Contextual Constraints for the Design of Patient-Centered Health IT Tools

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Abstract. Technologists are constantly working to improve clinical practice by developing new health information technology (Health IT) tools, yet may not always consider the context of how these tools may be used. Patient preferences can vary widely as a result of demographics, health conditions, physical limitations, and personal inclinations, with healthcare providers having to adapt clinical encounters to better suit patient needs. Health IT tools, too, need to be agile across different healthcare contexts, with each stakeholder's specific needs in mind. In this paper, we discuss the challenges and limitations associated with the design and automation of contextually sensitive devices in the healthcare environment. We target the various contexts in which health information is presented in patient-provider encounters, and discuss contextual constraints that may apply to the aforementioned situations. In addition, we present a number of suggestions for informational constraints and the design of informational tools in these settings so that patient and provider informational needs can be better met in clinical communication contexts.

Keywords. Health Informatics, Human-Computer Interaction, Context Awareness

Introduction

Healthcare is a complex, multifaceted subject that is difficult to design for considering the variety of situational contexts and environments that occur [1, 2]. Patients, providers, and caregiver stakeholders have a unique set of needs that can vary considerably across different types healthcare environments (outpatient exam rooms, emergency departments, hospital settings, etc.). When designing informational tools to supplement current clinical practices, technologists need to factor in the contextual use of their tools based on the needs and environment of each respective stakeholder [3–8]. For example, some patients in face-to-face clinical encounters may require more in-depth information regarding an illness that others in a similar situation would prefer not to have at the time [9-11]. Furthermore, clinicians in these settings may need flexibility to customize information to the needs of each patient, and also face considerable limitations on their time that can adversely affect how they use such tools.

When designing Health IT tools for clinical encounters, designers must provide the ability to constrain information based on the aforementioned challenges. There is great variability across patients in terms of how comfortable they are in hearing and seeing personal health information which is emotionally evocative in nature [12, 13].

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Information presented in clinical discussions between clinicians and patients is often sensitive. As a result, some of this information may need to be presented under privacy constraints to prevent exposure of personal data. These considerations can affect the design or platform of decision-making tools for clinical discussion settings. For example, patients might want visual imagery or details of their illness and its effects constrained when speaking with healthcare providers, and instead focus on treatment effects on their daily life.

All of these issues require the use of contextual information to resolve. However, context is a large and multifaceted concept with many competing definitions in various fields, many of which are too general to immediately implement in a computer system (e.g: Dey defines context as "Context is any information that can be used to characterize the situation of an entity" [14]). For the area of context-sensitive healthcare, we focus on analysis of the physical environment and patient preferences rather than developing contextual frames/narratives or using linguistic context.

Environmental constraints also play a role into the development of tools in the clinical discussion space. Exam rooms may have limited physical space, and tools may not always fit or be useful depending on the context of a discussion [4]. For example, in cancer discussion settings, patients typically receive and interpret information while sitting on an examination table. Similarly, hospitals and emergency environments may have very different requirements and environmental constraints such as direct access to patient health records for nurses and fast access to information in critical situations [1, 15]. Healthcare providers in these settings need agile and flexible platforms to accommodate critical situations and improve healthcare delivery.

Even tools developed for specific purposes or environments can have contextual complexities. For example, in our ongoing work regarding improving cancer discussions [9-11] patients prefer having information that is more personalized. Data personalization itself is a difficult concept, since tools such as electronic health records (EHRs) are relatively unstandardized and may vary by location [16]. While designers might intend to develop tools that can be generalized to meet the needs of a variety of stakeholders, most commercially available tools often fail to address the complexities that arise from patients' needs and environmental constraints [17].

1. Background

Identifying context in health situations is of particular interest to the human-computer interaction (HCI) community. A survey of literature found that despite researchers' efforts, there is little consensus on how to model and design for a given context in healthcare, let alone context-aware applications [1]. Issues resulting from patient misunderstandings in clinical communication, such as those in cancer discussions [12, 13, 18], exam room complications [4], emergency situations [15], and hospital settings [19, 20] have all been targeted by the HCI community with the interest of improving healthcare outcomes. While these efforts show positive change in improving healthcare settings, current technology is not suited to patient engagement, and may complicate face-to-face communication [21].

