exchange and greater transparency when we drill down to details and discuss specific examples we uncover various forms of resistance [25]. For this reason, 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 specific designs. We run the studies in several NHs throughout Italy, to also capture the different NH policies and attitudes related to staff-family interactions.

We report on three sets of user studies with staff members and residents' family members in four nursing homes, studying current information practices and their impact on the individuals and workload. We then build on successful practices and challenges and explore strategies to incorporate them in the design of current healthcare systems. Among the main findings, we identify that tech-mediated information sharing should i) allow formal caregivers to adjust communications to the profiles (or personas) of the information recipients, ii) facilitate the personalization of what to receive, as it might not always be easy to know or anticipate what updates informal caregivers would need - although the consensus was not to focus only on (critical) medical data but also wellbeing information, iii) allow staff members to use their knowledge in deciding whether information should be shared, when, and in what way - to the possible extent considering their resources, regulations and level of mutual trust; and in terms of presentation v) we also observed that design aspects such as modality of presentation, level of abstraction, and the use of comprehension aids, have a complex relationship with medical literacy of family members, their familiarity with the type of shared information and purpose of the visualization.

In the following, we provide an overview of the context, introduce the methods and results to conclude with a discussion highlighting the main challenges and design recommendations for computer mediated information sharing in aged care.

II. BACKGROUND

Technology has been largely explored as an instrument to improve the delivery and quality of care in health and care facilities in aged care. Previous work has focused on designing and evaluating ICT tools for improving the coordination, organization of care practices, and to a less extent, the mediation of its communication among various involved actors.

A. ICT MEDIATION OF COMMUNICATION IN AGED CARE

One of the recent studies on health information exchange (HIE) technology is the study of Alexander et al. [26] where they report on the HIE preparation in 16 U.S. nursing homes (NHs). Their findings paint a picture of the current status of technology deployment to support information exchange, describing the presence of some care support systems but with little integration with external entities. In the conditions of the lack of human and technological resources that is a recognized problem in aged care context, they underline the importance of supporting information flow between healthcare providers. Douglas et al. [27] also discuss the barriers to exchange information using aged care service systems emphasizing that their uptake strongly depends on understanding the workflows and processes, as they have a strong impact on information technology design. Besides the necessary high rates of information exchange among care staff, the communication of professionals with family members of the NH residents is an important part of the care process. An extensive body of literature shows that it contributes into the workload of the staff, which might not always be recognized, and affects the quality of care and satisfaction with provided care services both for older care recipients and their family members [8], [28], [29]. Overall, technological solutions are proven to support this communication and make it more efficient [20], [30].

Patient portals are a right step in breaking information silos to involve patients but also their family members. Being seen as a "hub for families" implemented through "proxy access" [31], an e-access to health and wellbeing information (HWBI) provided by most of them may enhance the. partnership between formal and informal caregivers of patients and better inclusion of into care process [32]. Caregivers believe that systems such as patient portals could reduce caregiving stress by providing better access to the health data of their loved ones [31].

In the same vein, previous work has explored televisits and distant caregiving [19], technology to improve the relationship between family caregivers and NH residents [33], [34], and technology-supported education of family caregivers to enhance communication with NH staff [35]. In their systematic literature review, Chi and Demiris [20] also investigate telehealth interventions from the angle of their usefulness to patients' family caregivers. Review outcomes provide strong evidence that using telehealth tools among informal caregivers result in less anxiety and improved coping. Moreover, while being proxy for the patient, the availability of tools providing access to information is particularly important. Findings also suggest that ICT medicated support can provide efficient care and save travel costs for caregivers of long-term care patients. Similar interventions with carers of older adults have also shown benefits, for example, in spousal carers [36], [37] – the carers in this scenario being older adults themselves.

Georgiou et al. [38] also studied information exchange processes and the role of technology in seven Australian long-term residential facilities. Their qualitative study points to three main tasks associated with information: storing and managing data, supporting decision making and communicating data; highlighting how poor information exchange can affect the quality of care. The results stress the need for effective communication technology support for continuity and organization of care, especially regarding accessibility and legibility of information. Illustrating that, Thomsen et al. explore technological support of the consultations between healthcare personnel, cancer patients and their relatives as they happen during the treatment of cancer in a hospital department of oncology [17]. Their findings indicate that using ICT tools among medical staff does not mean being experienced in applying them in communication with patients and their family members

These works and others (e.g., [27], [39]–[41]) provide valuable insights into how technology can support family caregivers but also point to scant involvement of family caregivers technology-mediated information flows, and highlight the need for better ICT-based support for information exchange in residential care.

B. PRESENTATION OF HEALTH AND WELLBEING INFORMATION

A vast literature has devoted to exploring visualization for self-reflection and behavior change [42]–[44], health risk prediction [45], and making medical data more intuitive [18], [46], [47], and even medicine information (leaflets) more understandable to consumers [48], [49]. In the following, we review some prominent examples related to HWBI presentation to informal caregivers.

The exploration of visualization formats for presenting HWBI to consumers has been explored in recent works. Desai et al. [18], conducted a series of studies to systematically explore different presentation approaches and attempted to identify visual features that resonate with individuals suffering from diabetes. Emphasizing that the effective usage of HWBI strongly depends on being understood by non-expert users, they identified that efficient medical data communication practices could have a significant effect by "clarifying mental models of disease, internalizing health risks and consequences" for the members involved in the care process [18].

TABLE 1. Summary of studies run in this project.

Study	Method	Instrument	Participants		Objective
			FM	Staff	
Study 1	Semi-structured interviews	Questionnaires	17	9	Communication practices, information access and relational attitudes
Study 2	Semi-structured interviews	Mockups	-	9	Exploration of design aspects of information sharing with formal caregivers
Study 3	Workshops (2)	Mockups	12	-	Evaluation of design alternatives with informal caregivers in terms of comprehension and expected reactions

Tao et al. [47] explored four visualization formats based on bar charts, which included name of test, exact test value, unit of measurements and normal ranges, for blood pressure and blood glucose. The study explored the basic bar chart visualization, color-enhanced visualization with and without reference text, and personalized information in terms of average value based on the participants' traits (age, sex). The results pointed to visualization format not affecting participant performance but having an impact on the user perception of the information. In terms of preference, the personalized presentation was the most preferred format. Although these works focus on an individual's own HWBI in a different context, they stress the importance of the information presented in facilitating understanding and shaping users' perception.

Healthcare settings and formal caregiving have also been scenarios for exploring information presentation. Zhang et al. [50] demonstrate the use of visual information displays within a healthcare informatics application, they identified that most existing electronic medical record (EMR) systems make it difficult to get a quick assessment of patient status. Belden et al. [51] identified a number of reasons why the adoption of EMRs has lagged behind expectations, and established the following usability design principles: (a) minimize caregiver cognitive load, (b) design for UI simplicity, naturalness and consistency, (c) make colour meaningful, and (d) preserve context. For instance, they emphasize the importance of color in conveying meaning to the user, such as all aspects of information presentation, navigation, or differentiation of screen areas. In their study with formal caregivers of long term care residents, Stevens et al. [52] designed a tablet based visual analytics tool that collects, structures, and visualizes healthcare data where they used "green/yellow/red voting system, with green indicating improvement, yellow stability, and red decline" to allow caregivers to consistently assess resident's status. Although these works support the fact that formal caregiver can also benefit from good information presentation, there is little about how they can contribute to making information more usable for informal caregivers (or consumers of information).

Information presentation for informal caregivers of older adults has been a topic within ambient assisted living. Davis et al. [53] illustrates how ambient intelligence can be used to provide peace of mind and display a qualitative sense of a senior's daily activities to caregivers concerned to foster the sense of connectedness through ambient displays. The same team also investigated an intelligent lighting system in AAL context to communicate activity levels of older adults to their family caregivers [54]. Study participants preferred 3 different colors as simpler visualization to combinations of

hue and brightness that was more informative. In the context of smart home monitoring, a systematic literature review of information visualization stressed that informal caregivers (e.g., spouses or friends) tend to face the same limitations as the old care receivers and therefore in interacting with HWBI presentations, and that there is a lack of studies focusing on delivering complex information in different forms. These works though focused on supporting independent living – and therefore on individuals and caregivers with different needs – point to the importance of simplifying information and in exploring presentation formats supporting this.

These works contribute to the efforts in making HWB information more intuitive and understandable, especially to non-experts. However, the information sharing and presentation requirements when it comes to sensitive scenarios, with a strong relational component, and targeted at family members and not patients, is still a largely unexplored topic.

III. USER STUDIES

We run a set of interviews and design activities as depicted in Table 1 intending to understand the context, explore the design space, and incrementally evaluate design choices related to information sharing between formal and informal caregivers. The questionnaires, the semi-structured interview guides as well as the additional examples of the mockups used in the studies are provided as the supplementary materials to this paper.

Three sets of user studies were conducted in four different nursing homes (NHs) in two regions in Italy. Each institution selected a variable number of family caregivers and staff members who signed an Informed Consent. The studies were approved by the University of Trento Committee on Research Involving Human Beings (Application N. 2017-003).

During every NH visit, there were at least two researchers from our research group conducting the interviews, one of them mainly for taking notes and assisting the lead researcher. Visits were scheduled and always accompanied by a gatekeeper; either the director or the chief nurse. All studies were carried out at the NHs in places deemed private and comfortable by the researchers and NH contacts. We paid peculiar attention towards the people involved, avoiding any questions or situations that could cause distress to the participants, in order to guaranty an efficient and respectful data collection. Prior to the start of each interview, participants were briefed by the researchers on the objective of the study and signed an informed consent, which included a written and verbal consent to record the session.

The recordings were transcribed by an Italian native speaker and, along with the notes from the sessions, were put

in an electronic document for later analysis. The quantitative information in questionnaires were loaded into a spreadsheet. All personal information information in the spreadsheets and transcripts was coded and anonymized.

The qualitative data was analyzed using thematic analysis [55]. Two researchers individually identified the main themes for each of the main questions of the questionnaires. After classification, the researchers combined the themes via consensus. All quotes used in this paper were translated to English (and reviewed) by Italian-English speakers.

In the following subsections we give an overview of the objectives and instruments used in each user study. We include a more detailed study description in the following sections when presenting the results.

