

# Finding Information, Fostering Connection, Taking Control: Towards Self-Advocacy Technologies for AYA Cancer Survivors

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## Abstract

As they enter long-term survivorship, young adult cancer survivors grow into Active Architects of personalized digital support ecosystems, strategically curating resources across diverse platforms, from social media to specialized forums. Previous HCI research has shown how these individuals use technology through the early stages of their journey, to both support their needs and leverage their strengths. However, less is known about how technology might support survivors' transition from self-management (task-oriented illness management) to self-advocacy, involving systemic, outward-facing action. This paper adopts a reflexive-interventionist approach, grounded in an interview study with 14 young adult cancer survivors who were diagnosed across childhood and adolescence. We show how their practices evolve across the journey, from family-mediated interactions during acute illness to autonomous curation, community stewardship, and advocacy. We articulate design implications for supporting ecosystem curation, accounting for evolving user expertise, and creating pathways that honor both ongoing challenges and developing capabilities.

## CCS Concepts

• **Human-centered computing** → **Empirical studies in collaborative and social computing.**

## Keywords

Childhood cancer survivors, Adolescent and Young Adult (AYA) Cancer Survivors, Self-Management, Self-Advocacy, Digital Ecosystems, Asset-Based Design, Reflexive-Interventionist Approach, Online Health Communities

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## 1 Introduction

Upon entering adulthood, childhood cancer survivors navigate a prolonged survivorship trajectory marked by evolving psychosocial, informational, and supportive care needs that persist post-treatment [18, 22, 54, 95]. The transition from intensive, pediatric-centered treatment to adult-oriented long-term follow-up care compounds these challenges, requiring survivors to assume greater responsibility for self-management, the inward-focused, task-oriented activities of managing their health, while developing the autonomy needed for self-advocacy in seeking ongoing support [45, 55, 61]. For Adolescent and Young Adult (AYA) survivors, self-advocacy often manifests as a form of compelled responsibility rather than chosen empowerment [1]. The structural fragmentation between pediatric and adult care systems forces them to ensure continuity of care, a task that requires them to bridge institutional information gaps and assert their complex needs [56]. This instrumental work is compounded as it occurs while survivors are simultaneously negotiating a post-treatment identity and new social norms [76]. This dual burden, managing systemic failures while constructing a new sense of self, provides a potent context for understanding the high-stakes nature of self-advocacy.

In response to these complex needs, HCI research has made strides in moving from deficit-focused approaches, which position survivors as patients with problems requiring technological solutions, toward asset-focused approaches that recognize survivors' resilience and capabilities [73]. Studies of online health communities (OHCs) demonstrate how survivors leverage collective experiential knowledge and peer support as valuable assets [96], with peer patients providing unique forms of social support and practical advice that clinicians cannot replicate [44]. However, little is known in HCI about how AYA survivors of childhood cancer navigate their dual journeys towards adulthood and self-advocacy.

To address this gap, we argue that the critical next step in supporting adult survivors of childhood cancer is to design for their full trajectory toward self-advocacy. This requires moving beyond viewing asset- and deficit-based support as a simple dichotomy and instead recognizing that this journey from self-management and self-empowerment to self-advocacy is defined by a dynamic negotiation. We adopt a reflexive-interventionist approach [39] to examine power relations, hidden assumptions, and unintended consequences within existing support structures, and to identify design implications that can account for this complexity, helping users navigate rather than be limited by these design tradeoffs as they develop into effective advocates.

Our study is guided by two central research questions:

- RQ1: How do young adult survivors of childhood cancers build digital ecosystems and use technology to manage their transitions from childhood to adulthood and from patient to survivor and self-advocate?
- RQ2: What design approaches are necessary to create technologies that help survivors navigate these tradeoffs and support their complex, evolving journey of empowerment?

Grounded in the experiences of young adult cancer survivors diagnosed across childhood and adolescence, this paper offers the following contributions to HCI: (1) A critical examination of deficit and asset-based paradigms in the context of survivorship technologies. Through reflexive-interventionist analysis, we demonstrate that the journey to self-advocacy is characterized by survivors' ongoing navigation of tensions between persistent needs and developing capabilities, moving beyond a simple binary to reveal a process of dynamic negotiation. (2) Empirical insights and design implications for socio-technical support systems in cancer survivorship. We detail survivors' sophisticated practices across three phases, including strategic platform selection, information vetting, identity management, and community stewardship, and translate these into actionable design implications addressing both individual navigation and collective capacity-building.

## 2 Related Work

### 2.1 The Cancer Survivorship Journey: An HCI Perspective

*2.1.1 The Challenges of the Survivorship Journey.* Rather than a discrete event, cancer survivorship for young adult survivors of childhood and adolescent cancers is an ongoing condition characterized by persistent uncertainty and significant psychosocial challenges [104]. This condition affects a significant portion of the U.S. population, representing a growing demographic with specific long-term care needs [80]. Within HCI, survivorship is understood not as a passive medical timeline, but as a profound life disruption that shatters established routines and support networks, forcing survivors to reconstruct their socio-technical lives in search of a “new normal” [65]. As they enter adulthood, survivors face distinctive challenges as healthcare responsibility shifts from parents to themselves [42, 48]. This transition is particularly stark for those diagnosed in childhood; they often move from a parent-managed care model to one requiring full autonomy with little gradual preparation, yet paradoxically remain dependent on caregivers for medical and financial support [1, 4].

Such life reconstruction requires navigation through a fragmented healthcare system characterized by parallel, often misaligned care journeys, where technology can bridge communication gaps between patients, providers, and care teams [46, 93]. However, survivors often lack a comprehensive understanding of their treatment history, crucial for their long-term health [7], and report inadequate preparation for post-treatment life, as Survivorship Care Plans (SCPs) are inconsistently provided [8, 50]. Consequently, these systemic gaps force survivors to educate new adult-oriented clinicians about their complex medical histories by managing “patient-mediated handoffs” [4, 28, 89], a transition that demands health literacy and self-advocacy skills they may still be

developing. Such burden of self-advocacy is well-documented in HCI, where patients with complex or rare conditions are often forced into an expert role to educate their providers and co-manage their own care [21, 47].

In long-term survivorship, survivors face complex unmet needs, including late effects like organ damage, secondary cancers, and cognitive challenges [43, 74]. Sexual and reproductive health concerns are among the most cited unmet needs [12], alongside financial toxicity, with young adult survivors reporting more work disruptions and higher costs than older survivors [13, 62]. When these multifaceted needs remain unaddressed, they face diminished quality of life and poorer outcomes compared to other cancer populations [22]. Beyond physical health, survivors of childhood cancer face psychosocial hurdles in young adulthood, including navigating social development and identity formation that was disrupted at an earlier age [104], as well as increased vulnerability to depression, anxiety, and trauma-related stress [95]. Those diagnosed during their adolescent years often experience more emotional difficulties and negative health perceptions in the long term compared to those diagnosed as younger children [54].

Moreover, the survivorship trajectory is understood as being temporally dynamic, with challenges changing significantly from one phase to the next. The needs during active treatment are intense and immediate, and differ fundamentally from those in survivorship, where concerns shift to long-term identity, managing late effects, and social reintegration. Addressing these evolving priorities requires adaptive systems that can facilitate different forms of peer connection and support as survivors transition through these distinct life stages [29]. Despite these challenges, many demonstrate remarkable resilience, proactively seeking information and peer support to regain a sense of control [31, 71].

*2.1.2 Mapping the Digital Response to Survivorship Challenges.* HCI research has established the value of digital tools for self-management, particularly through medication and symptom tracking apps tailored to survivorship needs [9, 11, 17, 27, 36, 51, 70, 82, 84–86]. Complementing these trackers are personalized health information systems that dynamically update content to encourage proactive care, though they often struggle to address the complexity of managing multiple chronic conditions [49]. Consequently, survivors are often compelled to shoulder this resulting self-management burden because professional cancer navigation services, while effective at eliminating barriers during active treatment, typically cannot provide sustained long-term follow-up due to resource constraints and focus on newly diagnosed patients [46].

Beyond individual-focused tools and the necessity to seek digital support [25, 58], survivors are increasingly engaging with social computing platforms and online communities to collaboratively address practical and informational challenges [27, 52, 90]. Such digital interactions primarily focus on specific information-seeking tasks, such as finding medical details about late effects or life-stage-specific guidance on topics like fertility, careers, and relationships [30]. Crucially, navigation through these spaces is not passive; survivors make strategic platform choices based on the task at hand. For instance, Facebook groups are valued for creating niche communities around specific or rare cancer types [58], while anonymous platforms like Reddit are preferred for seeking information on

sensitive or stigmatized topics [33, 68]. These deliberate choices reflect HCI research on online health information seeking, which has shown that users distribute their activities across platforms based on social stigma and topic severity, beginning with private channels like search engines for highly sensitive topics before moving to public social platforms for less stigmatized needs [26], demonstrating that even the earliest stages of digital engagement are a form of active self-management.

Beyond immediate information needs, a central motivator for engaging with OHCs is the desire to connect with similar others, which the literature identifies as essential for gaining validation and psychosocial support [38, 66, 81]. These peer interactions help survivors manage the identity distress that often follows a diagnosis in childhood or adolescence, allowing them to navigate feelings of difference and feel seen as more than just patients [5, 94]. A key indicator of this growing empowerment is a shift in how knowledge is valued, with survivors often preferring peer-generated narratives over formal medical advice for certain topics [59]. Peer communities fill a critical gray space by addressing health concerns, such as interpreting symptoms, preparing for appointments, or coping with side effects that formal medical advice often overlooks. When formal moderation attempts to shut down these discussions out of liability concerns, it fundamentally misunderstands users' needs: survivors seek not diagnosis, but shared experience and validation [44]. HCI scholarship expands the definition of health information beyond medical facts, recognizing that survivors' information sharing encompasses experiential knowledge, gained wisdom, and coping strategies [34]. Even during active treatment, the illness experience itself cultivates unique forms of wisdom and future-oriented thinking in young patients [77]. Within OHCs, such lived wisdom serves a resilience-building mechanism, where survivors contribute hope rather than solely focusing on problem-solving [3, 92].

