

Reconfiguring a New Normal

A Socio-Ecological Perspective for Design Innovation in Sensitive Settings

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Reconfiguring a New Normal: A Socio-Ecological Perspective for Design Innovation in Sensitive Settings

Abstract What can design do to address adverse life events like childhood cancer? Cancer is not just a health matter – it strains family relationships and profoundly disrupts the stability of everyday routines. In this article, we introduce a socio-ecological perspective that untangles the systemic complexity of the challenges families face when confronted with childhood cancer. We use this lens to identify potential design opportunities for reconfiguring a “new normal” in their lives. We present and discuss the results of a participant observation of childhood cancer survivors at a large support group conference. These findings we analyze and organize into five themes corresponding to specific coping strategies: accepting the transformation of one’s body, avoiding avoidance, maintaining interest in social activities, retaining a sense of belonging to one’s social networks, and dealing with social stigma. These themes reveal opportunities for design innovation in sensitive settings that traverse the fields of interaction design, developmental psychology, and pediatric oncology.

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Introduction

Disruptive life events, such as a serious illness, can significantly change a family's everyday routine and put stress on relationships among family members.¹ Childhood cancer, for example, confronts families with an uncontrollable situation that carries with it considerable uncertainty about the future.² In this article, we look at childhood cancer as a disruptive life event capable of generating high levels of stress and anxiety during hospitalization and at home, and therefore of undermining a family's existing routines and relationships.³ The severity of the illness, pain, medical procedures, and the specter of invasive or frightening treatments elicit stress and anxiety.⁴ Childhood cancer can be traumatic for the entire family.⁵ Immediately after diagnosis, the family unit faces an onslaught of bewildering and often frightening demands they must learn to manage. Not only do parents have to attend to the child's physical well-being, but also to his or her fears regarding invasive medical procedures that can generate significant distress (even after treatment) and also possibly try to alleviate the fears and concerns of their other children. The situation may lead to posttraumatic stress symptoms (PTSS)⁶ including intrusive thoughts, arousal, and hypervigilance in every family member.⁷ Therefore, reducing medical traumatic stress experienced by sick children and their families during and after treatment is vital to ensure the success of medical treatment, reduce adverse psychological reactions caused by the overall experience of the illness, and increase self-esteem and trust in the future.⁸

If we truly wish to understand how to address the disruption caused by cancer, every member of the family must be part of the discussion.⁹ Family-centered perspectives that have emerged in the field of developmental psychology see families as interdependent, self-regulating systems¹⁰ where each member influences the others.¹¹ These multiple, reciprocal, proximal influences have been studied using a developmental systems approach, notably through the lens of Urie Bronfenbrenner and Stephen Ceci's bioecological model, which was inspired by Bronfenbrenner's ecological systems theory.¹² The model aims at improving the understanding about the conditions and processes that influence human development, by showing how a child's inherent qualities and the characteristics of external environments and proximal processes interact and influence his or her lifespan over time.¹³ The model depicts this complex environment as a series of five nested interactive systems¹⁴ (Figure 1). The child sits at the center of the model, including his or her biological and psychosocial characteristics. Moving from closest to the child to furthest away, we find 1) the interpersonal level, which includes the child's interactions with close people such as family members, classmates, teachers and caregivers; 2) the organizational level, including the interrelations among the microsystems that the developing child finds him or herself in, such as family, school, hospital; 3) the community level, which includes interrelationships within the wider social system the child is embedded in and any social factors influencing their interaction; and 4) the sociocultural level, which represents the cultural values, customs, and laws governing inhabitants in the child's immediate geographical context; and, lastly, 5) the time level, the temporal dimension representing change and consistency in the characteristics of both the child and the child's environment.¹⁵ Despite its widespread prominence, only a handful of clinical research projects – in cancer support;¹⁶ cancer education,¹⁷ violence prevention,¹⁸ health promotion;¹⁹ childhood food and nutrition education, policy, and management;²⁰ and childhood chronic illness product development²¹ – have opted to utilize this model.

When disruptive life events occur, they greatly affect the interactions among these nested systems.²² Family members – part of the closest system layer – can play a crucial role in promoting adaptation to the change in circumstances and, together, can enable all concerned to more easily cope.²³ Technologists and designers

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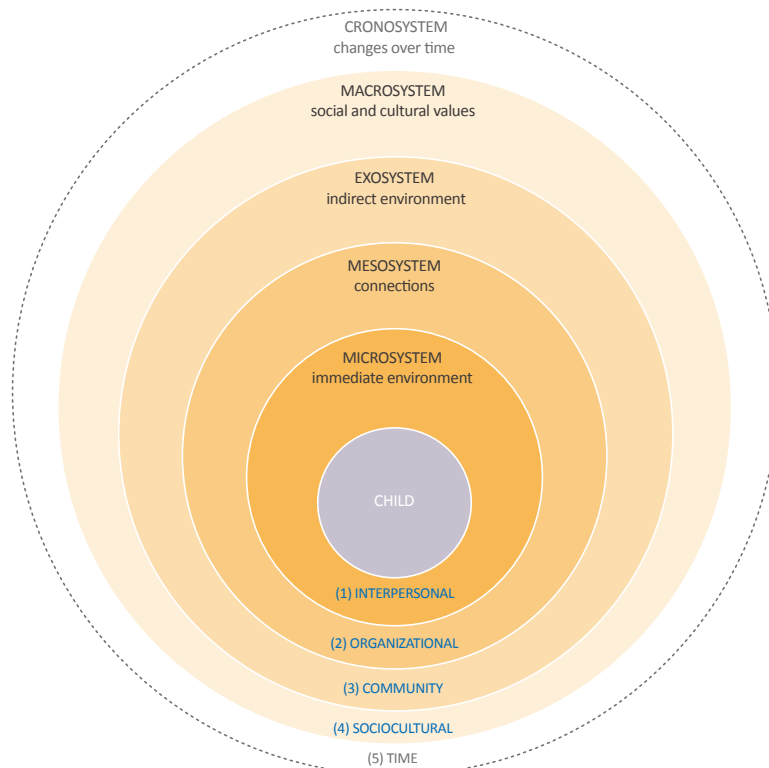
6 Margaret L. Stuber, Anne E. Kazak, Kathleen Meeske, and Lamia Barakat, "Is Posttraumatic Stress a Viable Model for Understanding Responses to Childhood Cancer?," *Child and Adolescent Psychiatric Clinics of North America* 7, no. 1 (1998): 169–82, DOI: [https://doi.org/10.1016/S1056-4993\(18\)30266-9](https://doi.org/10.1016/S1056-4993(18)30266-9).

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9 Patricia Minuchin, "Relationships within the Family: A Systems Perspective on Development," in *Relationships within Families: Mutual Influences*, ed. Robert A. Hinde and Joan Stephenson Hinde (New York: Oxford University Press, 1988), 8.