A. STUDY 1. COMMUNICATION PRACTICES AND RELATIONAL ATTITUDES

The first study focused on the RQ1 and aimed at exploring emerging communication practices in NH settings from the perspectives of NH staff and family members of the residents, so as to derive meaningful design challenges and dimensions to focus on. We did this through a series of semi-structured interviews with family members and NH staff.

The interviews with family caregivers focused on i) information seeking strategies, ii) expectations and attitudes towards the NH staff in relation to the sharing of information, and iii) reactions to different type of HWBI. The interviews with the NH staff followed similar themes, with an emphasis on i) information communication practices, and ii) factors that shape their practices and communication strategies.

B. STUDY 2. DESIGN CONSIDERATIONS FOR HWBI SHARING

In this study we build on the findings from the previous interviews and explore the emerging design dimensions of information exchange by navigating NH staff through low-fidelity prototypes. The goal is to identify the design dimensions that shape the design space of health and wellbeing information sharing (RQ2) focusing on relational quality and peace of mind of the stakeholders. This study focused on NH staff as we considered more appropriate to run the initial set of ideas through care professionals to understand the possibilities of sharing HWB updates and avoid unintended reactions from the family members.

Using mockups to drive the discussion, staff members were presented with the idea of ICT mediated dissemination of HWBI to families of the residents. Questions were specifically focused around the implications of different *design alternatives* characterized by type of event (medical, non medical), granularity (single events and trends) and presentation (raw events, and enriched). The designs alternatives resulted from the combination of such dimensions and were shown to the participants in a randomized sequence.

NH staff members are the main actors who would have to take care of the workload created by ICT based dissemination of information given the interest in such services from the side of the family members. Thus, their opinion, combined with their experience communicating information to family members was considered primary in getting early feedback in the design.

C. STUDY 3. INFORMATION PRESENTATION AND IMPACT

The aim of the third study was to evaluate interactive prototypes incorporating the insights from the previous studies in order to derive design recommendations - with a focus on information flow and presentation - and assess the potential impact on family members. We run this study with one of the target groups of end users, namely family members of institutionalized seniors, using an empirical evaluation method in a form of two workshops. For this study, we opted for a predominantly qualitative user study, complemented by minor quantitative questionnaires, since we judged that broad and deep insights were only attainable through observation in combination with an open and flexible discussion format, as it has previously been shown in previous research [56], [57].

The interactive mockups feature a combination of *type of trends* (medical or daily trends), *modality* of the presentation (visual or narrative), and strategies for *event enrichment* (translation, metaphors and value ranges). The analysis of the mockups was based on comprehension of events and potential reactions, also in light of potential information navigation paths.

IV. STUDY 1. COMMUNICATION PRACTICES AND RELATIONAL ATTITUDES

The first set of user studies was mainly set to explore information practices and mutual attitudes of formal and informal caregivers regarding information sharing in nursing homes.

Methods: Participants were recruited with the help of the nursing home contacts, so as to get a representative sample of family caregivers and NH staff (e.g., different roles). We conducted a total 26 semi-structured interviews with family caregivers (17, 65.5 mean age and 59% of females) and NH staff (9, 48.9 mean age and 55.6% of females) who volunteered to participate. Each interview was conducted by a native Italian speaking researcher with background in sociology (with experience in running studies with vulnerable populations) with the assistance of an HCI researcher.

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

A. COMMUNICATION PRACTICES OF NH STAFF

Critical events such as falls and going to the hospital are communicated proactively by the NH. For example, in the unfortunate case of a fall, the event is always communicated

immediately by phone. Alarms in relation to the specific health parameters, for example, blood pressure outside normal ranges, are usually not communicated. Instead, the doctor makes the necessary therapy changes and reaches family members if approval is necessary. Information is usually provided by doctors face-to-face via fixed appointment (unless there is an emergency), and with very little (to not at all in some cases) communication with family members over the phone. NH staff members call based on their competence area and cannot communicate the information they do not have access to.

Other types of information, such as test results and daily events are communicated upon request and mostly during the visits. Requests are mostly based on the condition of the resident. For example, for some family members the fact that a relative has eaten is very important, so skipped meals make them very worried. Overall, they communicate "trends" but not specific events, e.g., not if a person has skipped a meal but if the person is eating less in general. This is because in some cases they should first do a medical evaluation to understand the reasons, but also because NH staff finds that there is no sense in communicating events that might not be relevant anymore by the time they are received.

In general, for non-critical events, the professional judgment plays a main role in deciding what information to share: *"It depends from case to case. In the sense that if the parameters are outside of norm, I need to see. If things are very bad and worrying, I call the family members. Otherwise, no, we communicate it at the next appointment when we meet"* (P1, doctor).

It was consistently recognized that communicating with family members required a particular set of skills, and that staff who communicates with family members should have skills to do so: *"It is important to know how to communicate, those who can do it well should do it, otherwise, not communicate. There are ways of communicating the information, special words that should be used, it really matters how the information is delivered"* (P2, nurse). *"I would prefer just some of the nurses to communicate information to the FM, the ones who know how to do it"* (P1, doctor).

B. INFORMATION SEEKING BY FAMILY CAREGIVERS
We observed three distinct types of family caregivers among the participants based on their organization and involvement, which affects information exchange: individuals (5), care teams (6) and proxies (2). *Individuals*, makes reference to family members who play the role of primary contact and who reported little to no involvement from other family members. *Care teams* are a set of family members that share the responsibility and involvement. These teams were composed by children of the resident, siblings of the resident, or a child of the resident with his/her core family (partner and grandchildren). *Proxies* are persons hired by the family to visit and spend time with the resident on their behalf and rely information on their status.

All participants reported on-site interaction during visits as the main mode of information exchange. This is not surprising as the majority of family members visits twice a week or more. Interactions via phone were also mentioned as a mode of communication, which aligns with the information exchange practices reported by the NH staff. However, for the participants these communication were mostly initiated by NH staff, and in two cases participants even reported never having called or received a call (participants visiting on a daily basis and with the loved one in no critical condition). No other modes of information exchange with the NH were reported. The importance of human contact in communicating was explicitly raised by three participants from the relational perspective (*"They are people who take care of my mother, it would be nice to see them, to talk to them. And the same for them, I believe that they would like to see the family members,"* F1, daughter), while those with the loved one in a critical condition stressed the importance of the appointments with the doctor.

Most of the time the communication between nursing homes and family members of the residents happens during the visits, for the urgent cases NH staff calls to the family, usually the primary contact. For non-urgent but particular cases, family members come to the doctor's appointment.

When it comes to communicating among family caregivers, phone calls was reported as the dominating mode of communication. In care teams this is used to coordinate and update each other on information collected by the one visiting (*"we are always on the phone with each other [among sisters],"* F3, daughter). Individual carers report little communication with the direct family members not involved – though it was mentioned in one case occasional updates to the larger family. Proxies mentioned updating family members via phone and email.

As for the information source, all participants reported interacting with the NH staff for information exchange. This includes interaction with the doctors and the responsible nurses. Interestingly, four participants indicated the resident as their main source of information: *"My mother is the first one to tells me news. For example, that she did not sleep well last night. I ask staff only if there are problems"* (F10, son). *"My mother knows better, so she calls and tells us herself [about her condition]. If there is something, it is her who informs us. Because she knows better about her "values". She asks herself [to the staff] what are her values, what medicine they give her"* (F1, daughter).

The Web also emerged in three cases as an additional source to investigate about health-related information, e.g., *"If tomorrow I am told that he has herpes, of course I will search about it [on the Web]. Also if I don't know something now [about current illness]"* (F13, sister).

In terms of the general interest and need for information exchange, we observed different approaches determined particularly by the critical or non-critical condition of the resident 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 (e.g., *"yesterday I came here and I saw that [my mother] did not have socks on... then, I asked [the staff] to put some socks on her because she is a lady who is always feeling cold,"* F0, daughter). Two participants with relatives in a more critical conditions showed more interest in having access to all available information, but also reported negative experiences and differences with the NH staff (as we will expand on the next subsection).

When asked about the type of information they usually request, general information about the situation of their relative was the dominant theme (*"What is good, what is bad. Information about the day,"* F10, son). One participant even pulled out his mobile phone to show us the Fitbit[1] app as an example of the level of detail it collects about sleep, and mentioned that he did not need all that information, just to know if his father slept well in general (F12, son). Two participants (F5, proxy; F11, daughter) explicitly mention social and relational information as the most important one (*"[I want to know] about the mental state, if she interacts with others, if she communicates... I had my mother sick at home too and the most important for me was her mental decay. I would like to know if she interacts with others,"* F5, proxy).

Some participants mentioned their interest in medical information but were not precise about the specific parameters, and so their interest was leaning more towards what the NH could volunteer and deemed relevant. Indeed, one participant mentioned explicitly that she was not aware of the type of medical tests they were running. This aligns with the interviews with the NH staff, where they reported that family members rarely asked about specific health parameters, and that most were not aware of the specific tests.

C. MUTUAL VIEWS IN RELATION TO INFORMATION EXCHANGE

Most family caregivers reported being satisfied with the communication with the NH. One of the main contributing factor in these cases was the stable or non-critical condition of the resident (*"At this point therapy is quite consolidated"*, F12; *"My mother takes just one medicine, there is nothing much to discuss"*, F11). In two particular cases however, participants expressed dissatisfaction with the NH staff, which raised a series of communication exchange problems.

A participant who, along with other family members (care team), is involved in the caring process of his loved one (resident with diabetes and heart problems) 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:

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[1]Fitbit is a commercial fitness tracker: https://www.fitbit.com/

"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. Now, for about a month, we give a her a medicine [for her diabetes], the minimal dose. First, it went up and then down. 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 above quote encapsulates a couple of themes. First, the feeling that family was taking a better care of the resident at home, which was raised at other points during the interview (e.g., *"At home we had a diary where we put all the measurements with meals: breakfast, lunch, dinner, then at 10 p.m. and at midnight, to be sure. 5 controls at home"*). Second, an apparent lack of trust in the NH practices, shaped by the participant previous experiences. Third, the involvement of third parties (experts) to verify the care practices. Fourth, issues related to expectations and understanding of the information provided by the NH staff, a point that later followed up with a specific example (*"For example, yesterday she did a test of 'sodium', and it was outside of the normal range. [The NH staff] gave her a medicine for that. They didn't explain, they said 'no sodium, we start the therapy for sodium'. It would be useful to know the explanation"*).