Furthermore, the literature establishes that participation in OHCs is dynamic, with members' roles progressing from information-seekers to active contributors and support providers [102]. As tenure in OHCs increases, motivations shift from uncertainty reduction through information seeking to community-oriented information sharing, with survivors moving through distinct social roles from resource-seeking positions (e.g., Story Sharer, Informational Support Seeker) to generative roles (e.g., Welcomer, Provider), fundamentally transforming the survivor-community relationship across the illness journey [100]. Notably, information sharing in OHCs operates under distinct logic from general social media. Counter-intuitively, cancer survivors engage in more negative self-disclosure in public forums than private messages, as the strategic value of accessing collective expertise from a larger audience outweighs the increased privacy risk [101].

Ultimately, such role progression can be understood as a movement from self-empowerment, gaining power and control over one's cancer experience, to self-advocacy, which encompasses the action-oriented process of actively advocating on one's behalf when facing challenges [37]. Research reveals that self-advocacy in online spaces fundamentally involves asserting narrative control, with participants using social media platforms to challenge societal cancer stereotypes and maintain autonomy over how their illness experiences are shared and represented [25]. Beyond internal control,

participation often manifests as public advocacy, such as participating in structured awareness campaigns on X/Twitter (e.g., #ayacsm) [78] or using visual platforms like Instagram for narrative sharing that raises awareness [20].

Yet, the path toward advocacy involves significant obstacles, as survivors face difficulties finding age-appropriate communities [50, 52] and managing the emotional burden of online engagement [58]. HCI researchers note that while OHCs are crucial for peer support, they are not without risk, with members sometimes facing emotional burnout or even harmful microaggressions that can undermine the supportive environment [24, 83].

While HCI research has successfully mapped the trajectory of peer support and self-empowerment, a critical gap remains in characterizing the technological transition from individual self-management to active self-advocacy. Self-advocacy differs fundamentally from management; it is not merely about adherence to care, but involves autonomous verification, and the construction of informal support networks to fill gaps where formal healthcare falls short [6]. Current HCI frameworks, however, predominantly focus on the "assistive" role of technology, helping patients manage deficits or track symptoms [97]. While valuable, this focus leaves the 'enabling' mechanisms that allow survivors to evolve beyond a passive role lesser known [97]. Specifically, the ways in which technology supports the developmental leap from establishing "Knowledge of Self" (internal identity) to exercising "Leadership" (external stewardship) warrant deeper examination. Characterizing this shift is particularly vital for AYA survivors navigating the dual journeys into adulthood and long-term survivorship [3], requiring us to document the specific motivations, emotional labor, and pathways for this progression.

## 2.2 Asset-Based Approaches: Opportunities and Challenges

*2.2.1 From Deficit to Asset Framing in Health Technology Design.* Interventions aimed at improving health and well-being are frequently shaped by problem-based approaches, which identify problems and needs within communities as the primary starting point [64]. This perspective may focus on the "assumed inadequacies" of the subjects, viewing them through a lens of deficiency instead of richness [32]. In healthcare contexts, this deficit-based orientation leads practitioners to see "medicalized beings with problems" rather than "people as full human beings possessing the tools necessary for their own healing" [72]. The deficit-based orientation extends beyond direct clinical care into the design of health technologies, where it intersects with "technosolutionism," [39] defined as the belief that technology can unilaterally solve complex social problems without meaningful engagement with users' existing capabilities, social contexts, or cultural practices.

In healthcare technology design, this deficit-based orientation manifests through solutions that assume technological interventions can independently address health challenges without meaningful engagement with users' existing capabilities, social contexts, or cultural practices [60]. The deeply ingrained medical tendency to focus on problems rather than opportunities [91] thus becomes amplified through technological solutions that primarily address deficits rather than leveraging existing strengths and capabilities.

Such framing of health challenges as solvable engineering problems, rather than complex lived experiences, has been a subject of critique within HCI, particularly because needs-based views often lead to designs for the here and now, further marginalizing populations and perpetuating stereotypes [98]. Indeed, this mechanism inherently positions individuals as “passive recipients of services,” whose well-being is framed as dependent on solutions delivered by external experts and resources [39], with scholars arguing that “prioritizing user needs promotes dependency and robs agency from change-makers, thereby hindering sustained change” [98]. A significant critique of this model is its tendency to foster a “deficits outlook,” a perspective that can inadvertently create a disempowering “poverty-influenced mindset,” encouraging dependency while overlooking a community’s inherent capabilities [73].

In direct response to the limitations and potential harms of this deficit model, HCI scholars have increasingly turned to a strengths-oriented paradigm or “inside-out” perspective that begins not with a community’s problems, but by identifying and mobilizing its existing competencies, skills, and relationships, its “assets” [57]. This approach, rooted in Asset-Based Community Development (ABCD), has been increasingly adopted within HCI and CSCW across domains including education, healthcare, and community development to address the limitations of needs-based design, which often “dismiss marginalized users’ capacity for driving change” and lead to designs that perpetuate stereotypes [98]. In fact, the foundational framework of Asset-Based Community Development includes three interlocking components: asset-based, relationship-driven, and internally focused approaches [57]. As Shah et al. [87] explain in their exploration of electronic asset-based community development (eABCD), these components work together because “it is through relationships that assets can be identified and connected, and through an asset-based acknowledgment of a community’s wisdom and leadership that internal control can occur” (p. 193), providing a foundation for understanding community building in digital spaces. Within design practice and participatory design, researchers have developed methodological approaches such as appreciative exploration, collaborative articulation, and creative activation to operationalize asset-based principles [16]. Indeed, tangible resources, like solidarity, and social bonds, can be leveraged through technology design [53, 88]. Assets are not just pre-existing resources, but experiential knowledge from lived experience, creating assets like new mindsets and coping strategies, often invisible to traditional healthcare systems [88]. The challenge for researchers then becomes how to effectively translate these identified assets into meaningful designs that interact with complex systems of oppression without perpetuating them [98]. Ultimately, whether online or offline, the asset-based approach represents a fundamental shift in design, moving from a paradigm of solving problems for communities to one of co-creating futures with them by recognizing and building upon their inherent and developed strengths [53, 98].

**2.2.2 The Need for a Reflexive-Interventionist Stance.** While the shift to an asset-based paradigm offers a powerful alternative to deficit-oriented design, its application is not simple or neutral since, although asset-based approaches align naturally with design practices like participatory design values, this connection has remained

largely implicit rather than explicitly developed in design practice [16], contributing to inconsistent and potentially problematic applications. This risk is particularly evident in how asset-based approaches, despite their emphasis on recognizing community strengths and fostering self-empowerment, can create what healthcare research identifies as an “illusion of empowerment” where individuals experience personal empowerment while underlying institutional structures continue to reinforce top-down control mechanisms rather than enabling genuine participatory agency [67].

Scholars caution that an uncritical application of asset-based methods risks overlooking the complex interplay of power and context, and may inadvertently create new challenges even as it seeks to empower [99]. While prior research on youth-focused ABCD initiatives has identified a significant gap in understanding how these approaches translate to digital environments (eABCD), preliminary evidence suggests that online platforms can foster asset-based, relationship-driven interactions and leadership development, provided that the distinct challenges of sustaining trust and managing power dynamics in virtual spaces are addressed [2]. This duality is evident in digital contexts, where online environments present both opportunities for connecting geographically dispersed communities and challenges such as online disinhibition effects that can lead to harsh critique or insensitive language in asset-based community building [87]. The simple identification of assets does not automatically lead to equitable outcomes, necessitating a more nuanced engagement that acknowledges the inherent tradeoffs in any design process [39]. This awareness has led to calls for a reflexive-interventionist stance, one that combines critical self-examination with deliberate, methodologically-grounded action to navigate the complexities of community-engaged design [60].

Thus, a key tension that designers must navigate is the discrepancy that can exist between the assets valued within a community, such as culturally-specific digital practices, and the forms of knowledge privileged by formal institutions [69]. A reflexive designer acknowledges this gap not as a deficit to be fixed but as a critical site for intervention, which, rather than positioning technology as an inevitable end or a definitive solution, is seen as an intermediary that can facilitate an ongoing journey of reflection and action [99]. A reflexive-interventionist stance compels researchers to move beyond merely cataloging strengths and to instead grapple with the ideological underpinnings of their methods and the potential consequences of their interventions.

Ultimately, a reflexive-interventionist stance is not about choosing assets over deficits but about thoughtfully navigating the tensions between them. It encourages HCI practitioners to recognize their role within a complex sociotechnical system and to make intentional, ethical moves that support communities in building upon their own strengths to pursue sustainable, self-determined futures. This study addresses this gap by operationalizing a reflexive stance to eventually develop a conceptual basis for technologies that go beyond a corrective *fix* to support the difficult balancing act between a user’s persistent challenges and their developing strengths.

### 3 Methods

#### 3.1 Participants

Young adult cancer survivors who were diagnosed during childhood or adolescence were recruited through targeted advertisements in adolescent and young adult (AYA)-focused Facebook groups and via a professional recruitment firm (UserInterviews.com). Our inclusion criteria specified that individuals must be currently between 18 and 30 years old, U.S. residents, and diagnosed with cancer on or before the age of 18. The age range was intentionally chosen to capture the critical period of transition into and through young adulthood. Participants were diagnosed across a wide age range (ages 5-18), with most having survived childhood cancers and some having been diagnosed during adolescence. Our final sample (N=14) represents a unique spectrum of survivorship experiences, which we view as a key methodological strength. It includes participants at the cusp of young adulthood (e.g., age 19) whose experience of cancer survivorship is recent and immediate, alongside participants in their late twenties and early thirties offering a long-term, reflective perspective on their entire trajectory from diagnosis through young adulthood. This diversity enabled us to analyze the full longitudinal journey of digital survivorship, from childhood/adolescent diagnosis through the complexities of young adulthood. While we acknowledge that data from participants diagnosed at younger ages involves retrospective recall, our interview protocol was explicitly designed to leverage this, prompting participants to contrast their past and present digital practices to illuminate how their strategies, skills, and roles have evolved over time, charting their development from support-seekers to empowered advocates. Detailed demographic and cancer history information is presented in Table 1, an overview of participants' technology use and information access patterns is provided in Table 2, and an overview of participants' evolving technology use across the key stages of their survivorship journey is summarized in Table 3 (see Appendix A).