Figure 1 Bronfenbrenner and Ceci's bio-ecological model.
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Michael Massimi, Jill Dimond, and Christopher Le Dantec call these efforts to adapt to and cope with uncontrollable events "finding a new normal."²⁴ Their fieldwork led them to conclude that individuals and families affected by life disruptions tend to seek out a "reconfigured lifestyle" by constructively making use of "tenuous and emerging social groups and resources."²⁵ There is some existing work by design researchers seeking to support lifestyle reconfigurations innovatively, for instance in the case of a loved one's death. One set of proposals seeks to enable those in mourning to quietly communicate with others, share their grief discretely, and commemorate the deceased's life and passing, and also presents approaches to creating technology-based heirlooms.²⁶ Other researchers have explored how design can help families better navigate divorce by facilitating communication between family members. Still others have explored how technology can help women re-establish intimacy in relationships and rebuild their lives after domestic violence by using photography as a tool to express and represent ongoing tension.²⁷

Validated models and studies from the field of psychology²⁸ can help designers gather insights from the field, frame their data, and generate design ideas that will engage users in innovative, strategic, and tactful ways.²⁹ To us, Bronfenbrenner and Ceci's model can help designers describe, analyze, and deepen their understanding of the roles and interdependencies of routines and relationships in family life. By applying this understanding to the life disruption design process, designers are more likely to grasp how to turn everyday products into enablers of whatever new normal the users are adjusting to.

This article presents the findings gathered during participant observation of the 6th European Childhood Cancer Survivor (CCI) meeting. This explorative work was conducted to gather first-hand insights into the experiences of childhood cancer survivors and their family members and the challenges they face. In the results section, we describe and organize our findings using Bronfenbrenner and Ceci's model and the emerging coping strategies that occur at different systemic levels. Based on these results, we argue for a socio-ecological approach to design

innovation in sensitive settings. This approach emphasizes the social aspects that emerge from context analysis using Bronfenbrenner and Ceci's model and derives potential directions for design that address not only the child in his or her biological and psychosocial aspects, but also the whole family as system of social relations. We will also propose and analyze the benefits and limitations of this contribution to the literature. In our conclusion, we present avenues for future research and design directions for innovation in the context of childhood cancer.

Childhood Cancer and Psychosocial Cancer Care

The term childhood cancer refers to diagnoses of cancer in individuals between the ages of 0 and 18. Common types of cancer in this age range are leukemia and brain tumors.³⁰ When families are confronted with the possibility of childhood cancer, the medical aspect of the diagnosis typically has five phases: pre-diagnosis, diagnosis, treatment, follow-up, and the late-effects screening phase. We will briefly sketch out some of the stressors families encounter and the changes they are likely to make in their everyday routines as they adapt to each phase.

The pre-diagnosis phase is a short or long period of concern and insecurity about the child's health. The diagnosis phase includes the stressful and frightening medical examinations and emotional shock of a cancer diagnosis.³¹ From that moment on, concerns related to the diagnosis permeate every aspect of the family's existence. They must develop a realistic understanding of the considerable implications – for both child and parents – arising from diagnosis and treatment.³² The whole family feels powerless and anxious, and stress creates tensions between family members. Parents have to find some way to explain what is happening to the child or deal with their child's mix of anger and sadness if he or she is old enough to understand the impact of the illness. They will also have to divide their attention between the sick child and his or her siblings to avoid their feeling neglected or becoming jealous,³³ while also dealing with the stressor of making decisions about beginning treatment, and even possibly consider taking part in study randomization for new treatments.³⁴

Entering the treatment phase generates a big change in a family's everyday routines. At this stage, learning to deal with the effects of medical treatment is a significant source of stress. Chemotherapy usually starts shortly after diagnosis. The child rapidly comprehends what cancer treatment is about – painful medical procedures, sickness from chemotherapeutic agents, possible fatigue from radiotherapy, and side effects such as hair loss.³⁵ Parents have to organize regular hospital visits and make them fit with their work schedules. They also need to find the time to take care of domestic tasks, and in the case of larger families, care for the other children. Treatment also disrupts the sick child's and siblings' school attendance and engagement in hobbies and sports.³⁶ Beyond such practical issues, chemotherapy can lead to mood swings, feelings of isolation, and difficulty communicating with the family.³⁷ Sick children find it difficult to share their worries with their parents, and their parents don't want to show weakness to their children.

There is a tremendous transition in care when treatment ends, and this can be very stressful. Children and parents receive a lot of support, from a multidisciplinary team, during the length of the treatment phase. However, once treatment ends this guidance diminishes, and families find themselves with the urge to regain control of their lives.³⁸ The main challenges associated with this follow-up and late-effects screening phase are handling uncertainty about the future and considering life after cancer.³⁹ Families need to move on and look to the future but are faced with the threat of a possible relapse.⁴⁰ Sick children go back to school – where they have probably fallen behind – or, if older, must prepare for

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their future careers. Medical check-ups become less frequent, and life slowly gets back to normal. At this stage, survivors fully realize how they have changed, and must learn to accept the effects generated by the treatment on their bodies. Almost all children and adolescents who have been successfully treated for cancer have to deal with negative health outcomes.⁴¹ They may develop health problems as result of treatment – second cancers, cardiac conditions, brain tissue degeneration, endocrine problems, and infertility, for example – but also suffer cognitive or social disadvantages in terms of academic achievement, finding a job, a partner, and finding insurance coverage.⁴²

Since many of the sources of stress that develop during this long journey cannot be controlled,⁴³ coping strategies play an important role in supporting the emotional adjustment of everyone concerned.⁴⁴ Coping strategies are balanced reactions to stress that enable families to tolerate, minimize, accept, or ignore what cannot be mastered.⁴⁵ Emotion-focused coping strategies are directed towards regulating effects surrounding a stressful experience, and problem-focused coping strategies seek to tackle the problem causing the distress.⁴⁶ Patients or families who show the ability to adapt to stress and cope with a threatening situation develop resiliency⁴⁷ – the capacity to quickly recover after stress. Understanding the emotional and behavioral reactions and coping strategies of families in the throes of disruptive life events will help designers create more appropriate and beneficial products and services – ones that support the family's emotional adjustment and strengthen its resiliency.