Another participant (individual carer, brother not very involved), expressed dissatisfaction with the doctor in particular, but for different reasons: *"I am not very satisfied with the doctor because [with him] I cannot express myself. He doesn't update me [on my mother health condition] if I don't ask, even if there are things to be communicated. I would prefer to have more appointments, [but] he never calls. In 4 years I've had 3 calls. For the medical tests, they also don't tell about it, I don't even know they do them."*

This participant showed a different expectation in terms of how information should be communicated by the NH staff, wishing for a more proactive communication. The quote also highlights some more introvert personal traits that might get in the way of a more fluent communication, as the participant also raised several times during the interview (*"I don't like to ask. When I visit, they usually tell me. I don't like to keep asking."*, *"I don't like to ask and disturb much."*). As a way to manage the situation and uncertainty, the participant wish was to be inform if only to be told that 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 are to communicate critical events, so there is a sort of negative connotation around these calls as the "bearer of bad news". One participant exemplified this in a personal experience: (*"I heard someone calling, I run to the phone, it was the number from [the NH]. The nurse tells me not to be afraid, 'it's just your mother who wanted to talk'. Before they never called, [to me] it was an emergency"*).
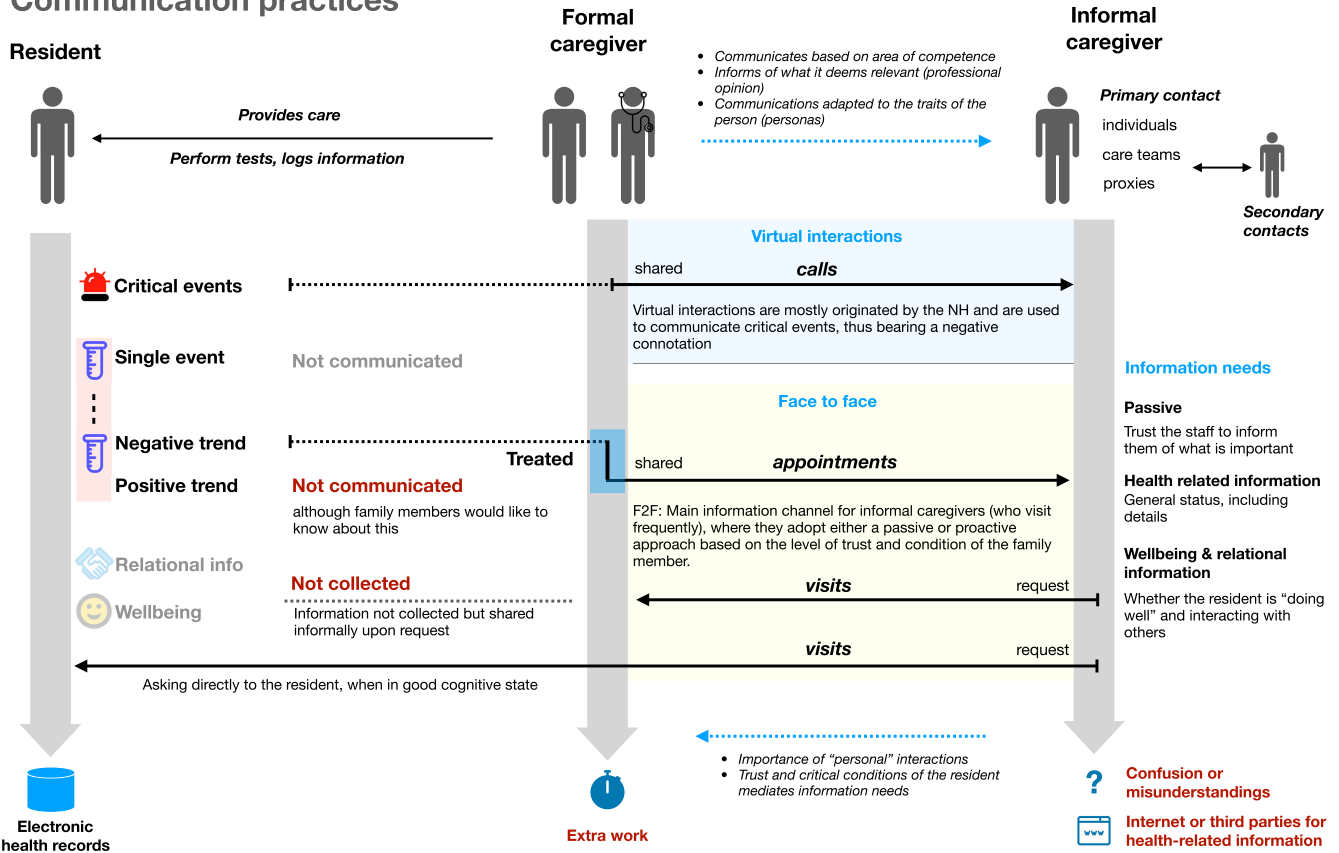
Communication practices

FIGURE 1. Summary of communication practices as of today.

The **interviews with the NH staff** gave a us rich perspective into different dimensions and traits they use to categorize and describe family members. The knowledge about these traits are used by the NH staff to accommodate their communications with family members. In Table 2 we report on the "personas" that emerged from our thematic analysis of responses to the following question: "*If you had to group FM into macro-classes based on how they react, how many classes and which classes would you define? Please, describe each class*". While current accommodation strategies might not be optimal, they point out to the need of effective communication practices to deal with the diversity of the family member population.

The knowledge of these characteristics is however implicit knowledge, and along with the different communication strategies, scattered through the NH staff. This translates into not all NH being able to properly communicate with family members. Thus, personal relations are very important: based on how well staff knows a FM, they communicate the events accordingly. It matters what are the personal relations, how comfortable they feel to communicate certain events directly or in a less detailed fashion.

Another related challenge is keeping track of what has been communicated and to coordinate communications in general. Family members tend to inquiry multiple staff members, and

discrepancies in communications as well as different views on whether certain information should be communicated at one point can reflect negatively in the relationship between the two actors ("*it has happened to me in the past that family members have called and asked 'How is my [older adult relative]? I mean, I don't give information if I don't know the relative personally.. it sounds bad, inhuman even, but..*", S9). Currently, shift handovers serve as the main coordination point for the staff, but these are centered around practices and treatments and not communications.

D. LESSONS LEARNED
In Figure 1 we summarise the main communication practices that emerged in the interviews. We highlight some key challenges below:

- **DC1. Sharing medical and wellbeing data**. Electronic health records are centered around health-related information, which is readily available for (digital) sharing, but lack relational and wellbeing information that is in the interest of informal caregivers. Sharing of this type of information is limited to visits, where information is communicated informally.

- **DC2. Dealing with granularity, connotation and perceptions on sharing**. Critical events are communicated as they occur, usually via phone. Other types of single

TABLE 2. Characteristics of family members that influence the way information is communicated by NH staff.

Aspect	Description	Implication for HWBI communication
Reactions	Personas based on reactions to receiving updates: e.g., level of worry, anxiety, irrational requests;	Knowledge about potential reactions frame the entire discussion and help staff reduce conflicts or unnecessary stress ("*Some FMs understand that a resident may fall, some don't, and it may become a conflict point,*" S5)
Care involvement	Personas based on care involvement or available time to spend with their relative at the NH;	This affects not only the way but how much information is shared ("*there are some FM that don't want to know about the [deterioration], they want to be called when it's over..*", S2)
Views about service and care	Personas based on views about the NH as a facility and services it has to provide them with;	This helps staff manage expectations in terms of treatment, procedures and role of their service ("*The there are those who think it's a 5 stars hospital*", "*those who think they pay and everyone owes to them..*")
Care knowledge	Personas based on care related knowledge and experience;	This determines the level of detail and language that is used in the communications ("*I am against talking in technical terms with the FMs because they could understand that some things are critical even when they are not..*" S1)
Trust	Personas based on trust on practices adopted by the NH professionals;	The general level of trust towards facility might affect comprehension of the communicated information, regardless its connotation or objectiveness ("*There are those who trust unconditionally and those who don't even trust scientific tests and bibliographic information,*" S3), or may as well result into the absence of questions ("*Those who trust 100% and don't come to the doctor [to ask],*" S5)
Feeling of guilt	Personas based on feeling of guilt towards moving their relative to the NH;	Knowing this susceptible group helps not only in accommodating the communication but in managing the type of involvement ("*Others have problems of the sense of guilt. They desperate when there are real problems, they come to the NH all the time.*" S3)
Inquiry level	Personas based on amount of questions family members ask the staff;	Knowing the inquisitive nature of family members can help NH staff prepare their communications to reduce further communications ("*To deal with those who are over controlling, I always tell [other NH staff] to agree, to say "you are right, I will solve this problem".*" S7)
Condition of relative	Personas based on health condition of the resident.	This affects the tone and amount of contextual information provided so as to manage expectations, in critical cases a long term process ("*So we try to prepare them for the moment.. It's not like we call them and say: 'hello, how are you? Your father is going to die in 2 days'. So there a gradual meditated change.. *")

events are not communicated until there is a trend. These trends, mostly negative, are first treated and then communicated to the family members during appointments. Positive trends are usually not communicated. For this reason, interactions initiated by the NH usually have a negative connotation.

- **DC3. Delivering personalized and relevant information**. Trust is very important and can give flexibility to the information sharing process: it gives control of information flow to the professional caregiver wh can use their professional judgement in deciding what information to share. Informal caregivers on the other hand might not be sure or be overwhelmed in deciding what specific information to receive.

- **DC4. Reducing misunderstandings and unnecessary distress**. How information is communicated is important as it can lead to confusion and misunderstanding. In this regard, knowing the family member characteristics (personas) can help in accommodating the way information is shared.

- **DC5. Improving communications while not increasing the workload of formal caregivers**. Formal caregivers are already busy and interactions with family members add to their workload. Solutions should look to alleviate this problem and not to cause additional workload.

- **DC6. Reaching out the larger care network**. Informal caregivers acting as primary contacts are in some cases

the forefront to a larger care team requiring coordination, or a larger network that needs to be kept informed.

We further explore the implication of these challenges in the following studies.

V. STUDY 2. DESIGN CONSIDERATIONS FOR HWBI SHARING

In this study we build on the lessons learned from the previous study and, through low-fidelity prototypes, explore the combination of following design dimensions:

- **Granularity**. We study *single events* and *trends*, so as to understand at what level of granularity and for what type of events to communicate (DC2).

