Learning from Positive Adaptations of Pediatric Cancer Patients to Design Health Technologies

Sun Young Park[1,2], **Woosuk Seo**[1], **Andrew B.L Berry**[4], **Hyeryoung Kim**[2],
Sanya Verma[1], **Sung Won Choi**[3], **Ayse G. Buyuktur**[1]
[1]School of Information, University of Michigan, Ann Arbor, MI, USA
[2]Stamps School of Art & Design, University of Michigan, Ann Arbor, MI, USA
[3]Michigan Medicine, University of Michigan, Ann Arbor, MI, USA
[4]Kaiser Permanente Washington, Seattle, WA, USA
{sunypark, seow, hyerykim, sanyav, abuyuktu}@umich.edu, ablberry@uw.edu, sungchoi@med.umich.edu

ABSTRACT

The diagnosis of cancer brings about significant changes in the life of a child. In addition to physical pain, pediatric patients face psychological and social challenges. At the same time, some patients also have positive experiences with and attitudes toward their illness and treatment. Drawing on 19 semi-structured interviews with pairs of pediatric cancer patients and their parental caregivers, we examined patients' perspectives on their experience of living with cancer. We identified four salient themes in patients' positive experiences: future-oriented thinking, developing strong personal bonds and relationships, gaining knowledge and life experience, and developing self-management and coping skills. Collectively, the patients' positive experiences indicate that they adapt to their new lives through an evolving process. Based on this process, we provide design implications for health technologies to support and promote positive experiences during illness and treatment.

Author Keywords

Positive experience; pediatric patient; cancer; adaptation; health technology.

CCS Concepts

•**Human-centered computing** → **Empirical studies in HCI;**
•**Applied computing** → Health informatics;

INTRODUCTION

In young children, chronic illnesses such as cancer can be particularly challenging. In addition to enduring physical pain from the long-term treatment, children with cancer are psychologically and socially affected by their illness, and so are their daily routines. They have to deal with potential stressors such as treatment regimens with side effects, changes in physical appearance, and social challenges like isolation from their peer group and losing opportunities to participate in normal family, social, and educational activities. Thus, pediatric patients often regard cancer as significantly stressful, burdensome, and traumatic [20, 33]. Nevertheless, medical and psychological research has shown that some patients find a silver lining during their experience of illness and treatment. For instance, young people diagnosed with cancer during adolescence perceived positive aspects of their cancer experience, like improved personal attributes and material gains [45]. These positive experiences promote hope for the future, which is sometimes related to coping strategies for health management [14], and they enhance optimism, which may influence the experience of physical pain [26]. While emphasizing patients' perception of positive experiences during their illness and treatment, prior work highlights the necessity of clinical practice improvements such as creating effective communication with pediatric patients and considering their psychological states (e.g., [28]).

Although the benefits of positive experiences have been noted in previous studies [14, 26], a few technological interventions for enhancing pediatric patients' positive experiences during the course of illness. Previous HCI studies have presented technical interventions to support pediatric patients with health conditions such as diabetes [4], and cancer [9]. These interventions (e.g., [4, 9, 12, 18, 19] have largely focused on identifying and addressing problems and minimizing negative experiences or impacts of such problems on pediatric patients. Our study, however, aims to identify pediatric cancer patients' positive experiences and to support them through the design of health technologies.

To understand the positive experiences of pediatric patients living with illness, we conducted 19 semi-structured interviews with pairs of patients and their parental caregivers. From the interviews, we identified four salient cases of patients' positive experiences: future-oriented thinking, developing strong personal bonds and relationships, gaining knowledge and life experience, and developing self-management and coping skills. Drawing on these cases, we articulate an evolving process of adaptation to life with illness through positive experiences. Based on this process, we present design implications that can help identify and enhance patients' positive experiences so they can build and maintain positive attitudes toward their illness and treatment. Thus, our study makes the following contributions to the HCI community:

CHI '20, April 25–30, 2020, Honolulu, HI, USA.

ACM ISBN 978-1-4503-6708-0/20/04 ...$15.00.
http://dx.doi.org/10.1145/3313831.3376397

- We offer insights into how pediatric patients perceive positive experiences while living with chronic illness and how these perceptions shape the way they understand and adapt to illness.

- We present design considerations to support pediatric patients in promoting and enhancing their positive experiences through health technologies.

RELATED WORK

Living with chronic illness

While negative experiences and impacts of chronic illness on pediatric patients have been dominantly studied and highlighted in prior work, several studies in the medical and psychological literature showed positive aspects of living with chronic illness along with negative ones. Wick and Mitchell [45] found that pediatric cancer patients not only suffered from a loss of control, which led to frustration and inadequacy, but also experienced some benefits, such as improved personal attributes and enhanced relationships with parental caregivers and peer patients. Similarly, Lehmann et al. [22] showed that, along with negative consequences of cancer treatment (e.g., thoughts about loss), positive outcomes existed among survivors of adolescent cancer in the form of a positive perspective on life. These included a greater sense of self and deepened relationships with others. Moreover, patients' interpretations of these negative or positive experiences can have a unique influence on their adjustment to the illness. For instance, positivity reduces distress while negativity increases vulnerability to distress [6]. Thus, it is important to address both positive and negative experiences to gain a better understanding of patients' lives with illness and potential health outcomes.

In managing chronic illnesses like cancer, pediatric patients are expected to learn and develop self-skills to adapt to their new life with the illness and attain an ultimate goal of regaining their health after their diagnosis. Thus, researchers have studied different types of patients' adaptation to illness. For instance, a repressive adaptation style was identified among adolescent cancer patients when they coped with their treatment (e.g., ignoring the difficulties that children experienced as cancer patients) [35]. Some others focused on positive aspects of their life in adapting to cancer. Adolescents who survived childhood cancer considered their cancer experience as positive and related specific positive consequences from cancer treatment during adolescence, including a positive attitude towards life, better relationships, maturity and improved self-esteem, and material gains [8, 15, 27, 28, 32, 46]. Studies in the field of positive psychology have suggested that the experience of positive psychological states can improve emotional and physical well-being by decreasing the damage which negative states may cause and helping develop defenses against future negative and stressful experiences [10, 42]. Despite these benefits, positive experiences and positive aspects of adaptation among pediatric patients have been relatively less examined. In particular, most prior studies largely focus on adolescent and young adults who had childhood cancer. Little is known about the perceptions of positive experiences of younger children with chronic illness. Moreover, some medical studies have suggested clinical implications for enhancing the positive experiences of pediatric patients, such as teaching life skills to improve their quality of life [28], but have offered only a few technical interventions.

