





Helping People to Control Their Everyday Data for Care: A Scenario-Based Study

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Abstract. With the advent of pervasive sensing devices, data captured about one's everyday life (e.g., heart rate, sleep quality, emotion, or social activity) offers enormous possibilities for promoting in-home health care for severe chronic care, such as can be found in Spinal Cord Injury or Disorders or the like. Sharing these Everyday Data for Care (EDC) allows care team personnel (e.g., caregivers and clinicians) to assist with health monitoring and decision-making, but will also create tension and concerns (e.g., privacy) for people with health conditions due to the detailed nature of the data. Resolving these tensions and concerns is critical for the adoption and use of a pervasive healthcare environment.

We examine data sharing of EDC to determine how we can better manage the tradeoffs between privacy on one hand and the pro-active sharing of data that one needs for better care. In this paper, we target one critical aspect of using EDC, the problem of sharing an overwhelming number of sensor outputs with numerous care team recipients. We report the results of a scenario-based study that examined ways to reduce the burden of setting policies or rules to manage both the pro-active data sharing and the privacy aspects of care with EDC. In summary, we found that our participants were able to use self-generated groupings of EDC data, and more importantly, largely kept those groupings when creating to share data with potential recipients and when dealing with changes in their health trajectory. These findings offer hope that we can reduce the burden of authoring and maintaining data sharing and privacy policies through semi-automatic mechanisms, where the system suggests policies that are consistent with the users' preferences - especially as health changes.

Keywords: Data sharing · Patient-generated health data · Chronic care · Privacy · Control · Self-care · Care team · Care network

1 Introduction

Support for people with chronic diseases is becoming more important in the US and around the world [68]. In the US, it is estimated that 6 out of 10 adults

have a chronic condition [26]. Because of this, there has been extensive interest in supporting people with chronic conditions in the Computer-Supported Collaborative Work and Social Computing (CSCW) community [9, 20, 41, 63, 76, 80].

Recently, using data captured during one’s everyday life for supporting care, or Everyday Data for Care (EDC), has received significant attention from the research community (e.g., including Observations of Daily Living (ODLs) [70] or Patient-Generated Health Data [30]) as well. EDC are defined as data captured about the everyday life of people with health conditions that could be useful for care, including data such as heart rate, fluid intake, sleep quality, and loneliness. These data could be generated automatically through sensors in a pervasive healthcare environment, wearable devices, or captured by care team members of people with health conditions. The use of EDC could provide benefits by bridging the hospital and home care environments by extending the monitoring of people’s health outside of a traditional medical setting.

To unlock the full potential of EDC technologies while protecting the concerns of people with health conditions¹, we are examining how we might support people in their use and dissemination of EDC. Based on the prior literature:

- We want to achieve appropriate *data sharing* for *care*. Data sharing not only includes the protective aspects of privacy, but it also has a pro-active component. For care, it is critical to consider disseminating the necessary health data to actors who can help. In general privacy research, some authors consider both aspects of data sharing, but others do not. Following Kariotis et al.’s call [44], we use the term “data sharing” to foreground both the protective and pro-active aspects of dealing with EDC data.
- Data sharing must be done in the context of care teams. People with severe chronic conditions often need to rely on teams of people who help with daily life, including self-care [4, 19, 20, 80]. Care teams are critical in supporting the health of people with health conditions. These care teams consist of the person with a health condition and caregivers (family members and/or paid/volunteer staff), who provide immediate day-to-day care, as well as clinicians [35]. Care teams are often dynamic, adding and losing members as health conditions change and as members turn over [20]. For illustration here, we consider spinal cord injury and disorder (SCI/D) [61], where the condition is life-time and where care teams of 10–20 people are not unusual.

To do this, we are exploring the designs that promote the following goals:

- Data sharing should be under the control of the people with health conditions or their surrogates to allow them take an active role in conducting care [8, 9,

¹ We use the term “person with a health condition” interchangeably with “patient” in this paper, to emphasize her identity as a human being. We recognize the unfortunate connotations of “patient” in that it privileges the medicalization of care and the clinical participants in care. However, we use “patient” in some parts of the paper, such as in the related work, to avoid confusion and to maintain consistency with some existing literature.

35,63]. We want to find ways to allow people to control their own data sharing, instead of putting it under the purview of large corporations or healthcare systems [44].

- If data sharing is to be under the purview of individuals, we have to keep the control from being overwhelming. With severe chronic care, a person with a health condition is likely to need to change sharing settings as their health deteriorates, a time in which they may not be able to focus or find the energy to do so. Moreover, this will become an increasingly difficult problem for users as healthcare sensors become cheaper and proliferate.

In this paper, we report a card sorting study to investigate whether EDC could be shared in groupings (i.e., grouping EDC types together as units to be shared) to simplify configuration. In short, we found our study participants were able to create groupings based on sorting Everyday Data for Care (EDC) into 5 bins based on their levels of comfort about sharing the EDC. More importantly, these groupings demonstrate their utility as high-level units that allow participants to discuss how to share EDC with care team members conveniently, as opposed to describing sharing settings for each EDC type. The use of these user-generated groupings allows us to observe people’s inclination to share more EDC when a person’s health deteriorates.

We view these results as preliminary but provocative. The findings suggest possibilities for creating new technical mechanisms that can help patients and caregivers in severe chronic care, and they also may resolve some of the difficulties of setting privacy policies overall.

Our contributions, then, from these results include:

- Showing that users can create groupings of EDC data that are meaningful to themselves and can be used to create EDC data sharing settings. Users can easily create these groupings.
- Demonstrating that our participants could reuse these user-defined groupings as high-level units to specify sharing settings in study tasks, implying that it may be possible to create stable groupings for each user that would simplify creating and potentially maintaining data sharing and privacy settings.

In the following sections, we first review related work on care team collaboration, everyday data for care, and support for data sharing and privacy. We then describe our study design, data collection, and analysis. We next present our findings. We conclude with implications for designing interactive systems to facilitate the creation and maintenance of sharing and privacy settings, as well as discuss the limitations of our study and future work.