#### 3.2 Study Procedure

The study procedure, which received Institutional Review Board (IRB) approval, involved hour-long semi-structured interviews with each participant. With explicit informed consent, all interviews were video-recorded to capture comprehensive data. The interview protocol began with participants' cancer journey narratives, then systematically explored their evolving technology use from diagnosis through survivorship. The interview protocol covered five main areas: (1) Background and diagnosis/treatment journey; (2) Early experiences with technology for health and social connection; (3) The transition to self-management and the role of digital tools in adulthood; (4) Experiences within online communities, including finding support and navigating challenges; and (5) Reflections on self-advocacy and a potential future role in supporting others. Sample questions included: "How did you use technology during your treatment? What devices or platforms were most helpful?"; "How did your technology habits change since completing treatment?"; "Can you describe what "peer support" means to you?"; "Have you ever been involved in peer support groups or networks? What motivated you to seek peer support?"; and "How has this involvement impacted your social life?" The adaptive protocol consistently

prompted participants to reflect on their evolving technology relationship from diagnosis to present, exploring transitions, changing needs, and ecosystem curation choices. This approach allowed the nuanced themes central to our research, such as the longitudinal journey, the navigation of tradeoffs, and the evolution of roles from support-seeker to community steward and advocate, to emerge directly from their lived experiences.

Given that survivors constitute a vulnerable population, we adopted enhanced ethical safeguards beyond standard IRB protocols. Prior to each interview, participants were informed of their right to skip any question or terminate without consequence, with consent obtained in writing and verbally reconfirmed at each session. Recognizing that retrospective discussion of cancer experiences can evoke distress, the interviewer monitored for signs of emotional discomfort and offered breaks as needed, allowing participants control over the depth of disclosure. We weighed the potential emotional risks against the benefits of contributing to research aimed at improving support systems for this population; participants themselves often framed the interview as an opportunity to have their experiences acknowledged and contribute to resources they wished had existed, a form of reciprocal benefit aligning with our asset-based approach. All data were de-identified immediately following transcription, with participants assigned pseudonymous IDs (P1-P14) and any potentially identifying information removed prior to analysis. All participants were compensated for their time.

#### 3.3 Data Analysis

We employed a multi-stage thematic analysis [15], informed by reflexive-interventionist goals, to construct an evidence-based critique (RQ1) that could inform a new design framework (RQ2). The analysis was facilitated by ATLAS.ti. After verifying the 14 interview transcripts, the first author wrote detailed descriptive memos to capture initial insights [14]. The primary coder then initiated thematic analysis with a first cycle of open coding using the constant comparative method to systematically compare data across participants. These initial codes (e.g., "difficulty finding active online groups," "preference for anonymous platforms for sensitive questions") formed the foundation for subsequent conceptual development. During a second cycle of coding, these initial codes were systematically reviewed and grouped into broader conceptual categories. However, guided by our reflexive-interventionist stance, this process moved beyond simple categorization of platform use.

We analyzed the underlying tensions, strategies, and transformations within survivors' narratives. For instance, we looked for instances where participants described navigating tradeoffs (e.g., choosing between a platform's public reach and its private safety), moments of consciousness change (e.g., realizing the value of peer experience as a collective asset), and actions representing a shift from inward-facing self-management to outward-facing self-advocacy. This allowed us to build our thematic framework around the dynamic negotiation of assets and deficits that define their journey. Theoretical saturation [35] was deemed to have been achieved by considering several indicators: the depth and richness of existing categories, ensuring they possessed sufficient explanatory power and nuance to capture the complexity of the phenomenon; the adequacy of the thematic framework to explain variation across

different participant experiences and contexts; the coherent integration of categories into a meaningful explanation; and the stability of findings across repeated analytical efforts. We determined the saturation point was reached after 12 interviews, with the final two interviews confirming that no new major themes were emerging from the data. The resulting framework forms the basis of our reflexive critique in the findings.

### 3.4 Positionality Statement

None of the authors are cancer survivors, positioning us as outside observers and allies seeking to understand and amplify survivor experiences and their resilient practices rather than speaking from lived experience. To manage potential researcher bias and ensure consistency in interpretation, regular peer debriefing sessions between the first and second authors occurred at critical junctures: after initial coding, during theme development, and before finalizing the analytical framework. These sessions included reviewing coded data, and structured discussion guides focused them on specific analytical questions like “How might our positioning as researchers influence this interpretation?” and “What alternative explanations could account for these patterns?”, challenging interpretations and ensuring rigor.

## 4 Findings

### 4.1 Foundations of the Ecosystem: From Deficit-Framed Self-Management to Asset Recognition

The initial phase of the survivorship journey is characterized by a profound paradigm shift, both in the survivor’s relationship with technology and in their own self-perception. They begin in a state that mirrors a traditional needs-based approach, where they are positioned as passive individuals with problems to be solved. However, through their first tentative steps into digital self-management, they undergo a consciousness change, recognize their latent capabilities, and the distributed experiential knowledge of the peer community as a powerful asset. This section documents that critical, foundational shift.

*4.1.1 Initial Dependency: Family-Mediated Technology Use and Deficit Framing.* During and immediately following treatment, survivors are cast in the role of the “patient,” an identity defined by its deficits: illness, vulnerability, and a reliance on outside experts. The onset of diagnosis represents a profound rupture, a moment that abruptly repositions the individual from developing autonomy to one of acute dependency.

In this context, technology functions not as a tool for empowerment but as a compensatory mechanism that addresses the immediate social and emotional challenges of hospitalization without building agency. Survivors’ well-being is framed as dependent on doctors and family members, who become the primary agents navigating the complexities of care. Caregivers assume the role of architects for the initial support network; the complex labor of seeking information is externalized to them. Technology, meanwhile, addresses surface-level symptoms such as isolation and boredom without empowering survivors to confront the root cause of their disempowerment.

This dynamic of survivor passivity and caregiver-led support was evident in our data. Family members often took the lead in locating informational resources and support communities while survivors focused on coping with treatment demands. As one participant explained:

*“My mom found it [the support group]... she was just researching online, and she found the group...” (P09)*

The reliance on caregivers reveals a power dynamic where survivors are not yet architects of their own support systems. In this context, technology serves primarily as a distraction, such as watching Netflix, movies, or playing games, rather than as a resource for active engagement with survivorship care. It functions as what we term a *palliative mechanism*, addressing surface-level needs like boredom without building agency. This pattern is evident in another survivor’s account:

*“I had an iPad when I went through treatment, and that... helped me have access to entertainment, like movies and games, as well as communication with friends” (P12)*

In some cases, technology was even framed as a potential risk to be managed by caregivers, further limiting the survivor’s agency.

*“When it came to technology during my treatment, I tried to stay away from it as much as possible. [My mother] didn’t want it to affect my treatments and stuff, so she told me to just stay away from the video games, the cell phones.” (P06)*

This deficit framing, where well-being depends solely on external help, risks creating a mindset of dependency that overlooks survivors’ own inherent capacities. In this state, technology functions merely as a palliative, a temporary fix for surface-level needs like boredom that offers a simple solution for the immediate voids of hospitalization but masks the survivor’s deeper, unmet needs for agency and control.

*4.1.2 The Pivot to Agency: Deficit-Driven Information Seeking as an Asset-Building Act.* The transition out of active treatment marks a critical turning point. Faced with new, often unaddressed informational needs about long-term survivorship, survivors begin to reclaim agency. This pivot from passivity to activity represents their first significant interventionist act, intervening in the established, expert-driven flow of information to reshape their own lives. This action is initially driven by a clear deficit, a lack of knowledge about what comes next, but in the process of addressing this deficit, they begin to build and recognize a new asset: their own capacity for autonomous research and digital navigation. P06’s account captures this transformative moment:

*“But after my recovery period was up, I was allowed to get on my electronics, and I did start doing more research about maybe finding people online with the same condition that I have because where I’m from, I couldn’t find anyone to physically talk to.” (P06)*

This statement demonstrates a conscious decision to move from being acted upon to taking action, using technology not for distraction but for purposeful connection and self-advocacy. The shift toward active self-advocacy represents a fundamental change in agency, marking purposeful, problem-oriented self-management aimed at addressing specific knowledge gaps left by formal medical

systems. This process embodies the complex tradeoffs inherent in the survivorship journey, where perceived deficits catalyze actions that ultimately build assets. To navigate this, this pivot involved strategic platform selection, moving from general search engines to more specific peer-led platforms like Reddit and Quora, where they could ask sensitive questions (P06) or find others with the same condition (P12). Survivors assume the role of researchers, driven by urgent personal needs demanding immediate answers, as one participant articulated:

*“I did most of my information hunting during and after my first surgery... information I got was information I went and hunted for myself in relation to the nature of my tumor. What kind it was, mortality rate, lethality, the different kinds of chemo I was on. I researched.”* (P01)

This proactive information seeking is often driven by high-stakes concerns about the future, which carry profound implications for adult life. Fertility, in particular, emerged as a critical driver of this search.

*“Fertility... Because I really wanted to become a mom. And when I signed a paper saying I couldn’t send to treatment, it said the possibility of infertility. And so the after effects of treatment is what I frequently searched.”* (P08)

Such targeted, deficit-driven research represents the beginning of an inside-out process of empowerment. It is the moment survivors stop being passive recipients and start becoming active participants in their own long-term care. This transition represents the first step in a slow, incremental transformation. While motivated by the need to address persistent deficits, the act of seeking information is inherently asset-building, as survivors begin to develop the digital literacies and critical evaluation skills that will become the foundation for architecting their own support ecosystems.

