

# Toward Designing for Social Connectedness in Cardiovascular Disease Self-Care

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## ABSTRACT

When people with chronic conditions are confronted with gaps in their understanding of their health status, they turn to their peers to make sense of their own situation. And yet, little is known about how to design to facilitate locating others in similar situations. Sharing personal health information with their peers is a strategy the sense-maker employs in constructing a new normal after health-related life disruptions. Even so, research on how to design digital health technology that leverages information-sharing behavior is lacking. This paper elaborates on a peer data-sharing model to inform digital health technology design. Based on this model, we herein propose a prototype that promotes social connectedness in cardiovascular disease self-care as a means to advance our understanding of how we might design to facilitate locating peers and gaining new insights into self-care from them.

## CCS CONCEPTS

• **Human-centered computing** → **Social content sharing; Social recommendation**; *Collaborative and social computing systems and tools.*

## KEYWORDS

data sharing, peer recommendations, personal health data

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## 1 INTRODUCTION

### 1.1 Turning to Peers in Seeking a Sense of Health Challenges

Current clinical guidelines on self-care for the prevention and management of cardiovascular disease (CVD) suggest that people are to self-monitor routinely and be aware of complications and the corresponding course of action [8]. In this regard, gaining and applying knowledge of health status are conducive to engaging in adequate self-care [8]. Nevertheless, knowledge of the self may be insufficient in making sense of health challenges [4, 7].

When people are confronted with gaps in their understanding of their health status, they turn to their peers to make sense of their own situation [7]. The experiences of others in similar positions often reassure and validate the sense-maker — ultimately shaping their notions of “normal” [4]. In constructing a new normal after health-related life disruptions, people expend great effort on information behaviors [4], including, among others, sharing personal health data with their peers (e.g., refs. [1, 11]) — from sociodemographic, anthropometric, and physiological data to self-care strategies, challenges, and experiences.

Empirical evidence shows that social support is among the perceived benefits that drive people to share their health information [12]. That is why the benefits of information-sharing behavior are proposed to be prominent in e-health contexts, presumably thereby increasing an individual’s willingness to self-disclose [12]. Still, it is not well-known how to design digital health technology that leverages self-disclosure of health data. A first step in this direction is understanding how people feel about sharing their health data and exploring those of their peers.

As a result of investigating the perspectives of people with the Human Immunodeficiency Virus, Bussone et al. [1] propose that the sharing of personal health data among peers, or, interchangeably, peer data sharing, could be considered an exchange of assets with the potential to support the development of a shared understanding of health-related issues. Although plausible, this proposition has the limitation that it overlooks the diverse forms, other than an exchange, the sharing itself may take and, in line with this, other purposes it might serve. In contrast, a recent body of literature [2] provides a new perspective on peer data sharing in chronic disease self-care, acknowledging the ambiguity of this information behavior and consequently suggesting a model on which to inform the design of digital health technology.

## 1.2 Peer Data Sharing in CVD Self-Care

Figure 1 depicts Cerón-Guzmán et al.'s [2] model of peer data sharing in the context of CVD self-care. The model consists of four stages ranging from self-disclosure to social comparison. For each stage, we provide a description below and elaborate on possible barriers individuals may encounter.

**1.2.1 Self-Disclosure and Peer Recommendations.** Since the experiences of others in similar situations support achieving a sense of normal [4], individuals need to address how to locate their peers early in the sensemaking process. In this context, self-disclosure, i.e., one-way data sharing, could facilitate locating similar others. To this end, digital health technology would play an intermediary role in making peer recommendations or recommendations on others facing similar health challenges. This technology could even tailor to the individual's notion of likeness and thus give them control over the recommendations they will receive.

