4-29-2022

When Worlds Collide: Boundary Management of Adolescent and Young Adult Childhood Cancer Survivors and Caregivers

Elizabeth A. Ankrah

Arpita Bhattacharya

Lissamarie Donjuan

Franceli L. Cibrian

Anamara Ritt-Olson

See next page for additional authors

When Worlds Collide: Boundary Management of Adolescent and Young Adult Childhood Cancer Survivors and Caregivers

Comments

This article was originally published in *CHI Conference on Human Factors in Computing Systems (CHI '22)* in 2022. https://doi.org/10.1145/3491102.3517544

Creative Commons License

Copyright

Authors

Elizabeth A. Ankrah, Arpita Bhattacharya, Lissamarie Donjuan, Franceli L. Cibrian, Anamara Ritt-Olson, Joel Milam, Lilibeth Torno, and Gillian R. Hayes

When Worlds Collide: Boundary Management of Adolescent and Young Adult Childhood Cancer Survivors and Caregivers

Elizabeth A. Ankrah
Department of Informatics, University
of California, Irvine, USA
eankrah@uci.edu

Arpita Bhattacharya
Department of Informatics, University
of California, Irvine, USA
arpitab@uci.edu

Lissamarie Donjuan
Pediatric Oncology Research
Department, Children's Health
Orange County, USA
Lissamarie.Donjuan@choc.org

Franceli L. Cibrian
Fowler School of Engineering,
Chapman University, Orange,
California, United States
cibrian@chapman.edu

Anamara Ritt-Olson
Division of Health, Society, &
Behavior - Program in Public Health,
University of California, Irvine, USA
arittols@hs.uci.edu

Joel Milam
School of Medicine and Program in
Public Health, University of
California, Irvine, USA
milamj@hs.uci.edu

Lilibeth Torno
Pediatric Oncology, Children's Health
Orange County, USA
ltorno@choc.org

Gillian R. Hayes
Department of Informatics, University
of California, Irvine, USA
gillianrh@ics.uci.edu

ABSTRACT

Adolescent and young adult childhood cancer survivors experience health complications, late or long-term biomedical complications, as well as economic and psychosocial challenges that can have a lifelong impact on their quality-of-life. As childhood cancer survivors transition into adulthood, they must learn to balance their identity development with demands of everyday life and the near- and long-term consequences of their cancer experience, all of which have implications for the ways they use existing technologies and the design of novel technologies. In this study, we interviewed 24 childhood cancer survivors and six caregivers about their cancer survivorship experiences. The results of our analysis indicate that the challenges of transitioning to adulthood as a cancer survivor necessitate the development and management of multiple societal, relational, and personal boundaries, processes that social computing technologies can help or hinder. This paper contributes to the empirical understanding of adolescent and young adult cancer survivors' social experiences. We further contribute sociotechnical design provocations for researchers, designers, and community members to support survivors.

CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Empirical studies in HCI.

KEYWORDS

Survivorship, Boundaries, Disclosure, Transitions, Childhood Cancer Survivors

1 INTRODUCTION

Illness is often pervasive, affecting multiple areas of life, within macro, meso, and micro levels of organization [16, 77]. This includes interactions with institutions (e.g., medical, educational, media), peers, family members, and others across social networks [16, 77]. Cancer, an umbrella term for a large number of diseases, is no exception, and childhood cancer provides a unique lens to understand the ways in which illness impacts the individual in multiple areas of life over time.

Individuals diagnosed with cancer earlier in life are at higher risk for experiencing poorer quality of life, onset of new diseases, cognitive impairment, and other challenges [14, 19, 69, 70]. Each year in the United States (US), it is estimated that 15,780 children and adolescents between the ages of 0 – 19 years are diagnosed with cancer [82]. Due to advancements in medicine, science, and technology, the overall survival rates of those diagnosed with cancer have greatly improved, especially among childhood survivors of cancer. Yet, by the age of 45, childhood survivors are at high risk for experiencing health complications, late or long-term biomedical complications, as well as economic and psychosocial challenges that impact their quality-of-life [46]. Thus, there is an important

need to understand and support the needs of survivors of childhood cancer during adolescence and young adulthood. Researchers should consider the unique boundaries and ways survivors attempt to present themselves during adolescence and young adulthood.

Boundaries allow for protection, identification, and organization [59, 72]. They are borders that determine who is in and who is out and allow others to distinguish between what is acceptable and what is not [15, 72]. An individual's boundaries are not always visible and may be perceived differently by others. Boundaries may be mental, psychological, and/or physical [59]. As survivors move from hospitals, boundaries that were once clearly defined become less so [1], especially concerning the disclosure of health information. It is crucial to identify the new boundaries that survivors and caregivers must manage.

In the Human-Computer Interaction (HCI) community, much of the knowledge presented about cancer survivorship is derived from studies of breast cancer patients [34–38, 68] and other adult cancers [24, 26, 29, 67], with few works focused on childhood cancer patients [45, 54, 64, 65] and fewer still derived from cancer survivors [23, 25]. Thus, there is a gap in the understanding of the cancer survivorship experience within HCI, researchers, designers, and community members may lack the knowledge necessary for designing appropriate sociotechnical solutions to help survivors manage and support their life-long care. More work is needed to understand the systemic factors that influence the lived experiences among adolescent and young adult childhood cancer survivors. In this study, we aimed to answer the following research questions:

- How do survivors manage boundaries across multiple contexts outside the clinic?
- What are the opportunities for designing sociotechnical solutions to support survivors in managing these boundaries?

In this study, we conducted interviews with 24 adolescent and young adult childhood cancer survivors (AYA CCS, henceforth referred to as survivors) and 6 caregivers. Through this paper, we reflect on the results of our empirical study and provide a conceptual understanding of survivors' and caregivers' social experiences. We discuss three areas of opportunity for the HCI community: (1) Addressing systemic issues, (2) preserve the context of disclosure and privacy, and (3) supporting growth through transitions. Our work contributes to two areas of research in HCI. First, we present an empirical understanding of issues experienced by cancer survivors and their caregivers outside the hospital by focusing on the societal, relational, and personal boundaries that influence their illness experience. Second, we identify key open areas of research for scholars at the intersection of survivorship research and the design of sociotechnical solutions for health information sharing and social computing.

2 BACKGROUND

In this section, we summarize relevant research focused on cancer survivorship in HCI. We discuss boundary management as it pertains to understanding the illness experience of survivors and caregivers.

2.1 Cancer Survivorship Research and HCI

Cancer survivorship is a distinct phase in the cancer care continuum [66]. It is the longest phase and has the largest population. Yet, within the HCI community, cancer survivorship is understudied, with cancer survivors often grouped with cancer patients [34]. In this work, we sought to explicitly build on existing HCI research around cancer and cancer survivorship as well as that from oncology, public health, and related areas to better understand cancer survivorship specifically.

Cancer survivorship researchers define the survivorship period as having three "seasons:" acute survival, extended survival, and long-term survival[1]. The acute survival season is defined as the period following diagnosis and concludes at the completion of treatment [11, 33]. Medical and psychosocial care related to cancer is administered during this period, often described as chronic cancer care [29]. Extended survival is the period following the completion of cancer treatment. In this season, clinicians continue to monitor patients for signs of remission [6, 11, 33], and survivors and caregivers focus on addressing the long-term consequence of treatment if present. This period may extend from the time patients receive the diagnosis of "no evidence of disease" to year five. Finally, in long-term survival, survivors are considered in remission with low chances of relapsing. This period occurs when patients pass the five-year mark with no evidence of cancer. Cancer research frequently follows a more clinical timeline, starting at the point an individual is diagnosed with a disease and concludes when the individual has no evidence of the disease. Cancer survivorship research often takes a broader view beyond the presence of cancer, to the long-term and late-term effects, and quality of life impact that survivors may face.

Cancer survivorship research focuses on the illness experience of survivors. Jacob et al. [34] describe the recruitment of cancer survivors and volunteers as "cancer navigators" for newly diagnosed cancer patients to help cancer survivors experiencing "survival loneliness" and other emotional challenges. Some cancer navigation programs may lack the time or resources needed to support the emotional challenges that survivors experience. Eschler et al. [24] highlight that survivors are generally the "life-blood" of online cancer communities. They provide the most support in the form of encouragement and advice through their lived experiences and receive emotional support in the form of identity validation [24]. This demonstrates a need to build on this work by understanding the illness experience of survivors as they seek support in situating themselves in their after cancer treatment and everyday life [24, 25, 43]. However, the gap we see in current research is likely due to challenges related to recruiting and distinguishing between cancer patients and cancer survivors.

Within the HCI community, extensive work has been conducted surrounding cancer patients [26, 29, 36, 41, 42, 67, 68, 73]. These works have contributed to the community's understanding of the cancer patient journey [36, 73] and have resulted in implications for the design of technologies that support the informational and social needs of patients and their caregivers during this critical clinical phase. However, as these patients move away from the

---

[1]Fitzhugh Mullan, originally refers to this term as permanent survival, however we change it to long-term survival to reflect the sensitivity of the term. The clinician we partnered with avoided using the permanent as remission is sometimes fragile, characterized by multiple relapses and partial responses.

highly clinical phase, we must understand the non-clinical needs of the survivor. Few works exist within the HCI community that explicitly aim to describe and understand the experiences of cancer survivors [23, 25]. Research among cancer survivors reveals that they have different needs and priorities than patients, which may include more need for contextualizing and coming to terms with their cancer experiences and returning to life as "normal," meaning without immediate fear of death brought from survivor cancer [34, 43]. Thus, understanding the experience of survivors is paramount to our understanding of health [83] as "a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity." Therefore, there is value in seeking to understand the experience of cancer survivors outside of their medical experience and particular implications for their experiences as they relate to social computing and information technologies. In this paper, we highlight the impact of personal and social factors on the survivors' experience.

2.2 Boundary Management

Boundaries refer to the temporal, relational, physical, emotional, or cognitive limits that define entities as separate from one another [5, 50]. The concept of boundaries has been particularly useful in understanding how professions became distinguished from one another (e.g., laypeople from experts, scientists from humanists). Boundary theory describes the process of the creation and main-tenance of boundaries by individuals as a means to define and distinguish among entities (e.g., roles, ideas, people, institutions, and more) in their environment. This may often be done through the erecting of "mental fences," demarcations or borders, created around geographic locations, people, ideas, or events in time that appear to be connected or otherwise linked. These demarcations create slices of reality that have particular meaning for the individual managing the boundary [5].

