“I’m so glad I met you”: Designing dynamic collaborative support for young adult cancer survivors

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ABSTRACT

Young adult cancer survivors—individuals in their 20’s and 30’s—must cope with complicated informational and emotional needs that differ from those of other age groups. Although young adult cancer survivors are resourceful in finding information and support to help meet those needs, they face three distinct, ongoing challenges during and after the cancer experience: (1) feeling isolated; (2) confronting a sense of mortality; and (3) struggling with changing body image and identity. We present empirical findings from qualitative interviews with young adult cancer survivors that demonstrate how these challenges change throughout the illness experience, complicating a survivor’s search for information and support. We also characterize the adaptive behaviors survivors employ to overcome these challenges. Given these findings, we suggest design implications for online spaces young adult survivors use to collaborate, as well as resources about privacy and self-presentation that can best support survivors in making decisions about sharing information.

Author Keywords

Online collaboration; health information seeking; young adult cancer; qualitative methods.

ACM Classification Keywords

J.3. Life and medical sciences: Health

INTRODUCTION

Approximately 70,000 adolescents and young adults (AYAs; defined by the National Cancer Institute, or NCI, as those 16 to 39 years of age) are diagnosed with cancer each year in the United States, and 700,000 AYA cancer survivors currently live in the U.S. [1, 38]. These cancer survivors experience outsized financial, health, and emotional repercussions of their diagnoses versus older cancer survivors [1]. In this paper, we focus primarily on the needs of individuals diagnosed with cancer in their 20’s and 30’s, as their needs can be quite different than those of adolescents, due to differences in the developmental stages each group inhabits. When we refer to **young adult survivors** in this paper, therefore, we exclude teenaged survivors.

Young adult survivors face a daunting variety of tasks, including choosing the appropriate treatment protocol after diagnosis; understanding health insurance benefits during and after cancer treatment; adjusting to permanent physical effects—such as physical disability or infertility; managing mental health post-treatment; and coping with under- and unemployment, sometimes long after cancer treatment ends [35, 41]. To accomplish these tasks, young adult survivors require access to timely, high-quality informational and emotional support during treatment and survivorship. Given the right support, young adult cancer survivors are better able to be active members of their health care teams. When young adults take an active role in their care, long-term outcomes can be improved through their involvement in treatment decisions, more active engagement in follow-up survivorship care, and enhanced communication with health care providers about long-term side effects and concerns [24].

Researchers have previously determined that younger cancer survivors are more likely to actively seek out information than older survivors, particularly in online spaces [2, 11]. We also know that young adult survivors use collaborative online tools—such as social media and online forums [9]—that help them connect with other survivors [37]. Evidence that young adult survivors use social media during cancer points to a need for collaborative spaces where survivors can share information with family and friends, as well as “safe” spaces where survivors can gather to cope with the cancer experience together [39]. However, only a small portion of research focuses on the specific hardships faced by young adults with cancer, who often face treatment, recovery and survivorship alone (e.g., without a spouse or partner) and in a developmental stage where aspirations for career and relationships must be paused to coordinate cancer care [41].

In this study, we present a qualitative exploration of young adult survivor needs during the cancer experience and in managing long-term quality of life issues. We frame these needs in terms of three distinct challenges faced by young

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CSCW '17, February 25-March 01, 2017, Portland, OR, USA
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ACM 978-1-4503-4335-0/17/03…$15.00
DOI: http://dx.doi.org/10.1145/2998181.2998326

adult survivors, as identified by the NCI's Adolescent and Young Adult Oncology Progress Review Group [1; p.10]:

(1) Feeling isolated;
(2) Confronting a sense of mortality; and
(3) Struggling with changing body image and identity.

Our research contributes empirical evidence of these three challenges, and presents survivors' strategies in coping with these challenges. We present a rich description of the challenges young adult survivors face, and the resulting adaptive behaviors survivors employ to cope. Then, we articulate implications for collaborative spaces that survivors use to cope during and after cancer, as well as characterize skills survivors require for overcoming these challenges. Offering helpful spaces and fostering skills among survivors will empower them to more readily face challenges related to informational and emotional needs, particularly as needs change over time and persist into survivorship.

BACKGROUND LITERATURE

In addressing the literature related to this study, we first review common threads in previous research on cancer survivor informational and emotional needs. We are careful to point out those studies that have focused on young adults specifically, although this body of research is more limited than the number of studies that focus older (ages 40+) survivors, due to the increased prevalence of many cancers in older age groups. Second, we review the benefits to survivors in entering or using collaborative technologies or spaces to meet their informational and emotional needs.

Cancer survivor informational and emotional needs

If information-seeking can be viewed as a spectrum, from seeking to avoidance [27, 28, 29], then younger cancer survivors trend toward seeking over avoidance. Several studies have shown that younger cancer survivors—including young adults, the focus of this study—tend to be more active in seeking information than older (and especially elderly) patients, e.g., [4, 23].

Young adult survivors may also seek information over a longer period of time versus older survivors—i.e., in the period after treatment—as they experience lasting struggles from the repercussions of cancer treatment for longer periods than older adults [1, 15, 35]. Many of these issues must be faced by young adult survivors through information seeking and advocacy for self in treatment and survivorship. However, young adult survivors often encounter barriers to finding age-appropriate information on challenges such as infertility and secondary cancer risks [42].

Although much of previous research addresses findings related to information seeking during the cancer experience, informational and emotional needs of individuals are often so closely intertwined as to be indistinguishable. In ethnographic work with breast cancer patients and survivors (ages 40-70) in an online forum, Rubenstein [36] found this to be the case, and therefore suggested social support could be considered a *subtype of information work* among cancer patients and survivors. This is the approach that we take in this study, and use participant quotes to present informational and emotional needs holistically, the way our participants described them.

The experience of finding solutions to informational and emotional needs in a collaborative setting can be influenced by a number of factors, including survivors' genders. In a study of in-person support groups, Gray et al. [13] found that men and women had very different ideas about the link between informational and emotional support. Specifically, men preferred to exchange information with other patients and survivors, but balked at the notion of sharing feelings or problems. Women interviewed for the same study were less focused on organizing information flows and the structure of the group and preferred to focus on supporting emotional and informational needs of group members.

Finally, the act of using technology is promising for serving diverse needs and can empower survivors to take control of their information seeking, giving them comfortable solutions to informational and emotional needs [18]. For example, in a qualitative interview study with twelve breast cancer patients provided a tablet and application to manage information about their diagnosis and treatment, Jacobs et al. [22] found that patients used the provided devices first for health and—at a close second—for entertainment. In this study, the authors found that use of a tablet came in handy for discreetly organizing and storing cancer information (which can become voluminous, in a "binder," as one participant in the study noted). In the following section, we give an overview of the work cancer survivors have been found to perform in online spaces.

