

Learning from Healthcare Providers' Strategies: Designing Technology to Support Effective Child Patient-Provider Communication

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ABSTRACT

Effective patient-provider communication is critical to promote patient satisfaction, encourage patient involvement in care, and improve health outcomes. Although prior HCI works aim to enhance the dyadic communication by improving patients' communication skills, little is known about healthcare providers' communication work to facilitate effective communication with their child patients. Through semi-structured interviews with 10 healthcare providers and clinic observations, our study identified four strategies that providers used in their communication with patients: building rapport, developing familiarity with care settings, respecting patients' communication modes and preferences, and delegating small decision-making and directing questions to patients. Based on these strategies, we discuss three key elements that providers value and work toward to achieve effective communication in pediatric care practice. Our study also uncovers the detailed process of how the providers develop their strategies to tailor their communication to the patients' specific needs and preferences, and we describe design opportunities for communication technology.

CCS CONCEPTS

• **Human-centered computing** → Empirical studies in HCI.

KEYWORDS

healthcare provider, communication, child patients, pediatric care

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1 INTRODUCTION

Effective communication between patients and health care providers increases patient satisfaction [54], promotes positive clinical outcomes [10], and encourages patient participation in their care [31]. Despite these benefits, it is challenging to achieve effective patient-provider communication due to various factors, including the gap in health literacy [20], providers' lack of interpersonal communication skills [9], and patients' distrust [19]. Effective communication can be even more challenging in pediatric care because of the patients' young ages; Children may lack the self-knowledge, sufficient communication skills, and maturity that the task requires. It has been noted in prior medical literature that child patients are not that engaged in their clinical consultations as the discussion of their diagnoses and treatments mostly involve their parents and providers [7, 27, 50]. Acknowledging the importance of effective communication and the challenges of communicating with child patients, guidelines (e.g., asthma¹) and implications for clinical practices have been suggested in prior medical studies, such as teaching children to take turns talking with the provider and directing questions to children [6]. However, these studies mainly focus on improving the general interpersonal communication skills of health care providers.

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¹Guidelines for the Diagnosis and Management of Asthma – <https://www.nhlbi.nih.gov/health-topics/guidelines-for-diagnosis-management-of-asthma>

In recent years, the interest in supporting patient-provider communication has been growing in the HCI community. While most studies have focused on the communication between adult patients and providers [2, 30, 36, 42] or between the parental caregivers of child patients and their providers [22, 25], a few studies have examined patient-provider interactions in pediatric care. These prior studies on pediatric communication have explored the child patients' communication needs and presented various forms of communication tools, such as tangible objects that support patients express their thoughts or initiate conversation with providers by letting them to choose topics [52] or a drawing app that supports patients to illustrate their symptoms with zoom-in feature which encourages them to provide detail information [23]. These tools help facilitate the dyadic communication between the child patient and provider during clinical consultations by providing aids through which child patients can develop and improve their communication skills; however, these tools often do not take into consideration the providers' current communication practices, including the specific challenges they encounter and the strategies they currently use as workarounds.

Only a few HCI studies have examined the communication needs of providers in interactions with patients in their design implications: for instance, an ambient visual display was designed to increase providers' self-awareness of their non-verbal communication toward patients [38] and a handheld projection device was developed to help providers effectively show and manage medical information for patients [34]. Extending on these prior works on providers' communication needs and behaviors, our study aims to provide insights for designing communication technology to enhance child patient-provider communication based on the communication challenges that providers encounter and the development of communication strategies and use. While the communication guidelines in prior health communication studies have helped to improve providers' interpersonal communication skills based on representative stereotypes of child patients, our study provides empirical understandings of providers' strategies developed through their own experiences interacting with child patients who have diverse personalities, preferences, and situations. Learning from the detailed process of the providers' communication strategy use, our study offers design opportunities for technology to promote more effective child patient-provider communication.

In this paper, we report findings from a qualitative field study involving semi-structured interviews with 10 healthcare providers and observations at a pediatric oncology outpatient clinic at a large hospital. We identify four communication strategies that were developed and used by the health care providers in order to achieve effective communication with child patients during clinic visits, as well as the challenges associated with using the strategies. We want to note that in this paper, our scope of communication goes beyond verbal communication styles and tones to include non-verbal and behavioral elements, and thus, communication strategies indicate a broad set of the provider's approaches to discussion of patients' well-being and needs during their hospital visits. Based on our findings and analysis of the providers' communication strategies, our study makes the following contributions to the HCI community:

- We provide an empirical understanding of how healthcare providers strategically interact with child patients to accomplish effective communication with them during their hospital visits.
- We identify the key elements of effective communication that healthcare providers value in their interactions with child patients.
- We present design opportunities for communication technology to support the providers' active, iterative design process of developing their strategies for effective pediatric communication.

2 RELATED WORK

2.1 Patient-Provider Communication in Pediatric Care

The importance and benefits of effective communication between child patients and providers in pediatric care have been shown in a number of medical studies, such as higher patient and provider satisfaction [10], better adherence to treatment [37], and the patient's active participation in their care [6]. To achieve those benefits, providers must be mindful of how they approach and communicate with child patients. Such approaches to communication are often based on a careful consideration of the patient's age and their health literacy. For instance, an appropriate approach for school-aged children is for providers to educate them about their disease and to demonstrate respect for their individual choices and preferences [35].

Despite the benefits of effective patient-provider communication, it is challenging for providers to have effective communication with child patients because of the patients' young age which indicates a lack of self-knowledge and underdeveloped communication skills. This often leads providers to only interact with their parental caregivers and focus on the caregivers' needs and concerns during clinical consultations, and not involve the patient, potentially overlooking their needs [7, 27, 50]. Having less engagement with child patients, providers risk losing opportunities to promote positive health outcomes. For instance, a lack of effective patient-provider communication may hinder providers from accurately or fully identifying their patients' symptoms [14] or other important signals for their psychological well-being and emotional development [5, 47]. In addition, there is insufficient training for providers on communication skills in general [29], and some available training programs fail to utilize the best practices for interacting specifically with child patients [16]. As a result, providers must frequently develop communication skills on their own to effectively interact with children.

To address the challenges of pediatric patient-provider communication, prior works have presented implications for clinical practices and interventions for training programs. For example, Carpenter et al., [11] emphasized interpersonal communication skill implementation in patient consultations (e.g., inviting the child to answer questions directly, showing emotion and empathy to the child), while Feraco et al., [16] suggested facilitating feasible, low-variability communication skills teaching through individual fellowship programs in a "train the trainer" approach. However, such guidelines and interventions in the medical literature largely focus on improving general interpersonal communication skills,

with less consideration on the unique, situated challenges that providers encounter in their interactions with child patients who have different personalities, preferences, and needs. Thus, further research is necessary to understand how providers develop their own strategies beyond the suggested guidelines, based on their actual lived experience with child patients and the specific challenges they encounter.

2.2 Technology Design for Patient-Provider Communication

In the HCI and Health Informatics communities, patient and provider communication during clinical encounters have been well studied from various perspectives. Prior works have attempted to enhance patient-provider communication by aligning different values and priorities among patients, caregivers, and providers for the patients' well-being [2, 30], promoting collaborative decision-making with providers through patient generated data [15, 41], working with tension around information exchange [22] and providing care-related information access to the patients and caregivers [32, 36, 44]. However, a majority of prior studies are based on communication between adult patients and providers or between caregivers and providers in pediatric care. Few studies have examined child patient and provider communication and discussed technology implications. Acknowledging the challenges in interacting with child patients, many interventions have been designed to support the child's ability to communicate their symptoms and understand medical knowledge. For instance, communication tools were developed to help child patients with verbal-communication-based consultation, such as an interactive multi-touch app that enables patients to draw their symptoms of chronic headache during face-to-face communication with physicians [23], and a tangible communication tool that empowers child patients to express their thoughts and opinions more actively and to initiate conversations with providers during clinical visits [52]. Also, educational games were designed to increase patient's knowledge about their illness management [13, 26] and promote collaborative activities between child patients, caregivers, and child life specialist through using interactive stories [4]. While these interventions are found to be effective in offering communication aids for patients to facilitate health literacy and potentially increase their engagement in care, these do not necessarily consider or address the specific needs and challenges of healthcare providers in their communication practices with child patients.

To our knowledge, only a few studies have looked at healthcare providers' perspectives and communication challenges for communication technology design. Ni et al. [34] introduced a handheld device that supports providers in educating and sharing medical information with patients during physical therapy sessions by projecting relevant visual contents, and Patel et al. [38] showed how the visual feedback from an ambient display increased providers' self-awareness of their non-verbal communication (e.g., gaze, gesture, body position) toward patients during consultation in real time. These interventions promote patient-provider communication by enhancing providers' communication skills and information delivery, but do not directly support the adjustment of communication

strategies to address an individual patient's needs and preferences or focus on specific communication challenges with child patients.

With the growing interest in pediatric care, prior studies in the HCI community have presented technology support for communication between child patients and providers; however, as pointed out above, these often focus on providing communication aids for the child's symptom-related discussion or education tools for child health literacy. Although it is critical to support child patients' communication skills, healthcare providers' communication challenges and needs for effective communication with child patients are not adequately considered. Our study is a step towards addressing this gap in the literature: we focus on the communication strategies that healthcare providers have developed through their own practices to improve communication with their child patients and the barriers that they encounter in implementing these strategies. We describe important elements of effective communication that emerge from our analysis and their specific meanings in pediatric care. Finally, we detail the iterative process through which the providers "design" their communication strategies to adapt to the specific needs of each child patient. Our design implications for communication technology focus on supporting these strategies and development processes.