Technology for pediatric patients

In the HCI community, researchers have examined specific needs of pediatric patients with a variety of chronic illnesses such as cancer or diabetes and presented technological support for the patients. Some identified needs of pediatric patients include a lack of peer support, communication gaps with clinicians, inadequate knowledge about their illness, and psychological distress caused by medical procedures. To address such needs, technology has been used to provide peer support in a hospital setting through online platforms [12] or tangible technology [44], to enable patients to illustrate their symptoms to clinicians with child-friendly interfaces [16, 36], to improve educational materials so that patients can better understand their illness [4, 21, 23], and to comfort patients and reduce their anxiety during clinic visits [18, 24]. Most of this prior work focuses on alleviating negative experiences, painful feelings, struggles of pediatric patients during their treatment process, or addressing communication or information gaps between patients and other caregivers, rather than attending to other aspects of patients' experiences with their illness, such as positive attitudes or gains.

A recent study discussed aspects of patients' experiences with illness other than negative impacts, with the goal of developing technology for pediatric patients. Liu et al. [25] described how pediatric patients adapted to their new social life after the diagnosis of their illness and presented design implications for technology to help them maintain their relationships with peers by addressing patients' lack of normalcy (being left out of friends' activities) and embracing their "new normal" through connecting to peer patients, educating healthy peers, and managing reactions. Although this approach still focused on negative impacts of illness, it provided a partial view of adapting to a new life.

The concept of positive computing which supports psychological wellbeing and human potential is well noted in previous studies (e.g.,[3, 2, 39, 31, 5]). They suggest that positive computing interventions have been actively implemented in patient populations, such as those with chronic pain medicine and diabetes. However, a few have focused on positive computing for children. To extend prior studies on existing technology-mediated reflection systems for children (e.g., [47]), we aim to understand patients' positive experiences while adapting to life with illness and to present design implications for enhancing those positive experiences. Enhancing positiveness through technological support would provide a unique opportunity to help children better adapt to life with illness.

METHOD

This paper draws on data collected as part of a larger project involving 19 pairs of pediatric cancer patients and their parental caregivers. The goal of the larger project is to understand patients' illness and health management practices and their

	Gender	Age	# of siblings
P1	Male	6	2
P2	Male	8	2
P3	Male	9	1
P4	Male	6	1
P5	Male	10	1
P6	Female	7	4
P7	Female	7	1
P8	Male	6	1
P9	Male	9	5
P10	Male	12	2
P11	Male	12	1
P12	Male	9	1
P13	Female	6	2
P14	Male	6	0
P15	Male	7	1
P16	Female	10	2
P17	Female	6	0
P18	Female	6	1
P19	Female	8	1

Table 1. Demographic information of patient participants

communication practices with caregivers and providers. In this paper, we focus on the experiences and perceptions of pediatric patients regarding their new life dealing with illness after diagnosis.

We recruited participants at an outpatient oncology section of a children's hospital. All patient participants met our inclusion criteria of 1) being between the ages of 6 and 12 years old and 2) diagnosed with cancer at least two months prior to the study. These requirements allowed us to interact with patients who had initiated the treatment process and required ample external care at the hospital or at home due to their young age. Caregiver participants identified themselves as the primary caregivers to their respective pediatric cancer patients.

This paper focuses on pediatric patients' perspectives but also incorporates interview quotes from caregivers since they provide valuable insights into patients' perspectives. This may have some limitations (e.g., discrepancies between children's and parent's views), but prior work [25] suggests that others' views influence one's own self-perception (i.e., a caregiver's perception can have a positive or negative impact on how a patient perceives his or her own condition, coping strategies, and self-management). We thus view including parental caregivers' perspectives as a valid way of triangulating findings regarding pediatric patients' perspectives as well as gathering information from both an individual and relational perspective.

Our semi-structured interviews with patients and caregivers occurred sequentially, one right after the other. The interviews with each pair, lasting about an hour, were held in a consultation room or an infusion unit. Questions pertained to understanding the patient's change in personality, interactions with friends, knowledge and understanding of the illness, routine and management, and more. Patients were also given a form on which to circle images or check boxes to help express their feelings or ideas. Their written answers were analyzed along with the interview transcript. The caregivers were present during the patient interviews; however, to reduce caregivers' influence on patients' answers their interventions were limited to helping children understand questions or reminding them of past experiences.

The interviews were audio recorded and transcribed. We removed all personally identifying information and assigned a unique identifier to each participant. The caregivers included 12 mothers, 3 fathers, 3 couples, and 1 grandmother. The patients included 12 boys and 7 girls, 12 of whom were between the ages of 6-8, and 7 whom were between the ages of 9-12 (See Table 1). One patient (P9) refused to participate the interview, while his parental caregiver participated. This interview study was approved by our university's Institutional Review Board (IRB) for Medical Research prior to data collection.

Data Analysis

Based on the first four interview transcripts, the study team assembled an affinity diagram to identify common themes, interesting patterns, and similarities or differences between patient and caregiver perspectives. Initially, we found salient themes regarding how pediatric patients engage in their daily illness management practices, and this led us to discover the two distinctive themes of negative and positive patient experiences. We then identified different categories of positive aspects that patients and caregivers experienced during the course of treatment. The findings on positive experiences allowed us to focus on specific themes and categories when we returned to re-code the remaining 15 pairs of interviews. The study team collaborated regularly to discuss emerging themes regarding how patients interpreted their experiences with cancer and how, with time, patients' habits and personalities changed. Themes produced by each researcher were compared, discussed and revised through weekly discussions until agreements were reached. Then, the study team executed axial coding to identify relationships between themes [41]. In this paper, we report our findings regarding positive aspects of the diagnosis and treatment process experienced by pediatric cancer patients.

FINDINGS

Pediatric cancer patients had negative perceptions of the impact of their illness on themselves and their daily lives. Due to the risk and side effects of treatment and medication, patients experienced numerous restrictions on their daily activities, often relying on others (e.g., parents, clinicians, teachers) to manage their illness, and they sometimes felt different from their healthy peers. However, our study discovered that patients developed positive attitudes toward their illness and treatment over time. Our analysis generated four themes regarding positive experiences while living with childhood cancer. In the following sections, we present how pediatric patients focused on positive experiences through future-oriented thinking, strengthened personal bonds and relationships, gaining knowledge and life experience, and self-management and coping skills that enabled independence in managing their illness.

Future-oriented thinking

After diagnosis, pediatric patients began to recognize the impact of illness on their lives. In our study, many patients consistently compared their past, in which they were able to engage in any physical or outdoor activities, to their present, in which they were unable or no longer allowed to engage in those activities. For instance, patients usually had less energy and muscle strength because of the side effects of medication, and therefore their activities were often limited. P11(age 12) shared his feelings in comparison to his life before diagnosis: *"I am not able to do playing sports I used to. [I feel] Sad that I can't do certain things."*

However, as they worked through their treatment protocol and adapted to new and different situations with illness, some started to develop future-oriented thinking, which allowed them to focus on a hopeful future rather than on their stressful present circumstances or comparisons to the healthy past.

