

Designing for the Dynamic Needs of Young Adult Cancer Survivors

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Abstract

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Young adult cancer survivors—individuals diagnosed with cancer between the ages of 18 and 39—face health and quality of life challenges long after treatment ends. Issues survivors face include forming and maintaining relationships, coping with unemployment or lack of health insurance, and struggling with lasting cancer recurrence risk or diminished fertility. Young adult survivors must cope with all of these problems while navigating health information for cancer survivors that is often written for a much older audience, and therefore lacks relevance. This growing population of health care consumers (72,000 individuals diagnosed each year, plus an estimated 600,000 young adult cancer survivors in the U.S. as of 2012) requires a more systematic approach for meeting their needs. To enhance and expand understanding of the

informational and emotional needs of young adult cancer survivors, I used a combination of qualitative research methods to elicit self-characterized experiences and needs of these survivors.

Working with young adult survivors, I found that their informational and emotional needs change over time, and these changes affect survivor tasks such as finding information outside the clinic, sharing stories about treatment and survivorship, and connecting with suitable cancer peers. Young adult cancer is also a uniquely social experience versus pediatric or adult cancer; survivors face a number of social risks, such as losing friends, coping with changing family dynamics, and connecting with their oncology care teams at a vulnerable time. In addition, I reflect on the combination of qualitative methods I used with participants, and point to my future work, which employs similarly creative strategies to enhance participant engagement in research. Finally, as a result of this work, I argue that better information systems and services design can lead to three powerful benefits for the young adult cancer survivor population: (1) increased survivor engagement in managing treatment and survivorship issues; (2) more effective communication between survivors and their oncology care teams; and (3) improved health outcomes through informed decision making about treatment and survivorship issues.

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DEDICATION

For Mom and Dad and Dave

Chapter 1. The Unique Challenges of Young Adult Cancer

Young adult cancer survivors—individuals diagnosed with cancer between the ages of 18 and 39—face health and quality of life challenges long after treatment ends. Issues survivors face include forming and maintaining relationships, coping with unemployment or lack of health insurance, and struggling with lasting cancer recurrence risk or diminished fertility. Young adult survivors must cope with all of these problems while navigating health information for cancer survivors that is often written for a much older audience, and therefore lacks relevance. This growing population of health care consumers (an estimated 600,000 young adult cancer survivors in the U.S. as of 2012; Siegel et al., 2012) requires a more systematic approach for meeting their information needs.

To enhance and expand understanding of the informational and emotional needs of young adult cancer survivors, I used a combination of qualitative research methods to elicit self-characterized experiences and information needs of these survivors. Findings from this research inform information systems and services design to increase the relevance and timeliness of information for young adult cancer survivors. This work can lead to three powerful benefits for the young adult cancer survivor population: (1) increased survivor engagement in managing treatment and survivorship issues; (2) improved communication between survivors and oncology care teams; and (3) improved health outcomes through informed decision making about treatment and survivorship issues.

1.1 Research Aims

Young adult cancer survivors currently make the best of information resources directed at a much older audience, which inadequately address their ongoing health and quality of life concerns. The purpose of these research aims is to describe young adult cancer survivor informational needs, as well as to incorporate the design dimension of illness phase, which can inform health information systems and interactions with clinicians that ensure young adult cancer survivors have access to the most salient

information. I used qualitative methods to make design recommendations for systems and services that increase the relevance and timeliness of information available to young adult survivors. I also examine the social experience of young adult cancer and related impacts on quality of life, interactions with oncology care teams, and outcomes. The outcomes of this work yield design recommendations for information systems and services that can increase survivor engagement in managing health, facilitate greater survivor empowerment in decision making with health care professionals, and improve long-term health outcomes.

1.1.1 Aim 1: Describe how informational and emotional needs, and related technology use, change during different illness phases during young adult cancer. I examine the relationship between young adult cancer survivors' informational and emotional needs and self-characterized phases of their illness. Qualitative inquiry captured survivors' changing information needs over time, and elicited details about meeting such needs using peer-to-peer communication technology. This analysis leads to description of a new design dimension for information systems and services: namely, survivor's current illness phase. By using this design dimension, information systems can facilitate providing the most relevant and timely information for managing health and quality of life. The research questions guiding this inquiry are as follows:

***RQ1.** How do young adult cancer survivors characterize informational and emotional needs at various phases of illness?*

***RQ2.** What role do young adult survivors' "cancer peers" play in helping to meet these informational and emotional needs?*

1.1.2 Aim 2: Examine the social world of young adult cancer survivors, and the role of oncology care teams in this context. Existing research largely explores the clinical, home, and online environments of cancer survivors separately; to address this gap, I describe the social worlds of young adult survivors in a holistic manner. Specifically, I articulate the experience of young adult cancer in

terms of the survivor's social experiences, such as with family members, friends, cancer peers, and clinical care team members. I then use this frame to suggest services and strategies for oncologists to tailor their care approach to the unique needs of young adult cancer. The research questions guiding this inquiry are as follows:

***RQ1.** How do young adult cancer survivors describe their experiences in terms of social relationships?*

***RQ2.** What role do oncology care team members fill in the social experiences of young adult cancer?*

1.1.3 Aim 3: Create and assess a new approach to incorporate both narrative and visual

perspectives of young adults with cancer. I employed two methods in data collection: (1) a semi-structured interview and (2) a visual elicitation (sketching) exercise. This combination of methods is not currently used widely with adult participants, but presents an opportunity to expand the methods available to researchers working with vulnerable populations. Here, I make a methodological contribution by creating a roadmap for using this approach with other vulnerable populations of interest in the health and patient-centered design spaces.

***RQ1.** How can researchers use visual expression to triangulate narrative data from interviews with participants?*

***RQ2.** What are the advantages and disadvantages of using a combination of narrative and visual data to elicit the needs of young adults (participants in their 20's and 30's)?*

1.2 Overview of Dissertation

Chapter 2, ***Current Understanding of Young Adult Cancer Survivor Needs***, gives an overview of previous work in the space of the cancer experience and related informational and emotional needs. Most of this work has occurred with diagnostic groups (e.g., breast cancer survivors) or focuses on older adult survivors. This section motivates (1) my focus on young adult cancer and its unique needs versus older

survivors, and (2) describes a gap in understanding illness phase-based needs among cancer survivors in general.

Chapter 3, *Using Interviews and Visual Elicitation to Learn about Information Needs*, describes the research design of this thesis study, outlining the interview protocol and the incorporation of the visual elicitation element of the interview. This section also includes considerations in formulating the research design with regard to ethics and access I have as a member-researcher in this group of vulnerable participants.

Chapter 4, *Phase-Based Informational and Emotional Needs of Young Adult Cancer Survivors*, describes the results of thematic analysis related to phase-based needs as articulated by the participants in this study. This chapter is framed specifically in related to psychosocial needs, as the particular social difficulties of young adult cancer emerged during the fieldwork. This chapter also explains the design implications of these results, which can improve dynamic survivor support in health information systems and resources (i.e., design that can respond to changing needs over multiple illness phases). The contributions of this chapter address Aim 1 of this thesis: Describe how informational and emotional needs, and related technology use, change during different illness phases during young adult cancer.

Chapter 5, *The Social World and Oncology Care Relationships of Young Adult Cancer Survivors*, examines how the social worlds of young adults shift as a result of a cancer diagnosis. The analysis included in this chapter includes insights not only from the interview, but also from the visual elicitation data. The themes identified in the analysis yield a holistic view of the social experiences of young adult cancer survivors, as well as the social risk they face during treatment and survivorship. This chapter fulfills Aim 2 of this thesis: Examine the social world of young adult cancer survivors, and the role of oncology care teams in this context.

Chapter 6, *Visual Elicitation in Qualitative Research with Young Adults*, presents a reflection on the use of visual elicitation as a component of the qualitative methods for this thesis study. This chapter (1) reviews an overview of the study procedure, (2) highlights the benefits of using data triangulation with interview and visual data for the purpose of thematic analysis, and (3) explains the process of determining appropriate application of visual elicitation with members of a vulnerable population, such as young adult cancer survivors. This chapter addresses Aim 3 of this thesis: Create and assess a new approach to incorporate both narrative and visual perspectives of young adults with cancer.

Chapter 7, *Summary and Conclusions*, summarizes the work and contributions of this thesis, and points to the opportunities for future research in the context of young adult cancer survivor informational and emotional needs.

“It did not occur to me while I was acutely ill or for some time afterward that the simple concepts of sickness and cure were insufficient to describe what was happening to me...Living on, as I have been fortunate to do, I have reflected on my experience and talked to many cancer patients about their experiences. Although the binary notion of cure versus noncure is understandably appealing to everyone concerned with cancer, most agree that it is not an accurate characterization of the experience. The vagaries, phases, and syndromes of survival are far more complex than that simple idea suggests.”

Fitzhugh Mullan, MD (1985)
Young adult cancer survivor and advocate

Chapter 2. Young Adult Cancer Survivor Needs

Approximately 70,000 adolescents and young adults (people between the ages of 15 and 39) are diagnosed with cancer each year in the United States (National Cancer Institute, 2014). Despite gains in survivorship for pediatric and older adult patients (Bleyer, 2007), survivorship rates of adolescents and young adult cancer patients have not improved in 30 years, and the prevalence of cancer in this group is increasing (Bleyer & Albritton, 2006). Adolescents and young adults diagnosed with cancer not only face health challenges through treatment, but also experience lasting struggles, both socially and economically (Adolescent and Young Adult Oncology Press Group, 2006; Guy et al., 2014; Parsons et al., 2014).

According to the National Cancer Institute (NCI; 2014), adolescent and young adult survivors¹ face many challenges, such as preserving fertility, protecting future livelihood, managing romantic and interpersonal relationships, retaining health care coverage, and staying vigilant for signs of recurrence. Adolescent and young adult survivors face these challenges using strategies of independent information seeking and self-advocacy from diagnosis to survivorship. However, these survivors often face barriers to finding age-appropriate information on survivorship challenges, such as infertility and secondary cancer risks (Zebrack et al., 2014). To achieve better long-term health outcomes, it is essential that adolescent

¹ Here, and throughout this document, “survivor” is used according to the National Cancer Institute definition: “Anyone who has been diagnosed with cancer, and is any phase of treatment, remission, or maintenance.” Although use of this term faces increasing scrutiny in the young adult cancer community, I have chosen to use the term for ease of communication, and for lack of a more appropriate suggestion emerging from the data presented herein. NCI dictionary link: <http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=450125>

and young adult survivors are able to find relevant and timely information, ensuring continued engagement and empowerment in managing and monitoring health.

In this thesis, I study the informational and emotional needs of a subset of adolescent and young adult survivors. Specifically, I focus on the cancer experiences of young adult survivors, or individuals diagnosed between the ages of 18 and 39 (rather than as young as 15). This subset of the adolescent and young adult population excludes adolescents, which is a separate developmental phase from that of young adults (American Psychological Association, 2002). Unlike adolescents, young adults are seeking independence from family (e.g., moving out of the family home), building their own families, and forming a new extended “family” among work colleagues, and friends (Zebrack 2011; 2014). This independence affects starts to permeate the individual’s life, such as in financial and social aspects. The intersection of a sudden cancer diagnosis, and the developmental stage of young adulthood, creates unique needs among individuals diagnosed between the ages of 18 and 39. In the following sections, I give an overview of the understanding of cancer informational and emotional needs, both in general (i.e., generally among older survivors), as well as previous work specifically among adolescent and young adult and young adult survivors.

2.1 Current Understanding of Cancer Survivor Information Needs

Van der Molen (1999) set out a relatively early call for studying information needs among cancer patients as a key method for supporting the coping needs of survivors. Van der Molen suggested that information seeking and use constituted a complicated set of behaviors involving emotions as well as intellect and agency. Understanding this complicated work requires research methods that can capture the nuance of seeking, using, and sharing information during diagnosis, treatment, and survivorship. Searching about cancer appears to loom large in online health information seeking in general. De Choudhury et al., (2014) found that cancer and related topics—including prevention—were searched

more than any other health-related subject, based on search engine use from a general population sample (this finding in the general population is also supported by Hesse et al., 2008).

The following overview of the literature addresses research framings in the existing research regarding cancer survivors' information needs. This body of research often focuses on more traditional, older cancer survivors, but I specify the cases where research focuses on young adult survivors. First, I present three traditional framings of cancer survivors' information behavior I find useful for understanding the current research in this context:

- The active and passive patient roles;
- The connections between informational and emotional work; and
- Online versus offline information behavior.

Then, I describe how the concept of illness narratives, which affected my research design decisions. Finally, I give an overview of the initial model I have devised to use illness phase, both as a lens for understanding survivors' information needs and behavior, as well as a potential design dimension for information systems and services intended to assist young adult survivors.

2.1.1 Active and Passive Patient Roles (Framing 1)

The first framing of cancer survivor information behavior involves that of an *active* or *passive* patient or survivor role. In the 1990's, the discipline of medical sociology abandoned the concept of the "sick role" (Burnham, 2014). In this outdated notion, a patient withdrew from the distraction of the world and focused her energy on getting well, "submitting" to the orders of the health care provider to "re-enter" society as a productive member as quickly as possible. Instead, as Burnham explains, we have moved into a model where the patient has agency and an active role in managing their illness. Accordingly, the discipline of medical sociology (and the theoretical frames intended to influence patient outcomes, such as the Health Belief Model; Becker, 1974) moved to models of "applied health behavior." There

continues to be a spectrum, however, of “passive” to “active” patient roles in information behavior research in medical contexts, including cancer survivorship.

For example, Lambert et al. (2009a, 2009b) present their model of “ranges” to incorporate the variety of information behaviors observed in their data collection during interviews and focus groups with cancer survivors. In an **active role**, patients independently seek, or interact with, information. Lambert et al. (2009a) describe the types of information seeking as a range of behaviors, from intense seeking (digging up information to present to clinicians) to complementary seeking (adding to information provided by clinicians) to fortuitous seeking—e.g., a patient encounters a resource shared by a friend or family member without actively seeking it.

In a **passive role**, however, a patient ignores or avoids information and relies upon the health care provider (usually a doctor) to make decisions based on all of the information available, which the patient prefers not to know. Lambert et al. (2009b) describe two types of passivity as *information avoidance* and *guarding against information*, such as rejecting an active seeking role that might lead to finding or encountering emotionally upsetting information. Leydon et al. (2000) also studied information avoidance and passivity among cancer patients. Leydon and co-authors found that patients avoided information in three circumstances: (1) when they preferred to rely on faith in their doctors; (2) when they felt more information would diminish hope and positivity; or (3) when they felt they were taking up valuable time with the doctor that sicker people needed more urgently.

Within this framing, researchers have also found patient characteristics or situations can affect the passive or active role inhabited by the patient. Bilodeau and Denger (1996) and Jenkins et al. (2001) identified differences in the desire to be an active patient among different age groups; in general, older cancer patients (especially elderly patients) fulfilled the passive role more often than middle-aged or younger patients. Unruh and Pratt (2008) identified barriers to using and organizing information that would assist patients to be more active in their care; these barriers included emotional, scalable, temporal, and functional barriers to a more active role in managing health information.

Civan et al. (2009) found that breast cancer patients employed gatekeepers in managing the flow of information, with gatekeepers acting as conduits (people who directed information to the patient), contact brokers (individuals who could introduce patients to other helpful people outside their circle), and champions (people who bridged a number of knowledge types and offered comprehensive support to patients). Communication with professional care teams, in particular, has also been found to depend on a survivor's assumptions about a clinician's interest in their problems and ability to help (Jacobs et al., 2015). All of these research findings point to nuanced, context-dependent survivor engagement with information.

Previous research has also begun to identify some temporal elements to the active/passive information seeking role. Ehemann et al. (2009) characterized patients as seeking information more actively before treatment than after treatment. This finding is supported by Butow et al. (1997), who found that changes in prognosis or condition—such as moving from treatment phase into survivor phase—could shift the patient from an active to a passive role. This previous research points to an opportunity for understanding information behavior using an illness phase-based lens, rather than grouping patients simply into “active” or “passive” roles. This opportunity aligns with the first research aim, which is to **describe how informational and emotional needs, and related technology use, change during different illness phases during young adult cancer.**

2.1.2 Connections between Informational Needs and Emotional Work (Framing 2)

The second framing in literature on the information needs of cancer survivors is that of the connection between *emotional* and *informational* work (although previous work in information science has posited various models of the relationship between cognitive and affective elements of information behavior—e.g. Fidel, 2012; Nahl & Bilal, 2007; Kuhlthau, 1991—here, I build on work in the cancer information needs space that does not separate the cognitive and affective elements). In ethnographic work with breast cancer survivors (ages 40-70) in an online forum, Rubenstein (2015) found that

informational and social (or emotional) support functions are so closely linked as to be indistinguishable, and therefore suggested social support could be considered a *subtype* of information work among cancer survivors. Other studies of online spaces for breast cancer patients (Orgad, 2005; Winefield, 2006) 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. (2007) found evidence of “active modeling” of supporting emotional needs in their study of threads on ten different cancer listservs, emphasizing the importance of more senior members in maintaining a culture of support in the online community. The notion of “empowerment” is also a manifestation of possible effects of information behavior, particularly in sharing peer knowledge. Høybye et al. (2005) enumerated the ways patients in an online breast cancer support group shared information and assessed how the interactions affected the online participants, and found that the women were “empowered” in sharing “knowledge and experience” with fellow patients (this notion is also supported in a meta-review by Barak et al., 2008).

In a study of in-person support groups, Gray et al. (1996) 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 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. The link between emotional and informational work regarding information behavior around cancer has been largely presented alongside gender-based analysis (as with the support groups work) or concentrated in overwhelmingly female support communities (as with breast cancer groups).

In working with young adult survivors for this study, I do not make a distinction between “male behavior” and “female behavior” in considering the link between emotional and informational work. Instead, by exploring the changing needs over young adult cancer survivors over time, I can situate linked emotional and informational work in the context of illness phase. This gap in current research aligns with

the first research aim in this proposal: **describe how informational and emotional needs, and related technology use, change during different illness phases during young adult cancer.**

2.1.3 Online versus Offline Information Engagement (Framing 3)

A third framing in previous work is that of online information seeking as a source of information supplemental, or tangential to, the “core” (offline) experience of cancer diagnosis, treatment, and survivorship. Particularly in early scholarship focused on online health behaviors, this framing makes sense, as access to the Internet expanded the information landscape of the “connected” patient (Ziebland, 2004). In an early study of online cancer information seeking, Helft et al. (2005) found that only 10% of oncology patients surveyed at a urban county hospital used the Internet to access information about cancer, and in that study, patients indicated that the most significant barrier was lack of access to the Internet at home. Tian and Robinson (2008) found that younger patients were more likely to seek cancer information on their own. The authors also found older patients who desired to find such information might need assistance from clinicians, though they were less inclined to want such information in the first place.

In recent research, online information environments tend to be studied in isolation from other contexts, such as the clinic, or offline services or support systems. Gill and Whisnat (2012) used iterative qualitative coding to assess the types of information shared in an online ovarian cancer support group. The authors described exchange of “technical and emotional knowledge” and noted that the forum structure particularly supported information seeker/information provider dyad matching. Huh et al. (2012) 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 for exchanging relevant data with clinicians and managing their treatment and side effects. Finally, Massimi et al. (2014) situate online community participation among

patients in terms of their motivations for finding, engaging in, and leaving online support groups in the context of real-world health experiences.

Both Huh et al. and Massimi et al. demonstrate how far research has come in first viewing the patient as an active or passive actor, to situating online work in real world health experiences. Supporting this progression, Germení and Schulz (2014) presented a “meta-ethnography,” studying 18 qualitative research papers and finding that information seeking and avoidance both online *and* offline is influenced by a complex set of circumstances, such as care context, illness characteristics, and patient characteristics. In a broader view, it may not be appropriate to segregate the use of technology in general from the rest of life experience when describing cancer survivor information behavior. 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. (2014b) 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).

The arc of research appears to be moving away from viewing online engagement among cancer survivors as a supplementary activity, to viewing online engagement as part of the *holistic* patient and/or survivor experience. In this view, online information can be examined to determine whether it complements or challenges clinical information provided to the survivor, and more accurately reflects the experiences of survivors in negotiating the influences of various modes of information seeking and use. The approach of this study breaks down the siloes of online and offline information, and incorporates the social world of young adult cancer. The second aim gives an overview of the interaction of many types of informational and social influences in young adult cancer by doing the following: **examine the social world of young adult cancer survivors, and the role of oncology care teams in this context.**

2.1.4 The Concept of the Illness Narrative

To better understand survivors' information needs in terms of illness phase and their social interactions throughout the cancer experience, my research design borrowed from the concept of the "illness narrative." Kleinman (1988) describes the illness narrative as a natural unit of meaning for the chronically ill (here, I extend this description to cancer survivors):

The chronically ill become interpreters of good and bad omens. They are archivists researching a disorganized file of past experiences. They are diarists recording the minute ingredients of current difficulties and triumphs. They are cartographers mapping old and new territories... There is in this persistent reexamination the opportunity for considerable self-knowledge. (p.48)

Charmaz (1999) points to narratives as part of the "work" chronically ill individuals perform to express self-as-process. To this point, Crossley (2001) suggests that "certain environments" (such as online forums) are chosen by survivors to affirm themselves through storytelling after a difficult life event. Corbin and Strauss (1988) also situate the center of illness experience in the home of the individual patient, rather than in medical facilities (as opposed to the oppositional medical-home experiences set up by the original sick role model; e.g., Suchman, 1965). This home-based view is important for recognizing the patient work that takes place outside of the clinic.

Further supporting the narrative as a useful unit of analysis, information sharing in online spaces among survivors is often rooted in stories about experience. Knowledge is therefore routinely presented as part of, or associated with, a narrative (Hartzler and Pratt, 2011). The use of narrative also appears to facilitate the construction of small communities online, as Huh et al. (2014) demonstrated in their content analysis of both online health vloggers and comments to vlog pages. Civan and Pratt (2007) found that the emotional weight of narratives was used to provide action strategies and recommended knowledge to patients from peers in online support groups. Narratives also seemed to incorporate the patient identity in patterns of information sharing: social media users described carefully balancing sharing their health information on with a desire to control their self-presentation (Newman et al., 2011), and cancer patient bloggers shared their stories "to be remembered" as individuals (Chiu and Hsieh, 2012).

Although the studies described above underline the importance of narrative and the cancer experience, none focused on information needs of young adults with cancer or young adult survivors specifically. The handful of qualitative studies that focused on young adults almost exclusively studied *information sharing* versus other types of information behavior, such as seeking or use. For example, Davis et al. (2008) piloted social media software for cancer patients between the ages of 18 and 25, giving pilot participants the ability to build out a (private, protected) virtual profile. The participants then invited friends and family to view the private page, and the researchers interviewed participants about their user experience. Relevant to illness phase-type work, Davis et al. identified patterns in social media use related to the cancer experience: when patients were in active treatment, there was a lull in updates to their profiles. Conversely, when patients were awaiting test results or dealing with other uncertainty, they tended to reach out for more reassurance and interaction on the social network.

These observed up-and-down patterns of use and sharing are likely a helpful component in understanding information needs in different illness phases. In another study, Hilton et al. (2009) examined the particular task of sharing cancer diagnosis news as narrated by young (between 18 and 34 years old) cancer survivors. Men were more likely to link gendered identity of being “strong” or “stoic” with the task of notifying loved ones of their diagnosis; thus, they were less likely to share information about their illness. One young man in the sample went so far as to hide his leukemia and ensuing treatment regimen successfully from his mother for a series of weeks. However, both men and women indicated some level of comfort with outward signs of cancer survivorship (e.g., scars) and were generally comfortable sharing information with inquisitive strangers.

Finally, two studies used content analysis of illness narratives shared by young adult cancer patients specifically, to identify themes in their writing. Keim-Malpass and Steeves (2012) 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

(2013) identified themes from content analysis of illness blogs on a young adult cancer site to shed light on non-medical issues faced by young adults with cancer. Kim and Gillham described themes related to emotional trauma (guilt, feelings of isolation), body image issues, fertility worries, and worries about starting, or resuming, a career. This research using narrative data gives rich context to the cycle of seeking, using, and sharing information and highlights the opportunity to elicit narratives in my semi-structured interviews. The third aim of this dissertation explores a combination of elicitation methods that combine two types of data collection, which are meant to complement one another: **create and assess a new approach to incorporate both narrative and visual perspectives of young adults with cancer.**

2.1.5 An Initial Model of Phase-Based Information Needs

Illness phase has been used in past studies primarily as criteria for selecting study population samples and recruiting participants for research around cancer information needs. For example, Bilodeau and Denger (1996) surveyed newly diagnosed breast cancer patients to describe the desire for involvement in treatment decisions. Similarly, Leydon et al. (2000) assessed information avoidance among cancer patients recently diagnosed (within 6 months) of qualitative interviews. Mendick et al. (2013) interviewed and observed patients who visited their surgeons' offices to discuss biopsy results, focusing on a very specific diagnostic procedure and portion of the cancer diagnosis/treatment timeline. Two studies (Civan et al., 2009 and Unruh and Pratt, 2008) focused on patients in the midst of their treatment experience, ranging from chemotherapy to radiation to surgery.

Although not specifically focused on illness phase, previous research has pointed to opportunities of customization of information resources based on patient information. For example, Jones et al. (1999) found that customizing information based on a cancer patient's medical record (e.g., based on illness staging or diagnosis) led to higher satisfaction with the information provided, and increased retention with follow-up activities in their research study. In addition, younger adults recruited to this study—relatively early in the use of patient-facing, computer-based health information systems—were more likely to opt in

to the study for the opportunity to use a computer-based system. Das et al. (2011) identified other considerations with regard to phase and information needs, including physical side effects of cancer treatment, such as nausea and fatigue.

A growing body of previous research has explicitly identified the need to frame cancer survivor information needs in new ways. Ankem's (2006) quantitative meta-analysis of cancer-related information needs underline the need for an illness phase-based analysis, showing the level of information need during the cancer experience is steady over time (and therefore, a pervasive feeling of uncertainty requires that information needs need attention at *all* illness phases). In addition, Ankem found that younger patients have more intensive information needs, and that information resources should "cater to their needs;" this finding also points to the importance of focusing on young adult survivors.

Supporting Ankem's findings, Lauver et al. (2007) found in longitudinal interviews with survivors of breast and gynecological cancers that although specific *stressors* changed over time, information seeking remained the number one strategy for coping with these stressors. This finding points to the importance of timely and relevant information as needs change. Van Mossel et al. (2012) called for the prospect of studying illness phase as a design dimension for cancer survivor information resources, noting in a meta-analysis of studies about information needs of colorectal cancer patients that most information needs research with this population focused on treatment and survivorship phases. Here, the authors specifically mentioned the dearth of research around illness phase-based information needs and called for more work around such a framing of information needs (as well as more consideration for directly including patients in such research).

Research in other illness contexts have demonstrated promise in designing for illness phase-based information needs; for example, Chen (2012) found that fibromyalgia patients' information seeking behavior changed with regard to topic between the phases of symptom onset, diagnosis, and present day (i.e., a point in time subsequent to diagnosis). Fibromyalgia patients shifted from searching for

information about the *why* and *what* of fibromyalgia, to researching comorbid symptoms and conditions (e.g., irritable bowel syndrome, depression), to symptom management in the long term.

