Understanding and Designing Computing Technologies that Convey Concerning Health News

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Abstract: As people receiving health information through computing technology increases, there is a potential loss of the human element that occurs during face-to-face doctor-patient dialogue. Technologies that convey health information have the potential to cause unnecessary anxiety and worry or cause avoidance of a serious problem. The purpose of this study is to make recommendations on how to reduce the discomfort of patients by re-examining the design of health information technologies and focusing on the ways information is presented to the users. We report on a literature survey of health information technologies and results from interviews with patients, clinicians, and patients’ family members on how they communicate and accept concerning health news. We identify strategies clinicians use when giving a diagnosis, including building a partnership of trust with patients, being honest and giving hope, presenting information simply, acknowledging physical and emotional discomfort, and communicating through non-verbal means. Based on the findings, we discuss design considerations for technologies that convey concerning health news to help people assimilate the information better and make informed decisions.

Key words: Health, communication, empathy, doctor-patient interaction, health informatics

1. Introduction

The proliferation of health technologies such as fitness games, exercise tracking websites, self-management tools, and personal health record system (PHRs) enables people be aware of their own health information more than ever before. Use of these tools helps people view their own health data, which brings awareness to problems that they might not have previously recognized. Although greater access to wider and credible health data will allow people to improve their health and manage their chronic diseases [1], they may also face new problems which have been arising due to the sensitive nature of the information and difficulty in accurately interpreting it.

Types of health information range from a casual notice of weight gain or loss or changes in cholesterol level and blood pressure to an official diagnosis of a serious disease. Much of the health information that had been traditionally communicated through face-to-face consultation is now being delivered via various channels, some of which do not involve human interaction. Games have become a new channel where players receive a piece of news about their health status. For example, Wii Fit¹, a fitness game for Nintendo, tells a person he is "obese" if his body mass index (BMI) is above a certain threshold. There are also a number of commercialized self-monitoring tools that help people track their health behavior patterns, such as pedometers for tracking step

¹ Nintendo. Wii Fit, http://www.wiiifit.com
counts\(^2\), devices for tracking sleep behaviors\(^3\), and journaling tools for tracking calorie intake and exercise\(^4\).

Some personal health records (PHRs) are tethered to the electronic medical records (EMRs) so that patients can check their lab results online without the presence of medical professionals who used to help them accurately interpret the results in the context of their specific health situation [2].

While people are empowered by having frequent and faster access to their health data, there exists the potential for removal of human interaction as can be seen in the above examples. In the absence of human elements, such as face-to-face informational or emotional support when encountering health news, people may have difficulty assimilating information and making informed decisions about treatment options, lifestyle changes, and medications. Research has shown that a poorly communicated diagnosis can cause damaging outcomes to patients, such as confusion, long lasting distress, or resentment [3]. However, these situations may be avoided if technology is designed with empathy to ensure that people understand the information and its implications.

The main contribution of this paper is to uncover opportunities for health technologies to deliver health news in the most appropriate manner by creating space for empathic communication as can be seen in clinician–patient interaction. We looked at how people encounter concerning health news through two lenses: first, by conducting a literature survey on how existing technologies designed for monitoring health convey information; and second, by conducting interviews with clinicians, patients, and family members to understand people’s experience in giving and receiving concerning health news, such as the diagnosis of severe or chronic conditions. From this, we determined design considerations for health technologies aimed to facilitate better self-managed care and explored design ideas that centered on understanding experience in sharing sensitive health information.

The remainder of this paper is organized as follows. We first provide a review of a literature survey on how people encounter health news. Next, we describe the study methods used for data collection and analysis. We present our findings and discuss design considerations for health information technologies. Finally, we conclude and provide directions for future work.

2. Ways People Encounter Health News

To understand how people encounter concerning health news, we first look at existing guidelines designed for clinicians to facilitate effective therapeutic dialogue. We then introduce some of the ways in which people encounter their health information without the presence of clinicians.

