Challenges in the Parent-Child Communication of Health-related Information in Pediatric Cancer Care

WOOSUK SEO, University of Michigan, USA
AYSE G. BUYUKTUR, University of Michigan, USA
SUNG WON CHOI, University of Michigan, USA
LAURA SEDIG, University of Michigan, USA
SUN YOUNG PARK, University of Michigan, USA

Previous works have shown that effective communication between parental caregivers and child patients has many benefits to the children, such as providing emotional support and coping skills for health management. Drawing on semi-structured interviews, we have identified the challenges parental caregivers face when communicating with their children about health-related information in daily illness management. Three salient challenges that the parental caregivers encountered include: (i) acknowledging different perceptions and approaches to being a cancer patient, (ii) choosing an appropriate communication method, and (iii) understanding their child's uncommunicated emotions. Based on these challenges, we recognize distinctive, yet implicit, needs that children develop during the illness trajectory, affecting the parent-child dyadic relationship. We discuss design opportunities for a collaborative system that enhances the parent-child dyadic communication by supporting the child's implicit and dynamically changing needs throughout the illness trajectory and beyond.

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

Additional Key Words and Phrases: Parents, child patients, communication, challenge, health, pediatric care

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1 INTRODUCTION

Effective communication with child patients is important to promoting better health outcomes for them. Prior studies in the medical literature emphasize the benefits of effective communication, such as a positive impact on the children's emotional wellbeing and psychological outcomes [3], and coping skills for illness and treatment [9]. Moreover, appropriate communication encourages the child's active involvement in their own healthcare, which can improve their self-confidence and self-management skills [8].

Despite these benefits, it is challenging to achieve effective communication with child patients because of their insufficient communication skills and limited knowledge of illness. Communication

Authors' addresses: Woosuk Seo, University of Michigan, Ann Arbor, USA, seow@umich.edu; Ayse G. Buyuktur, University of Michigan, Ann Arbor, USA, abuyuktu@umich.edu; Sung Won Choi, University of Michigan, Ann Arbor, USA, sungchoi@med.umich.edu; Laura Sedig, University of Michigan, Ann Arbor, USA, lsedig@med.umich.edu; Sun Young Park, University of Michigan, Ann Arbor, USA, sunypark@umich.edu.

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with them about their illness and its treatment is more sensitive and complex than it is with adults [11, 29]. Healthcare providers and caregivers require more time and effort to deliver medical information, identify the patients' needs, and provide proper support. Consequently, the effective communication with child patients frequently fails, negatively affecting their experiences with treatment.

To facilitate child patients' communication and care participation, the role of parental caregivers is essential. In addition to the healthcare providers who engage the children during clinic consultations, parents have the primary responsibility of sharing information with their sick child; their duties include translating illness and treatment-related information into appropriate language the child can understand, teaching health management skills, and providing emotional support [47, 48]. Healthcare providers and organizations strongly encourage parents in this crucial role to have open communications with their children. For instance, the National Cancer Institute offers caregiving guidelines for child patients of different ages and urges parental caregivers to have open and informative communications in age-appropriate ways [2]. However, such guidelines usually give generalized instructions such as "be prepared to answer the child's questions" [2] and do not adequately provide details of how parental caregivers should act when communication problems occur or how to make communication more informative or effective.

In the HCI and CSCW communities, prior studies have explored communication practices and interactions between parents and child patients [14, 15, 26, 30, 43]. These studies have presented design implications and technological interventions to support the parent-child collaboration in health management, such as tracking blood sugar for diabetes patients [43], monitoring asthma symptoms [30], or documenting medication and treatment related activities [14]. However, so far little is known about the fundamental communication challenges between parents and children about how they view, feel, and understand regarding illness and treatment in the broader context of pediatric care. Additionally, there has been less of a focus on the bi-directional relationship between parents and children, while communication with child patients has been mostly thought of as part of the caregiving task of addressing patient needs (e.g., translating and delivering information) in prior studies. Thus, a more in-depth understanding of the communication practices between parents and children is needed to inform the design of health systems that can help parent-child pairs overcome their fundamental communication challenges in the broader, everyday health management context.

Our study specifically focuses on gaining a better understanding of current parent-child communication practices in pediatric cancer care. We aim to answer the following research questions:

- What are the challenges and strategies in the communication about health-related information between parental caregivers and child patients in daily illness management?
- How can technology help parental caregivers and child patients enhance their communication about health-related information?

Drawing on semi-structured interviews with 52 participants (24 parent-child pairs and 4 healthcare providers), we report on three salient communication challenges that the parents faced: (i) acknowledging different perceptions and approaches to being a cancer patient, (ii) choosing an appropriate communication method, and (iii) understanding their child's uncommunicated emotions. Based on our analysis, we expand our prior knowledge on the roles of parental caregivers in communication with child patients and present the communication gaps that make it difficult to identify the child patients' implicit and dynamically shifting needs. We then outline opportunities for a collaborative system to enhance the parent-child dyadic communication and daily illness management. Aligning with prior studies on parent-child interactions in pediatric care, our study

makes contributions to CSCW community; we articulate the challenges in parent-child communication which have been under-examined and present possible directions for health communication technology to support addressing those challenges.

2 RELATED WORK

2.1 Impacts of and Barriers to Parent-Child Communication in Pediatric Care

The impact of parent-child communication on children's illness and health outcomes is well noted in medical and psychological literatures. The literatures emphasize the importance of the parental caregivers' open communication with their children [21], and present six characteristics of effective communication: completeness, truthfulness, consistency, comprehensibility, continuity, and personalization [3]. Based on these criteria, studies have shown the various benefits of having effective and transparent communication with child patients, including better health outcomes [37], positive emotional and psychological outcomes [3], and improved illness management coping skills [9].

Despite these benefits, there are also barriers that hinder the constructive communication between parental caregivers and their children. In particular, multiple psychological or emotional factors affecting caregivers, such as depressive symptoms [17, 35], posttraumatic stress [28], and their perception of their child's emotion of delivered information [9], have been reported. These factors influence the parents' information-sharing behaviors, often negatively, impacting what they share or hide from their children and how they choose to describe illness and treatment. A recent study found that a major obstacle to parent-child communication in the childhood cancer context is the desire of both parents and children to protect each other from the pain associated with discussions of treatment and its risks [38].

The role of parental caregivers in their child's health management is significant, as parents take on the primary responsibility of managing and coordinating all the caregiving tasks as well as communicating the information related to their child's health between healthcare providers and the child. How and what information parents share with their child, i.e., parent's communication style, is critical to ensure the identification of the child's needs and how to provide the necessary support accordingly. In particular, certain communication styles can have a negative impact and cause the child distress. Cline et al.,[10] identified four distinct communication patterns parental caregivers have when communicating with their child during clinic visits: normalizing, supporting, distancing, and invalidating. Among these, invalidation (e.g., lying about what has occurred or is about to occur, responding with anger or irritation) caused significantly more distress for the children than any other communication pattern. On the other hand, offering a full disclosure of information about the illness helped the children be better prepared for coping with their diagnosis [9, 10].

While parent-child communication in pediatric care has been extensively studied in medical literature, most of these studies either highlight the benefits of effective communication or individual communication styles that affect the quality of the communication of health information, by focusing on clinical implications (e.g., guideline development for clinical consultations). Apart from the individual and psychological factors on communication styles, little is known about when and how parental caregivers and child patients have communication challenges during which they fail to share health-related information. Further research is necessary to understand the potential gaps, barriers, and challenges to parent-child communication about illness and treatment, beyond interpersonal communication skills and patterns.

2.2 Technology for Caregivers and Patients in Pediatric Care

Along with a growing interest in health information technology, a large body of HCI and CSCW literature has explored parent-child interactions in the health management of more common chronic illnesses, such as cancer [14, 15], diabetes [43], asthma [30], and autism [26]. Some recent studies presented how technology can support parent-child communication and collaboration in health management. For example, a health monitoring technology can share a child's glucose levels with their parents [43], a system supports teens partnering with parents for long term treatment [15], and a collaborative child development tracking system allows parents to evaluate their child's development [39]. These interventions presented opportunities for technology to promote collaborative health management between parents and children. In addition, some studies developed tools to support caregivers' (e.g., parents, clinicians) communication with child patients during clinic visits, such as a tangible conversation tool that allows children to actively participate in clinic consultations (e.g., selecting a "token" for topics the child wants to discuss) [5], and an illustration tool that helps children describe their symptoms to clinicians [16].

While these technical interventions help facilitate the monitoring of children's health information and provide child-friendly tools that support communication with child patients, they do not always address the communication issues, such as having different viewpoints, preferences, and expectations regarding the illness or its treatment, that parents and children frequently have when discussing health-related information. There is a necessity for technology to enhance parent-child communication in daily illness management because illness has emotional, social, and psychological influences on a child, as well as physical symptoms. Little is known about how technology can intervene to support parent-child health-related communication in the broader context beyond either health data tracking/monitoring or the clinical setting. Building on this line of work in the CSCW literature, our study aims to extend our understanding of the communication challenges between parents and children and seek opportunities for technology to address them and to promote more effective communication.