Cancer survivors' information needs have not been studied in detail with regard to illness phase, with one notable exception. Ziebland et al. (2004) used transcripts of interviews with survivors who are or have experienced a number of cancers to examine the use of online information. Although online information behavior was a relatively new area for research with cancer survivors in 2004, Ziebland and coauthors linked different types of online information use with distinct illness phases (or "stages," in the paper's parlance). Patients were found to use the Internet to gather information about symptoms in the period prior to diagnosis, to "check on" information from the doctor after diagnosis, to form expectations upon assignment of the treatment plan, and to engage in periods of short- and long-term follow-up after treatment.

Subsequent research has examined factors other than illness phase in relation to survivor information behavior, such as demographics (age, gender, income) or situational factors (primary care provider assigned, diagnosis). Two out of three cancer survivors actively seek information, with information-seeking behavior occurring more often among younger survivors, female survivors, survivors with annual household incomes over \$25,000, and survivors with a regular primary care provider (Mayer et al., 2007). Nagler et al. (2010) found that cancer information seeking might vary based on cancer type (diagnosis). Specifically, early-stage colorectal cancer survivors reported in a questionnaire seeking information at lower rates than early-stage prostate or breast cancer survivors; later-stage survivors had similar rates of information seeking across the three diagnoses, however. Nagler and coauthors hypothesized that the differences among early-stage survivors may have to do with the level of uncertainty around treatment options, or availability of information for each type of diagnosis.

In this study, I describe the range (i.e., both online and offline) of information sought, used, and shared by young adult cancer survivors as they recollected illness experiences. This work is informed by

Corbin and Strauss's (1988) model of chronic illness management, which describes illness phases as part of a "trajectory":

*In sum, the term **trajectory** captures aspects of the temporal phases of the illness, the work, the interplay of workers, and the nonmedical features of management along with relevant medical ones. It captures aspects of the experiences of everyone involved in the [illness] management drama, experiences that are anxious, puzzling, painful, as well as those on the brighter side. (p.50, emphasis in original)*

In response to the opportunity for examining information behavior in terms of illness phase, I conducted a preliminary qualitative study using data from a general cancer forum (Reddit's r/cancer board; Eschler et al., 2015) to examine different needs expressed in text posts to the forum. I used a sample of the top posts from the forum over the years (based on net upvotes from users, used as a proxy to determine relevance and/or helpfulness of the resulting discussion). From the post contents, I assigned discrete illness phases based on user-characterized illness status. Phases articulated in this preliminary study included:

Pre-diagnosis/suspicion: Forum user suspects cancer or is undergoing tests to rule out/determine cancer.

Diagnosed: User has been given a determination of cancer, which may or may not be staged, but has not determined a course of treatment yet.

Pre-treatment: User has received definitive diagnosis, has a treatment plan in place, but has not yet begun treatment.

In treatment: User is actively undergoing treatment.

Completing treatment: User is about to complete treatment or has recently completed treatment; may be awaiting further testing to determine the effectiveness of treatment.

Survivor: User has completed a course of treatment and considers cancer to be inactive.

Recurrence: User has experienced a recurrence of the original cancer or a secondary cancer.

Terminal: User is focusing on quality of life and making arrangements for end of life.

The above is not the only model that integrates information needs in the cancer experience trajectory, however. The Hayes et al. (2008) model described a five-phase "cancer journey" model consisting of: "screening and diagnosis, initial information-seeking, acute care and treatment, no evidence of disease, and chronic disease and disease management." In the Hayes model, initial information seeking represents *its own phase* in the experimental trajectory of cancer. Jacobs et al. (2014a) build on the Hayes et al. model by describing the interactions between nurse and social work cancer navigators who advise

rural breast cancer patients: the fourth and fifth stages (NED and chronic management) are described as having “as needed” touch points with these professionals.

Importantly, the “survivorship” phase (post-treatment, post-NED status), is often depicted in current research as a time of poorly-defined information problems and uncertainty. Hesse et al. (2008) reflected that *“a diagnosis of cancer signifies a lifetime of ‘making sense’ in an information environment that appears fragmented, uneven, and even disparate in quality to survivors,”* but also that the information environment could be ostensibly re-engineered to act responsively to cancer survivors’ vigilance and self-management in the transition from active treatment to survivorship care. Given the vague information needs identified in the post-treatment period, it is perhaps unsurprising that Geng and Myneni (2015) found in their descriptive assessment and review of seven mobile applications designed specifically for cancer survivorship management (assessed according to the Patient Engagement Framework) that most of the apps failed to provide features that incorporated effective user engagement.

2.2 Summary: An Opportunity for Studying Young Adult Cancer Survivor Needs

It is in response to the dearth of research around illness phase and information behavior related specifically to young adult cancer that I set out the aims of this study. The implications of the aims detailed above are: (1) to identify the gaps in existing information systems and services for young adult cancer survivors, and (2) to make practical design recommendations that will improve the relevancy and timeliness of information offered by such systems and services intended to help those survivors.

I collected rich qualitative data from the experiences of individuals whose informational and emotional needs changed over time, identifying related technology use and suggesting improvements for the design of technology that can support young adult survivors (Aim 1). This work helped me to understand the social world of young adult cancer, related social risks, and young adult survivors’ preferences and needs in working with their oncologists (Aim 2). Finally, I reflected on the combination of methods used to elicit the data (Aim 3). The contributions related to these aims (particularly 1 & 2) can

be used to enhance the relevancy and timeliness of cancer information provided to young adult survivors, as well as formulate care interventions to ensure their psychosocial needs are being met. By improving information and support, it is possible to improve health outcomes for these young adult survivors.

Chapter 3. Interview & Visual Elicitation Methods

3.1 Introduction

The methods I propose in this study privilege the experiential narratives of young adult cancer survivors, exploring positive and negative events in seeking and using information to navigate the cancer experience. The research goal is to identify opportunities to design better information systems and services for young adult cancer survivors; thus, I sought themes from survivors' experiences that point to such opportunities. Improved information systems and services will enhance survivors' ability to find relevant and timely information during all phases of cancer, and potentially improve long-term health outcomes for these survivors. In this section, I start by describing how a grounded theory process guided the research design. Then, I describe the participant sample, the interview protocol, and the analysis approach in working with both the interview transcript and visual artifact data.

3.2 Methods

Because I am interested in improving the design of information systems and services for the use of young adult cancer survivors, and very little work has been done in this research problem area, my research design is based on a grounded-theory-as-process approach. Pickard (2013) argues that grounded theory refers to a plan for collecting and analyzing data rather than a comprehensive research method. Insofar as Pickard means that the approach to producing knowledge from the research planned is guided by emergent themes, I agree.

Here, I distinguish between the *process* of grounded theory (which guided the iterative nature of this study) and the production of theory to articulate a model from observations and data. Two types of theory can be generated by grounded theory work (Glaser and Strauss, 1967): *substantive* and *formal*. *Substantive theory* concerns an empirical area of research in a particular domain regarding a set of phenomena. *Formal theory* is that which describes concepts of social interaction, such as stigma or status.

This study is not intended to produce either type of theory. This is both a consequence of its design (e.g., a one-time interview that cannot inform theory related to changes over time), as well as my decision to incorporate the visual elicitation method as a research aim in and of itself. In effect, I was more interested in applying a qualitative method to the exploration of illness experience elicitation, and reflecting on its utility in answering research questions, than I was in designing a research study to produce rigorous, formal models of young adult cancer information needs or social experiences.

Using Pickard's approach, then, I emphasize the iterative nature of the process of grounded theory. Pickard writes that it is the researcher's job to ensure that the "*grounded theory fits the purpose of the research and the nature of the research question*" (p.180). Because my aims for this proposal are to frame information needs of young adult cancer survivors in new ways, asking "what" and "how" questions, grounded theory offers a useful process for discovering young adult cancer survivors' changing needs.

I applied an iterative process of data collection, analysis, and further recruitment of participants into the study. With this approach, I witnessed emerging themes from my collection of pilot data (n=13, as of my thesis proposal completion; total n=21 at the time data collection ceased), and I directed further data collection to both explore and test these emerging themes (Seidman, 2013; p. 94). Examples of themes that emerged during this iterative process, and guided further recruitment efforts and follow-up questions in subsequent interviews, are as follows:

Stigma associated with a particular cancer diagnosis (e.g., cervical cancer) affects information sharing and/or feelings of responsibility for advocacy after treatment. As difficult as it is to recruit participants with stigmatized cancers, I continued to pursue (with mixed success) further participants who felt their cancers were stigmatized. It is for this reason that I have 21, and not 20, participants in this study. Very late in data collection, as I was exiting the field, my final participant approached me to participate in an interview, despite her hesitance to speak about her lung cancer experience after facing a great deal of social stigma.

Aspects of identity, such as sexuality, or physical appearance can affect how participants perceive they are treated by health care professionals. As a result of this observation with a single participant early on, and noting the pattern that most of my participants were very satisfied with their care, I made a concerted effort to recruit individuals who may have had less positive medical care experiences. I altered the language used to recruit and communicate with prospective participants, asking them to consider participating if they believe they were *not* served well by the health care system. This language resulted in greater ethnic, racial, and socioeconomic diversity among my later study participants.

The cancer experience can fundamentally alter a survivor's perspective on other aspects of identity, such as career aspirations or goals for having a family. Participants spoke about changing careers, seeking employment that will accommodate ongoing disability, or coping with unplanned pregnancy as a result of their experiences. After noticing this pattern, I made a point of asking about survivors' changes in perspective—adjusting follow-up questions in the process of facilitating the interview—as a result of the cancer experience. Pursuing this theme led to rich data around struggles with long-term cancer identity, and I report on this theme in more detail in Chapter 4.

As evidenced by these examples, the grounded-theory-as-process approach proved effective in identifying emerging theories for further examination, as well as making adjustments to research strategies, such as recruitment.

Table 3.1 Study participants in completed sample (n=21)

Participant alias, Gender, and Age	Period between diagnosis & interview	Diagnosis**
Peter; Male, 31	9 months	Adenocarcinoma (head and neck)
Mark; Male, 32	1.5 years	Brain tumor
Monica; Female, 26	1 year	Breast cancer
Leah; Female, 32	1.5 years	Breast cancer
Michelle; Female, 37	1.5 years	Cervical cancer
Helen; Female, 31	6 months	Cervical cancer
Stephen; Male, 33*	10 months	Hematological cancer
Kathy; Female, 44*	10 years	Hematological cancer
Diana; Female, 30	2.5 years	Hematological cancer
Phoebe; Female, 36	3 months	Hematological cancer
Veronica; Female, 28	3.5 years	Hematological cancer
Rico; Male, 23	3.5 years	Hematological cancer
Emily; Female, 35	4 years	Hematological cancer
J.C.; Female, 34	4.5 years	Hematological cancer
Lucy; Female, 33	4.5 years	Hematological cancer
Kate; Female, 29	4.5 years	Hematological cancer
Bob; Male, 35	9 months	Hematological cancer
Dolly; Female, 33*	3 years	Lung cancer
Marie; Female, 42	30 years	Osteosarcoma
Emma; Female, 28	11 years	Thyroid cancer
Jo; Female, 28	2 years	Thyroid cancer

**Participant did not complete visual elicitation exercise*

***Several participants had rare types of hematological cancers; the exact diagnoses are withheld here to preserve participant anonymity*

3.2.1 Participants

Recruitment took place in two geographical regions of the United States: the Pacific Northwest (Washington and Oregon) and the Midwest (Illinois and Michigan); the geographical location of individual participants is not disclosed here to preserve participant confidentiality. I recruited 21 participants into this study, with the simple criteria that the potential participant was (1) over the age of 18 on the day of the interview, (2) spoke English, and (3) had been diagnosed with cancer between the ages of 18 and 39. A subset of 18 participants completed the visual elicitation exercise (the three participants not completing the visual elicitation are noted with asterisks in Table A). All participants identified as a binary gender (16 female, 5 male). The average age of all participants was 32.4 and most had been diagnosed with a type of hematological cancer, although solid tumor cancer diagnoses are also represented in the sample. Participants also experienced a range of treatments, including chemotherapy (infusion and oral), radiation, surgery, and stem cell transplant.

Recruitment took place largely online, using several support groups for young adult cancer survivors to post information and the opt-in recruitment link. I also answered questions in the comments sections of these forums in case the audience wanted to know how the data would be used or to explain the requirements of the study—the requirement to meet in person proved a difficult barrier to overcome, as many interested potential participants lived too far away to participate. Participants also occasionally recruited additional interested potential participants—usually “cancer peers”—and therefore participants ended up resulting from a combination convenience and snowball sampling.

Recruitment ceased when I reached 21 participants (Table 3.1), when I ascertained that I had achieved theoretical saturation (Glaser and Strass, 1967; p. 61) – that is, when I saw no new themes from collecting further data to enhance my findings given the scope of the research questions. The three chapters that follow this one include results from different “cuts” of the participant sample; to clarify how the sample and data sets are used in each chapter, please see Table 3.2.

Table 3.2 Study participant data included in the following chapters reporting on results

Chapter	Participants included	Data sets included
Chapter 4: Phase-Based Informational and Emotional Needs of Young Adult Cancer Survivors	15 of 21 participants: Reported on findings from the preliminary sample; recruitment not complete at time of publication	Interview transcripts only; visual artifacts excluded
Chapter 5: The Social World and Oncology Care Relationships of Young Adult Cancer Survivors	21 participants: 2 participants with thyroid cancer are largely excluded from findings because neither worked with an oncology care team	Interview transcripts and visual artifacts
Chapter 6: Visual Elicitation in Qualitative Research with Young Adults	21 participants: 3 participants did not complete the visual elicitation, but their data are included as examples of methods failure/adjustment in the field	Interview transcripts and visual artifacts

3.2.2 Semi-Structured Interview Procedure

All of the study procedures described in this section were reviewed and approved by the University of Washington Institutional Review Board. The interview questions applied a retrospective memory technique (e.g., Dunne et al., 2002) to (1) collect an oral history of the patient or survivor illness experience and (2) facilitate the creation of a visual artifact the participant was invited to construct, refer to, and build upon throughout the interview. Each participant met in person with me for a one-on-one interview that lasted between 60 to 90 minutes. I audio recorded each interview, including the portion of the interview during which I asked participants to “think aloud” while constructing the visual artifact. Interview audio was transcribed and anonymized; I also digitally scanned the visual artifacts created (when applicable, as three participants did not complete the visual elicitation portion of the interview, which is addressed more completely in Chapter 6). Participants were compensated \$50 for their participation, and were also given the opportunity to direct a \$25 donation to a non-profit of their choice.

I chose to use the visual elicitation exercise for two reasons. First, I sought to use a method that would build rapport and give participants a way to express themselves outside of the question-and-answer

of traditional interviews. Second, I wanted to try a method that was not commonly used with young adults in vulnerable populations. When I looked to qualitative methods literature, I found Guillemin's (2004) advocacy for the use of drawing and other creative activities as methods to build meanings between researcher and participant. Guillemin specifically urged using drawing and sketching especially with adults to capture the value of this meaning-making exercise. In this vein, Snyder (2014) demonstrated that this meaning-making could expand the modes of meaning-making between two adult research participants, and facilitate interactions such as *clarifying* and *integrating* information between two adults (in the case of this study, researcher and participant). I chose to use the visual elicitation, too, after reviewing literature on ethical interactions with vulnerable populations (Liamputtong, 2006; p.113; p.149) to ensure that this elicitation approach could be executed appropriately, as well as effectively.

Participants chose the meeting spaces where the interview occurred—often, the meeting space was in participants' homes, but occasionally I met with individuals in a public place (e.g., a café). Each participant received \$50, and directed a \$25 donation to a non-profit organization of their choice, for compensation. All participants chose a pseudonym for reporting purposes, and I use these pseudonyms—no real names—in this chapter. Each interview lasted approximately 90 minutes, with the first half spent using the traditional interview protocol, and the latter half spent constructing a visual depiction of the cancer experience. The visual artifact was intended to build on the interview portion of the procedures and to elicit a more nuanced telling of the illness narrative and/or progression. There were several special considerations in designing the research that specifically pertained to the visual elicitation piece; I have explained these considerations in more detail in Chapter 6.

First, at the beginning of the interview, participants received a consent form explaining the study procedures, including the interview and visual elicitation. Part of the consent form allows participants to indicate their preferences for sharing the visual data elicited. In this portion of the consent, participants determine whether their visual creations may be shared (1) publicly (e.g., on a blog post or YouTube); (2) in academic venues only; or (3) not at all, and destroyed at the conclusion of the interview. All

participants completed this portion of the consent, even if I subsequently decided not to offer the visual elicitation piece of the interview due to the public nature of our interaction, or the survivors' circumstances (n=3). All participants completing the consent form indicated their visual artifacts could be shared publicly (n=21), but in practice this portion of the consent form applies only to the 18 who completed both the interview and the visual elicitation portion.

After the consent form was completed, I gave a brief verbal overview of how my time with the participant would be spent—specifically, that the entire interaction would be audio recorded, the first half would be a traditional interview, and the second half would involve an activity I would introduce and facilitate. All participants were invited to ask questions at the time of completing consent, as well as after I explained the procedure (but before the audio recorder was turned on). Few participants had questions at this point, but a handful did ask me personal questions about my interest in young adult cancer, or informed me that they had Googled me to make sure I was who I said I was.

Once I started the audio recorder, I walked through the interview protocol. As the participant answered questions about diagnosis and treatment, I made sure I understood the cancer experience timeline. It was also important, I found, to cover questions about influential and helpful people in the participant's experience, because I found that the visual elicitation piece did not *naturally* capture the social world of illness (it was, instead, very reflective for the individual—even so, the visualization was critical for understanding how feelings evolved during the cancer experience).

To introduce the visual elicitation piece, I presented the same-sized, blank poster board piece to each participant, along with a clear Ziploc bag full of markers, pens, and Post-It notes, as well as a 64-piece box of crayons. Once the activity was introduced, I asked participants to talk through their thinking in producing the visualization, and most interspersed drawing and writing with speaking, as I had requested. All the participants turned their attention to the blank poster board, and eye contact with me decreased during this time. In the following section, I describe the analysis of interview and visual data.

3.2.3 Data Retention and Analysis

The use of narrative and visual elicitation in combination was useful in that the approach preserved two modes of interaction from the interview (Forceville & Urios-Aparisi, 2009; p. 22), i.e., the visual artifact and the narrative answers to interview questions. As Forceville and Urios-Aparisi go on to write, however, “*The old adage that a picture tells more than a thousand words should not blind us to the fact that pictures and other multimodal representations seldom communicate automatically or self-evidently*” (p.29). I digitized each visual artifact with high-quality scans, so that I could carry out qualitative coding using software (dedoose.com) while looking at the artifact on a split screen.

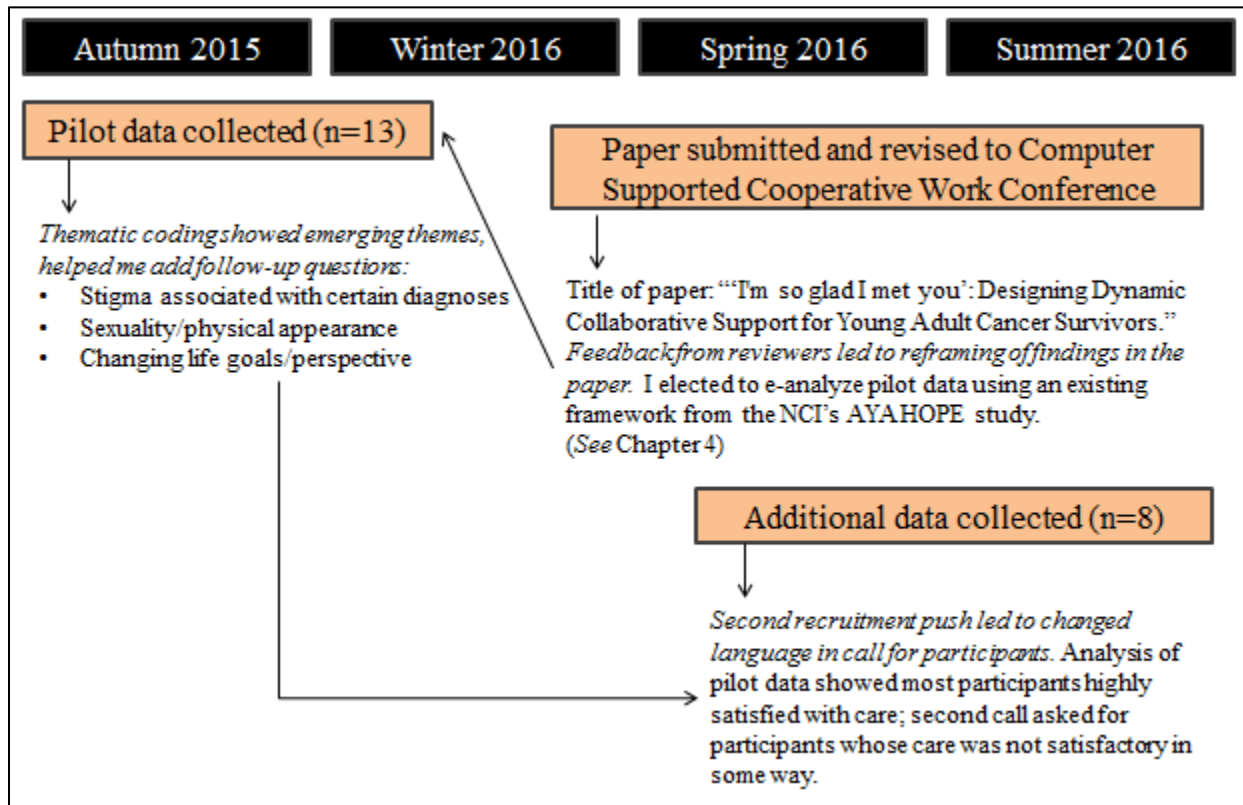


Figure 3.1 Timeline of iteration on data collection, analysis, and recruitment strategies

Preserving the think-aloud part of the interview in audio recording allowed me to keep data about the creation of the artifact. I analyzed the visual and transcript datasets in tandem, often referring back and forth between the two. Snyder (2014) used a similar approach in studying how visual representations are used as a communicative practice (e.g., discourse analytics). I was not explicitly using discourse

analytics, and instead used the combination of visual and narrative data to construct an understanding of phase-based changes in information needs. Additionally, I note that my data analysis process did *not* signify a new approach to data triangulation; rather, I applied the act of data triangulation (using two datasets in tandem) to build a comprehensive picture of lived experience in young adult cancer.

In using grounded theory as process, I utilized an iterative approach in collecting data, analyzing transcripts and photographs of the visual artifacts, and surfacing thematic codes to use for constructing meaningful theoretical interpretations (Patton, 2002, p.490). Figure 3.1 shows the timeline of iteration on data collection, thematic analysis, and adjustments to the recruitment strategy.

The data for each interview was used to understand individual experiences, and to compare among participants (1) verbal characterizations of experiences and (2) depictions of the visual artifact. Specifically, I coded interview transcripts using analysis software (dedoose.com), beginning with open coding and iterating toward axial coding as themes developed during data collection and analysis cycles. I analyzed visual artifacts using a combination of content analysis (Krippendorff, 2012), and compositional interpretation (Rose, 2007), as described in Chapter 6.

3.2.4 Validity and Reliability

The execution of qualitative research requires measures built into the research design that will ensure the reliability and validity of findings. With regard to validity, I point to Malterud's (2001) examination of qualitative research specifically in the medical context. Malterud bounds the aims, methods, and findings using a qualitative approach not from the frame of generalizability (which is the yardstick by which *clinical* research is measured), but by the scope of the inquiry. That is, given the research question and aims, how can the research design ensure that the right sample is obtained, the correct data is collected and analyzed, and that the answer applied is contextualized appropriately? Here, a quote from Malterud is particularly helpful in guiding the approach I used in this study design: "*The findings from a qualitative study are not thought of as facts that are applicable to the population at large, but rather as*

descriptions, notions, or theories applicable within a specified setting” (p.486). Although the point that Malterud makes here is not always the case with qualitative studies, this guidance is helpful given that I am studying a topic relevant to personal health and health care, a context in which qualitative research can be viewed with some skepticism. Therefore, the close tie between the descriptions of survivor experiences that surfaced and the context of the research problem drives my strategies to fulfill research validity.

Validation strategies are integrated into and constrained by the choices made in the research design. To address the subject of validity and verifying its alignment with my research designs, I use Chatman’s (1992) definition of validity: *“the degree to which the researcher is given a true picture of the phenomenon being studied”* (p.12). The elements in Chatman’s framework for research validity are as follows:

- (1) **Face validity** requires that observations “seem to make sense” in the context of observation, and can be assigned meaning given the world that the researcher is studying. Observations that are outliers or inconsistent should be noted as such if reported.
- (2) **Criterion validity** uses multiple methods of inquiry to establish the accuracy of findings; e.g., using two instruments, such as observation and interviews, to triangulate themes identified.
- (3) **Construct validity** ensures that the phenomena observed and described makes sense in terms of existing contextual frameworks. That is, in the analysis stage, making meaning from the data is enhanced by theoretical frameworks existing in the research space, rather than forced to comply with existing theory.

In this research design, face validity is supported by ensuring a comprehensive set of observations to inform content analysis and themes identified. To ensure face validity during interviews, I collected enough data to support findings, and executed the semi-structured interview script to clarify any ambiguous data elicited, if necessary. Here, I also employed pattern matching and negative case sampling,

as well as participant feedback (e.g., member checks) to verify the observations collected (Johnson, 1997). I supported criterion validity by employing data triangulation (Kirk and Miller, 1985; Johnson, 1997) by using the both visual artifact and the semi-structured interview script.

This combination of methods yields two types of elicitation with the participant and therefore strengthens criterion validity (Rich and Ginsburg, 1999; p.376). Ensuring construct validity began with the initial literature review of this study, and I surveyed the theoretical frameworks used in previous studies with cancer survivors (though often survivors older than my participants) to help make sense of data (Kirk and Miller, 1985). Finally, I used the participants' words as often as possible (i.e., low inference descriptors) and employed participant feedback, reflexivity, and peer review (Johnson, 1997).

Finally, to address research reliability, I adhered to the protocol approved by my institution's IRB (all application materials are included in Appendix A) and ensured that the same script was followed for each interview session. The protocol also covered appropriate spaces in which to meet, and gave me a template for arranging meetings and answering potential participants' questions prior to the interview, to enhance reliability.

3.3 Ethics

Considerations for ethics should be incorporated to every stage of research design, including determining proper research problems to address with empirical inquiry, identifying the population of interest and obligations to it, making recruiting decisions, formulating incentives for participating, conducting fieldwork, and communicating findings. In putting young adult survivors at the center of my inquiry, I believe it is ethical to treat my participants as lay experts in their own health and experience (Turner, 1987). Kirk and Miller (1985) advocate for reducing the use of "jargon," and Pratt and Kim (2012) advocate "designing for drift," meaning that researching online groups should not only take on their language, but also follow the lead of participants as "experts."

This strategy fits well with the process of grounded theory, which informed this thesis research design; as I continued fieldwork, I learned to pay careful attention to survivors' self-described current status (e.g., in treatment, in maintenance, cured from cancer, in remission), as using the wrong terminology could well be upsetting for the participant in some cases. For example, asking a participant with a terminal diagnosis about possibility of "remission" might be distressing for the participant. My tactic in adopting the participant's language in each interview involved carefully recording the terms to use, following the participant's lead or asking for clarification before forming a follow-up question.