3 METHOD

This paper draws on data collected as part of a larger project involving child cancer patients, their parental caregivers and healthcare providers. The aim of the larger project is to understand current communication practices among these stakeholders through participant interviews and clinic observations. In this paper, we focus on understanding child patient-provider communication from the providers' perspective based on in-depth semi-structured interviews with providers. While the interview data is the primary source for this study, observations of clinic consultations serve as a complementary source to provide more information related to the care context and the situational interactions between the patients and providers. The study was approved by our university's Institutional Review Board (IRB) prior to data collection.

We initially conducted ethnographic field observations in the Hematology and Oncology outpatient clinic at a large children's hospital to examine the challenges of the pediatric patient care practice. 12 observation sessions (3-4 hours/session) were conducted over a period of three months. Each session was documented using fieldnotes by two researchers. We identified communication challenges due to the patients' young ages during clinical consultations and we also observed the providers' various strategies to cope with these challenges. The preliminary findings from the observation shaped our focus for the interview study protocol with the healthcare providers.

We recruited and conducted semi-structured interviews with 10 healthcare providers on the same healthcare provider team we observed in the clinic (see Table 1). All 10 healthcare providers care for pediatric cancer patients and consistently interact with both the child and their caregiver during the patient's diagnosis and treatment trajectory. The providers include two nurses, two child life specialists, and six physicians (including "fellow" physicians who are receiving further training in a specialty and "attending"

Participant	Gender	Occupation	Years in Practice
H1	Female	Nurse practitioner	42 years
H2	Male	Fellow physician	5 years
H3	Female	Attending physician	8.5 years
H4	Female	Attending physician	10 years
H5	Female	Fellow physician	5 years
H6	Female	Attending physician	5.5 years
H7	Female	Child life specialist	10 years
H8	Female	Child life specialist	11 years
H9	Female	Attending physician	18 years
H10	Female	Nurse	5.5 years

Table 1: Demographic information of the healthcare providers.

physicians who have completed their training in their chosen specialty). Child life specialists are certified healthcare professionals who utilize various activities and tools to educate and provide emotional comfort for the child patients during their hospital visits. We recruited participants to the study via emails sent to a mailing list of providers. The 10 provider participants with different roles had received different formal medical training (e.g., physician, nurse, child life specialist). These providers have also been practicing pediatric oncology and worked together as care teams successfully for a long time (from five years to several decades). Thus, we consider them expert informants as they are trusted sources on a topic that can inform health communication technology based on their lived experience and communication strategy use.

All semi-structured interviews with healthcare providers were conducted in a private space (e.g. empty family room or consultation room) and each lasted between 45 minutes to one hour. All interviews were audio-recorded and transcribed at a later time. Interview questions pertained to the provider's communication practices with child patients aged 6 to 12 (as the focus of our project is communication with young children whose communication skills are not yet fully developed, which raises unique communication challenges) and their caregivers, care-taking strategies, perceptions of their role, and challenges and expectations held for patients and their caregivers. To ensure the anonymity of all participants, we removed all personally identifiable information and assigned each participant a unique identifier (e.g., H1, H2). Each participating individual was compensated with a \$20 gift card for their time.

The research team analyzed the first four interview transcripts using open coding [49]. Three researchers from the team coded the transcripts separately, compared their codes, and identified the recurring themes in the providers' communication patterns and care-taking approaches. Initially, some salient themes were identified regarding the providers' experiences with the child patients and their parental caregivers, as well as distinctive communication approaches used by the providers in their interactions with the child patients. This allowed us to focus on specific communication-related themes in the remaining six interviews. Through weekly meetings and discussions, the research team discussed categorizing and refining themes emerged (e.g., specific communication challenges the providers experienced, various communication strategies

used by providers and the significance and impact of the findings on the child patients and caregivers in the triangular relationships). Themes produced by each researcher were compared, discussed, and revised each week until agreements were reached. Axial coding [49] was used to identify relationships between themes. To gain a richer understanding of child patient-provider communication practices, we also used observational data to triangulate the interview, as the observational data provided more details on the specific situations and contexts in which providers used certain strategies (e.g., specific clinical procedures, child's gestures). In this paper, we describe the communication strategies used by the healthcare providers to communicate more effectively with child cancer patients and the barriers that they encounter when implementing these strategies.

4 OVERVIEW OF PATIENT-PROVIDER COMMUNICATION AT PEDIATRIC HEMATOLOGY ONCOLOGY OUTPATIENT CLINIC

In our study, communication between child patients and providers was primarily based on verbal, face-to-face interactions. During each clinic visit, child patients and their caregivers usually met different healthcare providers at different places in the clinic setting. In the consultation room, patients first met a nurse or fellow physician for an initial check-up. The nurse or fellow examined the patient and identified any symptoms. Then, an attending physician joined the consultation to address the patient and caregiver's concerns and make the medical decisions for treatment. After the consultation, most patients visited the infusion center where they received chemotherapy for anywhere between a half an hour to several hours.

Attendings sometimes requested Child Life Specialists (CLS), who work to educate children and families about the illness and help them adapt to the stresses of the illness, to join the consultations. The nature of the CLSs' interventions varied depending on when they were requested by the physicians, nurses, and sometimes even caregivers, who knew of the services they provided. However, for the most part, CLSs interacted with patients to provide emotional support before their treatment procedures. Although CLSs had more expertise in interacting with children using tools and resources (e.g., education books, toys), they still had to deal with communication challenges as they shared in our study.

Although the child patients whom the providers usually see range in age from infant to young adult, most of them follow a similar procedure (e.g., first clinical consultation, and then treatment) and have similar conversations with the providers during their clinic visits. In the communication with child patients, the health care providers in our study experienced several challenges. Due to their young age, the patients had limited verbal communication skills, making it more difficult for providers to identify their thoughts, preferences, and emotions. This challenge often led providers to talk with the caregivers instead of interacting with the patients directly.

Moreover, chronic care does not just involve the children's physical health, but their psychosocial and emotional well-being as well. The cancer treatment for child patients frequently interferes with

their normal development, which can make the children feel differently from their healthy peers. Thus, many child patients felt anxious or uncomfortable during the hospital visits. These negative feelings led to fewer interactions with providers and less cooperation with treatment procedures. Also, the time-constrained nature of the consultations and interactions with providers made it more difficult for the providers to build relationships with the patients.

5 HEALTHCARE PROVIDERS' COMMUNICATION STRATEGIES

Below we describe four strategies that healthcare providers developed and used to better communicate with their child patients during hospital visits. While the primary motivation of their strategies was to have more effective communication, providers found that these strategies not only helped them develop better relationships with their patients, but also improved patient engagement with clinical procedures, potentially benefiting patients' health outcomes. We also present the barriers to deploying these communication strategies reported by providers, including patients' individual personalities and situations and the influence of parental caregivers on the patient-provider relationship. Learning these communication strategies used by healthcare providers is useful to the design of communication technologies for child patient-centered care by considering the unique challenges of child patient and provider communication.

5.1 Building Personal Rapport with Child Patients

In our study, most child patients felt anxious and scared of the hospital environment. These feelings were more common among younger children who had previously spent most of their time in their home with family members and close acquaintances. Patients thus tended to perceive providers as strangers and were easily frightened of or uncomfortable with clinical procedures that the providers performed. To ease the patients' anxiety and the tension of their hospital visits, the providers in our study worked to build a rapport with patients before proceeding to the clinical procedures. Providers felt that building personal relationships with patients early on helped them better identify their clinicians, understand what and why clinicians do, and feel less scared of clinical procedures.

To build rapport with patients, the providers often began their consultations by acknowledging and talking about the patients' interests. They actively made an effort to ask or to identify and interpret contextual cues (e.g., things they brought with) that might indicate the patient's preferences so that they could create a shared interest, such as a favorite character or TV cartoon. Physicians, in particular, tried to seek information about the patient's interests and favorite things by asking the nurses since nurses had more opportunities to interact with the patients and caregivers. This strategy allowed the providers to get to know more about their patients while making the patients feel more comfortable and connected to their providers. For instance, H7 shared her strategy of reading cues, such as a character printed on a patient's t-shirt:

A lot of these kids are meeting a lot of strangers constantly, so we really try to approach them on their level.

It's a lot about reading their cues. (...) I might notice that they're wearing something Ninja Turtles and I'm like, "You like Ninja Turtles? Look, I have a Ninja Turtle." Even just kind of trying to spend that few minutes just trying to get to know them as a kid before we dive into this other part of their life – H7 (Child Life Specialist)

In this example, H7 acknowledges that child patients encounter a lot of strangers in the clinic environment and describes her strategy of getting to know the patient as a person before sharing illness-related information or performing clinical work. H7 intentionally shows interest in the character on the patient's shirt to create a more intimate connection. During our observation, we observed that personal information about individual patients, such as the patient's favorite character or possession, was often shared among care team members, primarily through verbal communication before and after consultations. Sometimes this information was also shared through additional notes in the electronic patient chart, so that other care team members could see and use that information. For instance, whenever she identified a patient's personal favorites, H8 actively added the details to the patient chart to share it with the other care team members:

Let's say I meet a patient and I learned a few things about them, I'll try to add those few details into [the name of electronic medical record system] note. I'll say, "Of note, patient really enjoys Frozen and has a cat at home named Bella and has two brother and sisters," or whatever (...) If somebody else ends up seeing them [information about patient's interests], like a different child life specialist or a social worker or a doctor, they have that information too. (...) That way, they have a little bit of knowledge about the patient too because oftentimes, rightfully so, doctors need to do the medical piece and don't always have time to add in that extra piece. – H8 (Child Life Specialist)

Although it is not required or a common practice to record patients' interests or preferences in the chart, this shared information helped providers show interests that aligned with those of the patients' more effectively in their initial rapport-building. Particularly, this information was deemed helpful to physicians who often did not have time to identify it themselves or note it in the patient charts.