**4.1.3 A Reflexive Shift: Recognizing Peer Experience as a Collective Asset.** The interventionist act of information seeking quickly leads to a crucial reflexive insight. Survivors realize that clinical data and official information, while important, are insufficient. They lack the context, nuance, and emotional reality of the lived experience. This is the consciousness change where survivors develop new eyes about themselves and their surroundings, undergoing a Reflexive Shift to recognize that their own experiences and those of their peers are a valid and essential form of knowledge. This insight transforms their understanding of what constitutes a valuable resource. They begin to see the distributed, peer-held knowledge of the survivor community as a powerful, collective asset, a shared fund of knowledge that exists outside of formal institutions. Their search patterns evolve from seeking facts to seeking stories and connections. P12’s shift toward peer narratives exemplifies this reorientation:

*“I remember reading a lot of, like, blog posts from people who underwent the same treatment or had the same cancer as me.”* (P12)

Indeed, the search for peer narratives is not just about finding emotional support; it is a recognition that peers hold practical, actionable knowledge that is often inaccessible elsewhere. The search becomes one for a different kind of data, the qualitative data

of lived experience that can inform critical health decisions and contextualize their own journey. At its core, this pivot is fueled by a need to make sense of their altered bodies and futures, and the search is for validation as much as for facts. Another survivor articulated this search clearly:

*“for me, it was a lot of resource groups, right? Connecting with other people that also have the same type of cancer... just talking to them what their experience is like... I think just like the side effects is probably the most important to me, just to understand how am I feeling, is what I’m feeling normal as part of my treatment.”* (P13)

Here, the survivor explicitly states that the value of peer connection lies not in clinical data, but in the validation of lived experience, understanding if their feelings are “normal.” This demonstrates the Reflexive Shift from seeking objective facts to seeking subjective, emotional resonance. This reflexive recognition provides the intellectual and emotional justification that enables survivors to move beyond individual self-management toward the more complex work of community building and participation. The realization of this collective asset can have life-altering consequences, as one participant discovered:

*“it was only because of that Facebook group that she [mother] was able to hear about that doctor, and then contacted that doctor. Now that doctor is my surgeon... if it wasn’t for that Facebook group, we would have never heard of this doctor that was studying about me.”* (P09)

Survivors now understand that the most crucial assets for their long-term well-being are not held by institutions but are co-constructed and shared among peers. This insight is the catalyst for becoming an architect of their own support ecosystem.

## 4.2 The Architect at Work: Navigating Tradeoffs and Cultivating Assets through Self-Empowerment

Having recognized the necessity of peer-based experiential knowledge, the survivor transitions from a mere information seeker into an Active Architect, consciously constructing a personalized digital support ecosystem. This architectural work is not a simple act of joining groups; it is a complex, reflexive-interventionist practice of navigating tradeoffs, cultivating critical personal assets, and making strategic choices. This is the messy, iterative process through which self-empowerment is forged not as a single event, but through a series of deliberate actions that build an internal locus of control and agency.

**4.2.1 Curating the Ecosystem: Strategically Navigating Platform Tradeoffs.** Survivors do not passively consume digital spaces; they actively curate them, making sophisticated choices that reflect a deep, often implicit, understanding of platform affordances and social dynamics. This curation is an intervention in their own support network, a deliberate act of designing an environment tailored to their evolving needs. This practice directly engages with the concept of tradeoffs, as survivors intuitively grasp that technological development is never a straightforward solution but a series of

choices with inherent gains and losses. Their platform selection is a calculated navigation of these tradeoffs, particularly the tension between reach and intimacy. Large-scale, public-facing platforms such as Facebook and Instagram offer access to a vast, diverse community, a clear asset, but at the cost of privacy and the potential of encountering negativity, a significant deficit. Conversely, more private or anonymous platforms can offer a safe space for vulnerable disclosure, but may lack the deep, identity-affirming connections found in known communities. This strategic selection is an interventionist move. Instead of accepting platforms as they are, survivors assemble a portfolio of spaces, leveraging the strengths of each to mitigate the weaknesses of others. Their platform use is not incidental; it is a calculated response to the need to balance these tradeoffs. For instance, P08 prioritizes the asset of safety on Tumblr over the asset of reach:

*“I felt like it was a place I can express myself without being judged [...] Versus like on Facebook or MySpace or Instagram... It just made for more ways to be judged.”* (P08)

This experience clearly illustrates the perceived deficit of mainstream platforms, specifically the risk of judgment, and demonstrates how survivors actively curate their digital spaces to find assets like safety and non-judgmental expression. The intentional, multi-platform engagement is a hallmark of the experienced survivor, who might simultaneously participate in several niche Facebook groups, a private group chat for immediate support, and an Instagram account for broader narrative sharing. This practice demonstrates a sophisticated understanding of each platform’s unique affordances and the cultivation of an interdependent collective tailored to their needs.

*“We do have a group chat Facebook Messenger. So I try to message the group there from time to time... I also try to make a post in the group at least once a month into the actual Facebook group, not the chat... I basically share what I share [on] my Instagram blog into the group.”* (P14)

This curation extends beyond platform choice to an evaluation of the community’s internal structure and norms. Survivors seek a delicate balance, recognizing the tradeoff between unstructured, casual spaces and more formal, moderated ones.

*“I feel like there should be some sort of formality to it... if it’s too formal, we kind of lose that personal connection. But I also feel like if it’s too casual, like a Facebook group chat... I feel like it’s no structure to it.”* (P13)

Building a support system is also a form of labor, undertaken in response to the deficit of readily available, high-quality support spaces. The digital landscape is not inherently supportive; it must be actively navigated and vetted, a process that can be fraught with disappointment.

*“finding an active group or Because the problem with internet groups is oftentimes the listings posted can be old... And pretty much would have nobody in like the group chats or...nobody active in the Zoom calls when I tried to do something with it during COVID. So I gave up on that”* (P01)

This is the beginning of community members creating and driving their own projects, only here, the project is their own well-being. This architectural work is not just about finding support, but about building it, piece by piece, across a digital landscape full of both opportunity and risk.

*“[...] an environment that doesn’t make you feel welcome to share or welcome to speak or ask questions. You know, if the person leading the group didn’t care, if the people in the group were hostile and rude, I just wouldn’t be interested”* (P01)

This dual burden of navigating repeated disappointment when communities fail to meet expectations, while evaluating both technical features and relational dynamics, such as leadership quality and member interactions, can lead capable survivors to disengage, underscoring why ecosystem curation is both demanding and essential.

**4.2.2 Developing Critical Literacies: Vetting Information and Building Trust.** Survivors learn to de-commodify information, stripping it of its surface-level claims and assessing its true, underlying value and credibility through community-generated criteria rather than market-determined worth. This process transforms health knowledge from a commodity into a shared resource, as peer-based knowledge sharing replaces commercial health information economies. This transformation often begins with a rejection of traditional online health resources, which are framed as a deficit to be avoided due to the anxiety they produce. As one survivor explained:

*“I think the kind of stereotypical thing is when you look up something on WebMD, they’re going to give you the worst possible diagnosis or the worst possible thing... it’s honestly quite frightening.”* (P05)

This fear of alarming content can lead survivors to deliberately avoid online health-seeking, particularly during earlier phases of their journey; P05 described this pattern when reflecting on their initial encounters with health information sites. For others, however, this experience catalyzes the Reflexive Shift: it pushes them to seek out a more valuable asset in the form of the lived, experiential knowledge held by their peers. This search for peer narratives over clinical data was a common strategy, as a different survivor articulated:

*“I remember reading a lot of, like, blog posts from people who underwent the same treatment or had the same cancer as me.”* (P12)

Members actively curate their own support ecosystems instead of purchasing pre-packaged solutions, developing alternative validation systems where trust emerges through sustained community relationships rather than institutional authority. These practices create collective knowledge assets that exist entirely outside formal healthcare markets yet prove invaluable for navigation and decision-making. This literacy becomes a protective asset, shielding them from harm. The stakes are incredibly high, as peer spaces can become conduits for potentially dangerous misinformation.

*“you also have people that are like, oh, I did [alternative treatment] and my cancer is cured... those are the hard things about like home grown peer support groups is you’ll have those people.”* (P11)

Beyond factual inaccuracy, the risk is also emotional. Unfiltered access to information can expose survivors to distressing content that exacerbates anxiety, making the cultivation of this literacy a matter of psychological self-preservation.

*“...like scariest thing that I saw was the recurrence rate... Which really freaked me out for a long time.”* (P07)

In response, survivors describe a methodology for evaluation, developing strategies for verifying credibility, such as cross-referencing information across reputable sources and fact-checking peer advice with their own healthcare providers.

*“If it’s coming from a legitimate and accredited organization such as American Cancer Society or anything like that...If it’s also coming from...information that matches the other sources, if the information matches many different sources, then I know it’s definitely correct.”* (P14)

The verification strategies were also emphasized by another survivor:

*“I usually go off of research studies because I know that not all the information is what it is. But I would take what I would find and bring it up to my oncologist and have the discussion with him before I determine if I believe it or not.”* (P08)

While survivors learn to be wary of the potential for misinformation in peer-led spaces, they also recognize that these communities hold invaluable, latent assets, a collective funds of knowledge that cannot be found elsewhere. Trust is not assumed but is cultivated over time through consistent, positive interactions and, most powerfully, through the validation of shared information that leads to tangible, positive outcomes. This validation often happens on a practical, daily level, where the community’s experiential knowledge offers practical self-management strategies that formal medical advice may not.