Use of collaborative technology and spaces

Cancer survivors often must seek out the best solutions for meeting informational and emotional needs on their own. Online spaces can provide safety, anonymity, and access to cancer survivors who might feel vulnerable, exposed, or isolated. Studies of online spaces for breast cancer patients [33, 40] linked the notion of a "safe space" to the emotional work observed through observation and content analysis. In studying interactions among users, Meier et al. [31] found evidence of "active modeling" of supporting emotional needs in their study of threads on ten different cancer listservs. Meier's findings emphasize the importance of more senior members in maintaining a culture of support in the online community.

The act of collaborating in online communities leads to individual benefits. Høybye et al. [19] enumerated the ways patients in an online breast cancer support group shared information and assessed how the interactions affected the online participants. Høybye found that users were "empowered" in sharing "knowledge and experience" with fellow patients and survivors. The notion of "empowerment" has also previously been emphasized in a survey of qualitative literature regarding online health support groups [3].

The types of information shared and offered online can be diverse, as well. Gill and Whisnat [12] described exchange of “technical and emotional knowledge” in an online ovarian cancer support group, and noted that the forum structure particularly supported information seeker/information provider dyad matching. Huh et al. [21] executed a study that went further, not only describing the types of information shared, but also suggesting enhancements to the design and function of online communities to better meet a patient’s comprehensive information needs. We take a similar approach in this study, attempting to learn from participants’ challenges and resulting adaptive behavior to cope with cancer and its lasting effects to suggest design enhancements for collaborative informational and emotional support resources.

METHODS

We used qualitative methods to elicit survivors’ challenges and strategies for coping with those challenges. The first author collected and analyzed data in an iterative process, and emerging themes informed subsequent interviews by inspiring new follow-up questions to probe insights from survivor to survivor (i.e., in an inductive approach to building themes in observations; [14]). The themes that emerged from an iterative cycle of qualitative coding are presented in the results below.

Participants

Participant recruitment was conducted both online (in Facebook support groups and through e-mail listservs) as well as offline (distributing recruitment materials with participants willing to approach others offline), in a combination of convenience and snowball sampling techniques. Because the research was meant to explore the subject of online as well as offline collaborative information behavior, the recruitment criteria was kept relatively simple. First, potential participants had to have been diagnosed with cancer between the ages of 15 and 40; second, the potential participants had to be over the age of 18 at the time of the scheduled interview. All research procedures were approved ahead of time by the Human Subjects Division at the University of Washington.

The first author conducted 15 interviews with cancer survivors experiencing a variety of diagnoses and treatments (Table 1). The resulting sample included mostly survivors in their 20’s and 30’s (a subset of the NCI’s “young adult” age range), and their experiences largely represented cancer experiences in post-adolescence. Four participants were male, and eleven were female. Although most of the survivors interviewed lived in and received treatment at medical centers located in the Pacific Northwest or Midwest regions of the U.S., at least one of the survivors had received at

Pseudonym (Gender, Age)	**Diagnosis**	**Elapsed time from first diagnosis to interview date**	**General treatment course**
Bob (Male, 35)	Hodgkin’s Lymphoma, Stage 4	9 months	Chemotherapy
Marie (Female, 42)	Osteosarcoma*	30 years	Surgery, Chemotherapy
Leah (Female, 32)	Breast Cancer, Stage 4	1.5 years	Surgery, Chemotherapy, Radiation
Emily (Female, 35)	Hodgkin’s Lymphoma, Stage 3	4 years	Chemotherapy
Jo (Female, 28)	Thyroid Cancer, Stage 1*	2 years	Surgery, radiated iodine
Kate (Female, 29)	Acute Lymphoblastic Lymphoma, Stage 4	4.5 years	Chemotherapy
Lucy (Female, 33)	Acute Lymphocytic Leukemia	4.5 years	Chemotherapy, Stem cell transplant
Peter (Male, 31)	Adenocarcinoma (head & neck)	9 months	Surgery, Chemotherapy, Radiation
Mark (Male, 32)	Brain tumor, Grade 2 or 3	1.5 years	Surgery, Chemotherapy, Radiation
Helen (Female, 31)	Cervical cancer, Stage 1B1	6 months	Surgery, Chemotherapy, Radiation
Michelle (Female, 37)	Cervical cancer, Stage 3	1.5 years	Surgery, Chemotherapy, Radiation
Diana (Female, 30)	Primary Central Nervous System Lymphoma*	2.5 years	Surgery, Chemotherapy, Stem Cell Transplant
Emma (Female, 28)	Thyroid Cancer, Stage 1	11 years	Surgery
J.C. (Female, 34)	Cutaneous T-Cell Lymphoma*	4.5 years	Chemotherapy, Stem cell transplant
Rico (Male, 23)	Acute Lymphocytic Leukemia	3.5 years	Chemotherapy, Radiation, Stem cell transplant

**Survivor has experienced recurrent or persistent cancer diagnosis*

Table 1: Study participants

least one course of treatment in other domestic geographical locations. The mean age of survivors was 32 years, and most participants were between 1 and 5 years out from their initial diagnosis as of the day of the interview. Some survivors had experienced recurring or persistent cancer (n=4) and one survivor was living in the maintenance phase for Stage 4 breast cancer. Participants are quoted in the results using their chosen pseudonyms.

Study procedures and analysis

The first author conducted one in-person interview with each participant, generally in the participant's home, using a semi-structured interview schedule. Interviews lasted between 75 minutes and 2.5 hours, and each participant was compensated for their participation. The interview scope entailed asking participants about information seeking, use, and sharing behaviors, both in clinical settings and at home. The interview schedule particularly focused on social aspects of information behavior, both online and offline. Questions posed during the interview included:

- When you needed more information about what to expect, where did you seek that information?
- What were your greatest needs in the clinic? At home?
- Who were the most helpful people during your experience?
- Who were the most influential people during your experience?
- What roles have other cancer patients and survivors played in your experience?

Interviews were transcribed and approximately 200 pages of the resulting transcripts were loaded into a cloud-based qualitative coding software package (dedoose.com). The first author cycled between field notes kept during data collection and the transcripts, in an approach meant to build on themes in real time. The first author applied open coding to converge on a final codebook after several iterations [14] focused on themes relevant to the participants' challenges.

To support the validity of data collection, analysis, and findings related to observed themes, the first author (1) incorporated peer checking (e.g., reviewing transcript excerpts with collaborators in the space of cancer survivor information behavior) and (2) adjusted interview follow up questions to examine the resonance of emerging themes in each subsequent interview [6].