One limitation of this approach to social connectedness is the size and diversity of the peer group. Still, recommendations on similar others are arguably convenient to the undertaking to locate "people like you." However, it is striking that peer recommendations have received so little attention as a research topic in the health recommender systems literature. More specifically, only two of 73 studies included in a recent review of related literature [3] addressed this topic. To top it all off, research on human factors in peer recommendations is lacking. The latter becomes particularly important in a context where the accuracy of the recommendation algorithm seems insufficient to ensure a good user experience [3, 5, 6]. Therefore, this research gap motivates us to formulate our first research question (RQ):

**RQ1:** How to design digital health technology that facilitates people with CVD in locating their peers?

Barriers to self-disclosure are, from our perspective, the most critical in the peer data-sharing model, as they can cause a ripple effect that propagates to the social comparison stage. To illustrate, the more uncertain people feel about the benefits, the more reluctant they may be to self-disclose and engage in the interactions described in subsequent model stages. This sense of uncertainty could be due to the questionable utility of one's data in the hands of peers. "Who knows if peers are medically versed enough to understand these data?" [2, sect. 4.1]. Hence, one could argue that the individual will move to later stages in the model only when the benefits of self-disclosure become more manifest.

Alongside uncertain benefits are privacy risks. In the interest of safeguarding their privacy, individuals may withhold certain data from their peers, which would negatively affect the quality of the recommendations they will receive later on. While one way to overcome this barrier to self-disclosure is to let people know that they are co-responsible for the effectiveness of recommendations [6], we argue that one will learn what and how much to self-disclose as one interacts with the system. This is an extension we make to the peer data-sharing model, reflected in the backward arrow from peer recommendations to self-disclosure at the top of Figure 1.

**1.2.2 Mutual Data Sharing and Social Comparison.** One of the main arguments scholars draw upon to motivate their work on sharing personal health data is increased social support preceded by

engaging in this information behavior (e.g., refs. [9, 11]). While this argument seems plausible [12], at the same time, several limitations can be identified that make it poorly applicable to informing digital health technology design. First, this argument appears to be built on the assumption that data sharing is beneficial in and of itself (e.g., ref. [9]). Nevertheless, recent evidence suggests that the benefits of interacting with peers in such a way are not as apparent to patients as one might think. In this regard, people with chronic conditions sometimes see little practical value in exploring peer data since these data only make sense to their owner or the treating physician [2].

Second, scholars who argue that peer data sharing is beneficial to increasing social support often do not describe how we might design digital health technology that helps achieve such increased support. Hence, unless the individual is clear about what they or their peers will gain from mutual data sharing, it seems unlikely they will engage in it.

Under these conditions, the notion of people with CVD regarding mutual data sharing — meaning to self-disclose health data and explore those of peers — is informative. For them, sharing personal health data with their peers "constitutes an opportunity to learn new ideas that would enhance CVD self-care" [2, sect. 4.1]. Here, a mechanism that would facilitate such learning, according to the individuals themselves, is social comparison. In their own words, peer data sharing "would be good to know what other people in a similar situation are doing ... this info would be valuable and help me with new ideas to better live and treat the disease" [2, sect. 3.2]. Thus, following the suggestion that a design opportunity exists in this context [2], we set out to seek answers to the second research question:

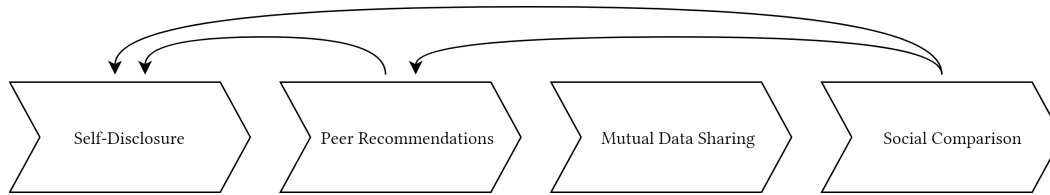
**RQ2:** How to design for social comparison enabled by peer data sharing so that the comparison is conducive to learning new ideas about CVD self-care from peers?

As for barriers in these later model stages, we refer to two. The first has to do with clinicians' willingness to discuss ideas that people might learn about self-care from their peers. So if clinicians are reluctant to discuss ideas patients bring to consultations with them, patients would refrain from gaining new insights into self-care on their own, as they would have no one to validate the appropriateness of the insights for their situation.

