

Designing Wearables for Caregivers of Young Children with Cancer: A Value-Sensitive Approach

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Abstract

Parental caregivers of young children with cancer face a distinct challenge in the home context: their children often cannot verbally articulate symptoms, requiring caregivers to develop embodied expertise through sustained observation and intuitive sensing. This paper examines how wearable technologies might support these caregivers, through semi-structured interviews with twelve primary caregivers, analyzed using Value Sensitive Design informed by Tronto's ethics of care. Our findings establish caregiver agency as the central organizing principle for wearable design in this context. Caregivers function as primary interpreters who translate behavioral and physiological cues into actionable understanding, and they require technologies that enhance rather than supplant this interpretive role. We identify three value tensions that structure the design space: visibility versus privacy in monitoring, palliative versus curative care orientations, and caregiver autonomy versus child safety. We conclude with design implications for wearables that support interpretive competence, manage information asymmetry between parent and child, and sustain caregiver wellbeing across extended treatment periods.

CCS Concepts

• **Human-centered computing** → **Empirical studies in ubiquitous and mobile computing.**

Keywords

Wearable Technology, Pediatric Oncology, Caregiver Support Systems, Value-Sensitive Design

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1 Introduction

The informal, home-based care of a child with cancer demands extensive emotional, financial, and logistical resources, requiring caregivers to navigate significant psychological distress, often sacrificing employment and facing social isolation [33, 34]. This burden, compounded by ongoing uncertainty and a debilitating loss of self, is particularly acute for parent caregivers managing care at home for children ages 0 to 7 who cannot verbally articulate distress, necessitating the interpretation of ambiguous behavioral and physiological cues [4, 10]. This interpretive work generates significant anxiety, as the core challenge extends beyond acquiring physiological data to achieving meaning and understanding necessary for responsive care. Such sustained uncertainty necessitates a value-centered approach to understanding technology requirements.

Wearable technology (WT), with its capacity for continuous monitoring, offers a potential means of support in this context [8, 19]. While CSCW and HCI research has explored various interventions in pediatric oncology [35, 47], there has been limited examination of how wearables might address the specific, value-laden needs of caregivers for young children with cancer, particularly the interpretive burden that arises when children cannot verbally communicate their symptoms.



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To address this gap, we conducted interviews with primary caregivers and analyzed their perspectives using Value Sensitive Design (VSD) [16] informed by the ethics of care [42]. While frameworks like Care-Centered Value-Sensitive Design (CCVSD) have successfully applied care ethics to health technologies, they were originally developed for clinical robotics and often privilege institutional values such as efficiency and provider needs [39]. To center the lived experience of the family rather than the hospital, we adopt VSD's broad stakeholder analysis while utilizing Tronto's four moral elements of care: Attentiveness, Responsibility, Competence, and Responsiveness as our primary value framework. This approach enables us to examine the informal family context, revealing dimensions of care work that are often obscured in institutional models, including emotional labor, identity erosion, and protective gatekeeping.

This paper contributes to HCI research on caregiving technologies and personal health informatics by establishing caregiver agency as the organizing principle for wearable design in pediatric palliative care contexts. Our value-sensitive analysis reveals that caregivers develop sophisticated embodied knowledge through intimate daily care, a form of expertise that current health monitoring technologies risk undermining. We identify three core value tensions that structure this design space: visibility versus privacy, palliative versus curative orientations, and caregiver autonomy versus child safety. Rather than treating these tensions as problems to be resolved, we argue that they must be navigated in ways that preserve caregiver interpretive authority. Our design implications advance HCI understanding of how wearable technologies can support competent care without displacing the human judgment that remains central to caregiving practice. This exploratory study is part of a broader longitudinal project examining sociotechnical principles for family resilience and care coordination during pediatric health crises [30–32].

2 Related Work

2.1 HCI Research in Cancer Caregiving

HCI research in pediatric oncology has explored diverse technological interventions, including social robotics [1, 12, 38, 47], mobile and gaming applications [21, 23, 36, 45], and communication technologies [40]. Social robots and mobile applications have been deployed to manage pain, anxiety, and caregiver stress [12, 21, 38, 41]. Despite these contributions, much of this work has focused on point-of-care interventions or clinical settings, leaving significant gaps in understanding how technology might support the ongoing interpretive labor caregivers perform at home, particularly when caring for non-verbal or very young children who cannot articulate their symptoms [4, 10]. Recent work has begun to emphasize personalized insights and timely interventions [7, 49], yet limited research addresses the value-laden dimensions of caregiving work, including emotional burden, identity erosion, and the relational dynamics between caregiver and child that define care in the home context.