In terms of conducting fieldwork with vulnerable participants, Chatman (1992) speaks of two ethical concerns: dirty hands and guilty knowledge. **Dirty hands** describes the decision to refrain from interfering in an observed situation to (possibly) effect positive change. **Guilty knowledge** involves learning something private about a participant's circumstances that he or she asks remains confidential, even though sharing the knowledge may (again, possibly) improve the participant's situation. In either of these states of potential ethical concerns, it is again important to weigh the potential help to the participant versus the promise of confidentiality at the outset (consent) stage of research.

To address these potential problems, I drew from research by Sharkey et al. (2011). Sharkey and co-authors described lessons from their work with self-harming young people online to formulate an approach of ethics-as-process, which is a real-time, responsive strategy for incorporating ethics into every step of research:

One useful concept was that of 'ethics as process,' which views ethics as relationally dynamic and revisited frequently over the course of a study. This approach draws attention to the complexities of qualitative research approaches and sustaining relationships with participants over time...especially with vulnerable people. (p.2)

I have incorporated this approach in recruitment and execution of this dissertation study, by focusing on building trust with participants (even potential ones). Some examples of applying ethics as process during this study are as follows:

- (1) I “groomed” the Google search results for my full name to point to my scholarly work in health informatics, and updated my public Twitter biography and website to give potential participants the ability to authenticate my identity as a research and cancer survivor.
- (2) Potential participants occasionally asked to see the list of questions before agreeing to interview. I compromised with them by characterizing the scope of the interview (e.g., assuring them that there would be no questions about sexuality or fertility). In this way, I avoided giving them the exact questions, but also addressed any anxiety about potential participation. All of the participants who requested this information, and received my response, ended up completing an interview for the study.
- (3) I frequently used “check-ins” during the interview, particularly if the participant became emotional, to offer a break or to wind down the interview. Related to this, there were times a participant would tell me they would like to avoid a certain topic during the interview, and I always obliged. (For example, one participant had a particularly traumatic experience related to radiation treatment, and declined to give further details.)

Since the close of this study, I have used this approach in my subsequent work on a cancer survivor tattoo project (described in Chapter 7). That interview study was conducted via phone, rather than in person, and I adapted my approach to use more frequent “check-ins” during interviews, given that I could not see the participants’ faces.

3.3.1 The Member-Research Stance

“Knowing is always a relation between the knower and the known.”
- Dorothy Smith (1990, p.33)

Liamputtong (2006) defines vulnerable populations as populations that may be disadvantaged economically or socially by participating in research, as a result of their perceived identity or circumstances through the information they share. Using this definition, young adults with cancer may be

particularly vulnerable in that they are susceptible to social stigma (due to physical appearance, perceived disability) or economic impact (unemployment or financial burden of medical bills). Essentially, the means of the research conducted with young adult cancer patients and survivors must not be further disadvantaging to participants to achieve the ends, as set out by human subjects rules (Bruckman, 2014). However, circumstances around my position as a member-researcher in the young adult cancer community require explicit incorporation of ethical considerations into each stage of research.

Adler and Adler (1987) define “member researching” as an interest in studying a population to which a researcher wishes to belong, already belongs, or joins through the execution of research. The authors argue that all qualitative researchers are themselves the major research instrument in their role as interpretative scholars, but that member-researchers have a particular epistemological positioning as having a shared experience with research participants. Further, according to Adler and Adler (who offer the most comprehensive overview of this subject), I am a **complete member-researcher**, i.e., a “native,” meaning that I and my participants share similar “experiences, feelings, and goals”; my membership in the group also preceded my interest in the research context, meaning I am engaging in opportunistic research.

In their examination of fieldwork approaches of member-researchers, McCorkel and Myers (2003) state that complications of researcher identity are addressed in academic literature in two ways: ignored altogether in communicating research design, findings, and implications; or briefly acknowledged in same, without “*explicating how their data, analyses, and conclusions were shaped by [researcher] positionality*” (p.200). In an effort to act transparently in my dissertation research design, I am here acknowledging (1) I am a member-researcher in this work, a role I examined using autoethnography (Eschler, 2016); and (2) the member-researcher role possesses a number of demonstrated advantages and disadvantages, which I discuss briefly below.

The primary advantage to member research include sharing spaces with other members of the cancer survivor community, leading to greater or more opportune access than a non-member. Junker (1960)

urges the member-researcher to think about ethics from the very beginning of her research, for example in terms of social introductions for the member-researcher. Junker asks questions such as: *How will the researcher introduce herself, and what role is hers when giving an introduction during fieldwork? Does this change when fieldwork concludes?*

To complicate these issues for the member-researcher, Rabe (2004) argues that membership status is a fluid concept, and one that changes depending on context. Rabe's review of African sociological research studies leads her to categorize insider/outsider status in three dimensions: first, power relations ("Who should speak for whom?"); second, in terms of knowledge ("What is 'insider knowledge?"); and third, by the emic/etic split in characterizing knowledge, participant motivations, and observed phenomena. With regard to Rabe's third point, etic expression of research findings is one that imposes a cultural system of values and power, requiring "classification" and "analysis" of the emic (social) construction of expression and interrelationships within the population of interest (Pike, 1954). I would argue that the fluid roles of the member-researcher are both an advantage, in that the emic is accessible, and a disadvantage, in that the member-researcher carries an additional burden of outwardly respecting the group in analyzing and communicating findings using the academic (etic) frame.

A major disadvantage to member-research is succinctly stated by Feldman et al. (2003): "*What is or becomes taken for granted can be difficult to study*" (p.140). That is, what is familiar can be difficult to examine, and shared knowledge between the researcher and participant can exacerbate this difficulty. For example, participants in my study were aware of my survivor status, and occasionally under-explained their thoughts as a result. In one instance, one participant stated a significant point in her survivorship would be "*five years from her clear scan.*" Five years of clear scans indicate complete cancer remission from a medical standpoint, but I wanted to know why this time period was significant to the participant, and capture that on the audio recording. At that point, I prompted her to tell me why five years was significant, and she smiled and said softly, "*You know why.*"

Here, I urged this participant to help not just *me* to understand why, but to help the audience for the research understand why, effectively employing a strategy suggested by Smith (1990), who calls for the member-researcher to reinforce the *authority* of data collected:

If we begin from the world as we actually experience it, it is at least possible to see that we are indeed located and that what we know of the other is conditional upon location...We may not rewrite the other's world or impose upon it a conceptual framework that extracts from it what fits with ours. Their reality, their varieties of experience, must be an unconditional datum. It is the place from which inquiry begins. (p.25)

In my responses to these occasional pitfalls of member-researcher identity, I also used advice from Seidman (2013), who emphasizes that the researcher control aspects of interaction with participants by: demonstrating respect but not friendship; maintaining observer-like distance when possible; and refraining from engaging in “experience exchange,” which can change the dynamic of the interview and affect participant responses. In this study, both the participants and I generally agreed beforehand to chat after the interview concluded, off the record, and this strategy seemed to work well (particularly because these interviews involved a single session). Occasionally, the participant would add information that was relevant to the research questions, and I would ask to take notes on something they had said after the recorder was turned off, although I never felt compelled to ask to re-start the audio recorder.

Finally, it can be difficult to defend an inherently “insider” identity to other researchers and the academic community, where I acknowledge greater access to participants, and I must articulate the rigor of my research. In a sense, both types of “membership” determine how to communicate findings and must dictate what information is public and what is private in the estimation of group members. This “role conflict” alluded to by Junker (1960) is addressed explicitly by Adler and Adler (1987): the authors state that complete member-researchers (like me) may have a particularly difficult time detaching from their member worldview in the analysis and writing stage (p.81).

In a potent example of the encroachment of my worldview—one where I did my best to address a particularly difficult emic/etic divide—a more experienced researcher asked me about my decision not to use the term “journey” to describe the fundamental arc of the cancer experience. The researcher who

asked the question has significant authority in this context, having worked extensively with cancer survivors. I was reluctant to express acceptance of the term, on behalf of all my participants who had scowled at the language of “the cancer journey,” or the notion of “fighting cancer,” or the archetype of the “brave cancer patient” that permeate the etic view of cancer in this time and in this culture. In the end, I chose to defend my choice by pointing to the preferences of my participants, with the reasoning that if we (as researchers) ask them to share their experiences, then we should also honor their choices in self-representation, lest we misuse their knowledge and alienate them from the benefits of research.

Chapter 4. Phase-Based Needs of Young Adult Cancer Survivors

4.1 Introduction

Approximately 70,000 adolescents and young adults (AYAs; defined by the National Cancer Institute, or NCI, as individuals 16 to 39 years of age) are diagnosed with cancer each year in the United States, and 700,000 adolescent and young adult cancer survivors currently live in the U.S. (Siegel et al., 2012). These cancer survivors experience outsized financial, health, and emotional repercussions of their diagnoses versus older cancer survivors (Adolescent and Young Adult Oncology Progress Review Group, 2006). In this chapter, I 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 the needs of adolescents, due to differences in the developmental stages each group inhabits. Specifically, when I refer to **young adult survivors** in this analysis, I 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 (Parsons et al., 2014; Zebrack and Isaacson, 2012). 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 (Keegan et al., 2012).

Researchers have previously determined that younger cancer survivors are more likely to actively seek out information than older survivors, particularly in online spaces (Ankem, 2006; Germeni and

Schulz, 2014). We also know that young adult survivors use collaborative online tools—such as social media and online forums (Davis et al., 2008)—that help them connect with other survivors (Scott, 2016). 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. 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 (Zebrack and Isaacson, 2012).

In this chapter, I present a qualitative exploration of young adult survivor information needs during the cancer experience and in managing long-term quality of life issues. I frame these needs in terms of three distinct challenges faced by young adult survivors, as identified by the NCI’s Adolescent and Young Adult Oncology Progress Review Group (2006; p.10):

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

This research contributes empirical evidence of these three challenges, and presents survivors’ strategies in coping with these challenges. I present a rich description of the challenges young adult survivors face, and the resulting adaptive behaviors survivors employ to cope. Then, I 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.

4.2 Background

In addressing the literature related to this study, I first review common threads in previous research on cancer survivor informational and emotional needs. I am 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, I review the benefits to survivors in entering or using collaborative technologies or spaces to meet their informational and emotional needs.

4.2.1 Cancer Survivor Informational and Emotional Needs

If information-seeking can be viewed as a spectrum, from seeking to avoidance (Lambert et al., 2009a; Lambert et al., 2009b; Leydon et al., 2000), 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., Bilodeau and Degner, 1996; Jenkins et al., 2001).

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 (Adolescent and Young Adult Oncology Progress Review Group, 2006; Guy et al., 2014; Parsons et al., 2014). 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 (Zebrack et al., 2014).

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 survivors (ages 40-70) in an online forum, Rubenstein (2015) found informational and emotional needs to be critically linked, and therefore

suggested social support could be considered a *subtype of information work* among cancer survivors. We take the approach that informational and emotional needs are linked 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. (1996) 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 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 (Hayes et al., 2008). 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. (2014b) 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.

4.2.2 Benefits of Using 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 (Orgad, 2005; Winefield, 2006) linked the notion of a “safe space” to the emotional work observed through

observation and content analysis. Meier et al. (2007) found that participants on cancer listservs employed “active modeling” to supporting emotional needs of peers. 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. (2005) 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 survivors. The notion of “empowerment” has also previously been emphasized in a survey of qualitative literature regarding online health support groups (Barak et al., 2008).

The types of information shared and offered online can be diverse, as well. Gill and Whisnat (2012) 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. (2012) 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. I 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.

4.3 Methods

I used qualitative methods to elicit survivors’ challenges and strategies for coping with those challenges. I 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; Guest et al., 2011). The themes that emerged from an iterative cycle of qualitative coding are presented in the results below.

4.3.1 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 18 and 39; 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.

I conducted 15 interviews with cancer survivors experiencing a variety of diagnoses and treatments (Table 4.1). 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. All participants used a binary gender designation; four participants were male, and 11 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 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.

Table 4.1 Study Participants (n=15)

Participant alias, Gender, and Age	Period between diagnosis & interview	Diagnosis*
Peter; Male, 31	9 months	Adenocarcinoma (head and neck)
Mark; Male, 32	1.5 years	Brain tumor
Leah; Female, 32	1.5 years	Breast cancer
Michelle; Female, 37	1.5 years	Cervical cancer
Helen; Female, 31	6 months	Cervical cancer
Diana; Female, 30	2.5 years	Hematological cancer
Rico; Male, 23	3.5 years	Hematological cancer
Emily; Female, 35	4 years	Hematological cancer
J.C.; Female, 34	4.5 years	Hematological cancer
Lucy; Female, 33	4.5 years	Hematological cancer
Kate; Female, 29	4.5 years	Hematological cancer
Bob; Male, 35	9 months	Hematological cancer
Marie; Female, 42	30 years	Osteosarcoma
Emma; Female, 28	11 years	Thyroid cancer
Jo; Female, 28	2 years	Thyroid cancer

**Several participants had rare types of hematological cancers; the exact diagnoses are withheld here to preserve participant anonymity*

4.3.2 Study Procedures and Analysis

I conducted one in-person interview with each participant, generally in the participant’s home, using a semi-structured interview protocol. 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 protocol 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 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). I reviewed (but did not code) field notes kept during data collection, and coded the transcripts iteratively between interviews, in an approach meant to build on themes in real time. Then, I applied open coding to converge on a final codebook after several iterations (Guest et al., 2011) focused on themes relevant to the participants' challenges.

To support the validity of data collection, analysis, and findings related to observed themes, I (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 (Chatman, 1992).

4.4 Results

Through my analysis, I 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. I 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.

4.4.1 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 during hospitalization). 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.

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 (re-connecting) 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.

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 used her “*connection to the outside world online*” to blog and share her experiences when she was in the hospital receiving chemotherapy treatments. 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 because her diagnosis was so rare, there was limited new information available from the chats.

One positive aspect of interaction with other survivors— even older survivors at different life stages—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 about other survivors 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 (Huh et al., 2014; Liu et al., 2013). Michelle explained why she liked the videos so much:

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.

Occasionally, participants described meeting peers online and attempting to migrate the relationship offline (e.g., Scott, 2016), 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. 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.

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.

4.4.2 Confronting Mortality Leads to Controlling Their Stories

Telling stories can be an essential act in making sense of and coping with the illness experience (Charmaz, 1999). I 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). I 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.

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

I 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. I 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 (Newman et al., 2011; Pang et al., 2013). 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."*

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."*

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.

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.

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.

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.

4.4.3 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.

Some participants described living with disabilities. Other participants 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.

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.

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."

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?

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, 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 she 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.

Table 4.2 Tasks related to challenges and responses in different phases of young adult cancer during diagnosis and treatment, and during survivorship

Challenge	Response	During diagnosis & treatment	During survivorship
Physical isolation	Reconnection	Using general social media (e.g., Facebook) to keep in touch	Not applicable: physical isolation often eased after treatment
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 survivor community	Not applicable: identity processing occurred primarily during the survivorship phase.	Helping others, reflecting on experience, moving on

4.5 Discussion

I 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, I 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.

4.5.1 Implications for Online Survivor Spaces

Online discussion forums are ideal for finding peer expertise versus clinical expertise (Civan et al., 2009; Hartzler and Pratt, 2011; Ziebland, 2004). 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].

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 (Hartzler et al., 2016). 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. I 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 4.2), which we describe in more detail below.

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 Eschler et al., 2015).

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). I 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 (Hartzler et al., 2016).

Survivorship

When survivors complete treatment and move into survivorship, they must cope with a different set of stressors. These stressors 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 (Adolescent and Young Adult Oncology Progress Review Group, 2006)—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 my 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 (Hartzler et al., 2016). I 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 (Eschler et al., 2015), which facilitates peer matching even as needs change.

4.5.2 Implications for Resources about Privacy and Self-Presentation

Young adult cancer patients often face their diagnosis 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 (Zebrack and Isaacson, 2012). 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.

I 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 (Pang et al., 2013). 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.² Participants dealt with

² This finding may indicate sample bias, meaning that individuals willing to participate in this study were also more likely to act as “public” cancer patients or survivors.

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 (1999) points to narratives as part of the “work” chronically ill individuals perform to express self-as-process, and Crossley (2001) suggested that illness survivors affirm themselves through storytelling after a difficult life event. In the young adult sphere, Keim-Malpass and Steeves (2012) 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 (2013) 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—I 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 an 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. These concerns include sharing diagnostic or treatment details, posting pictures, or informing professional contacts about treatment arrangements. I see these skills as useful for helping survivors to control the “cancer story” in the short term as well as bolstering a survivor’s 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, I 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, but individuals 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.

4.6 Limitations

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

4.7 Conclusion

My participants helped me explore their experiences, and informational and emotional needs, during the young adult cancer experience. I contextualized themes in findings using three challenges previously outlined by the NCI's working group on adolescent and young adult cancer: (1) feeling isolated; (2) confronting a sense of mortality; and (3) struggling with changing body image and identity. I not only add empirical evidence to support the assertion that these challenges exist, but was also able to elicit and articulate participants' adaptive behaviors used to face such these challenges. In this way, I am 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, I 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, I 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.

Chapter 5. The Social World and Oncology Care Relationships of Young Adult Cancer Survivors

5.1 Introduction

When a young adult—an individual between the ages of 18 and 39—faces a diagnosis of cancer, the diagnosis often comes out of the blue, even if preceded by ongoing symptoms. In addition to the sudden or unexpected manner of diagnosis, the phase of young adulthood is a developmental stage in life where individuals are meant to be making important life decisions and progress in the areas of social life, career development, and establishing long-term relationships (e.g., having children or deepening connections with a spouse or partner). A cancer diagnosis can significantly disrupt this developmental stage.

The oncology care team very quickly becomes a central information and support resource to the young adult cancer survivor. Research in the area of young adult survivor relationships with their oncology care teams has exploded in the past year, as a result of the National Cancer Institute's effort to understand the unique needs of young adult cancer (Adolescent and Young Adult Oncology Progress Review Group, 2006). This effort has included research to improve the guidelines for communicating with young adults and ensuring adherence with young adults in treatment (Morgan et al., 2010; Ramphal et al., 2016; Trevino et al., 2013).

Although the research into the survivor-provider relationship is essential to improving clinical care and clinical trial enrollment (Ramphal et al., 2016), relationships with their oncology care teams are not the sole influence young adults use to understand their cancer care and experience. Other types of social relationships that are influential to and affected by the cancer experience include friends, family, cancer peers, cancer organizations, and other medical care providers.

I interviewed 21 young adult cancer survivors, incorporating both a semi-structured interview protocol, as well as a visual elicitation exercise, to build a comprehensive view of the social world of young adult cancer. This analysis situates the information and influences from the oncology care team in

relation to other social relationships. Using content and thematic analyses, I present both the benefits and risks of the different types of relationships. I also articulate aspects of the survivors' relationships with their oncology care team that led to more successful interactions with their oncology care teams. The guiding research questions for this analysis are as follows:

How do young adult cancer survivors describe their experiences in terms of social relationships?

What role do oncology care team members fill in the social experiences of young adult cancer?

5.2 Background

The following section gives an overview of existing literature related to (1) the unique care context of young adult cancer; (2) the relationships of young adult cancer survivors and their oncology care teams; and (3) social relationships outside of oncology care affecting the young adult cancer experience.

5.2.1 The Unique Care Context of Young Adult Cancer

Young adults face many challenges around finding appropriate care—and sometimes even receiving a timely cancer diagnosis—and are insured for health care at the lowest rates of any age group in the United States (Bleyer, 2007)³. Young adults also participate at the lowest rates in cancer treatment clinical trials, which has stunted efforts to improve survival rates for the past thirty years (Bleyer, 2007). These low rates of clinical trial participation may be due to the design of such trials, which often lead young adults to perceive a lower level of control over the course of their care (Ramphal et al., 2016).

Morgan et al. (2010) more generally point to the challenge of young adults feeling a distinct loss of control and boundaries after a cancer diagnosis, even as their independence in life—such as making decisions and forming new relationships—is supposed to increase. Recent research has responded to the unique context of young adult care by striving to understand this group's preferences, priorities, and values in the context of oncology care (Ramphal et al., 2016). In essence, Patterson et al. (2015) call for

³ The incidence of insured survivors has potentially improved since the passage of the Affordable Care Act.

clinic-based professionals to balance two primary needs of young adults: (1) access to expert medical treatment and (2) the ongoing pursuit of developmental milestones that characterize emerging adulthood. Relative to these points, in their meta-review of young adult oncology care guidelines, Morgan et al., (2010) emphasize the need for these oncology patients to “feel normal” and have their lifestyles (e.g., sexuality, relationship status) understood by clinic-based providers in a “sensitive, non-judgmental” manner.

In addition, young adults preferred care that was both individualized (“I want to be known”; Belpame et al., 2016) and consistent (“I want to know and get to know my care team”; Jacobsen et al., 2015). Trevino et al., (2013) found that young adult survivors with metastatic cancer who felt they had a “stronger alliance” with their oncologist were more likely to perceive strong social support, were more likely to adhere to treatment plans and take oral medications, and were less likely to feel “severe grief” related to treatment. Finally, Belpame et al., (2016) also noted that young adults often feel more ill from their treatment than they did from the untreated disease of cancer, and the side effects of treatment can confound efforts to build a strong relationship with their oncology care teams.

Given the complications of the context of young adult cancer, it is understandable that young adults—like cancer patients more broadly—may seek or use information from resources outside the clinic, or seek social support from existing or new peers. In the final section of the background literature, below, I describe elements of extra-clinical information resources that research has found to be valuable for cancer survivors.

5.2.2 The Relationships of Young Adult Cancer Survivors and Their Oncology Care Teams

A number of patient and survivor characteristics have been shown to impact relationships with providers. At a high level, clinic-based providers (including oncology care teams) often face a lower level of trust in their care among younger patients than older patients (Blendon et al., 2014). Expectations around interactions among patient, lay caregivers and/or family, and clinic-based providers can be heavily

influenced by the patient and family culture (Goldzweig et al., 2010), and young adults from ethnic minorities can be particularly dependent upon family, friends, and “cancer peers” as additional sources of information and support during cancer treatment (Munoz et al., 2016). Attachment theory has also been used to explain different levels of patient trust among diverse cancer patients. Holwerda et al. (2012) found that “insecurely attached” cancer patients—patients who felt unworthy of care, or who saw their oncologists as a “threatening other”—had lower levels of trust and satisfaction in their oncology care, as well as higher levels of distress during treatment.

In general, patients expect their clinic-based providers to have (1) medical knowledge, (2) good intentions, and (3) good moral character (Hawley, 2015). However, specific aspects of clinical interactions (meaning the *how* of delivering medical knowledge, signaling good intentions, and expressing good moral character) can impact the patient-provider relationship, as well. Over the last thirty years, the clinical care model itself has changed over time, gradually shifting from a viewpoint of paternalism to patient-centered care designed to increase engagement (Committee on Quality of Healthcare in America, 2001). As a result, younger patients may be less responsive to a more traditional, paternalistic approach to care (e.g., Morgan et al., 2010).

Finally, previous research has also shown that physicians who explore the patient experience and spent more time with patients were more trusted than physicians who show less interest in their patients’ lives and social worlds (Fiscella et al., 2004); these social aspects of the working relationship can be essential to ably caring for young adult cancer patients. Morgan et al. (2010) found that young adult cancer survivors wished for their oncology nurses to be affable and collegial first, and knowledgeable second.

5.2.3 Social Relationships Outside of Oncology Care

Although the oncology care team is a central resource for young adult survivors, it may not be the sole resource a survivor finds, wants, or needs to make decisions and reduce uncertainty about the future.

Civan et al. (2009) previously articulated the difference in the expertise of patients' peers and their clinical care providers. The analysis presented here widens the scope, attempting to understand how young adult survivors balance their influences and attention among many social influences, inside and outside the clinic context, as well as online and offline.

In terms of the young adult developmental stage, Zebrack (2011; 2014) articulates the priorities of young adults in their specific developmental stage as encompassing the following:

- Establishing identity;
- Developing a positive body image and sexual identity;
- Separating from parents;
- Increasing involvement with peers and dating; and
- Beginning to make decisions about employment, education, and family.

The social needs of young adult survivors, therefore, are affected by the isolation cancer causes versus peers. In addition, family dynamics change in response to financial or logistical needs; sometimes, young adult survivors must move back into the family home to save money or simplify transportation to and from treatment and clinic appointments. In response to family turmoil or social isolation, keeping in touch with existing friends or family members through technology (texting, video chat, etc.) can be essential for young adults to help combat loneliness isolation (Eschler and Pratt, 2017).

Early analyses of peer-to-peer patient work, or independent research, occurring online was generally viewed as "supplementary" or "peripheral" to information and guidance obtained in the clinical care setting (Hawn, 2009; Ziebland, 2004). For the young adult patient, however, the use of extra-clinical resources is a complement to clinical care (Fox and Duggan, 2013; Magni et al., 2015).

Cancer survivors also must manage their social interactions in the context of cancer (Kay et al., 2016; Kaziunas et al., 2015). Online sources are particularly helpful in that they are "always-on" (Liu et al., 2013) and they can connect new "cancer peers" based on changing needs and despite geographical distance (Eschler et al., 2015; Eschler and Pratt, 2017). Furthermore, the user can assess aspects of online

resources such as the information quality and usability (Zhang, 2014) according to their own needs and preferences.

To address the factors outlined in previous research above, the interview protocol I applied for this study asked about both use and disuse of different types of clinical and extra-clinical information and support for each participant. I asked about aspects of relationships with oncology care teams, family members, friends, cancer organizations, cancer peers, and other medical care providers during the interview protocol questions and in facilitating the visual elicitation portion of the interview. I explain the methods applied in this study in detail below.

5.3 Methods

Each of 21 participants (see Table 5.1) in this study completed a semi-structured interview that lasted approximately 90 minutes. Young adult cancer survivors were recruited online and offline, primarily using support group spaces and forums for young adult cancer, resulting in a combination convenience and snowball sample. Participants lived in two regions of the United States: the Pacific Northwest (Washington and Oregon) or in the Midwest (Illinois and Michigan), and all were treated for their cancer in a domestic clinic. Recruitment criteria included (1) diagnosis of cancer between the ages of 15 and 39; (2) fluent in English; and (3) currently aged 18 or older. Most of the interviews took place in participants' homes or in public spaces chosen by the participant, and each participant received a payment of \$50, as well as directed a \$25 donation to a non-profit of their choice.

In the first half of the interview, I used an interview protocol to probe survivors' diagnosis and treatment experiences, as well as to ask questions about their social support systems and sources of information used to make treatment and care decisions. In the latter half of the interview, I facilitated an elicitation (sketching) exercise that invited the participant to depict their cancer experience in a visual manner. Many of the artifacts created during this exercise depicted a "cancer timeline" or a metaphorical expression of feelings about the cancer experience.

Participants were encouraged to “think aloud” while creating the visual artifact. This think-aloud portion of the interview was included in the complete transcription and both the interview transcript and visual artifacts were analyzed using thematic analysis. I progressed from open coding (identifying all aspects of the social relationships described by participants) to a fixed codebook that categorized significant types of social relationships and could be used to examine the intersections of social influences during the young adult cancer experience. I used qualitative analysis software (dedoose.org) to examine the themes emerging among code occurrences and co-occurrences, and chose participant quotes for the following section to illustrate resulting themes.