2.1. “Breaking bad news” in Medicine

In the medical literature, different guidelines and protocols tell clinicians how to communicate with patients and family members during therapeutic dialogue, or, put more simply, “how to break bad news.” When breaking concerning news, empathy is a part of the therapeutic dialogue that occurs between clinicians, patients, and family members [4]. Empathy is described as a “conscious and unconscious flow of thoughts and emotions between patient and physician” [5]. This allows clinicians to divulge information [4], family members to receive

\(^2\) http://www.omronhealthcare.com/product/1131-229-pedometers-hj-112
\(^3\) http://www.myzeo.com
\(^4\) http://dailymbn.com
and assimilate bad news [6], and patients and clinicians to engage in holistic decision-making [7]. The Six-Step Protocol, a tool used to train clinicians in delivering concerning news, consists of 1) getting started, 2) finding out how much the patient knows, 3) finding out how much the patient wants to know, 4) aligning and educating by sharing information, 5) responding to feelings, and 6) planning for follow-through [4]. Other studies describe therapeutic dialogue as consisting of an opening, description of current status, holistic decision-making, and logistics [7]. Acknowledging the difficulty of therapeutic dialogue and importance of active listening and empathy, Simpson et al. suggest that institutions should promote acquisition of communication skills during all levels of the medical school curriculum [8].

2.2. Interfaces that Convey Health News

People also receive health-related news not only from clinicians but also from various computer interfaces. Here, we provide a review of commercial products and a survey of research projects on how people encounter health news without the presence of clinicians. We also discuss the potential ramifications of these interfaces.

2.2.1. Self-monitoring

Self-monitoring tools are prevalent, especially for people with chronic diseases. For example, diabetics often use a blood glucose meter, which is a small, portable machine used to monitor blood sugar levels. The test result shows the blood glucose level at the time of testing and gives an idea of how well the diabetes is controlled. Patients take responsibility for testing their blood glucose level the number of times their doctor recommends, which may be several times a day. It is the patient's goal to keep the blood glucose level within a recommended range, and if not, the patient needs to change his or her diet, increase exercise, or take medication to lower his or her blood glucose level. The real benefit of self-monitoring comes from using it on a regular basis long enough to identify a trend. However, test results out of the normal range may cause a lot of anxiety. It is common to see panicked users asking for help in health-related message boards [9] (e.g., “My BS [blood sugar] levels are creeping upwards!”), so it is important for the users of the system be educated about the steps they should take when an unexpected outcome is reported. Other types of self-monitoring systems include, but are not limited to, an aneroid monitor and digital monitor for measuring blood pressure [6], an electronic scale for body weight and body fat percentage, a pedometer for daily step counts, and an actigraph device [7] for sleep behavior patterns. These self-monitoring devices produce objective data, which can be shared with doctors to inform a diagnosis or future treatment direction. However, these devices are not always accurate or used correctly [10], and they are not a substitute for regular visits to a doctor.

2.2.2. Journaling

Another method of self-monitoring is through the use of journaling, which involves the user entering information into a system over time for themselves or others, such as a sick child or an aging patient. Using journaling tools, people track their weight, food, drinks, exercise, pain, emotions, stress levels, amount of sleep, developmental

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progress, and illness symptoms. The purpose of this is often to increase awareness of the data, diagnose a disease or disorder, which may also increase the chances of treating it [11,12]. There are a number of journaling tools that leverage the strengths of computing technology. Websites\(^9\), mobile phone applications [13], and stand-alone software programs [14] are different methods of providing journaling tools that aim to help people minimize the cumbersome and tedious aspects of paper-based, manual record-keeping tasks. For example, Baby Steps, a record-keeping system for parents of young children, helps track both sentimental and developmental records [14]. A 3-month long deployment study revealed that Baby Steps improved the timeliness of reporting and encouraged parents to capture and access more data. However, there are still barriers to overcome in the design of journaling tools for health. Because of the level of effort involved, people have to have high motivation to track their data. They also have to learn how to use the tool correctly and remember to use it regularly. The type of data collected can be inaccurate or subjective because it is based on the person’s observation and recall, which can be unreliable [15]. Tracking data over time, while it may increase awareness, may also cause unnecessary anxiety if it does not meet the observer's expectation.