2 Related Work

2.1 Chronic Care

With the prevalence of chronic conditions [26,68], how to support chronic care becomes an important challenge to tackle. Chronic care refers to the tasks and

steps that are necessary to do on a daily basis to maintain and improve health for the long term [5]. This includes adjusting routines (e.g., taking medicine), making conscious lifestyle choices (e.g., diet), and monitoring one's health at home (e.g., monitoring urination) [33,61]. As mentioned, managing a severe health condition (e.g., SCI/D) at home will often require the participation of a care team that consists of family members (e.g., as caregivers), other personnel (e.g., hired caregivers), and occasionally medical professionals (e.g., occupational therapists) so as to effectively manage different aspects of care and everyday life [4,14,19,20,80].

While early studies focused more on design to support patient-clinician [59] or patient-caregiver [14,94] interaction, recent work, including Consolvo et al. [25], has called for a design to support the care team as a whole [65], with particular attention to diverse roles, the communication structure, and the importance of sharing information [25]. Designing systems to support the entire care team requires careful consideration of the diverse expertise of team members [25], relationships among them [20], how team members with different time commitments collaborate in a loosely coupled manner (e.g., with non-overlapped shifts) [14], and how the team membership changes constantly [25]. Team members need to collaboratively monitor changes in a patient's health [19], and adapt to the patient's priorities in life [69]. This paper builds on this previous literature about care teams and examines how users' control over data sharing within care teams can be facilitated.

We next review literature on the use of data captured about people's everyday life to support collaboration for chronic care.

2.2 Everyday Data for Care

Everyday data for care (EDC) hold great potential for supporting chronic care. EDC are defined as data captured about the everyday life of people with health conditions that could be useful for care. These data could be generated through different mechanisms (e.g., including sensors in a futuristic pervasive environment or captured by care team members of people with health conditions). These data could include those that are commonly collected during clinic visits (e.g., heart rate or blood pressure), data that characterize a patient's behavior (e.g., sleep pattern) or emotional wellbeing (e.g., mood), and even contextual factors that could be influential on the patient's life (e.g., weather).

The definition of EDC is very similar to Patient-Generated Health Data (PGHD), which is defined as health-related data captured by patients or their care team members (e.g., caregivers) outside of medical environments [30]. Another term that is closely related to EDC is Observations of Daily Living (ODLs), for ODLs contain patterns and observations about patients' lives that were not traditionally included in the medical record [70]. In this paper, we use EDC to include PGHD and ODLs in order to focus on potential data sources generated from a pervasive environment (e.g., a person's home) full of different sensors that could be used to support care.

EDC's definition also overlaps with Quantified Self (QS) [77] and Personal Informatics (PI) [53]. The prominent difference is that EDC specifically focus on using data for health, while QS and PI can include anything of personal interest. In this section, we will briefly review the literature on the benefits and concerns of using EDC. For more comprehensive review (especially patient-generated health data), please refer to Figueiredo and Chen [30].

EDC could be used to support all kinds of health decision-making. However, the range of data included in EDC and the context of data capture (e.g., at home) make EDC especially applicable to severe, long-term chronic conditions such as irritable bowel syndrome (IBS) [23], and spinal cord injury/disorders [19]. As chronic care requires consistent monitoring of how the lifestyle of person with a health condition affects the person's health and life, care team members could use EDC to investigate how different factors (e.g., diet) trigger changes in the patient's health (e.g., symptoms) and quality of life (e.g., sleep quality) [45]. EDC provide an excellent opportunity for people to get involved and take an active role in understanding their health as well as decision-making. Indeed, existing work has shown multiple benefits of using EDC for them, including allowing them to understand their conditions [8], increasing their sense of control [8, 35], supporting the planning of chronic care [29], empowering them to have a voice in the discussion of their health [9, 63], and supporting interaction with clinicians [23, 76].

While EDC provide a great number of benefits, existing research has also highlighted multiple challenges. First, tracking a wide range of data (e.g., including context [8]) could be overwhelming. Moreover, every person with a health condition might have a unique perspective on what is important to track [75]. Second, people with health conditions might have difficulty making sense of EDC [22]. Third, while care team members could help to make sense of EDC, care team members might have different expectations of what to track, the purpose of tracking, and consequently how to properly interpret the data [9, 41, 55].

Lastly, people with health conditions need to share EDC to support collaborative monitoring while maintaining a sense of control [63] and independence [20]. Our work follows this line of research to investigate how people think about sharing a variety of EDC to support care while respecting their sense of control and the need for privacy (i.e., avoiding surveillance). Maintaining the appropriate balance will be crucial for the success of a pervasive healthcare environment. We next review existing work on supporting sharing control and identify gaps for further investigation.

2.3 Privacy and Data Sharing

While sharing data can support our professional [16, 17] and daily lives [81], people might naturally want to perform impression management [21, 87, 89] and avoid negative consequences such as undesirable inferences about oneself [48, 81, 84] or data being leaked unexpectedly [51, 66, 87].

Concerns about the negative effects from sharing data have engendered research centered on privacy. Privacy has been generally defined as the ability

to decide “when, how, and to what extent, information about them is communicated to others [93].”

One approach to helping people with their privacy concerns consists of technical research that augments or facilitates user control.

Considerable research has been devoted to creating and editing privacy policies (and by extension data sharing policies). Privacy policies consist of computational statements [15] in first-order predicate calculus, specialized computer languages, and the like [32, 73]. Despite this considerable research, end-users cannot or will not write and edit policy statements, finding them too complex and difficult [49, 58, 95].

Instead, practice swung to another approach to allow users to create privacy settings through easier-to-use interfaces that used toggle buttons, elaborate tables, and other user interface widgets to manually manipulate privacy settings (e.g., Google’s privacy settings). Again studies have been largely technical. This research includes designing user interfaces that allow people to control the audience [40, 50, 60, 71, 72] and data presentation [28, 74, 88, 91], as well as interfaces that provide feedback (e.g., visualization or notifications) to help people understand the effects of privacy settings [2, 3, 36, 46, 85, 86, 92]. Despite the considerable evidence that users have trouble with these privacy interfaces [42, 56], these interfaces persist.