The concept of boundary management (i.e., boundary work [50]) has predominantly been studied in the context of organizational settings, often focusing on the organization of domains in life (e.g., home/family, work and other third places like places of worship) [5, 50, 61]. In the CHI and CSCW literature, boundary management has been studied to understand how information communication technologies (ICT) may be used to manage an individual's bound-aries within organizations and the work that is performed [15], between work and home [61, 74], with access to multiple tools [20], and across multiple life domains [62]. To understand how disease management in the home differs from traditional disease manage-ment in the hospital, Aarhus and Ballegaard explore five factors that affect boundary work: objects, activities, place, character of disease and collaboration. They hypothesize that boundary work occurs on a continuum of invisibility-visibility and integration-segmentation [1]. Individuals engage in boundary work by making their disease visible or invisible in their homes. For example, people may hide objects related to their healthcare in more public areas of the home (e.g., the living room) and more visible in private areas (e.g., their bedroom). Thus, people routinely and continually work to create or maintain their boundaries through the management of their health-related objects, rituals, and activities depending on the place, the characteristic of the disease (and treatment) and

the level of collaboration they have with others. Taken together, this work demonstrates that research is needed to understand the boundary management of hospital-home, illness-disease, patient-survivor, sick-well and other boundaries that were clearer when the patient was firmly integrated in a system/setting with established roles. The boundary management in cancer survivorship, particu-larly for those transitioning from childhood to adulthood, leaves open opportunities for understanding and designing sociotechnical experiences that aid in chronic health management.

3 METHODS

To understand the lived experience of navigating social spaces after cancer treatment, survivors' challenges, and opportunities for sociotechnical solutions, we conducted a qualitative interview study with 24 survivors and six caregivers.

3.1 Recruitment

Participants, both survivors and caregivers, were recruited through a convenience sampling procedure. We used advertisements placed throughout a children's hospital in the western US with active on-cology and survivorship programs and emailed patients of that same clinic. The clinical staff approached participants at clinic vis-its, recommended annually to prevent and address potential late effects of cancer treatment [21]. Recruitment was primarily led by the third author at the survivorship clinic, and she obtained informed consent from participants who expressed interest and were available. Participants who did not have time to complete the consent procedures during their visit to the clinic were told to contact the lead author or their emails were collected to be con-tacted later. The lead author reached out to interested individuals via a video call on the hospital's Health Insurance Portability and Accountability Act (HIPAA) protected Zoom account and obtained scanned written consent for those not consented at the clinic. Ad-ditionally, verbal consent was obtained from all participants before starting the interview. Each participant received $25 compensation in gift certificates. Recruitment occurred during the December 2020 - June 2021, during the Covid-19 pandemic, and recruitment prac-tices adhered to the criteria established by the hospital. All study procedures were approved by the children's hospital ethics review board and a secondary university review board.

3.2 Participants

All participants had received cancer treatment at the same children's hospital in the US. We report on the aggregated information to protect the confidentiality of the participants (and so parent-child pairs cannot identify each other in the study). We interviewed 24 survivors (age range 15-35 years), four of whom were minors under 18 years (Table 1). We obtained parental consent and child assent for minors.

Six caregivers participated in our study (Table 2), a much smaller number than we were able to recruit survivors even though every survivor was encouraged to share study information with their caregivers, and we also used alternate recruitment methods to con-tact caregivers directly. We speculate that the lack of caregiver participation compared to the young-adult survivors also demon-strated the shift in responsibility of care to the survivor as they age.

Table 1: Summary of participant information on demographics and cancer diagnosis (total n=24)

Age (range, median in years, SD)	15-35 years (median = 19 years, SD=4.9)
	<18 years (n=4)
Gender	Female (n=17), Male (n=7), Non-binary (n=0)
Race	White (n=9), Asian (n=3), Mixed (n=2), Non-identified (n=10)
Hispanic or Non-Hispanic Ethnicity	Hispanic (n=10), Non-identified (n=14)
Age of cancer diagnosis (range, median in years)	6 months to 17 years old. One survivor relapsed at 22 years old.
Years from end of cancer treatment	0-5 years: (n = 2)
	6-10 years: (n = 2)
	11-15 years: (n = 9)
	16-20 years: (n = 11)
Cancer Type	Hodgkin's lymphoma, Acute Lymphocytic Leukemia, Wilm's tumor Rhabdomyosarcoma, Neuroblastoma, Osteosarcoma, Langerhans Cell Histiocytosis

Table 2: Summary of caregiver information on demographics (total n=6)

Age range (median in years)	43-57 years (median =48)
Gender	Female (n=6)
Race	White (n=4); non-identified (n=2)
Ethnicity	Hispanic (n=2), non-identified (n=4)
Age of child at the time of study	15-20 years (median = 16 years, SD = 2)

All caregivers who participated had survivors under the age of 18 and/or dependent on the parent for healthcare/disability needs.

3.3 Study Procedures

We conducted 60–90-minute remote semi-structured interviews through Zoom, which were audio-recorded with permission from the participants and later transcribed. Interviews focused on a broad set of topics to understand the experiences of youth cancer survivorship and opportunities for technological support: health background and cancer treatment experience, social/community support, information seeking, caregiving, care management, survivorship advocacy and management, their identity, and demographics. Participants were additionally asked, "How do they balance their survivorship with other areas/roles in their life?" and advice they would give to other survivors. Additional subtopics, details, and questions evolved during the interviews to focus on those topics the participants found most salient. Participants were given the option to conduct their interviews in English (n=29) or Spanish (n=1). Two interviewers were present during 24 of the 30 interviews, wherein one researcher conducted the interview and the other took notes and asked follow-up questions as needed. In the other six interviews, a single researcher conducted the interview and wrote memos directly following the interviews to capture reflections from the interview that might not be clear in a verbatim transcription (e.g., tone of voice, facial expression). At the conclusion of each interview, interviewers discussed the interviews, wrote memos, and reflected on major themes in the interviews.

3.4 Data Analysis

Two members of the research team (first and second authors) initially read and used inductive coding methods for a subset of the interview transcripts and notes for five participants. This subset of participants was chosen to incorporate the diversity of experiences of survivors and caregivers (e.g., age of cancer, current age, memory of the cancer experience, long term effects of cancer treatment). First, they individually conducted in vivo coding [60], noting quotes and phrases that the patients used directly this game us a list of codes such as 'I was told,' 'getting to know how serious it was,' 'back to normal,' 'normal kid,' 'I hate when people pity me,' 'you have to set boundaries,' 'I don't post,' 'I don't tell people,' 'lucky that,' 'leaving hospital' and so on. Following these initial codes, coders independently asked reflective questions such as 'what is going on here' during a series of descriptive coding activities [60] in which they identified a series of topics such as boundaries, cancer identity, mental health support, social support, needs of survivors, parental caregiver roles, survivorship programs and more. Across these activities, the coders developed approximately 100 distinct codes. To minimize these topics, coders met to discuss their codes and determine how to combine them further. During these sessions, coders engaged in other activities, such as affinity diagraming [30] to visually determine the relationship between codes. They then met with others in the research team to discuss the preliminary findings and initial codes.

The initial focus of our analysis centered on our research questions about transitions through social aspects of survivorship. As our analysis progressed, and we wrote memos, a recurring theme emerged from the data about how survivors work to manage how they present or want to present themselves in different contexts as cancer survivors and as adolescents and young adults who have not had cancer. During discussions, we conceptualized this invisible work done by survivors in terms of boundaries in the cancer survivor's social life outside the clinical setting. The coders then revised

Table 3: Codes focused on boundaries in social lives of survivor

Code	Description
Boundaries (general)	Boundaries of the survivor in relation to the community through their life. These are fluid and change based on the context –people, online or offline spaces such as school, work
Boundaries in sharing about the illness experience	The survivor's privacy and comfort in sharing about cancer and treatment with their social network.
Boundaries in involvement in managing the illness	Boundaries of the survivor about resource and time management, persons involved and decisions to make about their health outside the clinic (e.g., transportation to and from the clinic, make their health information available in their social network).
Boundary crossing or violated	This included times when the survivor's boundaries were crossed or violated intentionally or unintentionally by people in their social network.
Identity	Survivor's perceptions of self
Social network	People in the survivor's and caregiver's network (e.g., parent, nurses, extended family, peers with cancer, peers without cancer, community service providers)
Location	Location of the interaction (if any) (e.g., School, Home, Work, Church, Hospital, Public Space, social media or online)

Table 4: Summary of themes in Findings

Types of boundaries	Definition
Societal	Encountered by the survivor or the caregiver(s) as they navigate systems including the healthcare system, educational system, and employment.
Relational	Between the survivor and one or more people in their social network, for example, parent(s), teacher(s), and social media.
Personal	Individual beliefs, worldviews, and values as they respond to and interact with life outside the hospital.

the code book and re-coded the subset of five transcripts (explained above) in Atlas.ti[2] using the finalized codebook (Table 3). The coders then met to review and resolve any discrepancies in coding and refined the code book and respective descriptions. Following this, each coder coded the remaining interviews independently (coder 1 coded 13 interviews and coder 2 coded 12 interviews). Coders wrote memos and discussed them with the research team throughout the analysis.

Following a process of making connections across themes in our memos [30], we aimed to find ways to better understand the boundaries identified by the final codes. Thus, we considered the illness experience [16] and examined it across different locations, and considered the level at which the interaction occurred such as the personal, dyadic, group, and systemic levels [16, 77]. Although our data set consists of empirical evidence of various complex phenomenon in a survivor's life beyond boundaries, the analysis and findings presented in this paper are scoped to the research questions of this study.

4 FINDINGS

Based on the context of the interactions of survivors outside the clinic, which included location, people in their network, and institutional and social norms, we categorized the empirically derived themes into boundaries that influenced survivors' and caregivers' illness experience outside the clinic into three: (1) societal, (2) relational, and (3) personal boundaries (summarized in Table 4 and Figure 1).

4.1 Societal Boundaries

We define societal boundaries as the implementation of legal and ethical rights that are pre-established by the institution that governs the setting of survivors and caregivers. Individuals may have little to no control over the construction of this boundary but may have legal, medical, or ethical protections in place. It may be impossible or illegal for people outside the institution to cross this boundary without the individual's explicit consent or awareness.