RESULTS

Through our analysis, we identified survivors' experiences related to three specific challenges young adult survivors face: (1) feeling isolated; (2) confronting a sense of mortality; and (3) struggling with changing body image and identity. We present each of these challenges in turn, first describing participants' experiences related to the specific challenge, and then outlining their adaptive behaviors to respond to each of the challenges. Survivors' responses to these challenges involved collaborating with family, friends, or newly-discovered "survivor-peers." The discussion that follows articulates implications for collaborative spaces that survivors use to cope with cancer, as well as characterizes skills survivors require to overcome challenges articulated in the results.

Feeling isolated leads to reconnecting and finding peers

Initially, participants found that their offline worlds contracted after diagnosis. Due to the burdens of treatment, such as fatigue or hospitalization, they simply could not interact in the real world with friends and family as they once had.

The challenge: feeling isolated

Participants described dual feelings of isolation after a cancer diagnosis. At first, they were often *physically isolated*, due to treatment effects (e.g., while neutropenic during chemotherapy, or while hospitalized). Even if there were no health restrictions, survivors often did not have the strength or energy to socialize. Social and family interaction circles offline shrank to those close, trusted friends and family members who made an effort to support the survivor.

The second type of isolation was *experiential*; participants simply did not have anyone in their social circles who could relate to their feelings and needs. Bob shared his epiphany while sitting in the chemo chair, late into his treatment protocol, one day:

> *I started to think about suffering…my cancer's not even one of the "bad ones," like I have a pretty good chance of getting through this. The 90-year-old guy next door is – I'm like, "What is he – I was a pretty healthy individual going into this, what is he feeling as he goes through it?" I'm a lot more empathetic than I was before.* (Bob)

As a result of this shifting context over a period time, participants described a process of learning when social or family interactions would be helpful, as well as how to find and interact with survivor-peers. Mark was grateful for his in-person survivor support group, because he was able to connect with other brain cancer patients, some of whom were young adults. He stated, *"nobody else in my friend group"* can provide the type of support other survivors give.

The adaptive behavior: reconnecting, or finding new peers

Moving interactions with friends and family online (reconnecting) was usually a welcome change to alleviate *physical isolation*. Participants used their existing technology (e.g., smartphones) and skills to keep in touch and supplement missing offline interactions. For example, Peter used texting to keep in touch with close friends and family while undergoing treatment in a faraway city. Texting was particularly helpful because he was being treated with radiation to the head and neck, and lost the ability to speak for a period of time. In another example, J.C. received her stem cell transplant over the Christmas holiday, and used FaceTime to watch her two young children open their presents on Christmas morning. These interactions provided valuable emotional sustenance for survivors.

The physical isolation, however, proved to be only the most immediate component to feeling lonely. Even when participants were not physically isolated from familiar people, interactions with those people started to shift. Kate recalled:

> *A former colleague of mine sat down with me a week after I was diagnosed, so I hadn't started treatment. [He] started naming off all the people he knew who died of cancer. And I know it came from a good place – he was just trying to cope – but it was very weird and uncomfortable for me.* (Kate)

Participants found that, in addition to any physical isolation, they would have to struggle to connect with people who would better understand the experiences and feelings that went along with having cancer as a young adult. This behavior was a response to the *experiential isolation* that survivors described: their existing circle of friends and family, as time went on, were unable to relate to their cancer experience. To cope with this experiential isolation, survivors often turned to online spaces they had not yet explored, such as cancer survivor discussion forums or Facebook groups.

One major purpose for use of online spaces involved finding ways to pass long, boring stretches of time from physical isolation. Particularly in the hospital, or when confined to the home, online spaces provided a valuable addition to distractions in the real world. Kate described being in the hospital for chemotherapy treatments and using her "*connection to the outside world online*" to blog and share her experiences. Similarly, Diana used the periodic Leukemia and Lymphoma Society chats to talk with other people online while in the hospital receiving treatment, though she stated that since her diagnosis was so rare, there was limited new information available from the chats.

One positive aspect of interaction with other survivors—even those who were older—was to provide inspiration for coming through the experience, if the peer was a long-term survivor with a similar diagnosis. *"There are people living a long time with [brain cancer],"* Mark pointed out, stating that knowing this helped him stay positive. Kate thought it important to connect with people who had similar diagnoses right away, especially on bad days: *"To see people [with my diagnosis] that seemed very good and whole and happy and healthy was amazing."* In seeking this kind of connection, social media sites were often appropriated to learn collaboratively or connect about cancer diagnoses. Diana started a new, private Facebook group to find others who had been diagnosed with the rare cancer she had survived twice. Although she found the Facebook group rewarding, she stated it was difficult to see members pass away over time.

In addition to Facebook, YouTube proved a surprisingly intimate resource for one of the cervical cancer survivors, Michelle. The source of such vlogs as a vital online information source has been noted in prior research [20, 30].

> *There's a woman who had cervical cancer who lives in the UK who was doing video diaries on YouTube. I think she did like 55 of them over the course of two years. Most were during and after her treatment, and some update ones. She's a real no-nonsense kind of gal. She really laid it all out there. That was the most helpful thing I have found.* (Michelle)

Occasionally, participants described meeting peers online and attempting to migrate the relationship offline (e.g., [37]), to deepen the relationship and talk about more emotional issues. Lucy met someone with her diagnosis through mutual friends on Facebook, and would hang out offline when they were both well enough to do so. Similarly, Diana met in real life with a member of the Facebook group she founded, so they could talk in depth.

Offline spaces were particularly advantageous for certain types of collaborative work in coping with experiential isolation. Offline spaces were seen as a good venue to work out emotional issues, such as anger or fear. Mark's wife insisted he find an in-person support group to *"take out my frustrations somewhere else than with us."*

Finally, helpful peers did not have to share the same diagnosis, or even particularly similar medical experiences, however. For example, Emily initially felt terrified about getting a port-a-cath placed with minor surgery, but a coworker who had experienced head and neck cancer helped her through the fear in anticipating the surgery. Similarly, Leah's most helpful peer had survived a different type of cancer as a young adult, but was instrumental in helping with tangible needs.

> *Well my friend who went – she had Hodgkin's. So she was there [in the hospital] almost every day. She was good with the paperwork, because she had gone through that stuff…[She] was in there helping my mom or me when the doctors were in the room, you know. Whatever jargon they were saying.* (Leah)

The next challenge survivors faced—which we found could be one component of experiential isolation, particularly among former social peers—was that of confronting feelings of mortality.