A third approach consists of studies that attempt to understand and model people’s privacy and data sharing preferences so as to ease the burden of configuration for different contexts, including social media [78], mobile application permission [67, 79], and Internet of Things (IoT) [6, 10, 11, 21, 27, 37, 52]. For example, Choe et al. [21], through a survey, found that self-appearance, intimacy, cooking and eating, media use, oral expression, personal hygiene, physical activity, and sleep are among the most frequently mentioned categories people would not want to be recorded at home. Emami-Naeini et al. [27], Barbosa et al. [11], and Apthorpe et al. [6] found that safety and security (e.g., an emergency situation) was a prominent reason, on the other hand, that people generally would approve data collection and sharing. Similarly, Lee and Kobsa [52] and Bahirat et al. [10] have found that people would be more willing to disclose information for a health-related reason.

Additionally, there are numerous studies that attempt to create one taxonomy or classification scheme that will be appropriate for all users. For example, Li et al. [54] used Mechanical Turk to create a taxonomy of “sensitive” photo features that classifiers could use to suggest photos that every user would not want to share. Others have developed ontologies of IoT sensors or healthcare devices (e.g., [7, 43, 57, 90]) to support privacy protection in larger IoT environments (e.g., hospitals or offices).

Finally, there are a handful of studies that examine user-generated groupings for privacy, such as using groups of locations to create privacy settings for mobile applications (Toch et al. [82]) and a set of privacy profiles for social media and marketing use (Knijnenburg [47]). These studies attempt to create groupings that work for all individuals. As far as we know, there are no studies that examine

whether having users group the types of data for themselves might help users, especially in healthcare settings. In this paper, we examine the possibility of using user-generated groupings of EDC to simplify sharing in a pervasive health care environment.

3 Methods

3.1 Participants and Recruitment

The goal of our study was to understand whether groupings of everyday data for care (EDC) could be created by users for simplifying data sharing with care team members in a chronic care setting. To obtain an initial understanding of whether such groupings were possible and potentially useful, we invited participants with different backgrounds to participate in our study. Anyone can potentially have a severe chronic condition later in their lives. However, we specifically encouraged people with caregiving experience or people with a close family member who has a chronic condition to participate so that their understanding of care and navigating health challenges for a range of chronic conditions could be properly brought into the discussion on EDC sharing.

Participants were recruited in the U.S. through university mailing lists and personal networks. We recruited 25 participants, all of whom had college degrees (or above) or were currently enrolled in a college program. There were 21 females and 4 males, with ages between 18 to 63 (22 as the median). Among the participants, 24 (out of 25) participants had either caregiving experience or at least one close family member with a chronic condition (see Table 2 in the Appendix for more details, including background). We excluded the data from P20 as P20 only provided partial data for this study. Participants with caregiving experience had provided care for people with a range of conditions, including epilepsy, autism, auto-immune disease, severe motor impairment, traumatic brain injury, and stroke.

3.2 Study Design

The study used card sorting followed by semi-structured interviews to investigate the possibility of using user-generated groupings for managing the sharing of EDC. As participants might not have had experience sharing a diverse list of EDC, using the card sorting allowed participants to engage in the process of comparing different EDC types before creating sharing settings. The semi-structured interviews allowed the research investigator to follow up with participants to understand the process of grouping and sharing EDC. All the study activities were done remotely through video conferencing software (i.e., Zoom [96]) and an online whiteboard platform (i.e., Miro [62]).

To properly help participants consider sharing data in a specific chronic care context, we presented each participant with a scenario that described a person with spinal cord injury and disorder (SCI/D). The scenario was designed to

introduce the setting of a particular kind of severe chronic care that requires a care team to assist the person. Many people with SCI/D utilize moderately sized care teams (8–25 people), whose members have different roles and expertise. Furthermore, monitoring ongoing health concerns would be beneficial for many people with SCI/D [19, 61]. The scenario was realistic for our purposes: As sensors become more and more available in a pervasive health care environment, people and caregivers will have to make data sharing and privacy decisions.

In this scenario, the person was injured severely as the result of a car accident. The person then required assistance from caregivers and health professionals to manage her health and everyday life throughout her lifetime (chronic care). The participants were asked to put themselves in the role of this person during the study to consider how they would group data about different aspects of their lives for sharing with a list of care team members. This list includes primary caregivers (e.g., family members such as a parent or a spouse), secondary caregivers (e.g., family members who occasionally help), hired caregivers, primary care physicians, psychotherapists, physical therapists, healthcare system/hospital IT workers, a nurse (e.g., from a spinal cord clinic), and an Emergency Room doctor.

A list of EDC was presented as everyday data for care that could be useful to share with care team members to support monitoring and diagnosis. Participants were first asked to review the list of EDC types and to understand the details captured in EDC. Inspired by prior work on people’s attitudes toward sharing data [18, 21, 64] and common care activities for people with SCI/D and their care teams [1, 19, 20, 61], 32 types of data were selected, which covered a range of aspects of a person’s life and her health condition (see Table 1).

Participants were asked to sort the data types into 5 bins based on how comfortable they were in sharing data with their care teams, from bin 1 (most comfortable) to bin 5 (least comfortable). We did not define “comfort”, but let participants supply their own definition. This ambiguity has been found to be useful in many card sorting studies (e.g., [13, p. 269] and [12, p. 249]).

Table 1. Selection of data types

Computer game	Exercise	Fluid intake	Flatulence
Food/diet	Hanging out	Heart rate	Internet history
Intimate behavior	Location	Loneliness	Medication
Messages	Mobile app usage	Mood	Conversational dialogs
Pain	Phone calls	Stool	Recreational drug use
Relaxation	Religious behavior	Romantic dates	Skin condition
Sleep	Smoking	Social media status	Stress
Urine	Video use	Weight	Work activity

This list of EDC types was entered into Miro [62] as digital cards for sorting (See Fig. 1 in the Appendix). In this paper, we will use “bins” to denote the pre-determined number of containers given to every participant in the Miro-based

card sort, and use “groupings” to denote the resulting collections of data types, which may be different for every participant, in the various bins.