2.2 WT in Pediatric Healthcare

WT represents a significant advancement in pediatric healthcare, offering continuous monitoring capabilities that extend beyond clinical settings [13, 48]. Studies demonstrate that wearables can

objectively assess physical function and performance status in pediatric cancer patients [8, 28], with potential to predict negative outcomes such as hospitalization [19]. These devices have been shown to be usable, feasible, and acceptable among children and adolescents with cancer, particularly when combined with social media-based peer support [20] or health coaches providing real-time feedback [18]. However, passive data collection alone cannot improve outcomes without interpretation [3], and efficacy of activity-tracking wearables for children with cancer remains insufficiently investigated [26]. Prior HCI research has developed methodological frameworks for age-appropriate wearable interfaces through child-centered design [46] and incorporated biofeedback features for emotional support [7]. Current consumer-grade wearables primarily rely on accelerometry and photoplethysmography sensors, enabling continuous tracking of physical activity, heart rate, sleep patterns, and, in newer models, blood oxygen saturation and single-lead electrocardiograms [9, 15]. In oncology populations specifically, accelerometers and actigraphs account for the vast majority of wearable applications, with heart rate and temperature sensors used far less frequently [9]. Notably, the oncology-specific clinical indicators most relevant to pediatric cancer care, such as white blood cell counts, infection markers, and blood chemistry, remain beyond the reach of current non-invasive wearable sensors [8, 15].

Despite this mismatch between available consumer metrics and desired clinical data, the parameters that are within scope, specifically heart rate and skin temperature, hold significant value for both child health and caregiver well-being. From a clinical perspective, heart rate and electrodermal activity have been validated as objective proxies for pain and distress in pediatric cancer patients and non-verbal children [2, 24]. Furthermore, continuous temperature monitoring is critical for the early detection of febrile neutropenia, a life-threatening complication in which prompt antibiotic administration is essential for survival [5]. Recent studies indicate that wearable patches can detect fever events up to 12 hours earlier than standard thermometers [29]. For caregivers, the ability to monitor these specific proxies addresses the interpretive burden of care. By objectifying the child's distress and infection risk, wearables can mitigate the psychological distress of uncertainty and replace constant hypervigilance with data-supported reassurance. Yet, critical gaps remain regarding how wearables might address the interpretive burden caregivers face when children cannot verbally communicate symptoms during extended periods between hospital visits.

2.3 Value Sensitive Design and the Ethic of Care

VSD is a theoretically grounded approach to technology design that proactively accounts for human values in a principled and comprehensive manner throughout the entire design process [16]. VSD is based on the belief that technologies are not ethically or socially neutral but rather reflect and reciprocally affect human values through their use and appropriation [17]. Within healthcare research, VSD is prominently paired with Tronto's relational ethics of care, which identifies four moral elements: attentiveness, responsibility, competence, and responsiveness [42]. While frameworks like CCVSD successfully apply these elements to clinical settings,

they have focused primarily on point-of-care interventions and institutional needs [25, 39, 43], leaving a significant gap in understanding how technology might support the direct stakeholder arguments of primary caregivers managing the value tensions and interpretive labor inherent in pediatric oncology care at home.

3 Methods

We conducted semi-structured interviews with 12 primary caregivers (7 female, 5 male) of children (6 female, 6 male; mean age=5.4, SD=1.3) diagnosed with cancer within the past three years, ensuring experiences reflected current pediatric oncology environments. Participants were recruited through UserInterviews using a multi-stage screening process, and recruitment concluded upon reaching data saturation (see Appendix A for details). Our Institutional Review Board approved all procedures. Interviews were conducted remotely to ensure caregiver accessibility. Three authors conducted the sessions, which lasted 40–60 minutes; participants received \$60 gift cards as compensation. The semi-structured protocol covered five key areas: (1) caregiving challenges and their impact on daily care, (2) initial perceptions of wearable technology for child health monitoring, (3) desired outcomes and features from wearable devices, (4) communication and care coordination with healthcare providers and family, and (5) emotional support and reassurance through technology. Questions emphasized emotional and logistical challenges and communication gaps when children have limited verbal ability.