3 METHOD

In this paper, we report and discuss findings from an interview study with 24 pairs of parental caregivers and pediatric cancer patients and 4 healthcare providers conducted in an outpatient oncology clinic in a large urban hospital in the U.S. This work is part of a larger study to identify ways for pediatric patients to increase engagement in their care and to promote effective child-parent-provider interactions in the pediatric care context. This study was reviewed and approved by our university's Institutional Review Board (IRB).

3.1 Participants

We interviewed a total of 52 individuals, including parental caregivers, child patients, and healthcare providers. The 24 child patients ranged in age from 6-12 with an equal number of boys and girls; 16 were between the ages of 6-8, and 8 were between the ages of 9-12. The parent participants included 16 mothers, 4 fathers, 3 couples (both parents), and 1 grandmother who was taking on the parenting role (See Table 1). All parental caregivers were in their 30's or 40's, except one who was a grandparent. The 4 healthcare providers consisted of 2 physicians and 2 nurses (See Table 2). In the paper, we have labeled parental caregivers with "CG", child patients with "P", and healthcare providers with "H". In some cases, both parents were willing to participate in the interview. In these cases, we treated both parents as one unit and interviewed them together. Our study participants were recruited using flyers at the clinic or by the research team in the clinic, and participants

Participant	*Relationship*	*Job Type*	*Occupation*	*Patient Age*	*Patient Gender*
CG1	Mother	Not working	Homemaker	6	M
CG2	Mother	Full-time	Contractor	8	M
CG3	Mother	Full-time	N/A*	9	M
CG4	Mother	Not working	Homemaker	6	M
CG5	Mother	Not working	Homemaker	10	M
CG6	Mother	Full-time	Elementary school teacher	7	F
CG7	Mother	Full-time	Physical therapist	7	F
CG8	Parents	Full-time	N/A*	6	M
CG9	Father	Full-time	Tradesman	9	M
CG10	Mother	Full-time	Property Manager	12	M
CG11	Parents	Full-time	F:Veterinarian, M:Homemaker	12	M
CG12	Mother	Part-time	N/A *	9	M
CG13	Father	Not working	Veteran	6	F
CG14	Grandmother**	Full-time	N/A *	6	M
CG15	Father	Full-time	Casino Housekeeper	7	M
CG16	Mother	Full-time	Nurse practitioner in training	10	F
CG17	Mother	Not working	Homemaker	6	F
CG18	Parents	Full-time	N/A*	6	F
CG19	Mother	Full-time	Counsellor at a college	8	F
CG20	Father	Full-time	Psychologist	8	F
CG21	Mother	Not working	Homemaker	11	F
CG22	Mother	Full-time	N/A *	6	F
CG23	Mother	Not working	Homemaker	6	F
CG24	Mother	Full-time	Magazine editor	8	F

Table 1. Demographic information of the caregiver participants and their child. ∗ *Some parents did not specify their occupations* ∗∗*P14 lives with his grandmother (CG14) only. Thus, we considered CG14 as a parental caregiver since she takes on the parenting role too.*

were compensated with a $20 gift card for their time. One patient (P9) refused to participate in an interview, but made comments while his parental caregivers (CG9) were being interviewed.

Study volunteers were considered eligible for the study if the child patient met the following criteria: between 6 and 12 years of age and diagnosed with cancer for at least two months. These requirements allowed us to interact with children who had already started the treatment process and required ample external care at the hospital or their home due to their young age. Initially, we identified more than 50 eligible pairs; however, only half agreed to take part in our study for various unexpected reasons (e.g., unknown personal reasons, the child's weak condition), a sudden schedule change based on their lab test results (e.g., being admitted to the hospital), or time constraints (e.g., having to drive their child back to school after their clinic visit). We followed our university's IRB requirements for obtaining child assent and parent consent for interviews; we obtained verbal assent from the child patients who were younger than 8 years old and written assent from those aged 8 or older. The caregivers provided written consent on behalf of their children as well as for their own participation. The informed consent and assent processes are standard for research in pediatric settings in the U.S.

Participant	*Gender*	*Occupation*	*Years in Practice*
H1	Female	Nurse practitioner	42 years
H2	Male	Fellow physician	5 years
H3	Female	Nurse	5.5 years
H4	Female	Attending physician	10 years

Table 2. Demographic information of the healthcare providers.

3.2 Semi-structured Interviews

We conducted semi-structured interviews with parent and child pairs. Since we wanted to examine each individual's own treatment-related experiences and perspectives on illness, we interviewed the parent and child separately to give them a chance to reflect on their own and truthfully respond to the questions. We tried to ensure that the child patients' voices were heard by asking them questions directly. While each pair answered the questions separately, they were still co-present in the same clinic area or room given the child patients' young ages. To help participants feel more comfortable, we let the parent-child pairs choose who would be interviewed first. In most cases, the parent interviews were done first so that the children could feel more comfortable by watching their parents participate in the interview. When the parent participated in the interview prior to the child, we had the child watch a video or play a game while wearing headphones, so that the child would not hear what the parent was saying (this was also the case when parents did their interview after the child, so that the parent could speak more comfortably without worrying about their child to hear what they would say). For a couple of younger children who were 6 years old and needed parental help to understand the interview questions, the parents assisted with interpreting. Though it might be possible that the child and parent still influenced each other's answers, we did not find a significant impact of the interview order on our data collection.

The interviews with each pair, lasting about an hour, were held in a consultation room or an infusion unit in the clinic. The parents' interview included a set of questions focusing on their current communication practices, such as health-related information sharing and their daily routine, challenges, and strategies. For the children's interview, we provided, along with verbal prompts, a set of questions that involved circling images, checking boxes, and drawing simple things to help each child express their feelings or ideas. The questions focused on the children's understanding of and feelings toward their illness and treatment, and their perceptions of the illness's impact on their lives (e.g., if their social relationships with peers had changed after diagnosis) based on the questionnaires from the Patient-Reported Outcomes Measurement Information System (PROMIS)[1]. The language used in the questions was revised with help of two child psychologists to ensure child-age appropriateness. The children's answers were analyzed along with the interview transcripts. The interview questions for providers included their current communication practice with child patients during clinical consultations, challenges and expectations regarding the children's engagement in the care process.

3.3 Data Analysis

Three members from the study team individually coded the first three interview transcripts. Based on this analysis, we assembled an affinity diagram [7] to identify recurring themes, and similarities or differences between the parents and children's perspectives. We identified different communication styles and challenges that the parents and children had during the course of treatment (e.g., how parents described medical concepts and how the children reacted to these explanations). This helped us focus on the specific themes related to parent-child communication about illness and

treatment when we coded the rest of the interview transcripts. During this process, the study team met regularly to discuss the emerging themes regarding the communication practices between parents and children, such as communication methods, preferences, and conversation topics. The themes produced by each researcher were compared, discussed and revised through a series of discussions until agreements were reached. Then, the study team used axial coding to identify any relationships between themes [40]. In addition to the interview data, we analyzed the data from the questionnaires used in the child patient interviews. By comparing the answers from patients and parents to the questionnaires, we triangulated the data related to parent-child communication about illness and treatment to identify difference in their perceptions. In this paper, we report on our findings regarding the communication gaps and challenges between parental caregivers and child patients in the pediatric cancer care context. We would like to note that some quotes in this paper describe the subjective experience of cancer patients which may be sensitive and trigger emotional responses in readers.

4 THE MEDICAL CONTEXT OF THE STUDY

This study involves child patients who have undergone either chemotherapy or a bone marrow transplant (BMT) for blood cancer or a blood disorder. BMT is a treatment that consists of a high dose of chemotherapy and an infusion of stem cells that produces new blood cells. Both chemotherapy and BMT have side effects and potential complications, including a weakened immune system. BMT patients often take medications that suppress their immune system for many months or even years partly to prevent a common complication known as graft-versus-host disease (GVHD). This complication occurs when donor cells recognize the patient's body as foreign and attack it. Because multiple organ systems can be affected by GVHD and the symptoms range from mild to fatal, it is essential to closely monitor the patient's status at home and other places such as school, as well as during clinic visits. In addition, some complications may occur – or reoccur– even months or years after the patient has had chemotherapy or a BMT. Given the risk of serious and potentially life-threatening complications, management of the illness is a big part of the caregivers and patients' daily lives. In pediatric care, most of this work is currently done by parental caregivers. Parents have to communicate with their child about the child's symptoms and feelings and educate them about medical concepts and procedures. Child patients may also develop distress or anxiety from managing their illness as their daily lives have significantly changed (e.g., restrictions on outdoor activities for potential infection risk). In the next section, we present when parental caregivers faced challenges communicating with their child about health-related information in daily illness management.