Along with creating personal bonds through shared interests, the providers in our study frequently gave the patients an explanation of their actions before the physical exams and treatment procedures that might make the patients afraid. When the patients experienced the procedures in the same way the providers had described them, they felt relieved; gradually, the patients felt comfortable with and trust toward the providers. This strategy also helped reduce uncertainty and anxiety for the patients by allowing them time to prepare for the clinical procedures and develop an appropriate expectation. For example, H4 shared her strategy of constantly providing details about what she was going to do before taking action:

I am always careful not to do anything without telling them what I'm going to do first. I think going to the doctor's is a very unique experience where suddenly a stranger is allowed to touch you and is allowed to

ask you these very personal questions. And so, I kind of frame it that “Now, I’m going to listen to your heart” or “Now, I’m going to listen to your lungs, and mommy and daddy are right here”. – H4 (Physician)

This quote shows H4’s acknowledgement that unfamiliarity with clinicians and the medical procedures they perform can be a source of discomfort for child patients. H4 helps patients build necessary expectations about the physical examinations and procedures by speaking out loud what she is going to do next. This way, the patients feel less anxious and are more mentally prepared even when she does something potentially uncomfortable, such as touching their body or asking personal questions. Although this strategy of building rapport within a short amount of time might not seem significant to the patients’ overall hospital experience, many providers emphasized that creating such personal connections was critical and beneficial for developing good long-term relationships with patients for their journey through the treatment process.

5.2 Developing Familiarity with Care Settings and Routinizing Clinical Procedures

The general hospital environment, including the consultation room (i.e., exam room), infusion rooms, and various clinical tools, was new, unfamiliar, and uncomfortable for most of the child patients. To alleviate stress and anxiety, the providers tried to familiarize the patients with the clinical procedures and care settings. For procedures, the providers often offered second-hand experiences before the actual procedure. In a second-hand experience, patients indirectly experience clinical procedures by observing a provider’s presentation of them or playing with the clinical tools. The goal of this indirect experiences is to help patients get a better sense of what to expect during the procedure so as to reduce uncertainty and fear. The providers also described for patients how certain clinical tools work and why they are necessary for their treatment. Child Life Specialists (CLS), who focused on patient education and comfort work, particularly utilized this strategy. For example, a CLS (H7) would use “needle play” with child patients before procedures:

I like to do needle play for kids that are developmentally appropriate to do so. I have a port [a tube that is connected to the vein], and I would get the real needle and for a 12-year-old, let them, with some help do the real needle and push it into a port so they can feel what that feels like, how much pressure it takes, things like that. Then when they have that procedure done on their own body, they know exactly what the nurse is doing and how it feels from their perspective. So, I use that at times. (...) I’d love to use a lot of the real equipment, syringes. We’ll play with them in non-threatening ways too, with water, we’ll put paint in them, they can paint with the syringes. – H7 (Child Life Specialist)

As described in this quote, H7 adjusts the play based on the patients’ age and level of maturity by appropriately selecting clinical tools (e.g., using a real needle for 12-year-olds). After selecting an appropriate tool, H7 then teaches the patients how to use it, how the procedure will be done, and how it might feel. This second-hand experience through the use of interactive play helped patients not only learn about specific tools and procedures, but also feel

encouraged by their newly gained knowledge and fun activity. H7 tried to provide these experiences in enjoyable ways (e.g., painting with colored water) so that patients would be less fearful about the unfamiliar medical tools and procedures.

Another provider approach to helping patients develop familiarity with the hospital environment was to build a routine for their visits. Specifically, providers tried to routinize the processes of hospital care and keep them consistent for each patient, such as who they would meet (i.e., same care team members), where they would go (e.g., same order of treatment procedures, same exam room), and the kinds of interactions they would have (e.g., same communication style and methods). This structured hospital care process allowed patients to build an accurate expectation for their clinic visits without experiencing any anxiety due to uncertainty. H8 described how a structured routine of clinical activities can be beneficial to the child patients:

We just know that kids often learn from schedule and routine and being habitual, so getting used to the same process can be beneficial for kids. So, we try to make their experiences somewhat of a routine, especially in the school age kids. They know if they first do this, then they can do this. Oftentimes we’re working with kids and saying, “The first step today is we need to access your port, so we’re going to do that first. Then, the next thing we’re going to do is draw your blood. After we draw your blood, then it’s time to come to the playroom and play.” That just helps set them up for success as we go one thing to the next thing to the next thing. – H8 (Child Life Specialist)

Here, H8 describes the benefits of routinizing to building familiarity for child patients. Through repetitive, structured clinical processes, patients become familiar with hospital visits because they learn and build expectations around how things are done for them. This strategy not only helps reduce stress for patients, it also promotes effective communication between the patients and providers. As patients become used to the routines, they feel more comfortable expressing their feelings or asking questions; eventually, providers may not need to explain every detail over and over again when performing procedures. Several providers in our study mentioned that over time, hospital visits become part of the patients’ life routines and some patients treat their hospital visits just like their other regular activities, such as playing with friends after school or going to a painting class, rather than a disturbance in their life.

5.3 Respecting and Adopting Patients’ Communication Modes and Preferences

For more effective and comfortable communication with child patients, most providers in our study respected patient’s communication preferences by learning and using language specific to individual patients. Providers stated that many patients have their own expressions for describing certain medical concepts or communicating things related to their illness. These expressions were typically based on their interests, personalities, and the influence of their parents and family culture. For instance, some patients’ families used “blood sickness” for (blood) cancer, and “owie” for a

cut. Instead of directly using medical terms or concepts that might impose emotional distress, this type of language facilitated a more efficient age-appropriate communication with patients. To learn the specific language preferences of individual patients, providers attentively observed how patients used specific words to describe their symptoms or illness at every consultation. For example, H6 described how she identifies and learns to use specific language in her communication with each patient:

Many kids have different words. Like, if they have a cut, then some people have a boo-boo, or an owie, or something like that. They'll say they have a boo-boo, if they have a cut. So, it's figuring out which word the child says. "Did you hurt yourself?" And then, it's like, "Oh yeah, I have a boo-boo, I have an owie." Like, "Okay, well do you have any other ones?" Then, using whatever word they use. (...) Usually the kids that you know well and that you're going to see repeatedly, you pick up their language. – H6 (Physician)

Recognizing that each patient might use their own specific words and expressions, H6 focused on picking up the words that patients used as a way to adopt their language. H6 also indicated that time and effort is required to do this. In our study, providers, particularly the fellow physicians or nurses who often saw patients first, shared the information about a patient's specific language choices (e.g., using "blood sickness" or "c-word" instead of cancer) with the attending physicians who would see the patients later.

In addition, many providers captured specific expression and words from the patients' family caregivers, particularly when the patients were very young, as their parental caregivers had to translate all information for them. By adopting language from the caregivers, the providers were able to have more child-friendly and child-specific communication with the patients since they readily understood the meaning of the familiar language and felt comfortable with it. This helped to avoid the confusion or distress caused by the use of unfamiliar, complicated terms. Several physicians, in particular, described their experiences with picking up specific words and cues after overhearing them from the caregivers and adopting them to translate information so that the patients could understand:

You also hear it [patient's specific language] from the parents, because the parents, if I ask a question that the parent doesn't think the child will understand, then the parent will usually translate that into words they think the child will understand, and then I can use whatever the parent said to re-ask the question later – H6 (Physician)

Often family is taking that translator role of what we're saying and the conversation that we're having and helping digest it and tell it to the kid in a way that they will understand. So, we'll take cues from them for language and things like that – H2 (Physician)

Another approach to respecting the patients' communication styles was to recognize and read their non-verbal cues. Knowing that child patients often have limited communication skills to express their emotions and thoughts, the providers made an effort

to identify non-verbal cues by carefully observing the patients instead of forcing them to talk. These non-verbal elements that providers paid attention to included gestures, facial expressions, and body positions (e.g., crossing one's arms or closing the eyes) that could communicate the patient's feelings or needs. Since these cues could be easily ignored left unnoticed, the providers in our study proactively and mindfully observed the patients to better understand their mood or preferences regarding when and how to communicate. For instance, H4 shared her communication strategy of identifying and interpreting the patients' current mood by observing their gestures, such as how they held their arms or where they sat on a chair during the consultation.

Well, if a kid is sitting like this [with arms crossed], you can't just pry their arms apart and listen to their heart, you have to do something to calm them down first. Or, if they're in a little ball [crouching and holding arms around their legs] on the exam table, clearly, they're scared and they don't want you to touch them, right? And so, you have to respect that and maybe spend a little more time talking to them before just trying to jump in and listen with your stethoscope and do these rather invasive things that we do with patients. – H4 (Physician)

Believing that proceeding directly to "rather invasive" procedures would overlook the patient's needs and preferences and thereby make them feel more scared and uneasy, H4 also included some buffer time to chitchat and make the patient feel more comfortable.