Table 5.1 Study Participants (n=21)

Participant alias, Gender, and Age	Period between diagnosis & interview	Diagnosis**
Peter; Male, 31	9 months	Adenocarcinoma (head and neck)
Mark; Male, 32	1.5 years	Brain tumor
Monica; Female, 26	1 year	Breast cancer
Leah; Female, 32	1.5 years	Breast cancer
Michelle; Female, 37	1.5 years	Cervical cancer
Helen; Female, 31	6 months	Cervical cancer
Stephen; Male, 33*	10 months	Hematological cancer
Kathy; Female, 44*	10 years	Hematological cancer
Diana; Female, 30	2.5 years	Hematological cancer
Phoebe; Female, 36	3 months	Hematological cancer
Veronica; Female, 28	3.5 years	Hematological cancer
Rico; Male, 23	3.5 years	Hematological cancer
Emily; Female, 35	4 years	Hematological cancer
J.C.; Female, 34	4.5 years	Hematological cancer
Lucy; Female, 33	4.5 years	Hematological cancer
Kate; Female, 29	4.5 years	Hematological cancer
Bob; Male, 35	9 months	Hematological cancer
Dolly; Female, 33*	3 years	Lung cancer
Marie; Female, 42	30 years	Osteosarcoma
Emma; Female, 28	11 years	Thyroid cancer
Jo; Female, 28	2 years	Thyroid cancer

**Participant did not complete visual elicitation exercise*

***Several participants had rare types of hematological cancers; the exact diagnoses are withheld here to preserve participant anonymity*

5.4 Results

In this section, I give an overview of social groups survivors encountered during the cancer experience. Five social groups (outside of the oncology care team) emerged as significant during the thematic data analysis: friends; family; cancer peers; cancer organizations; and other medical care providers. All five groups are described in detail below.

5.4.1 *The Importance of Friends*

In their stage of development, young adults are generally moving into independence, starting relationships or their own families, and generally becoming less reliant on parents for influence and support. In this new phase of independence, particularly after moving out of the house, attending college, or starting a career, friends can become a new kind of family and the most important influencers and supporters in the young adult's life. Some of the best support from friends resulted from these friends following the survivor's lead—asking them what they would prefer to do for an activity, or offering a specific type of help, such as with meal preparation or cleaning house. Some participants described their friends' essential assistance as fun social diversions (Veronica's friends threw her a "Make a Wish" weekend to take her mind off of chemotherapy). In another example, Bob's friends helped with household chores and childcare.

However, when a young adult is diagnosed with cancer, their friends might not have any kind of experience with cancer, or have only experienced cancer among older family members. The cancer experience can lead to a number of poor outcomes in friend relationships. Most devastating to some participants, their friends' lack of experience with cancer can cause disconnect or estrangement; some friends simply fall out of the survivor's life. Kate described that friends who ignored her during treatment tried to come back into her life "*but it was sort of hard to trust them after that again—they just disappeared.*"

Friends might also make misguided attempts to connect based on cancer survivor archetypes (e.g., “the brave fighter”). Bob felt exasperated by this archetype. He said, “*Man, I’m not brave—if I could not have [cancer], I would immediately not have [cancer].*” Sometimes, a “friend’s” behavior could verge on exploitative or hurtful; Veronica described one of her friends sharing a blog post she had written about being in treatment:

In the whole treatment phase, people really liked to say, “You’re really brave!” and I remember I wrote a blog post about how having cancer made me more interested in science...And my roommate from many, many years ago, who didn’t really like me, posted it on Twitter saying “[Veronica] is my HERO!” And I’m like—you didn’t even respond to my email telling you I had cancer.

In addition, participants described friends attempting to connect through gallows humor, which is not always welcome. Kathy’s friends would call and say they were “*checking to see if you were still alive.*” Kathy found these episodes frustrating and unsupportive.

Potentially less damaging to relationships—but nevertheless frustrating—some participants described their friends’ mis-timed efforts to support them. Participants often had friends rush into their lives during treatment, when they had little energy to socialize and needed to convalesce. After treatment and into survivorship, however, friends would withdraw, just as participants needed the most social support from friends. Emily stated that one of the hardest things about transitioning from treatment to survivorship were the social ramifications: “*I did find that people in my life—not really my close circle, but other friends—wanted [my cancer] to be over. And it wasn’t.*”

Michelle depicted the mis-timing of her friends’ support in her visual artifact (Figure 5.1). In her visualization, the central metaphor she used was that of a winding path, with darker colors indicating more sadness and anger. The circles surrounding the path signify her social relationships. Using this technique, she expressed a mis-match between her needs and ability to interact socially and the social support that friends offered her at various times:

The dots are about other people in my life. So at the time I was diagnosed, I feel like I did have some people in my life...And then during the treatment, there were people who were just all up in my business and everyone was off in the stratosphere. And I think a lot of people expected me to just permanently feel elated that I made it through that, and when I didn’t, people really scattered to the winds.

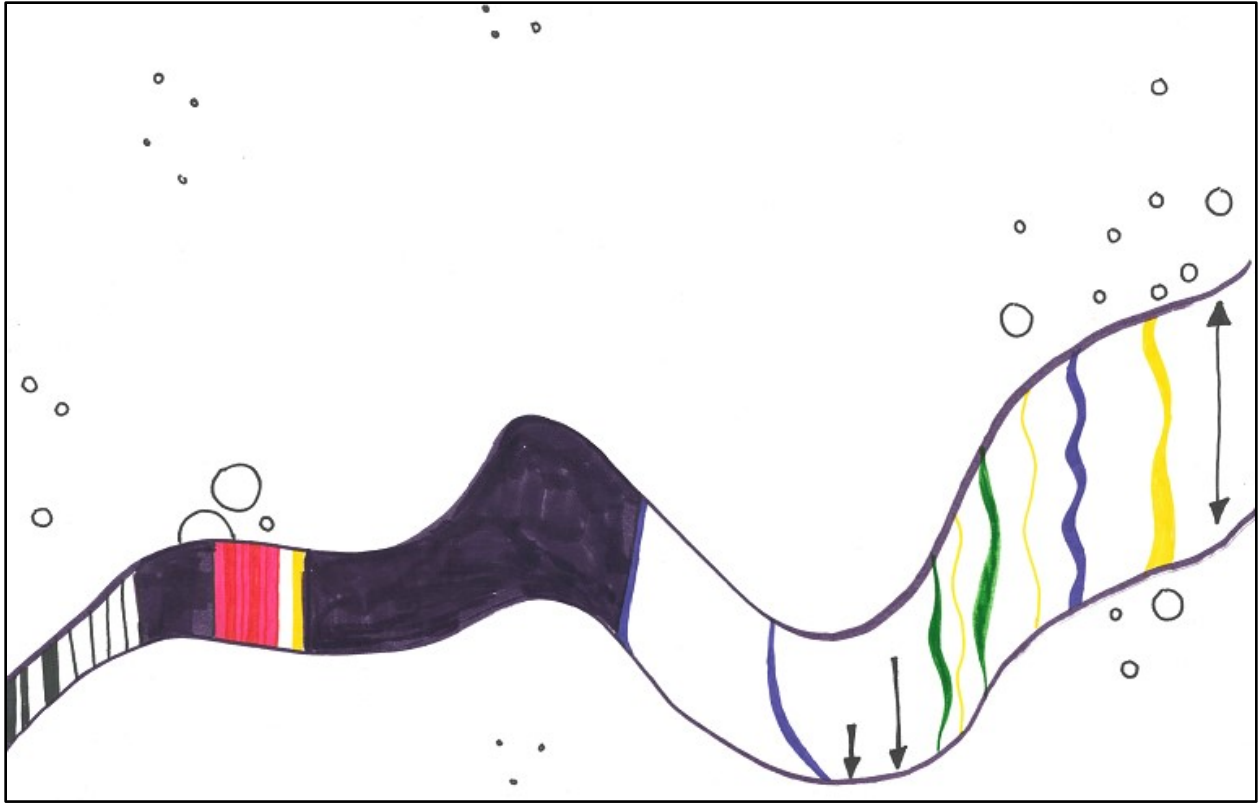


Figure 5.1 Michelle’s visual elicitation; the dots around the main “path” represent people in her life, and how close (or not) they felt at different phases of her illness.

5.4.2 The Role of Family

The first “involvement” of family in young adult cancer is that of family history. Only two participants—Michelle and Bob—had multiple instances of family cancer histories. For the other participants, some had relatives with cancer (Rico had an aunt who had breast cancer previously; Monica’s father passed away from cancer while she went through treatment). For most participants, however, the cancer diagnosis came “out of nowhere.”

The aspect of family support during the young adult cancer experience is complicated, again, by the developmental stage of young adulthood. Nineteen of the 21 participants had moved out of the family home to start independent lives by the time they were diagnosed with cancer. The two exceptions were both participants who were treated in a pediatric care facility. Marie, whose cancer relapsed after her first

bout of treatment, was an orphan by the time she returned to the same children's hospital to be treated for the second time. Emma was a teenager when she underwent treatment, and lived with her parents while trying to stay engaged at high school.

For the other 19 participants, who were at a more independent stage of life at diagnosis, six were married, and five had at least one child. For participants with children, family gave invaluable support by helping with childcare (Diana, Bob), transportation to and from treatment (Mark), and follow-up care (Dolly). Participants who were also parents expressed guilt at times when they did not have enough energy to keep up with their kids, but kids could also be very motivating in staying active and happy, as Stephen explained:

If I've had a crappy day, whether it's with the diagnosis or otherwise, I come home and [my kids] don't care about that—they're just smiling and wanting to play. It takes your mind off of things too, in a really helpful way.

In some cases, coordinating care and managing finances required that the young adult survivor move home to live with their parents. Five participants in this study found it necessary to move back in with parents, and described specific problems that could arise with this arrangement. In particular, conflict between the survivor and their family members was common in this arrangement. J.C.'s mother and father would take care of her two children while she was hospitalized or bedridden, and her aunt took on the role of primary lay caregiver for J.C.. Although J.C. was grateful for her aunt's help, there were times J.C. felt she was controlling. In one instance, a conflict about visiting friends arose:

When I was sick, I'd finally gotten out of bed and sat downstairs one day. And my friends came by—I'd asked my best friend to bring me some pie. She'd made these little mini pies. That's what I wanted, it made me feel better. When she got here, my aunt kind of jumped down her throat. You know, sugar feeds cancer, and I'm like—dude, this is what the hell I want right now...I know [my aunt] meant well, but at the time it kind of made us fall out.

Leah and Rico, who both moved back in with their parents during treatment, also felt a sense of regression—going back to being a teenager, living under “house rules”—after returning to the family home. In both cases, their parents would attempt to impose rules about their comings and goings. Dolly

felt “smothered” by her mother at certain points during treatment, and had to re-establish boundaries after starting to date again.

Beyond financial and logistical assistance, parents and partners were also powerful advocates in some cases. For example: J.C.’s aunt attended appointments to help manage clinical information from the her oncologist and other doctors; Mark’s wife persisted in getting him an appointment with the top surgeon in the country for his diagnosis; and Stephen’s father assisted with research around his diagnosis when Stephen felt emotionally unable to search for information independently. Participants whose family members interacted with their oncologists were universally grateful for their oncologists’ ability to communicate with these family members.

5.4.3 The Impact of Cancer Peers

For a young adult survivor, a “cancer peer” is another individual who has also experienced cancer as a young adult, although not necessarily the same diagnosis. Interactions and socialization with cancer peers assist survivors in feeling less alone in their fears and experiences (which I have previously described as “experiential isolation”; Eschler and Pratt, 2017). Participants who had at least one cancer peer often expressed a feeling of being unburdened, especially in cases where they did not see many other young adults in the clinic. Rico explained that the clinic proved to be a poor place to connect with other patients, in general:

I didn't have anyone really to talk to similarly...It's not like I'm going to wish anyone sick, but if they're going to be, at least let them be around to talk to. I didn't find really much of anyone else [at the clinic]. I saw some people maybe in the waiting area, maybe two or three individuals that kind of came around at the same time, but it's not like we really talked to each other.

Exceptions to the above scenarios were cases in which oncologists offered to introduce participants to other young adult patients. Although some young adult survivors might feel awkward about such a suggestion, all of the participants in this study stated that they were eager to meet a cancer peer through their oncologists if they did not have someone in their life to fill that role otherwise. In Monica’s case, her

oncologist's introduction to another young patient led to a helpful, new friendship when she felt very scared and isolated.

Cancer peers occasionally emerged from existing family and friend groups. One of Leah's friends had recovered from a different cancer diagnosis, but was able to give essential help while Leah was hospitalized, completing necessary paperwork and helping out with family matters. Peter had an existing friend who stepped up, knowing that the transition from treatment to survivorship could be difficult; she threw him a party when he returned home after a month of treatment in another city. Emily credited a colleague at work for talking her through getting her port placed, an upcoming event that caused her extreme anxiety:

Well, there's a woman at work who had cancer. She's a little bit older than me, early 40's...She actually was probably one of the most influential people in helping me process what had happened...[She] kind of let me take from her story what I needed, without just sort of telling me, 'You should get the port.'

Cancer peers found among family were not always as helpful in making emotional connections. For many participants, the family members they knew who had experienced cancer were older, and as a result, represented a different generation's attitudes about cancer. Rico's aunt kept her cancer experience more private, and although Rico respected her preferences, he pointed out that his approach was very different. For example, Rico signed up for an Instagram account specifically to share his cancer experience publicly. Kathy found that her family members were largely unable to talk about her going through cancer treatment due to their generational attitudes about cancer being a "private matter," meaning she had no opportunity to connect with cancer peers through family.

Finally, the work of finding cancer peers can be significant, particularly for young adult survivors with rare diagnoses. Diana looked for peers with her rare diagnosis, and when she found no spaces specific to her disease, she started a Facebook group to build a community. Rico, Stephen, and Monica used Instagram and hashtags to connect with their "cancer communities," reacting to a dearth of peers by "giving to get" and connect with people by sharing their experiences.

Veronica met a group of cancer peers through a young adult survivor support organization that specializes in outdoor treks. This small group of survivors bonded and maintained contact through group text. Veronica explained that cancer-peers-turned-friends were a difficult blessing.

One of my good friends passed away 6 weeks after [we met]. She had not told us how dire her situation was. That was my first experience of someone—I now say that cancer friends are high-risk, high-reward. They are some of the best connections that I've made, but you do have to grapple with the fact that they also have really serious illnesses.

5.4.4 The Lifeline of Cancer Organizations

Participants spoke about cancer-related organizations filling two primary roles: (1) reliable sources of medical information and (2) a place to find cancer peers. The first role does not, at first glance, seem to fulfill a social role in the cancer experience. However, cancer organization websites, in particular, were vital for participants in counteracting (often unsolicited) misleading information from friends, family, and acquaintances. Such sites were also used to confirm medical advice—e.g., from participants' oncologists.

Many participants reported that their oncologists discouraged them from “googling” about their cancer. Some of the same oncologists also recommended good sources of information. Emily appreciated her oncologist's recommendation to read *The Emperor of All Maladies*, for example, because she liked to understand the biological and physiological mechanisms of cancer. In general, participants were often left on their own to assess information online, without recommendations from oncologists. To be sure they were finding “good” information, participants often used the shortcut of relying on disease-specific foundations (or sometimes, government agencies, such as the National Institutes of Health) to identify quality sources of information.

A benefit to Internet searches, specifically, is the “always-on” nature of that information medium. J.C. reported searching the Internet in the middle of the night to ease her worries. Facebook groups were useful especially to those participants with rare cancers (Phoebe, Diana) and participants looking for inspiration (Monica, Kate). Veronica used a diagnosis-specific online forum to ask questions about losing her hair, a type of question she felt that her oncologist was not helpful in answering.

Participants were able to distinguish between the expertise of their oncologist and the expertise they could find online, even the information found through cancer organizations. Leah explained that she avoided information on the web, preferring to ask her oncologist questions as they arose:

I think the American Cancer Society, that was the one where I kind of looked—and they tell you, ‘Oh, for breast cancer, early detection is great, blah, blah, blah. And I look at it, ‘Oh, stage IV, you have a 20% chance, basically.’ ...after that it was more like—OK, chill, [my oncologist] is the doctor.

Cancer organizations also offer in-person services, such as support groups or fundraising events. These in-person activities were often inaccessible during treatment for participants, given immunosuppression, temporary disability, or fatigue. However, cancer organizations can offer essential services in long-term survivorship that are invaluable to young adults. For example, Diana described sending her son to a camp for kids whose parents have gone through cancer:

[My son] had an imaginary friend with cancer...[he] went to a Gilda’s Club Camp Sparkle, a camp for kids affected by cancer. After Camp Sparkle, he said his friend with cancer doesn’t have cancer anymore. It was funny, like he needed to go through that...I was really worried about how cancer would screw up my kid. But [the camp counselors] said it was healthy.

Finally, many participants sought out cancer organizations without guidance from clinical sources of information. The participants who connected with a cancer peer through Imerman Angels (imerman.org) often stumbled on the site through an Internet search. However, even these chance connections proved valuable to participants; for example, Helen depicted her connection with an Imerman Angel mentor as a significant episode in her cancer experience (Figure 5.2).

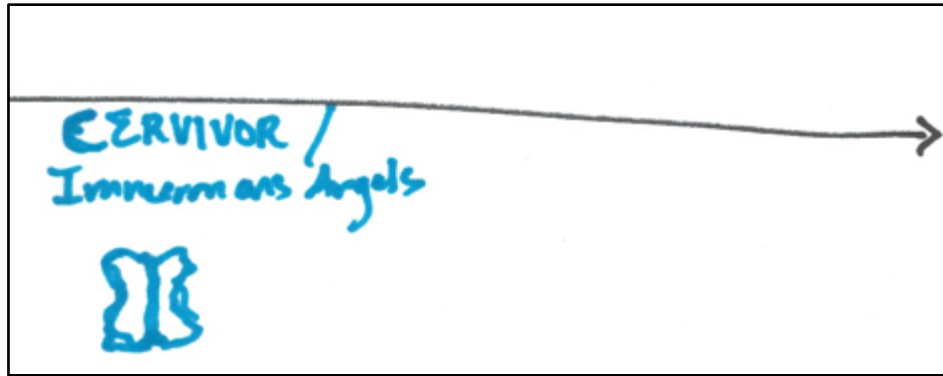


Figure 5.2 Excerpt from Helen’s visual artifact. Imerman Angels found Helen a cancer survivor with the same diagnosis, allowing her to connect with her first cancer peer prior to surgery. By connecting with another survivor with the same diagnosis, Helen was able to learn about expectations for her recovery and survivorship.

5.4.5 The Influence of Other Care Provider Interactions

Participant experiences with other medical providers, prior to diagnosis, could affect their attitudes and behaviors as patients working with their oncologists. Michelle, who required urgent surgery after being admitted to the hospital through the emergency room, experienced a HIPAA violation she found frustrating. Michelle’s cancer diagnosis, discovered during the surgery, was shared with family and friends in the waiting room before she was informed. *“I never signed any release of information or anything!”*

Participants who had been mis-diagnosed over a series of months or even years were often relieved to connect with an oncologist. Phoebe *“went to all types of doctors...no one could really figure out what was going on”* before being diagnosed in the emergency room with a rare form of cancer. Dolly faced months of uncertainty, waiting to see a lung specialist who was unconcerned about her since she was too young to have “serious problems,” only to find she had lung cancer. Leah sought help for back pain for a number of months; her primary care provider insisted she was experiencing muscle spasms, and drew her a picture of the muscle issues to convince her of the diagnosis. Leah reproduced this picture during the visual elicitation portion of her interview (Figure 5.3).

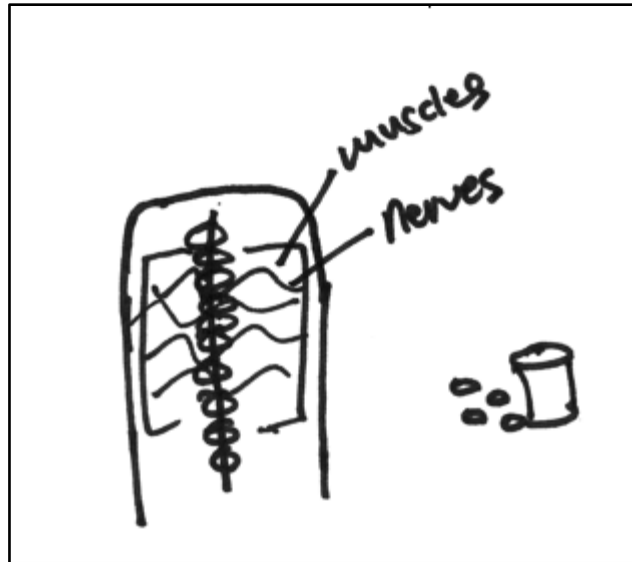


Figure 5.3 Leah reproduces the drawing her primary care provider created to convince her that ongoing back pain was caused by muscle spasms. Leah had a fractured spine from metastatic breast cancer that was eventually detected in an MRI.

Many of the survivors discussed having to learn to become their own advocates (Jo, Dolly), and being unsure of learning the role of an “active patient.” In another example, Kate had a negative experience with her original oncology consult, before she became a more empowered patient:

The [first] oncologist who met with my parents and I was not optimistic. It was a very scary meeting. He kind of stared at his shoes while he talked to us. It wasn't a matter of how I was going to beat it, it was if I survived and what my life would be like if I was survived...it was just really very grim, but he also admitted he didn't treat a lot of young adults...It was clear it wasn't the right place for us to get treatment. Of course when we started there, we had no idea what we were doing.

Finally, young adult survivors were not always aware of their “rights” in finding and assessing oncology care and treatment options. Bob and his wife were uncertain if his oncologist would be offended that he sought a second opinion about a treatment decision (Figure 5.4).

[The second opinion] was also hard to do as well, because you gain a certain relationship with your care team and it—you feel a little like, am I being betraying here? But I've got to make this decision and I need all the knowledge...But it was a little hard—we were both a little scared. [My wife] was like, 'what if [your oncologist] doesn't take you back?'

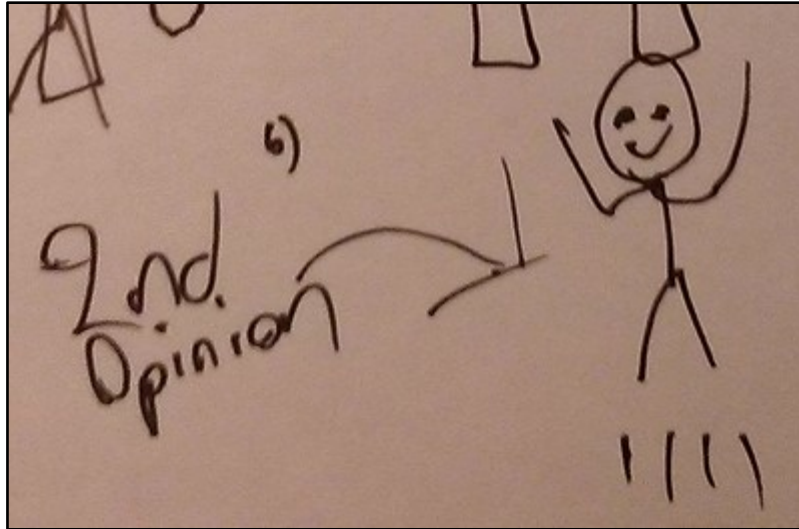


Figure 5.4 Bob depicts his elation as a stick figure “jumping for joy” at having received a second opinion that relieves him of another round of chemotherapy suggested by his primary oncologist.

5.5 Discussion

Young adult cancer survivors tend to feel like outliers in cancer care. They are not pediatric patients, and they are not the “usual” older adult patients. This in-between status means that when they work with an oncologist, they may be one of two or three young adults the oncologist has worked with in the past few years. To address the special care context of young adult cancer and its social world and influences, I have formulated an overview of the risks young adult cancer survivors face in their social worlds (Figure 5.5). This overview presents high-level risks of five social influences in the young adult world, detailed in the previous section: (1) friends; (2) family; (3) cancer peers; (4) cancer organizations; and (5) other care providers.

In this discussion, I highlight opportunities for oncology teams (the sixth social influence in Figure 5.5) to assist survivors with specific psychosocial problems that may arise in young adult cancer care, which may intersect with social risks among other groups. I describe five opportunities for oncology care teams working with young adults to address their specific needs.

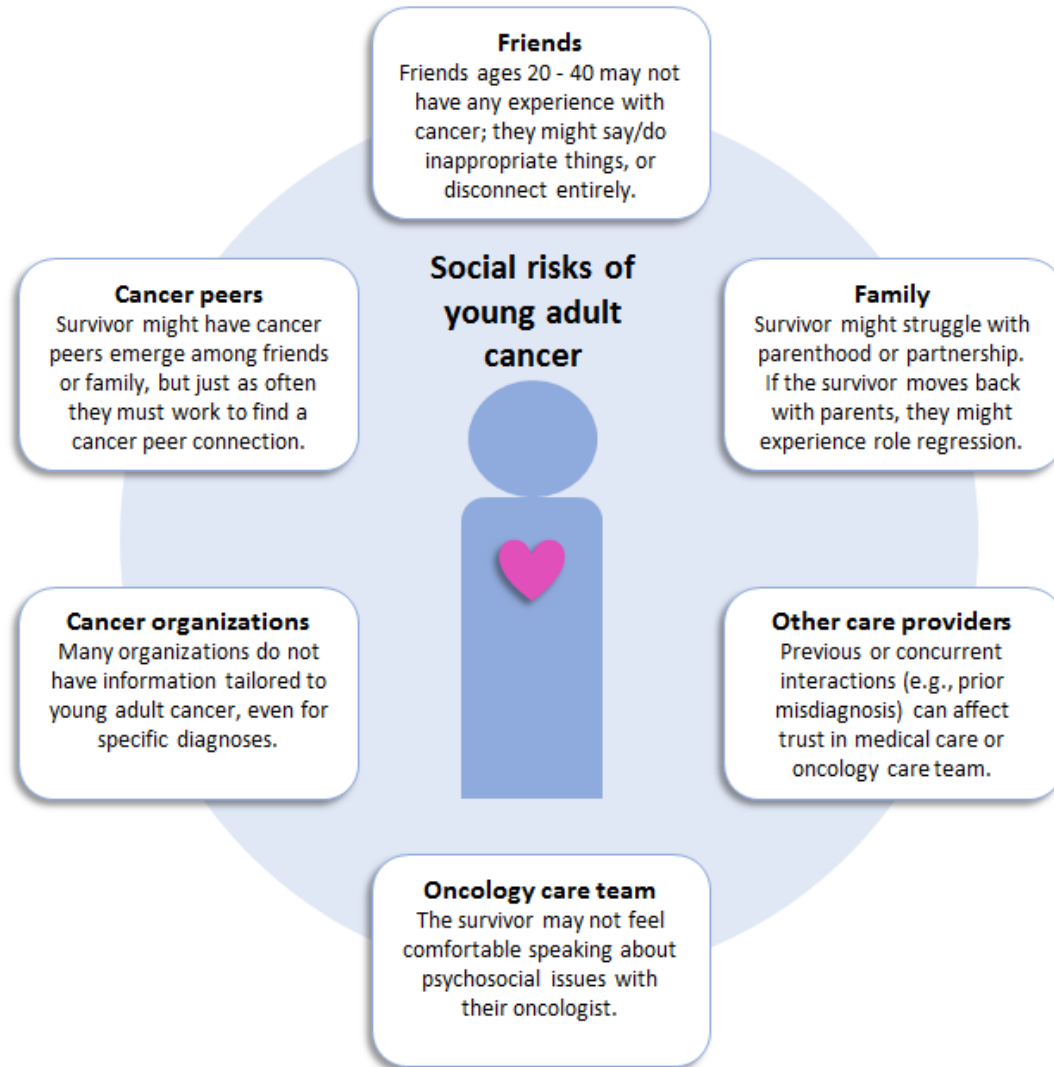


Figure 5.5 Social risks of young adult cancer among the six main social influencers: friends, family, other medical care providers, the oncology care team, cancer organizations, and cancer peers.

