The Communication and Care Plan: A novel approach to patient-centered clinical information systems

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1. Background

Historically, providers diagnose and render decisions while patients accept treatments. Communication about the plan of care with patients in such an environment does not incorporate the patient's life situation, and when care for a given condition includes multiple providers, the treatment planning often feels fragmented and unpredictable to patients. Healthcare rendered in this fashion is not patient-centered which is reflected by our current health information systems, which are also not patient centric. In order to better understand the patient's perspective on healthcare information access, we undertook a user-centered design process with the goal of addressing the specific needs, experiences, and values of the patient. We also undertook an assessment of the provider and staff needs to better understand the information they require for planning patient treatments in an effort to develop an integrated solution that, by simultaneously meeting the information needs of the stakeholders, could better serve the patient's needs as well. This was conducted in the context of breast cancer, which has multiple possible treatment regimens, each with a high information density and complex temporal associations. Information gleaned from this process led us to develop a novel component, the Communication and Care Plan (CCP).

2. Design process

The CCP tool development followed an iterative, user-centered design process. This involved three patient focus groups (N = 16) and two provider focus groups (N = 10). The intent of the focus groups was to reveal key stakeholder values, needs, and concerns about an online tool intended to facilitate entering, organizing, and integrating care plan information. Patients were recruited through online support groups and the UCSF breast cancer advocate group. Providers, which included oncologists, nurses, and surgeons were recruited from the UCSF Breast Cancer Center. Using information gleaned from the focus groups, we undertook an agile development process in which we iterated rapidly with multiple prototypes. During this phase, we created three prototypes (white board, power point, flash-based system). This allowed for inexpensive and rapid experimentation with various user-interface paradigms and information delivery models. With insights gleaned from focus groups and prototypes, we sought to implement a final prototype that embodied the major information requirements from the stakeholders.

3. Results

The desired functionality differed by our three different stakeholder groups.

The patient focus groups were interested in having access to summary data including original diagnosis, treatment plan,
information on progression, post-treatment care recommendations, and second opinions. They wanted a schedule of procedures, treatments (e.g. surgery, chemotherapy and radiation), and lab tests and a way to integrate their personal calendar and upcoming important events for scheduling. They also wanted access to chemotherapy flow sheets and drug information as well as pathology reports and MRI images that could be taken along with them to their provider appointments. This was especially important because so many women receive their care from so many different institutions and medical offices. They also thought it would be helpful to have a graphic rendering of the continuum of care (all treatment modules, not just one specialist at a time), so they could better visualize their entire care plan and where they were in the treatment cycle. A reminder system to push out messages or alerts to help them manage appointments and tests was also deemed to be important by the patient group.

The provider focus groups highlighted the need for information on histopathology, tumor size, tumor characteristics, and receptor status. They wanted to be able to view the current care plan as well as have a method to view care plans that are discontinued. They were interested in a repository of general information about decisions made as well as having templates to manage orders associated with treatments in a particular care plan. They were also interested in the ability to have electronic flow sheets that would be populated with labs and connected to an electronic health record system. Ideally this information could generate a treatment summary at the end of the course of therapy.

The staff focus group was looking for a way to easily view the patient’s entire care plan (all treatment modules, not just one specialist at a time), so they could answer questions patients might have and send them onto the appropriate person. They thought it would be helpful to have a clear list of the tasks they needed to complete for the patient and by when as well as an easy way to adjust future appointments that might be affected by a delay in treatment or complication.

The specific and varied functionality desired by patients, providers, and staff reflected the need for a new information infrastructure paradigm that supports a shared view of the care process itself. This led us to develop the Communication and Care Plan, an information framework supporting three goals: (1) enabling the capture of structured data from patients and providers, (2) organizing information and displaying options using a calendar, and (3) integrating information about care for both physician and patient, including important upcoming events and personal commitments for patients in their personal lives. Implementing the Communication and Care Plan in the Tolven eCHR required us to build two pieces of functionality: (1) a treatment planner and (2) a calendar component. The treatment planner allows a provider to construct a treatment plan as a sequence of events (surgery, chemotherapy, radiation, hormone replacement, or “wait”). Additional data elements are entered and specific to each event type. Once the treatment plan is stored, it can be rendered by the calendar component using two different views; a month/day view and a ‘swim lane view’ (Fig. 1). Treatment planner and calendars are available to providers. The patient has access to the calendar views, but can retrieve detailed information about the care plan events by clicking the event on the calendar. Patients can also add their own events to their calendar to facilitate integration with important life events (weddings, birthdays, holidays, critical work deadlines, or meetings).

4. CCP development and core components

The final prototype was developed as a module within an existing open source web-based clinical information system (Tolven eCHR, San Francisco, CA). The Tolven eCHR system is an open source web-based electronic healthcare record systems modeled on the HL-7 version 3.0 Reference Information Model (RIM) [1]. The system is built on a Java middle-tier framework (J2EE) with data storage accomplished in an open source relational database.

![Fig. 1A. Communication and Care Plan Manager: This screen shot demonstrates the view of the clinician as they put together a treatment plan scenario. The diagram with the arrows shows the summary view, and the detail can be entered for each procedure or treatment segment, below. The calendar view is demonstrated in Fig. 1B.](image-url)
server (PostgreSQL). We selected the Tolven eCHR platform because it is an existing electronic health record system supporting both provider and patient views of data, it adheres to a robust and emerging standard information model, and because the open source license allowed us to freely modify the system as well as make it available to others without constraints.

5. Discussion

At the opening of the 21st century, advances in technology have provided us an opportunity to fundamentally change the care process into a more patient-centric model. Web 2.0 technologies in healthcare enable a social construct with a more equitable balance of information access, and leads patient empowerment. This requires a process change and tools to support it. The CCP component and the user-centered design process we engaged reflects a development framework for patient-centered system designs. Providing patients with the information they need actually enabled us to improve the information for providers and staff as well. The CCP model of shared treatment care plans which are rendered as calendars that can be integrated with a personal calendar is a radical departure from the traditional EHR design. The CCP demonstrates the sometimes fundamental difference in design that occurs when we seek a patient’s point of view and use this to re-design our clinical information systems.

Conflict of interest

The authors declare that there are no conflicts of interest.

Reference