Method: Participant Observation of Childhood Cancer Survivors

Researchers have used different research methodologies in the context of childhood cancer and chronic diseases. Researchers typically carry out data collection and analysis of how children with cancer and their families deal with their condition via questionnaire, semi-structured interview, focus group with parents and caregivers, and direct patient participation on online platforms. Another method, based on the change management approach called Appreciative Inquiry, involves interviewing other stakeholders who may be involved – for example, people who educate families on how to deal with challenging situations.⁴⁸ In the field of design, probes, inclusive strategies, and elicitation methods including co-realization have been introduced to investigate and describe sensitive contexts and vulnerable people.⁴⁹ In these cases, design researchers develop and manage long-term relationships and engagement with participants starting from the sensitizing phase before the study, throughout the study, and after.⁵⁰ This enables them to collect deeper and richer data, and also to actively engage the participants so that they understand the value of their help throughout the life of the project.⁵¹ New approaches in clinical research apply creative techniques and sensitive tools that help researchers to empathize with patients while investigating therapeutic outcomes. For example, Meghan Marsac and her colleagues used toy puppets and card decks to ask patients to evaluate how they perceive their disease and treatment.⁵² Similarly, Jens Nygren and his colleagues used participatory design approaches to develop a model that can guide interventions aimed at promoting children's health by involving patients, parents, caregivers and other stakeholders directly.⁵³

Given the work that has been already developed in the domain and the approaches that already exist, here we explore the topic of childhood cancer by looking at how families with children in treatment can be tactfully supported *outside* of clinical contexts. Our findings are based on participant observation of 28 childhood cancer survivors at a large support group conference with 99 participants from 23 countries. The first author carried out data collection by immersing

herself in the context to observe and note down observations, anecdotes, and participants' opinions, rather than conducting interviews, proposing questionnaires, or organizing co-design sessions. By maintaining a moderate distance, she expanded her understanding of the context and learned how to interact with the participants without the risk of overwhelming them.⁵⁴ The second and the third authors collaborated with the first author on the data analysis, and the fourth and fifth authors helped the first author to theoretically frame the research within the context of childhood cancer. In this article, the word "we" acknowledges the collaborative efforts of the authors to frame and discuss the research. For the sake of consistency, we will use "first author" when discussing the fieldwork conducted among the conference participants.⁵⁵

Procedure

Establishing Rapport and Addressing Ethical Concerns

During an international 3-day conference, the first author carried out participant observations with childhood cancer survivors and their families. The annual Childhood Cancer International Europe Regional Meeting (CCI)⁵⁶ is a conference that promotes mutual learning and information exchange among representatives from European cancer survivor groups and parental associations. The choice to participate in this event was motivated by a need to document how families and children coping with childhood cancer openly describe the main difficulties and obstacles they face. 99 people from 23 countries participated in the CCI meeting. The assembly comprised mainly survivors, parents, medical professionals, and cancer associations. The conference was attended by 28 cancer survivors in total, which included boys and girls from 12 to 35 years old. Some of them already knew each other, and others were new. English was the common language used during the whole event.

The population of interest for the present research was children in treatment for cancer between the ages of 0 to 18 years old and their family members. Some parents joined the event, but the survivors group differed from the population of interest for the age range and the phase of their cancer condition. However, most of them had been cured of cancer during their childhood. The event provided the first author with the chance to get acquainted with different perspectives on the topic – an opportunity that would otherwise have been considerably more difficult to arrange with families undergoing treatment. Therefore, given the occasion created by such a public event, the authors agreed that it was a valuable resource for preliminary observation data.

To obtain consent to conduct the observation, the first author got in contact with one of the childhood cancer parents associations participating at the conference. This association was also involved in the overall research project as a partner. After introducing the aim and protocol of the research, she was invited to join the event by a member of the parents association. Before the conference started, she received written consent from the organizers to conduct her observations at the conference. Later on, at the plenary opening of the meeting, she introduced herself to the audience, explained the purpose of her presence, and explained that she would be keeping track of conference events by taking brief notes. One of the event organizers addressed the entire audience to ask if everyone consented to have the researcher at the conference and if anyone wanted to be included in the observations. The researcher obtained verbal consent and agreement by all the audience members. At the end of the event, she was also granted permission to use the materials produced by the conference organizers, including photos, videos, and presentations, but only for the purposes of analysis.

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Researcher Participation

During the conference, the first author maintained a discrete presence. She joined the presentation sessions and the survivors' workshop. Besides attending the formal event, she also shared coffee breaks and meals with the participants, engaging in informal conversations. On day three, the conference organizers planned a workshop for survivors. The workshop revolved around three topics: helping survivors recognize late effects and changes after treatment; providing information to hospitals and caregivers about how to organize follow-up clinics and keep track of a patient's history after his or her treatment is completed; and defining future guidelines for associations to connect survivors from different countries and identifying strategies to get them involved. Before the workshop session, the organizers asked the 28 cancer survivors again if the first author was allowed to join and if they wanted to be included in her observation notes. After a private consultation among the organizers and survivors, she was welcomed into the room where the workshop took place, and they gave their verbal consent once more. The activities alternated between discussion, brainstorming, and outlining key action points. The first author sat close to the group to observe but did not intervene. During the warm-up session, the participants introduced themselves by describing their character and favorite hobbies, and by giving details about their cancer experience. After that, the participants were invited to choose one of the three topics of the workshop to brainstorm about possible opportunities. During and after the workshop, the conference facilitators recorded testimonies from the 28 survivors on video, giving them the opportunity to share their impressions and experiences. The videos were screened at the closing event of the conference to the entire audience.

Data Collection, Narrative Analysis, and Analysis Validation

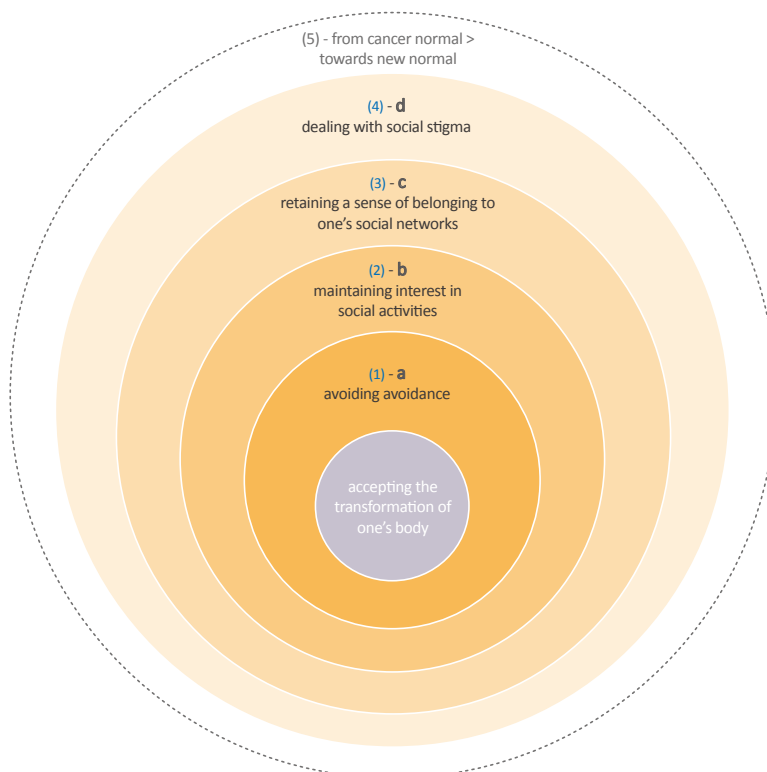
The first author immersed herself with the group of participants for the entire three days of the conference. She noted down behaviors, emotions, and thoughts in context and at the moment when individuals experienced them.⁵⁷ She paid particular attention to respecting participants' limits and used a sensitive approach that enabled them to share their feelings without judgment or interruption.⁵⁸ Showing empathy, especially during the sharing of personal life details, was central to enhancing her connection with the participants. She carefully documented the experiences shared by parents and survivors, details of events that happened during the conference, summaries of each formal presentation, and informal conversations. Given the sensitive nature of the context, she chose not to use an audio recording device. She transcribed and eventually anonymized the notes she took during and after the conference for use later during analysis. The conference organizers took pictures during the final presentations at the workshop. In addition to the data produced by the first author, and the video documentation produced by the conference organization, other analysis materials included: a conference newsletter published after the conference summarizing the meeting's key insights, photos and conference presentations published on the event website, and four video clips where one of the survivors participating in the conference together with other three young patients treated in the same hospital, creatively enact their vision of the cancer experience.