5 FINDINGS

Our findings revealed three challenges that parental caregivers faced in their communication with their children about the child's cancer and its management: (1) differing perspectives toward living with cancer, (2) choosing appropriate communication methods, and (3) the lack of communication on the child's emotion. These challenges were often not immediately apparent, but rather manifested over time as the parents and children developed their own preferences and communication strategies during the course of the illness. In this section, we describe how parents faced each challenge which could potentially result in their child's misunderstanding, disagreement or resistance to their approach towards the communication of health-related information in daily illness management. In this paper, parent-child communication is specific to health-related information, such as treatment and illness management.

5.1 Different Perceptions and Approaches to Being a Cancer Patient

We found that parental caregivers and their children frequently had different perceptions about what it meant to be a cancer patient. For the parents, living with a child with cancer was a state of endless anxiety. After their child's cancer diagnosis, parents had to immediately add caregiving responsibilities to their parenting, and would usually treat their child as a "patient" who needed careful monitoring, attention, and care. Even when their children were making good progress in their recovery, all of the parents in the study were still worried about their prognosis (e.g., reoccurrence of cancer) or the potential long-term side effects of treatment (e.g., weakened immune system). Such concerns often caused parents to see their children as patients who could become sick again at any time.

Because of concern about living with a serious illness with huge uncertainty, parents tried to communicate to their children about self-management skills, health behaviors, and limitations/restrictions in their daily lives in order to mitigate the risks. This was particularly true of parents whose children were first diagnosed and treated at a very young age because the children usually could not remember their cancer experience nor understand the importance of health management. For instance, when P8 (age 6) was diagnosed with cancer at the age of one, CG8 thought she would lose her son. This made CG8 fearful and she remained concerned that P8 could become sick again. This prompted her to establish a strict health management protocol for P8 and frequently remind him that he had been sick, so that he would learn to take care of himself. CG8 repeatedly warned him to be careful about infection:

> *I just say, if it's ... being around, can't be around people who are sick. Say, "Remember when you were a baby, you were really sick, and your body doesn't fight germies like it's supposed to. So, we need to be careful." This is how I explain it to him.* – CG8 (Mom)

Similar to CG8, many parents were strongly affected by their children's initial diagnosis and experience, which framed their perspectives on how to care for them even after the children had gone into remission.

On the other hand, the children who were diagnosed at a young age often had a different perspective than their parents as they did not fully understand the anxiety that their parents were feeling. Although the children knew that they had been sick or at least understood that they were different from their peers, they were often not aware of or did not fully recognize the limitations to their daily activities. They also did not realize the importance of maintaining their health, since they were too young at the time of their diagnosis to comprehend death or the serious side effects and long-term consequences of their treatments. The children tended to consider themselves as unexceptional and healthy as their friends, especially once they entered the post-treatment stage where they only went for regular check-ups and returned to school and socializing with their friends. This perception was especially common among those who were diagnosed at a very young age (age 1-4), as they believed their experiences were the same as others: "*At his age of 4, he [P2] assumed that everybody had hair loss and everybody had moon face and everybody had hospital stays and ports*" – CG2 (Mom)

This gap between the parents and children's understandings of life with illness led to conflict or reluctance on the part of the child to follow care protocols and health advice. P17 (age 6) and CG17, for instance, often disagreed when discussing P17's health protocols,

> *She couldn't do sit-ups. She had two major abdominal surgeries. So, I was like, "You can't do it the same." I told her to cheat. To fold up her legs. But, she couldn't embarrass her in front of her friends. (...) She can't physically do a sit-up. I don't think she got it. I wasn't doing it to be mean… Well, she then would have these emotional outbursts and get angry and say, "I'm not going to school anymore!"* – CG17 (Mom)

As this quote shows, P17 did not have a good understanding of her surgeries related to her illness, nor did she know what was physically doable in her condition. While her attempts to do sit ups with her peers caused CG17 concern about the potential harm to her body, P17 didn't understand CG17's intentions and didn't want to follow her advice.

The difference between the parents and children's perspectives was also observed by healthcare providers, particularly after the children started school, or resumed their schooling after treatment. The children placed more value on maintaining their activities and relationships with peers than managing their illness. One physician pointed out how child patients often perceive health management and living as a patient differently from adults (e.g., their caregivers):

> *I think children approach their health very differently than adults do. What I see in pediatric patients is that kind of despite a diagnosis with cancer, they're still trying to do the things that their peers are doing. And so, there's less kind of wallowing in their diagnosis or their symptoms, they're still trying to pick themselves up and play, and go to school, and do things. They don't do things like that for their health. They don't really control what they eat, right? Their parents give them [food or medication]. It's more that they're trying to maintain their pre-diagnosis activities as best as they can.* – H4 (Attending Physician)

This observation aligns with our finding; although the children would gain more knowledge about managing their health over time, their focus remained on maintaining the activities and daily routines that they had had before they became sick. Thus, even though the parental caregivers repeatedly articulated health management concerns, many children needed more time and experience to understand these concerns and change their perceptions and approaches to health management.

5.1.1 Caregiver's Communication Strategy. To help their children understand the need to maintain their health, a few parents used artifacts to record the treatment process, such as a series of pictures taken from the time the child was first diagnosed (CG8, CG9). These artifacts served as evidence and reminders of the child's experience with cancer. Using these artifacts, parents could share their captured memories of the painful treatment that their child had endured. This helped the child to remember or better understand that they had a serious illness when they were younger:

> *We had put together books as we went through it, like pictures. (…) Because we spent all of his first holidays, birthdays, all that stuff ... So, it's all documented. And he'll sit down and look through it, look at the baby pictures of what he went through. (…) He has all these storybooks and he tells people about it. They ask him what that's from; he's like "Oh, that's from when I had cancer."* – CG8 (Dad)

Rather than just telling their children that they had been sick, using pictures or records facilitated the parents' communication about why the children should be careful about their health and why they have certain limitations to their daily activities.

The other strategy that some parents used was to allow their child to experience their own limitations in order to learn from the experience. Instead of forcing them to follow directions, these parents let their child do what they wanted, as long as it was not too risky, and learn how to live not being able to do all the things that healthy children can do. For instance, P6 (age 7) had had motor integration issues, which makes difficult for any bilateral movement that requires to use left and right sides of the body at the same time or alternatively, since her treatment at the age of 2. Instead of telling what to do or not do, CG6 allowed P6 to determine the restrictions to her own activities:

> *She [P6] is very careful with everything she does. She thinks things through and makes decisions based on if she feels comfortable, then avoids.* – CG6 (Mom)

Since CG6 trusted P6's judgement, CG6 let P6 do anything she wanted under CG6's supervision. When they experienced difficulties firsthand, patients could understand the intentions behind their parents' health management rules. Nevertheless, we found that many caregivers enforced health management so that they could not only ensure their child's physical health but also alleviate their own anxieties.

5.2 Choosing Appropriate Methods to Explain Illness and Treatment

The next communication challenge parents faced was choosing how to deliver health-related information effectively. In our study, parents primarily used two different methods to deliver health information: 1) translating the information into highly simplified language and concepts, or 2) directly communicating the information in its complicated medical form. The parents used these methods interchangeably based on the situation and the complexity of information delivered. Simple language was often used to help children understand difficult concepts or to reduce the negative meaning and fear by using analogies and more common, neutral vocabulary (e.g., "sickness in blood" instead of "cancer" (CG12)). Using simpler vocabulary, the parents were able to provide sufficient information without making their child anxious or overwhelmed. Nearly all the parents believed that this method was the more appropriate way to communicate with their sick child. Although we found that parents differed in their level of abstracting information according to their own familiarity and experience with medical concepts, the parents were still unsure of whether their word choices or analogies had been effective as they had expected.

Sometimes, however, parents would still use the more complicated medical terminology to deliver information about cancer and its treatment to their child. Most notably, when they could not find better ways to explain the medical concepts in age-appropriate language but wanted to keep the translation accurate and consistent, parents used the same medical terms that the physicians used during consultations. In these cases, parents believed that using the complex terms would be more effective than using incorrect or inappropriate analogies to relay the medical information. For instance, CG22 shared her concerns about accidentally using inappropriate analogies to describe her daughter's treatment because it could confuse P22 (age 6) if reality turned out to be different than P22' expectations:

> *Because if I start sugar coating things and giving them new names, I feel like it might confuse her. And I don't want to do that. I don't want her to be thinking "Oh, why is there a butterfly on my chest?" Or something like that, when it's not. It's a needle. It is what it is. So, I want her to understand exactly what it is and why it's there. I don't want to change things because it's not what it is. So, I just try to tell her exactly what's happening, and I tell her why it's happening, why it's important (. . .) and I'm just straightforward like that, but she's always been really accepting like that.* – CG22 (Mom)

CG22 preferred to use medical terminology even if it scared her child, instead of misleading analogies which could distort the meaning of the medical procedure (e.g., a needle being inserted into a port is not a butterfly on the patient's chest, even though the needle has the shape of a butterfly).