Lastly, we found that providers frequently used artifacts that provided comfort to patients during hospital visits as a way to communicate with them. This strategy was useful to providers, especially in situations where young child patients refused clinical procedures, or did not want to say a word to the providers because of unfamiliarity and fear. For example, H7 described an incident where she purposefully used a patient's toy as a communication channel when one of her new patients refused to talk with any of the care providers:

Well, there was a kid last week who was brand new. Really scared. Had a stuffed dog with him though. So, we really kind of noticed the dog and talked to the dog, and he would answer for the dog. That's the only way he would talk to us. So, I would say like, "Brownie, tell me about this." Then he'd be like, "He says, 'Blah, blah, blah, blah, blah. I don't want to do this.'" Things like that. – H7 (Child Life Specialist)

As illustrated in the example H7 described, artifacts that patients are comfortable with and have some emotional attachment to, such as a stuffed dog, serve as facilitators that make patient-provider communication possible. In some situations, artifacts such as this were also used to provide second-hand experiences of procedures, a provider strategy that we discussed in the previous section. For example, in our observation, one of the physicians pretended to listen to the heart of a stuffed animal to demonstrate what the physical examination would involve (use of a stethoscope) to make the patient feel comfortable and better comply with the procedure. Not all providers in our study used artifacts as communication

devices, but those who did found that their communication and relationship with the patients improved.

5.4 Delegating Small Decisions and Inviting Patients in Conversations

In our study, healthcare providers reported that the majority of young child patients tended not to be involved in their care management, including the clinical consultations, and often lacked a sense of control in the care process. This was largely due to their insufficient communication skills, lack of knowledge, and the fact that their parental caregivers made decisions for them. To support their engagement, the providers tried to delegate trivial decisions to the patients and ask them direct questions. Unlike the major decisions made by the providers and caregivers, the trivial tasks given to patients offered small choices that were not essential to the diagnostic or treatment decisions but were still relevant enough to allow the patients to feel a sense of control and engagement:

They [patients] are vulnerable. I think kids are. They're in a scary, unfamiliar environment, so the more that we can make them comfortable and build trust with their clinicians I think the better that they'll cope throughout their experience. (...) Because they don't have a sense of control here [in clinic], we're trying to give them some sense of control and some opportunities for choices. In the hospital, as you know, there's oftentimes when they can't have that control. They can't say, "I don't want that IV," or, "I don't want that poke." It's not a choice, you have to have that. But, what is a choice is which arm you want to have it in or where you want to sit or do you want to lay down or do you want to sit up. Things like that, so giving them that opportunity. – H8 (Child Life Specialist)

In this quote, H8 describes child patients as vulnerable and lacking control, especially in the hospital setting. To offer support, H8 intentionally delegates small decisions to them. Making these decisions allows patients to feel that they have choices, are participants in the consultation, and have control over their care process.

We also found that a few of the providers in our study actively directed questions to the patients first, whenever possible, instead of directly seeking all the answers from the caregivers. By addressing and involving the patients immediately, these providers were trying to communicate that they take the patients and their role in the care process seriously. For instance, H6 described her strategy of prioritizing the interactions with the child patient when starting her consultations, particularly in the case of younger children (ages 6 and 7):

When I first walk in to try to make sure that they know that I'm not just here to talk to their parents, I will often ask the six, seven, younger kids. When I walk in, I'll usually talk to them first, before their parents (...) Then, I usually ask them who they brought with them, as if they were in control of that. Then, I want to figure out who the other people in the room are, because sometimes it is not who you expected the other people in the room to be, if I don't know them. But, it also gives them an opportunity to talk at the beginning, and so

that way... I think they hopefully pick up early on that we're interested in what they say. – H6 (Physician)

As described in this quote, H6 tries to empower child patients through conversation so that they will understand that their providers are interested in their thoughts and feelings. Ultimately, the goal is for the patients to eventually interact proactively with the providers and develop trustful relationships. Although this strategy was very helpful for promoting active patient engagement in conversations about care, we observed that the majority of providers in the study directed questions primarily at the caregivers. Reasons for this include being unable to completely trust a young child's answers in complex matters, difficulties with children who do not want to interact, and having a limited time for each consultation.

5.5 Barriers to Providers' Communication Strategies

The communication strategies described in the previous sections helped build rapport between patients and providers, develop patient familiarity with the care setting, align patient and provider communication styles, and create opportunities to engage patients in the care process. While these strategies promoted effective communication and patient engagement, providers faced two major barriers while deploying them.

The most common barrier was that providers encountered unanticipated, diverse reactions to the strategies resulting from the individual child's personality or current mood. Many providers in our study emphasized that there is a wide spectrum of patient types, and thus there is not a single strategy that meets the different needs and preferences of every patient. In addition to each child's unique personality and tendencies, the providers found the children to have frequent changes in mood and feelings, even within a single clinic visit; this required careful adjustment to their strategies. For instance, although H6 usually built rapport and trust with her patients by helping them to have proper expectations for their upcoming procedures, sometimes she noticed this did not work for those who became more scared the more they learned:

There are some kids who, knowing more information makes them more anxious. I think, for them, trying to make sure that we have the minimum that they need to know, so they're not surprised by things, and that they know what to expect. (...) Some patients get really anxious about knowing that scans are coming. For those patients we might not tell them that. That way, they [patients] don't have as much time to worry about it. – H6 (Physician)

This example shows that because of a patient's sensitive or anxious personality, H6's strategy of giving a heads-ups about clinical procedures does not always work as intended, and that she therefore has to adjust and change her strategy to sharing the least amount of information possible to minimize the patient's anxiety. However, it can be hard for providers to quickly address the need for adjustment, because it requires time and experience to understand a wide range of patient personalities and dynamic reactions and identify the most appropriate strategy for each patient over short, limited medical encounters. Therefore, some providers in our study emphasized the importance of getting to know individual

personalities efficiently in a short amount of time so that they could focus on delivering medical information in a patient-appropriate way.

The other challenge reported by the providers was that parental caregivers, rather than being a facilitator, sometimes became a barrier in the communication between the patient and provider. This was particularly apparent when providers tried to encourage patients to make their own decisions to offer a sense of control. The providers reported that some parental caregivers' oppressive parenting style or dominating personality interfered or prevented them from directly interacting with patients during consultations. Instead, these caregivers tended to make all the decisions for their children, resulting in their children becoming even more dependent on them. Such frequent interferences from caregivers significantly lessened the opportunities for the patients to engage with their providers and the care process, leading to a general lack of interest in their care and trust toward the providers. H10 indicated that patients whose parents have an overbearing parenting style could tend to disengage from the care process:

You see parents that are calm and patient, and then you see anxious, worried parents. Overbearing, I hate to say that word, but I would say that describes some of the situations. Controlling [the situations for patients]. (...) If it's an overbearing parent, I think sometimes children that age [6-12] shut down almost and don't participate in their own care because the parents are so involved. – H10 (Nurse)

As illustrated by this quote, the providers often witness how some caregivers' parenting styles significantly affect the patients' attitudes and engagement in the care process. In addition to the problematic parenting style, providers stated that the parental caregivers' unfavorable attitudes toward providers significantly hindered the clinicians from developing trustful relationships with patients and caused the patients to feel doubt and uncertainty during their interactions. All of the providers in our study observed that their patients had a strong tendency to follow and rely on their parents' attitudes since their own capabilities for judgment were not yet fully developed; thus, their parents were their main resource for acquiring new information, skills, and perspectives. In such cases, despite the providers' best efforts to use effective communication strategies, the patients would not easily develop rapport with and trust in the providers. H4 described this challenge:

The barriers [to build trust] for the six to 12-year-old that we run in, if they do arise, it's more with the caregiver. They might not trust or believe, even, what you're telling them is best. (...) And then, of course, that trickles down to their kids because they trust their parents. If they're hearing that from their parents, then that can fracture your relationship with your patient too. – H4 (Physician)

As H4 describes in this quote, parents can profoundly impact the child patient-provider relationship by influencing the child's perception of and trust in the provider. This indicates the importance of having the parental caregivers' cooperation in order to build effective child patient-provider relationships.

6 DISCUSSION

In this study, we have identified four distinctive strategies healthcare providers created and deployed to communicate more effectively with their child patients during hospital visits: helping them develop rapport with the providers, building familiarity with the care procedures and environment, using their language and preferred communication methods, and engaging them to participate in their own care. The providers in our study developed these strategies to reduce patient anxiety, stress, and fear during hospital visits. Based on the analysis of providers' communication strategy use, in this section, we first discuss the three essential elements the providers valued to achieve effective communication in pediatric care practice, and then discuss the detailed process of how the providers developed their strategies to tailor their communication to the patients' needs and preferences. Finally, we describe design opportunities for communication technology development.

