Abstract

An ideal healthcare delivery system would be centered on patients’ specific needs. These needs are diverse and merit a thorough analysis. In our pilot study, we examined these needs using qualitative interviews. We learned that empowering a patient requires a multi-faceted approach. There needs to be a balance of personalized delivery of health information and shared decision making with providers. Further, a learning element needs to be factored in such that knowledge generated from patients’ experiences can be shared across groups. This learned knowledge will be the key to empowering patients in the Learning Health System.

Objective: Early findings describing the conceptual design of a Learning Health System that empowers patients.

Method: Nine contextual inquiry interviews were conducted with patients. Using an affinity wall exercise, qualitative thematic analysis of the nine interviews was carried out by a group of researchers.

1. Introduction

In this paper, we present findings derived from contextual inquiry interviews with patients focused on their information access when engaged with complex health care delivery systems. We believe these findings will provide a strong base of user-centric design principles to technology developers building applications for the Learning Health System, which the Institute of Medicine describes as a system “… in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and healthcare [1]”.

The U.S. healthcare system is dealing with rising costs [2] and minimal increase in quality of care [3]. There are multiple initiatives at every level of the system to deal with this crisis. At the national level, policy makers are working to enhance access to care and to incentivize health care delivery systems to upgrade their information technology infrastructure. At the delivery system level, standardization of processes and use of quality improvement programs is leading to improved health outcomes [4]. However, the reach of translational research [5] is still limited and fails to positively transform clinical outcomes [6]. This brings out the need to synchronize our care delivery improvement efforts further. The ‘Learning Health System’ is quickly emerging as a concept that stands to provide approaches to many of the current healthcare delivery problems and pave the way to a system where we share ‘knowledge’ not just data.

The amount of data available in clinical settings can be overwhelming [7]. Therefore, providing the right amount of information to the right person at the right time is essential. For a prospective Learning Health System, the ‘Learning’ aspect must be studied from the perspective of each type of stakeholder. As patients are at the receiving end of the care process, special emphasis needs to be put on their requirements. It is imperative that our health system makes progress toward putting patients at the center of care.

Patient ‘empowerment’ is a term that has been in use for a long time with multiple definitions, often varying in the context. Before we move further on how a system should be designed, it is important to understand this key term and how it may play a role in the context of a Learning Health System. According to research by Aujoulat et al., patient empowerment can...
be understood from two different dimensions: from the provider-patient interaction and from the patient’s point of view alone. From the provider-patient interaction perspective, empowerment is a process in which care providers educate patients on their medical condition and put emphasis on shared therapeutic decision making [8]. When the process is seen from the point of view of the patient alone, empowerment is a process of self-transformation. The outcome, though, remains the same – an empowered patient is more informed about his or her condition and treatment options [8]. Therefore, in order to empower patients we must identify the needs of patients and assess the gaps in the current information technology infrastructure. This understanding will enable us to support the process of self-transformation and bring patients closer to their care providers. As we proceed through this paper, we will explore findings that echo this perspective. Next we describe the design and methodology used.

2. Design

The key research questions guiding our study were:

- How do patients find, evaluate, and use health information?
- What labeling on the source of information will cause patients to trust it, find it more credible, and pay more attention to it?
- How do authors of healthcare content get information to patients in a way that it is useful to patients and helps them engage to improve their health?
- What is the patient’s own self-learning cycle?
- Where are patients learning and how are they learning?

We conducted qualitative research-based semi-structured interviews with a total of nine patients associated with a Midwest health care delivery system. The delivery system’s patient engagement advisor provided a list of patients, all with chronic conditions, who had expressed interest in participating in research studies and were highly engaged in their own care. The authors selected a convenience sample of patients who were available for home interviews. The larger study, of which this is a part, involves interviewing providers and public health coordinators to provide a holistic set of principles to inform application design. The larger study will lead to the development of a software application, which will be deployed and evaluated in multiple healthcare delivery systems of different scale.

Using a contextual inquiry interview process provided in-depth user-centric information [9]. While a conventional interview can provide answers to what, where, and when, it lacks the capacity to dive deeper into learning the hows and the whys. As part of the methodology, home interviews helped patients feel comfortable and, in turn, gave our team an opportunity to observe each patient’s immediate environment.