2.2.3. Personal Health Records

Personal health records (PHRs) are electronic health records owned and managed by the patient, which are different from electronic medical records (EMRs) designed to serve the needs of health professionals. PHRs allow individuals to take a more active role in managing their health and keep their health information up-to-date. While PHRs can be independent applications, such as Google Health\(^10\) and Microsoft’s HealthVault\(^11\), they can also be incorporated into a health provider’s EMRs. These types of tethered PHRs reliably keep track of health data from EMRs and provide more diverse features than an independent PHR. For example, they often allow patients to access their lab test results online, provide ways to communicate with physicians, and allow people to make appointments or request prescription refills online. More and more patients are requesting access to their health information online, but the types of information to be shared has been the subject of heated debate among clinicians [16] since the effects of the release of information to patients without a doctor’s explanation have not yet been studied. While patients have the rights to access to all laboratory and diagnostic test results, care should be taken when releasing laboratory test results via electronic media, especially when the results are abnormal. When sharing laboratory and diagnostic test results online, it is hard for patients to receive the same level of therapeutic dialogue as with face-to-face communication. One way to address this problem is to have a provider review the test results prior to the release so that they have a chance to decide whether to deliver the results verbally or online, although there may be a tradeoff in the timeliness of release [16].

2.2.4. Games

It has become more common for people to receive health information through physical and cognitive fitness games like Nintendo’s Wii Fit, Electronic Arts’ Sports Active\(^12\), and the Nintendo DS’s Brain Age\(^13\). These

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12 http://www.healthvault.com/
games are designed to promote physical and cognitive activities and have methods to calculate players' scores based on performance. One potential problem with the games designed to promote healthy behaviors is that people may be misled by the scores presented and may equate the scores to their actual state. However, the scores presented do not necessarily reflect an accurate picture of actual physicality or cognitive capacity. In particular, games do a poor job in taking individual differences into account. For example, the BMI calculator that the Wii Fit frequently employs is inappropriate for young children because BMI is both age- and gender-specific for children and teenagers [17]. This game, however, would identify a person as overweight regardless of player's age or gender if their BMI is out of a certain range. The blunt approaches that games use may cause unnecessary emotional turmoil, especially for children, as doctors and parents with kids already have raised concerns over the way the games present information\textsuperscript{[14,15]}. 

2.2.5. Summary

We believe that tools to support tracking health information show much promise, but more design effort is required to reduce unnecessary anxiety and ensure that information is correct and accurate. Some self-monitoring and journaling tools provide feedback to users based upon their progress, such as a summary of current status or even an early warning, which can provide better user awareness and perhaps address health problems early while they are still treatable. However, due to the sensitive nature of health information, false positive or false negative results may provoke unnecessary anxiety or avoidance or negligence of serious problem. For example, one may feel sick but resist seeing a doctor because the self-monitoring tool does not show any abnormalities. On the contrary, one may suffer severe anxiety when a system sets off a false alarm, which could lead to calls to doctor’s and unnecessary and expensive testing. Inaccuracies and over anxiousness may also cause users to abandon a system that may otherwise be of great potential benefit. Thus, it is a challenging design problem to develop technologies that show an accurate status of a person's health situation without causing any confusion or harm to its users.

3. An Approach Informed by Human Practice

Doctors are trained to use patient-centered communication strategies to deliver concerning health news, and thus we explored this area to aid in our recommendations for the design of health technologies. Concerning health news might include a diagnosis of a serious disease, a poor prognosis, or a difficult surgical recommendation. We were interested in learning how clinicians deliver the concerning health news while helping patients and family members cope with the situation and make informed decisions. To understand this problem space more in-depth, we conducted semi-structured, open-ended interviews with clinicians, patients with chronic or terminal disease, and patients’ family members.