6.1 Elements of Effective Communication for Relationship-Building Between Provider and Child Patient

The goal of effective patient-provider communication in chronic illness management is ultimately to improve health outcomes for patients by building a strong, trustful relationship that encourages patient participation in the care process. A good, trustful patient-provider relationship can promote positive health outcomes for patients, such as higher treatment satisfaction [18], increased medication adherence [33], and reduced emotional distress [55], while unsatisfactory relationships have been associated with negative outcomes including decreased trust in care [21] and an inclination towards hopelessness (i.e. demoralization) [40]. Because of such direct impact on the patients' well-being and clinical outcome, it is crucial to ensure effective communication for building a good patient-provider relationship. In our study, healthcare providers used various communication strategies to better interact and promote good relationships with their child patients. Through their communication strategies, we identified key elements of effective communication that the providers valued the most in order to achieve a good quality patient-provider relationship: *Transparency* (providing transparent information about clinicians and their actions), *Respect-Acceptance* (respecting and adopting the language and communication styles specific to individual patients), and *Empowerment* (helping patients feel control over their care). Despite some variations in the specific strategies used among providers, these elements were considered crucial and necessary in their communication work in order to create strong relationships with their child patients who have insufficient communication skills and are experiencing stressful and time-constrained medical encounters. We also recognize that all three elements are embedded in every one of the providers' communication strategies, though specific elements seem to appear more obviously in certain strategies than others.

The terms used in the three elements of effective communication identified in our study – Transparency, Respect-Acceptance, and Empowerment – have been previously discussed in medical and health communication literatures. Although in the existing literatures they are frequently seen as the concepts that facilitate

successful patient-provider communication along with other interpersonal communication skills [39], our analysis reveals that each element presents distinctive values and needs that are unique to child patient-provider communication based on the strategies developed by the providers. In healthcare, “transparency”² refers to making information – from patient experiences to medical costs to the healthcare system’s efficiency and quality – available to the public in a reliable and comprehensible manner. Specifically, in the context of patient-provider communication, transparency has been identified as an important factor that affects patients’ health literacy and their trust towards their clinicians and care, since the exchange of information related to illness and treatment and the sharing of meaning and understanding alleviates patients’ uncertainty and promotes informed decision-making [48]. However, while the existing understanding of transparency is related to health literacy through information-exchange, transparency as identified in our study mainly focuses on creating familiarity and building a comfortable and safe environment for the child patients by letting them know who their clinicians are and what they do, rather than providing access to detailed medical information. For instance, specific provider strategies that emerged from our findings – such as giving a heads-up before a procedure, speaking out loud about each procedural action, and providing second-hand experiences of clinical procedures – were more about helping the patients have a better understanding and proper perceptions of their clinicians, and less about sharing medical knowledge.

“Respect-Acceptance” is also considered a facilitator to effective communication that determines the quality of patient-provider relationships. Prior studies have presented examples, such as providers listening what patients are saying, having nonjudgmental acceptance, eliciting and responding to concerns, and showing sensitivity to patients’ cultural backgrounds [46]. While it is critical to implement these interpersonal skills by respecting and addressing the patients’ needs and preferences for general care communication practices, our study indicates that for pediatric care communication, identifying the hidden or implicit needs and preferences of the child patients is necessary. As shown in the findings, providers made efforts to acknowledge the patients’ specific language and communication mode preferences and pay careful attention to their non-verbal cues and gestures as these patients have a limited ability to express their needs, wants, and feelings. This demands that providers make proactive efforts to look for, identify, and interpret hidden and nuanced information during their interactions with the child patients and immediately adopt what they have learned into practice.

Additionally, in our study, healthcare providers valued the importance of “empowerment” as a potential key to sustainable patient-provider relationships as it promotes the active engagement of patients in their long-term care. Patient empowerment is defined as having the motivation, knowledge, skills and support along with mutual trust and respect for patient autonomy [24]; It has been increasingly advocated for in patient-centered care along with similar concepts, such as patient engagement and activation. An important component of these concepts is that the patient has the knowledge to foster a relationship with their health, making the exchange of

information a core part of patient-centered communication. Empowered patients are able to ask questions, communicate assertively, and express concerns and feelings, all of which require that the patients are informed. Compared to this emphasis on empowering patients through information-sharing, our study uncovers the importance of enabling child patients to feel a sense of control during hospital visits. As described in our findings, patient empowerment was facilitated by the providers who delegated small tasks to the patients (e.g., making decisions about where to sit in the exam room or which arm to get an injection from) and directed questions at them (e.g., having opportunities to lead a conversation and speak first or answer on behalf of their parent). These tasks and questions allowed the child patients to feel empowered at their perceptual level. Even though making requests for the patients’ choices and allowing them to speak are not necessarily related to information exchange or knowledge acquisition, they are sufficient enough to draw the child patients’ attention and make them feel more confident, engaged, and interested in their own care. The awareness and realization of child patients fosters a more positive, trustful patient-provider relationship as it encourages active patient involvement.

Along with the three elements of effective communication, our study also indicates the impactful role of parental caregivers on patient-provider relationship-building. Parental caregivers’ attitudes and views toward their providers affect whether these communication elements can be achieved or not. Two elements in particular, Respect-Acceptance and Empowerment, are considerably influenced by the caregiver’s role and any tension between caregivers and providers, such as conflicting beliefs on child engagement in the care process and having different attitudes or beliefs regarding healthcare. In the example of the providers’ strategy for learning and adopting the patient’s language, the role of caregivers served as an information source; caregivers directly or indirectly provided useful information about the patients to providers. In contrast, caregivers could become a barrier that interferes with the provider’s strategy of giving opportunities for patient participation in the care process (Empowerment) when there was tension between the providers and caregivers. As mentioned by a physician (H10) in our study, parental caregivers who control and dominate their child’s activities may ultimately interfere with the provider’s efforts by taking away the chances for the child to participate in care process or showing disagreement with the child’s answers or choices. Thus, aligning with the caregivers’ interests, beliefs, and visions for the patients’ care was found to be critical. For good patient-provider relationship-building, it is essential for providers to not just work to identify each child patient’s hidden needs but also to balance these with the caregiver’s needs and preferences.

6.2 Designing Communication Strategies through the Response-Learning-Collaboration Loop

In addition to providers’ communication strategies used to achieve effective communication and relationship-building, our analysis also reveals the detailed process of how providers developed these communication strategies. In the process of development, providers went through the constant “*response-learning-collaboration*” steps

²National Academy of Medicine – <https://nam.edu/>

so that they could quickly adjust and better tailor their communication practices to the child patients. These steps occurred iteratively and created a loop until the providers developed, adjusted, and found appropriate communication strategies for individual patients.

Prior to using specific communication strategies, the healthcare providers in our study usually initiate an interaction to gain a quick sense of a patient's condition and mood. They begin the interaction by simply greeting the patient, asking certain questions or observing their facial or bodily expressions. In other words, they use both verbal and non-verbal cues to gain any *response* from the patient in the initial stage. After they gain some reaction or feedback from the initial interaction, providers try out an initial communication strategy to elicit further responses. For instance, while giving an explanation of their actions in a procedure, some providers carefully observed not only the patient's verbal response but also non-verbal reaction to figure out whether the kinds of language they were using and the amount of information they were providing were appropriate for that patient.

Based on the responses they received, providers *learn* the patients' own communication preferences, their personal characteristics, and current emotional states. This learned information is used to adjust the providers' approach to make it work for each individual patient. In our findings, H6 had to change her strategy of giving a heads-up about an upcoming procedure after learning about the patient's tendency to experience more anxiety if overwhelmed by medical information. She then only provided the least amount of information possible right at the moment of performing the procedure. This learning from responses takes time, since the providers may get different responses even from the same patient depending on the child's current mood and the changing situation of each clinic visit. As described in our findings, the providers in our study identified this as a frequent challenge in deploying their strategies.

The last step of this iterative process is *collaboration*. Once providers learn from the patients' responses, not only do they make the proper adjustments to their communication strategies for individual patients but they also actively share their learned knowledge and information about each patient with other care team members who interact with the same patient. This shared patient information is patient-personal, non-medical (and subjective sometimes) data, such as the patients' current mood, specific communication preferences (e.g., stuffed dog), personal favorites, and their interaction style with parental caregivers, rather than medical facts. It is critical for members of the same care team to share and know such information so that they can collaboratively create a coherent and consistent communication practice, which can facilitate and expedite each individual provider's effort to build personal rapport with the patients, develop the patients' familiarity with the care setting and engage the patient in their care. Sharing patient-related subjective data among care team members has been previously reported [56], with the researchers highlighting the physicians' information needs regarding the patients' psycho-social information during inpatient care through a study of the physicians' documentation in the electronic health records (EHR) system. In our study, sharing and collaborating around this patient-related subjective information was almost always done verbally, right before or after the providers' interactions with the patients, though one provider (H8)

proactively recorded this information in the electronic patient chart for other care team members. We think that the reason for this may be the frequent changes in the children's moods and feelings (even during one visit) and the varied patient interactions with different family caregivers during some visits (e.g., mom versus dad, step dad or grandparent), which might have made the providers feel that such information is too situational or contingent to be recorded. Additionally, our clinicians were handling relatively smaller numbers of patients at any given time, so it was still possible to remember specifics about each patient.

The shared information among the care team members (i.e., the patient-specific data and what strategy had worked for the patient) helps the providers utilize it usefully to set up their own interactions with the patient later on and efficiently assess the patient's response in order to better develop or refine their strategies. The process of providers' developing communication strategies thus becomes an iterative loop of response-learning-collaboration-response. They apply what they learned on their own in the *learning* step as well as what they obtained from others in the *collaboration* step to the *response* step in order to better understand, check, or identify the patient's responses more comprehensively. Thus, the providers constantly collect and aggregate the data (i.e., proper and sufficient responses received from the patients) to develop, modify, and refine their communication strategies.