With parents using simple language and complex medical terminology interchangeably to communicate illness- and treatment-related information, the inconsistency in the parents' communication method led some children to feel that method was improper. It sometimes led to mistrust or dissatisfaction, because when and how such methods were used by parents did not match with the children's expectation. When complex medical terms were used, children were sometimes overwhelmed and did not engage in the conversation due to its difficulty, particularly when the children did not have sufficient understanding or experience in the earlier stages of their treatment.

For example, CG12 observed her son's reluctance to speak during a clinic consultation in which she and a physician were going over diagnostic information using medical terms. When P12 was asked about his comprehension, he answered, *"I don't know"* or *"I don't want to hear this"*. Another parent (CG2) who usually used medical terminology such as "platelets", "white blood cells", and "bone marrow transplant" said she later realized that P2 had not developed an understanding of medical concepts as P2 never asked any questions. In fact, we found that most of the patients in our study had never been asked by their parental caregivers whether they understood the things they were being told. Hence, although using medical terms may be effective to correctly convey information about illness, it was not, at times, effective for the children to understand. Instead, it often led to the child's disengagement or discouraged them from learning more about their illness.

Interestingly, some children also felt uncomfortable with the easier and simplified terms and analogies. Even though they could understand this information, they considered the language somewhat misleading or manipulative, as though people were talking down to, or even tricking, them. This held especially true for those who gained more knowledge of and experience with treatment over time. For instance, while CG7 tried to use age-appropriate language to explain cancer and its treatment to P7 (age 7), P7 did not want to be treated like a little kid:

> *We [CG7 and husband] pretty much tell her [P7] everything on an age appropriate level. But she [P7] does not like to be talked to like she's a little kid. If you go to a regular doctor and you go to get blood pressure, and they're like, 'It's just going to give your arm a little hug.' And she's like, 'No, it's not!'. She doesn't like it when they try to... she thinks they're tricking her. They're not being honest.* – CG7 (Mom)

In this example, P7 had already experienced having her blood pressure taken and knew that it was not a 'hug' for her arm as she was told. She experienced this explanation as deceptive as though her doctors or parents were trying to trick her into getting treatment or a medical exam. Her reaction and expectation did not align with CG7's intention to alleviate P7's anxiety.

This variability in the parents and children's preferences for communicating health-related information was also observed by healthcare providers. A physician described the difference between younger and older patients:

> *One of the other challenges is that in that elementary school middle school age group it's highly variable between parents of what they want their child to know, and how they want them to find out the information (…) I think that kids will often change because they're both getting older, and getting more used to what we're doing simultaneously. As they get older, even when they're off therapy, start to worry a lot more about prognosis, and things coming back, and things that they didn't worry about when they were five, and on treatment, or six and on treatment, but now they're eight, or nine, and they're recognizing what cancer really is, and that people can get sick from it, or they have met other people who have relapsed, or who have died from their cancer, and then they start to worry more about big picture issues.* – H4 (Attending Physician)

While this physician observed that parents and children have different preferences for what information the children have and how it is provided, she also pointed out that the children's reactions to information changed as they grew older. As the physician noted, the children began to comprehend the seriousness of cancer and the risk of death as they got older. In the interview, she added that a cancer diagnosis causes children to mature more quickly. This suggests that even young children may have expectations for communication about illness and treatment that parents may not readily recognize.

5.2.1 Caregiver's Communication Strategy. To better communicate and help children understand their diagnosis and treatment, some parents proactively tried to identify the communication preferences of their children. Parents tried to carefully adjust their communication by observing their child's reactions and seeing which method their child valued and preferred. For instance, when CG18 first explained cancer to P18 by using medical terminology, he carefully waited for P18's reactions:

> *I'd try to explain it in like, the medical term and if she [P18] seems like she's confused, I try to just relate it to something like school or you know, something along those lines, numbers, stuff like that.* – CG18 (Dad)

By using medical terms to communicate with his daughter, CG18 maintained consistency, thereby improving accuracy of medical concepts. Based on how P18 responded, he also adjusted his communication method when necessary to use references to which P18 as a child could easily relate. Similar to CG18, a few parents in the study gave their children time to think about the information they received and to be curious about the illness and treatment so that they would not be overwhelmed or confused, and then explained things accordingly.

The reactions of the children also helped caregivers identify which communication method the children valued and preferred. For example, based on P24's reactions to the simpler language, CG24 realized that trust is particularly important to her:

> *We [CG24 and husband] realized really quickly, that her anxiety is best relieved by trusting that we're going to tell her the truth and what's going to happen with pokes and things like that. If she asks, 'Am I going to get a poke?', we don't say, 'No, it's not going to hurt.' Because if you tell her that one time, and it does, trust is gone.* – CG24 (Mom)

In her interview, CG24 explained that she initially used age-appropriate, softer language to make the medical concepts easier and more approachable for P24; however, once she realized that P24 valued trust above all else in communicating treatment procedures, she quickly adjusted her communication method to match what P24 valued (i.e., building trust). Although some parents proactively tried various strategies to identify their child's communication preference, like observing reactions of the child or utilizing the child's preferred activities to help deliver information in a more engaging way, not all the parents in our study were able to notice issues. Some in fact did not feel the need to identify their child's preferred method because the child had grown up with the illness from a very young age (e.g., CG2), or they had an insufficient or hard time gauging which method might work best. These parents largely assumed that their children would eventually come to understand their illness without them having to consider potential communication issues.

In conclusion, as the children became more experienced cancer patients, they frequently realized that certain communication methods did not meet their expectations or needs, and the communication breakdowns became more noticeable; the children felt mistrust toward their parents, disengaged from their care, or became dissatisfied with their discussion about health. Despite the parents' efforts to adjust their communication methods accordingly, it was still often challenging to identify their child's preferred method or to recognize if there were any communication issues at all since many parents did not know how to gauge their child's comprehension ability.

5.3 Children's Uncommunicated Emotions

A third communication challenge the parents faced had to do with their child's lack of emotional communication. For the parents in our study, it was critical to understand the feelings of their child so that they could provide better emotional support, as cancer and its treatment are a long and tough process. In particular, chemotherapy, a common treatment for cancer, itself can affect hormones which can lead to emotional changes.

During interviews, the child participants expressed various feelings about their illness and treatment, ranging from the positive (e.g., hopeful, comfortable), to the neutral (e.g., I don't care, bored), to the negative (e.g., nervous, scared). However, we found that these emotions were not effectively communicated with their parents in everyday life. The younger patients (age 6-8) in the study who did not fully understand the illness in the earlier stages of the treatment process often believed that they had done something wrong, causing them to be sick. One patient (P19, age 8), for instance, believed for a fairly long time early in her treatment that swallowing gum had caused her cancer. These kinds of beliefs made the children feel guilty and consequently hide such feelings from others:

> *The first time she had cancer, she [P19] didn't tell us for the first four or five months and then she started crying one day and saying how sorry she was. And I'm like, 'Why are you sorry?' And she's like, 'Because I swallowed that piece of gum and that's why I have a tumor.' But never told us that she felt that way for a really long time. (…) We [CG19 and husband] had told her, 'This isn't your fault. We don't know why you're sick.' But she had internalized it that way and just doesn't tell us these big stressors that she's having. – CG19 (Mom)*

In this interview, CG19 explained that the fact that her child hid her guilty feeling for a long time made her feel shocked and constantly worried about her child's true feeling since she became to realize her misunderstanding about her child for the entire time since diagnosis. In addition, many children hid their emotions from their parents because they had a desire to be treated normally. The children believed that letting their parents know their genuine feelings about their health and illness would result in certain restrictions or disruptions to their daily activities, which would make them different from others. This withholding was more apparent with children who had sibling(s), since they wanted the same treatment from their parents that their siblings received (e.g., going to school or doing outdoor activities together). However, the deliberate or unintentional hiding of emotions, in addition to the children's insufficient vocabularies due their young age, made nearly all the parents in our study struggle to figure out what their children were actually feeling.

Moreover, it was still challenging for parents to communicate about their children's emotions even when their children shared them, because the ways the children expressed their feelings were often abstract. The children tended to use highly figurative language to describe their emotional states. These expressions often required parents to guess or do interpretation work over time. For example, we saw P16 use abstract words to express different feelings in interviews with both CG 16 and P16:

> *She [P16] spoke a lot about the "darkness", back in the fall and the darkness is just her way of saying, "I'm depressed" or "I'm sad." So, she was expressing a lot of feelings of darkness and sadness and depression.* – CG16(Mom)
>
> *"I get drunk" when my mind goes all fuzzy* – P16 (age 10)

As seen in the first quote, P16's mother noticed a certain word (i.e., darkness) used by P16 to refer to specific emotions. Through the repeated use of the word, she was able to interpret what P16 was trying to convey: P16 was feeling depressed. The second quote, "I get drunk" is used in a highly subjective and nuanced way to express P16's complicated feelings.