- **Event enrichment**. We explore communication of *raw events* and *translated events* as a trade-off between personalization for reducing misunderstandings (DC3, DC4) and effort required in their elaboration by the formal caregivers (DC5). Raw events refer to baseline where events are sent as-is and no effort is invested on the formal caregivers side. Translated events include personalized message (by the formal caregiver) and a visual representation of the connotation (smiley face).

- **Type of event**. We explore the communication of *medical* and *wellbeing* data (DC1), and frame our questions in terms of the connotation.

These dimensions are combined in a low-fidelity mockups that aim at validating our previous observations and eliciting further feedback on the design direction.
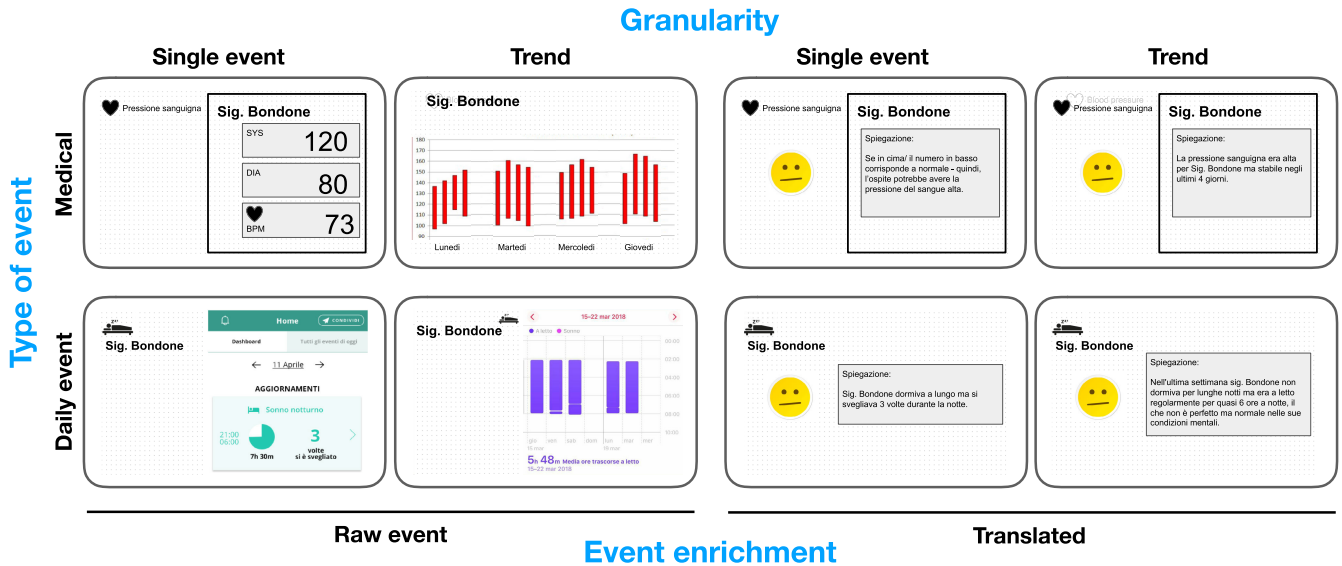
FIGURE 2. Information design alternatives. The screens are a combination of *event type* (medical or daily events), *information granularity* (single events or event trends) and *event enrichment* (raw events and events augmented with translations, i.e., explanation of the event).

Methods: We conducted semi-structured interviews, driven by low-fidelity mockups, with NH professionals that included questions on information architecture and information flow of HWBI to be communicated to family members of NH residents.

Overall, nine semi-structured interviews were conducted with NH staff members (50.6 mean age and 66.7% of females) who volunteered to participate. Each interview lasted from 20 to 40 minutes based on the workload of the staff. We particularly tried to assure staff members in the anonymity of their responses and non-disclosure to the administration of the facilities or any other third parties.

Participants were firstly asked about their background information, professional responsibilities, and their personal work practices of communicating information about the residents to their relatives.

Driven by the mockups shown in Figure 2, we presented the screens combining i) *granularity*, raw singular events (instant measurements or daily information) and trends of events over certain period, and ii) *event enrichment*, raw information with no support and messages "translated" by the formal caregiver in terms that the informal caregiver could more easily interpret the information. These screens were featuring either medical or daily / wellbeing information.

Regarding each screen, staff members were asked to express their informed opinion regarding expected reactions of the family members upon receiving information in a given way, and their expected level of stress, as well as the readiness of staff to share in that way (design alternative). They were also asked about the relevance, importance, and views on preferred ways of communicating the example events.

Notice that the design dimensions follow the previous observation on type of information, granularity and connotation of events, as well as their impact on communication and reactions.

A. PRESENTATION OF HWBI

Discussing *raw* singular events, daily or medical, NH staff emphasized the importance to add a reference value or range for raw values for the medical parameters, given that family members may not how to interpret them. However, they also noted that each case is unique and it is usually difficult to explain the meaning of the values generically: the interpretation of the vital signals depends on the specific health situation.

When shown the concept of event enrichment and explanation, which included smileys (Figure 2) as a way to facilitate the interpretation of the event (negative, neutral, or positive), most of the professionals stated that showing such summaries was a good idea. In particular, they saw it as additional support to understand the connotation of the event at a glance: *"they are the signs that make relatives understand that there is an extra explanation, that show things are going well"*, *"the smiley helps then to filter [the information]"* (P4, nurse coordinator). However, one participant expressed the opinion that a smiley can also miscommunicate information. At times, family members may know better the mood or state of their relative and indicating it with the smiley may mismatch their perception of the situation.

"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). *"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).

In case of events indicating an issue, for example, waking up at night or skipping the meal, NH staff stated that the visualization for the family should also contain the explanation, not leaving the relatives to wonder and ask staff additional questions increasing the workload of the latter (*"If [relative] sees that [the resident] has not eaten anything [for dinner] but maybe had a good snack at the birthday party, after he calms down,"* P2, nurse).

Events communicated directly without translation by the professionals and presented only graphically were seen as difficult to understand for family members in aged care context who usually also belong to the older population group and might lack knowledge in medical terms (*"As we have older adults, their children are older as well. Not all of them know what these values mean. I think, there should be a translation next to them with normal values,"* P3, nurse) or ICT skills (*"The relatives are not the experts, not all of them are experts with apps,"* P4, nurse coordinator). Such communication could also be perceived as "cold and distant." This theme came up, for example, in discussions with a professional who is most in touch with family members: *"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 evaluated as helpful for family members, for example, for seeing deviations and verifying past activities or therapy. Moreover, trends were seen as helpful for the staff members as well. Reports of the last several months were compared to the Individualized Care Project, an evaluation of the resident's health by the whole NH care team organized periodically, and seen as a way to monitor overall wellbeing or therapy. *"[On the trend of having meals] I think that having 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: *"[The best is] a weekly report, I would put a week, a sort of diary... I would make it for all the parameters"* (P6, nurse coordinator).

NH staff believe that retrospective information is less stressful for family members. However, they also pointed out that in cases where 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. If instead they already know the dynamics, they understand, expect it. They may not even call, they are informed" (P6, nurse coordinator).

Staff members expressed worries that sending singular events would overload family members with excessive information, and thought that trends would help manage this situation: *"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).

B. EXPECTED PREFERENCE AND REACTIONS

Together with the qualitative evaluation of the design alternatives, participants were asked to evaluate each of the screens presented to them in a random order in relation to two main factors: 1) preference based on efficiency and simplification of communicating events, and 2) expected reactions and stress level of family members upon receiving information in a given way.

1) EFFICIENCY

While talking to the staff members about their views that sending translated events to family members could make the staff-family 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.

2) SIMPLICITY

Simplicity of communication with family members was another aspect investigated in the survey. 66.7% of all comments on the design alternatives were positive that translated events could indeed simplify information the interaction. Only 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.

3) ANTICIPATED REACTIONS OF FAMILY MEMBERS

In regard to 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 questions asked during the visit, which was mentioned in the 38.5% of the responses.

As for the anticipated level of relatives' stress, medical events were seen as more stressful 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 bringing less stress 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%.

C. VIEWS ON MEDIATED COMMUNICATION

Despite the overall positive implications for family members, NH staff showed some concerns in terms of i) how the technology would affect their workload, and ii) and the implications of having written statement and what that would in terms of accountability.

Most (6 out of 9) of the interviewed NH staff members expressed concern of increase in the workload with introducing ICT tools in communication with family members, especially if information would have to be logged manually. This is a consequence of the working conditions of health professionals in care facilities, which are largely understaffed:

"More than anything else, for us such system would be difficult to manage, we have 102 residents, to know if they have slept... it is impossible to do, that is what I am saying" (p5, RAA). *"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).

Concerns were also expressed regarding additional questions in cases when family members will not understand the updates communicated remotely or find them worrying: *"I agree to give them this information but... I think afterwards they will come here to us and we will have to answer all the questions and worries of family members. I agree but I am scared"* (P3, nurse). This reiterates the initial findings that making sure that information is understandable is a key challenge to address.

The other emerging theme in the discussion was a general concern regarding having a trace of communications, especially if it unvels problems with procedure, as nicely described in an example given by a care professional:

"For example, yesterday I was on a visit with a doctor, and then arrives an operator and tells that one of the residents vomited the breakfast. [As a result we put the resident in bed and gave him soup for lunch - standard procedure]. [But later] comes an operator who was present during that event and tells that the resident did not vomit. Hence, we put the resident in bed and put a diet for no reason. But the vomiting event has already been documented [and shared in the system]. After 20 mins arrives the daughter of the resident and tells that she learnt that her mother vomited. And it is clear that the event of vomiting indicates that something goes wrong. Worrisome."

The above, as well as other examples, point to the general worry that digital trace of communications become a tool for family members to "audit" the work of the staff.