The field team consisted of two interviewers: one with responsibility to ask questions and the other to observe the patient’s environment and take notes. The interview was audio-recorded with the patient’s consent and the transcripts derived from the recordings were de-identified and cleansed of any personal or medical information.

The interview protocol is found in Table 1. Italics are meant to be supporting words/phrases to help the interviewer during the process. The interview team followed the protocol, which included opportunities to probe for additional information.

<table>
<thead>
<tr>
<th>Interview Protocol Questions</th>
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<tbody>
<tr>
<td><strong>Prompts related to a time when the patient could not find information.</strong></td>
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<tr>
<td>• Do you remember a time when you tried to find some information related to your condition but were not able to?</td>
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<tr>
<td>• Did your care provider help you in finding this information?</td>
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<tr>
<td>• If yes - What actions did you take based on the input you received from your care provider/friend/fellow patient?</td>
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<tr>
<td><strong>[Pre-Appointment]</strong></td>
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<tr>
<td><strong>Prompts related to self-learning.</strong></td>
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<tr>
<td>• Do you try to learn more about your condition [or progress] before your doctor’s appointment?</td>
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<tr>
<td>• What sources [Institute of Medicine of the National Academies, etc.] have you found to be most helpful for this pre-appointment learning? [Sources of information can be web based, friend or relative, magazine, etc.]</td>
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<tr>
<td>• Do you prefer using any specific source? Also, how did you find this source?</td>
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<tr>
<td>• Why do you prefer this source? [Inquire about specifics such as content, design of interface, ease of access, any additional feature that stood out.]</td>
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<tr>
<td><strong>[Appointment]</strong></td>
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<tr>
<td><strong>Prompts related to the patient’s appointment with his or her provider.</strong></td>
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<tr>
<td>• When you are with your doctor [or nurse, therapist, ...] do you like them to share information about your diagnosis and treatment plans verbally, on paper, as references to online resources, some other method, or a combination of methods?</td>
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</tbody>
</table>
Does your caregiver guide you through these resources? [Guidance on how to access them, what to look for or what not to look for,...]

[Post-Appointment]
Prompts related to follow-up.
- Has anyone from your care provider team followed up with you to check if you are comfortable in using the information that was provided to you?
- Would you prefer someone from your care team to contact you after an appointment?
- If yes - How would you prefer to be contacted? [Digitally via emails, text, phone call, or any other method?]
- Do you [at present] get any sort of reminders on your appointments or therapy? If yes - How do you get the reminders?

Prompts on access to information sources
- Do you own a smartphone? [And/or tablet, laptop, or any other device such as Fitbit?]
- Which device do you prefer using? Why this particular device? If there is no preference that is ok.
- If tablet/smartphone was the answer to above question, follow with - Do you use any health-related apps?
- If yes - Why this app? How did you find this app? What do you like in it?
- If patient answered ‘laptop/computer only’ follow with - Can you describe any health-related website you recently visited? What is your go-to website to find information? [Note this is post-appointment]
- Can you please show us how you access the website on your device? [Ask specifically- What did they recently search and ask them, if they are comfortable with doing so, to repeat the search.]
- Do you have any health-related magazine/journal subscriptions? Why this journal?

Other prompts
- Do you keep a log of blood pressure/other condition-related readings? How do you track the information - using a device or paper? Do you share the log with your doctor? How often do you share it? Does your doctor like that you do it?
- What do you typically do to keep your condition in check?
- How do you expect your care provider can help in managing your disease?
- What information do you think you could provide to your physician to help manage the disease?

The research team analyzed the de-identified transcripts over several hours using an affinity diagram [9]. The team gathered in a conference room and reviewed patient quotes and sorted and posted them by consensus on the wall. We conducted four levels of analysis:

- Tier 0 represented the raw quotes and notes from the interviews relevant to the research questions.
- Tier 1 represented the first level of thematic abstraction from the raw interview transcripts and notes. Tier 1 notes are written in the first person and use language close to the patients’ own words. The goal was to summarize relevant details from the interviews.
- Tier 2 represented a summary of Tier 1, placing the detailed comments into broader themes. These are also in the first person.
- Tier 3 represented a summary of Tier 2, stated as key design domains. These do not need to be in the first person.