3.1. Method

We chose to do a retrospective perception study rather than a study based on direct observation because patients who are receiving troubling news are generally in a heightened state of anxiety that affects reactions and

\textsuperscript{13} Brain Age reports a player's brain age after giving the player puzzles to complete (e.g., "Your brain age is 80")
\textsuperscript{14} http://www.dailymail.co.uk/news/article-566754/Obesity-experts-condemn-Nintendos-Wii-Fit-game-tells-10-year-old-girl-shes-fat.html
\textsuperscript{15} An expert on diet and nutrition discusses the potential ramifications of Wii Fit: http://wii.gamespy.com/wii/wii-fit/875451p1.html
responses. We recruited participants through word-of-mouth, snowball sampling, and web postings in the United States. Interviewees were offered a $20 gift card in appreciation for their participation. During screening, we sought clinicians who had completed many in-person medical diagnoses, prognoses, or consultations with patients. We also sought patients who had been diagnosed with severe or chronic conditions. In total, we interviewed 14 participants (see Table 1). Of the 14 interviews, 6 were conducted in-person and the rest were via phone. The interviews lasted between 30 minutes and two hours. We audio-recorded and transcribed all interviews to aid with analysis.

<table>
<thead>
<tr>
<th>ID</th>
<th>Group</th>
<th>Age</th>
<th>Sex</th>
<th>Area of expertise / Type of condition</th>
<th>Years of experience</th>
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<tr>
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<td>Doctor</td>
<td>62</td>
<td>M</td>
<td>Oncology</td>
<td>25</td>
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<tr>
<td>C2</td>
<td>Doctor</td>
<td>59</td>
<td>M</td>
<td>Women's health</td>
<td>25</td>
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<tr>
<td>C3</td>
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<td>32</td>
<td>M</td>
<td>Internal medicine</td>
<td>4</td>
</tr>
<tr>
<td>C4</td>
<td>Nurse</td>
<td>34</td>
<td>F</td>
<td>Intensive care unit (ICU)</td>
<td>3</td>
</tr>
<tr>
<td>C5</td>
<td>Doctor</td>
<td>45</td>
<td>M</td>
<td>Family medicine, psychiatry</td>
<td>19</td>
</tr>
<tr>
<td>C6</td>
<td>Doctor</td>
<td>39</td>
<td>M</td>
<td>Pediatric cardiology</td>
<td>11</td>
</tr>
<tr>
<td>P1</td>
<td>Patient</td>
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<td>F</td>
<td>Parkinson’s disease, breast cancer</td>
<td>17</td>
</tr>
<tr>
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<td>39</td>
<td>F</td>
<td>Diabetes, gastroparesis</td>
<td>27</td>
</tr>
<tr>
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<td>Patient</td>
<td>56</td>
<td>F</td>
<td>Stage 4 follicular lymphoma, diabetes</td>
<td>5</td>
</tr>
<tr>
<td>P4</td>
<td>Patient</td>
<td>57</td>
<td>F</td>
<td>Parkinson’s disease, breast cancer, knee replacement</td>
<td>12</td>
</tr>
<tr>
<td>P5</td>
<td>Patient</td>
<td>61</td>
<td>M</td>
<td>Sleep apnea</td>
<td>5</td>
</tr>
<tr>
<td>P6</td>
<td>Patient&amp; Family</td>
<td>45</td>
<td>M</td>
<td>Himself - Thyroid cancer, Wife - ovarian cancer</td>
<td>1 yr as a patient, 2 yrs as a caregiver</td>
</tr>
<tr>
<td>F1</td>
<td>Family</td>
<td>45</td>
<td>F</td>
<td>Partner of P3</td>
<td>5</td>
</tr>
<tr>
<td>F2</td>
<td>Family</td>
<td>43</td>
<td>F</td>
<td>Sister – diabetes</td>
<td>2 weeks</td>
</tr>
</tbody>
</table>

The interview questions were focused on learning the strategies to deliver unexpected news and common patient reactions. We used discourse analysis [18] and the constant comparative method [19] to analyze the interview transcripts. For inter-rater reliability, two researchers read separately through the transcripts and identified themes. We then vetted, defined, and merged the themes into one code set. We separately coded the transcripts with the preliminary code set using TAMS (Text Analysis Markup System) Analyzer software. Two researchers exchanged the coded transcripts and reviewed the other’s codes. The research team met regularly to discuss new themes and refine pre-existing categories in the code set, thereby iterating on the codebook.