The children's other ways of expressing their feelings about their illness were also difficult for the parents to understand. While most of the children in our study talked to their family members, such as parents or siblings, some listened to their favorite music (e.g., P6, P21), cried or yelled (e.g., P2, P14), or drew and painted (e.g., P17, P23). These forms of expression without explanation were not always easy for the parents to notice or interpret. In addition, some parents, who themselves

already felt an extreme emotional burden following their child's initial diagnosis, did not have enough capacity to try to identify and understand their child's emotions. These parents were also afraid to talk about their own emotions because they did not want to burden their child, other family members, or themselves, as they felt everyone had enough to deal with already every day physically, emotionally, and mentally. One caregiver (CG3) stated that she did not want to talk about illness and treatment unless her son asked:

> *Not often [we talk about our emotion] I was just waiting for test results and it has consumed our lives for so long that we just try to let it go. Not let it revolve and control our whole life. I think it just makes it easier for me, easier for him [P3]. So, if he brings about it, we talk about it or else we don't.* – CG3 (Mom)

In line with the parents' experiences, healthcare providers observed the children's tendency to not share their emotions. However, providers also noticed the children's attitudes towards emotion sharing change over time:

> *I've seen patients that are very shy or just don't want to engage at the beginning and then later on are telling me more about their symptoms as they get more comfortable with situations over time. So, I've seen it go both ways (…) It's how they're processing the situation. Some kids just don't want to keep talking, they don't want to interact. Their way of dealing with situations is shutting down. Others need to be more... Start out in shock and then they need to be more engaged as a way of taking more control of the situation.* – H2 (Fellow)

As observed by this provider, how a child shares her/his feelings might change, depending on how the child processes her/his situation. Children hiding their emotions from their parents in the beginning and then having sudden emotional outbursts later on or vice versa could be a way how children manage the distress caused by their illness.

5.3.1 Caregiver's Communication Strategy. To overcome the difficulty of communicating illness-related emotions, we found that a few parents tried to use alternative ways to get their children to express their feelings. Some sought professional help from a counselor or art therapist, because they acknowledged their own limitations. For instance, CG16, whose child used specific words to express emotions (e.g., "darkness" for depression), utilized feedback from a counselor to confirm her understanding of P16's emotional state:

> *That [talking about emotions and managing depression] is not my specialty at all. I mean I'm happy to discuss with you [P16] and give you analogies and other stuff, but I don't know the best age- appropriate strategies for [talking about emotions] … I think it [meeting the counselor] is helpful because she [P16] opens herself up more – CG16(Mom)*

As seen in the quote, the trained counselor was helpful because she was able to help with CG16's interpretation of P16's emotions, and aid P16 in becoming more open up and express her feelings. Other parents also tried to use feedback from others, such as an older sibling or other family member who might have better communication skills or a closer relationship with the patient. In addition, other parents used proxies, such as toys, with which the children felt comfortable, to help them communicate their feelings. These parents had noticed that their children often talked to dolls (P6, P21) or stuffed animals (P7, P17) about their feelings related to illness and tried to encourage their children to open up by participating in activities or child play alongside them. For instance, CG21, who had worked in child care for a long time, intentionally played with dolls to communicate with P21 when she was first diagnosed at the age of 7:

> *We'd talk about that [illness and treatment] through play with dolls (…) Not Barbie dolls, but little smaller dolls. You just play with them in a dollhouse. We could talk about, "We'll*

> *pretend like it's a hospital setting. Let's pretend like she[the doll]'s in the hospital," so we could play what goes on in her life, but still play through play – CG21(Mom)*

Using dolls to start a conversation about illness and treatment allowed P21 to project her feelings through doll play and helped both CG21 and P21 talk comfortably without feeling overwhelmed by the conversation. With her previous work experience caring for children, CG21 could understand P21's emotions while she was playing with dolls. While these alternative methods were found to be useful, very few parents had the knowledge or professional background to successfully be able to use toys or play to understand their children's feelings.

In conclusion, the children's emotions related to illness and treatment may be intentionally hidden, appear as in various forms, or remain vague and unexplained to their parents, which at times caused communication breakdowns, such as confusion and misunderstandings. However, the children's emotions related to illness usually changed over time as treatment progressed. While some children were willing to express their emotions, it required extra effort and experience from the parents to notice and understand their child's individualized expression. Some parents used external support or child play, but most parents did not have these skills and continued to struggled with their children's emotional communication.

6 DISCUSSION

Our findings revealed three challenges to communication between parental caregivers and child patients: different perceptions toward living with an illness, a disconnect between the parents' expectations of and the children's preferences for different communication methods, and a discrepancy between the parents' understandings of their children's emotions and what the children actually feel. These challenges not only sometimes caused communication problems, but led the children to disengage from conversation as well as their care. Below, we elaborate on how these challenges occurred and how they can be addressed by unpacking the dyadic parent-child relationship at the nucleus of the communication. We also discuss how the dynamic nature of the child patients' needs made it challenging for parents to identify how and when to properly support their children. Finally, we discuss design opportunities that address these challenges for more effective collaborative illness management.

6.1 Supporting Child's Implicit Needs

Interpersonal communication is an ongoing process that involves mutually interactive activities within a dyadic relationship [6]. For effective communication, one needs to not only understand the verbal information expressed, but interpret the other person's original intent and non-verbal cues in order to address her/his needs and wants [6]. In the case of parent-child communication, existing in a dyadic relationship, a parent and a child share various attributes that help their communication effective, ranging from personal-level elements like the child's personality, interest, expression [46] and the child's emotional relationship to their parents [13], to family-level elements like family structure and culture [4]. These attributes are unique to every parent-child dyad and often enhance the ability of parents to facilitate and maintain communication with their child. The attributes enable parents to quickly discern the child's intent, interpret the meaning of what the child says and does, effectively respond to the child's reactions, and adjust their communication skills accordingly.

The nature of parent-child communication is also often affected by context. There are multiple dyadic relationships, such as a more authority-based relationship in the context of discipline, or a more friendly relationship during play, depending on the roles that the parents and children take [36]. In the context of pediatric care, our study has discovered changes in the relationship between parental caregivers and child patients because of the impact of cancer; when the child is diagnosed,

the debilitating illness brings significant changes to both since each comes to have different roles, perceptions, emotions, and expectations of the other throughout the course of the illness. The new needs of the child patients and their parental caregivers that were identified in our study relate to their perceptions of being a cancer patient (*perceptional needs*), their communication preferences for illness- and treatment-related information (*informational needs*), and their emotions towards having cancer (*emotional needs*).

Ideally, parents and children would be able to clearly communicate all their needs and collaboratively manage the illness. However, our study indicates that the perceptional, informational, and emotional needs that arise during treatment are usually only recognized over time or unexpectedly discovered when communication problems occur. This is because, despite some variations based on personality, maturity, and state of treatment, the children's young age makes their needs particularly imperceptible. Thus, their needs primarily manifest in unspoken ways, such as gestures, nuanced uses of language, and emotional behaviors. For instance, CG19 failed to recognize her daughter's true feelings (i.e., guilt for having caused her cancer by swallowing gum) by not being aware of it for more than six months. She then found out when the child was no longer able to hold the feelings in. Thus, when the new needs the child has developed are not recognized and properly addressed, communication problems occur, which can lead to the child's dissatisfaction, disengagement from their care, and misunderstanding between the parent and the child. As seen in our study, unless there is additional help from others (e.g., a clinician, an art therapist, a child psychologist) or a parent's dedicated effort to carefully monitor or experiment with different communication methods, the needs of child patients associated with illness and treatment are extremely hard to recognize and identify.

6.1.1 Creating Partnership in Child-Parent Dyadic Communication. Traditional interventions in communication studies emphasize a directive approach, such as teaching partnering strategies and communication skills to the caregiver or helping the child achieve certain developmental milestones [31]; however, our study findings imply that optimal communication with the child is associated with an enhanced relationship with their parents through a nondirective, but responsive parental communication style, particularly for young child patients who may rely heavily on their parents for informational and emotional support. Thus, we believe that it is critical to actively invite the children to participate in their own care based on their ability and to create a partnership between the parent and child that effectively identifies and incorporates the child's needs.

A partnership established with the child would not only allow parents to understand and respect the child's own perceptions and preferences, but reinforce the role of the child in their care process by providing a sense of control. In typical communication with a child, the parent takes the responsibility for moving the communication process forward by interpreting the child's intent and behaviors. In the context of collaborative illness management, in order for parental caregivers to be able to identify and interpret the actual needs of the child, the child must be given opportunity to express her/his response to the illness and to actively participate in managing her/his health. This can be understood as an example of what is known as the Zone of Proximal Development [45] in the field of Education: a child can accomplish more with the help of a more skilled person than she/he can alone. The important task for the more skilled person, in this case the parental caregiver, is to enable the less skilled individual, the child patient, to frequently and freely express and share their feelings, understand their illness, and take part in her/his own care. This was evident in our study, such as in the example of the parental caregiver (CG6) who allowed her child to learn the risks and limitations of her health condition through her own experiences rather than forbidding activities.