Future-oriented thinking was often enabled and supported by patients' understanding of their health-related information. During the long-term process of treatment, when caregivers and clinicians explained information about treatment procedures, test results, and upcoming clinic visits, patients could understand and start anticipating what to expect in their care, with less anxiety and uncertainty. Future-oriented thinking encouraged patients to have cooperative attitudes about treatments and clinic visits and to anticipate more positive health outcomes while undergoing current hardship (e.g., treatment).

We identified two types of future-oriented thinking with different time scales: building expectations in the short-term (e.g., better treatment results) and developing long-term hopes for the future (e.g., desired career or life goals). In terms of the short term, some patients had positive expectations about their health status and treatment results. These patients were well-informed about their health status and treatment plans and had already experienced positive health outcomes (e.g., good test results), which helped them hope for more good health outcomes. For instance, P3 (age 9) mentioned that he knew *"things [e.g., treatment] are always gonna be good"* when he visited the clinic. This attitude toward treatment indicates that P3 developed optimistic expectations and gained confidence based on his previous experience with good health outcomes. Likewise, P2 (age 8) explained why he was hopeful when he visited clinic:

> I know when I stop Tacro [a medication] and Mag [a medication], I will get my broviac [a thin tube that is placed in a vein for long-term access to blood] pulled out. So I am hopeful. – P2

In this quote, we see that P2 was hopeful because he was well aware of his medications and knew what to expect about the upcoming treatment sequence. He was looking forward to achieving his short-term goal – having the broviac removed.

In addition, some other patients developed desires for a long-term future, beyond short-term treatment outcomes. Based on their own experience and knowledge that they gained from the treatment process over time, they attained new interests for their future, such as career goals. These expectations for the long-term future were often observed by the caregivers. For instance, CG10 shared P10 (age 12)'s desire to be a scientist:

> He [P10] actually wants to take everything he has learned and been through and become some sort of a scientist out of it. – CG10

As an older patient (above age 8) who was more likely to think about his future, P10 seemed to acknowledge his unique experience during his treatment process and to utilize it for his future career. We found that not only older patients, but also a few younger ones (6-8) had similar thoughts about their long-term future. For instance, CG18 (Dad) commented that P18 (age 6) developed her future goal of becoming a clinician based on knowledge gained from her own treatment process. CG18 (Dad) described how P18 imitated nursing tasks (e.g., blood draw) at home after seeing how the nurses work at the hospital:

> She [P18] either wants to be a vet or a cancer nurse [. . .] At home, she lays her stuffed animals all over the floor and acts like she's taking blood and doing other things [. . .] I think she's interested in it [becoming a cancer nurse] because when we're downstairs and she gets her port put in, she likes to help take the blood and things like that. – CG18(Dad)

This quote describes not only how P18 developed her career interest in becoming a cancer nurse, but also how P18 became cooperative with her current treatment due to her newly attained interest. As P18 wanted to learn more about nursing tasks, she proactively participated in treatment procedures (e.g., helping her parents with caregiving work).

In facilitating the development of future-oriented thinking, we found that caregivers' role was crucial. Some caregivers proactively shared and discussed health-related information with their sick children so the children could gain a better understanding and appropriately anticipate their condition, rather than simply feeling anxiety about uncertainty. For instance, CG3 mentioned that P3 (age 9) gained knowledge about his good prognosis through transparent, shared communication about his health: *"I tried to explain him [P3] that 'you are gonna be in hospital and this is going to happen.' And they[clinicians] had stuff in writing and showed him stuff what's gonna happen once he was in hospital."*

We note that this information-sharing among patients and their caregivers worked for some, but not all. There was a wide range of attitudes regarding what to share with patients and how to share it. Some caregivers avoided, selectively shared, or took a longer time to share information, particularly when they were concerned about negative test results or unnecessary emotional burdens on their patients. In those cases, we found that it was more difficult for patients to develop future-oriented thinking since they had less opportunity to understand their illness and treatment.

In this section, we described how some pediatric patients developed their expectations and hopes about their short-term (e.g., better treatment outcomes) and long-term (e.g., occupation) future by gaining a better understanding of their health condition over time. Future-oriented thinking enabled these patients to develop a cooperative attitude toward treatment in adapting to their lives with chronic illness, which may potentially positively influence their health outcomes, rather than feeling sad or anxious about their situation. The role of caregivers was also found for sharing health-related information facilitated and encouraged patients' future-oriented thinking.

Developing Bonds and Relations with Close Individuals

In our study, pediatric patients described the social isolation they experienced, such as limited physical interactions and outdoor activities, due to potential risks or side effects of treatment (e.g., infection, hair loss). They thus recognized that they were different from peers and felt left out of their social groups. For instance, many patients felt sad when they could not play with her friends outside; several caregivers reported their observation of such social isolation that sometimes their sick children intentionally kept their distance from peers to maintain their health.

However, while many patients experienced social isolation due to their illness, some also felt that they developed strong bonds and relationships with a few individuals such as their family members and clinicians. They began to notice that they felt cared for by these individuals in a different way than what they were used to prior to their diagnosis. In particular, patients enjoyed the special attention and treatment they received from clinicians and family members. The feeling of receiving special attention often helped them maintain a positive attitude about having the illness and having frequent clinic visits, despite negative experiences of illness. CG17 described how P17 (age 6) viewed having her illness as an advantage:

> She [P17] likes that she has an undivided adult's attention. She feels like. . . a benefit for having cancer is that she gets to do things that other kids don't. – CG17

This quote indicates how P17 recognized the full attention she constantly received from others and acknowledged the advantage of her situation compared to those of peers who were not in a similar situation. P17 thus portrayed a positive attitude about her situation with cancer. Similar to P17, most patients received attentive care from clinicians and staff in an effort to make the hospital as comfortable as home for the patients (e.g., *"home [hospital] away from home"* – noted by P16(age 10)). Another caregiver (CG1) described the intimate, caring relationship P1(age 6) developed with his clinicians, almost like an extended family:

> So, he [P1] remembers coming to the clinic was fun because everyone made him fun. This is like an extended family for him. – CG1

Across all patients and caregivers, we saw an intimate and strong relationship with clinicians that was developed over multiple hospital stays and frequent clinic visits. This helped patients build trust and positive attitudes toward the clinicians as well as the treatment procedures they would conduct, which became a driving force for patients' confidence in their long-term cancer treatments.