5.5.1 Opportunity: Work with the Young Adult Survivor as Care Partner

Previous studies have found that older cancer patients are less likely to prefer engaging in decision-making (Bilodeau and Denger, 1996; Jenkins et al., 2001); younger patients, however, prefer a more patient-centered model of care (Belpame et al., 2016, Jacobsen et al., 2015). Young adult participants in this study, they expressed two overwhelming preferences for their oncologists’ demeanor; they wanted

someone who was (1) knowledgeable about medical evidence and treatment options, and (2) confident about their ability to help.

These qualities do not manifest uniformly in delivery of oncology care. For example, Kathy struggled with denial of her cancer diagnosis, and her oncologist took an almost paternal approach, lecturing her on treatment and setting boundaries for her during treatment. Rico, however, described a situation in which his relationship with his oncology team had to “evolve” after miscommunication of treatment risks, specifically sterility post-stem cell transplant. Over time, his oncologists adapted their approach to give him all of the information, giving him time to make future decisions. Crucially, his oncologists also assisted Rico with family conflict, where Rico’s father had forbidden him to leave the house without a parent:

There was a time when my doctors and my dad, specifically, had another conflict, and it was surrounding the whole going out [of the house] with my parents versus anyone else. [I] had utilized the help of my doctors to kind of mediate that conversation...[my dad] used the doctors as the bad guys.

Oncologists can make the most of their relationship with young adults by embracing the patient’s role as part of the care team, by advocating for the patient if necessary (as in Rico’s case), and by engaging patients in understanding their care and to encourage asking questions.

5.5.2 Opportunity: Enact Goal-Based Care

Young adult patients may have children of their own, or be on the cusp of celebrating life milestones; Patterson et al., (2015) called for oncologists treating young adults to be sensitive to these milestones as they are affected by treatment decisions and burdens. For example, Mark got married in the midst of treatment, and Rico’s oncologists allowed him to postpone his transplant until he had celebrated his 21st birthday. Bob appreciated his oncologist’s respect for one last family holiday before starting chemotherapy, after he told the oncologist, *“I want to go home for Christmas, spend some time with my family.”*

This goal-based care indicates that oncologists treating young adults understand what is important to them and the social world that is essential to young adults outside of the clinic (Ramphal et al., 2016). This kind of awareness can lead to real, patient-centered care, as when Monica’s oncology care team sent her a condolence card after her father’s passing. Caring that addresses social needs proved essential to excellent young adult oncology care among participants in this study.

5.5.3 Opportunity: Recommend Appropriate Information Sources Outside the Clinic

Every participant sought out information on their own. Even Marie, who was treated for cancer prior to publicly-available Internet, ordered a cancer textbook so she could read about her diagnosis. Given that participants will inevitably seek out information, oncologists could help their young adult patients by recommending reputable, credible sources of information.

Providing suggestions for good sources of medical and health information would reduce social risks for young adults in the following ways:

- (1) Helping young adult survivors to refute unsolicited advice of dubious quality (e.g., “have you tried juicing instead of chemotherapy?” or “you probably got cancer from all of the Diet Coke you drank,” both of which are real examples from participants of questions they fielded from friends or acquaintances).
- (2) Introducing them to cancer organization sites that will help them feel less alone.
- (3) Relieving the burden for young adults to formulate their own standards for reputability and credibility of cancer-related information, particularly for those survivors with lower health literacy.

Information prescriptions (Ritterband et al., 2005; Timm and Jones, 2011) have been tested and studied for decades in the medical library tradition. However, such information guidance has not been formulated specifically for young adults or young adult cancer patients. This gap represents an opportunity for oncology care teams to help their young adult patients outside of the clinic.

5.5.4 Opportunity: Reassure Young Adult Survivors about Care Etiquette in Oncology

Young adult survivors sometimes struggled with seeking second opinions or seeking out specialists for rare diagnoses. The most engaged and active patients were able to set boundaries with their oncology care teams. For example, Stephen was wary of being treated like a “guinea pig” because he was very young for his diagnosis, and rejected a clinical trial offer that was not in his best interests. Phoebe’s experiences at a teaching hospital, with her rare diagnosis, led her to find a specialist who would treat her as an individual, rather than an interesting case study.

However, Stephen and Phoebe were not typical participants in this study. Many participants stated they were not aware of their rights, or they continued to work with the same oncologist because they perceived a lack of options. Veronica continued working with her oncologist into survivorship because—although his communication style was off-putting—his confidence and knowledge were reassuring. His behavior prompted her to prepare carefully for appointments with him:

I have questions [for my oncologist], I’ll write them down ahead of time, in the moment I tend to get flustered...So I go in prepared, and he might roll his eyes at it, ‘Oh god, she’s got her list’ – but it makes sure I at least ask it and get the full explanation that I want. [His care] caused me to be more playful.

To counteract this misconception, oncology care teams working with young adults should encourage their patients to ask questions, help them understand the importance of a second opinion, and help young adults understand the time frame for making decisions. If oncology care teams can offer this type of counseling, young adult survivors will potentially build skills over time to become active, engaged patients, working with care professionals for better long-term health outcomes.

5.5.5 Opportunity: Acknowledge the Social World Outside of the Clinic

Using the overview of social risks associated with young adult cancer presented here, an oncology care team working with a young adult would be able to inquire about the patient’s psychosocial needs. Here, getting a picture of the patient’s social needs could lead to interventions such as connecting the patient with a social worker, suggesting the services of a cancer organization (e.g., Imerman Angels), or

offering to introduce a fellow young adult survivor being treated at the clinic, if a potential cancer peer is known to the oncology care team.

This acknowledgement should not be isolated to interventions with the patient only. Many participants described their oncology care teams as working closely with family or friends acting as lay caregivers. It may be worthwhile—or even advantageous—for the oncology care team to bring up social needs of survivors with their lay caregivers in the room. Taking an opportunity to facilitate a discussion about feelings of isolation or vulnerability in social contexts may help the caregiver to better assist the patient in negotiating some of the social risks of young adult cancer. This discussion might also elicit helpful information from the caregiver related to social issues the patient faces but feels unable to broach during a clinic visit (in essence, giving the caregiver an opportunity to advocate for the patient’s social needs).

Perhaps most importantly, knowing that young adult survivors face a very different world outside of the clinic and acknowledging the potential difficulties facing that social world, could potentially improve communication between the oncology care team and a young adult survivor. Diana summed up the difference between being in the understanding world of clinical care, and the sometimes more risky social world outside the clinic:

When you meet someone, and you tell them you have cancer? Sometimes they look at you like you have the plague. You're no longer a human, you're this disease. I felt like, in the medical world, I was fine, but in everyday living, people just kind of didn't know how to deal with you...my friends, I don't think they [knew] how to deal with me, because I didn't know how to deal with me.

5.6 Limitations

This study included a small number of participants (n=21), and the recruitment and sampling technique could result in a risk of self-selection bias. Although I stop short of claiming generalizability of findings due to these factors, this qualitative study was designed and conducted to maximize reliability of findings among participants, as well as support validity measures (face, criterion, and construct validities; Chatman, 1992), to yield rich examples of the social world and related risks of young adult cancer.

5.7 Conclusion

Young adults experience a developmental life stage that should involve building a career or a family and gaining independence from family. A cancer diagnosis is a significant disruption in this developmental stage, and an oncology care team must focus on treating the survivor when they are undergoing this upheaval in life. The survivor-oncologist relationship is essential to the quality of cancer care, as well as long-term health outcomes, but other types of social relationships also influence the young adult cancer experience. In this study, 21 participants interviewed described the social world of young adult cancer; friends, family, cancer peers, cancer organizations, and other care provider interactions all proved important to the survivor experience. The analysis presented in this chapter situates the young adult survivor experience in working with the oncology care team in the context of the social world of cancer, to highlight opportunities for oncology care teams to improve communication with and interventions for these survivors.

Chapter 6. Using Visual Elicitation in Qualitative Research with Young Adults

6.1 Introduction

In designing this thesis study, and preparing to work with young adult cancer survivors—a vulnerable population—I looked to Liamputtong’s (2006) endorsement of using both oral histories and artifact construction as an appropriate way to engage with participants in vulnerable populations (p.113; p.149). In particular, Liamputtong calls for using “creative means” to work around issues (e.g., emergence of emotional topics that require a break from the study protocol) that may arise in interviewing individuals dealing with illness. Eliciting user-generated creative data, such as diaries, photographs, or videos as a method can bestow “*voice and independence*” to research participants (Rich and Ginsburg, 1999; p.373; see also Wilkin and Liamputtong, 2010), giving them a feeling of both contribution and control in the act of creating.

Sketching or drawing and other creative research elicitation methods have been traditionally used with children, and Rich and Ginsburg (1999) suggest using creative means of generating research data with young people as particularly important. However, Guillemin (2004) also advocates for the use of drawing and other creative activities as methods to use with adult participants, because of its power as a mode of meaning making between researcher and participant, in that it adds a mode of expression to assist the participant in articulating their thoughts (e.g., the potential for visual means to clarify or integrate information; Snyder, 2014). My participants ranged between 20 and 40 years old, and I found the incorporation of a visual elicitation aspect to be worthwhile for triangulating the interview transcript data. In this chapter, I explore the benefits and drawbacks of using this visual elicitation method with my young adult participants.

An important distinction of using visual elicitation is its centering of the participant’s point of view, which necessarily affects the position of the researcher (in a way that perhaps not all researchers would

find comfortable). Prosser and Loxley (2008) explained this researcher positioning very clearly in their review of *respondent-generated visual data*. The authors ultimately distinguished between two researcher stances. The first involves research *on* respondents, seeing them as an “other.” The second stance is that of collaborating *with* respondents and “seeing them as experts in their own lives” (p.17). The method I have described here, allowing participants to shape an artifact borne of their own experiences and predilections, requires the second stance.

I see this shift in researcher stance as an essential strength for exploring potentially emotional topics, such as young adult cancer. Focusing on constructing the visual artifacts relieves some burden on the participant to relate experiences in a dialogue constructed and facilitated by the researcher in a traditional face-to-face interview configuration (e.g., ensuring eye contact, regulating tone, choosing the right words). Reducing the pressure on research participants seems particularly advantageous in the context of this study, which involved working with young adults who may still feel powerful emotions when speaking about their cancer experiences, particularly if their memories of illness are fresh. As Prosser and Loxley (2008) wrote:

Respondents may feel less pressured when discussing sensitive topics through an intermediary artefact, since informants do not speak directly about a sensitive topic but work through a material go-between through which they are able to express difficult memories and powerful emotions.

Giving control over to the participants through facilitation of an intermediary artifact requires careful facilitation in practice—Prosser and Loxley (2008) primarily emphasized that using intermediary artifacts *reduced* pressure on research participants; however, research participants can also feel *increased* pressure if they do not feel confident as creators. It is the role of the researcher/facilitator to handle this shift in a manner that encourages the participant in a new mode.

6.1.1 Ethics of Applying Visual Elicitation Methods

To address the ethics of using visual elicitation in this study in a broad sense, I used Pink's (2001) approach. Pink (2001) calls for the application of visual methods when "*ethical, appropriate, and useful,*" contingent on the research context (p.34). Although much of Pink's own methods involve photographic or videographic elicitation work, her assessment of visual methods in context allows for consideration of a holistic view of research design. I adapt this three-point assessment for the application of visual methods to my own research design below.

To evaluate the *ethics* of applying visual methods, I considered implications for the participant's experience, such as projected risks (to the participant) and benefits (to the participant or individuals affected by the research). In this case, the participant has control over how their visual artifact is used in the informed consent document, and may decline to produce a visual artifact at all. The benefits to eliciting this type of data are described to participants to find new patterns in information needs and behavior throughout the cancer experience, which may not directly benefit the individual participant, but are intended to benefit the young adult survivor community. These risks and benefits are reviewed with participants before the interview commences.

The *appropriateness* of visual methods is highly dependent on its situation in the larger research design. Pink (2001) makes the point that cultural materialism and the setting of the research work should weigh heavily on aspects of visual methods, such as media used and facilitation of participant collaboration. In this case, I conducted most of the interviews in participants' homes, usually sitting at a table together, and as a result, the materials used during visual elicitation—markers, pens, crayons, and poster boards—fit in to the setting well. Participants were also familiar with the creative materials (particularly mothers, who were used to drawing with crayons), and took to the activity naturally.

Finally, the *usefulness* of employing visual methods was not completely guaranteed on the face of this proposed research—meaning I was not sure that the visual elicitation would add to the data supporting analysis of information needs changing over time, or articulating the social world of cancer

(although in fact, the visual elicitations did help with answering my research questions, as I found after executing pilot interviews). As Pink (2001) points out, with all qualitative data collection, the exact relationship between the researcher(s) and participants has to be borne out in the field (p.30; see also Pauwels, 2015); for example, I did not know if the visual representations would explicitly address named or designated illness phases (in fact, most did not). Having determined that the application of visual elicitation in this context fulfills the criteria of being “ethical, appropriate, and useful,” the next section addresses visual elicitation practices in the context of illness and in conjunction with illness narratives.

6.1.2 Using this Method to Capture the Illness Experience, or Narrative

Most approaches to illness narratives emphasize meaning making (Kleinman, 1988; Charmaz, 1999); specifically, illness narratives express perceptions of time and incorporate the major influences of the experience (which is not always clinic-based; most health experiences are grounded in home and social life). Mathieson and Stam (1995) and Little et al. (2002) also make a connection between illness narratives and transformed self-identity (Stets and Burke, 2003), which points to the value of an illness narrative as a unit of data that integrates reflection of the participant. By using visual elicitation, as well as a semi-structured interview, I intended to give participants two modes of expression for recalling experiences.

The hope was that study participants would be better able to express their illness experience in a way that de-emphasized the clinical spaces related to treatment and care, while amplifying participants’ needs over time in a way that they could self-characterize illness phase, social experiences, and adaptive behaviors over time. This type of work has been accomplished and written about previously in the health domain: for example, Rich et al. (2000) wrote about their work using visual and narrative elicitation with pediatric and young adult asthma patients. By using this method, the authors very clearly distinguished between concepts of diagnosis and disease (the medical) and social and illness aspects (the experiential):

The dichotomy between disease and illness is not unique to asthma. While it is perhaps more clearly characterized in the long-term setting of chronic conditions, the split between the biomedical and the experiential exists, to a greater or lesser degree, with any medical condition. (p. 252).

Visual elicitations have been used previously in research with people managing chronic illness, such as fibromyalgia (Chen, 2014; 2016). In this study, Chen asked participants to draw an “illness journey” timeline, which led to the identification of four primary health management features of the illness experience: (1) onset, (2) progression toward diagnosis, (3) acceptance, and (4) development of an illness management strategy. My aim in this study, which emphasized capturing dynamic informational and emotional needs in its empirical data collection, was very similar in attempting to elicit an illness trajectory or narrative progression with the aid of the visual elicitation.

In a similar approach to the context of cancer experiences, Thygesen et al. (2011) triangulated data between semi-structured interviews and a visual elicitation with gynecologic cancer survivors to gather illness narrative data. The authors found three enrichments to the data collected using the triangulation: (1) new information gathered about the same event between the interview and the visual artifact creation; (2) better connection between time, concrete events, and emotion; and (3) additional events emerging between events already discussed in the semi-structured interview through completion of the visual elicitation afterward.

I found the triangulation of my interview transcripts and visual artifacts resulted in benefits like those described by Thygesen, even though the approach to visual elicitation in this study was less structured than the method Thygesen applied. In this chapter, I give an overview of this method and its efficacy in capturing different aspects of the cancer experience, primarily through (1) visual analysis of the artifacts and (2) themes identified using triangulation between the semi-structured interviews and the visual data.

6.2 Methods

A brief overview of methods (which are explained in greater detail in Chapter 3) follows.

Table 6.1 Study participants (n=21)

Participant alias, Gender, and Age	Period between diagnosis & interview	Diagnosis**
Peter; Male, 31	9 months	Adenocarcinoma (head and neck)
Mark; Male, 32	1.5 years	Brain tumor
Monica; Female, 26	1 year	Breast cancer
Leah; Female, 32	1.5 years	Breast cancer
Michelle; Female, 37	1.5 years	Cervical cancer
Helen; Female, 31	6 months	Cervical cancer
Stephen; Male, 33*	10 months	Hematological cancer
Kathy; Female, 44*	10 years	Hematological cancer
Diana; Female, 30	2.5 years	Hematological cancer
Phoebe; Female, 36	3 months	Hematological cancer
Veronica; Female, 28	3.5 years	Hematological cancer
Rico; Male, 23	3.5 years	Hematological cancer
Emily; Female, 35	4 years	Hematological cancer
J.C.; Female, 34	4.5 years	Hematological cancer
Lucy; Female, 33	4.5 years	Hematological cancer
Kate; Female, 29	4.5 years	Hematological cancer
Bob; Male, 35	9 months	Hematological cancer
Dolly; Female, 33*	3 years	Lung cancer
Marie; Female, 42	30 years	Osteosarcoma
Emma; Female, 28	11 years	Thyroid cancer
Jo; Female, 28	2 years	Thyroid cancer

**Participant did not complete visual elicitation exercise*

***Several participants had rare types of hematological cancers; the exact diagnoses are withheld here to preserve participant anonymity*

6.2.1 Participants

Participant recruitment criteria were as follows: (1) over the age of 18 on the day of the interview, (2) spoke fluent English, and (3) had been diagnosed with cancer between the ages of 18 and 39. A subset of 18 participants completed the visual elicitation exercise (the three participants not completing the visual elicitation are noted with asterisks in Table 6.1). All participants (n=21) identified as a binary gender (16 female, 5 male). The average age of all participants was 32.4 years. Most participants (11) had been diagnosed with a type of hematological cancer, although solid tumor cancer diagnoses are also represented in the sample. The number of hematological cancer survivors represented in the sample likely

had two causes: first, I publicly identify as a Hodgkin lymphoma survivor, and second, the relative prevalence of hematological cancers in the young adult population.

Participants also experienced a range of treatments, including chemotherapy (infusion and oral), radiation, surgery, and stem cell transplant. Participants chose the meeting spaces where the interview occurred—often, the meeting was in participants' homes, but occasionally I met with individuals in a public place (e.g., a café). Each participant received \$50, and directed a \$25 donation to a non-profit organization of their choice, for compensation. I use pseudonyms chosen by participants for reporting results below.

6.2.2 Procedure

Each interview lasted approximately 90 minutes. Once I started the audio recorder, I walked through the interview protocol, which lasted approximately 45 minutes. The visual elicitation portion of the interaction also lasted approximately 45 minutes, and each participant received pens, markers, crayons, and a posterboard of uniform size to use as they saw fit. Eye contact between the participant and me generally decreased during this time. In the following section, I describe the results of this process in further detail. During the visual elicitation portion of the interview, I let the participant lead the construction of a visual depiction of the cancer experience. The visual artifact built on the structured interview and elicited nuances of the illness narrative and/or progression.

One consideration of the research design specifically pertained to the visual elicitation piece; as part of the consent process, participants determined whether their visual creations may be shared (1) publicly (e.g., on a blog post or YouTube); (2) in academic venues only; or (3) not at all, and destroyed at the conclusion of the data analysis. Participants were invited to ask questions at the time of completing consent; no one asked questions related to sharing the visual elicitation. All participants completed this portion of the consent, even if I subsequently deemed the visual elicitation inappropriate (n=3).

6.2.3 Data analysis

The visual artifact and interview transcript were analyzed in tandem, particularly in looking over the participant's statements elicited during the think-aloud protocol of creating the visual artifact.

Specifically, I used dual computer screens to view a digital scan of the visual artifact and code the interview transcript (using dedoose.com) simultaneously. The visual artifact and that portion of the transcript really cannot stand alone as data; the transcript often includes details regarding the participant's formulation of the visual artifact, or additions to the artifact in response to follow-up questions. Although this data analysis process does not represent a novel data triangulation approach, I describe my process here to emphasize that the datasets are not independent, and this tandem analysis gives a more nuanced understanding of participants' cancer experiences.

In the following section, I describe the following aspects of applying the visual elicitation method:

- (1) Types of visualizations;
- (2) Interactions using the visualizations, with illustrative cases;
- (3) Differences in participant engagement; and
- (4) Instances of failure in applying the methods.

Then, in the discussion session, I go on to reflect about the advantages and disadvantages of using this dual elicitation method, again using examples from interactions with participants to highlight discussion points.

6.3 Results

6.3.1 Types of Visualizations

To characterize the body of data elicited through the visuals, I evaluated each artifact for the type of experience conveyed, which ranged from very detailed and strictly chronological to conceptual, sometimes metaphorical, depictions of the cancer experience. I analyzed visual artifacts using a

combination of content analysis (the images contained in the artifacts; Krippendorf, 2012) and compositional interpretation (how the artifact's images were organized; Rose, 2007).

Here, triangulation with the think-aloud portion of the interview transcript was particularly useful, as it gave me data around the participants' words and musings as they constructed the artifact (I did not use video data collection), and allowed the participant to point out significant features of the artifact. Because my primary research questions focused on illness phase and changing information needs, the prompts for constructing the artifact incorporated a time- or progression-based view of the illness experience. When participants required a prompt, I would give the same progression in each case:

- (1) Where did your cancer experience start, according to *you* (not doctors or anyone else)?
- (2) If there is an "end" to the experience, where is it?
- (3) How would you depict the future?

Because the *n* of the visual elicitations was small (18), I used three broad categories to characterize the primary type of visual artifact produced, as follows (also see Table B):

Timeline type: A timeline visualization emphasizes (1) linearity of trajectory (usually, a timeline type of artifact contained an actual line), (2) continuity of experience, and (3) completeness of depiction, meaning the participant emphasized that all of the significant events were included on the timeline. Nine of the 18 visualizations constructed were timeline visualizations. During the think-aloud portion of the interview, participants producing timeline artifacts emphasized event continuity (the order and/or causes and effects of specific events).

Episodic type: An episodic visualization called out significant episodes in the illness experience, and lacked the linearity, continuity, and/or completeness of a timeline visualization. Episodes were often made discrete on the visualization by using "blocks" or numbering depictions of events, rather than using a line to flow from one to the other. Notably, participants producing episodic visual artifacts focused on anecdotes that were important to them in their story, and were more likely than participants producing

timelines to “jump around” in the cancer experience to expand on specific events. Five of the visualizations were episodic.

Metaphoric visualization: These visualizations represented a departure from either timeline or episodic types. These visualizations used an over-arching metaphor—which the participant often explained in detail—to describe the cancer experience. Four of the visualizations were coded as metaphoric types, they exhibited a variety of symbolic “takes” on the experience. Participants producing metaphoric visual artifacts used few words on the visuals (versus the other two types), and focused on constructing a coherent story using symbolism; participants also tended to reflect more on changes in their experience (at time X I felt A, at time Y my feelings changed to B).

Categorizing these visual types in analysis helped me to understand interview data and the process participants used to recall their illness experiences. The categories were not neat, however; the three visual types were sometimes confounded in the coding. For example, Bob (Figure 6.1) used a metaphor within his episodic type visualization; Diana also uses a straight line in her metaphoric type visualization. In the cases where types seemed to intersect, I used the think-aloud data captured during the creation of and reflection on the artifact to determine which aspects of the visual elicitation prevailed *according to the participant*. In Bob’s case, the episodes were paramount in his recall of the experience (true to the category of his artifact, his recall of events “jumped around,” which was helpful for analyzing his interview data). For Diana, the over-arching metaphor of her progression through the ups and downs of treatments was primary to understanding her depiction of the experience (in alignment with the visual expression, Diana’s interview focused on her progress of coping with her illness experience, the disabilities she faced, and helping her son to overcome his trauma).



Figure 6.1 An example of confounded visual types. Bob’s visual artifact was coded as an episodic type visualization, but it also incorporates a metaphor for cancer diagnosis (a previously peaceful island destroyed by an erupting volcano that had been building for years)

6.3.2 Differences in Participant Engagement

In a somewhat surprising observation, I found that older participants (30’s to early 40’s) tackled the visual elicitation portion of the interview eagerly, sometimes starting to draw before I had finished introducing the activity. Participants who indicated they were parents seemed particularly at ease with drawing and coloring, perhaps due to interacting with their children. Younger participants—i.e., in their 20’s—were less certain about the activity, and at least three of them commented that the activity reminded them of “school assignments.” Although I observed very little difference between men and women in relation to either visual content of the final artifact or willingness to engage with the activity, with the limitation that the sample was small (18 individuals), only 5 of whom were men.

In practice, also, some participants were timid with regard to their creativity or artistic talents, initially (Prosser and Loxley, 2008; p.18); however, this timidity was not universal, as individuals who prided themselves on organization could be eager to generate a timeline, regardless of artistic talent. I found it helped to have a script to guide the elicitation that starts “wide,” and offers flexibility as to the

amount of help that I gave as a researcher. When participants required a prompt, I would give the three questions about where the cancer experience started, how it “ended” (if applicable), and how the participant envisioned the future.

Often, these three prompts would offer plenty to get the participant started in “shaping” the experience. This process alternatively looked like: drawing a straight line; indicating an up-and-down or zig-zag pattern; starting to draw the first major event; or describing the metaphor they would like to use to depict the experience.

6.3.3 Interactions Using the Visualizations

The use of an artifact elicitation can stir unexpected emotions. For this reason, Prosser and Loxley (2008) call for a sensitive application of the technique, which must be mediated in real time by the researcher. I found a balance over time, with regard to sensitive application and effective data elicitation. Here, I describe three cases of facilitating the method. These cases illustrate four features of this method’s application: (1) reducing the need for eye contact (benefit to participant); (2) filling in details of the illness narrative (benefit to data collection); (3) shifting my facilitation protocol (learning real-time mediation); and (4) breaking out of the clinical narrative (benefit to participant and data collection).

In the first case, Peter and I met in his room at his house. His roommates were around and occasionally within earshot, so I asked him if it was still okay to conduct the interview at that time and place. He stated it was fine, and that his roommates knew his story. When it came time to introduce the activity, Peter approached the visual artifact construction tentatively. He seemed to be thinking as he searched for a pencil (the one writing implement I did not bring with me). Then, he broached a single (but illuminating) topic of his feeding tube during treatment. By concentrating on drawing an accurate depiction of his feeding tube from memory, as well as the scar from its placement, Peter was able to talk about the artifact rather than forced to make eye contact while discussing his feelings about the feeding tube. In this case, the visual elicitation portion of the interview was brief, but it highlighted an event in

Peter's experience that he had not previously explained in detail in the question-and-answer interview (Figure 6.2). This case illustrates the value of *reducing need for eye contact* and *filling in details* of the illness narrative.