While our inclusion criteria targeted children aged 0–7, participants' children varied considerably in verbal ability and in their prior experience with monitoring technology. Three children (P5, P10, P11) were non-verbal or pre-verbal, one (P7) had a diagnosed expressive and receptive language delay, and two (P12, P15) were verbally withdrawn and unable to articulate their feelings. The remaining participants had children with developing or typical verbal skills, yet still faced significant interpretive challenges: these children needed guidance in communication (P3, P16), used non-verbal aids such as a bell (P1), or relied on narrative framing (P9). This variation meant that even among older, ostensibly verbal children, caregivers performed substantial interpretive labor, making non-verbal interpretation central across the sample. Regarding technology experience, most participants discussed needs based on clinical monitor use, whereas P5 provided insights from active use of a customized consumer system involving a Pixel Watch 2 and Tile tracker.

We analyzed the transcripts through a two-phase process involving five team members. In the first phase, the lead author and the three research assistants independently read all transcripts and performed open coding, identifying caregiving challenges, emotional experiences, and technology-related themes. In the second phase, the lead author and the senior author collaboratively refined the analysis by applying two theoretical lenses. Using Tronto's ethics of care [42], we deductively coded for the four moral elements: Attentiveness, Responsibility, Competence, and Responsiveness [39], characterizing caregivers' moral labor and parent-child relational feedback loops. Simultaneously, we applied VSD constructs [16] to identify stakeholder values such as trust, identity, and psychological well-being. Throughout this phase, the lead and senior authors

met regularly to reconcile interpretive differences and examine emergent value tensions where caregivers described conflicting requirements, such as clinical safety versus child sensory comfort. Final themes emerged through iteratively mapping these moral elements and values onto the transcripts, following the principles of reflexive thematic analysis [6].

4 Findings

Our analysis revealed three interconnected themes. Caregivers navigate a significant interpretive burden, developing contextual agency through embodied expertise and peer networks. This interpretive work unfolds within an existential transformation marked by identity loss, hypervigilance, and a quest for calmness. Caregivers also manage a duality between their need for clinical data and their child's need for comfort, a gap that current consumer devices cannot bridge.

4.1 The Interpretive Burden and Contextual Agency

Caregivers described two dimensions of interpretive work: developing intuitive sensing to translate non-verbal cues, and asserting agency as primary interpreters who validate data through experience and peer networks.

4.1.1 Translation through Intuitive Sensing. Caregivers identify a fundamental communication barrier as their primary challenge. Children ages 0–7 cannot verbalize pain, creating diagnostic uncertainty and requiring heightened attentiveness. To address this, caregivers develop embodied expertise through intuitive sensing. P5 identified this as his “*biggest struggle*,” noting he had “*no idea what the symptoms were*.” P11 described deciphering cues: her daughter would communicate pain by “*hitting the area that hurt*” or crying. Caregivers rely on this knowledge over external data sources, with P3 stating she will “*observe his behavior more than anything else*.” These findings indicate intuitive sensing is a hard-won skill allowing the child's state to be understood through physical expression. Notably, this interpretive burden extended beyond pre-verbal children. Even among verbally developing children, caregivers performed substantial interpretive work; P16 described “*coming up with a bunch of different words to see if it's this one, this one, this one*” to help her daughter articulate pain, while P12 and P15's children were verbally withdrawn and unable to express their feelings, suggesting that verbal and physiological cues function as complementary rather than substitutive sources of understanding.

4.1.2 Caregiver Agency and Peer Meaning-Making. Caregivers assert agency by acting as primary interpreters and technical appropriators. P5, who utilizes a consumer wearable setup, customized wearable alerts for oxygen drops, noting this was “*really helpful*” for his non-verbal child. Similarly, P7 argued data must go “*through the caregiver first*” to incorporate daily context absent in clinical models. This interpretive authority is a requirement for moral competence, ensuring that metrics are validated against the child's typical behavior. To support this process, caregivers use peer communities as meaning-making tools; P9 explained that these networks help her determine if a symptom is “*normal in her phase of treatment*,” reducing diagnostic anxiety through shared experience and supporting

a state of calmness. These networks support the integrity of care by validating caregiver observations through shared experience, which reduces diagnostic anxiety.