In addition to emotional support from clinicians, many patients felt strongly tied to and emotionally supported by their family members at home. This greatly helped to reduce the loneliness and isolation patients felt going through the treatment process. Especially after significant medical procedures (e.g., bone marrow transplant (BMT)), when they were isolated at home in order to prevent infections, they spent their entire time with family members. Having a significant amount of family time at home allowed patients to feel closer to their relatives, though familial relations might not completely make up for the peer interactions they missed. Additionally, strong support from family also greatly influenced how the pediatric patients overcome physical and emotional difficulties in their everyday lives. For example, CG6 initially tried not to have P6 (age 7)'s sisters present when she was administering one of P6's medications, because P6 aggressively declined the medication and CG6 had to almost force the medication down. However, CG6 changed her perception after she saw how P6's sisters supported P6 in taking the medication:

> They [P6's sisters] were all outside the [room] door crying because they were sad for her [P6]. So I was like, "Let's just open the door. Let's just let them [P6's sisters] be part of it and they can support and cheer her on." And so, we did, we opened the door. They cheered her [P6] on like, "You can do it!". And, then it was like it changed the whole kind of atmosphere of everything that we did. So, we made sure that everything from that point was, this isn't just her [but the whole family]. - CG6

The quote above illustrates how emotional encouragement and cheering from siblings greatly helped P6 overcome the difficulty with her medication in-takes (most patients were on more than 20 pills daily after the transplant procedure). CG6 further explained that through all family members' working together as a whole toward P6's successful treatment and recovery, the entire family felt more bonded than ever. Similar to the case of P6, we identified that patients' bonding with family was beneficial and potentially could affect their mental wellbeing positively. For instance, P3 (age 9) mentioned that his illness did not make him feel isolated because he always had attention and support from his family: *"I am always with them [family members]"*.

Although some caregivers felt giving a lot of attention sometimes spoiled their sick children, we found that many adopted strategies to help patients feel more supported and fortunate. For instance, CG1 celebrated the day P1 (age 6) had his bone marrow transplant (BMT) with family members to acknowledge the transplant as a challenging but positive and important event by doing something memorable and fun.

> We started talking about it [P1's illness and treatment] a little bit more and he was four at that time. . . When we started, the first year was a big party. Since then, we treat it like a birthday. So, we go out and eat wherever he wants. We don't really buy a gift or anything. Just to recognize it. It's a very big deal. – CG1

As seen in this quote, CG1 tried to make the transplant day a memorable and positive experience that deserves celebration for P1, calling it “re-birthday.” By recognizing the transplant day, CG1 acknowledged and praised P1’s bravery in going through the painful and exhaustive medical procedures; and CG1 expected that the celebrating the day would make him look forward to it instead of recalling pain and negative things. The re-birthday could help him develop a fortunate and confident feeling about his illness experience.

In summary, we found that due to managing their illness, pediatric patients recognized greater limitations in their interactions with peers; however, at the same time they achieved positive experiences of building trust and developing strong emotional bonds with their clinicians and family members. This positive experience allowed patients to feel closely connected with others and maintain positive attitudes about their illness, which helped them to better adapt to their new lives, rather than feeling isolated. In addition, to encourage patients to be more positive about their situation, caregivers provided sympathy and helped them realize and understand how successfully they had gone through such challenging but important treatments.

Gaining Knowledge, Wisdom, and Life Experience

Similar to the feeling of isolation, patients in our study also recognized that they lost certain aspects of their lives due to illness. For instance, P10 (age 12) expressed his concern about falling behind in school, particularly when he missed lots of school days due to clinic visits or treatment: *“I worry that I will fall behind in school...sometimes. (. . .) Like when I miss lots of school”*. Like P10, most of older patients (age 8~12) expressed similar concerns related to school performance.

Although many patients experienced losing opportunities that their peers had, some recognized that they gained valuable knowledge and wisdom – not just about illness and treatment, but also about life – and developed personal growth from their illness and treatment. This experience led to confidence and positive attitudes about their unique situation of living with illness. Specifically, some patients mentioned that they gained a new perspective on other people with illness. For instance, P16 (age 10) felt she became “wiser” as she learned more about sickness and understood how sick people might feel after reflecting on her own experience of being chronically ill.

> I feel like it [cancer] made me wiser...When I see other people sick, I used to always treat them better because they have the sickness, but then after I got sick, I’m like being treated better doesn’t feel good. It makes you feel left out. Now if I see someone else, I act like they are normal unless they have to have something. – P16

In this quote, P16 realized an advantage of experiencing illness as she reflected on how her lived experience as a cancer patient allowed her to be able to think from the perspective of others who were also sick, which she would not have done otherwise. She now saw that merely treating sick people more nicely and carefully might not necessarily make them feel better and in fact it might make them feel more different from others. Such wisdom and awareness gained from her own experience brought growth inside her.

Beyond learning medical knowledge about their illness and treatment, a few patients also showed an ability to articulate acquired knowledge in simple language. They translated such knowledge for other people by adjusting the type and amount of information depending on whom they were talking to. Patients valued this ability and thought it was important because they could communicate and educate their peers about their situation. For example, P16 felt confident about her capability to learn about her illness initially from clinicians (with complex medical terms) and describe and communicate it using simplified language for her friends:

> I know complicated things that my mom would talk to an adult about and I talk to adults, but then if I talk to my friends like that, they are like, “what?” So, I say it simpler so that they would understand.(...) I don’t feel like I’m smarter than them or higher than them, I just know more about illnesses and how people feel because I’ve had it. – P16

As shown in this quote, P16 emphasized that having more medical knowledge did not mean she was smarter than her peers. Instead, P16 felt privileged to gain perspective from her experience with illness. Similarly, another patient, P17 (age 6), adjusted her communication style and the amount of information she shared based on friends’ ability to understand. For instance, she shared selective information about her illness with her peers at school, while she talked about everything with a friend whom she met at the oncology clinic. P17 learned which of her friends could understand more and which could understand less about her situation.

Along with personal growth, there was some evidence of greater maturity, including adult traits (e.g., complicated vocabulary), among several pediatric patients. This was mainly observed from their caregivers’ perspective. For instance, CG3 explained that P3 (age 9)’s vocabulary was observed to be way above the average for his age, and this was also recognized by an expert:

> His [P3’s] speech teacher tells for one his vocabulary is way above his age. He knows everything and manages to get really hard words. So, I think he just has a different life experience than other kids. – CG3

This quote describes how P3’s personal growth was shown through his ability to use complicated vocabulary based on medical knowledge and life experience gained by spending his early childhood (age 3~5) in the clinic for treatments.

In summary, some pediatric patients gained knowledge and life experiences that allowed them to develop personal growth, even though they lost certain aspects of their lives (e.g., missing school) due to their illness. These gains enabled the patients to feel they had valuable experiences, such as feeling confident and thinking more wisely and positively about being a cancer patient, since such knowledge and experiences were unique to their situation.

Developing Self-Management and Coping Skills

Due to a lack of self-care skills and their young age, many patients depended heavily on their parents or other adults (e.g., teachers at school) for their health management. Health management protocols required for patients were extensive and complex (e.g., taking pills, cleaning ports, washing hands, eating certain meals); thus, they required a lot of attention and assistance from their caregivers or others around them. In particular, ensuring medication adherence was very challenging even for parental caregivers, because there were over 20 different pills that most patients had to take daily and the instructions frequently changed after clinic visits. The challenging health protocol often caused patients to depend physically and emotionally on their parents and other adults.

