Information Design in An Aged Care Context

Views of Older Adults on Information Sharing in a Care Triad

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ABSTRACT

The adoption of technological solutions for aged care is rapidly increasing in developed countries. New technologies facilitate the sharing of health information among the "care triad": the elderly care recipient, their family, and care staff. In order to develop user-centered technologies for this population, we believe that it is necessary to first examine their views about the sharing of health and well-being information (HWBI). Through in-depth semi-structured interviews with 12 residents of senior care facilities, we examined the reasons why older adults choose to share or not to share their HWBI with those involved in their care. We examine how the purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control affect their opinions about sharing. We then explore how those factors define what granularity of data, communication frequency and channel older adults find appropriate for sharing HWBI with various recipients. Based on our findings, we suggest design implications.

CCS CONCEPTS

• **Security and privacy** → *Usability in security and privacy*; • **Human-centered computing** → *Empirical studies in HCI*; • **Social and professional topics** → *Seniors.*

KEYWORDS

HCI, e-Health, aged care, information sharing, care triad, older adults

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1 INTRODUCTION

Older adults require more professional (formal) and family (informal) care than any other age group. At later stages of life, they transition across a continuum of living conditions, from "aging in place" to institutionalized care [23]. This transition requires coordination and collaboration "among a long list of providers" [23, p.114] that comprise a "triad of care" [14] and include older care recipients, relatives, and professional medical and caregiving staff.

Professional medical and care staff often alleviate certain "technical" tasks related to caregiving (such as assistance with daily activities). However, institutionalization of older adults does not eliminate the emotional involvement in care for their loved ones [1, 24, 36]. As result, families adopt alternative strategies to stay engaged in care processes. One new approach is "caring through data" [19], which is based on collection and exchange of seniors' health and well-being information (HWBI). According to the biopsychosocial model of health status, HWBI is comprised of physiological, psychological, and social aspects of health and illnesses [8]. The increasing popularity of "health datafication" [19] transforms the traditional involvement of family members in practical care procedures into a more analytical partnership of family and staff. In addition, HWBI helps to prevent major health issues [9], improve the response to critical events [23], and assist in decision-making about an appropriate level of care [6], and end-of-life choices [32]. On the other hand, extensive information disclosure and delegation of control over decisions often result in seniors' psychological discomfort [22], as well as privacy [28] and security concerns [10]. Current research often addresses the burden on formal and informal caregiving duties [15]. However, the needs and concerns regarding health communication in the care triad, especially from the perspective of elderly care recipients, is understudied.

In this paper, through the analysis of in-depth semi-structured interviews, we explore the views of 12 older residential care recipients on information sharing with and among their professional and family caregivers, and on the role of technology in mediating this communication. We find that the dynamics in interpersonal and formal relationships between care triad stakeholders, including trust, communication culture, and alignment of views, have a dramatic effect on information exchange among them. Therefore, instead of considering the recipients in isolation, in this paper we analyze the opinions of older adults about exchange of information within the *dyads* of the care triad. We identify the dimensions of

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information sharing and how counterbalancing forces affect the communication decisions of older adults. Specifically, we illustrate how the interplay of purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes to privacy and control defines what granularity of data, communication frequency, and channels are appropriate for sharing information in certain recipient dyads. We discuss the opportunities of ICT in facilitating communication and providing aged care. We also discuss how low digital literacy, limited access to technology, and concerns about reliance and data integrity hinder the adoption of ICT among seniors. We summarize how the specifics of institutionalized care facilities affect seniors' attitudes to privacy and control. Finally, we provide recommendations for future work.

2 RELATED WORK

In this section, we review the related literature on the sharing of health and well-being information (HWBI) in the triad of aged care: elderly care recipients, care professionals, and family members. We review the benefits and issues of HWBI sharing, the role of Information Communication Technologies (ICT) in supporting and mediating information exchange, as well as older adults' privacy concerns.

2.1 Sharing Health Information in Aged Care

Aged care requires a wide and complex network of care actors, which usually consists of two main groups of caregivers: (i) professional or formal caregivers, such as nurses, doctors, and hired caregivers; and (ii) relatives or other informal caregivers [34].

Sharing HWBI among them has conclusively been shown to be important in the literature. Presenting a patient's information to their relatives increases family involvement in the caring process, and improves credibility towards medical staff, thus reducing their stress and workload [5, 25], and enhancing collaborative partnerships [12]. Care professionals tend to involve family members in care as additional resources [7, 38], because relatives often advocate for seniors' interests and know their preferences [16].

There is a difficult balance between providing care and respecting each other's independence [3]. Asymmetric values create tensions between care recipients and their caregivers. For instance, patients' motivation to share information may not always match health care providers' interests to receive it [17]. Hence, it is particularly important to focus on both recipients' and caregivers' perspectives, when designing systems aimed at facilitating their interactions [2]. Therefore, optimizing and facilitating HWBI sharing depends on the comprehension of the "organization of work" of the triad actors [33] and their invisible practices in coordinating care [31].

2.2 The Role of Technology

Various studies stress the potential for technology in supporting communication in aged care [11], as ICT channels can facilitate a coherent distribution of information among care stakeholders and improve their coordination [25]. For instance, Bossen et al. [4] demonstrate that the alignment of tasks and appointments between family and hired caregivers of older adults can be implemented by the shared use of a digital calendar.

However, technology might be perceived negatively by senior care recipients, if they do not understand how it can fit into their lives [20]. Although by reducing caregivers' care burdens, technology can make seniors more independent, ICT-enabled surveillance restrains seniors' perceptions of personal freedom [27]. Therefore, the design of these technologies must consider each group of care triad actors by gathering their requirements and including them in the design process from the very early stages [18, 29].

Our work contributes qualitative data on the views of older care recipients about how ICT solutions can support and coordinate information sharing among the actors in the care triad.