D. LESSONS LEARNED

Feedback from formal caregivers points to a potential positive impact of technology-mediated information sharing in residential care. NH staff expressed that such solutions could i) improve communication efficiency, and ii) potentially result in less follow up calls and unnecessary stress, specially when information is "translated". At the same time, concerns regarding the implications for their work practices further stress the need for considering operational requirements and simplifying the entire information flow, right from the data collection. In terms of the design aspects explored, we highlight the following:

- **Importance of visual aids**. In case of medical parameters, it is important to indication of normal ranges, making sure family members interpret correctly the information. Using metaphors for denoting how critical the event is, was seen as positive, though using "smiles" might not be a suitable representation.
- **Personalized explanations**. Raw presentation of data without context could lead to people misinterpreting information or incurring in additional questions, or even perceived as "cold". Thus, data should be accompanied with personalized explanation relative to the specific event.
- **Trends over single events**. Sending singular events was seen as excessive, favoring trends over time. Having (weekly) reports on trends was seen useful not only for sharing but for their own use.

Building on the above observations, in the following investigate aspects of presentation, comprehension and information flow, from the perspective of informal caregivers.

VI. STUDY 3. INFORMATION PRESENTATION AND IMPACT

Following the findings from the previous two studies (Sections IV and V), this third study was set to investigate the presentation aspects for the HWBI communicated to family members of institutionalized seniors, including preferred level of detail and presentation metaphors, and how these preferences are modified by the type of information and its positive or negative connotation.

More specifically, we explore the dimensions below, the first two associated with the focus of the study on presentation and interaction, and the last two as refinements of our previous findings:

- **Modality**. We explore two general approaches in information presentation: *visual representations*, in terms of charts or metaphors and *narratives*, referring to textual representations of the information.
- **Navigation**. We also explore how users would interact with HWBI, and specifically how they navigate different presentation modalities and levels of detail.
- **Type of trend**. Given the preference on trends over single events, in this study we focus on trends related to the two types of HWBI: medical and daily events.
- **Event enrichment**. We focus on approaches to personalizing and augmenting the raw data. We again compare raw events with *translations*, and given the feedback form the previous study add *visual aids* in the form of value ranges and further refine the *metaphors* to see how they affect overall comprehension and reactions.

Methods: As described in Section III, the sequence of interactive mockups varied for each subgroup of
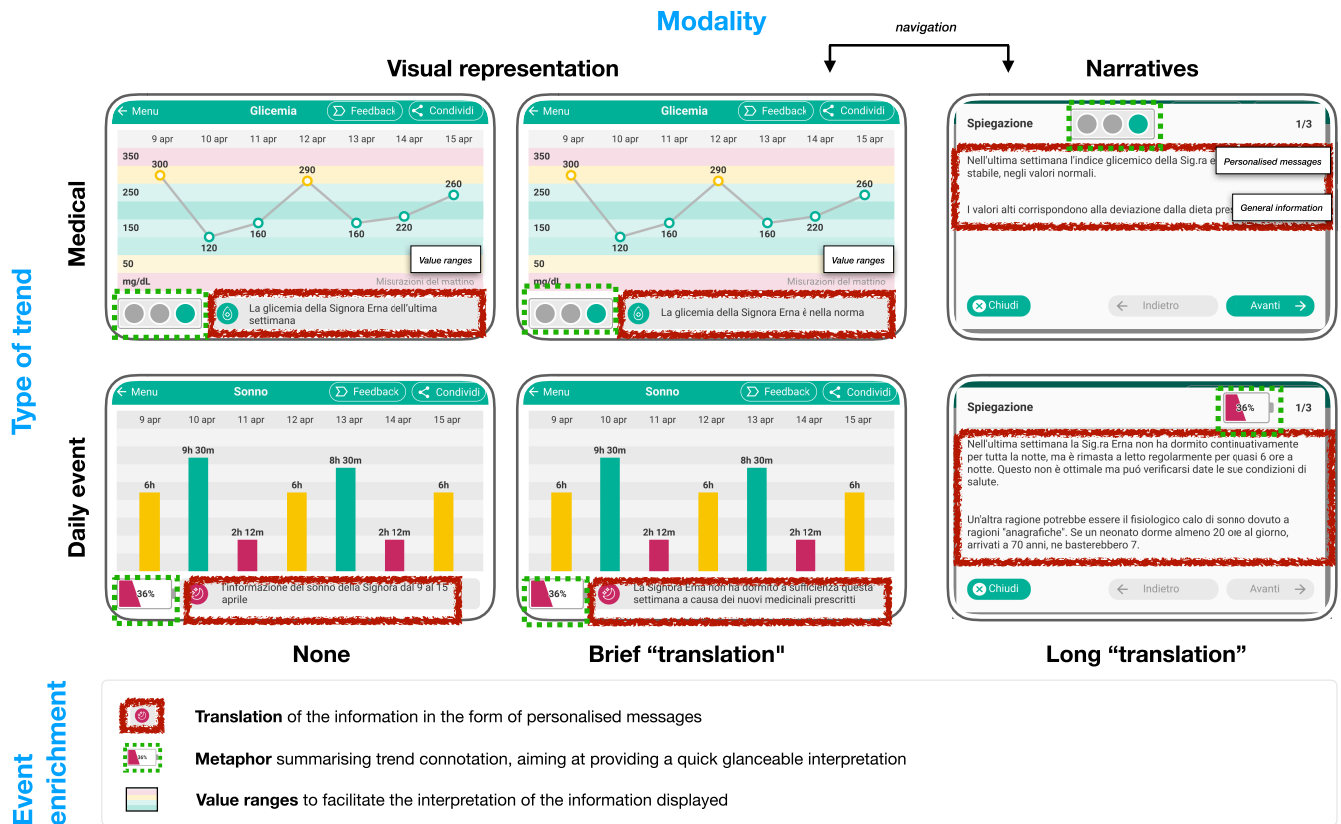
FIGURE 3. Interactive mockups. The designs feature a combination of *type of trends* (medical or daily trends), *Modality* of the presentation (visual or narrative), and strategies for *event enrichment* (translation, metaphors and value ranges). Navigation in the interactive mockup was from left to right, and right to left to avoid positional bias.

workshop participants. The mockups contained different amount and combination of textual (long and short narratives) and visual (metaphors, charts, colours) aids that aimed at making HWBI more understandable for the family members of older care recipients. However, the discussions always started from an example of NH daily events and followed by a medical event.

The aim of the third study was to evaluate interactive prototypes with one of the target groups of end users, namely family members of institutionalized seniors, using an empirical evaluation method in a form of two workshops. For this study, we opted for a predominantly qualitative user study, complemented by minor quantitative questionnaires, since we judged that broad and deep insights were only attainable through observation in combination with an open and flexible discussion format, as it has previously been shown in previous research [56], [57].

Two workshops took place at local aged care facility, which includes day-care and nursing home services, from where participants were recruited with the help of the facility staff so as to get a representative sample of family caregivers (e.g., different level of involvement in care). Overall 12 family members (58 mean age and 70% females) participated in the workshops.

Each of two workshops lasted about sixty minutes. The workshops were conducted using an Asus MEMO Pad with a 10.1'' screen running interactive mockups (Figure 3). The workshops were aimed at: i) evaluating the sufficient amount and preferred modalities of the alternative HWBI presentations, and the users' reasoning defining them, and ii) exploring the potential emotional reactions and actions of the participants on receiving information in a given way.

In the beginning of each workshop, we facilitated an initial group discussion of communication practices in place. Then, workshop participants were split into two smaller clusters of 2 or 3 people to explore and evaluate the mockups (Figure 3) in a co-discovery manner, to then reconvene back into a group for discussion of the participants' experiences and final recap. Each cluster was facilitated by one researcher who showed the interactive mockups on the tablet.

In order to continue addressing RQ2 and following the findings of the Study 2, the mockups presented 2 examples of weekly trends of medical and daily routine events at the NH (blood sugar level and sleep) in 3 modalities: chart with metaphor, chart with metaphor and a short explanation from the staff, longer explanation narrative from the staff.

Figure 3 depicts the mockups used during the workshops in each cluster of participants and includes 3 alternatives
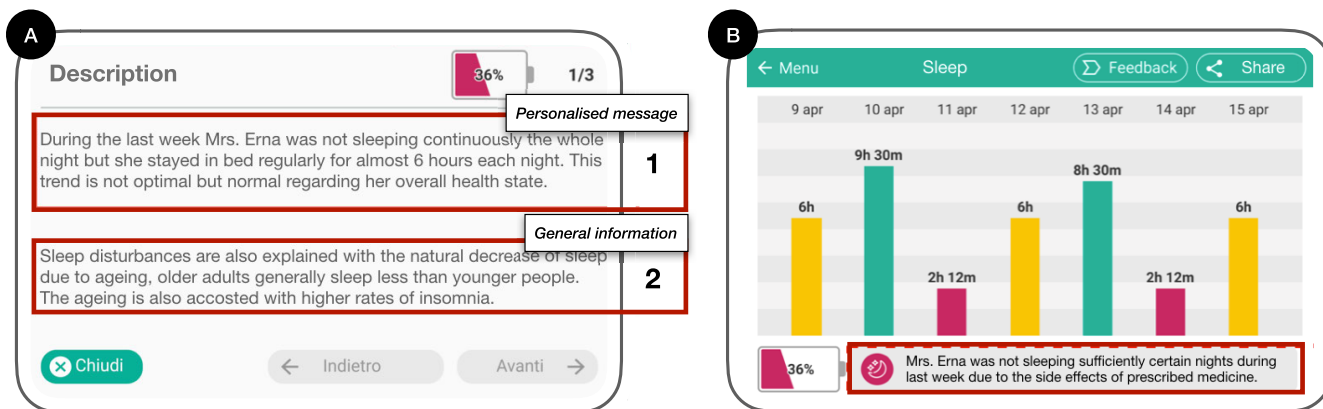
FIGURE 4. Weekly sleep trend example designs: a) long narrative, incorporating a personalised message as well as general information, and b) visual overview with a brief explanation.

for sleep and the values of blood sugar of older adults over the week time period: 1) a chart with numeric values and metaphor translating the values over the last week, 2) a chart with a metaphor and short textual explanation from the staff, 3) a long narrative explanation from the staff without numeric values.

A. INFORMATION FLOW AND PRESENTATION

1) DAILY EVENTS

The mockup alternatives with textual narratives of daily activities (sleep or meals) depicted in Figure 4A, included specific information of the resident's weekly trend (Part 1) and general description of values that hold for general older population, for instance, the fact that seniors sleep less with age (Part 2). Part 2 was incorporated with the idea of providing general context to understanding the information, but in this modality (text narrative) it created confusion among participants, who expected messages to be more personalized (*"I don't understand this "due to ageing" [referring to the Part 2]"*).