However, we found that some of the patients proactively attempted to be more independent by learning and developing self-management skills. Once they recognized changes and new routines for illness treatment, they began to learn self-care skills like keeping track of medication times, maintaining consistent mealtimes, and exercising regularly. Performing self-care allowed patients to take responsibility for their own health and body, and feel that they were in control of their lives. For instance, P16 (age 10) used her phone to remind herself to eat regularly:

> She [P16] has timers set on her phone to eat every couple of hours, just because we're still trying to gain weight and rebuild muscle mass. – CG16

> I just know I have to get my strength back. It's like if you get fat, you just have to work out to get the fat out and be skinny again. – P16

As seen in these quotes, P16 was motivated to acquire self-care skills (e.g., eating regularly). By describing her health condition (e.g., lack of strength due to chemotherapy) as analogous to gaining fat, she showed a positive expectation of regaining her muscle mass and strength, and considered that this was something she could take responsibility for.

As patients became more familiar with their treatment and health management protocols, they became more independent from parental guidance in managing their health. For instance, CG3 noted that at school, P3 (age 9) used to solely rely on his teacher to set the timer to remind him about medication times. Later P3 learned and managed his medications without help from the teacher:

> [For P3], his last year teacher at school set a reminder on her phone. The office will not call them down so if a teacher does not do it, then he has to remember – CG3

As this quote illustrates, P3 took responsibility for managing his own health so he would not have to rely on others (e.g., teachers) who might not fulfill P3's urgent health needs (e.g., assuring the medication times). Similar to P3, particularly patients aged 8 or older expressed confidence when they shared the self-management skills they developed (e.g., washing hands, eating healthy foods, keeping regular meals). Besides developing self-management skills, we found that based on various social interactions with others over time, some patients developed their own proactive strategies to better cope with comments or questions about their illness and side effects. For example, when some side effects of their treatments were physically obvious (i.e., hair loss), several caregivers were concerned that the patients might get hurt by others' reactions. However, we saw that some patients used humor and jokes to cleverly react to or answer comments from others. Some even used these strategies proactively, before being asked. For example, when P11 (age 12) had a "moon face" while on steroids as a part of his treatment, he joked about it, such as saying he looked like the kid "Dudley" in Harry Potter since his cheeks became chubby due to the medication. Similarly, P14 (age 6) proudly showed his bald head to his friends in kindergarten without feeling hesitance or shame, which made others feel comfortable about it.

> He was really proud to show his bald head [to his friends]. So, they could all have a good chuckle at his head. – CG14

In another example of using humor, P17 (age 6) joked about not having hair to explain it to others in a humorous way (e.g., *"Guess how fast I can shower!"*), which made CG17 feel proud of P17's witty reaction.

> We [CG17 P17] just met a four-year-old the other day who was very blunt and was like, "Why don't you have hair?" And we were like, "Well, you have medicine that works so good at fighting cancer, but also gets confused sometimes and also gets the hair." But [P17] was quick to say, "But guess how fast I can shower?" – CG17

Several patients noted that taking a positive approach using humor and jokes facilitated conversation about the illness and the side effects that were fun and optimistic rather than serious, since medical topics could be too heavy to discuss with their peers. These clever reactions helped reduce patients' feelings of being singled out by distracting their peers from focusing on differences and reducing the perceived seriousness of their illness.

In facilitating the developing of coping strategies, we identified the proactive role of caregivers. Caregivers often helped or wanted to help patients cope with situations in which other people's perceptions could be hurtful, especially when patients began attending school. For example, CG19 prepared P19 (age 8) to communicate about the illness with friends.

> [CG19 told P19 that] "It will feel different, not having your hair, but I'm already... I get a little tense about coming back [to school]. I know you [P19] get mad at me, but I think we should practice some lines to use, if people say odd things." So those are some things to work on... We can do a simulation of somebody's situation, so that she feels better equipped to deal with them. – CG19

Since CG19 knew she could not always be with P19 at school, she wanted P19 to be able to independently handle others' questions about the illness so P19 would not feel different and sad.

In this section, we identified how some pediatric patients developed self-management skills on their own to manage their illness, while in other cases, their caregivers coached them to develop such skills. In particular, patients not only learned self-care skills for managing their health but also developed protective coping mechanisms to better handle and prepare others' perceptions of their illness. Becoming independent in managing their health further indicated their active participation in their care.

DISCUSSION

In this section, we first discuss how patients achieved positive experiences in adapting to life with chronic illness and highlight the evolving process of patients' positive adaptation. We then discuss design implications to enable patient engagement with the positive adaptation process.

Pediatric Patients' Adaptation to Illness through Achieving Positive Experiences

Despite having negative experiences associated with illness, our findings showed that some pediatric patients also had positive experiences such as developing hope about their future, developing personal bonds and relationships, gaining life experience and knowledge, and developing self-management and coping skills. Pediatric patients' positive experiences identified in our study align with prior understandings of positive adjustment of cancer patients in the psychology literature. By recognizing and highlighting positive experiences along with negative ones, prior studies have found that positive psychological states can occur in the middle of highly stressful circumstances such as terminal illness, and that this can play a critical role in reducing damaging effects of negative states as well as provide a buffer against future stress and negative experiences [10, 42]. Studies also show that dispositional optimism (e.g., positive expectations for the future) is associated with benefits, such as achievement, less distress, better health-related quality of life, and longevity, throughout treatment [34, 38].

Nevertheless, as these prior studies noted, the positive experiences of pediatric patients are less examined than those of adult patients. Also, prior literature mostly focused on measuring either the effect of positive emotional states on negative emotions or the beneficial health outcomes stemming from positive emotional states. In contrast, our findings focus on patients' daily social experiences and uncover the process by which pediatric patients experience positive emotions and achieve positive attitudes in adapting to their illness, which has not been discussed previously.

Looking at commonalities across the pediatric patients' positive experiences, our study indicates mechanisms by which patients adapt to illness: when facing a stressor (e.g., changed appearance or limitations on activities), patients *recognized* the impact of the stressor on their lives; they worked to *understand* their illness and treatment process as they gained more health-related information from parents and clinicians; and they gradually *developed* skills, knowledge, and attitudes in response. During this process, patients had negative and positive experiences. As presented in our findings, positive experiences occurred when patients developed expectations for their short and long-term future, developed strong personal bonds with others, valued their newly gained knowledge, wisdom and life experience, and felt independent after developing self-management and coping skills. In summary, the process of positive adaptation to illness occurred through three mechanisms: *recognizing* (changes, problems, limitations), *understanding* (health-related information and situations), and *developing* (new thinking/views, relationships, knowledge, and skills), which led to positive experiences.