Medical rights protect survivors from potential harm when interacting with institutions. These rights seek to protect the survivor and caregiver from undue discriminatory, reputational, and other

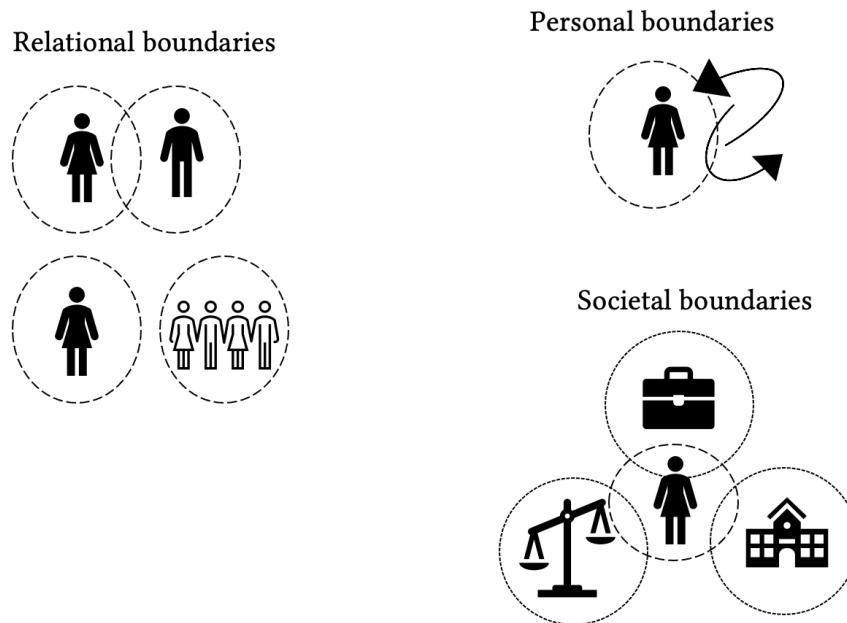---

[2]Atlas.ti: https://atlasti.com

Figure 1: Boundaries in survivors' interactions outside the clinic. All boundaries are permeable. Though societal boundaries are also permeable, we depict them as more solid than other boundaries, because at times, it is difficult for societal boundaries to be crossed.

societal harm that may result from their cancer experience. In the US, the management of medical, financial and educational status becomes the responsibility of the adult when they turn 18 years of age. For instance, although C06's child was legally an adult and could be held legally responsible for managing their medical, financial and educational status, C06's child was still interdependent as they experienced multiple co-occurring conditions and late and long-term effects of cancer treatment.

And all that has been another big problem because after you turn 18, your parents cannot get any information about your [medical] records, you know. Like a bill comes, and I cannot call to get the information. So, whenever I have to call, I have to have [my daughter] get on the line. Then she needs to give permission. They'll ask her 'Oh, do you give your mom permission to ask questions about your account' or whatever. (C06)

Laws, such as HIPAA in the US [84], ensure privacy and confidentiality protection for patients. Additionally, disclosing medical information, especially cancer information, is protected by the United States Freedom of Information Act of 1966, which notes cancer as the only disease considered an invasion of privacy when disclosed [66]. Thus, the decision of disclosure for childhood cancer survivors in the US rests completely on the childhood survivor once they are 18 years old. Managing societal boundaries might add to the burden of managing their health condition. Societal boundaries of young adult childhood cancer survivors are legally protected or institutionally managed, and survivors must go through proper

documentation and legal challenges. This disclosure can also be frustrating for caregivers who are primarily responsible for supporting the wellbeing of their children and managing their financial and medical needs.

Childhood cancer survivors and their caregivers must additionally navigate the educational system. Some participants experienced after cancer treatment effects, such as cognitive impairments (e.g., difficulty remembering, learning new things, or concentrating) and additional disabilities, including visual impairment or the loss of a limb. These challenges require additional services from schools. Caregivers often must inform their child's schools about their child's medical history and challenges to ensure that they receive appropriate accommodations to succeed in their academics. Here, C02 spoke about the difference between services and accommodations to support their child's learning in the school system:

And a 504 plan [3] (classroom accommodations for disabilities [52]) is just an accommodation and it doesn't cost our government anything, so what happens is if you want an IEP [4] (Individual Education Plan, which documents the accommodations required [53]), you have to go through a really hard process in order to get that. (C02)

_____

[3] A Section 504 Plan is an accommodation plan that requires classroom teachers and other school staff to provide accommodations and services for eligible students in the US.
[4] The Individualized Educational Plan (IEP) is a US plan or program developed to ensure that attending an elementary or secondary educational institution receives specialized instruction and related services.

Similarly, C06 described a community service that provided job training skills for her child who experienced multiple comorbidities and challenges. The community service provided her daughter resources and services (e.g., public bus services for people with disabilities) and taught her skills needed for different jobs. However, learning about these services requires additional knowledge, experience, and expertise; thus, caregivers need additional support to understand these policies. Both caregivers and survivors described relying on experts—such as social workers, school case workers, and others—to help them navigate post-hospital life, as C03 explained:

For the first time, I had somebody [who understood] what was going on, and I didn't have to fight. I started crying in the first 10 minutes of that meeting because [they were] the first person to actually look at this stuff and saw my child, and I didn't have to fight with them for help. She went from failing to honor roll. (C03)

Caregivers must continue to provide substantial support for their children as they transition through the primary and secondary educational system. This long-term care requires them to be knowledgeable about the different services available to them at each stage, for which they must stay continuously aware of their children's cognitive needs. Thus, caregivers continuously balance their role as parents, caregivers, advocates, and experts in multiple areas, at sometimes substantial cost to their own well-being [2, 64, 75].

4.1.1 Response to Societal Boundaries. The lack of control over the creation and deconstruction of societal boundaries may leave survivors and caregivers feeling powerless, an issue that better training and engagement in self-advocacy can address to a degree. Some caregivers in our study described teaching their children to advocate within the various systems they must navigate. For example, C05 shared that she taught her child to communicate with her teachers because she could not always remind the teachers herself. As her teachers changed each term, this need for self-advocacy only increased.

It was really important to teach [my daughter] to advocate for herself. She's been doing that since freshman year. She goes to her teachers, [or] she sends an email at the beginning of the Semester when she has new teachers. She [explains] her diagnosis, explaining her history of cancer and that she's really driven to do well, but she needs their help, and she lays out the things that are important for her. (C05)

Self-advocacy allows children to become more independent and build self-efficacy as they transition into adulthood [28]. When students transition from secondary education to post-secondary (e.g., university) education, regardless of their cancer status, they tend to experience the responsibility of navigating the healthcare system shifts from the parent to the child. In preparation for this shift, parents often begin teaching their children to advocate for themselves, by teaching them to ask questions and engage in health management. Highlighting the importance of the child's involvement in societal boundaries, C03 stated:

Allow your child to be a participant [in their care] instead of making them a victim in their care. (C03)

In this quote, C03 cautions other caregivers to involve their child in their care management, and failure to do so may result in victimization as they may lack the necessary skills to navigate the system and request the support they need. Effective communication between parent and child can help the family navigate societal boundaries and reduce unintentional harm. Thus, community engagement and building awareness among survivors and caregivers about social policies (labor market, criminal justice, anti-discriminatory) and public policies (educational, health, and social protection) are important [77].

4.2 Relational Boundaries

We define relational boundaries as interpersonal expectations and agreements among people, including one-to-one, one-to-group boundaries, and group-to-group boundaries[5]. During extended survivorship, people may need to form new relationships, strengthen current relationships, and let go of others [6, 11, 17, 22, 27, 33, 43]. In our study, survivors described being selective about disclosing their cancer experiences to others in their social network.

4.2.1 Familial relationships. During treatment, survivors may create boundaries to prevent their parents from knowing about their emotional difficulties, as P01 (18 years old) explained:

Well, it's given me the mentality, especially the fact that I got out [of the hospital] early [...] that I can survive practically anything. And it shows me that I'm not a whiner. [...] I don't want anybody to panic around me [...] And if I started crying too, I was like I had to be the strong one. [...] I knew [my parents] were sad for me when I was in the hospital. [...] So if I started showing [my emotion], I know it would definitely be worse for all of us. (P01)

Cancer survivors do substantial work to manage other people's health and wellbeing around them [9, 13, 68]. This mirrors emotional labor conceptualized for the workplace [4], in which workers must manage their own emotions and self-regulate to support the emotional needs of those they encounter. In this case, we see childhood survivors begin this extra labor at an incredibly early age (e.g., P01 began not wanting to burden their parents at age nine at the time of diagnosis). This formative experience of ensuring that others do not "panic" or experience stress or anxiety can lead to a lifetime of doing this additional care work. The boundary, in this case, is created to protect the survivor's parents from what they perceive as a threat to their parent's wellbeing. Additionally, the boundary—though developed as a child—can result in the survivor continuing to take it upon themselves to not burden others in addition to parents by limiting the disclosure of their cancer experience.

Even though they may limit disclosure with parental caregivers, some childhood cancer survivors selectively determine what to disclose to extended family members or their larger social network, including romantic partners. For example, P18 (24 years old) expressed that she did not inform her mother about her health because she did not want to worry her parents. In contrast, P07 (26 years

---

[5]We do not have an example from the data. However, an example of group to group boundaries at the non societal level would be boundaries between in-group and out-group in online communities for example, boundaries between a survivor peer community and those outsider.

old) stated that although she is now an adult who is responsible and able to manage her health, she still shared her medical information with her parents. She explained that sharing with her parents is important because she sees it as helping them cope with the guilt that they experienced throughout their child's cancer experience. Notably, we can see that even in the case of choosing to disclose, survivors may feel responsible for enormous amounts of emotional work to protect their parents. P09 (19 years old) on the other hand expressed frustration around the continued heavy involvement of her parents, a behavior that may be a potential consequence of high familism, which may be linked to her Hispanic heritage. Although we did not see substantial discussion of racial and ethnic background in our interviews, existing research indicates that racial and ethnic background can influence decisions and considerations around information seeking and disclosure [49, 51, 57]. In our study, we began to see indicators that a sense of responsibility may lead to the development of different boundary management systems and familial and cultural responses to these boundaries, in particular in response to helping parents manage their emotions.

Caregivers must manage their own boundaries and develop their own considerations for how much to share with others (including their own child) about the experience of having been a parent of a child with cancer. These difficult choices can impact children as they age into adulthood in a variety of ways. For example, P06 (22 years old) shared that his parents did not share their financial status with him at the time of the interview or about expenses related to his health in the past.

Honestly, my parents don't like to talk about that. They intentionally don't tell us exactly, or at least when we were younger, they would just tell us like don't ask that, so I've honestly never even asked them. (P06)

Parents may not always share information with children, specially at young ages, about their care or the financial cost of their health [9, 64]. This secrecy may prevent children from understanding the impact of their health on the family and affect their ability to plan in the future. A collaborative relationship and effective communication between the caregiver and child tends to result in positive outcomes for the child's long-term wellbeing [65], especially when care is taken in when and how the boundary is addressed [9].