Confronting mortality leads to controlling their stories

Telling stories can be an essential act in making sense of and coping with the illness experience [5]. We found that participants dealt with confronting mortality and feeling of uncertainty by working hard to control both the "outputs" and "inputs" of their stories. On the output side, participants also tended to tightly control how their cancer stories unfolded in public, particularly online. On the input side, participants were cautious about how to incorporate information they found or encountered into their internal narrative (e.g., avoiding unhelpful prognosis statistics). We discuss both aspects of control in this section

The challenge: confronting a sense of mortality

Many participants stated they had never been sick in their lives. Most were active, healthy young adults: Rico had been a football player; Marie was a ballet dancer; Leah enjoyed playing tennis and traveling to see family abroad. Kate described the unique experience of cancer as a disease and its attendant struggle with mortality:

You know, cancer is not a virus that comes from the outside or anything. It's your body self-destructing in this weird way. It was not something that was done to me, it's something my body did to itself, which is very scary…It was like my body tried to kill me, and it was a very weird emotional experience. (Kate)

Survivors dealt with these emotions even as most tried to carrying on working or socializing. As a result of their cancer diagnosis, each participant described a process of facing a new kind of uncertainty and vulnerability. These feelings, in turn, forced participants to figure how—and with whom—they would share their cancer stories, and to make decisions about what information to heed in formulating a narrative for themselves.

The adaptive behavior: controlling their own stories

We observed a substantial range in behavior regarding sharing information with friends and family online. However, the theme running through participant experiences is that of desiring control of their stories. In most cases, a participant's "audience" online—such as Facebook friends—included close friends and family, as well as distant acquaintances or co-workers. For this mixed set of people, each participant had to decide a method for depicting their cancer experience. We found that behaviors ranged from a single post about the participant's diagnosis to regular blog posts for Facebook friends.

Many participants shielded their cancer experience from a wider view to "online" audiences on social media, a finding supported by previous research on Facebook information sharing [32, 34]. Leah described that her "Facebook friends" largely did not know about her cancer diagnosis or treatment "*Obviously, my family and close friends know, but most of my Facebook friends, they would have no idea.*" (Leah)

Some participants specifically segregated the rest of life from the cancer experience. For example, Helen set up a private page to update close family and friends on her health. However, she also posted regularly to her broader Facebook friends to keep up appearances of normalcy. *"As far as everybody else is concerned, I'm just going to the coast and we're taking [our son] to the aquarium and just – life is life like it regularly was."* (Helen)

Peter opted to make an announcement on Facebook, but refrained from posting about cancer in general:

You know, I didn't really broadcast to the world about every little update. I mean, I kind of made a blanket update on Facebook about being in treatment once. Um, so the people who I really cared about knowing, I updated directly and called them or texted them. (Peter)

Other participants were very open with their experiences. J.C. posted regular blog updates to her Facebook about treatment progress. J.C. stated that she wanted acquaintances to be properly informed, even though she was confined to her home and could not share news in person.

Part of controlling one's story, too, involved deciding which spaces felt like healthy places to visit or participate. Overall, participants had mixed experiences with online cancer information spaces. Often, participants would encounter information that could actually increase stress or cause them to question information from their health care providers. (To this point, Marie observed that she was initially treated for cancer in the 1990's, before access to online health information was available; she said she was thankful the Internet did not exist then, because it would have increased her anxiety as a teenager.)

In response to distress caused by online information, Emily adjusted her behavior over time. She resolved to prioritize the relationship with her oncologist rather than look for online information: "*I tried to very much not seek out sources of information that would make me mistrust my doctor.*"

Sometimes, participants acted to limit their interactions with cancer peers after negative experiences. For example, Michelle described visiting an online forum for cervical cancer survivors shortly after her diagnosis. As she browsed the posts, she felt that many of the posts asked the same questions repeatedly and that many of the users (who were also recently diagnosed) sounded panicked and worried in their posts. Michelle felt that exposing herself to other people who were also *"freaking out"* about their diagnosis was detrimental to her emotional state. This experience discouraged her from using forums in the long term.

For her part, Jo expressed frustration with a Facebook thyroid cancer support group that she found early in her experience. She objected to the negative tone of the group:

After the initial treatment, which I had found a Facebook group of thyroid cancer patients, but I had to leave it because I just felt like everybody is being so negative…And if somebody would say, "Let's bring some positive!" people would start jumping on them. I think there are times people need to let out things. But I think there needs to be also a balance. They were just always constantly negative. (Jo)

Another fault with online spaces was the lack of tailored information available. Leah described the information she found about metastatic breast cancer to be "worst-case scenario" information, which did not present the same accuracy as the advice she received from her doctor.

I know there's a lot of information out on the web, so it's like, "Is this true?" Because you're always going to find *articles where it says one thing and another one says something else. So yeah. I kind of just stayed away.* (Leah)

One of the themes running concurrent to telling stories is the challenge of presenting a new self-image or identity as a young adult cancer survivor, which we describe in the next section.

Self-image struggles lead to strategizing presentation

The behavior described by participants not only conveyed their strategies in shaping cancer stories, but also incorporated aspects of how they appeared in their own stories, and the information they chose to share—in particular, how images were used, and what role they inhabited in their long-term self-image and identity (e.g., visible survivor or not, mentor, or advocate).

The challenge: self-image and identity are transformed

Cancer often causes changes to physical appearance that can cause distress for young adult survivors, who are still working on establishing a stable self-image. Even after the physical changes faded, or the survivor accepted them, a new identity as a cancer survivor could prove challenging. For example, Emily worried about her appearance on her wedding day, going so far as to wonder if she should call the wedding off if she had a recurrence and became bald again. Marie, whose leg was amputated as part of cancer treatment when she was in her teens, described how she witnessed her parents wrestle with her long-term prospects as a result of the amputation:

My dad was old school, they were older parents. To him, it was the end of my life as a woman. He didn't think I'd ever be able to get married or be normal. I'd be weird, with one leg. He took that harder. (Marie)

Some participants described living with disabilities, while others reflected on temporary changes in appearance, such as baldness, that affected the way they felt about physical beauty permanently. In the very long term—deciding how to be a cancer survivor in the world, and what that identity means—most participants were careful *not* to make a permanent decision about whether they would act as a visible survivor, mentor to other survivors, or a public cancer advocate. To this point, Emma described struggling with what she called the "*identity piece*" of being a cancer survivor

I think I often contextualize it in my cancer experience, and think about holding both celebration and appreciation and loss simultaneously, and going through transitions of who I think I am and hold myself to be – the standards I hold myself to and who I'm noticing that I'm becoming. (Emma)

Adaptive behavior: strategizing about self-presentation

Perhaps the most obvious strategies about participants' self-presentation emerged when talking about sharing images of themselves, particularly during treatment. Participants' experiences demonstrated a range of behaviors related to image sharing. J.C. did not feel comfortable posting photographs at all. Hair loss was particularly hard on women, illustrated by Kate's experience: "*I feel like I felt a bit of a dip when I lost my hair…the way I saw myself in the mirror really affected my mental capacity.*" Leah also suffered acne outbreaks from hormonal treatments in addition to hair loss.