Of course, we believe that it is also crucial to consider the current attributes of the dyadic parent-child relationship, such as beliefs, attitudes, values, and family culture, as well as the child's age, maturity, and personality. These attributes should be considered before deciding how much the child should participate in the care process, as we saw a wide range of variations in the study. At the same time, with recent medical studies that show the importance of informing child patients of their illness and treatment procedures for improved health outcomes [37] and trust-building [21], we recommend that active participation and partnership of young child patients would be still be valuable.

This study extends our understanding of the parental caregivers' role when communicating with their children about health management or working to support their children's needs. Prior literature in the HCI and CSCW communities have presented design implications by mostly focusing on the informational needs of the children (e.g., an interactive educational tool [24] and a tangible conversation tool for clinical consultation [5]) or emotional needs (e.g., interactive social robots [18, 25]). While these interventions are likely to be helpful, they do not support the dyadic parent-child relationship in the pediatric care context. Even with these technical aids, child patients still rely on their parental caregivers to communicate about their illness and emotions, especially when the aids do not match their unique needs. Accordingly, it is critical to enhance the parent-child relationship for addressing the child patients' needs. Building a partnership between caregivers and patients in pediatric care has been highlighted in recent works (e.g., [15, 27]). Hong et al.[15] emphasized how adolescents with cancer gradually develop ownership of their health management through a partnership with their parents. They also presented design considerations for a sociotechnical system to support teens in their care (e.g., accommodation of both patient- and parent-reported assessments of symptoms). They, however, focused on parents and adolescents who may have different needs that are more explicit (e.g., privacy) than parents with younger children. Based on prior work, our study highlights the importance of creating a partnership in parent-child communication in which parental caregivers acknowledge their child's latent needs and address the challenges in their communication through opportunities that help and encourage the child to have their own voice . The understanding of child patients' implicit needs within the dyadic parent-child relationship can also contribute to knowledge concerning the principles for achieving pediatric patient-centered care.

6.1.2 Discovering, Understanding, and Negotiating Needs. To identify the child patients' implicit needs, it is necessary to begin with acknowledging the impact of illness on the parent-child dyad. This requires careful monitoring on the part of the parents since their child's needs only become visible through attentive observation and direct interactions. We believe that the three communication challenges uncovered in our study provide specific areas where parents can start looking for important ways that their child may remain unsupported. For instance, when deciding which method to use to deliver treatment-related information, it might be necessary for parents to gauge the child's awareness based on their prior experiences with treatment and clinical consultations. Also, depending on the kind of information being communicated, parents can experiment using different activities that the child is usually interested in (e.g., doing a role play with dolls or their favorite imaginary characters). Then, with frequent feedback from the child, parents should be able to capture their child's needs, understand their preferences, and negotiate them in order to offer better support and mitigate the communication challenges while maintaining their own needs as caregivers.

Design opportunity: utilizing scenarios and simulations. In healthcare, clinical simulation is often used to help medical and nursing students improve communication skills (e.g., skill learning for peer students [12] or child patients [44] and their families [20]). For instance, Johnson et

al. [20] developed a simulation-based communication training course for fellow physicians on potential challenges in and strategies for their communication with the family members of pediatric patients through specific patient case scenarios. They found that this simulation-based learning increased the confidence and communication skills of physicians during difficult discussions (e.g., end of life options) that are common in the Pediatric Intensive Care Unit. Similar to this approach, communication simulation can be used to enable parents to observe and understand their child's behaviors and needs in different contexts. **Drawing-based scenarios or a virtual environment supported by technology** could allow parent-child pairs to dive into a specific context or experience related to illness management in daily life. Each could control their character in the scenarios so that they could create their own storytelling based on their unique relationship and situation. Specific contextual information and the child's expression of emotion/feeling drawn from the simulations could allow parents to better interpret and understand their child's unspoken needs, as we saw in the role-plays with the patients' dolls that were used effectively by a couple of the parental caregivers in the study. In this regard, these tools, i.e., patient-specific scenarios and simulations, could help parents discover the implicit, latent needs of their children since these needs only become apparent in certain situations, and it may be hard for parents to keenly notice these situations in real life. These tools could also enable a systematic way to explore various contexts and document the parent-child interactions to share with their health provider or other professional (e.g., a child psychologist or a counselor) as our findings show that the intervention of experts can provide a valuable third perspective and an opportunity to identify the child's needs, particularly the perceptional and emotional ones.

6.2 Supporting Temporal Differences in the Development of Needs

As discussed in the previous section, parental caregivers and child patients come to acquire perceptional, informational, and emotional needs during the child's illness. Our analysis indicates that these needs do not stay constant; rather, they shift over time as the parent and child gain more knowledge and face situational changes at different treatment stages. For example, in the case of informational needs, neither caregivers nor patients had preferences or expectations for what or how to communicate during the earlier stages of treatment because they had insufficient experience and knowledge of the illness. However, as the children had clinic visits and treatment procedures, it affected their preferences and expectations for how treatment-related information should be introduced and presented to them (e.g., direct language style with less analogy preferred by P7). On the other hand, parents tended to focus on how to appropriately share information so as to ensure their child's psychological wellbeing and safety and to facilitate the necessary treatments in a way that the child would cooperate without fear.

Likewise, in the case of emotional needs, while parents tended to have constant worries about diagnoses, test results, and an uncertain prognosis, the children emotionally processed their situations as the course of their treatment progressed. Some children initially responded with negative emotions, like anxiety or fear, to the unknown cause of the illness, hid their emotions for a period of time, and then became more expressive later on as they learned more about their illness and became more familiar with the clinicians; others were expressive at the beginning but became more intimidated or quiet over the lengthy, stressful treatment process. Understanding and meeting the dynamic needs of child patients is already more complicated than for adult patients because of the patients' young ages, insufficient communication skills, and lack of health knowledge. Furthermore, over the course of their treatment, child patients grow up and become more mature, which can significantly affect their specific communication method preferences. Building on prior works that have already shown how child patients mature due to the cancer experience [23, 32], our

findings reveal that this maturity can cause changes in the child patients' health-related information communication needs.

It is also important to recognize that this shift in the parents' and children's needs occurs at different temporal paces during the illness trajectory. In particular, changes in the perception towards being a cancer patient, i.e., perceptional needs, occur at distinctive temporal paces for parents and children. Children usually recognize themselves as cancer patients much later than the parents do. After diagnosis, the parents in our study immediately began to treat their children as "patients" with a life-threatening disease and tried to offer the appropriate support such as explaining the illness or limiting activities that might risk their children's health. However, the children needed more time to understand and adjust to living as a patient. Even if children knew they were sick based on the frequent clinic visits, some took time to learn about their different lifestyle and priority as a cancer patient before beginning to understand the meaning of living with cancer.

For example, as described in the findings, in the case of P17, who had just had major abdominal surgery, her mother advised her to pretend to do sit-ups in gym class because she did not seem to understand the importance of having a safe recovery from her surgery and the risk of physical activities on her condition. However, P17 still did not take her mother's advice because she was not sufficiently aware of her health condition or limitations and more worried about what her peers thought. Despite having had major surgeries and having been a patient for more than two years, the child's perspective had not changed yet to prioritize health management in her daily life, contrasting with the mother's perception of P17 as a cancer patient who needed continuous health monitoring and management. The temporal lag between their recognition of P17 as a cancer patient resulted in the child disagreeing with or disengaging from her mother's health advice. Although children's perceptions change at different times and vary based upon individual personalities, maturity levels, amount of knowledge about the illness and treatment, and specific circumstances (e.g., going back to school after treatment), it is worthwhile to note that the timing of the children's perception change (i.e., whether they consider themselves as patients) is a tipping point, since their other needs (e.g., emotional and communication needs) will also likely change accordingly. It is also necessary to recognize and respond to the temporal differences between the parental caregivers' and child patients' shift in needs so that parents can better distinguish and interpret the children's perspective, emotions, preferences, and needs without engendering irrelevant or unnecessary information, help, or worry, especially when there is a wide temporal gap. We thus believe that parental caregivers can provide proper informational and emotional support to their children at the right time by addressing the slow, gradual, and passive changes of their child's needs and by adjusting and aligning their goals and needs accordingly, which can help achieve successful communication and collaboration in their care.