The second barrier pertains to the complexity of the peer data-sharing model. Since this is the last stage of the model, social comparison is sensitive to the choice of peers with whom one connects or compares (peer recommendations) and the data that shape the comparison (self-disclosure and mutual data sharing). Such complexity could fatigue the individual to the extent that they would have to revisit previous stages to obtain results that meet their expectations.

## 1.3 Research Aim

In sum, we aim to advance our understanding of how we might design digital health technology that facilitates locating peers and gaining new insights into self-care from them. In this regard, we propose a prototype that promotes social connectedness in CVD self-care as a means to generate knowledge that informs future



**Figure 1: Representation of Cerón-Guzmán et al.'s [2] peer data-sharing model to inform digital health technology design. Initially conceptualized as sequential and non-iterative, we extend this model to suggest that the individual can go back and forth through the stages of the model as these stages interrelate, but especially as the benefits of engaging in data sharing become more apparent.**

design practices. This prototype resembles a mobile health application theoretically grounded in Cerón-Guzmán et al.'s [2] peer data-sharing model.

## 2 DESIGN OF A PROTOTYPE FOR SOCIAL CONNECTEDNESS IN CVD SELF-CARE

This section elaborates on the process we followed in designing a prototype that promotes social connectedness in CVD self-care. Figures 2 and 3 show this prototype. First, we describe the design goals we defined at the beginning of the process. Then, we discuss the prototype components, their interaction flow, and how they map to the design goals.

### 2.1 Design Goals

While the peer data-sharing model from Figure 1 provided us with a theoretical grounding, we sought to define design goals (DG) that would inform us about the user experience the prototype will enable people to attain. Thus, we drew on prior research to decide on the following DGs.

- DG1. Privacy control.** Bussone et al. [1] and Cerón-Guzmán et al. [2] emphasize a consent model whereby the individual chooses which of their data to share and to whom to share them. This consent model should be flexible enough to support an ongoing decision-making process. Therefore, we formulate that it is up to the individual what will be visible and to whom it will be visible.
- DG2. Explainability and controllability.** Contemporary research on the design of interactive information systems has brought the prominent role of human factors in accepting technology to the forefront of the debate. For example, explaining the outcome of a recommender system has been shown to favorably influence user confidence in that outcome [10]. Moreover, while allowing the user to exercise control in generating recommendations, their satisfaction appears to increase [5]. Based on these insights, we formulate that recommendations are to be understandable through explanations and that the individual can tailor them to their preferences.
- DG3. Keeping clinicians in the loop.** While they were enthusiastic about learning new ideas about self-care from their peers, participants in Cerón-Guzmán et al. [2] were also aware of each condition's idiosyncrasies and complexity [7] and of validating with healthcare providers the appropriateness of any idea for their situation. Hence, the prototype should

invite dialogue with clinicians to materialize this analytical orientation toward peer data sharing.

### 2.2 Design Components

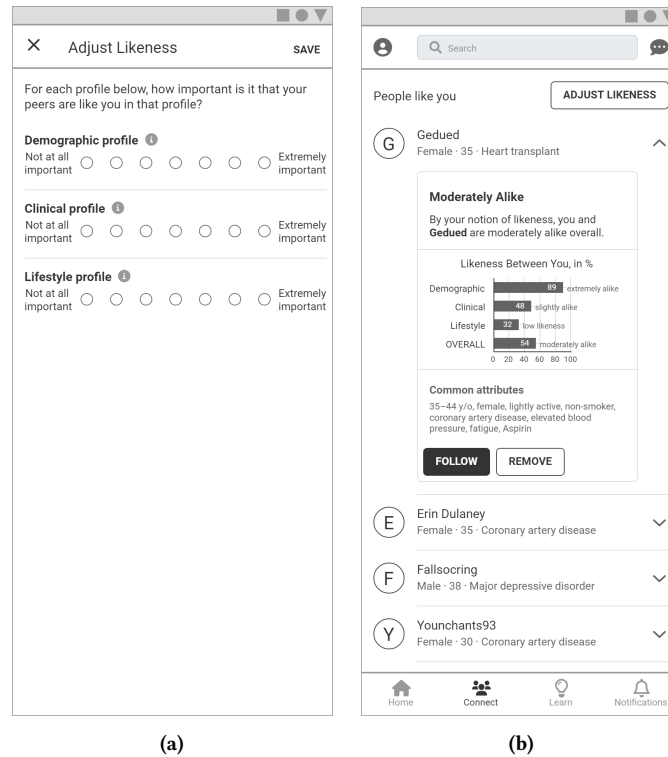
We implemented the prototype as a series of wireframes using Balsamiq (balsamiq.com, accessed on 28 March 2023). This prototype mimics a mobile health application with a low-fidelity look and feel. The fact that the look and feel of the prototype was low fidelity was deliberate. Typically, this level of fidelity allows for provisional and unfinished artifacts to be communicated, so the user might feel less constrained in expressing criticism and suggesting changes.