3.2. Results

Experienced clinicians are well aware of patients’ fears and the intrinsic value of empathic dialogue: the recursive process of understanding and communicating with patients in varying mindsets and physical and emotional situations. Empathy is hardly ever communicated without the clinician’s understanding and acknowledgment of the patient’s background—where they are coming from, where they are in their feelings, and their level of understanding of the disease and options. Furthermore, the clinician’s understanding of a patient’s situation and emotional state means little unless the clinician is able to skillfully communicate that understanding. In empathic dialogue, the patient is treated as a human being and not just a disease. Understanding and communicating happen simultaneously as clinicians consciously and continuously reassess the patient’s situation and modify their method of delivering unexpected news based on the patient’s feedback and life story.

16 The interview with C4 was conducted in Korean and translated to English by the interviewer during transcription.
3.2.1. Understanding

Before meeting with patients, clinicians reported a need to remind themselves of the patient narrative by checking the patient’s chart, reviewing the information, and looking for certain characteristics (e.g., the defect or disease, lab results, records of prior procedures, or other key events). However, in the case of emergencies or acute medical or surgical situations, clinicians do not have the luxury of time to establish partnerships based on empathic dialogue with patients. In these types of situations, before clinicians meet with patients, they first anticipate the patients’ level of understanding. Here, a pediatric cardiologist talks about how he prepares to deliver unexpected news to the parents of a sick child.

C6: “I try to put myself in their shoes. I have two children of my own and I try to think of, ‘if I had no medical background, if I were being told these things, what would I want to know?’ (...) I have to try to step out of the medical position to some degree in terms of the empathy that has to be conveyed.”

In preparing to deliver unexpected and life-changing news to patients, clinicians reported not only anticipating the patients’ emotional response and level of medical understanding, but also acknowledging patients’ feelings. Kubler-Ross’s five stages of grief model (denial, anger, bargaining, depression, and acceptance) [20] was often referenced during the interviews with clinicians when they explained the importance of knowing where patients are in their feelings. Knowing where patients are at in this general model helps clinicians gauge how much information to reveal when.

C5: “You have to watch them and watch their faces. You have to try at least to read and get a feel for where they are with the conversation, is the first step.”

The clinicians we interviewed stated that knowing where patients are at emotionally helps them work around the state of shock and anxiety that often prevents patients from fully absorbing critical information. To deal with this, they may step back and wait for a better time to reveal certain information, invite patients to call with more questions, or suggest that peers and family be present to help ask questions or make sense of the information. In this sense, the clinician’s ability to empathize with the patient is what helps the clinician aid the patient in assimilating troubling information.

3.2.2. Communicating

Clinicians reported that they commonly use their opening statement to reinforce partnership. Clinicians want patients to trust in the quality of their care. Trust between patient and physician alleviates patient fear, which smoothes the decision-making process that must occur around every new piece of clinical health information. One way that the clinicians we interviewed did this was by using language that reinforces an ‘us’ relationship rather than a doctor versus patient hierarchy.

C2: “I’m glad you came. Let’s look at that report. Let’s look at it together.”

C5: “I’m gonna have to tell you something that’s difficult and I’ll give you all the details so that you understand it. I want you to know that we’ll work with you to make sure you really, fully understand it.”

According to our participants, the actual diagnosis is the most important piece of information for patients. The same information can be delivered in various ways—from people in different positions in different circumstances using different means of communication. One patient we interviewed received an unexpected
phone call from a nurse saying, “Hi, we just wanted to let you know that the biopsy came back and it is a cancer” [P4]. Others were informed by an experienced clinician who carefully revealed the diagnosis along with descriptions of the condition, and then opened a dialogue wherein the patient and clinician can discuss treatment options, prognoses with and without treatment, as well as what the patient can expect to go through with surgical procedures, side effects, expectations for healing, and lifestyle changes. The clinician’s goal in creating a time and space for empathic dialogue is to make sure that a patient fully understands his or her condition in order to make informed decisions without becoming overwhelmed in the clinical details.