The first author analyzed the aggregated data gathered from the notes using a narrative inquiry approach, and so this article will not present actual quotes from the participants.⁵⁹ This approach seemed suitable for the context of this investigation because it can capture the emotion in the moments described, convey the meaning communicated by the participants, and clearly summarize the ways individuals organize and derive meaning from events.⁶⁰ The first author organized the data and removed irrelevant and redundant elements. She then listed the content

and clustered it into themes.⁶¹ The second and third authors reviewed and discussed each theme. To clarify the essence of each theme and reach agreement, the three authors framed them as a description of a specific challenge faced by the participants. This included a general definition of the challenge, information about the context and the stakeholders involved, the effect and complications the challenge generates, and the emerging coping strategies as results of that effect.⁶² Afterwards, the three authors synchronically arranged the themes according to the levels in Bronfenbrenner and Ceci's model. When all three authors had concluded the analysis, the first author shared the results with the conference association members who had invited her to the conference and one of the workshop facilitators, and invited them to provide feedback to validate the analysis.

Results: Learning from the Shared Testimonies of Cancer Survivors

Based on the results of the observations and informal talks conducted at the CCI meeting, five themes illustrating the experiences and coping strategies that cancer survivors and their families adopted during and after treatment emerged: accepting the transformation of one's body; learning to avoid avoidance, which can paralyze a family; maintaining interest in social activities, to reignite a sense of hope and optimism; retaining a sense of belonging to one's social networks, an important resource whose role and use can change dramatically during a life disruption; and dealing with the social stigma surrounding cancer, which can hinder survivors from engaging with normal, everyday life (Figure 2). Each theme reveals specific features representative of the coping strategies adopted at each level of Bronfenbrenner and Ceci's model, starting from the center where the child is positioned (Figure 3). The time dimension is intertwined with the other levels, and therefore no theme relates to it specifically. The themes together represent an overall summary of the main concepts mentioned by survivors, parents, and professionals present at the conference.



in *Cancer in Children: Clinical Management*, 6th ed., ed. Michael C. G. Stevens, Hubert N. Caron, and Andrea Biondi (New York: Oxford University Press, 2012), 111–17.

43 Susan Folkman et al., "Dynamics of a Stressful Encounter: Cognitive Appraisal, Coping, and Encounter Outcomes," *Journal of Personality and Social Psychology* 50, no. 5 (1986): 992–1003, DOI: <https://doi.org/10.1037/0022-3514.50.5.992>.

44 Shing et al., "Contextual Positive Coping," 1291.

45 Richard S. Lazarus and Susan Folkman, *Stress, Appraisal, and Coping* (New York: Springer Publishing Company, 1984), 140.

46 Last and Grootenhuis, "Emotions, Coping and the Need for Support," 172.

47 *Ibid.*, 170.

48 Hocking et al., "Parent Perspectives," 1287–94; Sasja A. Schepers, "Changing Pediatric Cancer Care: Development and Implementation of Electronic Patient and Parent Reported Outcomes" (PhD dissertation, University of Amsterdam, 2017), available at <http://hdl.handle.net/11245.1/18e59179-958e-48ab-a643-5d365e781c34>; Bernie

Figure 2 Synchronic overview of the themes and Bronfenbrenner and Ceci's model levels. Copyright © 2018 by Patrizia D'Olivo.

