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Involving Patients in their Care Plan: Patients' and Care providers' Perspectives

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Abstract

In this paper, we present the results of a series of qualitative studies involving patients and care providers to explore opportunities for involving patients in their care. Empowering patients in their own care can facilitate the treatment process, increase patients' quality of life, and support patients in reaching their goals. A cultural shift towards patient centered care is currently underway, however, at least in Canada, there is still much to be done. Through interviews and focus groups with patients and care providers, we aim to contribute to this cultural shift by identifying three areas of opportunity to involve patients in their own care and be a part of their care team. We then describe potential technology solutions to address these opportunities.

Author Keywords

Patient-centered care plan; care providers' and patients' perspectives; qualitative study; semi-structured interviews

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]:
Miscellaneous

Introduction

The research literature is filled with evidence that involving patients in their care can have positive effects on their quality of life and treatment plans [3, 7]. Providers are also starting

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to see value in involving patients in their care, however they may not have enough information about how and where to involve patients in their care. Meanwhile, patient centered care plans are a relatively new vehicle that is introduced for including patients in their care [4].

There are many definitions of what a patient-centered care is [1], therefore, we developed our own following definition based on the research we have conducted and with the purpose of facilitating the evolution of this concept. We define a patient centered care plan to be a living document (i.e. continually updated and refined) co-created by patients and their care providers. The patient centered care plan combines patient goals and values with provider expertise and guidance to facilitate a holistic approach to care.

Recently, there has been a movement towards strengthening patient-centered care plans within the Canadian healthcare systems [5, 6]. However, there is a lot of work that needs to be done towards better understanding the opportunities for involving patients in their own care. To fill this gap, and to expand our understanding of this problem, we conducted a series of focus groups and interviews with 18 patients who have chronic conditions, and interviewed with 38 care providers with differing expertise to help us identify possible opportunities for involving patients in their own care.

From the results of the focus groups and the interviews, we identify three main areas of opportunity for supporting and involving patients in their own care: i) *Patients and providers have different views on tracking data*, ii) *patients need information and support guidance*, and iii) *patients and providers have different goals*. Finally, we indicate possible future directions for the HCI community based on our results, and propose three potential technology solutions for the three main opportunities that we identified to support patients' involvement in their own care.

Eliciting patients' and providers' perspectives

Patients: In collaboration with the University of Calgary Patient and Community Engagement Research Group [9], we recruited 18 patients with one or multiple chronic conditions. Each participant took part in one or more study activities, including focus groups and/or individual interviews. Patients' chronic conditions included breast or thyroid cancer, diabetes, liver failure, leukemia, bone marrow transplant recovery, heart problems, scleroderma, chronic obstructive pulmonary disease, arthritis, depression, bi-polar disorder, and anxiety. In the session, patients were asked to relay their experience and talk about how they currently manage their ongoing care, as well as what they perceive as gaps. The patient focus groups and interviews lasted 60–120 minutes.

Care providers: We conducted semi-structured interviews with 38 care providers and support staff (see Table 1). We used semi-structured interviews in order to allow care providers to influence the conversation.

Provider Type	No.	Provider Type	No.
Physicians	10	Unit manager	1
Pharmacists	5	Kinesiologist	1
Nurses	11	Medical office assistant	1
Social Workers	3	Patient flow coordinator	1
Dietitians	1	Manager of health dept.	1
Health consultants	2	Clinic manager	1

Table 1: Care providers specialties

We asked care providers about their perspective on opportunities for involving patients in their own care plan and how a care plan can affect the communication dynamics between patients and care providers. The questions covered two main topics: 1) *How do you currently involve patients in your care planning?* and 2) *What kinds of information or content do you see as being vital to the success of a patient centered*

care plan solution? The care provider interviews lasted 30–60 minutes depending on providers availability and the interview process.

Analysis: We audio recorded all the interviews and the focus groups. Then, we transcribed and analyzed the interviews using inductive qualitative methods [8]. We then clustered codes with similar meanings. Finally, we identified the main categories and created an affinity diagram [10] to define and refine key themes (see Figure 1).



Figure 1: Affinity analysis of the interview transcript quotes.

Results

We analyzed the data for 38 care providers and 18 patients with different chronic conditions. In comparing patients' and providers' perspectives, we gained an in-depth understanding of the opportunities for involving patients in their care. The collected data is rich, however, due to the space constraints, in this paper we only discuss three key opportunities to evolve patient centered care plans.

Patients and providers have different views on tracking data Care providers in our study mentioned that in recent years patients are much more eager to track their health data and share this collected information with their providers. Patients collect various types of data including weight, medication, exercise routines, smoking habits, sleep habits, nutrition, and emotional states. Patients in our study also showed interest in collecting data as a mean to be involved in their own care.

However, the providers in our study said that not all of their patients are aware of the type and the amount of information that they need to collect for their disease. The care providers think patients often collect unnecessary information and as a result miss tracking the necessary information. Patients also get frustrated when they cannot see any effective use of their data. One of the providers told us one of his/her patients was collecting nutrition data in order to lose weight, however it was also important to track emotional states to identify the reasonings behind the patient's eating disorder: *"I know with eating behaviours instead of just writing what you eat and when, . . . [you should keep track of] what were your emotions you know, what were you thinking at that time, what were you feeling at that time"*.

Both providers and patients in our study expressed interest around more *effective* data collection indicating that this is an area in which work can be done to better support it.