3. Discussion

The affinity diagram was completed up to a Tier 3 level of abstraction. These are the general areas of concern for the patient stakeholder group in a Learning Health System as agreed by all members of the research group.

The resulting themes at different levels of abstraction are described in Tables 2, 3, and 4. The Tier 0 verbatim quotes are not included in this paper because of their sheer volume. Table 2 lists Tier 1 comments, indented and clustered under a Tier 2 abstracted theme. From the very first example, Tier 1 items “I do a lot of research online” and “I like to search Google” are abstracted into the Tier 2 theme “I research online.”

**Table 2: Tier 1 and 2 Themes**

<table>
<thead>
<tr>
<th>T2.1: I research online.</th>
<th>T1: I do a lot of research online.</th>
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</thead>
<tbody>
<tr>
<td>T1: I like to search Google.</td>
<td>T1: I trust information that I find on my own if it is authored by a reputable organization.</td>
</tr>
<tr>
<td>T2.2: I trust information from sources where I would go as a patient.</td>
<td>T1: I use the Kaiser Foundation and Mayo Clinic as a resource.</td>
</tr>
<tr>
<td>T2.3: I want to engage my healthcare team in between the appointments.</td>
<td>T1: I trust sites from organizations with good reputations.</td>
</tr>
</tbody>
</table>
T1: I prefer to converse with my physician than exchange email.

T1: I want my doctor to be more active in communicating with me.

T1: I want a summary sheet after each appointment.

T1: I want a confirmation when something is in progress.

T1: I email my physician only relevant issues.

T2.4: I record my health information.

T1: I keep logs of my own health information, but not consistently.

T1: I use the Fitbit app.

T1: I organize my own notes after an appointment.

T1: I use calendar to keep track of appointments.

T2.5: I want personal and provider information available at an appointment.

T1: I bring my logs with me to my doctor’s visit.

T1: I want information on hospital stays to be present with appointments.

T2.6: I prefer ease of access.

T1: I want to access my health information in one place.

T1: I want direct and easy access to resources.

T1: I prefer simple easy-to-use systems.

T1: I prefer portability of apps (compared to websites).

T1: I start with the information source that is the easiest first, then I move on to more credible sites.

T2.7: I want to have access over my health information.

T1: I want to be able to view my medical record.

T1: I use my provider’s health portal.

T1: I want a roadmap of my treatment.

T2.8: I would like to choose the medium in which I receive information.

T1: I prefer information on paper vs. electronic only.

T1: I prefer information to be presented visually, text is a good complement.

T1: I prefer information delivered orally.

T2.9: I consider who referred me to a resource in order to inform how much value it has.

T1: I trust information sources recommended by my providers.

T1: I use my family as a resource.

T2.10: I need to be able to share my health information with family and friends who help me manage my care.

T1: I like my family and broader caregiver community to be informed.

T1: I need a partner to help listen and remember things from medical appointments.

T1: I want to share information only with my family.

T2.11: I like the ability to turn on and off reminders.

T1: I like to be coached or reminded to complete tasks or actions.

T1: I like to have reminders for appointments and lab tests.

T1: I am active in self-monitoring and don’t need reminders.

T2.12: I want a voice in my care plan.

T1: I want to be able to put comments on my health portal.

T1: I want to be in control of my own information.

T1: I want to be a partner with my doctor concerning my care.

T2.13: I am discerning when I get information/advice.

T1: I pay attention to articles’ references.

T1: I consider the credentials and field of authors and referrers.

T1: I prefer information sources that are academic.

T1: I verify information across multiple sources.

T1: I prefer sources that are recent.

T2.14: I would share information with patients like me.

T1: I am comfortable sharing information about my condition with fellow patients.

T1: I share with my peers to help others.

T2.15: I do my own research.

T1: I do research to manage my own care.

T1: I do research on my medication.

T1: I do research to prepare for my doctor’s appointment.

T2.16: I would like to choose how much detail I receive.

T1: The more information I have the better.

T1: I like information to be given to me succinctly.

There were Tier 1 themes that we could not categorize under any particular Tier 2 theme. These are present in Table 3 below.