We consider the creation and use of communication strategies to be an individual as well as collective design effort by healthcare providers to find the best workable communication solution for their child patients. As noted in the health literature [29], most physicians do not get adequate communication training since with the exception of some primary care training programs, most training programs after medical school do not include or give sufficient attention to communication skills and education in their curricula. Communicating with child patients with cancer raises the challenge to a higher level. However, our providers did not simply accept or tolerate the lack of quality interactions with child patients in the current practice; they actively attempted to initiate interactions to gather and gauge the child patients' responses, learned how to modify and tailor communication to individual child patients' needs and preferences, collaborated with other care team members by sharing their knowledge, and applied this knowledge to more efficiently develop strategies. From this perspective, designing communication strategies does not end at one or two trials based on a provider's own limited data or knowledge, but rather extends to involve active input from the child patients, parental caregivers, and other care team members. Providers iteratively adjust and refine these communication strategies as they learn more about the patient, until they find the best solution, just like an iterative design process. Therefore, it is important to support and facilitate the loop of the communication strategy development from the individual provider's as well as the care team's perspectives.

6.3 Opportunities for Designing Communication Technology

Our study details the key elements underlying the healthcare providers' communication strategies for relationship-building with

child patients and the iterative design process of the communication strategies. Learning from the providers' use of communication strategies, in this study, the focus of communication technology development is to better support healthcare providers' communication practices for the unique challenges of child patients during hospital visits even when patients and caregivers are still considered the stakeholders of the technology. Based on our findings, we offer design opportunities for a communication technology to facilitate patient familiarity throughout the care process, to support providers' iterative learning through monitoring patient responses, and to recommend communication strategies for patient empowerment.

6.3.1 Facilitating patients' familiarity with providers and the care setting. As previously discussed, the first element of the providers' effective communication is to build rapport and patient familiarity with the care environment in a transparent manner (Transparency). In other words, it is crucial to help child patients develop a clear and accurate idea of the providers, the clinical procedures and the care setting; delivering such information as soon as possible when building new patient-provider relationships is critical because of the patients' likely negative perceptions of the hospital visits. We thus suggest designing communication technology that allow providers to be able to quickly create common ground for initial rapport-building by providing more frequent chances for child patients to receive transparent information throughout their hospital visit. An example of this could be a mobile application that collects, delivers, and shares information between a patient and a provider: for the provider, it collects and shares relevant information about the patient for rapport-building, such as the patient's favorite character, foods, activity, and personal interests, while for the patient, it provides brief heads-ups about care team members and treatment procedures during the downtimes between each interaction with different care team members (e.g., wait time in the waiting room, time in between each care provider in the exam room, wait time before treatment in the infusion area). A potential format of a mobile interaction for a child-friendly approach can be an interactive game [17] where a child can learn about different characters who resemble providers' roles and jobs and also carry out various missions that the child's own character has to complete which resemble the expected treatment procedures. With this communication tool, patient-provider communication could be facilitated and expedited despite the time-constrained medical encounters, since it could enable the patient to learn more about the care team providers' roles and jobs, and also enable the providers to quickly learn about the patient's personal interests and preferences based on the patient's input; providers could then use it to better initiate interactions in consultations. In this way, the tool could promote more effective child patient-provider communication and, ultimately, a more favorable relationship.

Prior works in HCI and Health Informatics have presented various technology designs to facilitate patient-provider interactions by providing information access for patients during their hospital visits [3, 28, 32, 43, 53]. These include mobile applications that provide information regarding a patient's hospital stay in an inpatient unit [32, 53] and a virtual agent that provides a patient's discharge-related information and facilitates the bedside nurses'

job [3]. Yet, these technology designs have largely focused on addressing the adult patients' or caregivers' information needs, which differ from the child patients' communication needs. Although a recent study developed an interactive educational tool to help child patients learn about their illness in the clinic waiting room [28], it did not promote patient familiarity with providers or care settings. Instead of only providing information access and teaching medical knowledge to patients, we argue that communication technology design should also consider other types of information, i.e., patients' personal interests, providers' roles and jobs, and facilitate such information for both patients and providers to achieve effective communication and initial rapport-building, which is essential for long-term pediatric care.

6.3.2 Supporting providers' iterative learning through patient responses. Respecting and adopting a patient's specific language and preferred communication mode (Respect-Acceptance) is more necessary for successful care communication in the pediatric setting than in adult patient care. This requires providers to identify and interpret various cues including non-verbal elements (e.g., facial or bodily expressions) to understand the patient's current mood and any other reactions to determine if their specific communication style is appropriate. To do this, providers actively engage in a constant, iterative process of learning through responses to better develop, adjust, and find the best workable communication strategies for each patient due to their individual differences. As shown in the case of one provider (H7) in our study, a child did not speak a single word to any of the care team members, until the provider found a way to initiate interactions using a comfort artifact (the patient's stuffed dog). It is therefore critical to acknowledge the individual differences of child patients regarding their communication modes and support the providers' iterative learning through patient responses.

To that end, we suggest a communication tool that aids the providers' efforts to capture and interpret patient responses and to make adjustments to find workable communication strategies during patient consultations. To improve patient consultations, HCI researchers have presented technical aids that monitor and visualize clinical discussions to improve the providers' interpersonal communication skills. Examples include behavioral visualization webtools that help create a shared understanding of developmentally delayed patients' behaviors in parent-provider communication (e.g., EnGAze and Plexline [25]) and a visual display tool that enhances the providers' self-awareness of their non-verbal communication through ambient visual feedback based on a real-time social signal processing of a video feed from the patient and provider's conversation (e.g., Entendre [38]). These earlier works on visualization tools provide evidence that reflective visualizations of non-verbal behaviors can be informative and acceptable to healthcare professionals and can enhance their patient-centered communication skills.

Building upon the earlier works, a tool that detects and interprets child patients' verbal and nonverbal cues (e.g., wrapping their arms around their knees as a sign of an unwillingness to interact) can be designed as a real-time communication aid for providers to better gauge the child patients' responses, and assess and adjust to their communication practices. With the parental caregiver's

permission, the use of this real-time assistive-assessment tool during consultations can help providers reflect on and better learn from their current communication strategies to improve in a more systemic way that does not solely rely on their intuition during the limited, time-restricted clinical encounters. In addition, information collected by this communication aid tool can be further used to help inform other care team members about the individual differences of each patient, or to support new providers who are less experienced with child patients, particularly given that traditional clinical communication training provides more generalized interpersonal communication skills that lacks specificity on non-verbal competencies with the expectation that providers will learn new skills at the point of care [12].

6.3.3 Sharing and collaborating on communication strategies for patient empowerment. The healthcare providers in our study strived to encourage child patients to participate in their care and feel a sense of control during their hospital visits by intentionally delegating small decisions or directly inviting them into conversation. These strategies were intended to make the child patients feel empowered and think that they could collaborate with their providers, such as taking a role in completing a clinical task together with a nurse (e.g., getting an injection). Although our study as well as prior studies [1] found benefits to empowering child patients, currently providers must rely on their own practical experiences to develop their own strategies of empowering their child patients since there has been no adequate training or formal education program available [29]. This leaves the chance for patient empowerment up to individual providers' volunteer and proactive efforts. Fortunately, there have been an increasing number of health education or illness management applications designed to promote child patient empowerment. Examples include an incentive-based game that invokes child patients' physical exercises and mental wellbeing to help fight cancer through a series of collectable awards and positive visualizations [8] and an interactive mobile application that supports adolescent with autism for their self-management in the transition to adulthood through behavior goal settings and self-reporting [45]. However, such applications still focus primarily on improving self-management skills through education rather than encouraging patient participation and a sense of competency during hospital visits, which is one of the most vulnerable health care contexts, especially for children.

The lack of useful resources available to providers to empower children during clinical encounters indicates an opportunity to develop an information repository. It synthesizes frequently used strategies among providers with corresponding patient response data to provide recommendations for providers. By synthesizing various communication strategies with corresponding patient responses, a repository like this could facilitate the care team members' sharing and collaborating practices around patient-specific data, which currently occur without a unified format at our field site (mostly shared verbally and sometimes recorded in electronic patient charts). In terms of getting strategy recommendations, we envision some cases where providers may want to find specific recommendations by selecting a certain topic related to different clinical procedures (e.g., blood draw) or patient type (e.g., age, gender) or other cases for which they want to receive auto-populated

general recommendations. We also suggest that it may be necessary to acquire brief feedback from providers and patients, as well as caregivers, about their experience with strategies used (e.g., for the provider, their perceived success with the recommended strategies; for the child, what they loved most during hospital visit), like a quick satisfaction survey. This feedback could be used to enhance the shared strategy repository and improve recommendations to better tailor them to each patient. If recommendations and the feedback obtained from parental caregivers include how to better communicate with the caregivers themselves about the benefits of child engagement and empowerment, it is possible that such a system may also hold potential for helping to develop stronger relationships among the provider-patient-caregiver triads.

7 LIMITATIONS AND CONCLUSION

The qualitative findings of our study are specific to the context of pediatric cancer care. However, we expect that the knowledge derived from our study can be transferable to other pediatric care settings or similar situations [51] that involve communication challenges with child patients, especially in long-term care situations where relationship building is instrumental. Our study is also limited due to the small sample size of providers that we interviewed as our field site is one specific pediatric oncology clinic. While our findings produced nuanced understandings of the communication strategies used by the particular group of providers that we interviewed, especially because our participants are experienced from their long years of practice in pediatric care and working together as a care team, future studies should examine provider strategies for child-patient-provider communication in other pediatric care settings to identify any differences or additional practices. Also, a future study may triangulate provider data on the topic with patient and caregiver perspectives.