Additionally, in our study, we found that managing familial boundaries required substantial work. Caregivers worked with their co-parents and designated primary roles for survivorship management. For example, C03 mentioned that during treatment she acted as primary caregiver advocating for the medical needs of her child, yet in survivorship, her husband has taken on the responsibility of advocating for her child's needs in the educational system. This distinction between the roles in the family helps the family members gain support from one another.

Siblings also play a role. C04 described how her younger daughter has voluntarily taken on the role of caregiver to support her sister who has cancer. P23, on the other hand, shared that although her sibling attends cancer survivorship with the family, not as a matter of choice but as a matter of duty, because it is a family value to support one another in all events. Even further on this spectrum, P15 articulated concrete steps that her family takes to reduce anxiety

felt by a sibling about the cancer experience, such as not mentioning anything related to cancer in the presence of that sibling.

The family is central to the survivor experience [8, 80]; therefore, familial boundaries must be carefully managed to preserve the relationship. Survivors may feel guilty about the impact of their cancer diagnosis on their families, while caregivers and other family members may feel guilty about the lost opportunities that the survivor may experience as a result of their diagnosis [80]. As a result, survivors and their family members may develop many boundaries to protect or may make sacrifices to support one another.

4.2.2 Peer Relationships. Some survivors spoke about experiencing alienation and bullying from peers without cancer after treatment, resulting in feelings of isolation and wanting to hide their cancer experience. For example, one survivor described wanting to feel more like his peers:

You feel like for so long you're like the focus of everyone's pity. Like, "oh [P10] I'm so sorry you're going through this" or [you] just feel like you're the bummer. You know? Not that anyone would say that, but you're like the downer. At the party [someone mentioned], "oh yeah Gordon has cancer" [and I said] "oh," [...], "I know, I don't want to talk about my cancer". I don't want to talk about this anymore like I've done it. I just want to be like your normal friends that you talked about [normal] things, but then, at the same time [...] I feel like we're a world apart, but I just want to feel like a little more [like] high schooler. (P10)

Finding peers who understand their experience and can relate to them can provide integral mental health support for survivors, as mentioned by P20.

My friends, like my cancer surviving friends, we all talk about like oh it's not cool how we have to go do this and miss out on all the fun stuff. Because they relate more to it than my parents or outside friends, so when we're talking about mental health with surviving, we go to each other. (P20)

Survivors expressed that having peers who had experienced cancer like them was especially helpful for dealing with feelings of depression and survivors' guilt. For example, P15 (29 years old at the time of the study) noted that she would have loved to have known other survivors in high school. The first time she met another survivor was during her residency in medical school, during which she and another survivor shared information about their experiences. She described feeling less alone knowing that her experience was shared by another.

Caregivers additionally expressed the importance of having peers and being part of a community with shared experiences. C05 was in an online community of caregivers who provided her with social support. C03 had a community of caregivers who supported her through cancer treatment and continued supporting each other long into survivorship. C01, who currently does not have a community support network, expressed interest in engaging in programs for caregivers of survivors.

Our results build on what is known about how survivors and caregivers seek to make sense of their experience after treatment [9, 13, 25, 39]. In particular, in our data, peer relationships provided an opportunity for them to safely share about their experience

and combat the isolation. However, current tools for this kind of sharing are limited and create their own challenges, as discussed in the following section.

4.2.3 Crossing Boundaries on Social Media. Family members and caregivers often share stories and details about the childhood cancer survivors' experience via social media [40]. For example, C02 recalled posting about her child's progress and accomplishments as a survivor on C02's personal Facebook page. When we interviewed her child, she described being comfortable with her mother using social media to post about her, perhaps because of the close relationship they continue to have or the large role she played in the survivor's cancer journey. However, in other cases, participants described tensions that arose when others wanted to share about the survivors' cancer experience without their consent, threatening the survivors' pre-established boundaries. P01 had a negative experience when a friend of their sibling created a post asking to pray for them on social media.

One of my sister's friends who I didn't really like in particular just because you know, it's like you girls who teased right? She made an Instagram post called pray for [Participant] and that disgusted me. Like I was like, look, I'm not doing that for myself. I don't want this type of attention. I don't want my pictures up there and that happened. So yeah, that was bad to me. I didn't like that at all that I didn't even know the person it was definitely for clout. (P01)

P23 said she did not like to discuss her cancer and survivorship experience directly in her own online social network but allowed her grandfather to post her cancer journey on his personal Facebook page.

My pop (Grandfather), his Facebook cover has me on it, and it's like gold, which stands for childhood cancer, and he was so proud of it and so proud of me. So even though I didn't really like it, and he knew that he wouldn't do [post] excessively. I never got mad. He could post it. It's fine like he's just trying to help other kids. (P23)

P08 stated that although her Facebook account was intended mostly to stay in touch with family, members of her church community were allowed to follow her and thus, were welcomed to know intimate details about her cancer and survivorship experience that she shared on Facebook.

Survivors described needing to feel a sense of control in the disclosure of their experience both in-person and online. At times, survivors and caregivers may collectively decide to disclose their experiences on social media, given that in many ways, their experiences were shared. However, non-guardians sharing such information without the knowledge and consent of the survivor is concerning, particularly for minors. Safeguards may need to be further developed to support the maintenance of such desired boundaries on these platforms.

4.2.4 Community Relationships. Cancer survivors also interact with community organizations that support them through their treatment (e.g., Miracles for Kids)[6]. C05 explained that her daughter experienced challenges in school, which resulted in her daughter not wanting to participate in cancer-related community activities, but this changed later:

There were some kids [at school] who made fun of her and said, the only reason she had friends was because she had cancer and people just felt bad for her. So, obviously, that is hard for someone to hear. [...] And so, **she didn't want to do anything in the cancer world she didn't want to do anything with Miracles for Kids, she didn't want to do anything with St Baldrick's** [7] **any of these organizations that she had been part of** [...] She just wanted to not think about cancer [. . .] so we didn't do anything, we didn't talk about it. If she asked, we talk, or you know, little things—when she goes to the doctors, we do that. But just last year, she started wanting to get involved again because she wants to get back, so I think that's the balance. (C05)

Many organizations support the long-term needs of cancer patients and survivors [85, 86]. However, most of these programs are locally run and thus require substantial support (e.g., volunteering, advocating, and donations) from the community members. There is a symbiotic relationship between survivors and community health organizations. However, poor interaction between other social network members may affect how survivors choose to interact with community organizations. In the case of C05's daughter, negative experience with peers from her school resulted in a limited engagement with the community organization by her and her caregivers. To protect their primary relationship (i.e., the mother-daughter relationship), C05 limited further disclosure of their survivorship experience by constructing a boundary to pauser community participation.

Not all disclosures about someone's cancer experience resulted in a negative experience within a community. P20 explained that at times, situations occur in which it is beneficial for a member of her theatre club to know about her cancer survivor status because they take immediate action to protect her health.

Sometimes my medical [history] does come up like if one person in the [theatre] cast is sick, my director/teacher will be like, 'okay get out.' I'll be like, 'Okay.' And then I just come back the next day if he's feeling better or if they've gotten rid of whatever's going on. They're very aware of my medical stuff and they're very conscious of it and I try to make sure that nothing bad is happening. (P20)

Many survivors expressed wanting the opportunity to give back to the communities or continue to engage with the communities. For example, P05 conveyed that volunteering with the Make-a-Wish [8] foundation [87] that supported her in her treatment gave meaning to her survival. She explained that sponsoring another child helped her reconcile her feeling of survivor's guilt. P19 talked about having mentors in their 20s come and talk to him about his concerns when he was in the hospital, which he wanted to pay forward. He did not want to talk about his cancer experience otherwise.

---

[6] Miracles for Kids is a nonprofit on the west coast of the US that aims to improve the lives of critically ill children and their families in need by providing financial aid, subsidized housing, and counseling to families.

[7] St Baldrick's Foundation is a nonprofit organization in the US, committed to finding a cure for childhood cancer through volunteer and donor powered charity.
[8] Make-A-Wish America is a nonprofit organization founded in the US that helps fulfill the wishes of children with a critical illness between the ages of 2 and a half and 18 years old.

[I feel comfortable sharing my story with] the people that are going through it, because I know when I was in the hospital, [...] people would come that had cancer, they would come talk to me. And I will try to relate to they would try to relate to my story, that helped me a lot because I would see them how there's chance me like get being successful and actually like getting through this so that really hooked me, so I wouldn't mind talking to people that actually have it in like they need someone to talk to you. (P19)

Cancer survivors play an integral role in cancer navigation programs and services [34]. Their engagement in these programs serves both themselves and current cancer patients. However, their engagement as volunteers should not be abused nor taken for granted given the other stressors they experience. Programs should find ways to serve and revive survivors without extracting additional emotional labor, a space that technology may be able to support by providing scalable support infrastructure for both survivors and patients. Cancer survivors are more than just mentors for current patients; they are individuals who still require just as much social support as patients as they navigate new life experiences [24, 25].

4.2.5 Meaning of Community. Beyond cancer related communities, survivors interacted with many other groups of people. Some of these groups included their church community, online support groups, sports teams, and other communities. Survivors' personal beliefs about notions of community can help them determine who is included in and who is excluded from their communities. Defining one's own community is an act of power. In particular, young survivors often have deep medicalized, sometimes traumatized, and frequently "othering" experiences of being defined by others as a person with cancer. Thus, creating their own definitions of community can be a way to reassert their own agency in this context [32]. Survivors in our study tended to use three criteria for determining their boundaries with communities: (1) trust, (2) a sense of belonging, and (3) having a common purpose.

Community, to me, doesn't have to be just doctors or family. It's both of those, but also your friends or maybe your teachers, if that's the person you can trust to confide in and help. Maybe lean on them and they can help you stand up when you fall [...] it's really nice knowing that you have those people that you can be around and, you don't have to hide behind a mask, you can show that you are not perfect and they won't judge you. It's really valuable to have that. (P02)

C04, who said she longs to have a community to support her as the caregiver of a cancer survivor, described that community should be connected by a common purpose:

There has to be some type of connection to be a community. [...] I have to feel like we're part of a greater purpose, there has to be a purpose, there has to be a reason and there has to be a connection. (C04)

An understanding of community is paramount for eliciting the participation and engagement of survivors in extended cancer survivor care. As such, survivor care should include not just aspects of clinical care but holistic care that include communities they form and interact with at school, work, and hobby activities. What we saw in our data, which should be interrogated further in future research, is that survivors appear to have a somewhat specific view of what community is that may or may not map to other views of community. Notably, the communities they described tended not to be geographically bound in the way that traditional views of community often do [32, 78].