*“[It’s] nice to know that if a medication makes you drowsy and you have to take X amount of it, some people are saying,... I just take X amount of it before bed, and I wake up and I’m not drowsy as much... it’s like, yeah, you could totally do that.”* (P09)

**4.2.3 Constructing Boundaries: The Reflexive Work of Identity Management.** To manage one’s own identity, survivors learn to perform a sophisticated, delicate balancing act, sharing enough to connect authentically while protecting themselves from vulnerability and privacy loss. This is a reflexive act of boundary-setting and a direct intervention to safeguard their emotional well-being. This practice is the epitome of navigating tradeoffs, with the core conflict being between the need for connection (an asset) and the risk of exposure (a deficit). To manage this, survivors engage in selective disclosure. This strategy is a reflexive practice of curating one’s narrative for different contexts and audiences. This practice is driven by a search for safety, a feeling that is actively constructed through platform choice and careful self-presentation.

*“On Tumblr, it’s like a, like blog posts... it was someplace that you can express yourself. And I rarely got any type of like negative communication from anybody because*

*everybody was their own person... it made it feel safe.”* (P08)

The act of making conscious choices about one’s own representation is the very definition of agency. It often involves a clear distinction between public-facing platforms and more private, trusted circles.

*“I usually don’t share anything on Instagram regarding my personal journey... I like to keep it more, a little bit more private”* (P13)

*“[Sharing online during treatment] I would share updates with friends and family, but it wasn’t to, like, a public forum. It was mainly just to kind of share my treatment updates and any scan updates.”* (P12)

Such identity management is not just a matter of personal preference; it is a necessary defensive skill developed in response to the unintended consequences of open digital environments. It is connected to the need to constantly verify the authenticity of others and protect oneself from the emotional and informational harm that can be caused by “fake peers” who misrepresent their experiences for personal gain.

*“there is someone... we recently learned was faking aspects of her diagnosis... how much of our stories... has she taken and pretended was her own experience... for her own gain”* (P11)

Discovering “fake peers” threatens the community’s collective asset of trust, reinforcing the need for protective, interventionist practices. Yet, the reward for this careful, risky work is the profound asset of genuine connection. Finding resonance with others who truly understand makes the architectural endeavor worthwhile, though particularly challenging for childhood survivors connecting with younger members.

*“I guess age would be like, because I know that there is people who, because I’m almost 30. There’s people who had childhood cancer who are teenagers already are not even adults. So, but unless there’s like a focused age group, it’d be difficult to understand what events are going on in somebody’s adult life. If they’re just becoming an adult”* (P08)

The goal is to move from being a passive recipient of care to becoming an active participant, producer, and owner of their own future [73]. Managing one’s digital identity is a key part of owning one’s story and, by extension, one’s future. This process of taking control over their narrative and their boundaries exemplifies the resilience central to self-empowerment.

**4.2.4 Divergent Paths: Recognizing the Limits and Labor of Engagement.** The development of this resilience, however, manifests differently for each survivor, marking a critical juncture where the path toward advocacy is not always the chosen or accessible route. Some participants, after the intensive labor of building their own support system, consciously choose to step back to preserve their emotional energy and focus on a post-cancer identity. This often involves rejecting the passive narratives found in support spaces; as P03 asserted:

*“I never did want to play a role that I’m a victim towards something. I always want to be my own hero towards my own case.” (P03)*

The constant engagement required for advocacy can feel like a tether to a past they wish to move beyond. As one participant explained, the idea of a support group felt counterproductive to their healing:

*“I don’t think that...a support group for something that for the most part I’m like over and done with...would be too beneficial.” (P10)*

For others, the emotional risks of online spaces themselves drove disengagement. The fear of encountering distressing content led some to avoid communities entirely:

*“I think the people who are most vocal on these platforms are the ones who have it the worst... they become like a negative spiral. And I think it can affect the silent readers, recently diagnosed, they think this is going to be way worse than what I already thought was possible.” (P04)*

For others, the architectural work itself proves too difficult or unrewarding, leading them to disengage. The digital landscape is not always welcoming, and even when groups are found, the emotional labor of forging connections can be a significant barrier, halting the journey before advocacy can begin.

*“afterwards, it was kind of like I was left to my own devices, you know. So I did look for support online and found some groups, but it was still really hard to connect to people. Because I find that children that go through cancer treatment kind of like to ignore it and move forward with their life...” (P06)*

Even within supportive communities, some survivors grapple with a persistent sense of isolation due to the rarity of their condition or the specificity of their experience. This can prevent them from developing the sense of expertise and belonging necessary to step into a leadership role. One participant with a rare tumor poignantly described this challenge:

*“[I] will Never find enough people with my tumor to have a whole support group like that... I have, just like, This rare one that, like not a lot of people have, so it kind of leaves me going, where do I fit in?” (P09)*

### 4.3 From Architect to Advocate: Deploying Collective Assets and Enacting Systemic Change

While many survivors build personal ecosystems, the decision to step into advocacy varies considerably. Some adopt a pragmatic and protective stance where the emotional risks of re-engaging with the cancer identity lead them to maintain a cautious distance. Others remain deeply engaged in the work of self-empowerment and continue to negotiate their personal deficits against the collective assets of the community, but they stop short of leadership roles. However, a specific subset of systemic advocates fully transitions to outward-facing action, transforming their lived experience into a community resource.

The differentiation between these groups often hinges on specific barriers versus a singular, powerful trigger. For those in the protective or self-management stages, the decision to stop short of advocacy was often driven by the desire to establish a post-cancer identity separate from their illness (P03), the emotional fatigue resulting from the architectural work itself (P06), or structural disappointments where online groups proved inactive or unresponsive (P01). In contrast, the decisive trigger for the participants who became systemic advocates was a profound sense of reciprocal responsibility. Their transition was not motivated solely by altruism but by a desire to intervene and correct a systemic deficit they personally encountered. As P02 and P14 articulated, they recognized a “fault” or a “gap” in the support system during their own treatment, and their advocacy became a strategic effort to become the specific resource or mentor they wished they had possessed.

For those survivors who do make this outward turn, their journey enters its final and most transformative phase, moving from building an ecosystem for oneself to stewarding that ecosystem for others. This is the full enactment of self-advocacy, moving beyond personal navigation to collective action and systemic intervention. Indeed, achieved self-empowerment is an internal state of agency, while advocacy practices are a system-oriented and values-focused process. This phase is the ultimate expression of an asset-based approach, where the community, led by its most experienced members, becomes the primary driver of its own development and well-being.

**4.3.1 The Outward Turn: Reciprocity and Reframing Experience as a Community Asset.** The catalyst for this outward turn is a powerful sense of reciprocity, rooted in the survivor’s own lived experience. The motivation is no longer solely about addressing personal deficits but about reframing one’s personal journey as a valuable community asset to be invested in for the benefit of those who follow. The survivor’s lived experience, once a source of personal struggle, is internalized and redeployed as a powerful community asset. They are no longer just members, but producers, actively contributing to the community’s capacity and making their resilience public and visible. The desire to “perpetuate an experience that is better” is a direct intervention to correct the critical gap in support they personally experienced, moving from a mindset of scarcity to one of abundance that enables the sharing of information and resources. One participant articulated this drive to intervene and reshape the system for others:

*“[My] motivation to help these communities comes from me wanting to perpetuate an experience that is better than the one that I encountered. I saw a lot of faults in the healthcare system during my experience. And by building a peer support group or a peer network of some kind, the intention would be is to provide a solution that I wish I had at the time” (P02)*

P02’s statement demonstrates this reciprocity motive through a conscious shift from addressing personal deficits to becoming a community resource. It is an active intervention to correct a systemic deficit that the survivor personally experienced. This decision to become a resource is a conscious one, marking the moment a survivor chooses to embody the support they once sought, hoping their story and knowledge can benefit others. In fact, this demonstrates the internal motivation and urgency that is core to self-advocacy.

*“I would like to share my story... I hope it might help someone else. And being able to share resources I was able to have would be really nice.” (P12)*

Another participant’s note:

*“I wanted to become that person to other people. And then halfway through cancer treatment, that’s when I was starting to be more people my age. I ended up becoming that person to walk up to them and say, hey, I’m [Name]. You know, I’m going through this treatment. And just so you know, you know, you know, everything will be OK. And that mindset continued on over into the Instagram blog and the Facebook group.” (P14)*

This choice to invest one’s personal story as an asset for community benefit is a powerful act of reframing, turning past vulnerability into a present-day strength that can be shared.

**4.3.2 Practices of Stewardship: Enacting Leadership and Protecting Collective Assets.** The desire to contribute manifests in a set of concrete leadership practices. These are not passive acts of sharing; they are deliberate interventions designed to build, protect, and sustain the community’s collective assets. These actions represent the often invisible work of para-advocacy routine practices, such as information sharing, peer support, and community maintenance, that enable advocacy but extend beyond “speaking up” [79]. This is Asset-Based Community Development in action, where the community is not waiting for outside experts but is leading its own development by co-investing its own assets. These stewardship practices are fundamentally interventionist and map directly to the core competencies of self-advocacy. Mentorship and validation represent a form of relational advocacy, a direct intervention to counter the deficit of isolation and self-doubt that new members face. By validating feelings, stewards foster a collective identity and create the context for resilience to emerge.

*“[Sometimes] I’ll validate what they’re saying, because some people would be like, I just got diagnosed, and I don’t know what to think or feel. I’m confused. So it’s really great to be able to be like, hey, you know, I was diagnosed at 16, but trust me, it’s gonna be okay” (P09)*

Knowledge translation, a form of strategic communication, is the mobilization of the community’s funds of knowledge [69]. Stewards translate their complex experiential and tacit knowledge into actionable advice, reducing the burden of translation for others and building the community’s collective capacity to navigate the healthcare system.

*“[It’s] a nice place where we don’t feel like we have to say, oh, it’s but it’s OK. Like we don’t feel like we have to appease anybody. We can just talk about our treatment. We can say, oh, like that really sucks.” (P11)*

*“So for example, we have the Calm app, we have the Thrive app, we have like the Talkspace, like all of these sorts of like resources. We talk about within this support groups, right? Because there’s so much resources out there... We use that support group to kind of share those resources...” (P13)*

Perhaps the most critical interventionist act is norm enforcement. By establishing rules like “no medical advice” or managing negativity, stewards are performing the crucial, often invisible labor of para-advocacy. They are protecting the community’s most valuable asset, its safety and trustworthiness, and actively intervening to prevent it from becoming another source of stress.