**Table 3: Tier 1 themes (not categorized)**

<table>
<thead>
<tr>
<th>Tier 1</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>T2.11</td>
<td>I like the ability to turn on and off reminders.</td>
</tr>
<tr>
<td>T2.12</td>
<td>I want a voice in my care plan.</td>
</tr>
<tr>
<td>T2.13</td>
<td>I am discerning when I get information/advice.</td>
</tr>
<tr>
<td>T2.14</td>
<td>I would share information with patients like me.</td>
</tr>
<tr>
<td>T2.15</td>
<td>I do my own research.</td>
</tr>
<tr>
<td>T2.16</td>
<td>I would like to choose how much detail I receive.</td>
</tr>
<tr>
<td>T1</td>
<td>I want to have tools that I can use to train myself for using an application.</td>
</tr>
<tr>
<td>T1</td>
<td>I think physicians should take more time for each appointment.</td>
</tr>
<tr>
<td>T1</td>
<td>I am more serious about my condition when my doctor says it is important.</td>
</tr>
<tr>
<td>T1</td>
<td>I appreciate when my provider shares updated knowledge.</td>
</tr>
</tbody>
</table>
While the above themes do not provide us a complete picture of how a Learning Health System and its applications should be designed, they do take us to the point where we can start imagining it conceptually. In fact, there were multiple ‘aha’ moments throughout the process where our team felt we peered into the near future and the possible design of a Learning Health System. In one of the patient interviews, when asked the question “During research on Medline how useful was the process and knowledge gained” the patient replied with “Oh, it has. It’s been empowering.” This comment demonstrated how self-learning can be transformative and lead to patient empowerment. A Learning Health System that integrates the vast amount of available clinical research can help make this self-learning process as easy as a click of a button or tap on the screen for the patient.

In another instance, a patient explained how her relationship with her provider made the experience empowering. The patient suggested that when the physician said to her, “You’re going to have to be your own advocate in the healthcare system because there’s going to be nobody around who will understand your condition” it helped build that connection where the patient felt that the physician specialist cared for her condition and took that extra step of telling her the truth.

Both of the above examples highlight how learning about a patient’s experiences from various dimensions can prove to be especially empowering in designing the Learning Health System.

Table 4 lists the Tier 3 design domains to consider when building a system that learns from and evolves with patient experiences. Table 4 lists Tier 2 themes, indented and clustered under a Tier 3 design domain.

<table>
<thead>
<tr>
<th>T3.1 Information gathering.</th>
<th>T2.1: I research online.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information gathering refers to how a patient obtains information on their condition, treatment, medications and from what sources.</td>
<td>T2.2: I trust information that I find on my own if it is authored by a reputable organization.</td>
</tr>
</tbody>
</table>

Table 4: Tier 2 and Tier 3 themes

<table>
<thead>
<tr>
<th>T3.2 Information sharing.</th>
<th>T2.10: I need to be able to share my health information with family and friends who help me manage my care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information sharing refers to patients’ willingness or need to share their personal health information to help others or to have others involved in their care.</td>
<td>T2.14: I would share information with patients like me.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>T3.3 Information access.</th>
<th>T2.6: I prefer ease of access.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access refers to the patient's desire to have access to their health information.</td>
<td>T2.7: I want to have access over my health information.</td>
</tr>
<tr>
<td>T2.8: I would like to choose in what medium I receive information.</td>
<td>T2.15: I do my own research.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>T3.4 Ownership and onus.</th>
<th>T2.2: I trust information that I find on my own if it is authored by a reputable organization.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-monitoring refers to the patient's general awareness of their health as well as their intent to proactively monitor specific aspects of it or be an active participant in their own health care.</td>
<td>T2.3: I want to engage my healthcare team in between the appointments.</td>
</tr>
<tr>
<td>T2.5: I want personal and provider information available at an appointment.</td>
<td>T2.4: I record my health information.</td>
</tr>
<tr>
<td>T2.6: I prefer ease of access.</td>
<td>T2.7: I want to have access over my health information.</td>
</tr>
</tbody>
</table>
T2.12: I want a voice in my care plan.
T2.13: I am discerning when I get information/advice.
T2.15: I do my own research.
T3.5 Communication.
Communication with providers, caregivers, and peers.
T2.3: I want to engage my healthcare team in between the appointments.
T2.10: I need to be able to share my health information with family and friends who help me manage my care.
T2.14: I would share information with patients like me.
T3.6 Personalization.
This refers to the level of customization a patient would like in terms of what information they have access to as well as how they view it.
T2.4: I record my health information.
T2.5: I want personal and provider information available at an appointment.
T2.8: I would like to choose in what medium I receive information.
T2.11: I like the ability to turn on and off reminders.
T2.12: I want a voice in my care plan.
T2.16: I would like to choose how much detail I receive.