2.3 Privacy Concerns Related to Sharing

Patients tend to have privacy concerns [22] and do not feel in control of information shared with their caregiving networks through digital channels [28]. These elevated privacy concerns may prevent people from using digital services.

In addition to personal views, recent changes in European and US legislation[1] are radically changing the boundaries of health information sharing, granting patients and their personal representatives with the rights to access health information, and share it with involved family members or friends [37, p.118]. However, these regulations still might inhibit the sharing of health information with and involvement of the family due to their interpretation and application complexity, as it is not always clear what can and cannot be done in health communication with family caregivers [21]. Moreover, regulations indicate that patient information is also stored and transferred using global networks, distributed databases, and the cloud. Health records might be fragmented and accessible from several locations and by multiple health care providers [10], which implies an increased risk of patient information disclosure within the contexts where it cannot be controlled [35]. Still, effective collaboration in aged care requires a coherent and consistent information flow among care actors [11] and relational continuity within the care triad [13]. Our study complements previous research by considering the views of institutionalized senior care recipients and examines how they communicate and share personal HWBI with their professional and family caregivers.

3 METHODOLOGY

We directly recruited inhabitants of long-term care facilities for older adults in the San Francisco Bay Area. We chose an urban and suburban area with relatively good technology resources and services for older adults, thus increasing the spectrum of potential participants who are aware of privacy and issues surrounding sharing information online or using ICT-based sharing platforms. The study was approved by the University of Trento Committee on Research Involving Human Beings (Application N. 2017-003) and was conducted in September 2018 at the long-term care facilities.

We administered screening surveys—over the phone, paper, or in person—and excluded individuals under 65, those with serious

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[1] Such as the European Union's General Data Protection Regulation (GDPR); the U.S. Health Insurance Portability and Accountability Act (HIPAA); and the 2018 California Consumer Privacy Act (CCPA).

cognitive impairments (e.g., Alzheimer's disease, dementia), or non-English speakers. To answer our research questions, we then conducted 12 in-person semi-structured interviews[2] that focused on: (1) opinions of older adults about collection and sharing of care-related information between the care triad actors, including their previous experience with sharing HWBI with healthcare professionals before the institutionalization; and (2) the role of technology in the care-related information exchange. Before each interview, participants signed their consent to participate and be recorded during the session. Finally, after the interviews, we administered exit surveys about participants' individual characteristics. Interviews lasted about 0.5–1 hour each, and were audio recorded and transcribed by a professional. All participants received $15 as compensation.

For the data analysis, three coders iteratively coded two transcripts to develop individual codebooks. They then reconciled disagreements to create the final codebook. The coders used this final codebook to code all interviews. Two coders independently coded each interview, resolved coding application disagreements, and then conducted thematic analysis of the data.

Study participants. Participants were between 71 and 103 years old ($mean = 90.5, SD = 7.9$), and ten were female. The majority (9/12) had "Native or bilingual" English language proficiency, described race and ethnicity as "White" (11/12), and had a Bachelor's degree or higher (10/12). Participants self-reported their physical conditions mainly as "Good (normal physical health)" (6/12) and "Acceptable (slight deficit in some primary functions, conserved autonomy)" (4/12), while just 2/12 seniors admitted major deficits in functions or limitations in regular activities ("Precarious" or "Fair").

All of the participants lived in long term care facilities or senior housing longer than 2 years. Most of them (7/12) pursue independent living (i.e., no one assists them with their activities of daily living), while some have informal (3/12) or hired (4/12) caregivers.[3] Most of the respondents (9/12) were completely satisfied with the care services provided and claimed in the interviews that they either completely (6/12) or somewhat (6/12) trust the professional care providers. Respondents reported "Good" (6/12) or "Excellent" (6/12) relationships with the care providers.

Four participants (of 12) stated that they connect to the Internet every day, 3/12 never, and 5/12 connect 1-3 times a week. Six out of twelve respondents have tablets (6/12), 4/12 smartphones, and 4/12 computers/laptops; some of them own several devices, while 3 respondents have none. Participants were also asked whether they find working with computers easy, 3/12 of them agreed and 2/12 strongly agreed on that, 2/12 disagreed and 3/12 strongly disagreed, and 2/12 were either undecided or never used a computer.

4 RESULTS

Older adults' views on information sharing depend on communication context, relationships among actors, and individual preferences. Moreover, the specifics of senior care facilities affect seniors' attitudes toward privacy and control. While ICT can potentially improve communication in a care triad, we identified a number of barriers and concerns that hinder adoption among older adults.

Our respondents had elaborate views on sharing: on their willingness to share personal information, many said "*it would depend on the circumstances*" (P3). The analysis of those "circumstances" revealed a few prominent dimensions of information-sharing preferences, which we summarize in Table 1 and describe in the remainder of this section. These dimensions are associated with the recipients, purpose of use, data, delivery, and individual attitudes.

4.1 Dimensions of Sharing: Recipients

The recipients of health and well-being information (HWBI), directly involved in aged care, and comprising the triad of care, are older adults, their family members, and staff (including healthcare professionals, hired caregivers, and care facility management). Instead of considering the views of older adults on recipients in isolation, here we analyze the dyads, because we believe that *relationships* between stakeholders—including subordination, trust, family culture, and alignment of views—have considerable effect on information exchange between them.

In the **Senior–Family** dyad, the intimacy of relationship, family culture, and general style of communication often affect the health information exchanged between the family members. Some families are very engaged, open, and transparent: "*I have two brothers and we sort of share all of our medical, and financial information. We are not a secretive family*" (P8). Other families have well defined communication "etiquette," boundaries, and strategies about what and how to share: "*Our system is, we really wait for [our son] to text us [...] and if we text him, it's something major*" (P1).