4.3 Personal Boundaries

Personal boundaries include expectations, beliefs, and worldviews that survivors hold and use to navigate their survivor experience. These personal boundaries influence the survivors' awareness of their identity and expression and engagement with others.

4.3.1 Survivor Identity. To support and engage cancer survivors beyond the clinical setting, we must understand their illness experiences, which are often defined and shaped by many social factors and their current medical status. In our study, all survivors except for P23 identified as survivors of cancer as a general state of being. P23, as the lone exception, is notable in her explanation. She described needing to feel safe in the larger social context to identify as a cancer survivor in response to negative past experiences related to disclosure of her cancer:

No [I do not identify as a survivor]. I am [a cancer survivor] to my really close friends like my whole family, my boyfriend and his whole family. They know but it's not a topic that I like to talk about like outside of doctors appointments and then with my family [...] It's a sensitive topic. I don't want myself out there, like that, but like I have done a lot of events for [local hospital], like the Gala and stuff like that [...] so to me that's fine, but I don't see a need to tell my high school friends that like I just don't. (P23)

In contrast, P18 wanted a way to commemorate their cancer experience with a tattoo that would then be publicly visible to most people. Despite identifying as cancer survivors, some others, like P12, minimized their cancer experience or said that they did not consider that these experiences during childhood have impacted their identity as much as it would have if they had cancer as adults. This reveals that cancer survivors may feel disconnected from their experience because they were not practically involved in their care management. Contrary to survivors who may feel disconnected from the cancer experience, some caregivers may feel connected with the survivors' identity as they were heavily involved during treatment. For example, C01 identified as a cancer survivor along with her daughter and compared her experience to surviving an earthquake.

You know, [it feels like being a] part of a natural disaster [. . .] or if there was some sort of natural disaster here in Southern California, you would say you are a survivor of that even if your house wasn't the one that got washed away in a flood. [...] Yeah, that's definitely how it feels. It definitely feels like there was an earthquake and, you know, parts of your life are just changed, just different. (C01)

Two parental caregivers (C01, C04) identified as survivors along with their children, three did not, and C03 did not lean either way. This deviation amongst parental caregivers of childhood survivors demonstrates that the survivor's identity is a personal boundary that is shaped by the individual's perception.

Some survivors shape their identity by creating experiences outside of their cancer experience. For example, P13 had a physical disability that made her visible as a cancer survivor. Thus, she attempted to redefine herself by participating in different extracurricular activities. Managing a group's perspective can be challenging as there are multiple factors that a survivor might have to account for, and some are outside of their control.

I didn't want to be known as the [P13's name] with cancer, you know. So, I joined journalism, [wrote in the] newspaper, I was in theater [...] So, it was kind of me trying to make a name for myself before you knew me just for a disability that I couldn't control. It wasn't helpful because [in] senior year I was in a wheelchair. So, then I became known as the girl with a wheelchair but the people who knew me as a person. I could trust that they could refer to me as just P13 like by my previous identities that I tried so hard to like ingrain in people's heads, [...] 'I'm more than a cancer survivor and more than a cancer patient.' (P13)

As such, survivors were very selective in how, when, and with whom they chose to share their identity as cancer survivors. For example, P12 spoke about examining a person's perceived privilege and empathy to determine whether it would be appropriate to share about their cancer journey. Additionally, they expected an appropriate response after sharing, with appropriate in this case being others sharing about their own experiences in response to this disclosure about their cancer journey.

The presentation of a survivor's identity should be respectfully left to the survivor, for them to express in the way and at the time they are most comfortable, but social computing systems can make this kind of nuanced disclosure management difficult. Understanding the differences in perceptions of cancer or an illness as a part of the identity of an individual is essential for improving the designs of social computing systems, particularly those meant to be inclusive of survivors. Identities can be dynamic and complex. Developing and seeking multiple ways to represent oneself and switching between these identity-roles depending on the context of the interaction are commonplace. It is not simple to design for personal boundaries that can help survivors represent, manage, and in some cases, hide aspects of their complex identities online and offline. However, the need to do so (and the risk of not doing so) is evident in this work.

4.3.2 Managing Online Identity. Survivors often manage interactions with their online audiences by establishing boundaries around the disclosure of their medical history and survivor experience. While a few survivors did not have any social media accounts, some others who had accounts established contextual boundaries around what was appropriate to share about their cancer experience on their social media accounts. For example, P07 explained:

I do put [on social media], like, 'hey like look, this is what I've been through, and here I am after everything I've been through and look at what I'm doing'. But it's not [for] bragging purposes. It's more so for empowerment purposes for others that may be going through it then don't talk about it, so that they know that they're not alone right. [...] Oh, I don't have any of that kind of stuff [referring to the

survivor identity in her bio] out there [...] but if somebody snoops through my posts, then that's how they would [know]. (P07)

P01 explained that they wrote that they were a cancer survivor as the last thing on their bio on social media but did not consider it appropriate to share about cancer unless someone asked them about it first. P17 had social media accounts but did not share about cancer, only followed the children's hospital they were treated at. He said that he was not a part of any online peer communities as he did not think his condition was "as serious" as those in such communities and he would feel out of place.

Survivors might consider it important to share about their cancer experience for themselves regardless of varying social responses and perceptions. P13 shared on Instagram that she was a cancer survivor but still had reservations about people treating her differently. For P13, social media presented an opportunity for her to share her truth. This also presented a low stakes opportunity for her to gauge the response of those on social media in a less intimidating manner than in-person.

And [after coming out as a survivor on Instagram] I got a lot of DMs (Direct Messages) from people like, [...] 'thank you for sharing your story,' '[you] are so strong' and stuff. But it was from people that I never even heard of so [a] part of me was like, 'y'all are fake but thanks.' It was a good reaction, overall. You can just kind of tell who's more performative than the others. At least for people at school, like they didn't treat me differently, [...] so that was the reaction I wanted. I didn't want anyone to treat me differently, I just wanted the truth out. (P13)

Social media platforms can strive to allow individuals to manage their personal boundaries. In an ideal world, such platforms could enable survivors to purposefully shape their narrative, by choosing when they want to initiate dialogue, restrict communication, and gauge potential initial responses [12, 44, 76] to the disclosure of their information. Social media could then be a tool that allows survivors to build confidence to share with people in their lives [12]. However, maintaining personal boundaries online requires extensive emotional work, and perceptions of others are not easy to manage.

Overall, personal boundaries in our study appeared to help individuals identify themselves and make decisions based on their worldviews. In turn, these mechanisms may then help them to determine the kinds of support they are willing to receive and those that are not helpful to them.

5 DISCUSSION

The survivors' experience is influenced by how they manage societal, relational, and personal boundaries. Below, we discuss opportunities for understanding the problem space and designing sociotechnical solutions to support survivors in managing these boundaries including (1) addressing systemic issues, (2) preserving the context of disclosures for survivors, and (3) supporting the survivor's growth through transitional stages of adolescence, young adulthood, and survivorship.

5.1 Address Systemic Issues: Societal Boundaries

To manage societal boundaries, survivors must educate and advocate for themselves across multiple institutions to meet their everyday needs [43]. Thus, societal boundary management for the survivor is about receiving the accommodations they need to carry out everyday activities after cancer treatment. Within the US, multiple resources, policies, and programs exist to support survivors; however, they can still experience challenges in knowing and finding the appropriate accommodations to support their needs and collaborating and coordinating with and between institutions such as schools, insurance companies, and clinics.

As demonstrated in this work, caregivers and survivors often encounter obstacles when attempting to find the information needed to support their education and pay bills (see section 4.1). In our work, this resulted in feelings of frustration as they attempted to coordinate with the institutions. Survivors and their caregivers worked to keep themselves educated and informed about different resources, programs, and policies, often emphasizing the importance and burden of self-advocacy and lack of support from systemic stakeholders, such as social workers. Future work must seek to understand how experiences with and perceptions about systemic support continue to manifest within survivors who may stop reaching out for support from survivorship programs.

To find ways to lessen the burden of self-management experienced by survivors and their caregivers, we advocate for researchers to understand and address societal level concerns through the design and development of upstream interventions [77]. Such interventions include understanding how existing policies are influencing an individual's access to resources and including systemic stakeholders in research and design processes. For example, researchers and designers can study how government agencies, clinics, or insurance companies relay information to survivors and design for effectively organizing and communicating information.

Overall, societal boundaries may prove to be of great interest to HCI, CSCW, and science technology and society (STS) researchers who focus on understanding how organizations and information flow change over time, and how these different practices influence the survivor. For example, Rolland and Eschler's [58] work on the types of posttreatment survivorship resources available on a prominent cancer center website yielded several valuable insights, including a need for findable survivorship specific information. Their work demonstrates that the responsibility of finding and knowing the information should not fall on the survivor who is not the domain expert. Rather, it is the responsibility of the institution to make sure that these resources are readily accessible and digestible to survivors.

5.2 Preserve the Context of Disclosure and Privacy: Relational Boundaries

Our results indicate that survivors intentionally set boundaries depending on how they want to present themselves to their peers (with and without cancer) and communities. Survivors considered multiple contextual parameters when managing boundaries between themselves and others in their social communities. Some survivors set boundaries based on the perceived and experienced proximity to their cancer journey (e.g., P23, section 4.2). These boundaries would change depending on the place (e.g., school, or social media) and changing interpersonal dynamics over time. Thus, relational boundaries are the most nuanced and volatile of the boundaries.

Survivors must find ways to manage these relational boundaries from unintentional interruptions through disclosure. Disclosure plays an important role in boundary management. Revealing aspects of one's identity to others, often called self-presentation, preserves and develops boundaries around what to disclose and how to express information about oneself to another person [44]. Individuals may present themselves in different ways that they perceive appropriate depending on the situation, their relationship with an individual, or the places they choose to present themselves [4, 71]. Through acts of self-disclosure, an individual communicates messages about the self to others, often with the goal of social validation, stress relief, or relationship development [79].