In contrast, Rico started an Instagram account *after* he was diagnosed to share *"everything"* about his experience. This posting turned out to have a significant benefit for him; by sharing his story, he received an encouraging private message from a college friend he admired very much.

Self-image could also be affected by short- or long-term disabilities during the cancer experience. Mark woke up from brain tumor surgery with aphasia, and struggled for three weeks to regain language skills through therapy. In response to that experience, he felt grateful to be accepted back to work, if only part-time, to feel competent and useful again. Leah learned to cope with people questioning her disability, which is invisible to the naked eye—she had to stand up for herself to strangers:

I have a handicap placard [for my car]. Some days I am tired, my back is sore, and I'll use it. If I do use it, people are like [gives side-eye]. I had a lady – it was maybe a couple of months out – and I was just running in to get lunch real quick at Whole Foods and she kind of questioned me. (Leah)

Jo had a similarly public cancer survivor profile, due to very visible scars on her neck from two thyroid surgeries. Like, Leah, Jo also learned to respond to strangers in public:

Most people don't know. And they're like, "what's the scar on your neck?" And I'm like, "I had thyroid cancer." And they say, "WHAT?" And I say, "Yeah, it's a thing." And they're like, "You're so young!" "Well, typically it's actually women under 40. I'm like the perfect demographic for thyroid cancer." (Jo)

Diana's stroke required her to use a wheelchair during treatment, and—like Bob, who had a child of a similar age—she felt guilty as a parent, being unable keep up with her son for many months. Both Diana and Bob stated they learned to take each day as it came in response to this challenge. Peter similarly learned to be patient with himself, stating *"there's a new baseline for how things work"* with his body, and healing fully could take a long time.

In the long term, participants described interactions with peer-survivors as part of rebuilding identity and finding a source of strength, particularly in being a "public" cancer survivor. Emily participated in an offline support group with other young adults with a variety of cancer experiences, which she felt "normalized" the cancer experience and its aftereffects:

You know, I've talked to a lot of cancer survivors, young adult cancer survivors, and the consensus is that your cancer is never over…Just – I mean, when people try and tell *me it should be over, it's like 'Whoa, show me your scars, and then we can talk.' You know?* (Emily)

Sometimes identifying with others, or participating actively in the survivor community, was detrimental to a participant's informational and emotional needs. For example, Lucy had contacted two survivors of her diagnosis, only to watch them pass away from treatment complications. "*My therapist told me to stop being around other cancer survivors and patients. I tend to take on other people's burdens.*"

Finally, it is important to acknowledge that although many participants described wanting to stay active in the survivor community, the feeling was not universal. Helen looked forward to her five-year point in remission, when should could effectively exit the survivor community:

I associate the [teal cervical cancer] ribbon with the fight. You're in it, you're a survivor, and I will be a survivor here, but I don't – like, women get teal tattoos, and stuff like that…I'm too young to let this define my life. And so I might see myself let go of some of that...This is my fight and this is when it's over. I'm a little more – I'm free, I'm not just a cervical cancer survivor. My life is free. If that makes sense. (Helen)

DISCUSSION

We found many opportunities to learn from participants' experiences, particularly in eliciting evidence of informational and emotional needs that prompted participants to adapt their behavior. In accordance, we synthesize design implications for (1) online spaces young adult cancer survivors use to collaborate with their survivor-peers and (2) resources about privacy and self-presentation for young adult survivors.

Online spaces survivors use to collaborate

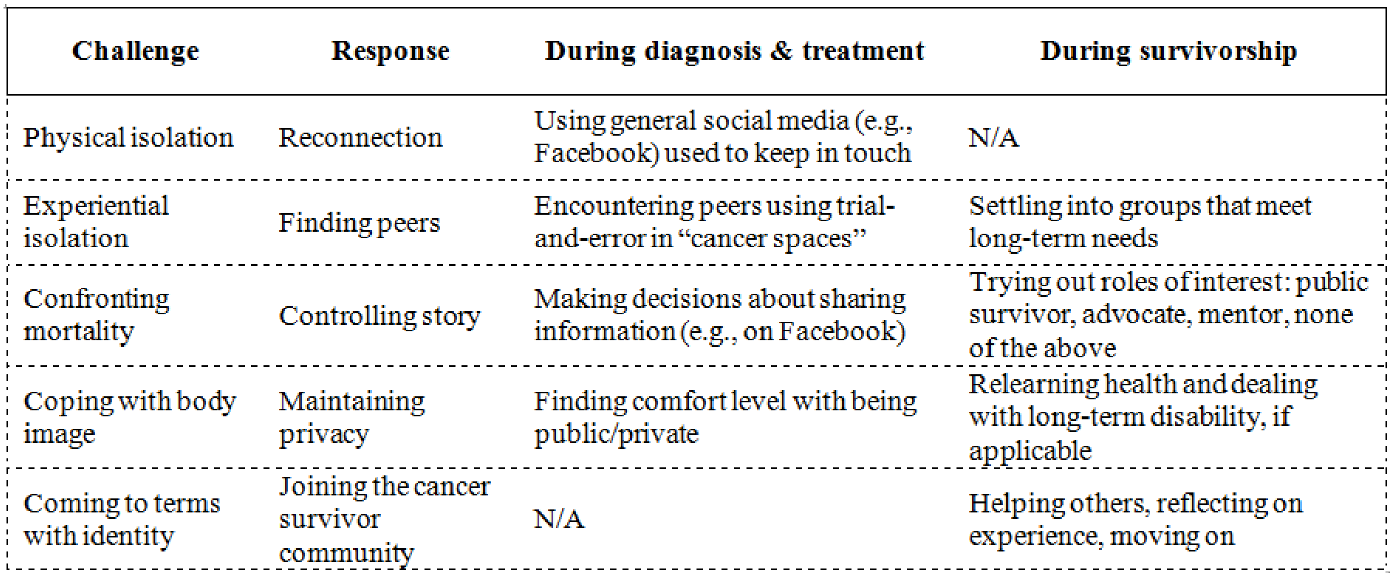
Online discussion forums are ideal for finding peer expertise versus clinical expertise [7, 16, 43]. Participants described using online spaces in the following ways:

- To distract themselves, particularly during long, boring hospital stays (Kate, Diana);
- To read other survivors' stories (Michelle, Peter); or
- To share information about the cancer experience (J.C., Rico).