A number of applications have been developed to augment clinical discussions between patients and healthcare providers. Klasnja et al. focused on the informational management of cancer patients to meet discussion needs with doctors during routine

follow-ups [22, 23]. They found that providing patients with tools to prepare for clinical sessions benefited patient understanding and efficacy during their discussions.

Other researchers have assessed the implications of hospital and emergency contexts, and how these affect the design of tools for more patient-centered care [15], [19, 20]. One example, designed by Ni and Karlson, utilized projectable images to help doctors describe complications in limbs and joints to patients undergoing physical rehabilitation [24]. These visualizations facilitated patients' conceptualization of their condition while remaining generalizable across different physical conditions.

Researchers are now also looking at the technological complexities due to the incorporation of contextual awareness, particularly when signal processing (of video, audio, etc.) is required to provide a degree of automation [25]. Typically this work falls within the area of social signal processing, which inherits challenges pervasive throughout signal processing and social science.

One aspect of context sensitive interfaces which requires computer vision is the ability to sense the environment. It has been shown in literature from psychology, neuroscience and anthropology that the environment in which an action takes place affects its expression [26-28]. However, adapting to such constraints automatically requires at least a partial solution to the computer vision problems of scene understanding and object recognition [29, 30]. These are considered huge problems in computer vision and the complexities of noisy real world data from medical environments only emphasize this. Varying lighting levels, camera occlusion and privacy concerns related to recording patients must all be dealt with.

2. Contextual Complexities in Clinical Encounters

Designing for clinical encounters is itself a difficult issue. Healthcare providers have different needs from patients in clinical communication. Providers have varying time constraints during or between meetings, and limited time to prepare. Furthermore, doctors oftentimes have to adjust discussions and information to meet the tolerance and informational needs of patients without causing issues in face-to-face communication.

Patients also have a variety of needs. These vary by age, demographic, illness, and physical constraints [12, 13]. Medical history may also play a role in prescribed treatment. Patients may want visual aids or personalized information targeted to their illness or diagnosis [10, 11]. In general, meeting all these needs is difficult, especially considering that current EHRs vary between hospitals and clinics. This makes integration of data for tools using patient information unnecessarily complicated.

For patient-centered care, information may need to be constrained physically depending on the device used in a given context. For example, patients diagnosed with diseases involving more personal parts of the body (such as gynecological and prostate cancers) may have reservations about how their information is displayed to them in the exam room. Larger displays could prove problematic in such a context, as patients may feel loss of control of their information. In contrast, mobile platforms may also be problematic for individuals with low-vision.

Finally, environmental considerations are also a factor in the delivery of patient-centered healthcare. Unruh et al. [4] assessed the effects of the exam room on doctor-patient communication, and highlighted potential issues arising in cancer discussion settings relating to human factor considerations. The authors suggest designers consider the creation of tools for agenda management, interactive collaboration interfaces, and

informational spaces for clarifying information to cater to patient-provider needs without requiring major changes to current clinical set-ups. In similar work, Flentge, Weber, and Behring [15] showed how the context of emergency situations can have an effect on the design considerations for tools aimed at improving healthcare delivery. Such tools must be designed so that stakeholders can appropriately accomplish their tasks and improve healthcare outcomes at reduced costs.

3. Suggestions for Contextual Constraints and Context-Sensitive Health IT

There are a number of reasons designers might want to impose informational constraints in tools designed for the clinical setting. Informational tools for clinical discussions should be developed with the capability to prevent data from being shown to patients before they are ready [11]. Individuals in cancer discussions may want to see certain imagery and information at a later time, when emotions are not so high. Clinicians may constrain information depending on the information a patient is interested in, such as issues relating to daily life, rather than other areas that are more in-depth with regards to an illness and how it is impacting their body.