In the online environment, the possibilities of data leakages and tracking and sharing of online behavior may result in unintentional boundary crossings or violations. Social media provides visibility of a person's activity to others (e.g., likes, comments, and followings). While this seemingly innocuous information can be beneficial for allowing for connection between virtual peers, it may unintentionally cause harm. An unsolicited disclosure, without the survivor's permission can cause psychological, relational, and reputational harm online and offline [48]. In the event of unintentional disclosures on social media (e.g., a visitor posting a photo of P01 on Instagram without P01's consent, see section 4.3.2), technologies should provide mechanisms to reduce if not undo reputation damage. For example, tools can help survivors keep track of where and what information they share online publicly without their consent. Although increased online visibility may increase the potential to find and interact with peers, it can also increase the survivor's emotional burden and make them targets for harassment as also seen in those with marginalized political views [55].

Social media platforms may identify survivors' interests algorithmically. This kind of data-based personalization may make it easier to provide beneficial resources and connections to the survivor [18]. However, such use of data for recommendations may unintentionally cross relational boundaries by disclosing that a person has cancer via automated advertisements or other mechanisms against the will of the survivor. To prevent such harm, designers must consider providing transparency to the survivor about their shared information. For example, survivors should be able to understand why social media posts, advertisements, and other content are provided to them. Although new laws (e.g., GDPR and California Consumer Privacy Act) require such data to be downloadable and theoretically analyzable, much of the interpretation that platforms do remains secret, making such understanding difficult to develop for the average person [3, 81]. Survivors may need help understanding and responding to inherent trade-offs in risks and benefits of sharing and how they are perceived online. Ultimately technology should help survivors navigate changes in expectation in the online environment, including a variety of emergent social considerations in response to such changes [7, 56].

Overall, the management of relational boundaries depends on the interpersonal dynamics of survivors, including responses to a

wide social network from the immediate family and close peers to extended family and friend networks and other communities (e.g., faith communities). Technologies should be designed to incorporate these varying social dynamics among multiple stakeholders, particularly in response to the roles they inhabit as part of the survivorship experience. For example, designers can systematically consider the tensions in the use of sociotechnical systems involving caregivers and peers as the survivor ages and their responsibilities change. These tensions may arise between the autonomy and privacy of the survivor, trust among the parent and survivor, and trust among peers and survivor.

5.3 Support Growth through Transitions: Personal Boundaries

After treatment, survivors may seek opportunities to define, reconstruct and come to terms with their experiences, values, and identity [23, 34, 47]. As such, the management of personal boundaries involves responding to cancer as a traumatic event or life disruption [9, 23, 47]. Understanding the survivor's response after treatment as they age and progress through different life stages (e.g., getting a job, finding a significant other, parenting, being a student, and more) may help computing researchers and designers to target supports to their specific needs. Survivors in our study defined what being a survivor or finding community meant to them, and some explained how it changed with time (see section 4.3). Reconciling one's identity as the survivor transitions from inpatient life of being confined to the hospital among patients to adjusting to life and socializing as "normal" as an adolescent going to school can be very difficult. Some survivors considered it inappropriate to ask others for help regarding their mental health such as when experiencing survivor's guilt and instead, sought that help online (e.g., P15, P05). Although there is a need for consistent systemic support for identifying and intervening during such difficulties, technologies can support the survivor with self-reflection tools to keep track of the changes they are experiencing [63].

Understanding the survivors' experience through a trauma-informed lens may produce additional insights surrounding support for survivors and respecting their personal boundaries. However, part of trauma-informed design also must recognize that such sensitive and transitional experiences may be difficult to recall and talk about during clinical visits, research, or design processes. This need for researchers and designers to get information about traumatic experiences while still respecting and caring for participants can lead to substantial feelings of conflict for all involved. Eschler et al. [23] provide one model for overcoming this conflict by exploring artifacts (e.g. tattoos) that were meaningful and relevant to patients and survivors. This provides insights into the language and values of the survivor community. Following the language and norms of the community will continue to be key practices to further develop in the HCI and well-being space, particularly in relation to minoritized and marginalized groups.

6 LIMITATIONS AND FUTURE WORK

All survivor participants in this study received treatment at the same children's hospital in the US and continued to engage with survivorship care to some capacity. We could not reach people who

had discontinued treatment, as they were not responsive to the affiliated hospital's call for recruitment. Additionally, a majority of those we successfully recruited identify as females, and our sample size of caregivers is limited. In the future, researchers should strive to increase outreach and explore perspectives and barriers for people who discontinue care during survivorship and with other informal caregivers such as siblings, extended family members, and romantic partners [80]. We conducted this study in the US, therefore, some boundaries and experiences may be unique to the US health coverage system.

Design provocations for health design and social computing communities emerged from our analysis of the findings and the research team's ideations. Thus, they remain somewhat speculative at this point, calling for future work in more detailed design, co-design, and testing of such technologies. We plan to include survivors in the design process and encourage future researchers to also involve survivors in co-design. In this work, we included perspectives of survivors and caregivers. Researchers should triangulate experiences from community service providers and other grassroots stakeholders to understand efforts that can be made towards systemic changes. As the survivors' social experiences are not independent of their medical care, in our future analysis, we aim to focus on survivors' challenges within the healthcare system and their experiences with mental health.

Designing sociotechnical systems that include cancer survivors requires considering nuances to the changing identity of the adolescent or young adult who experienced cancer and their caregivers. Designing for the unique ways in which each person may connect with different terms and experiences is challenging and our results indicate key areas for additional exploration. Although none of our participants spoke about the impact of negative stereotypes (e.g., perception of one's own emotional and physical frailty [9, 10, 31]) or the burden of positive stereotypes (e.g., their resilience [9, 10, 31]) associated with being a childhood cancer in their lives, a future examination specifically of how stereotypes influence their self-presentation, self-disclosure, and personal boundary management should be undertaken.

7 CONCLUSION

Based on our interviews with 24 childhood and adolescent cancer survivors and six caregivers, this paper presents an empirical understanding of participants' needs in navigating boundaries in their life outside the clinic during survivorship that are needed when designing technological tools to support them. Survivorship after cancer treatment is often a "forgotten" space and is an important area of research and societal need for the HCI community. Survivors do not often have streamlined guidance and navigate uncertainties, not knowing what to do or where to look for resources. Substantial challenges and opportunities for harnessing community support through technologies and preparing the community remain. Researchers and designers in this space must be aware of the struggles of the survivors and their families after cancer treatment. Continued research in HCI and cancer survivorship can lead to designing and developing innovative sociotechnical solutions to support the lived experiences of survivors and caregivers.

ACKNOWLEDGMENTS

REFERENCES

[1] Rikke Aarhus and Stinne Aaløkke Ballegaard. 2010. Negotiating boundaries: Managing disease at home. Conference on Human Factors in Computing Systems - Proceedings 2, (2010), 1223–1232. DOI:https://doi.org/10.1145/1753326.1753509

[2] Mohsen Adib-Hajbaghery and Bahareh Ahmadi. 2019. Caregiver Burden and Its Associated Factors in Caregivers of Children and Adolescents with Chronic Conditions. Int J Community Based Nurs Midwifery 7, 4 (October 2019), 258–269. DOI:https://doi.org/10.30476/IJCBNM.2019.73893.0

[3] Jane Andrew and Max Baker. 2021. The General Data Protection Regulation in the Age of Surveillance Capitalism. Journal of Business Ethics 168, 3 (2021), 565–578. Retrieved January 10, 2022 from https://ideas.repec.org/a/kap/jbuset/v168y2021i3d10.1007_s10551-019-04239-z.html

[4] Blake E. Ashforth and Ronald H. Humphrey. 1993. Emotional Labor in Service Roles: The Influence of Identity. AMR 18, 1 (January 1993), 88–115. DOI:https://doi.org/10.5465/amr.1993.3997508

[5] Blake E. Ashforth, Glen E. Kreiner, and Mel Fugate. 2000. All in a Day's Work: Boundaries and Micro Role Transitions. The Academy of Management Review 25, 3 (2000), 472. DOI:https://doi.org/10.2307/259305

[6] Noreen M. Aziz and Julia H. Rowland. 2003. Trends and advances in cancer survivorship research: Challenge and opportunity. In Seminars in Radiation Oncology, W.B. Saunders, 248–266. DOI:https://doi.org/10.1016/S1053-4296(03)00024-9

[7] Karla Badillo-Urquiola, Scott Harpin, and Pamela Wisniewski. 2017. Abandoned but Not Forgotten: Providing Access While Protecting Foster Youth from Online Risks. In Proceedings of the 2017 Conference on Interaction Design and Children (IDC '17), Association for Computing Machinery, New York, NY, USA, 17–26. DOI:https://doi.org/10.1145/3078072.3079724

[8] Lisa Bashore, Kathy Ruccione, Ann H. Johnson, Joanne Quillen, Karen Johnston, and Wendy Hobbie. 2020. Cancer survivorship in the era of precision health. In Pediatric Oncology. Springer, 251–274. DOI:https://doi.org/10.1007/978-3-030-25804-7_14

[9] David J. Bearison and Caesar Pacifici. 1984. Psychological studies of children who have cancer. Journal of Applied Developmental Psychology 5, 4 (1984), 263–280. DOI:https://doi.org/10.1016/0193-3973(84)90001-7

[10] Dori Michelle Beeler. 2020. When my four-year-old got cancer: a retrospective on resilience in a paediatric oncology ward. Anthropology and Medicine 27, 3 (July 2020), 347–362. DOI:https://doi.org/10.1080/13648470.2019.1689071

[11] Kirsten Bell and Svetlana Ristovski-Slijepcevic. 2013. Cancer survivorship: why labels matter. J Clin Oncol 31, 4 (February 2013), 409–411. DOI:https://doi.org/10.1200/JCO.2012.43.5891

[12] Farnaz Irannejad Bisafar and Andrea Grimes Parker. 2016. Confidence & control: Examining adolescent preferences for technologies that promote wellness. In Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW, Association for Computing Machinery, 160–171. DOI:https://doi.org/10.1145/2818048.2820028

[13] Christina G. Blanchard, Terrance L. Albrecht, John C. Ruckdeschel, Charles H. Grant, and Rebecca Malcolm Hemmick. 1995. The role of social support in adaptation to cancer and to survival. Journal of Psychosocial Oncology 13, 1–2 (1995), 75–95. DOI:https://doi.org/10.1300/J077V13N01_05

[14] Archie Bleyer. 2005. The adolescent and young adult gap in cancer care and outcome. Current Problems in Pediatric and Adolescent Health Care 35, 5 (May 2005), 182–217. DOI:https://doi.org/10.1016/j.cppeds.2005.02.001

[15] Susanne Bødker, Jannie F. Kristensen, Christina Nielsen, and Werner Sperschneider. 2003. Technology for boundaries. Proceedings of the International ACM SIGGROUP Conference on Supporting Group Work (2003), 311–320. DOI:https://doi.org/10.1145/958208.958210

[16] Phil Brown. 2016. Naming and Framing: The Social Construction of Diagnosis and Illness. Journal of Health and Social Behaviour 366, May (2016), 34–52.