The prototype consists of the following sections. The user profile section is where the individual can self-disclose demographic information, such as gender, age, and education level, as well as lifestyle information, including activity level, smoking status, and health and personal interests. This user profile section is supplemented by health conditions, symptoms, and treatments. The individual can subjectively evaluate each treatment according to its effectiveness, side effects, burden, and affordability. We were inspired by the information architecture of the PatientsLikeMe platform (patientslikeme.com, accessed on 28 March 2023) to model how the entities in our prototype relate to each other.

To manage which of their data will be visible and to whom it will be visible (DG1), the individual can use the features provided in the privacy control section. They can adjust their data-sharing preferences to make individual data items visible to themselves, people who follow them, or all community members. In addition, the individual can decide how others find and connect with them.

Regarding peer recommendations, we implemented them in two sequential flows. First, the prototype does not make any recommendations but asks about one's notion of likeness. To this end, it breaks down this concept of likeness into demographic, clinical, and lifestyle profiles and, accompanying each of these with a brief description of its scope, asks to rate, using a Likert-type scale, the importance of peers being like oneself in each profile (see Figure 2a). The purpose of this feature is twofold: it should satisfy the controllability to which DG2 aspires and serve to alleviate the cold start problem, i.e., not knowing what to recommend to newcomers [5].

In the second flow, the prototype makes peer recommendations and provides an explanation of each (see Figure 2b): it calculates an overall likeness between the individual and the recommended peer, according to the former's notion of likeness, and breaks it down into demographic, clinical, and lifestyle similarities; it also



**Figure 2: Peer recommendations. (a) The individual is first asked to rate, using a Likert-type scale, how important it is that peers are like them in demographic, clinical, and lifestyle profiles. (b) Then, the prototype makes recommendations and explains each “on-demand.”**

lists attributes common to both. This explanation should satisfy the other human factor with which DG2 is concerned.

The learning section comprises a main screen and a detail (treatment) screen. The former shows an aggregate-level comparison of treatments taken or used by others in similar situations (see Figure 3a). The idea behind this instance of social comparison is to mine the individual’s social network, which the prototype helps build through peer recommendations, to show what else peers are doing in coping with their disease and, perhaps in this way, introduce new self-care ideas. This feature should partially satisfy the DG2 since, although it explains recommendations superficially, it does not provide any control mechanism over their generation.

Once the individual distinguishes relevant content, the detail screen shows the treatment’s purposes and side effects, as reported by other members. It also lists individual evaluations and related treatments, for example, that meet criteria of high affordability and little or no burden (see Figure 3b). Last, the prototype informs about the appropriateness of the treatment for one’s situation and invites dialogue with healthcare providers using a discussion list managed by the individual (see Figure 3c). This discussion list is the mechanism we devised to satisfy DG3.