*“occasionally... you have some of those people who... just kind of want to make a scene in the group... my initial intention is to try to calm the person down...if it doesn’t work, then... I just remove them from the group...” (P14)*

This includes setting clear boundaries around the type of information shared, intervening to prevent the community from becoming another source of stress or misinformation.

*“In our group, we actually don’t allow any sort of medical advice. You know, that’s for the doctors to give.” (P14)*

Through these multi-faceted acts of stewardship, leaders are not just participating in the community; they are actively architecting a safe and generative environment.

**4.3.3 Systemic Intervention: Narrative Reframing and Creating New Pathways for Support.** The final stage of this journey transcends internal community management and becomes a form of external advocacy. By constructing and promoting a new narrative of survivorship, these stewards perform a systemic intervention, achieving institutional agency and challenging the dominant, often deficit-focused, societal view of cancer survivors. This is the ultimate rejection of the needs-driven dead end. Instead of being defined by their problems, they are defining themselves by their strengths, resilience, and capacity for growth. This positive narrative construction is a deeply reflexive act of meaning-making and a powerful outward-facing action. Where deficit-based systems can lead to the internalization of negative labels, these survivor-advocates are actively creating an alternative script. The participants’ pride and ownership over their stories become a form of strategic communication and a means of advocacy.

*“I’m very proud of my experience and very open about it.” (P02)*

*“being a cancer patient being a cancer survivor and having a history as a patient are very are they are parts of my history i’m very proud of um just that it in the journey that’s taken me to who i am now” (P11)*

Reframing the experience or public recognition of resilience at a systemic level is an asset, a source of identity and wisdom, eventually becoming a form of advocacy in itself, creating cultural resources that empower the entire community. The final step in this evolution is to move from shaping existing spaces to creating new ones. Recognizing gaps in the support ecosystem, some stewards take the ultimate step of founding their own groups. This outward turn often manifests in the creation and stewardship of new communities, such as the collaborative work of P11 and P14 in co-administering a Facebook group, or P14’s public-facing advocacy on his Instagram blog. By starting their own groups, these advocates are not just filling a service gap; they are making an argument for a different, asset-based model of support.

*“I started [my group] with actually one of my friends who I met through the AYA network... And we connected with other cancer patients... So we all kind of like joined. They all kind of joined my group. And then like we all have like we’re all in different groups together kind of thing.” (P11)*

By creating new communities and completing the journey, survivors are no longer just participating in an ecosystem; they are generating new parts of it, designed according to their own asset-based values and intervening to create the community they believe should exist, thereby advancing cancer awareness on their own terms. It is the ultimate act of self-advocacy.

## 5 Discussion and Implications for Design

Cancer advocacy emerged from a fundamental recognition that survivors require multidimensional support beyond medical treatment, navigating physical, psychological, social, and spiritual dimensions through distinct stages demanding different capabilities at each phase [41]. We demonstrated that survivors do not passively switch from a deficit to an asset mindset. Instead, they reflexively analyze their evolving needs and the limitations of existing support structures by strategically building assets and curating personalized support ecosystems. Supporting this complex journey requires adaptive systems that evolve alongside the user rather than static solutions. A key challenge in this space is ensuring appropriate technologies are available and identifying the right point to introduce them [64]. We address this challenge by organizing our design implications around three developmental stages, synthesized in the Design Framework presented in Table 4 (see Appendix B). This staged approach directly responds to the dynamic nature of survivorship: our findings demonstrate that survivors’ technological needs shift fundamentally as they progress from overwhelmed novices to skilled architects to community advocates, with each phase presenting distinct challenges while building upon capabilities developed previously. Rather than proposing a single monolithic platform, we envision a coordinated feature layer that augments the existing social media and community platforms survivors already use rather than displacing them. Indeed, this design philosophy aligns with asset-based frameworks that identify three mobilization strategies: connecting assets, raising awareness, and enabling assets to thrive [19], mirroring the survivor trajectory from ecosystem curation to community stewardship.

Throughout our recommendations, we have sought to navigate a tricky balance: how to enhance community-based ecosystems without undermining the peer-driven dynamics that make them valuable. The labor we documented offers guidance here. Vetting information, managing identity boundaries, evaluating community quality, and stewarding peer groups constitute work that is contextual, fragmented, and high-volume, often exceeding sustainable manual effort, as evidenced by the disengagement patterns we observed. These properties necessitate intelligent, adaptive assistance capable of personalization and cross-platform synthesis capabilities that static tools cannot provide, given the dynamic and individualized nature of survivorship trajectories. Where appropriate, we suggest ways in which AI or machine learning technologies could be deployed in service of these broader aims. However, we never want

AI to take the place of self-management and sensemaking; instead we emphasize that AI should augment survivor agency rather than replace it: systems surface options and flag risks while users retain decision-making authority over their ecosystem construction.

### 5.1 From Passive Patient to Active Architect: Designing for the ‘Reflexive Shift’

The transition from passive patient to Active Architect is not merely a behavioral shift in technology use but a profound consciousness change from a deficit-oriented mindset to one of asset recognition and empowerment [73]. Survivors, including those who participated in our study, often begin their journey positioned in a classic deficit model, where their inherent funds of knowledge are overlooked by external experts [64, 69]. As survivors progress, they undergo a Reflexive Shift, realizing that the most valuable knowledge is not the aggregated wisdom of the crowd but the socially negotiated collective intelligence of their peers [23]. Current platforms often lack sufficient support structures, overwhelming users with unmoderated peer data or dispensing decontextualized medical facts. This labor compounds with the parallel journey of transitioning to adulthood, creating a dual crisis where the developmental need for autonomy clashes with the burden of managing survivorship [103]. HCI can support this delicate transition by designing systems that validate these emerging capabilities, transforming the ability to search and connect online into a core component of survivors’ personal “funds of knowledge” [69].

To support survivors as they approach the ‘Reflexive Shift’, we propose three design guidelines. Each targets a distinct challenge identified in our findings: information overwhelm, the mismatch between static resources and evolving expertise, and the fragmentation of support across platforms. Rather than a standalone platform, we envision these guidelines as a coordinated feature layer implemented across existing platforms, from enhanced onboarding in online health communities to browser-based tools, meeting survivors where they already engage.

**Guideline 1: Adaptive Pathways for Graduated Exposure.** Supporting the Reflexive Shift requires systems that offer structured, evolving pathways acknowledging users’ changing expertise. For a novice survivor overwhelmed by the frightening experience of unmoderated searches (P05), such a system should present a protected, introductory mode sitting beside or ‘on top of’ existing systems, such as online forums or search results pages. Such an interface for early-stage survivors would prioritize gently framed, accredited information and feature anonymized, aggregated peer data, for instance, displaying prompts like, “You’re not alone: 70% of survivors report similar feelings of uncertainty,” directly addressing the validation needs expressed by participants like P13. As users gain confidence, the system can unlock more complex layers of support, prompting exploration of moderated discussions or personal stories, creating a developmental framework that moves them from safe information consumption to active community engagement.

**Guideline 2: AI-Driven Pacing and Personalization.** To implement graduated exposure, the most responsive solutions would dynamically pace information delivery to match survivors’ growing agency and independence. A conversational agent or recommendation engine can personalize this journey, making the ‘information

hunt' (P01) both safer and more effective by bridging clinical facts and lived experiences. When a survivor searches for a high-stakes topic like fertility (P08), at this stage the best interface would not just return a simple list of links but also deliver a balanced portfolio of resources: a clinical article on fertility preservation from the American Cancer Society (validating P14's trust in accredited sources), a blog post from a survivor who navigated this decision (meeting P12's need for lived experience), and a link to a private, moderated support group on this topic. This system would adapt over time, shifting recommendations from foundational knowledge to nuanced discussions as user expertise develops. This aligns with Hartzler et al.'s finding that static profiles fail to capture the evolving nature of the cancer experience; systems must explicitly model the temporality of health interests to connect users with appropriate support at the right time [40]. Combined with prior research demonstrating that dynamically pacing information delivery can catalyze proactive health behaviors [49], this approach actively guides survivors through their developmental trajectory.

**Guideline 3: Cross-Platform Contextual Guidance.** To integrate these adaptive support features into survivors' daily workflows, we can design unobtrusive guides that function across the diverse platforms survivors use to curate their ecosystems (P14). Rather than forcing users onto a new platform, browser extensions can provide just-in-time guidance within existing social media environments. As a survivor browses a public Facebook group, this tool could offer contextual advice: "This group is known for strong emotional support but sometimes shares unverified medical advice. Remember to cross-reference with your oncologist (as P08 does)." If a user drafts a post about a sensitive topic, the tool could prompt selective disclosure: "This post contains personal health details. Would you like to share it in your private group chat first?" This approach respects user autonomy and established digital practices while providing assistance that develops the critical literacies and boundary-setting skills necessary for safe, effective self-advocacy.

These three guidelines represent a coordinated system rather than isolated features. Adaptive pathways (Guideline 1) prevent overwhelm during initial exposure; AI-driven pacing (Guideline 2) personalizes the journey across evolving expertise levels; cross-platform guidance (Guideline 3) embeds support within existing digital practices. Structure without personalization feels rigid; personalization without cross-platform reach remains siloed. Together, a system that embodies these three guidelines could help survivors develop the vetting, filtering, and boundary-management skills that enable the autonomous ecosystem curation detailed in Section 5.2.