Prior work on design for chronic care has suggested how changes in a person’s health requires the care team to revise care routines (e.g., maintain proper fluid intake) and hence the use of data (e.g., monitoring) [19,38]. We used three situations (see below) in our study to examine whether EDC groupings could be used to support sharing when there were changes in health, and whether there were patterns that could be useful for simplifying EDC sharing.

- New normal: a regular day living with the chronic condition.
- Something going on: exhibiting new symptoms with the causes unknown.
- Emergency: feeling ill and being rushed to the emergency room.

After observing participants’ sorting with a think-aloud protocol, we then conducted semi-structured interviews to understand how easy or difficult it was to group the EDC, and how these groupings could be useful for expressing sharing settings with different care team members under different care situations.

The guiding questions for the interviews were, for the presented scenario:

- How would you describe the data in this grouping?
- Were there data that were tricky to assign to a grouping? What were they (walking through each grouping)?
- When you stated how you would share data with this care team member (walking through each potential recipient), what went through your mind?
- When you stated how you would share data in this care situation (walking through each potential recipient), how was it different than the other situations?

3.3 Data Analysis

We used Clarke’s Situational Analysis [24], an updated version of Grounded Theory, to analyze the interview transcripts and think-aloud data. Open coding was applied to interview notes and transcripts using Atlas.ti [34] to generate initial themes. The authors discussed themes and categories through weekly meetings to identify emerging themes. Analytic memos were written summarizing the emerging themes, and themes that emerged were used to re-code all the transcripts to maintain consistency. This process was repeated iteratively.

Participants who successfully finished the study were compensated with a \$20 e-gift card for their time and effort. This study was reviewed by our university’s Institutional Review Board. Any data presented here have been anonymized; we have lightly edited some of the data presented here for presentation clarity.

4 Findings

In this section, we describe our participants’ sharing preferences for EDC generated in a pervasive healthcare environment. We provide a description of whether

our participants were able to group the set of EDC types, as well as how any groupings were used to express sharing settings both with different care team members and in varying care situations. We start with a description of how our participants grouped data types and whether they found these groupings useful and usable.

4.1 Grouping EDC is Usable and Useful

In our study, we asked our participants to perform a card sorting activity to put a list of EDC types into 5 bins, telling them to sort the types by their “comfort” of sharing that data with care team members (1: most comfortable, 5: least comfortable).

The participants were able to utilize the bins to group the EDC types. Figure 2 in the Appendix visualizes how participants grouped the data types. Three things leap out. First, all 5 bins were used by nearly all participants. In fact, only P01 excluded bin 5, while all other participants distributed the EDC to all 5 bins. Participants were at ease in doing so, as their think-aloud data indicated.

Second, there was some agreement among participants about the contents of each bin, but overall the contents could differ widely. Participants put largely physiological data in bin 1, as can be seen in Fig. 2, and all participants felt most comfortable sharing that data. (Remember this was in a scenario about health care.) Bin 5 tended to include deeply personal data, such data about sexual activity or drug use, and was not shared frequently:

Um, religious behavior, I don't really see the health relationship with my health, but I guess I would worry about how people perceive me based on religious practice. (P19)

and

These data [phone calls, social media messages, and recreational drug use] are the most personal. We don't share that with people that often. (P08)

However, the contents in bins 2–4 varied widely. There was some consistency. For example, phone calls were commonly assigned to bins 4 and 5 but also to other bins. If we look at how often participants used the same bin, one can see the variation: One data type (i.e., heart rate) was assigned to adjacent bins (i.e., within one bin of one another); 4 data types are assigned to one of consecutive three bins, but the rest of the 27 data types were assigned to more than three. For example, participants differed on their comfort level with sharing data such as smoking and location, where they could be placed by different participants in bins 1 through 5:

Mostly like loneliness, relaxation, stress, work, and mood, I was mostly considering whether it was important for them [the care team members] to know that... and whether I would want to share that. (P24)

It follows that some EDC types were likely to be collocated within a grouping. For instance, heart rate and pain as well as stool and urine were pairs of data types that typically were put into the same grouping. On the other hand, heart rate and intimate behavior were less likely to be put into the same grouping, as people typically considered sharing data about intimate behavior to be uncomfortable.

Admittedly, some participants did signal that they found some EDC types to be challenging to assign to a specific grouping, resulting in ambivalence about the correct grouping. Note this ambivalence was not about what was uncomfortable to share per se – they could assign a data type that was uncomfortable to share to bin 5 (the most uncomfortable). Debating what grouping to which to assign a type was relatively uncommon, and what types were challenging was idiosyncratic to the individual.

Some participants who were found themselves ambivalent about a grouping indicated that their ambivalence resulted when a EDC type's potential connection to health and the benefits of sharing were unclear to them:

I think maybe weight and work, that are the ones I am debating,... because it's not like... the most embarrassing thing and it is for your health... but I am still hesitant. [P21]

This ambivalence, however, only adds to the difficulty of finding *one* set of groupings that will hold across all users. The differences in individuals' binning could be significant; our participants did not agree on what EDC data types should go in a specific bin (i.e., a comfort level). Figure 2 in the Appendix shows the variance in the groupings. Because of this variance, it is unlikely that any *one* taxonomy or classification scheme will suit all users.

Regardless, individuals were able to group the data types for themselves, suggesting that groupings could be potentially usable. While some participants needed to deliberate slightly more about a relatively small set of data, they were able to settle quickly. In other words, sorting EDC into groupings based on comfort level was a rather doable process for our participants.