[17] Eleanor R. Burgess, Madhu C. Reddy, Andrew Davenport, Paul Laboi, and Ann Blandford. 2019. Tricky to get your head around. In Conference on Human Factors in Computing Systems - Proceedings, 1–17. DOI:https://doi.org/10.1145/3290605.3300895

[18] Jacquelyn Burkell and Alexandre Fortier. 2013. Privacy policy disclosures of behavioural tracking on consumer health websites. Proceedings of the ASIST Annual Meeting 50, 1 (2013). DOI:https://doi.org/10.1002/meet.14505001087

[19] Jacqueline Casillas, Kevin C. Oeffinger, Melissa M. Hudson, Mark L. Greenberg, Mark W. Yeazel, Kirsten K. Ness, Tara O. Henderson, Leslie L. Robison, Gregory T. Armstrong, Qi Liu, Wendy Leisenring, Yutaka Yasui, and Paul C. Nathan. 2015. Identifying Predictors of Longitudinal Decline in the Level of Medical Care Received by Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Health Services Research 50, 4 (2015), 1021–1042. DOI:https://doi.org/10.1111/1475-6773.12282

[20] Marta E. Cecchinato, Anna L. Cox, and Jon Bird. 2017. Always On(line)? User experience of smartwatches and their role within multi-device ecologies. Conference on Human Factors in Computing Systems - Proceedings 2017-May, (2017), 3557–3568. DOI:https://doi.org/10.1145/3025453.3025538

[21] Children's Oncology Group. 2018. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers Version 5.0. Retrieved September 9, 2021 from http://www.survivorshipguidelines.org/

[22] Katie A. Devine, Adrienne S. Viola, Elliot J. Coups, and Yelena P. Wu. 2018. Digital Health Interventions for Adolescent and Young Adult Cancer Survivors. JCO Clinical Cancer Informatics 2 (2018), 1–15. DOI:https://doi.org/10.1200/cci.17.00138

[23] Jordan Eschler, Arpita Bhattacharya, and Wanda Pratt. 2018. Designing a reclamation of body and health: cancer survivor tattoos as coping ritual. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems, Montréal, QC, Canada, 1–12. DOI:https://doi.org/10.1145/3173574.3174084

[24] Jordan Eschler, Zakariya Dehlawi, and Wanda Pratt. 2015. Self-characterized Illness Phase and Information Needs of Participants in an Online Cancer Forum. In Proceedings of the International Conference on Web and Social Media (ICWSM). Retrieved from https://jordaneschlerdotcom.files.wordpress.com/2014/09/eschler-icwsm-2015.pdf

[25] Jordan Eschler and Wanda Pratt. 2017. "I'm so glad i met you": Designing dynamic collaborative support for young adult cancer survivors. Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW (2017), 1763–1774. DOI:https://doi.org/10.1145/2998181.2998326

[26] 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 Changing our world, changing ourselves - CHI '02, ACM Press, New York, New York, USA.

[27] Scott M. Gilbert, David C. Miller, Brent K. Hollenbeck, James E. Montie, and John T. Wei. 2008. Cancer survivorship: Challenges and changing paradigms. Journal of Urology 179, 431–438. DOI:https://doi.org/10.1016/j.juro.2007.09.029

[28] Becky Wilson Hawbaker. 2007. Student-Led IEP Meetings: Planning and Implementation Strategies. Teaching Exceptional Children Plus 3, 5 (May 2007). Retrieved from http://escholarship.bc.edu/education/tecplus/vol3/iss5/art4

[29] Gillian R. Hayes, Gregory D. Abowd, John S. Davis, Marion L. Blount, Maria Ebling, and Elizabeth D. Mynatt. 2008. Opportunities for pervasive computing in chronic cancer care. In Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics), 262–279. DOI:https://doi.org/10.1007/978-3-540-79576-6_16

[30] Karen Holtzblatt, Jessamyn Burns Wendell, and Shelley Wood. 2004. Rapid Contextual Design: A How-to Guide to Key Techniques for User-Centered Design. Elsevier.

[31] 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 (CHI '16), Association for Computing Machinery, New York, NY, USA, 5337–5349. DOI:https://doi.org/10.1145/2858036.2858508

[32] Peter S. Hovmand. 2014. Introduction to Community-Based System Dynamics. In Community Based System Dynamics. Springer New York, New York, NY, 1–16. DOI:https://doi.org/10.1007/978-1-4614-8763-0_1

[33] Institute of Medicine and National Research Council. 2006. Cancer Survivors. In From Cancer Patient to Cancer Survivor: Lost in Transition. DOI:https://doi.org/10.17226/11468

[34] Maia Jacobs, James Clawson, and Elizabeth D Mynatt. 2014. Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey. (2014). DOI:https://doi.org/10.1145/2531602.2531645

[35] Maia Jacobs, James Clawson, and Elizabeth D. Mynatt. 2015. Comparing health information sharing preferences of cancer patients, doctors, and navigators. In CSCW 2015 - Proceedings of the 2015 ACM International Conference on Computer-Supported Cooperative Work and Social Computing, Association for Computing Machinery, Inc, New York, New York, USA, 808–818. DOI:https:

//doi.org/10.1145/2675133.2675252

[36] Maia Jacobs, James Clawson, and Elizabeth D Mynatt. 2016. A Cancer Journey Framework: Guiding the Design of Holistic Health Technology Technology for Grief Support View project A Cancer Journey Framework: Guiding the Design of Holistic Health Technology. Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare PervasiveHealth (May 2016), 114–121. DOI:https://doi.org/10.4108/eai.16-5-2016.2263333

[37] Maia Jacobs, Janice Hopkins, Matthew Mumber, and Elizabeth Mynatt. 2019. Usability Evaluation of an Adaptive Information Recommendation System for Breast Cancer Patients. In AMIA Annual Symposium Proceedings, 494–503.

[38] Maia Jacobs, Jeremy Johnson, and Elizabeth D Mynatt. 2018. MyPath: Investigating Breast Cancer Patients' Use of Personalized Health Information. Proc. ACM Hum.-Comput. Interact. 2, CSCW (2018), 21. DOI:https://doi.org/10.1145/3274347

[39] Madeleine Marie Hortense Janin, Sarah Jane Ellis, Claire Elizabeth Wakefield, and Joanna Elizabeth Fardell. 2018. Talking About Cancer Among Adolescent and Young Adult Cancer Patients and Survivors: A Systematic Review. J Adolesc Young Adult Oncol 7, 5 (October 2018), 515–524. DOI:https://doi.org/10.1089/jayao.2017.0131

[40] Elizabeth Kaziunas, Ayse G Buyuktur, Jasmine Jones, Sung W Choi, David A Hanauer, and Mark S Ackerman. 2015. Transition and Reflection in the Use of Health Information: The Case of Pediatric Bone Marrow Transplant Caregivers. In CSCW '15: Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing, 1763–1774. DOI:https://doi.org/10.1145/2675133.2675276

[41] Predrag Klasnja, Andrea Civan Hartzler, Kent T. Unruh, and Wanda Pratt. 2010. Blowing in the wind: Unanchored patient information work during cancer care. In Conference on Human Factors in Computing Systems - Proceedings, ACM Press, New York, New York, USA, 193–202. DOI:https://doi.org/10.1145/1753355

[42] Predrag Klasnja, Andrea Hartzler, Christopher Powell, and Wanda Pratt. 2011. Supporting cancer patients' unanchored health information management with mobile technology. AMIA Annu Symp Proc 2011, (2011), 732–741. Retrieved December 30, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3243297/

[43] Rachel Klimmek and Jennifer Wenzel. 2012. Adaptation of the illness trajectory framework to describe the work of transitional cancer survivorship. Oncology Nursing Forum 39, 6 (November 2012), E499. DOI:https://doi.org/10.1188/12.ONF.E499-E510

[44] Yuting Liao. 2019. Sharing personal health information on social media: Balancing self-presentation and privacy. ACM International Conference Proceeding Series (2019), 194–204. DOI:https://doi.org/10.1145/3328529.3328560

[45] Leslie S. Liu, Kori Inkpen, and Wanda Pratt. 2015. "i'm not like my friends": Understanding how children with a chronic illness use technology to maintain normalcy. CSCW 2015 - Proceedings of the 2015 ACM International Conference on Computer-Supported Cooperative Work and Social Computing (2015), 1527–1539. DOI:https://doi.org/10.1145/2675133.2675201

[46] Jordan Gilleland Marchak, Brooke Cherven, Rebecca Williamson Lewis, Paula Edwards, Lillian R. Meacham, Michael Palgon, Cam Escoffery, and Ann C. Mertens. 2019. User-centered design and enhancement of an electronic personal health record to support survivors of pediatric cancers. Supportive Care in Cancer (December 2019), 1–10. DOI:https://doi.org/10.1007/s00520-019-05199-w

[47] Michael Massimi, Jackie Bender, Holly O Witteman, and Osman Hassan Ahmed. 2014. Life Transitions and Online Health Communities: Reflecting on Adoption, Use, and Disengagement. In Proceedings of the 17th ACM conference on Computer supported cooperative work & social computing, ACM, New York, NY, USA. Retrieved from http://dx.doi.org/10.1145/2531602.2531622

[48] Mark W. Newman, Debra Lauterbach, Sean A. Munson, Paul Resnick, and Margaret E. Morris. 2011. It's not that i don't have problems, i'm just not putting them on facebook: challenges and opportunities in using online social networks for health. In Proceedings of the ACM 2011 conference on Computer supported cooperative work (CSCW '11), Association for Computing Machinery, New York, NY, USA, 341–350. DOI:https://doi.org/10.1145/1958824.1958876

[49] Quyen Ngo-Metzger, Gillian R. Hayes, null Yunan Chen, Ralph Cygan, and Craig F. Garfield. 2010. Improving communication between patients and providers using health information technology and other quality improvement strategies: focus on Asian Americans. Med Care Res Rev 67, 5 Suppl (October 2010), 231S-245S. DOI:https://doi.org/10.1177/1077558710375432

[50] Christena E. Nippert-Eng. 1996. Home and Work Negotiating Boundaries through Everyday Life. University of Chicago Press, Chicago, IL.