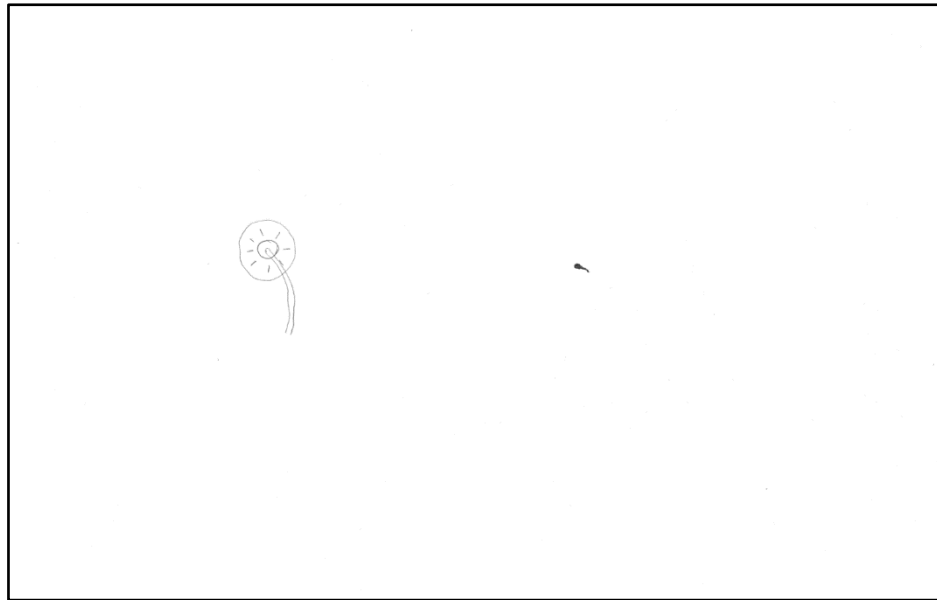


Figure 6.2 Peter's visual artifact: on (L) is his drawing of the inserted feeding tube; (R) is the comma-shaped scar. Using the visual elicitation allowed Peter to add detail about needing a feeding tube, which he had initially avoided explaining in the interview (Type: episodic)

In the second case, I met with Leah in her kitchen. Leah's diagnosis of metastatic breast cancer is relatively unusual for a young adult, and we spent much of the interview talking about her lack of peers and adjustment to ongoing maintenance treatment with oral chemotherapy. Leah had a difficult time getting a diagnosis; when her symptoms were finally addressed, she had been living with a fractured spine for some time. A chaotic period followed diagnosis, involving spine-stabilizing surgery and hospitalization, followed by coordinating with her new oncologist. Leah approached the visualization with some uncertainty, meaning I had to go further into my list of prompts to help her construct the artifact. In the end, Leah focused on her initial misdiagnosis, her period of hospitalization, and meeting her oncologist as major markers of her narrative timeline. Most significantly, to depict her diagnosis, Leah replicated the drawing her primary care provider had made for her to explain her back pain as

muscle spasms (her spine was likely fractured at that point; see Figure 6.3). Leah also struggled with depicting the future, due to the implications of her prognosis; for this reason, I generally declined to introduce the activity with subsequent participants who indicated an uncertain, “maintenance,” or terminal diagnosis. This case illustrates *filling in details* of the illness narrative, as well as a *shift in my facilitation protocol* (i.e., incorporating prognosis information into the decision of introducing the visual elicitation).

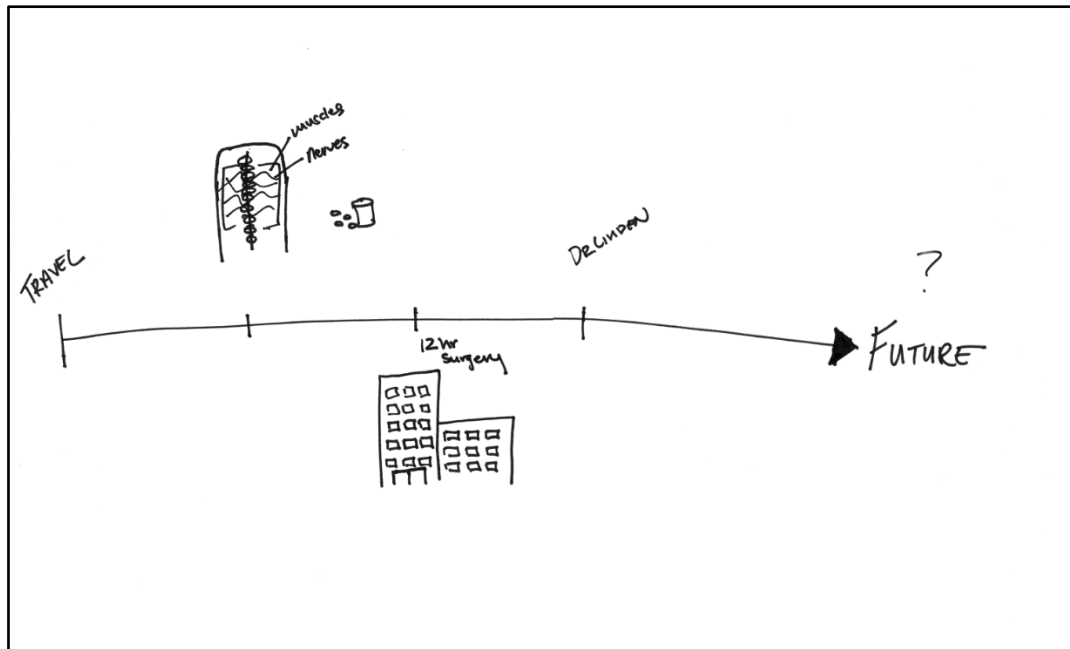


Figure 6.3 Leah’s visual artifact expresses uncertainty about the future with a question mark (Type: timeline)

The third case took place in Lucy’s apartment. We sat on her sofa and went through the interview protocol. Lucy had limited mobility in her shoulders due to joint deterioration from long-term steroid use. As a result, I was a bit apprehensive about introducing the activity, but she was very enthusiastic about drawing once I explained the elicitation activity. Although she had answered all of my questions about her diagnosis and treatment experiences thoroughly, with the visual elicitation, Lucy was able to focus on the positive episodes *she* most valued during her experience (Figure 6.4). The visual elicitation revealed aspects of her coping mechanisms (travel/escapism) and expressed an almost superstitious belief that her odd-numbered age years were more positive than her even-numbered age years. Lucy was also able to

talk about her aspirations, looking forward to being five years cancer-free and looking forward to moving to Hawai'i. This case illustrates a participant *breaking out of the clinical narrative* as well as a further *shift in my facilitation protocol* (i.e., allowing participants to decide whether they wanted to engage with the visual elicitation, rather than making assumptions about their abilities).



Figure 6.4 Lucy’s visual artifact contains most of the content on the top half of the poster board due to her limited range of motion (Type: episodic)

In summary, the interplay between artifact creation (visual) and narrative recollection was a powerful way to find gaps in the conversation and remembered experience. Some participants described the visual elicitation exercise as “cathartic;” essentially, they could represent their cancer experiences from start to finish with more perspective on its total effects. There were unintended benefits of the method, too. For example, a participant who had recently completed treatment for a malignant brain tumor occasionally wrestled with aphasia in verbally answering questions, but was better able to articulate some aspects of his illness experience with the poster board and markers provided. In this way, using multiple modes to collect data resulted in a more successful data collection effort.

6.3.4 Instances of Failure

Participants who did not complete the visual elicitation exercise did not decline the exercise. In these instances, I opted to forego the exercise for a variety of reasons. The most prominent context of failure in applying this method occurred with participants who had a terminal and/or maintenance diagnosis. In these cases, essentially, there was no future to depict visually (in terms of current medical technology) that didn't involve some manner of ongoing treatment(s) or disruption of everyday life. In this case, my prompts proved at least inadequate, or at most inappropriate. Essentially, it was unfair to try and elicit an "arc" of experience when few positive feelings or certain future plans could be ascertained.

Specifically, in the first instance, I did not feel the setting was appropriate (in public, in close quarters with strangers). In the second instance, the participant did not have childcare during the interview, so I elected to use the interview protocol only. In this case, although it may have been possible to engage the participant's children with paper and markers and crayons while conducting the visual elicitation, I did not feel interacting with the participant's children was appropriate or covered by the nature of the participant consent form. In the third instance, the participant indicated they had an uncertain prognosis; in this context, I learned from a previous participant interaction that the visual elicitation exercise could be difficult (see Leah's case, below), and I declined to introduce the activity.

Upon reflection, I could have adjusted the artifact elicitation prompts in real time in response to terminal or maintenance prognoses (although moving the site of the interview was a more difficult problem). I did not adjust the prompts in response to this barrier for two reasons: (1) I did not feel confident in formulating new prompts off the cuff; and (2) given that I hoped to communicate my findings in the health care space, I was particularly preoccupied with future scrutiny related to the reliability of my data.

6.4 Discussion

This section illustrates benefits to using the visual elicitation with the semi-structured interview. I discuss the benefits in terms of two previous works: first, the benefits Thygesen et al. (2011) articulated in

their study using visual elicitation with cancer survivors; second, Wagner's (2001) position that creative elicitation can "challenge or confirm" participants' realities. I include examples from participants' statements about their visualizations to illustrate these points. Finally, I summarize the lessons learned from using this method with my participants.

6.4.1 Benefits of Visual Elicitation with Regard to Recall

I saw clear benefits of my approach in assisting participants with their illness narrative recall, and I give examples of such moments in this section. These benefits were similar to Thygesen's (2011) findings regarding data triangulation between interview and visual elicitation. These benefits were (to reiterate from above): (1) *gathering new information about the same event* between the interview and the visual artifact creation; (2) *connecting time, concrete events, and emotion*; and (3) *additional events emerging* between events already discussed in the semi-structured interview through completion of the visual elicitation afterward.

There were specific aspects of the visual artifacts that seemed to assist with the three elements. For (1) *gathering new information about the same event*, participants would often be better able to recall vivid anecdotes after depicting the place a particular event happened (e.g., Leah and the hospital where she had spinal surgery). Leah also used her visualization to show the drawing a primary care provider had used to explain that her back pain was caused by pulled muscles (rather than the spinal fracture she likely already had; see again Figure B), which she found particularly convincing.

Interviewer: I'm amazed that you remember this drawing from your doctor so well—

Leah: *Yeah, because I was like, oh, that makes sense, he's right—muscles, nerves, that's there, yeah. I know obviously if you touch a nerve—yeah, it all makes sense. After [I was diagnosed with cancer], I was like, son of a— [Laughs]*

To the second benefit, (2) *connecting time, concrete events, and emotion*, the visual exercise was particularly illuminating in capturing happy and sad times. For example, Marie talked about the day her leg was amputated as a good day for her (though a bad one for her parents, who were worried she would

be “a freak” after surgery); Marie was excited to end the pain of the osteosarcoma tumor. In a similar case, Monica depicted herself with smiling faces throughout her visual. When I asked about the smiling faces, Monica was able to reflect on her positivity even at bad times (Figure 6.5).

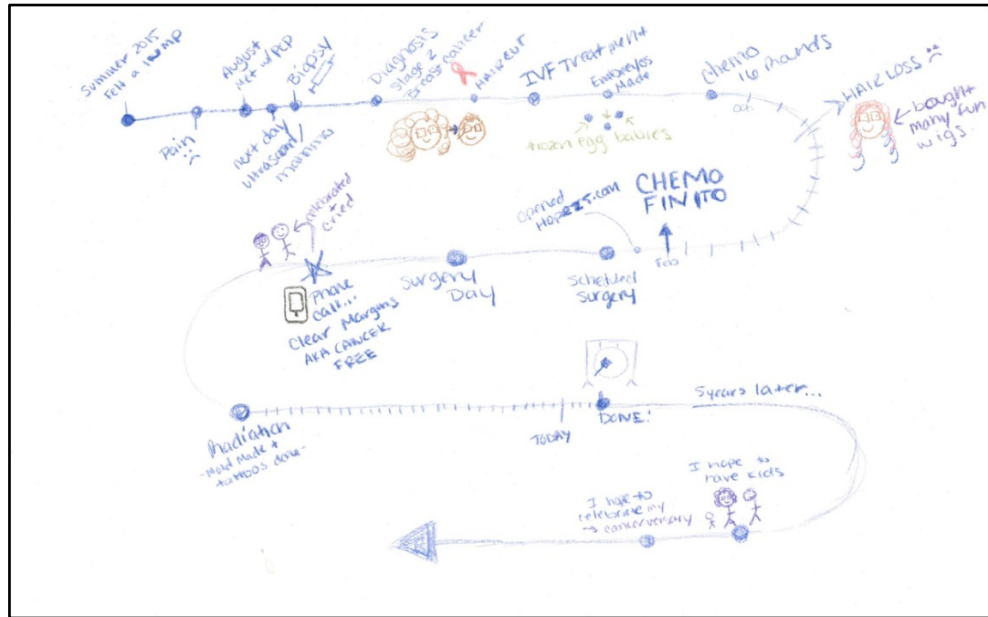


Figure 6.5 Monica’s visual artifact emphasized the “linearity” of her experience, with one event following the other. Monica filled in extra details of her experience (versus the interview data) as she built the timeline. (Type: timeline)

Interviewer: You’re smiling in all the—you managed to draw a smile every time.

Monica: *I tried to remain positive, but with the hair loss, when I realized what was happening...I planned a party, and went to my cousin’s hair salon, and I’d bought a special-made wig to look like my old hair. I just wanted to turn something that was so dark into something beautiful and I wanted to smile through it, at the end of it.*

Similarly, Jo was able to depict the emotion (loneliness) associated with the process of having her thyroid irradiated. She was confined to her apartment post-irradiation. “*That’s me in my apartment, by myself...It was just this not being able to personally interact with anybody was—yeah [trails off].*”

For the final benefit, (3) *additional events emerging*, the visual elicitation exercise often allowed participants to append important information to the narrative. Emily was able to address her fears about getting married to her partner in the context of her worries about cancer recurrence. This detail about her “moving on” from cancer that had not arisen earlier in the interview (Figure 6.6).

Emily: *As we were planning the wedding...I thought, what if [my oncologist] tells me I'm sick again and I have to go back to treatment? And instead of thinking, 'I'll just call everything off,' I thought: 'I'll just have to figure out how to incorporate a head scarf into my wedding dress.' It was a moment: I could actually be with her. I could think about [the future] a little more logically.*



Figure 6.6 Emily's visual artifact emphasized a therapeutic metaphor of a natural disaster followed by the eventual tranquility of a calm ocean (Type: metaphoric)

Veronica added a number of anecdotes to her narrative while working on her artifact, including experience of interacting with young adult health care professionals at the cancer clinic (Figure 6.7).

Veronica: *So [for radiation therapy] they gave me tattoos, to line me up with the machine...A lot of the radiation techs were my age, and [the one who tattooed me] asked, 'Did you know I used to be on LA Ink?' And it's a pretty good joke, but not the right time—there were a lot of strange interactions that way. In a normal context we could be friends, I guess, but at the time—it was weird.*

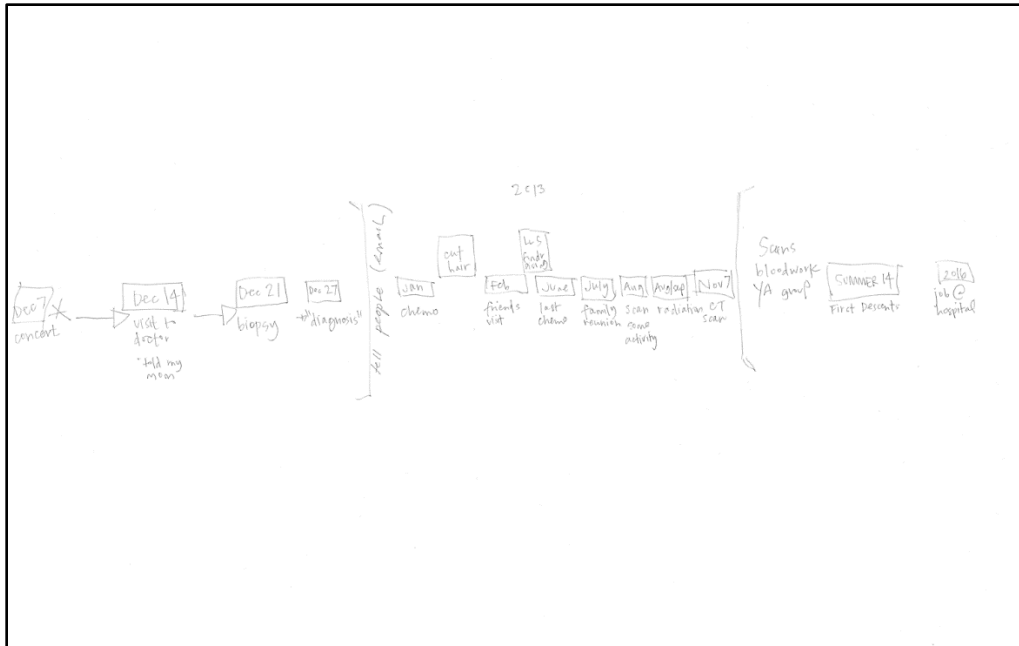


Figure 6.7 Veronica’s visual artifact demarcated important episodes during treatment and survivorship (Type: episodic)

6.4.2 The Ability to “Challenge or Confirm” Participants’ Realities

The visual elicitations offered an artifact, a thing, to which and with which participants could react. After fulfilling the original prompt, occasionally participants would be surprised about the way they had depicted an event, or would suddenly remember a new event in their narrative. To this point, Wagner (2001) points to the use of visual artifacts in research inquiry to “*deliberately challenge or confirm what people already know to be true...to offer [the images] up as evidence of other subjective realities, including those tied to negotiated inquiry with people we have studied*” (p. 19). In this study, the challenging and confirming parts of the visual elicitation often emerged in the questions and answers about the artifact, and I describe some moments where the visual artifact did so.

For example, because the visual elicitation called for a depiction of the experience arc, each participant completing an artifact had to address some kind of “end” to the experience. For Kate, the “end” of cancer involved her reflection on how her senses of time, and even bodily aging, had changed.

Those feelings arose from talking about her depiction of fertility struggles and the long-term impact of having experienced chemopause (temporary menopause caused by chemotherapy; Figure 6.8).

Kate: *I felt unsure about the future in the sense that I was being told I was going into menopause in my 20's. I thought, my body's prematurely aging—I'm doing something I'm supposed to do in my 50's—what does that mean for everything else? It's hard to believe I'll live till 80 or 90 if everything's happening so soon. The timeline is being squished down. That's obviously not—it doesn't have a lot of scientific basis—but that's how it felt.*

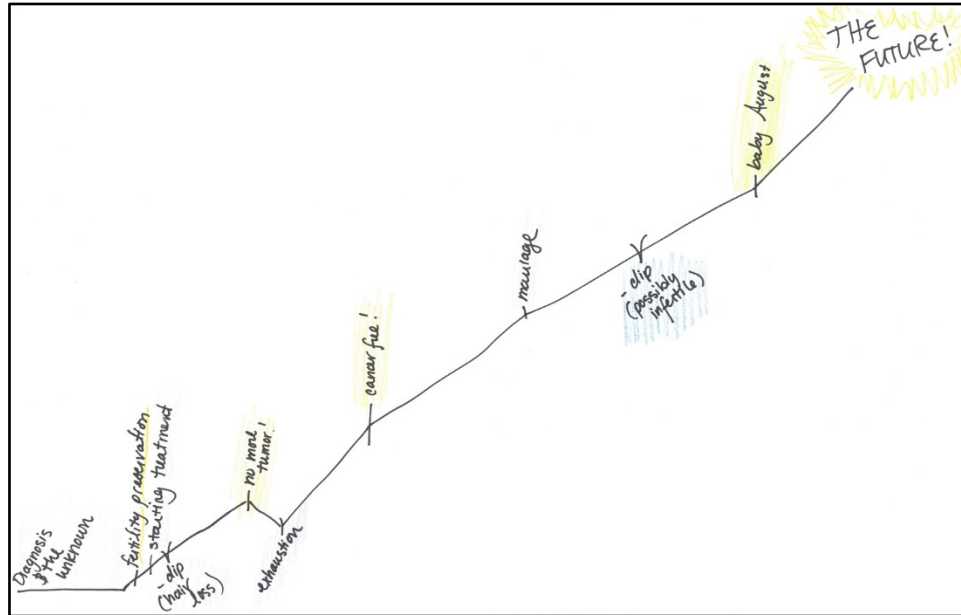


Figure 6.8 Kate's visual artifact emphasized reclamation of “real life” after starting a family, as well as the “ups and downs” of treatment (Type: timeline)

Some participants left the “end” open-ended. Rico expressed this in a playful way on his visual artifact (Figure 6.9).

Rico: *Does this have to be to scale?*

Interviewer: It does not have to be to scale, good question.

Rico: *Good, because the likelihood of that happening is slim to none. It's supposed to be until present? Future?...It's like one of those really bad invitations to a party from grade school. It's going to be till “question mark” ...so you never really are—you're never really free from cancer. Ever.*

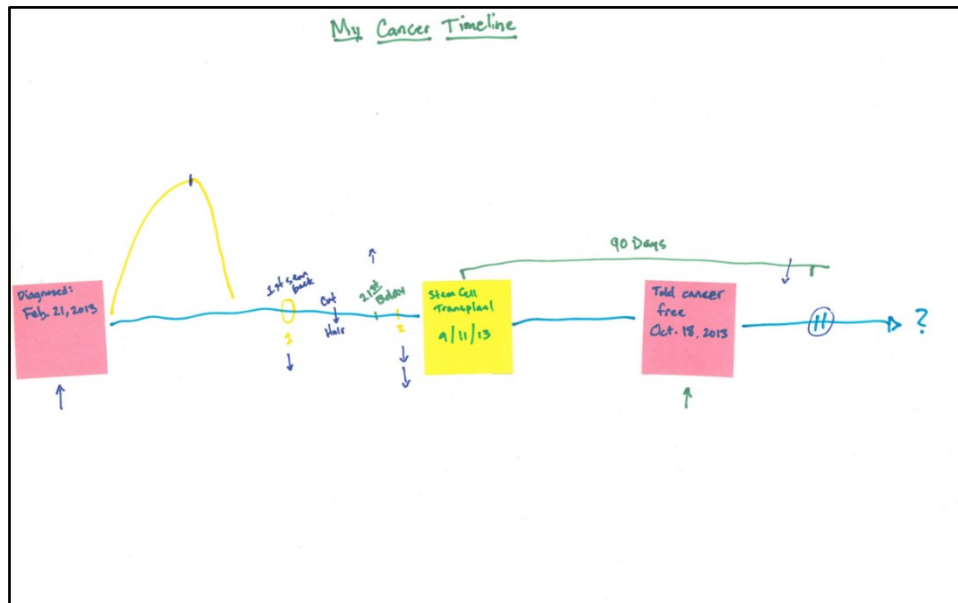


Figure 6.9 Rico’s visual artifact expressed “ups and downs” through failed first-line treatment, and weaved important “real-life” events—such as his 21st birthday—into the illness experience. (Type: timeline)

Finally, some aspects of the artifact allowed participants to reflect on their identity and emotions related to the cancer experience. Emma, who depicted her experience as a train ride (Figure 6.10), where she had little control over where the tracks carried her, explained why that metaphor worked.

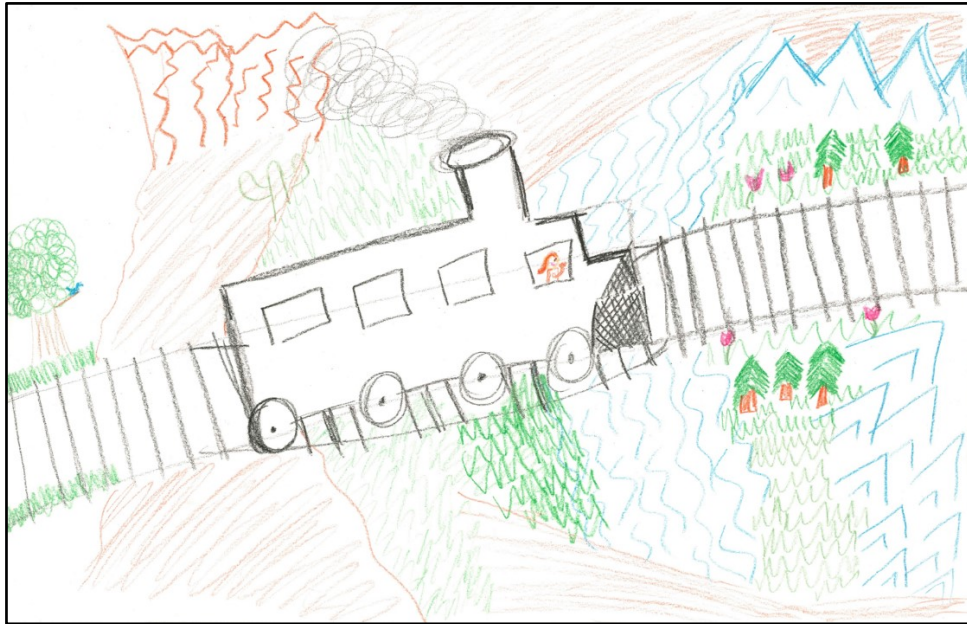


Figure 6.10 Emma’s visual artifact used a metaphor of a train ride to express uncertainty and lack of control, as well as “changes” in the landscape of her life (Type: metaphor)

Emma: *[The cancer experience] is totally not linear. If the certainty were bends in the road, you know how you can’t really see the road or the tracks when you’re going around a curve on a train or a car or a bus? And you’re feeling the centripetal force—you’re feeling the physical forces move you in one direction, but you’re not sure which way the vehicle is moving. I guess that’s the way [the uncertainty] feels sometimes.*

Finally, for Helen, reflecting on the symbol of her cancer (teal for gynecological cancers; Figure 6.11) led to a realization about her attitude in moving on from the experience.

Interviewer: You have—you became a teal lady up here [at the start of the experience], but there’s no ribbon at the end.