Somewhat to our surprise, while our participants did not always agree on the types that went into each comfort grouping, these groupings seemed useful for themselves to allocate data to care team members. (To make it clear that we are talking about the individuals' set of groupings, we will call these “user-groupings”.) ***That is, once participants grouped the data types, they were able to use those user-groupings to describe their sharing preferences for different care-team members and care situations efficiently***, finding the grouping they did useful and usable for themselves. This strongly suggests their own groupings could be used to reduce the number of data sharing or privacy policies that users might need to construct and maintain.

In summary, participants were able to put EDC into groupings based on how comfortable they were in sharing these EDC with care team members. These groupings were idiosyncratic enough to each individual that one classification scheme for all users is impossible or unlikely. While the exact data types in

each grouping varied from individual to individual, the user-groupings appeared to be useful, since each individual participant was able to use her groupings consistently as units in expressing sharing settings.

Below we will discuss how participants used the groupings to deal with the subtleties of who might receive the data, namely by varying the groupings specific recipients could see. We will then deal with how participants also used the user-groupings to share data when the patient's health situation changed.

4.2 Utility of Groupings for Sharing Within a Care Team

Many patients with SCI/D, as discussed above, rely on care teams. For a condition such as SCI/D, patients might experience different degrees of neurological impairment, and for those with more severe conditions, they often require a care team to assist with different tasks in everyday life. Sharing EDC within the care team would allow team members to collaboratively monitor the patient's health and handle changes that might arise.

The care team for a patient with SCI/D is not homogeneous. Primary care givers, who are likely to be parents or spouses, are generally trusted more than paid or volunteer caregivers. Secondary care givers, such as siblings or other relatives, may lie between primary care givers and paid caregivers. Care teams may also involve a range of clinicians including different kinds of doctors, nurses, physical and occupational therapists, and the like. In this section, we described how the user-created groupings (user-groupings) were useful for sharing data with different care team roles.

In the process of determining what EDC to share with different care team members, the user-groupings provided guidance for our participants to quickly identify what to share with a particular care team member. Instead of considering every single EDC type, the user-groupings served as units for our participants in their evaluations of what to share. Indeed, participants often considered multiple groupings at the same time for inclusion or exclusion. For instance, P02 commented on how she decided what to share with the primary caregiver and paid caregivers; she excluded three groupings at once and decided to share the other two groupings:

I think [groupings] 3 to 5 is like more personal... The first group... everyone in my team should know. The second group ... I spend most of time with primary caregivers and hired caregivers, so I would like to share [data about] my life [in group 2 for this participant] with them. [P02]

Similarly, P03 explained how she would share EDC with her primary care doctor by including and excluding the groupings she created.

For my primary care doctor, this one is more like... they [have to] kind of know my condition overall. That is why I share [up to] group 3, so that they would have a basic idea of how I feel and how my physical body works [groupings 1 and 2 for this participant], but they don't necessarily need to know my personal activities [groupings 4 and 5 for this participant]. (P03)

As shown in the comments above, our participants found their EDC user-groupings, created based on comfort level, were useful units for determining sharing with specific care team members. In the study tasks, our participants went through each role and decided what groupings to share. (See Table 3 in the Appendix for the set of roles given to participants in the study tasks.) Only two participants deviated from using their initial user-created groupings, and they did so only once each.

That is, with the exception of P06 and P07, participants did not feel the need to restart the grouping process in order to specify sharing preferences for each role.

These user-generated groupings are by no means perfect, as some groupings might contain data that were not as relevant for a given care team personnel. Participants might decide to share the whole group when (1) there were data that were relevant or even critical to share, and (2) they don't feel strong discomfort for sharing those less relevant data.

Data such as loneliness, religious behavior, social media [, some data types from those groupings I share)... I would be more comfortable sharing these data with psychotherapists because they are more socially and mentally oriented. They probably wouldn't need to know my skin conditions [a data type from those groupings I share), but I would be comfortable with them knowing more. [P10]

Again, we stress that the exact groupings for any given individual are not what is interesting here – it is, instead, that individually participants were able to reuse these user-groupings to create sharing settings without major challenges or re-grouping.

While our participants were able to use their groupings for assigning sharing to care team roles, we acknowledge that a role is quite abstract. Sharing may differ from abstract roles (e.g., paid caregiver) to specific individuals (e.g., Sally, a specific person who has been with the patient for a decade). Changes to the groupings might be required, for example, to allow different sharing settings for different individuals in the same role. Changes might also be required as patients or caregivers better understand their sharing and privacy needs; this could be seen with P06 and P07, who changed their groupings in specific study tasks. However, we must note that the groupings would still be useful in jump-starting a process of customization. We will return to this point in the Discussion.

In summary, our participants found the user-created groupings of EDC useful for deciding how to share EDC with a specific care team roles. One major benefit for participants was to use the groupings to quickly assess the sharing threshold for a given recipient. Participants were able to consider multiple EDC at the same time, without the need to examine every single EDC type for each recipient, which for this number or slightly more care team members or sensors would have been an overwhelming task.

4.3 Utility of Groupings for Sharing with Changes in Health Condition

Chronic care involves working with a care team to address any health changes over time. To design support for people to control EDC sharing for severe chronic care contexts, for example SCI/D, it is critical to understand how sharing preferences might change across care situations. We prompted participants to express their preferences about sharing EDC in three care situations: a regular day (the baseline condition), a situation where something may be starting to affect the patient's health, and an emergency. We found that these user-groupings created based on comfort level for sharing, again, provides a good framework for participants to decide what EDC data to share in different care situations. We also found that the care situation did affect the threshold for sharing (i.e., sharing up to grouping X), generally in a positive direction as the patient's health condition deteriorated. In other words, people are inclined to share either the same or additional groupings of EDC when their health situations escalate in severity.

Table 4 in the Appendix shows how sharing increased as the health needs were perceived to have become greater. We show the sharing threshold (i.e., the highest grouping that will be shared) for primary and paid caregivers, as well as two doctors, the primary care physician and an Emergency Room doctor.