## 5.2 Architecting Resilience: Designing for the Demands and Tradeoffs of Ecosystem Curation

The transition from information seeker to "architect" places survivors at the center of a fundamental tension in community development: the act of building a valuable community asset simultaneously exposes it to risks that can degrade or destroy it [39]. Our analysis reveals that survivors actively engage in "protective stewardship" to navigate these tensions. For instance, survivors strategically prioritize intimacy over reach (P08) and deploy sophisticated "critical digital literacies" [69] to protect the community's shared funds of

knowledge from corruption (P11). This vigilance indicates that the digital landscape is not inherently safe or supportive. However, the divergent paths we observed, where some survivors disengage due to the intensive labor of this work (P03, P06, P10), demonstrate that relying solely on self-directed effort is unsustainable [73].

This creates a clear design opportunity to reduce the burden of architectural labor. We term this approach "Augmented Architecture": three guidelines comprising a system of tools that function atop existing platforms to support the architect's journey. Each targets a distinct form of labor driving disengagement: the search labor of finding safe communities, the verification labor of vetting information, and the boundary management labor of controlling disclosure across spaces.

**Guideline 4: Reputation Metrics to Reduce Search Labor.** To mitigate the trial-and-error fatigue of finding safe groups (P01), technology should augment existing platforms with community-driven reputation tools. Visible metrics such as a Welcoming Score or an Evidence-Based Discussion rating would empower users to make informed choices about where to invest their energy without requiring exhaustive manual vetting.

**Guideline 5: AI-Driven Credibility Assistance for Verification.** The cognitive load of vetting information can be addressed through integrated support tools. While human judgment remains vital, an AI-driven credibility assistant can alleviate this burden by automating the verification strategies that survivors currently perform manually (P14, P08). When a user encounters a post promoting an alternative treatment (a risk highlighted by P11), the assistant could non-intrusively display a notification: "This post discusses a treatment not validated by major cancer organizations. Would you like to see related research from accredited sources?" This strategy protects users from misinformation while managing the emotional toll of encountering distressing content (P07).

**Guideline 6: Privacy Dashboards for Boundary Management.** Addressing the complex relational dynamics of boundary construction requires privacy and identity management dashboards. These tools help survivors visualize and control their selective disclosure across the various public and private spaces they inhabit, providing prompts such as, "You've shared your treatment history in three public groups. Would you like to review who can see these posts?" or "A new member has joined your private chat. Here's a reminder of this group's privacy norms." This makes the often-invisible labor of boundary setting tangible, reinforcing safety and control while protecting the community's trust from the threat of "fake peers" (P11).

These three guidelines systematically reduce each form of labor driving disengagement. Reputation metrics (Guideline 4) address search labor; credibility assistance (Guideline 5) addresses verification labor; privacy dashboards (Guideline 6) address boundary management labor. By targeting these burnout sources simultaneously, this approach makes ecosystem curation sustainable rather than overwhelming, enabling architects to maintain the stable communities necessary for collective advocacy (Section 5.3).

### 5.3 From Architect to Advocate: Mobilizing Assets for Systemic Intervention

Building on the previous stages, the outward turn to advocacy presents complex challenges extending far beyond individual participation. The transition embodies a critical tradeoff between the empowering potential of collective action and the significant, often invisible, labor required to sustain it [39]. This tension is not theoretical; it is empirically demonstrated by the divergent paths where some survivors disengage because the demands of building and maintaining a support system become overwhelming (P10, P06). The transition to advocacy, therefore, is not a simple final step but a complex negotiation of costs and benefits.

Successful advocates manage this labor by transforming personal assets into sustainable community resources, a powerful evolution of “positive adaptation” [77]. Our findings suggest that the wisdom and coping skills fostered during the illness experience eventually mature into advocacy. This evolution builds directly on the capabilities developed through guided information-seeking (Section 5.1) and autonomous ecosystem curation (Section 5.2), where survivors learned to vet information, manage boundaries, and navigate platform tradeoffs skills that now enable effective community stewardship. They operationalize lived experience by building the community’s advocacy capacity, a crucial process for which formal online mentoring programs have been developed [75].

However, we observed parallel difficulties in online survivor communities: long-term survivors disengage due to burnout, while newcomers face isolation in inactive communities. Addressing this issue requires moving beyond informal, self-directed paths. Here we present a ‘Stewardship Development Program’ comprising three integrated guidelines for identifying, equipping, and amplifying community advocates. Together, these guidelines form a cohesive pathway from recognition to support to amplification. Each targets a distinct barrier to sustainable advocacy: the invisibility of emerging leaders, the unsupported burden of stewardship labor, and the lack of tools for external impact.

**Guideline 7: Proactive Identification of Emerging Stewards.** While formal e-mentoring relies on structured matching [75], our findings show advocacy often emerges organically. Systems should leverage AI to identify and nurture these natural advocates. An AI-powered analysis of engagement patterns could recognize members who consistently demonstrate stewardship qualities (P13), such as offering validation or gently correcting misinformation. By systematically identifying these contributors, the system operationalizes the value of connecting newcomers with experienced survivors [10]. Instead of leaving contributions unrecognized, the system could send a private message validating their expertise and offering access to the stewardship toolkit (Guideline 8). This provides an explicit entry point into a leadership track, transforming organic participation into recognized stewardship.

**Guideline 8: Back-Stage Toolkits for Para-Advocacy Support.** Para-advocacy encompasses the informal stewardship that builds community capacity from within. However, this work is made difficult by the digital context, which lacks the nonverbal cues traditional ABCD relies upon to build trust [87]. Interventions must reduce the invisible labor of stewardship so advocates can focus on relational labor that counters the “online disinhibition effect” [87].

Equipping stewards with a dedicated “back-stage” toolkit powered by multi-agent systems addresses this need. A Moderation Agent could triage flagged content to alleviate constant vigilance (P14), while a Synthesis Agent could generate concise digests of complex conversations. This transforms ad-hoc labor into manageable practice, freeing advocates to perform the intentional “language moves”, such as validation and mentorship (P09) that build rapport and promote healthy behaviors [63].

**Guideline 9: Narrative Modules for Systemic Intervention.** Only when a community is strong, safe, and cohesive can it effectively mobilize its collective intelligence [23] to create new support pathways (P11) or challenge dominant narratives. The final component focuses on external advocacy through a Narrative-Building Module. A Vision-Language Model (VLM) could help advocates transform anonymized community moments into compelling visual assets. Most critically, this module would enable advocates to generate Community Insight Reports by querying anonymized data to produce evidence-backed summaries on challenges like fertility. This positions the community’s lived experience as a powerful tool for systemic change.

These three guidelines function interdependently: identification without support tools would overwhelm recognized stewards; tools without recognition would lack users; narrative amplification without stable stewardship would lack authentic community voice. By structuring this pathway from recognition through toolkit provision to narrative amplification, the Stewardship Development Program completes the developmental trajectory. Survivors who began as overwhelmed novices (Section 5.1) matured into skilled architects (Section 5.2) and now emerge as equipped advocates capable of driving systemic change. This staged approach ensures that technological support adapts as survivors’ roles evolve, creating a cohesive ecosystem that sustains communities across the full survivorship journey.

## 6 Limitations and Future Work

This study has several limitations that suggest directions for future research. Our sample of 14 participants, while providing rich insights into the survivorship journey, was limited in demographic diversity and survivorship experiences. The majority of participants were long-term survivors, which may have introduced recall bias when reflecting on their early technology use during diagnosis and treatment. Our sample included a few participants with rare cancer types, limiting our understanding of how survivors with less common diagnoses navigate the challenge of finding relevant peer communities. The cross-sectional interview design captured participants’ retrospective accounts but did not allow us to observe the process of ecosystem construction and advocacy development in real time. Future work should address these limitations through complementary approaches. Larger-scale studies with greater demographic diversity could validate our findings across different survivor populations and explore how socioeconomic and cultural factors influence digital ecosystem construction. Longitudinal ethnographic studies following newly diagnosed survivors could provide deeper insights into the mechanisms of the Reflexive Shift and identify optimal intervention points. Participatory design studies involving survivors as co-designers could help translate

our design implications into concrete technological prototypes. Future research should examine the sustainability of the advocacy pathway, investigating how to support long-term advocates while ensuring community leadership continuity.

## 7 Conclusion

This paper has traced the journey of young adult survivors of childhood cancer as they evolve from passive patients to Active Architects of digital support ecosystems and to self-advocates. Through our analysis, we have shown that this transformation is not a linear progression but a complex negotiation of tradeoffs between deficits and assets, individual needs and collective responsibilities, and safety and connection. Our findings challenge both deficit-focused and asset-focused approaches to health technology design, revealing that survivors' empowerment emerges through their strategic navigation of these tensions across three critical phases: the shift from family-mediated technology use to autonomous information seeking, the work of curating personalized support ecosystems while developing digital literacies, and the turn to advocacy through community stewardship and narrative reframing.

For the HCI community, understanding this ecosystem construction process is essential for designing adaptive technological systems that recognize and scaffold users' developmental trajectories from novice information seekers to expert community stewards. Our work demonstrates that supporting survivor empowerment requires designing not just for individual self-management, but for collective capacity building that enables communities to become self-sustaining sources of peer support and systemic change. As the population of childhood cancer survivors continues to grow, the imperative to create technologies that honor both their ongoing challenges and developing expertise becomes increasingly urgent.