6.2.1 Aligning Needs of Parent and Child through an Integrated Timeline. The temporal aspect of collaboration and communication in patient care has been discussed in the CSCW literature on information work in the medical setting. In particular, a study by Reddy et al. [34] presents the concepts of temporal trajectory and rhythms by examining the informational work of medical workers in a hospital care unit . By focusing on the temporal characteristics of medical work at a collective level, their analysis reveals medical work's temporal rhythms (i.e., how people use their knowledge of re-occurring patterns in their patient care work and organizational activities in the unit), and further suggests that temporality and flows are ways of imposing structure onto the past, allowing workers to anticipate and plan for future events. Here, we use the concepts of temporality and rhythm in a slightly different manner to recommend how to address the temporal differences between the needs of the parent and child that were found in our study. Unlike the

medical practitioners' work at the care unit where temporality in their collaborative work followed regular patterns (rhythms), parental caregivers and child patients lack structure and re-occurring patterns in the communication of their collaborative healthcare management. Instead, the changes in the needs of child patients occur on a different time scale than their parents and are not always easily noticeable. However, we still see the necessity in offering parental caregivers support to identify and create patterns of communication about health-related information with their child, so that the parents can better deal with the temporality of the child's needs over time. This means that by focusing on a broader temporal orientation of the child patient's health progress with illness, their treatment trajectory, and their unique dyadic relationship with their parent, the parents' knowledge of the rhythms of their child's past and current needs can enable them in some sense to anticipate and prepare for when information will be needed and when it will become available, even if they are not always accurate. In fact, we saw that a few caregivers in our study engaged in this effort to various degrees, such as the parent who repeatedly asked her child about her feelings about her treatment right before the child's bedtime every night and another parent who periodically asked for her child's understanding of health management instructions at social/outdoor activities that the child was not allowed to do.

Design opportunity: timeline-based collaborative system. We suggest a collaborative system that allows the parent-child pair to create **a comprehensive, integrated timeline to track, record, and align their needs throughout the illness management process**. Collaborative tracking and monitoring technologies for family members have been suggested for various contexts, such as monitoring family conversations and recording a child's food intake during mealtimes (e.g., MAMAS [19]), tracking a child's development (e.g., BebeCode [39], Baby Step [22]), and tracking family members' sleep behaviors [33]. Although one recent study [33] acknowledged children's capability to be involved in the tracking and the need to involve them in it, most interventions mainly involve parental caregivers as the primary users, and do not engage the children's participation since the technology does not require the children's input or feedback. These studies also do not consider identifying or aligning the gaps in the child's and parent's needs. Extending the work on tracking interventions, we suggest tracking the needs of both parents and children in their communication about pediatric illness management. For a partnership, an integrated timeline would be helpful to track each individual's needs related to perceptions, emotions, and health-information communication, and to better prepare for potential needs in the future.

By integrating the parent's and the child's timelines of illness management, the system would capture and document not only their communication barriers or disagreements, but also their agreements and any congruence between their behaviors. These records could aid them in analyzing specific patterns or preferences for what can be (or should be) communicated, when and how interactions take place, and any temporal changes in the patterns and preferences over time. Although the system may not directly suggest a specific communication style or solution for each child and parent, it could allow the parent to better understand, identify, and adjust to their child's preferences so as to have more effective communication with them; it would also provide opportunities for the child to express their needs more explicitly. Thus, timeline-based, accumulated logs can serve as reference points which can be used to identify any changes, problems, or improvements. By addressing these changes in a timely manner, parents can adjust their expectations and communication practices to better meet their children's implicit needs.

In addition, by leveraging the existing treatment trajectory or the child's developmental milestones [22, 39, 41, 42], such as Baby Steps software [22] that allows parents to keep a variety of records on their children's development in various formats (e.g., video, text, pictures) and to check whether their child meets various developmental milestones properly, the system can provide a relevant guide or tips based on the child's treatment process timeline or developmental timeline. For

example, based on the child's current treatment trajectory, the system can recognize or anticipate certain changes in the child's emotions or attitude during periods of difficult treatment, strict regimes, or in response to certain care instruction (e.g., restriction on outdoor activities); and it can also provide proper guidelines and options about what to look for and how to handle it. Furthermore, this information could be useful for parents in the future when handling similar incidents, such as the next blood test or gym class, which made most of the parental caregivers in the study feel uncertain and stressed. Through the integrated timeline with accumulated logs of their illness/treatment related information and communication behaviors, the system could thus provide systematic ways to help parental caregivers more effectively make sense of the information related to the child's needs in a temporal context – by allowing them to compare former actions (i.e., what and how they had communicated) to their consequences (i.e., what worked well or did not work), and align the parents' caregiving goals, needs, and care tasks accordingly (i.e., what to anticipate and how to prepare more appropriately).

Finally, the timeline-based, accumulated logs in the system can also help the child patient navigate information that was previously discussed in the past and plan for information that will be communicated in the future. This may encourage the child to have an interest in and expectations for future health discussions and be more engaged in their own care. We believe that such a collaborative system has the potential to enhance communication in pediatric care contexts by helping parents recognize and respect the child's preferences, emotions, and perceptions and maintain the psychological and emotional wellbeing of their child. We want to acknowledge that the degree of partnership to be expected should be based on each child's different capabilities, as we saw growth and developmental changes even across our child participants (6-12 year age range), impacting their implicit needs. For those who are too young to participate in their care (younger than 8 years old), the partnership could be more for parental caregivers to get oriented toward future communication needs. Our suggestion for a collaborative system through partnership calls for researchers and designers to consider the dyadic parent-child relationship when developing technology for child patients in long-term illness management contexts.

7 STUDY LIMITATIONS

Our work identified the challenges of and strategies for the communication of health-related information between parental caregivers and child patients, and offered design opportunities to support their communication practices; however, this study has some limitations. This qualitative study focused on the experiences of patients (age 6-12) with blood cancer and their parental caregivers at a clinic in a large urban hospital in the U.S. The findings are specific to the particular context that we examined. Since communication methods, topics, and goals may be different in each illness context, further research is necessary to explore how parents and children in other care contexts communicate their health-related information (e.g., diabetes, asthma). However, we expect that factors related to perceptions of being a patient, methods of communication, and implicit emotions may arise in other chronic illness contexts. Additionally, most of the caregiver participants in this study were mothers. Although this indicates that mothers usually take on the role of the primary caregiver who takes the child to the clinic, more data from fathers should be collected in a future study so that a different parent-child relationship can be explored and supported. Lastly, given the children's young ages, we had to have the caregivers co-present in the room during the interviews. Even though we minimized the parents' involvement in the children's interviews, there might have been some potential influence on the children's answers, and vice versa; however, the study still shows clear differences in their perspectives.

8 CONCLUSION

In this paper, we examine the communication challenges parents and their children encountered when managing the child's illness. Our study makes three important contributions to the CSCW community: 1) we show three specific challenges to the parent-child communication: differing perceptions of living with an illness, a disconnect between the parents' expectation of and the children's preference for different communication methods, and a discrepancy between the parents' understanding of the children's emotions and the children's actual feelings; 2) we reveal the detailed process underlying these challenges in the parent-child communication by focusing on the child's unsupported implicit needs and the temporality of these needs; and 3) we present design opportunities for a health communication technology to support more effective dyadic communication in the collaborative illness management of parent-child pairs by extending the literature on technical interventions for pediatric care. We believe that this is the first study in CSCW to focus on the communication between children and parents in pediatric illness management. Based on our findings on the communication gaps in the perceptional, informational, and emotional needs between child patients and their parental caregivers, we invite researchers in the CSCW community to further examine the specific needs and challenges of this dyadic relationship in designing future health technologies for pediatric and family care.

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REFERENCES

[1] [n.d.]. PROMIS:Patient-Reported Outcomes Measurement Information System. http://www.healthmeasures.net/explore-measurement-systems/promis

[2] [n.d.]. Support for Families When a Child Has Cancer. https://www.cancer.gov/about-cancer/coping/caregiver-support/parents

[3] Annarita Adduci, Momcilo Jankovic, Sandra Strazzer, Maura Massimino, Carlo Clerici, and Geraldina Poggi. 2012. Parent–child communication and psychological adjustment in children with a brain tumor. *Pediatric blood & cancer* 59, 2 (2012), 290–294.

[4] Paula L Antognoli-Toland. 2001. Parent-child relationship, family structure, and loneliness among adolescents. *Adolescent & Family Health* (2001).

[5] Marleen Van Bergeijk, Bart Hengeveld, and Selma Otto. 2017. Dok: Enhancing Child Patient Empowerment. *Proceedings of the Tenth International Conference on Tangible, Embedded, and Embodied Interaction - TEI 17* (2017). https://doi.org/10.1145/3024969.3025066

[6] David K Berlo. 1977. Communication as process: Review and commentary. *Annals of the International Communication Association* 1, 1 (1977), 11–27.

[7] Hugh Beyer and Karen Holtzblatt. 2000. *Contextual design defining customer-centered systems.* Morgan Kaufmann.

[8] 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.

[9] Sally-Ann Clarke, Helena Davies, Meriel Jenney, Adam Glaser, and Christine Eiser. 2005. Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 14, 4 (2005), 274–281.

[10] Rebecca JW Cline, Felicity WK Harper, Louis A Penner, Amy M Peterson, Jeffrey W Taub, and Terrance L Albrecht. 2006. Parent communication and child pain and distress during painful pediatric cancer treatments. *Social science & medicine* 63, 4 (2006), 883–898.