For departures from a regular day (i.e., when there is a change in the patient's health), the necessity of sharing increases. Such an increase is motivated by the need to have more people monitoring a patient and help with care and treatment, including both medical professionals and non-medical care team members. As seen in Table 4 in the Appendix, participants tended to keep or raise the threshold for each care team member in order to share more with each of them so as to allow EDC to flow smoothly to care team members. On average, 30% of the care team members were given access to all data (group 1 to group 5) in when there were changes in health (i.e., the something going on situation), a 5% increase from the normal situation.

The data is important for them [primary care doctors] to make medical decisions. Hopefully, they are working in my best interest. ...so a proper decision is made for my health. (P19)

Even if they [hired caregivers] are college kids without medical training, they might be like the next best option [when there is a health change and other caregivers are not around]. (P13)

Participants wanted to share the most data in emergency situations. On average, 56% of the care team members were given access to all data (group 1 to group 5).

There were only two exceptions to the general trend, sharing the same or more data when the situation worsened. P25 preferred sharing rather limited data with primary caregivers, secondary caregivers, and psychotherapists when her health deteriorated (in the something going on condition). P16 preferred to maintain a sense of control when there was a non-threatening change (i.e., something going

on), but would let go of the control and entrust recipients with more data in an emergency when her life was at stake. Both P16 and P25 explained that a lack of medical expertise and the situation (e.g., health deterioration) were the main factors for such adjustments. For instance, primary caregivers, who were highly involved in care but were considered to have less medical expertise, were given even fewer EDC groupings in an emergency compared to a regular day.

Again, our results showed that the user-generated EDC groupings appear to be a useful way for people to express sharing preferences – this time across care situations. As people’s health changed, the inclination to share more EDC was observed at the grouping level: participants either share the same groupings or share more groupings of EDC, as the people’s health condition escalates.

5 Discussion

Repeatedly in our study, we saw evidence that our participants could bin EDC data types into groupings based on a criteria of “comfort”. *We also observed them reusing those user-generated groupings. The groupings differed from individual to individual, but one’s groupings appeared to be valuable for the individual participant.* These groupings were not perfect, but seemed to be robust enough to support EDC sharing configuration. Few participants changed their groupings when setting up privacy and data sharing, and more importantly, they constructed a number of nuanced settings using them in a number of study tasks. Our participants were able to use these user-groupings to select what EDC to share with different care team members and in changing health conditions.

As far as we know, these findings have not been studied or observed before. These findings need to be confirmed, but they suggest that these user-groupings could be a valuable tool in easing the burden of dealing with the increasing amount of sensors and EDC data in a pervasive healthcare environment. Our study substantially extends the ideas of Toch et al. [82], Knijnenburg [47], and Li et al. [54]. Toch et al., Knijnenburg, and Li et al. merely examined user-generated taxonomies that were supposed to fit everyone; we found that such taxonomies are not likely to do as well as individualizing groupings. We, on the other hand, showed that user-groupings (i.e., individualized groupings) could be useful for configuring data sharing (e.g., of EDC).

In the next subsections, we consider the possibilities we believe our study uncovered – namely, the semi-automatic configuration of data sharing – as well as the potential limitations of this study and future work.

5.1 Creating Semi-automatic Assistance

The findings above strongly suggest that allowing people with health conditions or their caregivers the ability to bin EDC data types creates valuable shortcuts and forms of assistance to people and caregivers in creating and potentially maintaining privacy and data sharing settings. A wizard-like mechanism would

allow the simple binning of EDC data types and then the creation of straightforward sharing rules.

Future work could also apply the methodologies proposed by Knijnenburg [47] and Li et al. [54] to investigate semi-automated approaches for EDC sharing configuration, where sharing profiles could be extracted from some user-generated groupings and applied to new types of data. The individual differences we observed, however, indicate that some user involvement will be necessary. For users, allowing them to further customize automatically generated settings would still be easier than creating settings from scratch.

In addition to the possibility of using user-generated groupings for data sharing configuration [47, 83], our findings further suggest that such groupings could be reused across different care situations, which is important in severe chronic care as care team members need to collaboratively monitor and adapt to changes in health and care [19, 69]. Reusing groupings in different health situations would reduce the user burden of configuration, again reiterating the utility of such user-generated groupings for the chronic care context.

Finally, extending the findings of prior work that suggest safety and health could be reasons for people to share data [6, 10, 11, 27, 52], our findings further demonstrate that in the context of chronic care, people have the general tendency to share more at the grouping level when health problems escalate. Architectures or frameworks designed to support EDC data management should consider explicitly supporting the interaction between care situations and the threshold of comfort for sharing. For instance, having a system that made suggestions of sharing settings, potentially with customization, would ease the burden of people with health conditions or their caregivers. This would avoid the burden of creating separate settings for different health situations. Future work may uncover similar tendencies for roles. For example, the sharing with a secondary caregiver (e.g., a family member) will likely be a superset of the sharing with a hired caregiver. Such tendencies based on user-generated groupings of recipients (e.g., roles) could provide further simplification of EDC sharing to empower patients in directing their care [9, 20, 23, 29, 63, 76].

5.2 Limitations and Future Work

There are several potential limitations to this work.

Our exploratory study used non-probability sampling, but we believe our study has theoretical generalizability [24]: The use of user-generated groupings without requesting major changes was prevalent in this study. Yet, while we were careful when prompting participants to double-check that they were satisfied with their groupings, it is admittedly an unknown and surprising result. We do recognize that to gain widespread acceptance in health informatics or in medicine, additional studies, especially empiricist studies, will be required.

Additionally, we provide a pre-determined number of bins to guide the EDC grouping process. While the number seems to provide a good scaffolding for participants in our study, future studies could consider systematically examining other numbers to structure the grouping process. One direction worth exploring

could be to identify whether there exists an ideal range where the resultant number of groupings is still manageable (under a certain threshold) while providing enough distinction (above a certain threshold) that supports the necessary differential treatment for different care team members and under different situations.