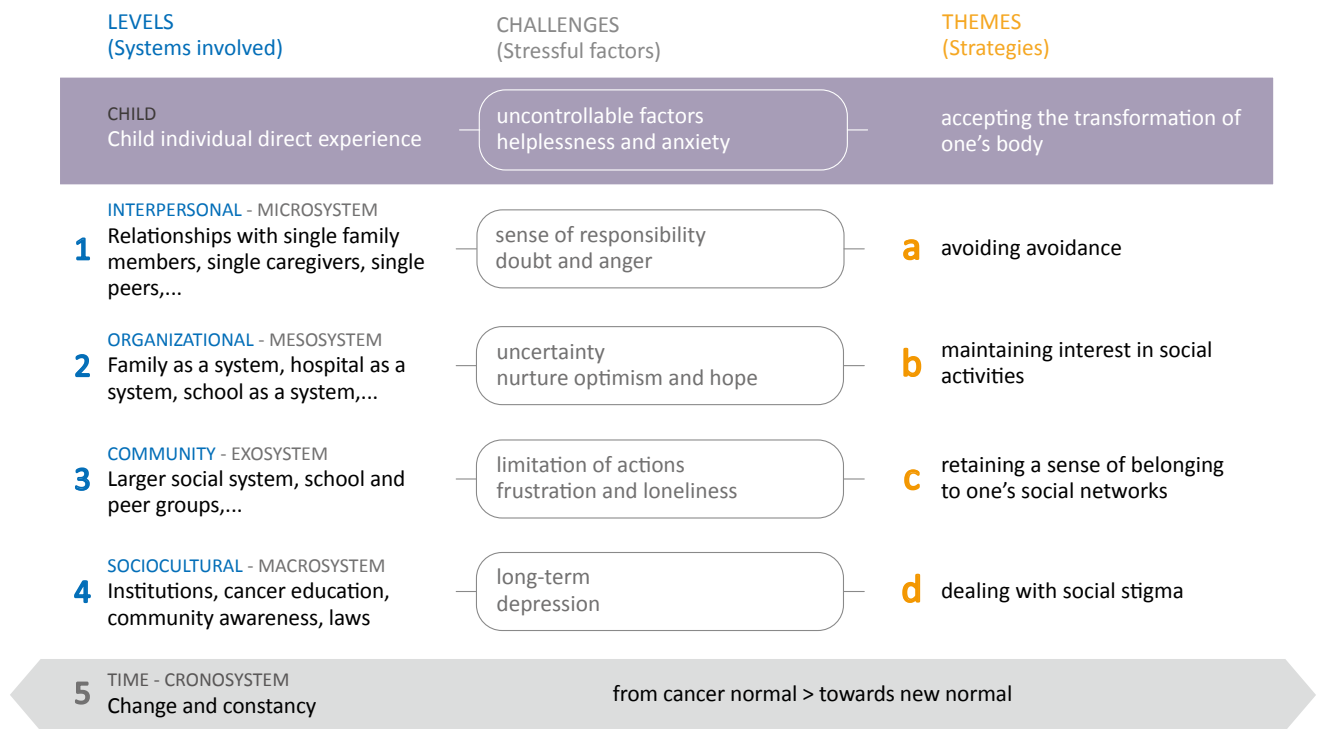


Figure 3 Correspondences between Bronfenbrenner and Ceci's model levels, challenges, and coping strategies. Copyright © 2018 by Patrizia D'Olivio.

Carter, Caroline Sanders, Clare van Miert, and Anne Hunt, "Knowing the Places of Care: How Nurses Facilitate Transition of Children with Complex Health Care Needs from Hospital to Home," *Comprehensive Child and Adolescent Nursing* 39, no. 2 (2016): 141, DOI: <https://doi.org/10.3109/01460862.2015.1134721>.

49 Peta Wyeth and Carla Diercke, "Designing Cultural Probes for Children," in *OZCHI '06: Proceedings of the 18th Australia Conference on Computer-Human Interaction: Design: Activities, Artefacts and Environments* (New York: ACM, 2006): 385, DOI: <https://doi.org/10.1145/1228175.1228252>; Hee Young Jeong, Sun Young Park, and John Zimmerman, "Opportunities to Support Parents in Managing Their Children's Health," in *CHI EA '08: Extended Abstracts on Human Factors in Computing Systems* (New York: ACM, 2008), 3227, DOI: <https://doi.org/10.1145/1228175.1228252>.

Themes and Coping Strategies

The Individual Level: Accepting the Transformation of One's Body

Being treated for childhood cancer causes bodily changes that children, and especially adolescents, have to learn to accept. Some of these changes are temporary, such as hair loss and weight gain, but sometimes the damage caused by the cancer itself can be permanent – an amputated limb as a result of bone tumor or hearing loss and attention deficit as a late effect of cancer treatment. According to some of the survivors, these bodily changes can severely undermine a person's self-confidence. During and after treatment, patients must reevaluate their strengths and learn to see themselves in a new light. In the literature, bodily changes are classified as uncontrollable factors that, if not taken into consideration, can lead to feelings of "helplessness and anxiety."⁶³

The experiences shared during the conference highlighted that, for the patients, working on one's self-esteem during cancer treatment can help strengthen a sense of confidence. Survivors explained how important it was to work on accepting limitations to their mobility due to muscle weakness and bone fragility caused by treatment and also learn to control their diet and regimen to regain energy. Clinical professionals participating at the conference pointed out that teenage patients especially must learn to reevaluate their bodies in relation to their peers in healthy ways, so they can have the confidence to approach others and start new relationships. They may also need to be informed about the consequences that the treatment will have on their ability to become parents. All the participants said it was important to encourage children in treatment and survivors to reflect on their bodies, feelings, and emotions to help them create awareness of themselves in the world, find the motivation they need to pursue their goals, and establish healthy relationships with others more effectively.

The Interpersonal Level: Avoiding Avoidance

When a child is diagnosed with cancer, his or her family members can also experience feelings of vulnerability and powerlessness. As reported by parents during

the conference, dealing with the unexpected is frightening, and being faced with the possibility that the child might suffer or even die is extremely stressful. According to the literature, family members share a sense of responsibility towards each other, and not being able to maintain control over that sensation can generate feelings of self-doubt and self-anger.⁶⁴ The parents and survivors said that although sharing feelings with each other is difficult, sharing helps everyone to cope with the stressful emotions and creates a constructive family environment where everybody has an equal right to ask for help. Children have the right to express their pain and sadness, and parents have the right to show and talk about their insecurities and fears. Therefore, finding ways to support ongoing communication seems vital for families in this context.

The experiences shared during the conference highlighted that families need support if they are to avoid avoidance – they need help dealing with difficult topics and emotions. The conference participants talked about how social media helped them share their feelings with family members. When direct, face-to-face communication felt daunting, indirect and mediated communication through screens and text messages seemed to make it easier for family members to talk. The survivors and parents agreed that there are many ways to help family members talk about difficult issues and that, in general, they preferred to use the same communication channels that people use in everyday life. During the proceedings, they intimated and sometimes expressed a need to find ways of sparking conversation even when the situation involves difficult topics.

The Organizational Level: Maintaining Interest in Social Activities

Childhood cancer can seriously undermine hope and optimism as the situation deepens in severity and becomes possibly life threatening. The conference participants explained that when they feel well, they take pleasure in what they are doing – they are interested in and motivated by life in general. They engage in leisure activities and hobbies and do fun things together with family and friends. According to the participants, these kinds of activities can help them bolster their sense of hope and optimism.⁶⁵ In particular, they said laughter and engaging in fun activities were effective ways for survivors and family members to overcome feelings of uncertainty.⁶⁶ For instance, the survivors joked about the severity of their cancer by debating which type of cancer was the “coolest.” The parenting association organizers reported that a high number of families joined summer camp initiatives to foster motivation in their children, help them bond with new friends, and involve siblings more directly.

The experiences shared during the conference highlighted that engaging in social activities, reinforcing family bonding, seeing how other people are dealing with the same problem, and keeping spirits up is important for families to instill hope and better cope with the emotional challenges accompanying childhood cancer. Cancer treatment can last a long time – anywhere from months to years – and participants appeared to truly benefit from focusing on the present and enjoying simple daily experiences together. Gently being reminded about the small, positive things in life might be a way to prevent defensive behaviors and the feeling of being neglected.

The Community Level: Retaining a Sense of Belonging to One's Social Networks

During cancer treatment, the social landscape surrounding the family changes. The psychological impact of cancer and the resources it demands intensify family bonds and increase the search for fresh sources of input. The participants confessed that it was harder to maintain contact with friends and everyday life events because of frequent hospital visits and their friends' difficulty comprehending the situation.