In the **Senior–Staff** dyad, trust plays a major role in seniors' willingness to share data. They tend to trust highly skilled medical professionals, as inferred from education level, feedback from other patients, or personal experience: "*I don't like to share personal information with people I don't know, but if it's something that she as a doctor feels that needs to be discussed, I have no problems with that. She respects my privacy. But I respect her judgment too*" (P2). Trust is also an essential factor in the decision of a doctor to engage in direct communication with patients, or in their remote treatment and medication management as well: "*I have a very good relationship [with the doctors], I keep good records and [...] they trust me because they know that I am giving them accurate information*" (P4); "*I communicate with my doctor by email [...] Most doctors do not want that. [...] I don't think she communicates with all her patients, [but only] with those whom she considers to be responsible*" (P5).

The duration of the relationship contributes to the formation of trust: many seniors have the same doctor or caregiver for decades and form bonds of friendship with them ("*It takes time to develop those kind of relationships,*" P4). This sometimes results in an overlap of their professional and informal roles: "*I know [my doctor] like family*" (P7); "*He was a [general practitioner], but he was an old friend [...] and so we talked about our families*" (P2).

Finally, seniors' perceptions about staff's motivation and intentions affect relationships within the Senior–Staff dyad: "*I value [my doctor] so very much [...] She really is dedicated to the business of medicine and helping people. [...] There is an entirely different group of doctors who are only interested in how much money they can make. And there are others who like to write papers or become famous*" (P5).

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[2] Study materials including the interview script and surveys can be found here: https://leysann.github.io/sharinginagedcare/interviews.html

[3] Some of the participants had several care-giving service providers at the same time.

Table 1: Dimensions identified in the interviews and discussed in the paper as affecting sharing

Dimensions	Sub-dimensions	Definitions
Recipients	Family members	Relationship with people with whom information is shared
	Friends, neighbors, other residents of senior care facilities	
	Professional medical and care staff	
Purpose	Desirable	Positive/beneficial expected purpose of use
	Undesirable	Negative/harmful expected purpose of use
Data	Functional relevance: relevant, irrelevant	The applicability of information to fulfill the purpose
	Urgency: critical, non critical	The degree of importance of the information
	Granularity: detailed, not detailed, intermediate	The level of detail of the information
Delivery	Frequency: regular, irregular, event-based	Regularity of communication episodes
	Channel	The medium of information sharing
Individual Attitudes	Privacy: concerned, unconcerned	Attitudes to information privacy
	Anticipated emotional reaction	Anticipated emotional response of information recipients
	Control: high degree, low degree, conditional delegation	The level of control over personal data and life decisions

In the **Family–Staff** dyad, some families choose a participatory approach: "*Not only does my daughter go to my appointments with me, my son-in-law, her husband goes also, frequently when he can*" (P6). Others believe the involvement of family is not necessary or even detrimental: "*Personally, I would not want to have my family involved because they have really nothing to contribute to the solution of this problem [...] In fact, family is in the way*" (P5).

Regarding the relationship of care professionals and families, participants believe that "*there has to be trust, but there should be collaboration. [...] If you need medical help or supervision of some kind they should cooperate. [...] If the family is close. [...] If you have nothing to do with the family then you probably don't want them to know what your problems are*" (P2).

Participants also mentioned information exchanges without their involvement. For instance, seniors usually do not object to sharing information between staff members (**Staff–Staff**), because it improves care and facilitates the coordination of multiple conditions, chronic diseases, or sophisticated medication and treatment plans. However, information exchange between doctors is not always transparent: "*I am amazed when I look on the records [from my gynecologist] and I see something from my internist. [...] They know exactly what [medications] I take, [...] and it's like a miracle*" (P8); "*I don't know what my [new] doctor [has], she must have my files, because I guess [the recently retired doctor] gave them to her*" (P2).

Similarly, in the **Family–Family** dyad, participants are typically not bothered if family members exchange senior's HWBI directly, or assign one of the members to disseminate it to other relatives: "*I don't know what information my son gives to my daughter. That is up to him and that is fine with me. I have no secrets*" (P10).

Friends and neighbours, while not considered formal or informal caregivers, are often involved in information sharing as well: "*I talk very little, because this is actually a small close community. [...] [Other residents] are always very interested in everything, or everybody [...] That's fine. I don't mind that. I would rather have people be interested in me and checking on me than not at all*" (P6).

4.2 Dimensions of Sharing: Purposes

Our participants described different reasons for accessing their personal information that were both desirable and undesirable. The most common **desirable** purposes of HWBI use include health diagnostics and monitoring, emergency notifications, professional care provisions and family assistance, followed by the delegation of end-of-life decisions: "*I don't have a problem with [sharing health records]. [My adult children] have to make the final decisions when I can't make them. So that is why I make sure that they are up to date on everything*" (P6).

Another reason to disclose was to share the knowledge and best practices related to medical treatments, or personal experiences with doctors: "*If anybody else is considering this kind of surgery, it would be good for them to know that I had it and I would be willing to share with them any information that I had about it*" (P6).

Some seniors believe that collecting HWBI for personal use "*would be a fun experiment*" (P3), and can educate or motivate self to stay healthy: "*I don't set any records, [...] but at least 5,000 [steps] a day is my objective*" (P1). This information may be shared with others, as far as the intentions of such disclosure are not misinterpreted: "*[The doctors] will ask [about my physical activity], and I have shown them [Apple's Health] app, 'Oh look what I did.' But it does seem like you are bragging on yourself*" (P1).

Even though sharing with family and staff members is generally perceived as safe and beneficial, three respondents mentioned **undesirable** purposes of HWBI use, such as fraud or public release of their private data: "*I had [a caregiver] doing paperwork before I had a stroke, [for] a number of years, but then she ended up forging my signature and changing–so even though I trusted her, her husband needed the money, and so she did [the] forging*" (P7).

