Supporting Care Teams with Participatory Governance over Data Sharing

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Abstract. We have been studying Spinal Cord Injury (SCI) for a number of years, and have designed an application, Data Checkers, to help people with SCI control their data being disseminated among their care team. The paper describes the care teams for SCI, the application, and new features we are designing for the collaborative, on-going negotiation of data sharing.

Introduction

Care, especially for chronic conditions, is increasingly moving away from patients depending entirely on medical system and clinicians. Often, patients get access to clinicians only if their conditions worsen or change; otherwise, they must understand their conditions and care for themselves. New technologies, however, offer the hope of a more coordinated and cooperative system of care that better supports people with chronic conditions and their caregivers.

We have been studying Spinal Cord Injury (SCI) for a number of years because it is a particularly fruitful condition in which to study the changes that are occurring in care. Spinal Cord Injury (SCI) is a difficult, complex, and chronic condition. Injuries commonly result in paralysis and loss of normal function. Currently, there is no known cure. For those with an injury, managing one's health and mitigating

secondary conditions is often physically and psychologically hard. Care must be maintained over one's lifetime.

Managing a spinal cord injury is complex and highly individualized, as noted by Hammond (2000) and Maddox (2006). Each affected individual must master a range of self-care skills, including physical self-care, exercise, medication adherence, healthy eating, stress management, and emotional self-awareness (Meade and Cronin, 2012; Nunes and Fitzpatrick, 2015).

Much of the long-term burden of care falls on the patient and her family. Care can include help with continence and even breathing, assistance with the necessary exercises to maintain physical tone, and even making sure that helpers and supplies show up. Every patient is different, and requires customized care at some level (Hammond, 2000).

Büyüktür et al. (2018) detailed the care team for people with SCI. Assistance with care is often provided by a group of people including spouses, parents, and siblings. Some families are able to hire healthcare helpers, people with relatively low-skill levels who can assist the individual and/or family with required tasks at home. Helpers may come from an agency, but they may also be college students and volunteers. Family members are often prominent in assisting with care.

The age of the injured person and time after a traumatic injury affect dependence on caregivers: children and those who are newly injured tend to rely more heavily on caregivers. Individuals gradually take more responsibility for self-care, although reliance on caregivers for certain activities may be permanent depending on the level of injury. Hiring outside caregivers for a few hours per day or per week is common.

In addition, clinicians continue to oversee medical care on an outpatient basis. For those with access to specialty centers, the care team includes doctors specializing in physical medicine and rehabilitation, urologists, occupational therapists, physical therapists, rehabilitation psychologists, and rehabilitation engineers. Depending on the needs of the individual, other specialists (e.g. respiratory therapist, dietitian, social worker) may also be involved.

Thus, people with SCI often have a care team, one that is moderate in size, ranging from a few people to several dozen. The composition can shift over time and often does.

SCI clinicians and patients are potentially amenable to the use of monitoring. In SCI, records of care activities and health condition may need to be recorded and shared among patient-side care team members to maintain awareness and support coordination among themselves, while sensors, systems, and apps can be deployed to support semi-automatic health tracking, a concept proposed by Kim et al. (2017).

We are particularly interested in allowing the person with SCI to maintain control over sharing their data. Sharing data is likely to be tricky, and will require technical support, because of the distribution of responsibilities and expertise, the simultaneously hierarchical and ad-hoc relationships within the patient-side (non-clinical) care team, the often distant and formal relations between the patient-side and the clinical-side care teams, and necessarily, privacy concerns. For

instance, an experienced primary caregiver (e.g., the mother of the patient) within such a team could be overseeing the overall picture of the care, while a hired caregiver, who is a college student without particular medical training, will only assist 3 hours a day. Considering the responsibilities alone, it might seem reasonable to provide the primary caregiver with all kinds of data, while limiting the hired caregiver's access to only particular data categories. However, the patient could also want to withhold some data from his or her mother (perhaps the primary caregiver), given the potential tensions between parent and child over, for example, a sense of independence.

It is critical to support the patient in maintaining control over data sharing within the care team. If nothing else, as suggested by Nafus and Sherman (2014) and Unruh and Pratt (2007), having control over data could potentially allow individuals with SCI to obtain a sense of control over their lives. To do this, Büyüktür et al. (2018) identified several design requirements for sensor-based systems. First, systems should allow fine-grained control over sharing policies to align with different care team compositions (e.g., roles). Second, users should be equipped with tools to understand the effect of sharing policies (e.g., visualization). Third, sharing policies should be easy to understand and easy to share for reuse so as to avoid the need to start from scratch. Lastly, care team members should be able to continuously negotiate data sharing in reaction to changes in health and other contingencies.

System Design

In this section, we briefly describe the current state of an application, called Data Checkers, designed to provide patients with control over their data sharing, along with our current work to extend its policy authoring, manipulation, and negotiation to the entire care team. The design of Data Checkers features a board-game inspired, grid-based interface to create and edit fine-grained sharing policies. The interface consists of three components: a board, three boxes of game pieces, and an informational panel, where users can create and modify sharing policies by laying out different game pieces that represent data sources (data), data receivers (persons, such as a care team member), and modifiers (controls, such as releasing only a weekly summary instead of raw data). The informational panel allows users to simulate what data will be provided to individuals, groups, or roles according to specific policies. Figure 1 shows Data Checkers's interface.