[org/10.1145/1358628.1358835](https://doi.org/10.1145/1358628.1358835); Andy Crabtree et al., “Designing with Care: Adapting Cultural Probes to Inform Design in Sensitive Settings,” in *Proceedings of OzCHI 2004, New Directions in Interaction Information Environments, Media and Technology* (Brisbane: University of Queensland, 2004): 4, available at <https://www.cs.nott.ac.uk/~pszaxc/work/OzCHI03.pdf>; John Vines et al., “Special Topic: Designing for and with Vulnerable People,” *interactions* 21, no. 1 (2014): 44–46, DOI: <https://doi.org/10.1145/2543490>.

50 Anja Thieme et al., “Enabling Empathy in Health and Care: Design Methods and Challenges,” in *CHI EA '14: Extended Abstracts on Human Factors in Computing Systems* (New York: ACM, 2014): 139–42, DOI: <https://doi.org/10.1145/2559206.2559237>.

51 John Vines et al., “Configuring Participation: On How We Involve People in Design,” in *CHI '13: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (New York: ACM, 2013): 429–38, DOI: <https://doi.org/10.1145/2470654.2470716>.

52 Meghan L. Marsac et al., “The Cellie Coping Kit for Sickle Cell Disease: Initial Acceptability and Feasibility,” *Clinical Practice in Pediatric Psychology* 2, no. 4 (2014): 392–93, DOI: <https://doi.org/10.1037%2Fcpp0000062>.

53 Jens M. Nygren, Susanne Lindberg, Pontus Wärnestål, and Petra Svedberg, “Involving Children with Cancer in Health Promotive Research: A Case Study Describing Why, What, and How,” *JMIR Research Protocols* 6, no. 2 (2017): e19, DOI: <https://doi.org/10.2196/2Fresprot.7094>.

54 Virginia Dickson-Swift, Erica L. James, Sandra Kippen, and Pranee Liamputtong, “Doing Sensitive Research: What Challenges Do Qualitative Researchers Face?,” *Qualitative Research* 7, no. 3 (2007): 330, DOI: <https://doi.org/10.1177%2F1468794107078515>.

55 Allison Tong, Peter Sainsbury, and Jonathan Craig, “Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups,” *International Journal for Quality in Health Care* 19, no. 6 (2007): 349–57, DOI: <https://doi.org/10.1093/intqhc/mzm042>.

56 “Conferences and Forums,” *Childhood Cancer International*,

accessed October 2, 2018, <https://www.childhoodcancer-international.org/cci-signature-events/conferences-forums/>.

57 Danny L. Jorgensen, "Participant Observation," in *Emerging Trends in the Social and Behavioral Sciences: An Interdisciplinary, Searchable, and Linkable Resource for the 21st Century*, ed. Robert A. Scott and Marlis C. Buchmann (John Wiley & Sons, Ltd./Wiley Online Library, 2015), DOI: <https://doi.org/10.1002/9781118900772.etrds0247>.

58 Virginia Dickson-Swift, Erica L. James, and Pranee Liamputtong, *Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks* (Cambridge, UK: Cambridge University Press, 2008), DOI: <https://doi.org/10.1017/cbo9780511545481>; Dickson-Swift et al., "Doing Sensitive Research," 330.

59 Dan P. McAdams, "Exploring Psychological Themes through Life-Narrative Accounts," in *Varieties of Narrative Analysis*, ed. James A. Holstein and Jaber F. Gubrium (Thousand Oaks: SAGE Publications, Inc., 2012), 15–17, DOI: <http://doi.org/10.4135/9781506335117.n2>.

60 Charles P. Smith, "Content Analysis and Narrative Analysis," in *Handbook of Research Methods in Social and Personality Psychology*, ed. Harry T. Reis and Charles M. Judd (Cambridge, U.K.: Cambridge University Press, 2000), 313–35.

61 Matthew B. Miles and A. Michael Huberman, *Qualitative Data Analysis: An Expanded Sourcebook* (Thousand Oaks: Sage Publications, 1985).

62 William Labov, "Some Principles of Linguistic Methodology," *Language in Society* 1, no. 1 (1972): 97–120, DOI: <https://doi.org/10.1017/S0047404500006576>; Last and Grootenhuis, "Emotions, Coping and the Need for Support," 169–79.

63 Last and Grootenhuis, "Emotions, Coping and the Need for Support," 175.

64 Ibid.

65 Ibid.

66 Ibid.

Some parents and survivors explained that their friends or close relatives just wanted to forget or avoid talking about the experience. The uneasiness that the children and their family members feel when trying to broach the topic of what is happening limits their actions, and the disconnect leads to feelings of frustration and loneliness.⁶⁷

However, during the conference, the participants did highlight two ways their social networks were expanding or becoming more consolidated. Some explained that their network had begun to include not only doctors, nurses, and fellow patients facing the same problems, but also new institutions, environments, and associations offering safe harbor throughout the cancer journey. They suggested creating a group chat that could unite new friends together during hospitalization, for example, to enable people sharing a similar trajectory in life to keep in contact. Other participants noted that social media helped families to challenge limitations in mobility associated with cancer and also re-establish contact with old friends. Parents and teenage survivors presented blogs they used to update friends outside the hospital during cancer treatment or share their experiences with children in treatment and their families in other countries.

The Sociocultural Level: Dealing with Social Stigma

The participants stated that, for most people, cancer still carries a social stigma. In spite of the medical information available on the topic and continually improving clinical outcomes, they explained that some parts of society find it difficult to perceive cancer as curable – or even as a viable topic of conversation. Some people still have difficulty saying the word "tumor" or "cancer" out loud. According to the survivors and the parents, people do not know how to broach the topic of severe illness diagnosis, a treatment for which the final outcome is uncertain, and the long term effects that may emerge. The uneasiness coupled with the long duration of the condition often pushes people away,⁶⁸ frightens them, creates misunderstandings, and elicits pity, effectively isolating the sick child and his or her family. All the participants agreed that people in general harbor misconceptions about cancer and are not accurately informed about the disease. Even after treatment, when patients have been cured, in certain contexts – at school or work, or at sports practice for example – people may still perceive them as needing special attention. For instance, one conference participant working as an English teacher in an elementary school revealed how important it is for professionals working in educational contexts to learn how to communicate with children in treatment while they are in school, and explain to their classmates what is happening in a careful, respectful, and understandable way.

The survivors communicated that once cured, they just wanted to go back to their normal lives. But, here too, social stigma can inhibit them, and in the long run, that limitation can lead to depression.⁶⁹ In line with that need to express themselves and be treated as cancer-free people, during the conference the survivors used pictures, videos, and graphics to express and visualize what they were going through. One of the facilitators, who was also member of the survivor community, proudly introduced her way of reinventing herself and her position in society: a website and fashion blog she developed to start her career as youth influencer. Her presentation afforded the audience with a valuable example – she demonstrated how the experience of cancer did not stop her from reaching her career goals, cultivating her interests, and showing society how normal life can be after cancer. These examples show that it is possible to educate others about cancer, break down the stigma surrounding it, and enable survivors and their families to re-appropriate their lives in any way they wish.