Some participants had only vague ideas about how information could be misused: "*To what advantage I don't know. I mean what would be the benefit for a doctor to give false information?*" (P3).

Finally, one participant was deeply concerned about data-driven business models: "*In theory I would say to have information is always a good thing. [...] In practice [...] most of that information is used for [...] for-profit business [...] not to provide me with information*" (P5).

4.3 Dimensions of Sharing: Data

We observed that the willingness to share information depends less on the data type or its sensitivity *per se* than on specific *attributes* of the data. Among prominent parameters, participants mentioned functional relevance, urgency, and granularity of the content.

Functional relevance defines the applicability of given information to fulfill a specific purpose or achieve an intended goal. Relevance is primarily associated with practical usefulness, such as help in an emergency situation, diagnosing a condition, or carrying out end-of-life decisions: "*I would only want to share with someone who is going to help the medical situation*" (P12); "*The only involvement [in care] that I in any way look for or advocate would be one that was effective in solving the problems, but not just for feeling good*" (P5).

In addition to practical relevance, emotional support, and expression of care were important to many respondents: "*[Sharing] information, especially like trend data [...] is the equivalent of having somebody come and visit you every day and check you out*" (P4).

The opinions of older adults and caregivers about relevance may or may not align. In some cases, information is deemed relevant by both the older adult and the caregiver: "*There is talk of wearing a monitor all the time, so they would know what is going on with my blood pressure. I would be very interested in knowing this and the doc would too*" (P1). Relevance may be associated not only with the benefits to older adults, but to others: "*I would [share] if I thought it was something that [my children] could benefit from [or] possibly inherit [...] otherwise no*" (P8); "*Something that is going to affect the length of your life, the kids should know about it*" (P1).

Some information is deemed irrelevant by both older adult and caregiver: "*That's how I feel, and everybody in my family feels: [...] if we can't do anything to help, let's not get in the way just to make somebody feel better*" (P5); "*My blood pressure is taken when I go to my doctor. Sometimes it's months. [...] He doesn't want anybody to take it in-between and it has worked out very well that way*" (P12).

Sometimes information is deemed relevant by the caregiver but not by the older adult (mentioned by 4/12 respondents): "*If you are independent, you don't need a lot of support. [...] The support staff has their hands full. They don't need to be bothered*" (P3). Professional care may substitute family care, alleviating the need for extensive HWBI sharing with family members: "*That is why I moved here [...] to not be a burden on my family. [...] One of the reasons for being in a place like this is your guarantee to have somebody who is looking out for you professionally. [...] That is another reason why I don't have to share so many stuff*" (P4). The lack of interest may also be *assumed* by the seniors rather than explicitly expressed by the recipients: "*Son [...] is too busy to be bothered. In my opinion. He wants to know, but I don't want him buried under information*" (P1).

Finally, in some cases (mentioned by 3/12 respondents), information is deemed relevant by the older adult but not by the caregiver. Such misalignment of views presents a particular challenge for communication design. For instance, one common situation is when older adults are ready to share more information with the family or want them to be more engaged, but the family does not respond with much interest: "*I would show [health records] to the kids if they wanted to see it [but] they never say, 'Hey I want to see it mom'*" (P8).

This lack of interest is sometimes accompanied (or maybe even caused) by the limited understanding of medical terms or conditions. In response, some family members actively seek information and are eager to learn: "*If there is something that bothers [my daughter], she doesn't think I explained it to her or she understands, or there is anything she has questions about, she calls the doctor*" (P9). Others do not attempt to fill this gap in their knowledge: "*[If my son doesn't understand something about my medical health] he doesn't call. He doesn't know my current doctor and I've had her like ten years*" (P11); "*[My son] doesn't want to know too much. [...] He thinks I am gone forever*" (P7). Even when presented with an abundance of information, many families choose not to face reality: "*[My son] knows what the normal range is [...] but [...] he does not like even thinking about me not being perfectly [healthy]. [...] He hasn't accepted the fact that I could die tomorrow*" (P11).

Urgency is the degree of importance of the information. In our interviews, we identified 2 levels of HWBI urgency: non-critical (routine events) and critical (emergencies, major changes). Despite having similarities, relevance and urgency are different concepts: relevant information may be non-urgent, but instrumental in achieving a goal; urgent information may be important in certain contexts, but not relevant for fulfilling a particular purpose. While urgency relates to the situation and can be assessed (somewhat) objectively, relevance relates to the recipient's subjective perceptions and attitudes.

The more critical the information, the greater the willingness to share it: "*It has to be tragic before I tell [my son]*" (P10); "*I don't think it's necessary. If I am in crisis it would be*" (P9). However, too much routine information could distract focus from something critical: "*I think routine stuff would be overkill. But I think communication would lose their effectiveness unless it was a real problem*" (P1).

Granularity is the level of detail of the information. We distinguish between detailed, intermediate (trends, deviations from norms), and not detailed (summary) information. The optimal granularity of information depends on recipients' engagement in care, comprehension of medical information, and the importance of their involvement to fulfill the end goal. For instance, thorough conclusions of a medical examination without quantifiable test results may be considered detailed by a family member without medical background, but not by a medical professional. However, family roles and needs in the context of chronic long-term care evolve, as the family becomes increasingly educated about a condition: "*[My niece] learned over time what my particular diagnoses are, how serious they are [...] and how they affect me physically*" (P4).