We have recently completed an evaluation (in submission) that showed that Data Checkers is not only usable, but is generally more effective for data sharing than a state-of-the-art interface. It can be used by a wide range of users, including beginners, in a manner that allows them to both create new policies and to understand existing policies.
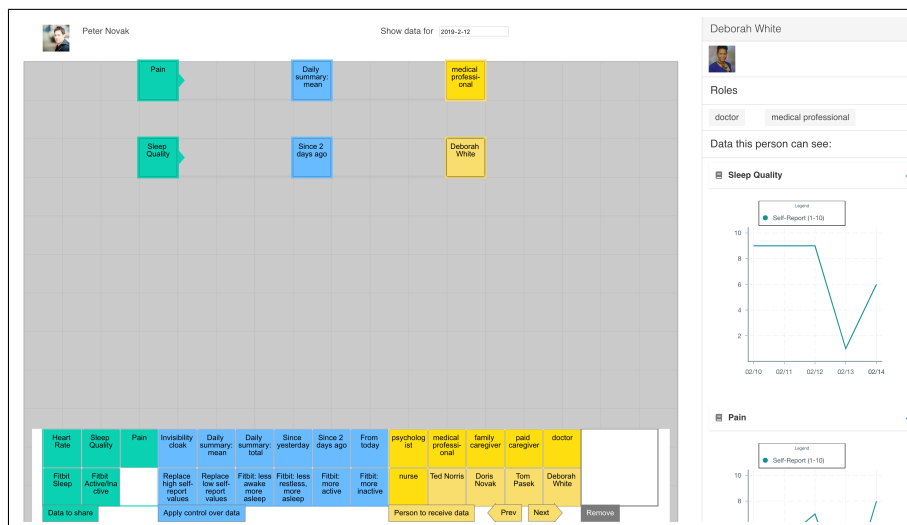
Figure 1. Data Checkers: on the left is a board-game style interface for specifying sharing decisions, and on the right is a panel that shows the preview of data being shared in a receiver's view.

Next Steps

We are now extending Data Checkers to share, negotiate, coordinate, and collaboratively settle on policies. Policies can be easily reused by sending the layout of different pieces to another person, who can subsequently modify and tailor the policies to his or her care team's needs. In the same way that they could when authoring the policies themselves, users can also view simulations of shared policies. For instance, if a patient adopts a shared policy (e.g., from the clinician side or from another patient) to share with a clinician the weekly summary of his or her sleep quality, the user can see the data visualized (e.g., in a line chart showing average sleep quality per week).

Data Checkers will offer an additional set of features to support the negotiation of sharing policies for care team members to collaboratively shape data sharing in support of the care and health of the patient. In addition to the ability to understand policies' effects on data sharing, the following issues are critical for the on-going negotiation of data sharing:

- Since care team members have different responsibilities and expertise, it is beneficial to allow different care team members to participate in the negotiations necessary to collaboratively create and curate data sharing policies. As Büyüktür et al. (2018) found, care teams vary greatly in composition and arrangement, so it is important to accommodate the uniqueness of the care team, as opposed to a simple voting mechanism that might fail to recognize the differences in commitment and expertise of each member. At the basic level, Data Checkers will allow sharing policies to be fine-tuned collaboratively by different care team members. For instance, clinicians could provide suggestions on the data they need, while the patient can control the amount of details to share. If necessary, the primary

caregiver could be tasked to provide suggestions. Data Checkers will also provide the necessary means to involve different members and have them participate in such fine-grained negotiations, such as the ability to propose a sharing policy, provide a counter-proposal, express approval on a proposed policy, and confirm a policy and have it take effect.

- Detailing the negotiation process will be challenging. On the one hand, sharing negotiation details could provide transparency for the negotiation process and allow care team members to learn about one another's data needs (e.g., knowing how much data is necessary to diagnose a health issue). On the other hand, revealing the process might be not only overwhelming but also privacy-sensitive (e.g., potentially revealing the patient is explicitly limiting data sharing with a family member). Data Checkers will allow users to selectively reveal and hide negotiation details. For instance, users will be able to hide certain elements (e.g., fine-grained controls policies) while sharing policies during the negotiation process. Such a feature will allow a certain level of plausible deniability since a patient can release summarized data without being explicit.

- The care team needs to coordinate in reaction to contingencies in care (including employment and medical changes). If participatory negotiation is to be supported, Data Checkers must offer the capability for users to tailor governance over sharing policies. As a first step, our design includes assigning negotiation capabilities to designated care team members (or roles) who have the need and expertise. For instance, a patient can agree to share a list of data to the ventilation team (vent team) at the hospital and a team liaison (e.g., a registered nurse) could serve as the gatekeeper to approve individual data requests from those vent team members. In that manner, the patient maintains basic control but the designated clinical team member can handle how the data is distributed among the clinicians. The redistribution of negotiation responsibilities not only may reduce the burden of the patient, but also increase care team members' ability to react to changes.

Acknowledgements

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