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## A Participant Demographics and Data

### A.1 Table One

**Table 1: Demographics and Cancer History of Survivors**

ID	Age	Gender	Race/Ethnicity	Cancer Type	Survivorship	Dx Age
P1	21	Male	Black/Hispanic	Central Nervous System	>5 years	12
P2	24	Male	White	Acute Lymphoblastic Leukemia	>5 years	9
P3	30	Male	Black	Gastrointestinal Stromal Tumors	<6 months	6
P4	27	Male	Asian	Acute Lymphoblastic Leukemia	>5 years	18
P5	29	Male	White	Rhabdomyosarcoma	>5 years	5
P6	19	Female	Black	Papillary Thyroid Carcinoma	>5 years	13
P7	22	Female	White	Central Nervous System	>5 years	10
P8	29	Female	White/Hispanic	Acute Lymphoblastic Leukemia	>5 years	14
P9	22	Female	White/Hispanic	Soft Tissue Sarcoma	2-5 years	16
P10	27	Male	Black	Bone Sarcoma	>5 years	12
P11	30	Female	Asian	Osteosarcoma	2-5 years	16
P12	28	NB	White	Ewing Sarcoma	>5 years	16
P13	25	Male	Asian	Lung Cancer	>5 years	5
P14	29	Male	White	Osteosarcoma	>5 years	18

### A.2 Table Two

**Table 2: Technology Use and Information Access**

ID	Social Media	Tech Usage	Tech Access
P1	Instagram	Several times/day	Great difficulty
P2	YouTube	Several times/day	Very easily
P3	Facebook, Instagram, Reddit	Once/day	Easily
P4	Instagram, TikTok, Snapchat, Reddit	Several times/day	Easily
P5	Facebook, Instagram, TikTok, Reddit	Several times/day	Some difficulty
P6	Instagram, Reddit, YouTube	Several times/day	Very easily
P7	Facebook, Instagram, Twitter, TikTok, Snapchat, Reddit	Several times/day	Easily
P8	Reddit	Several times/day	Neutral
P9	Facebook, Instagram, Twitter, TikTok, Snapchat, Reddit	Several times/day	Very easily
P10	Instagram, Snapchat	Several times/day	Neutral
P11	Facebook, Instagram, Reddit	Several times/day	Very easily
P12	TikTok, Snapchat, Reddit	Several times/day	Very easily
P13	Facebook, Instagram, Twitter, TikTok, Snapchat, Reddit	Several times/day	Very easily
P14	Instagram, Facebook	Several times/day	Very easily

*Note:* Platforms reflect general daily usage reported in the survey. Qualitative findings (Section 4) reveal how participants strategically utilize these tools: platforms like Facebook and Reddit are often co-opted for cancer-specific support, whereas others (e.g., Snapchat, TikTok) are primarily used for general entertainment and non-cancer social connection.

### A.3 Table Three

**Table 3: Tech Usage Across Survivorship Phases**

Survivorship Phase	Technology Purpose	Platform Use-Cases & Behaviors	Participants
<b>1. Acute Treatment Phase</b> (Diagnosis & Active Therapy)	<b>Palliative &amp; Distraction</b> Technology is used to escape the hospital environment or is managed entirely by parents.	<b>Entertainment &amp; Escapism:</b> <ul style="list-style-type: none"> <li>Using iPads/Gaming to disassociate from pain (P10, P12).</li> <li>Watching Netflix with family to pass time (P14).</li> </ul> <b>Parent-Mediated Info:</b> <ul style="list-style-type: none"> <li>Parents manage research; patient is protected from data (P06, P09).</li> </ul> <b>Early Education:</b> <ul style="list-style-type: none"> <li>Using tools like Leapfrog for reading assistance due to cognitive load (P03)</li> </ul>	P02, P06, P09, P10, P12, P14
<b>2. Transitional Phase</b> (Immediate Post-Treatment & Re-entry)	<b>Navigational &amp; Info Seeking</b> The "Pivot to Agency." Survivors turn to the internet to answer questions about fertility, side effects, and normalcy.	<b>Specific Information Hunting:</b> <ul style="list-style-type: none"> <li>Researching mortality rates/chemo (P01).</li> <li>Searching for fertility data (P08).</li> </ul> <b>Anxious Searching:</b> <ul style="list-style-type: none"> <li>Encountering frightening stats on WebMD (P05).</li> </ul> <b>Finding Peers:</b> <ul style="list-style-type: none"> <li>Seeking others with rare diagnoses on Facebook/Reddit (P06, P11).</li> </ul>	P01, P05, P06, P08, P11, P12
<b>3. Long-Term Survivorship</b> (5+ Years / Established Life)	<b>Divergent Usage</b> Survivors split into paths based on coping styles and barriers: <i>(A) Maintenance</i> <i>(B) Stewardship</i> <i>(C) Emergent</i>	<b>(A) Maintenance (The Protective Stance):</b> <ul style="list-style-type: none"> <li><b>Strictly Utility:</b> Using portals only for appointments (P03, P05, P10).</li> <li><b>Avoidance:</b> Disengaging from cancer content (P01, P04).</li> <li><b>Selective Seeking:</b> High-stakes research (e.g., fertility) but avoiding community judgment (P08).</li> </ul> <b>(B) Stewardship (The Advocate):</b> <ul style="list-style-type: none"> <li><b>Community Building:</b> Administering groups (P11, P14).</li> <li><b>Public Narrative:</b> Blogs/Public speaking (P07, P14).</li> <li><b>Resource Sharing:</b> Curating apps for peers (P13).</li> </ul> <b>(C) Emergent (Engaged but Constrained):</b> <ul style="list-style-type: none"> <li><b>Active Participation:</b> Validating peers but not leading due to tumor rarity (P09).</li> <li><b>Aspiring Sharing:</b> Desire to share story but inhibited by anxiety (P12).</li> </ul>	<b>Group A:</b> P01, P03, P04, P05, P08, P10 <b>Group B:</b> P02, P07, P11, P13, P14 <b>Group C:</b> P09, P12

*Note:* This table illustrates the temporal progression of technology use. In the final phase, usage diverges: some become Advocates (Group B), others maintain a Protective Stance (Group A), while a third group remains Emergent (Group C), engaged but constrained by structural or internal barriers.

## B Design Framework

**Table 4: Design Framework for Supporting the Transition from Patient to Advocate**

Survivorship Phase & User Mode	Observed Behaviors & Evidence (from Interviews)	Design Guidelines & System Interventions	Tensions & Trade-offs to Keep in Mind
<p><b>Phase 1: Initial Dependency</b> (<i>The Passive Patient</i>)</p> <p><b>Mindset:</b> Deficit-framed; reliant on caregivers; overwhelmed by medical trauma.</p>	<ul style="list-style-type: none"> <li>• <b>Palliative Use:</b> Using tech primarily for distraction (e.g., Netflix, gaming) rather than health management (P02, P12).</li> <li>• <b>Mediated Access:</b> Caregivers act as gatekeepers to protect the patient from scary statistics (P06: “<i>My mother... told me to just stay away from the video games</i>”).</li> <li>• <b>Anxious Searching:</b> Encountering “worst possible scenarios” on WebMD, leading to avoidance (P05).</li> </ul>	<p><b>G1: Adaptive Pathways:</b> Provide a “protected mode” with graduated exposure to complex medical info.</p> <p><b>G2: AI-Driven Pacing:</b> AI agents that deliver information based on emotional readiness, not just keyword relevance.</p> <p><b>G3: Contextual Guidance:</b> Browser extensions that offer gentle warnings or context when users stray into unverified medical forums.</p>	<p><b>Protection vs. Autonomy:</b> Over-protecting users can delay their development of digital health literacy. Systems must balance safety with the user’s need to eventually take control.</p> <p><b>The “Negative Spiral”:</b> Early exposure to raw peer narratives before a user is ready can cause immediate disengagement (P04).</p>
<p><b>Phase 2: Self-Empowerment</b> (<i>The Active Architect</i>)</p> <p><b>Mindset:</b> Asset-building; strategic curation; seeking validation over facts.</p>	<ul style="list-style-type: none"> <li>• <b>Strategic Curation:</b> Selecting specific platforms for specific needs (e.g., P08 chose Tumblr for safety over Facebook’s reach).</li> <li>• <b>Vetting Labor:</b> Manually cross-referencing peer advice with doctors to verify safety (P01, P14).</li> <li>• <b>Identity Management:</b> Carefully separating “cancer life” from “normal life” to avoid stigma (P03: “<i>I never did want to play a role that I’m a victim</i>”).</li> </ul>	<p><b>G4: Reputation Metrics:</b> Automated “Welcoming Scores” or “Evidence-Based” badges to reduce the labor of finding safe groups.</p> <p><b>G5: Credibility Assistants:</b> AI tools that auto-flag alternative treatments in forums and offer accredited context.</p> <p><b>G6: Privacy Dashboards:</b> Tools to visualize where and how a user’s health data is visible to manage the “patient” vs. “person” identity.</p>	<p><b>Connection vs. Privacy:</b> To get deep support, users must share vulnerable data, but this exposes them to privacy risks. “Lurking” protects privacy but limits the benefit of reciprocal support.</p> <p><b>The Burden of Architecture:</b> The labor required to vet and curate these ecosystems is high; if the cognitive load is too heavy, users will abandon the tools (P01, P06).</p>
<p><b>Phase 3: Systemic Advocacy</b> (<i>The Community Steward</i>)</p> <p><b>Mindset:</b> Reciprocity-driven; transforming personal trauma into community assets.</p>	<ul style="list-style-type: none"> <li>• <b>Para-Advocacy:</b> Performing invisible labor like moderating disputes or correcting misinformation (P14: “<i>my initial intention is to try to calm the person down</i>”).</li> <li>• <b>Resource Bridging:</b> Curating external tools (e.g., Calm, Thrive) to share with the group (P13).</li> <li>• <b>Systemic Intervention:</b> Creating new groups to fill gaps they personally experienced (P02, P11).</li> </ul>	<p><b>G7: Steward Identification:</b> Algorithms that identify users providing high-quality support and prompt them to take leadership roles.</p> <p><b>G8: Back-Stage Toolkits:</b> Moderation agents to reduce the emotional toll of policing bad actors and “fake peers.”</p> <p><b>G9: Narrative Modules:</b> Tools to help advocates transform personal stories into anonymized, systemic data for advocacy.</p>	<p><b>Burnout vs. Engagement:</b> The most active advocates are at the highest risk of compassion fatigue. Systems must support them without exploiting their free labor.</p> <p><b>Authenticity vs. Safety:</b> Advocates want open communities, but “fake peers” (P11) threaten trust. Strict verification protects the group but raises barriers to entry for new, vulnerable patients.</p>