Helen: *I associate the 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. That’s a good catch. This is my fight, and this is when it’s over—I’m free, I’m not just a cervical cancer survivor.*

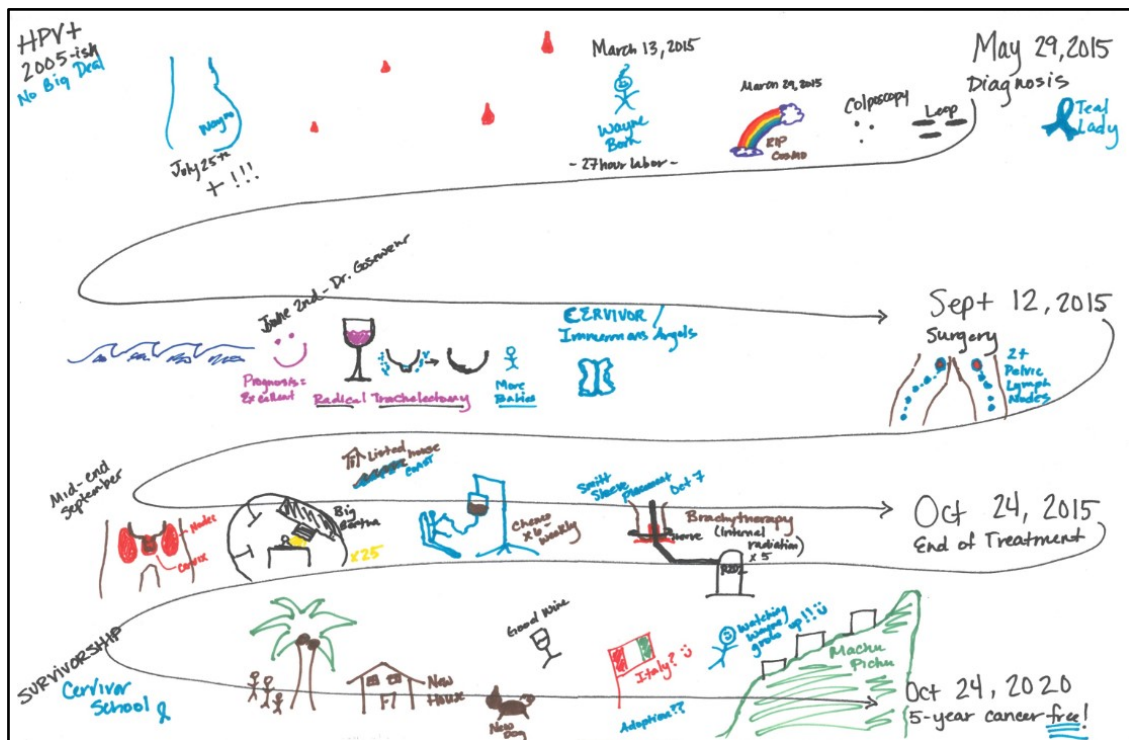


Figure 6.11 Helen’s visual artifact wove family life and hopes for future family plans in with multiple treatment experiences, and emphasized moving on after five years of cancer-free living. (Type: timeline)

6.4.3 Assessing Use of the Method and its Appropriateness

Having applied a visual elicitation method in the context of young adult cancer illness experiences, I identified three primary lessons in applying the method and ensuring its appropriateness when engaging with research participants. *First*, this method requires a period of “warm-up,” meaning that participants benefit from a period of reflection on the phenomenon of interest (here, the cancer illness narrative). In essence, I do not think that facilitating the visual elicitation “cold” would have worked particularly well for this context; however, I was also engaging with members of a population who may have cognitive difficulties from the effects of treatment or the trauma itself.

Second, the facilitation of the visual elicitation requires from the research a focus on real-time decision making. The researcher must manage time for the research activities well, and ask the following questions when the time comes to introduce the activity, or not:

1. Is the participant emotionally prepared to engage with the visual elicitation activity?
2. Is the space where the interaction taking place “safe” for the participant?
3. Is there any evidence that further questions and answers will increase participant distress?
4. Is the activity designed to sensitively elicit the participant point of view, according to their circumstances?

Third, if or when the activity is introduced, the researcher should continue to act and react in real time, for example adjusting protocol to accommodate participant engagement and letting the participant “lead the way” in owning the construction of the artifact. This aspect of the visual elicitation can tip the balance toward the participant as an expert in their own experience, thereby offering the participant a new “position” from which to reflect on and shape their narrative(s).

6.5 Limitations

This study was executed with a relatively small sample (n=21; n=18 completed all study procedures) and self-selection bias likely attracted individuals who are more “open” about their cancer experiences, in both its positive and negative aspects. In addition, at least one participant mentioned having received art therapy, which may have affected that participant’s visual elicitation work. Future research is required to explore the contexts in which triangulation with interview and visual data is appropriate, though this study points to the promise of employing visual elicitation with participants who are young adults and adults, not just children.

6.6 Conclusion

By using and reflecting on the use of this data triangulation method, I expand the tools that qualitative researchers can use to elicit valuable information about the *how* and *why* of experience, such as with participants from vulnerable populations (Liamputtong, 2006; Malterud, 2001). By eliciting visual data about survivor experiences, I demonstrate a model of eliciting rich, multi-modal qualitative data that gives a more complete view of research participants’ experiences in context. Specifically, this approach

enriched my ability to understand my participants' illness experiences, which can contain a great deal of nuance that might be lost using a single data collection method. The alternating modes of control and expression (in the interview, researcher as interviewer and participant as respondent; in the visual elicitation exercise, researcher as curious observer and participant as leader) also lend a "balance" to the research act, building trust between researcher and interviewer. Upon reflection, this combination of methods is both appropriate for studying illness experiences or for other, analogous questions around traumatic and/or formative experiences; furthermore, this visual elicitation method points to the opportunity to use such visual elicitation methods more often with young adult research participants.

“Survivorship is a complicated notion because people often confuse a process of survivorship with a mythic identity of being a cancer survivor...Living is a process. Living with cancer is a process.”

Brad Zebrack, PhD (2015)

Young adult cancer survivor and researcher

Chapter 7. Summary and Conclusion

7.1 Describing Dynamic Needs of Young Adult Cancer Survivors

In this thesis, I have described the experience of young adult cancer survivors in terms of changing needs over time, from the period of seeking medical answers, to diagnosis, to treatment and survivorship or maintenance care. The needs I have detailed are (1) informational: related to health management, finding care, forming expectations about future events and quality of life, and (2) emotional: the invisible work of finding cancer peers to reduce experiential isolation, coping with changes in friendships and family dynamics related to diagnosis and treatment, as well as struggles with long-term identity.

I found that informational and emotional needs did, in fact, change over time; participants in this study adjusted their adaptive behaviors to meet each new challenge during their illnesses. For example, survivors often sought out “cancer peers” to reduce the experiential isolation of a cancer diagnosis, but the characteristics of helpful cancer peers changed over time—most often shifting from criteria around medical information needs (e.g., sharing similar diagnoses) to criteria related to life circumstances (e.g., finding another young parent who had cancer to discuss children’s emotional needs). The dynamism of young adult survivor needs extended beyond temporal shifts, however; the social repercussions of cancer were also a potent force in the progression of the illness narrative. Participants described friends abandoning them, strangers commenting on their appearance or disabilities in public, and a new, crucial working relationship with their oncology care teams at a frightening time. In the following section, I detail the contributions of this thesis in terms of relevant disciplinary domains.

7.2 Thesis Contributions

7.2.1 Computer Supported Cooperative Work

In February 2017, I presented my findings addressing Aim 1 (Chapter 4 of this thesis), describing the collaborative work of young adult cancer survivors. Here, I described survivors' use of technology and exchanging of informational and emotional support online. Currently, online spaces and clinical care support do not respond well to young adult survivor needs as they change over time, and therefore I presented dynamic (changing) design implications for (1) online spaces survivors use and (2) support from social workers or other clinical team members, who can counsel survivors related to finding cancer peers or appropriate support organizations, or can help survivors understand managing their privacy.

7.2.2 Young Adult Oncology

Findings related to Aim 2 (Chapter 5) will be submitted to a journal for oncology care team members treating young adult survivors (e.g., the *Journal of Adolescent and Young Adult Oncology*). Opportunities for improving care for young adult survivors is important because the experiences of these young adults survivors differ from that of pediatric patients, who remain wholly independent on their parents or guardians for family support, as well as older adult patients, who have likely dealt with cancer in the course of their lives. Here, I contribute a holistic viewpoint of the young adult cancer experience. In conducting a thematic analysis of the relationships my participants describe, I argue that a young adult's relationship with their oncologist, although central to treating cancer, is just one of many influential relationships during the cancer experience. In this contribution, I point to opportunities for oncologists better support, counsel, and treat young adult survivors given their social worlds and related risks.

7.2.3 Visual Elicitation Methods with Young Adults

In response to Aim 3 of this thesis (Chapter 6), I reviewed and reflected on my choice of visual elicitation methods in this study. Visual elicitation methods such as sketching are generally associated with engaging young participants (i.e., children) in qualitative methods studies. To explore using a version of these methods with older participants, I describe my use of the combination interview and visual elicitation method with young adults between the ages of 20 and 40 years old. I found sketching enhanced participants' abilities to express certain emotional aspects of their cancer experiences, sharpened recall of events, and led to creative expressions such as metaphors to relate feelings of both grief and growth. In addition, the visual elicitation method allowed participants to express changes in their needs and experiences over the course of the young adult cancer experience. I intend to submit this chapter to a journal such as *Field Methods*, to share my findings from facilitating the visual elicitation method.

7.3 Limitations

This study design involved only one in-depth interview-focused contact with each participant; thus, I do not present a longitudinal understanding how an individual's information needs change over time. In addition, the use of an interview with survivors at different points of their experience introduces recall bias—although in analyzing the data, it remains unclear whether this bias skews to negative or positive emotions or associations in remembered events (and it is possible this bias depends upon the individual). In future work that examines the effect of illness phase on information needs, or asks cancer survivors to reflect on their relationships with oncology care team members, a longitudinal approach would add rich detail and enhance the validity of findings related to dynamic information needs.

A further limitation of this study is its focus on young adult cancer. The findings herein may be applicable primarily to young adult survivors, rather than younger or older survivors, by design. In addition, many pathologies and prognoses are represented among the experiences of 21 participants. Given the tendency for cancer information needs research to focus on cancer information spaces—which

tend to be segregated by pathology or diagnosis (e.g., breast cancer versus metastatic breast cancer)—the approach of including a range of diagnoses is unusual in the context of this information needs inquiry. However, this work explores the experience of young adult cancer broadly, finding that participants' attitudes about finding peers and exchanging information often conflicted with the segregation-by-diagnosis convention.

7.4. Designing Information Resources and Support for Young Adult Cancer Survivors

7.4.1 Phase-Based Systems and Tools that Respond to Dynamic Needs

The phase-based tools I describe in Chapter 4 add a new dimension for designing tools for young adult cancer survivors. For example, I suggest tools that help newly-diagnosed survivors to quickly connect with peers, who can assist in finding good information; in the long term, survivors want safe spaces to talk to a broader range of survivors who share life circumstances in common. In a similar way, technology tools that support multiple modes of storytelling (photos, text, hashtags, hyperlinks) can support the survivor in controlling their own stories; in long-term survivorship, the role of storyteller may be subsumed by different roles, such as advocate or mentor. Finally, I suggest survivors need to be able to change their privacy settings over time, to adapt technology tools that not only let them share information about their cancer experience in different ways, but also supports a “right to forget” their cancer experiences, letting them move on from cancer altogether, if desired.

7.4.2 Oncology Services and Care that Meet Young Adult Survivor Needs

The social world of the young adult survivor includes friends, family, cancer peers, cancer organizations, previous medical interactions, and the crucial working relationship with an oncology care team. I describe the social world of young adult cancer given its unique context, occurring at an important developmental stage in an individual’s life. The social risks of young adult cancer that emerged from participant experiences include losing friends, struggles to find cancer peers, coping with sudden changes in family dynamics, and building a new relationship with oncology care teams at a vulnerable time. Given these findings, I outline five opportunities for oncology care teams to improve communication with young adult patients: (1) partnering with the young adult survivor; (2) enacting goal-based care; (3) suggesting information resources outside of the clinic; (4) reassuring survivors about cancer care etiquette (e.g., second opinions); and (5) acknowledging the social world and related difficulties of young adult cancer.

7.4.3 Visual Elicitation to Engage Participants in Vulnerable Populations

Participants in this study proved willing to engage with the visual elicitation exercise in addition to the more traditional interview. Although there were situations where I chose not to facilitate the elicitation method, due to circumstances of the interview or the participant, the method itself calls for such real-time decision making. I describe this challenge, as well as other benefits and challenges, in reflecting on my use of the method in this study. I will continue to use unique elicitation methods in future work with vulnerable populations, and have already experienced some success in probing long-term coping processes of cancer survivorship in running a subsequent study about cancer survivor tattoos.

7.5 Future Work

Findings from this study describe some difficult aspects of managing survivorship, such as coping with trauma, loss, and grief, ongoing disability and changes in the body, and survivor work related to reconciling “before cancer” and “after cancer” life. Because of these preliminary findings, I have undertaken work that attempts to extend and deepen descriptions of coping mechanisms in the survivorship phase.

Specifically, I conducted a new interview-based study with cancer survivors who have tattoos related to their experience(s) with cancer. Similar to the use of visual elicitation in this thesis, the interview for this subsequent study used an artifact to spark conversation with cancer survivors about their coping processes in long-term survivorship (of which their survivor tattoos were a part). Data collection for this study is complete, and I intend to write two papers for the following audiences: (1) health professionals in oncology and (2) fellow researchers in critical design of interactive systems (e.g., patient-provider interactions).

In addition, I have begun examining the online resources available to cancer survivors and offered by the 47 comprehensive cancer centers in the United States (all funded by the National Cancer Institute).

Preliminary results from this research are as follows:

- (1) The taxonomy of survivorship services, even at world-class cancer clinics, often mimics the chaos and confusion of the survivorship phase itself.
- (2) Accessing survivorship care appears to involve at least as much invisible patient work as does cancer treatment.
- (3) Survivorship care, although guided by best practices at a national level, is effectively a “black box” of confusing services and entitlements that may lead to disengagement among survivors.

The final results of this analysis will be written in partnership with Dr. Betsy Rolland, of University of Wisconsin-Madison, and published in a journal for the benefit of survivorship clinic managers and clinicians.

7.6 Concluding Remarks

This thesis study contributes a framework for the relationship between illness phase and information needs in the young adult cancer experience, and creates a view of the social world and related risks of young adult survivors. These perspectives were formulated using a combination of qualitative methods capable of yielding new insights for young adult survivors’ unique, and dynamic, information needs. The results of this study inform practical design recommendations for information systems and services supporting young adult cancer survivors. To improve information systems, I identify illness phase as an additional dimension that can inform design of online spaces young adult survivors use to connect and learn about their health. To improve information services in this context, I describe opportunities for oncology care teams to improve their abilities to meet the unique needs of young adult patients, motivated by recognition of the social world of young adult cancer. Better information systems and services design can lead to three important benefits for the young adult cancer survivor population: (1) increased survivor

engagement in managing treatment and survivorship issues over time; (2) improved communication between survivors and oncology care teams; and (3) improved health outcomes through informed decision making about treatment and survivorship issues.

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Appendix A. Interview Guide and IRB Materials

A.1 Consent form

**UNIVERSITY OF WASHINGTON
CONSENT FORM
Qualitative Study of Young Adult Cancer Survivor Illness Phase**

Researchers: Jordan Eschler Email: jeschler@uw.edu Phone: 206-218-4582

Researcher statement

I am asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what I will ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When I have answered all your questions, you can decide if you want to be in the study or not. This process is called “informed consent.” I will also give you a copy of this form for your records.

PURPOSE OF THE STUDY

This study investigates the how cancer survivors characterize their cancer experiences. By asking participants to reflect on their cancer experience, this study will investigate the changing information needs at each illness phase. The information collected during the study, from 20 to 40 individual participants, will be used to determine if and how information needs change over time. This study is intended to design better information systems and services for cancer survivors in the future.

STUDY PROCEDURES

All procedures in this study are expected to take 60-90 minutes to complete.

The first procedure is an interview. The researcher will use a script of questions to conduct an interview with you. You will choose an alias to be used in coding the information collected. During the interview, I will use an audio recorder to capture information; then, the audio file will be transcribed and immediately destroyed afterward. If you want, we will contact you to review the coded transcript and request any changes if you feel it is inaccurate. If you want, we will contact you when our analysis is complete to provide you with research findings.

The second procedure in the study is a task in which you will asked to visually express your cancer experience by creating a Timeline. I will supply you with poster board, markers, and other art supplies to create this Timeline. I may ask you questions about the Timeline as you sketch or

write. In addition, I will take a digital photograph of the Timeline you create for the purpose of collecting study data. This photograph will contain no identifying information about you. At the conclusion of our session, you are welcome to keep or discard the Timeline as you wish.

You may refuse to answer any question in the interview, or decline to complete part or all of the Timeline portion of the study.

RISKS, STRESS, OR DISCOMFORT

This study is not intended to expose you to undue risk or stress. If, at any time, you find you do not want to answer a question, you may refuse to answer with no penalty to you. Additionally, you will have the opportunity to review the interview transcript to make any changes you wish once the anonymized transcript has been completed.

BENEFITS OF THE STUDY

Although you may not benefit personally from participating in this study, the information you share is intended to benefit cancer survivors in the future, by improving the effectiveness and utility of information systems and services.

SOURCE OF FUNDING

The researcher is receiving financial support from the National Science Foundation.

CONFIDENTIALITY OF RESEARCH INFORMATION

All of the information you provide will be confidential. We will retain the link between the alias and your identifiable information until you no longer wish to be contacted for follow up. However, if we learn that you intend to harm yourself or others, we must report that to the authorities.

For the Timeline artifact that you create, you will choose how you wish the photographs of that artifact to be used and shared, from the following options: (1) retained in a secure manner after analysis for research and not shared in any venue; (2) retained in a secure manner and published in academic journals or conferences only; or (3) retained in a secure manner and published in academic journals or conferences as well as in other contexts (e.g., publically, such as on YouTube or in other social media publications related to the study).

OTHER INFORMATION

You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. Whether you complete all study procedures or not, you will be compensated \$50 for participating, and have the opportunity to direct a \$25 charitable donation to the organization of your choice at the conclusion of the interview.

RESEARCH-RELATED INJURY

If you think you have a medical problem related to this research, contact Jordan Eschler at jeschler@uw.edu. She will refer you for treatment as necessary.

PERMISSION RELEASE FOR PHOTOGRAPH PUBLISHING

Please indicate how you would prefer the photographs of your timeline to be used:

It is acceptable to publish the photographs of my timeline with no identifying information in public or academic venues (including YouTube, blog posts, etc.)

Please limit publishing the photographs of my timeline with no identifying information in academic venues ONLY (including conference proceedings or online journals)

Please securely retain the photographs of my timeline after analysis of the data is concluded and refrain from publishing them

Researcher’s signature

Printed name of researcher	Signature	Date
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Subject’s statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, or if I have been harmed by participating in this study, I can contact the researcher listed on the first page of this consent form. If I have questions about my rights as a research participant, I can call the University of Washington Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.

Printed name of subject	Signature of subject	Date
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Copies to: Researcher
Participant

A.2 Recruitment language v.1

Tweet/Facebook text 1:

Are you an adolescent or young adult cancer survivor? You may qualify for a compensated interview for UW research! [URL]

NOTE: URL will lead to **Intake form for interested potential participants** (Addendum B)

Tweet/Facebook text 2:

UW researchers would like to know more about adolescent and young adult survivor experiences. Click here for more info: [URL]

NOTE: URL will lead to **Intake form for interested potential participants** (Addendum B)

Tweet/Facebook text 3:

Please RT and share! UW researchers are seeking participants for research with adolescent and young adult cancer survivors. Click here: [URL]

NOTE: URL will lead to **Intake form for interested potential participants** (Addendum B)

A.3 Intake form for interested potential participants v.1

Hi! My name is Jordan Eschler and I am a PhD student at the University of Washington Information School.

**Were you, or have you been, diagnosed with cancer between the ages of 15 and 40?
Are you 18 or over as of today?**

If so, you qualify for a compensated interview in a research study designed to explore how cancer survivors use information related to their diagnosis and illness. This study has been designed by a current cancer patient (I am a Stage 4 Hodgkin's Lymphoma survivor). This research is intended to benefit current and future cancer survivors by getting them better information when they need it. Compensation for this interview, which takes approximately 90 minutes, is \$50.

Please fill out the form below if you would like a researcher to contact you.

This research study design has been reviewed by the University of Washington Institutional Review Board (IRB) Human Subjects Division. If you have any further questions, please contact Jordan Eschler: jeschler@uw.edu or call or text 206-218-4582.

Please note: The confidentiality of information sent by email or text cannot be guaranteed.

1. Please indicate the name you'd like me to use when emailing or texting:
2. Please enter your email address:
3. Please enter a phone number where I can text you from a secure study phone:

I will get back to you as soon as possible. Thank you for your time!

A.4 Semi-structured Interview protocol v.1

[Consent form will be presented and collected prior to reading the preamble]

I will be using a list of questions to stay on track during the interview. Sometimes I might ask follow-up questions as we go, too. Once we have covered the first few questions, we can also talk about putting together a timeline of your experiences. You can express yourself however you'd like in putting together the timeline. Do you have any questions before we begin?

First, what would you like your pseudonym for this interview to be? I will use that to anonymize your transcript and my reporting on findings.

Thank you. I have a few simple questions to start.

How old are you?

What is your gender?

When did you receive your cancer diagnosis? What was your diagnosis?

How would you describe where you are right now – in treatment, in remission?

Can you describe your course of treatment for me?

Let's start with you telling me about your experience in your own words. How did your cancer experience start?

What are some things you remember the symptoms you experienced?

What were your greatest needs when you were at home?

What were your greatest needs when you were at the clinic or in the hospital?

Who were the most helpful people during your experience? Why?

Who were the most influential people during your experience? Why?

Were there any books or movies or other things you experienced while you were ill that seemed helpful or insightful? How so?

Were there any books or movies or other kinds of information you avoided that you can think of? When did that happen? How did it make you feel?

When you felt like you needed more information about what to expect or other aspects of your experience, how did you find information?

What role did other cancer patients or survivors play in your illness experience?

A lot of times, doctors or nurses or informational pamphlets for cancer patients will talk about the “new normal” after a cancer diagnosis. What does this phrase mean to you?

Let's move into the timeline exercise. I'm going to spread out a bunch of materials, like paper and markers and scissors, and I'd like you to put together a timeline of your illness. It doesn't have to be anything fancy, but I'll give you as much time as you want. [Allow participant to construct timeline, refrain from asking questions]

It looks like you've got a good start. May I ask you some questions about your timeline?

Where did you start your journey? What does the “start” mean to you?

What are the major markers for you during your experience? [Ask about each]

What are the highlights of your experience when looking at this timeline? [Ask about each]

Were there any occasions, looking back at your timeline, where you felt the way people treated you or talked about you didn't line up with the way you felt about yourself or your experiences?

How do other people figure into your timeline?

Are there any places on the timeline you remember feeling uncertain? How did you overcome that uncertainty?

Can you point out any places on the timeline where you were more or less confident about the future? Why do you think that was?

Is there anything else you'd like to share about your timeline?

Thank you for your time today. I would like to take a picture of your timeline if that is okay. It will be used according to your wishes from the consent form.

A.5 List of materials for constructing timeline v.1

- Poster board (2' X 3')
- Scissors
- Dot-shaped stickers
- Markers
- Crayons

Appendix B. Codebooks for Data Analysis

B.1 Chapter 4 Codebook

Code	Definition
Offline information	Information found offline (e.g., verbal from oncologist, pamphlet, support group, etc)
Communication with care team	Act of discussing treatment, side effects, other concerns or questions with oncology care team.
Social	Statement refers to socialization not specifically related to cancer or on a social media site
Online information	Information found online (e.g., website, forum, Facebook, etc)
Similar experience	Statements that talk about similar experiences with cancer peers
Uncertainty	Reflections on levels of uncertainty or coping with uncertainty
Avoiding information	Participant explicitly gives example of information avoidance, either on a particular medium or in a specific situation
Information from the body	Participant talks about noticing physical symptoms or changes in the body
Information sharing	Episodes of sharing information about the cancer experience with others
Other mode	Modes not captured in online/offline divide (usually telephone calls with Imerman mentors)
Time sensitivity	Situations in which participant felt pressured to find information or make a decision in haste
Encountering	Participant describes "stumbling" on helpful information
Other processing information	(dropped-not used)

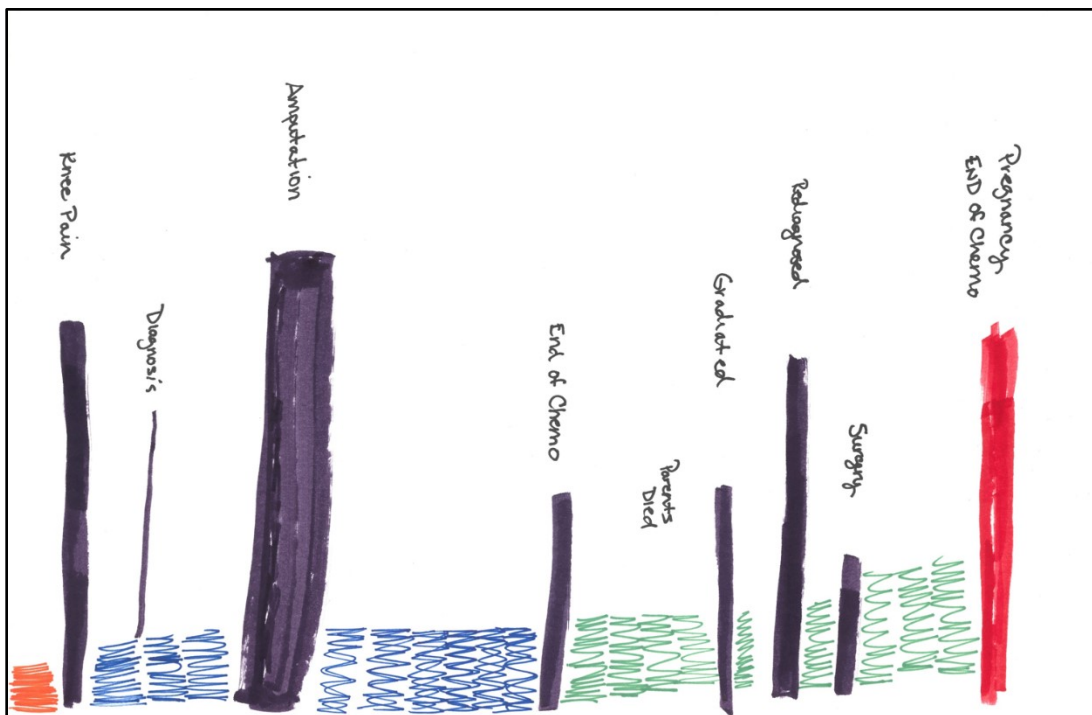
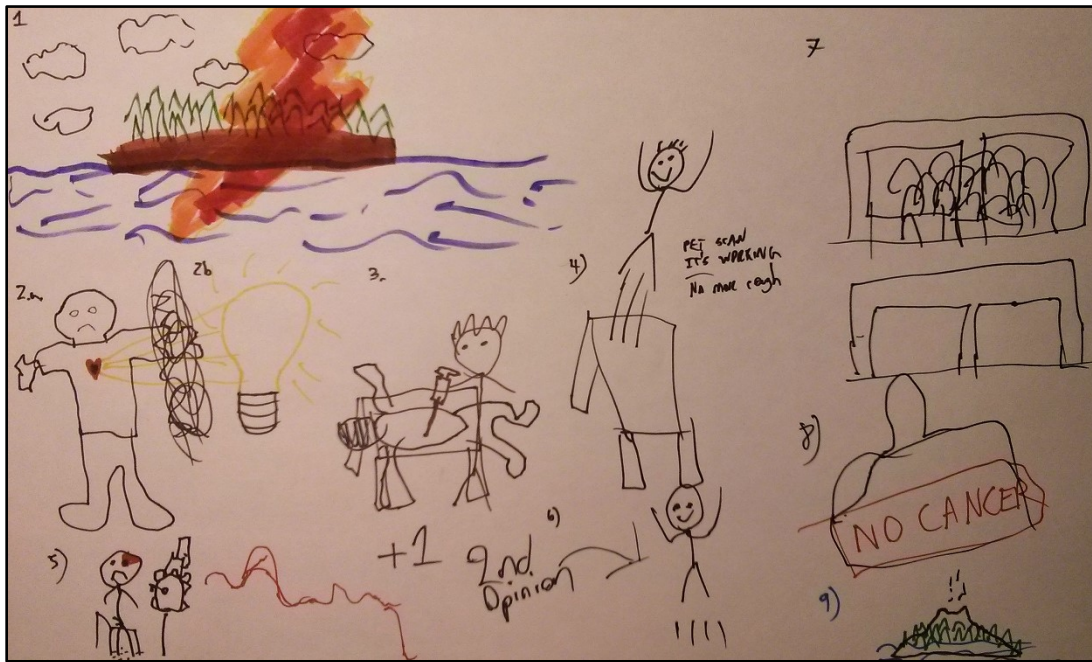
B.2 Codebook for Chapter 5