Importantly, our analysis indicates the evolving nature of the patients' adaptation process, as positive experiences directly influenced patients' perceptions of new problems brought by their illness. For instance, a positive attitude developed through personal growth (positive experience) affected perceptions and recognition of the impact of a new stressor. Positive adaptation in our study is, thus, an evolving process that occurs when positive experiences encourage patients to develop positive attitudes toward illness and treatment so that they can better perceive and focus more on positivity, rather than negativity. In other words, patients initially "recognize" negative impacts of the illness, begin to "understand" their illness and treatment, and "develop" new views, skills, and coping strategies that in turn help them better "recognize" positivity during later challenges.

Most existing technological support presented in HCI promotes the repressive adaptation style [35] of pediatric patients by alleviating their negative experiences (e.g., a robot that helps to reduce anxiety during clinic visits [19]) or focuses on a single aspect of patient adaptation and technology design (e.g., "understanding" illness or "developing" social skills [21, 25]). Positive experiences of pediatric patients, especially in their adaptation process, have not been discussed or highlighted in prior works. However, based on our study, we believe there are more design opportunities for health technology to support other crucial elements of the adaptation process, such as recognizing positive aspects and developing valuable skills, to facilitate positive experiences.

Design Implications

In this section, we suggest design considerations to enable pediatric patients to re-orient their views and facilitate positive thinking so they can further develop and maintain positive attitudes toward living with their illness. These design considerations aim to support or enhance each phase of the patients' positive adaptation process: goal setting to work toward the future (*understanding*), proactive coping skills using positive scenarios (*developing*), and remembering positive experiences of finding benefits (*recognizing*). As discussed earlier, considering the evolving nature of their positive adaptation process, we suggest that the patients' understanding of their illness and treatment trajectory should be supported first, so that based on their learned, gained knowledge, patients can develop new skills, views, and thinking, which can eventually facilitate their ability to recognize positivity better.

Support Goal Setting to Orient and Work toward the Future

Despite their complaints about limitations on daily activities due to illness, our findings indicate that some pediatric patients had positive experiences when they developed future-oriented thinking and self-management skills. In the process of developing new thinking and skills, *understanding* health-related information about their illness and treatment was very important; this was mostly taught and shared by their parental caregivers. Thus, to enhance these positive experiences, we suggest supporting patients' *understanding* of their health conditions through setting goals and plans in collaboration with caregivers, so patients' goals can orient their thinking toward a positive future and instead of making comparisons with the past.

Setting goals can provide valuable opportunities for patients and caregivers to discuss patients' current health conditions, ongoing progress, and expectations about future together, so that they can make plans about health-related tasks or social activities based on short- and long-term goals that align with the patient's treatment trajectory and situation. For instance, when patients cannot play sports post-BMT procedure due to potential infection risk or weak muscles, they can add that activity (e.g., "Go swimming with David") to their short-term goal list. In doing so, the caregivers can assist in determining feasibility and appropriate timing for each goal (e.g., Go swimming "after" getting the port removed) and can provide necessary knowledge about the illness accordingly. Patients should also be able to set long-term goals (e.g., future career), which help maintain their positive outlook over time and redirect patients' perspectives from the negative (e.g., comparison with the past) toward the positive (e.g., hopeful outlook).

In addition, setting a list of goals can encourage patients' learning and development of self-management skills. Setting a specific goal may motivate patients to practice self-care skills as well as acquire new skills. For instance, patients can set taking medication as a task-driven goal to achieve a short-term goal, as seen in the cases of P3 and P16 who actively created and used reminders (regular meals, medication time) to achieve their short-term goals .

Integrating with individuals' treatment milestones, proper visualizations also need to be implemented in order to present the patient's progress toward achieving the goals. This feature can be specific to the needs of our patient population, such as patients understanding and learning about their progress in their treatment trajectory through using visual or physical cues (e.g., counting the number of d-days until they can go back to school or to remove broviac from their chest). In some cases, the representation of goals might cause patients to feel depressed about not being able to achieve or make progress toward those goals, particularly when they have setbacks and worsening health conditions. To manage such situations, the system can help patients set concrete and realistically achievable goals. Drawing on existing goal setting frameworks [7], child-friendly interfaces (e.g., pictures or animations, rather than texts) can be utilized to construct achievable goals by asking about a specific sport they want to play, or suggesting other related activities or tasks they might enjoy or need. Moreover, visualization of current goal progress status should be able to show different degrees of granularity of achievement, including even incremental and small progress, which can allow patients to experience achievement and confidence and increase self-efficacy, an important element in the process of learning self-management [21].

Patients' goal setting related to medical tasks is not new in existing health application designs (e.g., [11]); however, those features may not be supporting a positive adaptation process by supporting patients' understanding and re-orienting their thinking toward the future. We, thus, suggest that identifying and highlighting improvements, such as tasks patients can do themselves or indicators that their health is improving, can help them learn about their illness/treatment trajectory, orient them toward a hopeful future, and boost positive experiences in the process of setting short-term goals and achieving long-term goals.

Support Proactive Coping Skills Using Positive Scenarios

In addition to gaining medical knowledge, life experience, and self-management skills, patients proactively developed coping skills over time to handle other people's questions or reactions to their illness and appearance by making jokes instead of hiding visible side effects (e.g., covering hair loss with a hat). These coping skills the patients proactively developed were critical since they helped effectively manage and mitigate potentially stressful situations and improve patients' outlooks.

To support the process of *developing* skills and enhance positive experiences, we suggest facilitating proactive coping skills using positive scenarios. Simulations with scenarios are often used with technology to help children experience various situations and learn different skills. (e.g.,[43]); and this was also seen in our study in which some caregivers proactively helped their sick children practice strategies by envisioning relevant situations (e.g., CG19). Thus, positive scenarios for learning coping skills can present patients with potential situations where they may encounter various challenges (e.g., managing peers' reactions to their changed looks at school). The positive scenarios can also provide tips or guidance on patients' interpretation by nudging patients to take a more positive approach to such situations. By learning about such situations, patients can experience and think about how to manage challenges proactively. This indirect experience may help patients develop self-determination, discuss issues with caregivers, and practice their responses without experiencing them in actual situations and being hurt unexpectedly. Thus, scenario-based learning can allow patients to develop coping skills that may positively manage actual crises. The aim of scenario-based learning is not to persuade pediatric patients to acquire coping skills that are widely used among peer patients. Instead, it aims to enable patients to indirectly experience different situations and develop their own coping skills, which may ultimately support more positive attitudes in adapting to their illness.

Remind about Positive Experiences for "Benefit Finding"

Our analysis shows that pediatric patients with cancer tend to *recognize* positive gains in their lives, such as strong relationships with family members and clinicians, in spite of their tough, isolating treatment period. In fact, *recognizing* positive aspects based on previous positive experiences was a key part of the evolving process of patients' adaptation to their new life with illness. In the psychology literature, such positive gains are referred to as 'Benefit Finding,' defined as 'positive effects that result from a traumatic event' [13]. Drawing on this concept, we present a design implication that leverages positive moments and seeks to enhance them. While communication tools exist (e.g.,[16]) to enhance patients' relationships with clinicians and family members, these tools mainly focus on information-sharing, rather than fostering positive experiences.