Discussion: Towards Socio-Ecologically Informed Design for Sensitive Settings

The results reveal that cancer, a truly disruptive life event, has contemporaneous impact on several levels – personal, interpersonal, familial, and societal. In this section, we discuss how design practice in sensitive settings can be informed and enriched by applying insights from the healthcare domain, explore opportunities that emerge from this collaboration, and consider the benefit of introducing design as a lever for innovation in healthcare.

A Socio-Ecological Perspective to Introduce Design Practice in Sensitive Setting

The conference participants shed light on the emotional burdens they carried and the tumultuousness of living through changes that had altered their sense of normal life and attested to the importance of reestablishing this normality.⁷⁰ The findings reveal that, beyond advanced medical treatments and psychosocial support, families and children who are experiencing (or have experienced) childhood cancer are looking for everyday ways of tactfully leveraging their internal resources innovatively.⁷¹ Supporting families' internal resources means supporting relationships and social interactions among family members.⁷²

To inspire designers' and design researchers' thinking about potential forms of support for family relationships and social interaction in light of the insights provided by Bronfenbrenner and Ceci's model, let us look at the context from a broader, socio-ecological perspective that brings these social dynamics to the fore. Design cannot influence the child's biological condition or the physical side effects generated by the treatment, but it can work on the proximal social elements that influence his or her normal development by supporting and nurturing the resilience of the entire family. Focusing on the family as a whole means creating opportunities to support the personal growth of each member – by empowering them to be more supportive of themselves and one another when needed; finding ways to keep relationships alive and maintain them; and raising their awareness about their strengths so they can harness these as resources for the future.⁷³

Socio-Ecologically Informed Design Opportunities

Interesting design concepts can potentially address family needs at different systemic levels.⁷⁴ However, for a solution to be effective in the short term – and have a direct impact on the family's well-being – it should be designed to work within the child's immediate environment at the levels of self and family (in Bronfenbrenner and Ceci's model, these are levels 1 and 2). The design should encourage and inspire family members in a tactful, personal, and attentive way. According to our findings, children with cancer and their family members use communication and social engagement as recurrent coping mechanisms to help them relax and remain optimistic.⁷⁵ To shape designs capable of appropriately facilitating these coping processes and carefully invite and enable families to develop the skills they need to recreate a normal family life, we suggest that designers introduce these coping mechanisms into their design solutions.⁷⁶

First of all, to reestablish normality, any design initiative should foster positive thinking, which is an important element in cognitive behavioral interventions.⁷⁷ Moreover, communication keeps a person apprised of what others are doing and at the same time offers a way of bonding.⁷⁸ It follows that interactive product designs may be a sensitive way to encourage family members to openly talk to each other. Finally, simple everyday interactions and rituals can be a distraction for the family and also stimulate a child's development and curiosity.⁷⁹ Sharing special moments together is key to maintaining healthy connections among family members,

67 Ibid.

68 Last and Grootenhuis, "Emotions, Coping and the Need for Support," 175; F. Daniel Armstrong, "Cancer and Blood Disorders in Childhood: Biopsychosocial-Developmental Issues in Assessment and Treatment," in *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: A Biopsychosocial Approach*, ed. Ronald T. Brown (New York: Oxford University Press Inc., 2006), 23.

69 Last and Grootenhuis, "Emotions, Coping and the Need for Support," 175.

70 Joän M. Patterson, Kristen E. Holm, and James G. Gurney, "The Impact of Childhood Cancer on the Family: A Qualitative Analysis of Strains, Resources, and Coping Behaviors," *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 13, no. 6 (2004): 390–407, DOI: <https://doi.org/10.1002/pon.761>.

71 Amii C. Steele et al., "Psychosocial Interventions and Therapeutic Support as a Standard of Care in Pediatric Oncology," *Pediatric Blood & Cancer* 62, no. S5 (2015): S585, DOI: <https://doi.org/10.1002/pbc.25701>.

72 Cox and Paley, "Families as Systems," 243–67.

73 Melissa A. Alderfer and Anne E. Kazak, "Family Issues When a Child Is on Treatment for Cancer," in *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: A Biopsychosocial Approach*, ed. Ronald T. Brown (New York: Oxford University Press Inc., 2006), 56.

74 Patrizia D'Olivo, Marco C. Rozendaal, and Elisa Giaccardi, "AscoltaMe: Retracing the Computational Expressivity of a Tactful Object for Sensitive Settings," in *DIS '17: Proceedings of the 2017 Conference on Designing Interactive Systems* (New York: ACM, 2017), 943–55, DOI: <https://doi.org/10.1145/3064663.3064801>.

75 Martha A. Grootenhuis and Bob F. Last, "Children with Cancer," in *Communication in Cancer Care*, vol. 168, ed. Friedrich Stiefel (Berlin: Springer, 2006): 74–75; Heather L.

Christiansen et al., "Providing Children and Adolescents Opportunities for Social Interaction as a Standard of Care in Pediatric Oncology," *Pediatric Blood & Cancer* 62, no. S5 (2015): S726, DOI: <https://doi.org/10.1002/pbc.25774>.

76 Massimi et al., "Finding a New Normal," 723.

77 Phipps, "Psychosocial and Behavioral Issues," 93.

78 Grootenhuis and Last, "Children with Cancer," 74.

79 Susana Santos, Carla Crespo, M. Cristina Canavarró, and Anne E. Kazak, "Family Rituals and Quality of Life in Children with Cancer and Their Parents: The Role of Family Cohesion and Hope," *Journal of Pediatric Psychology* 40, no. 7 (2015): 664, DOI: <https://doi.org/10.1093/jpepsy/jsv013>.

80 David S. Kirk, David Chatting, Paulina Yurman, and Jo-Anne Bichard, "Ritual Machines I & II: Making Technology at Home," in *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (New York: ACM, 2016): 2474–86, DOI: <https://doi.org/10.1145/2858036.2858424>.

81 Anne E. Kazak and Robert B. Noll, "The Integration of Psychology in Pediatric Oncology Research and Practice: Collaboration to Improve Care and Outcomes for Children and Families," *American Psychologist* 70, no. 2 (2015): 149–51, DOI: <https://doi.org/10.1037/a0035695>.

82 Thieme et al., "Designing Wellbeing," 789–90; Vines et al., "Special Topic," 44–46.

83 Ajna Thieme et al., "Enabling Empathy in Health and Care: Design Methods and Challenges," in *CHI '14 Extended Abstracts on Human Factors in Computing Systems* (New York: ACM, 2014), 139–42, DOI: <https://doi.org/10.1145/2559206.2559237>.