Participants often longed for interaction and collaboration online, but identifying peers who would be most helpful and engaged could be difficult. Peter and Leah both found that online forums contained information about much older people, and Leah was particularly disappointed in an mobile phone app she downloaded for breast cancer patients:

I actually had an app – let me find it here [picks up phone to look]. It was for breast cancer. Oh, here. My Breast Cancer Team – myBCteam.com or something. But I felt like it was the older crowd…I get a lot of the older generation kind of like, "Oh, hang in there – I've gone through this twice," or "I've been doing this for ten years." I think at the time when I started, I didn't want to hear that crap. Like OK, cool. I haven't really gone back. I still have the app on my phone, and I still get alerts that someone wants to join your team…but I don't really [respond]. (Leah)

As illustrated by Leah's experience, for online spaces to be effective venues for this type of peer collaboration, support is needed for identifying *helpful* peers and facilitating interaction [17]. From the gaps in experience observed between needs, we suggest peer matching functions of online spaces should adapt to changing informational and emotional needs over the duration of the cancer experience, from diagnosis and treatment, to survivorship. We found a need for better peer matching functions in online spaces to more effectively support survivor information needs as they change over time (see Table 2), which we describe in more detail below.



Challenge	Response	During diagnosis & treatment	During survivorship
Physical isolation	Reconnection	Using general social media (e.g., Facebook) used to keep in touch	N/A
Experiential isolation	Finding peers	Encountering peers using trial-and-error in "cancer spaces"	Settling into groups that meet long-term needs
Confronting mortality	Controlling story	Making decisions about sharing information (e.g., on Facebook)	Trying out roles of interest: public survivor, advocate, mentor, none of the above
Coping with body image	Maintaining privacy	Finding comfort level with being public/private	Relearning health and dealing with long-term disability, if applicable
Coming to terms with identity	Joining the cancer survivor community	N/A	Helping others, reflecting on experience, moving on

Table 2: Tasks related to challenges and responses in different phases of young adult cancer during diagnosis and treatment and during survivorship

Diagnosis and treatment

Specifically, after diagnosis and during treatment, survivors prioritize relevant experiential information from survivors with similar diagnoses and/or receiving similar treatments. Exchanging information with peers with very similar treatment progressions benefits survivors by helping them manage expectations as treatment progresses; assisting them in normalizing physiological and psychological effects of treatment; and serving as an aspirational guide to enduring the treatment regimen [see also 10].

In this stage, when survivors are experiencing self-image issues we described, it may be especially helpful to find peers who experienced a similar treatment course to cope with such issues. In particular, survivors can find help in coping with changes in ability or disability, or even just a traumatic change in appearance (particularly hair loss). We suggest that to match peers in the diagnosis and treatment stages, useful criteria would include: cancer diagnosis and stage; treatment protocol; and age and gender information, for example [17].

Survivorship

When survivors complete treatment and move into survivorship, they must cope with a different set of stressors. These include: fear of cancer recurrence or secondary cancer occurrence; long-term disability or side effects from treatment; potential loss of fertility; and negotiating a new identity as a cancer survivor. This set of issues requires *less* support from peers with very similar experiences, and *more* support from peers who have some experience in negotiating survivorship in general, including the longer-term identity issues that emerged in our analysis.

In this transition to a new phase of the cancer experience, survivors might want to *"join the club,"* as J.C. stated—meaning, survivors will be less concerned with peer matching criteria and more concerned with finding a community of survivor-peers with similar long-term concerns in managing survivorship. For example, Diana felt a great sense of pride in the help she could offer fellow survivors: *"They'd say, '"I'm so glad I met you, I want to be like you.'"*

An online space could offer this group of survivors a place to mingle and discuss issues—such as employment or dating [1]—that are not necessarily clinic-based. To match peers in the survivorship stage, useful criteria would include: age and gender; location (if the peer-matching function allowed in-person meetups); whether or not the survivor had children, was married, or single; and years of survivorship.

The problem with diagnosis-based online spaces

Online spaces are usually segregated by cancer diagnoses, but our participants indicated that diagnosis distinction becomes less important as time elapses past treatment; thus, online spaces should offer areas that are not diagnosis-specific, but instead facilitate survivor connections based on other criteria listed above—such as age, experiential factors (e.g., in college, married or single), or by topic (e.g., employment or dating).

Previous research supports the observation that criteria survivors use to find peers is complicated, and most online forums are not optimized to support such a task [17]. We build on this prior research by focusing on young adult cancer survivor needs, as well as adding a time dimension to design implications—i.e., designing for survivor needs over the duration of the cancer experience [10], which facilitates peer matching even as needs change.

Resources about privacy and self-presentation

Young adult cancer patients often face their diagnosis of without having known someone who has had cancer, and therefore lack role models. At the same time, young adults inhabit a developmental stage when they are establishing aspects of their identity, and attempting to fulfill goals related to relationships, career, and lifestyle [41]. Without guidance on how to be a cancer survivor, and at a time when the rest of life is being disrupted, young adult survivors can struggle with what information to share, and when, particularly on social media.

We found that one way participants coped with fear of mortality, as well as effects on self-image, were to take control of their own stories. Participants were often able to clearly articulate the boundaries they set for sharing information, including photos or updates about their treatment progress. This result echoes previous research with older patients managing chronic illnesses, although those participants were less likely to use Facebook than the survivors we interviewed [34]. These boundaries were particularly important to participants who felt their cancer was stigmatized (e.g., both cervical cancer survivors refrained from sharing information publicly). Moreover, all of the participants appeared to appreciate that their cancer experience required some sort of public presence. Participants dealt with these factors in real time, finding they needed to decide when or what to tell different groups of family, friends, and acquaintances.

"Cancer stories" are not new…

The idea of the "cancer story" (or, more broadly, the "illness narrative") is not a novel one. Charmaz [5] points to narratives as part of the "work" chronically ill individuals perform to express self-as-process, and Crossley [8] suggested that illness survivors affirm themselves through storytelling after a difficult life event. In the young adult sphere, Keim-Malpass and Steeves [25] analyzed illness narratives of young women (ages 20-39) blogging about their experiences to urge the use of narrative elicitation in nursing. This practice, the authors argue, can surface clues about emotional problems or other contextual information that can improve care for patients or survivors. Similarly, Kim and Gillham [26] described themes related to emotional trauma (guilt, feelings of isolation), body image issues, fertility worries, and worries about starting, or resuming, a career on a young adult cancer site.