Participants did not expect to be worried or to require further follow-up information upon receiving **positive trends** of their loved ones daily information overviews (Part 1) e.g., calling to get more information: *"If they tell me she has slept and she is calm, I wouldn't call anyone, everything is fine. If that's what they tell me, things written here [emphasizing that the message is positive], no worries."*

The visualization in the form of long narratives was seen as enough information in this case. Participants also expressed that an application communicating these events might be less relevant to those with loved ones' overall health not critical: *"I think that if the [older adult] is doing well, [the application] is not needed, one can just visit. However, if there is a problem, one could use the application."*. To family members who visit frequently, communication in virtual channels revolve around negative events, an aspect also observed in our previous study.

Imagining the future, in cases when there is a **negative trend** over some time, for instance, a sleep disturbance over a month period, participants would like to know if the NH staff has done something about it (performed an intervention) and

if their loved one could be helped in general: *"If just once—no, if she doesn't sleep for a month, well, then yes, I ask if [staff] did something about it." "If she is helped to understand why she doesn't sleep, why she doesn't sleep during the night".* This was an aspect not covered in the mockups but that points to how important pieces of information depend on the type of trend.

When shown the chart visualization, participants switched to a more analytical state trying to interpret the data. They were able to understand the chart, reading aloud the sleeping hours per day (*"Well, it says she slept 9 hours, 6 hours"*) but were not able to easily derive the trend, even with the help of the metaphor of the battery charge. However, seeing the chart with numbers could give some family members higher confidence that the information is trustworthy, more than the textual narrative explanation: *"The chart like this [is good] for me. It is more fundamental than 'the Mrs. slept...' [referring to the narrative]. Because maybe... [implying that it might not be the case]. Like that [in the chart], I understand immediately"*. This preference appears to be related more to a desire of having level of scrutiny than in comprehension, an aspect already observed in our previous study where the need for detailed information was in some cases rooted in negative experiences or lack of trust in NH staff.

Comparing to the screen alternatives that contained a visual overview (chart), detailed textual narratives from the staff were considered by participants as being "warmer" or more human-like communication, showing more effort from the staff to make family understand the information: *"I think that the [detailed narrative], I think it is much better because they did an analysis... they had to reflect about her health. Instead, another one [chart with short message] is without any reflection, let's say very "cold."* In this case, adding a short message to accompany and explain the chart (a message on Figure 4B) was seen as beneficial.

2) MEDICAL EVENTS

The second category of events presented to the participants was medical information that is being collected and shared

within care facilities and with family members, for instance, blood pressure or blood sugar level.

Similarly to daily routine information, generic information in the long narrative was also seen as redundant and lacking the value for the medical events: "is it same for everyone and generated by a computer?" Moreover, one of the participants commented that such general information may also compromise their trust and demotivate them to read such descriptions in future: "*I am only interested if the blood pressure of my relative was at least evaluated. Just that. This information is not useful [the part 2]. I would not even read the rest. I would not trust the information you would give me anymore.*"

Most of the comments were not in favor of long messages, for example, expressing the concern that they might trigger "Dr. Google" behaviour [58]: "*more information you give, more effort you have to provide, more... of those who continue searching on computer for various sicknesses and then has all the symptoms.*" Participants also recognize that long messages might overload them with information: "*[you can show this information] even without [the long message] to read because when you are at home, your head is already full*", and expressed their preference to request additional information in cases when they need it.

Chart visualization of medical information, however, was perceived as more understandable by the participants "*I see that [chart] is something that you understand immediately,*" "*I am for the chart. The chart is more straightforward.*" This representation of the information put participants again in an analytical state and there were discussions among the participants – who showed knowledge of how to interpret the glucose levels and the implications. Interestingly, the information in the chart was easier to interpret than the daily information, possibly due to the familiarity with the type of data and well established critical values (also displayed in the chart).

It became evident during the analysis of medical events that information presented should carry not only the "numbers" but also contextual information, in a way that it is precise and accurate. The lack of event-specific context (e.g., whether the measure was taken before or after a meal) raised questions that made it difficult for the participants to decide on whether the information was of concern or not: "*I mean, here she has 120 of sugar level that means it is high but perhaps it is after a meal. [...] in the morning, is it before or after the breakfast? Because it is one problem if that's before breakfast, and another if it's after.*" Adding a short message from the staff to the chart gave a reassurance that the values were previously assessed by the medical professional whom family members trust, hence, giving more clarity: "*Practically, I can say that [chart with a short message] was already seen and evaluated by a doctor, so it was after the meal because it is inside the normal values.*"

This becomes particularly valuable in cases when certain medical test values might be unfamiliar for the relatives with low level of medical literacy, as the chart values might not be enough info to interpret and make sense of the information

about an event: "Well, if one doesn't know the values [of medical tests]. Well, what would it say [to this person]?" Providing contextual information and aids to interpret correctly the data was thus more appreciated and needed in visual representations than in narratives (e.g., the same information we tried to convey in Part 2).

Overall, participants expressed strong preference towards seeing the chart values for medical events, which is supported both by many qualitative comments ("*No, anyways, now, after seeing the chart, I am for the chart. To see the values*"). Quantitatively, this alternative was considered slightly less efficient than the narrative for both events.

As we observed during the workshops, naturally, participants explained their preferences and provided comments by comparing the screen alternatives "*No, anyways, now, after seeing that chart, I am for the chart. To see the values [about the narrative after seeing chart].*" However, the views of the family caregivers still converged for each type of events, e.g. daily routine and medical events, regardless the flow.

3) ADDITIONAL COMMENTS

Overall, participants strongly emphasized the importance of personalizing the HWBI they would like to receive, as the same event could be very important for one family caregiver and irrelevant for another: "*[I would like to know] that my aunt managed to leave the bed for an hour. For another person it could be [important to see] other daily events*", which may also depend on the specific health state of the senior ("*For my aunt, to walk in the room after the lunch and to walk around alone is important*"). In particular, the importance to see certain medical information is dynamic and depends strongly on its relevance. Moreover, family members expressed their preferences to opt out from receiving certain events if they are not critical for their loved one's health or do not change over time. For example, they might rarely check the blood pressure that fluctuates around the same values: "*if it is always the same, [I would check it] maybe not all days, but maybe once a week*".

The interest of participants to receive certain types of information also depends on the facility service their loved one is provided with (nursing home or daycare), which can also change over time with transition of aged care. As can be seen in Section III, most of the participants belong to the older population group, and indeed, they emphasized the importance of accessible design of the mockups. Moreover, one of the participants was colour blind, which yet another time indicated the importance of accessibility of such applications: "*I am a bit colourblind, it is a limitation. Put like that, I see it a bit more intense, but if not, for me they are all the same.*"

As NH residents stay in the care facility, family members always rely on staff's judgment and generally wish to be notified in case when something is wrong: "*as we are not obliged to see them every day, as they are under a continuous control here. Because they are always under control, so this [application] is a little... yes, I could ask how she is doing but, to my mind, they will tell me if there is something*
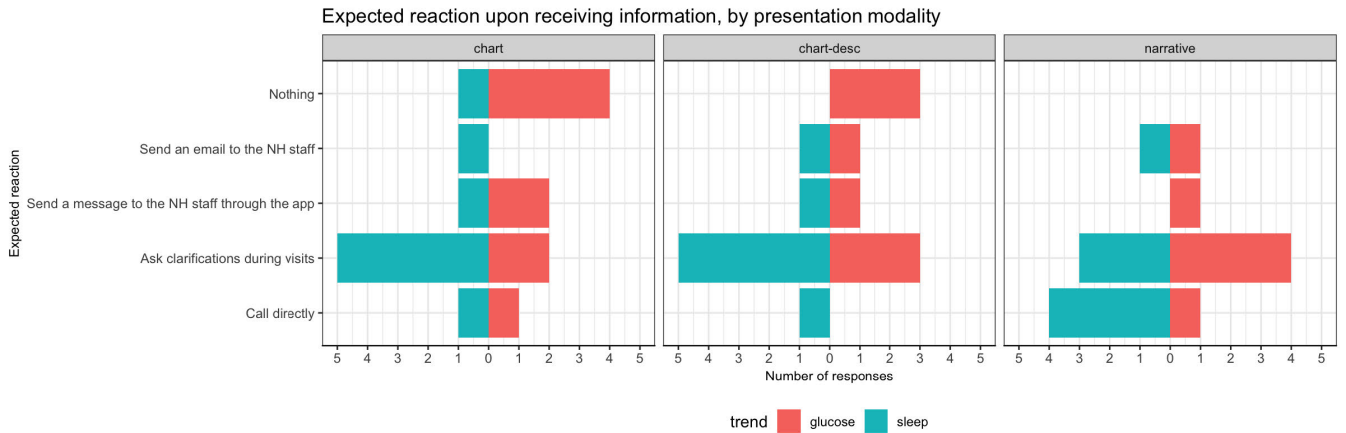
Expected reaction upon receiving information, by presentation modality

FIGURE 5. Anticipated reactions of family caregivers upon receiving HWBI in a certain modality.
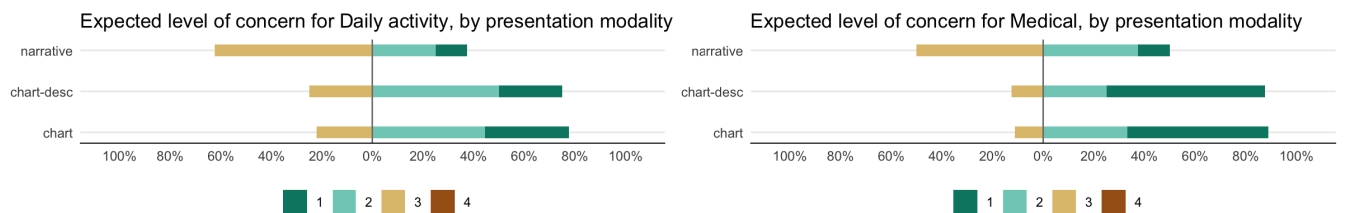

FIGURE 6. Expected level of concern upon receiving HWBI in a certain modality (1="No concern", 4="Very concerned").

wrong," while feeling of obligation to dive into practical care processes again is undesirable for them.