[11] EA Ely. 1997. Collaborative practice with children and parents. Enhancing preparation for and management of cancer treatment. *Cancer practice* 5, 6 (1997), 387–390.

[12] Cynthia Foronda, Karina Gattamorta, Kenya Snowden, and Eric B Bauman. 2014. Use of virtual clinical simulation to improve communication skills of baccalaureate nursing students: A pilot study. *Nurse education today* 34, 6 (2014), e53–e57.

[13] Ernest VE Hodges, Regina A Finnegan, and David G Perry. 1999. Skewed autonomy–relatedness in preadolescents' conceptions of their relationships with mother, father, and best friend. *Developmental Psychology* 35, 3 (1999), 737.

[14] Matthew K Hong, Udaya Lakshmi, Kimberly Do, Sampath Prahalad, Thomas Olson, Rosa I Arriaga, and Lauren Wilcox. 2020. Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–16.

[15] 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*. ACM, 5337–5349.

[16] 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 *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2609–2618.

[17] Sarah S Jaser and Margaret Grey. 2010. A pilot study of observed parenting and adjustment in adolescents with type 1 diabetes and their mothers. *Journal of pediatric psychology* 35, 7 (2010), 738–747.

[18] Sooyeon Jeong, Cynthia Breazeal, Deirdre Logan, and Peter Weinstock. 2018. Huggable: the impact of embodiment on promoting socio-emotional interactions for young pediatric inpatients. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. 1–13.

[19] Eunkyung Jo, Hyeonseok Bang, Myeonghan Ryu, Eun Jee Sung, Sungmook Leem, and Hwajung Hong. 2020. MAMAS: Supporting Parent–Child Mealtime Interactions Using Automated Tracking and Speech Recognition. *Proceedings of the ACM on Human-Computer Interaction* 4, CSCW1 (2020), 1–32.

[20] Erin M Johnson, Melinda F Hamilton, R Scott Watson, Rene Claxton, Michael Barnett, Ann E Thompson, and Robert Arnold. 2017. An Intensive, Simulation-Based Communication Course for Pediatric Critical Care Medicine (PCCM) Fellows. *Pediatric critical care medicine: a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies* 18, 8 (2017), e348.

[21] Erica C Kaye, Jared Rubenstein, Deena Levine, Justin N Baker, Devon Dabbs, and Sarah E Friebert. 2015. Pediatric palliative care in the community. *CA: a cancer journal for clinicians* 65, 4 (2015), 315–333.

[22] Julie A Kientz, Rosa I Arriaga, and Gregory D Abowd. 2009. Baby steps: evaluation of a system to support record-keeping for parents of young children. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 1713–1722.

[23] Vicky Lehmann, Helena Grönqvist, Gunn Engvall, Malin Ander, Marrit A Tuinman, Mariët Hagedoorn, Robbert Sanderman, Elisabet Mattsson, and Louise von Essen. 2014. Negative and positive consequences of adolescent cancer 10 years after diagnosis: an interview-based longitudinal study in Sweden. *Psycho-oncology* 23, 11 (2014), 1229–1235.

[24] Zeina Atrash Leong and Michael S Horn. 2014. Waiting for learning: designing interactive education materials for patient waiting areas. In *Proceedings of the 2014 conference on Interaction design and children*. 145–153.

[25] Szu-Chia Lu, Andy Wu, and Ellen Yi-Luen Do. 2011. mediPuppet: an interactive comforting companion for children while visiting a doctor. In *Proceedings of the 8th ACM conference on Creativity and cognition*. ACM, 367–368.

[26] Gabriela Marcu, Anind K Dey, and Sara Kiesler. 2012. Parent-driven use of wearable cameras for autism support: a field study with families. In *Proceedings of the 2012 ACM Conference on Ubiquitous Computing*. ACM, 401–410.

[27] Andrew D Miller, Sonali R Mishra, Logan Kendall, Shefali Haldar, Ari H Pollack, and Wanda Pratt. 2016. Partners in care: design considerations for caregivers and patients during a hospital stay. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. 756–769.

[28] Lexa K Murphy, Kristopher J Preacher, Jason D Rights, Erin M Rodriguez, Heather Bemis, Leandra Desjardins, Kemar Prussien, Adrien M Winning, Cynthia A Gerhardt, Kathryn Vannatta, et al. 2018. Maternal communication in childhood cancer: Factor analysis and relation to maternal distress. *Journal of pediatric psychology* 43, 10 (2018), 1114–1127.

[29] Sarah J Naber, Lois K Halstead, Marion E Broome, and Maureen Rehwaldt. 1995. Communication and control: Parent, child, and health care professional interactions during painful procedures. *Issues in Comprehensive Pediatric Nursing* 18, 2 (1995), 79–90.

[30] Nikhila Nyapathy and Rosa I Arriaga. 2019. Tracking and Reporting Asthma Data for Children. In *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing*. 330–334.

[31] Cecilia Olsson. 2004. Dyadic interaction with a child with multiple disabilities: A system theory perspective on communication. *Augmentative and Alternative Communication* 20, 4 (2004), 228–242.

[32] Carla Parry and Mark A Chesler. 2005. Thematic evidence of psychosocial thriving in childhood cancer survivors. *Qualitative Health Research* 15, 8 (2005), 1055–1073.

[33] Laura R Pina, Sang-Wha Sien, Teresa Ward, Jason C Yip, Sean A Munson, James Fogarty, and Julie A Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing* (Portland, Oregon, USA) *(CSCW '17)*. Association for Computing Machinery, New York, NY, USA, 2300–2315.

[34] Madhu Reddy and Paul Dourish. 2002. A finger on the pulse: temporal rhythms and information seeking in medical work. In *Proceedings of the 2002 ACM conference on Computer supported cooperative work*. 344–353.
[35] Erin M Rodriguez, Madeleine J Dunn, Teddi Zuckerman, Leighann Hughart, Kathryn Vannatta, Cynthia A Gerhardt, Megan Saylor, C Melanie Schuele, and Bruce E Compas. 2013. Mother–child communication and maternal depressive symptoms in families of children with cancer: Integrating macro and micro levels of analysis. *Journal of pediatric psychology* 38, 7 (2013), 732–743.
[36] Alan Russell, Jacqueline Mize, and Kerry Bissaker. 2002. Parent-child relationships. *Blackwell handbook of childhood social development* (2002), 205–222.
[37] Christoph Rutishauser. 2003. Communicating with young people. *Paediatric respiratory reviews* 4, 4 (2003), 319–324.
[38] Heeyeon Son, Joan Haase, and Sharron L Docherty. 2019. Parent-child communication in a childhood cancer context: A literature review. *Pediatric Nursing* 45, 3 (2019), 129–141.
[39] Seokwoo Song, Juho Kim, Bumsoo Kang, Wonjeong Park, and John Kim. 2018. BebeCODE: Collaborative Child Development Tracking System. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. 1–12.
[40] Anselm Strauss and Juliet M Corbin. 1997. *Grounded theory in practice*. Sage.
[41] Hyewon Suh, John R. Porter, Alexis Hiniker, and Julie A. Kientz. 2014. @BabySteps: Design and Evaluation of a System for Using Twitter for Tracking Children's Developmental Milestones. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems* (Toronto, Ontario, Canada) *(CHI '14)*. ACM, New York, NY, USA, 2279–2288. https://doi.org/10.1145/2556288.2557386
[42] Hyewon Suh, John R Porter, Robert Racadio, Yi-Chen Sung, and Julie A Kientz. 2016. Baby Steps Text: Feasibility Study of an SMS-Based Tool for Tracking Children's Developmental Progress. In *AMIA Annual Symposium Proceedings*, Vol. 2016. American Medical Informatics Association, 1997.
[43] Tammy Toscos, Kay Connelly, and Yvonne Rogers. 2012. Best intentions: health monitoring technology and children. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. 1431–1440.
[44] Aaron K Vallance, Ashish Hemani, Victoria Fernandez, Daniel Livingstone, Kerri McCusker, and Maria Toro-Troconis. 2014. Using virtual worlds for role play simulation in child and adolescent psychiatry: an evaluation study. *The Psychiatric Bulletin* 38, 5 (2014), 204–210.
[45] Lev S Vygotsky. 1978. Mind in society Harvard university press. *Cambridge, MA* (1978).
[46] Harald Werneck, Maximilian Oscar Eder, Takuya Yanagida, and Brigitte Rollett. 2014. Predicting adolescents' parent–child relationship quality from parental personality, marital conflict and adolescents' personality. *European Journal of Developmental Psychology* 11, 2 (2014), 159–176.
[47] Bridget Young, Mary Dixon-Woods, Michelle Findlay, and David Heney. 2002. Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science Medicine* 55, 10 (2002), 1835–1847. https://doi.org/10.1016/s0277-9536(01)00318-5
[48] Bridget Young, Mary Dixon-Woods, Kate C Windridge, and David Heney. 2003. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *Bmj* 326, 7384 (2003), 305.

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