4.2 Existential Transformation and the Quest for Calmness

Sustained caregiving reshapes caregivers' sense of self and emotional capacity. Participants described profound identity loss and chronic hypervigilance, while seeking reassurance through trusted clinical relationships and, potentially, technology.

4.2.1 Identity Loss and Hypervigilance. Caregiving for a child with cancer results in a change in the caregiver sense of identity. This burden reaches into financial, social, and physical dimensions, resulting in what participants describe as a *“loss of self.”* P10 identified this as her primary challenge, stating that she was *“battling a lot of mental anguish”* characterized by chronic anxiety and the cognitive load of constant medical decision-making, while her *“health overall deteriorates.”* This represents a harm to human welfare, as the requirement for attentiveness necessitates the suspension of personal goals to recognize the child needs. P12 described the totalizing nature of this responsibility, stating that he was *“deleting all people in my life and just concentrating on my patient, my child.”* This loss of self occurs within a state of constant hypervigilance. P1 described waking at *“3:00 in the morning to make sure she’s still breathing,”* while P9 noted that the requirements of the fever sepsis protocol create a state of perpetual readiness that depletes the caregiver emotional capacity.

4.2.2 Relational Trust and the Value of Reassurance. Caregivers rely on trusting relationships with the clinical team to navigate diagnostic turmoil and maintain psychological well-being. This trust is built through staff responsiveness and honesty. P15 described the medical team as providing safe guidance through unknown territory. He valued their positivity and their commitment to using *“layman terms.”* Where trust is present, caregivers feel that the integrity of care is maintained and their own expertise is validated. P11 provided a contrast between the oncology floor where nurses *“knew us well”* and the ICU where she faced difficulties in having her expertise recognized. Ultimately, the primary value caregivers seek from technology is reassurance. P1 stated that a wearable device would allow him *“to sleep at night,”* framing the value of monitoring as psychological relief. P6 sought technology to *“calm me down”* when she is *“feeling overwhelmed.”* However, a value tension exists as reassurance is often unattainable; P10 noted that *“there is no reassurance”* because caregivers are always *“existing for the next scan.”*

4.3 Stakeholder Duality and the Diagnostic Aspiration

Caregivers described a tension between protecting their child from the burden of monitoring and securing the clinical data needed to ensure safety. This tension is compounded by a gap between consumer wearable metrics and the oncology-specific indicators they require.

4.3.1 Information Asymmetry and Physical Tolerance. The care of a pediatric oncology patient reveals a value tension between the child requirement for comfort and the caregiver responsibility for safety. Caregivers describe a bifurcated set of needs where the child is shielded from clinical data while the parent is informed through monitoring. P1 identified this as a deliberate information asymmetry, stating that *“the monitoring, all that information should just be for the parents”* while the child should be kept *“comfortable”* and helped to *“relax.”* He stated that carrying the diagnostic burden is the *“parents’ job.”* This protective stance extends to the physical body, which represents a boundary where monitoring technology can cause distress. P9 rejected a temperature monitor because her daughter was *“over stimulated”* and *“anything that’s sticky, they hate.”* P11 recalled monitoring leads that would *“pull off some skin,”* expressing a desire for tools that protect the child human dignity and physical welfare. These findings indicate that caregivers prioritize the child responsiveness and sensory well-being over their own desire for monitoring data.

4.3.2 Clinical Data Gaps and Diagnostic Aspiration. Participants identify a mismatch between consumer health metrics and the specific clinical indicators required for oncology. P3 noted that devices like the Apple Watch are limited to *“basic vital signs”* when the *“red blood cell or white blood cell count”* is the primary concern. The absence of oncology specific data leads to ambiguity during medical episodes. P5 described an instance where her daughter pulse rate dropped on a watch, but the device *“failed because it can’t tell me like what’s going on exactly with her blood.”* These experiences result in a diagnostic aspiration where caregivers seek tools for proactive detection of infection or relapse. P1 expressed a desire for technology that could perform a *“blood test, the test for lymphocytes”* non-invasively. P16 similarly noted the difficulty of interpreting survival statistics, wishing for tools that provided actionable information. This search for specialized metrics represents a struggle for moral competence, as parents seek objective indicators that align with the high stakes requirements of their child treatment.