Additionally, context and urgency matter: simple summaries are typically sufficient for daily monitoring ("*They only want the high points. How do you feel? Are you feeling any better? What are you doing about it?*" P6) but they may not be enough in critical situations ("*I think trend data would be more useful. My niece is very busy. I don't think she would even look at it on a daily basis unless [I] was critically ill,*" P4). Whether deviations from the norm are worth sharing depends on what side of the urgency spectrum participants are on. For instance, frequent small deviations and '*little aches and pains you don't put on the big deal*" (P10), while large unusual deviations and consistent patterns become "newsworthy," i.e., "deserving to be shared" [3, p.6], especially if they require the attention of medical professionals. Importantly, older adults believe that for deviations from norms to make sense, they should be customized and considered in relation to personalized trends: "*I would like to have my health measured [and to] be compared to my normal, not to the world's normal*" (P5).

Individual abilities and preferences in information processing and visualization also play a role in defining optimal granularity and format of data representation: "*[My son] is a summary person.*

My daughter is a detail person" (P11); "*It depends on whether you are a visual learner. Some people like graphics because they are more visually oriented. Some people are text oriented, so reading is better than graphics [for them]*" (P4).

4.4 Dimensions of Sharing: Delivery

The way information is shared—defined by the frequency and channels used for information delivery—affects participants' opinions about information disclosure. We found that the main challenge for identifying the optimal frequency and channel of communication is to balance the quality of care and response in critical situations with information fatigue, intrusiveness, and usability.

Frequency of information delivery, or regularity, can be split into 3 groups: regular (or periodic), irregular (on occasion, without hard rules), and event-based (triggered by a specific situation). While more regular information exchange provides a potential for better care, 6/12 respondents mentioned that too-frequent sharing could result in information overload and overwhelming the recipients, as "*they have their own families that they are looking after, I just wouldn't want to add to and give them a lot of other information because after a while if you get a lot of other information it gets pushed aside*" (P6). "*A barrage of information*" (P6) is excessive for seniors themselves, too, because it "*doesn't mean anything to me*" (P10) or because they "*don't want to become neurotic*" (P9).

Channels of information delivery indicate the medium of information sharing. Communication channels may be digital—including online (email, patient portal, video conferencing, social media), and offline (calls, text messages)—as well as paper-based (mail, print) and in-person. While traditional communication channels, such as phone calls and in-person conversations, remain prevalent among our participants, older adults appreciate that electronic health records keep their complete medical history in one place, and can be used by or exchanged between doctors: "*Every time I see a new doctor [they] go and read my record*" (P4).

However, for personal use, older adults often prefer to keep paper records: "*I haven't had any need to [use patient portal]. Every time I leave [doctor's] office, I have three or four sheets of paper, so I think they have given me all of the information that I need. [...] Sometimes they send me emails to confirm an appointment, but I am very good about my appointments and so it is usually not necessary*" (P6).

At the same time, 8/12 respondents appreciated the convenience of electronic channels for communicating with doctors and family: "*You have to go [to the doctor] if [...] they need to examine you, [...] but otherwise I manage my medical condition by email or telephone appointment mostly. I could have a Facetime appointment if I wanted without us having to figure out [the logistics]*" (P4). Using ICT channels is also helpful in communication with remote family members: "*I have an iPad. That's how I hear from my son from Switzerland. [...] I have six grandchildren spread across the country. Once in a while I will Skype with [them]*" (P9).

Beside facilitating the direct interaction, ICT provides room for improvement of the quality of care: "*A friend of mine has a pacemaker and he puts his phone up to the pacemaker and that transfers to his physician. That stuff's great*" (P8). One participant sees potential in even more progressive use of technology in health care so that "*you wear something, and it takes your vital signs, if you do anything, shiver, all of these things can be [monitored 24/7]. And whenever my readings are off [...] a signal goes up automatically and somebody [...] would call me up, call the doctor*" (P5).

Our participants appreciate the opportunity to learn through ICT about their medical conditions:"*[...] this helps with the recovery. If the patient knows what they are going to get and knows what to expect*" (P6); "*if somebody is going to say, 'Let's prescribe a medication for you,' I'm going to say, 'Well, what's it for? What's the advantage of that one over the one that I am currently taking?' [...] We discuss things, and I do my own research too. [...] It's a lot of work, but it's also kept me alive, basically*" (P4).

Generally, older adults try to use whatever channels are least disturbing to their caregivers, except in emergency situations, when an immediate response is required. Oftentimes the choice of communication channel not only depends on, but even signals, the urgency of the situation: "*I would never call [my son] at work. I'm texting. If something bad happened to [his mother] I'd call him [...] If I called him during work, he would be worried 'Oh my God, what has happened!'* " (P1); "*I communicate with my doctor by email [...] I don't want to be interrupting her with a telephone call. You answer whenever you are [available]. [...] I only call when there is a good reason for it*" (P5).

Nevertheless, while ICT adoption grows, many older adults "*like personal contact. I don't like to do this with the technical stuff*" and they are "*concerned about losing human communication*" and feel that "*there are so many new devices around. Apparently, you don't even need to see a doctor, you can talk to your screen. I don't like it*" (P2). Hesitation to use ICT channels is also related to:

(1) **limited or no access to electronic means of communication, or lack of knowledge:** "*I haven't figured out how to send photos [to a doctor from a phone] through that or do a report, but evidently in the system it's possible to do that, maybe through computer. I don't have a computer*" (P4);
(2) **concerns about data integrity related to technology:** A violation of integrity does not have to be a result of purposeful change or misuse; it can be just a mistake due to human factors: "*I don't think [electronic records are] that terribly accurate. [...] Somebody will either not hear you correctly or they change something*" (P4); "*When I got home, my medicine was changed [...] somebody along the line made a mistake*" (P10). Changes related to advancement in medical research may also invalidate information: "*Twenty years later the medical knowledge about this has changed [...] The finding that they had made [twenty years ago] about blood factor was incorrect*" (P4). Furthermore, older adults find it difficult to correct mistakes in personal records: "*I don't think you can change [the electronic record]. You can just tell the next person that it is not accurate. You can't go back and actually change things*" (P4).
(3) **concerns about reliance and data loss:** "*I'm not sure what happens to [email]. [...] I think it's probably better to just fax it directly, [and doctors] know how to [...] put it in your medical file. [...] Otherwise you might lose something important*" (P4);
(4) **usability issues:** "*I don't want somebody texting me. [...] call me on the phone. I don't want to sit and type on my little phone*" (P4); "*I don't use email. [...] My eyesight is worse, and reading is worse. I'd prefer human contact*" (P2).