By categorizing themes by their level of abstraction, we can summarize patient-centric design principles under six major design domains.
- Information gathering
- Information sharing
- Information access
- Ownership and onus
- Communication
- Personalization

Software architects are currently using these design domains to develop a Learning Health System prototype application. When needed to make any particular design decision, we can draw on the Tier 0 through Tier 2 details.

Research has shown that patients need more information when it comes to their health [10]. When this information is made available, it has a positive impact on health outcomes, leading to reduced patient anxiety and enhanced perception of control [11]. From our Tier 0 quotes, we know patients need to be able to see their treatment plan, medication list, health logs, and appointment history all in one place. Patients further desire an ability to customize information to their individual preference. For treatment therapies that require at-home care, patients need step-by-step instructions on how to use any devices that are suggested. Following some appointments, patients are handed packets that explain their condition and related information. Patients would like credible sources attached with these materials that describe why a particular treatment or medication applies to them. It is often difficult for patients to determine which sources of information to trust or not trust. However, we found that patients generally trust research undertaken by public universities as patients felt the institutions’ ‘public’ status meant they were less inclined to present material that only benefited them financially.

Patients would like to choose how information is presented. While text is a good complement to information provided verbally in appointments, the preferred mode for our interviewees was visually constructed information. Research shows that pictorial representation of health data supplemented with easy-to-understand captions increases the retention and recall of information in patients. [12] Although it is beneficial to all patients, it is especially useful in educating patients with low literacy level [12]. Patients also want the ability to search through and put comments on individual elements of their profile (e.g., in a personal health record). These comments or notes should be available to the providers, potentially contributing to the patient’s treatment plan. This commenting ability would provide patients freedom to express their opinion beyond the appointment. Further, patients expressed a desire to actively share their health data within a broader patient community, creating a sense of altruism that is an essential part of self-transformation.

It is important to understand that while some patients may be actively engaged in their care, there are many that are not. From the interviews, we learned that patient behavior is more frequent during the onset of a condition. Therefore, a timeline showing how the patient’s condition may progress and what might be the possible consequences of current or future therapeutic procedures can enforce positive decisions on behavioral and dietary changes.

Patients prefer having a community of caregivers, which includes not just providers but also their close family, relatives, and friends. This involvement proves to be a motivating factor throughout the process of care and serves to avoid loneliness [13]. Patients also expressed interest in sharing information with peers. In a study of postings in an online support group, Klemm et al. found the messages could be broadly categorized into eight groups: information giving and seeking (25.4% of the interactions), personal opinions (22%), encouragement/support (17.4%), personal experiences (16.4%), thanks (7.7%), humor (4.5%), prayer (2.9%), and miscellaneous (3.2%) [14]. With the availability of such online communities, the Learning Health System
may be expected to provide both tools and coaching for patients wishing to engage with peers.

4. Conclusion

The process of empowerment is an outcome of the relationship that patients have with their provider [8], which, as we have shown, is set in the context of information sharing and patient education involving multiple healthcare stakeholders. We have shown that patients desire more information, particularly information they trust. Patients also desire to control the frequency, types, and mode of information they receive and that they share with others.

By structuring patient interview data to inform design themes, we are providing a framework for software developers to start creating the initial set of Learning Health System applications.

Further, it is imperative that the design of the Learning Health System be seen from the perspective of patients but not only from that perspective. This study developed design principles for Learning Health System applications developed for patients, but is part of a larger study that is engaging providers and public health coordinators in order to create an information ecosystem that is self-learning and self-sustaining. As a result, not just patients but all involved parties should feel empowered and thus the cycle should truly become a learning one in its own.

5. References