[51] Antonio Noguera, Sriram Yennurajalingam, Isabel Torres-Vigil, Henrique Afonseca Parsons, Eva Rosina Duarte, Alejandra Palma, Sofia Bunge, J. Lynn Palmer, and Eduardo Bruera. 2014. Decisional Control Preferences, Disclosure of Information Preferences, and Satisfaction Among Hispanic Patients With Advanced Cancer. J Pain Symptom Manage 47, 5 (May 2014), 896–905. DOI:https://doi.org/10.1016/j.jpainsymman.2013.06.010

[52] Office for Civil Rights. 2020. Protecting Students With Disabilities. U.S. Department of Education. Retrieved September 7, 2021 from https://www2.ed.gov/about/offices/list/ocr/504faq.html

[53] Office of Special Education and Rehabilitative Services. 2000. IEP Guide. U.S. Department of Education. Retrieved September 7, 2021 from https://www2.ed.gov/parents/needs/speced/iepguide/iepguide.pdf

[54] Sun Young Park, Woosuk Seo, Andrew B.L. Berry, Hyeryoung Kim, Sanya Verma, Sung Won Choi, and Ayse G. Buyuktur. 2020. Learning from Positive Adaptations of Pediatric Cancer Patients to Design Health Technologies. Conference on Human Factors in Computing Systems - Proceedings (2020). DOI:https://doi.org/10.1145/3313831.3376397

[55] Katy E. Pearce, Jessica Vitak, and Kristen Barta. 2018. Privacy at the Margins| Socially Mediated Visibility: Friendship and Dissent in Authoritarian Azerbaijan. International Journal of Communication 12, 0 (March 2018), 22. Retrieved September 7, 2021 from https://ijoc.org/index.php/ijoc/article/view/7039

[56] Anthony T. Pinter, Pamela J. Wisniewski, Heng Xu, Mary Beth Rosson, and Jack M. Caroll. 2017. Adolescent Online Safety: Moving Beyond Formative Evaluations to Designing Solutions for the Future. In Proceedings of the 2017 Conference on Interaction Design and Children (IDC '17), Association for Computing Machinery, New York, NY, USA, 352–357. DOI:https://doi.org/10.1145/3078072.3079722

[57] Yuxia Qian and Yuping Mao. 2021. Coping with cultural differences in healthcare: Chinese immigrant mothers' health information sharing via WeChat. International Journal of Intercultural Relations 84, (September 2021), 315–324. DOI:https://doi.org/10.1016/j.ijintrel.2021.05.001

[58] Betsy Rolland and Jordan Eschler. 2018. Searching for Survivor-Specific Services at NCI-Designated Comprehensive Cancer Centers: A Qualitative Assessment. JNCCN Journal of the National Comprehensive Cancer Network 16, 7 (July 2018), 839–844. DOI:https://doi.org/10.6004/jnccn.2018.7019

[59] C. Salazar. 2001. Building boundaries and negotiating work at home. Proceedings of the International ACM SIGGROUP Conference on Supporting Group Work (2001), 162–170. DOI:https://doi.org/10.1145/500307.500311

[60] Johnny Saldaña. 2013. The Coding Manual for Qualitative Researchers (2nd ed.). SAGE. Retrieved from www.sagepublications.com

[61] Martina Schußand Tom Gross. 2019. Availability and boundary management: An exploratory study. Conference on Human Factors in Computing Systems - Proceedings (May 2019). DOI:https://doi.org/10.1145/3290607.3313088

[62] Martina Schuss and Tom Gross. 2019. Boundary management: Between clear separation and ad-hoc decisions. PervasiveHealth: Pervasive Computing Technologies for Healthcare (September 2019), 547–551. DOI:https://doi.org/10.1145/3340764.3344456

[63] Bryan C. Semaan, Lauren M. Britton, and Bryan Dosono. 2016. Transition Resilience with ICTs: "Identity Awareness" in Veteran Re-Integration. In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16), Association for Computing Machinery, New York, NY, USA, 2882–2894. DOI:https://doi.org/10.1145/2858036.2858109

[64] Woosuk Seo, Andrew B L Berry, Kaiser Permanente Washington, and Prachi Bhagane. 2019. Balancing Tensions between Caregiving and Parenting Responsibilities in Pediatric Patient Care. Proceedings of the ACM on Human-Computer Interaction 3, CSCW (November 2019), 1–24. DOI:https://doi.org/10.1145/3359255

[65] Woosuk Seo, Ayse G. Buyuktur, Sung Won Choi, Laura Sedig, and Sun Young Park. 2021. Challenges in the Parent-Child Communication of Health-related Information in Pediatric Cancer Care. Proc. ACM Hum.-Comput. Interact. 5, CSCW1 (April 2021), 110:1-110:24. DOI:https://doi.org/10.1145/3449184

[66] Charles L. Shapiro. 2018. Cancer Survivorship. New England Journal of Medicine 379, 25 (December 2018), 2438–2450. DOI:https://doi.org/10.1056/NEJMra1712502

[67] Kazi Sinthia Kabir, Erin L Van Blarigan, June M Chan, Stacey A Kenfield, Jason Wiese, and Stacey A Ken-field. 2019. "I'm Done with Cancer. What am I Trying to Improve?": Understanding the Perspective of Prostate Cancer Patients to Support Multiple Health Behavior Change ACM Reference Format. In Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare, ACM, New York, NY, USA. Retrieved from https://doi.org/10.1145/3329189.3329207

[68] Meredith M. Skeels, Kenton T. Unruh, Christopher Powell, and Wanda Pratt. 2010. Catalyzing Social Support for Breast Cancer Patients. Proc SIGCHI Conf Hum Factor Comput Syst 2010, (April 2010), 173–182. DOI:https://doi.org/10.1145/1753326.1753353

[69] Ashley Wilder Smith, Keith M. Bellizzi, Theresa H.M. Keegan, Brad Zebrack, Vivien W. Chen, Anne Victoria Neale, Ann S. Hamilton, Margarett Shnorhavorian, and Charles F. Lynch. 2013. Health-Related Quality of Life of Adolescent and Young Adult Patients With Cancer in the United States: The Adolescent and Young Adult Health Outcomes and Patient Experience Study. J Clin Oncol 31, 17 (June 2013), 2136–2145. DOI:https://doi.org/10.1200/JCO.2012.47.3173

[70] Ashley Wilder Smith, Nita L. Seibel, Denise R. Lewis, Karen H. Albritton, Donald F. Blair, Charles D. Blanke, W. Archie Bleyer, David R. Freyer, Ann M. Geiger, Brandon Hayes-Lattin, James V. Tricoli, Lynne I. Wagner, and Bradley J. Zebrack. 2016. Next steps for adolescent and young adult oncology workshop: An update on progress and recommendations for the future. Cancer 122, 7 (2016), 988–999. DOI:https://doi.org/10.1002/cncr.29870

[71] Susan Sontag. 1977. Illness as metaphor. Farrar, Straus and Giroux.

[72] Iben Sandal Stjerne and Silviya Svejenova. 2016. Connecting Temporary and Permanent Organizing: Tensions and Boundary Work in Sequential Film Projects. Organization Studies 37, 12 (2016), 1771–1792. DOI:https://doi.org/10.1177/0170840616655492

[73] Jina Suh, Spencer Williams, Jesse R Fann, James Fogarty, Amy M Bauer, and Gary Hsieh. 2020. Parallel Journeys of Patients with Cancer and Depression: Challenges and Opportunities for Technology-Enabled Collaborative Care. Proc. ACM Hum.-Comput. Interact 4, CSCW1 (2020), 38. DOI:https://doi.org/10.1145/3392843

[74] Ludwig Thormann and Tom Gross. 2019. Boundary management between factual constraints and emotional ties. PervasiveHealth: Pervasive Computing Technologies for Healthcare (September 2019), 553–557. DOI:https://doi.org/10.1145/3340764.3344457

[75] Filiberto Toledano-Toledano and Miriam Teresa Domínguez-Guedea. 2019. Psychosocial factors related with caregiver burden among families of children with chronic conditions. BioPsychoSocial Med 13, 1 (March 2019), 6. DOI:https://doi.org/10.1186/s13030-019-0147-2

[76] Penny Trieu and Nancy K. Baym. 2020. Private Responses for Public Sharing: Understanding Self-Presentation and Relational Maintenance via Stories in Social Media. Conference on Human Factors in Computing Systems - Proceedings (April 2020). DOI:https://doi.org/10.1145/3313831.3376549

[77] Tiffany C. Veinot, Jessica S. Ancker, Heather Cole-Lewis, Elizabeth D. Mynatt, Andrea G. Parker, Katie A. Siek, and Lena Mamykina. 2019. Leveling Up: On the Potential of Upstream Health Informatics Interventions to Enhance Health Equity. Medical Care 57, (June 2019), S108–S114. DOI:https://doi.org/10.1097/MLR.0000000000001032

[78] World Health Organization. 2020. Community engagement: a health promotion guide for universal health coverage in the hands of the people. World Health Organization, Geneva. Retrieved January 10, 2022 from https://apps.who.int/iris/handle/10665/334379

[79] Diyi Yang, Zheng Yao, Joseph Seering, and Robert Kraut. 2019. The channel maters: Self-disclosure, reciprocity and social support in online cancer support groups. Conference on Human Factors in Computing Systems - Proceedings (2019), 12. DOI:https://doi.org/10.1145/3290605.3300261

[80] Jaehee Yi and Brad Zebrack. 2010. Self-portraits of families with young adult cancer survivors: Using photovoice. Journal of Psychosocial Oncology 28, 3 (May 2010), 219–243. DOI:https://doi.org/10.1080/07347331003678329

[81] Tal Z Zarsky. Incompatible: The GDPR in the Age of Big Data. SETON HALL LAW REVIEW 47, 26.

[82] US Childhood Cancer Statistics. ACCO. Retrieved January 6, 2022 from https://www.acco.org/us-childhood-cancer-statistics/

[83] Constitution of the World Health Organization. Retrieved January 10, 2022 from https://www.who.int/about/governance/constitution

[84] Health Insurance Portability and Accountability Act. Retrieved September 9, 2021 from https://www.govinfo.gov/content/pkg/PLAW-104publ191/pdf/PLAW-104publ191.pdf

[85] Miracles for Kids. Miracles for Kids. Retrieved September 7, 2021 from https://miraclesforkids.org/

[86] St. Baldrick's Foundation. St. Baldrick's Foundation. Retrieved September 7, 2021 from https://www.stbaldricks.org/

[87] Make-A-Wish America. Make-A-Wish America. Retrieved September 7, 2021 from https://wish.org/home