4.5 Dimensions of Sharing: Attitudes

Individual privacy attitudes and concerns, anticipated emotional reactions, and desired level of control over personal data affect older adults' opinions. Moving to a care facility "*narrows down*" (P3) their world and forces them to give up some privacy and control.

Privacy attitudes split our 12 respondents between 7 who are generally unconcerned and 5 who tend to be concerned about privacy. The unconcerned consider their lives "open books": sharing HWBI with family, friends, and care professionals does not bother them, and is seen as indispensable, especially if they have good relationships and trust: "*The family should know what goes on and what went on. It's important that you don't keep secrets*" (P10).

Some seniors are not aware of potential risks or believe their information is not valuable (in line with the "nothing to hide" argument [30]): "*I don't think [a fitness tracker like FitBit is] intrusive. I have no idea what they do with that information. I guess that could be intrusive. [But] I wouldn't object to wearing it. I lead such a bland life, I have no reason to object*" (P3).

While regulations aim to protect seniors' information, some see them as burdensome: "*Under HIPAA, [staff] could only share certain types of information in certain types of situations. [...] But there are certain situations that I would want my niece to know more*" (P4).

However, 5 of 12 participants said they would not share their personal health information due to *privacy concerns*. Those concerns are sometimes triggered by the potential use of data for malicious purposes discussed in §4.2, or simply because some topics are considered more sensitive than others: "*I don't share financial information. And I don't discuss religion*" (P3).

The specifics of the institutionalized care environment also affect privacy attitudes. Respondents often see their senior living facility "*like a small village and everybody pretty much knows what goes on around here and that is why I don't talk a lot about some things*" (P6), "*My world has really narrowed down over the years. [...] So, the friendships that I have are here. And we are all pretty reserved about what we talk about. [...] Your world gets smaller and there isn't a lot to confide to anybody*" (P3). Seniors admit that "*one gives up a certain amount of freedom when you move into any facility like this. [...] Of course, when I was living alone in a house, my next-door neighbors didn't know [everything] and couldn't care less*" (P3).

Respondents typically "*trust [care facility staff]. I never had any objection since I moved here*" (P3), because "*there have been so many lawsuits they are just scared to death on privacy*" (P1) and "*the people that run the [care facility] are very very aware of privacy. If you want to know something about someone, ask the someone, don't ask the nurse on the floor or whatever. [...] Gossip is gossip*" (P8). Nevertheless, constant surveillance may make them feel vulnerable and uncomfortable: "*It would bother me to be monitored 24/7. I'm already bothered by 24/7 surveillance anywhere*" (P2).

Business practices related to the trafficking of personal information are trusted less: "*Mr. Zuckerberg [...] is more interested in having [his business] grow fast. That's his model. So, he is far far removed from worrying about what happens to that information. He couldn't care less*" (P5).

Power asymmetries and limited control and transparency dilute seniors' confidence in privacy and security protections: "*It's protected. There's supposedly no way that people who aren't allowed access [to] it can have access to it. Now whether they do or not, I don't know. If somebody is breaking, or looking at my medical records who is not authorized, I have no idea. I have no way of knowing*" (P4).

Finally, legal and technical policies do not guarantee protection against privacy violations resulting from staff negligence: "*[S]upposedly if you go to the doctor they look at your medical record and you hope that they close it up when you leave so that some nurse or somebody else walking in the room doesn't look at it [...] but who knows what they do in their office*" (P4).

Anticipated emotional reactions are another driver of seniors' sharing habits. For example, some mentioned sharing information to mitigate family members' worries: "*[Children] feel better [after talking to my doctor] [...] they really want to feel comfortable and to know what's going on*" (P9); "*[My family] would be concerned but they would know that I am aware of [the spike in the blood pressure] myself and I am doing what is needed*" (P6).

Some older adults do the opposite and limit information sharing to protect their families from worrying about them: "*It depends on the individual that is receiving it. I guess for some patients, more might be too much because it would make them nervous [...] And I guess it depends on [whether] it's reassuring rather than worrying*" (P6); "*After I find out what's wrong and everything, then I will share. There is no point in sharing with [children] now. I don't know what it is*" (P8); "*I don't paint too bad a picture [...] I make things as light as I can*" (P12).

Sometimes the act of recipients requesting information is seen as an expression of care, and a reason to be proud of their caring family member: "They are all concerned and they all pay attention. I let them" (P9) "*My son was there all the time I was in the operating room and talked to the doctor afterwards. [It] makes me teary to talk about it. He's just so caring and he will want to know what the doc said*" (P1); "*Some of the people here say that they are jealous of me because I have so much family support*" (P6).

Embarrassment was not frequently mentioned in our interviews, perhaps due to generally trustful and close relationships within the triad of care. However, several participants were concerned about potential misinterpretation of their intentions to disclose. One participant was concerned that explicit disclosure of his relatively high physical activity will make it "*sound like he is bragging on himself*" (P1). In contrast, excessive sharing of negative information about one's health may appear to others as nagging and whining: "*Once in a while I'll say, as everybody else, 'I had a horrible night.' [But] I don't come every day and say, 'I didn't sleep well today'*" (P2).

The level of control over personal data or life decisions that respondents find optimal vary along 3 degrees: high, low, and conditional acceptance of delegation of control to others.