Even though it is discomforting for clinicians to tell patients the news, “This is what you will die from” [P6], all clinicians we interviewed stated the importance of being honest, clear, and straightforward when delivering diagnoses. What is more important yet more difficult is to obtain the balance between being honest about a poor prognosis and giving hope at the same time. Giving hope is different from giving false hope, which several participants also referred to as “sugarcoating.” Sugarcoating is telling patients glossy stories and ensuring them that everything will be fine when in fact the patient is in failing health. All clinicians asserted that sugarcoating is harmful for patients and it only protects clinicians who want to avoid dealing with the patient’s emotions. Giving hope, however, helps in a situation when patients have to develop both the physical and emotional strength and resilience to endure a difficult situation. The gynecologist we interviewed told a story in which he encouraged a cancer survivor to consider undergoing a high-risk surgical procedure that would dramatically alter her physically, but would also extend her life.

C2: “I looked at this woman—tremendous will, tremendous spirit—I brought her back and said, ‘There’s something that can be done. It’s a very radical surgery, and not many survive it. But those who do, they do well. So I need you to consider this. You will be sick, you will be in hospital for many days… but you may live. I think that you are tough and you can make yourself come through this. Are you up to this challenge?’ In term, this patient needed one more chance of hope.”

The quote above illustrates not only the physician’s confidence in the patient’s capacity to endure a radical procedure based on his prior knowledge of the patient’s life story and medical history, but also the level of trust in the doctor-patient relationship that allowed him to speak with honesty and candor about the surgical outcome. Such candor, trust, and knowledge about the patient’s life story are indicative of empathic dialogue.

Creating a space for empathic dialogue between doctors and patients requires that patients be in a position to be able to understand and speak about their condition with confidence. Thus, the experienced clinicians we talked to present complex information in plain language to “make the person in charge of their situation” [C2] and to give patients “good information so they can make good judgments about their lives” [C1]. When explaining data, clinicians take difficult concepts into down-to-earth terms and use visual aids such as drawings, graphs, pictures, and x-rays. Another strategy the clinicians we interviewed used was to tailor their language to the patient’s life experience. For example, one clinician described speaking in probabilistic terms with patients who were engineers and thus appreciated the mathematical explanation.

All clinicians explained the importance of being mindful of non-verbal communication during consultation. They prefer face-to-face communication with patients in a quiet, private space where they can maintain eye contact.
and, if needed, sit beside patients to look at data together. Some clinicians said they do not allow sensitive information to be delivered over the phone or by staff who do not know how to appropriately interpret the information. They also emphasized the importance of active listening, careful observation, responsiveness, and spending time with the patient.

4. Toward the Design of Empathic Health Technologies

One of the key findings from the current health technologies survey was that technologies for tracking and conveying health information have the potential to cause anxiety and worry that may be unnecessary or avoidance or negligence of serious problem. Moreover, technologies often do not take into account individual differences of users, and they bluntly present information, which may have negative impacts on sensitive user groups (e.g., teenagers, older individuals). Our study identified strategies clinicians use when giving a diagnosis, including building a partnership of trust with patients, being honest and giving hope, presenting information simply, acknowledging physical and emotional discomfort, and communicating through non-verbal means. Thus, there is a substantial gap between the ways people encounter concerning health news from clinicians and from computing technologies. So how might an understanding of this problem impact the way health technologies are designed? In affective computing research, there have been many attempts to design computers that understand human emotion to help people in various situations [21-24]. However, research has shown how agent-based systems are not yet sophisticated enough to replicate the subtlety and complexity of human empathy [25]. Instead of designing computers to be more like humans, we suggest rethinking the ways in which health technologies present information to help people better understand their condition, provide timely support, and encourage interactions with clinician and support group.

4.1. Design Considerations

*Technologies are not doctors.* When an interface presents concerning health information, it should not reinforce the notion that this is a diagnosis. Rather, the presentation should make it clear that the receiver of the information should first consult a doctor. For example, a person may receive a blood glucose level of 200 mg/dl when he or she is expecting to receive a meter reading less than 126 mg/dl. There can be many reasons for the abnormal result: it can be due to a wrong usage of a test meter, individual differences, time of the day, or the technology itself being inaccurate. In this case, the interface may use similar “partnership” language to guide the patient through possible reasons for getting the abnormal data, what to try next, and how to make the situation better (Figure 1).