To support the process of recognizing positive experiences, we suggest reminding pediatric patients of positive experiences to emphasize silver linings of living with illness, such as personal bonds. For instance, patients can capture and record daily positive moments with their family or clinicians or positive thoughts in the form of texts, photos, videos, or drawing. The accumulated records can serve as reminders of the positive moments when they are going through difficult times later. Also, integration with existing reminder systems for patients (e.g., reminders for medication [37, 40] or exercise [30]) as well as the patients' treatment trajectory can provide the right timing for reminding about and highlighting positive moments – such as at the most stressful moments (e.g., after the BMT procedure) versus similar moments (e.g., receiving test results, missing school day). By reflecting upon previous positive experiences, the reminder serves as a bridge that links the positive memory patients experienced to patients' perspectives on current situations and maintains their sense of gratitude, even if they are currently experiencing difficulties. This can ultimately reinforce patients' positive thought processes through repeatedly capturing, recording, and reminding them about positive moments.

Design Example: An Interactive Journal System

Each consideration we suggested for health technology design above should work together with the others rather than individual design requirements, as they are part of the positive adaptation process that evolves by nature. We thus provide an illustration of how our design implications can be applied in practice. For instance, an interactive journal system for pediatric cancer patients can be designed. Journaling is known as a way to promote positive psychology through reflection (e.g.,[29, 17]). People feel gratitude when writing journals about their daily experience. Such an interactive journaling system with a goal list, reminders of positive moments, and proactive scenarios to develop coping skills will enhance the positive experiences of pediatric patients. Specifically, to create journal entries, patients should be able to use different methods, including writing, drawing, or uploading photos, videos, or music to describe their daily experiences. Considering differences based on their age and gender, various options will allow pediatric patients, particularly younger ones, to easily illustrate their distinctive experiences or feelings. These features will support pediatric patients' ability to understand illness and treatment, develop their skills and strategies, and recognize positive moments in their daily lives. Aligning with prior works on positive computing for children [47], our analysis also showed that pediatric patients may have different interpretations of positive experiences. Thus, the system should allow patients to highlight positive experiences by manually marking them in journals based on the patients' own interpretations; but it can also automatically highlight and respond to negative emotions by suggesting positive experiences. Although this system may also provide a caregiver version so that caregivers can help patients set goals and have access to shared journals or post their stories/questions, we suggest that caregivers may not be allowed to read patients' journals unless the patients grant access. In addition, while existing journal systems, such as electronic daily symptom reports for adolescent cancer patients [1] work well to address important health concerns, patients may remember negative experiences when they look back. Our suggested journal system, in contrast, encourages patients to capture and focus on positive moments. With notifications and prompts, the system will communicate with patients to support them in maintaining positive thinking about living with their illness.

LIMITATIONS AND CONCLUSION

This study has limitations due to the particular oncology context that we examined. Positive experiences that we identified may be specific to pediatric participants with cancer. Thus, further research is necessary to explore positive experiences of pediatric patients with other chronic illnesses (e.g., diabetes). In this study, we examined positive experiences that pediatric cancer patients had while adapting to their illness. Based on our analysis, we reveal the evolving process of adaptation though positive experiences. We also present specific design implications to support pediatric patients in understanding their illness, developing new perspectives and coping skills, and recognizing more positive moments in their lives with the illness. Extending the literature on technical interventions for pediatric patients, this study suggests that researchers account for positive experiences of pediatric patients along with their challenges.

ACKNOWLEDGEMENTS

We would like to thank the child patients and their parental caregivers who participated in our study. We also appreciate Dr. Laura Sedig and other clinicians for helping with recruitment. This work was funded by NSF(#1657411) and the U-M Office of Research (UMOR).

REFERENCES

[1] Christina Baggott, Faith Gibson, Beatriz Coll, Richard Kletter, Paul Zeltzer, and Christine Miaskowski. 2012. Initial evaluation of an electronic symptom diary for adolescents with cancer. *JMIR research protocols* 1, 2 (2012), e23.

[2] Linda Bolier, Merel Haverman, Gerben J Westerhof, Heleen Riper, Filip Smit, and Ernst Bohlmeijer. 2013. Positive psychology interventions: a meta-analysis of randomized controlled studies. *BMC public health* 13, 1 (2013), 119.

[3] Rafael A Calvo and Dorian Peters. 2014. *Positive computing: technology for wellbeing and human potential*. MIT Press.

[4] Gang Chen, Nilufar Baghaei, Abdolhossein Sarrafzadeh, Chris Manford, Steve Marshall, and others. 2011. Designing games to educate diabetic children. In *Proceedings of the 23rd Australian Computer-Human Interaction Conference*. ACM, 72–75.

[5] Michael A Cohn, Martha E Pietrucha, Laura R Saslow, Jen R Hult, and Judith T Moskowitz. 2014. An online positive affect skills intervention reduces depression in adults with type 2 diabetes. *The journal of positive psychology* 9, 6 (2014), 523–534.

[6] Joseph M Currier, Susan Hermes, and Sean Phipps. 2009. Brief report: Children's response to serious illness: perceptions of benefit and burden in a pediatric cancer population. *Journal of Pediatric Psychology* 34, 10 (2009), 1129–1134.

[7] Trevor Day and Paul Tosey. 2011. Beyond SMART? A new framework for goal setting. *Curriculum Journal* 22, 4 (2011), 515–534.

[8] Karin Enskär, Marianne Carlsson, Marie Golsäter, and Elisabeth Hamrin. 1997. Symptom distress and life situation in adolescents with cancer. *Cancer Nursing* 20, 1 (1997), 23–33.

[9] Shelly Farnham, Lili Cheng, Linda Stone, Melora Zaner-Godsey, Christopher Hibbeln, Karen Syrjala, Ann Marie Clark, and Janet Abrams. 2002. HutchWorld: clinical study of computer-mediated social support for cancer patients and their caregivers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 375–382.

[10] Barbara L Fredrickson. 2001. The role of positive emotions in positive psychology: The broaden-and-build theory of positive emotions. *American psychologist* 56, 3 (2001), 218.

[11] Ankit Gupta, Tim Heng, Chris Shaw, Linda Li, and Lynne Feehan. 2018. Designing pervasive technology for physical activity self-management in arthritis patients. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare*. ACM, 1–10.

[12] Shefali Haldar, Sonali R Mishra, Maher Khelifi, Ari H Pollack, and Wanda Pratt. 2017. Opportunities and design considerations for peer support in a hospital setting. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 867–879.

[13] Vicki S Helgeson, Kerry A Reynolds, and Patricia L Tomich. 2006. A meta-analytic review of benefit finding and growth. *Journal of consulting and clinical psychology* 74, 5 (2006), 797.

[14] Caroline McKnight Hexdall and E Scott Huebner. 2007. Subjective well-being in pediatric oncology patients. *Applied Research in Quality of Life* 2, 3 (2007), 189–208.