5 Discussion and Implications for Design

We translate the value tensions caregivers navigate into design implications, arguing that wearable technologies must support caregiver agency rather than replace it, address the ethical complexity of monitoring a vulnerable child, mitigate sustained hypervigilance, and bridge the gap between consumer metrics and clinically meaningful indicators. Critically, implications involving clinical data interpretation require interdisciplinary collaboration with oncologists and biomedical engineers to ensure medical validity.

5.1 Supporting Caregiver Agency through Enabling Design

Our findings indicate that caregivers of young children with cancer function as the primary interpreters of non-verbal symptoms. They rejected automated diagnostic models because these systems exclude the *“intuitive sensing”* required to understand a non-verbal child (P7, P3). In VSD, providing data without context undermines the value of caregiver *Competence*. We argue that wearables should

be designed as enabling technologies rather than replacement technologies [44]. Enabling designs share the role of monitoring to enhance human performance, whereas replacement designs attempt to fulfill the task in place of the human. To support this, we suggest that designers prioritize “Interpretation Support” over automated binary alerts. Specifically, we propose a “Contextual Annotation Interface” where caregivers can overlay qualitative observations (e.g., whimpering, restless sleep, hitting a specific area) directly onto physiological timelines through a simple long-press interaction on the companion application. This creates a hybrid record that validates the caregiver’s embodied knowledge against sensor data, which is particularly vital for children aged 0 to 3 who cannot verbalize distress (P5, P10, P11). Over time, this annotated history enables caregivers to identify patterns between observed behaviors and physiological changes, strengthening rather than replacing their interpretive competence. This design ensures that the technology functions as a tool for Attentiveness rather than a surrogate for parental judgment[39].

5.2 Managing Stakeholder Duality through Information Asymmetry

The tension identified between the child’s sensory comfort and the parent’s safety monitoring represents a fundamental ethical challenge where values are “incommensurable”[14]. Since there is no objective unit to weigh physical over-stimulation against data-driven reassurance, designers must rely on “voluntarist reasons” to justify a design path that prioritizes the most vulnerable actor in the relationship[14]. To manage this tension, we propose a design pattern of deliberate “Information Asymmetry.” As identified in studies of pediatric oncology technology, the system must fulfill the social role of a “companion” for the child while acting as an “informational tool” for the parent [25]. We suggest that the physical wearable be integrated into soft fabrics or non-adhesive accessories to protect the child’s skin and prevent over-stimulation (P11). Simultaneously, all high-stakes clinical data should be restricted to the caregiver’s companion application. This approach respects the child’s *Responsiveness* by shielding them from the psychological weight of constant monitoring, which participants characterized as a parental responsibility (P1).

5.3 Mitigating Identity Loss through Calm Awareness

Caregivers reported a “loss of self” resulting from a state of constant hypervigilance (P10, P12). This condition aligns with the state of chronic psychological distress and high emotional demand identified in pediatric oncology families [34]. While wearables offer reassurance, the specific properties of the technical system can inadvertently increase the user’s emotional burden [37]. Following the *interactional perspective* of VSD, we argue that values are not merely embedded in the device but are implicated through the engagement between the system’s features and the caregiver’s lived experience [11]. Additionally, to support the value of *Calmness*, which is defined as a composed psychological state [16], designers should avoid real-time surveillance streams that require frequent decision-making. As specific technical properties can distort a designer’s original intent and generate unintended negative impacts

on well-being [11], the system must proactively mitigate the risk of increasing the user’s emotional burden. To operationalize *Calmness*, we propose an On-Demand Status Check interaction model. Rather than displaying a constant stream of vitals, which risks reinforcing the hypervigilance reported by P1 and P10, the caregiver’s companion interface remains in an ambient or dormant state until the caregiver explicitly initiates a check (e.g., through a double-tap gesture) to reveal numerical data. Between active checks, the system communicates through a subtle haptic heartbeat pulse that serves solely to confirm device connectivity and child stability, rather than to alert to minor physiological variances. This design separates awareness from surveillance: the caregiver retains access to detailed information on demand but is not subjected to continuous decision-making that depletes emotional capacity for hands-on care. Additionally, Summary Views that aggregate trends over configurable intervals (e.g., the previous four or eight hours) allow caregivers to review their child’s status at natural transition points, such as before sleep or after medication, rather than in response to real-time fluctuations.