…but young adults must understand privacy implications

Specific to young adults—who may lack role models in their illness experience, while also experiencing a major disruption in life—we see an opportunity to offer resources to young adult survivors about privacy and self-presentation. If a survivor can be coached early on (in person—by a health care provider, through on online tool, or through a pamphlet about coping with the cancer experience) about their right to share information as they see fit, this resource could help survivors make informed decisions about key privacy concerns—such as sharing diagnostic or treatment details, posting pictures, or informing professional contacts about treatment arrangements. We see these skills as useful not only in controlling the "cancer story" in the short term, but also benefitting a survivor in bolstering their ability to self-advocate in the long term.

What could privacy guidance look like?

One opportunity for facilitating young adult survivors' skills in managing privacy and self-presentation in their cancer stories is embedding such help tools in the online spaces they use to collaborate. Participants described their adept use of familiar online platforms (such as Facebook or Instagram), but spaces specific to cancer support were more alien and less easily integrated into their lives. One way to make such spaces more inviting and easier to understand—particularly if young adults are eager to own their presence online during cancer—is to help them understand what type of presence is possible in these spaces.

For example, we see opportunities to help survivors decide what type of *role* they would like to inhabit in an online cancer community at a given time. The online space could let survivors designate whether they were in treatment (needing support), or wanted to act as a mentor to another survivor, or whether they wanted to have a presence as a public advocate for young adult cancer survivors. Each of these roles, then, would afford different features on the site: public advocates may wish to use more images, while people in treatment may wish to exchange only text information.

Alternatively, a user of such a space who is willing to mentor another survivor may wish to keep most medical details private, but share such information once a peer-survivor has been matched as a mentee. Although this exact application might not be necessary for facilitating better control of story and self-presentation for online cancer sites, we do recognize from our participant feedback that young adult survivors know they need control. However, most of our participants had to experiment with new online spaces—or rely on familiar online spaces—to achieve such control. We believe collaborative online spaces for young adult survivors could support this facet of informational and emotional needs more effectively, and have offered just one solution to that effect.

LIMITATIONS

For this study, we recruited young adult survivors in the Pacific Northwest and Midwest regions of the United States. For this reason, our findings may not extend to other contexts or cultures, particularly where technology use is not widespread or accessible among survivors.

CONCLUSION

Our participants helped us explore their experiences, and informational and emotional needs, during the young adult cancer experience. We contextualized our findings using three challenges previously outlined by the NCI's working group on AYA cancer: (1) feeling isolated; (2) confronting a sense of mortality; and (3) struggling with changing body image and identity. We not only add empirical evidence to support the assertion that these challenges exist, but were also able to elicit and articulate participants' adaptive behaviors used to face such these challenges. In this way, we are better able to understand how young adult survivors fulfill their informational and emotional needs throughout the cancer experience, despite difficulties.

In analyzing challenges and adaptive behavior, we use gaps observed in survivors' experiences—where they struggled to overcome the three challenges—to inform better designs for resources survivors are apt to use, such as online spaces. Specifically, we identified design implications for (1) online spaces that facilitate survivor collaboration with survivor-peers and (2) resources that can inform survivors about privacy and self-presentation issues. Online spaces should accommodate the changing criteria for finding helpful peers for survivors, the criteria for which we found to shift among the illness phases of diagnosis, treatment, and survivorship. Additionally, support resources should inform survivors about strategies for coping with changes in self-image and identity that they must consider in interactions with friends, family, survivor-peers, and the public. By designing better resources for young adult cancer survivors to find their own answers and collaborate with peers, these survivors can build a sense of agency in managing their health, and have a better chance to meet complicated financial, emotional, and health needs that persist after cancer treatment ends.

ACKNOWLEDGMENTS

We are indebted to our study participants for sharing their stories. Authors gratefully acknowledge their grant from the National Science Foundation (# 1117187).

REFERENCES

1. Adolescent and Young Adult Oncology Progress Review Group. 2006. Closing the gap: research and care imperatives for adolescents and young adults with cancer (NIH Publication No. 06-6067).
2. Kalyani Ankem. 2006. Factors influencing information needs among cancer patients: A meta-analysis. *Library & information science research* 28, 1: 7-23.

3. Azy Barak, Meyran Boniel-Nissim, and John Suler. 2008. Fostering empowerment in online support groups. *Computers in Human Behavior* 24, 5: 1867-1883.
4. Barbara A. Bilodeau and Lesley F. Degner. 1996. Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology nursing forum* 23, 4: 691-696.
5. Kathy Charmaz, 1999. From the 'sick role' to stories of self. In *Self, Social Identity, and Physical Health: Interdisciplinary Explorations,* Richard J. Contrada and Richard D. Ashmore (Eds.). Oxford University Press, New York, USA, 209-239.
6. Elfreda Annmary Chatman. 1992. *The information world of retired women.* Greenwood Publishing Group.
7. Andrea Civan, David W. McDonald, Kenton T. Unruh, and Wanda Pratt. 2009. Locating patient expertise in everyday life. In *Proceedings of the ACM 2009 International Conference on Supporting Group Work (GROUP)*, 291-300.
8. Michelle L. Crossley. 2001. Sense of place and its import for life transitions: The case of HIV-Positive individuals. In *Turns in the road: Narrative studies of lives in transition,* Dan P. McAdams, Ruthellen Josselson, and Amia Lieblich (Eds.). American Psychological Association.
9. Hilary Davis, Frank Vetere, Shawn Ashkanasy, Gavin Dyson, Penelope Schofield, Kate Thompson, Giselle Withers, and David Thomas. 2008. Towards social connection for young people with cancer. In *Proceedings of the 20th Australasian Conference on Computer-Human Interaction: Designing for Habitus and Habitat*, 319-322.
10. Jordan Eschler, Zakariya Dehlawi, and Wanda Pratt. 2015. Self-characterized Illness Phase and Information Needs of Participants in an Online Cancer Forum. In *Proceedings of the International Conference on Web and Social Media (ICWSM).*
11. Evi Germeni and Peter J. Schulz. 2014. Information seeking and avoidance throughout the cancer patient journey: two sides of the same coin? A synthesis of qualitative studies. *Psycho‐Oncology* 23, 12: 1373-1381.
12. Preetinder Singh Gill and Billy Whisnant. 2012. A qualitative assessment of an online support community for ovarian cancer patients. *Patient related outcome measures* 3, 51.
13. Ross Gray, Margaret Fitch, Christine Davis, and Catherine Phillips. 1996. Breast cancer and prostate cancer self-help groups: Reflections on differences. *Psycho‐oncology* 5, 2: 137-142.
14. Greg Guest, Kathleen M. MacQueen, and Emily E. Namey. 2011. *Applied thematic analysis*. Sage.
15. Gery P. Guy, K. Robin Yabroff, Donatus U. Ekwueme, Ashley Wilder Smith, Emily C. Dowling, Ruth Rechis, Stephanie Nutt, and Lisa C. Richardson. 2014. Estimating the health and economic burden of cancer among those diagnosed as adolescents and young adults. *Health Affairs* 33, 6: 1024-1031.
16. Andrea Hartzler and Wanda Pratt. 2011. Managing the personal side of health: how patient expertise differs from the expertise of clinicians. *Journal of medical Internet research* 13, 3.
17. Andrea L. Hartzler, Megan N. Taylor, Albert Park, Troy Griffiths, Uba Backonja, David W. McDonald, Sam Wahbeh, Cory Brown, and Wanda Pratt. 2016. Leveraging cues from person-generated health data for peer matching in online communities. *Journal of the American Medical Informatics Association*.
18. Gillian R. Hayes, Gregory D. Abowd, John S. Davis, Marion L. Blount, Maria Ebling, and Elizabeth D. Mynatt. 2008. Opportunities for pervasive computing in chronic cancer care. In *Proceedings of Pervasive Computing,* 262-279.
19. Høybye, M. T., Johansen, C., & Tjørnhøj‐Thomsen, T. (2005). Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho‐Oncology* 14, 3: 211-220.
20. Jina Huh, Leslie S. Liu, Tina Neogi, Kori Inkpen, and Wanda Pratt. 2014. Health vlogs as social support for chronic illness management. *ACM Transactions on Computer-Human Interaction (TOCHI)* 21, 4.
21. Jina Huh, Rupa Patel, and Wanda Pratt. 2012. Tackling dilemmas in supporting "the whole person" in online patient communities. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI),* 923-926.
22. Maia L. Jacobs, James Clawson, and Elizabeth D. Mynatt. 2014. My journey compass: a preliminary investigation of a mobile tool for cancer patients. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI),* 663-672.
23. Valerie Jenkins, Lesley Fallowfield, and Jacky Saul. 2001. Information needs of patients with cancer: results from a large study in UK cancer centres. *British journal of cancer,* 84, 1.
24. Theresa HM Keegan, Daphne Y. Lichtensztajn, Ikuko Kato, Erin E. Kent, Xiao-Cheng Wu, Michelle M. West, Ann S. Hamilton et al. 2012. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *Journal of Cancer Survivorship* 6, 3: 239-250.
25. Jessica Keim-Malpass, and Richard H. Steeves. Talking with death at a diner: young women's online narratives of cancer. 2012. In *Oncology Nursing Forum-Oncology Nursing Society* 39, 4: 373.