In this study, we asked participants, who understand the care context (i.e., through caregiving or having a close family member with a chronic condition) but were not people with health conditions (except one), to role-play a person with a health condition. This allowed us to obtain initial results about whether EDC could be shared in groups to simplify sharing configurations and to understand considerations participants have when sharing EDC in groups. However, we acknowledge that people with health conditions might have additional perspectives on the utility of user-groupings. Future studies should examine using people with health conditions as well to develop a more thorough understanding.

Moreover, as we noted earlier in this paper, we asked about sharing with abstract roles, but real sharing occurs with specific people in specific contexts. This issue remains for future studies to reaffirm the usefulness of user-groupings.

As well, we examined only the ambiguously-defined criteria of “comfort” in this study, and participants were clear that “comfort” included understanding how the data might be used in a care context. Future work should examine these and additional factors related to the care context to guide user-grouping creation.

Finally, our findings were generated through a one-time engagement with participants. In reality, supporting chronic care, by definition, will engender a different style of engagement across a longer period of time. Future studies should examine how stable these user-generated groupings are and factors that necessitate changes in these groupings. It is also possible that the attitudes toward sharing these EDC data types might change for people with health conditions as they encounter different events in their health journeys and develop a better understanding of the benefits and risks of sharing. Future research could consider exploring machine-initiated intervention (e.g., using intelligent agents [31]) that will periodically examine EDC groupings and call for attention (e.g., check-in after a new development in one’s health). This method could be integrated with other methods that provide an estimate of a person’s understanding and expertise in EDC (e.g., using expertise estimation based on user behavior logs [39]). The integrated approach will allow adjustments based on people’s educational backgrounds or experiences to allow interactive systems to reassess whether and what aspects of the EDC groupings need to be modified to reflect people’s preferences and expertise.

6 Conclusion

Our work aims to support patients and their caregivers in a pervasive healthcare environment through controlling their sharing of Everyday Data for Care (EDC), specifically in the context of severe chronic conditions that require a care team and healthcare over time. This paper presented findings that examine how to help users set sharing and privacy preferences for EDC. Through a scenario-based study with think-aloud card sorting and semi-structured interviews, we found that our participants were able to use self-generated groupings of EDC data, and more importantly, kept those groupings, with only minor exceptions, when creating sharing settings for potential recipients and when dealing with changes in the health trajectory. The major contribution from this work was the surprising and speculative finding that users could garner assistance from their user-generated groupings of EDC data. This work offers hope that we can reduce the burden of authoring and maintaining data sharing and privacy policies through semi-automatic mechanisms, where the system suggests policies that are consistent with the users’ preferences - especially as health changes and especially in difficult chronic care.

A Appendix

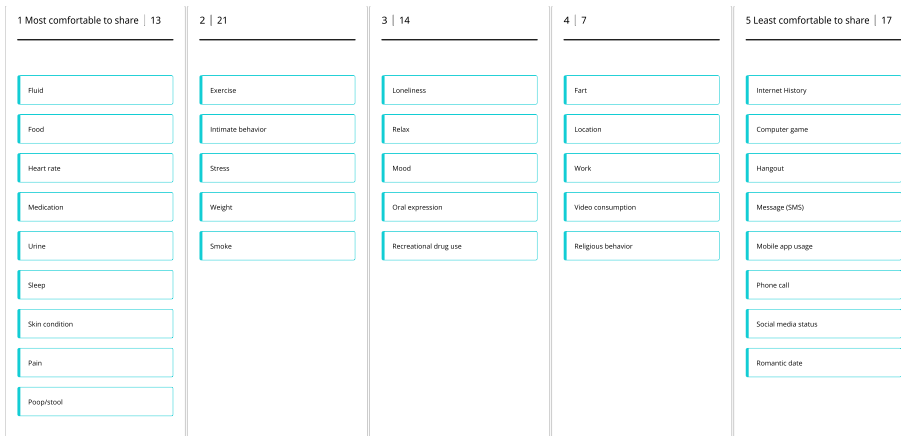


Fig. 1. Participants created groupings of EDC by the level of comfort from the most comfortable (bin 1 on the left) to the least comfortable (bin 5 on the right).

Table 2. Participant description: “Caregiver” (C) refers to a participant who has caregiving experience (including as a nursing professional), “person”(P) refers to “a person with a chronic condition and/or a disability”, and “PFC” refers to “a person with a close family member who has a chronic condition”.

	Age	Gender	Background	Occupation	Experience
P01	26–30	F	Fashion	Student	PFC
P02	26–30	F	Counseling	Research assistant	C
P03	26–30	F	Linguistic	Student	PFC
P04	31–35	F	Education	Instructional designer	PFC
P05	26–30	M	Computer Science	Software engineer	PFC
P06	31–35	M	Computer Science	UX designer	PFC
P07	36–40	M	Social Work	Social worker	C
P08	31–35	F	Linguistic	Student	No
P09	31–35	M	Computer Science	Student	PFC
P10	18–25	F	Nursing	Student	C
P11	18–25	F	Nursing	Patient Care Technician	C
P12	18–25	F	Nursing	Student	C
P13	18–25	F	Nursing	Patient Care Technician	C
P14	18–25	F	Nursing	Student	C
P15	18–25	F	Nursing	Nurse aide	C
P16	18–25	F	Nursing	Nursing assistant	C
P17	18–25	F	Nursing	Student	C
P18	18–25	F	Nursing	Student	C
P19	18–25	F	Nursing	Student	C
P20	61–65	F	Nursing	Clinical nurse educator	C
P21	18–25	F	Nursing	Student	C
P22	26–30	F	Psychology	Care navigator	P & C
P23	18–25	F	Nursing	Student	C
P24	18–25	F	Nursing	Student	C
P25	18–25	F	Nursing	Student	C

Table 3. EDC groupings shared with different care team roles: primary caregiver (primary), secondary caregiver (secondary), hired or paid caregiver (hired), primary care physician (PCP), psychotherapist (psych), physical therapist (PT), and healthcare system IT specialist (IT). The value represents the highest grouping shared. The last column shows whether a participant adjusted groupings in the process of creating sharing settings. (P20 was omitted since their data was partial.)