Code	Definition
Oncologist	Interactions with oncologist or onc care team
Cancer Peers	Interactions with cancer peers (may overlap with friends/family)
Online	Interactions with people online--can be cancer peers or others
Independent Research	Research the participants undertakes on their own
Family	Interactions with family members, including children
Other Medical Interaction	Interactions with medical professionals who are not part of onc care team
Phase Change	Participant describes moving from one state of mind to another, or a change in medical phase (e.g., treatment to survivorship)
Organizations	Interactions arranged by cancer organizations, or consulting info from those orgs
Friends	Interactions with friends
General Social	Participant describes episodes of "being out in the world" when cancer affected a social interaction (can be with a stranger, in the clinic, etc)
Complication	Participant describes a side effect or medical complication of treatment/other medical care
Hospital Culture	Participant refers to aspect of hospital stay or care that impacted their experience
Nursing	Participant refers specifically to interaction with nursing or comments on nursing care
Primary Care Doctor	Interactions with PCP
Media Portrayals	Participant comments on media portrayals of cancer, compares their experience, etc
Church	Participant refers to worship community as part of social circle

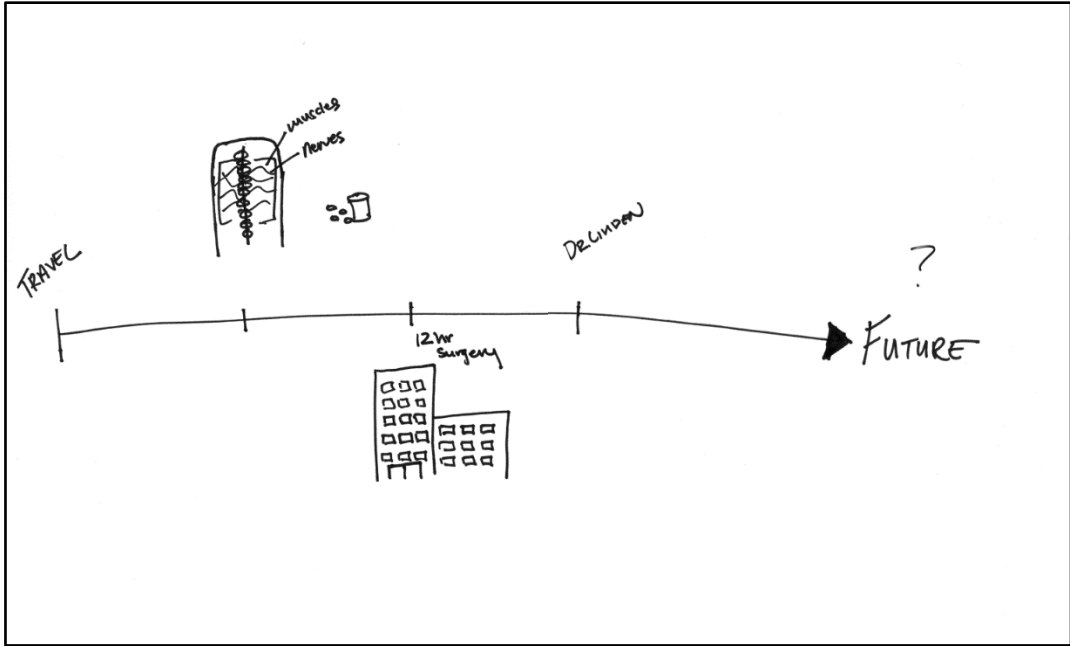
B.3 Codebook for Chapter 6

Code	Definition
Question	When participant asks a question about the artifact or the elicitation process
Coaching	When participant requests further prompts to get started on visual elicitation
Enhancements to recall	When a participant added an episode to a story or recalled more detail about an event
Highs/lows	When a participant points out a high/low in the experience, particularly if it is unexpected or contrary to expectations
Capturing doctor visual communication	Participant replicates visual artifacts oncologist or other provider has used to communicate (e.g., drawing of a surgical procedure)
Perceptions of time	Participant mentions significant measures of time, or perceptions of time speeding up/slowing down
Metaphor	Participant incorporates metaphor into visual, or explains a concept using a metaphor verbally
Moving on	Participant addresses concepts like coping, moving on from cancer, the future
Cancer symbolism	Ribbons, wigs, hats, etc
Uncertainty	Use of question marks or other placeholders to denote uncertain aspects of experience
Creativity comments	Participant expresses some judgment of their abilities to draw, be creative, etc

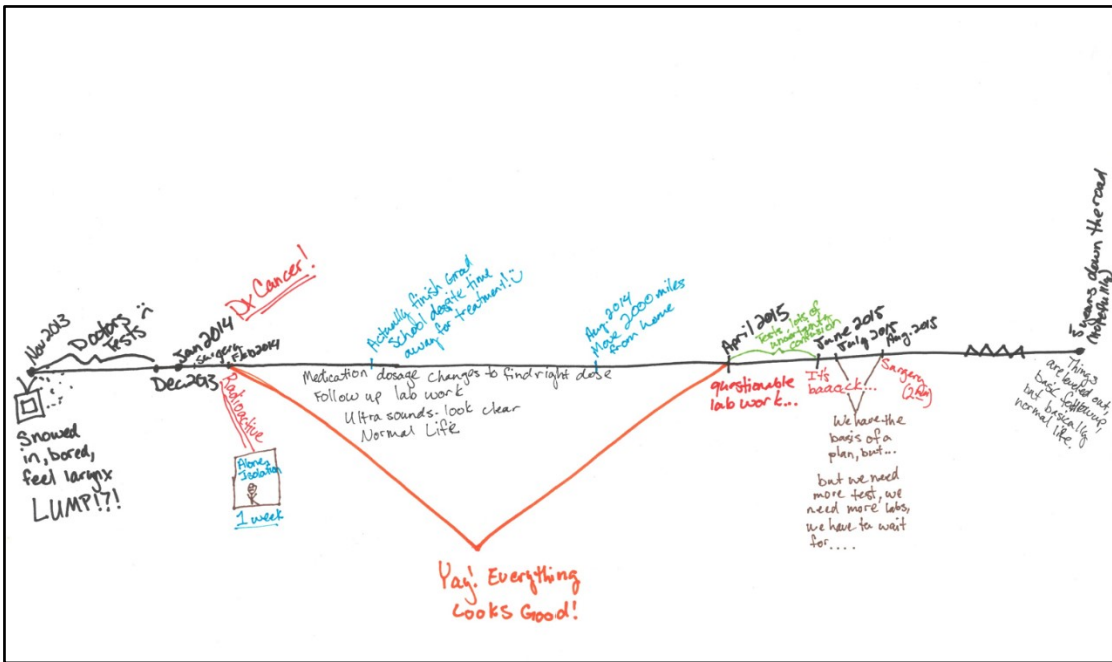
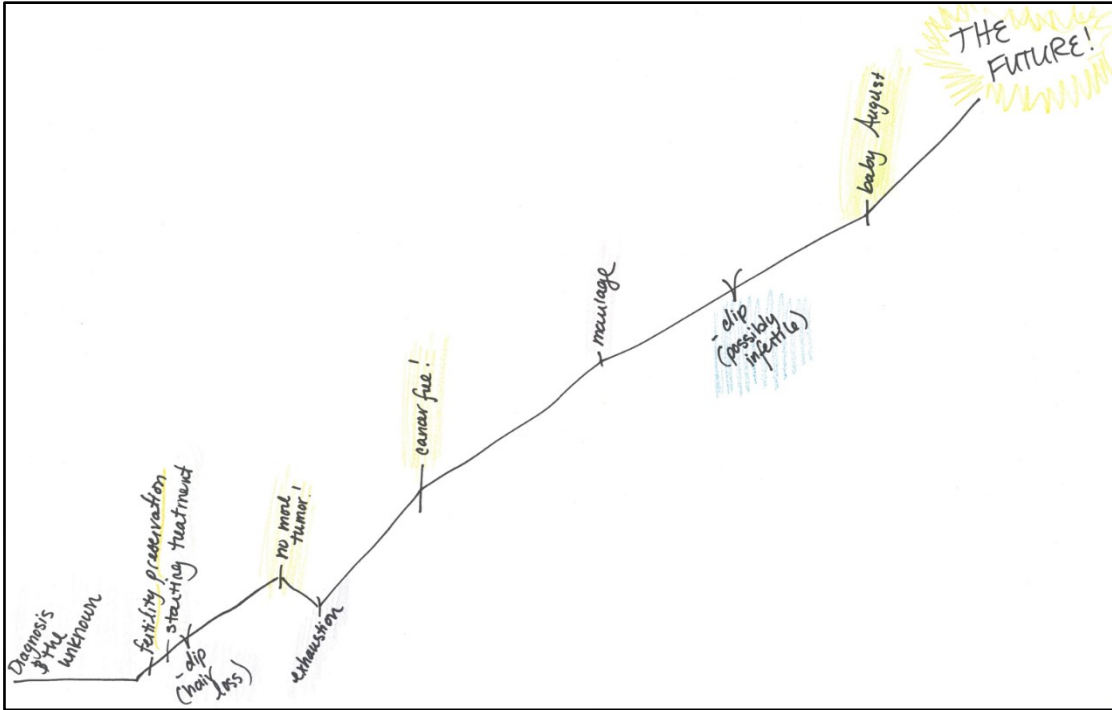
Appendix C. Catalogue of Visual Artifacts



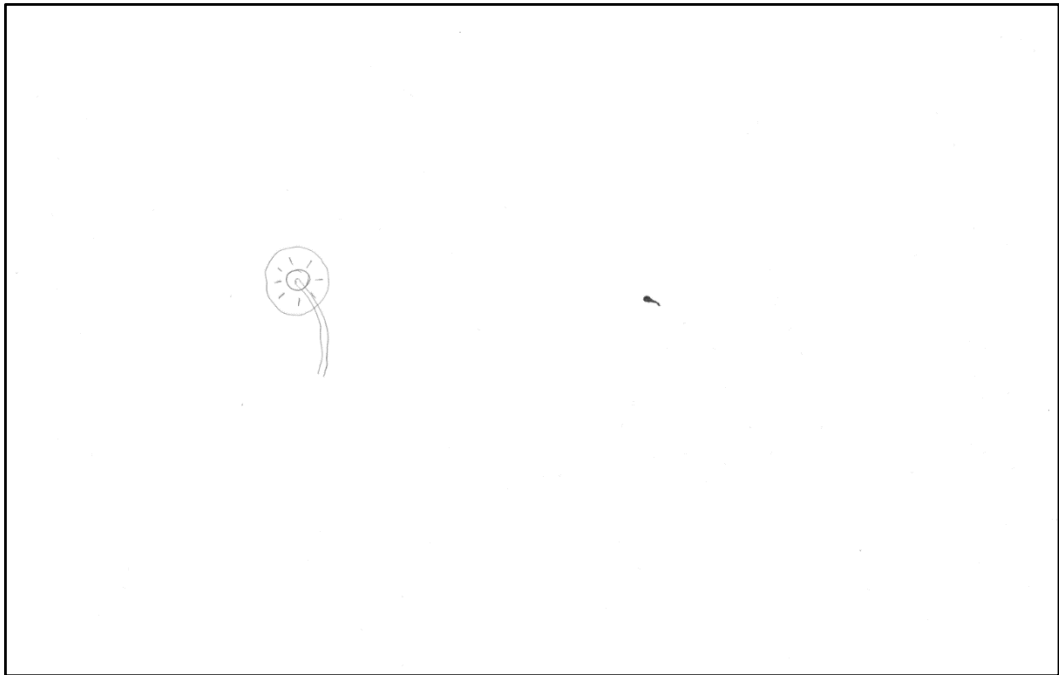
Bob (top); Marie (bottom)



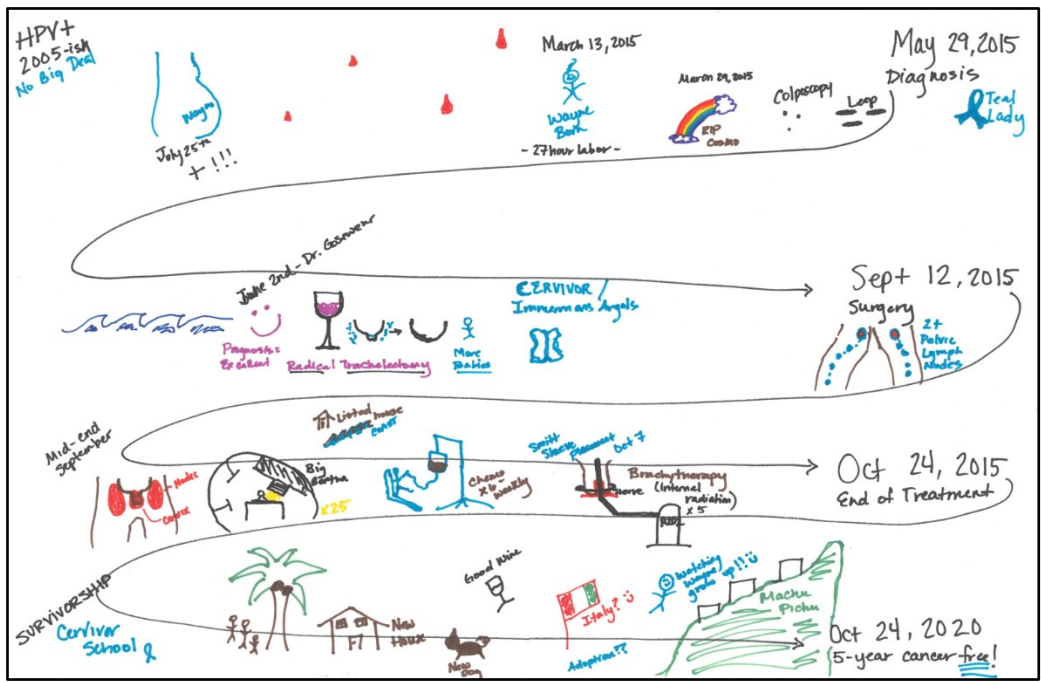
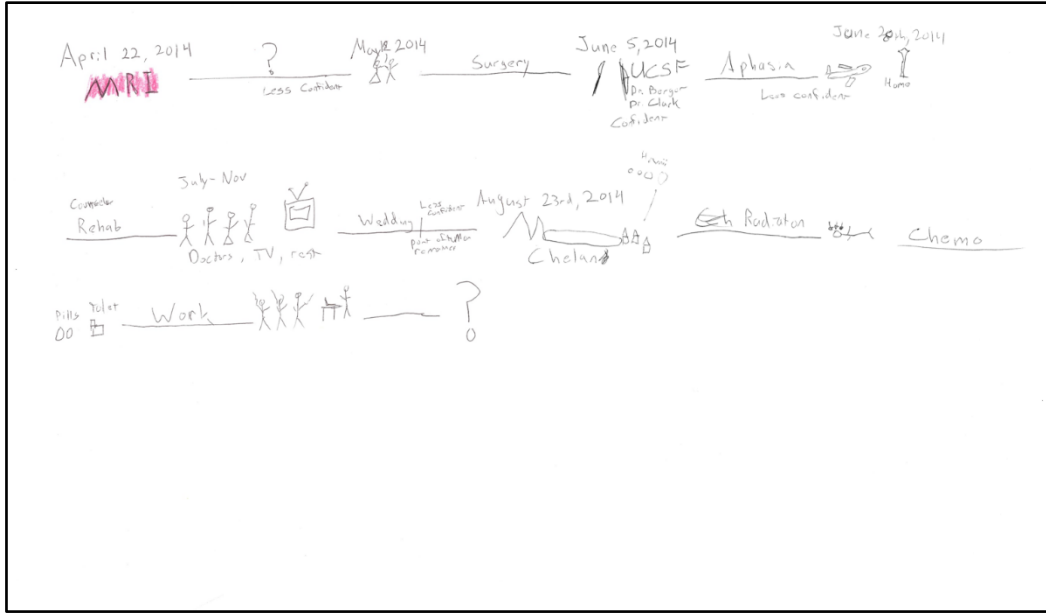
Leah (top); Emily (bottom)



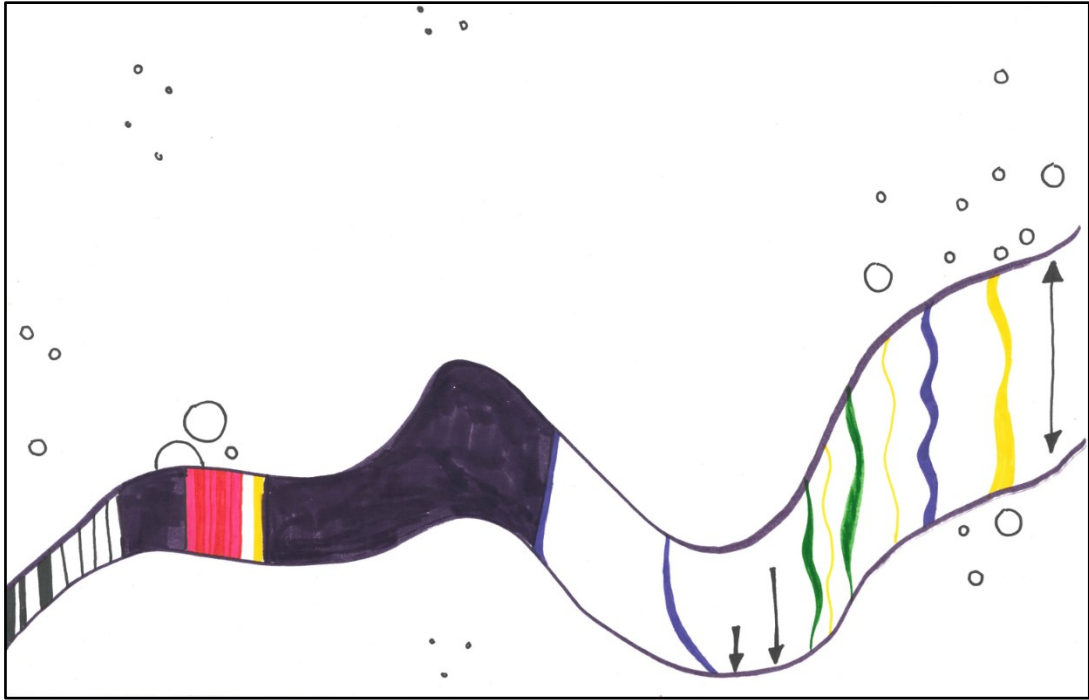
Kate (top); Jo (bottom)



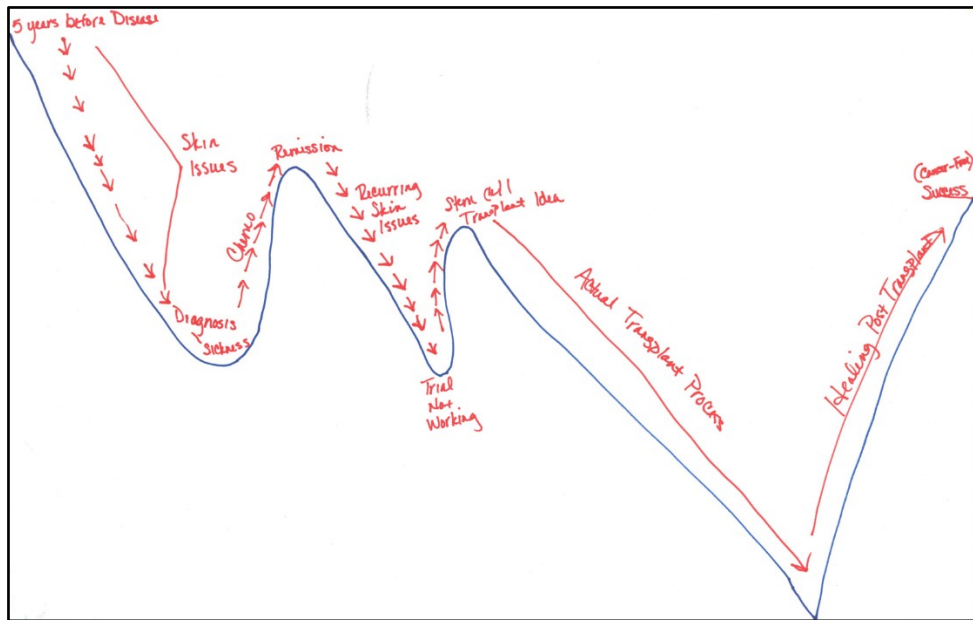
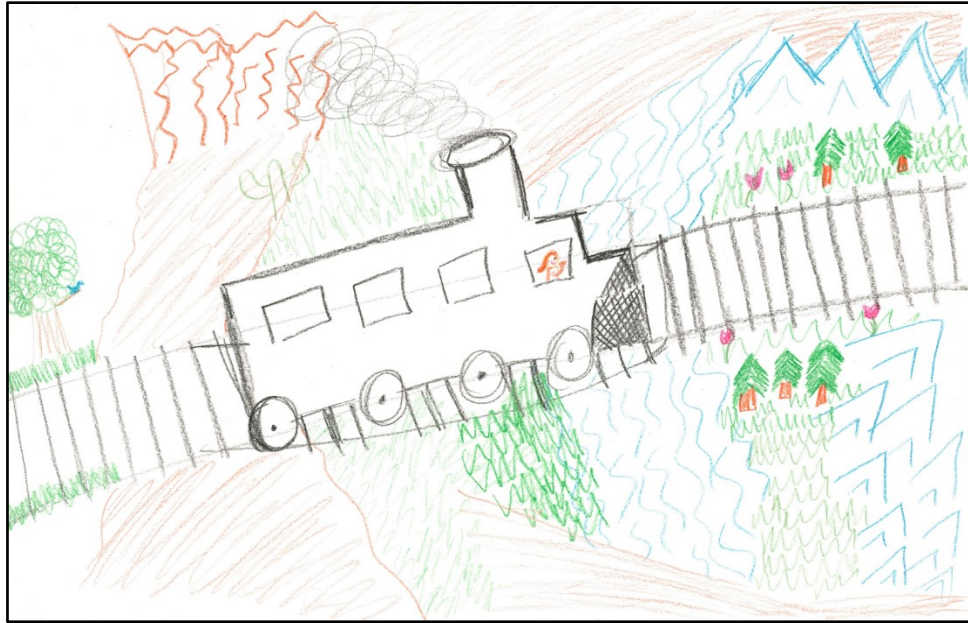
Lucy (top); Peter (bottom)



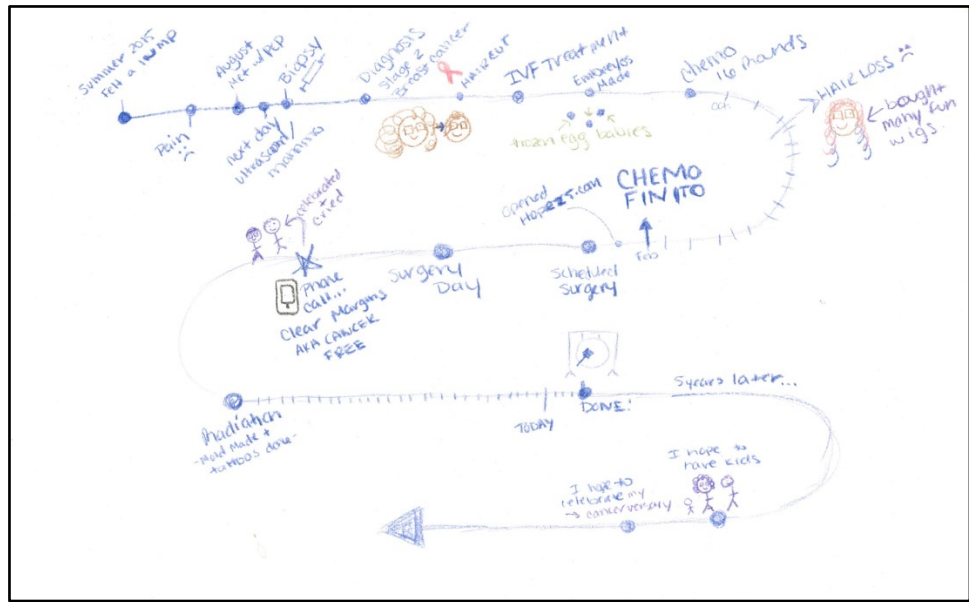
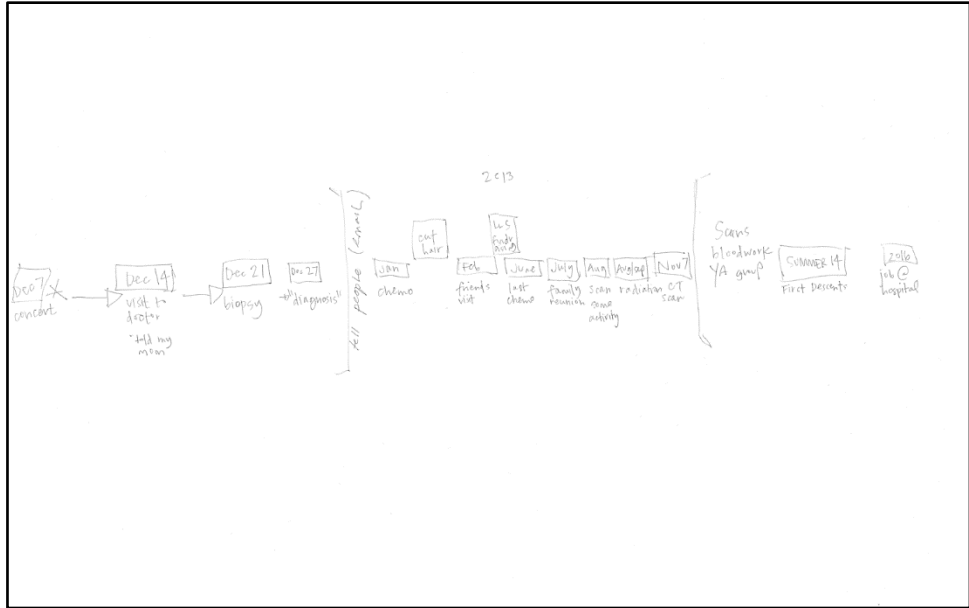
Mark (top); Helen (bottom)



Michelle (top); Diana (bottom)



Emma (top); J.C. (bottom)



Veronica (top); Monica (bottom)