In this vein, participants suggested introducing an alert system of notification, expressing the reoccurring topic of their trust towards NH staff in pointing out the problematic events: "*Maybe if there is something that is wrong, they could put an alert—"look". And they tell you to check if something is wrong*." They also suggested that the nursing home staff could ask them if they prefer to be more or less informed through the application: "*would you like to be informed, do you need to be informed daily about the health of your parent?", one could say "yes", one could say "no" and makes this choice, to be informed or not*."

B. REACTIONS AND ACTIONS OF INFORMATION RECIPIENTS

The purpose of information sharing in this context is to facilitate the information flow with family caregivers and improve the interactions with the NH. Thus, we present here insights into the potential impact of information sharing, in terms of expected reactions and communication improvement upon receiving information through a digital channel and the specific presentations we introduced.

Investigating the expected reactions (Figure 5), daily activities resulted in more follow-up interactions (96%) compared to medical events (71%), and these interactions are expected to increase as we add narrative information, regardless of the type of information. Indeed, narrative presentation of daily activities are expected to result in the most invasive type of interactions from the perspective of the NH: direct

calls, from 50% of the responses. Among the questions that emerged while showing the information to the participants we have: "*How come [the sugar level is so high]? How come, was it before eating, what did she eat?*," "*if she would have 200 of blood pressure here, which is outside [the norm], perhaps I would ask "but did you follow this up? To know what they did, whether they resolved the problem*." Some of these questions could be anticipated with further information about the reason behind the trend and ongoing treatments.

The qualitative input also tell us that reactions of family members might also be based on specific situation. For instance, in case of the values inside the norm the participants wouldn't do anything. But if it is not normal, there are some questions." Participants emphasized that the connotation of an event would play a major role in their actions upon receiving it: "*it depends how is the information, if the health is not good, well, I would call, but if it is normal, I wouldn't call*." The reported level of concern upon receiving the HWBI puts narratives as a modality of presentation that can potentially cause more concern (56% of responses) in comparison to the graphical representations (18% of responses). However, this is when considering narratives that include personalized as well as contextual information (Part 2), to which participants reactive negatively as discussed in the previous subsection. Looking at the type of information, participants expected to be less concern about the medical information presented, although we must note that this can also be attributed to the clarity of the information presented rather than the type itself. These results, depicted in Figure 6 confirm that emotional
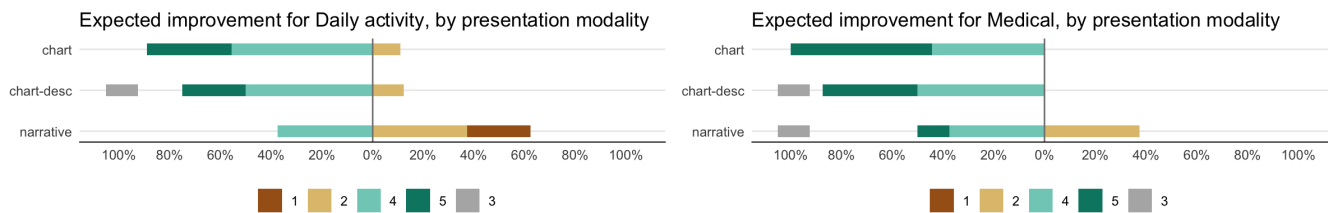
Expected improvement for Daily activity, by presentation modality

Expected improvement for Medical, by presentation modality

FIGURE 7. Expected improvement of communication upon receiving HWBI in a certain modality (1="Completely agree", 5="Do not agree at all").

responses would strongly depend on the type of event and the modality of its presentation.

In terms of the improvement in the communication with the NH staff upon receiving information in a particular modality (see Figure 7), the majority of participants reported an expected improvement when resorting to graphical representations while they the views were split on narratives (at most 50%). Looking at the type of information, there was a larger consensus on the sharing of medical information in improving communication with the NH.

Participants also recognize that introducing an additional communication channel and communicating to them larger amount of information through it could add more workload to the staff and asked questions the way information would be gathered and communicated ("*but do [staff members] put this here? Would they manage to have such results?*", "*yes, but is this [information] inserted by a doctor or is it some statistics from the chart?*").

The lessons learned from this study, in combination to the previous ones, are summarised in the following section.

VII. DISCUSSION

The aim of this work was to examine communication strategies, mutual attitudes of family and professional caregivers regarding information sharing in nursing homes (NHs), and the strategies of presenting health and wellbeing information (HWBI). Starting from the high level overview of the information exchange practices the caregivers adopt and information architecture principles, we moved to the evaluation of the design alternatives that could mediate sharing of HWBI in NH care context.

All three studies included in this paper build on each other's results and provide cumulative findings that inform the design of ICT systems, which could be accepted by both staff and family members and integrated into the daily practices of each caregiver groups. Overall, we identify several main challenges that emerged across all three studies and discuss each of them in detail translating the results of this work into design aspects and recommendations to be taken into account when addressing the identified challenges. These are summarized in Figure 8 and explained in detail below.

A. INFORMATION ACCESS AND DELIVERY

Family members involved in care of institutionalized older adults form a heterogeneous group in relation to their information needs and care involvement. For instance, among

other variables, they differ depending on the specifics of care facility services their older relatives receive, their loved one's health state, and personal care experience or ICT skills. In this work, we identified both a large number of "personas" of individual family caregivers and family care organization styles, such as individuals, care teams, and proxies, that affect their communication practices with care facility staff. Together with variety of family situations, relationships among family caregivers and between them and NH residents, our findings reveal a major challenge that comes with the introduction of ICT channels in aged care, specifically how to access and deliver HWBI, resulting in the following recommendations.

1) ACCOUNT FOR INDIVIDUAL CHARACTERISTICS AND INFORMATION PREFERENCES OF FAMILY MEMBERS

Personalization is known to increase satisfaction but the information needs are not always evident to the family members. The NH staff in this regard has the capacity and knowledge to help in making these "hidden" needs evident to family members, and to map the way they classify family members today (from a communication perspective) into a digital channel to tailor information communication.

2) ADDRESS BOTH POSITIVE AND NEGATIVE HWB UPDATES

Regarding the connotation of the HWB updates, while proactive communication practices are centered around communicating critical and negative information, positive trends emerged as a need for family members: i.e., "knowing that things are going fine," especially to those who are not able to visit or briefed regularly. This is also important so as to not turn the digital channel as the "bearer of bad news." But when negative trends need to be communicated, the timing for each type of events is important. For instance, a month could be an acceptable time period before starting to receive specific updates on the sleep disturbance of a NH resident, while for medical events immediate communication in case of abnormal values is extremely important.

3) CONSIDER THE PROPER GRANULARITY FOR HWBI SHARING, FROM SINGLE EVENTS TO "TRENDS"

Single events can be useful in reporting critical events, but others forms could be more informative when looking at trends (e.g., alarms or improvements). More specifically,
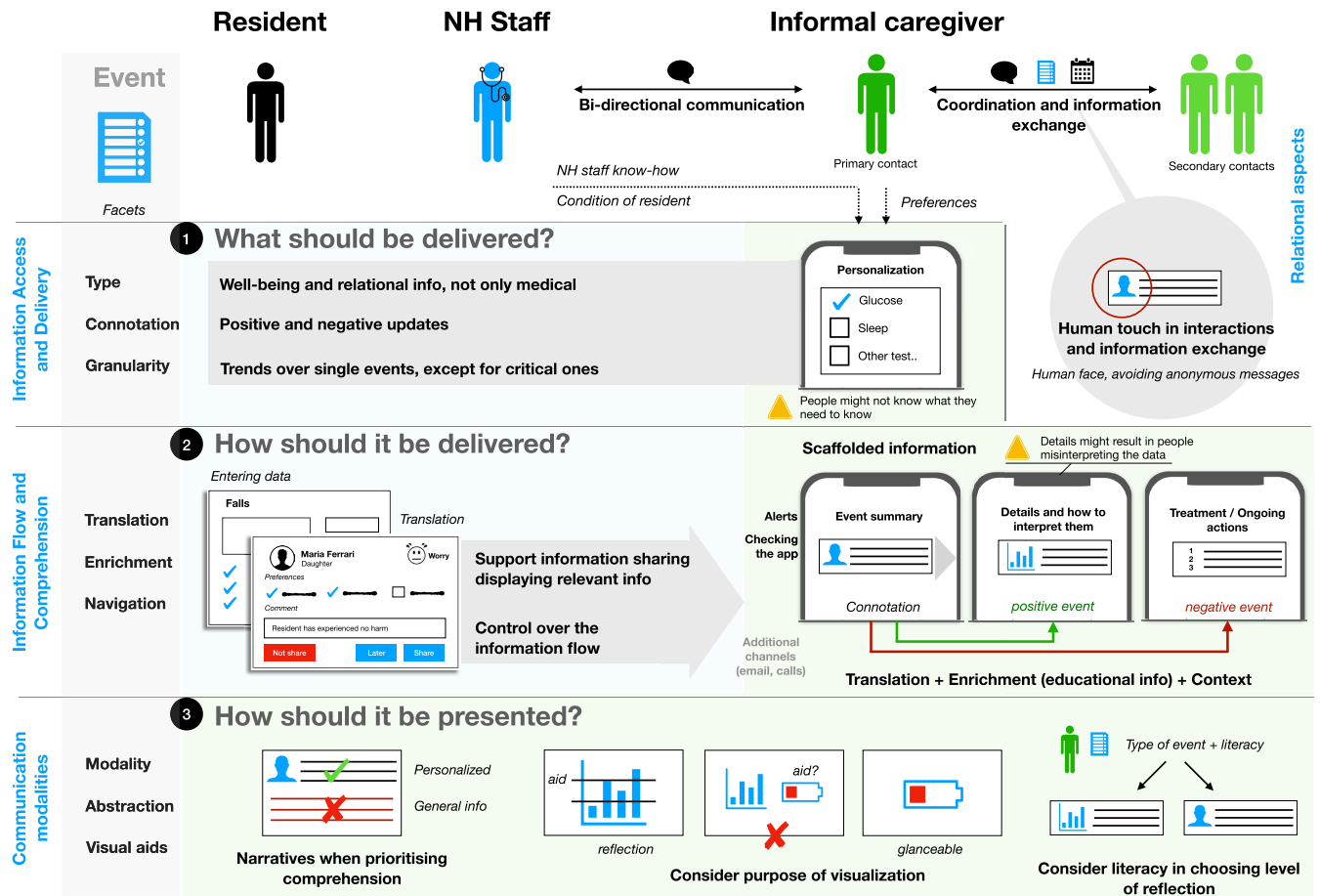
FIGURE 8. Summary of design aspects and recommendations.

trends of medical and daily routine updates should be communicated differently. While daily events could mimic the personal communication of family members with the NH staff and be shorter and less formalized, medical updates are preferred to be very specific and precise, with explanations to avoid confusion and room for misinterpretation.