5.4 Addressing Clinical Requirements through Composite Data Indicators

Participants expressed a requirement for clinical indicators, such as white blood cell counts, to assist in detecting infections or relapses (P1, P5). In VSD, the limitations of consumer sensors identify a technical infrastructure that can foreclose certain kinds of designs for supporting the human activity of early complication detection [16]. To address this, designers must proactively identify alternative technical levers to ensure the system supports the user’s values [16]. While emerging biomedical research demonstrates the feasibility of detecting white blood cells through non-invasive dynamic spectrum analysis [22] or microfluidic point-of-care testing [27], current commercial gaps necessitate an immediate design bridge. To fill this void, we suggest developing oncology-specific composite indicators. Designers should synthesize available data streams, such as sleep disruptions and variations in skin temperature, into a single Infection Risk Index. This technical shift transforms general physiological metrics into specialized information that supports the caregiver’s moral Competence and responsibility in identifying medical risks [39, 44]. This logic is grounded in the interactional perspective, which states that the influence of a technology is determined by how its design properties interact with the goals of the people interacting with it [11]. By tuning the system’s properties to the caregiver’s clinical goal of detecting medical crises, the design provides actionable support that aligns with the trajectory of future non-invasive sensing capabilities. Importantly, developing and validating such a composite indicator requires interdisciplinary collaboration among HCI researchers, oncologists, and biomedical engineers. The role of the wearable designer in this process is not to define clinical thresholds but to design an interface architecture that can integrate clinically validated parameters and present them in ways that support caregiver interpretation without replacing clinical judgment.

6 Limitations and Future Work

This study's sample (N=12) and recruitment platform may limit generalizability across diverse socioeconomic contexts, while retrospective interviews introduce potential recall bias. Future work should involve co-designing wearable prototypes using child-centered design methodologies to ensure technical solutions are developmentally appropriate and clinically effective. To achieve a more comprehensive VSD stakeholder analysis, researchers should integrate the perspectives of healthcare providers and patients. Finally, longitudinal studies are necessary to examine how these interventions impact caregiver identity and hypervigilance across treatment phases, ensuring technology supports the ethics of care without exacerbating emotional burden.

7 Conclusion

This study applies VSD informed by Tronto's ethics of care to examine wearable technology for caregivers of young children with cancer. Our findings reveal that caregivers function as primary interpreters of non-verbal symptoms and require enabling technologies that support their agency rather than replace their judgment. We offer design implications that address stakeholder duality, mitigate identity erosion, and honor the relational nature of care.

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A Participant Demographics and Data

A.1 Table One

ID	Marital Status	Gender	Ethnicity - Race	Employment	Child Age	Cancer Type	Care Type
P1	Married	Male	Non-Hispanic - Asian	Full-time	6	Non-Hodgkin Lymphoma	At-home
P12	Married	Male	Non-Hispanic - Black/AA	Full-time	7	Bone Marrow Cancer	At-home
P5*	Single	Male	Hispanic - White	Part-time	4	Acute Lymphoblastic Leukemia	At-home
P9	Married	Female	Non-Hispanic - Black/AA	Full-time	6	Acute Lymphoblastic Leukemia	Hospitalized
P6	Married	Female	Non-Hispanic - White	Full-time	5	Acute Lymphoblastic Leukemia	At-home
P3	Married	Female	Non-Hispanic - White	Full-time	5	Acute Lymphoblastic Leukemia	At-home
P10	Married	Female	Asian	Full-time	3	Atypical Teratoid Rhabdoid Tumor	At-home
P11†	Single	Female	Non-Hispanic - White	Full-time	0–6	Central Nervous System	At-home
P15	Married	Male	Non-Hispanic - White	Full-time	5	Acute Lymphoblastic Leukemia	At-home
P7	Married	Male	Non-Hispanic - White	Full-time	5	Acute Lymphoblastic Leukemia	At-home
P16	Married	Female	Hispanic - White	Full-time	5	Acute Lymphoblastic Leukemia	At-home
P17	Married	Female	Non-Hispanic - White	Full-time	6	Acute Lymphoblastic Leukemia	At-home

*Note: Black/AA = Black/African American; * = Participant used a Pixel Watch 2 on his daughter to monitor vitals (e.g., oxygen levels, heart rate) and location, supplemented by a Tile Tracker for additional location monitoring. The device was customized with the help of a computer programmer to send push notifications triggered by specific health thresholds. † Child diagnosed at 8 months; caregiving experience spanned ages 0–6 until the child's passing.*