26. Bora Kim and David Michael Gillham. 2013. The experience of young adult cancer patients described through online narratives. *Cancer nursing* 36, 5: 377-384.
27. Sylvie D. Lambert, Carmen G. Loiselle, and Mary Ellen Macdonald. 2009. An in-depth exploration of information-seeking behavior among individuals with cancer: part 1: understanding differential patterns of active information seeking. *Cancer Nursing* 32, 1: 11-23.
28. Sylvie D. Lambert, Carmen G. Loiselle, and Mary Ellen Macdonald. 2009. An in-depth exploration of information-seeking behavior among individuals with cancer: Part 2: Understanding patterns of information disinterest and avoidance. *Cancer nursing* 32, 1: 26-36.
29. Geraldine M. Leydon, Mary Boulton, Clare Moynihan, Alison Jones, Jean Mossman, Markella Boudioni, and Klim McPherson. 2000. Cancer patients' information needs and information seeking behaviour: in depth interview study. *Bmj* 320, 7239: 909-913.
30. Leslie S. Liu, Jina Huh, Tina Neogi, Kori Inkpen, and Wanda Pratt. 2013. Health vlogger-viewer interaction in chronic illness management. In *Proceedings of the SIGCHI conference on Human factors in computing systems (CHI)*, 49-58.
31. Andrea Meier, Elizabeth J. Lyons, Gilles Frydman, Michael Forlenza, and Barbara K. Rimer. 2007. How cancer survivors provide support on cancer-related Internet mailing lists. *J Med Internet Res.* 9, 2: e12.
32. Mark W. Newman, Debra Lauterbach, Sean A. Munson, Paul Resnick, and Margaret E. Morris. 2011. It's not that I don't have problems, I'm just not putting them on Facebook: challenges and opportunities in using online social networks for health. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work (CSCW),* 341-350.
33. Shani Orgad. 2005. The transformative potential of online communication: The case of breast cancer patients' Internet spaces. *Feminist Media Studies* 5, 2: 141-161.
34. Carolyn E. Pang, Carman Neustaedter, Bernhard E. Riecke, Erick Oduor, and Serena Hillman. 2013. Technology preferences and routines for sharing health information during the treatment of a chronic illness. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, 1759-1768.
35. Helen M. Parsons, Susanne Schmidt, Linda C. Harlan, Erin E. Kent, Charles F. Lynch, Ashley W. Smith, and Theresa HM Keegan. 2014. Young and uninsured: insurance patterns of recently diagnosed adolescent and young adult cancer survivors in the AYA HOPE study. *Cancer* 120, 15: 2352-2360.
36. Ellen L. Rubenstein, 2015. ‘They are always there for me’: The convergence of social support and information in an online breast cancer community. *Journal of the Association for Information Science and Technology* 66, 7: 1418-1430.
37. H. Alan Scott. 2016. How Instagram Helps Young People Cope with Cancer. *Vice.* Retrieved May 22, 2016 from https://www.vice.com/read/how-instagram-helps-young-people-cope-with-cancer
38. Rebecca Siegel, Carol DeSantis, Katherine Virgo, Kevin Stein, Angela Mariotto, Tenbroeck Smith, Dexter Cooper et al. 2012. Cancer treatment and survivorship statistics, 2012. *CA: a cancer journal for clinicians* 62, 4: 220-241.
39. Kenton T. Unruh and Wanda Pratt. 2008. Barriers to organizing information during cancer care: “I don’t know how people do it”. In *AMIA Annual Symposium Proceedings (AMIA).*
40. Helen R. Winefield. 2006. Support provision and emotional work in an Internet support group for cancer patients. *Patient Education and Counseling* 62, 2: 193-197.
41. Brad Zebrack and Sinéad Isaacson. 2012. Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology* 30, 11: 1221-1226.
42. Brad Zebrack, Erin E. Kent, Theresa HM Keegan, Ikuko Kato, Ashley Wilder Smith, and Aya Hope Study Collaborative Group 1. 2014. “Cancer sucks,” and other ponderings by adolescent and young adult cancer survivors. *Journal of psychosocial oncology* 32, 1: 1-15.
43. Sue Ziebland. 2004. The importance of being expert: the quest for cancer information on the Internet. *Social Science & Medicine* 59, 9: 1783-1793.