4) PROVIDE HWBI, INCLUDING WELLBEING AND RELATIONAL INFORMATION, AND NOT JUST HEALTH DATA

While interest in medical information was varied, we noticed an overwhelming interest in the basic questions we also ask each other every day, such as how we slept and ate or if we took part in (social) activities. Family members want to have the same information, which is only partially collected by NHs today but that technology now can help us get semi-automatically (e.g., through sensors).

B. INFORMATION FLOWS AND COMPREHENSION

Another important design dimension we identified has to do with the entire information flow, aiming at reducing unnecessary stress on the family member side as well as being attentive to the work load of the NH staff. Family caregivers might not always have a full understanding and knowledge of their loved one's condition or a possibility to visit frequently,

which introduces another challenge of ICT mediated information communication by the care facilities. As emerged from our studies, updates out of context might cause additional confusion, worry, and follow-up questions by family caregivers, as they might fail to interpret communicated information. In addition, the HWBI is multi-dimensional and have a complex nature, which imposes a challenge in terms of how to introduce it in a way that it does not cause further or unnecessary distress. The resulting solution should also not be an additional source of confusion, resulting in further workload to the NH staff. Overall, a new digital channel should support the communication practices and not cause additional problems or distress to the involved actors.

In this regard, the following design recommendations can guide the design of successful HWBI flows.

1) ALLOW HEALTH PROFESSIONALS TO CONTROL THE INFORMATION FLOW, WITHIN POSSIBLE IN THE LEGAL FRAMEWORK

There are existing communication practices and information flows in the NH context that happen in person, as well as through other channels, such as phone and online, which are based on internal and legal regulation within aged care context. Not all the updates should be communicated via app, as a way to bring to light invisible work of staff. NHs are still

in control of what information is shared and how (some events might be preferable to discuss in person or via phone)— their know-how should provide the possibility for staff to have control of shared information, as staff also have the responsibility of shared information and the outcomes of the sharing.

2) SUPPORT PROPER HWBI SHARING BY MAKING FM PERSONAS VISIBLE TO NH STAFF

Making explicit the communication personas among the NH staff members could support them in adapting the communications to the sensibility of diverse family situations.

3) IMPLEMENT STRATEGIES TO MAKE SURE HWBI IS CLEAR AND UNDERSTANDABLE

It is important to provide as much context as possible, for instance, by considering the resident's ''normal'' ranges for medical tests and ''translating technical vocabulary'' to what non-experts can understand. Misinterpreting information can lead to situation of stress and uncertainty, which in turn can harm the relation with the NH. Both family members and professional caregivers of NH residents stated that medical events could be the most stressful and causing the most problems, which emphasizes the importance of making them as clear as possible and providing further details when needed.

4) FAVOUR SIMPLICITY OVER RICHNESS OF INFORMATION, AND PROVIDE DETAILS ON DEMAND

Delivering raw HWBI to family members could increase the efficiency of family – staff communication but in limited cases, when updates on the specific medical events are requested. Possible updates could include the information on the actions or medical interventions that were undertaken to mitigate acute symptoms, the updates on the future prevention plans, or the reasons why this event has occurred.

5) PROVIDE SCAFFOLDED AND CONTEXTUAL HWBI PRESENTATION

Give family members the possibility of understanding the situation at a glance and navigating information at their desired level of detail. To this end, allow them to navigate from summaries of what is the general condition of the resident, to summary of health parameters, to specific details. In addition, provide information that is relevant to the time and context of the event communicated, which implies thinking in terms of what information can be delivered through synchronous and asynchronous channels.

6) CONSIDER TOOLS FOR CONTEXTUAL EDUCATION SO AS TO ALLOW FAMILY MEMBERS TO BUILD HEALTH LITERACY

In providing educational information explaining the HWBI, users can learn about the meaning and implications of the information they receive, especially when they are first confronted with the type of information presented.

C. COMMUNICATION MODALITIES AND CHANNELS

This dimension has to do with the actual presentation of the information, so as to convey the actual meaning and facilitate comprehension. We have seen that HWBI is complex in nature and have many facets associated. Information presentation is associated with all these facets presented before such as information enriching, translation, type of event and their connotation. Deciding on a presentation modality - from raw data to summaries to metaphors - is thus a challenging task that should consider all these aspects. In the following we provide some general guidelines:

1) PRESENT HWBI AS NARRATIVES WHEN PRIORITIZING COMPREHENSION

Narratives have the potential to provide the most clear and personalised presentation of events. They are more suited for presented digested information when the purpose is to communicate the meaning of events. In preparing narratives, avoid mixing the personalised message with contextual or educational information as it can lower the benefit of the personalization and create confusion on the receiving end.

2) CONSIDER THE PURPOSE OF THE VISUALIZATION IN CHOOSING VISUAL AIDS

In augmenting the presentation of visual information with visual aids, one should consider whether the purpose is for users to *reflect* on the data and derive meaning from the information, or whether it is there to communicate the meaning directly through *glanceable* information. For example, in presenting charts to support reflection, visual aids connected to the event visualization were more successful at supporting the task. We observed that such aids could have more chances to be used and support the comprehension when connected to the data, for example, through colours or ranges incorporated into the visualizations rather than ''external'' metaphors, as users want to make sense of the data. Including glaceable summaries via metaphors was not a successful approach in this context, as the summary did not help users interpreting the information but rather created a gap between information and meaning.

3) ENABLE ''REFLECTION'' ON HWBI AT A LEVEL OF GRANULARITY MATCHING THE HEALTH LITERACY OF FAMILY MEMBERS

Information should be presented at a level of detail that users can understand, especially when the purpose of the visualization is for users to reflect on the data. We observed this in action while testing the chart visualization of raw sleep and glucose levels, where to our surprise participants were much better at reflecting on the medical data than the daily information. Participants were familiar with this medical information and much better at understanding the data than the supposedly simpler but in their case less familiar sleep information. Thus, the visualization, and related aids, should consider the literacy of the target population, or individuals

in case of heterogeneous users without overloading the user or even being misleading.

D. RELATIONAL ASPECTS OF INFORMATION EXCHANGE

While we started our research with the original generic idea of sending HWB updates from the care facility to residents' family members, studies emphasized the need for bidirectional communication that mimics the human interaction, and this bidirectional channel is important for both family and staff. NH care practices and related processes might not always be transparent and clear to the family members of the residents, hindering the workload of the staff. Hence, the following design solutions could be beneficial in introducing ICT mediation of such communication.

1) GIVE A HUMAN FACE TO VIRTUAL INFORMATION EXCHANGES

One aspect of concern in taking communications to a virtual channel was losing the human touch to social interactions. It is thus important to show a human face in the interactions with the family members instead of hiding behind institutional accounts, facilitating mutual awareness through profiles. Emphasize the ICT channel as an additional channel supporting and enhancing personal communication but not replacing it.

2) ALLOW FOR FAMILY TO STAFF COMMUNICATION, SO AS TO HAVE A BIDIRECTIONAL COMMUNICATION IN THE CONTEXT OF HWBI

Enable family members to follow up on communications on the same digital channel, but making sure conversations remain in this context. Our previous study on relational aspects beyond information sharing [59] also points to the potential of this channel to let staff know the care preferences and habits of the resident that the family member wants to be respected if possible.

3) PROVIDE TOOLS TO ALLOW FOR COORDINATION AND INFORMATION EXCHANGE IN FAMILY CARE TEAMS

It is important to consider that there is not just one person but a family behind the NH resident. Thus, the technology support should cover aspects of coordination in care teams, as well as tools to relay information to the larger family within the limits of GDPR and related regulations. Not addressing these sharing practices could expose HWBI to informal and less safe channels.

Overall, this work strengthens the idea that it is critical to consider both preferences of family members of nursing home residents and work practices of the staff in designing information services such as e-health systems. However, the studies have also reshaped the initial belief of nearly all actors involved (including us), from a focus on communication of medical information from staff to family to focus on i) bidirectional interaction, ii) appropriate delivery of various types of events (daily or medical) with their positive or negative connotation, iii) social and wellbeing events, and

iv) paying attention to personas and personalized explanations and contextualizations.

VIII. CONCLUSION

We identified some key challenges in enabling HWBI sharing in residential care, especially considering the current state of healthcare systems currently deployed in this context. At a fundamental level, there is a need for incorporating wellbeing data in addition to medical information, which might pose a non-trivial challenge to data collection practices and systems in deployment. At a more cultural level, proactive communications from NH nowadays have a negative connotation, requiring a switch in these perceptions to enable HWBI sharing in a virtual channel. Then, information needs are also very different, as health conditions and preferences greatly vary, and yet people don't really know what they need or want. More importantly, HWBI, if not communicated properly, can cause misunderstandings and unnecessary distress.

In this regard, the set of recommendations provided can be a starting point for guiding the design of information architecture, information flows and presentation. Although the cultural and legal context can vary from countries, we acknowledge as fundamental ingredients for success involving the health care professional in shopping the information flow but providing them with the necessary tools to accommodate the communications to the needs and sensibilities of the information recipients. On the family side, adaptation to health literacy needs as well as presenting HWBI in a way that can be understood at a glance are paramount. Being aware of their communication practices is also important in avoiding sensible information to fall in informal sharing channels.

LIMITATIONS

The study has several limitations and the most frustrating one for us was the difficulty in approaching family members that are remote or visit rarely. This is due to a variety of factors including the fact that we were asked to go through NH to contact relatives. However, this is also the group of family caregivers who most frequently interacts with the nursing home staff, and therefore experience the benefits and pains of current practices.

Another important limitation of the study is the exclusion of the care recipients, NH residents. Obliviously also their needs and requirements should be also taken into account, which we addressed in other publications [60], [61]. However, NH care in Italy has its specificity, as the residents mainly belong to the "oldest old" population group with a high degree of impairments.

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