A high degree of delegation of control usually happens in families with close relationships: "*I have that set up through a lawyer so that [my children] can make health decisions for me and I am very comfortable with any one of them doing it*" (P6); "*My son takes care of everything now. We used to take care of ourselves. But when I came here, everything had to be changed. I said, '[...] Change is all up to you. Financial. Insurance. The whole spiel.' Anything that comes in the mail, I don't know what it's about. I leave it for him*" (P10).

Other seniors stated that maintaining control is crucial, and giving it up is an uncomfortable or even traumatic change, so they prefer to keep a low degree of delegation: "*I just can't stand a loss of* *control. I don't feel comfortable at all. I had to put my daughter on my checking account. [...] it killed me when I had to do that. [...] Nothing is private, but I want to take care of it myself. [...] It is a control issue, not a privacy issue*" (P9); "*I always have the last word*" (P12).

Conditional delegation of control depends on explicit consent and permission granting, transparency, relevance, and urgency: "*I would like to be aware of what is shared*" (P3); "*I don't mind the communication between [my family and doctors], but I'd like to have a say if [...] I can still choose. I would like to be in on the decision. And I would take my daughter's judgment, if I'm no longer capable*" (P2).

Even when older adults have control over the formal flow of information, they cannot avoid inferences or implicit data collection: "*The clinic knows we go [to the gym] regularly because the way it is positioned you come out the back door of the clinic and you are in the rehab gym, so the nurses will see us in there*" (P1); "*I am in a position where everybody can see what my health is*" (P12). Some facilities use social mechanisms and even encourage the implicit information exchange as "*an additional check of keeping track of [each other]. [...] If they don't show up at the breakfast table, I know our eight people, we'll call them after breakfast*" (P1). Others described monitoring systems: "*Security goes around at night and puts the tag on. If the tag still is up at 9:30am, the housekeeper, the receptionist calls and if there is no answer, then security goes in*" (P3). Typically older adults accept such implicit monitoring because "*that makes me feel safe. That's one good reason for being here*" and prefer it over wearable devices as they "*don't want to carry, wear anything*" (P2).

5 DISCUSSION AND CONCLUSIONS

Aged institutionalized care is a pervasive process that involves multiple stakeholders whose motivations, opinions, and interests may not always align or be clearly expressed. Willingness to assist, provide care, and emotionally support often competes with the burden of redundant information, worry, privacy concerns, and legal boundaries related to HWBI sharing, posing challenges for the design of effective communication. In this section, we discuss the tradeoffs and suggest design implications to support communication in the aged care context.

5.1 Relations among Sharing Dimensions

Among the factors discussed, older adults unanimously use the purpose of use as a "sanity check" when making decisions about information sharing. Unsurprisingly, they are more willing to share HWBI with trusted recipients and expect them to use personal information favorably. However, the benevolent end goal alone is not a sufficient prerequisite for information exchange, and therefore other factors are considered. In this section, we illustrate how the interplay of purpose of use, functional relevance, urgency, anticipated emotional reactions, and individual attitudes all define the most appropriate data granularity, communication frequency, and channel for sharing information with a certain recipient.

5.1.1 Choosing recipients based on information relevance. For effective care communication, recipients need information that is useful for intended goals, e.g., making changes in a treatment plan, executing end-of-life decisions, or providing emotional support. Information relevant to one recipient may be less or more important to another group, depending on the urgency of the situation, recipients' role and involvement in care, and interpersonal relationships. The combination of urgency and relevance is often referred to as "newsworthiness," describing events that "deserve to be shared" [3, p.6]. For example, in situations where urgent medical assistance is required, health care professionals should receive all necessary information first, while the family notice can be suspended until the diagnosis is verified, to avoid unnecessary worry. If a situation requires family decisions, the priority of involving a health care proxy in decision making grows. Finally, information about how an older adult spent her day may be of high relevance to the family, but irrelevant to medical professionals. Therefore, it is important to consider the priority and level of relevance when designing the communication in a care triad.

The views of older adults, their families, and staff on the relevance of information may not always align. Designers should be mindful about framing to avoid direct confrontation or opposition of views. The communication platform may allow users to customize the priority of informing various recipients, and facilitate the collaborative and informed agreement between them, e.g., by encouraging users to make their preferences visible to each other. Moreover, after receiving shared data, the lack of a recipient's response due to constrained time may be misinterpreted by seniors as a signal of low relevance of this data or lack of interest, resulting in decreased self-motivation to continue close monitoring of health. Design solutions providing the necessary feedback about "quantified self" may fill this gap and encourage older adults to control their health and promote interventions aiming at improving it. The platform can also remind recipients that even if they are not able to help directly, it is reassuring to elderly people to simply know that family stays up-to-date.

5.1.2 Communication frequency based on urgency, relevance, and individual attitudes. Generally, event-based sharing is important for emergencies or critical deviations from norms, while irregular information exchange is optimal for communicating relevant-but-not-urgent information. Regular information exchange may be limited to brief updates about a patient's overall status or health metrics. To ensure relevance, non-critical (routine) information may be made available on an on-demand basis instead of being disseminated in a top-down manner. Recipients' requests to share data may even signal to older adults their interest in engaging in the care process. However, designers should ensure that information exchange occurs with informed consent and is aligned with seniors' preferences for privacy and control. As transfer of control occurs gradually, depending on elders' health and functional status [6], the delegation process should be dynamic to maximize autonomy.