Based on the healthcare provider semi-structured interviews and clinic observations, our study has identified communication strategies that the providers use to build good relationships with their child patients, and challenges they face when carrying out these strategies. The strategies the study identified include building personal rapport with child patients, developing patient familiarity with care settings and routinizing clinical procedures, respecting and adopting patients' communication modes, and delegating small decisions to and directing questions at the patients. Based on our analysis of these strategies, we make two contributions to the HCI community: 1) we reveal how healthcare providers iteratively design and use their communication strategies to achieve essential elements that they value in their interactions with child patients, and 2) we present design opportunities for technology to enhance the providers' current communication practices. Extending on prior work about provider and patient communication, we encourage designers and researchers to consider these current practices of providers when designing communication tools for healthcare, while supporting patients with their own needs and preferences.

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REFERENCES

- [1] Mariela Acuña Mora, Carina Sparud-Lundin, Åsa Burström, Katarina Hanseus, Annika Rydberg, Philip Moons, and Ewa-Lena Bratt. 2019. Patient empowerment and its correlates in young persons with congenital heart disease. *European Journal of Cardiovascular Nursing* 18, 5 (2019), 389–398.
- [2] Andrew B.L. Berry, Catherine Y. Lim, Tad Hirsch, Andrea L. Hartzler, Linda M. Kiel, Zoë A. Bermet, and James D. Ralston. 2019. Supporting communication about values between people with multiple chronic conditions and their providers. In *Conference on Human Factors in Computing Systems - Proceedings*. Association for Computing Machinery, New York, New York, USA, 1–14. <https://doi.org/10.1145/3290605.3300700>
- [3] Timothy W. Bickmore, Laura M. Pfeifer, and Brian W. Jack. 2009. Taking the Time to Care: Empowering Low Health Literacy Hospital Patients with Virtual Nurse Agents. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (Boston, MA, USA) (CHI '09). Association for Computing Machinery, New York, NY, USA, 1265–1274. <https://doi.org/10.1145/1518701.1518891>
- [4] Matthew Bonner, Lan Wang, and Elizabeth D. Mynatt. 2012. Activity-Based Interaction: Designing with Child Life Specialists in a children's hospital. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM Press, New York, New York, USA, 2087–2096. <https://doi.org/10.1145/2207676.2208360>
- [5] Sarah R Brand, Karen Fasciano, and Jennifer W Mack. 2017. Communication preferences of pediatric cancer patients: talking about prognosis and their future life. *Supportive care in cancer* 25, 3 (2017), 769–774.
- [6] Arlene M Butz, Jennifer M Walker, Margaret Pulsifer, and Marilyn Winkelstein. 2007. Shared decision making in school age children with asthma. *Pediatric nursing* 33, 2 (2007), 111.
- [7] Patricia Cahill and Alexia Papageorgiou. 2007. Triadic communication in the primary care paediatric consultation: a review of the literature. *British Journal of General Practice* 57, 544 (2007), 904–911.
- [8] Craig Caldwell, Carol Bruggers, Roger Altizer, Grzegorz Bulaj, Troy D'Ambrosio, Robert Kessler, and Brianne Christiansen. 2013. The intersection of video games and patient empowerment: Case study of a real world application. In *ACM International Conference Proceeding Series*. ACM Press, New York, New York, USA, 1–7. <https://doi.org/10.1145/2513002.2513018>
- [9] Robyn Patricia Cant and RA Aroni. 2008. Exploring dietitians' verbal and nonverbal communication skills for effective dietitian-patient communication. *Journal of human nutrition and dietetics* 21, 5 (2008), 502–511.
- [10] April Idalski Carcone, Angela J. Jacques-Tiura, Kathryn E. Brogan Hartlieb, Terrence Albrecht, and Tim Martin. 2016. Effective Patient-Provider Communication in Pediatric Obesity. , 525–538 pages. <https://doi.org/10.1016/j.pcl.2016.02.002>
- [11] Delesha M. Carpenter, Guadalupe X. Ayala, Dennis M. Williams, Karin B. Yeatts, Stephanie Davis, and Betsy Sleath. 2013. The relationship between patient-provider communication and quality of life for children with asthma and their caregivers. *Journal of Asthma* 50, 7 (sep 2013), 791–798. <https://doi.org/10.3109/02770903.2013.808347>
- [12] Donald J Cegala and Stefne Lenzmeier Broz. 2002. Physician communication skills training: a review of theoretical backgrounds, objectives and skills. *Medical education* 36, 11 (2002), 1004–1016.
- [13] Gang Chen, Nilufar Baghaei, Abdolhossein Sarrafzadeh, Chris Manford, Steve Marshall, and Gudrun Court. 2011. Designing Games to Educate Diabetic Children. In *Proceedings of the 23rd Australian Computer-Human Interaction Conference* (Canberra, Australia) (OzCHI '11). Association for Computing Machinery, New York, NY, USA, 72–75. <https://doi.org/10.1145/2071536.2071546>
- [14] Lei Cheng, Liying Wang, Mengxue He, Sheng Feng, Yehui Zhu, and Cheryl Rodgers. 2018. Perspectives of children, family caregivers, and health professionals about pediatric oncology symptoms: a systematic review. *Supportive Care in Cancer* 26, 9 (2018), 2957–2971.
- [15] Chia-Fang Chung, Qiaosi Wang, Jessica Schroeder, Allison Cole, Jasmine Zia, James Fogarty, and Sean A. Munson. 2019. Identifying and Planning for Individualized Change: Patient-Provider Collaboration Using Lightweight Food Diaries in Healthy Eating and Irritable Bowel Syndrome. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 3, 1, Article 7 (March 2019), 27 pages. <https://doi.org/10.1145/3314394>
- [16] Angela M. Feraco, Sarah R. Brand, Jennifer W. Mack, Jennifer C. Kesselheim, Susan D. Block, and Joanne Wolfe. 2016. Communication Skills Training in Pediatric Oncology: Moving Beyond Role Modeling. *Pediatric Blood & Cancer* 63, 6 (jun 2016), 966–972. <https://doi.org/10.1002/pbc.25918>
- [17] Marie Glasemann, Anne Marie Kanstrup, and Thomas Ryberg. 2010. Making Chocolate-Covered Broccoli: Designing a Mobile Learning Game about Food for Young People with Diabetes. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems* (Aarhus, Denmark) (DIS '10). Association for Computing Machinery, New York, NY, USA, 262–271. <https://doi.org/10.1145/1858171.1858219>
- [18] Amanda M. Hall, Paulo H. Ferreira, Christopher G. Maher, Jane Latimer, and Manuela L. Ferreira. 2010. The Influence of the Therapist-Patient Relationship on Treatment Outcome in Physical Rehabilitation: A Systematic Review. *Physical Therapy* 90, 8 (aug 2010), 1099–1110. <https://doi.org/10.2522/ptj.20090245>
- [19] Marit Helene Hem, Kristin Heggen, and Knut W Ruyter. 2008. Creating trust in an acute psychiatric ward. *Nursing ethics* 15, 6 (2008), 777–788.
- [20] L Kari Hironaka and Michael K Paasche-Orlow. 2008. The implications of health literacy on patient-provider communication. *Archives of disease in childhood* 93, 5 (2008), 428–432.
- [21] Nynke Holwerda, Robbert Sanderman, Grieteke Pool, Chris Hinnen, Johannes A. Langendijk, Willem A. Bemelman, Mariët Hagedoorn, and Mirjam A. G. Sprangers. 2013. Do patients trust their physician? The role of attachment style in the patient-physician relationship within one year after a cancer diagnosis. *Acta Oncologica* 52, 1 (jan 2013), 110–117. <https://doi.org/10.3109/0284186X.2012.689856>
- [22] Matthew K. Hong, Lauren Wilcox, Daniel Machado, Thomas A. Olson, and Stephen F. Simoneaux. 2016. Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (San Jose, California, USA) (CHI '16). Association for Computing Machinery, New York, NY, USA, 5337–5349. <https://doi.org/10.1145/2858036.2858508>
- [23] Juan Pablo Hourcade, Martha Driessnack, and Kelsey E. Huebner. 2012. Supporting face-to-face communication between clinicians and children with chronic headaches through a zoomable multi-touch app. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM Press, New York, New York, USA, 2609–2618. <https://doi.org/10.1145/2207676.2208651>
- [24] Teresa A. Jerofke. 2013. Concept analysis of empowerment from survivor and nurse perspectives within the context of cancer survivorship. *Research and theory for nursing practice* 27, 3 (jan 2013), 157–172. <https://doi.org/10.1891/1541-6577.27.3.157>
- [25] Ha-Kyung Kong and Karrie Karahalios. 2020. Addressing Cognitive and Emotional Barriers in Parent-Clinician Communication through Behavioral Visualization Webtools. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) (CHI '20). Association for Computing Machinery, New York, NY, USA, 1–12. <https://doi.org/10.1145/3313831.3376181>
- [26] Charalampos Kyfionidis and Marilyn Lennon. 2019. Making Diabetes Education Interactive: Tangible Educational Toys for Children with Type-1 Diabetes. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland UK) (CHI '19). Association for Computing Machinery, New York, NY, USA, 1–12. <https://doi.org/10.1145/3290605.3300671>
- [27] Veronica Lambert, Michele Glacken, and Mary McCarron. 2011. Communication between children and health professionals in a child hospital setting: a Child Transitional Communication Model. *Journal of Advanced Nursing* 67, 3 (2011), 569–582.
- [28] Zeina Atrash Leong, Michael S. Horn, Lisa Thaniel, and Emily Meier. 2018. Inspiring AWE: Transforming clinic waiting rooms into informal learning environments with active waiting education. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2018-April. Association for Computing Machinery, New York, New York, USA, 1–12. <https://doi.org/10.1145/3173574.3173672>
- [29] Wendy Levinson, Cara S. Lesser, and Ronald M. Epstein. 2010. Developing physician communication skills for patient-centered care. , 1310–1318 pages. <https://doi.org/10.1377/hlthaff.2009.0450>
- [30] Catherine Lim, Andrew B.L. Berry, Tad Hirsch, Andrea L. Hartzler, Edward H. Wagner, Evette Ludman, and James D. Ralston. 2016. "It Just Seems Outside My Health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems* (Brisbane, QLD, Australia) (DIS '16). Association for Computing Machinery, New York, NY, USA, 1172–1184. <https://doi.org/10.1145/2901790.2901866>
- [31] Svetla Loukanova, Rachael Molnar, and John FP Bridges. 2007. Promoting patient empowerment in the healthcare system: highlighting the need for patient-centered drug policy. *Expert Review of Pharmacoeconomics & Outcomes Research* 7, 3 (jun 2007), 281–289. <https://doi.org/10.1586/14737167.7.3.281>
- [32] Sonali R. Mishra, Andrew D. Miller, Shefali Halder, Maher Khelifi, Jordan Eschler, Rashmi G. Elera, Ari H. Pollack, and Wanda Pratt. 2018. Supporting collaborative health tracking in the hospital: Patients' perspectives. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 2018-April. Association for Computing Machinery, New York, New York, USA, 1–14. <https://doi.org/10.1145/3173574.3174224>
- [33] Alex Molassiotis, Kate Morris, and Ian Trueman. 2007. The importance of the patient-clinician relationship in adherence to antiretroviral medication. *International Journal of Nursing Practice* 13, 6 (dec 2007), 370–376. <https://doi.org/10.1111/j.1440-172X.2007.00652.x>
- [34] Tao Ni, Amy K. Karlson, and Daniel Wigdor. 2011. AnatOnMe: Facilitating doctor-patient communication using a projection-based handheld device. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM Press, New York, New York, USA, 3333–3342. <https://doi.org/10.1145/1978942.1979437>