![Figure 1: When the blood glucose level is out of range, the interface guides the patient through possible reasons—medication, food, and amount of exercise—while using language that reinforces an ‘us’ relationship.](image-url)
Provide further explanations and guidance from an authoritative source. When a person receives a lab test result at home through a personal health record that is integrated with an EMRs, the person may not know how to accurately interpret the data and understand its implications. Therefore, if an interface is to present concerning or troubling news, the information should be presented in a clear and straightforward manner using plain language to ensure the receiver understands what it means. Similarly to the clinicians in our study using visual aids when explaining difficult concepts to patients, technologies that convey health news should incorporate visual aids, such as graphs, photos, and x-rays when presenting health news to patients because it enhances the understanding of their condition further. Providing links to other related resources from an authoritative source and local support groups may be helpful for patients seeking more information. Above all, technologies should provide a means for patients to contact their provider (e.g., email, voice mail) if there are any questions or concerns. Through this, doctors can have a better picture of patient’s condition and its trend over time while the patient can ask questions, which reinforces the notion of the partnership in health for which doctors strive.

Reducing the risk of concerning news shared inadvertently. When laboratory test results are available, the system may have a clinician review the data first, allow them to make any annotations, and then allow the patient to access the result. For people viewing their health information online, people should be given the option to wait until a medical professional can help them accurately interpret the results with an explanation of terms (e.g., the meaning of the medical terms, screening, sensitivity, specificity) in the context of their specific health situation. For example, if a screening test result needs to be further examined, there may be an option to wait and receive the results verbally from a doctor (Figure 2). It is not our intention to hide the information, because people can still view the information if they want to see it. Rather, it is a compassionate way of delivering a piece of concerning information by providing it at the right time in an appropriate way. For example, a blood test result of an expectant mother could show that she may be at an increased risk for an infant affected with Down’s syndrome. In this case, the user interface should not just show the result saying “Result: abnormal,” which will only create anxiety and fear, but provide other ways to help her assimilate information correctly by providing the option to withhold information until the doctor can help her to interpret the result.

Figure 2: The interface prompts the user with choices that say, “Wait and send Dr. Smith a message to contact me as soon as possible” or “Continue and view my test results.”

Lowering the barriers to technology for tracking health data. Our study indicated that self-monitoring and journaling require a considerable amount of effort over time and there were not many lightweight and
inexpensive tools for monitoring health data. Technology should not become another barrier to entry for receiving quality care, especially for those who do not own a computer or do not have time dedicated for tracking health information. There are opportunities for designing health information tracking tools using existing technologies, such as text messages and mobile phones. These are already prevalent and relatively inexpensive technologies for tracking and recording health data, and we may apply these technologies for parents tracking their children’s developmental milestone [14]. Encouraging people’s record-keeping practices through timely prompting from providers and reward structures (e.g., giving stars or stamps for completed days), the goal is to minimize the effort made in record-keeping, build a conduit for the patient-provider partnership of trust, and promote high information awareness by processing the data collected and presenting it in a meaningful and intuitive way.

5. Conclusion

We have looked at how current health technologies such as self-monitoring and journaling tool, PHRs, and games deliver health-related news. We have also addressed how the human elements are conveyed during medical practice, especially when communicating diagnoses of severe, chronic, or degenerative diseases. Clinicians use various ways to understand patients and communicate with them: acknowledging patients’ physical and emotional discomfort, building a partnership of trust, being honest and giving hope, presenting information simply, and communicating empathy through non-verbal means. We claim that tools and technologies that were initially designed for better medical record-keeping purposes may not serve the needs of clinicians’ and patients’ if designers do not consider the ways in which clinicians communicate empathy and share information during therapeutic dialogue.

The goal of this work is to reduce the discomforts of patients by re-examining the design of health information technologies. Although patients’ needs and situations are different and a ‘one-size-fits-all approach’ may not work in all cases, there is still a room to improve technologies for health. Health technologies may provide communication channels to encourage richer doctor-patient interaction. They may provide further explanation from authoritative source when presenting test results. One’s health information should not be hidden or made unavailable, but people should be given news in the way that they can best assimilate its meaning. As our next steps in this research, we will focus on elaborating the designs of empathic interfaces for patients and doctors in the context of treating specific conditions, such as in the case of post-traumatic stress disorder or the treatment of cancer.

6. References