### 3 CONCLUSION AND ONGOING WORK

This paper elaborated on a peer data-sharing model in the context of CVD self-care. In describing its stages, we highlighted how

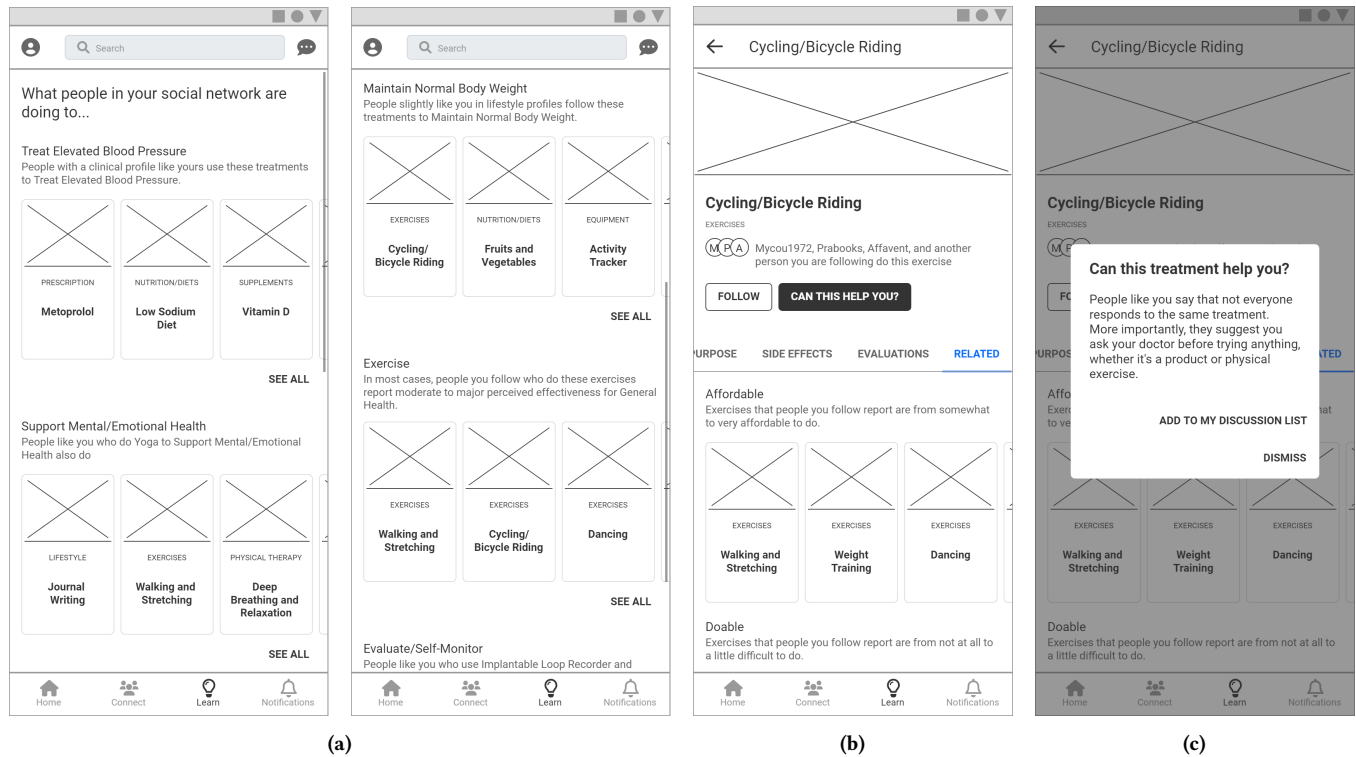
information-sharing behavior might support people in locating others in similar situations and learning new ideas about self-care from them. Additionally, we presented a prototype theoretically grounded in the peer data-sharing model. As a subsequent step, we plan to explore the perspectives of people with CVD and physicians on our prototype, following a participatory design approach and a qualitative orientation to research.

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**Figure 3: Learning section. (a) Comparison at the aggregate level of treatments taken or used by peers. (b) Page of treatment and others related to it that, for example, meet high affordability and low burden criteria. (c) Dialogue to inform about the appropriateness of the treatment for one's situation and to invite discussion with healthcare providers about it.**

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