- [35] Debra L Palazzi, MEd I Martin Lorin, Teri L Turner, MEd A Mark Ward, and Antonio G Cabrera. [n.d.]. *Communicating with Pediatric Patients and their Families: The Texas Children's Hospital Guide for Physicians, Nurses and other Healthcare Professionals*. Technical Report. www.bcm.edu/pediatrics/patient-communication-guide
- [36] Sun Young Park, Yunan Chen, and Shriti Raj. 2017. Beyond health literacy: Supporting Patient-provider communication during an emergency visit. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW*. Association for Computing Machinery, New York, NY, USA, 2179–2192. <https://doi.org/10.1145/2998181.2998357>
- [37] Niraj J Patel, Karishma A Datye, and Sarah S Jaser. 2018. Importance of patient-provider communication to adherence in adolescents with type 1 diabetes. In *Healthcare*, Vol. 6. Multidisciplinary Digital Publishing Institute, 30.
- [38] Rupa A. Patel, Andrea Hartzler, Wanda Pratt, Anthony Back, Mary Czerwinski, and Asta Roseway. 2013. Visual Feedback on Nonverbal Communication: A Design Exploration with Healthcare Professionals. In *Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare (Venice, Italy) (PervasiveHealth '13)*. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering), Brussels, BEL, 105–112. <https://doi.org/10.4108/icst.pervasivehealth.2013.252024>
- [39] Maryam Peimani, Ensieh Nasli-Esfahani, and Roya Sadeghi. 2020. Patients' perceptions of patient-provider communication and diabetes care: A systematic review of quantitative and qualitative studies. , 3–22 pages. <https://doi.org/10.1177/1742395318782378>
- [40] Leonhard Quintero Garzón, Susan Koranyi, Dorit Engelmänn, Rebecca Philipp, Katharina Scheffold, Frank Schulz-Kindermann, Martin Härter, and Anja Mehnert. 2018. Perceived doctor-patient relationship and its association with demoralization in patients with advanced cancer. *Psycho-Oncology* 27, 11 (nov 2018), 2587–2593. <https://doi.org/10.1002/pon.4823>
- [41] Shriti Raj, Mark W. Newman, Joyce M. Lee, and Mark S. Ackerman. 2017. Understanding Individual and Collaborative Problem-Solving with Patient-Generated Data: Challenges and Opportunities. *Proc. ACM Hum.-Comput. Interact.* 1, CSCW, Article 88 (Dec. 2017), 18 pages. <https://doi.org/10.1145/3134723>
- [42] Fateme Rajabiyazdi, Charles Perin, Jo Vermeulen, Haley MacLeod, Diane Gromala, and Sheelagh Carpendale. 2017. Differences That Matter: In-Clinic Communication Challenges. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare (Barcelona, Spain) (PervasiveHealth '17)*. Association for Computing Machinery, New York, NY, USA, 251–260. <https://doi.org/10.1145/3154862.3154885>
- [43] Cornelia M. Ruland, Harald H. Holte, Jo Røislien, Cathy Heaven, Glenys A. Hamilton, Jørn Kristiansen, Heidi Sandbæk, Stein O. Kvaløy, Line Hasund, and Misoo C. Ellison. 2010. Effects of a computer-supported interactive tailored patient assessment tool on patient care, symptom distress, and patients' need for symptom management support: A randomized clinical trial. *Journal of the American Medical Informatics Association* 17, 4 (jul 2010), 403–410. <https://doi.org/10.1136/jamia.2010.005660>
- [44] Lyndsey Runaas, David Hanauer, Molly Maher, Evan Bischoff, Alex Fauer, Tiffany Hoang, Anna Munaco, Roshun Sankaran, Rahael Gupta, Sajjad Seyedsalehi, et al. 2017. BMT roadmap: a user-centered design health information technology tool to promote patient-centered care in pediatric hematopoietic cell transplantation. *Biology of Blood and Marrow Transplantation* 23, 5 (2017), 813–819.
- [45] Myeonghan Ryu, Eunkyung Jo, and Sung-In Kim. 2017. COSMA: Cooperative Self-Management Tool for Adolescents with Autism. In *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility* (Baltimore, Maryland, USA) (ASSETS '17). Association for Computing Machinery, New York, NY, USA, 409–410. <https://doi.org/10.1145/3132525.3134825>
- [46] Elizabeth Salt, Graham D Rowles, and Deborah B Reed. 2012. Patient's perception of quality patient-provider communication. *Orthopaedic Nursing* 31, 3 (2012), 169–176.
- [47] D Shaligram, SC Girimaji, and SK Chaturvedi. 2007. Psychological problems and quality of life in children with thalassemia. *The Indian Journal of Pediatrics* 74, 8 (2007), 727–730.
- [48] Jonathan Silverman, Suzanne Kurtz, and Juliet Draper. 2016. *Skills for communicating with patients*. crc press.
- [49] Anselm Strauss and Juliet M Corbin. 1997. *Grounded theory in practice*. Sage.
- [50] K. Bates and L. Meeuwesen. 2001. Doctor-parent-child communication. A (re)view of the literature. , 839–851 pages. [https://doi.org/10.1016/S0277-9536\(00\)00193-3](https://doi.org/10.1016/S0277-9536(00)00193-3)
- [51] Sarah J Tracy. 2010. Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative inquiry* 16, 10 (2010), 837–851.
- [52] Marleen Van Bergeijk, Bart Hengeveld, and Selma Otto. 2017. DOK: Enhancing child patient empowerment. In *TEI 2017 - Proceedings of the 11th International Conference on Tangible, Embedded, and Embodied Interaction*. Association for Computing Machinery, Inc, New York, New York, USA, 589–595. <https://doi.org/10.1145/3024969.3025066>
- [53] Laura Pfeifer Vardoulakis, Amy K. Karlson, Dan Morris, Greg Smith, Justin Gatewood, and Desney S. Tan. 2012. Using mobile phones to present medical information to hospital patients. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM Press, New York, New York, USA, 1411–1420. <https://doi.org/10.1145/2207676.2208601>
- [54] Henry N. Young, Maria E. Len-Rios, Roger Brown, Megan M. Moreno, and Elizabeth Cox. 2017. How does patient-provider communication influence adherence to asthma medications? *Patient Education and Counseling* 100, 4 (apr 2017), 696–702. <https://doi.org/10.1016/j.pec.2016.11.022>
- [55] R. Zachariae, C. G. Pedersen, A. B. Jensen, E. Ehrnrooth, P. B. Rossen, and H. Von Der Maase. 2003. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *British Journal of Cancer* 88, 5 (mar 2003), 658–665. <https://doi.org/10.1038/sj.bjc.6600798>
- [56] Xiaomu Zhou, Mark S. Ackerman, and Kai Zheng. 2010. Doctors and psychosocial information: Records and reuse in inpatient care. In *Conference on Human Factors in Computing Systems - Proceedings*, Vol. 3. ACM Press, New York, New York, USA, 1767–1776. <https://doi.org/10.1145/1753326.1753592>