84 Leslie S. Liu, Kori M. Inkpen, and Wanda Pratt, "'I'm Not like My Friends': Understanding How Children with a Chronic Illness Use Technology to Maintain Normalcy," in *CSCW '15: Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social*

because family life is based on shared routines and habits. Therefore, bespoke products could be a means of gently helping those families to keep doing things together.⁸⁰

Design as a Lever for Healthcare Sector Innovation

We used knowledge from the field of developmental psychology, especially Bronfenbrenner and Ceci's model, to inform our research into the childhood cancer experience and help us better organize the complexity it presents.⁸¹ We do believe, however, that just as design research can benefit from knowledge coming from the healthcare domain, psychosocial cancer care – and health care research and practice more broadly – can benefit from our findings. By detailing opportunities for action in the field and introducing alternative approaches to establishing rapport with vulnerable populations, design research can provide valuable alternatives for actors in sensitive contexts.⁸² Design can support novel ways of conducting research and intervention projects.⁸³ Design can also work as a lens through which experts from multiple fields can look at the same context and understand each other.⁸⁴ Design can pinpoint areas of intervention for people experiencing life disruptions by seeking out their opinions in less standardized ways.⁸⁵ And finally, designers can create interactive products that can also be used to help researchers and professionals engage and empathize differently with children and their family members.⁸⁶

Benefits and Limitations

Although the observation process was quite challenging for the first author, the experience enabled her to gather compelling and detailed real-world data that would have been difficult to obtain otherwise. After becoming better acquainted with the topic by reading the literature and holding meetings she had with clinical experts, she gained first-hand experience with the overwhelming nature of the context.⁸⁷ At first, she felt as though she was invading what appeared to be a close-knit, private network. The community seemed to have its own rules and dynamics. For instance, most of the survivors were used to introducing themselves with their name followed by the type of cancer they had. This way of identifying themselves demonstrated how differently they engaged in any form of conversation with strangers at the event. Internal dynamics such as these indirectly impacted the first author's conversational sensibility throughout the whole event. In fact, during every interaction, she was indirectly reminded of how challenging the everyday life experience of the survivors was compared to her own. Therefore, even if the participants felt comfortable talking about their conditions, she painstakingly chose her words during every single conversation to avoid sounding impolite or intrusive.

Involving more researchers, and researchers with different backgrounds, to perform the data collection could have had perhaps both positive and negative outcomes. On one hand, the data collection would have been performed by multiple subjects and therefore objectively validated in the field. Furthermore, multiple researchers could have supported each other in overcoming personal inhibitions due to the sensitive topic. For instance, the presence of researchers with a psychology background, would have been supportive for a researcher with a design background as designers could perhaps be less equipped for when emotional or stressful situations arise. On the other hand, the presence of more researchers at the same event could have been perceived as overwhelming and intrusive or also altered the participant's engagement and comfort level during the conversations. The participants would have needed to build trust and learn to feel at ease with an entire group of new people external to the cancer community, and adapt continuously to a different level of sensitivity and empathy in each exchange with the different researchers.

This event was a valuable opportunity to gather information about the

childhood cancer experience that was beyond the clinical data provided by experts or found in the literature. This approach did not place families and their children under the focus group spotlight or ask them to undergo long personal interview sessions. The researcher stepped out of her comfort zone instead, and in so doing demonstrated her willingness to earn acceptance into their tight community.⁸⁸ To gain their trust, she had to clarify and explain her purpose and be completely transparent about herself. Knowing that the survivors' perceptions and responses may very well have been different with another person, we chose to ask the conference association members and workshop facilitators for feedback regarding our analysis. In this way, we hoped to acknowledge any potential bias and further validate our findings.

Finally, it is important to note that this exploratory work was conducted among survivors of childhood cancer, including family members, volunteers, and clinical professionals. The authors are aware that this population does not necessarily reflect the demands of children currently undergoing treatment, and the unmet needs of their families in general. In fact, we found that cancer survivors and their parents had quite different recollections of how they experienced coping with cancer. This implies the necessity of considering the individual characteristics and behaviors of survivors and their families to help interpret their past experiences. Future research would benefit from the participation of families that are currently in treatment for childhood cancer and of children in the age range of interest.

Contribution and Future Work

This research was based on qualitative data collected by observing and engaging with childhood cancer survivors and their families at a large support group conference. In this article, we have categorized the experiences they shared into five challenges that together create a picture of the complex personal and familial challenges of coping with childhood cancer: accepting the transformation of one's body, avoiding avoidance, maintaining interest in social activities, retaining a sense of belonging to one's social networks, and dealing with social stigma. The five themes also describe coping strategies that emerge when people deal with stressful disruptive life events.⁸⁹ We have matched them to the levels of a model we adopted from developmental psychology to better articulate their interdependencies and associations with levels of individual, familial, and social experience. Although medical studies on psychosocial support in childhood cancer have used this model before, to the best of our knowledge no other study has used this model to explore design opportunities for novel and sensitive forms of support that both address the population's unspoken needs in a tactful way and address the family collectively. Our main contribution is an understanding of how insights from developmental psychology can help to simplify and disentangle the complexity of a sensitive context. This preliminary inquiry also serves to frame a new perspective from which to identify design opportunities that can profoundly and effectively address the needs of the family system in its parts and as a unit.

We expect that the field of design can add to the support and sense of empowerment felt by these families and, more generally, provide a lever for innovation in sensitive settings. With these initial reflections in mind, we would like to see designers developing designs capable of nurturing the family as a whole and also involving families directly in the design feedback loop. The optimism that we wish to promote can be stimulated by introducing playful and yet tactful products that capture the interest of different family members and spur their interactions. We believe that future work in line with the socio-ecological perspective we have

Computing (New York: ACM, 2015), 1530–36, DOI: <https://doi.org/10.1145/2675133.2675201>.

85 Jeong et al., "Opportunities to Support Parents in Managing Their Children's Health," 3227–29.

86 Leslie S. Liu, "Designing Communication Technologies for Children with a Chronic Illness," in *GROUP '14: Proceedings of the 18th International Conference on Supporting Group Work* (New York: ACM, 2014), 258–59, DOI: <https://doi.org/10.1145/2660398.2660434>; Liu et al., "I'm Not like My Friends," 1534.

87 Dickson-Swift et al., *Undertaking Sensitive Research*, 33–54.

88 *Ibid.*, 40–41.

89 Last and Grootenhuis, "Emotions, Coping and the Need for Support," 175.

explored here is relevant and broadly applicable to other contexts where disruptive life events cause dysfunction within families. We also believe that there is much opportunity for innovation in the way that vulnerable populations are engaged. Interaction design can be used to tackle disruption through approaches that ask different disciplines to collaborate. In terms of pediatric oncology, for example, such methods will enable design and technology experts to better understand how best to strengthen family ties and empower families to explore and create their new normal. In light of our findings and these conclusions, we authors have already begun to design interventions for families dealing with childhood cancer.

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