5.1.3 Information granularity based on information relevance, and characteristics of recipient. We identified that too much information is overwhelming for both seniors and caregivers, especially when information is too specific or does not match the recipient's level of knowledge or cognitive style. Interactive screens may be helpful in minimizing information overabundance. For example, a preview screen may contain an overview of the patient's general state, including a graphic representation and short textual summary that are comprehensible for a lay person. Designers should explore and thoroughly test the use of metaphors, icons, and other graphic elements to ensure clarity and uniformity of understanding across individuals and cultures. In emergencies, this screen should also display notifications containing critical information. To educate older adults about their medical states, promote healthy lifestyles, and mitigate worry and concern about medical treatments, additional details and more granular information can be made available to interested recipients, by using, e.g., a "learn more" button, videos, "serious games," and interactive materials.

Designers should allow users to set preferences and defaults, and switch between different formats of data visualization (e.g., images, audio, video, text, numbers) to accommodate different information processing styles. We also encourage designers to use our framework, when rationalizing about design elements, and explore how data visualization strategies relate to urgency, relevance, granularity, frequency, channels, and individual attitudes.

Deviations from norms should be personalized according to the limitations related to age, ailments, and personal and family medical history (and therefore predispositions and risks). Furthermore, our participants were interested to know not only the trends and spikes, but also the reason for a specific deviation.

Communication platform designers may facilitate conversation between older adults and recipients to establish the appropriate level of granularity for exchanged information. Older adults could choose the maximum levels, and recipients could choose the modality of visualization within that range. In the beginning, the explanation of medical information using accessible language can enforce the engagement of family members in the care process and improve the emotional well-being of older adults. As family learns about the particular condition, the granularity and depth of information may be adjusted accordingly.

5.1.4 Delivery method based on urgency and established communication style. The channel is not only a medium for communication, but also a signal about the urgency of the shared information. Phone calls often suggest that something important has happened, therefore, use of this channel for communicating non-critical events may cause unnecessary worry. Text-based channels do not require or guarantee immediate response, and thus are more suitable for the communication of non-critical information. Because the associated meaning and convenience vary based on individual preferences and established communication "etiquette" (defined by internal culture and rules within the communication dyad), the sender and recipient should be able to choose and agree upon what communication channel works best for both of them.

Moreover, designers should be careful in framing positive and negative messages, and emphasize the intentions of a person disclosing information to avoid misinterpretations. For example, to avoid positive HWBI appearing overly optimistic or boastful, affirmative signals about patient's good health may be presented as a recovery progress together with a note about best practices and effective therapy methods. Such framing will be positively received by family, will provide feedback on effectiveness of the treatment plan to the staff, and will set an example for peers. Similarly, sharing negative information about health is important and expected to be met with compassion, but sometimes provokes annoyance or is perceived as nagging. Therefore, providing an opportunity for the recipients to request information may not only satisfy their desire to express care, but also to reduce older adults' fears to appear bragging or grumpy. However, designers should be cautious to not turn the absence of recipient-driven requests into a signal of disinterest.

Generally, older adults are more comfortable with electronic channels for *communication* purposes (e.g., exchanging emails with doctors) than for *information storage and retrieval* (e.g., patient portals), in which case they mostly prefer paper documentation. However, they do not oppose the use of electronic means for the exchange of information *between other actors* without their involvement (e.g., between doctors). The reluctance to use electronic means is often related to: (1) suspicion about channels' reliability (i.e., fear of losing important data or introducing mistakes), (2) lack of knowledge about how to use them, (3) limited or no access to the devices or services, and (4) usability issues (e.g., physical limitations, such as small screens or low acuity due to hand tremors).

To overcome these issues, designers should provide "tips" or an introductory platform "tour" to facilitate the on-boarding process and encourage new users. Designers can follow the state-of-the-art accessibility and design guidelines[4] for older adults to improve usability of their systems and interfaces [26]. Finally, designers should embed in their platforms the functionalities that allow for printing of materials easily (e.g., using single-click highly-visible buttons), which will help to address reliability concerns, and mitigate opposition and reluctance during the transition from paper to electronic records.

5.2 Care Facilities and Information Sharing

In order to provide the best quality of care, institutions often install monitoring technologies, as well as implicit mechanisms of checking on older adults, which result in constant surveillance. Such 24/7 attention from care staff removes the necessity for high engagement in care with family members, and therefore minimizes the need for HWBI sharing with them. Moreover, long-term care facilities are obliged by law to respect confidentiality, therefore they are deemed to be safe and private. (Indeed, we did not observe many privacy concerns regarding information sharing within the care triad among our respondents.) In rare cases, participants saw legal privacy protection mechanisms as a barrier to effective information flow, which raises questions about the unintended consequences of some of these regulations and their implementation.

However, deteriorating health conditions and transfer to higher levels of care often require extensive delegation of control. Moving into care facilities requires extensive sharing of information, including full medical records, with management and care staff, and therefore, giving up some privacy and freedom. A few respondents admitted that their privacy can be violated (by mistake, if not purposefully), and are not fully confident sharing their personal information with caregivers, companies, or "non-medical people." Finally, the community within a care facility is a world that has been "narrowed down" to a size of a "small village," where "everyone knows everything" about each other. Older adults accept the necessity and trade-off, but feel vulnerable, and express desire to maintain control as long as they can. Thus, addressing privacy

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[4] http://design-review.mateine.org.

concerns related to HWBI-sharing in the institutionalized care environment may reduce stress associated with diminishing autonomy and further increase the satisfaction with the quality of care.

5.3 Limitations and Future Work

The participants recruited for this study might not be representative of the general population of this age group (70+ years), as the majority of them were female, white, self-reported as being relatively healthy, highly educated, and experienced in using technologies. Our qualitative study provides insights and identifies the dimensions of sharing, while future (large-scale) surveys may investigate the prevalence of opinions in the general older adult population.

In future research, we plan to complement our current work with the perspectives of older adults living independently (not in senior care facilities), their family members, and care staff, to compare the views of all stakeholders of the care triad. We also plan to involve all actors in collaborative participatory design and role-playing sessions, to further explore the dynamics in communication within the care triad and refine the design recommendations.

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