[15] Hannele Hokkanen, Elina Eriksson, Outi Ahonen, and Sanna Salantera. 2004. Adolescents with cancer: experience of life and how it could be made easier. *Cancer nursing* 27, 4 (2004), 325–335.

[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] Şerife Işık and Bengü Ergüner-Tekinalp. 2017. The effects of gratitude journaling on Turkish first year college students' college adjustment, life satisfaction and positive affect. *International Journal for the Advancement of Counselling* 39, 2 (2017), 164–175.

[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*. ACM, 495.

[19] Sooyeon Jeong, Kristopher Dos Santos, Suzanne Graca, Brianna O'Connell, Laurel Anderson, Nicole Stenquist, Katie Fitzpatrick, Honey Goodenough, Deirdre Logan, Peter Weinstock, and others. 2015. Designing a socially assistive robot for pediatric care. In *Proceedings of the 14th international conference on interaction design and children*. ACM, 387–390.

[20] Anne E Kazak. 2005. Evidence-based interventions for survivors of childhood cancer and their families. *Journal of pediatric psychology* 30, 1 (2005), 29–39.

[21] Charalampos Kyfonidis and Marilyn Lennon. 2019. Making Diabetes Education Interactive: Tangible Educational Toys for Children with Type-1 Diabetes. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 441.

[22] 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.

[23] Zeina Atrash Leong, Michael S Horn, Lisa Thaniel, and Emily Meier. 2018. Inspiring AWE: Transforming Clinic Waiting Rooms into Informal Learning Environments with Active Waiting Education. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 98.

[24] Stefan Liszio and Maic Masuch. 2017. Virtual Reality MRI: Playful Reduction of Children's Anxiety in MRI Exams. In *Proceedings of the 2017 Conference on Interaction Design and Children*. ACM, 127–136.

[25] Leslie S Liu, Kori M Inkpen, and Wanda Pratt. 2015. I'm not like my friends: understanding how children with a chronic illness use technology to maintain normalcy. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, 1527–1539.

[26] Margaret M Mannix, Jonathan M Feldman, and Karen Moody. 2009. Optimism and health-related quality of life in adolescents with cancer. *Child: care, health and development* 35, 4 (2009), 482–488.

[27] Elisabet Mattsson, Anders Ringnér, Gustaf Ljungman, and Louise von Essén. 2007. Positive and negative consequences with regard to cancer during adolescence. Experiences two years after diagnosis. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 16, 11 (2007), 1003–1009.

[28] C Nadeane McCaffrey. 2006. Major stressors and their effects on the well-being of children with cancer. *Journal of pediatric nursing* 21, 1 (2006), 59–66.

[29] ME McCullough and RA Emmons. 2003. Counting blessings versus burdens: An experimental investigation of gratitude and subjective well-being in daily life. *Journal of Personality and Social Psychology* 84, 2 (2003), 377–389.

[30] Nicholas Micallef, Lynne Baillie, and Stephen Uzor. 2016. Time to exercise!: an aide-memoire stroke app for post-stroke arm rehabilitation. In *Proceedings of the 18th International Conference on Human-Computer Interaction with Mobile Devices and Services*. ACM, 112–123.

[31] Rachel Müller, Kevin J Gertz, Ivan R Molton, Alexandra L Terrill, Charles H Bombardier, Dawn M Ehde, and Mark P Jensen. 2016. Effects of a tailored positive psychology intervention on well-being and pain in individuals with chronic pain and a physical disability. *The Clinical journal of pain* 32, 1 (2016), 32–44.

[32] Biljana Novakovic, Thomas R Fears, Leonard H Wexler, Linda L McClure, Donna L Wilson, June L McCalla, and Margaret A Tucker. 1996. Experiences of cancer in children and adolescents. *Cancer nursing* 19, 1 (1996), 54–59.

[33] Andrea Farkas Patenaude and Mary Jo Kupst. 2005. Psychosocial functioning in pediatric cancer. *Journal of pediatric psychology* 30, 1 (2005), 9–27.

[34] Christopher Peterson. 2000. The future of optimism. *American psychologist* 55, 1 (2000), 44.

[35] Sean Phipps. 2007. Adaptive style in children with cancer: Implications for a positive psychology approach. *Journal of Pediatric Psychology* 32, 9 (2007), 1055–1066.

[36] Cornelia M Ruland, Justin Starren, and Torun M Vatne. 2008. Participatory design with children in the development of a support system for patient-centered care in pediatric oncology. *Journal of biomedical informatics* 41, 4 (2008), 624–635.

[37] Sirat Samyoun, Md Abu Sayeed Mondol, Ifat A Emi, and John A Stankovic. 2019. iAdhere: A voice interactive assistant to improve adherence to medical treatments: demo abstract. In *International Conference on Cyber-Physical Systems*.

[38] Michael F Scheier and Charles S Carver. 1985. Optimism, coping, and health: assessment and implications of generalized outcome expectancies. *Health psychology* 4, 3 (1985), 219.

[39] Nancy L Sin and Sonja Lyubomirsky. 2009. Enhancing well-being and alleviating depressive symptoms with positive psychology interventions: A practice-friendly meta-analysis. *Journal of clinical psychology* 65, 5 (2009), 467–487.

[40] Katarzyna Stawarz, Anna L Cox, and Ann Blandford. 2014. Don't forget your pill!: designing effective medication reminder apps that support users' daily routines. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*. ACM, 2269–2278.

[41] Anselm Strauss and Juliet M Corbin. 1997. *Grounded theory in practice*. Sage.

[42] Michele M Tugade, Barbara L Fredrickson, and Lisa Feldman Barrett. 2004. Psychological resilience and positive emotional granularity: Examining the benefits of positive emotions on coping and health. *Journal of personality* 72, 6 (2004), 1161–1190.

[43] Marco Vala, Pedro Sequeira, Ana Paiva, and Ruth Aylett. 2007. FearNot! demo: a virtual environment with synthetic characters to help bullying. In *Proceedings of the 6th international joint conference on Autonomous agents and multiagent systems*. ACM, 271.

[44] Jillian L Warren. 2019. Exploring the Potential for Tangible Social Technologies for Childhood Cancer Patients within the Hospital. In *Proceedings of the Thirteenth International Conference on Tangible, Embedded, and Embodied Interaction*. ACM, 733–736.

[45] L Wicks and A Mitchell. 2010. The adolescent cancer experience: loss of control and benefit finding. *European journal of cancer care* 19, 6 (2010), 778–785.

[46] Roberta Lynn Woodgate. 2005. A different way of being: adolescents' experiences with cancer. *Cancer nursing* 28, 1 (2005), 8–15.

[47] Svetlana Yarosh and Stephen Matthew Schueller. 2017. "Happiness inventors": Informing positive computing technologies through participatory design with children. *Journal of medical Internet research* 19, 1 (2017), e14.