	Primary	Second	Hired	PCP	Psych	PT	IT	Grouping changes
P01	3	4	2	2	3	2	0	No
P02	2	3	2	1	2	1	1	No
P03	5	5	3	3	3	1	2	No
P04	5	2	1	3	3	2	2	No
P05	5	3	2	4	5	2	1	No
P06	4	4	4	3	1	1	0	Yes
P07	5	4	3	3	5	3	2	Yes
P08	2	2	2	2	2	2	2	No
P09	4	4	1	5	4	3	3	No
P10	3	1	3	3	4	2	0	No
P11	5	5	5	5	5	5	5	No
P12	2	2	2	5	5	5	1	No
P13	3	4	4	4	5	2	1	No
P14	4	3	2	3	5	2	1	No
P15	2	2	2	5	5	5	0	No
P16	5	2	2	3	5	2	1	No
P17	3	3	3	5	4	3	2	No
P18	2	2	4	3	5	3	1	No
P19	3	0	0	2	2	1	1	No
P21	5	2	3	5	5	2	0	No
P22	3	3	3	4	5	2	2	No
P23	2	2	2	5	4	3	5	No
P24	5	5	1	4	4	1	0	No
P25	3	3	0	2	3	2	0	No

Table 4. EDC groupings shared with care team roles increase when health situation deteriorates. Roles include: primary caregiver (PC), hired caregiver (HC), primary care physician (PCP), and emergency room doctor (ERD). The health situations included a regular day (Normal), when symptoms begin to emerge (Symptom), and an emergency requiring a trip to the ER (Emergency). We did not include the hired caregiver role in the emergency situation in our study; we omit participants for which we have only partial data.

Participant	Normal			Symptoms			Emergency		
	PC	HC	PCP	PC	HC	PCP	PC	HC	ERD
P06	4	4	3	4	4	4	4		4
P07	5	3	3	5	4	5	5		5
P08	2	2	2	2	2	3	2		3
P09	4	1	5	4	2	5	4		4
P10	3	3	3	3	3	3	4		4
P11	5	5	5	5	5	5	5		5
P12	2	2	5	2	2	5	5		5
P13	3	4	4	3	5	5	3		5
P14	4	2	3	5	3	5	5		5
P15	2	2	5	2	2	5	2		5
P16	5	2	3	3	2	5	3		5
P17	3	3	5	4	4	5	5		5
P18	2	4	3	2	4	3	2		3
P19	3	0	2	3	0	2	4		4
P21	5	3	5	5	3	5	5		5
P22	3	3	4	4	3	4	5		5
P23	2	2	5	3	3	5	4		5
P24	5	1	4	5	1	4	5		4
P25	3	0	2	2	0	2	2		2

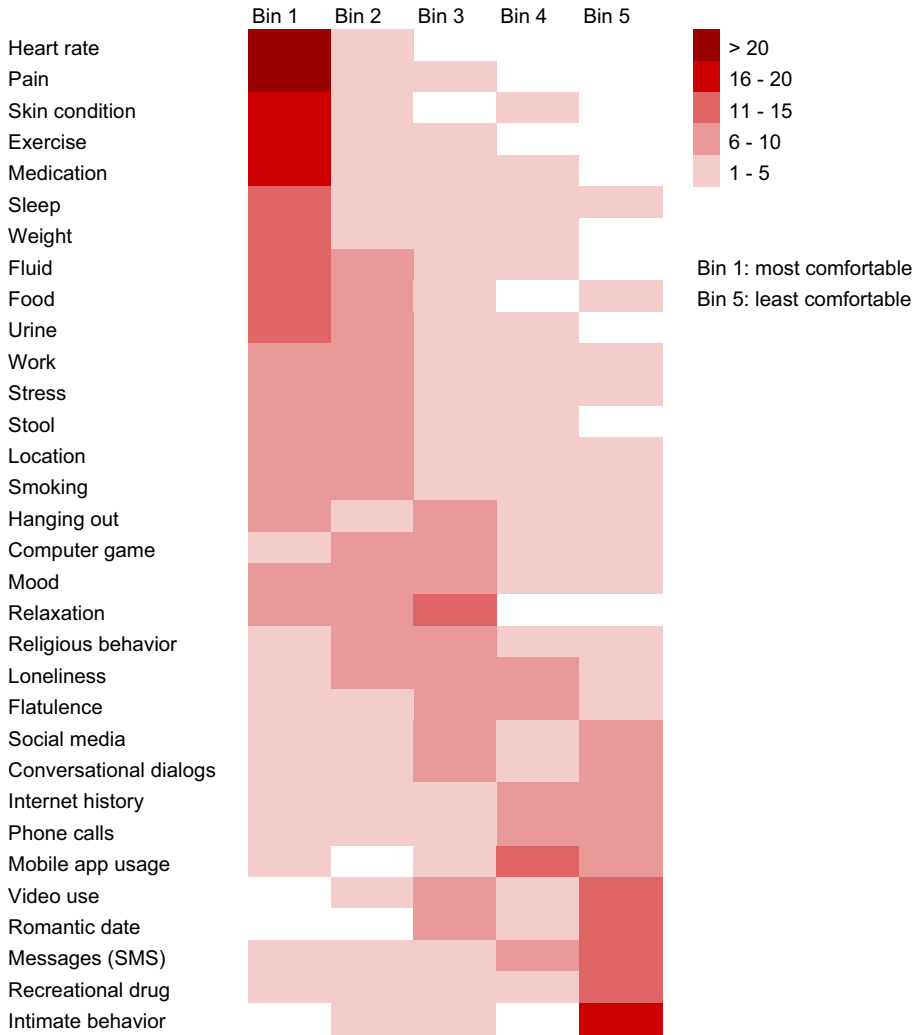


Fig. 2. Heatmap showing how frequently participants assigned an EDC type to each bin. Very light pink 1–5, light pink 6–10, medium pink 11–15, dark pink 16–20, dark red >20 (n = 24). Some participants omitted because of partial data. (Color figure online)

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