Patients need information and support guidance

The care providers in our study told us one of the problems they face with involving patients in their own care is that often patients lack awareness about their disease. Both patients and care providers indicated that a greater understanding of patients' situation could assist them in their journey. Therefore, the care providers found educating patients one of the important opportunities for involving them in their care plan. The care providers in our study told us that they try to edu-

cate patients during their visit by providing them with information about their disease and their conditions. This information includes, but is not limited to:

1. Adjustment to chronic condition support (providing education and support in graduated steps, in consultation with care providers).
2. Medical literature (someone who has medical or scientific background might want or appreciate academic publications).
3. Guidance on using platform of choice including self-management technologies to support goals, conditions, etc, such as Fitbit, Glucose meter, food logging apps, and sleep monitors.
4. Using the internet wisely (how to critically evaluate the credibility of information found on the internet).
5. Information on support groups (i.e. www.patientslikeme.com, Facebook groups , online communication support).

Many patients are also eager to be involved in their own care and to learn about their situation, however, they may not be ready to grasp all the information, they may not be able to remember all the information, or there may not be enough time to go through all the necessary information during a clinical appointment. One of the patients said: *“in the beginning when I had cancer and I saw the surgeon which was the day after I found out that I had cancer, I got a folder with so much information, like it was all booklets . . . you are bombarded with so much information. I went through a couple of leaflets and I thought ‘I don’t want all of this’, so I put it all in with the binder, closed the zipper and I put it away”*. There are multiple factors that could influence the patients’ ability to understand their situation, including educational background, information seeking preferences, and stage of disease, e.g., *“the fact that it’s [the care plan] patient centered and so it has to*

be understandable, it has to provide information that useful to a patient . . . it needs to be tailored”. As such, personalized patient knowledge support is another area of opportunity to involve patients in their care plan.

Patients and providers have different goals

Patients’ goals are not always aligned with care providers’ goals. Patients sometimes have goals such as being able to play with grandchildren once a week, attending special events (e.g., a wedding), traveling, retiring, reducing their number of medications etc.. that may not be their providers’ priority when planning patient care. The care providers in our study told us that sometimes the disagreement between patients’ and providers’ goals cause difficulty in communicating with patients and in planning for patients’ care. For instance one provider described one of his/her patients’ situation as *“[She is] a 37 year old woman with metastatic cancer, she has a 2 years old and a 5 years old. She said her goal is to live long enough so her 2 year old remembers her. And she said physicians never talked to her about her end of life goals . . . and she said she’s willing to put up with some difficult treatments . . . she is looking at longevity”*.

Ensuring a shared understanding of patients’ and providers’ goals for a treatment plan is the third area of opportunity for involving patients in their care.

Technology Solutions

Findings from our study revealed three areas of opportunities for involving patients in their care. In this section, we propose a potential technological solution for each of these patient centric care components.

Patient-Generated Data Visualization

Collecting patient-generated data is becoming increasingly common in disease management. Patients use various tools to collect health and lifestyle data in disparate places. How-

ever, aggregation and effective use of this data remains a challenge. In addition, most of the existing tools do not support collaborative data sharing between care providers and patients, thereby exacerbating these challenges [2]. Both providers and patients in our study agree that this data could be used to make smarter decisions regarding patient disease or treatment options, to improve patients' quality of life, and to share patients' data with their providers to aid making decision about their ongoing care. Patients spend a lot of time preparing the information in an effort to promote a shared understanding. However, care providers also need to invest time in making sense of the patients' data.

To address this problem, providers in our study told us they are willing to guide patients in collecting necessary data types. However, they currently lack support. The first technology solution we propose is to design a collaborative platform for care providers and patients to select together the type of data that patients need to monitor. From this collaborative platform it would be possible to explore an overview visualization of patient-generated data that is designed for providers to be able to gain an understanding of the patients' wellbeing in a short period of time.

Collaborative Information Sharing

Patients receive a lot of information during a clinical visit. This information is prepared by care providers in different formats including verbal, printout documents, booklets, link to related websites etc. however, sometimes the information is hard to understand for patients. To fill this gap, care providers spend time with patients going through more details, trying to make sure patients grasp all the necessary information. However, as the providers in our study mentioned, patients may not understand all the information or they may have difficulty internalizing it.

To support patients in accessing appropriate resources in a timely manner, we will examine the potentials for designing interactive documents through which care providers can educate patients about their situations and care mechanisms processes in a collaborative environment. In this platform, patients could have access to appropriate information concurrently with care providers providing them with more opportunities and greater knowledge to actively participate in their care. Patients could also potentially add their own notes and share them with providers. This platform would have the capacity to involve patients in the education process, to include them in decision making, and to support both parties in a shared awareness of patients' understanding.

Follow Up Care Timeline Visualization

As previously described, the goals of patients and providers are sometimes different. When providers plan patient care without considering patient priorities and goals, they think patients may feel disconnected from their own care. We propose an interactive adjustable timeline visualization that demonstrates all the patients' care treatment processes. This visualization could allow providers to collaboratively incorporate patients' goals with their own expert opinion into the patients' ongoing care plan. This also facilitates the often-expressed patient need to have a clear view and understanding of *what is next*, therefore enabling them to plan their life around their care.

Conclusions

While there has been a considerable increase in awareness of the importance of involving patients in their care, more work remains to be done in identifying opportunities to evolve patient-centered care. In this paper, we reported on a series of qualitative studies from the perspective of both providers and patients and explored opportunities for effectively involving patients in their care. Our results allowed us to iden-

tify three key opportunities: 1) supporting different views of tracking necessary data, 2) providing patients with information and guidance, and 3) incorporating patients' and providers' goals. Based on our results, we introduced three possible directions for future work in terms of designing technologies for empowering patients in their care: 1) designing a patient-generated visualization, 2) providing patients and providers with a collaborative information sharing platform, and 3) supporting patients with a follow up care timeline visualization.

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