Visualizations can be useful tools to help patients understand medical concepts. However, designers should be aware that not all patients may be responsive to these implementations. In our previous work [9-11], we used the participatory design process with oncologists and patients to inform our own design of a supplemental mHealth (mobile Health) tool for diagnosis and treatment planning discussions for individuals with cancer. In these discussions, both oncologists and patient participants expressed concerns regarding tools that offer too much information visually. This may differ from patient to patient, but may also depend on the patient's condition, tolerance, or illness at the time. For example, a patient with a malignant brain tumor might be more inclined to see their imagery on large displays if it is helpful for improving their understanding. In contrast, those with illnesses affecting more personal parts of the body might not be so inclined to have imagery on large screens. Device choices must appropriately match the discussion context, physically constraining data to more personalized interfaces such that information cannot be seen by outsiders or at a sensitive time.

Figure 1. Prototype of a patient-centered, shared-decision making health IT tool for oncology that our group is developing [9-11]

Patients in clinical encounters also want to see or hear information constrained to their case. Designers in this space might want to consider personalizing interfaces to appropriately match the patients' diagnosis and staging, which can be rather difficult without access to patient health records or additional time requirements from healthcare providers to manually input information. Providing methods that can pre-fill peer-reviewed, evidence-based information based on this information can help providers quickly and easily input information personalized to the illness of a patient from a general data source.

In addition, informational interfaces designed to accommodate both patients and their healthcare provider in the context of discussions can help healthcare providers identify issues resulting from poor communication. Informational interfaces that include constraints such that healthcare providers and patients move though information at the same pace can help improve doctor-patient communication in clinical encounters. Designers may want to consider including checklists or ways for patients and providers to review information in a conjoined manner so that each party feels information is appropriately covered [31].

Furthermore, patients will require layman terminology in clinical encounters to better understand their illness. This can be rather difficult for designers to account for or maintain without external professional support or sources. Content needs to be reliable and come from evidence-based sources, while still tailored to patients with regard to terminology.

Adaptable design choices can also be useful to fit patient, caregiver, and provider needs in these settings. "Zoomable" interfaces can be useful to accommodate providers' and caregivers' access to information much more quickly depending on the context [15]. Similarly, these interfaces can be useful in clinical communication settings that involve the elderly patients or those with low-vision. An example of how these interfaces on mobile platforms might be used is shown in Figure 1. This flexibility allows healthcare providers to accommodate patient requirements so a discussion can focus on the informational needs of patients in an adaptable manner.

Finally designers should consider the environment in their development of applications targeted toward improving patient and provider communication. Information presented in hospitals, emergency environments, and exam rooms may vary widely in terms of requirements and needs of caregivers, nurses, doctors, patients, and their companions. Designers should ensure that tools developed for specific contexts accommodate patient and provider needs through the implementation of constraints that accommodate each respective party and their environment.

4. Discussion

In general, informational constraints are difficult to design for considering the wide array of variances between patient and provider needs in a given healthcare environment. Each person may want different information, and healthcare providers, clinics, hospitals, and emergency rooms might have different processes and procedures that can affect how these devices integrate into a given situation.

Technologists will further need to accommodate for needs of patients and healthcare providers in ways that can be generalizable. Capabilities such as font scaling, generalizable imagery with annotation capabilities, and flexible design that allows users to restrict information in an easy manner can allow healthcare providers to better

meet patient needs without making the design of such tools overly specific for a certain demographic or age. Inclusion of such capabilities is useful to suit a given context so devices can be generalized to meet the needs of a variety of patients with different illnesses (such as different types of cancers), yet still personalizable.

Technologists also have an interest in automating tools to better serve patients and providers in clinical communication. Despite their efforts however, research has shown that context-aware applications are a difficult paradigm. Background work on the perception and organization of contextual information clearly shows how large a problem it will be to automatically adapt healthcare interfaces based on contextual constraints. However, this is a key research area, which will help the efficacy and safety of patient interactions mediated by technology.

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